HIV SCREENING IN PREGNANCY

ANNE KATZ

A Dissertation
Submitted to the Faculty of Graduate Studies in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

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BY

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

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ABSTRACT

The College of Physicians and Surgeons of Manitoba, the Canadian Medical Association, and the Society of Obstetricians and Gynecologists of Canada have recommended that HIV screening be offered to all pregnant women regardless of risk. However, the extent of compliance with these recommendations is unknown and the experience of pregnant women is not well described.

Using a variety of methodologies including feminist qualitative interviews, this dissertation examines the issue of prenatal HIV screening from a number of different perspectives. Physician compliance with the recommendations for prenatal HIV screening and their attitudes to this intervention are described. The experience of pregnant women offered screening is articulated through a qualitative analysis of their recollections. A chronological analysis of the policy process in the province is performed, as well as a cost-effectiveness analysis at two levels of seroprevalence.

While physicians agree with the recommendations to offer screening to all pregnant women, the consistency with which they actually offer the test is variable. Pregnant women are also supportive of this intervention and will do whatever they can to ensure a healthy outcome of the pregnancy. The policy for screening in Manitoba is one of universal offering of the test with voluntary uptake and informed consent. Findings from this study support the present policy. Screening is cost-effective in both areas of high and low seroprevalence.

Pregnant women, while appearing to have choices in their health care, in reality have limitations placed on their choices by lack of comprehensive information and a desire to be "good"patients. Health care providers, while striving to provide comprehensive care, are also limited by time constraints. Implications for practice, education, and research are suggested to address many of these issues.

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To Alan - now I know what the nth really means.

To our children, Ayli and Zak - for your patience while I needed space and time.

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CHAPTER ONE

INTRODUCTION

A number of serum screening tests are performed as part of prenatal care. Some are offered to those thought to be at risk for a particular disease and others are offered according to the age of the pregnant woman, country of origin or other criteria. Some are performed routinely on all pregnant women regardless of criteria. This study investigated the complex and timely issue of HIV (human immunodeficiency virus) screening in pregnancy. The College of Physicians and Surgeons of Manitoba, the Canadian Medical Association, and the Royal College of Obstetricians and Gynecologists have all recommended that HIV testing be offered to all pregnant women regardless of risk. However, the extent of compliance with these recommendations is unknown and the experience of pregnant women is not well understood at this time.

For the purposes of this discussion, screening will be described as (a)voluntary where it is performed only with the informed consent of the individual; or (b) routine where it is part of usual prenatal care and express consent is not required from the individual for the test to be performed (Jurgens, 1997, p.57).

Screening in pregnancy is a unique situation as there are essentially two patients involved and potentially affected, the pregnant woman and the fetus. When screening for open neural tube defects or Down Syndrome, the patient under scrutiny is the fetus. Other than abortion, no treatment for either condition

exists. While the pregnant woman is undeniably affected by the threat of bearing an affected baby, there is no threat to her physical health although her mental and emotional state is clearly at risk. In screening for sexually transmitted diseases (STDs) such as syphilis, both patients are affected. Treatment may prevent consequences for the fetus, although up to 14% of these pregnancies will result in a stillbirth or an infant with congenital syphilis (Sanchez & Wendel, 1997), and will treat the woman. Screening for HIV antibodies is different as treatment of the pregnant woman may decrease transmission to the fetus, however, the treatment is not a cure for the woman and there is still a possibility that the fetus will be infected despite treatment.

For the pregnant woman, screening for disease places her in a situation where the pregnancy may not seem 'normal' to her and she may be perceived to be at high risk in the pregnancy (Marshall, 1996). Additional testing may lead to even higher levels of anxiety. Even if further testing suggests that no disease exists, anxiety may persist throughout the pregnancy and may only be allayed when she has delivered and has visible "proof" that her baby is healthy and unaffected (Santalahti, 1996). Screening for disease in low-risk populations, such as pregnant women, will identify some who have abnormal screening test results but are found to be disease-free on diagnostic testing. This should be explained to the woman and this may help her to cope in the period between screening and further testing.

Principles of Screening

Screening involves identifying individuals with potential unrecognized disease in a presumably healthy population. Screening is a means of detecting early disease before the individual has experienced symptoms and sought medical attention. It is not a means of diagnosing the individual; rather it identifies those that have a probability of developing or have the disease, that can be confirmed by additional testing or examination (Valanis, 1992, p. 331; Wilson & Jungner, 1968). Screening may be selective in that only high risk groups are screened or it may be applied to entire populations and is then described as mass screening. When more than one type of screening test is performed at the same time, the term multiphasic screening is used (Wilson & Jungner, 1968). When screening is performed as part of a routine examination and an affected individual is subsequently diagnosed as having a disease and is offered treatment, the term case finding may be used (Valanis, 1992, p. 333).

Foltz and Kelsey (1978) have developed a widely accepted method of critically appraising screening tests. The following criteria should be met before a screening test is applied to a population. The disease should be of importance and have a high prevalence in the community. The screening test should be simple to administer, accurate, reliable, and acceptable to the population. The disease screened for should have a recognizable latent or pre-symptomatic stage and the natural history of the disease should be well understood. There should be efficacious diagnosis and treatment for the disease. Finally, all costs associated

with case-finding should be both politically and socially acceptable. This includes personal costs associated with both false positive and false negative results.

Unless the screening test is valid and reliable, it is of no use. Validity refers to the ability of the test to distinguish those who have the disease from those who do not. If the test is able to reliably classify those with the disease, a true positive result, it is said to be sensitive. Conversely, the ability of the test to identify those without the disease, a true negative, is described as its specificity. Reliability in the context of screening refers to the ability of the test to give consistent results in repeated applications.

Screening tests have both benefits and detrimental effects. Sensitive tests, those that have a high yield of true positive results, provide potential benefit to the individual by identifying a disease state and allowing for medical follow-up. Associated harmful effects include anxiety during the time from a positive screening test to diagnosis, as well as those associated with diagnosis (anxiety) and treatment (side effects). A good screening test should be highly sensitive so that the vast majority of cases of disease are identified; specificity is somewhat less important in screening as those with a positive screening test will undergo further testing to confirm the diagnosis. If, however, the screening test misses the case (a false negative test) no further testing results. The individual is thus presumed not to have the condition being screened for, which is a harm resulting from lower sensitivity. Highly specific tests benefit those tested by reducing unnecessary anxiety associated with false positive tests and avoiding further

testing; harmful effects resulting are side effects of the test itself (Evidence-Based Care Resource Group, 1994). Essentially, the aim in screening is to identify as many individuals as possible who may be affected and to then apply a highly specific confirmatory test to identify those who are definitely not affected. The predictive value of a screening test is in some part dependent on the prevalence of the disease in the general population. For example, in a population of low prevalence, the likelihood of a false positive test is increased.

Wilson and Jungner (1968) suggest that the yield of a screening test is also important. Yield is associated with the prevalence of a disease and the more prevalent the disease, the greater the yield. Yield is often a factor in determining the cost-effectiveness of screening. Although most screening tests are inexpensive to perform and can be administered by an individual with minimal training, the cost of follow up for those with abnormal results may be high. Thus if the yield of a particular screening test is high but many of those individuals are found to be normal on confirmatory testing (in other words, the rate of false-positive results is high), then the cost of screening may not be justified (Vanalis, 1992, p. 334).

The Canadian Task Force on the Periodic Health Exam (1994) and the U.S. Preventive Services Task Force (1996) have each issued a set of recommendations for screening tests based on a thorough review of the evidence. Based on the quality of the evidence, recommendations are rated in a hierarchical manner and are suggested as guidelines for the clinician. These recommendations are widely

recognized as being based on rigorous evaluations of trials.

Routine Tests

In addition to screening for STDs and genetic illness, the following screening tests are performed on pregnant women in Manitoba: hemoglobin, blood sugar, D antibody (Rhesus) status, and antibodies to rubella. These tests are performed at the first prenatal visit and generally do not involve a discussion on the benefits and harmful effects of testing. Abnormal results are usually discussed with the patient and treatment is instituted where necessary.

Sexually Transmitted Diseases

Women in Manitoba are routinely screened for syphilis and hepatitis B surface antigen. Recommendations by the College of Physicians and Surgeons of Manitoba (1995) and the Society of Obstetricians and Gynecologists of Canada (1997) suggest that women be offered screening for antibodies to HIV as well.

1. Syphilis

Syphilis during pregnancy may result in transmission to the fetus and the serious consequences of congenital syphilis. Although less than 1 % of pregnant women are infected, if left untreated, up to 20 % of their neonates will have congenital syphilis (Whitley & Goldenberg, 1990). Transmission commonly occurs during the first and second trimester and the fetus may have a variety of medical complications, however, almost 40 % of infected fetuses are aborted or stillborn (Sanchez & Wendel, 1997). As treatment of the infected pregnant

woman will prevent transmission to the fetus, it is vital to identify women who are infected and initiate treatment (Stepanuk, 1994).

The Venereal Disease Research Laboratory (VDRL) test, a nontreponemal test will be reactive 4 to 8 weeks after infection and confirmation is carried out by means of specific treponemal antibody tests (Charles, 1983). The specificity of the VDRL is in the range of 75 to 85 % and in individuals with certain conditions, including pregnancy, false-positive results are not uncommon. For this reason, any positive reaction is always followed by a treponemal test (U.S. Preventive Services Task Force, 1996., p. 288). The laboratory performs a confirmatory test automatically, thus avoiding the anxiety of a false-positive VDRL. Screening in pregnancy is performed at the first prenatal visit and later in the pregnancy for those women with high risk behaviors for transmission of sexually transmitted disease (Schmid, 1996; U.S. Preventive Services Task Force, 1996, p. 291). The treatment of choice for syphilis in pregnancy is penicillin as this is effective in preventing congenital syphilis. Women treated for early syphilis should have monthly quantitative serologies throughout the pregnancy and should be retreated if a four-fold drop in titers does not occur (Brunham et al., 1990). The long term health care costs associated with untreated syphilis are enormous (Tillman, 1992). The epidemiologic link between syphilis and HIV infection is an important one, as common risk factors predispose both women and their fetuses to infection (Ault & Faro, 1993).

Even though syphilis is a relatively rare disease, the consequences in both

human suffering and costs to the health care system of undiagnosed disease are considerable. The reliability of the VDRL is acceptable, however, higher sensitivity and specificity are achieved with non-treponemal tests which are used for confirmation of infection (Sanchez & Wendel, 1995), and the natural history of the disease is well known. Treatment for syphilis and prevention for the fetus is effective. Screening for syphilis meets the criteria of a good screening test (Foltz & Kelsey, 1978), however the common practice of not discussing the test before it is performed is concerning.

The detection of syphilis during routine prenatal screening can be an enormous shock to a woman. With the long latency period characteristic of the disease, it may reflect on her past sexual history or it may alert her to her partner's risk behaviors for STDs (Hart, 1986). Testing for syphilis is routinely done without explicit permission because this disease is believed to be sufficiently serious that screening is necessary, but sufficiently rare not to burden the woman with unnecessary anxiety (Boyd, 1990). This is of concern as the ramifications of a positive test are far-reaching for the woman and her sexual partner(s). Even though there is an effective treatment available, the stigma of contracting a sexually transmitted disease persists and may have severe emotional consequences for the woman. This continues with the legislated contact tracing and testing which are necessary as a public health intervention to control spread (Sanchez & Wendel, 1997). It has been suggested that prenatal screening for syphilis has not only benefitted pregnant women but also society as

a whole. Because screening for the disease occurs in virtually all pregnant women, this constitutes a mass screening program of both women of childbearing age and, indirectly, the men with whom they are sexually active (Clay, 1989).

While the benefits of screening and treatment to both the individual and the community are apparent, it is important that women are informed before the test is performed. Informing the woman serves to educate her about the risks and consequences of this and other sexually transmitted diseases that are commonly screened for in pregnancy, including gonorrhea and chlamydia.

2. Human Immunodeficiency Virus

The prevalence of HIV seropositivity in Canada varies from a low of 3.2 / 10,000 pregnant women in Manitoba to a high of 8.7 / 10,000 in Newfoundland (Ratnam et al., 1996). However, this rate may be skewed by a cluster of infection in one particular county. The highest reported seroprevalence rate in the rest of Canada is 6.1 / 10,000 in Quebec (Hankins, Laberge, Lapointe, Lai Tung, Racine & O'Shaughnessy, 1990). Perinatal transmission occurs in up to 25 % of pregnancies (Sperling et al., 1996) and it is hypothesized that transmission occurs around the time of delivery (Kuhn et al., 1997). Transmission is more likely to occur if the mother is severely immune compromised (St. Louis et al., 1993), when delivery is premature (The European Collaborative Study, 1996), when there are operative interventions during labor and delivery (Bardequez, 1996), and when there is prolonged rupture of membranes (Landesman et al., 1996).

In 1994, Connor and associates published a landmark study in which the vertical transmission rate was decreased by two thirds if a regimen of zidovudine was taken by the HIV-infected woman during pregnancy and labor, and also given to the neonate for the first six weeks of life. Based on these results, the universal offering of screening to pregnant women for antibodies to HIV has been recommended by the Society of Obstetricians and Gynecologists of Canada (1997), and the College of Physicians and Surgeons of Manitoba (1995). The Canadian Pediatric Society (1995) has recommended that all pregnant women be routinely tested for antibodies rather than merely being offered testing. The U.S. Preventive Services Task Force (1996, p. 315) recommends that universal offering of testing should be encouraged in areas of high prevalence of HIV but they do not recommend for or against this in areas of low prevalence. Ecker (1996) estimates that HIV screening in pregnancy is cost effective when prevalence is greater than 9 per thousand. In his analysis, the costs of screening include counseling costs and costs of early medical treatment not associated with prevention of perinatal transmission. Manitoba's prevalence is much lower than this and a more complete cost effectiveness analysis will be performed as part of this dissertation.

The screening test for HIV is an enzyme linked immunoassay (ELISA) with sensitivity and specificity greater than 99 %. A positive ELISA is routinely confirmed by the laboratory using a Western Blot test which has a specificity of 100 % (U.S. Preventive Services Task Force, 1996, p. 305).

The costs of screening to the woman are complex. While the risks involved with venipuncture are minimal, the emotional costs, particularly for a woman who is unsure of her actual risk, are substantial. The waiting period before getting results may be fraught with anxiety, and considerable stigma continues to be associated with HIV infection (Lindgren et al., 1993). Although treatment during pregnancy and labor and for the neonate substantially reduces the vertical transmission rate (Connor et al., 1994), at this point in time there is no cure for HIV infection. While early diagnosis and treatment have obvious benefits, the long term effects of treatment on both mother and infant are not known (Downes, 1995; Minkoff & Willoughby, 1995; Whitley & Kimberlin, 1997). The possibility of the development of zidovudine-resistant strains of HIV in an infected child is a real one and the effects of zidovudine on the uninfected infant after exposure in utero and the neonatal period are unknown at the present time (Lancet, 1994).

As a screening test, HIV antibody testing falls short of the criteria for a good screening test (Foltz & Kelsey, 1978). A cure for HIV infection remains elusive, however anti-retroviral therapies continue to improve in efficacy and availability. Prevention remains the cornerstone for the eradication of this disease and for this reason, the results of AIDS Clinical Trials Group (ACTG) Protocol 076 (Connor et al.,1994) have altered the way screening for HIV is carried out during pregnancy. By screening pregnant women, those who are infected and unaware of their serostatus can be offered treatment that reduces

the risk of the fetus being infected. In addition, procedures during labor that are thought to increase the transmission rate can be avoided.

Screening for HIV antibodies should only occur with informed consent and with the necessary counseling and information so that women will be able to give truly informed consent. For some women, the emotional costs of HIV screening may be too high and so they may refuse. The consequences of screening women without their permission may be devastating as this remains a disease with no cure and with significant social stigma.

The Manitoba Policy of Prenatal HIV Screening

Policy makers in the province of Manitoba responded with speed to the results of AIDS Clinical Trial Group (ACTG) Protocol 076 (Connors et al., 1994). Within months of the publication of the results of the clinical trial, policy was in place that recommended prenatal screening for women at risk. A short while later, the policy was amended to include all pregnant women. There was recognition by Manitoba Health that the policy needed to be reviewed on a regular basis and to that end, a working group was established that included a variety of care providers and stake holders. This working group reports to an umbrella committee comprised mainly of physicians and public health experts. There have been some differences of opinion between members of the umbrella group (the Manitoba Advisory Committee on Infectious Diseases [MACID]), and the working group which has representation from nursing and community health clinics as well as community physicians and public health. The main

difference related to how an HIV test for prenatal patients should be ordered. One option was to use the provincial requisition form which does not contain the name of the woman, only a non-nominal code. It does however contain information related to risk factors and activities for HIV infection. The other option was to request the HIV test on the regular serology form which is used for all the other routine tests in pregnancy and which does contain the woman's name. Members of MACID were in favor of not using the HIV requisition and including the HIV test on the serology requisition. This issue was debated by the working group and it was decided that the existing system be continued, namely that HIV screening for pregnant women should continue to be non-nominal. This decision was fairly contentious, with some members of the committee defending present policy from the perspective of women's rights to privacy and the need for pregnant women to be treated the same as the general population when it comes to HIV testing (i.e. in a non-nominal manner). Others on the working group spoke of the need to normalize HIV screening in pregnancy and used as an example the situation in Alberta where nominal testing for pregnant women is the policy, as opposed to non-nominal for the rest of the population.

The present policy states : "it is strongly recommended that all physicians offer HIV testing and counseling to all pregnant women as part of routine prenatal care. The decision to be tested should be voluntary and based on informed choice." It was also recommended that educational material be available to support this change in policy, that non-nominal testing be continued,

and that the prenatal record be changed to reflect the change in policy.

The College of Physicians and Surgeons of Manitoba also responded to the publication of the results of ACTG Protocol 076, however its response was precipitated by correspondence with a single physician who was insistent that screening of all pregnant women without express consent be instituted. The College of Physicians and Surgeons of Manitoba is the licensing body for all physicians in the province. They issue a series of Guidelines which describe recommended practices and in 1995, a Guideline regarding prenatal HIV screening was issued.

The College appears to have taken a reasoned approach, consulting with Manitoba Health and other bodies in the development of a guideline (Appendix A) that includes treatment information for both the pregnant woman and the neonate. The guideline is intended to not only inform physicians of the recommended standard of practice but also of the treatment issues involved. The College has continued to include updates in newsletters, detailing the percentage of pregnant women who are being screened for HIV antibodies and encouraging physicians to comply with the recommendations. Whether this is an effective mechanism to encourage compliance is not known.

The College appears to be responsive to the needs of its membership. A request for written information for patients that would expedite the counseling process was forwarded from the College to the Medical Officer of Health for the province and is being acted upon. While this process has taken some time, in the

interim, a pamphlet from the Canadian Public Health Association was distributed across the province to all providers of prenatal care.

The present policy in Manitoba appears to be effective. Health care providers have in the past been involved in, and continue to be consulted on, the development of the policy. The policy has been developed based on the scientific evidence available, and the opportunity exists for ongoing review based on the latest published reports from the medical literature. Manitoba Health and the College of Physicians and Surgeons of Manitoba maintain a distance in the implementation of the policy with updates of the percentage of prenatal blood specimens that are screened for HIV antibodies, but do not require quotas such as those expected in the USA under the Ryan White Act. Despite intense pressure, the policy that has been recommended is one that reflects the rights of women to be informed and to make a voluntary decision about HIV screening in pregnancy based on that information.

Lovvorn, Quinn and Jolly (1997) undertook an analysis of current prenatal HIV screening policy in the United States. They reviewed five states which have different policies, ranging from Minnesota which has no specific policy, to Illinois which attempted to institute mandatory prenatal screening in 1995. Their analysis suggests that counseling all pregnant women to be screened for HIV antibodies with voluntary uptake is the most effective policy. According to the authors, this policy applies to all women, avoids stigma, ensures the right to privacy, and is effective and feasible.

This description of the policy for HIV prenatal screening in Manitoba reflects an ongoing process of discussion and analysis among stakeholders in the health community and policy makers. The process appears to be flexible with opportunities for changes to be made to reflect changing attitudes and practice.

Purpose of the Study

This study investigates the complex and timely issue of HIV screening in pregnancy. The College of Physicians and Surgeons of Manitoba, the Canadian Medical Association, and the Royal College of Obstetricians and Gynecologists have all recommended that HIV screening be "offered to all pregnant women regardless of risk." However, the extent of compliance with these recommendations is unknown and the experience of pregnant women is not described at this time. Findings from this research may in the future be used by policy makers and individual health care providers to guide and improve practice and service delivery.

The specific research questions are :

1. What are the attitudes and practices of Manitoba physicians regarding HIV testing in pregnancy ?

a. How are these similar to or different from their attitudes and practice regarding routine syphilis screening ?

b. How is pre- and post-test counseling for HIV testing currently performed by physicians ?

2. What are the experiences and attitudes of pregnant Manitoba

women regarding HIV testing ?

3. Is universal HIV screening in pregnancy cost-effective in Manitoba where the seroprevalence is extremely low ?

Conceptual Framework

The conceptual framework guiding this study is liberal feminism. Feminism is a term that has been used in different ways through the ages. Its origins lie in the women's movement, a 19th century phenomenon in which the advancement of women was advocated. In the early 20th century, feminism in North America came to mean the representation of women as unique and involved in the mystical experience of motherhood as well as possessing a special purity. This view of women is termed sexual romanticism and is contrasted with the perspective of sexual rationalism in which women are viewed as essentially the same as men and any subordination of women is seen as inherently irrational. Today feminism is used to refer to a movement to end women's subordination, and the underpinnings of late 20th century feminism rest on the notions of the liberation of women (Jagger, 1983, p. 5).

Central to a feminist analysis is the notion of the end of male dominance. This male dominance is called patriarchy and reflects the social structures and practices in which men dominate and oppress women. The notion of social structures is important as it takes into account different situations such as the household, paid employment, male violence, sexual relationships, culture and society (Walby, 1990, p. 20). Patriarchy occurs in both the public and private

spheres, although some believe that while private patriarchy has diminished over time, public patriarchy continues in the arena of employment and the state (Walby, 1990, p. 24).

Traditional liberals view human beings as rational agents and, despite obvious physical differences between men and women, see no reason to support the notion that men and women have different reasoning capacity. Liberal feminism is grounded in this perspective and from this flows the idea that gender is irrelevant when considering an individual's rights. However, individuals differ in their wants and desires, and these differences are seen as originating in differences in social experiences. Equality of men and women is contradicted by laws that ascribe different rights, responsibilities, and opportunities to men and women, and the existence of these laws are, according to liberal feminists, the manifestation of basic injustice in society (Jagger 1983, p. 181).

A liberal feminist analysis of prenatal HIV screening considers the central theme of choice, or agency, and the rights of women as bearers of children. The distinction between choice and consent is important. While consent is concerned with allowing a medical procedure to occur, having choices means that viable alternatives are possible (Overall, 1993). It is generally accepted that autonomy reflects a state wherein an individual is found to be sufficiently competent to make a decision, makes a reasonable choice from a range of options, has

information about and understanding of the options, and is free of coercion in making the choice (Sherwin, 1998, p. 26). Sherwin further suggests that there is a difference between autonomy, or self-governance, and agency, the exercise of reasonable choice (1998, p. 32). While agency may be possible for many women, true autonomy is generally more difficult to accomplish. This is due to the pervasive oppression of women and the consequences of this oppression in their daily lives. This oppression acts to restrict women's choices by forcing women to make decisions in a narrow focus, and not allowing them the true freedom, or autonomy, of creating alternative choices.

This study uses a liberal feminist perspective to explore how women experience prenatal HIV screening and how health care professionals view and practice this test. Liberal feminism is based on the traditional liberal values of individual dignity, autonomy, equality, and self-fulfillment. These values will serve as the benchmarks against which interactions in the health care setting pertaining to prenatal HIV screening are described. They will also be used to frame the experience of screening for pregnant women and to contextualize the decision making process for the women interviewed.

Summary

This chapter has described the principles of screening, and the routine screening tests performed in pregnancy in Manitoba. The present policy in Manitoba and its development were described. The purpose of this dissertation

and the research questions asked were outlined and finally, the conceptual framework guiding the study was identified and described. The following chapter contains a review of the current literature on this subject.

CHAPTER TWO

REVIEW OF THE LITERATURE

In this chapter, the current literature pertaining to HIV screening in pregnancy is reviewed. The review begins with an overview of HIV screening in pregnancy in the larger context of women and HIV infection, the epidemiology of this disease among women, and issues related to HIV in pregnancy and the treatment of HIV-infected women. An analysis of the landmark study conducted by Connor and associates (1994) that precipitated the intense discussion about screening for HIV antibodies in pregnancy follows. The literature review continues with a description of what has been written about physician and midwife attitudes to, and practices of, prenatal HIV screening. A review of cost-effectiveness analyses that have been carried out will also be presented.

Women's Lives and Risk for HIV Infection

Discussion of the social aspects of HIV infection among women in general cannot exclude the unique social context of women in society. Many women with HIV infection are members of visible minorities and are poor. They are sometimes drug addicted or the partners of men who are drug addicted. These factors are known to lead to disenfranchisement. To further complicate this, the stigma associated with HIV infection may influence the woman to isolate herself and avoid all but the most critical interactions with health and social service agencies (Anderson, 1996). Fear of family disruption may further influence the

woman to keep her infection a secret (Davison et al., 1993). However, the social role of woman as mother cannot be underestimated and many women are willing to experience the guilt and uncertainty concerning a child's serostatus in order to become a mother (Williams, 1992). Women often put the concerns of their children and families above their own health care needs (Rose & Clark-Alexander, 1996). Any interventions planned must take this into consideration. A woman may be judged as being non-compliant with her medical care where in fact she is merely trying to meet the needs of her family and puts her own needs in the background.

A number of socioeconomic factors predispose women to HIV infection. While the situation for women in North America differs markedly in degree from women in developing countries, poverty and lack of power lie at the root of HIV infection for most women. The World Health Organization lists three reasons for the increasing numbers of women infected worldwide (Highsmith, 1997). These include the biological vulnerability of women, epidemiologic vulnerability, and social vulnerability. That is, women by virtue of their anatomy, are susceptible to the virus and by virtue of their relationships with men, both sexual and economic, are placed at risk for transmission of the virus.

In the United States, the vast majority of HIV infected women are poor women of color (Centers for Disease Control, 1996). It has been pointed out that transmission of HIV, either through sexual intercourse or injection drug use, is linked to issues of race, gender, class and sexuality (Zierler & Krieger, 1997).

While statistics are available in the United States that identify the incidence of AIDS along racial and economic lines, similar statistics are not available in Canada. A seroprevalence study in Quebec of women undergoing abortion found that the rate of HIV among women from Haiti was 147 times higher than women born in Canada, and in women born in other countries where HIV is endemic, the rate was 33 times higher than for women born in Canada (Remis et al., 1995).

A number of studies suggest that the rapid growth of HIV infection among women in the United States has occurred mainly among impoverished women affected by the economic recession of the 1970s, and the social and economic policies of the Reagan administration. Linked to this poverty is the escalating use of illicit drugs and the need for impoverished women to support themselves and their children by involvement in the sex and drug trade (Zierler & Krieger, 1997). While data on race and economic status are not collected as part of the demographic information required for HIV screening or reporting of AIDS cases, it is useful to consider the example of Aboriginal women in Canada and speculate on how issues of race, gender and class may influence their risk for HIV infection.

Aboriginal women are disproportionately poor and have less education and fewer opportunities for work. Many are forced to leave their communities because of family violence and they migrate to the city where they are limited to sub-standard housing in areas of the city that are disintegrating. They may be

exposed to substance abuse and sexual assault, isolation and stress from urbanization (Stout, 1996). A study conducted in Winnipeg in 1993 demonstrated that despite participation in high risk activities such as more than one sexual partner in the past year and a history of previous sexually transmitted disease, Aboriginal women were half as likely to use condoms as non-Aboriginal women (Katz, 1995). This study was conducted at the Mount Carmel Clinic which is situated in an area of Winnipeg which has the lowest average national household income level as determined by Statistics Canada. This study also found that younger women were less likely to use condoms and this was linked to the use of alcohol and drugs. Only 28% of the sample of women perceived themselves to be at risk for HIV infection, despite 64% having a prior sexually transmitted disease.

The underlying causes of oppression for Aboriginal women in Canada may be compared with those of black women in the United States. Race forms a backdrop for issues of patriarchy and the experience of women of colour may be different from that of white women. The site of oppression for women of colour may not be centered in the home as it is for many white women. The home may in fact be the site of resistance against racism (Walby, 1990, p. 14). In addition, young women are often controlled by notions of romance, love and caring which make decisions about avoiding risk and promoting safety harder to make (Holland et al., 1990).

A small study of 134 Black and Hispanic women in the United States presents some interesting and contradictory evidence to the notion of decreased power due to gender issues. Kline and associates (1992) conducted focus groups with women who were intravenous drug users or sex partners of intravenous drug users. The women who participated reported that they preferred independence in their relationships and that they had power in their sexual relationships. They saw the men they were involved with as unreliable sources of economic support and so found other ways of supporting themselves and their children. Paramount in these women's lives was the protection of their children. Women insisted on condom use. For HIV-negative women, condom use was based on their assessment of personal risk vis-a-vis the male partner; HIV-infected women insisted on condoms to protect their male partners. The women who participated in this study may be different from other women who have been studied in the past. Their experiences as women of colour in the sub-culture of intravenous drug users likely influenced their perception of personal power. The use of focus group methodology may have prompted socially desirable responses in a group situation. However, the findings of this study are interesting in that it appears that in some circumstances, minority women perceive they have power and are able, despite the complications of intravenous drug use, to protect themselves and their partners.

Women are susceptible to HIV infection because they are often powerless in their relationships, they are disadvantaged in their ability to find meaningful

and adequately remunerated work, and they may be subject to violence in their daily lives. The transmission of HIV infection is not only linked to biology but is also bound to social and economic relations. As economic policies of increasing conservatism impact on the working poor and those on welfare, the only recourse for survival for many women is illicit activities such as the sex and drug trade. Thus women continue to be placed at risk, not only by their risk activities, but by the context of their lives. Entry into high risk situations is often characterized by powerlessness and little control over sexual health. When women are in high risk situations they are less likely to be concerned about their health, their risk taking increases and they have less concern about casual sexual relationships (Zwi & Cabral, 1991).

The attitudes of pregnant women and the reality of their lives that place them at risk for this disease are an essential part of the discussion of prenatal HIV screening. The foregoing review has highlighted the realities that influence women which may be far removed from dispassionate statistics describing how many women are tested and how many are infected.

Women and HIV Infection

In 1981, six women in the United States were observed to have similar symptoms of immune deficiency as five previously healthy gay men (Guinan & Hardy, 1987). However, it was the occurrence of this constellation of symptoms in the gay men that prompted the first official report of acquired immunodeficiency syndrome (AIDS). Before the syndrome was called AIDS, it

was termed Gay Related Immune Deficiency (GRID) and in the lay press, the "gay plague" (Shilts, 1988, p. 121). In Canada prior to 1985, there were 20 reported cases of AIDS among women and this number has grown to an adjusted- for-reporting-delay total of 1,055 at the end of June 1997, the last period for which national data are available. The predominant method of transmission of HIV for women in Canada is heterosexual transmission (65.9% of cases) with intravenous drug use calculated at 24.7% (Health Canada, 1998). Heterosexual transmission includes those who report heterosexual intercourse with individuals at risk for HIV infection, for example injection drug users and bisexual men. It is important to note that heterosexual intercourse is relatively unstigmatised and people may be more likely to report this as a risk for HIV infection rather than more stigmatized behaviors (Mertz, Sushinsky & Schuklenk, 1996).

The experience of women with HIV/AIDS went largely unreported in the early years of the epidemic. Assumptions were made early on that this was a disease of gay men and injection drug users, and the natural history of the disease in women was thought to mirror that of men. When reports of gynecologic manifestations in women began to appear, guidelines for management of the disease in women followed (Modlin & Saah, 1991). However, it took some years before the U.S. Centres for Disease Control definition of AIDS was amended to include specific gynecologic symptoms.

Early research focused largely on issues related to perinatal transmission,

and critics have suggested that interest in women and HIV has largely focused on women as infected vessels carrying fetuses, and vectors of disease to their sexual partners. In their review of funded research in the United States, Faden, Kass and McGraw (1996) report that in the late 1980s, only four studies could be identified that involved women and all were restricted to women as transmitters of disease, whether to their children or to men through their work as prostitutes. It was not until 1993 that a pilot study was begun to trace the natural history of HIV infection in women, and in late 1994, that funding for additional research was made available through the Women's Interagency HIV Study. The result of this delay may have been the inability of medical professionals to recognize the disease in women. Care and treatment of women also has been compromised due to the delay.

Women have traditionally been represented as vectors of disease, from the days of Typhoid Mary, a cook who unwittingly transmitted typhoid to the family for whom she worked, to the present where prostitutes are seen as the ones who infect heterosexual men who, in turn, transmit diseases to their wives and children. In the case of sexually transmitted diseases, and HIV in particular, men are much more likely to transmit the virus to women than women are to men (Padian, Shiboski & Jewell, 1991). Prevention of sexual spread has been focused on male oriented barrier methods with the condom as the only barrier method shown to be effective in preventing the spread of the virus during sexual intercourse. It has taken many years for the female condom to be

developed, tested for efficacy and made available, and it remains an expensive and cumbersome alternative.

Women were largely ignored in education and outreach initiatives especially in developing countries where they are particularly vulnerable in their economic and sexual relationships with men (Scheper-Hughes, 1994). Research linking inequality and women's risk for HIV infection has only recently been published and needs to be expanded. This research needs to link surveillance data with the incidence of HIV infection at an individual, household, community and regional level (Zierler & Krieger, 1997).

While women are regarded as the fastest growing group of the population that is becoming infected with HIV, it is not always that clear just how many women are infected. The next section deals with the epidemiology of the disease, specifically the rates of infection among women in Canada.

Epidemiology

In North America, variation is seen between seroprevalence rates in different regions as well as between the United States and Canada. Some of the variation may be due to different methods of reporting, as some jurisdictions report only those cases of persons diagnosed with AIDS. There is also a lag time in reporting AIDS cases to the Laboratory Centres for Disease Control as individual physicians must complete an extensive form and this may be delayed for months (Health Canada, 1996).

The number of HIV positive individuals who have tested in Manitoba continues to increase. Up till the end of June 1999, the last date for which statistics are available, a total of 648 men and 104 women (total 752) have tested positive for HIV antibodies in Manitoba. This of course does not take into account the number of people who live in Manitoba who may be infected but were tested elsewhere. The majority of these women, eighty six, are between the ages of 15 and 39 years, the childbearing period.Most of the men claim same sex intercourse and injeciton drug use as the route of transmission however, 85 men claim heterosexual intercourse as the source of their infection (Manitoba Health, 1999).

A number of seroprevalence studies have been conducted in Canada and the results of these indicate large variation. Manitoba had the lowest rate with 3.2 cases per 10,000 pregnant women. This rate reflects six women found to be HIV-infected on a blinded seroprevalence study performed on 18,639 prenatal blood samples between August 1994 and the end of July 1995. An earlier study in Manitoba conducted between April 1990 and September 1991 found a total of three pregnant women to be HIV-infected out of a total of 27,627 prenatal blood samples (Dr. J. Blanchard, personal communication, 6 January, 2000). British Columbia reported 2.7 cases per 10,000 pregnant women and Ontario 2.8 cases per 10,000. The provinces with the highest seroprevalence rates were Quebec and Newfoundland with 6.1 cases per 10,000 pregnant women and 8.7 cases per 10,000 pregnant women, respectively. The rate in Newfoundland reflects a very

high seroprevalence in one specific county and may not reflect accurately the seroprevalence in the province as a whole (Johnston et al., 1997).

The Canadian Perinatal HIV Surveillance Program tracks pediatric HIV infection across the country. As of December 1995, there were 234 confirmed cases of HIV infection in children. Forty new cases were identified in 1995 alone (King et al., 1996). While absolute numbers of perinatal transmission remain low in Canada, it appears that the trend is increasing. In Manitoba to date, there have been 2 cases of perinatally acquired HIV infection and 86 women of childbearing age have been identified as HIV positive by Cadham Provincial Laboratories (Manitoba Health, 1999).

In the United States, 0.17 % of all childbearing women are HIV positive with variations in rate according to geographical area. Inner city areas in New York City, Florida and the District of Columbia account for the largest numbers of seropositive women (Luzuriaga & Sullivan, 1997). In 1994, HIV infection was the third leading cause of death for women between the ages of 25 and 44, the childbearing years (Centres for Disease Control, 1996). In Canada, the seroprevalence rate is much lower with an average rate of 3 per 10,000 pregnant women. Manitoba has shown a dramatic change in rate from 0.7/10,000 in 1991 to 3.2/10,000 in 1994/1995. This is likely a reflection of the changing nature of HIV infection in the province with spread of the disease to the heterosexual population.

The rate at which pregnant HIV infected women transmit the virus to

their infants is also variable. In parts of Africa the transmission rate was reported at 40 % in the early years of the epidemic; European studies have reported a rate of 13 %. Recent studies suggest an average rate of 25 % in Western countries (European Collaborative Study, 1992; Peckham & Gibb, 1995). Prophylactic therapy with zidovudine to prevent transmission has lowered the rate of perinatal transmission to 7.6 % in one study (Sperling et al., 1996) and 5.7 % in another (Fiscus et al., 1996). It is predicted that with universal zidovudine use in pregnant HIV infected women, the rate of perinatal transmission can be lowered to 2 % (Bryson, 1996).

Following this description of the epidemiology of HIV infection in women, what follows is a review of what is known about HIV infection in pregnancy and the treatment of pregnant women.

HIV in Pregnancy

A discussion about HIV screening in pregnancy is not complete without mention of how the disease affects women, particularly pregnant women. Both pregnancy and HIV infection are associated with altered immunity (Biggar et al, 1989). Recent advances in the understanding of the natural history of this disease in women provide opportunities for interventions to reduce perinatal transmission and to maintain immune function in the woman (Bryson, 1996). In addition, it appears that the rate of disease progression in the infant is directly related to the severity of the disease in its mother (Blanche et al., 1994). A marker used to measure immune functioning is the CD4 cell (leu3/T4), which is the

helper T lymphocyte cell to which the human immunodeficiency virus attaches and destroys during viral replication. The number of CD4 cells per cubic milliliter of blood is regarded as an indication of immune functioning.

Gloeb et al. (1992) investigated the survival and disease progression in a cohort of HIV infected women after an index delivery. One hundred and three women were followed for three years after delivery; 79.6 % were asymptomatic at entry into the study, 12.6 % had lymphadenopathy and 7.8 % had an AIDS diagnosis. Over the three years of the study, 69 % of the asymptomatic group had evidence of progression of disease, primarily development of lymphadenopathy. The ethnicity of this cohort was largely Haitian (53.4 %) and African American (35.9 %) and only a small percentage of whites (10 %). This study was conducted early in the epidemic, between 1986 and 1988, which calls for caution in the generalization of these results. However, the results do provide a snapshot of disease progression during and following pregnancy.

Biggar and associates (1989) conducted a longitudinal prospective study of HIV-infected pregnant woman and a matched control group of uninfected women at the same stage of pregnancy. This study showed that in the infected group, CD4 levels fell during pregnancy and did not recover in the postpartum period. CD8 levels, another immunological marker of HIV infection, in the infected group also increased greatly in the post partum period. This loss of CD4 cells occurred at a rate of 2% per month compared to uninfected women and was in addition to the normal immune suppression seen in pregnancy, most

commonly in the third trimester.

Alliegro and others (1997) followed a cohort of 331 women for five and a half years in fourteen clinical centres in Italy. This study found that women with HIV infection did not experience more rapid progression in their disease during pregnancy. Sixty nine of the cohort had at least one pregnancy before or after being diagnosed as HIV infected. There was no difference between those who experienced a pregnancy and those who did not in terms of progression to AIDS or CD4 count less that 100 cells per mm^3 of blood.

While there is conflicting evidence regarding the effect of pregnancy on disease progression as discussed above, HIV-infected women in one study reported declining perception of quality of life as well as decreased levels of social and cognitive functioning (Larrabee et al., 1996). Compared to HIV negative women, the entire perinatal period was perceived to be increasingly stressful and associated with poorer functional status. Pregnancy is a stressful time generally, however of note in this study is that for HIV-infected women, the post partum period was one of perceived decline in both physical and mental functioning.

HIV in the Prenatal Period

HIV has been isolated from fetal tissue at 10 weeks gestation and also from amniotic fluid. Perinatal transmission is theorized to occur by passage of the virus across the placenta (Luzuriaga & Sullivan, 1997). It is thought that some infants are infected early in the pregnancy and this may be evidenced by positive

polymerase chain reaction (PCR) within 48 hours of birth (Dunn et al., 1995). Placental factors may play a role with breaks or leaks in the placenta caused by infection increasing the risk of viral passage and infection (Bryson, 1996).

Immunological and Virological Factors

Women with advanced clinical disease and those with primary infection during pregnancy have a high risk of transmitting HIV to their infants. Maternal virus load (the number of viral particles) appears to be a strong predictor of transmission and is related to low CD4 count (Bryson, 1996). A study reported at the 11th International AIDS Conference demonstrated that for pregnant women with a viral load greater than 32, 000 per millilitre, the transmission rate was 65%. In the group with viral load below detection the transmission rate was still 22%. This study also found that viral load had the greatest predictive value in women with a CD4 count greater than 500 x 10^6 per litre who did not have an AIDS diagnosis. For every 10 fold increase in viral load in this group, there was an 18 fold increase in the likelihood of transmission (Thea et al., 1996).

Sperling and others (1996) in a further analysis of data from AIDS Clinical Trials Group (ACTG) Protocol 076, found that perinatal transmission rates decrease as viral levels decrease, however, they could not show an absolute plasma RNA level below which transmission does not occur. They found that women in the control group (i.e. not treated with zidovudine) had lower CD4 counts and higher CD8 counts, and also had higher rates of transmission of HIV to the fetus (22.6% in the placebo group vs. 7.6% in the treatment group). These

results appear to confirm the findings of Biggar et al. (1989) relating to CD4/CD8 counts in pregnant women. A more recent study from Europe found that viral ribonucleic acid (RNA) levels were higher in women with low CD4 counts. However, viral RNA levels did not vary during pregnancy which suggests that pregnancy does not lead to increased short term disease progression (Mayaux et al., 1997). The women did not receive zidovudine in pregnancy in this study. This appears to contradict the earlier findings of Biggar (1989) however, the difference may be related to the sample; fewer of the women in Mayaux's study were infected through drug use (17 %) compared to Biggar's study (79 %). Burns and associates (1997) measured RNA in 160 HIV infected women and found a strong association between third trimester RNA level and vertical transmission. This association remained significant when a variety of factors were controlled for including CD4 count, p24 antigenaemia (the presence of components of the viral envelope in the blood) , duration of ruptured membranes, drug use during pregnancy, and frequency of sexual activity. Lillo and others (1997) suggest that careful control of maternal viral markers, such as CD4 count and viral load, through the use of anti-retroviral and other therapies may be a way of reducing perinatal transmission.

St. Louis et al. (1993) studied HIV infected pregnant women in Kinshasa, Zaire and also found a strong association between high maternal CD8 count and perinatal transmission, however no association was found for CD4 count. This study found that the highest perinatal transmission risk was associated with p24

antigenaemia and corresponded to increased risk of perinatal transmission in early maternal infection. The study population, 324 HIV infected women in Zaire was compared to a control group of 254 non- infected women, and may be unique to sub-Saharan Africa. Results may not be generalizable to North American women as the strain of HIV that these women were infected with may differ markedly from the strain commonly found in North America. The French Pediatric HIV Infection Study Group (Blanche et al., 1996) found that perinatal transmission was highly associated with p24 antigenaemia in the mother (odds ratio = 3.49, 95 % confidence interval, 1.93 to 6.30, $p < .001$). The sample in this study comprised 34.1 % from sub-Saharan Africa and the Caribbean and 36.5 % injection drug users. The European Collaborative Study (1996) found an almost linear positive relationship between CD4 count and perinatal transmission but no relationship between CD8 count and transmission. This study did not measure viral RNA or p24 levels. This sample was largely white and risk for maternal HIV infection was twice as likely to be related to injection drug use as sexual contact.

Tuomala and colleagues (1997) compared 226 HIV infected women with 100 uninfected controls and found that CD4 counts increased slightly each week of pregnancy but there was an overall stability of lymphocyte parameters in HIV infected women during pregnancy. They found that in the first postpartum year, all lymphocyte markers increased to non-pregnant values.

The role of maternal antibodies in vertical transmission remains

controversial. It is thought that the ability of the mother's antibodies to neutralize her strain of HIV may play a role in vertical transmission. The efficacy of administering poly- and monoclonal antibodies to both mother and infant in order to reduce vertical transmission is under investigation (Bryson, 1996).

HIV in the Intrapartum Period

There is increasing evidence that intrapartum transmission of HIV may be one of the major routes of perinatal transmission. This transmission may occur through ascending infection in the birth canal, through exchange of blood between mother and infant, or through direct contact of the infant with vaginal or cervical secretions (The European Collaborative Study, 1994).

One of the first studies suggesting the link between mode of delivery and perinatal transmission was a study of serodiscordant twins, that is twins where one is HIV infected and the other is not. First-born twins born vaginally were more likely to be HIV infected than second-born twins, born by Caesarean section. These results led to the theoretical link between maternal secretions and transmission (Goedert et al., 1991). HIV is found in cervicovaginal secretions in up to 30 % of pregnant women (Bryson, 1996) and it is thought that contact with secretions in the birth canal facilitates transmission from mother to child.

The European Collaborative Study (1994) reported that transmission to the infant was reduced in women having caesarean births. This prospective study of 1,254 mother-child pairs found that the risk of transmission was 51 % lower in caesarean deliveries (emergency or elective) than in vaginal deliveries.

This result was obtained after controlling for confounding factors such as CD4 count. This reduction is thought to occur as a result of decreased direct contact with blood and cervical secretions in the birth canal, as well as a decrease in late ascending infection and transfusion of maternal blood into the fetal circulation. In this study, transmission rates were 17.6 % for vaginal deliveries and 11.7 % for caesarean section. This finding is supported by a study from Switzerland reported at the 11th International Conference on AIDS (Kind, 1996) in which the additive effect of zidovudine treatment during pregnancy combined with elective caesarean section reduced vertical transmission in the treatment group from 14 % to 0%. Caesarean section alone in this study reduced vertical transmission from 21 % to 9 %. A recent meta-analysis of 15 prospective cohort studies investigating the relation between elective cesarean birth and vertical transmission suggests that vertical transmission is reduced when cesarean births are performed and this is independent of the effects of treatment with zidovudine (International Perinatal HIV Group, 1999). This meta-analysis considered 7,840 mother-child pairs and found that the likelihood of transmission was reduced by 87% when both zidovudine therapy and elective cesarean section were used. The rate of vertical transmission in women who took zidovudine and had an elective cesarean birth was 2% as compared with 7.3% with other types of delivery. However, these benefits must be weighed against the risks associated with operative delivery including blood loss, infection, and higher rates of maternal mortality.

Reduction in transmission by cesarean section was not supported by a study conducted by the French Pediatric HIV Infection Study Group (1996). This prospective multi-centre study involving 1,842 HIV infected women between 1985 and 1993 found that procedures such as amniocentesis and amnioscopy during pregnancy were associated with a two-fold increase in transmission, and bloody amniotic fluid with a four-fold increase. They failed to show an increase in transmission with instrumental delivery, fetal skin abrasions, prolonged labor or damage to the perineum. Transmission was not decreased by caesarean section. They concluded that transmission is independent of factors associated with management of labor.

The French Pediatric HIV Infection Study Group (1996) did, however, find that premature rupture of membranes was associated with increased vertical transmission. Stepwise logistic regression demonstrated that this event increased the risk of transmission (odds ratio 1.55, 95% confidence interval 1.06 to 2.25, $p < 0.03$) however, this was not related to length of time of rupture. Landesman and colleagues (1996) showed a 25% rate of transmission when membranes had been ruptured for longer than four hours compared to 14% in cases when rupture of membranes was of less than four hours duration (odds ratio 1.82, 95 % confidence limits, $p = 0.02$). The concept of ascending infection and involvement of cervico-vaginal secretions is supported by both studies.

The role of preterm labor also has been investigated. The European Collaborative Study (1994) found that infants born before 35 weeks had a much

higher risk of vertical transmission ($X^2 = 9.91$, 2 df, $p = 0.007$) which they theorize to be related to immaturity of the infant's immune system and low levels of maternally derived antibodies. Mandelbrot and associates (1996) also found that prematurity is related to increased rates of transmission but they suggest that this is more likely due to premature rupture of membranes. They found that the mean duration between rupture of membranes and delivery is longer for infected infants than for uninfected infants but the difference is not statistically significant. Landesman's study (1996) found an association between gestational age, low birth weight and vertical transmission (odds ratio = 1.86, $p = 0.04$). Two American studies found no association between transmission and gestational age. Minkoff et al. (1990) conducted a small study comparing 101 HIV infected women with 129 uninfected women in the Bronx and Brooklyn, New York. After controlling for confounding variables such as drug use and maternal age, no significant association was found for pediatric serostatus and gestational age. Another study looked at a cohort of women who were 98% Black and 59% injection drug users; 27% of the women denied any other risk factor for HIV infection (Nesheim et al., 1994). This study found no association between prematurity and vertical transmission.

St. Louis et al. (1993) suggested that post-maturity with permeability of the placental barrier, the cracked and peeling skin often seen in post-mature infants, as well as complications of delivery associated with advanced gestational age may play a role in vertical transmission. However, in North America,

women are generally induced before reaching more than 42 weeks gestation. The condition of the placenta and infection of the cord or membranes may also play a role in vertical transmission. St. Louis et al. (1993) and Landesman et al. (1996) found that funisitis and chorioamnionitis were associated with higher rates of vertical transmission. Prolonged maternal fever is statistically associated with vertical transmission (St. Louis et al., 1993) but this may be associated with chorioamnionitis or other infectious disease in the mother.

An association between sexually transmitted disease (STD) and vertical transmission has been reported in the literature. HIV infected women who have an STD during pregnancy are more likely to transmit HIV to their infant (odds ratio 1.5, 95% confidence interval 1.1 to 2.0, $p = 0.003$) (Mandelbrot et al., 1996).

Breast Feeding and Other Factors

Breast feeding, although not an intrapartum event, has been associated with a 14 % increase in transmission to the infant (Dunn, 1992). A small study from Soweto, South Africa reported 46% of breast fed babies were HIV infected compared to 18% of formula fed babies (McIntyre et al., 1996). Another study from Cote d'Ivoire (Ekpini et al., 1997) followed a cohort of babies for 48 months. All were breast fed, with the median duration of breast feeding being 20 months. Twelve percent of these children who were not HIV infected at six months of age were infected by 24 months of age. Twenty eight percent of the sample became infected before six months of age. These authors and others (Kuhn & Stein, 1997) make the suggestion that by weaning children at six months, late postnatal

transmission may be reduced. If these children are weaned directly onto solid foods, many of the risks of diarrheal disease may be avoided. This debate is ongoing with the risks of contracting HIV from breast feeding being weighed against the risk of dying from disease which may be prevented by breast feeding (Kennedy et al., 1990; Zimmer & Garza, 1997). Another suggestion for women in developing countries is to discard colostrum and early milk to reduce postnatal transmission and to discourage mothers with clinical AIDS, depressed CD4 counts and PCR positive cells in breast milk from breast feeding (Mok, 1993; Van de Perre et al., 1997). The presence of HIV infected cells in breast milk 15 days postpartum was found to be a strong predictor of HIV infection in the neonate (Van de Perre et al., 1993). In North America, HIV infected women are instructed to avoid breast feeding, however, this mode of transmission may play a role if a woman does not know she is HIV infected and inadvertently breast feeds her infant.

In a study from Malawi (Semba et al.,1991), vitamin A deficiency was linked to an increased risk of perinatal transmission. A recent report from the United States (Greenberg et al., 1997) supported the theory that severe vitamin A deficiency is associated with perinatal transmission. Multivariate logistic regression analysis showed a positive association (adjusted odds ratio = 5.05, 95% confidence interval 1.20 - 21.24) after controlling for factors including percentage CD4 cells and duration of rupture of membranes.

There appear to be differences between American and European studies of

factors influencing perinatal transmission. The women in North American studies tend to be predominately injection drug users and those in European studies are largely of African ethnicity and have become infected through heterosexual intercourse. These demographic variables may account for the differences in results comparing caesarean birth, gestational age, and rupture of membranes. Factors such as access to care may influence interventions used in the intrapartum period.

Treatment of HIV Infected Women

The major focus in treatment for HIV infected pregnant women has been on reducing the risk of vertical transmission. Reported studies have largely described asymptomatic women who have never taken zidovudine and have been prescribed this anti-retroviral in accordance with recommendations following ACTG Protocol 076.

Drug Therapy

Some of the questions arising from the publication of Connor's (1994) landmark trial focus on the effect of zidovudine on the woman's disease process and the potential for development of resistant strains of HIV (Downes. 1995). A small study by Frenckel and associates (1995) demonstrated that perinatal transmission of zidovudine-resistant HIV is possible. Some of the women in this study received zidovudine as part of routine care before conception; they were not given the drug during labour and their infants were not treated in the neonatal period. In this study, the average duration of zidovudine therapy was

52 weeks and women had low CD4 counts, suggesting more advanced disease. Vertical transmission occurred in 5% of the women treated with zidovudine compared to 26% of those not treated. One of the infants born to a woman in the treatment group had a zidovudine resistant strain of HIV. Although these numbers are small, they are an indication that resistant strains of the virus can be transmitted. Until it is known definitively how zidovudine prevents transmission, by its effect on viral load or on reverse transcriptase in the infant, the optimal protocol for zidovudine therapy remains in question.

Zidovudine use in pregnancy does not appear to have adverse effects on the woman herself. Sperling et al. (1992) reported on 43 women taking zidovudine at doses ranging from 300 to 1,200 mg per day. In this group, two women reported toxicity, one gastrointestinal and the other hematological. Connor et al. (1994) reported 18 cases of hematological toxicity in the sample of 400 women.

Compliance with therapy is an issue with any pharmaceutical regimen but particularly with a disease like HIV infection where infected individuals are often asymptomatic. Compliance also may be affected by belief about the efficacy of zidovudine to reduce vertical transmission, access to health care, costs associated with the medication, social and cultural attitudes to medication, and other lifestyle factors such as maternal recreational drug use (Wiznia et al., 1996). Wiznia and associates studied 49 HIV infected women who were offered zidovudine therapy. Seventy five percent (37 women) chose to receive the drug

during the antenatal period, during labor, and for the neonate. Of these, only 67% received all components of the regimen. Many of these women were active recreational drug users and this was found to be a predictor of refusal of treatment or failure to complete the recommended regimen. An additional complication with this cohort was the late presentation at time of delivery which often prevented intravenous infusion of zidovudine. Seals and colleagues (1996) presented 184 HIV infected women in Atlanta, Georgia with a variety of scenarios and asked them to indicate their acceptance of zidovudine therapy under various conditions, including health care provider attitude to therapy (strong supports vs some doubts). Results of the study suggest that while women generally have an interest in zidovudine therapy, they are influenced primarily by the attitude of their health care providers.

Gwinn and colleagues (1997) conducted an anonymous population based study in Florida to estimate the proportion of HIV infected women who received zidovudine during labor. They found that approximately half of the HIV infected women in Florida who delivered during the period of the study received intravenous zidovudine but this was somewhat dependent on where they delivered. Hospitals where more than 10 HIV positive women had delivered during the study were more likely to offer this treatment.

A recent study of abbreviated regimens of zidovudine prophylaxis suggests that reduction in perinatal transmission can occur even when zidovudine is given in the intrapartum period only or in the first 48 hours of life

(Wade, Birkhead, Warren, Charbonneau, French, Wang, Baum, Tesoriero, & Savicki, 1998). This study showed that if zidovudine was started during the intrapartum period, the perinatal transmission rate was 10%. When treatment was given to the neonate within the first 48 hours of life, the transmission rate was 9.3%, and when given to the neonate on day three of life or later, the rate rose to 18.4%. In comparison, the transmission rate for those who began treatment in the prenatal period was 6.1% and for those who received no treatment at all, the rate was 26.6%.

One of the questions arising from ACTG Protocol 076 is the effect of zidovudine use in pregnancy on the long term health status of women. Beyond the immediate toxicities discussed earlier, there appear to be no major side effects. Concerns about zidovudine-resistant strains developing from short term use of the drug during pregnancy may be alleviated by clinical reports of resistance developing only after 18 to 24 months of therapy (Minkoff & Augenbraun, 1997).

The use of other anti-retrovirals during pregnancy to reduce perinatal transmission is currently being studied. Phase I trials of lamivudine have demonstrated that the drug crosses the placenta and is well tolerated by the maternal-fetal pair (Johnson et al., 1996). There are no reports in the literature of trials involving pregnant women and protease inhibitors (Minkoff & Augenbraun, 1997). Nevirapine, a non-nucleoside reverse transcriptase inhibitor passes through the placenta and may prove to be a useful drug for use during

labour (Bryson, 1996). A study using this drug from Africa demonstrated a 50% reduction in perinatal transmission in a breast feeding population during the first 16 weeks of life. Of note is that this drug is given in a single dose to the laboring woman and once to the neonate within 72 hours of birth (Guay et al., 1999).

Minkoff and Augenbraun (1997) suggest that pregnant women with CD4 cell counts below 500 per cubic millimetre should be given combination therapy despite a lack of evidence of safety. They state that zidovudine therapy was given to pregnant women before the safety of that therapy in pregnancy was proven. An ongoing problem with clinical trials is that pregnant women are usually excluded and thus until specific trials to establish safety during pregnancy are undertaken, pregnant women are effectively precluded from clinical benefits derived from new findings. Minkoff and Augenbraun (1997) suggest that women be allowed to exercise their autonomy in deciding which drugs to take during pregnancy, provided that any drugs under consideration be shown to be safe in animal models and not closely related to proven teratogens. They further state that any therapy regimen for the pregnant woman should contain zidovudine for the potential benefit of reduced perinatal transmission. Rachlis and members of the Canadian HIV Trials Network Anti-retroviral Working Group (1998) have recently suggested that if a woman on combination therapy becomes pregnant, she should be allowed to continue with her treatment and should be carefully monitored.

The future of anti-retroviral therapy for pregnant women will

undoubtedly offer many challenges. Currently, clinical trials focus on the long term effects of zidovudine and other anti-retroviral drugs on the health of the woman both during pregnancy as well as after the delivery (Wilfert, 1996). As more women with HIV infection choose to become pregnant, there will need to be further consideration of how combination therapy may benefit these women at the same time as examining the potential benefits and harms to the fetus.

Antenatal Care

Care for the HIV infected woman during pregnancy should be multidisciplinary and patient-focused recognizing the unique biopsychosocial circumstances of each woman. In the antenatal period, it is important to monitor hematological indices as well as markers of immunological functioning. Nutritional assessment is important for both maternal and fetal well-being. In the future, the role of vitamin A supplementation may be part of routine prenatal care of HIV infected women (Bardequez, 1996). The woman should be taught the signs and symptoms of preterm labor as well as the need for prompt hospitalization should rupture of membranes occur.

Cervical screening for dysplasia and neoplasia is an important aspect of ongoing health care for HIV-infected women and the antenatal period presents a window of opportunity to begin surveillance and to educate the woman (Dinsmoor, 1994). HIV-infected women are more likely than seronegative women to have a prior history of sexually transmitted disease (STD) (Zenilman et al., 1992). Syphilis in particular is more common among HIV-infected women

and, if untreated, can have severe consequences for both mother and child. Congenital syphilis can lead to stillbirth (Ault & Faro, 1993) and untreated syphilis in the adult can lead to the development of neurosyphilis, a common neurological manifestation in HIV-infected adults (Bardequez, 1996). Syphilis may represent a behavioral risk for HIV infection or facilitate transmission of the virus through the occurrence of genital ulcers (Williams, 1992).

Intrapartum Care

HIV infected women need special attention during labour and delivery to minimize the risk factors thought to increase perinatal transmission occurring at this time. These include avoidance of invasive procedures such as amniotomy and the insertion of scalp electrodes (Landers & Sweet, 1996), induction of women who present with spontaneous rupture of membranes without contractions (Bardequez, 1996), and of course initiation of intravenous zidovudine at the recommended rate. Vaginal lavage with virucidal agents, theorized to reduce transmission as the baby travels down the birth canal, has not proved to be effective in reducing transmission (Mandelbrot et al., 1996). Elective caesarean section as a means of reducing vertical transmission remains controversial due to inconsistent evidence supporting this as a method of reducing transmission and the associated risks of maternal morbidity with operative delivery (Bardequez, 1996; Stringer, Rouse & Goldenberg, 1999). However, results of a randomized clinical trial in Europe of 408 pregnant women show that the perinatal transmission rate among those who had undergone

elective caesarian section was 1.8% . The rate among those women who delivered vaginally was 10.5%. Authors concluded that elective caesarian birth lowered the risk of perinatal transmission by 80% (The European Mode of Delivery Collaboration, 1999). A meta-analysis of 15 prospective cohort studies included data on 8,533 mother-child pairs. The authors of this analysis concluded that elective caesarian birth reduces the risk of perinatal transmission independent of the effects of treatment with zidovudine (The International Perinatal HIV Group, 1999). Stringer, Rouse and Goldenberg (1999) suggest caution before routinely performing elective caesarian sections for HIV-infected women because those women on zidovudine had a non-significant reduction in perinatal transmission in clinical trials and those on combination therapy have not been included in clinical trials of prophylactic caesarian section to date. Due attention to the woman's emotional state at this time is important to identify potential problems with coping or depression in the immediate postpartum period.

AIDS Clinical Trials Group Protocol 076

The importance of HIV screening in the prenatal period changed dramatically in 1994 when Connor and colleagues demonstrated both the safety and efficacy of zidovudine for the reduction of perinatal transmission. Before that, identification of HIV infected women was important so that surveillance of both women and infants could be undertaken and prophylaxis of opportunistic infections could be offered. There was very little therapy available and a "wait and see" approach was practiced (Heagarty & Abrams, 1992; Smith et al., 1996).

In this landmark paper by Connor and colleagues of the Pediatric AIDS Clinical Trials Group Protocol 076 Study Group, the results of the first interim analysis of data were so promising that it was recommended that further enrollment of subjects be halted and the study unblinded. Based on this early analysis, a number of organizations called for routine testing of pregnant women for the presence of HIV antibodies or at least that pregnant women be routinely offered HIV testing in the prenatal period (College of Physicians and Surgeons of Manitoba, 1995; Society of Obstetricians and Gynecologists of Canada, 1997).

The reason for Connor et al.'s study is described as the assessment of the safety and efficacy of zidovudine for the prevention of maternal-infant HIV transmission. Animal studies had shown that zidovudine had an effect on perinatal transmission and Phase 1 studies in pregnant women indicated that zidovudine crossed the placenta and was safe when used for short periods.

The importance of this study cannot be overstated. Perinatal transmission is the primary cause of HIV infection in children and up to 40% of pregnancies in HIV infected women result in HIV infected infants (Centers for Disease Control and Prevention, 1994). Any intervention that reduces perinatal transmission could save lives and reduce the burden of suffering to families and save health care dollars. The recommendation to offer HIV testing to all pregnant women has generated a great deal of discussion about mandatory versus voluntary screening as well as fetal and women's rights. Health care professionals have been challenged in the arena of routine screening in pregnancy and informed

consent for such interventions.

The design used in Connor et al.'s study was a double-blind, placebo controlled, randomized clinical trial. Fifty sites in the United States of America and nine in France participated in the study. Inclusion criteria were clearly stated in the paper and included pregnant HIV-infected women between 14 and 34 weeks gestation with greater than 200 CD4 cells per cubic millimetre of blood who were asymptomatic. It is unclear why this particular level of CD4 count was used other than a presumption of relative health at this level as well as the absence of prophylactic medications for opportunistic infection that are usually recommended below 200 CD4 cells per cubic millimeter of blood. A number of laboratory criteria had to be met and the fetus had to be free of anomalies on ultrasonographic investigation. In addition, women who had received anti-retroviral drugs, immunotherapy, cytolytic chemotherapy or radiotherapy in this pregnancy were excluded. It is reasonable to assume that excluding any treatments would avoid confounding of results.

Two groups were identified among those eligible for enrollment. One group comprised those between 14 and 26 weeks gestation and the other greater than 26 weeks gestation. Subjects were randomly assigned to receive either zidovudine or placebo. Route of administration varied with oral AZT for the woman in weeks 14 through 34, intravenous AZT during labor and oral AZT for the neonate for the first six weeks of life. The rationale for administering the drug through these three stages is that the exact timing of vertical transmission is

uncertain. Further justification for the regimen stated that intravenous infusion during labor eliminates the problems of oral administration during a time when gastric motility is altered and women are usually restricted from oral intake. The dosage of AZT for the neonate was based on studies of AZT in newborns when HIV infected maternal cells may be circulating in the neonate's system. Following established guidelines, the treatment was offered only after the first trimester of pregnancy to avoid the period of organ development. With further research and clearer understanding of the mechanisms and timing of vertical transmission, it may be possible to administer AZT for shorter periods of time and in larger or smaller doses.

The pregnant women were monitored clinically and by ultrasound examination through the pregnancy. Clinical monitoring continued for six months after delivery and the neonate was monitored for 7.5 months after birth. HIV cultures were performed on the infants' blood at birth, and at 12, 24, and 78 weeks of life. ELISA and Western blot assays were performed at 72 and 78 weeks of age. All laboratory testing was performed in certified laboratories using commercially available methods.

The endpoint for defining HIV infection in the infant was defined as a single positive culture at each of four stages. The researchers instituted a double check by performing a second Kaplan-Meier analysis requiring two positive cultures or two negative cultures, one of which had to have occurred at more than 24 weeks of age. This conforms to the current clinical practice of confirming

a single positive culture by a second culture or polymerase chain reaction.

Statistical analysis compared the two treatment groups using the Kaplan-Meier method which allows comparison of the two groups by percentage of those infected at a predetermined point, in this instance at 18 months of age. This method of analysis is a type of survival curve and is a useful way of measuring "survival" prospects facing individuals at risk for a certain disease. For this study, HIV infection rather than death was the endpoint.

Investigators intended to enroll 636 mother-infant pairs into the study. At the time of the analysis, 409 mother-infant pairs were included. The initial sample of 636 pairs was calculated based on the necessary power, however, the results of the first analysis were so significant that the trial was ended with the enrollment at 409 pairs. An analysis was performed on the results from 400 cultures to September 1994, nine months after the initial analysis. The updated results supported the findings from the first analysis.

The paper reported on data available from subjects enrolled between April 1991 and December 1993. In this period, 477 pregnant women were enrolled and 409 of these gave birth. The 68 women who were not part of the analysis included two women who had a history of positive serostatus but were later found to be uninfected. Twelve women withdrew before delivery. The other 54 are presumed to have been undelivered as of December 1993 when the initial analysis was performed, although this is not stated explicitly in the paper. Twelve of the pregnancies resulted in twins and these were regarded as a single

delivery in the analysis. In the instance of twins, all had concordant negative serostatus.

Both groups were very similar. Information about intrapartum events reported that might relate to perinatal transmission was restricted to mode of delivery, premature rupture of membranes, placental abruption, and fetal scalp monitoring or sampling. There is no report of other risk factors for perinatal transmission such as maternal p24 antigenaemia, maternal CD8 count, persistent fever during pregnancy, chorioamnionitis, inflammation of the cord at its insertion into the placenta (St. Louis et al., 1993), bloody amniotic fluid (Mandelbrot et al., 1996) , or rupture of membranes for more than 4 hours (Landesman et al., 1996). These factors have been identified as being associated with increased perinatal transmission in studies conducted prior to 1993.

Rates of seroconversion according to the Kaplan-Meier analysis at 18 months were 8.3% for the treatment group and 25.5% for the placebo group. Further analyses with a more stringent definition of HIV infection were performed (two positive cultures for positive serostatus and at least two negative cultures with no positive culture for negative serostatus) for two groups; infants older than 32 weeks and infants older than one year. In both groups the percentage infected with HIV remained almost the same and the results were once again highly significant.

The intention to study safety was addressed by describing adverse effects on maternal health. No women died during the course of the trial. In both the

treatment and placebo groups equal numbers of women stopped therapy due to anemia (n = 18 and n = 17 respectively) and also due to electrolyte and liver function abnormalities (n = 8 and n = 7). The latter are attributed to labour and delivery with no further comment made in the study.

Brief mention is made of six women in total (three in each group) who stopped therapy due to 'toxic effects'. There is no description of exactly what these were. Although the absolute number of those stopping therapy is very low, there is no mention of the acceptability of this therapy for women. The authors report on CD4 counts during follow-up but these statistics are confusing and seemingly not comparable. While 95% of the women had greater than 300 CD4 lymphocyte cells at six months, the median CD4 count at the beginning of the trial was 550 per cubic millimetre and only 21% of women continued with zidovudine therapy after the trial (40 of 189 at six months). Zidovudine therapy is recommended for anyone with less than 500 CD4 cells and it would have been enlightening to explore the issue of patient acceptability in this cohort in greater depth.

Measures of CD4 lymphocyte counts at six weeks and six months after delivery showed no significant differences between the two groups. It is unclear why the CD4 count should increase for those in the placebo group and this is not dealt with in any way. The authors state that the increase in CD4 count from baseline was greater for the treatment group than for the placebo group, however, these results are not statistically significant (p = 0.02 at six weeks and p

= 0.12 at six months).

Evaluation of infant safety is described in terms of deaths, prenatal and neonatal evaluation, structural abnormalities, and adverse effects. Fifteen deaths were reported, eight in the fetal or neonatal period (five in the treatment group and three in the placebo group) and seven in infants beyond the neonatal period (two in the treatment group and four in the placebo group; one infant in the treatment group died as a result of trauma unrelated to disease). No deaths were attributed to zidovudine use, however, two fetal deaths could be surmised to have occurred due to factors related to HIV infection in utero, namely chorioamnionitis and preterm labour (St. Louis et al., 1993). These deaths were both in the treatment group. There is no mention of post mortem HIV testing of any of these, thus excluding them from the preliminary analysis. There was no evidence of any difference between the two groups in terms of prenatal ultrasonographic examination or structural abnormalities.

There was a difference noted in the incidence of anemia between the two groups with infants in the treatment group experiencing lower hemoglobin concentrations. This difference was greatest at three weeks of age and by 12 weeks both groups were equal. The authors state that other outcomes of safety measures were observed as being similar. This refers to measures of serum bilirubin, neutrophil and platelet count, and alanine aminotransferase concentration. Median birth weights were similar in the two groups, as were gestational age and number of infants with low birth weight. It is unclear why

the authors used median measures rather than the mean. They did not include Apgar score at birth as a parameter which could have been useful as a descriptor of neonatal well being.

The researchers concluded that AZT use during pregnancy, labour and in the neonatal period successfully reduced perinatal transmission by two thirds. The safety of this intervention is supported by the lack of toxic side effects and no evidence of progression to AIDS or difference in CD4 count from the placebo group. Transient anemia was observed in the treated infants but this was reversible and mild.

The authors further speculated on the mechanisms by which the intervention may have reduced perinatal transmission and also on the reasons why the intervention failed to protect some of the cohort. The exclusion of women with more advanced HIV disease, those who have had prior anti-retroviral treatment, and those with AZT-resistant strains of the virus were identified as potential threats to the generalizability of the results of this study. In addition, suggestions for further research are made including testing a simplification of the treatment regime.

The primary aim of the study was to assess the efficacy and safety of zidovudine therapy during pregnancy. Few safety issues were identified beyond transient anemia in the newborn which resolved by twelve weeks. The dramatic reduction by 67% of perinatal transmission attests to the efficacy of this intervention.

The authors chose to discuss only risk reduction in this study. Other measures of efficacy were not reported. One such measure is relative risk and a calculation of relative risk indicates the risk of infection among infants in the treatment group compared to the untreated group to be 0.014. This confirms the dramatic reduction of risk indicating the relevance of the measure used.

This study effectively demonstrated that administration of AZT during pregnancy, labor and in the neonatal period reduces perinatal transmission substantially. The publication of these results has led to widespread recommendations for the identification of HIV infected pregnant women so they may be offered treatment for themselves and their infants. The CDC Perinatal AIDS Collaborative Transmission Study reports the perinatal transmission rate in the USA has dropped to 11% from 21% since 1994 with AZT use increasing from 17% to 80% among pregnant women (Wilfert, 1996). These figures would be consistent with the change in relative risk associated with AZT use in pregnancy to reduce perinatal transmission as found in ACTG Protocol 076. The issue of reaching women who perceive themselves to be at low risk for HIV infection and educating them on the need to be tested for HIV antibodies is one that continues to challenge health care professionals.

Research now focuses on the role of maternal viral load in perinatal transmission (Sperling et al., 1996), short course AZT therapy (Frenkel et al., 1995; Mansergh et al., 1996), the potential for further reduction by using other drugs including protease inhibitors (Bryson, 1996), and the additive effects of

anti-retroviral drugs with interventions in labor (Coutino et al., 1996).

Connor's study (1994) resulted in calls for mandatory testing of all pregnant women. Mandatory testing means that women would be tested without consent and without the option of refusal (Jurgens, 1997, p. 57). Some suggested that mandatory testing would assist women in making treatment decisions. It was suggested that even if a woman is tested against her wishes, once she knows she is infected and is made aware of interventions that can reduce perinatal transmission, she would comply with pharmaceutical treatment (Hoffman & Munson, 1995). Bayer (1995) countered this by stating that mandatory testing of pregnant women for any disease is unjustified particularly if the disease is lethal with no cure, as is the case of HIV infection. He further stated, as have others (Fordham Knorr, Gantes & Lowe, 1996; Simonds et al., 1996), that mandatory testing violates the ethical principles of autonomy and self-determination as well as the right to privacy. Mandatory testing may jeopardize the physician-patient relationship and may cause some women to avoid prenatal care entirely or not return for test results and ongoing care (Downes, 1995; Simonds et al., 1996). Some have suggested that in areas of high seroprevalence, the physician may be justified in being somewhat more directive than merely offering testing. In these areas, physicians should recommend it highly to their patients and continue to discuss the issue at every opportunity with women who continue to refuse testing (Moreno & Minkoff, 1992).

In Canada, recommendations have been made that all pregnant women

should be offered HIV screening as a part of routine antenatal care. The Society of Obstetricians and Gynaecologists of Canada (1996) and the College of Physicians and Surgeons of Manitoba (1995) have both issued guidelines that screening should be offered to all pregnant women. The Canadian Pediatric Society (1995) recommends testing all pregnant women, however they state that testing should be voluntary and accompanied by appropriate counseling.

In the years since the publication of Connor's (1994) article, much discussion has focused on increasing the number of pregnant women being tested, sometimes to the exclusion of women's rights and consideration of their attitudes to testing. Central to this discussion is the attitudes and practices of health care professionals .

Care Provider Attitudes to Screening

Physician attitudes towards prenatal testing and their actual practices are of interest in the discussion of prenatal HIV screening. Segal (1996) asked 550 members of the American College of Obstetricians and Gynecologists about their attitudes to prenatal HIV testing and their practice. Sixty four percent of the respondents were in favor of mandatory testing but 92% believed that their own patients had a low seroprevalence and almost 20% of those surveyed did not provide any level of HIV counseling and testing in their own practice. In contrast, a study of physicians in the San Francisco Bay area in 1995 showed that 90% supported voluntary testing but only 40% were likely to encourage pregnant women without overt risk factors to have the test (Phillips et al., 1996).

In Australia, a 1992 survey of obstetricians and family physicians found that while 60% offered testing, only 20% of women were actually tested. This may be reflective of the time of this survey when the evidence was not yet available to support effective intervention for pregnant women (Elford et al., 1995). The manner in which the subject of HIV testing is raised by physicians and counselors plays a part in a woman's decision to be tested for HIV and whether she returns for the test results. Sorin and colleagues (1996) found an increase in acceptance of testing as the time taken for counseling increased. They also found that with an aggressive effort, most of those who tested positive returned for their test results.

In a Canadian study in Hamilton, Ontario, Ogilvie et al. (1997) found that only 8% of family physicians surveyed stated that they always discussed HIV as part of antenatal care and 5% always offered the HIV test in the first trimester of pregnancy. While most of the physicians' offices had written material available, almost half of the physicians gave out this information selectively. This survey was conducted in 1996 and the results are outstanding in that two years after the publication of the results of ACTG Protocol 076 and with recommendations for universal offering of the HIV screening test, the vast majority of family physicians in this study were still not offering the test to all pregnant patients.

A study conducted in Minnesota with obstetricians and family physicians found that 89% were in favor of universal prenatal HIV screening and 43% of the sample recommended HIV screening to pregnant women, however, the median

percentage of prenatal patients actually screened for HIV was only 10%. In this sample, female physicians were twice as likely to recommend universal screening (Mills, Martin, Bertrand, & Belongia, 1998).

In the United Kingdom where much of the antenatal care is provided by midwives, a study found that the discussion of HIV screening impacted negatively on the midwife-patient relationship and took on average 21 minutes to complete (Chrystie et al., 1995). Another British study found that the information given to women was inadequate due to lack of training on the part of midwives or lack of written information being available (MacDonagh et al., 1996). A small study of general practitioners in the United Kingdom (Sherr et al., 1992) reported that 55% of the sample stated that there were no high risk women in their practice and thus they were less likely to offer HIV screening. Grellier (1997) asked midwives, student midwives and their tutors about how they believed their knowledge about HIV impacted on their practice. Participants responded that it was common for midwives to make decisions about a woman's risk for HIV based on physical indicators such as color of skin and presence of tattoos. There was a tendency to avoid open discussion about risk factors due to a fear of negatively impacting on the client/midwife relationship. This may reflect discomfort on the part of the midwives in discussing matters that influence risk taking, such as injection drug use.

Methods of Offering HIV Screening

Screening for HIV in the antenatal period has historically been "selective". Only women identified by the health care provider or who self identify as being at risk for HIV infection have been tested. This method is seen as discriminatory and may give those not tested a false sense of security. Women may believe that if the physician does not assess them as being at risk then they do not need to be tested and can continue with their present behaviors (Mercey, 1993). The women who are selectively offered the HIV test may feel singled out and may become defensive, creating a barrier to effective communication and care (Remis & Patrick, 1998). There have been a number of problems identified with selective testing. Krasinski et al. (1988) reported that between 1986 and 1987, selective testing failed to identify 86% of HIV infected women in a small study in New York. Hawkens and associates (1995) conducted a study in the United Kingdom of 1,264 women. They wanted to ascertain the ability of their health care providers to identify risk factors for HIV from a routine history. Thirty nine percent of women in the study reported risk factors to the researchers that had not been identified by the health care provider. Barbacci, Dalabetta, Repke, Talbot, Charache, Polk and Chaisson (1990) determined that in the late 1980s at an inner-city prenatal clinic, 43% of seropositive women denied risk factors for infection. They concluded that limiting prenatal screening to those who acknowledge risk factors will fail to identify almost half of HIV-infected women. Thus it seems that selective testing is not effective in identifying those at high

risk. In fact, selective testing may stigmatize women perceived to be at high risk for HIV infection, and may be a barrier to antenatal care (Ammann, 1995). This form of screening has received a Grade D recommendation according to the evidence-based guidelines for Canadian health care workers (Samson & King, 1998) which means that there is fair evidence that selective screening should not be part of the periodic health exam.

The protocol of HIV testing in pregnancy has evolved from selective testing, where only women with identified risk factors are offered testing, to the routine offering of the test to all pregnant women (Moreno & Minkoff, 1992). Barbacci, Repke and Chaisson (1991) suggest that routinely offering an HIV test to all women instead of only to those at high risk improved acceptance rates. In their study, acceptance rates improved from a low of 48% with selective testing to a high of 90% with universal offering. A study from England demonstrated that acceptance of HIV testing in the prenatal period rose to 96% in a central London clinic after a policy of universal offering of HIV testing was instituted (Mercey et al., 1996).

Universal offering of the test means that all pregnant women are offered the test regardless of their apparent risk status. The offer of testing includes sharing information about the test and the benefits, or providing the woman with written information about the test and the opportunity for her to ask questions. This form of screening has received a Grade B recommendation for Canadian health care providers which means that there is fair evidence to

support the universal offering of the HIV test to all pregnant women as part of routine care.

A somewhat confusing method of screening for HIV antibodies in pregnancy is routine screening with voluntary opt-out for those who do not wish to be screened. This method means that all women will be screened unless they specifically request that the test not be carried out (Jurgens, 1997, p.57). The opt-in / opt-out debate is dealt with in detail later in this chapter.

The final method of screening for HIV in the antenatal period is mandatory screening where all pregnant women are screened without their express consent and with no ability to refuse the test. This method is patently in violation of the principle of autonomy of the individual patient, however, this method has been suggested as way of preventing the spread of HIV infection (Jurgens, 1997, p.57).

Pretest Counseling and Uptake

The counseling guidelines for HIV testing published by the Canadian Medical Association (Canadian Medical Association, 1995) suggest that prenatal testing for HIV should occur over several prenatal visits. It is recommended that at the first visit the reasons for testing should be explored and information given on perinatal transmission. In addition, risk reduction strategies should be discussed and written material and information on local resources should be provided. It is also suggested that the woman be given a separate requisition for the HIV test so that if she decides not to have the HIV test, she will still have the

other prenatal screening tests as marked on a requisition. The guidelines state that if the woman refuses to be tested or is undecided, the reasons for this should be explored on subsequent visits and duly recorded in the medical record.

The SOGC Practice Guidelines for Obstetrical and Gynecological Care of Women living with HIV (1994) comprehensively address the issue of HIV testing in the context of reproductive health care but do not deal specifically with prevention of perinatal transmission. These guidelines were written shortly before the publication of the results of ACTG Protocol 076. These guidelines clearly state the need for assessing high risk behavior and suggest the comprehensive education necessary for pretest counseling including information on the nature of HIV infection, the meaning of positive and negative results, confidentiality and informed consent as well as ethical issues, reporting and contact tracing. These follow quite closely the "traditional" framework for pretest counseling in a non-obstetrical setting.

Both of these methods are relatively time consuming and are likely to be perceived as an obstacle for busy practitioners. A recent Canadian study found that family physicians took an average of 10.6 minutes to provide pretest information to prenatal patients, with female physicians taking 14.2 minutes and males taking 7.5 minutes. Not surprisingly, most of the physicians surveyed believed that more funding should be available for this type of counseling (Ogilvie, Adsett & MacDonald, 1997). A study from London, England found that the average time taken for discussion was seven minutes in a clinic with a policy

of universal offering of the test (Gibb et al., 1998).

A large randomized controlled study compared the uptake of testing by a sample of 3,024 pregnant women who were assigned to one of four groups with different methods of pretest information (Simpson et al., 1998). Two of the groups were given a leaflet containing information about screening in pregnancy in general and either minimal or comprehensive discussion with a midwife. The other two groups were given a leaflet with specific information about HIV screening and either a minimal or comprehensive discussion with the midwife. A control group received neither leaflet. There was no statistical difference between the four groups, however, those having no information at all had much lower uptake (5% compared to 34%). The best predictor of screening was being offered the test. The minimal discussion took on average four and a half minutes and the comprehensive discussion took seven minutes. Gibb and colleagues (1998) found that women who disclosed risk for HIV had higher uptake than those who did not disclose, and discussing HIV with all pregnant women increased the uptake of testing two fold. Yet another study found that, as recently as 1994 and 1995, only 16% of HIV infected women were identified before delivery (Jones et al., 1998). The uptake of testing increased to 24% after a new program was instituted and women were twice as likely to accept testing if the pretest discussion lasted longer than five minutes.

Another study from the United Kingdom reported that 35% of those pregnant women who were offered the test accepted it, but a third changed their

minds between the time of offer and going for the test. Uptake was highest in hospital clinics (42%), with community clinics having an uptake of 30% and midwife clinics only 10%.

A more recent study from San Francisco found that 72% of the women interviewed accepted prenatal HIV screening and this acceptance was positively associated with knowledge of the interventions used to reduce maternal-child transmission of HIV infection. Of interest in these results is the fact that 69% of the women thought that the test should be part of routine blood work while only 27% called for specific written consent prior to performing the test (Carusi, Learman, & Posner, 1998).

In a study in London, England 67% of those interviewed thought that all pregnant women should be offered the test and then allowed to make a choice. In this sample, 35% of those offered accepted the test with those seeing a midwife accepting less often (10%) than those seeing physicians in either community clinics (30%) and hospital clinics (41%) (Duffy, Wolfe, Varden, Kennedy, & Chrystie, 1998). Another study from the United Kingdom found that while women generally were in favour of the test, they did not necessarily have the test themselves. Their perception was that the test may help the baby but they did not describe the test as being of benefit to themselves (Boyd, Simpson, Hart, Johnstone & Goldberg, 1999).

<u>The "Opt In" versus "Opt Out" Debate</u>

Much debate has centered around the issue of specific consent for the HIV screening test and the terms "opt in" and "opt out" have been used resulting in some confusion. To "opt in," a woman has to specifically request that the test be performed or consent to the offer of the test. This is after she has been given information, oral or written, about the test and this is what is commonly understood as informed consent. A system of "opting out" however, means that the woman would be screened unless she states that she does not want to be tested (Boyd, 1990). The same provision for information should apply, however, the onus is on the woman to decline. This is described as passive consent which is considered to be unethical for a number of reasons (Gunderson, Mayo & Rhame, 1996). The woman may not have understood the information given to her, she may not have received any information due to error on the part of care givers, and she may not have had the opportunity to have her questions or concerns addressed. She thus is not giving informed consent to be tested and the results can be devastating to her and her family, as well as impacting negatively on her relationship with her physician.

The "opt out" route is used in some practice settings (Lindgren et al., 1993) and it has been suggested that is it useful in areas where the seroprevalence is high and most women should be expected to know their risks for HIV infection as well as knowing that HIV screening is a routine part of antenatal care (Smith et al., 1996). In the Canadian context where reported seroprevalence ranges from a low of 3.2 per 10,000 in Manitoba (Ratnam, Hogan & Hankins, 1996) to a high

of 6.1 per 10,000 in Quebec (Hankins et al., 1990), the seroprevalence remains low and thus the assumptions stated above likely do not apply.

The latest recommendations from the Society of Obstetricians and Gynecologists of Canada (Society of Obstetricians and Gynecologists of Canada, 1997) call for physicians to offer HIV screening to all pregnant women and to provide these women with the information needed to make the decision whether or not to have the test. This guideline also recommends that a review of pretest counseling be performed to bring HIV testing in line with other forms of prenatal testing. There is a paucity of research concerning what information is provided to pregnant women regarding prenatal testing in general. Most of the tests, with the exclusion of the maternal serum alpha-fetaprotein (MSAFP) test, are performed without any information and without express consent. In contrast, the pretest counseling for HIV appears cumbersome, time-consuming and complicated to many physicians and as a result, may be ignored altogether.

A meta-analysis of articles from 1985 to 1995 identified a number of factors associated with high acceptance rates of HIV testing in the prenatal period. These include the woman's perception of risk for HIV infection, acknowledgment of participating in high risk behaviors, protection of her confidentiality, the belief that testing was indeed routinely offered to all women, and the health care provider's belief that testing would benefit the patient. The range of acceptance of prenatal screening reported was from 23 to 100 % with public hospitals testing more than 40 % of their patients. Routine offering of the

screening test, as opposed to selective screening, resulted in 96 % acceptance (Irwin et al., 1996). This suggests that acceptance of HIV testing is multi factorial and that in order to increase acceptance rates, attention should be paid to a range of factors having an impact on a woman's decision to be tested.

It appears from the foregoing discussion that while physicians appear to be in favour of prenatal HIV screening, their agreement with the recommendations does not always translate into high levels of uptake of the test. This is likely due to some reluctance on the part of the patient, the pregnant woman, to agree to testing. The following discussion will highlight some potential reasons for this.

Women's Experiences of HIV Screening in Pregnancy

The attitudes of women towards HIV screening in pregnancy has not been studied extensively. Only one study has looked at what women think about this intervention (Mawn, 1998). This study of 33 women, mostly women of colour attending medical clinics, found that most of those participating felt strongly that knowledge of HIV status was important for both the women and her child. They also stated that screening should only be performed under conditions of voluntary choice.

What is better known is the uptake of HIV screening in a variety of practice settings. Lindsay (1993) reported on a program aimed at young single Black women in the United States where a comprehensive protocol including risk behavior profile, pretest counseling in small groups, and post-test

counseling and education resulted in a 95% rate of prenatal screening. This program was coordinated by a perinatal nurse specialist and the high rate of adherence is likely due to a combination of factors including the actions of the nurse, the comprehensiveness of the program, and the demographics of those targeted.

Perception of risk is difficult to measure as both women and their physicians are often unable to accurately assess risk for HIV transmission. Hawken and colleagues (1995) found that 39% of HIV infected pregnant women had risk factors, personal or partner, that were not disclosed by routine history taking. Another study (Meadows & Catalan, 1995) found that women who were given better health education were more likely to have an accurate perception of their risk. This study also found that women were more likely to talk openly with a health care provider, counselor or nurse who was not directly involved with their care. Sorin and associates (1996) suggest that the time spent counseling women and the rapport established between patient and counselor are the best predictors of who will agree to the test.

A small study from Johns Hopkins (O'Campo et al., 1997) found that only 41% of women who reported being tested for HIV antibodies had this confirmed in their hospital charts. The reasons for this are varied but consideration should be given to some women stating that they had been tested previously when this was not true, to avoid prenatal testing. Also many women may think that testing is part of routine care and may thus assume that they have been tested in the

past. Women frequently do not return for HIV test results (Sorin et al., 1996) and those who defer a decision about testing may be lost to follow-up if this is not clearly documented in the medical record (Dalzell et al., 1995). When studying the predictors of antenatal HIV screening, Meadows and associates (1993) found that younger women who were single were more likely to agree to testing and also those who perceived a benefit of testing for themselves and who saw themselves at risk for HIV infection. Sixty percent of the sample of 318 women thought they did not need to be tested. In a study in the Bronx of women in the postpartum period, 79% reported being tested at some point. Seventy five percent of these women did not want to know results and felt that if they were diagnosed with HIV infection while pregnant, they would be coerced into either having an abortion or taking zidovudine (Webber et al., 1997).

Some have suggested that HIV-infected women should be strongly counseled to avoid pregnancy altogether (Bayer, 1989). Even with the possibility of reducing perinatal transmission by two thirds, the likelihood exists that any child born to an infected mother is going to lose his/ her mother prematurely. The strain associated with caring for a family may exacerbate physical symptoms, and living with HIV infection in both herself and possibly one or more of her children may exact a great deal of suffering (Faden et al., 1993). However, some HIV infected women do decide to become pregnant while other women learn of their serostatus as a result of HIV testing during pregnancy. The decision whether to continue a pregnancy at any time is a complex one for many

women, and this is complicated in the face of terminal illness.

Before there was any evidence that perinatal transmission could be prevented by the use of zidovudine, one of the rationales for HIV testing in the antenatal period was to enable women to make informed decisions about pregnancy. Implicit in this was an assumption that women may want to abort the fetus, given the range of possibilities that the fetus would be infected. Faden and colleagues (1993) asked African American women in an inner-city hospital whether they would have an abortion under shifting probabilities of HIV transmission. Even with a theoretical probability of 100% transmission rate, 25% of women stated that they would not have an abortion. With a 50% probability, half the women said they would not have an abortion. In contrast, 78% of the women stated that they would avoid pregnancy at any transmission rate. The researchers concluded that decisions about continuing a pregnancy are influenced by transmission rates however, at least in a hypothetical situation, women seem to think that avoidance of pregnancy if one is HIV infected is the better option. It is important to note that none of these women was HIV infected but all of them had been offered HIV testing as part of their antenatal care.

How HIV infected women respond to decisions about pregnancy resolution is the subject of a study conducted by Kline and associates (1995). They interviewed 55 HIV infected women who were pregnant at the time of the study or who became pregnant while enrollment was proceeding. The researchers found that these women did not only consider the risk of perinatal

transmission and medical consequences of continuing the pregnancy. Socio-cultural factors were very important in making a decision about the continuation of the pregnancy. One factor is the attitude and reproductive intention of the woman's sexual partner. Women in this study seemed to attach more importance to their partner's desire for children than their own. Another factor is previous reproductive behavior which showed consistency over time in that if a woman had a previous abortion, she would be more likely to have an abortion with a subsequent pregnancy than if she had never had one. HIV infection by itself appeared not to significantly alter reproductive behavior. However, those with declining health status were more likely to terminate the pregnancy than those who were more healthy (70% vs. 40%).

In a qualitative study of 11 seropositive women on the east coast of the United States, Hutchinson and Kurth (1991) identified a number of factors influencing reproductive decision making. Those who took their pregnancy to term were more likely to believe that even a shortened life for the child was worthwhile. These women had strong religious beliefs and an optimistic view regarding the future of medical advances. In contrast, those more likely to terminate the pregnancy wished to avoid the stigma of HIV for the child and saw fewer opportunities to provide ongoing care for the child as either she or the child became more ill. Directive counseling by health care providers to terminate the pregnancy also played a role in the decision to abort the pregnancy. It is important to note that this study was completed before the results of ACTG

Protocol 076 and the changing probability of perinatal transmission rates will undoubtedly alter reproductive decision making.

A French study (Vincenzi et al., 1997) investigated the incidence and outcome of pregnancy after an HIV diagnosis in a cohort of 412 women prior to Connor et al.'s study. They found that in the years between 1988 and 1993, the incidence of pregnancy in the sample declined from 20.4 pregnancies per 100 person-years before HIV diagnosis to 7.9 per 100 person-years after diagnosis ($p < .001$). They also found that in the same period, termination of pregnancy doubled (6% vs 29 %). A more recent UK study (Stephenson et al., 1996) of a cohort of 503 HIV infected women also showed an increase in termination of pregnancy after HIV diagnosis from 3.5 % before diagnosis to 6.5% after diagnosis.

An American study (Sowell & Misener, 1997) focusing on the decision to become pregnant and to remain pregnant found that a number of factors influenced women's decisions. Included are religious beliefs, knowledge and beliefs about HIV, personal health and motivation to have a baby, attitudes of family and sexual partner, as well as previous experience with childbearing. Of interest from the results of this qualitative study is the notion that both chance and the mother's health status determined which babies would be born HIV infected. Some thought that if the woman was healthy it was less likely that her child would be infected and they were afraid that anti-retroviral therapy would negatively affect the woman's health status by "tearing down" her health. Those

who were aware of the role of anti-retrovirals in reducing perinatal transmission believed that they could influence control in decision making about reproductive choices. The women interviewed for this small study voiced some negative opinions of the role of health care providers in making reproductive decisions. They reported instances of directive counseling and were distrustful of information given by health care providers who were seen as emphasizing a biomedical model and not involving the woman in making treatment decisions. While this study is limited by both small sample size and a predominantly African American sample, it provides some insight into the thoughts and feelings of seropositive women experiencing pregnancy after the results of ACTG Protocol 076.

An HIV infected woman has an ethical obligation to notify her sexual partner(s) of her serostatus. Efforts to encourage this disclosure should be made that are consistent with local policy regarding partner notification. In the same vein, an HIV infected woman may be strongly encouraged to comply with medical interventions that reduce the risk of perinatal transmission. If a woman has decided to take a pregnancy to term, she has a benificence-based obligation to attempt to reduce vertical transmission for the fetus (Chervenak & McCullough, 1996).

Discussion of how women feel about prenatal HIV screening must take place within an analysis of women's risk for HIV infection and the role that power and gender play in facilitating or impeding women's ability to alter their

risk activities.

Cost-effectiveness Analyses

The cost-effectiveness of HIV screening in pregnancy has been examined in both the United States and Canada. Cost effectiveness refers to the calculation of the costs of one program compared to another. No financial value is assigned to the disease other than the cost of care. Ecker (1996) found that when the seroprevalence is above 9/10,000 it is more cost-effective to screen for HIV than to not screen. Using a mathematical model of decision analysis to calculate marginal cost-effectiveness, the change in cost effectiveness per dollar increment of cost variables, of screening for HIV in pregnancy, he found that at a low seroprevalence level of 7.5 / 10,000, marginal cost-effectiveness was $436,927 and at an average seroprevalence level of 15 / 10,000 it was $198,510. He calculated the cost of screening as $97 per person and this prevented one additional case of neonatal HIV infection per 4000 women tested. Mauskopf et al. (1996) analyzed the economic impact of zidovudine treatment of HIV infected pregnant women and found that overall cost savings are to be found by treating HIV infected women and their infants. They identified cost savings in voluntary screening programs for pregnant women when seroprevalence rates are greater than 46/10,000.

Bueckert (1996) calculated that in Canada, the lifetime medical costs of treating an infected child are $280,000 ($35,000 per year for 8 years). There are approximately 400,000 deliveries in Canada per year and each HIV test costs $5

(not including counseling time) with an estimated cost of $2 million dollars per year if all women are tested. It costs $2,200 to treat each mother-infant pair according to the protocol for zidovudine use to prevent perinatal transmission.

Remis and Vandal (1995) found that in Quebec, universal screening would cost approximately $242,000 per infection prevented. Patrick and associates (1998) found that the savings from preventing HIV infections in neonates were $75,266 per case prevented in an area of low HIV prevalence.

Myers and colleagues (1998) used decision analysis to determine the cost-effectiveness of mandatory screening as compared to voluntary screening under different assumptions of patient behavior. They found that with a prevalence of 17 cases per 10,000 women, costs per case prevented were $255,158 for mandatory screening and $367,998 for voluntary screening. The incremental cost-effectiveness of mandatory compared with voluntary screening was $29,478 per case. As either the lifetime pediatric cost of HIV infection or the prevalence of HIV increased, these values decreased. The authors concluded that mandatory screening would prevent more cases of pediatric HIV infection but that any savings would be mitigated by the behavior of those screened. For example, if women who are screened without consent refuse to comply with the zidovudine regimen, or if women avoid prenatal care to avoid mandatory screening, these cost savings decrease. The cost effectiveness of any HIV screening program is, according to these authors, dependent on the acceptance of treatment by pregnant women.

Nakchband and associates (1998) compared the cost-effectiveness of mandatory and voluntary HIV screening in pregnant women. They reasoned that mandatory testing is likely to deter some women from accessing medical care during pregnancy and if the deterrence rates were 5 in 1,000, a policy of mandatory testing would mean that the number of infant deaths from lack of prenatal care would be greater than the number of deaths from AIDS. According to their decision analysis, if the overall seroprevalence rate is greater than 58 per 1000 then mandatory testing may be of benefit. However, this would likely increase the number of women not receiving prenatal care and ethically is problematic as the autonomy of an entire segment of the population would be sacrificed. Lewis et al. (1995) found voluntary universal screening to be cost effective and at the center where the analysis was carried out, such a program would result in a savings of $175,500 per year. The evidence thus suggests that voluntary screening is cost-effective and there is little support for mandatory screening.

Summary

This literature review has covered the broad topic of HIV infection in women with an emphasis on the detection of disease in pregnancy. The current epidemiology of this disease among women in North America was described as well as the care and treatment of HIV infected women throughout the perinatal period. The review presented an analysis of Connor's (1994) study that precipitated much of the ongoing discussion about prenatal HIV screening.

Physician and midwife attitudes to screening for this disease in pregnancy were discussed as well as the experience of women with regard to screening and the risk factors that predispose women to HIV infection. The costs of prenatal screening programs, whether voluntary or mandatory, were examined. In the next chapter, the methods of this research are described.

CHAPTER THREE

METHODS

This chapter details how the research was undertaken. The study had three parts : how physicians in Manitoba view HIV screening in pregnancy and how they provide this screening in their practices, how pregnant women in Manitoba have experienced this screening, and finally, a cost-effectiveness analysis of voluntary screening for HIV antibodies. All instruments for measuring these attitudes, interview schedules, and consent forms are included in the appendices.

Physicians' Attitudes and Practices

A survey design was utilized to describe physicians' attitudes to HIV screening in pregnancy, their current practice of screening for HIV antibodies in the prenatal period, and how this is similar to or different from their attitudes to and practice of syphilis screening in pregnancy.

All obstetricians and family physicians in Manitoba who were registered with the College of Physicians and Surgeons of Manitoba during the period September to December 1998 (see Invitation to Participate, Appendix B) were eligible to participate. The population size was 884 practicing physicians.

A questionnaire (Appendix C) explored the attitudes and practices of Manitoba physicians regarding HIV screening in pregnancy. For comparison purposes, questions about attitudes and practices regarding routine syphilis

testing in pregnancy were included. Questions 11 through 15 asked specifically about how HIV testing is performed. In order to maximize the number of responses, Dillman's Total Design Method (1978) for mail surveys was used. This involved mailed reminders at two and four weeks.

Analysis was performed using SPSS-PC and descriptive statistics were generated for the demographic variables and attitudes and practices. Inferential statistics such as Chi-square and McNemar testing was used to test for differences in attitudes and practice between HIV and syphilis testing. Responses to the survey questions about current practice of HIV screening in pregnancy (routine offering of the test to all pregnant women or only to those thought to be at risk) and how this testing is carried out (with or without specific consent, with or without counseling, and how results are communicated to the women) were compared between physicians according to type of practice (family physician, general practitioner, obstetrician), location of practice (urban or rural), gender, age, and years in practice. Attitudes to HIV screening were compared to attitudes to syphilis screening and responses were compared across type of practice, location of practice, age, gender and years in practice. The attitudes explored include physician agreement with the recommendations to offer testing to all pregnant women, suggested pre- and post-test counseling, and whether prenatal screening is seen as cost-effective. Compliance with provincial recommendations for HIV screening was measured as was knowledge about

these recommendations. A step-wise logistic regression was performed using demographic variables (gender, location of practice, type of practice, and number of years in practice) to identify which of these variables best predicts the universal offer of this test to pregnant women.

Care Provider Interviews

Interviews were conducted with a purposive sample of four obstetricians, an infectious disease specialist, a midwife working in a special program at a local hospital, and four family physicians. These interviews focused on the reasons behind clinical decisions regarding HIV testing in pregnancy. A purposive sampling technique was used to identify ten health care providers who have a large number of antenatal patients and represent a broad range of experience (generalist and specialist), type of practice (hospital and community), and gender of practitioner (female and male). Interviews were conducted by the researcher (Appendix I) during the winter of 1999. Interviews were taped and transcribed verbatim. Participants were required to give written consent to participate in the interview (Appendix E).

Transcripts of the interviews were analyzed for common themes related to clinical decision making and practice to provide rich data on this aspect of antenatal care. The transcribed interviews were analyzed using coding and concurrent memos. Memos are said to facilitate analytic thinking (Maxwell, 1996, p. 78) and were written on reading the transcripts for the first time. They were supplemented by listening to the tapes at first reading to contextualize the

transcripts and allowed for enrichment by listening for pauses, inflection, and expressive tone.

Experiences of Pregnant Women

Research using a feminist methodology involves constantly considering the significance of gender, and the importance of consciousness raising as a methodological tool. It also involves challenging the notion of objectivity and distance between researcher and subject, paying attention to ethical issues particularly the exploitation of women as objects of research, and acknowledging and encouraging the empowerment of women through the research process and the changing of the dominant patriarchal structure of society through research (Cook & Fonow, 1990). Duffy (1985) states that feminist research begins with a woman as principal investigator, that the study has the potential to help the subjects as well as the researcher, that the research is focused on the experience of women, and that nonsexist language is used in the report of the research.

Research involving pregnant women and their experience of prenatal HIV screening focuses on the experience of pregnancy and being tested for a terminal disease when one has no symptoms. Pregnancy is a female specific experience and the relationship between the pregnant woman and the fetus is one which is unique to women. Through participation in the research process, women can be made aware of a variety of perspectives that previously were not known to them. This is both consciousness raising and empowering in that the knowledge gained can be used for their benefit. A discussion of risk behaviours

for HIV infection can provide a woman with knowledge to change her behavior in the future and thus protect herself.

Results of research must be written in language that is accessible to all women and not only to those in the health professions. Women who participate in research should be offered the opportunity of reviewing transcripts of interviews, they should be given information about their scores on instruments used in studies, and the results of the study should be mailed to participants who wish to read them (Campbell & Bunting, 1991). Traditionally, reports of research have been in the domain of academics and professionals, and participants have been denied access to the results of studies that would not have been possible without their co-operation. Offering women these opportunities for involvement throughout the process makes feminist research very different from traditional positivist research.

Perhaps most important, research must be used to effect change in the lives of women. By linking the social circumstances of women's lives with their risk activities, practical prevention strategies can be formulated that are relevant to women and ultimately improve their lives. The goal of feminism is to end oppression of all women and while an isolated practice of prenatal HIV screening may affect only those who attend a specific women's health clinic, the hope is that this approach to care will influence the broader health care system and society.

The exploratory and descriptive nature of the research questions

suggested the use of interviews as a way of collecting data about pregnant women's experiences. This method enables the researcher to identify both common and disparate themes. This method of inquiry is particularly useful when not much is known about the subject and where there is value in learning about the subjective experiences of participants. In keeping with principles of feminist research, this research focused on women's' experiences and was conducted with the aim of improving women's interactions within the health care system. The researcher endeavored to be respectful of each woman's experience and paid attention to the significance of each woman's experience of the health care system. The researcher provided substantive information to participants, when requested, to emphasize empowerment and raise consciousness. The researcher has extensive experience in the field of HIV infection and prevention education as well as care of pregnant women and their families. This knowledge was used to supplement the information given to participants as part of their usual care. Women who asked for information expressed their appreciation to the researcher when this information was given.

All women who attended either Women's Hospital, the Saint Boniface General Hospital, and those who attend family physician clinics (Family Medical Center and the Mount Carmel Clinic) for antenatal care were eligible to participate in the study. All sites serve the city of Winnipeg as well as women from rural and northern Manitoba. Each of the two hospitals has approximately

4,000 deliveries per year and physicians from the two clinics conduct deliveries at the two hospitals.

Women were invited to participate in the study by letter (see Invitation to Participate, Appendix D) and were required to give written consent (see Consent Form, Appendix E). Women self selected themselves as participants by indicating their interest in taking part in the study by filling out a tear-off form, after which they were contacted by the researcher (see Invitation to Participate, Appendix D). Participation was voluntary and the woman could revoke consent at any stage without penalty. No record was kept as to how many women received the invitation to participate so it is not known what percentage of women agreed to participate.

A convenience sample of 32 women was interviewed in the winter of 1999. Some of these women had refused to have an HIV test and some had decided to have the test. While a convenience sample was the original method of gathering data, some of the women interviewed recruited pregnant friends who they thought might be interested in participating in the study. This snowball technique provided four of the total sample. Data collection was stopped when new themes were no longer generated and saturation was reached. The inclusion of women who have refused to have the test served to highlight differences in personal decision making and risk assessment and is a form of controlled comparison (Maxwell, 1996). By recruiting from a variety of clinics, it was anticipated that a heterogeneous sample would be generated and every attempt

was made to recruit Aboriginal and Caucasian women, married and single women, women across the range of the childbearing years, as well as rural and urban dwellers.

Interviews were recorded and transcribed verbatim (see Interview Guide, Appendices F and G). Women were asked whether they wished to review the typed transcripts and were given the opportunity to explain, correct, or add to the transcribed interviews before analysis began (Appendix E). None of the women were interested in reviewing their transcripts.

The method of analysis used (Burnard, 1991) combines elements of grounded theory and content analysis and involves a fourteen stage process to produce a detailed and systematic report of themes and issues contained in the interviews. In the first stage, notes are made after each interview describing the content of the interview. In stage two, transcripts are read through and general themes are noted. The transcripts are read again in stage three and multiple headings are noted in the margins. In stage four , headings are grouped together under higher order categories. Stage five involves reviewing the list of headings and categories to identify repetitions which are then deleted. Stage six requires a review of the categories by a colleague and if there is agreement, the process is continued in stage seven with a review of the transcripts and the headings and categories. In stage eight, the transcripts are coded according to the headings and categories, usually by highlighting the transcripts with different coloured highlighters. The coded transcripts are cut up and grouped together in stage

nine. These cut up sections are glued to large sheets of paper in stage ten. Stage eleven involves asking participants to check the appropriateness of the categories. Stages twelve and thirteen involve filing the sections together for the written analysis and beginning the writing process. The final stage concerns deciding how the analysis is written and whether it is related to the literature in the same chapter as the findings or whether the analysis is written up in a separate chapter. Concurrent memos were written while coding the transcripts to identify emerging themes and guide analysis. Emergent themes are displayed as a focus for the researcher during analysis.

Cost-effectiveness Analysis

A cost-effectiveness analysis was carried out to determine the relative costs of the present screening program in Manitoba and how this compares to the rest of Canada and the United States. Costs include laboratory fees, time taken by the health care provider to give information to the woman, treatment costs for medication during pregnancy and labour as well as for the neonate, and lifetime medical costs for both the woman and baby should they be infected. A cost-effectiveness analysis is more appropriate for this than a cost-benefit analysis because it is impossible to accurately estimate the 'cost' of a human life saved by preventing HIV infection. This type of analysis is useful when comparing alternative strategies for a health care goal or for identifying practices that are not worth their cost. No attempt is made in this type of analysis to assign

a financial value to the disease prevented beyond the cost of care for those with the disease. Results are presented in the form of cost per case prevented and the reader is allowed to make a value judgment about the outcome (Haddix & Shaffer, 1996).

Validity

Physician Survey

The internal consistency of the survey instrument was measured using Cronbach's alpha, a widely accepted measure of the reliability of an instrument. The normal range of values for Cronbach's alpha is between 0 and 1 with higher values reflecting a higher degree of internal consistency (Polit & Hungler, 1991, p. 372). Internal validity of the questionnaire achieved a Cronbach's alpha of 0.72.

Care Provider Interviews and Interviews with Women

According to Sandelowski (1986, p. 28), qualitative research "emphasizes the meaningfulness of the research product rather than control of the process." However, measures of the rigor of this type of research are possible and this study will be examined using the criteria of credibility, fittingness, auditability, and confirmability (Guba & Lincoln, 1981).

Credibility refers to the "faithful descriptions or interpretations of a human experience that the people having the experience would immediately recognize from the descriptions or interpretations as their own" (Sandelowski, 1986, p. 35). To this end, the researcher asked a sample of the participants to

review the findings and validate the themes as appropriate and reflective of their experience. Three participants were chosen at random from the list of women who participated in the study and they were contacted by telephone and asked if they wish to review the findings and comment on them. These women agreed to review the findings; one of the women had refused screening while the two others had agreed to the screening.

Fittingness is a term used by Guba and Lincoln (1981) to describe the 'fit' of research findings into contexts separate from the study and when others who read the findings find them meaningful in terms of their own experiences. The fittingness of this study was assessed by discussing the findings with health care professionals who work in prenatal care and who have experience in dealing with women who have had prenatal screening. Findings are said to be auditable when others can follow the process used by the researcher to arrive at the findings.

The final criterion, confirmability, is said to occur when credibility, fittingness and auditability are achieved. Maxwell (1996) suggests that validity is not some objective truth to which findings from a study can be compared. This is supported by a principle of feminist research which focuses on the subjective dimension as a reaction to the preponderance of 'objective' studies (Cook & Fonow, 1986).

As the study was conducted from a feminist perspective, it was essential to ensure that the process was indeed valid in terms of that perspective.

Transcripts were reviewed with the aim of checking that the researcher was respectful of each woman's experiences. Care was taken to present findings in a manner which seeks to lessen the objectification of women as research subjects. The sharing of substantive information in the interviews is in keeping with the principle of consciousness raising and empowerment. To this end, women were encouraged to ask questions during the interview and they were answered at the time. The interviews at times were more like discussions and this allows women to be partners in the research process rather than the subjects of research. Women were invited to review their transcripts and add their views or make corrections to ensure that their voices were heard.

Traditional threats to validity are bias and reactivity. Bias in quantitative research refers to an influence that produces a distortion to the results (Polit & Hungler, 1991, p. 641) and in qualitative research refers to the researcher's theories and preconceptions or values (Maxwell, 1996). One way to deal with this is by stating at the outset that as a researcher I bring to the study prior experience of working with this population, and I have strongly held beliefs about the nature of screening in pregnancy. As a woman working in health care I am acutely aware of issues of gender, patriarchy, and injustice in the health care system.

Reactivity is described as the influence of the researcher on the individuals being studied (Maxwell, 1996). In qualitative research this cannot be controlled and once again, in keeping with the principles of feminist research, this

interaction between researcher and researched is one to be encouraged if it is empowering and consciousness raising. When two individuals interact, there will be mutual influence and as long as this is acknowledged, it does not necessarily invalidate the findings.

A research journal was kept for the duration of the study. In this journal, I reflected on the process and my feelings. As a nurse involved in the practice of prenatal HIV screening, I am aware that my position is often one of privilege in comparison with the women who receive care. As a feminist, my view is influenced by my belief in the rights of women to live free of oppression in any form. As a white, upper middle class woman with a graduate degree, my perspective is influenced by immense privilege which may obscure the realities of life as lived by women who are poor and disenfranchised, the women who may be most at risk for HIV infection. As a mother, I can recall my feelings while pregnant, with the hopes and dreams I harboured for the fetus that I carried. Those feelings are memories now but the importance of the experience of pregnancy has remained with me and has guided my interactions with pregnant women as a nurse and advocate for women in the health care system. As a student, my perspective is both enriched and narrowed by the privilege of the written word. This view is based on my standpoint as a woman, a feminist, a graduate student deeply immersed in this field, and a nurse involved in the screening of pregnant women for HIV antibodies. Standpoint refers to a perspectival view of the world and a feminist standpoint is one that reflects the

perspectives of women while challenging the social dominance of men' s perspectives (Mahowald, 1996). These are the strengths and limitations that I brought to this work.

Ethical Issues

Ethics approval was granted by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba (Appendix H). Following the recommendations of the Medical Research Council of Canada, all data will be secured in a locked filing cabinet for ten years. For this study, data includes tapes and transcripts of the interviews as well as completed questionnaires.

Any and all identifying information was removed from the transcripts to protect the confidentiality of the participants. Only the researcher had access to raw data. This was explained to the participants in the consent form which was signed before the participant began the interview.

The cost to participants in this study was that of time as each interview lasted up to one hour. It was anticipated that risks to participants were minimal, however some women might have experienced anxiety when discussing their personal risk for HIV infection. I am an experienced nurse-midwife with nine years of experience working in the field of HIV care and prevention and felt capable of working through any anxiety with the woman concerned. Risks to physicians who participate in the interviews were minimal as these are not vulnerable individuals.

Attention must be paid to the ethical issues of women as research subjects.

To this end, the research was conducted in an atmosphere of respect and recognition of women in their multiple roles. If a woman asked for information during the interview, this was given fully and freely. Women were encouraged to make changes to their transcripts when reviewing them and to include additional thoughts and ideas, as was appropriate.

Summary

This chapter has described how the research was carried out. Physicians in Manitoba were invited to complete a mailed questionnaire which focused on their attitudes and practices of HIV and syphilis screening. A small sub-set of health care providers was interviewed to gain a more detailed description of their attitudes and practices. A sample of women was interviewed to elicit a description of how they experienced this screening. In addition, some women who refused to be screened were interviewed to gain an understanding of why and how they refused this intervention. Finally, a cost-effectiveness analysis was carried out to determine whether voluntary screening is cost-effective in an area of extremely low seroprevalence.

CHAPTER FOUR

PHYSICIAN SURVEY

This chapter presents the findings of the survey of physicians in Manitoba. In the pages that follow, the results will be presented for each of the questions asked in the survey. Results are reported by type of practice (family physician, general practitioner or obstetrician). Later sections deal with differences in practice related to location of practice (urban or rural), gender, and number of years in practice. As a comparison, results of questions regarding physician attitudes and practice of syphilis screening will be presented.

Physician Survey

Surveys were mailed to 884 physicians in the Fall of 1997. Four hundred and eighty six surveys were returned, a response rate of 55%. Of these, 38.4% were family physicians, 51% general practitioners, and 5.7% obstetrician/gynecologists. This sample represents 26% of the total general practitioners, 90% of the family physicians, and 48% of the obstetrician/gynecologists in the province. There is no way of knowing if those who did not respond differ from those who did. In the interests of confidentiality a record was not kept of who did not respond as many of the potential respondents are known to the researcher. After the final reminder was mailed, no record was kept of non-responders.

Sixty six percent of the sample was male and 33.3% female. Of those who

responded to the survey, 64.5% (n=160) of general practitioners, 83.1% (n=154) of family physicians, and 76.6% (n=22) of obstetricians provide prenatal care. Of those who provide prenatal care, 51.5% see up to 30 new prenatal patients a year, 11.6% see between 31 and 60 new prenatal patients a year, 2.7% see between 61 and 100 new prenatal patients a year, and 4.5% see over 101 new prenatal patients a year.

Questions pertaining to the practice of HIV screening were answered only by those physicians who actually provide prenatal care (n = 336). The survey was structured in such a way that even those who do not provide prenatal care should answer the questions related to attitude towards prenatal screening. Even though they may not provide prenatal care, the opinions of physicians regarding this topic remain influential in policy development. All questions were not answered by all respondents. Tables I through VII reflect only those respondents who provide prenatal care.

The mean age for the sample was 44 years and average number of years in practice was 15. The majority practiced within the city of Winnipeg (58%) with 18.3% practicing in smaller towns (those with a population of between 5,000 and 30,000) and 21.6% stated that their practice was located in a town with population less than 5,000 people.

Internal validity of the questionnaire achieved a Cronbach's alpha of 0.72. The participation rate was fairly low at 55%. Some physicians may have chosen not to respond given the subject matter of the questionnaire which is often not a

popular one. The occupation of the researcher, a nurse, may have influenced some physicians as well.

How do physicians screen their pregnant patients for HIV ?

When asked about their current practice of HIV screening in pregnancy, most physicians offered the screening test to all pregnant women, however some continue to offer the test only to those deemed to be at high risk for HIV infection, and others do the test only when requested by the pregnant woman. These results are presented in Table I.

Table I : Method of Screening *

	Family Physicians n= 150	General Practitioners n=155	Obstetricians n=21
Performed on all	3 (2.0 %)	5 (3.2%)	1 (4.8 %)
Offered to all	120 (80.0 %)	105 (67.7 %)	17 (81.0 %)
High risk	22 (14.7 %)	32 (20.6 %)	2 (9.5 %)
Patient request	5 (3.3 %)	13 (8.4 %)	1 (4.8 %)

$X^2 = 8.156$, 6 d.f., N.S. * only those who answered this question are reported

Respondents were offered the opportunity to include comments on the survey. They offered a variety of opinions regarding the recommendation to offer this test to all pregnant women. Some saw it as an opportunity to educate women, others felt that universal offering solves the problem of women who do not know that they are at risk because of their partners' behaviors. There was recognition that some women do not divulge their past history so an accurate

assessment of individual risk is not always possible. Others disagreed with universal offering, stating that this test is of no use if the woman has been in a monogamous relationship for years. There were a number who commented that this test should be offered to "high risk" women only, however there were no comments on how to identify these women at high risk.

Are physicians aware of the recommendations for screening?

Most of those surveyed were aware of the recommendations to offer the test to all pregnant women (93.5% of family physicians, 88.8% of general practitioners, and 100% of obstetricians) (X^2=4.703, 2d.f., N.S.).

However, the percentage of those who were aware of the recommendations was greater than the percentage of those who offer the test. Female physicians were as aware as male physicians, and those in practice in towns or cities with populations greater than 30,000 were more aware. As years in practice increased, knowledge about the recommendations decreased. It appears that knowing that this screening test is recommended does not necessarily translate into practice. However, the guidelines as issued by the College of Physicians and Surgeons of Manitoba are guidelines only and as such, can be acted upon or ignored at the discretion of the physician.

Do physicians agree with recommendations for screening ?

When asked whether they agreed with the recommendations to offer HIV screening to all pregnant women, most physicians agreed (92.1% of family physicians, 84.4% of general practitioners, and 90.9% of obstetricians).

This is in keeping with other studies, with a high percentage of the physicians surveyed supporting universal offering of this test to prenatal patients but, as stated previously, this belief does not necessarily translate into action.

Do physicians agree with the recommendations for counseling before and after the HIV test ?

Fewer physicians agreed with the recommendations for pre- and post-test counseling of women (78.7% of family physicians, 86.0% of general practitioners and 61.9% of obstetricians). These recommendations include a comprehensive discussion of whether the woman wants to be tested or not, risks for HIV infection and perinatal transmission, and risk reduction strategies.

Regulatory bodies have the authority to mandate or suggest practice protocols. However, physicians are accorded the right to comply with these protocols or guidelines or to ignore them even though they reflect the standard of care. This is vividly detailed in how physicians provide pretest counseling to their pregnant patients.

When asked about the recommendations for counseling before and after the test, an average of almost 80% of physicians surveyed agreed that counseling should occur. However, those in practice for longer were not in agreement to the same extent. While those supporting the counseling appear to be in the majority, some of the physicians interviewed personally stated that the counseling was

time consuming and not remunerated adequately. These physicians were part of the population surveyed however, they were not asked in the interview if they had responded to the mailed survey. From the conversations with pregnant women which will be reported later, it appears that very little counseling actually takes place as reflected in the relative lack of knowledge about this intervention, and the recollections of the discussion with physicians both before and after the test. This apparent discrepancy may be reflective of physicians wanting to answer in the affirmative because they want to appear to be doing the right thing, or of a genuine support of the principle of counseling but a practical inability to perform the counseling in the reality of day-to-day practice.

Do physicians provide pretest counseling ?

The recommendations clearly state that pretest counseling, as described earlier in the literature review, must occur before the test is done. In response to this question, 95.4 % of family physicians replied that they did provide counseling, while 93.1 % of general practitioners and 81.0 % of obstetricians replied in the affirmative.

Some of the respondents commented that the pretest counseling was an opportunity to educate patients about the disease and dispel ignorance. One felt that counseling should be broadened to include information about all STD testing, and another suggested that counseling should be explained to a level that the patient desires. Additional support for pretest counseling was suggested in the statement that "a positive test affects the whole family." Some physicians

commented that they lacked the time and expertise to perform the counseling.

Most physicians stated that they perform counseling prior to doing the HIV test. More female (77.2%) than male (58.7%) physicians reported counseling patients prior to testing and as years in practice increased, the percentage of physicians performing this decreased. When comparing stated use of the Manitoba Health counseling guidelines with the experience of pregnant women, there appears to be a large discrepancy between stated practice on the part of physicians and the reports of women. While the Manitoba Health Guidelines are extensive and detail the information to be given for individuals to make an informed decision about consenting to the test, women described a cursory discussion, if any, and appeared to have gained very little information from the discussion.

It may be that physicians have decided that, while the Guidelines are appropriate in case finding, (that is when an individual presents specifically requesting HIV testing), for the many low risk pregnant women, the counseling suggested by the guidelines is too cumbersome and detailed. As a result, in practice they perform a much abbreviated form of counseling.

What is the form of this counseling ?

Physicians differ in how they provide their patients with information prior to prenatal HIV screening. Results are presented in Table II.

Table II : Form of Pretest Counseling [1]

	Family Physician n=154	General Practitioner n=160	Obstetrician n=22
Manitoba Health guidelines	76 (49.4 %)	60 (37.5 %)	4 (18.2 %)
Individual discussion	99 (64.3 %)	102(63.8 %)	10 (45.5 %)
Pamphlet	33 (21.4 %)	23 (14.4 %)	8 (36.4 %)
Discussion with nurse	13 (8.4 %)	10 (6.3 %)	5 (22.7 %)

$X^2 = 27.314$, 6 d.f., $p < .01$

1. Columns may do not add up to 100% as respondents may have answered more than one category or may have not responded

Very few physicians appear to be giving their patients written material as an adjunct to verbal discussion. Some physicians have designed their own information sheets to give to patients, the two tertiary care institutions have each designed and printed a pamphlet, and one is available from the Canadian Public Health Association and was distributed by Manitoba Health to all physicians providing prenatal care. However, these do not appear to be given to pregnant women. This may be a function of who is responsible for distributing educational material in any given practice scenario. For example, the physician may assume that the receptionist is handing out the material to patients and this is not happening consistently. In the hospital clinic setting, the nurses appear to be responsible for this and they may forget to do it or may be too busy to do it

consistently.

How long does this counseling take ?

For those who do provide pretest counseling, the time taken for this counseling was generally less than 15 minutes (77.6% of family physicians, 78.1% of general practitioners, 81.8% of obstetricians) but some family physicians (15.8%) and general practitioners (11.9%) took between 15 and 30 minutes and a few took more than 30 minutes to provide the counseling (1.3% of family physicians and 3.1% of general practitioners) ($X^2 = 11.147$, 8 d.f., N.S.).

Female physicians, in general, spend more time talking about testing to their patients. Twenty percent of female physicians spent more than 15 minutes on this while 11.8% of male physicians took more than 15 minutes to impart the information. These results are in keeping with Ogilvie's study (1997) from Ontario in which the average time taken for counseling was 10 minutes . It was found in a study from England (Gibb et al., 1998) that having a discussion about HIV infection increased the uptake of screening even when the discussion took less that seven minutes. Jones and colleagues (1998) report that uptake of screening increased two fold if there was discussion with the women which lasted more than five minutes. It thus appears that even minimal discussion will increase the likelihood that women will agree to have the test.

The time needed for completing the pretest counseling as suggested by the Manitoba Health guidelines is in the 30 to 45 minute range. This was cited by physicians as one of the most significant barriers to pretest counseling.

Physicians also stated that they lacked the expertise to properly discuss this issue with patients according to the guidelines. In addition, many physicians felt that low risk pregnant women, the vast majority of their patients, do not need an extensive and detailed discussion. This too is borne out by the women in their interviews where discussion was described as cursory at best, or entirely absent at worst. Almost 30% of physicians in the survey stated they performed the counseling according to Manitoba Health guidelines, however, more than 70% stated that this counseling took less than 15 minutes. The best case scenario is that physicians are basing their discussion with patients on the Manitoba Health guidelines and doing it in an extremely abbreviated fashion. The reality appears to be that they mention the test is recommended and spend little if any time in imparting information. This is confirmed by the descriptions of the counseling by the pregnant women interviewed, some of whom recalled only being told that the test would be done, with virtually no discussion or information sharing as suggested by the counseling guidelines.

While many physicians acknowledge that they are very busy, little attention is paid to how this affects the patient. They describe how little time they have for each prenatal appointment , how the prerequisite counseling for HIV testing takes a long time, and how remuneration is not adequate. Some admit that they feel inadequate in properly imparting the information to patients, however, others feel that women should know enough about HIV based on reporting on the topic in the media. There was no indication that physicians

asked the women what they needed to know, or of assessing knowledge with each woman and embarking on a discussion with the patient as an equal partner in her care.

How is consent for HIV screening obtained ?

When asked about consent for screening, significant differences were found. Some physicians do not require consent for this test even though the guidelines clearly state that this test should only be performed with the express consent of the woman. The percentages of those requiring consent are presented in Table III.

Table III : Consent for testing *

	Family Physician n=142	General Practitioner n=145	Obstetrician n= 20
Verbal	79 (55.6 %)	74 (51%)	13 (65.0 %)
Written	61 (43.0%)	69 (47.6 %)	5 (25.0 %)
Not required	2 (1.4 %)	2 (1.4 %)	2 (10.0 %)

$X^2 = 9.940$, 4 d.f., N.S. * only those who answered this question are reported

Most health care providers require either written or verbal consent to be tested, with verbal consent being more common. A very small percentage of physicians, mostly obstetricians, responded that they do not require consent before doing this test.

One of the central tenets of rationality is the ability to consent to treatment. From the results of this survey and from the interviews with care providers to be

reported later, most women are asked whether they want to have this test or not. Implicit in the offer of the test is that if women agree, they are consenting. However, how informed the consent is relates to the nature of the information the woman has been given prior to agreeing to have the test. If the woman is led to understand that this test is common or routine in that all women are being offered the same test, that the physician strongly recommends the test, and that there is very little to be concerned about, can we really say that she is giving informed consent ? This is a subtle form of coercion and the woman may feel that she has no choice but to agree to the test.

How are test results provided to women ?

Most of those surveyed provided test results in person only (86.4% of family physicians, 90.2% of general practitioners and 94.1% of obstetricians) however, some do not communicate the results of the test if the test is negative (5.4% of family physicians and 2.6 % of general practitioners). Some give results over the phone (6.8% of family physicians and 6.5 % of general practitioners) ($X^2 = 14.219$, 10 d.f., N.S.). Those in practice for many years were more likely than their younger counterparts to give results over the phone.

Withholding test results is a form of paternalism in that the physician knows something about the woman that the woman does not know. While the "no news is good news" attitude may save the physician time at a subsequent visit, it perpetuates that idea that the physician is the one who holds the power and that women are somehow less capable human beings who do not need to

know normal results. This attitude extends to most of the tests performed in pregnancy and certainly to the VDRL test which most women do not know has been performed as part of routine prenatal care. Prenatal care appears to be so "routinized" that in an attempt to do all the tests that need to be done in a short space of time, care becomes standardized across all pregnant patients. Assumptions may be made about what women ought to know from reading books and pamphlets and if the woman has been pregnant before, and the tests are then performed, often with no explanation. Women are told to go to the lab, and because many go without asking which test are being performed, it is assumed that they either know what tests are being done or are consenting to have the tests done without information.

Have these physicians cared for HIV infected individuals?

About half of all the physicians surveyed (including those who do not do prenatal care) had cared for an HIV infected person in the past (47.1% of family physicians, 45.6% of general practitioners, and 68.2% of obstetricians).

Should prenatal HIV screening be voluntary or routine?

When the total sample was asked whether prenatal HIV screening should be voluntary or routine, a greater percentage answered that it should be voluntary rather than routine (54.3% of family physicians, 54.8% of general practitioners, and 45.5% of obstetricians) ($X^2 = 0.690$, 2 d.f., N.S.). While these percentages are about 50%, this does not show overwhelming support for the voluntary nature of the existing policy.

Do physicians think that prenatal HIV screening is cost effective?

When asked whether they thought that universal HIV screening in pregnancy was cost effective, almost half the total sample (40.5%) thought that it was, however, many did not know.

Many physicians commented that they had no way of assessing the cost effectiveness of universal HIV screening. Others thought that in rural areas it would definitely not be cost effective due to the low prevalence. One physician stated that "women at high risk are more likely to refuse testing." Yet another saw universal offering as not cost effective as "physicians do not get paid enough even if it takes less than 15 minutes." Still others thought that it is cost effective as "saving five children would probably pay for 100,000 tests." One respondent stated that screening in pregnancy would offer women the "choice of termination rather than the high medical costs of caring for an infected baby." This statement reflects an attitude common in the earlier years of the HIV epidemic where HIV infected women were strongly discouraged from bearing children (Bayer, 1989). Some stated that as physicians their responsibility was to patient care and they could not be expected to think about costs to the health care system.

Predictors of prenatal screening practice

A forward stepwise logistic regression was performed to determine the effects of demographic variables on the likelihood of offering screening for HIV antibodies while controlling for the influence of other variables. All demographic

variables were entered into the model, namely gender, location of practice, type of practice, and number of years in practice. Only sex and number of years in practice were found to be predictive. Male physicians are half as likely to offer HIV screening as female physicians (odds ratio = .4275, 95 % confidence limits 0.2776 to 0.6584). Years in practice was also found to be significant with likelihood of offering this test to patients declining with number of years in practice (odds ratio = 1.44, 95 % confidence limits 1.1925 to 1.7409).

Physician sex and number of years in practice will be examined in greater detail in the following pages. Although location of practice was not predictive of the likelihood of offering screening, this will be reported to look for variation between urban and rural practice, an important issue in the province of Manitoba.

How does sex affect the practice of prenatal screening ?

There are a number of areas of practice where male and female physicians differ markedly. In the sample for this study, more male physicians (61.0%) provide prenatal care than do their female counterparts (38.7%). This may have introduced bias into the sample. Sixty seven percent of male physicians in Manitoba report that they offer this test to all pregnant patients as compared to 86.3% of female physicians. Twenty one percent of male physicians stated that they offer this test to women whom they regard as at high risk, as compared to 9.7 % of female physicians ($X^2 = 19.90$, 6 d.f., $p < 0.01$). Female physicians were as likely to know about the recommendations for prenatal screening as their male

counterparts. While the percentage of physicians, both male and female, who agree with the recommendation to offer this test to all pregnant women was high (83.3% of males and 96.9% of females), male physicians (16.3%) were more likely than female physicians (3.1%) to disagree with the recommendation ($X^2 = 22.23$, 6 d.f., $p < 0.01$).

Eighteen percent of both male and female physicians disagreed with the recommendation regarding the provision of pre and post test counseling ($X^2 = 5.966$, 4 d.f., N.S.). More female physicians provide counseling (77.2%) than do their male counterparts (58.7%) ($X^2 = 17.668.$, 6 d.f., $p < 0.01$). Female physicians use the Manitoba Health guidelines to provide pretest counseling more often than male physicians (51.5% vs. 35.1%) and many more female physicians (26.9%) provide their patients with written information than do males (14.0%) ($X^2 = 9.232$, 6 d.f., N.S.). Female physicians also spend a longer time counseling their patients. Results are presented in Table IV.

Table IV : Counseling Time [1]

	Female n=96	Male n=169
< 15 minutes	95 (73.6 %)	169 (80.9 %)
15 - 30 minutes	19 (14.7 %)	24 (11.8 %)
> 30 minutes	7 (5.4 %)	0

($X^2 = 13.399$, 8d.f., $p < 0.01$)

1. Columns do not add up to 100% as some respondents did not answer this question

Women physicians appear to be slightly less consistent in obtaining

consent with 50.4% asking for verbal consent compared to 56.4% of male physicians, and 48.7% asking for written consent compared to 41.0% of male physicians. In contrast, 2.7% of male physicians do not require consent at all compared to 0.8% of female physicians ($X^2 = 2.717$, 2 d.f., N.S.). Female physicians are more likely to give test results in person only (92.0%) compared to their male colleagues (86.4%).

In this study, male physicians were less likely to offer the test to their pregnant patients. This confirmsthe results obtained by Mills and colleagues (1998) who reported that female physicians were twice as likely as their male counterparts to recommend this test. When looking at risk assessment as a basis for the offer of the test, this study shows that male physicians are more likely than female physicians to offer this test to those they regard as at high risk. This may be reflective of an increased paternalistic attitude on the part of male physicians who are willing to make a risk judgment. These physicians may think they can assess risk based on what the woman looks like or where she lives. It also reflects an attitude of "the physician knows best."

How does number of years in practice affect the practice of prenatal HIV screening ?

Significant differences were found between physicians according to the number of years they have been in practice. As years in practice increased, physicians were less likely to agree with and to comply with the various recommendations in the guidelines. These results are presented in Table V.

Table V : Effects of number of years in practice on HIV screening 1

	< 10 yrs n=153	11-20 yrs n = 117	21 - 30 yrs n=43	31 - 40 yrs n=15	> 41 yrs n=8
Offer to all *	116(78.4 %)	93 (79.5 %)	24 (61.5%)	5 (33.3 %)	4 (57.1 %)
Aware of recommendations	141 (92.2 %)	109 (93.2 %)	39 (92.9%)	11 (73.3 %)	7 (87.5 %)
Agree to universal offer *	136 (89.5%)	105 (90.5 %)	37(86.0 %)	10 (66.7 %)	7 (87.5 %)
Agree to counseling	127 (84.1 %)	89 (78.1 %)	33 (80.5%)	11 (73.3 %)	6 (85.7 %)
Provide pretest counseling *	150 (98.7 %)	108 (93.9 %)	35 (85.4%)	9 (60.0 %)	7(87.5 %)
Use Manitoba Health guidelines *	65 (42.5 %)	53 (45.3 %)	14 (32.6%)	5 (33.3 %)	3 (37.5 %)
Individual counseling*	104 (68.0 %)	71 (60.7 %)	25 (58.1%)	5 (33.3%)	6 (75.0 %)
No consent required *	1 (0.7 %)	2 (1.8 %)	1 (2.5%)	2 (16.7%)	0 (0.0 %)
Test results in person*	138 (93.2 %)	93 (84.5 %)	35 (89.7%)	9 (69.2%)	6 (85.7 %)
Voluntary testing	83 (55.0 %)	68 (59.1 %)	18(42.9%)	6 (42.9%)	3 (37.5%)

* $p < .01$ using Chi square testing

1 This table is a summary of results according to years in practice. Rows and columns do not equal 100%.

The length of time that a physician has been in practice was found to be a predictor of offering this test. As years in practice increase, physicians offer this test less frequently. When they reach more than 41 years in practice, they appear to offer the test with greater frequency. Ogilvie et al. (1997) did not find any difference based on those who had been in practice more than, or less than, ten years. This study used a more sensitive measure of years in practice (ten year

increments), and has shown a difference between physicians depending on their years in practice.

As years in practice increased, physicians were less likely to agree with the recommendations, however those in practice more than 41 years agreed to the same level as those with less than 10 years in practice. This may reflect a greater compliance with official guidelines with relative inexperience and also with older age. Those younger physicians with experience caring for people with HIV infection as part of their residency program may have a better understanding of HIV and therefore may be more likely to support universal offering. Older physicians may be concerned that they are out of touch and therefore may be more compliant with guidelines and recommendations.

Older physicians also are less likely to seek consent for screening. This appears to reflect an attitude where "the doctor knows best" and as one of the physicians interviewed suggested, these physicians may be quite cavalier in their practice of screening women without consent or education because they have never had to deal with the consequences of telling someone that they are HIV positive.

<u>How does location of practice influence the practice of prenatal screening?</u>

Depending on where a physician practices, differences were noted in how the test was offered (see table VI).

Table VI : Location of practice and method of screening 1 *

	Winnipeg (n = 167)	Medium size town 5,000 - 30,000 (n = 62)	Small size town < 5,000 (n = 92)
Offered to all	134 (80.2 %)	41 (66.1%)	65 (70.7 %)
High risk women	20 (12.0 %)	16 (25.8 %)	19 (20.7 %)
Patient request	6 (3.6 %)	4 (6.5 %)	8 (8.7 %)

$X^2 = 22.24$, 9 d.f., $p < .01$ * only those who responded are reported

1 Columns do not all add up to 100% as some respondents did not answer all the questions

Differences were noted in how information was presented to women. The results of this analysis are presented in Table VII.

Table VII : Location of practice and information given to women 1 *

	Winnipeg (n = 173)	Medium size town 5,000 - 30,000 (n = 64)	Small size town < 5,000 (n = 94)
Manitoba Health guidelines §	82 (47.4 %)	22 (34.4%)	33 (35.1 %)
Individual counseling §	98 (56.6 %)	49 (76.6 %)	63 (67.0 %)
Nurse §	22 (12.7 %)	0	6 (6.4 %)
Pamphlet	41 (23.7 %)	10 (15.6 %)	12 (12.8 %)
Other agency	1 (0.6 %)	0	2 (2.1 %)
< 15 minutes §	123 (71.9 %)	59 (92.2 %)	76 (80.9%)

§ $p < .01$ using Chi square testing * only those who responded are reported

1 Columns do not add up to 100% as this is a summative table

Winnipeg physicians responded differently to their counterparts in small and medium sized communities when asked about counseling prior to HIV screening. Eighty nine percent of Winnipeg physicians responded that they provide counseling prior to HIV screening. This is lower than the 96.8% of physicians in small towns and 98.4% of physicians in medium sized communities who provide counseling. Regardless of location of practice, most physicians agreed that screening should be voluntary rather than routine.

How test results were communicated to patients was also different depending on where the physician is located with many of those living in Winnipeg and in medium sized communities (87.7% and 80.3% respectively) and 95.5 % of those in small communities conveying results in person only ($X^2 = 14.077$, 15 d.f., N.S.).

Physicians in smaller communities might be more reluctant to offer the test to their pregnant patients. Working and living in a smaller community may result in closer social relationships with patients which may alter the way in which the test is offered. It has been suggested that physicians in smaller communities may think their patients are at lower risk due to their geography and so offer the test less frequently. However, rural physicians stated they offered the test to women perceived to be at high risk for HIV infection more often than do Winnipeg physicians. This is of concern because it may reflect an erroneous belief system regarding both who is at risk as well as the physician's ability to accurately predict risk.

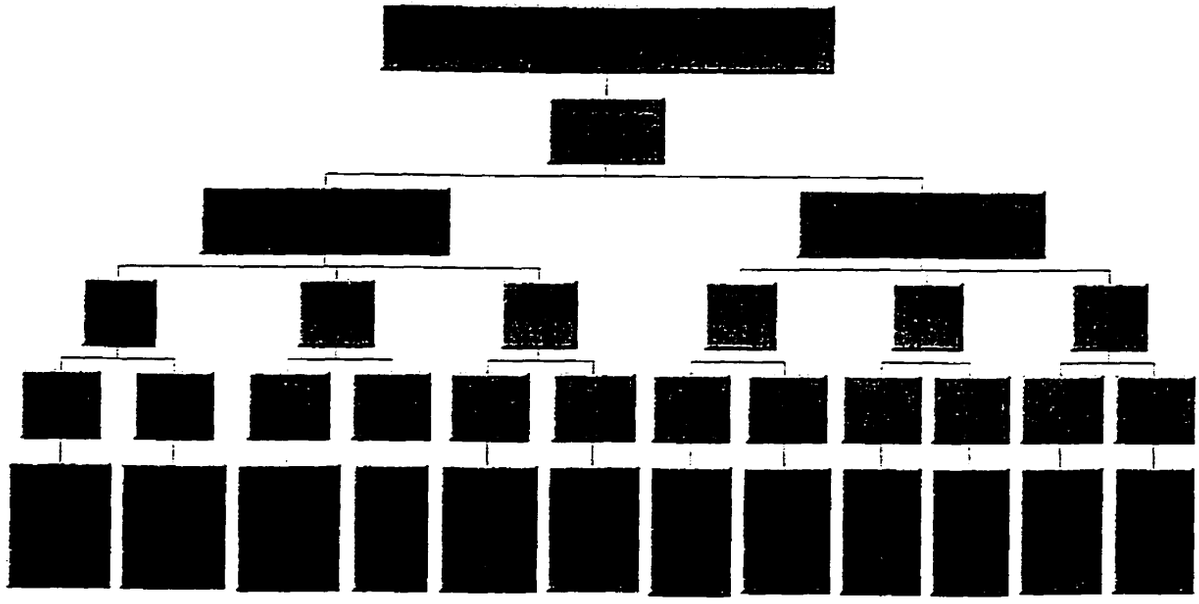
Effect of number of new prenatal patients on screening

The number of new prenatal patients that the physicians see each year did not influence the practice of prenatal screening at all.

Limitations

The response rate to this survey was low at 55%. As stated previously, this may be due to the nature of the enquiry or to the fact that the researcher is a nurse asking physicians to participate in a study. Every attempt was made to increase response rate by sending out mailed reminders twice after the initial survey.

There is no way of knowing if those who responded are in some way different from those who did not respond. It may be that those who responded have a particular interest in this topic and feel strongly, either in favour of prenatal screening or opposed. Those who do not feel strongly about this may not have responded. This will limit the generalizability of the results. Local factors within Manitoba may also limit the interpretation of these results to physicians in Manitoba. A breakdown of those who participated is presented below.



* Some respondents did not respond to certain demographic questions. Two respondents did not state whether or not they provided prenatal care. Twenty two of those who do not provide prenatal care did not state what their qualifications were. Four did not state whether they were male or female. Of those who do provide prenatal care, eight did not state whether they were male or female.

There was variability in the number of questions answered by respondents. Some physicians answered all the questions while others answered only some of them. Even if respondents did not provide prenatal care, they were asked to answer part of the survey as their attitudes towards prenatal screening were thought to be important. This may have biased the results of the survey as their attitudes are not reflective of their practice however, as only 336 of the sampleprovide prenatal care, the size of the sample would have been reduced

considerably if those who do not provide prenatal care were excluded completely.

Summary

Physician practices of, and attitudes to, HIV prenatal screening encompass a wide range. While most Manitoba physicians agree with the recommendations for prenatal screening, there was a divergence of attitude as to how this should be performed in the clinical setting and this is reflected in how physicians actually perform the various components of prenatal screening. Differences are seen between area of specialty, gender, location of practice, and number of years in practice.

There were a number of general comments made by respondents. These comments reflect the wide range of opinion held by physicians about this topic. One physician stated that the test "induces anxiety in women that is needless" while another suggested that we "need to know the HIV status of pregnant women to protect health care professionals." One suggested that "decreasing the paperwork would encourage more widespread testing," while another stated that "HIV testing is not accepted by more than 50 % of women."

Some strategies thought to improve uptake of testing are using a

pamphlet to impart information, incorporating the test into the prenatal form, and "making the test routine would decrease stigma and facilitate an increased rate of testing." The code used to protect the confidentiality of those having the test was seen as a barrier and the comment was made to "get rid of it." Yet another respondent saw the pre test counseling as "adding to an over-inclusive first visit which is underpaid." One physician suggested that a "special referral for consistent counseling is needed due to the time needed to counsel patients." Yet another commented that "all testing and treatment should be voluntary recognizing the autonomy of women" and another suggested "screening the male partner too."

Interviews with Health Care Providers

Ten health care providers were interviewed; four obstetricians, four family physicians, a midwife, and a pediatric infectious disease specialist. Location of practice included a community health clinic, full time hospital practice, and private practice in the community. Interviews were conducted in physician offices, at the hospital, and in one instance, at the physician's home. Interviews were taped and transcribed and lasted between 30 and 60 minutes. Health care providers were asked to describe their practice of prenatal screening and their opinion on the present policy of voluntary screening. They were asked to reflect on their practice of this intervention in the light of their personal beliefs as well as the nature of their patient population.

All health care providers stated that they offered HIV screening to all

pregnant patients, usually at the first prenatal visit. Many had started to do this as a result of the publication of the College of Physicians and Surgeons of Manitoba Guideline. Others had read about the results of clinical trials of zidovudine and the lowering of maternal-child transmission and incorporated prenatal HIV screening into their practice before the guidelines were available. In these cases, the recommendations served to reinforce their clinical decision. One physician had always offered prenatal HIV screening as part of a personal philosophy about HIV infection. This physician stated,

> The reason I offered it was because I felt strongly that women were not seen as a population that might be at risk for HIV and that women weren't generally offered HIV testing. They might not know that it was available to them. Might not recognize themselves in a risk group at all so wouldn't think to ask for it.

Some of these health care providers have changed their practice from attempting to identify risk factors and then offering the test to now offering the test to everyone, regardless of risk factors. Others discussed the test as part of preconception care with women. One obstetrician reported that some women do not see the importance of being screened before becoming pregnant. "[HIV] is not an issue. There's no baby there yet and so it's not even tangible."

Some of these health care providers rely on other members of staff, often nurses, to make the offer of HIV screening and fill out the requisition form. A midwife described how pregnant women are first seen by a nurse to determine whether the woman wishes to continue with the pregnancy before seeing the

midwife. At that time, a pamphlet is given to the woman and the nurse initiates the discussion. This is then followed up by a repeated offer by the midwife once the woman's health history and physical examination have been completed. The midwife stated that after taking the history and performing the physical examination, she has a picture of the woman's health status and by the end of the visit, "I've already more than likely established a really good rapport with her," which facilitates a discussion about prenatal HIV screening.

Nurses are often the first contact in hospital settings and they provide pregnant women with information about routine tests as well as pamphlets and the opportunity to ask questions. In some settings, nurses fill out the requisitions for the HIV test as well as for other routine tests in pregnancy. In other settings, they hand out the pamphlets and the physician asks the pregnant woman whether she wants to have the test or not and then fills in the requisition if the woman accepts the offer of screening.

In private practice, most physicians make the offer of HIV screening themselves as they do not employ nurses to assist with patient care. The offer is made in the context of all the other blood tests performed as part of prenatal care and is generally accompanied by a statement such as, "Although this is not part of the prescribed practice, we strongly recommend that a woman get HIV testing." A family physician reported that with women whom he has been caring for over time and who have never had an HIV test before, he will make the offer at the first prenatal visit and if it is accepted, he will ask the woman to return at

another time to have the pre-test counseling. If the woman is new to his practice, he will often do the pre-test counseling at that visit, presumably to prevent women being lost to follow up if they are concerned about having the test and do not return for care.

Health care providers suggested that they do not think that their patients are particularly at risk for HIV infection. Some see their practice as mainly middle class and therefore as low risk for HIV infection. Others describe the risk of their patients based on the geographic location of their practice, for example the core area of the city, presumed to be high risk, as opposed to suburban, presumed to be low risk. An obstetrician who has a large adolescent practice saw these young women as at higher risk, so has been offering HIV screening with greater frequency to adolescent patients as compared to older women. One physician gave this rationale, stating that "I think people have the perception that it's women from the core area who are at risk. No, it's any woman who is sexually active."

Some physicians offer written material to pregnant patients as part of the offer of HIV screening, however, the source of that material is different. One obstetrician has developed reading material based on the SOGC and College of Physicians and Surgeons of Manitoba guidelines. Another, together with a multidisciplinary team, helped to develop a pamphlet which is used in the large tertiary care institution where he practices. Some use pamphlets produced by public health associations. Others provide written material only to those who

specifically request HIV testing, in other words, pregnant patients are not given this material as a matter of routine. Written material is seen as not always being helpful. Some women with low literacy were perceived to have difficulty with written material and will often not read any pamphlets at all. Their situation is described thus :

> They do better with person-to-person communication than they do with written pamphlets. They'll read a pamphlet if they're strongly motivated to and the best way to use them is to be sitting with them while they're reading it but I don't always get to do that.

Others report that pregnant women are often overloaded with information from both formal sources, such as physicians, and informal sources such as the media, family and friends. One physician saw the information in the media as a source of education for women.

> I think women have read enough about this in newspapers and magazines and they don't feel they have to read a pamphlet. I don't see very many women nowadays for whom HIV is a word they've never heard of or don't understand its implications.

One family physician felt that written information is merely a supplement to discussion and that there is time over the course of the pregnancy to cover all aspects of patient education. He stated that "if you're the type of person to overload the patients with information and a really rushed visit, more information isn't necessarily better knowledge."

Whether pamphlets are actually read by pregnant women is not known to any degree. The midwife interviewed described what women attending prenatal

visits at her hospital do with the HIV pamphlet which is handed out to them.

> I virtually never see anyone reading it. Some of them will intentionally just leave it on the counter. They don't even take it out when they leave the room. I haven't asked them why they would leave it there but it seems to me by knowing who these women are, I think they just don't want to be seen carrying a pamphlet with [information about] HIV. You'll see the pamphlet just dumped in the stairwell.

The books and pamphlets women are reading may or may not have information about HIV infection and prenatal screening. Some women may prefer to read books they have purchased or loaned from friends rather than pamphlets given to them in the doctor's office. Others may be reluctant to be seen in possession of a pamphlet about HIV. Some physicians delegate the provision of verbal information to the clinic nurse and this interaction takes place before the physician sees the woman at her prenatal appointment.

A problem with physicians assuming that another member of staff has provided the information is that sometimes mistakes are made and the test is not performed or the requisition is completed and the woman has not had the opportunity to engage her physician in a discussion on the issue. However, many physicians, especially family physicians in private practice, reported engaging their pregnant patients in an ongoing and complete discussion with time for questions and due attention to the woman's needs for taking time to make the decision. There was a general

recognition that women are given a large amount of information in a short period of time and care providers are often not sure how much information has been absorbed. With prenatal visits often taking only a few minutes, both the women and their care providers are aware that time is pressured, and there is generally little opportunity to validate knowledge.

Health care providers reported that some women are asked to give written consent for HIV screening while others are asked for verbal consent. This may be dictated by the policies of the institution where the health care provider practices. In some institutions, the nurse gets either written or oral consent from the women before they are seen by either a physician or midwife. Some women are offered the choice of whether they want the results of the test to be part of their chart. Others do not have this choice and are told that if they do not want the results to be part of their medical record, they will have to go elsewhere to be tested and then report the result to the physician. Some physicians use a written consent form and utilise this piece of paper as part of the system to keep track of the code and requisition number of the HIV test itself. At one community health clinic, the policy is that the entire process (counseling, filling out the requisition, and receiving results) is carried out by other personnel. The physician has no knowledge of whether the woman has had the test or what the results are, unless the woman personally tells her physician. This is a unique situation whereby the results go to the prenatal

nursing staff who disclose the results to the woman and not to the physician who ordered the test.

Physicians claim to be in compliance with provincial and national guidelines regarding the need for consent prior to screening. Some women may choose not to tell the physician and this is supportive of women's autonomy and the freedom to control her body and health care. While on the surface this appears to be supportive of the empowerment of women, there may be some issues of concern in this particular example.

The woman may not be aware of the institutional policy and may neglect to inform the physician of the results. In the event that the test was positive, it may result in a delay of the initiation of treatment or treatment not being started at all. This policy reflects a case finding mentality common to community health clinics which strives to maintain patient anonymity, sometimes to the detriment of good health care. This policy likely serves to create a barrier to doctor-patient communication and is undoubtedly frustrating to physicians and nurses. The secrecy perpetuated by this practice also results in inaccurate record keeping in that, if the physician does not know whether the patient agreed to screening and the result of the test, an appropriate notation will not be made on the prenatal record. This may result in further problems when the patient presents in labour at the hospital. At that time, staff there may question the woman's HIV status and the woman may be subjected to intense questioning at a time when she would rather be concentrating on her labour. It is hoped that communication

between physicians and their patients is in fact open and honest, and that all the women disclose to their care givers whether they have had the test and what the results were.

Uptake of this offer of HIV screening was described by health care providers as variable. An obstetrician in full time hospital practice thought that two-thirds to three-quarters of the patients agree to the test and those that decline do so "from the feeling that neither she nor her partner are at particular risks so they don't see the necessity of it." Another physician described how some women state that "I don't think we should waste the health care dollars because I really don't have any risks" however "those most at risk have the most difficulty deciding to do the test." Many women are seen to be at low risk, however, they agree to the test, "They say, 'I'm in your hands. You know what test I need'." An obstetrician with a largely middle class suburban practice stated that most of her patients declined the test. However, " I haven't come across any patients yet that have been annoyed or surprised that I bring this up and talk about it. They recognize that it's worthwhile thinking about." One obstetrician noted that patients sometimes assume that the testing is routine and that they had been tested in a previous pregnancy.

> When you ask patients now [if they wish to be tested] they say 'Well, five years ago when I had my last baby, you mean it wasn't a routine test?' So people are expecting that it's part of the routine and not that you have to ask their permission to selectively screen them.

Some physicians continue to offer HIV screening following an initial refusal. These offers are usually at the same time as other blood tests are performed, for example, with the alpha-fetoprotein test at 16 weeks gestation, and again at 28 weeks, in case the woman has changed her mind or if her circumstances have changed. Women are thought to accept or decline the offer for different reasons,

> Most patients that do accept are either extremely low risk, in a monogamous relationship, or those individuals that really want to ease their minds. Those that don't accept either feel they're an extremely low risk population or they don't want to know because they're in an extremely high risk population.

This may be due to a number of factors including how strongly the physician recommends the screening, how the woman assesses her risk, whether women who have been tested previously agree to the test, and erroneous knowledge about how screening is performed. There was acknowledgement that some women are passive in their interactions with physicians and state that the doctor should do what she or he regards as best. This was not seen as out of the ordinary and physicians did not comment that they tried to counteract this attitude.

Physicians reported that results are usually given in person only however, some health care providers do not report results in the normal range at all. Some women specifically ask for their HIV test results because they are "always very curious to know when the results come back.'Have I got the

result?' They want to know." The results of HIV tests are treated differently than other test results by some physicians. "I generally work on the principle that no news is good news. But with HIV, I'll let somebody know for sure. I tell people that we'll definitely go over the results of the test." However, some physicians report that women do not ask about their HIV test results.

> I think they [women] assume you're going to tell them if it's positive. I think most people go, have the test, they know or assume that it's going to be negative and they think "Well, you know, if the test is not negative, I'm going to hear about it."

There was a great deal of variety in how physicians provide results in practice. Some physicians make sure that the HIV result is given in person and others do not give the result if it is negative, in keeping with the attitude of "no news is good news" often taken with the other routine tests. While there was general recognition that HIV infection is a disease like no other screened for in pregnancy, the perception of low risk and the fact that most of the physicians interviewed had never had to convey a diagnosis of HIV infection to a pregnant patient, has allowed most of the physicians in this sample to take a fairly casual approach to the disclosure of test results. Those who have cared for HIV infected women spoke about the need for a cooperative relationship between physician and patient. Some remarked how sometimes those with significant risk factors are often the ones who are most reluctant to agree to testing. A solution to this posed by another physician was to emphasize the benefits to the fetus of screening. Women can often be persuaded to make lifestyle and other

changes "for the good of the baby." These changes may not necessarily result in any positive benefits to the fetus, but the overiding desire of most women for a perfect baby is a powerful impetus for making the changes (Enkin et al., 1995, p. 21).

There was general recognition among those interviewed that HIV infection is unique because of the implications of having the disease. "If you find out you're HIV positive, you might find out very bad news that sentences you to a premature death." Due to the lack of effective treatment for HIV infection, a positive test result "tears the woman's life apart. It changes her job, her family, she has to look at her children differently and her life differently." For pregnant women, the ability to prevent transmission to the fetus was seen to be of paramount importance,

> Our best argument for having it done is the baby. The only way we can get the high risk kids to be tested is they will do something for the baby that they may not want to look at themselves.

Some barriers to prenatal screening were identified by those interviewed. Time and the lack of remuneration for educating patients were cited as the major barriers to physicians spending any length of time discussing this and other issues with prenatal patients. The time needed for pre-test counseling was mentioned frequently as a barrier. The lengthy (30 to 45 minutes) pre-test counseling described in the Manitoba Health guidelines for HIV testing was seen as not possible in busy practices, and many physicians thought that this

extensive pre-test counseling is not necessary for prenatal screening. Providing pregnant women with written material was seen as a way of saving time for the health care provider. "There's not enough hours in the day to see prenatal patients and to provide them with all of the information." Another barrier to more extensive screening of pregnant women may be the attitude of physicians themselves who may regard Manitoba as a low risk area and thus not offer this test to their patients.

> [Physicians may think] "I have a practice of really nice middle class people who would never do anything like this....my patients would never participate in (high risk) activities."

One of the barriers to prenatal screening was described by one physician as the physicians themselves, their fear of HIV and having to identify one of their patients as infected.

> There are some older physicians that really and truthfully are reticent about doing it [screening patients], particularly if they are in a smaller community. They are as frightened as the patient that it's going to come back positive because they are going to have to deal with it and they're going to find out things about people in their community that they don't want to know. They're worried about their patients and dealing with the emotional stresses of somebody they know being HIV infected. They may just not want to face it.

Another barrier mentioned is the fear of the pregnant woman which leads her to refuse screening. One physician described the response of a young woman who had participated in many high risk behaviors who was very reluctant to be tested as "she knew there was a possibility that she might be

[HIV] positive. What we've noticed is that the patients most at risk have the most difficulty deciding to have the test."

Some health care providers were opposed to the idea of routine screening for HIV in pregnancy. Reasons for this include the need for physicians and their patients to work together, as well as the basic rights of pregnant women in making decisions. One obstetrician who cares for a number of HIV infected pregnant women each year stated,

> I dislike the concept of forcing people...for doctors to force things to be done. I think in the long term one gets better results overall when one tries to enlist the cooperation of your patients. Doctors and patients should be trying to cooperate, not be antagonistic.

A family physician thought about the broader implications for society in considering routine screening but concluded that "from a public health standpoint it's probably important to do it [routine testing] ... on the other hand, from a human rights standpoint I think you sacrifice something if you enforce it."

There was acceptance by one family physician that this test is anything but a normal test and this plays a part in consideration of making the screening routine.

> This isn't the normal test because we don't have a simple cure..... I really believe you should know what you're getting into. Now you could argue that you're putting someone else's life at risk if you don't have this test and you're positive and you don't go for AZT treatment during the pregnancy. I think there's just as much chance of people bolting and running if they found out that they're positive and that they'll just disappear from the system.

In contrast, some thought that by treating the HIV test the same as all other tests in pregnancy, some of the stigma may be removed. The test could then be ordered using the woman's name instead of a code and that as long as women knew this was happening, the test would be normalized and the stigma would be lessened.

Each of the health care providers interviewed presented a unique perspective of this intervention based on personal experience, practice style and patient profile, as well as adherence to institutional policy where such policies exist. Their comments were thoughtful and often a result of personal analysis of their practice. These interviews served to provide rich data and an opportunity to reflect on the attitudes and practices of these health care providers. The physicians who were interviewed, with the exception of the infectious disease specialist, were part of the population who were invited to participate in the survey. Some of the physicians interviewed stated that they had completed the survey which formed part of this study; others could not recall or, in the case of the infectious disease specialist and the midwife, were not included in the study population.

Those interviewed did not regard their patient population as high risk, except perhaps for one physician who sees a predominantly adolescent population. Most described their patients as middle class and therefore at low risk. There was geographical bias described with suburban women being seen as low risk and core area women as higher risk.

A lack of consensus was also seen in care providers' thoughts on making this test routine for pregnant women. In keeping with published studies (Mills et al., 1998; Segal, 1996), many of the care providers interviewed were in favor of prenatal HIV screening, however, this did not necessarily translate into large numbers of their patients agreeing to the test. There was recognition that despite this being an important public health issue, the issue of women's rights cannot be ignored or superseded. There is a tension inherent in weighing the good of the public, the traditional public health approach, with the rights of the individual. While the need for public health policy cannot be ignored, it does limit the individual's ability to be autonomous and to have self dignity and fulfillment.

A woman-centered analysis of these interviews suggests that women are not central to their care in pregnancy and that the day-to-day practice of prenatal care is structured around making the physician's practice as efficient as possible. Policies and procedures exist to ensure that care is consistent across all patients and as efficient as possible. This negates the individual needs of the women who access physician offices for care. Information needs are generally addressed in a cursory fashion, and women do not attempt to get their needs met, in part due to the impression they have that the physician is very busy and in part because they want to be "good" patients and not make a fuss. While there is a sense that women are offered a range of options or choices in their care, this is often illusory as they are presented with limited information and are told what is recommended. They are often passive in allowing the physician to do what is best for them with little or no

knowledge of what is actually best for them and not for the physician's practice. One physician in particular, a self described feminist, has made an attempt to incorporate women centered principles into her practice, but she too is hampered by institutional policies which severely curtail her freedom to practice medicine as she wants to.

There was generally a great deal of support for prenatal screening for HIV antibodies from both the physician survey and the ten interviews with health care providers. Physicians agreed that this needed to be done and the majority claimed to be doing it consistently. Physicians are generally very busy and may not be giving their patients the time they need to answer all their questions and explain all the tests they will have in pregnancy. Manitoba is a province with a low seroprevalence rate and most of the physicians have not cared for an HIV infected pregnant woman, nor had to communicate a diagnosis of HIV infection to a pregnant woman. This may have resulted in a false sense of "it won't happen here, not in my practice, not in Manitoba." This attitude may affect how the test is offered to women and lead to the tendency to treat this test as much the same as all the other tests in pregnancy.

Limitations

The ten care providers who were interviewed all agreed to do so after being approached by me on the phone or by letter. A number of physicians who were contacted either did not return my phone call or stated that they were too busy to participate. Most of those who eventually agreed to be interviewed were known to

me through my work in women's health. These professional relationships may have biased the discussion. However, the ten care providers do represent a cross section of care providers in Manitoba. Among those interviewed are a number who provide care to women from outside the perimeter of Winnipeg. This small sample of care providers may not be representative of all care providers in the province of Manitoba .

During the course of the interview, care providers were asked to describe their personal practice of prenatal HIV screening. While some may have presented an idealized description in an attempt to be seen in a positive light, others admitted to screening women without consent and giving women incorrect information about how the specimen is coded. These physicians were honest in their admission of doing something contrary to the recommendations, and it is hoped that the other care providers were as honest in their interviews.

Syphilis Screening

Questions were asked in the survey regarding syphilis screening in pregnancy, as a contrast to the practice of HIV screening. This test is routinely performed on all pregnant women as part of the panel of blood tests done at the first prenatal visit. Syphilis screening was chosen specifically because it carries stigma like HIV infection, is transmitted sexually and there is no vaccine available, unlike Hepatitis B. In 1999, 14,500 pregnant women had syphilis screening as part of their prenatal care; less than 100 of these were positive and all were known cases previously diagnosed (Dr. M.Dawood, personal communication, January 5, 2000).

Do physicians provide counseling prior to syphilis screening ?

Most physicians who provide prenatal care did not provide specific counseling prior to VDRL screening (82.1% of family physicians, 79.7% of general practitioners and 100% of obstetricians). This held true for urban and rural physicians as well. Male and female physicians also did not differ significantly in this regard. There was no statistically significant difference between physicians based on the number of years that they were in practice.

Of those who actually did provide counseling prior to VDRL screening, 17.4% of family physicians and 21.8% of general tailored the discussion to the individual patient. Most physicians surveyed felt that VDRL screening in pregnancy should be part of the routine work up, however, there were some who felt that it should be discretionary, based on the need for the test as assessed by the physician. Any counseling prior to this test is likely to take less than 15 minutes (22.7% of family physicians and 25% of general practitioners.

Is consent required for syphilis screening ?

Most physicians do not require any form of consent for this test although some do ask for verbal consent.

How are results of theVDRL test provided to women ?

Most physicians either do not provide patients with negative test results or if they do, they provide the results in person only. Some will provide test results over the phone. The longer a physician has been in practice, the less likely he or she is to not give results to the patient. Fifty percent of those in practice less than ten years

do not give the result to the patient if it is negative ($X^2 = 17.877$, 16 d.f., N.S.).

Do physicians think that prenatal syphilis screening is cost effective ?

When asked whether VDRL screening in pregnancy is cost effective, most thought that it was not cost effective and a number did not know ($X^2 = 5.102$, 2 d.f., N.S.).

With increasing number of years in practice, the percentage of those who thought that VDRL screening was not cost effective fell from a high of 66.7% of those in practice 10 to 19 years, to a low of 50.0% of those in practice more than 41 years ($X^2 = 3.25$, 4d.f., N.S.).

Are physicians' practices of prenatal HIV and VDRL screening different ?

When the practice of HIV and VDRL screening was compared using a McNemar's test, physician practices regarding these two tests were significantly different. Physicians are more likely to provide counseling prior to HIV screening than VDRL screening (McNemar's $X^2 = 243.190$, $p < 0.01$). Consent is asked for more often for HIV screening than VDRL screening (McNemar's $X^2 = 186.005$, $p < 0.01$), and the time taken to give information about the test is longer for HIV than VDRL screening (McNemar's $X^2 = 10.5625$, $p < 0.01$). How results are conveyed to the patient was also different with HIV results more likely to be communicated to the patient in person compared to results of syphilis screening where negative results are often not given to the patient (McNemar's $X^2 = 113.0087$, $p < 0.01$).

Is prenatal HIV screening regarded as different from syphilis screening ?

Family physicians and general practitioners believed that HIV screening is

different from VDRL screening (56. % of both), however, obstetricians were divided equally on this issue (50% in agreement and 50% disagreeing). There was a difference with respect to this question between male and female physicians, with female physicians more likely to state that there is a difference. Those in practice for a shorter time were more likely to say that there is a difference ($X^2 = 20.667$, 4 d.f., $p < 0.01$).

This question (whether prenatal HIV screening is different from prenatal syphilis screening) was asked in response to the often quoted example of the acceptance of syphilis screening in pregnancy as a rationale for routine HIV screening. Comments on the perceived difference between these two tests focused on the social and political aspects of HIV infection. One physician stated that "the medical community has fostered HIV as different by demanding pre test counseling." There was recognition that syphilis has an effective cure while a diagnosis of HIV infection has "far reaching social implications" and screening for HIV elicits a "stronger emotional response." Another physician commented that there are "medical parallels but socially the two diseases are very different" and another noted that "society is frightened of HIV and more condemning of the HIV infected individual." Still another suggested that in today's world, "HIV testing is more relevant than testing for syphilis as the incidence of HIV is greater." Some stated that this test is not necessary and is "a waste of money." A number of physicians stated that in all their years of practice, they had never seen a positive test and that this is a "left over test from previous age." One physician stated that

there is a need for "clear guidelines from the College" relating to this test and another questioned whether the test should be performed if the swabs for chlamydia and gonorrhea are negative.

Most physicians do not provide any information to their pregnant patients about VDRL screening and do not require consent. Location of practice, area of specialty or gender of the physician do not play a part in this statistic. Most physicians stated that it should be part of the routine work up although there were some who suggested that the physician should assess whether the test was necessary for the individual patient and then make a decision whether to perform it or not. For the few who did provide their patients with some form of counseling prior to the test, this information was given in less than 15 minutes and the discussion was based on the perceived information needs of the individual patient. In keeping with most of the other tests performed in pregnancy, most physicians did not inform their patients about the results of this test. VDRL screening was seen by most physicians as not cost effective with many stating that in all their years of practice, they had never seen any pregnant patient test positive. Older physicians, however, were more likely to think that the test was cost effective. This may reflect their experience many years ago when syphilis was more prevalent and they may have actually been involved in the treatment of individuals with active or latent syphilis.

Most of the critique discussed previously relating to the practice of HIV screening in pregnancy applies to syphilis screening. However, while many

physicians at least mention to pregnant women that HIV testing is recommended, this is not the case with syphilis screening. Most women have no idea that this test is being performed and might refuse it if they were informed. Not informing women that the test was being performed ignores their rights as rational human beings and the continued performance of this test without informing women is a matter of concern. While effective treatment is available for both the pregnant woman and the fetus should she test positive, the harm done by withholding information outweighs the benefits. The harm that may be done relates to the emotional response to being told one has tested positive for syphilis. Syphilis, by virtue of it being a sexually transmitted disease, carries stigma, and to be told that one has a sexually transmitted disease is distressing. While in years past, a VDRL was required before a marriage license could be issued, the assumption was that most people could be expected to know that this test was being performed. However, it is no longer required before issuing a marriage license and most people do not know anything about this test.

Summary

The attitudes and practice of both HIV and syphilis screening in pregnancy are well grounded in a paternalistic structure that is perpetuated each and every time a woman attends a physician's office for care. Women are generally treated as an aggregate with little attention to individual dignity in that their needs are not assessed on an individual basis but rather as "pregnant patients," a homogeneous group. They have few choices and these are dictated by the information given to

them by physicians or nurses providing care. Women are treated differently from each other in that they are judged to be at high or low risk for HIV infection based on the way they look or where they live and this assessment of risk is not developed with their participation. The women often receive standardized care, a cookie cutter approach to prenatal care, where the focus is on seeing as many patients as possible, with little if any possibility of the women controlling or contributing to the nature of their care. Physicians have the power to decide who needs information, how much they need, and how long it should take to impart this information. There is no notion that women may want to define their information needs, and the idea of asking women what they want was never mentioned in the interviews with care providers or by comments included with the surveys. Guidelines are set to inform physicians of the standard of care, however, physicians remain free to conform to those guidelines or ignore them in part or in their entirety.

The following chapter will examine how women view their experience of HIV screening in pregnancy and how they see the issue of routine versus voluntary screening.

CHAPTER FIVE

INTERVIEWS WITH PREGNANT WOMEN

This chapter details the discussions held with pregnant women and includes an analysis of their reported experiences. Thirty two women were interviewed in a four month period in the winter of 1999. These women were recruited from two tertiary care institutions, a community health clinic in the core area, and a family practice unit associated with the University of Manitoba. Some of the women who participated recruited their friends who contacted the researcher and offered to be interviewed. The interviews were conducted in the homes of the women, and took between 15 and 45 minutes to complete. Women gave their consent to be interviewed and were asked demographic questions during the course of the interview.

Demographics

The average age of the women was 27 years, with a range from 16 to 40 years. For some, this was their first pregnancy, while others were experiencing subsequent pregnancies; one woman was pregnant for the sixth time and two women were expecting twins. Gestational age ranged from eight weeks to 37 weeks at the time of the interview. Most of the women were Caucasian, 29 in total, and three were of First Nations descent. Twenty two of the women were married, two were living in common-law relationships, and eight described themselves as single. Sixteen of the women had completed all or some high school education, 12 had

undergraduate degrees or diplomas, and four had graduate degrees. Occupations of the women included students, homemakers, nurses, a musician, two speech pathologists, two physicians completing their residency training, office workers, an insurance agent, and an accountant.

Information about total household income revealed that six women were living on less than $24,000 per year, five were in the $25,000 to $39,000 and another five in the $40,000 to $54,000 bracket, and 11 had a total household income of between $55,000 and $69,000. Four families earned more than $70,000. Most of the women (17 in all) were seeing an obstetrician for their prenatal care, while 12 were seeing a family physician, and three a midwife at one of the tertiary care institutions. Of the 32 women interviewed, 21 had been screened for HIV antibodies in this pregnancy and 10 had declined screening in this pregnancy. One woman was not offered the test at all.

The interview process

Interviews were recorded and transcribed verbatim. Women were offered the opportunity to review the transcripts of the interviews, however, none indicated interest in doing this. Many were interested in receiving a summary of the findings of this study. Interviews yielded seven main themes which describe the experience of prenatal HIV screening for these women.

The first theme describes being offered the screening test and is followed by two themes, knowledge of HIV infection and how the decision was made whether or not to be tested. The fourth theme describes women's feelings while waiting for

the test results. The fifth describes how results were communicated and the sixth how women felt on learning results of the test. Finally, women's thoughts on the way screening is offered are described.

"They asked me - do you want to do this" - the offer of the test

Those interviewed were asked to recall the discussion about prenatal HIV screening they had with their care provider. The majority of women were asked whether they wanted to have the test. This offer was made either by the physician or midwife, but in the hospital setting, often by one of the clinic nurses. One woman seemed surprised that she had some choice, "They actually asked me...they didn't say that it was necessary. (They) actually asked me, like do you want to do this or don't you." Another woman, having been screened in a previous pregnancy, suggested to the staff at her doctor's office that she have the test along with her pregnancy test.

For most women, the offer of the test was accompanied by very little information about the reason for testing or the policy for prenatal screening. A pregnant health care provider was informed by her physician that the test would be done with the other routine blood work. "She said, 'Well, we're just going to do all your blood work, we're going to do HIV screening'." Although this woman recalls a very brief discussion about risk factors at that time, she was never asked whether or not she wanted to be screened, the assumption was made that the test would be done.

When information was provided to the women, it was generally very brief

and focused on "helping the fetus." One woman was told by the clinic nurse that "we really recommend that pregnant women get tested for HIV and she sort of placed it in terms that, because if you do have HIV there's something that can be done to help the fetus." Other than the two physicians in the sample, none of the women had any knowledge of the reasons why HIV screening in pregnancy was being offered. When it was explained to them how the clinical trial had been conducted and the discovery of the two thirds reduction in maternal-child transmission, all the women expressed surprise and interest in the findings and thanked the interviewer for the information. Many of the women were not given any reading material about the test and were merely offered the test with little discussion.

For women who had been receiving care from the same physician for years prior to the pregnancy, the offer of the test was often not made. One woman reported that her family physician did not discuss this with her at all, "he never offered the test and it never occurred to me. I didn't ask." This woman had been tested some years ago and was not tested again in this pregnancy. Another woman was almost discouraged from having the test by her physician who said, "If you want it we can give it, but I don't feel that we need to at this point." A nurse, and mother of two in her third pregnancy, was offered the test after she had transferred care to a family physician after her previous doctor had left the province. She agreed to have the test in this pregnancy and described how she had not been screened in either of her other two pregnancies, "I'd asked about it actually with my

other doctor and he had felt it wasn't necessary." Yet another woman had never been offered the test in any of her three pregnancies which had occurred in the past six years.

One young woman, who presented late in pregnancy for her first prenatal visit, was told that HIV screening "was normal in all prenatal care. I guess she (the nurse) didn't ask if I wanted it or not. She just told me I had to take it." Another was informed by the nurse that "we're doing HIV testing for all pregnancies now and so I'll be doing the test for you." She was told that the test was confidential but was not left with the impression that she had any choice at all.

Only one physician was reported to have explained the policy to his patient who described the conversation, "My doctor said that there's a new policy that he offers HIV screening for each pregnancy and for each woman who's pregnant. And it's completely optional and it's completely anonymous and you can choose to or not to."

It appears that while most of the women were offered this test as part of prenatal screening, some women were left with the recollection that this test was performed routinely with no option for the woman to refuse. Still others were surprised that their permission for testing was asked.

<u>"I don't know what I need to know" - women's knowledge of HIV infection</u>

Women described what they knew about HIV infection in general, and the rationale for HIV screening in pregnancy. Most of the women, besides the health care professionals who were part of the sample, had a very basic knowledge of HIV

itself and why it is important to identify infected women during their pregnancies. Women stated that their knowledge came from school and television primarily, with a few mentioning that they had read a pamphlet provided by their health care provider.

Most knew that the virus affected the immune system and that there were essentially two stages to the disease, HIV infection and AIDS. One woman described the process in this way:

> To be HIV positive doesn't mean you have AIDS. There are different problems that can result from the immune deficiency and I've heard about AZT treatment. It not only affects those infected, it can affect their baby and whoever else is involved in their life.

Most women knew that HIV is spread through sexual intercourse and some knew that the virus could be spread from a pregnant woman to the fetus she is carrying,

> It's very easily spread from mother to fetus if you are positive when you are expecting and if they know that you have HIV, as an expectant mother, they can give you treatments, certain medications at the time up until delivery and shortly afterwards to prevent the child or lower the risk of the child being infected with HIV.

Another woman described how the disease can be spread sexually but "not on toilet seats" and that she knew "which are the high and low risk groups and I am in a very low risk group." Another woman, a nurse, thought that even after testing negative a number of times, it was possible for HIV to "show up ten years later and it worries me."

Interestingly, the women interviewed mostly saw themselves as low risk, despite many living in the core area, which is often seen as an area where women at higher risk for STDs live. Women's assessment of risk was in contrast to the physicians', and was based on risk behavior and not social class or residential area. It is obviously easier for women to assess their own risk based on personal sexual and injection drug using history. Unless physicians know their patients very well and have asked specifically about risk behaviors for HIV infection, their assessment of their patients' risk is going to be much less accurate and based on indicators that may or may not have any relevance to risk behavior. This inability to accurately predict risk is well documented (Barbacci et al., 1990; Hawkens et al., 1995; Krasinski et al., 1988) and the reality is, as one of the physicians interviewed stated, that "any woman who is sexually active is potentially at risk."

A few of the women did not know or understand why it was important to screen women in pregnancy. One of the pregnant nurses stated, "I didn't see the connection between pregnancy and HIV. Sure, HIV can be transmitted to the infant but I didn't realize that it was necessary to screen while you're pregnant." Another woman described how she had now "learned that if I have HIV and I find out about it, then they can give me medication during my pregnancy to try and stop it from going to the baby and I didn't know they could do that." Yet another woman suggested that she "didn't know what else she needed to know" and this had prevented her from seeking out additional information from her health care providers.

As described by the women interviewed, knowledge of HIV infection was very basic and information specific to HIV in pregnancy was generally lacking. There appeared to be very little information given to the women by their care providers, despite a number of pamphlets specific to HIV screening in pregnancy that are available.

"I said yes when they said it could be prevented from going to the baby" - making the decision to be tested

Women were asked to recount what factors they took into consideration when deciding whether or not to have the test. For most of the women, it was not difficult to decide to agree to the test. The predominant rationale was that the women wanted healthy babies and they would do whatever they could to ensure that outcome. One young woman recounted how the midwife had offered the test and told her that she could take her time in deciding whether to have the test. Her response was,

> Basically, as soon as she said that it could be prevented from going to my baby, I said yes right away. It's pretty important. If it's going to be good for the baby then I'll take any kind of tests they want to give me. I just don't understand why people wouldn't want to. Why would they even ask [permission] ? Why would I decline that ? Cause what if I did have HIV and I didn't get tested and I gave it to my baby. I'd feel awful.

Women described how pregnancy alters one's view of health and how "you get very cautious in pregnancy. If they can check a level of something, you want to check just to make sure." Another stated, "If they are already taking my blood I might as well have the HIV test. I didn't find it intrusive."

Some of the women initially assessed their personal risk when making the decision to be tested but made their decision based on the fact that they were pregnant.

> I've been with my husband for 11 years and chances are that if I haven't developed any symptoms or come down with AIDS by now.....the chances are pretty low [that I am infected]. So I knew that the risks were pretty low so I just never bothered [to be tested before] because it never really mattered. Once I found out that there's a baby and that if I am carrying the virus they can do something to prevent the baby having it, I started thinking about my baby and I did it for that, not for me so much but for the baby.

While some of the women agreed immediately to have the test when it was offered to them, others were unsure or undecided and talked to their husband or partner about it.

> I came home and talked to my husband and he said, 'You might as well do it.' And I asked why. And he said to just make sure everything is fine. There's no reason to believe that it would be positive, but that is why we did it.

The young woman who recalled being told that she had to have the test thought that she would have had the test if it were offered to her, however, "I didn't really have a decision. She just basically said I had to take it [the test]. There was no option there. But I think it's good. I felt that if I said no, they wouldn't have responded very well to that."

Others felt a little ambivalent about having the test in case the results showed that they were infected. One woman explained her ambivalence in this way, "Like you wouldn't want to know... but you want to know." An element of

self doubt was described by a nurse who has been tested a number of times following needle stick injuries. She described her feelings in this way, "When you really think about it, you could be positive, you could be negative. Chances are you're negative but you just could be positive." Another felt that her physician wanted her to have the test, " Finding out about HIV, it's got a level of importance. From the tone of his voice it was , 'Get it done'. "

One of the women was surprised at being offered the test and did not understand why consent was asked before doing this particular test. She explained herself in these words,

> I probably would have trusted him (the physician) to just go with whatever he thought. I'm not a doctor, I don't know. He's the professional, he should be telling me what to do. He knows what's best and I don't. So if he was to give me tests and not really explain in detail, I would probably just go ahead and have them.

Another woman was also surprised at being offered the test because she thought that she had been tested before without being asked, as part of routine care. "I actually thought that whenever you get a blood test they also check for HIV. I figured that they probably already did it every time I came in for a blood test so I didn't think it was a big deal." Still another woman "assumed something like that [HIV testing] would be necessary but I just thought it was kind of odd that there was a choice."

Some of the women had been tested before the pregnancy for a variety of reasons so this was not new to them. One of the nurses interviewed had been tested, along with her fiancee, before they got married. She explains herself in the

following words,

> We had both been sexually active prior to marriage so we both did it then. And obviously for pregnancy, I wanted to know. Originally I got it done just because I was going to spend the rest of my life with one guy and we both wanted to know where we stood. HIV affects both of us. It affects your whole life.

One other woman, also a nurse, had requested testing prior to getting pregnant. She had read an article in a magazine about a couple who on the surface appeared to be at low risk for HIV infection but during a pregnancy, the woman was found to be infected. She identified with the woman in the article and before getting pregnant herself, wanted to have the test.

> It [the article] sparked my sense that this was really close to the surface. I don't know if I would have had the test before reading the article. I thought 'If this can happen to her, why not us?'. I wanted to be tested prior to conception. I felt that's when we should do it so we can make a better decision rather than after the fact.

One woman agreed to be tested despite that fact that she had a negative test before. She was given very little information about the test and decided to have it. On considering her reason for having the test she stated that "If I had had something to read and I thought about it logically, and given the amount of time between my previous test and everything, I probably would have convinced myself that it wasn't necessary."

In considering women who refused to have the test in this pregnancy, one woman's story stands out. She was in her third pregnancy and had tested negative for HIV antibodies before her marriage which was reported by her to be

monogamous. Her self-assessed risk for HIV infection was one sexual encounter long before her marriage and even though an HIV test after that encounter was negative, doubts remained, "It's always in the back of my head and I'm always afraid to get retested." When her physician offered her the test in this pregnancy, her husband refused on her behalf, "I looked at my husband and he said no. That's basically what happened. He said 'You don't need to, we've done it before. Put it in the past and it's over with'. " In essence, her husband refused the test on her behalf and she did not contradict him or request the test at another visit.

Others who had tested negative before were confident that they had not been exposed to HIV and so refused to be screened in this pregnancy. One woman was firm in her reasons for not being tested. "I just assumed that I'm still negative and what was the point of the test again ? I think nothing has changed." Another was equally confident that the results would be negative, "I don't see any point....I'm quite comfortable that the result would be negative. I don't see myself as somebody at risk. I know where I've been, I know where my husband's been."

It appears that some women consider the fetus in making a decision about prenatal HIV screening and, even though their personal assessment of past behavior would indicate that their risk is very low, agree to be tested for the sake of the fetus. Others, however, refuse on the basis of a reasoned assessment of both their risk and their partner's risk and do not feel the need for testing.

"Even though I had no reason to fear, you still think 'what if' "- waiting for test results

When asked to describe their feelings after having the test, most of the women reported that they had not given it much thought in their daily activities. Generally, women waited for the results of the HIV test until their next prenatal appointment, four weeks after the blood was drawn. Most of the women interviewed were not concerned in the period between having the test and receiving the results. In fact, some did not receive the results at their next visit and waited another month or two before remembering to ask what the results showed. As one woman recalled, "I didn't worry about it. I didn't get them back I think until my third visit." Another woman, now in her sixth pregnancy and looking after two young children recounted how busy she is and how her attitude has changed in this pregnancy,

> I'm just a little busy in my life right now, because [in other pregnancies] it was like I could hardly wait to get any results ... it was like I wanted to phone to know what the results were. And this time, it's like 'when the results come, that's fine'.

Some women, even though they thought they were at low risk for HIV infection, worried that the test might come back positive. One woman, who is married to a physician, was persuaded to have the test by her husband "Just to make sure." She reflected, "I had no reason to believe that it was positive but you still think, well what if....." Another described her feelings while waiting as, "This little piece in the back of your mind thinks 'Man, I hope I wasn't one of the unlucky

ones'. "

In contrast, some of the women interviewed related that they were nervous while waiting for their results. One explained that this pregnancy, her first, was unexpected and it had taken a while for she and her husband to come to terms with the fact that they were going to be parents. She described herself as a 'worrier' and described waiting for the results in these words,

> I think I worried for the whole four weeks until I had my next appointment, until I knew they came back. Maybe in your first pregnancy you're more anxious or maybe it's just me but because I'm so anxious about things going wrong, I was really paranoid even though I had a low risk for HIV.

Two of the women interviewed were very concerned between appointments. One stated plainly, "I was scared. If I had the virus, I didn't know what I was going to do." Another young woman described how she was worried but, at the same time, afraid to get the results,

> It [waiting] was disturbing... to wait for the test to come back... I never wanted to not know so badly. It's bad that you have to wait two weeks to find out the results. That's like fourteen 24 hour days of trying to figure out whether or not you're going to live for 10 more years. It was very scary because it's so unknown. You just don't know until you're going to get it [the result] back.

Fear of being HIV positive and not knowing about support in that eventuality seemed important to one woman who explained herself in these words, "I was really nervous. I was scared that if I do have HIV then what am I going to do. I don't know if my family will be there for me in the end."

Most of the women interviewed seemed unconcerned during the waiting period. This is likely due to a sense of confidence that the test would indeed be negative. However, for the few who were worried, the wait between appointments was fraught with thoughts of uncertainty and concern for personal support and coping should the test be positive.

"All the tests came back and everything is fine"- receiving the test results

The women were asked to describe how and when the results were communicated to them, and by whom. Receiving the results of the HIV test usually occurred at the next prenatal visit, usually four weeks after having the test. Results were most often given along with the results of other tests and were not accorded great importance. However, some women were particularly interested in the HIV results and made a point of asking for them.

For some women, the HIV test being negative was included with all the other results of prenatal blood tests. A common experience for many women was the nurse or physician saying "All the tests came back and everything was fine." One woman has never had the results of the test communicated to her. Her experience is described in this way, "I did them [the tests] and I never heard anything back so I figured if something bad had happened I would have gotten a response. So I just assumed that everything was okay, every test that I did."

One woman recalled being told that if the test was positive, someone would call her. She remembers that time, "Nobody phoned me and I went back and there was really no mention of it and I think it was at the next appointment that she [the

nurse] said it was negative. I kept thinking that because she told me that somebody was going to phone me immediately if it was positive, I wasn't that worried." Yet another woman thought that she would be called by the hospital if there was something wrong with the results. At her next visit she mentioned to the nurse that "I figured if there was something wrong I would have gotten a call...I was never called so what's with the results....and she said that everything was fine."

One of the nurses interviewed recounted how her physician informed her of the results of her prenatal screening.

> She didn't even say "HIV negative"....she just turned the computer screen and said "Have a look yourself'. She just pointed to the screen. There were some tests there and all I was really looking for was for negatives down the side and then I remember purposively looking for the HIV, looking over to the left and seeing 'HIV negative'.

One young woman recalled how the nurse at the hospital went through all the results with her.

> The nurse came in and told me about all the tests and the results. She read off all my results to me, from the very top of the list to the very bottom and she explained them all and what it meant, if they were positive or negative and how the levels were. She didn't take any separate time on the HIV test though.

From the experiences described by the women interviewed, very little attention was paid to the results of the HIV test, despite some women feeling that this test result was "special". Most women were told that the tests were "fine" and were left to assume that the HIV test was negative.

"I never worried about it anyway" - thinking about the results

When asked about their response to receiving the test result, many of the women had some difficulty remembering how they felt. In general, feelings on receiving results of this test ranged from relief to no emotional response at all, because the women were so confident that the test would be negative. In fact, all the women tested HIV negative. As described in the preceding section, some women were never told explicitly that their HIV test was negative so there was no opportunity for them to feel anything on being told their results.

One woman who was confident of the results described how the physician told her not to worry and that she was negative and her response was, "I never worried about it anyway."

However, for some women, receiving these results was very important. One woman stated,

> That [the HIV test] was the one I really wanted to find out the result. It was the only test I followed through to find out what was I actually seeing... that I was negative. The others are just like negative, negative, oh I don't really care. I just wanted to know what that one was.

Many of the younger women who were interviewed described feeling very happy and relieved when the test came back negative. One woman, while relieved herself, described her husband's response, "I think my husband was more relieved. I think he knew that if I was positive, it wouldn't have been my actions necessarily.....he was probably more relieved than I was."

It appears that any emotional response to the test result was predicated on

the confidence that women had that the test would be negative. However, for those women who were concerned about the test, the predominant feeling on receiving negative test results was one of enormous relief.

"Women should be informed and given the choice" - thoughts on HIV screening in pregnancy

The women were all told about the existing policy for prenatal HIV screening in Manitoba. Some expressed surprise that it was necessary to explicitly offer the test to pregnant women. They suggested that the test should be done as part of routine screening. One woman stated, "I think they should test you anyway for HIV... just to make sure that you're not carrying the virus... I think that HIV tests should be included [with the other tests]." Another felt that over time, the stigma associated with HIV infection has decreased and that people are more educated today. She went on to say that "HIV is just as much of a risk as anything else, like syphilis, so why wouldn't it be part of the battery of tests that are done while you are pregnant ?" The best interests of the fetus were an impetus for those who felt that prenatal screening should be routine, as exemplified by the following statement, "I hope that any responsible adult would want to know if there was a possibility that their child may have this. If you don't want to consider yourself, consider your child." The issue of maternal-fetal rights was addressed clearly by one woman,

> I think that if you're going to carry a child, you have a responsibility and if something can be done to prevent the child from contracting any of those diseases, then you should take those steps to protect the fetus. I guess that boils down to the issue of is it the mother's choice or do you recognize that there is an unborn child that needs to be protected and there are health concerns related to another life.

Yet another spoke strongly about the issue of routine testing,

> If I was in charge, I wouldn't make it an option. I mean, you have to have blood tests anyway when you're pregnant so it's not such a big deal to get one more. I wouldn't make it a choice. It's not like you're invading their privacy. It's something you need to find out.

Women considered their personal feelings and experience when giving an opinion on this issue. One young woman described her fear and extrapolated her feelings to others,

> I think every one should take the test.....I was really nervous about it. I guess lots of people if they're pregnant and they're told they have to take this test or if they're given a choice, lots of them would be scared to know if they have it. They may say 'Well, I don't want to take that test.' Not because they have HIV and they don't want protect their child but because they're scared themselves about the result. So if they have a choice, lots of people would be too afraid to know. It would be nice to have a choice to a certain extent, but I'm not afraid to know.

Some women wavered in their opinion of this issue. On the one hand they considered the fetus and the responsibility of the pregnant woman to that fetus and yet they also recognized the rights of women to choose whether they wanted to be tested or not.

> At first I thought it should be mandatory and because a lot of women may not realize it, whether they had been at risk or not, and if they give birth to a baby ... and everybody wants a healthy baby. And if they had been at risk without knowing it and then they give birth to a HIV positive baby, well that baby is going to be suffering for the rest of its life... and then the mother is going to feel really bad, wondering what happened and where did it come from. On the other hand, I was thinking that perhaps it wasn't a good idea to have mandatory testing because a lot of people would think it would be an infringement of their rights.

Other women considered what would happen, in the long term, if a woman were tested without being told and then was found to be HIV positive, "I don't think it is proper to withhold information from a patient. It's life altering you know. If you don't tell them and then you get a positive result... it could be devastating, not to have any preparation for it." Another spoke about how having HIV "can change a woman's whole life."

Some women spoke out strongly for women to have choices. They described how women are "held hostage with how they treat the fetus," citing the case of the solvent using woman in Winnipeg who was initially ordered into a rehabilitation program. A nurse verbalized her frustration with a medical system which

> ....takes away choices from women during pregnancy. All of a sudden you're in delivery and you've discussed certain things with your doctor and before you know it, you're getting an episiotomy. I think a choice is a choice and it should be left to the woman.

The issue of choice went beyond just the HIV test for one woman who described how women are sent to have other blood tests without enough information.

> I think that women should be more informed and should be given the choice and the information about any kind of testing you do in pregnancy. They hand you all the things [requisitions] and send you down to the lab... I think of younger women who haven't experienced pregnancy or who don't have good communication with their doctors. It can be very intimidating. You just assume that the doctor is God and if a doctor or nurse tell you that this is what you are going to do, you just automatically do it without asking any questions.

Another woman saw the value in asking a woman's consent to perform the test as a way of opening up the discussion. "If it was routine it would just be checked off whereas this way, it's like a question that's posed by the doctor and then you can discuss it. It opens the door for education." One woman expressed herself simply as follows. "It's up to us if we want to do it or not. They can't force us to have the HIV test. It's not right."

The thirty two women who shared their thoughts and feelings were all different and unique in their recollections and opinions. Some were not offended by the idea of routine screening while others were more vocal in their support of women's choice. Most recognized that women want healthy babies, but were divided in how that responsibility was acted upon.

<u>What are Women's Experiences of HIV Screening in Pregnancy ?</u>

The women interviewed in this study were all offered the test, often at the first prenatal visit. Some reported being surprised by the offer because they either assumed that the test would be done and were thus surprised when it was offered, or because they did not realize that they had a choice. Others were told that the test would be done and seemed to be unsure whether they could refuse or whether a

refusal would be seen in a bad light by the health care provider. The women interviewed seemed to be passive and did not articulate an active role for themselves in their interactions with their health care providers.

Sharing Information

Women in this study were generally not given written information, despite the fact that in the two tertiary care institutions, a special pamphlet has been printed specifically for this test. The midwife who was interviewed stated that some of the patients are reluctant to be seen in possession of or reading the pamphlet, so leave it in the examination room or discard it. Day-to-day experience with women not reading the pamphlet may have led to these health care professionals abandoning the practice of handing them out. However, this impacts on the women who attend the clinics who may want to read the information and would benefit from the knowledge gained. A solution to this may lie in asking women how they see their information needs. By identifying their information needs and selecting the most appropriate method to access information, they will hopefully be able to make an informed decision about having the test. This allows women to define for themselves what they need and personalizes their care to a certain extent. It also speaks to the feminist values of individual dignity and self fulfillment which are decidedly lacking in the care of women in this context.

Many of the women were reading books about pregnancy and child care while others stated that they relied on friends and health care providers for information. For some women, the opportunity to discuss the issue with a health

care provider or to view a video may be most appropriate. Busy health care professionals are likely to state that they are too rushed to have this conversation about how information needs can best be met and so they take a "lowest common denominator" approach to patient education. Some of the women commented in their interviews that they do not ask any questions as they are so aware of how hurried their physician is. They are intimidated by the perception that their physician is so busy, with a crowded waiting room and an apparent eagerness to complete the visit, that they do not attempt to engage the physician in discussion and are left with unanswered questions or feel that they have agreed to something without full disclosure of what they have consented to. Physicians, while recognizing that prenatal visits are often brief, may not realize the full extent of their patients' response to their haste and the pressures they are under which are very apparent to the pregnant women in their care. What is equally disturbing is that most of these women do not verbalize their dissatisfaction with the care they are receiving and seem merely grateful for whatever attention they do get. One physician wrote a comment on a returned survey suggesting that information should only be given if the test is positive. This is alarming, suggesting that information would be passed to a woman who has just been given devastating news for which she was not prepared about a test she likely did not know she was having. Some rely on office staff to distribute educational material and this may occur in a random fashion depending on how busy the office is on any given day and whether the pamphlets and books provided by pharmaceutical companies are

available.

Information regarding the offer of prenatal HIV screening may be presented to women in such a way that the notion of choice is an illusion and through subtle persuasion, women may consent to screening without realizing that they may refuse or take time to consider their decision before having the test. The information may be presented in such a way that women may feel by refusing the test they are in some way acting in a manner that is detrimental to the health of the fetus. Some have suggested that protecting the well-being of the fetus by treating the pregnant woman is justification for mandatory prenatal HIV screening (Allen, 1991). If a pregnant woman decides not to be tested for HIV, it may be argued that she is not being rational and thus her rights to choose may be overridden in the "interests" of the fetus. This is an inherently paternalistic argument, one in which an outsider, perhaps a physician or the state, assumes that the woman cannot decide for herself what is best for her and the fetus, and therefore, makes the choice for the woman. This was the case for one young woman who described how the nurse told her that she had to have the test and she did not know enough or feel empowered enough to even question this attitude, much less refuse to be tested.

There appeared to be differences in how women were offered the test. Some were told explicitly that they could choose to have the test or not, others were made to feel that they should have it, and still others were left feeling that they did not actually have a choice at all. The information most were given was couched in the language of helping the fetus with little or no information of what would happen to

the woman if she tested positive. Most of the women did not question this imbalance in the presentation of information. It is almost as if, by virtue of the pregnancy and the presence of a fetus, the needs of women are secondary or even absent. The purpose of prenatal care is to ensure that the pregnancy has a good outcome, that is, that a healthy baby is born (Enkin et al., 1995). The needs of the woman are not always considered in the attainment of this goal and she may be seen as an incubator of the fetus. This notion of pregnant women as walking incubators has been described by some feminist writers, most notably Shelia Kitzinger (1978, p. 74). Pregnancy has increasingly been viewed in a mechanistic fashion and the woman may be seen as the vessel who carries the uterus where the fetus grows, and an artificial separation of pregnant woman and fetus ensues.

Generally, women had a very basic understanding of HIV infection and most knew the infection could be passed to the fetus if the pregnant woman was positive. Some knew that there was treatment that could be given to pregnant women. Besides the two physicians who were part of the sample of pregnant women and one other woman, none of the women had any knowledge of how treatment during pregnancy and the intrapartum period could reduce transmission to the fetus. These women did not appear to be particularly inquisitive about this intervention. There appeared to be an overriding assumption that health care providers have their best interests at heart and if something is offered to them, there must be a good reason for this. Lack of knowledge about the details of HIV screening and treatment for both the pregnant woman and the fetus did not seem

to be a barrier in this instance.

While many of the women interviewed described having choice regarding HIV screening in pregnancy, they in fact have limited choice. They are given limited information about the test itself, are told that it is recommended, are not given the rationale for the test in pregnancy, and are told almost nothing about what would happen if the test were to come back positive. The assumption is that they are low risk, often based on where they live or on the assumption of their class status, and the expectation is that they will test HIV negative. While fortunately this is most often the case, they remain inadequately prepared should they be found to be HIV positive. Younger women, and those thought to be at risk, are often subtly pressured into having the test by being told that it is for the good of the baby and many believe that having the test will result in a healthy baby. Having the test will identify those women who are HIV infected, and treatment can reduce the risk of transmission to the fetus. Linking screening to a healthy baby is reductionist and part of the phenomenon of using the fetus as an incentive to agree to some form of intervention.

While they are asked for consent to perform the test, it is unclear if they fully understand the consequences of this screening. The test is often included with all the other routine tests of pregnancy which are not explained in great detail. This may give the illusion that this test, and the disease itself, is somewhat routine. This is far from the truth. While health care providers admit that this test and the disease it identifies, is different socially, politically and medically, from all the other

diseases screened for in pregnancy, it is not accorded the gravity it deserves. There almost seems to be an illusion of wishful thinking associated with the entire process; if we believe it is unlikely to happen, and we treat it lightly, then the awful consequences will not happen.

Waiting for and receiving test results

While waiting for results, most of the women interviewed for this study were unconcerned and went about their daily lives, not really thinking about the result. This often translated into a lack of curiosity about the results at the next prenatal appointment. Some, however, were concerned and stated that they experienced significant anxiety between appointments. They gave no indication that they sought support for this anxiety and there was no mention of being able to get the results sooner from the clinic or physician. While most of the women indicated that their risk was not particularly high, there was for some, an element of "what if" in this waiting period. It appears that the lack of information prior to having this test may result in fear while waiting for the result. A discussion with a health care provider where risk can be established to some degree may lessen this anxiety and represent an educational opportunity as well. Some women, however, may be worriers and may suffer anxiety despite the best evidence that they are at low risk. Anxiety about other events may be transferred to the HIV test, as was the case of the woman interviewed who was still coming to terms with being pregnant and admitted that she worried obsessively about many things in the pregnancy.

The women were told of the results in a very casual fashion by health care

providers. Communication about results ranged from not being told anything at all with women assuming that "no news is good news," to asking specifically about the HIV result. Often the result of the HIV test was included in a general statement about all the tests being "fine." Most of the women accepted this, even if they did not know what other tests had been performed. There appears to be a passive acceptance of tests being done without much information and a subsequent acceptance of results being conveyed as a group and in vague language. While it is common practice for physicians not to report the results of test with normal results, this speaks to the lack of regard for the dignity of women who should be told about everything related to their health status. In addition, hearing that the results of tests are normal may reinforce good habits and give women confidence that their lifestyle choices are sound and should be continued. On the other hand, some women who have been participating in high risk activities and have tested negative, may feel invulnerable because they have taken risks and yet not become infected. These women would benefit from the risk reduction education that is included as part of post test counseling that is done when HIV testing is performed as part of case finding, rather than mass screening as is seen with prenatal HIV testing.

A few of the women did ask specifically about the HIV test and were told that the result was negative. One woman, a nurse, was invited to view all her results on a computer screen and she paid particular attention to the HIV test result as she had a potential exposure in the work setting. However, her physician did not

notice or enquire about her anxiety and an opportunity for discussion was lost or avoided. There was generally no other discussion at the time of giving the results and women were left to process the information about all the tests being "fine" by themselves.

The participants in this study reported that when they were given the results, they generally had little, if any, emotional response. This is in part a recognition that for many, the risk of HIV infection was very low. Others however were relieved, particularly those who had been concerned regardless of their risk profile. It is unclear if the health care professionals imparting the results were aware of any reaction as they were not really aware of the feelings of the women in the time between having the test and receiving the results.

This apparent attitude of the health care providers is interesting. They appear to act as if most of the pregnant women they care for are at very low risk and so seem to be very relaxed when giving information about the test. This may reflect the low prevalence rate of HIV infection in Manitoba and the likelihood that most of them have never encountered a woman who was HIV infected, much less had to tell someone that their test was positive. From the interviews with physicians, those who had cared for HIV infected women in the past or had the experience of communicating positive test results had a much less relaxed attitude to the topic. There was recognition from physicians interviewed and from comments included with physician survey responses that HIV infection dramatically alters a person's life. However, the link was not made between

preparation for a potential positive test result and the cursory nature of pretest counseling as it is generally performed.

Should this test be voluntary or routine ?

When women were asked their opinion of how this test should be performed in pregnancy, the answers were overwhelmingly in support of including the test with all the other routine tests in pregnancy and not requiring specific consent . This contradicts the findings of other studies, most notably those of Duffy and associates in England (1998) where 67 % of women surveyed thought that the test should be offered to all pregnant women who could then make a decision. The participants in Mawn's study (1998) thought that the test was important for the health of both the woman and her baby but stressed that the decision to have the test should be voluntary. On the other hand, Carusi and colleagues (1998) found that 69 % of their respondents said that prenatal screening should be routine with 27 % stating that it should be done only with written consent. This particular study found no association between personal risk assessment and test acceptance. The results of this study agree with those of Boyd and colleagues (1999) where women stated that the test should be offered universally however, they did not wish to be screened themselves.

This response, to test all women routinely without specific consent, also contradicts public policy which cites ethical concerns with routine testing. It is interesting that when you ask women, the same ethical concerns are either not considered or the experience of pregnancy and the responsibility to the fetus

seemingly overrides recognition of women's rights. This apparent willingness to be tested for a range of conditions, at least one of which is life threatening, may be reflective of a general passivity and trust in the medical system or based on a lack of knowledge about HIV infection in women and the perception that women in Manitoba are at extremely low risk. When asked about their personal risk, most of the women stated they were extremely low risk. Only the health care providers in the sample of pregnant women admitted to some occupational risk and even though most of them had experienced needle stick injuries, they had all had negative HIV tests subsequent to those incidents and so were probably more likely to see their risk as low as well.

A minority of the women spoke about the rights of women and how they need information before making a decision that may result in a life altering diagnosis. For one woman, this extended to all the other tests performed in pregnancy. She recognized that many women do whatever the physician or nurse suggests without questioning and that the relationship is often intimidating to women, particularly younger women. Another woman saw the educational value in asking permission to perform tests as this opened the lines of communication which ultimately benefits the woman and her family through knowledge gained by discussion and information sharing. There was also mention made of the loss of freedom many pregnant women experience with the example given of how decisions made before delivery are often changed without consulting the woman and how the woman is "held hostage" for the benefit of the fetus.

Despite the fact that many of the women did not appear to consider their rights in supporting routine screening, some did speak of the rights of women as individuals and not only as the vessels that harbour a fetus. When considering the liberal feminist approach to this and other tests, asking for informed and voluntary consent before screening pregnant women will not overide basic human rights and will serve an educative function. There is support for the voluntary nature of the test from both physicians surveyed and interviewed, and Manitoba Health, the College of Physicians and Surgeons of Manitoba, and the SOGC continue to support this. Based on the evidence presented in this dissertation, continuing this policy of voluntary screening in pregnancy is warranted. This approach respects women's rights to informed consent and is acceptable to both individual practitioners and governing bodies.

Women's choices

The women interviewed were often surprised by the offer of screening and said that they had no idea that they even had a choice. This reflects the lack of choice that they have in other areas of prenatal care. When asked to name the tests they had in the pregnancy, most could only name tests for glucose and alpha-fetaprotein. This is likely due to the fact that for glucose testing, they are instructed to either fast or to have a meal two hours before the test. With alpha-fetaprotein testing, there is generally a discussion with the physician about whether or not they wish to have the test. All the other tests that are commonly performed are not discussed with them, including testing for syphilis and cervical

swabs for chlamydia and gonorrhea. Even when presented with a choice, it does not appear as if many of these women acted on this choice. Some women have been socialized into being passive in the area of health care and they may not feel empowered to make health care choices (Lundy & Mason, 1994). This is exemplified in the case of one woman who stated clearly that she would do whatever her physician told her because he was the professional and should be telling her what to do. Another woman said that she did not know what she needed to know and so did not feel empowered to ask questions of her health care providers.

Those women who felt that they had a choice whether to have the test or not made the decision based on the need to protect the fetus and the overriding desire to have a healthy baby. Despite not knowing the details of how, and to what extent treatment in pregnancy may reduce the transmission rate, when told that this test would somehow relate to a healthy baby, most women agreed to it with very little, if any, consideration for their own health should the test be positive. This seemingly blind faith may relate to many of these women regarding themselves as at very low risk. Most were very confident that the test would be negative and yet they still agreed to have the test.

There were a number of those interviewed who did refuse the test based on a personal assessment of no risk for HIV infection, however, these women were in the minority. Their experiences stood out among the other stories of women. They made a decision based on their life circumstances and did not report any pressure

from health care providers when making that decision.

Women were influenced by their partners. One woman had the choice removed from her by her husband who refused on her behalf. Many women are accompanied to prenatal appointments by their husbands and partners. There may be subtle, or at times overt, attempts by these partners on how women make their choices. Information about the sexual and needle sharing activities of their partner(s) may be withheld from them and they may assume that they are at no or low risk for HIV infection while the opposite is true. Some women told of how they were unsure whether to have the test or not and their husband or partner told them to have it. One woman related how her husband was more nervous about the result than she was. This appears to be a case of testing by default; he did not have the test himself but was relying on her test result to reassure him that he was not infected.

Implicit in the discussion of women's ability to define their own risks and make choices is the assumption that all women are able to do this. The ability to make choices must be placed within the reality of women's lives. Women in abusive relationships may not be allowed to make independent choices. Women who do not know that their partners are at risk for HIV infection may make choices based on erroneous information. When presented with very little information about HIV infection, women are still expected to define their own risk for HIV infection and decide based on this definition whether or not they needed to be tested. While many assume that there is enough information in the public domain about this disease, this study suggests that women do not have specific knowledge

about the disease, particularly as it pertains to maternal-child transmission.

Some women may be agreeing to testing simply because they do not have enough information to make a reasoned decision not to. The case of one of the pregnant registered nurses comes to mind. Even though she had tested negative a number of times in the past, she thought erroneously that at some time in the future she may develop antibodies and then test positive. Another woman who was interviewed recognized that if at the time of the offer of the test, she had been given some written information and had time to think about her risk, the timing of her last test, and the need for a test in this pregnancy, she probably would have decided not to have the test.

Limitations

Thirty-two interviews were conducted in this phase of the study. Women were recruited and interviewed until saturation was reached, that is, no new ideas or comments were identified from the transcripts of the interviews. On reviewing the demographics of the participants, there appears to be heterogeneity within in the sample however, this sample, and the results obtained, may not be truly representative of the population in Manitoba. Only three First Nation women were interviewed. Staff at the hospitals and clinics where recruitment took place pointed out to me that, in their experience, these women are extremely reluctant to take part in research. Many do not have a telephone at home and are thus difficult to contact to make arrangements for interviews.

Women self selected to be part of the study by returning a tear off portion of

the invitation to participate. They were then contacted to set up a time and date for an interview. While both those who had agreed to be tested and those who had refused were included in the study, it is entirely possible that those who were most at risk did not volunteer for the study. All the women interviewed stated that their risk for HIV infection was very low so it is possible that higher risk women did not want to be interviewed. It is also possible that some of the women did not disclose their true risk status and chose instead to tell me only what they thought I wanted to hear. This may be a sensitive topic for some women however most of the women seemed comfortable discussing their experience with me. Some of the women were interviewed early in their pregnancies and therefore quite close to the time that they were offered the test. Others were interviewed some months after the prenatal visit at which the test was offered. This time lag may have affected recall of the offer of the test.

The findings of the qualitative research were validated by having three women who participated in the study review the results of the interviews with the women and two health care professionals, a family physician and a midwife, review the results of the interviews with the health care providers. All agreed that the results as presented were an accurate reflection of their experience.

Summary

This chapter described and discussed the experiences of thirty- two Manitoba women who were offered HIV screening while pregnant. The women detailed their recollections of the offer of the test, how much information they

were given and how much they knew about HIV, how they decided whether or not to have the test, what they felt while waiting for the results and after receiving the results from their care providers. The chapter concluded with a discussion of these experiences in the context of women's choices. The next chapter will present a cost-effectiveness analysis of HIV screening in pregnancy.

CHAPTER SIX

COST-EFFECTIVENESS ANALYSIS

This chapter presents a cost-effectiveness analysis of prenatal HIV screening in Manitoba. This type of analysis is useful when comparing alternative strategies for a health care goal. No attempt is made in this type of analysis to assign a financial value to the disease prevented beyond the cost of care for those with the disease. Results are presented in the form of cost per case prevented and the reader is allowed to make a value judgment about the outcome (Haddix & Shaffer, 1996).

It is unclear how cost effective universal screening for HIV is in areas of very low seroprevalence such as Manitoba. Early identification of HIV infected women will allow them to make decisions about continuing or terminating the pregnancy. If the former option is chosen, then prevention of perinatal transmission may be possible with a regimen of AZT for the woman and the neonate.

Assumptions

A number of assumptions must be made when performing a cost-effectiveness analysis. In the following consideration of the cost effectiveness of HIV screening in pregnancy in Manitoba, the first assumption is that all pregnant women will present for prenatal care in pregnancy and, if found to be HIV infected, will continue with the pregnancy to term. It is also assumed that they

will be offered treatment, and will be compliant with the treatment. Thirdly, there is an assumption that there is an equal distribution of HIV infected women among those screened and not screened. The fourth is that the treatment will reduce the transmission rate by 67% as found by Connor and associates (1994). There are 86 women of child bearing age who have been diagnosed as HIV-infected in the years between 1985 and 1999; it is assumed for the purposes of this analysis that these women will not be screened during pregnancy as they are already known to be HIV-infected.

No costs have been assigned for pain and suffering of those infected and their families. Indirect costs such as years of productive labor lost due to illness and premature death and the cost of caring for children orphaned when a mother dies of AIDS also have not been accounted for. In addition, the costs of caring for the woman with HIV infection are not entered into the analysis as this is extraneous to the effectiveness of HIV screening programs, the aim of which is to reduce perinatal transmission.

Treatment Regimen

The analysis is based on the regimen used by Conner and associates (1994) in AIDS Clinical Trial Group Protocol 076. This includes oral zidovudine (AZT) for the pregnant woman after 14 weeks gestation at a dose of 500 mg orally per day. Intravenous AZT is given from the onset of labor at a loading dose of 2mg/kg of body weight for the first hour and then 1mg/kg of body weight for the duration of labor. The neonate is given AZT syrup for 6 weeks at a dose of

2mg/kg of body weight every six hours.

For the purposes of this analysis, initiation of treatment is calculated from 24 weeks gestation which is the midpoint of the range of 14 to 34 weeks as used by Connor et al (1994) in their study. An average weight of 70kg for the pregnant woman is used and the average length of labor is 12 hours. The weight of the neonate for the first six weeks is assumed to be 5kg which allows for a lower birth weight and lower weight gain in the neonatal period. The program costs per woman-infant pair are presented in Table VIII below. The costs of performing ELISA screening and confirmatory Western Blot testing are the only screening costs included in this analysis. The costs of venipuncture are assumed to be covered by performing the venipuncture at the same time as other screening tests. No additional costs have been included for counseling prior and after HIV screening as these are covered by the total prenatal package billed directly to Manitoba Health. Intervention costs have been calculated using the costs of the drug to the tertiary care hospitals where they are dispensed free of charge to all HIV-infected individuals. The cost of the intravenous AZT is that of the drug only as the woman will usually have an intravenous inserted for the delivery for hydration or the delivery of other medication as needed. No additional costs for medical care during the pregnancy are included as it is assumed that the woman would be receiving prenatal care regardless of HIV status and this is billed as a prenatal package.

Lifetime Pediatric Treatment Costs

Lifetime costs for the infant are based on figures suggested by Hsia et al. (1995) converted to Canadian dollars at a conversion rate of CA $1.31 to US $1.00. There are no published estimates of costs in Canada. Hsia et al. (1995) included visits to the emergency unit, hospital stays, physician visits, home care services, dental services, and HIV related drug costs. HIV infected children may either be rapid or slow progressors (The European Collaborative Study, 1994). Rapid progressors are those children who survive for one year with HIV infection and one year with AIDS and then die. Slow progressors are those who survive for five years with HIV infection and two years with AIDS before death. These estimates are crude because of the rapidly changing opportunities for treatment and opportunistic disease prophylaxis. For the purposes of this analysis, lifetime costs for rapid progressors are calculated at $ 61,976.61 and for slow progressors, $ 160,823.46 (Hsia et al., 1995). A 1:3 ratio of rapid to slow progressors (The European Collaborative Study, 1994) is presumed so the average lifetime treatment costs per child are $ 136,111.75.

Table VIII. Program costs

Screening test			$5.00
Confirmatory test			$40.00
		Total =	$45.00
Zidovudine			
•mother	16 weeks @ $33.25		$532.00
	intrapartum loading dose		
	2mg/kg (70 kg average)		$11.31
	maintenance		
	1mg/kg/hr (12 hr av.)		$6.79
•neonate	8mg/kg/day (5 kg average)		
	6 weeks @ $50.61		$303.66
		TOTAL =	$898.76

Pediatric HIV treatment (conversion CA$1.31 per US$1.00)

•rapid progressors/child		
	1 yr with HIV	$12,290.42
	1 yr with AIDS	$49,685.68
	Lifetime cost	$61,976.61
•slow progressors/child		
	5 yrs with HIV	$ 61,452.10
	2 yrs with AIDS	$ 99,371.36
	Lifetime cost	$160,823.46

Sensitivity Analysis

A sensitivity analysis at three levels of acceptance of HIV screening examines the difference between 100% acceptance of HIV screening, 80% acceptance (which is the rate claimed by both tertiary hospitals in Winnipeg), and 50% which is the average rate of HIV testing in all prenatal serology performed by Cadham Provincial Laboratory. This sensitivity analysis is applied at two seroprevalence levels, namely 3.2 per 10,000 pregnant women (as found in Manitoba) and 9.1 per 10,000 pregnant women as found in Quebec. There are approximately 15,000

deliveries each year in Manitoba and for convenience, the seroprevalence rate as stated above will be converted to the number of HIV- infected pregnant women per 15,000 deliveries. This conversion results in 4.8 per 15,000 pregnant women as an example of low seroprevalence and 13.7 per 15,000 pregnant women in an area of high seroprevalence in the Canadian context. This is still much lower than the United States where the rate in 1991 was estimated to be as high as 17.1 per 10,000 pregnant women in metropolitan areas of the east coast (Mauskopf et al., 1996).

Table IX : Screening Program Costs at Different Seroprevalence Rates

	Low 4.8/15,000			High 13.7/15,000		
	100%	80%	50%	100%	80%	50%
Screening Costs						
ELISA	75,000	60,000	37,500	75,000	60,000	37,500
Western Blot	240	192	120	685	548	342
Medical Costs (mother)						
AZT po	2,553.60	2,042.88	1,276.80	7,288.40	5,830.72	3,644.20
AZT iv	86.88	69.50	43.44	247.97	198.37	123.98
Medical Costs (baby),						
AZT po	1,457.57	1,166.05	728.78	4,160.14	3,328.11	2080.07
TOTAL COST	79,338.05	63,470.43	39,669.02	87,381.51	69,905.20	43,690.75

In order to calculate the cost-effectiveness of the screening program, it is necessary to calculate the cost savings resulting from the reduction of perinatal transmission by the treatment regimen. Perinatal transmission rates are considered to be 25% without treatment and 8 % with the recommended treatment (Connor et al., 1994). Table X presents the lifetime pediatric costs at the two levels of vertical transmission as well as the cost savings resulting from

the 66 % reduction in vertical transmission. The lifetime costs without treatment are the same regardless of acceptance of HIV screening as 25% of babies born to infected mothers will still get sick and need medical treatment. When considering the lifetime costs of babies born to women who were identified by screening but at acceptance levels less than 100 %, the cost of treating those babies whose mothers were not identified must be factored into the aggregate lifetime costs. These babies will also get sick and require medical treatment.

Table X : Lifetime Pediatric Costs

	Low 4.8/15,000			High 13.7/15,000		
Vertical transmission	100%	80%	50%	100%	80%	50%
25 %	163,334.10	163,334.10	163,334.10	466,182.74	466,182.74	466,182.74
8 %	52,266.91	75,405.91	107,800.50	149,178.49	213,967.67	308,837.56
Savings	111,067.19	87,928.19	55,533.60	317,004.25	252,215.07	157,345.18

The costs per case prevented are calculated from the 17% reduction in vertical transmission rates which results in a 67% savings, and applying this to the different seroprevalence rates and total screening costs. Converting the seroprevalence rates of 4.8 and 13.7 per 15,000 pregnant women to actual numbers of women identified as HIV infected by screening at the different acceptance rates results in the number of absolute cases. These are 4.8 at 100%, 3.8 at 80% and 2.4 at 50% in areas of low seroprevalence, and 13.7 at 100%, 10.9 at 80% and 6.8 at 50% in areas of high seroprevalence. With the recommended

intervention, the absolute numbers of babies (cases) infected decreases, and is reflected in Table XI as cases prevented. By factoring the screening costs at the various levels of acceptance, the costs per case prevented can be calculated and are presented in Table XI.

Table XI : Costs per Case Prevented

	Low			High		
	100 %	80%	50 %	100 %	80 %	50%
Cases prevented	.82	.65	.41	2.33	1.85	1.16
Screening costs *	79,338.05	63,470.43	39,669.02	87,381.51	69,905.20	43,690.75
Costs/case prevented	96,753.72	97,646.82	96,753.70	37,502.79	37,386.59	37,664.44

* From Table IX

The cost-effectiveness of the screening program is calculated by subtracting the costs per case prevented from the lifetime treatment costs per infected baby. This analysis is presented in Table XII

Table XII : Savings per Case Prevented

	Low			High		
	100%	80%	50%	100%	80%	50%
Treatment costs	136,111.75	136,111.75	136,111.75	136,111.75	136,111.75	136,111.75
Costs/case prevented	96,753.72	97,646.82	96,753.70	37,502.79	37,386.59	37,664.44
Savings/case prevented	39,358.03	38,464.93	39,358.03	98,608.96	98,325.16	98,447.31

When only considering health care costs and ignoring the costs of lost productivity, pain and suffering, it appears that there are savings for the health care system for each case of vertical transmission prevented.

Is HIV Screening Cost-effective ?

The results of the cost-effectiveness analysis must be viewed within the constraints of the assumptions as stated. For the purposes of the analysis, it was assumed that all pregnancies would be carried to term. There are no figures available for abortion rates among HIV infected women in Canada and at this time it is unclear how many women, on finding that they were HIV infected through screening in pregnancy, would decide to abort. A study from England found that of 29 HIV infected women who tested in the prenatal period, 24 % terminated the pregnancy (Stephenson et al., 1996). This study was conducted prior to the publication of results form ACTG Protocol 076. A Scottish study of 163 HIV infected women found that 45 % terminated the pregnancy compared to 35 % of uninfected women (Johnstone et al., 1990). This result was not statistically significant and the study was carried out prior to ACTG Protocol 076 so at the time, there was no hope of reducing vertical transmission. The subjects were all infected as a result of injection drug use so the results are likely not applicable to a more general population. Thackway and colleagues (1997) reported on reproductive choice among HIV infected women in Australia up until the end of 1994 and found that of the 23 % of women who became pregnant after diagnosis of HIV infection, 47 % chose to terminate. Termination rates were higher among injection drug users than women infected through heterosexual contact alone. A more recent study from the southern United States among predominately Black women reported that 50 % of the women had become

pregnant after diagnosis of HIV infection. This small study found that these women believed that perinatal transmission was related to chance or maternal health status, and pharmaceutical intervention, including the use of zidovudine was seen to "tear down" health rather than help the woman (Sowell & Misener, 1997). The decision to continue a pregnancy appears to be multi factorial (Kline et al., 1995; Selwyn et al., 1989; Sunderland, 1990) and in the light of the findings of ACTG Protocol 076 and evidence of reduction in vertical transmission, studies are needed to investigate if this intervention affects a woman's decision regarding resolution of pregnancy.

Another assumption was that women would agree to take zidovudine and take it consistently throughout the pregnancy. The issue of compliance with the recommended intervention has not been studied widely. Wiznia and colleagues (1996) found that 75 % of HIV infected women chose to use zidovudine during pregnancy to reduce vertical transmission. Those who refused or were non-complaint were more likely to be cocaine users. A recent report by Siegel and Gorey (1997) on barriers to zidovudine use among women suggests that in their sample of mainly Black and Puerto Rican women, attitudes to the use of AZT were extremely negative. The women interviewed regarded the drug as highly toxic, inadequately tested in women and minorities, prescribed indiscriminately, promoted for the wrong reasons and inappropriate when they were feeling well. How these attitudes impact on the use of zidovudine during pregnancy is unclear, but it is possible that fear of toxicity may prevent women

from taking the medication while pregnant and that some may view the 75 % chance of an uninfected baby as good enough odds to avoid zidovudine as a means of preventing vertical transmission. Findings from this study also reflect inconsistent use of the drug among those who did take it with many taking less than the prescribed dose but not telling health care providers for fear of being regarded as "not wanting to be helped." It is interesting that these women, who may be seen as belonging to a traditionally disenfranchised group, have strong views about the drug that are in contrast to the mainstream medical view. Whether they are able to act on these views and refuse to take the drug remains unknown, however, if they are able to do so, they are acting within the values of autonomy, dignity, and self fulfillment as well as being equal to others who have the right to refuse treatment.

An assumption of the cost-effectiveness analysis was that women discovered to be HIV infected during pregnancy would be offered treatment. Gibb and associates (1997) reported that in Midwife Obstetric Units in London, England, 48 % of HIV infected women received the full regimen of zidovudine treatment for themselves and their babies however 83 % received at least two components of the regimen. In North Carolina, 75 % of HIV infected women were prescribed zidovudine for prevention of vertical transmission after the results of ACTG Protocol 076 were published (Fiscus et al., 1996). Wiznia and colleagues (1996) reported that 75 % of HIV infected women attending an urban community hospital received zidovudine and of those who refused the

intervention, most were injection drug users who continued to use drugs during the pregnancy. A study of hospital variation in the use of zidovudine in the intrapartum period reported that HIV infected women were more likely to receive this intervention if they gave birth at a hospital where more than 10 HIV infected women had delivered (Gwinn et al., 1997). This study was undertaken soon after the publication of the results of ACTG Protocol 076 and may reflect the state of dissemination of information at that time. In a province like Manitoba where there are very few pregnancies to known HIV infected women per year, it is likely that these women would be well connected to a range of physicians and specialists and that labor and delivery would take place in a tertiary care centre with all the necessary treatments well planned.

The final assumptions of the cost-effectiveness analysis relate to distribution of seropositive women in the population and rate of perinatal transmission. There is no way to determine whether there is an equal distribution of infected and non-infected women among those accepting and refusing antenatal screening in Manitoba. The population of interest is large enough to assume this however. In areas where seroprevalence is high, it is likely that there would be more undiagnosed cases which would be identified by a screening program in pregnant women.

Since the publication of the results of ACTG Protocol 076, a number of studies have confirmed that perinatal transmission is reduced with the recommended intervention. Reported transmission rates with zidovudine

treatment range from 5.7% (Fiscus et al., 1996) to 7.6% (Sperling et al., 1996).

Uptake of screening among pregnant women has varied according to the way in which screening is offered. When screening is routine, uptake can be as high as 95% and when screening is selective, uptake can be as low as 1% (Noone & Goldberg, 1997). A British study of voluntary universal screening reports uptake of 44% with named testing (Chrystie et al., 1995). In clinics where there was little written information for patients, uptake ranged from 1.5 % to ten percent (MacDonagh et al., 1996). These clinics were staffed by midwives who had no specific training in HIV screening and this may have biased the results in that these midwives may have been reluctant to offer screening. Another British study found that after midwives had received training , a protocol to offer screening to pregnant women resulted in uptake of 41 % (Mercey et al., 1996). American studies suggest that acceptance rates increase when women are not told that they can refuse the test (Irwin et al., 1996). Among a population of young, Black, indigent women who attended a clinic in Atlanta, Georgia, 95% agreed to HIV screening within the context of a highly structured protocol including pretest counseling in small groups, written informed consent, and post-test counseling and education (Lindsey, 1993). A survey of physicians in Australia demonstrated that while 60% offered the test to pregnant women, only 20% were actually tested (Elford et al., 1995).

The results of this cost-effectiveness analysis differ from the conclusion reached by Ecker (1996) who found that in the United States, screening is

cost-effective when prevalence is greater than 9 / 1000. This is in part due to high counseling costs factored into his analysis as well as increased treatment costs. The same counseling costs were not included in this analysis as the pretest discussion is included in the prenatal visit.

Another caution relates to who is included in screening programs. If women known to be HIV-infected are included in screening programs, then the cost-effectiveness is decreased to the point where a universal screening program may not be justified. In areas of low seroprevalence, accurate identification of women at high risk for HIV infection may be sufficient for early diagnosis and this too may alter the need for universal screening. Given the highly sensitive nature of this topic, it is unlikely that policy makers would agree to not maintaining a universal screening program, with the memory of the Krever Commission still fresh in the collective memory. Even though the seroprevalence rate of HIV infection among pregnant women in Manitoba is low, the rationale for screening this population appears sound. The last seroprevalence study in Manitoba was conducted in 1994/1995. We have no way of definitively knowing whether the seroprevalence has changed significantly from that time. However, it is reasonable to assume that the seroprevalence rate has increased since then and may be as high as 6/10,000. If this were accurate, the cost effectiveness of this approach would be even better. Identifying HIV infected women and treating them to prevent perinatal transmission is good primary prevention.

Screening is essential for primary prevention of disease and pregnant

women are a unique population in that they have contact with the health care system on a regular basis for the duration of each pregnancy and present the opportunity to prevent disease in the fetus. Detection and treatment of disease during this period decreases morbidity and has the potential to improve the general health of women and their families.

Summary

This cost-effectiveness analysis has demonstrated that screening for HIV in pregnant women saves the health care system money at both low and high seroprevalence rates and at a variety of screening uptake levels. This lends support to the current practice of offering HIV screening to all pregnant women. The analysis demonstrates that greater cost savings are to be found at a higher seroprevalence rate and in fact, when the seroprevalence rate is 13.7 / 15,000, the savings are almost the same regardless of screening uptake. This lends further support to the current policy regarding HIV screening in pregnancy in the light of increasing incidence of HIV infection among women in Manitoba.

CHAPTER SEVEN

DISCUSSION

In this final chapter, the issue of women's choice will be discussed in the context of prenatal HIV screening. Recommendations for practice, education, and further research will be made.

Do women have choices ?

Central to this discussion of prenatal HIV screening is the issue of whether women have choice in the area of prenatal care. The debate on whether women have true choice in their lives given the power differences between women and men in Western society (Raymond, 1993, p. 99) is not the intent of this dissertation. However, the issue of power underlies the daily context of women's lives and the choices they are presented with, and the decisions they make.

It may appear that in our health care system, women have freedom to choose their care givers, what tests they have in pregnancy, and to choose where they deliver their babies. However, there are many constraints in this seemingly simple scenario. Women's choices of care giver are limited by the supply of physicians who provide comprehensive prenatal and intrapartum care. Many physicians no longer attend deliveries and while they may provide prenatal care, the woman must be referred to another physician, usually a specialist, for the actual delivery. Very often this referral is made based on the collegial relationship between the referring physician and the obstetrician and the woman

may not know of an obstetrician that she would prefer to be referred to, or may not know that she can request an obstetrician of her choice. She then receives care for a critical life experience, the birth of her child, from a stranger with whom she has no relationship.

Freedom of choice of care giver is still denied to women in Manitoba in that, at the time of writing, midwives are not legal in the province. While discussion on this issue has been going on for years, the proclamation of a bill to legalize the practice of midwifery has yet to be enacted after numerous delays. It is still unclear where midwives will practice as this is dependent on the remuneration structure that has yet to be resolved. Women in Manitoba have little choice concerning where they deliver their babies. Many Northern women are routinely flown to Winnipeg in the latter stages of pregnancy to await labour and delivery in the city. Women in Winnipeg have limited choice in that only three hospitals provide obstetric service, and their choice is further limited by where their physician carries out deliveries. Physicians are limited to hospital births by the College of Physicians and Surgeons of Manitoba which forbids the involvement of physicians in home births.

The tests women have in pregnancy, as discussed earlier, are often performed without the express consent of women as they are couched in the terminology of 'routine' tests and women do not know that they can refuse to have any one, or all, of these tests. There is an expectation that the doctor will do what is in the best interests of women and many women do not question what

tests have been ordered and the rationale for them. Some might suggest that if women were to question their physicians, an explanation would be forthcoming. However, this ignores the difference in power between a woman and her physician which is likely one of the reasons that women do not question their care givers. The amount of time allotted to each prenatal visit no doubt also plays a role in this. Physicians recognize that they have limited time to spend with patients due to the pressures of the fee for service structure and women are aware of these time restraints and so are reluctant to use more than their allotted time in asking questions or seeking validation for their concerns.

The subject of this dissertation is prenatal HIV screening which according to policy, is a voluntary test. The issue of choice in relation to HIV screening in pregnancy must be viewed within the context of how the test is offered to women. If this test is offered to only some women, selective prenatal HIV screening, then some women are treated differently than others. This treatment may be based on the colour of a woman's skin, the area of town where she lives, her perceived economic status or level of education. If only these women are offered prenatal HIV screening, other women who may be judged to be unlikely to be at risk for HIV infection may not be offered this test . There is inequality in that these women, and the fetuses they bear, are not accorded the benefit of early diagnosis and treatment. While not negating the risks that accompany poverty and powerlessness, the predominant HIV risk for women remains heterosexual intercourse, and so any pregnant woman, by virtue of her condition, has

participated in a risky activity.

Even though most pregnant women will have participated in sexual intercourse (some may be pregnant by artificial insemination), women should be accorded individual dignity in encouraging their assessment of their own risk. If a woman states that she is sure that her relationship is monogamous and both she and her partner have no other risk behaviors, then she does not need prenatal HIV screening unless she requests it. To cast suspicion on her belief that her relationship is monogamous is not justifiable. However, she may not know that he partner has placed her at risk and the universal offer of this test allows her to agree to testing without feeling singled out.

On the surface, the offering of an HIV test to pregnant women may be seen to be in keeping with the feminist theme of choice and the rights of women as bearers of children. However, when the offer is made only to those perceived to be at risk for HIV infection, some women will be singled out and treated in an unequal manner. This contradicts the feminist theme of equality of women, not only with men, but among themselves. I suggest that unless the choice is offered with women truly able to refuse, the offer of testing is not really a choice at all and merely an illusory attempt at making the woman feel that she has choice. The way the offer is worded is important, and if the wording of the offer includes statements such as "we strongly recommend," the choice is illusory as a professional in a position of power is seen to be making a recommendation that for many women would be hard to ignore.

The action of offering the test is in itself a paternalistic one with images of a benevolent physician, male or female, making an offer to a woman who may or may not know much about the subject. This is a reflection of the lack of knowledge and information that women have and these issues of information sharing and consent have been addressed earlier in this dissertation. The entire process is, in reality, predicated on a system that encourages and perpetuates paternalism. The image of the women in this scenario was described in greater detail earlier, but in this context, pregnant women are generally not active participants in their care.

On the surface it appears that women in our society have many choices. This is a market philosophy and is fundamentally different from the freedom to choose which is limited by personal power, gender, poverty, and race. The notion of autonomy which lies at the base of individual choice is in part dependent on the recognition of rationality. Historically, rationality has been denied to children and women or those in oppressed groups (Sherwin, 1996). Thus the concept of rationality/autonomy may not be seen to apply when a woman decides to make a decision that contradicts the views of those with power.

Both the medical system and the policy process are male driven and derived. They reflect a private and institutional patriarchy that is pervasive and well entrenched. This patriarchy is perpetuated by both male and female care givers, as well as male and female policy makers and members of committees

that review and rewrite policy. Perhaps of deeper concern is the lack of awareness on the part of many women of this patriarchy, and a subscription to many of the same paternalistic attitudes.

Implications for Practice

In health care, women's knowledge and experience should be respected and they should make individual and informed choices in all aspects of their lives, particularly in the area of reproductive health. While policy makers and professional organizations may hold power and enact guidelines and recommendations for health care practices, the decision to seek care and whether to comply with these practices must rest with individual women. Pregnant women should be told about the latest research findings related to HIV infection and should be encouraged to assess their own risk and, based on this, decide whether they wish to be screened for HIV antibodies during the pregnancy or at any other time. The same freedom to choose should apply to all tests in pregnancy in contrast to the usual practice of routine screening without consent or even information sharing.

Barriers exist within the current social structure which compromise women's choices. Some women may not be able to define their needs initially and it is vital that for those who cannot, viable alternatives are provided to overcome this. Being able to choose involves identifying the strengths and resources available to the individual, creating the conditions that make it possible to use those resources, and to make additional choices available so that

the woman makes her choices in a personal and meaningful way (Bricker-Jenkins, 1994).

Women need to feel that they are entitled to as much time as they need from their health care providers and must disavow themselves of the notion that the physician is so busy that to ask questions is an imposition on his or her time. All women have a right to take as much time as they require when they have an appointment with their health care provider and these professionals need to be aware of how their subtle and sometimes not so subtle messages are received by patients. The current fee-for-service structure does not encourage physicians to spend adequate time with patients, however, remunerating physicians by a salary may not necessarily increase the amount of time they spend with patients.

Brown, McWilliam and Weston (1995, p. 102) describe the importance of the patient-centred approach in primary care and how time and timing play a pivotal role in the doctor-patient relationship. They suggest that when a patient indicates that he or she needs to ask questions or take more time at an appointment, the physician should respond to that need and disrupt the office schedule if necessary. While it may not be possible to address all the issues that the patient has at that particular time, by listening and prioritizing with the patient, a plan for future interactions can be set in place and this will encourage the patient to return and for both parties to make progress in working through issues. The authors of this approach also describe the "doorknob" phenomenon, where patients ask a question or describe a symptom as the physician is about to

leave the room. An equally common manifestation of this phenomenon is the physician leaving the room when the patient has questions or concerns that have not been addressed during the appointment and the physician is seen to be ending the encounter before the patient is ready. Clear communication is vital to ensuring that this does not occur. The appointment should end with the physician asking the patient if they have any more questions, and this should occur when both parties are seated and the patient is fully dressed in street clothes. If there are issues that can be addressed at the next appointment, this should be clearly stated and agreed upon by the patient.

An ongoing relationship with a primary health care provider sets the stage for health care interactions that are based on personal knowledge of the patient, her family, her social and health history. Continuity of care allows for the establishment of a relationship over time that facilitates healing (Weston & Brown, 1995, p. 29). The importance of this relationship stands in contrast to the experience of many pregnant women who have to be referred to an obstetrician for much of the care in their pregnancy because their family physician does not perform obstetric care. While a relationship may develop with this specialist over the weeks of the pregnancy, it generally does not develop the same depth and breadth as an ongoing relationship with a family physician who knows the woman's history, her family and its history, and who will care for the neonate after delivery. However, the reality of women having expanded choice in their health care will be a challenge for many physicians who are comfortable in the

role of benevolent patriarch.

The introduction of midwifery in Manitoba may help to facilitate the development of strong relationships between women and their care providers. Midwives have a woman-centered approach to care based on respect for women's knowledge and life experience. It is hoped that many women will have access to these professionals who will care for women not only during pregnancy, but for well woman care following delivery as well. Midwives are encouraged to work with family physicians and obstetricians and with this collaboration, it is hoped that women will experience continuity of care and the benefits of an ongoing relationship with health care providers.

Implications for Education

It is not enough merely to pass on information and assume that women understand the often complex concepts and language. Information regarding prenatal HIV screening must be presented to women in such a way that they have an understanding of what the test means to them as individuals and not only the possible benefits to the fetus. It must be made clear that they may refuse or take time to consider their decision before having the test. The information must not be presented in such a way that the woman might feel that by refusing the test she is in some way acting in a negligent manner that is detrimental to the health of the fetus. While refusing testing or treatment may have detrimental effects on the fetus, it is her right to make these choices and accept the consequences of her actions for both herself and her fetus.

The process of obtaining information and access to medical care and health care providers should be inclusionary so that women are not alienated from their care. This is particularly important for women who traditionally have been marginalized but applies equally to women who are passive in the health care setting and do not ask questions of their care providers. By asking women how their information needs may best be met and by acting on the information provided, educational initiatives can be planned that are responsive and accessible to these women. For example, providing information which involves simple diagrams for those with low literacy, and providing opportunities for women to interact with staff as often as needed before making a decision about testing, may be appropriate.

Health care providers must tailor their message about prenatal HIV screening in content, language, and presentation styles that best suit the individual client. The emphasis should be on a collaborative relationship with a recognition that power influences the decisions that women make. Despite our best efforts, health care providers usually possess more power relative to the client and this influences all aspects of care. While most professionals recognize that women have the right to make health care decisions and ultimately the right to choose what is best for them, women's choices are often limited by the information they are given. They do not have true autonomy but instead, a range of choices circumscribed by the quality of written information, the limited opportunity to ask questions and engage in discussion with their care providers,

and an assumption that they are at low risk for HIV infection.

While there appears to be some notion of the rights of women according to the words of some of those interviewed in this study, these stand in direct contradiction to the comments made by some physicians. Written comments on returned surveys generally portrayed a paternalistic attitude which, if acted upon, would affect the women attending those practices for care. One physician stated that "some women may not be mature enough to cope with a positive diagnosis." One wonders whether this particular physician is suggesting that we do not screen women in case these "immature" women are then diagnosed, or if the physician should withhold a positive diagnosis from the infected women due to her perceived inability to cope with the diagnosis. Another physician stated that giving information to women who test negative is a waste of time, however, how one decides who is likely to test negative and thus not deserving of information, and who is likely to test positive and thus needing information, was not described. It would be interesting to ascertain exactly how this particular physician actually performs this testing and how he or she imparts information, if at all. There is also the comment by one physician that the reason to screen pregnant women is to find out their HIV status to protect health care professionals. These comments, while obviously in the minority, are suggestive of a complete disregard for the status of women as rational human beings who are capable of making autonomous choices.

What about the women who refuse prenatal HIV screening ? Presently,

about 50 % of prenatal blood samples are also tested for HIV antibodies. Much discussion has taken place about the optimal percentage of prenatal HIV tests. The Working Group on HIV Prenatal Screening suggests that 80 % is the number to be aiming for and that educational initiatives for both health care providers and women will allow for that number of pregnant women to be tested. In the United States, recent legislation requires that states seeking federal funding under the Ryan White Act must show that 95 % of women receiving prenatal care are being screened for HIV antibodies (Mills et al., 1998). The notion of a target percentage for prenatal HIV screening leads to health care providers feeling pressured into meeting those targets and the potential exists for them to compel women into accepting HIV screening even when they are in fact low risk and may have previously tested negative with no additional risk factors having occurred. It is also possible that if quotas or targets have to be reached, some women will be tested without consent.

Implications for Research

This study has identified the importance of prenatal education in the routine care of pregnant women. While many of the women stated that they have read about HIV infection in books and pamphlets provided by their physicians, friends, and family, it is not evident how comprehensive or even accurate that information is. It is also not clear how many women are actually reading and educating themselves during the forty weeks of pregnancy. This bears further study. Where are pregnant women finding information and do they

read the numerous pamphlets and books available in physician offices and on the shelves of libraries and bookstores ?

Secondly, this study has shown that different women have different needs in the area of decision making in pregnancy, particularly in the area of screening. How do women differ and how are they similar in the process of assimilating the information they are given and then making a decision about agreeing or refusing a test ? Can a model be constructed and tested that predicts how certain women would prefer information be passed on to them?

These are two areas of study that can be situated in the larger of field of women's information and decision making needs. While pregnancy is a normal healthy event in the lives of many women, if offers an opportunity to set the stage for well woman care in the years to come. Interactions, both positive and negative, can influence how women react and respond to health care providers in the future.

Summary

Prenatal HIV screening is seen to take place in the context of a patriarchal medical and policy system. Physicians generally agree with the recommendations to offer this test to all pregnant women with sharing of information and informed consent. However, compliance with the recommendations for screening are not universal.

While women appear to have choice in this matter, in reality their choice is circumscribed by limited information and subtle coercion. However, women

appear to be accepting of this intervention and overwhelmingly support the inclusion of this test with all the other tests of pregnancy. Despite very basic knowledge about HIV infection and almost no information about why screening for HIV infection in pregnancy is recommended, women seem to think that screening is valuable. This attitude of women, coupled with the support of physicians for this intervention, suggests that the present policy in Manitoba is viable.

While screening in pregnancy is essentially voluntary, most women readily agree to screening in the best interests of the fetus. Any notion of screening without consent is likely to raise barriers and impact negatively on the physician-patient relationship. The net result of this could, in the worst case scenario, result in women avoiding antenatal care to avoid screening. As voluntary screening has been shown in this analysis to be as cost effective as routine screening, the argument can be made that the preservation of women's rights to make health care decisions must prevail. Universal offering of this test to all pregnant women should continue with voluntary consent for screening. This method of offering respects women's self dignity and autonomy. It allows for women to be regarded as individuals who make sound health care decisions based on reason and the best interests of both the woman and the fetus, not one at the expense of the other.

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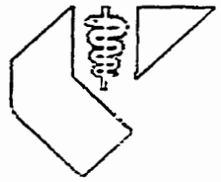
Appendix A

College of Physicians and Surgeons Prenatal HIV Screening Policy

College on the Web

Guidelines and Statements



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MATERNAL AND NEONATAL HIV TESTING AND MANAGEMENT

BACKGROUND

As knowledge about HIV/AIDS increases, there is a need to continuously review and evaluate our management of HIV infections. A seroprevalence study of over 27,000 women in Manitoba in 1990/91 showed a seropositivity rate of 0.72/10,000. Studies in four other Canadian provinces indicate provincial seroprevalence rates in young women of childbearing age ranging from 2.7 to 11.5/10,000. It is estimated that between 13-39% of infants born to HIV seropositive mothers will be infected.

Webmaster

In the past, due to the relatively low seroprevalence of HIV in Manitoba, routine HIV testing of pregnant women was thought to be inappropriate and testing had been offered in specified cases only. However, recent data suggest that routine testing may be indicated.

CLINICAL TRIAL OF AZT TREATMENT

Preliminary results of a recent clinical trial to prevent perinatal transmission of HIV reveal that treatment of HIV infected pregnant women and their newborn children with AZT reduces the risk of HIV transmission to the newborn by 67% (from 25.5% to 8.3%). The study was a multicenter trial conducted by the Pediatric AIDS Clinical Trials Group and the preliminary results were announced by the U.S. National Institutes of Health on February 21, 1994.

The results reported to date are preliminary and it is unknown whether the maternal or neonatal component was the effective target of AZT treatment. Since the women who participated in the study were asymptomatic, the effectiveness for those who are symptomatic of HIV disease is undetermined. As well, the teratogenic and longterm effects on the infant of AZT are unknown. Despite these limitations, the study was terminated because of the significant findings, and all participants who had not yet delivered were offered AZT.

RECOMMENDATIONS

1. **HIV testing should be offered to all pregnant women regardless of risk factors identified.**

· Physicians should discuss HIV infection issues related to pregnancy with all women presenting for prenatal care.

· Testing to be done in accordance with the principles of informed consent.

· Adequate pre and post test counselling should be provided (HIV Counselling Guidelines available from Manitoba Health Resource Centre, Rm 214, 880 Portage Ave, R3G 0P1, Fax #945-5063).

2. HIV seropositive pregnant women.

· Should be informed of the aforementioned study and its limitations.

· Should be encouraged to receive AZT to reduce the risk of perinatal transmission.

3. Women placed on AZT.

(Recommended dosages at time of publication. Consultation with an appropriate specialist in Infectious Diseases is strongly recommended for updated dosages.)

· Should receive 100 mg AZT orally five times per day beginning anytime after the 14th week of gestation and continued during the rest of the pregnancy.

· Complete Blood Count should be monitored monthly.

· Should be instructed to come to the delivery hospital at the earliest signs of labour onset.

· During labour, should receive AZT intravenously with a loading dose of 2 mg per kilogram body weight over one hour and then 1 mg per kilogram of body weight per hour until delivery.

· Continuation of AZT post delivery must be individualized for each patient dependent on her stage of HIV related illness.

4. Infants born to mothers who received AZT treatment during pregnancy.

(Recommended dosages at time of publication. Consultation with an appropriate specialist in Infectious Diseases is strongly recommended for updated dosages.)

· Should receive 2 mg AZT syrup orally per kilogram body weight per dose given every 6 hours for the first six weeks of life beginning at 8-12 hours following birth.

· Complete Blood Count should be monitored every two weeks while the infant is receiving AZT.

·Consultation to the Pediatric Infectious Diseases Service at the Children's Hospital in Winnipeg, (204) 789-3619, for assistance in the management of the follow-up of the infants is strongly recommended.

5. Infants born to mothers of unknown HIV status.

·Testing of the mother or newborn should be recommended if the mother has high-risk behaviours or is from an area of high seroprevalence. If the mother refuses testing in this high-risk setting, the infant should be followed and monitored as an infant of indeterminate HIV status.

·HIV testing should be recommended for abandoned infants to be placed in foster or adoptive care, particularly if testing will facilitate decisions for placement. Consent should be obtained from the legal guardians or Family Services. This testing could be performed soon after discharge.

6. Breastfeeding is associated with an increased risk of transmission of infection to the infant and is not recommended.

·For all women who are HIV seropositive.

·For all women who are HIV seronegative, or whose status is unknown, and who will likely be engaged in activities which would put them at increased risk for HIV acquisition during the postpartum period (eg injection drug use, prostitution).

NOTE: Recent data from developing countries suggest that risk of transmission is present primarily if breastfeeding is continued beyond 6 months.

For more information, refer to Manitoba Health, *Management Guidelines: Human Immunodeficiency Virus (HIV) Infection, Section III - The Pregnant Patient* (p.12-13) *and Section IV - The Neonatal and Pediatric Patient* (p. 14-17).

References:

Canadian Paediatric Society. Perinatal Human Immunodeficiency Virus (HIV) Testing. *CPS Statement: ID 94-01*, 1994.

Sekla, L., Hammond, G., Tate, R., Stackiw, W., Eibisch, G., & Shewchoak, S. Human Immunodeficiency Virus as a Sexually Transmitted Disease: Manitoba's HIV Unlinked Seroprevalence Study. *Canadian Journal of Infectious Diseases*, 1992, 3:295-298.

Manitoba Health. *Management Guidelines: Human Immunodeficiency Virus (HIV) Infection, Addendum to Section III - The Pregnant Patient*, 1994.

Appendix B

Physicians - Invitation to Participate

Invitation to Participate

Dear Physician,

The College of Physicians and Surgeons of Manitoba, the Canadian Medical Association, and the Royal College of Obstetricians and Gynaecologists have recommended HIV screening be offered to all pregnant women. This research is part of a PhD dissertation looking at the issue of HIV testing in pregnancy in the province of Manitoba. It is in no way connected to an earlier survey conducted by Manitoba Health and the College of Physicians and Surgeons of Manitoba.

As part of a larger study investigating the acceptability and compliance with this recommendation, you are invited to complete the following questionnaire. The questionnaire asks questions about your practice with antenatal patients and whether you routinely offer HIV testing, the type of pre and post-test counseling you do or where you refer your patients to for this counseling, and your opinions on these issues. For comparison purposes, questions are also asked about your attitudes and practices regarding syphilis testing in pregnancy. Manitoba physicians (family practitioners and obstetricians) are being sent this questionnaire which will take about 15 minutes to complete.

Please complete the questionnaire and return it in the envelope provided as soon as possible. By completing and returning the questionnaire, you are indicating your consent to take part in this survey. Participation is entirely

voluntary.

All information from the survey will be treated confidentially. Code numbers will be used on the envelopes to facilitate sending reminders if necessary. Only aggregate data will be used to describe the results of the survey and no identifying information will be published at any time.

This project has been approved by the Ethical Review Committee of the Faculty of Nursing of the University of Manitoba. If you would like any additional information, please do not hesitate to contact my advisor, Dr Annette Gupton, at 474 9080 or me at 474 8266. Thank you for considering completing this questionnaire and for assisting me in my research.

Appendix C

Physician - Questionnaire

PHYSICIAN SURVEY

Thank you for taking the time to complete this questionnaire.

BACKGROUND INFORMATION

1. Gender: male ☐ female ☐

2. Age: ☐

3. Years in practice: ☐

4. Area of practice: certified family physician ☐ general practitioner ☐
   obstetrician ☐ other ☐

5. Location: Winnipeg ☐
   Outside Winnipeg (pop. <5,000) ☐ (pop. 5,000-30,000) ☐

6. Do you provide antenatal care? yes ☐ no ☐

If the answer to #6 is no, please go to question #16.

7. How many **NEW** antenatal patients do you see per year?

0-10	☐	61-70	☐
11-20	☐	71-80	☐
21-30	☐	81-90	☐
31-40	☐	91-100	☐
41-50	☐	101 +	☐
51-60	☐		

HIV TESTING IN PREGNANCY

8. What is your current practice with regard to HIV testing in pregnancy?
   - ☐ routine (all pregnant women tested without specific consent)
   - ☐ offered to all pregnant women regardless of risk
   - ☐ offered to those women suspected to be at high risk
   - ☐ performed at request of patient only

9. Were you aware of recent recommendations to offer HIV testing to all pregnant women prior to receiving this questionnaire?
   - ☐ yes
   - ☐ no (*if you answered no to this questions, please continue with #11*)

10. If yes, has your practice of HIV testing in pregnancy changed as a result of recent recommendations?
    - ☐ yes .....
      - ☐ now test all pregnant women
      - ☐ test those with risk factors only
    - ☐ no .....
      - ☐ was testing women prior to recommendations
      - ☐ other (please specify reason) _____

TESTING PROCEDURE

11. Do you provide counselling to women prior to HIV testing?
    - ☐ yes
    - ☐ no (*if you answered no to this questions, please continue with #14*)

12. What is the form of this counselling? *(check as many as apply)*
    - ☐ discussion with patient according to Manitoba Health guidelines
    - ☐ discussion tailored to individual patient
    - ☐ nurse or other staff discuss with patient
    - ☐ brochure for patient to read
    - ☐ refer to other agency for test (please specify where) _____
    - ☐ other (please explain) _____

13. On average, how much time does this counselling take?
    - ☐ less than 15 minutes
    - ☐ 15 to 30 minutes
    - ☐ more than 30 minutes

14. How do you ask the patient to give consent for testing?
    - ☐ verbally
    - ☐ in writing
    - ☐ do not require specific consent

15. How do you provide women with results of the HIV test?
    - ☐ in person only
    - ☐ on telephone by physician only
    - ☐ on telephone by other staff
    - ☐ do not give result if it is negative

ATTITUDE TO HIV TESTING

16. Do you agree with the recommendation to offer HIV testing to all pregnant women?

- ☐ yes (please explain) _____
- ☐ no (please explain) _____

17. Do you agree with the recommendation for pre- and post-test counselling?

- ☐ yes (please explain) _____
- ☐ no (please explain) _____

18. Do you think universal testing of pregnant women in Manitoba is cost-effective?

- ☐ yes (please explain) _____
- ☐ no (please explain) _____

19. Do you think HIV testing in pregnancy should be:

- ☐ voluntary (performed only with patient consent)
- ☐ part of the routine diagnostic work up (specific consent not required)

Why? _____

20. Have you cared for HIV infected patients in the past?

- ☐ yes
- ☐ no

21. If a pregnant woman in your practice tested HIV positive, would you continue to provide care for her?

- ☐ yes
- ☐ no

22. Do you have any other comments regarding HIV testing in pregnancy?

_____

SYPHILIS TESTING

23. Do you provide specific counselling to women prior to VDRL testing?
- ☐ yes
- ☐ no *(if response is no, please continue with questions #26)*

24. What is the form of this counselling?
- ☐ discussion tailored to individual patient
- ☐ nurse or other staff discuss with patient
- ☐ brochure for patient to read
- ☐ other (please explain) _____

25. On average, how much time does this counselling take?
- ☐ less than 15 minutes
- ☐ 15 to 30 minutes
- ☐ more than 30 minutes

26. How do you ask the patient to give consent for testing?
- ☐ verbally
- ☐ in writing
- ☐ do not require specific consent

27. How do you provide women with results of the VDRL test?
- ☐ in person only
- ☐ on telephone by physician only
- ☐ on telephone by other staff
- ☐ do not give result if it is negative

28. Do you think universal testing of pregnant women in Manitoba is cost-effective?
- ☐ yes (please explain) _____
- ☐ no (please explain) _____

29. Do you think VDRL testing in pregnancy should be:
- ☐ discretionary (based on patient risk factors)
- ☐ part of the routine diagnostic work up

Why? _____

30. Do you think HIV testing is different from VDRL screening?
- ☐ yes (please explain) _____
- ☐ no (please explain) _____

31. Do you have any other comments regarding VDRL screening in pregnancy?

_____

_____

_____

_____

Thank you for taking the time to answer this questionnaire. Please return it in the envelope provided.

Appendix D

Women - Invitation to Participate

Invitation to Participate
Women's Experience of HIV Testing in Pregnancy

You are being asked to participate in a study on the experience of Manitoba women who are pregnant and have been offered HIV testing as part of their prenatal care. The information gained from this study will provide a better understanding of what pregnant women think about HIV testing and what their experience has been. Your assistance would be greatly appreciated.

If you agree to participate, please fill in your name and phone number at the bottom of the form and give the form to the receptionist. I will call you to set up a time for an interview. The interview will take about one hour and will take place at a time and place that is agreeable to you. Participating or not participating will not affect the care you receive in any way. There are no known negative consequences to study participants.

All interviews will be taped and then transcribed; your name will not appear anywhere and any identifying information will be removed from the typed transcripts. At any time during the interview you may refuse to answer a question and you may end the interview without any penalty. You will have an opportunity to review the transcript of your interview and make changes if you wish.

This study has been approved by the Ethical Review Committee of the Faculty of Nursing at the University of Manitoba. If you have any questions about this study, you can call me at 4748266 or my supervisor, Dr Annette Gupton at 474 9080.

Thank you for taking the time to consider this request. If you are interested in participating, please fill out the tear-off portion below and give it to the receptionist. I will call you within a week if you are interested in participating.

Anne Katz RN MN

Women's Experience of HIV Testing in Pregnancy

I am interested in being part of this study.

Name_____
Phone Number _____

Appendix E
Consent Forms

Consent Form
Women's Experiences with HIV Testing in Pregnancy

I agree to participate in the study "Women's Experiences with HIV Testing in Pregnancy."

I understand that I will be asked questions about my experiences with being offered HIV testing as part of my prenatal care. I will also be asked questions about my pregnancy and my background.

After I receive my results, I will be interviewed for about one hour. The interview will be recorded.

At any time I can choose not to answer particular questions. I can ask the researcher questions and raise any concerns I may have. At any time during the interview I can refuse to continue. This will not affect the care I receive at the hospital.

I understand that any information I give will be kept confidential. Only the researcher and members of her dissertation committee will have access to the transcripts. My name and any other identifying information will not be used. The information will be kept in a locked filing cabinet for ten years. After that time tapes and transcripts will be destroyed.

[ ] I wish to review the transcript from my interview
[ ] I do not wish to review the transcript from my interview

[ ] I am interested in receiving a summary of the findings from this study
[ ] I am not interested in receiving a summary of the findings from this study

I have read and understood this consent form. I agree to participate in the study "Women's Experiences with HIV Testing in Pregnancy."

Signed : _____

Date : _____

Consent Form
Physicians' Opinions of HIV Screening in Pregnancy

I agree to participate in the study "HIV Screening in Pregnancy".

I understand that I will be asked questions about my opinions and practice regarding HIV screening as part of prenatal care. The interview will be recorded and transcribed.

At any time I can choose not to answer particular questions. I can ask the researcher questions and raise any concerns I may have. At any time during the interview I can refuse to continue.

I understand that any information I give will be kept confidential. Only the researcher and members of her dissertation committee will have access to the transcripts. My name and any other identifying information will not be used. The information will be kept in a locked filing cabinet for ten years. After that time tapes and transcripts will be destroyed.

[ ] I wish to review the transcript from my interview
[ ] I do not wish to review the transcript from my interview

[ ] I am interested in receiving a summary of the findings from this study
[ ] I am not interested in receiving a summary of the findings from this study

I have read and understood this consent form. I agree to participate in the study "HIV Screening in Pregnancy".

Signed : _____

Date : _____

Appendix F
Interview guide

Interview Guide - Women who have Agreed to Testing

The questions are open-ended to allow each woman to tell her personal story relating to her experience with HIV testing. These questions are guidelines only; any opinions expressed by the women interviewed will be welcomed even if they seem to be unrelated to the direct questions.

Background

Tell me about your past pregnancies and childbirth experiences.....

Probes : Is this your first pregnancy ? If no, how many times have you been pregnant ?

How many children do you have ? What are their ages and gender ?

Where are you receiving antenatal care ? Where do you intend having the baby ?

Screening tests in pregnancy

What tests have you had this pregnancy .....

Probes : What do you feel about having these tests ?

How much information were you given about these tests ?

If you have been pregnant before, has your experience of testing this pregnancy been different from the other pregnancy (ies) ?

HIV Test

Tell me what you know about HIV .....

Probes : Have you had an HIV test ?

Who first mentioned you having the HIV test ?

Had you thought of having it before the doctor / nurse mentioned it ?

Why did you decide to have the test ?

Pretest Counseling

Tell me about your experience of being tested for HIV antibodies.....

Probes : What information were you given about the test ?

Do you think this was enough information to make a decision ?

What did you think about when making the decision to have the test ?

Did you discuss this with your partner ?

Were you given enough time to think about having the test ?

Did you think you were given enough choice in making your decision ?

Were you given an opportunity to ask any questions ?

Were your questions answered to your satisfaction ?

What information was useful to you ?

Do you think there is a better way for doctors / nurses to give you information ?

Waiting for the Results

Tell me how you felt while waiting for the test results .....

Probes : How long did you wait for the results of the test ?

Did you discuss the test with anyone while you were waiting for the results What were your feelings while you were waiting for the test results ?

Post test Counseling

What happened when you received your results .....

Probes : Who gave you the results ?

How was this done ?

What was your response to receiving the results ?

Were you given any new information when you were given your test results ?

Additional Questions

Do you think you may have been at risk for contracting HIV ?

How did you reach this decision ?

Do you think you are more or less at risk than other people you know ?

Appendix G

Interview Guide

Interview Guide - Women who have Refused Testing

The questions are open-ended to allow each woman to tell her personal story relating to her experience with HIV testing. These questions are guidelines only; any opinions expressed by the women interviewed will be welcomed even if they seem to be unrelated to the direct questions.

Background

Tell me about your past pregnancies and childbirth experiences.....

Is this your first pregnancy ? If no, how many times have you been pregnant ?

How many children do you have ? What are their ages and gender ?

Where are you receiving antenatal care ? Where do you intend having the baby ?

Screening tests in pregnancy

What tests have you had this pregnancy .....

Probes :What do you feel about having these tests ?

How much information were you given about these tests ?

Pretest Counselling

Tell me about your experience of being tested for HIV antibodies.....

Probes :What information were you given about the test ?

Do you think this was enough information to make a decision ?

What did you think about when making the decision to refuse to have the test ?

Did you discuss this with your partner ?

Were you given enough time to think about having or not having the test ?

Did you think you were given enough choice in making your decision ?

Were you given an opportunity to ask any questions ?

Were your questions answered to your satisfaction ?

What information was useful to you ?

Do you think there is a better way for doctors / nurses to give you information ?

Additional questions

Were you told where you could have the test if you change your mind at some point ?

Have you had second thoughts related to your decision ?

What would you tell a friend if she asked for your opinion regarding HIV testing ?

Do you think you may have been at risk for contracting HIV ?

How did you reach this decision ?

Do you think you are more or less at risk than other people you know ?

Appendix H

Ethical Approval

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#96/11

Proposal Title: "PHYSICIANS' ATTITUDES AND PRACTICES OF HIV AND SYPHILIS TESTING IN PREGNANCY."

Name and Title of Researcher(s): ANNE KATZ, RN, BN
GRADUATE STUDENT
FACULTY OF NURSING, UNIVERSITY OF MANITOBA

Date of Review: MARCH 04, 1996.

APPROVED BY THE COMMITTEE: MARCH 06, 1996.

Comments: APPROVED WITH CHANGES SUBMITTED MARCH 07, 1996.

Date: MARCH 08, 1996.

Karen I. Chalmers

Karen I. Chalmers, PhD, RN — Chairperson
Associate Professor
University of Manitoba Faculty of Nursing

Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#97/02

Proposal Title: "EXPERIENCE OF HIV TESTING IN PREGNANCY."

Name and Title of Researcher(s): ANNE KATZ, RN, MN
CLINICAL NURSE SPECIALIST
ST. BONIFACE GENERAL HOSPITAL

Date of Review: JANUARY 06, 1997.

APPROVED BY THE COMMITTEE: JANUARY 17, 1997.

Comments: APPROVED WITH SUBMITTED CHANGES DATED JANUARY 13, 1997.

Date: JANUARY 17, 1997.

Karen Chalmers

Karen I. Chalmers, PhD, RN — Chairperson
Associate Professor
University of Manitoba Faculty of Nursing

Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

Appendix I

Physician Interview Guide

Interview Guide - Physicians

The questions are open-ended to allow the physican to explain his/her practice and opinions with regard to HIV testing. These questions are guidelines only; any opinions expressed will be welcomed.

What is your practice of HIV screening in pregnancy ?

Probes : routine, selective ?

Do you see HIV screening as different from syphilis screening ?

Probes : sexual spread, effective treatment

What kind of information do you give patients before blood tests ?

Probes : pamphlets, information sheets, discussion

How do you obtain consent for HIV screening ? For syphilis screening ?

Probes : verbal, written, no specific consent required ?

How do you discuss results of blood tests with patients ?

Probes : normal and abnormal results

Have the recommendations of the College of Physicians and Surgeons of Manitoba, the Canadian Medical Association, the Society of Obstetricians and Gynecologists of Canada, changed your practice in any way ?

Do you see HIV infection as a health care issue in <u>your</u> practice ?

Probes : seroprevalence in Manitoba, risk activity vs. risk group

What do you see as a barrier to HIV screening in pregnancy ?

Probes : information sharing, time needed, risk of offending patient

What would make it easier ?

Probes : information sheets, routine testing