

1994

Psychological and psychosocial responses of women seeking pregnancy counseling to HIV antibody testing

Geoffrey Wayne Ludford
College of William & Mary - School of Education

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**Psychological and psychosocial responses of women seeking
pregnancy counseling to HIV antibody testing**

Ludford, Geoffrey Wayne, Ed.D.

The College of William and Mary, 1994

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PSYCHOLOGICAL AND PSYCHOSOCIAL RESPONSES OF WOMEN SEEKING
PREGNANCY COUNSELING TO HIV ANTIBODY TESTING

A Dissertation Presented to
the Faculty of the School of Education
The College of William and Mary

In Partial Fulfillment
of the Requirement for the Degree of
Doctor of Education

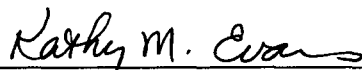
by
Geoffrey Wayne Ludford
April, 1994

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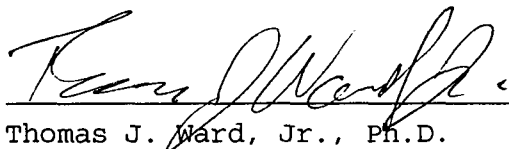
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Dedication

This study is dedicated to all the persons I have known and loved who have suffered from the debilitating effects of this terrible epidemic; to those who encouraged me to give generously of my time and talents to combat HIV and AIDS; and to those who have taught me to continue to pursue life with dignity and hope in the face of overwhelming sorrow and grief. I want to especially recognize the lives of Rick K., Michael Callen and Larry Kramer - "life-fighters" of incomparable strength and courage. As a result of those who have struggled with this disease, I've learned the most valuable lesson about life. Passion.

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Visualizing this research and having it finally realized involved a great deal of time, expense and effort on the part of many individuals. The following people are acknowledged for their assistance, generosity and encouragement during my times of anxiety and apprehension. There are many people to whom I am indebted:

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CHAPTER I

Statement of the Problem

The purpose of this study was to investigate psychological and psychosocial variables that influenced women, specifically women seeking pregnancy counseling, with regards to decision making on choosing or declining HIV (Human Immunodeficiency Virus) antibody testing.

Need for the Study

Most HIV research has been based on men, although women are now considered equally at risk for HIV infection (Reid, 1988), and a hundred thousand women in the United States are estimated to be infected with HIV (Gath, 1992). In fact, since the late 1980s, women have been the fastest growing group with HIV infection (HIV Education Case Studies, 1990; Stuntzner-Gibson, 1991; Gath, 1992). Acquired Immunodeficiency Syndrome (AIDS) ranks among the top five causes of death for women in this country (Gath, 1992). In two states--New York and New Jersey--the number one cause of death for African-American and Hispanic women is AIDS (Gath, 1992), and nationally, women of color comprise a disproportionate 74 percent of reported AIDS cases among women (Gath, 1992). In New York City, women now comprise 20 percent of the total AIDS cases and, in New Jersey, women make

up 27 percent (Staff in Virginian-Pilot, 1992). In fact, it is projected that eighty thousand to one hundred twenty-five thousand children under the age of 18 will become orphans of HIV infected mothers by the year 2000 (Staff in Virginian-Pilot, 1992). An added complexity for a pregnant woman deals with the possible HIV infection of her fetus. Abortion issues for pregnant women who are infected with HIV are laden with moral and ethical decisions. Currently, the number of infants born with the deadly virus continues to climb. Global cases of HIV infected babies now number above two hundred thousand (Cowley, 1994).

The physical, psychological and psychosocial intricacies of AIDS have been shown to differ for women than for men, and could perhaps be even more pronounced for pregnant women. Physical differences continue to become more evident, as studies compare the effects of the retrovirus in men and women (e.g., Anastos, 1992; Pfeiffer, 1992; Tross & Hirsch, 1988). Most complexly, pregnant HIV infected women must not only endure their own illness, stigma, and discrimination, but may suffer the anxiety and anguish of dealing with the possibility of an HIV infected child.

Psychological and emotional reactions of women and men were noted by Blachman (1988), who discovered that both sexes experience fear, denial, shame and anger when facing HIV disease or AIDS. These similarities have

particular significance in the area of HIV antibody testing. Testing an individual's blood for HIV antibodies has been seen as a critical step in controlling the spread of AIDS. Controversy over the use of HIV antibody testing has raised questions about the effectiveness of this step in protecting public health. It has also raised serious issues about the protection of personal rights as opposed to the protection of public health (Kleiman, 1988; HIV Education Case Studies, 1991).

Furthermore, research has shown that individuals testing positive for HIV antibodies differ widely in their reactions to knowledge of this information (O'Malley, 1988). Some individuals use the knowledge of their HIV positive status to plan and prepare themselves for the plausible deterioration of their health. Others fixate only on significant negative consequences, disabling these sufferers to the point of dysfunctional behavior. In a few cases, this dysfunctional behavior extends to thoughts of suicide. A mental health practitioner, seeking to help an individual make a responsible choice about HIV antibody testing, needs a thorough understanding of the psychological and psychosocial ramifications of the client's situation and reactions to HIV antibody testing. The therapist's role in investigating the factors influencing men or women is even more important should testing confirm a positive status. The manifestations of each sex tend to be

significantly diverse; however, the consequences are reflected differently in women (Tross & Hirsch, 1988).

Although HIV patterns in women have many of the serious infections demonstrated in men, women have an entire set of additional infections. Women are subject to complications dealing with chronic gynecological manifestations (Gath, 1992). A very high incidence of persistent infections, including recurrent vaginal candidiasis, bacterial vaginosis, trichomoniasis, genital ulcers, and Pelvic Inflammatory Disease (PID) are common among HIV infected women. While Pneumocystis carinii pneumonia (PCP), cytomegalovirus and dementia are as common in HIV infected women as they are in HIV infected men, Kaposi's sarcoma is not nearly as prevalent (Anastos, 1992).

Although the physical differences and similarities are becoming more descriptive as research compares the disease in men and women, the findings in different studies contrasts gender differences. As a result of disputes regarding the speed of the illness and severity of its effects that exist in the female population, Anastos (1992) concludes that more research is necessary to more fully understand HIV disease in women. In one study, women were shown to become more intensely ill while simultaneously suffering from multiple secondary infections (Newsweek, 1987). According to this same report, men who have AIDS tend to live approximately six months longer than women (Newsweek, 1987). However,

women who were compared to men in three clinical courses in a similar setting demonstrated a slower disease progression than men (Anastos, 1992). Nevertheless, the difference disappeared when pertinent facts were adjusted regarding T-helper cell counts. In yet another study, women were shown to have been failing in the fight against progressive HIV with rapid development towards advanced stages of AIDS and exhibited shorter survival periods (Anastos, 1992).

Since pregnant women have engaged in sexual behavior, unless they are certain of their partner's HIV status, then it's possible that they may have been exposed to HIV. Thus, stresses of pregnancy, both physically and psychologically, for the infected HIV expectant mother are even more salient. Attempts at prevention of mother-fetal perinatal transmission are being explored (Anastos, 1992). Evidence from studies of attempts to safeguard the unborn fetus from HIV infection show that protection was possible from the utilization of Caesarean section; yet, the results were still inconclusive (Anastos, 1992).

Since the beginning of the crisis, public reactions to the disease have involved controversy, misconceptions, and antagonism toward those identified as at risk of infection. As the disease spread and the number of infected individuals increased, the range of feelings generated by the crisis intensified. However, public awareness has also often revealed a sense of

denial about the seriousness of the disease. Thus, high levels of emotions surround attempts to control the spread of AIDS. In particular, controversy surrounds the role of HIV antibody testing, which is designed to detect HIV antibodies in a person's blood.

Difficulties dealing with HIV antibody testing are numerous. More specifically, testing is frequently seen as a divisive matter that pits the issues of personal rights against the protection of public health. The personal benefits of knowing HIV antibody test results are weighed against the deficits of such knowledge, with wide variations in individual reactions and assessments.

The division of opinion over HIV antibody testing occurs among those infected with the HIV virus. O'Malley (1988) demonstrated that those individuals who have tested positive for the HIV antibody test are polarized as to whether or not they should ever have taken the test. For some individuals who tested positive, testing was a means to help them prepare for all the familial, medical and monetary planning that they felt was necessary. Moreover, they were also able to optimize support from friends and family for the psychological aspects of knowing the positive test results. Others, however, suffered a much more intense feeling of isolation and psychological foreboding, even to the extent of being completely debilitated or suicidal. According to O'Malley, one of the most crippling aspects of the disease is the fear of

dementia, where infection causes mental faculties to be significantly impaired. O'Malley deduces that not enough is known about who will react well and adjust to an HIV antibody test and who respond adversely.

The controversy over the advisability of HIV antibody testing is part of the complex web of challenges facing mental health professionals. Unlike other psychological concerns that are inherent in illnesses deemed terminal, AIDS represents a multitude of simultaneous decision making processes. For men, the problems of ego dystonic homosexuality, IV drug use, promiscuity, cultural issues and other hidden burdens make it crucial for a universal response that covers both prospectives of individual private rights and the demand for public health protection. In the case of women, these same sort of issues need to be determined by the practitioner in order to know what is salient for HIV decision making, particularly for pregnant women. For example, will a pregnant woman recognize whether her sexual behavior has put her at risk of HIV infection? If she tests positive for HIV, should she abort her fetus to protect her own health? Should she take the risk that her fetus may also be HIV infected? If she is already a mother and wife, how will this knowledge affect her family? If she is becoming a single parent, will she react differently from women who have the support of a husband or significant other? Will she fear being subjected to stigma and discrimination, as

others with HIV infection have experienced as reported by Coates, Morin, & McKusick (1987). Research is lacking not only to help the mental health practitioner with these questions but is lagging even on significant questions of physical treatment for women with AIDS (White, 1991).

Little research exists on the range and depth of feelings dealing with the grief of the disease, not to mention the complications of childbirth and abortion (Sowell, Bramlett, Gueldner, Gritzmacher, Martin, 1991). Before mental health practitioners can counsel women appropriately on the issue of HIV antibody testing, they need to know what responses and psychological implications are likely to be consequential for women as opposed to men. Previous studies of HIV infection and progression in women were defined from HIV studies on homosexual men (Pfeiffer, 1991). As a consequence, HIV disease evaluation has overlooked certain symptoms in women, such as oral candidiasis (thrush) or pelvic inflammatory disease, which may be the first signs of HIV infection for women (Minkoff in Pfeiffer, 1991). Unfortunately, due to the relatively low number of women with AIDS, many women still do not think that they are at risk for HIV infection (HIV Education Case Studies, 1991).

Distinct understanding of the personal issues faced by women trying to decide whether or not to have an HIV antibody test will have implications for public policy.

Currently, there are conflicting speculations about the best strategy and use for HIV antibody testing. Within political camps, there are individuals who suggest that insufficient information and inadequate practices exist that give misleading communication with regards to HIV/AIDS prevention and education. However, policymakers disagree about the amount of funding and type of public education that should be implemented. Some politicians (William Dannemeyer, 1989) believe that protection from HIV is guaranteed by mandatory testing for everyone, thereby identifying most individuals who are infected. For example, HIV antibody testing of prisoners and couples who are getting married would conceivably protect those who are not infected and inform those who are. But this thinking ignores false negative and positive test results. Problems arise in the varying developmental stages of antibodies to HIV in the human body, which vary from months to years, and detection of the virus may not appear in those who have been infected.

Others suggest that the frequently disenfranchised groups, such as gays and IV drug users, may avoid HIV antibody testing for fear of repercussions without "good faith" policies to protect the rights of those testing positive (Lyter in Valdisseri, 1989). Women who practice prostitution are also unlikely to get HIV antibody tested since they may feel shameful about what they do sexually and suspicious of the system.

Moreover, policymaking is complicated by the tendency of many to equalize the disease with socially condemned forms of sexual excitement, setting up the dispute between "moralists and civil libertarians" (Kleiman, 1988; HIV Education Case Studies, 1991).

For the most part, most public health agencies currently tend to discount mandatory testing, indicating that mandatory testing would be too expensive, too imprecise and too invasive to be of practical value. Wood (1987) states that mandatory testing would worsen the AIDS epidemic, by spending money on testing programs that might be spent on education and research. Although the proposed objective is to lower the spread of the disease, enforcing HIV antibody testing may produce negative results. Knowing one's HIV status does not equate with reducing high risk behavior. In the beginning of the epidemic in the United States, it was concluded that homosexual men were seen as a "high risk group," due to exceptionally high incidence of HIV infection found in gay men. Unfortunately, a preponderance of material was summarized that addressed risk groups as opposed to risk behavior, perhaps giving the impression that if one did not belong to a particular group, then the risk of HIV infection was negligible (Redman, 1990).

Hence, certain educational material on HIV and AIDS is not only perplexing, but has served to alienate or stigmatize segments of the public (Redman, 1990).

Evolution of the epidemic has progressed in the United States showing that women are very much at risk (Redman, 1991). Pregnant women, in particular, have a double price to pay for being HIV infected. There are indications that the number of HIV infected children is swiftly rising (Miller & Carlton, 1988).

Theoretical Rationale

Janis and Mann (1968) have developed a theory of personal decision making for situations involving conflict. Based on Festinger's (1964) postulate, Janis and Mann divide decision making into a predecision position and a postdecision view. They theorize that a person making a decision moves from predecision to postdecision by traversing through five sequential stages, ultimately producing a conclusive decision (Janis, 1968). The stages were described by Greenwald, Brock and Ostrom (1968) as follows:

- Stage One: Appraisal of challenge or situation
- Stage Two: Appraisal of alternatives.
- Stage Three: Selection of the best alternative
- Stage Four: Commitment to the new policy.
- Stage Five: Adherence to the new policy despite negative feedback.

The stage process model allows for the detailing that is needed in considering both internal and external conflicts.

In Stage One, an individual is subjected to information that challenges his or her present direction

of action or inaction by postulating that consequential losses will ensue if he or she does not change (Greenwald, Brock and Ostrom , 1968). According to Janis and Mann, this stage can give rise to a sort of attitudinal change and may bring about a transitory dilemma. The contradiction that may evolve between pertinent new facts and the person's current resolutions can produce a critical problem about continuing his or her present guidelines.

Stage Two of the decision making process directs the individual's attention to certain courses of action. These are then evaluated on the basis of whether or not they can be effective in meeting the challenges of the conflict. Meanwhile, the individual seeks alternatives that could help avoid or minimize losses presented by the challenge or conflict.

Stage Three is a continuation of the decision making process where a decision was formulated. A model of pros and cons was established to weigh the advantages and disadvantages of each alternative. Janis and Mann discuss a "maximization of net gains" formula versus a "minimization of serious losses" (Greenwald, Brock and Ostrom , 1968, p.330). The more options available in the decision making process, the less commitment the individual has to his or her choice.

Stage Four was a process of committing to the choice made in Stage Three, involving the addition of reasons in favor of the choice to strengthen support for

the decision. Janis and Mann note, "Postdecision bolstering is likely to be most pronounced when the alternatives had been initially close in value during Stage Three, making it difficult to arrive at the decision" (Greenwald, Brock and Ostrom , 1968, p.331)

Stage Five was described as being somewhat parallel to Stage One. Reasons that would be against the decision reached in Stage Three and bolstered in Stage Four were now either disproved or omitted, enabling the individual to adhere to the decision.

The Janis and Mann conflict theory of decision making permits the inclusion of denial as a coping strategy, refusal to believe facts, and inadequate information processing as part of the process by which individuals reach decisions in conflictual situations. As a part of decision making strategy, it was sometimes assumed that the decision maker was sufficiently informed and rational, but studies have attacked this premise for inadequately portraying reality (McClain, 1983). The conflict of decision making for pregnant women, faced with the choice of either taking or rejecting an HIV antibody test, was created when volatile information on AIDS or HIV infection interacts with values concerning family, career and psychological health. Many influencing variables present in this research sample - minority issues, lower socioeconomic status, little or no education, single parent difficulties - create a matrix of decision making

processes. A complex changeable infrastructure also has an influence on the outcomes of established value systems. If a person chooses to test and shows that she has been infected, that person must make decisions on abortion, family issues, self-health care, discrimination probabilities, and mortality consequences. If uninfected, other sets of issues need to be considered as time progresses. Motives and reactions to HIV antibody testing invokes decision making processes to HIV infected women, who are at a point in their lives where many think of themselves as wife and, possibly, mother. Sometimes, they are a single parent with more decisions to make about themselves, but primarily about their children. Some women, it was anticipated, would not take the test. Some of the rationale behind their decision were the variables of discrimination, psychological stress, and obligations to their family, husband or loved one. It was also anticipated that many women will want to take the HIV antibody test in order to eliminate psychological stress of not knowing, to insure that they are not passing the retrovirus on to other sexual partners and to make sure that any physical problems may not be as a complication from HIV infection. Clearly, decision making processes will vary from one woman to another, depending on personal values and perceptions that each woman holds about herself and others, as well as the concept of control she has in personal

relationships and challenges that affect her life. Conflicted about knowing or not knowing the issues involved about an HIV antibody test result, specifically when a positive outcome could bring about so many different reactions and conclusions, each woman was anticipated to differ from person-to-person as to what was the most important aspect of HIV positive outcome. In brief, women need to know the risks of HIV antibody testing and how this perceived risk influences them.

Janis and Mann also discuss the possibilities and aspects of attitudinal change. Janis and Terwiller (1962) demonstrated the use of conflict theory when research was conducted to inform smokers about the hazards of lung cancer. It was determined that "a strong threat version of a factual pamphlet on smoking and lung cancer elicited more psychological resistance and somewhat less attitude change than a milder threat version, but the latter version succeeded only in making some of the smokers feel uneasy and doubtful about continuing to smoke cigarettes (Stage 1 and Stage 2)" (Janis & Terwiller in Greenwald, Brock and Ostrom, 1962, p.332). In the initial research, no smokers were actually convinced to slow down on consumption of cigarettes. Follow-up data suggested that a "psychodramatic procedure" (Mann & Janis in Greenwald, Brock and Ostrom, 1968, p.332) showed that many subjects went through the five stages of the theory.

One research project that utilized conflict theory

dealt with pregnancy - with the emphasis on associated child management. McClain (1983) studied a sample who were asked to review certain perceived threats of childbearing and assessed the "bolstering" concept used with Janis and Mann. In Step four of the five stage conflict theory, Janis and Mann (1968) reported "a general tendency to avoid negative feedback, to adduce new reasons that *bolster* the decisions, and to 'spread' the attractiveness of the alternatives" (Greenwald, Brock and Ostrom, 1968, p.331). This study indicated that the subjects discounted the risks, magnified the benefits of certain birth services, and expanded the risks and diminished the benefits of the rejected health services. For McClain (1983, p.1858), "Risk will be defined as a probability of known magnitude of an occurrence of injury, damage or loss. Perceived risk, rather, was the decision maker's subjective or intuitive assessment of features of alternatives as disvalued, and of the likelihood of experiencing negative consequences should such an alternative be selected." HIV, therefore, as a perceived risk for pregnant women, could be viewed in this study from the context of childbirth. The degree and severity of this risk could be measured by a means established by the Health Belief Model, which has as a part of its framework, a perceived risk and perceived severity scale.

A more relevant study was carried out by Friedlander, Kaul and Stimel (1984) which dealt directly

with the issues of abortion and conflict. The authors used this theory to investigate how 291 women, ages ranging from 13 to 42 years old, struggled with attitudes and behaviors related to abortion decision making and the use of contraceptives. Diverse decisions about abortion were formulated as those judgments occurring when a woman, who was desiring pregnancy, later considers the abortion alternative when the decision processes were protracted and subjectively more difficult. The five stages of Janis and Mann's Conflict Theory that were utilized in this study were: (1) the affective response to acknowledgment of pregnancy, continuing on to (2) formulation of alternatives to pregnancy, (3) to consideration of available options, (4) commitment to the decision that they make about these options, and (5) adherence to the decision.

Research Questions

This descriptive study collected data to answer the following questions:

1. What factors stand out in pregnant women's appraisal of the need to seek HIV antibody testing (Stage One)?
2. What attitudes are associated with pregnant women's decisions to seek testing or not seek testing (Stage Two)?

3. What was the relationship between pregnant women's locus of control and their decision to take or decline an HIV antibody test?

4. How are pregnant women's decisions affected by their marital status?

Therefore, this study attempted to search for motives that the sample would employ in order to justify taking or declining the HIV antibody test. Even though much of the medical community stresses the promotion of early intervention as a primary means to staving off the debilitating effects and, ultimately, the fatal results of AIDS, a substantial percentage of possible carriers of HIV opt to avoid the antibody tests. Moreover, this study provided information on the variation of a pregnant population and the range of reasoning inherent in this decision making process. While investigating this population, research emphasized comparisons and contrasts to other populations who have disclosed their decisions with regards to HIV antibody testing. There was also an accent on issues that are specific to a pregnant population. For example, the research examined if patterns existed as to whether single mothers and married mothers-to-be had differences in their willingness to be tested, or if the sample's locus of control evidenced any tendencies as to whether women who were internally controlled were more or less likely to test than women who were externally controlled. Control issues, discrimination, perceived risks of taking the

HIV antibody test, and consideration for others involved in the life of pregnant women are all factors in decision making. These variants modify individual decision making, and may influence the decision whether to seek testing.

Definition of Terms

AIDS. (Acquired Immunodeficiency Syndrome or Acquire Immune Deficiency Syndrome). A manifestation of the retrovirus HIV, resulting in a clustering of physical disorders, such as Kaposi's sarcoma (KS), Pneumocystis carinii pneumonia (PCP), or Cytomegalovirus (CMV), and/or a plethora of other opportunistic infections associated with the collapse of the immune system. In 1992. the Center for Disease Control asserted that a reduction of CD4 Helper cells in the immune system due to HIV infection to levels below 200, promulgating a possible vulnerability to diseases, would also be known as a classification of AIDS. At the onset of the disease in the United States, it was known as "GRID," which was an acronym for Gay Related Immune Disease. The retrovirus has been identified in different worldwide laboratories and given different names at various times. The International Committee on the Taxonomy of Viruses proposed(1986) the term *HIV (Human Immunodeficiency Virus)* to include all of the terms referring to the retrovirus that can lead to AIDS

(Campbell, 1986).

AZT. Azidothymidine, a controversial antiviral drug that has been shown to prolong life in AIDS patients (O'Malley, 1988).

Bacterial Vaginosis. Bacterial infections of the vagina. As a chronic condition, it could be an indicator of HIV infection in women.

Center for Disease Control and Prevention. Also known as the CDC, it is the federal agency in Atlanta, Georgia that publishes reports dealing with HIV and AIDS and is accountable for tracking the AIDS epidemic.

CD4 Helper Cells. Also known as T-helper cells or a T-helper lymphocytes, they are a genre of white blood cells responsible for synthesizing the interactions of different blood cells in the immune system. Acting as a host for the incubation of HIV, the CD4 Helper cells can act as a useful indicator of the progression of HIV in certain individuals.

Cytomegalovirus. A very common virus which may result in a mononucleosis-like illness in young adults and is transmitted sexually. In persons with depressed immune system, this virus can reactivate and cause invasive disease of the eyes, lungs, bowels, and other vital organs (O'Malley, 1988).

Dementia. Organic loss of intellectual functioning, sometimes associated with HIV progression.

ELISA test. The Enzyme-Linked Immunosorbent Assay test is the preliminary test given to individuals who

are investigating their HIV status, attempting to determine whether or not antibodies have been developed against HIV.

Genital ulcers. Skin lesions in the genital area, which would allow an easy means for HIV to enter the body. Frequently, genital ulcers are sexually transmitted; once a woman is HIV infected, it may very difficult to treat because of the chronic nature of the disease.

HIV. The retrovirus that causes AIDS. Formerly referred to as LAV or HTLV-III (O'Malley, 1988).

HIV antibody test. A test whose purpose is to reveal the presence of antibodies to HIV. It is commonly used on all donated blood and organs in medical and clinical testing programs. If antibodies to this retrovirus are detected by means of this screening, it is assumed that the individual, organ, or blood sample is infected (O'Malley, 1988).

HIV Positive. The guidelines from the Center for Disease control specify that an individual is "considered positive for antibodies to HIV when a sequence of three tests is consistently positive" (National Institute of Justice, 1988). If a preliminary *ELISA* test (see definition for *ELISA*) is positive, then a second *ELISA* test is used on the same blood sample. If both tests are positive, then an affirmation test is administered, generally a *Western Blot* test, which, if positive, will confirm an HIV positive status.

Homophobia. Negative attitudes toward homosexuals and homosexuality, reflecting both conscious and unconscious fears and reactions. Homophobia includes not only irrational and persistent fear of homosexuality (often exhibited in extreme rage reactions to homosexuals), but also the self-hatred experienced by gay men and women because of their homosexuality (Campbell, 1989).

Kaposi's Sarcoma (KS). A tumor of the blood vessels most frequently seen in the skin or mucous membranes and associated with AIDS (O'Malley, 1988).

Locus of control. Judgment by an individual as to whether or not that person's control is determined by internal factors, such as cognitions and personalized perceptions versus external factors. External variables, for this study, affect concerns about health and how an individual views his/her inability to control these variables. In this particular study, subjects were judged as to whether or not they had internal control over the disease or whether or not the factors involved in the disease had control over them.

Opportunistic infections. Those diseases which are caused by agents that are frequently present in our bodies or environment but which cause disease only when there is an alteration from normal healthy conditions - for instance, when the immune system becomes weak or damaged (O'Malley, 1988).

Pelvic inflammatory disease (PID). Inflammation of

the pelvis, which manifest a host of ailments of a woman's upper genital area, which, on a chronic basis, can be one of the first signs of HIV infection in women.

Pneumocystis carinii pneumonia (PCP). A type of pneumonia that is commonly seen in HIV infected clients and, due to the compromised state of the immune system, is viewed as an opportunistic infection resulting in a diagnosis of AIDS (O'Malley, 1988).

Retrovirus. A genus of viruses which contains the enzyme reverse transcriptase and which requires the synthesis of proviral DNA for its replication (O'Malley, 1988).

T-Helper cell. The "host" cell for HIV infection, where replication of HIV occurs. It is also known as a CD-4 cell.

Thrush. A type of yeast infection that is inside the oral cavity, also known as oral candidiasis. A white, cotton-like coating of the tongue and cheeks, this is one of the first and primary symptoms of HIV infection (O'Malley, 1988).

Trichomoniasis. A protozoal form of a parasite, also known as *Trichomonas vaginalis*, which presents as inflammation in the vagina. This parasite is commonly passed on by sexual intercourse.

Vaginal Candidiasis. Fungus or yeast infections that present in the vagina. Recurrent, chronic infections could signal the presence of HIV infection.

Western Blot test. After the initial *ELISA* test indicates that the possibility of HIV antibodies exist in an individual's blood, this test is effectuated as a confirmation of a positive HIV status.

Limitations of the Study

The outcomes of this research should be evaluated in the framework of some distinct limitations. First, the use of random sampling techniques was unachievable and, therefore may have jeopardized the study's external validity. Caution should be utilized in assuming generalization of the results for all women since the reactions specifically dealt with HIV antibody testing from a sample who were seeking counseling on pregnancy. Moreover, most of the participants of this study resided in the Hampton Roads area of Virginia and may be dissimilar from other populations outside this geographic location. Since standardization of the instruments for AIDS locus of control and the questionnaire was limited in this study, internal validity may be affected by the adaptation of measures used in other research. Finally, despite the considerable efforts made to accommodate the sensitivities regarding the subject of HIV/AIDS and sexuality, participants may have falsified or misrepresented some of the answers to the questions on the survey. Therefore, a degree of caution needs to be

exercised in evaluating the reliability and validity of the results of the questionnaire

The need for incentives in this study was deemed necessary for good participation, but created certain difficulties. Observations provided by the volunteer person at the Planned Parenthood sites suggested that some women took the test in a hurried fashion, hypothesizing the possibility that various women were answering the questions in an indiscriminate manner, wanting only the monetary incentive. In order to participate in the test, every woman had to be a client of Planned Parenthood and was randomly assigned a number. Directions for taking the questionnaire, proper return procedures of the questionnaire to the volunteer attendee and incentive payment guidelines were addressed. Although the HIV questionnaire that was developed provided many items or responses as possible decision making variables for taking or declining the HIV antibody test, pilot respondents were encouraged to add pertinent items that were either overlooked or excluded. Given this opportunity, the pilot participants did not indicate any additions, although suggested wording changes for clarification were specified. Hence, no additional variables were added in the final questionnaire by the participants. One additional question was provided by the administrators at Planned Parenthood. A question regarding the status of taking the HIV antibody test without knowing the

results was added. However, the question did not yield any affirmative responses and was eliminated as a statistical item.

CHAPTER II

Historical Overview of Related Literature Theory - Events - Direction

HIV and AIDS in Women in the United States

As noted in Chapter One, women continue to be the fastest growing group of HIV infected individuals in the United States. From 1992 to 1993, new AIDS cases in women in the United States have jumped 151 percent (N.Y. Times News Service, 1994). In fact, the World Health Organization has estimated that 3 million or more women and children worldwide will die from AIDS in the 1990s (Denenberg, 1990). In the United States, Richardson (1988) estimated that there were about 2500 cases of AIDS in women, and the number of HIV infected women ranged from fifty to a hundred times the number of AIDS cases. Although about half the women with AIDS in the U.S. are injection drug users (Saalfeld, 1990), the Public Health Service (Denenberg, 1990) predicts that by 1995 the principal form of transmission of AIDS will be heterosexual. In fact, in 1992, 39 percent of women's AIDS cases were attributable to heterosexual contact, an increase of 42 percent since 1990. (Staff in Virginian-Pilot, 1993). Statistics provided by the CDC comparing 1992 to 1993 demonstrated 130 percent increase

in HIV exposure in the heterosexual population (N.Y. Times News Service, 1994). This predication suggested increasing risk for women in general, with corresponding increasing risk for women who were pregnant. Research done at the Eastern Virginia Medical School, presented at the Ninth International Conference on AIDS, demonstrated transmission rates of HIV from mother to unborn children were nearly 40 percent in the Hampton Roads area compared to only 14 percent in San Francisco area (Virginian-Pilot, 1993).

Women's Susceptibility to HIV

Women have not been identified as a group at high risk of HIV infection, although the increasing number of cases may lead to this designation soon (Denenberg, 1990). Thus, as with men, a woman's risk of HIV infection was associated with behavior. Due partially to the fact that HIV in women had primarily been associated with other factors involving high-risk behavior, such as injection drug use, unprotected sexual intercourse with a bisexual male or a male who was involved with injection drugs, reclassification of women as a higher risk category in a general sense may or may not be forthcoming. Yet, while heterosexual transmission has steadily increased as a cause of HIV infection in women, the women's rate of unknown causes was more than twice that of men (Denenberg, 1990).

Perinatal transmission of HIV infection has been found associated with drug use in the mother or her partner in 80 percent of AIDS cases (Evans, Beauchamp, Deyton, Newman, Osborn, Rosenbaum & Van Ness, 1989). Statistics on HIV infection for women clearly revealed evolving trends were evident, especially when perceived globally or pandemic terms. In North America as well as some European countries, cases of HIV infection tended to show an greater number of men being infected than women. However, in central and eastern Africa as well as in many Caribbean nations, the ratio of male to female cases was almost equal. A third trend, in countries in eastern Europe and Asia, there was little or no pattern, with a smaller number of HIV cases being reported.

As indicated in Chapter One, Hispanic and African American women have been at risk for HIV infection more traditionally than white women (Evans et al, 1989). In December 1989, African American women made up 52 percent of the caseload for all infected woman. Hispanic women constituted 20 percent of the women's infected population. Comparing 1993 statistics to 1992, Whites increased 102 percent, while African Americans rose 123 percent and Hispanics rose 114 percent increased (N.Y.Times News Service, 1994). On a year to year basis, the principal form of transmission of HIV disease is slowly changing. In 1985, the AIDS caseload was more narrowly focused on the male homosexual population, and heterosexual transmission accounted for a mere 1.9

percent. In 1993, however, heterosexual transmission accounted for the biggest rate increase in AIDS cases in the United States (N.Y. Times News Service, 1994).

Decision making for pregnant women dealing with HIV

Hutchison and Kurth (1991, p.19) reported on the "modes of thinking by HIV positive women during their reproductive decision-making" interval allow us to understand and "tune in" to how women regard HIV antibody testing. The authors suggest that there was a "locus of decision-making" (Hutchison & Kurth, p.19, 1991) where women "cite pressure from family and/or significant other(s)" while making decisions about reproduction. In their study, only a few women reported pressure and that they alone made decisions about their outcomes. Women consistently reported the loneliness of their decision making, contemplating their health and the feeling as though it was "themselves and their children against the world" (Hutchison & Kurth, p.19, 1991). "Many of the women's fundamental ethical principles could be summarized as 'First, take care of the children'" (Hutchison & Kurth, p.19, 1991). In this same study, however, more emphasis was placed on the morality question regarding abortion than bringing a child into the world who is HIV infected. Control issues were also demonstrated in this study. The research discuss two women and their responses - "Tess"

and "Tammy" - the former being a poor, African American woman and the latter, a white, middle income woman. "Tess does not see herself as someone who has control over what happens to her, and is left with the option of acceptance of HIV as yet another variable in her life" (Hutchison & Kurth, p.20, 1991). "Tammy, when confronted with HIV, desperately seeks ways to feel more in control. . . She feels that *she* can control *her* environment" (Hutchison & Kurth, p.20, 1991). Poverty, coupled with loss of control in sexual relationships, were problematic issues for minority women. Poverty frequently translates into prostitution for some women who are in a survival mode. Another study on minority women, which used a focus group interview process, determined that Hispanic women, aged 17 to 67 years, experienced lose of control feelings when dealing with sexual issues and survival (Nyamathi & Vasquez, 1989). Feelings of helplessness and low self-esteem were also pervasive. Ultimately, these women were taught coping strategies, mostly by acting as a major supporter for the health and welfare of their children.

Control issues were also researched by Levine and Dubler (1990), who questioned the duality that advocated HIV antibody testing for women, while simultaneously proposing that HIV positive women disavow pregnancy. Poverty, for both Hispanic and African American women, is a significant issue with regards to locus of control. Generally, women who were in a depressed economic status

- where being able to feed, clothe, and shelter themselves and their offspring is frequently difficult - feel powerless in relationships.

A different locus of decision making was studied by McClain (1983), who used the decision making theory of Janis and Mann that investigated the perceived risk of pregnant women with respects to childcare services. Seven available child care services were delineated and women were told to choose the service that best fit their needs, while providing the least amount of risk. Dealing with the first analysis of cognitive information processing in decision making, McClain (1983) used the concepts of "bolstering," the concept of discounting risks and magnifying the benefits of a particular selected childcare service. Conversely, the study also demonstrated that women discounted the rejected services, where women exaggerated the risks of a particular service and discounted the advantages. The women's concept of bolstering provided "a persuasive interpretation of women's aversion to certain risks of childbirth and its care and their willingness to accept others, which they acknowledge, but discount" (McClain, 1983, p.1860).

Control of AIDS Spread and HIV antibody testing in the
United States

At this time, HIV antibody testing is the only procedure for early detection of HIV infection. Public health policy has called for two methods of attempting to control the spread of AIDS: public education and HIV antibody testing of groups considered at high risk of HIV infection (GAO/HRD, 1990). Higher risks of HIV infection are associated with specific behaviors: use of intravenous or injection drugs, unprotected sexual intercourse with individuals at high risk of HIV infection, exposure to blood and/or body fluids of infected individuals and perinatal transmission from mother to offspring.

The rationale for use of HIV antibody testing as a method of controlling the spread of the disease has been based on several expected outcomes. First, it was expected that individuals identified as HIV infected would initiate behavior changes to protect others (Kleiman, 1988). Another expectation was that early identification of HIV infection would ensure early medical treatment. The success of HIV antibody testing as a control measure, in either case, depends on the willingness of individuals at high risk of infection to obtain HIV antibody testing.

However, the use of HIV antibody testing to identify infected individuals has been seen also as a

means to deny human rights and privileges. Franke (1988) described policies on HIV antibody testing as often the result of a duel between public and criminal laws. Further, although early detection of HIV infection has been shown to have some benefits, negative psychological and psychosocial consequences may also occur, and legal protection of HIV infected individuals against discrimination has also been seen as needed (National Commission on AIDS, 1991).

At any rate, it has been estimated that fewer than 20 percent of HIV infected individuals are thought to have been identified through CDC-sponsored testing services (GAO/HRD, 1990). . Even though these programs have tested an estimated 3 million people, the low yield is thought to be a direct result of testing the "worried well" as opposed to those who have been involved in high-risk behavior (National Commission on AIDS, 1991).

There have been proposals for mandatory HIV antibody testing of all women of childbearing age or all pregnant women, although those who have been tested show a low incidence of infection (Evans, Beauchamp, Dayton, Osborn, Rosenbaum & Van Ness, 1989). In fact, mandatory HIV antibody testing has been investigated as a possibility for pregnant women in Florida and Michigan, with New York and New Jersey considering similar requirements (Leonard, 1990). Proponents of mandatory testing insist that this does not constitute any form of discrimination; instead, these proponents conclude that

it is only a form of judicious business planning, for people with AIDS could significantly deplete insurers' funding (Rosner & Brennessel, 1989). Furthermore, The Centers for Disease Control encourage HIV antibody testing of pregnant women who are considered in higher risk categories (e.g., associated with a partner who uses intravenous or injection drugs). Viewing AIDS and HIV infection globally, evidence suggests HIV antibody testing is a frequent practice. For example, in Britain, the government concluded that it was wise to voluntarily test pregnant women for HIV antibodies (Kingman, 1988). No adverse reactions were noted regarding this government proposal. Conversely, a report that proposed HIV antibody testing of pregnant women in France became a hotly debated issue which led to a political backlash (Coles, 1988). Moatti, leGales, Seror, and Papiernik (1990) surveyed French women who were pregnant as to the social acceptability of HIV antibody testing. The survey, which was carried out in two maternity hospitals, suggests that social acceptability was high (68.8%), but also suggested that abortion of HIV infected women was also high (80.1%). Another article on decision making was researched by Kingman (1988) Pregnant women living in Great Britain were given the option of taking the HIV antibody test; many of them declined. When the first HIV antibody tests became available in March 1987, only 2 to 5 percent of pregnant women declined the HIV antibody

test. In a later follow up, however, 32 percent of pregnant women from this facility chose not to take the test, with no reasoning being disclosed in the article as to why they declined. Of the women who tested HIV positive, which was approximately 1 percent of 1500 patients at postnatal clinics in West London, none elected for an abortion. Another study in the United Kingdom demonstrated that 82 percent of women who attended an postnatal clinic felt that the HIV antibody test should be made available, but only 48 percent reported that they would take the test (Stevens, Victor, Sheer & Beard, 1989). Again, no rationale was given for the 52 percent who indicated that they would decline the HIV antibody test. For whatever reasons, there exists a large percentage of women who did not choose to test and may not know their HIV status for causes undisclosed. In any case, in the United States, HIV antibody testing has been criticized because individuals identified as HIV infected have been subject to discrimination, setting up a conflict between concerns for the needs and rights of the infected individual and the need for public safety (Swartz, 1988). In addition, fixating on HIV antibody testing as a solution for control of the disease may prevent attention to the need for education, prevention and treatment, not to mention concerns for the loss of civil rights (Leonard, 1990; O'Malley, 1988). Regarding the latter concern, a law suit has been filed in Frederick County, Maryland against the

county officials who forcibly removed a man from his vehicle, arrested him and administered an HIV antibody test because he was suspected of carrying the virus (Associated Press, 1994).

In the United States, "prenatal HIV antibody testing is never conducted in a social or political vacuum" (Franke, p.226, 1988). Suggestions are made that policies regarding HIV antibody testing are often set up as duel between public and criminal laws, sometimes with the end result being that women are envisioned as being "guilty of HIV infection" (Franke, p.226, 1988). In a study by Berrier, Sperling, Preisinger and Evans (1991), the effects of a program designed to educate a predominantly female minority did increase the standards of knowledge about AIDS and HIV infection, but did not increase the desire to be voluntarily HIV antibody tested.

Historical description of HIV Antibody Testing

A report issued by the National Institute of Justice (Hammett, 1988) stated the "significant confusion about the nature and meaning of HIV antibody testing". Much of the confusion stems from terminology associated for HIV antibody testing. Even though terms such as "AIDS testing" exist, the fact is that there is no test for AIDS (Hammett, 1988). The current 3-step test for HIV detection looks for antibodies produced by

the individual's body, but does not determine whether or not an individual has AIDS. Until 1993, AIDS can only be diagnosed through identification of opportunistic infections or malignancies or central nervous system disorders now known to be caused directly by HIV infection (Hammett, 1988). The Center for Disease Control issued new guidelines denoting that an HIV infected individual with a CD4 Helper Cell count of below two hundred, with or without opportunistic infections or malignancies, can now be classified as having AIDS. Advocates for HIV antibody testing cite the benefits of early detection, but also identify negative psychological and psychosocial consequences of programs that exclude applicable medical treatments (National Commission on AIDS, April 1991). Furthermore, an emphasis by this same commission presumed that legal protections against discrimination needs to be put into place. At the moment, HIV antibody testing is the only procedure for early detection of HIV infection.

Reactions and motives of 120 gay men to HIV antibody testing were studied by researchers Siegel, Levine, Brooks, and Kern (1989), who questioned the reasons and responses of this sample either to take or decline the HIV antibody test. For those men who decided to take the HIV antibody test, their reasons for this decision were to: a) obtain medical treatments pertinent to HIV infection, b) modify lifestyle changes, (c) to determine if a precarious medical status existed,

d) be informed and to advise others of their sexual decision making, and e) to diminish psychological suffering associated with not knowing their HIV status. For those men who chose not to test, the most frequently cited reasons were: (a) avoid the adverse psychological consequences of testing HIV positive, (b) avoid social discrimination and repressive governmental actions associated with testing HIV positive, (c) avoid an ambiguous or unreliable test result, and (d) avoid having to make undesired lifestyle changes. In another comparison study by Hull, Bettinger, Gallaher, Keller, Wilson, Mertz (1988), a sexually transmitted disease clinic was set up to allow HIV antibody testing for those subjects who wanted to volunteer for testing. Eighty-two percent of all clients who attended this particular clinic volunteered to be tested. The results indicated that less than 10 percent of subjects who volunteered to be tested were HIV positive. Of the 18 percent of the sample who declined HIV antibody testing, four percent of the subjects later tested positive. This study determined that more research was needed on those subjects who decline HIV antibody testing, but also indicated that those male subjects who decided not to take the test were more likely to be HIV infected..

Testing Centers in the United States

Testing for HIV antibodies has created a

groundswell of different thought as to the best methods to administer the test. Guidelines used at the testing centers call for pretest and posttest counseling to be given whenever an individual decides to have the test administered. Two of the major considerations inherent in testing are: 1) the site location and 2) whether or not the testing site is organized to promote confidentiality and anonymity for those who are seeking information about their HIV status. (Valdiserri, 1989). Currently, there are two forms of test sites: (1) the confidential test site, where a clinic carries on counseling and testing procedures in a confidential manner, but is mandated to report positive findings to the C.D.C. or other public health institutions, or (2) the anonymous test site, where the individual is assigned a number and test results are unreported to any other health organization. The latter site is strongly preferred by some individuals, and at least one study indicates that providing anonymous testing sites could increase the consent rate for testing by 50 percent over the alternative method of confidential testing site (Fehrs, Foster, Fox, Fleming, McAlister, Modesitt & Conrad, 1988)

A newsletter from the Center for Disease Control (April 1991) states, "The world's attention is focused on an HIV/AIDS epidemic among women that has been slowly escalating as an international threat." The consequences of the pandemic among women is devastating.

As mentioned previously, by the end of 1991, AIDS is estimated to have risen to be among the five leading causes of death in all women of reproductive age (Fauci, p.54,1991). By certain estimates (GAO/HRD, 1990), an enormously disproportionate amount of the population infected with Human Immunodeficiency Virus have not been tested. Reactions internationally to the HIV epidemic in women are diverse. Due to the unique nature involving the associated stigma that has accompanied the disease, a psychological / psychosocial schism has been created.

Injection drug users, still an enormously high risk population, is specified in the National Commission on AIDS report as the "twin epidemics" of AIDS and substance abuse (July, 1991). A study at the Long Island methadone treatment program illustrates some of the reasons why the individuals would choose not to be HIV antibody tested. Because of the burden of psychological implications of an HIV positive status, insights may be gained from a study on injection drug users. According to the GAO/HRD 91-52 AIDS Prevention Program (1990, p.20) "researchers found that the injection drug user's perception of counselor interest in his or her taking the test affected the decision. Furthermore, there was some evidence that the AIDS education provided in the pretest counseling discouraged undecided clients from taking the test." Breakdowns for male and female injection drug users weren't delineated.

Along with these elements, there were further rationale for not testing. "Other reasons cited for not taking the test were that the injection drug user (1) had enough problems without more bad news, (2) believed being tested would serve no purpose, (3) feared or was unwilling to learn the outcome, or (4) was concerned about confidentiality" (GAO/HRD 91-52 AIDS Prevention Program, 1990, p.20). When examining women and the use of injection drugs, Denenberg (1990) reported that women encounter supplemental medical problems more than male intravenous drug users (IVDUs) or injection drug users. By some accounts, IVDUs make up about 21 percent of all AIDS cases (Saalfield, 1990). About half the women with AIDS are injection drug users (Saalfield, 1990).

Effects of HIV and HIV Antibody testing on women

Until recently, women as a group have generally been excluded from being studied when investigating psychological and psychosocial reactions to HIV and HIV antibody testing. Jacobsen, Perry and Hirsch (1990) suggested that studying psychological reactions of other risk groups to HIV antibody testing would be a direction for future research. Certainly, women fare no better than men with regards to stigma that is attached to HIV infection. Discrimination against women who are HIV infected in the United States is established by their

gender, their medical status, and exclusion from funding and research (Stuntzner-Gibson,1991). Social issues are the main sources of stigma for women, especially women of color (Stuntzner-Gibson,1991). Deep-seated racism, discrimination of lower socioeconomic class as well as unemployment/underemployment are all elements that adversely affect the manner in which women with HIV have to interact with society (Stuntzner-Gibson,1991). Watley (in Aggleton & Homan,1988) reports a certain amount of sexism, racism and misogyny when the coverage discusses the virtuous housewife with AIDS versus the infested African "harlot ".

However, for women who are HIV infected and who intend on becoming pregnant, there are growing judicial, medical, and societal pressures that affect a woman's decision about pregnancy or carrying the fetus to full term (Stuntzner-Gibson, 1991). "In addition to the fear and guilt HIV infected mothers and pregnant women experience, they are sometimes judged critically by their friends, families, and the professionals who work with them" (Ryan in Stuntzner-Gibson, p. 24, 1991). Stuntzner-Gibson (1991, p.22) indicates that racism and sexism are frequently a part of the "ignorance and neglect of the conditions confronting women with HIV disease". Furthermore, Stuntzner-Gibson (1991) suggests that women usually do not recognize that they are at risk for acquiring HIV and, therefore, tend to be in more denial than men.

Cognitive processing for pregnant women who decide to test or not to test is engaged, since pregnancy means they had unprotected sex and may have put themselves at risk for HIV infection. Obviously, condoms were not used or failed when used and some risk to HIV infection may have been involved, unless the woman involved is 100 percent certain that her partner is not HIV infected. The decision for aborting or keeping the fetus is frequently a confusing issue for women who are pregnant, especially if they may feel that they are at risk for being HIV positive. Others suggest that abortion is a positive solution since pregnancy weakens the immune system and can be viewed by some as "institutional neglect" if medical experts are silent about the issue of pregnancy and immune compromise (Stuntzner-Gibson, p.24, 1991). However, due to the interest in the viability of the fetus, the mother's health may be discounted if the woman is found to be HIV positive (Franke, 1988). Once again, women who are pregnant have a great deal of fear and guilt dealing with HIV infection. In truth, in 1985, the Centers for Disease Control advised HIV infected women not to conceive and gave guidelines for prevention of HIV infection through perinatal transmission. More recently, however, the idea that HIV pregnant women would increase the risk of exacerbating an onset of AIDS has been disputed by doctors in Europe who presented a rebuttal at the Fourth International Conference on AIDS in Stockholm, Sweden,

contradicting the CDC authorities by suggesting that pregnancy may not deteriorate the immune system or increase the possibility of moving to an AIDS diagnosis (Watstein & Laurich, 1991).

Discrimination and Stigma Associated with HIV and AIDS

Stigma is not a phenomenon unknown in history and certainly not over the timeframe of the AIDS epidemic. Just below the surface of the stereotypical culpability, it is easy to discover the emerging prerequisites for discrimination of entire populations of people (Aggleton & Homans, 1988). Leonard and Thistlethwaite (in 1990) recall the instance in World War I, where the federal government decided to quarantine over thirty thousand women accused of prostitution as opposed to giving enlisted men condoms. Researchers Herek and Glunt (1988, p.887) reported on the "epidemic of stigma." They were also quoted as having heard suggestions that everyone who tested positive for HIV be tattooed on the forearm or buttocks, and that they be sequestered "compulsorily, immediately, and permanently." Although current reports indicate that even though continued discrimination and stigma exists towards HIV infected individuals, risky behavior is still evident in the growing HIV infected heterosexual population (Gelman, 1993).

Indeed, the stigma that is attached to HIV disease,

regardless of terminology connoting innocence or guilt, is associated quite strongly with women. HIV positive pregnant women are a focus for some of the most deep-seated value judgments about AIDS. The media's persistent portrayal of a health-failing infant or toddler with AIDS pushes the concept of 'innocent' versus 'guilty' to the extreme (Denenberg, 1990). Originally, the idea of testing women has been generally justified only if they are envisioned as being "high risk" individuals involved in either injection drug use or prostitution or possibly involved heterosexually with a high risk partner. Therefore, the question that evolves is whether or not testing means being fearful of being associated with injection drug use, prostitution as well as having to deal with the consequences of a contagious disease.

The knowledge of someone's positive HIV status generally has enormous social and cultural implications. "A whole gallery of folk devils have been introduced - the sex crazed gay, the dirty drug abuser, the filthy whore, the blood drinking voodoo-driven black - side by side with a gallery of 'innocents' - the hemophiliacs, the blood transfusion 'victim', the new born child, even the 'heterosexual'" (Aggleton & Homans, 1988, p.). Nevertheless, AIDS is unlike the conglomerate of other communicable diseases. "The public identification of people infected with the AIDS virus that would be required under many proposed screening programs . .

alienating individuals from their communities and livelihoods just as effectively as frank policies of isolation or quarantine" (Juengst & Koenig, 1989). Once again, the associative idea of two separate diseased and non-diseased categories exists, with the stigma appearing to alienate those suffering from HIV. The thoughts on this issue are quite divisive. Professional responsibilities tended to depend significantly on whether one's patients were categorized as 'incurable sources of infection' who instituted the epidemic or as 'innocent victims', paying the price of someone else's irresponsible conduct (Juengst & Koenig, 1989). Although the Director of the Third International Conference on AIDS has suggested that deceptively disguised biases about race, social status and ethnicity exist in insurance businesses when assessing the AIDS epidemic, there are counter-suggestions that valid medical and economical aspects need to be considered by insurance companies (Rosner & Brennessel, 1989). Insurance companies, in order to stay "profitable", have avoided selling life, health, and disability policies to individuals who are HIV infected (Rosner & Brennessel, 1989). Many companies now require that an HIV antibody test be given for policies that exceed one hundred thousand dollars. Some disability carriers are also testing for HIV antibodies, especially in lieu of the longer lifespan of many of the long term survivors of AIDS.

According to some professionals, (Wood and Philipson,1987) the implications are already present that suggest discrimination policies have been in place regarding HIV antibody testing, having produced consequential social ramifications. O'Malley (1988) reports that some life insurance companies have ceased writing policies in places like Washington,D.C. and California as a result of strict antitesting laws and legislation. As of 1989, there were very few federal, state, and local legislative initiatives that would prohibit the nature of discrimination. A reluctance to test for HIV antibodies goes up as guarantees of confidentiality and anonymity decrease (Coates & McKusick, 1990). Stigmatization affiliated with HIV infection also prevents the person from testing (Coates & McKusick, 1990). Conclusions that some case work scrutiny of a current HIV antibody test program demonstrates that significant discrimination exists with regards to confidentiality and the right of privacy. Even though state and local government policies clearly are designed to protect individuals who are positive for HIV, breaches are frequent.

Another aspect of testing that could often be disturbing for women is the wording used in the consent forms that may ask for exchange of information from one agency to another, warning of the possibility of psychological and social ramifications. A sample consent form (Valdiserri, 1989) alerts the individual to

the fact that "the results might also be used as basis for discrimination by other individuals or institutions." For women, the question that evolves is whether or not HIV antibody testing will become a part of routine maintenance for pre or postnatal care (Richardson, 1988). Currently, many pregnant women are not routinely screen for HIV antibodies. With the new discoveries about AZT lowering the transmission rate between the mother and the developing fetus, predictions now forecast that pregnancy testing policies will be reviewed and be given as a routine procedure (Cowley, 1994). Furthermore, the presence of the disease as a cause of isolation is evident. Misconceptions about the transmission of the disease within various cultural, ethnic, and neighborhood groups have maintained the feeling of alienation towards individuals and their families (O'Malley, 1988). In certain instances, churches have even been fearful to give solace to families affected by HIV (O'Malley, 1988).

The moral views of the disease present a preponderance of ethical and social dilemmas which continue to appear. Studies suggest that individuals who are infected may be angry and resentful, choosing to infect others or avoid the implications of HIV antibody testing (Tanay, 1988). The infected HIV person sometimes cannot feel safe even in a psychological sense, since there are psychiatric associations unwilling to provide crucial psychiatric intervention

and reject infected individuals due to the nature of transmission (Seeman, 1989),

As new facts and knowledge continue to emerge with the progression of the disease, other populations are seeing tremendous jumps in infection. The AIDS epidemic is devastating to young women in certain metropolitan areas, with physical and psychological complications that compromise their lives. Denenberg (1990) reports that women infected with HIV who reside in Newark, New Jersey, live about 15.5 weeks after the diagnosis of AIDS as opposed to a white gay male in the northeast region of the United States with HIV illness lives an average of 20.8 months following diagnosis.

Decision Making Theory

Support for Janis and Mann's stage concept of bolstering was found by McClain (1983), who used the conflict theory of decision making to investigate pregnant women's choices of birth services. McClain found evidence that the subjects both bolstered their choices by discounting risks and magnifying the benefits of their choice and engaged in a process (Stage Five) of discounting the rejected services, exaggerated the risks and , minimizing the advantages of the services they did not choose. Kingman (1988) investigated this sort of decision making when examining women's decisions about testing and abortion. While Maiman and Becker (1974)

related various psychological decision making theories with regards to health behaviors, which included Lewin's uncertainty model, Tolman's analysis of performance behavior, Rotter's concept of reinforcement, Edward's decision model of Subjective Expected Utility, Atkinson's view of risk-taking behavior and Feather's analysis of decision making under uncertainty, an interesting association can be drawn from looking closer at both the Health Belief Model and Janis and Mann's Conflict theory of decision making. Both are constructed in a very similar pattern, taking into consideration elements of determination from a multitude of sources, both externally and internally. Both models consider a value system essential for decision making. Moreover, the Janis and Mann's Conflict theory of decision making has been utilized in decisions dealing with the pertinent issues of reproduction (McClain, 1983) and abortion (Friedlander, Kaul, and Stimel, 1984). Conflict theory of decision making was also used with substance abuse (Loneck & Kola, 1988), specifically alcoholism and intervention, another issue relevant to HIV infection in pregnant women.

With respects to the Health Belief Model, a study done by Nyamathi, Schuler and Porche (1990) utilized the Health Belief Model in examining the need for HIV antibody testing availability with minority women considered vulnerable to HIV infection. It was used to examine and clarify preventative health behavior,

perceptions and signals about behavior in this population. Obvious connections to the theoretical rationale on decision making concerning discounted risks and promoted benefits are apparent. In the Health Belief Model, certain facets, like demographic factors, sociopsychological elements and structural variables are clustered together as a group that is called "modifying factors."

Locus of Decision-Making in Women

Hutchison and Kurth (1991) found that most of the HIV infected women in their study felt pressured by their families and their significant others while making decisions about reproduction. The authors reported that the women in the study felt lonely in their decision making, contemplating their health and the feeling that it was "themselves and their children against the world" (p.19). In considering whether or not to opt for abortion, the subjects were more concerned about the morality of abortion than about the idea of bringing an HIV infected child into the world.

Feelings of not being in control were found by Hutchison and Kurth, as well as Nyamathi and Vasquez (1989), who studied Hispanic women , aged 17 to 67, through a focus group interview process. Levine and Dubler (1990) also concluded that there were significant issues of control loss (p. 24). Poverty, in particular

for Hispanic and African American women, presents issues of control, where being able to feed, clothe, and shelter themselves and their children is frequently difficult and is associated with feelings of powerlessness in relationships (Nyamathi & Vasquez, 1989).

SUMMARY

Ramifications of HIV Antibody Testing

Testing positive for HIV triggers some consequences that involve the individual's family of origin as well as the person's significant other. Case studies frequently demonstrate that family reactions are both tragic and compassionate (Rieder and Ruppelt, 1988, Kubler-Ross, 1987) Studies (U.S.General Accounting Office, 1989) suggest that counseling procedures be reviewed and studied for possible problems with follow-up and long term therapy. Any complications on implementation of partner notification as well as stricter controls on anti-discrimination protection policies for persons infected with HIV should also be instituted. Success of testing is dependent on its capacity to attract people to seek testing and therapy (Evans, Beauchamp, Deyton, Newman, Osborn, Rosenbaum & Van Ness, 1989)

For women, it is crucial to understand the issues

of HIV antibody testing and the issues that arise as a result of an HIV positive test. As with their male counterparts, women fear prejudice and know that a positive test result could possibly be a means to breach confidentiality and become a major source of discrimination. Counseling for those about to take an HIV antibody test deals with the idea of success, specifically the notion of having better control over the outcome of a positive result. Nevertheless, as researchers have discovered, there is significant suspicion that breaches in confidentiality occur and that distrust occurs as a result of discrimination against HIV infected people or those suspected of having HIV infection (Evans, Beauchamp, Deyton, Newman, Osborn, Rosenbaum & Van Ness, 1989) Indeed, O'Malley (1988) pointed out that an insufficient amount of evidence and information is currently accessible about the "specific personality profile" or cognitive facets of those individuals who react well and adjust to an HIV antibody test as opposed to those who respond poorly. An individual attempting to decide on whether or not to test has to take into considerations how the test results will impact his or her family, employment, living conditions and health benefits.

The challenges presented by this disease have far-reaching effects for the woman who is thinking of taking the HIV antibody test. Unlike the psychological areas covered by other illnesses that are seen as terminal,

AIDS represents a multitude of simultaneous decision making processes. Little research has emerged regarding the range and depth of feelings dealing with the grief of the disease in women, not to mention the untold complications (Sowell, Bramlett, Gueldner, Gritzmacher, Martin, 1991). The decision making process is complicated by factors unseen in the male population. For pregnant women, not only do they have to weight the considerations for themselves, there is always the health concerns of the developing fetus.

Research over the past few years indicates that variables dealing with testing are numerous. Fear of discovering one's mortality, as viewed by many of those who are HIV infected, does not explain or elaborate the self-loathing, nor the psychological and sociological stigma attached to HIV. Simple denial to a deadly infection or to even cancer is a primary component or reaction to testing, but too rudimentary to cover the broad range of psychological and/or psychosocial responses to what is publicly believed to be a shameful disease. In a study by Kegeles, Catania, and Coates (1990), subjects were questioned about how they perceived the risk of HIV infection. One hundred and eighty subjects, including homosexual, bisexual and heterosexual men and women, conveyed apprehension about choosing to be HIV antibody tested if anonymity was not guaranteed. The conviction that one was HIV infected was connected with a lessened tendency to obtain testing

under certain situations. The more the individual suspected that he or she was HIV infected, the less likely she or he would be tested. In this study, bisexual men, in particular, were quite hesitant to seek testing if there was mandatory reporting. Further research is needed to study views held by other segments of the population that have not, as yet, felt the full impact of this fatal retrovirus and to determine more effective means to ease the epidemic spread. Although it has been amply evident that men and women are equally vulnerable to HIV infection, the disease continues to be characteristically envisioned by the American populace as primarily affecting gay men and injection drug users. Albeit that worldwide statistics suggests that transmission is predominantly heterosexual in nature on a global scale, the primary state of denial for the American population is to categorize HIV as less of a risk for mainstream America. Advances toward dismissing nonempirical beliefs regarding this disease continue to be promoted, but ingrained indoctrination over the past decade are proving difficult to repudiate. Further research into the female population may dispel more myths about the nature of the disease or the character of those infected.

In addition, the need for research which focuses on the psychological and psychosocial impact of the testing itself, in particular for the female population, has been grossly overlooked. As with the clinical trails

for treatment, men have dominated in these studies. Once again, investigating responses in women would be helpful in discovering similarities and differences in reaction to HIV antibody testing with other populations already significantly affected. Demographical data and reactions will be evaluated by the use of a questionnaire given to the respondents. Control issues, specifically those health elements with respects to AIDS or HIV infection that women feel that they able or unable to regulate, will be assessed by the use of an Multidimensional AIDS Locus of Control Survey, developed in Germany, as a offshoot of the Wallston and Wallston Multidimensional Locus of Control. Questions translated from an earlier German study that investigated the significance of Locus of Control aspects of HIV in adults can be found at the appendices section of this report. In earlier studies by Dalton (1983) regarding Wallston and Wallston's health locus of control, research was done to investigate relationships between psychological maladjustment and stressful life events and locus of control. Results indicated that subjects with disagreeable life events' numbers and a more external locus of control were more likely to suffer stress, depression, and bodily illness. Locus of control issues were also studied by Nyamathi and Vasquez (1989), in the study of HIV infected Hispanic women. In the abortion study by Friedlander, Kaul, and Stimel (1984), a locus of control scale was also used

to inquire about the relationships of control and the intricacy of abortion. Salient relationships between the locus of control studies already researched regarding Hispanic women and HIV and studies on abortion ascertain the need for the use of locus of control in this research. As mentioned previously, the questionnaire developed from instruments used in this research consisted of a 35 item locus of control scale by Levenson (1973) and a Self-Control subscale by Buonocore (1977). A Likert scale, using a six point categorization ranging from strongly agree to strongly disagree, was used for each item of the two scales. A demographical or "Personal Background" section was also included that inquired about personal health care. Findings indicated that personal and social values and variables were expected to further complicate the decision making process. Results suggested that a firm commitment to one's sexual companion tended to promote contraceptive use, but confounded decisions dealing with abortion. Furthermore, findings indicated that unwanted pregnancies and decision making are separate processes, both being affected by work and love issues.

Using Janis and Mann's conflict theory of decision making, the study attempted to clarify pregnant women's attitudes about whether or not to opt for HIV antibody testing, and particularly whether their attitudes were similar to or different from those already identified in male samples. In addition, the study will explore

their attitudes in relationship to locus of control and to decisions faced by pregnant women with HIV infection.

CHAPTER III

Population and Selection of the Sample

This descriptive study investigated relationships among variables from data collected at four pregnancy counseling agencies in the Hampton Roads area. The target population consisted of women seeking pregnancy counseling. The accessible population utilized in this study was drawn from four specific locations of Planned Parenthood of Hampton Roads. These four sites were: Hampton, Chesapeake-Portsmouth, Norfolk and Virginia Beach. Every effort was made to establish population validity by comparing age, racial makeup, marital status, education, and socioeconomic status between the clientele of Planned Parenthood and the sample. Cluster sampling was used in the research of this project.

A pilot study consisting of 20 women was conducted at the Hampton branch of Planned Parenthood. These 20 women were asked to make comments and give opinions regarding the HIV questionnaire. From their comments, corrections or enhancements were implemented to clarify the wording and text of the questionnaire.

One hundred and five participants were contacted through Planned Parenthood affiliates in the Hampton Roads area. The questionnaire was administered to new women coming into the centers as well as women who received services from these agencies in the past.

Women seeking information about pregnancy and birth control were asked to fill out a six page questionnaire on HIV and respond to questions regarding HIV antibody testing. Acting as a sampling frame for demographic information, the 1992 Planned Parenthood Annual Report and the Planned Parenthood Affiliate Annual Service Census form (CL7-92) supplied composite data on the women who attended the area agencies.

With the exception of a strong Hispanic influence generally thought to be absent in the Hampton Roads area, certain cultural aspects associated with the group from Planned Parenthood were anticipated to be closely associated to those of groups formerly investigated for HIV related issues. Specifically, issues dealing with the African American culture were expected to emerge. Nevertheless, a certain amount of diversity among the participants enabled results to be scrutinized for various demographic comparisons and contrasts. For example, as with earlier studies of other HIV groups, it was expected that the socioeconomic status of the majority of the women involved in this study would be drawn from the lower end of the socioeconomic scale. Educational achievement was also anticipated to be low. Another theory concluded from this sample was that the majority of participants would be unmarried.

Data Gathering

One hundred five women inquiring about information or counseling on pregnancy were selected to participate in this HIV study. The responses of these women were divided into two categories: those who decided to take the HIV antibody test and those who declined. Additional questions on decision making, such as decisions about abortion and childbearing, were also asked in the questionnaire. The sample received a cover letter and a questionnaire distributed and collected by trained volunteers, familiar with HIV and with the HIV questionnaire (see Appendices A and H respectfully). The cover letter stated the intent of the study, covering topics related to anonymity and confidentiality. It also stated that the participants would be remunerated with a monetary incentive, if they completed the entire test. The letter indicated that a number would be given to each participant and that the names of the participants would not be known, thereby insuring confidentiality and anonymity. Subjects were informed that they might withdraw from the study at any time and that their anonymity would be honored. However, participants were given the option of providing their names and addresses with the purpose of being contacted with the completed results of the research. In addition, participants with questions about HIV antibody testing or who sought information about

HIV/AIDS were directed to either the Virginia Health Department AIDS hotline, the National AIDS Hotline or to agencies dealing with AIDS in their immediate vicinity. Due to the sensitivity of the subject matter, coupled with the problems of ensuring confidentiality, volunteers knowledgeable about HIV were at the various administration sites to distribute the questionnaire, answer any questions and give the participants the incentive payment upon completion of the questionnaire. The self-report questionnaire on AIDS and HIV infection had been reviewed and evaluated by the administrators of Planned Parenthood for content assessment as a part of the pilot study. Pertinent comments and criticisms were considered and implemented. As suggested by Borg and Gall (1989), an appeal was made to the curiosity of the participants by discussing the purpose of the test. The cover letter outlined the intention of the questionnaire and signs were drawn indicating where participants could list their names in order to find out the test results.

Instrumentation

In part, a field-tested questionnaire developed by the U.S. Department of Health and Human Resources was administered. However, only items that were relevant to issues being researched in this study of women were used. The questionnaire employed by the U. S. Department of Health and Human Resources (see Appendix

F) needed alteration to accommodate the concerns of pregnant women. The selection of some items on the questionnaire developed in this study of women reflect the psychological responses to HIV antibody testing generated by U.S. Department of Health and Human Resources personnel. Also drawn from the U.S. Department of Health and Human Services were questions relating to AIDS/HIV knowledge. The expanded version of the questionnaire used in this research added more emphasis to variables that investigated a wider range of psychological and psychosocial issues specifically pertinent to pregnant women.

Added elements were also incorporated from a prototype called the the Health Belief Model. This model embodies added dimensions which contain relevant aspects of women's health as it pertains to HIV infection and HIV antibody testing. The basis for using the Health Belief Model was the desire to examine and judge elements of "perceived susceptibility" to HIV and the "perceived seriousness" or severity of the disease when coupled with other major life events, such as, childbearing. Factors written into questions examined: (1) perceived susceptibility, (2) perceived severity, (3) perceived benefits of preventive action in terms of taking the HIV antibody test and (4) perceived barriers to taking action, or reasons for declining the HIV antibody test. Maiman and Becker (1974) used the Health Belief Model to theorize about health related behavior,

specifically with regards to two main variables. These were: (1) the merit placed by an individual on a particular outcome for a health related issue and (2) the person's assessment of the likelihood that a given action would result in that outcome.

Demographic items, such as age, race, socioeconomic status and education, were the initial part of the supplemented questionnaire. Psychological elements, those variables that have been delineated by the motives and reactions of HIV antibody testing in gay men and IVDUs, were also posed to the sample. Structural variables, those facets of the disease concerning knowledge and comprehension of AIDS and prior contact with a person who has contracted the retrovirus, help predict susceptibility to HIV and its perceived threat. Therefore, the purpose of using the Health Belief Model, in conjunction with the use of the structural variables mentioned, was to develop a questionnaire that analyzed elements of susceptibility and severity while delineating relevant psychological and psychosocial issues.

Another instrument incorporated to study control factors in the sample was the AIDS Locus of Control questionnaire, developed by Wallston and Wallston and based on their 1978 Multidimensional Health Locus of Control Scale. The original AIDS Locus of Control instrument, developed by Wallston and Wallston, was translated from German into English. (See Appendix H).

This addition to the questionnaire inquired about women's locus of control, when seeking information about pregnancy, and how they project this control regarding HIV disease. The German research project researched 173 adults, aged 18 to 53. They were asked to participate by answering questions about control over their general health, as well as questions of control with respects to HIV. The idea was that since subjects can show a "high controllability" (Lohaus et al., p.106, 1988) of HIV infection when compared to other types of disease, individuals could also demonstrate special control beliefs that are different from the general health locus of control. The results showed that internal locus of control was correlated positively with better knowledge and a willingness to search for information regarding prevention, such as the use of condoms or changing behaviors. Individuals with internal locus of control also illustrated a greater fear about HIV infection and a decreased expected probability of infection (Lohaus et al., p.106, 1988). External locus of control individuals demonstrated just the opposite.

The issues of HIV antibody testing would be expected to affect one's value system. Single mothers, in particular, don't have a support system centered around a spouse or sexual partner. Decision making processes that pertain to abortion may involve value systems about commitment to children for single mothers that may vary from mothers who have an involved,

supportive husband. It was anticipated that some mothers would want to know their health status in order to relieve the psychological stress of not knowing their HIV condition while others might deliberately not want to know for fear of adverse consequences it could pose to themselves, their family and work. For example, if there are children already present, the question of whether to test or not to test would seem influenced by the mothers's decision as to whether or not she would be able to support them if she were HIV infected. Once again, a decision, influenced by the bonds of employment and familial love, will have a bolstering affect towards values that are more important and where certain risks are diminished and certain advantages promoted.

As mentioned previously, participants in this research were asked to fill out all sections of the questionnaire completely. Due to the nature of the sample and the expected unwillingness of the majority of women to answer survey questions dealing with HIV, incentives were used to persuade participants to participate in answering a six page questionnaire. Grant money was allocated for the purpose of persuading women to participate and to cover expenses involved in conducting the study. Collection of the grant scholarship will be procured after completion of the study. Although both the Health Belief Model and the AIDS Multidimensional Locus of Control have been used with AIDS/HIV infection prior to this study, there is

little knowledge about validity and reliability of these instruments as it pertains to the disease. A pilot study, with participation of twenty women, was done with Planned Parenthood of Hampton in order to reduce the potential research biases, while removing inappropriate or adding relevant questions that could jeopardize the validity and reliability of the study.

The use of a pilot study and a content analysis of the questionnaire shed light on important wording that was confusing and/or confounding. As a result of this pilot study, new phrasing was incorporated into the research. An additional question was instituted by staff administrators at Planned Parenthood when they evaluated the survey. The question that was added stated, "I have taken the HIV test, but don't know the results." This question was implemented in the post pilot questionnaire; however, none of the participants answered this question as "yes," and it was eliminated as part of the final statistical analysis. Clarification on the wording for questions regarding testing choices were implemented. For example, if a participant answered that she had already tested for HIV antibodies, then answering questions as to whether or not she would choose or decline HIV antibody testing were superfluous. Therefore, specifications were added to the last section of the test that stated, "Please answer the following questions only if you have not taken the HIV Antibody test." This addition affected

only the last two questions of the survey. A few comments provided by the participants of the pilot study pertained to "AIDS paranoia" and testing sites, but were irrelevant to the development of the questionnaire itself. One participant indicated that she would commit if she "got AIDS and was very sick". Having been familiar with the wording of the pilot questionnaire, the volunteer person administering the pilot test was able to translate content meaning of the questionnaire to the participants as well as direct any participant to HIV resources if an individual sought information or assistance. Therefore, participants in the pilot study were incorporated into the entire research sample.

Statistical Hypotheses / Questions

The design of this research study was predominantly descriptive in nature, since the intent was to examine psychological and psychosocial reactions to HIV and HIV antibody testing. The extent and diversity of potential responses prevent the application of an experimentally controlled design. As previously stated, the investigation examined the reactions that members involved at Planned Parenthood personalize towards HIV antibody testing. It was hypothesized that several variables would indicate some significance when compared to other groups, specifically, homosexual men and injection drug users. It was also hypothesized that

individuals who have already decided to take or decline the HIV antibody test would demonstrate forms of bolstering their decision to take the test or minimize risks for declining it. These variables included: psychological stress related to HIV antibody testing, discrimination associated with AIDS and HIV infection, beliefs about medical benefits of early detection and sexual decision making regarding sexual behavioral patterns. The reactions elicited to HIV antibody testing were compared to national norms studied regarding reactions formulated by homosexual men and injection drug users. Correlation coefficients were calculated between the participants' decision whether or not to have HIV antibody testing and the reasons for making this decision (e.g. discrimination questions or confidentiality questions).

Due to the specificity of the issues with regards to decision making processes of this sample, the following questions were proposed:

(1) How many women indicate that they would choose to take the HIV antibody test, and how many women decline it?

(2) What are the decision making factors involved with women seeking pregnancy counseling in choosing to take or choosing to decline the HIV antibody test?

(3) Do women who engage in high risk behavior tend to be less willing to be HIV antibody tested?

(4) Of the women willing to be HIV antibody tested,

how many would choose to abort their fetus if they tested HIV positive?

(5) Do single mothers demonstrated a greater or lesser desire than married women to be HIV antibody tested ?

(6) How does locus of control influence decision making with regards to HIV antibody testing?

Ethical Considerations

The considerations for ethical concerns involved in this research are categorized into three main areas. First, the area of informed consent was addressed in the cover letter to all individuals participating, laying out the details about the nature of the study and the sensitivity of the topic. Also, the cover letter denoted the concern of the individual who might withdraw from the study at any time. Due to the nature of survey site policies on abortion and prenatal care, HIV/AIDS counseling is made available to those who attend Planned Parenthood. Planned Parenthood programs are in place that educate and address the specifics of HIV infection in women and individuals are encouraged to attend.

In the second area, the idea of confidentiality was communicated to all individuals who chose to be a part of the study. All information regarding anonymity and confidentiality was explained, with any pertinent information, records and published material from the

data to be coded as a precaution. Because of the nature of the policies protecting individuals and their identity, the use of Planned Parenthood sites automatically assured participants of anonymity; procedures for survey administration complied with this policy.

The state of Virginia, in which this study was conducted, has very limited civil rights protections for discrimination on the basis of sexual orientation. Indeed, homosexual behavior is considered a felony in the Commonwealth of Virginia, which inflicts a costly penalty of incarceration and/or fines (Conner, 1988). Sensitivity to this concern is necessary; as recently as September, 1993, a Virginia circuit court judge ruled that a lesbian mother was deemed "an unfit parent" because of her sexual orientation. The court awarded custody of the mother's two year old son to the maternal grandmother (Henry, 1993). Lesbian mothers who may have participated in this research, therefore, were protected under the same codes of confidentiality and anonymity as heterosexual mothers. Finally, the results of the research were made available to those who were interested. Any participants who were involved in the study and requested information regarding AIDS or HIV infection or testing were directed to the sources most accessible to them. The proposed research design was subject to the student's dissertation committee as well as to the Human Subject's Review Committee of the School

of Education and the College of William and Mary. It was determined by the Human Subject's Review Committee that the subjects would be at a minimal risk of psychological anguish as a result of filling out this questionnaire. Confidentiality was also addressed by this committee, suggesting that Planned Parenthood had the proper qualifications and training to assure complete confidentiality of the participants at the test sites. Special letters of consent for women under 21 were not needed as long as the participants were taking the survey under the direction and environment of the Planned Parenthood sites. No methodological procedures in this research required concealment or deception.

CHAPTER IV

RESULTS

The results of this research are arranged into several sections. The first section will report on demographic data, providing a description of the sample and comparing and contrasting the sample against demographic information of clients provided by Planned Parenthood of Hampton Roads. The second section will identify the participants' knowledge about HIV, primarily with regards to transmission and infection. Section three will investigate the attitudes projected in women's appraisal of the need to inquire about HIV antibody testing, evaluating these beliefs in view of Janis and Mann's Stage One theory of decision-making - assessment of the challenge or situation. Section four will investigate women's selections on Wallston and Wallston's AIDS Locus of Control. Section five will examine the personal responses to questions about HIV infection risk and HIV antibody testing. Finally, section six will answer the research questions specifically posed to subsets of the sample.

Section One

Demographic Data

Since four different Planned Parenthood sites were

used to collect data - Hampton, Virginia Beach, Norfolk and Chesapeake - the questionnaires were color coded to identify each site and to determine the numerical breakdown of participants in each site. HIV knowledgeable volunteers were on site at the four different locations to administer the questionnaires. As indicated previously, one hundred and five participants were involved in the study, but only one hundred and four women completed the questionnaire. One woman failed to complete the survey and was not included in the research analysis. Thirty-nine participants were surveyed in Hampton; fifty women participated in Virginia Beach; eleven women completed the survey in Norfolk and only four women finished the questionnaire in Chesapeake. Once again, provisions were available to assist participants who might have been visually impaired, although no women asked for this assistance.

Frequency tables, contrasting age, racial makeup, marital status, economic status and educational achievement are provided for the sample and the Planned Parenthood clientele.

Age

Table 1 examines the age breakdown for the sample. The sample demonstrated a similarity in age to the 5,627 clients of Planned Parenthood. Although the age range differed by one year (20-24 years for Planned

Parenthood), the 21-25 year old category of the sample showed remarkably similar percentages when compared to the clientele of Planned Parenthood. In fact, all age ranges of the sample demonstrated corresponding percentages when compared to the age ranges of Planned Parenthood.

Table 1
Age Range of Sample

<u>AGE</u>	<u>FREQUENCY</u>	<u>PERCENT</u>	<u>CUM.</u>
<u>FREQUENCY</u>			
12 - 15 YEARS	1	1.0%	1
16 - 20	29	27.9%	30
21 - 25	46	44.2%	76
26 - 30	20	19.2%	96
31 - 35	7	6.7%	103
OVER 50	1	1.0%	104

Comparatively, the 1992 Annual Report filed by the Planned Parenthood services of Southeastern Virginia recorded 5,627 individuals who were seen as patients. The median age of these women is 20-24, similar to the age of the sample, which is 21-25. In fact, comparing all age ranges of the sample to the Planned Parenthood population indicates similarity. The age range percentages specified in the Planned Parenthood report are contained in Table 2.

Table 2
Age Range of Planned Parenthood Clientele

<u>CATEGORY</u>	<u>PERCENTAGES</u>
Age 17 and under	13%
Age 18-19	16%
Age 20-24	44%
Age 25-29	18%
Age 30 and over	9%

Race

Tables 3 and 4 present the racial breakdowns for the sample and Planned Parenthood clientele. The largest number of participants were White and African-American women participated in the survey. Seventy-seven White women (74 %) and twenty-three African American or Black women (22 %) answered the questionnaire. One woman indicated that she was Hispanic and another woman chose the "other" category and classified herself as "mulatto."

Table 3
Racial Breakdown of Sample

<u>RACE</u>	<u>FREQUENCY</u>	<u>PERCENT</u>	<u>CUM. FREQUENCY</u>
African American, Non Hispanic	23	22.5%	23
Asian Caucasian, Non Hispanic	0	0	23
Hispanic	77	75.5	100
Other	1	1.0	101
Unreported race	1	1.0	102
	2	0	104

The racial demographics provided by the 1992 Planned Parenthood Annual report for Hampton Roads also demonstrate a comparable breakdown in percentages. Table 4 illustrates this similarity.

Table 4

Racial Breakdown of Planned Parenthood Clientele

<u>RACE</u>	<u>FREQUENCY</u>	<u>PERCENT</u>	<u>CUM. FREQUENCY</u>
African, American, Non Hispanic	1144	21.7%	1144
Asian/Pacific Islander	110	2.0%	1254
Caucasian, Non Hispanic	3912	74.2%	5166
Hispanic	67	1.2%	5233
Other	34	.6%	5267

Marital Status

Sixty-one women (58.7%) chose the "never married" category. Only twelve women (11.5%) indicated that they were married, suggesting that the vast majority of women (88.5%) in the sample were either unmarried, divorced, separated, widowed, or living with someone. Seventeen women said they had children; eight women had one child, eight women had two children and one woman had three children. Table 5 provides the summary of marital status for the sample.

Table 5
Marital Status of Sample

<u>MARITAL STATUS</u>	<u>FREQUENCY</u>	<u>%</u>	<u>CUM. FREQUENCY</u>
Never Married	61	58.7%	61
Married	12	11.5%	73
Divorced	7	6.7%	80
Separated	2	1.9%	82
Widowed	2	1.9%	84
Living with someone	20	19.2%	104

Education

Thirty-eight (36.9%) women said that they had some college background; thirty-seven (35.9%) indicated that they had completed college. Educationally, the majority of women who participated in this survey either had some college background or were college educated. Although the sample was asked about education, available data from the 1992 Planned Parenthood reports did not provide comparable educational breakdowns. Table 6 supplies the educational demographics of the sample.

Table 6
Educational Breakdown of Sample

<u>EDUCATION</u>	<u>FREQUENCY</u>	<u>%</u>	<u>CUM. FREQUENCY</u>
Unreported	1		1
Middle school	2	1.9%	3
High school	23	22.3%	26
Some college	38	36.9%	64
College	37	35.9%	101
Graduate school	3	2.9%	104

Socioeconomic status

The salary and income levels indicated by the participants of the sample demonstrated that 25 women (24.5%) earned a salary below five thousand dollars. Twenty-four (23.5%) participants said that they earned "below \$10,000", indicating that 49 women (49 %) taking the survey were earning between zero and \$10,000. This compares correspondingly with the Planned Parenthood figures reported in their 1992 report (Planned Parenthood of Southeastern Virginia, Inc. Fee Scale). Twenty-one participants (20.6%) indicated that they earned \$15,000 annually, while eleven reported an annual income range of \$15,000 to \$20,000. Only seven women (6.9 %) reported earning more than \$20,000 annually, while fourteen women (13.7 %) selected the "full time student" category. Table 7 presents the income levels of the sample. Table 8 shows the socioeconomic status of clients of the four Planned Parenthood locations, broken down into income categories for 2,910 patients. Please note that formatting differences exist in salary ranges between Planned Parenthood and the sample. Three categories - "On Medicaid" in the Planned Parenthood population and "Unemployed" and "Full time student" in the sample - can not be compared. However, by comparing percentages in other categories, a contrast is noticeable.

Table 7

Socioeconomic Status of the Sample

<u>INCOME</u>	<u>FREQUENCY</u>	<u>%</u>	<u>CUM. FREQUENCY</u>
Below \$ 5,000	25	24.5%	25
\$ 5,000-\$10,000	24	23.5%	49
\$10,000-\$15,000	21	20.6%	70
\$15,000-\$20,000	11	10.8%	81
Above \$20,000	7	6.9%	88
Unemployed	0	0 %	88
Full time student	14	13.7%	102
Unanswered	2		104

Table 8

Socioeconomic breakdown of Planned Parenthood Clientele

<u>INCOME CATEGORY</u>	<u>REPORTED NUMBERS</u>	<u>%</u>
\$1,000 - \$10,000 SINGLE OR \$1,000 - \$15,000 SHARED EXPENSES	1,364	46.87%
OVER \$10,000 SINGLE OR OVER \$15,000 SHARED EXPENSES	776	26.67%
OVER \$20,000 SINGLE OR OVER \$25,000 SHARED EXPENSES	460	15.81%
ON MEDICAID	310	10.65%

Question 7 in the demographic section asked women to indicate their partner's sexual orientation. Two women left the question unanswered, one women said that her partner's sexual orientation was "unknown", and one hundred and one women choosing heterosexuality as their selection. No existing data from Planned Parenthood regarding sexual orientation was provided.

Finally, question 8 of the survey asked women about the number of children that they had. Eighty seven

women (83.7 %) had no children; eight women had one child and eight women had two children. Only one woman said she had three children. Again, no comparison data was provided by Planned Parenthood.

Section Two

HIV knowledge and transmission

Nine questions were asked about HIV knowledge and transmission. Of the 104 participants who answered these questions, the following itemized breakdown is presented. All participants were aware that "having sex" can transmit HIV. Question two, however, revealed that only 34.6 percent of those surveyed knew that HIV could be spread by breast feeding a newborn. Responses from the sample also indicated that 82.7 percent knew that HIV infection can not be spread from "eating food from plates where a cook is HIV infected".

Only one person did not know that HIV could be transmitted by blood transfusions and that "sharing needles with someone" is a form of transmission. However, 14.4 percent of those surveyed reported that HIV could be transmitted from "using public toilets" and over 22 percent thought that "giving blood to organizations like the Red Cross" was a means of HIV infection. In response to the question concerning medication for those who are HIV infected, 63.5 percent knew there was certain medicines that were helpful to

people who are suffering from HIV. Finally, 65.4 percent recognized that being pregnant can be harmful to HIV infected women. Table 9 illustrates the responses of women with regards to itemized questions on HIV and AIDS.

Table 9
HIV Knowledge and transmission

A PERSON CAN GET HIV/AIDS FROM:

<u>ITEM</u>	<u>FREQ. WITH</u> <u>RT. ANSWER</u>	<u>FREQ. WITH</u> <u>WRONG ANSWER</u>	<u>%</u> <u>RT.</u>	<u>%</u> <u>WRONG</u>
1. Having sex	104	0	100.0%	0.0%
2. A mother's breast milk	36	68	34.6%	65.4%
3. Prepared food where cook is HIV infected	86	18	82.7%	17.3%
4. Getting a blood transfusion	103	1	99.0%	1.0%
5. From using public toilets	89	15	85.6%	14.4%
6. Sharing needles	103	1	99.0%	1.0%
7. Giving blood	81	23	77.9%	22.1%
8. Medication for HIV infected people	66	38	63.5%	36.5%

A PERSON CAN GET HIV/AIDS FROM:

<u>ITEM</u>	<u>FREQ. WITH</u> <u>RT. ANSWER</u>	<u>FREQ. WITH</u> <u>WRONG ANSWER</u>	<u>%</u> <u>RT.</u>	<u>%</u> <u>WRONG</u>
9. Pregnancy harmful to HIV infected women	68	36	65.4%	34.6%

Section Three

Attitudes about HIV and HIV antibody testing

Twenty-seven questions were asked of all participants that dealt with attitudes and statements about HIV and HIV antibody testing. Appendix B, which is provided at the end of the last chapter, provides a detailed account on all of the twenty-seven questions regarding attitudes of women and HIV antibody testing. Many of the questions regarding HIV dealt with individual risk and perception of risk of infection to HIV. Participants were asked to respond to survey questions on their dispositions regarding HIV as it influences them personally. Using a Likert scale to strongly agree, agree, be uncertain, disagree or strongly disagree with statements about HIV and AIDS, individuals were required to respond more introspectively.

Five additional questions were posed to those participants who had children which investigated mother's attitudes and beliefs regarding aspects of HIV

and AIDS that affected their parenting. Some items of this section sought to explore differences in responses and reactions between mothers, and women who are seeking advice on pregnancy. Other responses to this section, however, search for reactions to discrimination towards HIV infected mothers and how mothers generally feel about HIV infection. Only seventeen mothers answered questions in this section and therefore, generalization of the sample is limited. A breakdown of these reactions is provided in Table 10.

Table 10

Mothers responses to HIV and children

<u>RACE</u>	<u>NUMBER</u>	<u>TEST SELECTION</u>
African American/Black	4	3 indicated that they would test. 1 specified she would not test.
Caucasian	11	10 indicated that they would test. 1 specified she would not test.
Hispanic	1	She would test.
Unanswered	1	She would test.

Section Four
Control over HIV

Twelve questions were presented to participants that examined a woman's perspective of control over HIV. Originally translated from German, four statements presented indicated a perspective that women promote an internal locus of control, if answered affirmatively. Conversely, eight questions, demonstrating statements that promote an external locus of control, if answered positively. Hence, if a participant were to answer the four questions on internal locus of control affirmatively (as true), while answering the eight questions on external locus of control negatively (as false), then that individual would have a "perfect" score on the internal locus of control scale. Countering the perfect score on the internal locus of control, if a person selected "false" for the four questions demonstrating internal locus of control and selected "true" for the eight questions demonstrating external locus of control, that individual would have a perfect score on the external locus of control. The following table represents the means, standard deviation, the minimum and maximum scores for both the Internal Locus of Control (ILC) variable and the External Locus of Control (ELC).

Table 11

Locus of Control

<u>VARIABLE</u>	<u>N</u>	<u>MEAN</u>	<u>STD.DEV.</u>	<u>MINIMUM</u>	<u>MAXIMUM</u>
ILC	96	9.52	1.673	5	12
ELC	96	2.48	1.673	0	7

Appendix D illustrates the distribution of ILC and ELC scores. Again, the highest score for an internal locus of control mindset is twelve, based upon adding the four "true" responses to questions corresponding to internal control to those eight "false" responses to questions corresponding to a external control mindset. Conversely, the highest score for an external locus of control is also twelve, using the reverse formula mentioned for the internal locus of control.

Section Five

Risk of HIV exposure and infection

Eight behavioral questions were asked of participants to calculate the risk of HIV exposure and infection. All questions dealt with HIV infection as a result of sexual contact, injection drug use, prostitution or blood transfusion. Questions were also posed that asked if participants had ever taken an HIV antibody test or, if they hadn't, would they be willing to take the test. This question on choosing or declining the HIV test perplexed some participants. Of the one hundred and four women who participated in the

study, only twenty-three (22.1%) women clearly indicated that they had taken the HIV antibody test. Although thirty-five women choose this category originally, twelve of these thirty-five women also marked various conflicting categories. If more than one answer was given and they conflicted, the answers were considered unreliable and, therefore, these women were eliminated. The responses are summarized in Table 12.

Table 12

Participants' behavioral answers

<u>BEHAVIORS</u>	<u>ANSWERED</u>		<u>ANSWERED</u>		<u>ANSWERED</u>	
	<u>YES</u>	<u>%</u>	<u>NO</u>	<u>%</u>	<u>D</u>	<u>K</u>
1. I have shared a needle to inject drugs with someone else.	0	0.0%	104	100.0%	0	0.0
2. My sex partner used a needle to inject drugs.	1	1.0%	95	91.3%	8	7.7%
3. I had sex in order to get money.	2	1.9%	102	98.1%	0	0.0%
4. I had a blood transfusion before 1985.	5	4.8%	97	93.3%	2	1.9%
5. I have tested HIV positive.	0	0.0%	103	99.0%	1	1.0%
6. I have tested HIV negative. UNANSWERED	35 9	38.9%	58	61.1%	0	0.0%
7. I have never taken the HIV test, but would. UNANSWERED	58 19	68.2%	26	30.6%	1	1.2%

<u>BEHAVIORS</u>	<u>ANSWERED</u>	<u>%</u>	<u>ANSWERED</u>	<u>%</u>	<u>ANSWERED %</u>	
	<u>YES</u>		<u>NO</u>		<u>D</u>	<u>K</u>
8. I have never taken the HIV test, and won't.	12	14.1%	71	83.5%	1	1.0%
UNANSWERED	20					

Section Six

Research Questions

Question 1: How many women indicate that they would choose to take the HIV antibody test, and how many women decline it? Even though one hundred and four women participated in the study, only ninety-six were clear of their intentions of whether or not they would or would not take an HIV antibody test. The results are tallied in the Table 13:

Table 13

Choice of HIV antibody testing

<u>CHOICE</u>	<u>FREQUENCY</u>	<u>PERCENT</u>	<u>CUMULATIVE FREQUENCY</u>	<u>CUMULATIVE PERCENT</u>
WOULD TEST	84	87.5%	84	87.5%
WON'T TEST	12	12.5%	96	100.0%

Question 2: What are the factors that influence decision making in choosing to take or to decline the HIV antibody test?

A stepwise discriminant analysis looked for significance using the two class variables of choosing,

the participants' decision on choosing or declining an HIV antibody test, measured against the three variables of behavior, knowledge and locus of control. These variables of behavior, knowledge and locus of control were shown to have no significance in decision making process when the stepwise discriminant analysis was performed. The following table gives the statistics for this stepwise discriminant analysis.

Table 14
Discriminant Analysis for Decision Making

The method(s) for selecting variables was:
stepwise.

Significance level to enter = 0.1500
Significance level to stay = 0.1500

Class level information:

Choice 1 = Women who chose to take the HIV antibody test

Choice 2 = Women who decline taking the HIV antibody test

CH	FREQUENCY	PROPORTION
1	84	0.875
2	12	0.125

Stepwise selection: Step 1
Statistics for entry, DF = 1, 94

Variables included in this stepwise selection were:
Behavior (BR), Knowledge (KR), and Locus of Control (LOC).

Variable	R**2	F	PROB > F	Tolerance
BR	0.0046	0.431	0.5133	1.0000
KR	0.0159	1.520	0.2207	1.0000
LOC	0.0027	0.255	0.6146	1.0000

No further steps could be taken with the statistical analysis, using the stepwise discriminant analysis.

Therefore, no significance was noted.

Question 3: Do women who engage in high risk behavior also tend to be less willing to be HIV antibody tested? Only twelve women indicated that they would decline HIV antibody testing. This small number significantly influences statistical analyses regarding decision-making. Of these twelve women, a frequency distribution was done to see if these women had engaged in any unsafe behavior that would have put them at a higher risk of HIV infection. The first question asked regarding "risky" behavior sought information as to whether or not any participants had shared a intravenous needle to inject drugs with a friend or partner. All participants answered this question "no". The second question asked if the participant's sex partner had used a needle to inject drugs. Only one woman indicated that her partner had used a needle to inject drugs. However, eight women did not know if their partner had used intravenous needles to inject drugs. Of these nine women, only two of them indicated that they would not take the test.

Information sought from the fourth question that was posed to participants asked if they would abort their fetuses if they were HIV infected. Ninety-six women answered this question. Another frequency table was created which indicated that a significant number of women would choose to abort if they were HIV infected. Twenty-one (21.9%) women strongly agreed to aborting

their fetus, while seventeen (17.7%) agreed. However, forty-three (44.8%) women were uncertain; seven (7.3%) disagreed and eight (8.3%) strongly disagreed with having an abortion due to HIV infection.

The fifth question dealt with whether single mothers demonstrated a greater or lesser desire than married women to be HIV antibody tested. Only seventeen participants qualified to answer this question. The marital status of these women were (1) never married, (2) divorced, (3) separated, (4) widowed and (5) living with someone. Of these seventeen single mothers, fifteen indicated that they had either taken the HIV antibody test or were willing to be tested. Only two specified that they would decline taking the test. Responses to the questions posed to mothers in the questionnaire are shown in Appendix C.

Finally, question six dealt with whether women who had an internal locus of control tended to be more willing to be HIV antibody tested than women who had an external locus of control. As a part of the questionnaire, a German to English translated Multidimensional AIDS Locus of Control was given to the participants. This twelve item section investigated whether women demonstrated an internal or external locus of control with regards to the HIV infection. Appendix D provides detailed information on the answers to these twelve questions. Again, a general linear models procedure was used to determine the correlational

findings. Table 15 provides the results of this procedure. The table demonstrates that women in this study had a greater degree of internal control when answering questions regarding HIV and HIV infection

Table 15

Internal vs. External Locus of Control
and HIV antibody test choice

General Linear Models Procedure

Dependent Variable: Internal Locus of Control (ILC)

<u>SOURCE</u>	<u>DF</u>	<u>SUM OF SQUARES</u>	<u>MEAN SQUARE</u>	<u>F VALUE</u>	<u>PR>F</u>	<u>R-SQ.</u>
<u>C.V.</u>						

Model	1	0.00384093	0.00384093	0.04	0.8460	.0003 23.95
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Error	102	10.33476751	0.10132125		ROOT MSE	ILC
MEAN						
Corrected						
Total	103	10.33860844			0.3183099	
1.32932692						

SOURCE

CH	DF	TYPE 1 SS	F VALUE	PR > F	DF	TYPE 111 SS
(CHOICE)	1	0.00384093	0.04	0.8460	1	0.00384093

F VALUE	PR > F
0.04	0.8460

General Linear Models Procedure

Dependent Variable: External Locus of Control (ELC)

<u>SOURCE</u>	<u>DF</u>	<u>SUM OF SQUARES</u>	<u>MEAN SQUARE</u>	<u>F VALUE</u>	<u>PR>F</u>	<u>R-SQ.</u>
<u>C.V.</u>						

Model	1	0.00673497	0.00673497	0.22	0.6400	.00215
9.47						

Error	102	3.12111585	0.03059917		ROOT MSE	ELC
MEAN						
Corrected						
Total	103	3.12785082			0.17492620	
1.84684066						

FSOURCE

CH	DF	TYPE 1 SS	F VALUE	PR > F	DF	TYPE 111 SS
(CHOICE)	1	0.00673497	0.22	0.6400	1	0.00673497

F VALUE	PR > F
0.22	0.6400

CHAPTER V

Summary, Conclusions, and Recommendations

This chapter is arranged into three primary sections. A summary will be presented first. Next, ramifications of the findings based on the data analysis are specified and, finally, the last section will consist of a discussion of the study's results and will include recommendations for further research.

Summary

The purpose of this study was to investigate perceived psychosocial and psychological factors and stringencies of women seeking pregnancy counseling as to the decision making process for HIV antibody testing. These elements, seen as possible impediments to HIV antibody testing by homosexual men and injection drug users, consisted of loss of employment, loss of insurance, loss of friends and/or familial support, inaccuracy of test results, and the hopelessness and despair of finding out an HIV positive test result. However, added variables to the decision making process on HIV antibody testing for these women included abortion issues, single parenthood and the care and apprehension of raising existing children. The element of sexuality of this sample, specifically promiscuity,

was not addressed. The researcher assumed that if women were seeking pregnancy counseling, sexual activity may have already occurred to varying degrees and HIV infection, therefore, may be a factor. Due to the low number of women who indicated that they would decline taking an HIV antibody test, the outcome of this research was inconclusive. Only 12 women clearly indicated that they would not take the HIV antibody test out of the 104 participants sampled. From the reactions of the declining women to questions presented in the survey, no definitive decision making processes could be concluded. Of the 84 women who indicated that they would take the HIV antibody test, there was significant evidence that these women wanted to know the test results in order to protect their sexual partner. Of all the 104 participants, 92.3 percent of the sample strongly agreed or agreed that protecting their partner was influential on their decision to be HIV antibody tested. Seventy-nine percent of participants agreed or strongly agreed to be HIV antibody tested in order to get early medical treatment. Seventy-four percent of the sample wanted to know their HIV status in case they needed to change their sexual habits.

Regarding responses to HIV antibody testing that corresponded to those given by other populations, little correlation or comparison existed. The stigmatization associated with HIV antibody testing, as reported by Coates and McKusick (1990) was not strongly indicated.

Twenty-five percent of participants thought others might conclude they were gay or used drugs if they were HIV positive. Other factors suggested by Coates and McKusick (1990) were the lack of confidentiality and the anonymity of the HIV antibody test, which was also reported to have inhibitive aspects regarding HIV antibody testing in other populations, were absent in this sample. HIV antibody test accuracy was also ruled out by the sample as a constraint to testing. None of 104 participants who completed the survey agreed or strongly agreed to the statement stating that the HIV antibody test was inaccurate. Over 88 percent of women surveyed agreed or strongly agreed that they would take the HIV antibody test to make sure that any health problems were not as a result of HIV infection. Eighty-six participants disagreed or strongly disagreed that they had enough problems in their life and that this factor would prevent them from being HIV antibody tested. Psychologically, 88.5 percent of participants surveyed suggested that they would take the test to assuage anxiety.

Although the participants were aware of the insurance and employment discrimination associated with HIV and AIDS, there was little relationship between these recognitions and the unwillingness to test. Questions emerged from this study, however, that relate to the sample's willingness to take the HIV antibody test as opposed to actually taking the test. Data from

the sample indicated that a large majority of women would take the HIV antibody test, but only about twenty-two percent clearly indicated that they had actually taken it. This percentage of women, a discounted, adjusted percentage which accounted for conflicting answers on the survey, coincides with the national norms for HIV antibody testing supplied by the United States Government Accounting Office (GAO/HRD - 91-52 AIDS Prevention Programs, 1990). These government figures demonstrated that about twenty percent of higher risk individuals actually take the HIV antibody test. When comparing the sample with the Planned Parenthood figures, a review of the HIV antibody testing numbers provided by Planned Parenthood sites in the Hampton Roads area (Affiliate Annual Service Census - C17-92 report), indicated that none of the five thousand plus continuing or new clients were HIV tested in 1992. However, it is unclear from the report how HIV antibody testing procedures are procured and whether or not testing is offered as a routine procedure.

The questioning of the sample as to whether or not the answers to HIV antibody testing are real ruminates back to the decision making model presented by Janis and Mann. An overview of Janis and Mann's Stage Three and Stage Four Theory of the decision making processes may offer some explanations to the questions of choosing the best selection and then committing to it. Stage Three suggests that if more options or variables are working

in the process of decision making, the less likely an individual is willing to commit. Stage Four recognizes that "postdecision bolstering (or commitment) is likely to be most pronounced when the alternatives had been initially close in value during Stage Three making it difficult to arrive at the decision" (Greenwald, Brock, and Strom, 1968, p.331).

Another possible confounding variable of this survey is the "Halo effect", whereby the sample is conscious of the socially "right" decision and scores their surveys accordingly. Further research to eliminate this effect might be offered by the use of focus groups. The possible use of a longitudinal study to examine whether women in this sample actually implement HIV antibody testing would also be beneficial in determining whether women commit to Stage Four and Stage Five of the Janis and Mann's decision making process.

Finally, questions regarding women's perceived low risk of HIV exposure based on existing data regarding heterosexual transmission may be another factor in decision making. Although the facts stipulate that the heterosexual transmission for HIV infection is raising precipitously, the HIV infection rate of overall cases is still only 9 percent (New York Times News Service, 1994). However, this is a dramatic raise from 1985, when the heterosexual transmission rate was only 1.9 percent.

Conclusions

The following conclusions have been drawn from this research:

1. The sample for this research consisted primarily of young white, high school or college educated, lower SES women. Therefore, caution should be exercised in generalizing the findings of this study to the entire female population or to the entire pregnant population.

2. The women in this study have an adequate knowledge base of HIV and HIV infection, with the exception of knowing that transmission of HIV can be rendered through breast feeding.

3. Although the study failed to provide significant evidence that women fear personal discrimination as a deterrent to getting an HIV antibody test, a significant number of women indicated their awareness of HIV and AIDS discrimination in general.

4. Most women in the sample think that the HIV antibody test is accurate.

5. Most participants are uncertain about keeping their fetus or would abort their fetus if they were HIV infected.

6. A majority of participants who had children would be afraid of infecting their child or children if they were HIV infected and would have difficulty coping

7. The majority of participants demonstrated an

internal locus of control with regards to questions regarding HIV and HIV infection.

Recommendations for future study

As the article by Stuntzner-Gibson (1991) implied, women may indeed be more in denial about HIV infection than men. Although most women in the study chose to be tested for HIV antibodies, the study is inconclusive about the perceived risk that women have about HIV infection and how it is passed along to infants. Currently, women are still the fastest growing HIV population (HIV Education Case Studies, 1990; Stuntzner-Gibson, 1991; Gath, 1992; New York Times News Service, 1994). In fact, the number of AIDS cases in women, as reported by the Center for Disease Control and Prevention (CDC), has risen 151 percent from 1992 to 1993 (New York Times News Service, 1994). In spite of intensive research done in the medical profession relating to HIV treatment and prevention, minimal investigation has been produced regarding the psychological and psychosocial aspects of women who face increasing odds of HIV infection. One of the latest medical discoveries indicates that pregnant women taking the anti-viral HIV drug Azidothymidine (AZT) shows a marked decrease in the transmission rate of HIV from mother to infant (Cowley, 1994). When the questionnaire was given to the sample at Planned Parenthood, this new

medical notice was not known. The ramifications of this new information now indicate the possibility of mandatory testing of pregnant women for HIV. Hence, the reactions of another sample could demonstrate differences in the outlook of women towards HIV antibody-testing. One of the observable outcomes of this study was the fact that so many women said that they would test, while only a few declined. However, women who have already chosen to be HIV antibody tested was also minimal. One supposition that women might feel is that they are at minimal risk of exposure and infection to HIV and taking the HIV antibody test

The sample in this research is primarily a white, low income earning, college or high school educated representation of the pregnant population. Hence, external validity is questionable and generalization to a larger segment of pregnant women is inadvisable. Also discernible in this study was the large number of unmarried women who participated. A study investigating married women who are pregnant or exploring the possibility of pregnancy may give added dimensions to the process of decision making regarding HIV antibody testing. The nature of the questions in the survey developed for this study may have also played a significant role in the responses of women in this area. Respondents to surveys which focus on sexuality and related topics tend to yield distorted views of reality (Hyde, 1986). When questioned about the most effective

methods of getting clients to answer questions candidly and factually, Planned Parenthood staff stressed that using focus groups as opposed to using surveys or questionnaires had proven most successful to them in past studies dealing with HIV. Research that AIDS and HIV discrimination is still evident and frequently observed in the homosexual population. Therefore, this study finds an initial psychological and psychosocial reaction of women seeking advice on pregnancy to this phenomenon as it applies to HIV antibody testing. Further studies utilizing a more diverse, larger sample in other agencies or institutions would allow for greater research validity. AIDS and/or HIV infection, as a dynamic disease, is constantly evolving and continually challenging our basis of knowledge as well as our ability to cope. Research investigations, adopting a more elaborate system of the Health Beliefs Model, could identify additional problem areas of perceived risk and susceptibility in other populations. These factors are seen as expanding on a yearly basis, in conjunction with the transforming demographics of the epidemic. The figures of this disease remain startling. The number of new cases of women reported infected with HIV in the United States jumped 151 percent from 1992 to 1993 (New York Times News Service, 1994). Heterosexual transmission in the United States, accounting for a relatively small number of cases in the overall count, rose 130 percent from 1992 to 1993 (New York Times News

Service, 1994).

As previously suggested, the sample in this study indicated that they would take the HIV antibody test for a plethora of reasons. However, only a few had actually taken the test. As research into the disease continues to divulge new methodologies for using established drugs, such as the revelation that AZT significantly cuts the risk of HIV transmission from mother to fetus (Cowley, 1994), questions arise that deal with new psychological consequences and conflicts for the female population. Would this new information compel pregnant females to submit to HIV antibody testing, as suggested by a Canadian newspaper? (Staff at Associated Press Online, 1994).

Intimacy levels, researched by Conner (1988), suggest that gay men transformed their behavior to adapt to the perceived risk of HIV. If the perceived risk and susceptibility levels are on the rise in the heterosexual population, new investigations into these areas would be helpful in researching changes in sexual practices in the heterosexual population. In conclusion, educational programs dealing with the risks of HIV infection and the perceived risks to heterosexual and female populations needs to be emphasized.

Appendix A

Appendix A
Cover letter

Dear Planned Parenthood Client,

Thank you for your interest and participation in this study regarding HIV testing and pregnancy. This study is research that is being done at the College of William and Mary by a doctoral candidate. All participant responses will be held in the strictest of confidence and your participation will be anonymous. The purpose of this study is to investigate counseling to HIV antibody testing.

Before you begin this questionnaire, please make sure that any paperwork regarding your visit to Planned Parenthood is completed. Also, any questions you may have concerning this survey should be directed to the person who is giving you the test, not the personnel at Planned Parenthood. There is a section on the last sheet of the questionnaire for any comments you may have regarding this survey. Your participation is completely voluntary and you may stop at anytime. However, the ten dollars in cash will only be given to those individuals who complete the entire test. If your are interested in the results of this survey, please sign your name and address on the paper provided at the table where you picked up this questionnaire. After the data analysis

has been completed, the results will be sent to you.

Again, thank you for your participation. Once you finish the test completely, please give it back to the person who gave it to you. She will inspect the test to make sure that it is completed, and then give you the monetary incentive for participation.

Appendix B

Appendix B

ATTITUDES ABOUT HIV

CODE: STRONGLY AGREE = SA AGREE = A UNCERTAIN = U
 DISAGREE = D STRONGLY DISAGREE = SD

<u>QUESTIONS</u>	<u>FREQUENCY</u>		<u>PERCENT</u>	<u>CUM. PERCENT</u>
1. Friends and/or family told me that I should take the HIV antibody test.	SA	16	15.4%	15.4%
	A	35	33.7	49.0
	U	16	15.4	64.4
	D	26	25.0	89.4
	SD	11	10.6	100.0
	UNANSWERED	0		
2. I know someone who is HIV infected.	SA	14	13.6%	13.6%
	A	18	17.5	31.1
	U	18	17.5	48.5
	D	30	29.1	77.7
	SD	23	22.3	100.0
	UNANSWERED	1		
3. I have seen or heard about AIDS and HIV protection in the newspaper, on the radio, and on TV.	SA	79	76.0%	76.0%
	A	24	23.1	99.0
	U	0	0.0	99.0
	D	0	0.0	99.0
	SD	1	1.0	100.0
	UNANSWERED	0		
4. I want to know my HIV results in case I need to change sexual habits.	SA	53	51.0%	51.0%
	A	24	23.1	74.0
	U	11	10.6	84.6
	D	11	10.6	95.2
	SD	5	4.8	100.0
	UNANSWERED	0		
5. I couldn't take the stress of being HIV infected and won't take the test.	SA	1	1.0%	1.0%
	A	4	3.9	4.9
	U	25	24.3	29.1
	D	26	25.2	54.4
	SD	47	45.6	100.0
	UNANSWERED	1		
6. A positive test result would create employment problems.	SA	19	18.3%	18.3%
	A	31	29.8	48.1
	U	27	26.0	74.0
	D	16	15.4	89.4
	SD	11	10.6	100.0
	UNANSWERED	0		

**CODE: STRONGLY AGREE = SA AGREE = A UNCERTAIN = U
 DISAGREE = D STRONGLY DISAGREE = SD**

<u>QUESTIONS</u>	<u>FREQUENCY</u>	<u>%</u>	<u>CUM.%</u>
7. A positive test result would mean rejection from my friends and family.	SA	7	6.8%
	A	19	18.4
	U	31	30.1
	D	24	23.3
	SD	22	21.4
	UNANSWERED	1	
			6.8%
8. I would take an HIV test so that I could get medicine for early treatment.	SA	48	46.2%
	A	35	33.7
	U	17	16.3
	D	3	2.9
	SD	1	1.0
	UNANSWERED	0	
			46.2%
9. A positive HIV test result would cause health insurance problems.	SA	37	35.6%
	A	32	30.8
	U	24	23.1
	D	6	5.8
	SD	5	4.8
	UNANSWERED	0	
			35.6%
10. A positive HIV test result would cause disability insurance problems.	SA	25	24.5%
	A	23	22.5
	U	45	44.1
	D	4	3.9
	SD	5	4.9
	UNANSWERED	2	
			24.5%
11. I would be HIV tested to make sure that any health problem I might have is not a result of HIV infection.	SA	40	38.5%
	A	52	50.0
	U	11	10.6
	D	1	1.0
	SD	0	0
	UNANSWERED	0	
			38.5%
12. I have enough problems in my life and don't want to be HIV tested.	SA	1	1.0%
	A	3	2.9
	U	14	13.5
	D	45	43.3
	SD	41	39.4
	UNANSWERED	0	
			1.0%

CODE: **STRONGLY AGREE = SA** **AGREE = A** **UNCERTAIN = U**
 DISAGREE = D **STRONGLY DISAGREE = SD**

QUESTIONS		FREQUENCY	%	CUM.%
13. I need to know that I'm not HIV infected so I won't have to worry.	SA	40	38.5%	38.5%
	A	52	50.0	88.5
	U	11	10.6	99.0
	D	1	1.0	100.0
	SD	0		100.0
	UNANSWERED		0	
14. I wouldn't want to make changes in what I do sexually and won't test.	SA	0	0.0%	0.0%
	A	3	2.9	2.9
	U	8	7.8	10.7
	D	40	38.8	49.5
	SD	52	50.5	100.0
	UNANSWERED		1	
15. I need to know if I'm HIV infected so I won't infect my sexual partner.	SA	57	54.8%	54.8%
	A	39	37.5	92.3
	U	4	3.8	96.2
	D	2	1.9	98.1
	SD	2	1.9	100.0
	UNANSWERED		0	
16. The HIV test is not accurate and, therefore, I will not test.	SA	0	0.0%	0.0%
	A	0	0.0	0.0
	U	9	8.7	8.7
	D	35	33.7	42.3
	SD	60	57.7	100.0
	UNANSWERED		0	
17. My strong religious beliefs have protected me from HIV infection.	SA	2	1.9%	1.9%
	A	1	1.0	2.9
	U	4	3.9	6.8
	D	35	34.0	40.8
	SD	61	59.2	100.0
	UNANSWERED		1	
18. I am bothered by what others may think about me if I were HIV infected.	SA	16	15.4%	15.4%
	A	41	39.4	54.8
	U	21	20.2	75.0
	D	15	14.4	89.4
	SD	11	10.6	100.0
	UNANSWERED		0	

CODE: STRONGLY AGREE = SA AGREE = A UNCERTAIN = U
 DISAGREE = D STRONGLY DISAGREE = SD

<u>QUESTIONS</u>		<u>FREQUENCY</u>	<u>%</u>	<u>CUM.%</u>
19. Even if I were infected, my health is so good that I would not get sick.	SA	0	0.0%	0.0%
	A	0	0.0	0.0
	U	9	8.7	8.7
	D	42	40.4	49.0
	SD	53	51.0	100.0
	UNANSWERED	0		
20.. Since I may be forced to tell sexual partners that I was HIV infected, I won't be tested.	SA	0	0.0%	0.0%
	A	0	0.0	0.0
	U	8	7.7	7.7
	D	40	38.5	46.2
	SD	56	53.8	100.0
	UNANSWERED	0		
21. I would be suicidal if I were HIV positive and won't test.	SA	4	3.9%	3.9%
	A	4	3.9	7.8
	U	12	11.6	9.4
	D	41	39.8	59.2
	SD	42	40.8	100.0
	UNANSWERED	1		
22. I don't trust any authorities to keep my HIV test results confidential.	SA	5	4.9%	4.9%
	A	10	9.7	14.6
	U	21	20.4	35.0
	D	40	38.8	73.8
	SD	27	26.2	100.0
	UNANSWERED	1		
23. If I'm HIV infected, people would think I'm gay or use drugs.	SA	4	3.8%	3.8%
	A	22	21.2	25.0
	U	19	18.3	43.3
	D	37	35.6	71.6
	SD	22	21.2	100.0
	UNANSWERED	0		
24. I would have little or no support if I tested HIV positive.	SA	1	1.0%	1.0%
	A	9	8.8	9.8
	U	27	26.5	36.3
	D	36	35.3	71.6
	SD	29	28.4	100.0
	UNANSWERED	2		

CODE: **STRONGLY AGREE = SA** **AGREE = A** **UNCERTAIN = U**
 DISAGREE = D **STRONGLY DISAGREE = SD**

<u>QUESTIONS</u>		<u>FREQUENCY</u>	<u>%</u>	<u>CUM.%</u>
25. If I were pregnant, I would have my child even if I were HIV positive.	SA	5	4.8%	4.8%
	A	9	8.7	13.5
	U	39	37.5	51.0
	D	17	16.3	67.3
	SD	34	32.7	100.0
	UNANSWERED	0		
26. If I am pregnant, I would want to be HIV tested to make sure I was healthy.	SA	49	47.6%	47.6%
	A	49	47.6	95.1
	U	5	4.9	100.0
	D	0	0.0	100.0
	SD	0	0.0	100.0
	UNANSWERED	1		
27. If I were HIV infected, I would have an abortion, if I were pregnant.	SA	25	24.0%	24.0%
	A	18	17.3	41.3
	U	45	43.3	84.6
	D	7	6.7	91.3
	SD	9	8.7	100.0
	UNANSWERED	0		

Appendix C

Appendix C

MOTHER'S ATTITUDES ABOUT HIV

CODE: STRONGLY AGREE = SA AGREE = A UNCERTAIN = U
DISAGREE = D STRONGLY DISAGREE = SD

<u>QUESTIONS</u>		<u>FREQUENCY</u>		<u>PERCENT</u>
<u>CUM. PERCENT</u>				
28. I am afraid my	SA	1	5.9%	24.0%
child(ren) would be	A	4	23.5	41.3
taken from me if I	U	3	17.6	84.6
tested HIV positive.	D	7	41.2	91.3
	SD	2	11.8	100.0
	UNANSWERED	87		
29. I am afraid of	SA	2	11.8%	11.8%
infecting my	A	10	58.8	70.6
child(ren) if I'm	U	1	5.9	76.6
HIV infected.	D	4	23.5	100.0
	SD	0	0.0	100.0
	UNANSWERED	87		
30. I couldn't cope	SA	5	29.4%	29.4%
knowing I'm HIV	A	9	52.9	82.4
infected and possibly	U	0	0.0	82.4
not see my child(ren)	D	3	17.6	100.0
grow up.	SD	0	0.0	100.0
	UNANSWERED	87		
31. There is no one to	SA	1	5.9%	5.9%
support my child(ren)	A	1	5.9	11.8
and they'd have to	U	2	11.8	23.5
be raised in foster	D	6	35.3	58.8
homes.	SD	7	41.2	100.0
	UNANSWERED	87		
32. If I were HIV	SA	3	17.6%	17.6%
infected, I would	A	10	58.8	76.5
also want to test	U	3	17.6	94.1
my child(ren).	D	1	5.9	100.0
	SD	0	0.0	100.0
	UNANSWERED	87		

Appendix D

Appendix D
Locus of Control

<u>INTERNAL LOCUS OF CONTROL QUESTIONS</u>	<u>ANSWERED TRUE</u>	<u>%</u>	<u>ANSWERED FALSE</u>	<u>%</u>
1. If I get infected with HIV, I am to blame.	65	62.5%	39	37.5%
2. Whether I get HIV or not is determined by how I behave.	81	80.2%	20	19.8%
	UNANSWERED 3			
3. Whether I can be protected from HIV depends entirely on me.	83	79.8%	20	19.2%
	UNANSWERED 1			
4. If I get infected with AIDS, it's because I haven't taken good enough care of myself.	47	45.2%	57	54.8%
<u>EXTERNAL LOCUS OF CONTROL QUESTIONS</u>	<u>ANSWERED TRUE</u>	<u>%</u>	<u>ANSWERED FALSE</u>	<u>%</u>
1. It's only a question of time until I get infected with HIV.	3	3.0%	98	97.0%
2. If HIV infected people act irresponsibly, I can't protect myself from AIDS.	22	21.2%	82	78.8%
3. For me, getting HIV in the future will depend on how quickly scientists find a cure.	14	13.6%	89	86.4%
	UNANSWERED 1			

<u>EXTERNAL LOCUS OF CONTROL QUESTIONS</u>	<u>ANSWERED TRUE</u>	<u>%</u>	<u>ANSWERED FALSE</u>	<u>%</u>
4. If I get infected with HIV, then it is entirely by fate.	27	26.0%	77	74.0%
5. Fate will determine if I become HIV infected.	11	10.6%	93	89.4%
6. If the government won't act more quickly, I can't be protected against HIV.	9	8.7%	95	91.3%
7. Whether I get infected with HIV is determined by my sexual partner.	27	26.0%	77	74.0%
8. Whether I can be protected from AIDS is mainly a matter of luck.	5	4.9%	98	95.1%
UNANSWERED	1			

<u>INTERNAL LOCUS OF CONTROL TENDENCIES</u>	<u>FREQ.</u>	<u>%</u>	<u>CUM. FREQ.</u>	<u>CUM. %</u>
5	2	1.9%	2	1.9%
6	4	3.8%	6	5.8%
7	9	8.7%	15	14.4%
8	16	15.4%	31	29.8%
9	19	18.3%	50	48.1%
10	19	18.3%	69	66.3%
11	25	24.0%	94	90.4%
12	10	9.6%	104	100.0%

<u>EXTERNAL LOCUS OF CONTROL TENDENCIES</u>	<u>FREQ.</u>	<u>%</u>	<u>CUM. FREQ.</u>	<u>CUM. %</u>
0	11	10.6%	11	10.6%
1	27	26.0%	38	36.5%
2	19	18.3%	57	54.8%
3	18	17.3%	75	72.1%
4	17	16.3%	92	88.5%
5	8	7.7%	100	96.2%
6	3	2.9%	103	99.0%
7	1	1.0%	104	100.0%

Appendix E

APPENDIX E
U.S. DEPT. OF HEALTH AND HUMAN RESOURCES
QUESTIONNAIRE

Section Q – AIDS KNOWLEDGE AND ATTITUDES – Continued

12. Have you ever given or donated blood?	<input type="checkbox"/> Yes (13) <input type="checkbox"/> No } (15) <input type="checkbox"/> DK }	54
13. Have you donated blood – a. since March 1985?	<input type="checkbox"/> Yes (13b) <input type="checkbox"/> No } (15) <input type="checkbox"/> DK }	55
b. in the past 12 months?	<input type="checkbox"/> Yes (14) <input type="checkbox"/> No } (15) <input type="checkbox"/> DK }	56
14. How many times IN THE PAST 12 MONTHS have you donated blood?	00 <input type="checkbox"/> None in past 12 months _____ Times (Number) 97 <input type="checkbox"/> Refused 99 <input type="checkbox"/> DK	57-
The next questions are about the blood test for the AIDS virus infection. No question will ask what the results are of any tests you may have had.		
15. To the best of your knowledge, are blood donations routinely tested for the AIDS virus infection?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> DK	59
ITEM Q1	Refer to question 13a.	60
16. Was one of your reasons for donating blood because you wanted to be tested for the AIDS virus infection?	<input type="checkbox"/> Yes <input type="checkbox"/> No	6
17a. (Except for blood donations since March 1985), Have you had your blood tested for the AIDS virus infection?	<input type="checkbox"/> Yes (18) <input type="checkbox"/> No (17b) <input type="checkbox"/> DK (31)	6
b. Why haven't you been tested? Mark each that applies.	<input type="checkbox"/> Don't consider myself at risk of AIDS <input type="checkbox"/> Don't believe anything can be done if I am positive <input type="checkbox"/> Don't like needles <input type="checkbox"/> Afraid of losing job, insurance, housing, friends, family if people knew I was positive for AIDS infection <input type="checkbox"/> Don't trust medical clinics/hospitals to keep test results confidential <input type="checkbox"/> Already know whether I have the AIDS virus infection <input type="checkbox"/> Don't know where to go for a test <input type="checkbox"/> Other – Specify _____ _____ _____ <input type="checkbox"/> DK why	6 6 6 6 (31) 6 6 7 7
18. How many times have you had your blood tested for the AIDS virus infection, NOT including blood donations?	_____ Times (Number) 99 <input type="checkbox"/> DK	72
19. How many times IN THE PAST 12 MONTHS have you had your blood tested for the AIDS virus infection, NOT including blood donations?	00 <input type="checkbox"/> None in past 12 months _____ Times (Number) 99 <input type="checkbox"/> DK	74
ITEM Q2	Refer to question 18.	<input type="checkbox"/> "1 time" (21) <input type="checkbox"/> Other (20)

Section Q – AIDS KNOWLEDGE AND ATTITUDES – Continued

3-4

Did you have any of the AIDS blood tests –

Read list. Mark each that applies.

- 01 For hospitalization or a surgical procedure? 5-8
- 02 To apply for health insurance? 7-8
- 03 To apply for life insurance? 9-10
- 04 For employment? 11-12
- 05 To apply for a marriage license? 13-14
- 06 For military induction or military service? 15-16
- 07 For immigration? 17-18
- 08 Just to find out if you were infected? 19-20
- 09 Because of referral by the doctor? 21-22
- 10 Because of referral by the Health Department? 23-24
- 11 Referred by your sex partner? 25-26
- 12 Because it was part of the blood donation process? 27-28
- 13 For some other reason? Specify ↴ 29-30
- _____
- 97 Refused 31-32
- 99 DK 33-34

35-38

When was your (last) blood test for the AIDS virus infection NOT including a blood donation?

____ / 19 ____
 Month Year

9999 DK

Did you have your (last) AIDS blood test –

Read list. Mark each that applies.

- 01 For hospitalization or a surgical procedure? 39-40
- 02 To apply for health insurance? 41-42
- 03 To apply for life insurance? 43-44
- 04 For employment? 45-46
- 05 To apply for a marriage license? 47-48
- 06 For military induction or military service? 49-50
- 07 For immigration? 51-52
- 08 Just to find out if you were infected? 53-54
- 09 Because of referral by the doctor? 55-56
- 10 Because of referral by the Health Department? 57-58
- 11 Referred by your sex partner? 59-60
- 12 Because it was part of the blood donation process? 61-62
- 13 For some other reason? Specify ↴ 63-64
- _____
- 97 Refused 65-66
- 99 DK 67-68

69-70

i. (Not including a blood donation) Where did you have your (last) blood test for the AIDS virus?

Mark only one.

- 01 AIDS clinic/counseling/testing site
- 02 Community health clinic
- 03 Clinic run by employer
- 04 Doctor/HMO
- 05 Hospital/emergency room/outpatient clinic
- 06 STD clinic
- 07 Family planning clinic
- 08 Prenatal clinic
- 09 Tuberculosis clinic
- 10 Public clinic
- 11 Other clinic
- 12 Drug treatment facility
- 13 Military induction or military service site
- 14 Immigration site
- 99 Other location – Specify ↴
- _____
- 99 DK

Section Q – AIDS KNOWLEDGE AND ATTITUDES – Continued

<p>The next questions concern COUNSELING about the AIDS virus infection, that is, discussing transmission, prevention or treatment of AIDS virus infection.</p>																																					
<p>24. Did you receive any counseling AT THE TIME of your (last) blood test for the AIDS virus infection?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK</p>																																				
<p>25. Did you get the results of your (last) blood test?</p>	<p>1 <input type="checkbox"/> Yes (27) 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK</p>																																				
<p>26. Was this because you decided you didn't want the results or was it because you were unable to GET the results? <i>Mark only one.</i></p>	<p>1 <input type="checkbox"/> Didn't want results 2 <input type="checkbox"/> Unable to get results 3 <input type="checkbox"/> Both 9 <input type="checkbox"/> Other – Specify _____ 9 <input type="checkbox"/> DK</p> <p align="right">} (31)</p>																																				
<p>27. Did you also receive any counseling about the AIDS virus when you received the results of your (last) test?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK</p>																																				
<p>28. Were the results given in person, by telephone, by mail or in some other way? <i>Mark only one.</i></p>	<p>1 <input type="checkbox"/> In person 2 <input type="checkbox"/> By telephone 3 <input type="checkbox"/> By mail 9 <input type="checkbox"/> In some other way</p>																																				
<p>29. Do you believe the results of your (last) test were accurate?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK</p>																																				
<p>30. Do you feel that the confidentiality of the results of your (last) test for the AIDS virus infection was handled properly?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK</p>																																				
<p>31. Do you expect to have a blood test for the AIDS virus infection in the next 12 months?</p>	<p>1 <input type="checkbox"/> Yes (32) 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK } (34)</p>																																				
<p>32. I am going to read some reasons people might have the blood test. Tell me if each statement explains WHY YOU expect to have the blood test in the next 12 months.</p>	<table border="0"> <thead> <tr> <th></th> <th>YES</th> <th>NO</th> <th>DK</th> </tr> </thead> <tbody> <tr> <td>a. Because it will be part of a blood donation.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>b. Because it will be part of hospitalization or surgery you expect to have.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>c. Because you expect to apply for life or health insurance.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>d. Because you expect to apply for a job.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>e. Because you expect to join the military.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>f. Because you expect to apply for a marriage license.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>g. Because you want to know the results.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> <tr> <td>h. Because it will be a required part of some other activity that includes automatic AIDS testing.</td> <td>1 <input type="checkbox"/></td> <td>2 <input type="checkbox"/></td> <td>9 <input type="checkbox"/></td> </tr> </tbody> </table>		YES	NO	DK	a. Because it will be part of a blood donation.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	b. Because it will be part of hospitalization or surgery you expect to have.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	c. Because you expect to apply for life or health insurance.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	d. Because you expect to apply for a job.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	e. Because you expect to join the military.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	f. Because you expect to apply for a marriage license.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	g. Because you want to know the results.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>	h. Because it will be a required part of some other activity that includes automatic AIDS testing.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>
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b. Because it will be part of hospitalization or surgery you expect to have.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>																																		
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h. Because it will be a required part of some other activity that includes automatic AIDS testing.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	9 <input type="checkbox"/>																																		
<p>33. Where will you go to have a blood test for the AIDS virus infection? <i>Mark only one.</i></p>	<p>01 <input type="checkbox"/> AIDS clinic/counseling/testing site 02 <input type="checkbox"/> Community Health Clinic 03 <input type="checkbox"/> Clinic run by employer 04 <input type="checkbox"/> Doctor/HMO 05 <input type="checkbox"/> Hospital/emergency room/outpatient clinic 06 <input type="checkbox"/> STD clinic 07 <input type="checkbox"/> Family planning clinic 08 <input type="checkbox"/> Prenatal clinic 09 <input type="checkbox"/> Tuberculosis clinic 10 <input type="checkbox"/> Public clinic 11 <input type="checkbox"/> Other Clinic 12 <input type="checkbox"/> Drug treatment facility 13 <input type="checkbox"/> Military induction or military service site 14 <input type="checkbox"/> Immigration site 15 <input type="checkbox"/> Home collection/testing kit 99 <input type="checkbox"/> Other location – Specify _____ 99 <input type="checkbox"/> DK</p>																																				

Section Q – AIDS KNOWLEDGE AND ATTITUDES – Continued

<p>34. Tell me whether you think the following statements about the blood test for the AIDS virus infection are true or false or if you do not know whether they are true or false.</p> <p>a. Sometimes the results of a blood test for the AIDS virus infection can be wrong.</p> <p>b. After a person becomes infected with the AIDS virus, there can be a period of time before the test shows the infection.</p>	<table border="0"> <tr> <td></td> <td align="center">TRUE</td> <td align="center">FALSE</td> <td align="center">DK</td> <td></td> </tr> <tr> <td>a.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">89</td> </tr> <tr> <td>b.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">90</td> </tr> </table>		TRUE	FALSE	DK		a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	89	b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	90															
	TRUE	FALSE	DK																												
a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	89																											
b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	90																											
<p>35. An accurate method for testing yourself at home for the AIDS virus infection is being considered. To use this method, you would take a blood sample from your finger and send it to a laboratory for testing. You would receive the results confidentially in the mail or by telephone.</p> <p>If this test were available, how likely would you be to use it – very likely, somewhat likely, somewhat unlikely, very unlikely, or don't you know how likely you would be to use it?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>Very likely</td> <td align="right">91</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>Somewhat likely</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>Somewhat unlikely</td> <td></td> </tr> <tr> <td>4 <input type="checkbox"/></td> <td>Very unlikely</td> <td></td> </tr> <tr> <td>5 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	Very likely	91	2 <input type="checkbox"/>	Somewhat likely		3 <input type="checkbox"/>	Somewhat unlikely		4 <input type="checkbox"/>	Very unlikely		5 <input type="checkbox"/>	DK																
1 <input type="checkbox"/>	Very likely	91																													
2 <input type="checkbox"/>	Somewhat likely																														
3 <input type="checkbox"/>	Somewhat unlikely																														
4 <input type="checkbox"/>	Very unlikely																														
5 <input type="checkbox"/>	DK																														
<p>36. If such a test were available, would you be more likely to choose – to test yourself at home, to go to a doctor's office or clinic, or not to be tested?</p> <p><i>Mark only one</i></p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>To test yourself at home</td> <td align="right">92</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>To go to a doctor's office or clinic</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>Not be tested</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	To test yourself at home	92	2 <input type="checkbox"/>	To go to a doctor's office or clinic		3 <input type="checkbox"/>	Not be tested																						
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2 <input type="checkbox"/>	To go to a doctor's office or clinic																														
3 <input type="checkbox"/>	Not be tested																														
<p>37. Have you ever heard of a drug called AZT, also known as Zidovudine (ZI-doo-view-deen) (ZDV) or Retrovir?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>Yes (38)</td> <td rowspan="3" style="font-size: 2em; vertical-align: middle;">}</td> <td rowspan="3" style="vertical-align: middle;">(39)</td> <td></td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>No</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	Yes (38)	}	(39)		2 <input type="checkbox"/>	No		3 <input type="checkbox"/>	DK																				
1 <input type="checkbox"/>	Yes (38)	}	(39)																												
2 <input type="checkbox"/>	No																														
3 <input type="checkbox"/>	DK																														
<p><i>Hand card Q3</i></p> <p>38. Tell me whether you think the following statements about AZT are true or false or if you don't know whether they are true or false.</p> <p>a. AZT can delay or slow down the symptoms of AIDS virus infection.</p> <p>b. AZT cures people with AIDS</p> <p>c. AZT has no known side effects.</p> <p>d. AZT is appropriate for a person with the AIDS virus infection ONLY at certain times during the illness.</p> <p>e. There are other drugs available to treat AIDS related illnesses.</p>	<table border="0"> <tr> <td></td> <td align="center">TRUE</td> <td align="center">FALSE</td> <td align="center">DK</td> <td></td> </tr> <tr> <td>a.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">94</td> </tr> <tr> <td>b.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">95</td> </tr> <tr> <td>c.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">96</td> </tr> <tr> <td>d.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">97</td> </tr> <tr> <td>e.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">98</td> </tr> </table>		TRUE	FALSE	DK		a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	94	b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	95	c.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	96	d.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	97	e.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	98
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a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	94																											
b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	95																											
c.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	96																											
d.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	97																											
e.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	98																											
<p>39. Did you have a blood transfusion at any time between 1977 and 1985?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>Yes</td> <td align="right">100</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>No</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	Yes	100	2 <input type="checkbox"/>	No		3 <input type="checkbox"/>	DK																						
1 <input type="checkbox"/>	Yes	100																													
2 <input type="checkbox"/>	No																														
3 <input type="checkbox"/>	DK																														
<p>40. Do you have frequent blood transfusions because of Sickle Cell or Chronic Anemia?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>Yes</td> <td align="right">101</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>No</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	Yes	101	2 <input type="checkbox"/>	No		3 <input type="checkbox"/>	DK																						
1 <input type="checkbox"/>	Yes	101																													
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3 <input type="checkbox"/>	DK																														
<p>Some people use condoms to keep from getting the AIDS virus through sexual activity.</p> <p>41. How effective do you think the use of a condom is to prevent getting the AIDS virus through sexual activity? Would you say very effective, somewhat effective, not at all effective, or you don't know how effective it is?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>Very effective</td> <td></td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>Somewhat effective</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>Not at all effective</td> <td></td> </tr> <tr> <td>4 <input type="checkbox"/></td> <td>Don't know how effective</td> <td></td> </tr> <tr> <td>5 <input type="checkbox"/></td> <td>Don't know method</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	Very effective		2 <input type="checkbox"/>	Somewhat effective		3 <input type="checkbox"/>	Not at all effective		4 <input type="checkbox"/>	Don't know how effective		5 <input type="checkbox"/>	Don't know method																
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4 <input type="checkbox"/>	Don't know how effective																														
5 <input type="checkbox"/>	Don't know method																														
<p>42. Tell me whether you think the following statements are true or false or whether you don't know if they are true or false.</p> <p>a. Latex condoms and natural membrane condoms are equally good at preventing transmission of the AIDS virus.</p> <p>b. Oil-based lubricants can cause latex condoms to break.</p>	<table border="0"> <tr> <td></td> <td align="center">TRUE</td> <td align="center">FALSE</td> <td align="center">DK</td> <td></td> </tr> <tr> <td>a.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">102</td> </tr> <tr> <td>b.</td> <td align="center">1 <input type="checkbox"/></td> <td align="center">2 <input type="checkbox"/></td> <td align="center">3 <input type="checkbox"/></td> <td align="right">103</td> </tr> </table>		TRUE	FALSE	DK		a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	102	b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	103															
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a.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	102																											
b.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	103																											
<p>43. What are your chances of HAVING the AIDS virus; would you say high, medium, low, or none?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>High (45)</td> <td align="right">104</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>Medium</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>Low</td> <td></td> </tr> <tr> <td>4 <input type="checkbox"/></td> <td>None</td> <td></td> </tr> <tr> <td>7 <input type="checkbox"/></td> <td>Refused</td> <td></td> </tr> <tr> <td>9 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	High (45)	104	2 <input type="checkbox"/>	Medium		3 <input type="checkbox"/>	Low		4 <input type="checkbox"/>	None		7 <input type="checkbox"/>	Refused		9 <input type="checkbox"/>	DK													
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4 <input type="checkbox"/>	None																														
7 <input type="checkbox"/>	Refused																														
9 <input type="checkbox"/>	DK																														
<p>44. What are your chances of GETTING the AIDS virus; would you say high, medium, low, or none?</p>	<table border="0"> <tr> <td>1 <input type="checkbox"/></td> <td>High</td> <td align="right">105</td> </tr> <tr> <td>2 <input type="checkbox"/></td> <td>Medium</td> <td></td> </tr> <tr> <td>3 <input type="checkbox"/></td> <td>Low</td> <td></td> </tr> <tr> <td>4 <input type="checkbox"/></td> <td>None</td> <td></td> </tr> <tr> <td>7 <input type="checkbox"/></td> <td>Refused</td> <td></td> </tr> <tr> <td>9 <input type="checkbox"/></td> <td>DK</td> <td></td> </tr> </table>	1 <input type="checkbox"/>	High	105	2 <input type="checkbox"/>	Medium		3 <input type="checkbox"/>	Low		4 <input type="checkbox"/>	None		7 <input type="checkbox"/>	Refused		9 <input type="checkbox"/>	DK													
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7 <input type="checkbox"/>	Refused																														
9 <input type="checkbox"/>	DK																														

Section Q – AIDS KNOWLEDGE AND ATTITUDES – Continued

<p>45. Have you ever had a co-worker who had AIDS or the AIDS virus?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> Never worked, never had a co-worker 4 <input type="checkbox"/> Don't know if someone has/had AIDS or the AIDS virus</p>	<p>106</p>
<p>46. (Besides a co-worker) Have you had a friend or relative who had AIDS or the AIDS virus?</p>	<p>1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 3 <input type="checkbox"/> Don't know if someone has/had AIDS or the AIDS virus</p>	<p>107</p>
<p><i>Hand card Q4. Read list if telephone interview.</i></p>		<p>108</p>
<p>47. (I'm going to read a list of statements. AFTER I have read them all.) Tell me if ANY of these statements is true for YOU. Do NOT tell me WHICH statement or statements are true for you. Just IF ANY of them are.</p> <p>a. You have hemophilia or another blood clotting disorder and have received clotting factor concentrations since 1977.</p> <p>b. You are a man who has had sex with another man at some time since 1977, even one time.</p> <p>c. You have taken illegal drugs by needle at any time since 1977.</p> <p>d. You have had sex for money or drugs at any time since 1977.</p> <p>e. Since 1977, you are or have been the sex partner of any person who could answer "Yes" to any of the items [I have read./ above on this card.]</p>	<p>1 <input type="checkbox"/> Yes to at least one statement 2 <input type="checkbox"/> No to all statements</p>	

Notes

Appendix F

APPENDIX F
ORIGINAL AND TRANSLATED COPIES OF
THE AIDS MULTIDIMENSIONAL LOCUS OF CONTROL

Die Verhaltensanteile der Prophylaxebereitschaft wurden ebenfalls über vier Einzelfragen erhoben. Es handelt sich dabei einerseits um eine Frage zur Häufigkeit der Kondombenutzung, andererseits um globaler formulierte Fragen nach dem Ausmaß bereits vorgenommener bzw. zukünftig beabsichtigter Verhaltensänderungen.

Die prophylaxebezogenen Items waren (mit Ausnahme der Multiple-Choice-Fragen zur Informiertheit) mit Hilfe mehrstufiger Antwortskalen zu beantworten. Über die Kontrollüberzeugungen und prophylaxebezogenen Variablen hinaus wurden Alter, Geschlecht, die Art der sexuellen Orientierung (homo- und heterosexuell) und die Häufigkeit des Partnerwechsels im vorausgegangenen Jahr erfragt. Die Beantwortung der Fragen nahm etwa 30 bis 40 Minuten in Anspruch.

Resultate

Da sich wesentliche Teile der nachfolgenden Ergebnisdarstellung auf den Fragebogen zur Erhebung aids-spezifischer Kontrollüberzeugungen stützen, soll vor der hypothesenbezogenen Auswertung zunächst auf die Analyse der Struktur dieses Fragebogens kurz eingegangen werden. Die Items des Fragebogens wurden dazu einer Faktorenanalyse mit anschließender Varimax-Rotation unterzogen. Die Ergebnisse sind (zusammen mit den Trennschärfen und Schwierigkeiten der Items) in Tabelle 1 zusammengefaßt. Es zeigt sich, daß die theoretische Struktur des Fragebogens durch die Faktorenanalyse recht gut bestätigt wird: Die Internalitäts- und Externalitätsitems lassen sich weitgehend jeweils spezifischen Faktoren zuordnen.

Tabelle 1 *Faktorenanalyse der Items zur Erhebung aids-spezifischer Kontrollüberzeugungen, Schwierigkeitsindices und Trennschärfen der Items*

Items mit Item-Nummer im Original-Fragebogen	Faktor I	Faktor II	Faktor III	Kommunalität	p(i)	r(ic)
Internalität (I)						
02 Wenn ich mich mit AIDS infiziere, bin ich selbst schuld daran.	0.694	0.109	-0.064	0.500	0.45	0.48
05 Ob ich AIDS bekomme oder nicht, wird vor allem von meinem Verhalten bestimmt.	0.696	-0.318	-0.078	0.592	0.78	0.51
07 Ob ich mich vor AIDS schützen kann oder nicht, liegt größtenteils an mir selbst.	0.698	-0.171	0.010	0.517	0.81	0.48
11 Wenn ich mich mit AIDS infiziere, habe ich nicht genug auf mich selbst geachtet.	0.677	-0.162	-0.005	0.484	0.58	0.53

Fortsetzung nächste Seite

Fortsetzung Tabelle 1 *Faktorenanalyse der Items*

Item mit Item-Nummer im Original-Fragebogen	Faktor I	Faktor II	Faktor III	Kommunalität	p(i)	r(it)
Externalität (P)						
03 Wenn sich die AIDS-Infizierten rücksichtslos verhalten, kann ich mich nicht vor AIDS schützen.	-0.035	-0.174	0.703	0.526	0.35	0.26
04 Es hängt vor allem davon ab, wie schnell die Wissenschaftler ein Heilmittel finden, ob ich in der Zukunft AIDS bekomme.	-0.154	0.219	0.620	0.456	0.27	0.24
09 Wenn die Bundesregierung nicht einschneidender vorgeht, kann ich mich nicht gegen AIDS schützen.	-0.502	-0.282	0.015	0.332	0.10	0.04
10 Es liegt vor allem in der Hand meiner/s Sexualpartner/in, ob ich mich mit AIDS infiziere.	0.104	0.010	0.652	0.437	0.28	0.28
Externalität (C)						
01 Es ist nur eine Frage der Zeit, bis ich mich mit AIDS infiziere.	-0.341	0.268	0.359	0.317	0.18	0.24
06 Wenn ich mich mit AIDS infiziere, dann hat es das Schicksal so gewollt.	-0.035	0.790	-0.191	0.661	0.10	0.37
08 Wenn es der Zufall so will, bekomme ich AIDS.	0.028	0.667	0.261	0.514	0.20	0.36
12 Es ist vor allem Glückssache, ob ich mich vor AIDS schützen kann.	-0.435	0.610	0.051	0.559	0.16	0.46
Varianzaufklärung:	24,7 %	12,3 %	12,1 %			

Lediglich bei zwei Items ist die Faktoreuzuordnung weniger eindeutig. Da bei diesen Items gleichzeitig besonders niedrige Kommunalitäten und niedrige Trennschärfen auftreten, spricht dies dafür, daß diese Items weitere inhaltliche Aspekte enthalten, die über die Internalitäts-Externalitäts-Strukturierung hinausgehen. Diese Vermutung ist

Zusammenfassung. Die vorliegende Arbeit beschäftigt sich mit dem Zusammenhang zwischen Kontrollüberzeugungen und der Bereitschaft zur AIDS-Prophylaxe. Es wird dabei davon ausgegangen, daß die Bereitschaft zur AIDS-Prophylaxe höher ist, wenn die Einstellung vorherrscht, daß das eigene Verhalten für die Infektionsvermeidung ausschlaggebend ist (Internalität). Wird dagegen angenommen, daß das Eintreten einer Infektion vom Verhalten anderer und (insbesondere) vom Schicksal oder Zufällen abhängt (Externalität), dürfte die Präventionsbereitschaft geringer sein. Zur Klärung dieser Frage wurde eine empirische Untersuchung durchgeführt, an der 173 Erwachsene im Alter von 18 bis 53 Jahren teilnahmen. Es wurden sowohl die allgemeinen Kontrollüberzeugungen zu Krankheit und Gesundheit als auch bereichsspezifische Kontrollüberzeugungen zur AIDS-Thematik erhoben, da die guten Beeinflussungsmöglichkeiten des HIV-Infektionsrisikos möglicherweise zu spezifischen Kontrollüberzeugungen führen, die von den Kontrollüberzeugungen in anderen Krankheitsbereichen abweichen. Die Ergebnisse weisen auf eine spezifische Ausbildung von Kontrollüberzeugungen für den Bereich der AIDS-Prophylaxe hin und zeigen weiterhin, daß bei Internalität ein höherer Informationsstand, eine größere Bereitschaft zur Informationssuche und eine größere Bereitschaft zu Präventionsmaßnahmen (Kondombenutzung, Verhaltensänderung etc.) besteht. Gleichzeitig sind die Angst vor einer Infektion und die subjektive Infektionswahrscheinlichkeit (vermutlich wegen der größeren Präventionsbereitschaft) geringer. Bei Externalität zeigen sich tendentiell umgekehrte Relationen. Die Implikationen der vorliegenden Ergebnisse für die Steigerung der AIDS-Präventionsbereitschaft werden herausgearbeitet und diskutiert.

Abstract. The present paper focusses on the relation between control beliefs and AIDS-prophylactic behavior. It is assumed that the readiness to engage in prevention will be higher when the own behavior is regarded as most important for the prevention of an HIV-infection (internal locus of control). Little readiness for prevention will be shown, when the occurrence of an infection is regarded as dependent from the behavior of others or (in particular) from fate or chance influences (external locus of control). To prove this assumption an empirical study was conducted with 173 adults aged 18 to 53. The participants were asked about their general health locus of control beliefs as well as their special control beliefs regarding the HIV-infection, because it was possible that the high controllability of the HIV-infection (compared to other kinds of disease) leads to special control beliefs which are different from the general health locus of control beliefs. The results confirm the assumption of specific control beliefs for the HIV-infection. Thereover, it could be shown that internality is related to a better information about the HIV-infection, a greater readiness for the search of information and for the performance of preventive behavior (use of condoms, change of behavior). The fear about an infection and the judged probability of an infection are decreased. For external control beliefs the results show the opposite direction. The implications of the present results for the enhancement of the readiness to engage in AIDS-preventive behavior are elaborated and discussed.

¹ Die empirische Untersuchung, über die in dieser Arbeit berichtet wird, entstand im Rahmen eines Wahlpflichtvertiefungsblocks am Fachbereich Psychologie der Universität Münster. Wir danken allen Beteiligten für ihre engagierte Unterstützung.

Anschrift der Verfasser: Dr. Arnold Lohaus, Chrissoula Gaidatzi, Markus Hagenbrock, Psychologisches Institut III, Universität Münster, Schlaunstr. 2, D-4400 Münster.

QUESTIONS AND COMMENTARY
Lohaus/Gaidatzi/Hagenbrock

Internality (I)

- 02 If I get infected with AIDS, I myself am to blame.

The German says "If I infect myself with AIDS" but this is misleading. German also says "The door opens itself" and "I anger myself" when the best English translation of the latter is "I get angry". Since the expression "I infect myself" does not exist in common English usage, it is inappropriate here because of the connotation. Yet there is an aspect of the original German which simply cannot be translated.

- 05 Whether I get AIDS or not is determined above all by my behavior.

- 07 Whether I can be protected from AIDS or not depends mainly on me.

Here again the German says "Whether I can protect myself" but that is, as in 02 above, redundant and prejudicial in English to a degree which the German is not.

- 11 If I "get infected" with AIDS, [it's because] I haven't taken good enough care of myself.

"Taken good care" is more literally "Paid close enough attention to" or "Held in high enough regard".

Externality (P)

- 03 If people infected with AIDS act in an irresponsible manner, I cannot protect myself from AIDS.

Here the expression "protect myself" is the same as in 07 above, but the slant is different.

- 04 Whether I get AIDS in the future depends above all on how quickly scientists find a cure.

- 09 If the federal government doesn't act in a more decisive manner, I cannot be protected against AIDS.

Note the (perhaps unconscious) change from *vor* ("from") to *gegen* ("against"). They mean basically the same thing and can be used interchangeably, but *gegen* is more frequently used with illness (*Was [d.h. welche Schutzmittel] haben Sie gegen meine Krankheit* ["What (medicines) do you have for (i.e. against) my illness"] as opposed to *Wer soll mich vor dem Feind schützen* ["Who is going to protect me from the enemy"]).

- 10 Whether I get infected with AIDS is determined above all by my sexual partner.

"Infect myself" again; "is determined by" is literally "it lies in the hands of".

Externality (C)

- 01 It's only a question of time until I get infected ("infect myself") with AIDS.

- 06 If I get infected with AIDS, then it is the work of fate.

"Infect myself" again; "it is the work of fate" is literally "fate wanted it that way", which is of course more personal.

- 08 If happenstance works out that way, I'll get AIDS.

"Happenstance" (*Zufall*) is more like "chance"; "fate" in 06 above (*Schicksal*) is more ponderous, but less so than "doom" (*Los*).

- 12 Whether I can be protected ("protect myself") from AIDS is mainly a matter of luck.

Glück, used here, is a bit more frivolous.

Appendix G

APPENDIX G
HIV QUESTIONNAIRE DEVELOPED
FOR THE SAMPLE

HIV / AIDS QUESTIONNAIRE

NUMBER: _____

1. **Age:** (CIRCLE ONE)
 12-15 16-20 21-25 26-30 31-35 36-40 41-45 46-50 ABOVE 50

2. **Race:** (CIRCLE ONE)
 AFRICAN AMERICAN, NON HISPANIC ASIAN CAUCASIAN, NON-HISPANIC
 HISPANIC OTHER (Specify) _____

3. **Sexual orientation:** (CIRCLE ONE) HETEROSEXUAL (straight)
 BISEXUAL (both men and women) HOMOSEXUAL (gay)

4. **Your present marital status:** (CIRCLE ONE)
 NEVER MARRIED MARRIED DIVORCED SEPARATED WIDOWED
 LIVING WITH PERSON

5. **Education:** (CIRCLE ONE) COMPLETED THE FOLLOWING:
 MIDDLE HIGH SCHOOL SOME COLLEGE COLLEGE GRADUATE SCHOOL

6. **Salary/ Income:** (CIRCLE ONE)
 Below \$5,000 \$5-10,000 \$10-15,000 \$15-20,000 ABOVE \$20,000
 UNEMPLOYED FULL TIME STUDENT

7. **Partner's sexual orientation:** (CIRCLE ONE)
 HETEROSEXUAL (STRAIGHT) BISEXUAL (BOTH MALE AND FEMALE) HOMOSEXUAL (GAY)
 UNKNOWN

8. **Children:** None 1 2 3 Above 3

Please circle either yes (Y), no (N) or don't know (DK) after the following questions.

	YES	NO	DON'T KNOW
A PERSON CAN GET HIV / AIDS FROM:			
09. Having sex.Y	N	DK
10. A mother's breast milkY	N	DK
11. Eating food from plates where a cook is HIV infected.Y	N	DK
12. Getting a blood transfusion.Y	N	DK
13. From using public toilets.Y	N	DK
14. Sharing needles with someone.Y	N	DK
15. Giving blood to organizations like the Red Cross. .Y		N	DK

APPENDIX G
HIV QUESTIONNAIRE DEVELOPED
FOR THE SAMPLE

HIV / AIDS QUESTIONNAIRE

NUMBER: _____

1. **Age:** (CIRCLE ONE)
 12-15 16-20 21-25 26-30 31-35 36-40 41-45 46-50 ABOVE 50

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 AFRICAN AMERICAN, NON HISPANIC ASIAN CAUCASIAN, NON-HISPANIC
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 BISEXUAL (both men and women) HOMOSEXUAL (gay)

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 UNKNOWN

8. **Children:** None 1 2 3 Above 3

Please circle either yes (Y), no (N) or don't know (DK) after the following questions.

	YES	NO	DON'T KNOW
A PERSON CAN GET HIV / AIDS FROM:			
09. Having sex.Y	N	DK
10. A mother's breast milk	Y	N	DK
11. Eating food from plates where a cook is HIV infected.	Y	N	DK
12. Getting a blood transfusion.	Y	N	DK
13. From using public toilets.	Y	N	DK
14. Sharing needles with someone.Y	N	DK
15. Giving blood to organizations like the Red Cross.Y	N	DK

26. A positive HIV test result would cause health insurance problems	SA	A	U	D	SD
27. A positive HIV test result would cause disability insurance problems.	SA	A	U	D	SD
28. I would be HIV tested to make sure that any health problem I might have is not a result of HIV infection. . .	SA	A	U	D	SD
29. I have enough problems in my life and don't want to be HIV tested. . .	SA	A	U	D	SD
30. I need to know that I'm not HIV infected so I won't have to worry. . .	SA	A	U	D	SD
31. I wouldn't want to make changes in what I do sexually and won't test. . .	SA	A	U	D	SD
32. I need to know if I'm HIV infected so I won't infect my sexual partner .	SA	A	U	D	SD
33. The HIV test is not accurate and, therefore, I will not test. . .	SA	A	U	D	SD
34. My strong religious beliefs have protected me from HIV infection. . .	SA	A	U	D	SD
35. I am bothered by what others may think about me if I were HIV infected.	SA	A	U	D	SD
36. Even if I were infected, my health is so good that I would not get sick .	SA	A	U	D	SD
37. Since I may be forced to tell sexual partners that I was HIV infected, I won't be tested.	SA	A	U	D	SD
38. I would be suicidal if I were HIV positive and won't test	SA	A	U	D	SD

- | | | | | | |
|---|----|---|---|---|----|
| 39. I don't trust any authorities to keep my HIV test results confidential. | SA | A | U | D | SD |
| 40. If I'm HIV infected, people would think I'm gay or use drugs. . . | SA | A | U | D | SD |
| 41. I would have little or no support if I tested HIV positive. | SA | A | U | D | SD |
| 42. If I were pregnant, I would have my child even if I were HIV positive. | SA | A | U | D | SD |
| 43. If I am pregnant, I would want to be HIV tested to make sure I was healthy. | SA | A | U | D | SD |
| 44. If I were HIV infected, I would have an abortion, if I were pregnant. | SA | A | U | D | SD |

PLEASE ANSWER THE FOLLOWING ONLY IF YOU HAVE CHILDREN.

- | | | | | | |
|---|----|---|---|---|----|
| 45. I am afraid my child(ren) would be taken from me if I tested HIV positive. | SA | A | U | D | SD |
| 46. I am afraid of infecting my children if I'm HIV infected. . . . | SA | A | U | D | SD |
| 47. I couldn't cope knowing I'm HIV infected and possibly not see my child(ren) grow up. | SA | A | U | D | SD |
| 48. There is no one to support my child(ren) and they'd have to be raised in foster homes | SA | A | U | D | SD |
| 49. If I were HIV infected, I would also want to test my child(ren) . . . | SA | A | U | D | SD |

PART TWO

50. It's only a question of time until I get infected with HIV.
(CIRCLE ONE) **TRUE** **FALSE**
51. If I get infected with HIV, I am to blame.
(CIRCLE ONE) **TRUE** **FALSE**
52. If HIV infected people act irresponsibly, I can't protect myself from AIDS. (CIRCLE ONE) **TRUE** **FALSE**
53. For me, getting HIV in the future will depend on how quickly scientists find a cure. (CIRCLE ONE) **TRUE** **FALSE**
54. Whether I get HIV or not is determined by I how I behave.
(CIRCLE ONE) **TRUE** **FALSE**
55. If I get infected with HIV, then it is entirely by fate.
(CIRCLE ONE) **TRUE** **FALSE**
56. Whether I can be protected from HIV depends entirely on me.
(CIRCLE ONE) **TRUE** **FALSE**
57. Fate will determine if I become HIV infected.
(CIRCLE ONE) **TRUE** **FALSE**
58. If the government won't act more quickly, I can't be protected against HIV. (CIRCLE ONE) **TRUE** **FALSE**
59. Whether I get infected with HIV is determined by my sexual partner.
(CIRCLE ONE) **TRUE** **FALSE**
60. If I get infected with AIDS, it's because I haven't taken good enough care of myself.
(CIRCLE ONE) **TRUE** **FALSE**
61. Whether I can be protected from AIDS is mainly a matter of luck.
(CIRCLE ONE) **TRUE** **FALSE**
62. There is a vaccine to protect people from HIV infection.
(CIRCLE ONE) **TRUE** **FALSE**
63. There is no cure for AIDS.
(CIRCLE ONE) **TRUE** **FALSE**
64. There is medication that can help people if they get symptoms from HIV infection.
(CIRCLE ONE) **TRUE** **FALSE**
65. Being pregnant can be harmful to a mother's immune system, if she is HIV infected.
(CIRCLE ONE) **TRUE** **FALSE**

Please circle either yes (Y), no (N) or don't know (DK) after the following questions.

	YES	NO	DON'T KNOW
66. I have shared a needle to inject drugs with someone else.	Y	N	
67. My sex partner used a needle to inject drugs.	Y	N	DK
68. I have had sex in order to get money.	Y	N	
69. I had a blood transfusion before 1985.	Y	N	DK
70. I have tested HIV positive.	Y	N	
71. I have tested HIV negative.	Y	N	
72. I have taken the HIV test, but don't know the results.	Y	N	

PLEASE ANSWER THE FOLLOWING QUESTIONS ONLY IF YOU HAVE NOT TAKEN THE HIV ANTIBODY TEST.

73. I have never taken the HIV test, but would.	Y	N
74. I have never taken the HIV test, and I won't.	Y	N

Your participation in this survey is greatly appreciated. If you would like a summary of the findings, please put your name and address on the sheet provided at the volunteer desk. Thank you.

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Abstract

PSYCHOLOGICAL AND PSYCHOSOCIAL RESPONSES OF WOMEN SEEKING PREGNANCY COUNSELING TO HIV ANTIBODY TESTING

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The College of William and Mary, Williamsburg, Virginia, April,
1994

Chairperson: Thomas J. Ward, Jr., Ph.D.

The purpose of this descriptive investigation was to study the reactions of women, specifically women who were seeking pregnancy counseling, to the psychological and psychosocial impact of HIV antibody testing. A questionnaire was developed that surveyed women on HIV knowledge, behaviors associated with HIV infection, and locus of control issues related to the disease. Additionally, questions regarding the stigma and discrimination associated with the disease were posed that may have acted as barriers to taking the HIV antibody test. Finally, supplemental questions related to HIV and the issue of abortion were also presented.

The sample for this research consisted entirely of women who were new or returning clients of Planned Parenthood. Four sites from Planned Parenthood in the Hampton Roads area of Virginia were utilized. One hundred and four women completed the survey. The ages of women sampled ranged from 12 to above 50. Median age range for this sample was 21-25 years of age. Other demographic information presented a composite of mostly white, lower socioeconomic status, high school to college educated women.

Eighty four women indicated that they would take the HIV antibody test; twelve indicated that they would decline taking it. However, many of the women who said that they would take the HIV antibody test had not taken the test at the time the survey was

conducted. It was concluded that the majority of women had sufficient knowledge regarding the disease, although over half of the women surveyed did not know that HIV could be spread by an HIV infected mother who breast feed her newborn. A majority of women also demonstrated an internal locus of control with regards to HIV infection. Using a Likert Scale, ninety-six women answered the question posed about HIV infection as it pertained to the option of abortion. Twenty-one women (21.8%) strongly agreed to aborting their fetus if they were HIV infected, while seventeen participants (17.7%) agreed. However, forty-three women (44.7%) were uncertain as to their decision to abort their fetus; seven women (7.2%) disagreed and eight (8.3%) strongly disagreed to having an abortion as a result of being infected with HIV.

Further study is needed in this area which would demonstrate a more diversified sample of women in order to increase the external validity of the findings of this study. As research into the disease continues to divulge new methodologies for using established drugs to combat HIV, such as the preliminary revelation that AZT significantly cuts the risk of HIV transmission from mother to fetus, questions arise that deal with new psychological consequences and conflicts for the female population.