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**The Consequences of Perinatal HIV Antibody Testing for
Women and Infants**

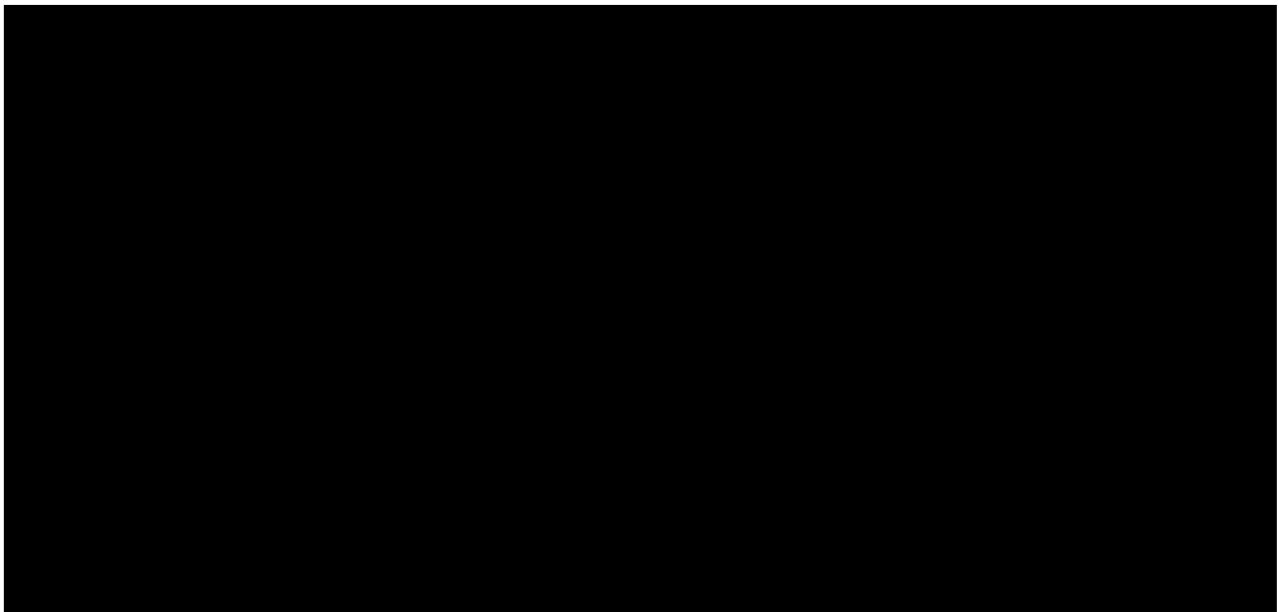
by

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A Thesis

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ABSTRACT

Routine perinatal HIV antibody (Ab) screening identifies neonates at risk for HIV infection but holds risks as well as benefits for women and infants. We report the mother's understanding of pretest counseling and consent (Study A), and describe the effects of seropositivity on infant placement and medical care (Study B), as well as on maternal socioeconomic status, medical care, risk-taking behaviors, emotional support, and psychological status (Study C). Of 32 post-partum women interviewed after HIV Ab test informed consent, only 31% understood that a positive cord blood test result was inconclusive for the infant, and most (78%) did not identify any associated socioeconomic risks. Most (88%) stated an interest in learning their serostatus, but only 22% returned for test results. In a cross-sectional analysis of 327 tested infants, seropositive infants (13) had a higher rate of discharge home (62%) than did controls (31%). More case infants (100%) received follow-up medical care than control infants (46%). In an interview study of 20 matched HIV positive and negative mothers, mean anxiety scores were significantly higher in seropositive women. Many (35%) seropositive women cited health care discrimination due to HIV status. Both groups showed low rates of change in insurance, housing, and income levels. While HIV positive women reported satisfaction with social support from friends (100%) and family (80%), many had not disclosed their HIV status to any friends (65%) or family (25%). Seropositive women were more likely to be separated (50%) from their main partners following disclosure of HIV status than controls (10%). Of those with substance use history, seropositive women showed greater reductions in alcohol (100%) and drug (75%) use than seronegative women (50%, 67%). Many seropositive (62%) and seronegative (80%) women reported having sex without condoms. More HIV positive women planned to limit future childbearing (85% vs. 15%); however, only 21% of those able to become pregnant would abort a future pregnancy. Despite the measured benefits of HIV Ab testing, current counseling and testing procedures inadequately inform women, limiting the testing benefits to them. Further, the risks of seropositivity to women are inadequately addressed by current HIV medical and social service care delivery.

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In the United States, perinatally-acquired human immunodeficiency virus (HIV) has affected a growing number of HIV-infected women and infants (1). In 1989, an estimated 6079 infants were born to HIV-infected women in the United States (2), and in each subsequent year the number of reported acquired immunodeficiency syndrome (AIDS) cases in women has increased (3). Since 80% of HIV positive women are of reproductive age, more widespread testing is occurring in obstetric and neonatal settings. In 1985 the Center for Disease Control (CDC) recommended perinatal HIV antibody (Ab) testing for women living in high prevalence areas and having significant risk of infection including transfusion, sexual risk factors, and intravenous drug use (4).

HIV testing based on targeted epidemiological research and an individual informed consent model may offer the most practical use of the limited resources available for testing; however, concern remains about this model's failure to identify a significant number of HIV-infected women and infants. First, targeting high risk populations based on historical HIV risk factors depends on careful clinical surveys and self-reporting (5). Further, as HIV seroprevalence increases in non-injection drug-using heterosexual populations, targeting traditionally high risk groups may be unsuccessful (6). Reliance on seroprevalence epidemiology may result in targeting populations based on ethnicity and economic class, raising the spectre of discrimination (7). Second, others have questioned the efficacy of the maternal informed consent model, citing the cost and the failure of case identification in certain high seroprevalence areas (8). Subsequently, some health care providers and public health officials have called for an expanded HIV Ab testing policy for pregnant women and even universal HIV screening for newborns (7-10). Most health care providers believe that knowledge of maternal serostatus may improve maternal, fetal, and newborn health care through appropriate HIV prevention counseling, therapeutic abortions, access to continuity care focused on HIV illness, and early prophylactic and therapeutic interventions for women and their infants (11,12). Since 1987, San Francisco General Hospital (SFGH) has used a policy of voluntary HIV Ab testing of at-risk pregnant and postpartum women in this high prevalence population.

Because many young women have contact with the health care system only during pregnancy, the CDC's policy for testing women and identifying infants at risk for HIV infection primarily targets pregnant women. Consequently, the first opportunity to identify women who are HIV seropositive is often during prenatal care or in the immediate postnatal period. The benefits of perinatal HIV Ab screening include early zidovudine therapy and *Pneumocystis carinii* pneumonia (PCP) prophylaxis for mothers, and early disease detection and treatment in their infants. Determining maternal infection during the obstetric period also allows women the choice of enrolling in any existing research protocols

focused on the interruption of vertical HIV transmission. However, perinatal screening raises the same socioeconomic and psychological risks that have been articulated about HIV testing in different settings: loss of housing, employment, insurance, medical care access, child care, and family support (13,14). These issues are of particular concern in a population at risk for discrimination due to race and poverty, and for whom social and health care services are often inadequate. Compounding these factors, a positive maternal or neonatal Ab test provides inconclusive information about the infant's long-range condition; indeed, only 25-35% of these newborns retain a positive serostatus at 15 months of age (15,16), yet they are treated medically and socially as if they are HIV-infected in many settings. Despite its inability to conclusively determine the newborn's viral status, a positive maternal HIV Ab test may pose potential harm to the infant: isolation, abandonment, and less aggressive treatment by some health care providers (17). These risks remain unexplored and unquantified, yet the arguments for widespread testing and even universal screening have increased proportionally with both the rising HIV seroprevalence in women of childbearing age and the growing benefits of early HIV therapy and prophylaxis (18).

Perinatal health care providers are familiar with the difficult balance among their own values, the mother's rights, public health interests, and fetal and/or infant well-being and rights (19,20). In California, the legal requirement for written informed consent for perinatal HIV Ab testing has the potential to precipitate tensions among these parties. These tensions are exacerbated in the postpartum period when the pediatric caretakers are focused on newborn care. In this context, just as for other newborn procedures, the clinician must obtain maternal informed consent as proxy consent for the infant. The physician discloses all reasonable risks and benefits associated with the HIV Ab test and describes the available alternative procedures to the newborn's mother. Then, the mother must weigh the test's risks and benefits for both herself and her newborn. This decision is based on her understanding and experience of complex medical and social issues and of the testing procedure and results. Thus, ethical and effective informed consent and pre-test counseling depends on a realistic appraisal of the test's risks and benefits for a given population. Little is known about the collective successes and failures of HIV testing informed consent in the perinatal setting, or about the impact of seropositivity on this heterogeneous population of women and children. For these reasons, we developed a series of studies which begin to address these questions.

Historically, these studies emerged sequentially resulting from clinical experience with HIV counseling and testing in the neonatal nursery and were then expanded to include an evaluation of prenatal testing. Because many women on this urban obstetric service

received little or no prenatal care, the first opportunity for HIV risk factor screening and serostatus determination was often in the immediate postpartum period. Initially, we sought to evaluate the effectiveness of maternal HIV test counseling and informed consent in this setting by administering a post-counseling and informed consent questionnaire to every postpartum woman tested during a discrete time period. Then, to better understand the consequences of a positive maternal HIV Ab test for infants in the first two years of life, we reviewed the discharge summaries and medical records of all HIV seropositive infants identified at SFGH between 1988-90 and compared these to matched seronegative infants. Our results raised questions about the risks and benefits of perinatal HIV testing for women and led to an evaluation of the impact of HIV seropositivity on recently delivered mothers. This third study population included prenatally-identified HIV positive women caring for their children at the time of the study.

In summary, we assessed three aspects of the actual consequences of the current HIV counseling and testing in the perinatal period for a select urban population in a high seroprevalence area: the mother's comprehension and decision-making during informed consent for postnatal testing (Study A), infant disposition and care following maternal serostatus testing (Study B), and the socioeconomic and psychological impact of HIV seropositivity on women caring for their children (Study C). In Study A, we used an open-ended, verbal questionnaire to evaluate the mother's understanding of the clinician's informed consent counseling and risk and benefit disclosure for HIV Ab testing. This questionnaire evaluated the mother's understanding of the test's significance, her ability to recall benefits and risks, her motivations for consenting to the test, and her intention to return for results. We also documented whether the study group women actually returned to the follow-up appointment for post-test counseling and results. In Study B, all newborns identified as seropositive by a postpartum HIV Ab test over a two year period were compared to seronegative infants matched for race, maternal risk factors, and maternal age to determine whether a positive maternal HIV test affects infant disposition and subsequent medical care. In Study C, we assessed the actual consequences of HIV seropositivity for women within California's current perinatal HIV counseling and informed consent testing protocol. We used a structured questionnaire to test hypotheses about the expected differences between HIV positive and negative mothers who were matched for race, income level, HIV risk factor, and delivery date. This questionnaire quantitatively evaluated the differences in routine health care, housing relocations, insurance cancellations, employment losses, risk-taking behaviors, relationship changes, and family planning concerns. Standardized psychological scales were used to measure stress, depression, and anxiety in both HIV positive and negative women. Further, an

open-ended interview assessed the qualitative impact of seropositivity on the women's lives.

Such an assessment of the effects of a positive HIV test on women and their children is central to developing testing policy and health care delivery which provide early and full access to appropriate HIV services and health care, yet respect the independent needs of both women and their children. In addition, knowledge about the interpersonal environments of women affected by HIV may provide important information for the development of HIV prevention and education services. All research procedures were approved by the University of California at San Francisco (UCSF) Committee for Human Research.

POPULATION AND METHODS

Study A: The Woman's Comprehension of HIV Ab Test Informed Consent and Counseling

Since 1985 at SFGH, the perinatal HIV Ab test informed consent protocol has specified that pregnant and post-partum women would be provided with information about the HIV test's purpose, its risks and benefits, as well as the significance of a negative or positive result for women, and following delivery, their children. The clinician describes alternatives and emphasizes the voluntary nature of the test consent. Finally, a follow-up clinic appointment for the mother is made, and she is given a slip with the time, day, and location where she should return for results and counseling.

During two months of 1990, an interview was added to the maternal informed consent process used routinely in the neonatal nursery. All women (33) tested during this time period were consecutively referred to one of the study investigators (JCP, PL) following informed consent and prior to the return of cord blood test results. Of these, 32 agreed to participate as interview research subjects. Seven of the 32 women interviewed had undergone prenatal screening and were shown to be HIV negative; they were retested at delivery to rule out a false negative result after recent infection.

Within 48 hours of counseling and informed consent for HIV cord blood testing, mothers were approached to participate in the study. After signing the research subject consent form, subjects responded to an interviewer-administered questionnaire designed to evaluate the critical components of information transfer (Appendix 1). Open-ended questions were asked in a neutral, non-leading fashion to prevent systematic response bias. All subject responses were recorded and then assigned to content-coded categories. When individuals provided more than one answer for a given question, each response was recorded separately. Interview responses have been reported as percentages of total

subjects answering that question. Finally, we followed all subjects to see if they returned to clinic for a scheduled post-test counseling appointment.

Study B: The Impact of Maternal HIV Seropositivity for Infant Disposition and Care

Between 1988-90, routine care of recently delivered mothers (n=3753) at SFGH included a standardized risk assessment to identify mothers at risk for HIV infection. At least one medical or social risk factor for HIV infection was identified in 345 delivered mothers. Due to house staff error or practical constraints, 38 mothers were not approached before discharge. The remaining 307 were approached by nursery house staff or attending physicians for written informed consent for cord blood serologic testing; 279 (91%) agreed to the test and 269 were actually performed. Ten of the tests were not performed because an inadequate amount of cord blood was obtained. The maternal characteristics of this study population are described in Table 1. Thirteen (5%) HIV Ab cord blood tests were positive during this period. Controls were retrospectively selected from the 256 negative cord blood ELISA tests done during the same study period. They were matched for maternal race, age, and risk factors used by nursery staff during routine identification of HIV risk. To evaluate the effects of a positive maternal HIV Ab test on the infant during the first two years of life, we measured the proportion of control and case infants discharged to three possible locations: home, extended family, or foster care. In addition, we evaluated follow-up health care after discharge by comparing frequency of vaccinations and continuity care in the two groups.

Table 1: Study B--Maternal characteristics for total tested population

Characteristic	Women tested n=269 (%)	
Mean Age	26.4	
Ethnicity		
Caucasian	57	(21.2)
African-American	182	(67.6)
Latina	22	(8.2)
Asian/Pacific Islander	6	(2.2)
Other	3	(0.7)
HIV Risk		
Only partner	177	(65.8)
IDU	85	(31.6)
Transfusion	7	(2.6)

Study C: The Consequences of HIV Seropositivity for Recently Delivered Mothers

Between December, 1989 and April, 1992, 50 seropositive women were enrolled in the Bay Area Perinatal AIDS Center (BAPAC) during the obstetric period. These pregnant women were recruited from all women in the greater Bay Area who were identified as HIV positive during pregnancy and chose to bring their pregnancies to term. After delivery, women-infant pairs were clinically followed through the early childhood period. Forty three percent of this study population was African-American, 36% Caucasian, 13% Latina, 6% Asian/Pacific Islander, 1% Hatian, and 1% Native American. HIV transmission risk categories for the entire group were 36% injection drug users (IDU), 9% transfusion, and 54% heterosexual sex. BAPAC receives HIV seropositive subject referrals primarily from UCSF's and SFGH's obstetric and family practice clinics, as well as regional clinical sites in the greater Bay Area.

At the time of this study, 8 seropositive women-infant pairs had moved from the geographic area and were considered inactive subjects. Fifteen women could not be contacted due to illness or incarceration. Of the 27 women contacted, 22 agreed to participate in the study protocol. The 5 non-participants either failed to respond or declined participation due to scheduling difficulties.

An HIV seronegative comparison group of women was obtained from perinatal HIV screening done at UCSF obstetric and pediatric care sites between 1988-92. Members of the comparison group tested seronegative during the prenatal period, delivered an infant, and subsequently received personal primary and/or well baby care within the UCSF clinic system. Of 452 records reviewed, 62 women were identified as appropriate matches for the seropositive women and infant pairs. Of the 62 women contacted by mail, 20 agreed to participate in the interview. One woman refused, citing a negative experience on the SFGH obstetric service. The remaining 41 women were either non-respondents (26) or had moved and could not be contacted by mail or phone (15), reflecting a stability bias in the interviewed group. Twenty HIV seronegative women completed the interview and were compared to their seropositive counterparts.

A standardized interview was constructed around 6 a priori hypotheses (Appendix 2). To address these, a verbal questionnaire and 3 psychological inventories for stress, anxiety, and depression (Appendices 3-5) were used. For both seropositive and seronegative women, a study interviewer (PL, JCP) administered the verbal questionnaire and coded the women's responses. In addition, HIV seropositive women were asked standardized, open-ended questions about the impact of HIV on their lives. Their responses were carefully noted by the interviewer at the time of the interview. During a 4

month study period, all of the women were interviewed at least 6 months following delivery. All study participants gave informed consent for participation and were reimbursed for travel expenses and child care.

Statistical Methods

For dichotomous and polychotomous variables, the chi-square test was used to test for statistical significance except when the cell value was less than 5. In these cases, Fishers Exact test was used. For continuous variables, the paired t-test was used for comparisons between matched pairs. All p values are reported as calculated, and a p value of less than 0.05 was considered statistically significant. All tests were 2 tailed tests.

RESULTS

Study A: Maternal Comprehension of HIV Ab Test Purpose and Result Significance

Over a 2 month period, 32 consecutive postpartum women agreed to participate as interview research subjects. Seven of the 32 women interviewed had undergone prenatal screening and were shown to be HIV negative; they were retested at delivery to rule out a false negative result after recent infection. The racial demographics and socioeconomic status of the interviewed mothers reflected the distribution already reported for Study B (Table 1).

In response to this interview, most mothers understood that they had given permission for an HIV Ab test, but did not understand its clinical implications. Two of the 32 women (6%) could not recall the purpose of the cord blood test. Only 6 mothers (19%) believed that the HIV test evaluated their own serostatus. Thirteen (41%) believed that the test was only for the infant, and 11 (34%) thought it was for both mother and infant.

Most of the women appeared to understand the general concept of vertical transmission; however, 13 (41%) cited reasons other than "wanting to know if I have AIDS/HIV or the baby has AIDS/HIV" as the reason they consented to testing. These additional, more ambivalent motivations for consenting to the test ranged from acquiescence to the physician's or a parent's authority (16%) ("the doctor/my mom wanted me to") to confirmation of negative prenatal tests (22%).

Confusion about the implications of a positive test for both the mother and baby was prevalent. Twenty-two women (69%) viewed a positive cord blood result as indication that the mother was either infected with HIV or had AIDS. Eleven mothers (34%) believed that a positive test meant the baby had AIDS and another 5 (16%) said the baby would be infected with HIV. Notably, only 10 women (31%) knew that a positive test only indicates

a risk factor for infection in the baby and that the baby would require later testing. Six of the 9 women (67%) counseled by an attending physician understood the test's medical meaning, in contrast to just 4 of the 23 women (17%) counseled by house staff.

Despite the description of risks (confidentiality, loss of housing, insurance, and work) which is a component of the informed consent protocol, these mothers identified very few risks associated with the test for either themselves or their infants (Table 2). However, of the 9 women counseled by the attending physician, 6 (67%) could identify at least one risk, as could only 4% of those counseled by house staff. Echoing previous studies on informed consent in other settings, our population had a better understanding of test benefits than of risks (21, 22).

The mother's personal attitudes toward the HIV cord blood test were varied: the majority felt that the HIV test was not stressful, and most stated an interest in knowing their own serostatus. Nineteen study subjects (59%) reported no stress and 10 (31%) indicated only mild stress when discussing the test or waiting for results. Just 3 mothers (9%) reported moderate to high stress related to the cord blood test. Twenty-eight women (88%) said they intended to come back for the result. Only 3 women (9%) indicated that they would not return because they felt certain the test would be negative, and 1 woman said that she just did not want to know the result. Despite the frequency of a stated desire to know the test results, only 7 (22%) came to scheduled appointments in the hospital clinic to obtain these results.

Table 2: Study A--Maternal understanding of HIV antibody test risks and benefits

Maternal Response	Personal.n=32 (%)		Infant.n=32 (%)	
Risks				
None	25	(78)	28	(88)
One or more	7	(22)	4	(12)
Stress/other's knowledge	5	(16)	0	(0)
Socioeconomic	1	(3)	0	(0)
Unclear	3	(9)	4	(12)
Benefits				
None	8	(25)	8	(25)
One or more	24	(75)	24	(75)
Early treatment	18	(56)	18	(56)
"Just knowing"	10	(31)	10	(31)
Other	1	(3)	1	(3)

Study B: The Impact of HIV Ab Seropositivity on Newborn Disposition and Care

In this cross-sectional analysis, 13 newborns defined as cases had a positive cord blood ELISA test confirmed by Western Blot. Maternal race distribution included 9 African-Americans, 3 Caucasians and 1 Latina. Maternal age ranged from 24 to 40. Of the 13 infants, 10 showed signs of neonatal drug withdrawal; 8 were either premature or small for gestational age. Two died before 15 months of age, 1 of HIV-related illness. Three infants are now symptomatic with HIV-related illnesses. Of the 13 cases, 7 have seroreverted, and 1 infant has an indeterminate serostatus. Of 13 control infants, 10 experienced neonatal drug withdrawal; 6 were either premature or small for gestational age. With the exception of gastrointestinal surgery in one case infant, both the case and control infant groups required only routine neonatal care. Table 3 compares mean birth weights, gestational ages, and Apgar scores for cases and control infants. Although case infants tended to have smaller birth weights and lower gestational ages, this difference was not statistically significant given the sizes of the two groups.

Table 3: Study B--Birth weight, gestational age & Apgar scores for case & control infants

	Cases (n=13)		Controls (n=13)		
	x	sd	x	sd	
Birth weight (g)	2320.8	± 744.3	2770.0	± 533.0	p > 0.05
Gestational Age (weeks)	36.1	± 2.98	38.4	± 2.77	p > 0.05
Apgar					
1 minute	7.3	± 2.02	7.4	± 1.32	p > 0.1
5 minutes	8.6	± 0.75	8.7	± 0.48	p > 0.1

Seropositive newborns were discharged to their parents more frequently than their seronegative counterparts. Of the 13 cases discharged from the nursery between 1988 and 1990, 8 infants (62%) went home with a parent, 2 to extended family, and 3 to foster care. Of the matched controls, 4 (12%) were discharged to home, 6 to extended family, and 3 to foster care. Because the number of cases and controls was small, the difference in rate of discharge home with parents did not reach statistical significance (p=0.12).

During the first year of life, the seropositive infants received more complete follow-up care than did the controls. All case infants received appropriate follow-up care and vaccinations in contrast to only 6 (46%) of 13 control infants (p<0.01). Nine of the 13

cases were followed by BAPAC, a treatment and research group established to study perinatal HIV transmission in women and infant pairs, 1 through a foster care program for infants with special medical needs, and the remaining 3 were cared for by private physicians.

Study C: The Consequences of HIV Seropositivity for Mothers

The ethnic, socioeconomic, and HIV risk factors of the interviewed group closely reflected those of all women currently enrolled in BAPAC. Notably, study respondents were a group of seropositive pregnant women enrolled in an active clinical care and research protocol. Bay area seropositive pregnant women not enrolled in BAPAC may represent a more socially and psychologically fragile population. Table 4 compares the ethnicity, age distribution, HIV risk factors, income levels, and delivery dates of the 20 matched HIV positive and negative women.

When measured by standardized psychological scales for anxiety, stress, and depression, HIV seropositive women were expected to have increased negative psychological sequelae following identification of their HIV status when compared to seronegative counterparts. Both groups belong to sociodemographic groups which were at higher risk for increased stress, anxiety, and depression independent of their HIV status. Table 5 describes the mean scores on all 3 scales. On a 10 item perceived stress inventory, both groups of women scored similar, high mean scores when compared to population norms for women ($x=13.7 \pm 6.6$) (23). Seropositive women scored higher than the comparison group on the Center for Epidemiologic Studies Depression scale. While the difference between the two groups did not reach statistical significance, the mean depression score found for the HIV positive group was above the score used in the diagnosis of major depression ($x=16$). On the anxiety inventory, HIV positive women had a significantly higher mean score when compared to the seronegative women ($p=0.04$). Further, mean scores for the 3 women with known HIV infected children were markedly higher than the seropositive group (Stress=22, Anxiety=42, Depression=23).

Table 4: Study C--Maternal population characteristics

	HIV+ Women. n=20 (%)	HIV-Women. n=20 (%)
Ethnicity		
African-American	8 (40)	8 (40)
White	7 (35)	7 (35)
Latina	3 (15)	3 (15)
Asian/Pacific Islander	2 (10)	2 (10)
HIV Risk Factor		
Sexual Partner	12 (60)	12 (60)
IDU	5 (25)	5 (25)
Transfusion/Health Care Worker	3 (15)	3 (15)
Delivery Date Before Study		
6-12 months	7 (35)	7 (35)
12-24 months	7 (35)	11 (55)
>24 months	6 (30)	2 (10)
Current Household Income (dollars)		
< 500	0	5 (25)
500-999	13 (65)	12 (60)
1000-1999	7 (35)	3 (15)
>1999	0	0
Prior Household Income (dollars)		
<500	8 (40)	8 (40)
500-999	6 (30)	5 (25)
1000-1999	4 (20)	7 (35)
>1999	3 (10)	0
Age Range (years)	20-42	20-39

Table 5: Study C--Mean scores for stress, state anxiety, and depression inventories

	HIV+ (n=20)		HIV- (n=20)		
	mean	SD	mean	SD	
Stress	17.65	± 9.8	17.20	± 5.7	(p=0.84)
Anxiety	41.65	± 15	34.45	± 9.1	(p=0.04)
Depression	17.85	± 14	13.85	± 5.3	(p=0.15)

Additionally, qualitative reports from the study subjects provided specific information about the psychological impact of a positive HIV Ab test on these women. When one woman (IDU, child indeterminate) described how HIV had affected her life, she said, "I feel depressed, suicidal, but I can't tell anyone, not even here because they might take my son away." In contrast, others recounted that testing positive had a transformative effect on their lives. One women, a recovered IDU, remembered having the HIV test:

I was kind of expecting to be positive. I just expected that I would die soon. That's how you feel when you're using -- that you're going to die anyway. So what the hell, you go ahead and do whatever because you gave up on living. Kind of like suicide, but instead of doing it you wait for dying to happen to you.
(Child indeterminate)

Following her HIV test, she decided to carry her pregnancy to term, joined Narcotics Anonymous, and became a church activist. Another women described a similar experience:

When I found out I was positive I was in an emotional basin. It made me make some choices. I wanted to be married--not like I took the first thing out there, but I knew some things I wanted in my life. I got involved. I went to work as an herbalist. I volunteered in the community.
(Partner risk, child indeterminate)

A more frequent discussion of the mixed emotional impact of newly acknowledged HIV infection, parenting excitement and strain, and concern about the baby's future was characterized by this woman:

Some days I'm depressed, but there's a lot to do and I focus on the baby. He is my world. I have been given everything I want and had it taken away from me at the same time. I don't think I could go on without him.
(Partner risk, child indeterminate)

While increased discrimination and violations of patient confidentiality were expected after a positive HIV antibody test (24), the HIV positive women reported a lower incidence of health care refusal and general negative interactions with the health care system than their seronegative counterparts (Table 6). The 1 seropositive woman who reported refusal of health care following the HIV test cited payment problems as the reason. Similarly, the 3 seronegative women reporting care refusal noted payment and racial issues as the causes. While HIV positive women also had a lower "bad experience" score on a standardized scale (Appendix 6) than the comparison group, 7 seropositive (35%) and 0 seronegative women reported episodes of discrimination and loss of confidentiality in their interactions with the health care system related to the HIV test.

Table 6: Study C--Health care interactions

	HIV+ Women n=20 (%)	HIV- Women n=20 (%)	
Women refused care following HIV test:	1 (5)	3 (15)	(p=0.30)
	Mean Score	Mean Score	
Bad experience score* Range (0-15)	3.6 + 2.1	4.3 + 2.2	(p=0.30)

* See Appendix 6 scale

All of these episodes of discrimination occurred in health care settings other than the BAPAC clinic, or prior to the woman's enrollment in BAPAC. One woman who was HIV antibody tested in a city hospital clinic reported a direct violation of confidentiality: "The nurse at Highland broke confidentiality with my test results because I didn't tell anybody and pretty soon all my friends knew" (IDU risk, child indeterminate). Similarly, other women reported that medical staff had given them "funny looks" or had even been angered about the risk of HIV exposure: "One nurse was drawing my blood without gloves and I asked her to wear them. She wanted to know why and got angry with me when I told her" (Transfusion risk, child indeterminate). Others described the impact of inaccurate health

care delivery, as did one woman who was told by a United States Navy physician that she had "six months to live" following a positive HIV antibody test, and was offered no further treatment.

Women also reported conflicts with their physicians secondary to pregnancy. One seropositive woman was counseled to "have an abortion," and another with a late pregnancy was told to have a tubal ligation after delivery; the first refused and the second complied. Two other women described what happened when their doctors discovered they were both pregnant and HIV positive:

One doctor that I had for 8 years ran a pregnancy test on me. He knew that I was HIV positive from an insurance screen 6 months earlier. He acted like I was infected all of the time. When the pregnancy test came back positive, he said "why do you think you're pregnant?" like it was unthinkable. I never went back to him.
(Partner risk, child indeterminate)

One other thing I knew I wanted in my life was to have a baby. They wouldn't accept that at the Family Practice clinic. The doctor kept writing in the chart that I hadn't made up my mind about terminating the pregnancy. But I was very clear, I had a feeling. I'm psychic and could sense what would happen. And the baby's fine.
(Partner risk, child indeterminate)

Both women subsequently transferred their obstetric care to the BAPAC clinic. Such experiences demonstrate a potential outcome of directive medical counseling, as well as the complex negotiations between pregnant HIV positive women and their physicians.

Other seropositive women indicated that both they and their infants have been treated inappropriately by both physicians and medical staff, particularly in the newborn nursery. Two women's experiences characterized this interaction:

It seemed like all the other doctors and nurses knew about HIV from the chart. At least they all knew when they came in the room. They put a big sign on the baby's chart and wouldn't touch him without gloves. My family wanted to know what was going on, but I didn't want them to know. They acted like we were aliens.
(IDU risk, child indeterminate)

Kaiser never offers anything. You have to ask them first. When I had my baby there...they wouldn't allow me in the room with another woman. They hung a big "Infectious Precautions" sign on my door. The only private room they had was like a closet. When the nurses touched my baby, they wore protection -- gloves and things.
(Partner risk, child indeterminate)

In several circumstances, vague or inappropriate hospital policy for newborn care led to confusion for parents, families and medical caretakers, and to a violation of the woman's confidentiality during the post-partum period.

While evidence suggests that HIV seropositive mothers experience diminished emotional support from their friends, families, and main sexual partners following a positive HIV antibody test, standardized, self-reported perceptions of satisfaction with social support did not differ dramatically from the HIV negative comparison group. In fact, greater numbers of HIV positive women reported being somewhat or very satisfied with the support they get from friends and family than their seronegative counterparts (Table 7). However, when seropositive women were asked who they had told about their HIV status, 13 (67%) had not told a single friend and 5 (25%) had not told any family members. Only one woman had not disclosed her status to a primary sexual partner who lives out of the country.

Table 7: Study C--Perceived level of support from friends and family

	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
Very or somewhat satisfied with support from friends	20 (100)	15 (75)	(p=0.02)
Very or somewhat satisfied with support from family	16 (80)	15 (75)	(p=0.50)

The seropositive women who had not disclosed their HIV status to either friends or family cited lack of public knowledge about HIV infection and fear of rejection as the reasons. One woman, who described her friends and family as generally "very supportive" said:

My friends aren't educated in regard to HIV. They are supportive and mature people, but none of them know my status. None of my family knows about my HIV status either. My mother wouldn't be able to understand what HIV positive is.
(IDU risk, child indeterminate)

Unable to locate support through her trusted social network, another women felt that she could not ask her brother for life insurance advice, saying "I can't disclose to my family

because I know what my brothers would think--'How many men were you with?'"
(Partner risk, child uninfected).

In fact, after disclosing their serostatus, several women were confronted with actual rejection, betrayal, or an isolating silence. After notifying her roommate out of social obligation, one woman experienced a loss of privacy:

I only told the woman I lived with at first. I thought it would be fair to let her choose if she wanted me in the house. And then she told her boyfriend and he told his and he told his old girlfriend, and that was right around the time I had to go to jail and the rumor went all around...I learned to be careful who you trust. Now I don't tell any friends; they don't even know what it means, really.

(Partner risk, child indeterminate)

Other women who sought commitments from friends or family for long range child care planning were met with uncertain support: "I told my family-- they all live in the South-- about my HIV status. My brothers said they'd take care of my children, but they haven't been in touch since then." (Partner risk, child indeterminate). Some of the women attributed their own difficulty in locating support to the public stigma of HIV seropositivity: "There is too much taboo about HIV. I can't look for the support I'd normally have. The public doesn't know much and it was worse before Magic Johnson announced he was HIV positive" (Partner risk, child uninfected), and to the social isolation of women in general:

Positive women are like wall flowers...Men have a community, a sense of humor about being positive. Women are different. I've tried to start groups, but the women never come. Maybe they have too many other demands on them. They seem to be so isolated from each other.

(Partner risk, child uninfected)

While seropositive women showed unexpected satisfaction with general support from friends and family on a standardized scale, they reported less satisfaction with their primary sexual partner than their seronegative counterparts (Table 8). They also had increased upheaval in their primary sexual relationships following the HIV test. While the comparison group reflected expected patterns of increased marriage/marriage equivalence after child bearing, the seropositive women had both a higher rate of separation in those previously married and lower rate of marriage in those previously single. Because of the small sample size, these rates reflect only trends in the disruptive impact of a positive HIV test on these women's relationships.

Table 8: Study C--Impact of HIV seropositivity on relationship with primary sexual partner

	HIV+ Women (n=17) (%)	HIV- Women (n=18) (%)	
Very or somewhat satisfied with support from main sexual partner	11 (65)	15 (83)	(p=0.19)
	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
With primary sexual partner/married before HIV test	16 (80)	10 (50)	
With partner after HIV test	7/16 (44)	8/10 (80)	(p=0.08)
Separated since test	8/16 (50)	2/10 (20)	(p=0.08)
Partner died since test	1/16 (6)	0/10 (0)	(p=0.62)
Without primary sexual partner/unmarried before HIV test	4 (20)	10 (50)	
Married/like married since HIV test	3/4 (75)	9/10 (90)	(p=0.51)
Remains single	1/4 (25)	1/10 (10)	(p=0.51)

The seropositive women reported that efforts to communicate HIV information to their partners often resulted in denial, anger, and sometimes abandonment. One woman, a recovered IDU, recounted her partner's response to her HIV infection:

Well, I've only told my partner and his mom about HIV. My boyfriend doesn't believe he can get sick. He pretends I don't have it. He doesn't see why I don't want to have sex all the time like before. He doesn't think he'll get it, so he won't use any protection. He won't talk about HIV.

(Partner risk, child indeterminate)

Several other subjects described the impact of HIV infection on an already strained relationship with their sexual partner. In the following, one woman told of the difficulty of seeking emotional support within a setting of guilt and powerlessness:

HIV has been real bad for me and my husband. I knew I was HIV positive before we met; he didn't know about it when we got involved and then married. He won't talk about it; he doesn't communicate at all. He gets violent you know... I thought he would leave when I told him about being HIV positive. He stood by us though, me and the kids. He's never left. And even though he's violent...I feel guilty about being positive and him always being there for us. We're under a lot of stress. If I get sick, I can't trust him to take care of the kids.

(IDU risk, child infected)

Communication difficulties with a main sexual partner were a central issue particularly when negotiating safer sexual behavior.

Even though all of the sexually active seropositive women had disclosed their HIV status to current or recent main sexual partners (n=18), many did not know their partner's serostatus. The low rate of awareness about the partner's status was similar for both seropositive and seronegative groups (Table 9). Although HIV positive women were expected to have significantly decreased high risk sexual behavior when compared to seronegative women, the majority of sexually active seropositive women rarely if ever used condoms during sexual intercourse with their male partners--much like their seronegative counterparts. Of particular concern was the high number of women in both groups having sex without condoms whose partners had an unknown serostatus, and those seropositive women having unprotected sex with seronegative partners (Table 10).

Table 9: Study C--Knowledge of partner's HIV status

Partner's status	HIV+ Women (n=18) (%)	HIV- Women (n=18) (%)	
Unaware of male partner's HIV status	8 (44)	9 (50)	(p=0.74)

Note: value of χ^2 varies due to subjects' changing relationships with partners

Table 10: Study C--Changes in risk taking sexual behavior

Condom use	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
No sex currently	5 (25)	5 (25)	(p=0.72)
Sexually active since test	15 (75)	15 (75)	(p=0.72)
Always use condoms	6/15 (40)	3/15 (20)	(p=0.21)
Sometimes/never use	9/15 (60)	12/15 (80)	(p=0.21)
Partner positive	2/9 (22)	0/12 (0)	(p=0.17)
Partner negative	2/9 (22)	5/12 (42)	(p=0.32)
Partner unknown	5/9 (56)	7/12 (58)	(p=0.62)

The high number of sexually active seropositive women still engaging in unprotected sex with their main partners was explained primarily as the partner's decision. This is reflected in earlier reported remarks, and typified by this woman's statement: "He hasn't been tested for HIV, or if he has he hasn't told me. We don't use condoms -- that's his choice" (IDU, one child infected). Another woman described her efforts to use safer sex practices with her husband after learning of her serostatus:

I want to tell you the truth about my marriage. My husband moved away after the test. He wanted to have sex, and when I put on the condom, he took it off. He said he wasn't afraid of getting it; he'd been having sex with me for two years now. I couldn't do that.

(Transfusion risk, child indeterminate)

Despite the risk of reinfection for partners who are both seropositive, the two women in such partnerships rarely used condoms: "We always seem to get too excited to wait to put it on. Also, we figure we are both positive, so it doesn't matter" (IDU risk, child infected). The significant number of seropositive women who were able to negotiate condom use with their partners described a greater sense of control over their lives: "I live each day to the fullest. It's like I came out of the clouds and now I know what I want. We have money, we don't want for anything. Now I'm more serious, more health oriented. I never have unprotected sex" (Partner risk, child indeterminate).

While sexual risk taking behaviors were not significantly reduced in the seropositive women, some high risk health behaviors were decreased following the HIV Ab test. Of the 13 seropositive women who used alcohol prior to their HIV test, all had decreased their

decreased their weekly intake, as had only half the seronegative women ($p < 0.05$). The majority of both HIV positive and negative women with a history of non-IDU reported a decreased frequency of other drug use. Of the 5 IDU in both the HIV positive women and comparison group, all of those with a history of sharing needles had ceased this activity following HIV testing and counseling (Table 11).

Table 11: Study C--Changes in risk taking health behaviors

	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
Never used alcohol	7 (35)	8 (40)	(p=1.0)
Prior alcohol use	13 (65)	12 (60)	(p=1.0)
Decreased use	13/13 (100)	6/12 (50)	(p=0.00)
Increased use	0/13 (0)	3/12 (25)	(p=0.10)
Same use	0/13 (0)	3/12 (25)	(p=0.10)
Never used drugs	8 (40)	8 (40)	(p=0.75)
Prior drug use	12 (60)	12 (60)	(p=0.75)
Decreased use	9/12 (75)	8/12 (67)	(p=0.50)
Increased use	1/12 (8)	2/12 (17)	(p=0.50)
Same use	2/12 (17)	3/12 (25)	(p=0.50)
History of IDU	5 (25)	5 (25)	(p=0.72)
Women sharing needles prior to test	4/5 (80)	5/5 (100)	(p=0.50)
Number of those sharing needles who stopped after HIV test	4/4 (100)	5/5 (100)	(p=0.99)

Surprisingly, evidence of increased socioeconomic losses in other seropositive populations was not seen in the HIV positive women in our study. While 5 (25%) of seropositive women lost major medical insurance due to divorce or their partner's unemployment, similar losses were seen in the comparison group (10%). Moreover, 2 women in both study groups gained a major medical policy following their HIV test. Some women in both groups had no insurance policy prior to their pregnancies, but gained

Medicaid during this period. Similarly, both study groups had comparable rates of change in monthly family income levels, with 7 (35%) experiencing decreases (Table 12). Following the HIV test, 1 woman in each group lost a shared apartment, with the seropositive woman moving to a housing project and the seronegative becoming homeless for a period of time. The majority of women in both groups remained in a shared apartment or house rental after finding out their HIV results.

Table 12: Study C--Changes in insurance, income and housing

	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
Lost major medical insurance	5 (25)	2 (10)	(p=0.20)
Gained Major medical	2 (10)	2 (10)	(p=0.70)
Gained Medicaid	3 (15)	8 (40)	(p=0.08)
Insured, no change	10 (50)	8 (40)	(p=0.75)
Decreased household income	7 (35)	7 (35)	(p=0.74)
Increased household income	8 (40)	8 (40)	(p=0.75)
No change	5 (25)	5 (25)	(p=0.72)
Lost apartment	1 (5)	1 (5)	(p=0.76)
Gained improved housing	5 (25)	4 (20)	(p=0.53)
No change	14 (70)	15 (75)	(p=1.0)

As expected, most HIV positive women planned to have fewer or no more children, as did only 15% of the comparison group (p=0.05). Six seropositive and 2 seronegative women had tubal ligations following delivery of their children. However, the majority of HIV positive women able to become pregnant said that they would definitely carry a future pregnancy to term, and 3 more of this group responded "Don't know." Only 3 (21%) seropositive and 1 (6%) seronegative woman indicated that they would abort a future pregnancy should it occur (p=NS) (Table 13).

Table 13: Changes in child bearing plans

	HIV+ Women (n=20) (%)	HIV- Women (n=20) (%)	
Changed plans for number of desired children	17 (85)	3 (15)	(p=0.00)
No more:	20 (60)	2 (10)	(p=0.00)
Fewer:	5 (25)	1 (5)	(p=0.09)
No change	3 (15)	17 (85)	(p=0.00)
Had Tubal Ligation	6 (30)	2 (10)	(p=0.12)
Able to become pregnant	14 (70)	18 (90)	(p=0.12)
Will bring pregnancy to term	8/14 (57)	16/18 (89)	(p<0.05)
Will abort pregnancy	3/14 (21)	1/18 (6)	(p=0.21)
Don't know	3/14 (21)	1/18 (6)	(p=0.21)

When asked open-ended questions about how their HIV status would influence future child bearing, seropositive women provided a range of responses reflecting the heterogeneity of the study group. In cases of early or prior serostatus knowledge, several women had already weighed the odds of carrying a pregnancy to term, determining the best path for themselves and their families:

I think we (husband and speaker) understand each other better now, that things are better since HIV. We planned to have the baby after I had 2 abortions. We weighed the odds, you know. My husband really wanted a boy of his own...We've got 6 kids living with us, my 15 and 9 year old, his 15 year old girl, and a 14 and 10 year old nephew and niece. And now the baby. We've been lucky.
(IDU, child indeterminate)

Among the majority of seropositive women who had decided to limit future childbearing, but who would not abort a future pregnancy, most rejected abortion as an acceptable option, and several invoked a larger power such as fate or religion in their reasoning:

HIV is just part of my life. I focus on the baby and positive aspects of life, on having fun. I get sad about not getting to see my son grow up. I pray this doesn't affect him. I used to want three kids, but now I only want two. I'm going to space them

out more so that I'm sure I'm strong enough to do it. You can't know about the future anyway. I could be hit by a bus or car or get cancer. I have to live day-to-day.
(Partner risk, child indeterminate)

If I get pregnant again, I would have the baby. I don't plan on having another, but god only gives us how much we can handle. My 15 month old is negative. If I had another and the baby was positive, that would be god's destiny.
(Partner risk, child indeterminate)

Notably, of the 3 HIV positive women with HIV infected children, 1 had a tubal ligation, a second indicated she did not plan to have more children secondary to her illness, but she did "not believe in abortion," and the third said she would have an abortion if she became pregnant in the future: "I wished I found out sooner (with prior pregnancy) -- I would never bring a child into the world for this. It was too late to have an abortion when I knew" (IDU risk).

DISCUSSION

This study series evaluates both the strengths and weaknesses of current perinatal HIV testing for women and infant pairs in the setting of a model urban HIV health care delivery program (BAPAC). While Studies A and B were conducted in a postnatal setting and Study C examined a population defined as seropositive in the prenatal period, all 3 populations shared similar ethnic, socioeconomic, and HIV transmission risk distributions, as well as a common health care delivery setting. In this evaluation of postnatal informed consent and counseling within a large urban nursery, confusion about the meaning of a positive test indicates that many women compromise their privacy without fully appreciating personal risks or benefits associated with the HIV test. However, review of the infant population demonstrates that determination of HIV seropositivity was associated with both a higher rate of discharge home with parents and better medical care for infants.

Just as for the infant follow-up study, the impact of a positive HIV Ab test for women in this study population must be evaluated against the background of a population already at high risk for negative socioeconomic and psychological outcomes. In this maternal population, determination of seropositivity presented a complex constellation of both benefits and risks. Several of the measured outcomes countered our expected a priori hypotheses about the impact of seropositivity on this group. Despite an absence of greater economic losses than their seronegative counterparts, the HIV positive women did have increased measures of anxiety and depression, as well as with a notable incidence of negative interactions health care system. More complete information on how HIV infection has affected this population is provided by the seropositive mothers' qualitative responses.

While the cumulative data from these studies suggest many benefits to early HIV status identification for each study population, special care must be taken to verify that the HIV testing and counseling, as well as social and health care services, maximize benefits and reduce risks for both women and their infants (25).

Study A: Perinatal HIV Ab Informed Consent and Pre-test Counseling: How much does the mother understand?

Our study indicates that current informed consent procedures do not ensure the mother's understanding of the test's medical implications or socioeconomic risks. In any setting, ethical informed consent requires that a competent individual select or reject a recommended procedure or treatment after understanding all reasonable risks associated with that therapy, and any alternative procedures. Informed consent for newborn care is more complicated, requiring a proxy decision maker, usually the parent(s). Conflict may arise when the infant's providers, the parent(s), and, in some instances, the state disagree about what is best for the newborn. The situation is further complicated in the case of HIV cord blood testing because the test, ostensibly an evaluation of the infant's blood, actually provides information about the mother's status.

Today, HIV seropositivity still generates a highly charged social response. Given clear demonstrations of violations of confidentiality within the health care and social service system within our own study and others (24), and the lack of adequate social and health services for women who do test positive, the mother's individual circumstances may reasonably warrant an estimation of risk which outweighs the current medical benefits of the HIV Ab test (25). Hence, our current refusal rate of 9% for cord blood testing may be an acceptable, if not optimal, outcome. Greater refusal rates such as those reported by the NYS Department of Public Health (1992) are of concern in a setting of high seroprevalence, and may suggest the need for a large scale evaluation of testing informed consent and counseling protocol (8). With the future promise of better diagnostic tests, zidovudine, and other treatments for HIV diseases, the precarious balance of rights between the proxy-mother and her infant may increasingly favor testing.

In addition to an evaluation of proxy decision-making, these results raise concerns about the methods of HIV counseling and testing in this population. Different possibilities exist which might explain why these mothers were unable to reiterate the meaning of HIV cord blood testing. First, while compromised by clinical concerns, the postpartum hospitalization may be the only practical period to undertake HIV counseling and testing because these women frequently receive little or no prenatal care and often lose contact with the health care system after hospital discharge. Second, the mother's limited understanding

of the medical implications and socioeconomic risks associated with a positive HIV test may also reflect problems with physician's ability to communicate during the informed consent discussion. When conducted by the infant's physician, postnatal HIV testing may be especially problematic, since the pediatrician is focused primarily on the infant's medical needs and may not accurately assess the mother's understanding. A perinatal HIV Ab test is relatively difficult to comprehend, and the concept of maternal antibodies implying the possibility of infection in the newborn is abstract. Ideally, HIV testing and counseling for women should be done during routine medical or gynecologic care, when the physician or counseling service can focus their attention on HIV education.

The simplest explanation for these mothers' decisions to accept testing without fully understanding the test's implications may be that the risks discussed during the current protocol bear little relation to their own perceptions of risk. The HIV Ab positive mothers are largely unemployed and on Medicaid; they have been referred for testing due to a history of injection drug use, physical abuse, homelessness, or a partner's risk behavior. A positive test outcome cannot remove financial and social advantages that were never present. Less visible forms of discrimination, especially by family and friends, are more difficult to measure, yet may have a much greater effect on the fabric of these women's lives. In our study and others, the women expressed concern primarily about the repercussions of a positive test result on their relationships -- anger or alienation from their partner, parents, or other family members (26).

The observation that 78% of those tested did not return for test results suggests a systemic failure of current counseling and testing to engage women at high risk for HIV infection into a comprehensive HIV prevention and care plan. Certainly, this result could imply a reluctance to engage the medical establishment or fear of a positive diagnosis; however, the majority of women indicated that they perceived few or no risks associated with the HIV Ab test. This suggests that other factors affected their decision not to return. Maternal understanding could be improved by a number of strategies which should be evaluated: 1) House staff training in informed consent and HIV counseling; 2) HIV counseling conducted by non-physician counselors; 3) Aggressive follow-up of all women tested in order to provide post-test counseling. Other opportunities for improved follow-up counseling include prompt availability of results, enabling serostatus determination and counseling to occur before the woman's discharge (27). Test counseling will also be improved when a diagnostic test capable of determining the newborn's viral status becomes widely available (28,29).

Study B: Postnatal HIV Antibody Testing-- What does it mean for the newborn?

HIV Ab testing in the nursery is best undertaken in the context of a comprehensive, multidisciplinary treatment and counseling program for both infants and their mothers (30,31). While most health care institutions have developed HIV testing policies designed to meet these goals, testing programs vary widely among hospitals. The successful follow-up seen in this SFGH group indicates the potential benefits of voluntary HIV testing in a model perinatal care program. In our infant study population, most case infants and their families became enrolled in HIV research and treatment programs (BAPAC). Because the mothers and infants were followed as pairs, BAPAC was able to provide psychological, medical, and social services aimed at the needs of both the mothers and infants. BAPAC included follow-up of women who did not return for test results, as well as reimbursement for child care and transportation expenses, a virtual necessity in this population. Further, BAPAC undoubtedly contributed to the high rate of discharge home with parents in this study population. Clearly, the outcome seen for the case infants contrasts with anecdotal evidence from high prevalence urban areas where HIV risk infants have been abandoned in large public hospitals (32).

While this testing program resulted in improved infant care, some risks to the infant associated with a positive cord blood test result remain to be evaluated. The seropositive infant may experience increased social risks, including abandonment by parents and barriers to adoption (33), as well as the potential risk of less aggressive medical care by health providers reluctant to treat such infants at-risk for HIV infection (17). However, only one infant in our group required aggressive medical treatment, which was performed promptly.

Study C: Perinatal HIV Ab Testing-- What does a positive test mean for women caring for their children

As in Study B, the measured impact of a positive HIV test on this study group must be partially interpreted as an evaluation of the mediating effect of BAPAC in the lives of a population at high risk for negative psychological and socioeconomic outcomes. Given the relatively low incidence of HIV seropositivity in Bay Area pregnant women, as well as the inherent recruitment difficulties in this often transient, high risk population, the study sample size primarily provides preliminary data which serves to identify areas for future study and interventions. The quantitative data compiled from the standardized behavioral questionnaire is contextualized by the narrative evidence given by study subjects. For some of the tested hypotheses, the parallel data set generated by open ended questions provides explanatory support for the standardized data, and for others, it describes an

alternate view of the women's lives. While the small sample size limits the power of comparison for the quantitative data, taken together, these interdependent sets of responses begin to elaborate the complex impact of HIV infection for the study women, as well as their families and communities. Further, the contrasting information provided by the two data sets for several of the hypotheses suggest limitations in the ability of standardized, quantitative questionnaires to probe psychological and cultural realities for this study population.

Surprisingly, HIV positive women and their children did not experience increased insurance, income, and housing losses when compared to the seronegative group. Of those who lost such services, none believed HIV discrimination to be the direct cause. Several explanations for the absence of economic losses are possible. First, none of the women in this study had been diagnosed with AIDS, and many had kept their seropositivity a secret from all but their partners and few family members. This level of non-disclosure may have precluded some negative repercussions. Second, as suggested by our earlier study, few of the women in either group had jobs or private insurance prior to the HIV test, and thus had little economic status to lose. In fact, for many women in this population, pregnancy often represents an initial intersection or renewal with the medical and social service system, which results in increased access to various supportive services, including insurance, and financial, drug rehabilitation, and continuity care enrollment. Most importantly, these seropositive women were enrolled in BAPAC, resulting in aggressive social services which may have minimized their losses.

More ambiguous results emerged from an evaluation of risk taking health behaviors in the study population. All of the women in this study were undoubtedly motivated to lessen drug and alcohol use during their pregnancies, but a significantly greater number of the seropositive women maintained a reduction in alcohol use beyond the post-partum period. Further, the majority of women in both groups decreased non-injection drug use and needle sharing. This study does not measure whether the overall substance use reductions were due to pregnancy and prenatal care or to HIV counseling and testing for both groups of women and subsequent social services for HIV positive women. To determine these differences would require a comparison group of recently delivered women who had not been HIV counseled or tested during pregnancy, an unlikely scenario given the population's risk factors for HIV infection.

When measured by a standardized scale, maternal seropositivity did not result in a higher rate of negative interactions with routine health. However, this scale failed to probe HIV-related problems associated with health care delivery, which were revealed by open ended responses. These provided a more detailed, if conflicting, account of how over one

third of seropositive women experienced various forms of discrimination, patient confidentiality violations, and inappropriate health care in many care settings, including health maintenance organizations, private medical offices, military, university, and county hospitals. In addition, several women were actively coerced by their physicians to change their child bearing plans. While the interviewed women were able to transfer their obstetric care to BAPAC, their experiences raise concerns about women who had no clinical alternatives or who had a more dependent relationship on their medical provider. For many HIV positive women, health care delivery became a site of public exposure and personal anxiety, where they were neither adequately supported nor educated about HIV transmission and infection. Only by enrolling in research protocol were most of the study women able to access multidisciplinary primary and HIV care in the setting of emotionally supportive services, a situation raising questions about the role of consent in clinical trials. Despite the common assumption that health care is an individual right in our society, many of the women in BAPAC travel significant distances and spend many hours involved in research protocols so that they can secure adequate and confidential care for themselves and their children.

The fear of abandonment expressed by the mothers during our prior evaluation of HIV Ab test counseling and informed consent was echoed by these seropositive women despite their quantified perceptions that both friends and family were generally supportive. In this case, the study survey may have failed to address the women's feelings about support in relationship to HIV infection. The majority of seropositive women had not told any friends about their HIV status, and several who did share the information were met with rejection or betrayal. Further, the high levels of anxiety and depression reported by these HIV positive women indicate significant psychological sequelae which have not been adequately addressed even within BAPAC. While these women represented a group with more stable social support than the larger seropositive female population, they often did not feel the current level of HIV knowledge within their communities was sufficient to protect their best interests among their closest personal contacts. For many of these women, as for all parents with HIV infection, social secrecy served to obstruct long term child care planning required by any terminal illness.

Perhaps the most complex and socially charged issues for the seropositive women emerged from their relationships with primary partners, including the negotiation of condom use and plans for future child bearing. While the higher incidence of relationship strain in the seropositive group was expected, their main sexual partners' frequent refusal to acknowledge their HIV infection was not. Most sexually active seropositive women were unable to negotiate regular condom use with their male partners. Despite aggressive

risk reduction counseling for BAPAC study subjects, over one half of the sexually active seropositive women could not persuade their male sexual partners to regularly wear condoms, and over half of these men had an unknown or negative serostatus. Of equal concern, the comparison group reported similar irregular use of condoms. While their persistent high risk behavior appears surprising, the women's narrative responses described their partners' denial of illness, lack of HIV transmission information, and refusal to engage the health care system. Additionally, some women, whether through denial or rational risk-benefit analysis, chose to accept the risk of vertical HIV transmission for a number of highly individual reasons, including family pressures or personal fulfillment in the context of a foreshortened future.

In summary, the data from Study C provide several surprises. As suggested earlier, this study sample represents a group of women actively involved in a comprehensive HIV research and care program. While we acknowledge BAPAC's role in diminishing the impact of HIV infection on the lives of these women, many negative consequences were still described. Further, much of the quantitative data generated by this necessarily small study sample does not reach statistical significance, and some of it directly contradicts the narrative information provided by the study subjects. We believe that the descriptive information reveals specific weaknesses in the standardized scales used to assess perceptions of support and discrimination, and provides important insight that may guide both perinatal HIV testing policy and further research and interventions for women and their families.

Perinatal HIV Ab Testing & Education Policy: Unanswered Questions

While most public health and care provider organizations agree that HIV testing, counseling, and treatment programs should be offered to pregnant and postpartum women, questions remain about the appropriate type of testing for these women. Some have suggested routine perinatal HIV screening programs on the grounds that targeted testing is both discriminatory (7) and fails to identify a significant portion of the HIV-infected population. As improved adult and infant HIV treatment or cures emerge, routine voluntary HIV testing for both pregnant and postpartum women will become essential, especially in high seroprevalence populations.

We believe that voluntary perinatal HIV Ab testing of women and children via written informed consent remains the most ethical and practical method for testing in current conditions (9). Knowledge of the mother's and infant's serostatus plays an important role in providing optimal care and social support for the family. This information should not, however, be obtained against the woman's wishes or without her understanding. To do so

would strain the maternal infant dyad under already fragile social circumstances. Even within this unusual comprehensive care environment (BAPAC), mothers with HIV disease face considerable psychological harm and risk of discrimination--both at home, in the community, and at the doctor's office. These results raise many questions about the both ethics of the current HIV Ab informed consent procedures, and the practice of confidentiality in obstetric and pediatric care settings. They also suggest that in our current social environment, women with HIV infection are forced to do the work of educating themselves, their families, and sometimes their health care workers about living with and preventing HIV infection.

As we advocate for more perinatal HIV Ab testing, we should define and implement counseling and testing procedures that do more than identify cases. We must develop HIV health care delivery, prevention, and education strategies not just for pregnant women and newborn infants, but for all women, as well as their partners, families, and communities. Specifically, we need a larger psychological needs assessment coupled with long term interventions to address increased anxiety and depression found in HIV positive women. To diminish negative health care interactions, we must develop confidential and non-directive continuity HIV care for women and children at one site. This care should include not only obstetric and pediatric services, but long-term women-focused primary care. Finally, to address diminished partner support and persistent unsafe sexual practice, we need further data on the cultural determinants of sexual behavior in this population, as well as health care and education programs targeting the women's sexual partners.

BIBLIOGRAPHY

1. Feinkind L, Minkoff HL: HIV in pregnancy. *Clin Perinatol*. 1988; 15:189-202.
2. Gwinn M, Pappaioanou M, George JR, et al. Prevalence of HIV infection in childbearing women in the United States: Surveillance using newborn blood samples. *JAMA*. 1991;265:1704-1708.
3. Centers for Disease Control: Update: Acquired Immunodeficiency Syndrome -- United States. *MMWR*: 1991: 463-68.
4. Centers for Disease Control: Recommendations for assisting in the prevention of perinatal transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus and acquired immunodeficiency syndrome. *MMWR*. 1985;34:721-732.
5. Partridge JC, Sokal KB, Wong DF, et al. Maternal history does not predict perinatal HIV exposure. *Pediatr Res*. 1990;27:251A (1492).
6. Capell FJ, Vugia DJ, Mordaunt VL, et al. Distribution of HIV Type I infection in childbearing women in California. *Amer J of Pub Health*. 1992; 82(2):254-6.
7. Working Group on HIV Testing of Pregnant Women and Newborns. HIV infection, pregnant women and newborns: a policy proposal for information and testing. *JAMA*. 1990;264:2416-2420.
8. New York State Public Health Department. Conference Communication: Project on HIV in the NICU. Columbia-Presbyterian Medical Center. October, 1992.
9. Wachter R, Cooke M, Brandeau M, et al. HIV testing of pregnant women and newborns (letter). *JAMA*. 1991;265:1525.
10. Almond B, Ulanowsky C. HIV and pregnancy. *Hastings Center Report*. 1990. March/April:16-21.
11. Centers for Disease Control: Publicly funded HIV counseling and testing--United States, 1985-1989. *MMWR*. 1990;39:137-140.
12. Committee on Ethics, The American College of Obstetricians and Gynecologists: Human immunodeficiency virus infection: physicians' responsibilities. *Obstet Gynecol*. 1990;75:1043-1045.
13. Bayer R, Levine C, Wolf SM: HIV antibody screening: an ethical framework for evaluating proposed programs. *JAMA*. 1986;256:1768-1774.
14. Katz S: Driving the sick underground: HIV testing--a phony cure. *The Nation*. May 28, 1990:738-742.
15. European Collaborative Study. Mother-to-child transmission of HIV infection. *Lancet* 1988; 2:1039-1042.

16. Italian Multicentre Study. Epidemiology, clinical features, and prognostic factors of pediatric HIV infection. *Lancet* 1988;2:1043-1045.
17. Levin B, Driscoll J, Fleischman A: Treatment choice for infants in the NICU at risk for AIDS. *JAMA*. 1991;265:2976-81.
18. Kaunitz AM, Brewer JL, Paryani SG, deSausure L, Sanchez-Ramos L, Harrington P: Prenatal care and HIV screening. *JAMA*. 1987;258:2693.
19. Strong C: Ethical conflicts between mother and fetus in obstetrics. *Clin Perinatol*. 1987;14:313-328.
20. Kliegman RM: Bioethics of mother, fetus, and newborn. In Fanaroff AA, Martin RJ, eds. *Neonatal-perinatal medicine: diseases of the fetus and infant*. St. Louis, Mo: CV Mosby Company;1987:280-292.
21. Cassileth B, Zupkis R, Sutton-Smith K, March V: Informed consent--why are its goals imperfectly realized? *N Engl J Med*. 1980; 302:896-900.
22. Wu W, Pearlman R: Consent in medical decision making: the role of communication. *J Gen Intern Med*. 1988;3:9-14.
23. Cohen S, Williamson G. Perceived stress in a probability sample of the United States. In Oskamp S, Spacapan S, eds. *The social psychology of health: Claremont symposium on applied social psychology*. Newbury Park, California: Sage. 1988:31-67.
24. Brown K: Descriptive and normative ethics: class, context and confidentiality for mothers with HIV. *Soc Sci Med*: publication forthcoming.
25. Nolan K: Ethical issues in caring for pregnant women and newborns at risk for human immunodeficiency virus infection. *Semin Perinatol*. 1989;13:55-65.
26. O'Campo P, Faden R, Kass N, Gielen A, Geller G, and Project S.T.A.R.R. Research Team: Pregnant women's attitudes about HIV antibody testing. Presented at the Sixth International Conference on AIDS, San Francisco, June 21, 1990.
27. Caspe W, Hand I, Ballard C: HIV testing in a high-risk post-partum population. Bronx Lebanon Hospital Center, Albert Einstein College of Medicine, Bronx NY. Presented at the Sixth International Conference on AIDS, San Francisco, June 23, 1990.
28. Rogers MF, Ou C-H, Rayfield M, Thomas PA, Schoenbaum EE, Abrams E, et al: Use of the polymerase chain reaction for early detection of the proviral sequences of human immunodeficiency virus in infants born to seropositive mothers. *N Engl J Med*. 1989;320:1649-1654.
29. Weiblen BJ, Lee FK, Cooper ER, Landesman SH, McIntosh K, Harris J-AS, et al: Early diagnosis of HIV infection in infants by detection of IgA HIV antibodies. *Lancet*. 1990;335:988-90.
30. Fraulino LJ, Simpson BJ: The AIDS epidemic: developing an institutional response. *Semin Perinatol*. 1989;13:44-48.

31. **Minkoff HL, Landesman SH: The case for routinely offering prenatal testing for human immunodeficiency virus. Am J Obstet Gynecol. 1988;159:793-796.**
32. **Macklin R: HIV infection in children: some ethical conflicts. Technical report on developmental disabilities and HIV infection. American Association of University Affiliated Programs. September, 1989;3:1-4.**
33. **Hankins CA: Issues involving women, children, and AIDS primarily in the developed world. J Acquir Immune Defic Syndr. 1990;3:443-448.**

APPENDIX 1

Interview to assess maternal understanding of HIV antibody test informed consent

- 1) What was the purpose of the cord blood test?**
- 2) Why did you agree to have the test done?**
- 3) What were the test's risks and benefits for you and your baby?**
- 4) What would a positive and negative test mean for both you and your infant?**
- 5) Did hearing or thinking about the test upset or worry you at all?**
- 6) Do you intend to come back to find out the test results? Why or why not?**

APPENDIX 2

Study Hypotheses--Expected differences between HIV positive and negative women

1. HIV positive women were expected to have increased negative psychological sequelae when compared to their seronegative counterparts.
2. HIV positive women experience more discrimination when seeking health care than their seronegative counterparts.
3. HIV positive women experience decreased social support and increased abandonment when compared to their seronegative counterparts.
4. HIV positive women have a decreased incidence of risk taking behaviors when compared to their seronegative counterparts.
5. HIV positive women were expected to have an increased incidence of socioeconomic losses when compared to their seronegative counterparts.
6. HIV positive women were expected to have changed their plans for future child bearing when compared with controls.

APPENDIX 3

Perceived stress inventory

	Almost Never	Some- times	Fairly Often	Very Often	Never
In the last month, how often have you...					
1. Been upset because of something that happened unexpectedly	0	1	2	3	4
2. Felt that you were unable to control the important things in your life	0	1	2	3	4
3. Felt nervous and "stressed"	0	1	2	3	4
4. Felt confident about your ability to handle your personal problems	0	1	2	3	4
5. Felt that things were going your way	0	1	2	3	4
6. Found that you could not cope with all the things you had to do	0	1	2	3	4
7. Been able to control irritations in your life	0	1	2	3	4
8. Felt that you were on top of things	0	1	2	3	4
9. Been angered because of things that happened that were outside of your control	0	1	2	3	4
10. Felt difficulties were piling up so high that you couldn't overcome them	0	1	2	3	4

(Cohen, S., Kamarack, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 385-396.)

APPENDIX 4

State anxiety inventory

	Not at all	Somewhat	Moderately so	Very much so
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I am regretful	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel rested	1	2	3	4
9. I feel anxious	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I am jittery	1	2	3	4
14. I feel high-strung	1	2	3	4
15. I am relaxed	1	2	3	4
16. I feel content	1	2	3	4
17. I am worried	1	2	3	4
18. I feel over-excited and "rattled"	1	2	3	4
19. I feel joyful	1	2	3	4

20. I feel pleasant 1 2 3 4

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APPENDIX 5

Center for Epidemiologic Studies--Depression Scale (CES-D)

	1 Day	1-2 Days	3-4 Days	5-7 Days
During the past week:				
1. I was bothered by things that usually don't bother me	0	1	2	3
2. I did not feel like eating; my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help from my family or friends	0	1	2	3
4. I felt that I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3
13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3

18. I felt sad	0	1	2	3
19. I felt that people disliked me	0	1	2	3
20. I could not get "going."	0	1	2	3

APPENDIX 6

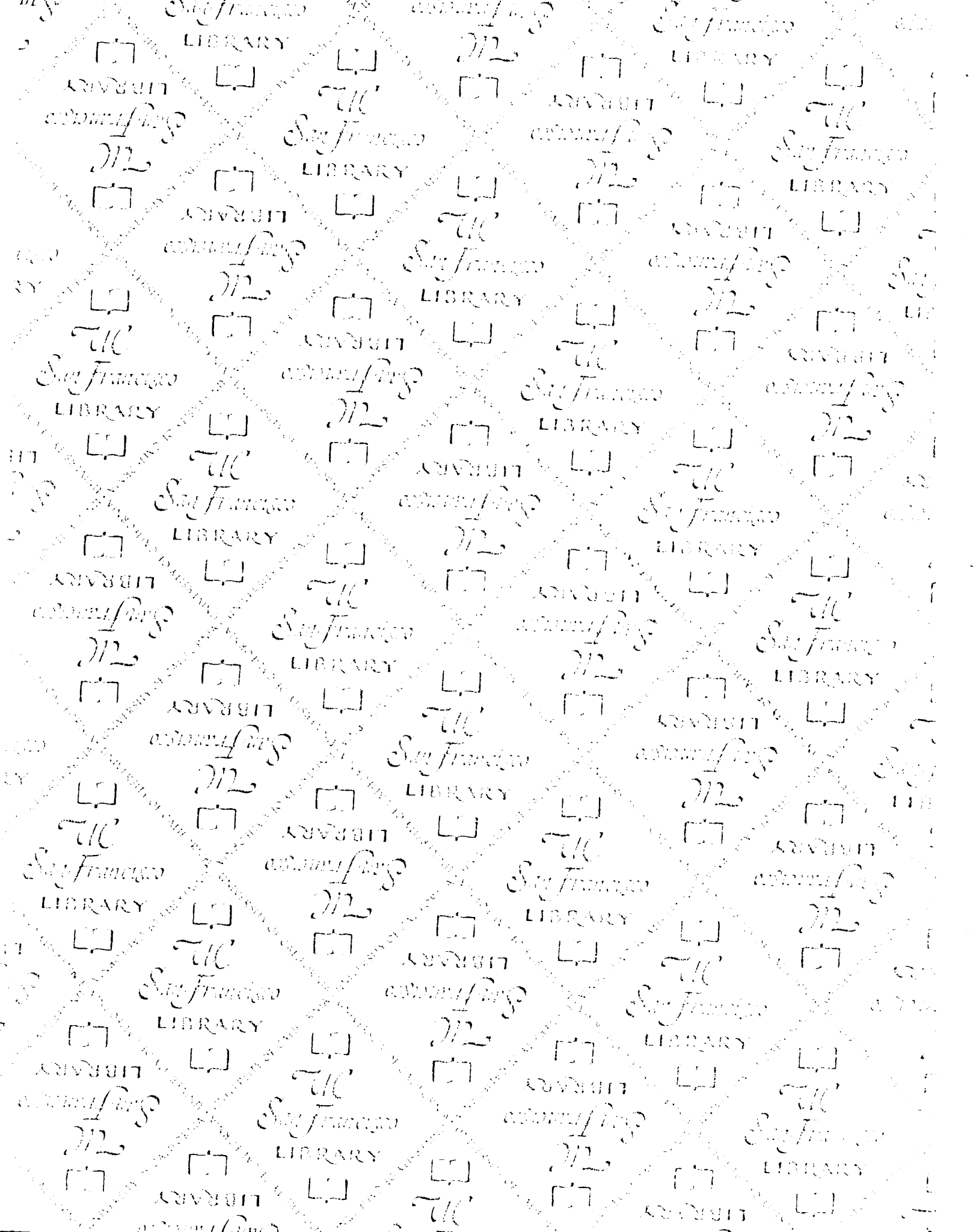
Negative health care interaction scale

Instructions: Some women have had bad experiences when they seek health care. I am going to read some of the negative experiences women have reported. Please tell me if any of these things have happened to you never, almost never, almost always, or always when going to medical people such as doctors, nurses, and physician assistants.

	<u>Never</u>	<u>Almost Never</u>	<u>Almost Always</u>	<u>Always</u>
I had to wait a long time	0	1	2	3
They talked loudly about me in front of others	0	1	2	3
I see a different person every time I go	0	1	2	3
They acted like my sickness was my fault	0	1	2	3
They were rude to me	0	1	2	3
Other experiences:				

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