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INJECTION AND NON-INJECTION DRUG USERS' BELIEFS ON MANDATORY NEWBORN HIV TESTING LAWS IN THE STATE OF CONNECTICUT

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INJECTION AND NON-INJECTION DRUG USERS' BELIEFS ON MANDATORY NEWBORN HIV TESTING LAWS IN THE STATE OF CONNECTICUT

A Thesis Submitted to the Yale University School of Medicine in Partial
Fulfillment of the Requirements for the Degree of Doctor of Medicine

By

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2006

DRUG USERS' BELIEFS ON MANDATORY NEWBORN HIV TESTING IN THE STATE OF CONNECTICUT.

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We examined health beliefs among drug users about mandatory HIV testing of newborns and voluntary versus mandatory testing of pregnant women. We also examined to what extent negative experiences and stigmatization affect attitudes towards HIV testing**.**

Baseline structured interviews of active drug users from 1997-2001 were examined. Multivariate data analysis was performed using SAS statistical software. Subsequently, five distinct focus groups were conducted in September 2003. Focus groups were transcribed, coded and analyzed using Microsoft Word 2000.

Of 610 drug users interviewed, nearly all (89%) had been previously HIV tested. Nearly all (91%) subjects believed pregnant women should be tested for HIV. More subjects who had prior HIV testing believed all pregnant women should be HIV tested (92.9% vs. 82.6%, $p=0.008$). Though 86% of subjects agreed with testing of all newborns, only 57% of all subjects believed that this should be mandatory. Among women, however, more injectors than non-injectors would avoid prenatal care if HIV testing was required during pregnancy (16.2% vs. 6.1%, $p<0.01$). Of the 499 subjects reporting a usual site for care, 31.8% believed that "certain types of people" received better treatment than others. Not using drugs, being of a certain race/ethnicity, and having private insurance were associated with receiving better care. Perceived discrimination by the healthcare system was also cited as a barrier to acceptance of testing strategies. In the focus groups, arguments against mandatory testing of pregnant women included the loss of choice, right not to know HIV status, and the belief that mandatory testing was both a means of provoking rebellion and promoting discrimination. Concern for the baby's health was the primary reason for supporting mandatory newborn testing.

The current practice of mandatory newborn and voluntary prenatal screening for HIV in Connecticut appears to have been acceptable to a population of stigmatized drug users with or at risk for HIV. Despite acceptance, perceived discrimination by the healthcare system persists and may result in adverse outcomes for drug using men and women.

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I. INTRODUCTION

Pediatric acquired immunodeficiency syndrome (AIDS) is now a chronic disease, with those infected now living well into adulthood. As a result of an evolving epidemic, most pediatric AIDS results from maternal to child transmission (MTCT). Through many policy changes and laws, states such as Connecticut have aggressively sought ways to eradicate perinatal transmission. Despite advances in both antiretroviral and obstetrical interventions, perinatal human immunodeficiency virus (HIV) transmission continues to occur in the United States. MTCT occurs largely due to missed opportunities for prevention, namely among women who are not receiving prenatal care (1) or are not being tested during prenatal care (2). In addition, suboptimal use of antiretroviral medications in HIV-infected pregnant women continues to allow for transmission to occur.

In 1994, the AIDS Clinical Trials Study Group 076 (PACTG 076) published the results of their randomized, double-blind, placebo-controlled trial designed to test the efficacy of zidovudine (AZT) in decreasing vertical transmission of HIV. The HIV positive women in the treatment arm had received oral AZT throughout their pregnancy. In addition, AZT was given intravenously during the labor and infants were started at birth on oral drug to complete six weeks of therapy. The results of this trial demonstrated that zidovudine (AZT) reduced vertical transmission from 25% to 8% (3). Studies by the International Perinatal HIV group later proved that Caesarean section could reduce transmission by 50% (4). With the implementation of these regimens, by the year 1999 there had been an 83% decline in perinatal HIV cases compared with 1992 (5). Despite these advances, the Centers for Disease Control (CDC) estimates that between 280 and 370 infants continue to be born with HIV infection each year in the U.S. (6)

Since the CDC's initial issuance of guidelines, much debate has occurred over developing policies to most effectively reduce MTCT. In addition, many revisions to policies have occurred. Although HIV/AIDS appeared globally in the early 1980's, the development of a coordinated governmental policy response would be years in the making. The initial casting of the epidemic was as one affecting gay white men predominantly. Nearly a decade passed before the government acknowledged the high rates of HIV infection in mostly poor and minority women and children. As a response to the PACTG 076 results, the CDC issued guidelines in 1995 stating that pregnant, HIV-infected women should be offered antiretroviral therapy. Specifically, these guidelines promoted voluntary counseling and testing. Outside the health care arena, in 1996 Congress' attention was gained, leading to reauthorization of the Ryan White Comprehensive AIDS Resources (CARE) Act of 1990. This legislation gave funds to states, hospitals, and cities with high numbers of AIDS cases to provide treatment and support for persons living with the disease. The 1996 amendments represented the first time Congress had addressed MTCT. The new requirement was such that all states were admonished to adopt the CDC's guidelines for HIV counseling and voluntary testing for pregnant women. States were penalized such that by failing to adopt these guidelines, they risked loss of funding. To evaluate state efforts to reduce perinatal HIV transmission, Congress then requested that the National Academy of Science conduct a study of state compliance.

Stemming from the congressionally commissioned study, the Institute of Medicine (IOM) issued a report in 1999 recommending “that the United States adopt a policy of universal HIV testing with patient notification, as a routine component of prenatal care”. Universal testing means that all pregnant women will be offered testing, regardless of risk status. Under routine testing, a woman is told that HIV testing will be performed with a battery of prenatal screening tests unless she specifically declines (7). As women are not explicitly asked to accept testing, this is also known as the opt-out approach. This policy is in contrast to both voluntary testing (where an individual must explicitly accept the offer of an HIV test with written consent required or recommended) and mandatory testing (which carries no option for refusing a test). Voluntary testing is also known as the opt-in consent approach. Previously, the IOM supported universal HIV counseling and voluntary testing. The continued occurrence of pediatric HIV cases in the face of this policy, however, prompted a revision of their position statement.

Though implementation of new state and federal guidelines led to an increase in HIV testing, the goal of testing all pregnant women had not been met by the year 2000. This then prompted the CDC to revise it’s recommendations for HIV counseling and testing of pregnant women in the year 2000. The main change in the new guidelines was the decreased emphasis on pretest counseling and simplification of the consent process. They did, however, continue to advocate the voluntary, ‘opt-in’ consent process (8). With much progress to be made before eradication of infection of newborns, the CDC continued to seek more aggressive ways to combat MTCT. The advent of rapid HIV testing, which could be used to screen women in labor and allow them to begin intrapartum antiretroviral therapy, provided another avenue to support screening women at delivery. In a November 2002 Morbidity and Mortality Weekly Report publication, the CDC examined the different HIV testing approaches (9). Here they found that the highest rates of maternal testing were being achieved with ‘opt-out’ testing. As a result of this, in 2003, CDC adopted the initiative, *New Strategies for a Changing Epidemic*, for the first time promoting an opt-out approach to HIV testing of pregnant women (10). As the government sought to maximize efforts to reduce MTCT, medical professional organizations issued position statements and recommendations to guide health care practitioners. Although these statements are not mandates to health workers, they are widely used in determining the “standard of care” for members practicing in those fields. Of all the organizations, the American College of Obstetricians and Gynecologists (ACOG) was the most aggressive in it’s efforts. Specifically, ACOG recommended “implementation of universal testing with notification and the right to refuse”. (Press Release, American College of Obstetricians and Gynecologists, HIV Tests Urged for All Pregnant Women: Ob-Gyns Launch Campaign for Universal HIV Screening, at http://www.acog.org/from home/publications/press releases/nr05-23-00-2.cfm. May 23, 2000).

Other organizations, including the American College of Nurse Midwives, American Academy of Pediatrics and the American Medical Association issued statements advocating pretest counseling of pregnant women with an ‘opt-in’ consent process. Of note, none of the professional organizations advocated mandatory testing for pregnant women (11). In 1999, the state of Connecticut implemented legislation requiring providers to inform patients that HIV testing would be part of routine prenatal care. It was required that such notification be given twice during the pregnancy. If there was no available evidence of prior testing at delivery, the mother would be informed that HIV testing would be done unless she specifically objected in writing. Faced with initial opposition (12), rates of maternal testing in the state increased from 31 to 81% after implementation of the new law (13,14). Success of this policy is illustrated in the fact that in the year 2000, all infants born to HIV-infected mothers in the state’s capitol tested negative (City of Hartford Health Department, HIV/AIDS Surveillance Report, January 2002). Routine testing has certainly led to improved rates of HIV testing among pregnant women (15,16). In addition, studies have demonstrated that routine testing is cost-effective and improves detection of HIV in community (17) and correctional settings (18).

Other states have responded to the success of routine and voluntary testing. A survey in 2002 found that 17 states in the US had statutes regarding prenatal HIV testing. The remaining states used general HIV testing laws for the rest of the population and applied them to pregnant women, or had some other policy to guide prevention of maternal-to-child transmission. Of the seventeen states, eleven required universal offering of HIV counseling and a voluntary testing strategy for pregnant women. The remaining six had statutes based on routine, opt out testing (19). The remaining states had various policies that in some way addressed perinatal HIV transmission.

Along with testing pregnant women, newborn HIV testing with subsequent treatment presents another option in reducing maternal-to-child transmission. Abbreviated AZT regimens begun in the intrapartum period or in the first 48 hours of newborn life have also reduced the rate of MTCT. This has created a safety net for cases missed by prenatal screening (20). As of 2002, only four states had addressed newborn HIV testing. In Indiana, physicians may test newborns if deemed medically necessary. There is no legal requirement of the physician to test, though testing may be performed without parental consent (21). The provision does, however, state that the mother must be notified that testing has been done. In Rhode Island, informed consent for HIV testing is not required of anyone less than one year of age (22). New York State, with its history of disproportionately high rates of births to HIV infected women, was the first to adopt a mandatory HIV screening law for newborns in 1996 (23). Connecticut passed a similar law in 1999, requiring testing of all newborns without record of maternal testing during pregnancy or delivery, in the absence of parental consent. The other component of this law with respect to testing of pregnant women has been previously mentioned in this article. There have been challenges to acceptance of these laws as well. In essence, a woman who did not learn her HIV status during her entire pregnancy would be subjected to that information indirectly by having her newborn tested at birth, in spite of her own objections. Disapprobation of this law was primarily based on the idea that women would be forced to learn their HIV status, thus being no different from a mandatory testing law of pregnant women.

Opponents of mandatory newborn testing have also cited ethical concerns. The most salient of these are an individual's basic right to privacy and, more specific to the medical field, informed consent. Much of the subtleties in the different testing strategies proposed by the IOM and the CDC have differed in the manner in which informed consent was addressed. The issue has been raised as to whether Connecticut and New York's laws represent a form of coercion by effectively presenting a threat of an unwanted action to the baby unless the mother takes a test. Lending credence to this idea, a study of prenatal patients in Connecticut found that some women would accept testing in order to keep their babies from being tested (24).

In addition, debates over risk/benefit balance in screening tests (such as HIV) have raised ethical concerns. By definition, screening tests assess healthy individuals whom are not seeking medical attention for the condition being screened. In considering HIV, it is known that early diagnosis and treatment prolongs survival. For many diseases, opponents argue that the cost, injury and stigmatization a patient may incur by testing positive for a test may not justify the risk (25). What effect a positive test may have on the individual's experience of stigmatization and injury continues to evolve with the epidemic. Others remain opposed to mandatory HIV testing based on the notion that if a pregnant women is faced with undergoing what may be perceived as a mandatory test, she might avoid prenatal care altogether. This is of particular concern with respect to women who are drug users, as these groups have historically been shown to have lower rates of attending prenatal care (26).

There are special considerations when considering routine or mandatory testing among pregnant women who use illicit drugs. In comparison to the general U.S. population, drug users are more likely to experience preventable acute illness, insufficient medical management of chronic illness, or lack of access to appropriate care (27). Drug users have been shown to be more likely to avoid health care treatment than compared with non-drug users (28). Even when health care is obtained, this group has also been demonstrated to be less satisfied with access to the healthcare system than the general population (29). Compounding the issue of drug use with those of living with HIV/AIDS in this society, one would expect that there are still barriers towards HIV testing in the nation. Self perceived risk can serve as both a motivating (23) and deterring factor to obtaining HIV testing. Considerations of these issues are required when discussing HIV testing in this population. Drug using women may not seek knowledge of HIV status after weighing the consequences of revealing status to partners or child protection agencies (30). In addition, historical mistrust of the medical system by marginalized groups of society continues to affect participation in health care (31,32).

In understanding the complex history between physicians and drug users, it is appropriate to consider how drug use, specifically opiate addiction, emerged in the context of the psychiatric paradigm. Lawrence Kolb was an early 20th century physician with vast public health and psychiatric training. He was known throughout much of his later career for his psychiatric explanation of addiction and advocacy for medical rather than judicial handling of such people. At the same time, he also led credence to the ideas of distinguishing “accidental” medical addicts from willful ones (33). These ideas provided much of the framework for the common day issues of drug users and their relationships with health care.

II. STATEMENT OF PURPOSE, HYPOTHESIS AND SPECIFIC AIMS

Connecticut’s laws on HIV testing of pregnant women and newborns continue to be met with reprehension. Initial concern was based primarily on the fear that disenfranchised groups would avoid prenatal care as a direct result of knowledge of these laws. Though previous studies have addressed drug users’ motives for HIV testing, none have adequately studied the acceptability of both routine prenatal testing for pregnant women and mandatory testing of newborns. As rates of newborn HIV testing have continued to decline, we hypothesized **that despite initial concern, drug using men and women in Connecticut do not find the laws on testing unacceptable**. The purpose of this study is, 1) to understand the attitudes and beliefs of a group affected by the current laws, the drug using patient population, and, 2) to specifically address the issue of avoidance of prenatal care secondary to implementation of these laws.

III. METHODS

Both quantitative and qualitative methods were used in two different arms of this study. Structured interviews from two longitudinal studies of drug users (DU's) with subsequent qualitative methods using focus groups were used to obtain insights into drug users' knowledge and attitudes on mandatory HIV screening policies for newborns.

Quantitative Longitudinal Cohort Studies. The first arm of this study, which consisted of surveys, was conducted prior to the introduction of the current author to the project. These were conducted prior to and around the time of implementation of mandatory newborn testing in Connecticut. From 1997-1999, Project CHEER (Community, Health Education, Evaluation and Research) was conducted by a group of researchers affiliated with Yale AIDS Program. Project CHEER consisted of 373 out of treatment injection drug users (IDU's). The second cohort, Project 2000, was comprised of 234 out of treatment non-injecting drug users (NIDU's). These NIDU's were recruited from 1999 to 2000 at various drug treatment centers in and around New Haven. Both were recruited using respondent driven sampling, often used to recruit representative samples of difficult to reach populations (34). The cohort of IDU's has been previously described (35,36). After informed consent was obtained, each participant was administered a standardized questionnaire with questions regarding demographics, drug use, health services utilization, sexual behavior, and psychological well being. In 2003, the initial survey data was revisited to assess attitudes regarding HIV testing of pregnant women and newborns. The current author extracted the following queries:

1) Do you think pregnant women should be required to be tested for HIV?

2) Do you think all newborns should be required to be tested for HIV?

and

3) If there was a law that required all pregnant women to get an HIV test, would you avoid seeing a provider for prenatal care to avoid taking the test?

Multivariate statistical analyses were performed with SAS statistical software, version 8.0 (SAS Institute, Cary, NC, U.S.A).[1]

Qualitative Focus Group Study. After an initial analysis of the data to examine the range of attitudes regarding mandatory HIV testing, a qualitative approach was introduced. Approval for the study was obtained from the Yale School of Medicine Human Investigation Committee. As we were particularly interested in the responses of HIV-infected, drug using women, we recruited two distinct groups: one comprised of IDU's and the other NIDU's. In September 2003, focus groups were conducted with a sum total of 25 HIV-infected and uninfected, drug using men and women. Five groups were conducted in total: one consisted of five HIV positive men, one with five HIV positive/ injection drug using women, one with five HIV positive non-injection drug using women, one with five HIV negative women, and one with five HIV negative women. The rationale for separating groups according to sex and serostatus was to maintain homogeneity and capitalize on people's shared experiences and attributes. Males were

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[1] Performed by Carol Chelimo, BS, MPH at Yale AIDS Program.

included as a vital part of this study with the rationale that a male partner may be involved in a woman’s decision to access prenatal care and/or obtain an HIV test.

Similar to the two longitudinal cohorts, individuals were eligible if they were over the age of 18 and had a history of cocaine or heroin use within the previous six months. Exclusion criteria included non-English speakers and those unable to provide informed consent. Subjects were recruited by staff from various clinical drug treatment and community based outreach sites in New Haven. Each focus group was held at the site from which the participants were recruited. Identities were anonymous, with codes (double letter initials) used for reference during the interview and transcription. Informed consent was obtained from each participant in the group setting. Focus groups covered four thematic areas: 1) knowledge of HIV transmission, 2) attitudes towards voluntary versus mandatory testing of pregnant women and newborns 3) HIV testing and counseling experiences, and 4) stigma and trust of the medical institution. Each taped focus group session lasted approximately 90 minutes. Participants were provided lunch and paid $25 at the conclusion of each session. The male focus groups were moderated by two researchers, one male (John Hodges, coauthor) and one female (Odicie Fielder, author). All groups containing women were conducted by the author. All groups were taped and transcribed by the same author. Transcripts were analyzed multiple times to identify and code broad themes. Once themes were identified, anecdotal elements were isolated by theme and gender using Microsoft Word.

IV. RESULTS

Quantitative Longitudinal Cohort Studies

Tables 1 through 5 are derived from the 610 original participants in the two longitudinal cohort studies. For Table 3, the data set was limited to the 586 (96%) of the 610 subjects who had undergone prior HIV testing. Tables 4 and 5 are limited to the 499 (82%) of subjects who reported having had a usual place of health care. Data from these tables may therefore not equal the total sample size stated at the top of the table due to missing data.

Table 1 displays selected baseline demographic and drug use characteristics of the 610 (376 IDU and 234 NIDU) study participants. The mean age was 38.7 years and 66.6% were non-white. Of all drug users, 238 (39.0%) were women. Nearly all subjects (88.7%) had been previously tested for HIV, of which 26% reported being HIV-infected.

Table 2 shows attitudes on mandatory testing of newborns and pregnant women with respect to drug use history (injection versus non-injection). The majority of subjects reported that pregnant women should undergo HIV testing. With regard to testing newborns for HIV, 56.7 % (N= 337) felt that they should be tested without the mother’s consent, which would constitute mandatory testing. Nearly 14% of subjects did not support testing of newborns. None of these values were statistically significant. There were no differences between IDU’s and NIDU’s with regard to those beliefs. Among the 238 women surveyed, however, more IDU’s would avoid prenatal care than NIDU’s (16.2% vs. 6.1 %, $p<0.01$) if HIV testing was mandatory during pregnancy.

Table 3 describes attitudes toward HIV testing of pregnant women and newborns stratified by history of previous HIV testing. Subjects who had been tested for HIV in the past were significantly more likely to believe that pregnant women should undergo HIV testing (92.9% v. 82.6 %, $p < 0.01$). There were no statistically significant differences between all subjects who had and had not been tested for HIV in the past with regards to newborn testing and willingness to participate in prenatal care among women.

We examined experiences with and attitudes towards health care in the longitudinal cohorts. Of the 610 participants, 499 (82%) participants reported a usual place of health care that included specialty clinics, mental health care, community vans, and prisons. Of these, 173 (31.8 %) believed that certain people at their site received better treatment than others. Of participants who agreed with this statement, women were nearly 40 percent less likely than their male counterparts to agree with this statement, {AOR = 0.61; 95% CI(0.41-0.93)} In addition, having tested positive for HIV was associated with believing that certain people receive better care services. {AOR = 0.42; 95% CI (0.25-0.72)} (Table 4). In table 5, we examined the health care experiences and attitudes among those engaged in care. Types of people whom these participants felt received better care included those who didn’t use drugs (74%), those of a particular race/ethnicity (70%) and those who had private insurance (68%). In general, participants harbored negative feelings about the healthcare environment related to it’s attitude toward drug users. Drug users were found to have negative experience with the healthcare system because their symptoms were not taken seriously (65%) and avoid seeing doctors because of their drug use (74%).

Qualitative Focus Group Analysis

Focus group information was used to provide further clarification of the responses from the longitudinal cohort data. Direct excerpts were extracted into the following three categories: 1) attitudes toward testing of pregnant women; 2) attitudes towards testing in newborns and attitudes toward prenatal care; 3) healthcare experiences and attitudes.

Attitudes Toward Testing of Pregnant Women:

When discussing HIV testing of pregnant women, male and female participants were asked,

Would you be more likely to get an HIV test if I told you: As a pregnant woman, it is required that you have an HIV test or, As a pregnant woman, it is the law that you undergo an HIV test?

Nearly all participants, regardless of HIV status or gender, disagreed with mandating HIV testing by law. The primary and most frequent objection to this method was fear of a loss of autonomy and choice. Participants also cited a woman’s right to not know her HIV status as an important reason for being against mandatory testing. Voluntary testing, with the implicit right to consent, was the preferred method for administering HIV testing. G.X., an HIV negative female with eight children, recounted her experience with testing before implementation of the routine testing laws.

> *GX: I have 8 children. So whenever we go, you know for prenatal or whatever, that's one thing that they definitely do.*
> *OF: So when you went and had your children they tested you then? 9 years ago.*
> *GX: Oh yeah.*

Although the subject had an expectation that she would be tested for HIV, her response to the issue of mandatory versus voluntary testing was that reflected by most participants.

> *GX: I say it should be required. I don't like that word, "the law", because the law, it sounds so demanding. See I still believe in pro choice, you know. Everybody should have their own choice.*

In response to disagreement with mandatory testing, participants reacted with a sense of rebellion towards the law. Agreement with this belief was similar with respect to gender. D.X., an HIV negative male expressed,

> *If you say it's the law, I have to do it. It's like you're telling me what to do, like I have to do it. I'll just tell you no just to be rebellious.*

E.X., a 60 year old female who disclosed that she had been positive for 23 years, discussed the difference in mechanism of being asked to test would have on her willingness to comply.

> *EX: I can't function on a demand. And I know I won't. If you let me go on my time, I'll jump with a quickness. But don't tell me what you've gotta do cuz the law says.*

However, she also stipulates situations that would make it suitable for HIV testing to be a law. EX, in additions to others in all focus groups, agreed that certain groups, such as women with high risk lifestyles (commercial sex workers and active heavy drug users) they may not have the capacity to make a sound testing decision. They therefore expressed belief in the necessary institution of mandatory testing in these special circumstances.

> *OF: Okay, so when it comes to pregnant women, is it okay for us to tell them that it's the law?*
> *EX: It depends on how old they are....the older ones can make up their minds a little better. But these young ones, they are gonna dodge. Afraid of they boyfriends, and family, to get knocked down with ridicule. Talk to a young girl, but still you have to make them.*
> *JS (HIV negative male): Definitely, definitely, cuz lets say like you have the woman still running the streets doing drugs and alcohol. They don't have time to sit down and really take care of their selves, so it should be mandatory definitely. You gotta worry about the baby, I know a few pregnant women who they don't even care about their self. So they can't care about their baby.*

P.X., an HIV negative female without children felt that refusal to assent to testing was associated with a higher likelihood of actually having HIV.

> *Especially if the lady tells you, "you're not gonna test my kid". Why would they tell you not to? Why would I not want my kids to be right? That brings your antennas up then. That's something to think about. Why would somebody not want to know if there's something wrong.*

Many were able to concede that if given the choice, themselves and most women would consent to testing for the safety of the child. Some participants felt, therefore, that another exception to allowing mandatory testing in pregnant women should be for the sake of the unborn child. All of the women in our HIV-infected groups had children, none of whom were HIV-infected. M.X., an HIV-infected female with 6 children, was known to have HIV when her last 2 children were born. Here, she expresses her belief that she would compromise herself (and as she believes, would all women in general) for the sake of the child.

> *MX: I'm saying that most people would think selfishly, but when it has do with another person, another human being, your child now…You love this child, and you want this child you want to know this child is gonna be alright. So therefore, you're gonna take the test. You're gonna want to take this test. For me, myself, regardless of whether they say that it is mandatory or not, if they say do you want to take the test, I would say yes because they (the child) deserve a chance for life…….and you wanna know cuz there is something you could prevent.*

Attitudes Toward Testing in Newborns

Support of mandatory testing of newborns was unanimous. Participants felt that even in the absence of parental consent, if the mother had not been tested then the newborn should be. Central themes in support of this were the ideas of innocence and helplessness in the unborn child. In addition, participants cited that the baby would deserve the best chances at attaining a healthy life.

P.W., an HIV negative female with no children, evaluated the benefits of testing the newborn to both newborns and society.

> *PW: I think it's beneficial for everybody. I mean children don't have a choice in the world. They don't have a choice to be born to this disease. They clueless, you know. They don't have a choice. I think, yeah they should be tested. We talking about babies, here, a life that's born into this world clueless.*

J.S., also spoke of his reasons for supporting mandatory testing in newborns.

> *….because of the baby. With me it's just me, you know. So if I choose not to have it, I'm just speaking for me. I'm not hurting anyone but myself. And that's a decision that I make; when I make a decision for more than one person, you can almost say that's like murder, you know what I mean? In a way, you know what I mean? Like neglected homicide, or something. But if it's just me, then I should suffer for it, then that is me. But when you gotta be concerned about taking another life involved you gotta answer for that life too*.

Attitudes Towards Prenatal Care

When asked about attendance at prenatal care should HIV testing become mandatory, most women agreed that they personally would not be deterred. Both genders, however, were able to cite various reasons that other women may avoid prenatal care, including high risk lifestyles such as drug addiction. Other reasons included being a commercial sex worker, fear of stigmatization by both society and (exacerbation of mistrust) from healthcare providers. Similar to attitudes regarding testing women, with regards to the effects of addiction, prostitution, and other high risk behaviors, participants felt that women in these categories would not have sufficient control over their actions to make a decision for testing. High perceived risk and fear of testing positive were also felt to represent important deterrents to prenatal care.

> *OF: Do you think that pregnant women would avoid coming to get their prenatal care if they had to get the HIV test?*
> *PW: It depends. When a person feels you are making them do something, a lot of people rebel. A lot of women will neglect prenatal care because of that.*
> *PX: Right. There's some of us that…I would want to know. But heaven forbid if she's an addict and she's out here ripping and running and it's a law. Heaven forbid if she's got a warrant somewhere. First thing we think is, that's a setup. I'm going to jail. Now they then set me up. I ain't going down there so they can lock me up. That's how we think. A lot of us will not take the* time *and get prenatal care if it's changed to a law.*

<u>Health Care Experiences and Attitudes</u>

Another theme during the focus groups was negative experiences with healthcare. In all sessions, participants spoke at great length with regards to persistent stigma surrounding drug use in the context of and as a barrier to attaining health care. In group 1, with HIV uninfected males, there was large agreement and sharing of experiences.

> *DX: Exactly, I just had a back operation, and they wouldn't give me anything for the pain cuz they knew I was in the methadone program. And they still won't….. I mean it hurts but I'm not gonna be in pain for like a year and a half and them not give me anything for it cuz I'm in the methadone program. And that is what they said. (agreement in the background)*
>
> *OF: So do you think that they were doing that because they don't trust you?*
> *DX: Yeah because I'm a drug addict, yeah, definitely. They told me that, yeah.*
> *JX: About 6 weeks ago, I was in a car accident. So right away I told them that I was on the methadone program, that I*

> *needed to get my methadone. As soon as this nurse heard that it was like night and day the way she treated me. I was like a piece of you know what.*
> *JX: Yeah, after that she is asking me personal questions, like "oh yeah, how many milligrams are you on. 90 milligrams , whoa! And then she asked me what were you using and I didn't even answer her. It's like very stigmatizing.*
> *NX: That's part of what I had noticed. I don't like to go to the doctor and they ask me "are you taking any medications?" ….. So I say yes, I'm on methadone. And they treat you different. It's like you don't have the right to be a good person.*
> *JS: Like a second class citizen.*
> *NX: Yeah, like you don't have the right to be a good person just because you made a mistake when you were young using drugs.*
> *DX: See some people see it like you're an addict and….*
> *NX: You're never gonna change.*
> *DX: See methadone is your medicine, just like a diabetic takes insulin.*

While most spoke about drug use, negative experiences related to HIV status and race were also discussed. P.W. told of the burden of multiple stigmatizations that effected her willingness to pursue (and therefore access) to care.

> *PW: It's true. We all prejudge and we all stereotype. Me, I already got three strikes against me because I'm black, I'm a woman, and I'm a lesbian. And then to be a drug user.*

With regards to HIV status and treatment by health care providers, though negative experiences continue to occur, some were able to cite progress on the part of healthcare providers in dealing with people infected with HIV.

> *MX: Until that person's status is known, you would be surprised how many people would change in a heartbeat. I've*

> *had it done to me in churches, hospitals. I gotta give (this organization) kudos though. This organization, in the 10 years or so that I've been associated with it, its been far and few between that people have come in from the outside, like yall for example. I've had nothing but good experiences. ... I really have found that people have treated me just like a normal human being, like they would treat their own.*
> *JH: Has it been more with your HIV status that you feel stigmatized than your drug use?*
> *JR: Yes, I feel it's more with my HIV status. I would say. Not with the…I felt more stigmatized with my HIV.*
> *OF: Was he scared about the drugs or the HIV?*
> *JN: I guess because of the HIV.*
> *EX: I guess because of the HIV. Because I had been with this doctor all the time.*
> *JH: And he knew about your drug use?*
> *EX: Well no. He didn't know about the drugs. He knew I was HIV positive. And then he sent me to another doctor.*
> *MX: So yes it has happened a few times. But it's not as bad as I feel that it used to be.*
> *JH: So you feel that physicians and nurses are becoming less judgmental about drug users?*
> *MX: Less judgmental, yes, I think so. And they are getting better with the HIV. But the people I've worked with my HIV status and I have really no complaints at all because they have treated me with the utmost respect. I'm very glad that they are around. I can talk to them and I feel comfortable with them.*

As HIV became more prevalent, clinics and hospitals moved towards more specialized care. M.T., an HIV-infected female commented on this and its relation to her satisfaction with her healthcare.

> *MT: That's why I have nothing bad to say about 9-5 {an HIV floor at the local hospital} because the doctors and the nurses they want to work there. They ask to work there.*
> *OF: That's the HIV floor.*
> *DX: They are beautiful people.*

V. DISCUSSION

Our study finds that the majority of injecting and non-injecting drug users, regardless of HIV testing status, believe that pregnant women should be tested for HIV. Based on our cohort and focus group data, we find that most favor voluntary testing. Overwhelmingly, our patients emphasize the ability to give consent. Our finding is consistent with that of others (37) indicating that most women were concerned with the need to maintain voluntary choice as well as being aware of HIV status for the sake of their children. Pregnant women have expressed concerns that women may be being tested without knowledge and having received information about HIV testing and infection (38). This further emphasizes the role of informed consent and it's value to patients. As the method of prenatal screening currently in place in the state of Connecticut is voluntary testing with informed consent (an opt-in process), we find this information to be relevant. The association between having been tested in the past for HIV (regardless of infection) and agreement with voluntary testing is reassuring. This may suggest that those who have actually been exposed to the counseling and testing process do not find it to be bothersome, thereby leading them to recommend it as a standard of care.

Voluntary, 'opt in' testing has led to improved testing rates in both New York and Connecticut (39, 40); there is, however, room for progress before these numbers reach 100%, as would likely be seen with mandatory testing. In Connecticut, having the safety nets of both opt-out testing at delivery and newborn screening is designed to not miss any cases of HIV in pregnant women or infants. Resch et al. (18) found that the benefit of switching to ‘opt-out’ screening from ‘opt –in’ in Connecticut’s correctional system to be a reduction of only one infection every 21.5 years. This small benefit is in fact due to the relative success of voluntary (opt–in) prenatal testing partnered with mandatory newborn screening. In fact, another important conclusion was that routine (opt-out) prenatal screening would be highly more effective only in places where no program or only voluntary screening is in place. This seems to argue against the need for a more aggressive screening program in the state of Connecticut. These findings, coupled with the acceptance of voluntary prenatal screening, suggest that voluntary prenatal screening should be continued in the state of Connecticut. It is likely then, that more focus should be on optimizing strategies to obtain consent during prenatal counseling. In addition, our data suggests that even when presented with a choice at delivery that mostly all women would consent to testing if such consent is sought. We believe that by optimizing prenatal testing, the need for the safety net at delivery will be lessened.

In spite of overwhelming support for voluntary testing, focus group participants identified only one subgroup of women who were not felt to be willing to provide informed consent, thereby necessitating a mandatory law. These individuals were described as the young women who were commercial sex workers and active drug users – groups at highest risk for HIV infection. This belief highlights an important concern. To bolster the argument in support of voluntary testing, focus group participants first cited the belief that mostly all competent women would consent to prenatal testing in concern for the best interest of her unborn child. They therefore considered women in the above mentioned groups to be unable to maintain control of her own actions for the best interest of her child, necessitating mandatory testing. By examination of the inclusion criteria, we note that every single participant in our study at one time belonged to at least one of the groups felt to need mandatory testing. This is a well-documented phenomenon of discrimination, especially racism. Brown described ‘internalized oppression’ in 1986. Internalized oppression is a process by which a member of an oppressed or stigmatized group will internalize all or part of the negative stereotypes and expectations held by their culture regarding his group (41). Similar ideas of this phenomenon have been described in oppressed groups such as racial minorities (42) and homosexuals. Similarly, internalized homophobia is described as a self loathing and fear felt when in close proximity with others because of their sexuality. Internalized homophobia has been shown to be associated with higher risk sexual behavior and problems with drug use in gay men (43). Therefore, in order to address these maladaptive behaviors, this would suggest that more work is needed in breaking down the oppressive barriers facing gay men and drug users.

Considerable time was devoted to discussing discrimination experienced from healthcare providers due to drug use and HIV. This is best represented in the statement from NX, speaking about his being treated as a second class citizen due to drug use: “Yeah, like you don’t have the right to be a good person just because you made a mistake when you were using drugs.” Similar ideas have been published in literature on attitudes towards drug treatment. The self defeating idea carried by some users, “once a junkie, always a junkie” has been shown to be borne out of a feeling that while providers don’t expect a drug user to overcome addiction, many users agree and are able to cite many instances of personal and observed failure as corroboration (44). These ideas are at the essence of this belief in our groups, where instances of perceived discrimination were discussed at great length.

Though our focus groups were not designed to test the correlation of internalized oppression with attitudes towards HIV testing, this is not a surprising finding. Though this belief in our study was cited by both men and women, the unique issues of oppression in women warrant some attention. The dynamics of oppression often impede a woman’s ability to negotiate sex and reduce risk for HIV, especially in people of lower socioeconomic status and minorities. Several studies have suggested that women who may feel at risk for HIV with their partners in their relationships may not vocalize this or attempt to negotiate during sexual encounters. They suggest a correlation with fear of partner violence, socialization of passive feminine gender roles, and fear of losing mates when there is a belief that there is a shortage of suitable male partners (45, 46). Therefore, it may not be that public education messages regarding HIV prevention are not effective. Internalized oppression in women is likely one of many factors contributing to minority women accounting for the disproportionate current rates of HIV infection in women in the United States. This issue must be further addressed in our society before real progress can be made. In developing countries where women do not have the status that American women have attained throughout history, combating this issue warrants even larger effort.

Notwithstanding, here we found ideas consistent with internalized oppression amongst our drug using men and women. This begs the question of whether or not our groups truly do not accept mandatory HIV testing laws for newborns and the current testing laws for pregnant women. Their accepted position as “victims” of the healthcare system may render them unable to truly voice their dissension. In fact, they may have come to expect and feel that laws regulating their actions are necessary. A study in which an index of oppression was measured by inclusion in some of the above mentioned categories and their relations to attitudes on HIV testing policies for newborns and pregnant women would reliably give us this information. These findings do not, in and of itself, warrant a policy change towards mandatory testing of pregnant women. More importantly, perhaps, they provide some direction as to which groups may need to be more closely targeted with regards to the message of HIV testing during prenatal care.

In the past, it has been shown that women with high risk sexual behaviors, prostitutes, and women who share needles may have a low level of perceived risk despite full knowledge of HIV risk factors (47). This would lead credence to the beliefs amongst our focus group subjects that the high risk women have the poorest insight into their personal behaviors and lend credence to their beliefs that they should be subject to mandatory testing.

With regards to newborn testing, attitudes in the focus groups and cohort populations were not uniform. Over 80% of survey subjects believed that all newborns should undergo HIV testing. Of those, approximately 60% advocated testing in the absence of maternal consent. This is consistent with the definition of mandatory newborn screening. Surprisingly, approximately 14% of those surveyed did not support testing of all newborns, though not statistically significant. In the focus groups, however, most believed that the overall safety of the child should supersede the mother's decision making. They almost unanimously supported mandatory newborn testing. The discrepancy in beliefs between the longitudinal sample and focus groups may be due to an increased support for mandatory newborn testing after years of implementation of this law had produced positive results. As the focus of the epidemic continues to stress prevention, mandatory newborn screening may be becoming less alienating and more acceptable in certain settings. A salient belief was that most women would agree to test primarily for the well being of her child, thus eventually negating the need for it to be mandatory. We found this to be consistent with previous studies where women, regardless of drug using status, reported concern for baby as being a large motivation for undergoing HIV testing (48,49).

Here we found that since implementation of the law, the affected patient population supports mandatory newborn screening. It is important that mandatory newborn screening is shown to be acceptable. The main factors that may be deterring states other than New York and Connecticut from implementing mandatory newborn screening may be ethics and acceptability, cost-effectiveness and overall efficiency. One study found that this policy is cost effective alone when compared with no screening (18). In addition, the authors found that mandatory newborn screening leads to decreased MTCT even when there is a successful prenatal screening process. These findings may be interpreted to suggest that newborn screening may pose fewer barriers to adaptation in other states, with or without prior screening policies in place. Conversely, if most women would agree to newborn testing even if it was not the law, some would question the risk of violating the will of the small few with the threat of perceived coercion. We found that even though women may be testing to avoid their newborns being tested, this is their choice and may not represent coercion. Secondly, there is already a highly effective method of screening in place in our state. Instead of focusing on policy change, effort would be better spent elsewhere, such as assuring that women in high risk groups are always receiving prenatal care.

The majority of women in both samples felt that mandatory HIV testing of pregnant women would not deter pregnant women from prenatal care. This is con

sistent with studies by the Perinatal Guidelines Evaluation Project Group. They have shown that factors facilitating prenatal care in pregnant women often include prevention of vertical transmission and concern for the well being of other family members (50). A statistically significant minority of IDU's (16.2%) said they would avoid prenatal care if HIV testing was the law. Though no one in the focus groups voiced this opinion for their personal behavior, there was the belief that “others” would avoid prenatal care. This correlates with earlier negative beliefs by focus groups participants toward young women, active drug users, and commercial sex workers. We also believe that the difference in opinion between the focus groups and the cohort sample can be explained by the temporal relationship between the two.

Although mandatory HIV testing of pregnant women is not the law in the state of Connecticut and our findings suggest that most women do not support it, it is reassuring that none of our focus groups subjects feel it would be a deterrent. IDU’s have historically had lower rates of attending prenatal care. Due to needle usage being a more stigmatizing form of drug use, they may have been more likely to be further displaced by mandatory testing .While we expect to find no change, formal studies are needed to show if there have been changes in prenatal care utilization post implementation of the mandatory testing law for newborns in the state of Connecticut.

Patients continue to feel discriminated against due to their drug use and HIV status. Many in our study felt, however that major improvements have occurred surrounding the latter. Our cohorts illustrate the fact that patients believe that certain people receive better treatment than others in the healthcare system. With respect to drug use, many described instances of being denied adequate analgesia by their physicians, being denied care, and being disrespected by other healthcare providers. In our focus groups, many told stories of nurses and physicians attitudes towards them changing once their drug using status was disclosed. Similarly in our cohorts, approximately 26% of subjects believed that their symptoms were not adequately attended to and that they did not receive care equal in quality to that of non-drug users. This continues a history of some distrust in disenfranchised groups due to well studied physician bias and discrimination (51,52). The negative experiences of drug users with the health care environment has been reported previously but is echoed in both the cohort and focus group findings (53,54,55). These negative experiences with and attitudes toward the healthcare system are likely to result in poor health outcomes for drug users. They may not, however, ultimately influence outcomes for HIV testing of pregnant women and newborns. It would, however, strongly encourage changes in the delivery of health care toward this population. In order to further explore this issue, focus groups with healthcare providers from local Connecticut sites would be needed.

Our study has several limitations. Our focus groups were small, and were recruited by counselors at drug treatment centers. They therefore may not represent the general drug using population. This may explain the difference in support of newborn and prenatal screening laws versus the larger longitudinal sample. Second, all participants were either in treatment or at least in good standing with their treatment institutions, and therefore may have also been less likely to disagree with institutional regulations. We believe that this has a very small contribution towards attitudes, as instances of perceived discrimination and rebellion against institutions were discussed at great length. Another limitation of focus groups is that subjects may have been less likely to express dissenting opinions in the presence of other members. Lastly, the development of themes to be discussed was determined primarily before starting the first focus group. We may have neglected other aspects on the issue of prenatal and newborn screening that participants wanted to discuss.

To avoid confusion over the language used in our focus groups, the difference between ‘required’ testing versus ‘the law (mandatory)’ was discussed in great detail. For our purposes, required was synonymous with what is defined as a routine testing strategy. We did not however, discuss the real difference in consent process between routine and voluntary testing, as it has been defined, to allow participants to draw their own conclusions regarding which consent process was more acceptable leading them to choosing between one versus the other. We based this decision on studies that have shown that patients and providers often differ in perception of information given during prenatal counseling. Others have illustrated that even when providers inform women that testing is routine, she may not realize that she has the right to refuse testing (22). Whether or not this distinction is made and fully understood in clinical practice is important as even now women may be undergoing testing without full knowledge of the process in place and their rights.

More than ten years following the publishing of ACTG 076 and subsequent implementation of more aggressive HIV testing strategies, the U.S. moves closer to eliminating AIDS in infants(56). Debate continues, however, regarding ethics and legality of HIV testing programs. In conclusion, we found that implementation of mandatory testing of newborns and universal, voluntary testing of pregnant women is largely accepted in the drug using patient population. Pregnant women prefer choice with regards to testing. Our work suggests that most women would assent when counseled regarding the overarching benefits to the unborn child. As some women would avoid prenatal care if HIV testing for women was made mandatory, we strongly discourage consideration of a move towards this policy. Health care providers should recognize that there will always be exceptions and seek ways to target women in special situations as well.

VI. LEGEND OF TABLES

Table 1: Demographic and social characteristics of longitudinal cohort of injecting and non-injecting drug users

Table 2. Knowledge and attitudes about mandatory testing in pregnant women and newborns among non-injecting and injecting drug users

Table 3. Knowledge and attitudes on compulsory HIV testing of pregnant women and newborns by HIV testing status

Table 4. Social and demographic correlates associated with belief that certain people receive better treatment from health care providers, among subjects with a usual place of health care

Table 5. Health care experiences and attitudes among clients with a usual place of health care

Table 6. Focus group participant characteristics

Table 1.

Characteristics	n(%)*
Age	
17 to 34 years	160 (26.2)
35 to 39 years	166 (27.2)
40 to 44 years	154 (25.3)
45 to 64 years	127 (20.8)
Gender	
Male	371 (60.8)
Female	238 (39.0)
Race	
White	204 (33.4)
Black/African American	289 (47.4)
Hispanic	81 (13.3)
Other	32 (5.3)
Highest level of education	
Elementary	47 (7.7)
Some high school	182 (29.8)
High school graduate/GED	247 (40.5)
Some college or higher	131 (21.5)
Currently employed	
No	492 (80.7)
Yes	111 (18.2)
HIV testing	
Never had a HIV test	69 (11.3)
Tested negative for HIV	389 (63.8)
Tested positive for HIV	137 (22.5)
Regular health care provider	
No	323 (53.0)
Yes	283 (46.4)
Received public assistance/ public medical insurance in last 6 months	
No	147 (24.1)
Yes	458 (75.1)
Medicaid/Medicare coverage in last 6 months	
No	285 (46.7)
Yes	317 (52.0)

* Numbers may not add up to totals due to missing data. Percents may not add up to totals due to rounding.

Table 2.

Characteristic	Non-Injecting Drug Users (n=234)	Injecting Drug Users (n=376)	
	N (%)		p-value
Men and Women (N=610):			
Pregnant women should undergo HIV testing			
No	21 (9.1)	33 (8.9)	0.930
Yes	209 (90.9)	337 (91.1)	
All newborns should undergo HIV testing			
No	28 (12.3)	55 (15.0)	0.671
Yes, only *with* mothers' consent	68 (30.0)	107 (29.1)	
Yes, even *without* mothers' consent	131 (57.7)	206 (56.0)	
Women only (n=238):			
Avoid prenatal care if a law required HIV testing in pregnancy			
No	83 (83.8)	123 (93.9)	0.014
Yes	16 (16.2)	8 (6.1)	

Numbers may not add up to totals due to missing data. Percents may not add up to totals due to rounding.

Table 3.

Characteristic	Never had a HIV test (N=69)	Prior HIV Testing (N= 517)	p-value
Men and Women (N=586):			
Pregnant women should undergo HIV testing			
No	12 (17.4)	40 (7.7)	.008
Yes	57 (82.6)	477(92.9)	
All newborns should undergo HIV testing			
No	10 (14.5)	70 (13.6)	.831
Yes, only *with* mothers' consent	18 (26.1)	152 (29.6)	
Yes, even *without* mothers' consent	41 (59.4)	291 (56.7)	
Women only (n=238):			
Avoid prenatal care if a law required HIV testing in pregnancy			
No	18 (78.3)	183 (90.6)	.144
Yes	5 (21.7)	19(9.4)	

Numbers may not add up to totals due to missing data. Percents may not add up to totals due to rounding.

Table 4.

Characteristic	Adjusted odds ratio* (CI)
Mode of drug use	
Non-injecting drug users (NIDU)	Referent
Injecting drug user (IDU)	1.51 (0.96, 2.38)
Age	
17 to 34 years	Referent
35 to 39 years	1.17 (0.68, 2.03)
40 to 44 years	1.16 (0.66, 2.05)
45 to 64 years	1.65 (0.91, 3.00)
Gender	
Male	Referent
Female	0.61 (0.40, 0.93)
Race	
White	Referent
Black/African American	1.08 (0.68, 1.72)
Hispanic	0.74 (0.37, 1.46)
Other	1.85 (0.75. 4.54)
Highest level of education	
Elementary	1.26 (0.58, 2.73)
Some high school	1.02 (0.64, 1.63)
High school graduate/GED	Referent
Some college or higher	1.08 (0.65, 1.81)
HIV testing	
Never had a HIV test	1.24 (0.65, 2.37)
Tested negative for HIV	Referent
Tested positive for HIV	0.42 (0.25, 0.72)
Received public assistance/ public medical insurance in last 6 months	
No	Referent
Yes	1.22 (0.72, 2.06)
Medicaid/Medicare coverage in last 6 months	
No	Referent
Yes	1.06 (0.68, 1.65)

Variables in the table are adjusted for each other. Analysis is valid for subjects without missing data for variables in the tables.

Table 5.

Experience/Attitude	N (%)*	
A) Related to general health care	**No**	**Yes**
Certain people get better treatment than others (n=531)	326 (59.9)	173 (31.8)
The types of people who get better treatment includes (n=178)**:**		
The sickest	167 (93.8)	10(5.6)
People who make appointments	173 (97.2)	4 (2.3)
People who just walk in	177 (99.4)	0 (0.0)
People who make the most fuss	175 (98.3)	2 (1.1)
One particular race/ethnic group	124 (69.7)	53 (29.8)
People who do not use drugs	131 (73.6)	46 (25.8)
People with private insurance	121 (68.0)	56 (31.5)
B) Related to drug use (n=499)	***Disagree***	***Agree***
Symptoms not taken seriously because s/he is a drug user	353 (64.9)	147 (27.0)
Does not receive as good of care as others because s/he is a drug user	357 (67.2)	134 (25.2)
Provider often suspects that symptoms are related to drug use	277 (50.9)	216 (40.6)
Sees another type of provider instead of a doctor because s/he is a drug user	401 (73.7)	93 (17.1)

* Numbers may not add up to totals due to missing data. Percents may not add up to totals due to rounding.

Table 6.

Focus Group	**Gender**		**HIV Status**	**Mode of Drug Use**	
	Male	**Female**		**IDU**	**NIDU**
1 (N=5)	5	0	Negative	3	2
2 (N=5)	5	0	Positive	2	3
3 (N=5)	0	5	Positive	0	5
4 (N=5)	0	5	Positive	5	0
5 (N=5)	0	5	Negative	2	3
Total	**10**	**15**		**12**	**13**

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