

# Confidentiality Concerns, Perceived Staff Rudeness, and Other HIV Testing Barriers

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The objectives of this project were to identify barriers to human immunodeficiency virus (HIV) counseling and testing in public sexually transmitted disease (STD) clinics and to obtain recommendations for improving access to clinic-based HIV testing among low income persons. This was a cross-sectional project examining data collected from 10 gender-specific focus groups conducted from June 2000 to July 2001 in a North Carolina city with high STD and HIV prevalences. Focus group participants were enrolled through purposive sampling of members of community-based organizations serving at-risk and indigent populations. The most frequently reported barriers to clinic-based HIV counseling and testing were concerns about confidentiality, perceptions of being treated rudely by clinic staff and perceptions about costs associated with obtaining HIV testing. To promote HIV testing in public STD clinics, future research and interventions should improve confidentiality protections and improve the quality of patient provider interactions. Increasing awareness that HIV testing is free to patients who cannot afford to pay for it also is crucial.

Keywords: health services accessibility, HIV infections, AIDS serodiagnosis, prevention and control, sexually transmitted diseases, urban health services

**H**uman immunodeficiency virus (HIV) counseling and testing are central to current HIV prevention approaches, which aim to increase the proportion of persons who know their HIV serostatus (Centers for Disease Control and Prevention, 2003; Valdiserri, 1997). Approximately one-fourth of HIV positive U.S. residents have not yet been diagnosed (Janssen et al., 2001). HIV screening has not always been well-integrated into existing sexually transmitted disease (STD) control efforts in part because of extreme stigma associated with HIV and acquired immune deficiency syndrome (AIDS).

Increasingly, however, routine HIV testing is provided at no cost or minimal cost to patients seeking care at public STD clinics. This is an optimal setting for delivering HIV

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counseling and testing to at-risk, underserved populations with limited access to preventive or primary care (Centers for Disease Control and Prevention, 2006; Ford, Daniel, & Miller, 2006).

By making HIV counseling and testing a routine part of any general STD screening, these clinics can provide tailored primary HIV prevention to at-risk, HIV negative persons (Janssen et al., 2001) and facilitate early detection and entry into treatment for previously undiagnosed HIV positive persons (Bos, van der Meijden, Swart, & Postma, 2002).

To achieve maximum effectiveness, however, routine HIV testing must be based upon improved understanding of the factors influencing use of STD clinics for these purposes. Benefits of STD clinic care-seeking include the low cost of care, convenience of walk-in service and the possibility of keeping any STD diagnoses confidential from primary care providers (Celum et al., 1997). Nonetheless, at-risk persons may delay or avoid clinic-based HIV testing for a variety of reasons (Crosby, Yarber, & Meyerson, 1999).

Current recommendations are that HIV prevention strategies build upon existing STD control efforts and that adults routinely receive HIV testing whenever they present for other clinical care (Centers for Disease Control and Prevention, 2000, 2003; Janssen et al., 2001). Public STD clinic staff diagnose a substantial proportion of HIV infections among patients presenting with classic STDs such as gonorrhea. This population represents an underserved group with elevated risk of transmitting HIV sexually—the primary mode by which HIV transmission occurs (Centers for Disease Control and Prevention, 2001, 2004; Ford et al., 2006). In 2004, a greater proportion of HIV tests (30%) were administered in CDC-supported STD clinics than in all other testing settings (Centers for Disease Control and Prevention, 2006). In addition, the prevalence of previously undiagnosed HIV infection is higher among STD clinic populations than in other populations with diagnoses of 23% of 2004 HIV infections occurring at public STD

clinics (Centers for Disease Control and Prevention, 2006; Groseclose et al., 1994).

A number of factors are known to influence HIV testing. A systematic review of studies addressing acceptability of voluntary HIV counseling and testing in clinical, drug treatment, and prison settings found that test acceptance ranged considerably from 3% to 100%, even within settings (Irwin, Valdiserri, & Holmberg, 1996). Acceptability of testing is influenced by multiple factors, including having a regular source of care, admitted risk behaviors (Irwin et al., 1996), perceived risk of infection (Anonymous, 2001), access to anonymous HIV counseling and testing (Bindman et al., 1998; Grinstead, Peterson, Faigeles, & Catania, 1997; Kegeles, Catania, Coates, Pollack, & Lo, 1990; Spielberg, Kurth, Gorbach, & Goldbaum, 2001), fear of consequences associated with a positive diagnosis (Rotheram-Borus et al., 2001; Spielberg et al., 2001), and confidentiality protections (Irwin et al., 1996; Phillips, Coates, Eversley, & Catania, 1995; Spielberg, Kurth, Gorbach, & Goldbaum, 2001). Other motives for HIV testing include the belief that knowing one's HIV status demonstrates personal responsibility as a sex partner (Riess, Kim, & Downing, 2001), new sexual partners' desire to alleviate fear of contracting HIV by jointly confirming their HIV negative serostatuses at the beginning of new relationships (Lupton, McCarthy, & Chapman, 1995), and for persons previously exposed to establish their actual HIV status (Riess, Kim, & Downing, 2001). Women have been found to be more likely than men to seek an HIV test. They endeavor to maintain good health in order to better care for loved ones, such as children (Riess et al., 2001). Among substance abusers, anxiety over one's HIV status seems to impel HIV testing (Downing et al., 2001).

Additional factors may influence decisions to obtain HIV counseling and testing at public health clinics (Beardsell & Coyle, 1996; Berrios et al., 1993; Irwin et al., 1996; Lupton, McCarthy, & Chapman, 1995; Spielberg et al., 2001; Weinhardt, Carey,

Johnson, & Bickham, 1999; Weinstock, Dale, Linley, & Gwinn, 2002). These include having STD symptoms and perceiving oneself at risk of STD or HIV infection (Barnes, Anderson, Weisbord, Koumans, & Toomey, 2003; Crosby et al., 1999). Among women, some research suggests African Americans may prefer to obtain HIV counseling and testing at public STD clinics rather than other settings (Crosby et al., 1999). A growing body of research indicates that provider characteristics and the quality of patient-provider interactions impact clinic-based behavior. One study (Ford et al., 2008) has examined associations between patient provider racial concordance (i.e., a patient being seen by a provider who shares the patient's racial background) and HIV testing. Preliminary findings were that black women STD patients seen by black clinicians had higher odds of obtaining routine HIV antibody testing (OR=3.41; 95% CI=1.28, 9.08). Finally, low cost and free testing also potentially improve low income persons' access to testing. However, community members must know that testing is available for free or low cost (to patients) in order to avail themselves of it.

While some proportion of patients seeking care at STD clinics do so solely to obtain HIV counseling and testing, many do not. Clinicians, therefore, typically offer HIV counseling and testing to all patients newly seeking STD diagnosis. Many individuals only seek STD diagnosis when they have recognizable symptoms. Therefore, it is important to explore factors influencing STD clinic-based HIV testing in both the presence and absence of recognizable STD symptoms.

The objectives of this project were to identify barriers to accessing public STD clinic-based HIV counseling and testing for underserved, indigent populations. We sought to understand factors influencing testing even when symptoms are not present. Understanding barriers to clinic-based HIV testing is particularly important in the increasingly diagnosis-oriented HIV prevention climate, which emphasizes early diagnosis of disease more than it does

primary prevention through outreach and education.

## Methods

We conducted a cross-sectional analysis of focus group data collected from June 2000 to July 2001 in Raleigh, NC, where the prevalence of reportable bacterial STDs and HIV were among the highest in the U.S. during the period (Centers for Disease Control and Prevention, 1999, 2001; Henry J. Kaiser Family Foundation, 2002). The public STD clinic provides the majority of HIV antibody tests in the region, between 3,000 and 4,000 tests annually (Anonymous, 1999).

We used a Grounded Theory approach with open coding to generate lists of emergent salient factors according to participants' experiences and perspectives (Strauss & Corbin, 1990). Recent community assessments indicated that multiple HIV prevention efforts exist in the area; this project, therefore, sought to improve community members' access to public STD clinic-based HIV testing.

To recruit participants we used purposive sampling of community-based organizations (CBOs) that routinely provide services to indigent populations and populations with elevated risk of HIV infection due to sexual and drug abuse behaviors (e.g., drug rehabilitation programs, homeless shelters). Each of the six CBOs approached permitted project staff to conduct focus group interviews with clients of their organization during regularly scheduled group meeting slots (such as weekly health education sessions). CBO management announced the focus groups ahead of each group interview; the topic of the group discussions was explained by project staff at the time of each interview. The project staff explained that the purpose of the focus groups was to understand barriers to public STD clinic-based HIV testing and to identify ways to improve access to HIV testing. Previous use of the STD clinic was not necessary for participation.

The focus groups were one component of a multi-site project that examined

the feasibility of enhancing the provision of STD services to reduce HIV incidence in selected U.S. communities. The project was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

A total of 91 individuals participated in 10 gender-specific focus groups (six women-only groups). Group size ranged from three to 19 participants (median was seven participants). Four of the groups were conducted with residents of public, short-term, inpatient substance abuse recovery programs, two with adults in an outpatient substance abuse recovery program, two with residents of a public housing community, one with residents of a shelter for homeless women, and one with residents of a shelter for homeless men. Facilitators estimated 95% of participants were African American.

We developed a semi-structured interview guide based upon discussions with key informants about STD and HIV prevention in the area. Key informants were community leaders, members of neighborhood improvement projects, and HIV prevention outreach workers who lived or worked in these high prevalence communities.

Two trained facilitators conducted each focus group. Refreshments and up to \$10.00 value remuneration were provided to participants at the conclusion of each session. Facilitators obtained verbal informed consent prior to the beginning of each interview and recorded the sessions on audiotape. Numeric identifiers were used instead of names to preserve participants' confidentiality. An independent commercial medical transcription service transcribed the interviews. The transcriptions represented verbal and non-verbal contributions during the group interviews. For example, transcripts were coded "(AGREEMENTS)" to indicate that other group members were nodding in accord with a comment. All tapes were destroyed after transcription.

A qualitative researcher with expertise in STD and HIV prevention reviewed the guide for content validity. We piloted the focus group guide and procedures among participants in a substance abuse recovery

program. The final guide comprised nine items and explored four main questions:

1. What is important to know about sex, sexually transmitted diseases, and HIV?
2. How do interactions with and characteristics of providers influence use of the public STD clinic for HIV and/or STD counseling and testing?
3. What are barriers to accessing HIV counseling and testing in the STD public clinic when patients do not have recognizable symptoms of STD or HIV?
4. How can access to HIV counseling in the public STD clinic be improved for individuals who either have symptoms of STD or HIV or are specifically seeking a test for suspected infection?

We used simple coding and retrieval to categorize emergent themes and concepts. We defined barriers broadly as any factor that interferes with individuals seeking HIV testing at the public STD clinic. The analyses were conducted using QSR NUD\*IST VIVO® ("QSR NUD\*IST VIVO," 2000) and MS Word® ("Microsoft Word," 2000).

## Results

A clear pattern emerged in which the most salient barriers to public STD clinic-based testing were similar across focus groups. Table 1 lists the most commonly reported barriers by focus group type. Overall, the three most common barriers were confidentiality concerns, perceived staff rudeness, and perceived cost. A number of other barriers also were reported; however, they were much less often reported and were considered less salient to participants.

### *Confidentiality Concerns*

Confidentiality concerns have to do with individuals' privacy regarding care-seeking for the purposes of HIV testing. Of all barriers mentioned, confidentiality concerns were most salient for most of the groups. Four types of confidentiality con-

**Table 1. Most frequently reported barriers to seeking STD and HIV services in public health department clinics among groups by decreasing frequency of report**

<b>MEN</b>	<b>WOMEN</b>	<b>HOMELESS</b>	<b>RECOVERING SUBSTANCE ABUSERS</b>
Confidentiality concerns	Perceived rudeness by staff	Perceived rudeness by staff	Individual level factors*
Individual level factors*	Perceived cost	Confidentiality concerns	Perceived cost
Perceived cost	Individual level factors*	Perceived discrimination‡	Confidentiality concerns
HIV and STD Stigma	Confidentiality concerns	Addiction	Perceived discrimination‡
Addiction-related factors†	Perceived discrimination‡	Perceived cost	Perceived rudeness by staff

\* Included perceived risk of STD or HIV infection, fear, shame, embarrassment, and low knowledge about HIV and STDs

† Included inability to wait for extended periods, fear of needles, concern about finding a healthy vein for venipuncture, etc.

‡ Rude treatment by staff on the basis of clients' race, gender, socioeconomic status, and/or addiction history

cerns emerged: concerns about being seen by people they know while en route to or from the STD clinic; confusion between the terms ‘confidential’ and ‘anonymous’; perceived confidentiality breaches by clinic staff; and limited privacy during clinic visits. In half of all focus groups, confidentiality concerns were among the first three barriers to be reported by participants in response to questions about what would keep them from seeking clinic-based HIV testing. Women were more likely than men to note confidentiality concerns as a barrier.

Only two groups, women clients of a substance abuse treatment program and African American women residing in a public housing community, did not report confidentiality concerns as barriers.

One homeless woman participant’s comments reflect the first confidentiality-related construct (i.e., being seen while en route):

*“My biggest issue would be going some place where I could feel like and know that it was a confidential situation, like there are some places that you could go and you see people that you see every day, and that may not be something that I want everybody to know about that I’m doing. So, if I walk into say the women’s center, I’m in contact with a lot of women who go to the Women’s Center, and if I’m there to do that, that may not be something I want everybody to see.”*

A young woman recovering from drug addiction also explains:

*“And then I saw someone I knew in the place. How embarrassed was I! You know! (laughter) I mean, you know, I was so embarrassed. But then I thought about, well, for her to be in here, (laughter) you know, she has it too! So, you know, it’s not like she’s gonna go talking.”*

Although reported as privacy- or confidentiality-related barriers, participants’ statements about these issues reflected underlying concerns about HIV stigma, which

as one disabled homeless man explained, can delay diagnosis:

*“...for the simple reason, that’s a doctor, the word hospital, medical treatment, see? In a lot of people’s opinion when you went to medical doctors or hospital they figure something wrong with you... And first thing they’re going to say, man, ...my associates know that I went to the doctor, they might think I got that package... So that’s going to make them shy away from doctors and hospitals...”*

Several respondents described instances where their medical records had been used for research (e.g., anonymously) or other purposes such as to guide the provision of social services (i.e., confidentially). Respondents perceived such uses as violations of their confidentiality and trust. A conversation among women residents of an inpatient substance abuse treatment program reflected this:

*Participant #1: “I tell you what. I do medical transcription and I type reports on people every day, and I’ve been extremely fortunate, as far as I’m concerned, I’ve only typed reports on a couple of people that I knew. And everything I type is confidential... But when you go to a doctor and you tell that doctor something or that nurse, you think it’s going to stay there, but it doesn’t. I mean, that report that they dictate could be transcribed by somebody in Utah, California, Canada, New York, anywhere.”*

*Participant #2: “Yeah. Well, that’s how they get your name, social security number, by just – I mean, you know, yeah, you can’t just trust”*

In another women’s group a participant stated:

*“Like if you kept their identity [secret], you know. I think if they come down there – like keep the identity concealed. Only information that we releasing be between that person and the doctor, you know, or something like that.”*

In every focus group, participants described at length both intentional and unintentional breaches of confidentiality as barriers to care-seeking and testing. One substance abuse recovery program participant explained how intentional breaches impeded clinic-based HIV testing at her academic institution:

*“...they would have HIV testing on a specific day, but the nurse, while she was supposed to be confidential, she had her favorites and they would come visit and she would let them know what was going on with other [patients] people. That’s why no one ever went.”*

Unintentional breaches were described as instances where clinic staff inadvertently disclosed—for example, to a third party known both by the patient and the staff person—that an individual had visited the STD clinic.

Participants reported that privacy violations become barriers to HIV testing if staff members carelessly handle medical charts or speak loudly about patients while they are being seen. Prior experiences with these perceived violations may create barriers to seeking testing at the clinic in the future. Participants desired privacy in the clinic’s reception area, during clinicians’ hallway conversations, and in the exam room. An indigent community member’s comment illustrates this concern:

*Participant: “seemed like [clinic staff] was talking about everybody, the majority that came in the window...they discussed what was going on with them and I didn’t think that was cool. I actually have never been back to the clinic since.*

*Moderator: As a result of that?*

*Participant: Yes, as a result of that.*

### **Perceived Staff Rudeness**

In nearly all groups, some participants perceived clinic staff, whether receptionists or clinicians, as generally rude or disrespectful

of patients; participants in many groups reported having personally had negative experiences.

A homeless woman focus group participant noted:

*“I went to get tested at the health department; I had a nurse there. I’ll never forget...she talked to me like I was a speck of dirt on the floor, because I had had...unprotected sex...when I left there, I was walking down the sidewalk crying, ‘cause she made me feel that bad...”*

Men in an inpatient substance abuse recovery program discussed the issue, too:

*Moderator: [So,] you think they treat you bad because you don’t have to pay?*

*Participant #14: Yeah*

*Participant #5: Yeah. Or like we just ain’t making enough money that we can afford doctors of our own and they just figure that, well, you’re just a sorry sleazy...*

*Participant #3: Mm hmm, they must.*

*Participant #2: --scum, you know.*

A woman inpatient substance abuse recovery program client stated it candidly:

*“They’re rude to you. And, I know.”*

Some participants perceived non-clinical staff, such as receptionists, as ruder than clinicians:

*Participant #4: Well, now, the physicians are nice, it’s just the people you have to deal with.*

*Participant #2: Get through the gate to them, yeah.*

*Participant #4: They’re rude!*

*Participant #1: They’re not all of them.*

*Participant #3: They act like they're better than you.*

In some groups, concerns about perceived rude treatment led to discussions about possible reasons underlying such treatment. Some participants believed that rude treatment by clinic staff reflected staff's prejudicial attitudes regarding patients' race/ethnicity, gender, economic status, or addiction history. Even so, when asked whether they had any preferences regarding provider race, participants generally reported not having any.

An illustrative comment was made in a homeless men's group:

*"I mean, it's hard to believe in the medical field that we have prejudiced people, but there are prejudiced doctors in the medical field, and they don't give you 100% service."*

A woman in a substance recovery program made a similar observation:

*"I think that, you know, sometimes people do treat you different because they look at you and, you know, pretty much size you up just by what they see ..."*

An outpatient substance abuse recovery program client further noted:

*"I mean, I think lately the switch has been from looking down on black folks to looking down on a lot of the Mexicans who are here now, you know, or the Latin Americans or whatever."*

Some focus group participants intimated that the reason they are subject to rude treatment is because the quality of care in public clinics may be lower than that in private care settings. Several indicated that they tolerate rude treatment because they have no other options. These participants claim that they would not allow what they perceive as rude treatment to keep them from obtaining needed diagnosis or care.

### **Perceived Cost**

The construct perceived cost reflected participants' concerns about the extent to which not being able to afford testing would prevent them from obtaining it. Although the ways in which participants discussed cost-related responses suggested that the absolute cost of obtaining an HIV antibody test was prohibitive testing is free to those who cannot afford it in this region. Therefore we categorized such responses as reflective of *perceived* cost. Participants in every focus group reported that cost was a major barrier to testing. In half of all groups it was among the first three barriers to emerge in response to a question asking participants what factors keep them from obtaining clinic-based testing even if they believe they really need it. Women were more likely than men to note it as a barrier. Confusion about the actual cost to obtain testing was common during the group discussions. Further, perceptions that the cost of HIV testing made it prohibitive were often linked to perceptions that the cost of healthcare more broadly make access to care prohibitive, as evident from this comment from an inpatient substance abuse recovery program participant:

*"I mean, no matter how bad, you know, I might want to go, the only time I can basically go is when I'm sick, and then it's how in the world am I going to pay for this? 'Cause I don't have any insurance."*

Although individuals knew the clinic services were available, their approaches to accessing public HIV testing were informed by their experiences accessing care more broadly. Participants were ambivalent about whether available tests were free. Many had heard through their social networks that to obtain HIV testing they would have to pay a nominal fee. Several reported that when they had previously sought testing in other settings they were required to cover some portion of the cost. They assumed that testing at the public STD clinic, therefore, also would in-

volve some costs.

*“Sometimes you don’t have no money to take care of these things...how would you take care of the bill, you know? I think about that ‘cause I just went to have a test done, and it cost me \$15, and I was like, oh, you know what I’m saying? A person in my status, homeless, I don’t have that kind of money.”*

In general, reports of cost as a barrier reflected misinformation regarding the cost of HIV testing. Some participants reported that free testing could only be obtained at the clinic by proving one’s inability to pay as illustrated in the discussion below among women clients in an inpatient substance abuse treatment program:

*Participant #1: What about those of us who, yeah, we have a roof over our head, but we don’t have medical insurance?*

*Participant #3: Right*

*Participant #2: That’s what I’m saying, the ones that don’t have...*

*Participant #4: Like S. said, you know, you can go to Planned Parenthood, but you have to meet certain criterias [sic] for income and you know.*

*Participant #3: But you cannot be turned down [by] any government facility. If you can’t pay, no government facility is supposed to turn you down...*

*Participant #3: With inability to pay, they can’t say, “no, we can’t help you because you can’t pay for this service.” No! Make payment arrangements with them, tell them a quarter a month, anything, as long as they see that you’re trying. You know what I’m saying? To reimburse them for their services. They can’t—a government—I mean, private hospitals, yeah, they can tell you no, but a government facility they cannot—or, they’re not supposed to.*

Perceptions of cost as a barrier thus not only reflected any real or perceived financial burdens of paying for HIV testing. Perceived cost also encompassed both the additional work low income individuals believed they must do to be able to obtain testing at an affordable rate and the emotional burdens including such feelings as humiliation that may accompany attempts to prove oneself eligible for free testing available to low income persons.

### **Other Findings**

Although participants focused primarily on the aforementioned issues, several additional barriers also were mentioned. These factors, which were reported less frequently and were less salient to participants, included perceived risk of HIV infection; fear of the testing process or of a positive test result; shame about previous sexual or drug related risk behaviors and denial about susceptibility to infection. Both low and high perceived risk of HIV infection were barriers to seeking care. Individuals who perceived themselves as having low HIV risk were not motivated to seek counseling and testing because they thought it unnecessary or inappropriate. Those who perceived their HIV risk as high assumed they were already infected and therefore did not see the benefit of formal diagnosis.

*Participant #14: I’d rather not know...*

*Participant #9: If I got AIDS I’d rather not know if I got AIDS*

*Moderator: Why wouldn’t you want to know?*

*Participant #10: I’d be scared to know.*

In addition, long waits upon sign-in at the clinic were sometimes reported as barriers to testing. A woman inpatient substance abuse recovery program client stated:

*“The wait is forever, and then they treat you like you’re just, you know.”*

Among men, participants in one group reported past experiences with painful urethral swabs for STD diagnostic tests as a major reason to delay HIV counseling and testing even though urethral swabs are not used to diagnose HIV infection. Two of the groups reported needles as barriers to HIV diagnosis.

*Participant #13: Drawing blood, a lot of people are scared of needles*

*Participant #7: I didn't know it was about drawing no blood. No, I ain't doing that! (everyone laughing)*

Further, several recovering injection drug users explained that any needle use, even if for HIV diagnosis, may pose a serious threat to “staying clean.” In fact, in half (n=2) of the groups conducted among men, addiction-related concerns emerged as barriers to clinic-based testing. For example, participant in a men’s group:

*“[Clinic staff] are dealing with an addict. [Staff are] too slow over there... (Agreements) They sitting there fidgeting when, you know, it taking too long, they getting up and leave. (Agreements)”*

### ***Recommendations to Improve Access to HIV Counseling and Testing***

All groups offered recommendations for improving access to clinic-based HIV counseling and testing (Table 2). Across gender, the most commonly cited recommendations were to: 1) integrate STD and HIV testing into conveniently located social services, which would help to reduce stigma related to test seeking in a known HIV or STD treatment facility; 2) teach providers to be non-judgmental and to demonstrate compassion when interacting with patients; 3) promote greater visibility of HIV prevention outreach workers in community settings; 4) improve the quality of available STD and HIV education in clinic and community settings; and 5) ensure confidentiality of personal health information in the clinical setting.

Other creative suggestions were to make the clinic’s physical environment more welcoming and to offer at-risk persons incentives (e.g., cash) to motivate them to follow through with counseling and testing.

A recurring recommendation was that clinicians be more compassionate:

*“I think with some of the doctors it’s a thing of they forget that they’re also human, and when you go in to get a test, they look down on you like [these patients] have put themselves at at-risk behavior, and what they fail to realize is the only difference between you and me is that [finger snap]. You turn your nose up, ‘How old are you? Why haven’t you been doing this?’ It could be you, it could be your wife or your son or your daughter or even your mother sitting in the same chair I’m sitting in and they need to realize that you treat me the way you want to be treated. I’m already scared to death because I’m here to see you, and then you making it worse by looking at me and fussing at me, chastising me in a condescending manner like I’m 2 or 3 years old. I’m a grown woman who’s scared to death that I may be getting ready to die.”*

### **Discussion**

Although HIV prevention initiatives increasingly emphasize routine HIV counseling and testing to facilitate early diagnosis and entry into treatment, barriers to public STD clinic-based HIV counseling and testing persist. We sought to identify and understand barriers to accessing existing STD clinic-based HIV counseling and testing among indigent persons in a high STD and HIV prevalence region. We observed that, while in general, focus group participants knew that HIV screening was available through the local public health STD clinic, they commonly reported several barriers to obtaining HIV testing. These included: four types of confidentiality concerns (being seen while seeking care, confusion between the terms ‘confidential’ and ‘anonymous,’ perceived confidentiality breaches by clinic staff, and limited privacy during the clinic visit);

**Table 2. Recommendations for improving access to HIV diagnosis by participants' gender**

<b>Most Frequently Reported Recommendations by Gender</b>	
<b>Among men</b>	<b>Among women</b>
Integrate STD and HIV services into existing, community-based, less-stigmatized preventive services or non-traditional testing sites	Employ providers and clinic staff who are caring and compassionate
Provide testing and treatment in convenient locations	Increase STD and HIV outreach education to encourage STD and HIV care-seeking at health department clinics
Make testing quick, easy, and anonymous	Provide testing and treatment in convenient locations
Make HIV testing mandatory	Ensure patients' confidentiality
Increase outreach and STD/HIV education	Hire providers who share their demographic or experiential background characteristics

perceptions that public clinic staff are often rude to patients (for example, judgmental or patronizing); and perceptions that the cost of HIV testing likely is prohibitive. Other, less salient, barriers included low perceived risk of HIV infection or having to wait a long time to be seen after signing in at the clinic. In general, women were more likely to report cost, confidentiality concerns, and long wait times as barriers, while men were more likely to report concerns about confidentiality and privacy. The concerns about confidentiality may reflect underlying HIV stigma, which

remains pervasive in the broader society. Although some research suggests that only a small proportion of persons diagnosed with HIV experience discrimination as a result of a positive diagnosis (Kilmarx, Hamers, & Peterman, 1998), intersectional models of stigma suggest that for certain socially marginalized groups HIV-related stigma exacerbates ways in which members of these populations already are stigmatized (Berger, 2004; Meyer, 2003).

Confidentiality concerns were considerable barriers to clinic-based HIV

testing across all groups. Many participants, however, erroneously interpreted the term ‘confidential’ to mean that no one would ever know about a given clinical interaction except the patient and the clinician involved in that interaction. The confusion surrounding the terms ‘confidential’ and ‘anonymous,’ suggests that clinicians should more carefully explain future uses of patient information at the time of consent. The community from which this sample was drawn is frequently targeted for research studies; therefore, these findings have implications for researchers. Specifically, researchers should take precautions when recruiting indigent participants to ensure that they fully understand the implications of “informed consent”. Policies such as the Health Insurance Portability and Accountability Act (HIPAA) help to protect health information; however, the processes by which such policies are implemented should be evaluated constantly, especially when being implemented in low literacy populations. HIV infection and some STDs are reportable diseases in most states; therefore, some confidentiality concerns may vary according to whether or not patients’ diagnoses are reportable. Clarifying local guidelines about reporting HIV infection versus AIDS can provide patients with concrete information that may allay some of these concerns. Training clinic staff is recommended to help them to appreciate patients’ legal privacy rights but also their needs. Clinics must also ensure that strategies are in place and that staff are trained to guard patient privacy in reception areas, when communicating with other staff and in all other circumstances.

Misperceptions about the cost of HIV testing were common and contributed to perceptions of cost as a barrier even though testing in the region is free. Similar findings have been reported elsewhere (Meyer-Weitz, Reddy, Van den Borne, Kok, & Pietersen, 2000). Rumors about peers’ prior experiences obtaining testing in various settings (for example at private doctors’ offices) appeared to contribute to perceptions of cost as a barrier. Because perceived cost was one of the most salient barriers, we strongly

encourage media -based interventions to increase awareness about the availability of free HIV testing at public clinics. We also recommend that future research determine whether some populations are more likely than others to perceive cost as a barrier.

Perceptions about rude treatment by staff emerged during discussions about barriers as well as during discussions about recommendations for improving access to testing. All groups reported rude, insensitive or non-confidential treatment by health department staff. Participants frequently reported that access to testing could be improved by training staff to be more compassionate when interacting with patients. These findings captured patients’ perspectives; however, they did not reflect the full scope of patient-provider interactions. Future research should explore how characteristics of patient provider interactions influence STD clinic-based HIV testing. Interventions should aim to improve the quality of clinical encounters.

These data suggest that persons with histories of or current addiction may require special consideration for walk in services (for example, regarding excessive wait time) to ensure they follow through with obtaining needed diagnosis or treatment, a finding that corroborates previous research (Spielberg et al., 2001). Emerging alternatives to needle-based diagnosis might be one way to increase routine screening among persons who dislike needles or who have a history of drug injection. We encourage the development of policies that support alternatives to needle-based diagnosis in this population.

According to participants, providing STD and HIV services in conveniently located, non-clinical, non-stigmatized settings that have flexible hours may increase acceptability of testing. This approach already is in use in many areas. Participants appreciated non-traditional approaches to HIV prevention such as community-based outreach for primary and secondary HIV prevention. Such efforts, if expanded, might promote higher rates of diagnosis among hard-to-reach populations by, for instance, providing rapid tests in street and other outreach locations.

This evaluation had several limitations. The focus group convenience samples may not have been representative. Focus groups ranged in size (n=3 to n=19 participants per group) and large groups were not optimal for in-depth discussion; however, the rigid group schedules of the CBOs with whom we partnered made this the only feasible option. The findings also may not be generalizable to populations that seek STD or HIV testing outside of public health department clinics.

Strengths include the quantity of focus groups (n=10) conducted, the inclusion of both men's and women's groups, and the diversity of at-risk groups included. Moreover, participants constituted important priority populations within current HIV prevention efforts.

Although working with CBO programs ultimately was a practical way to recruit participants from indigent populations, the preliminary process of establishing trust with the CBOs, community members and outreach workers was lengthy and intensive. Laying this foundation of trust was essential, but it took more than one year. During early stages of outreach, CBO managers acted as gatekeepers and could prevent access to these populations. Gatekeepers expressed concerns about the sensitive, potentially stigmatizing nature of the project and about whether their clients would receive any long term benefits from participation. Upon conclusion of the analyses, the findings were shared with participating CBOs and staff from the public clinic. In general, all phases, especially the formative phases, of such projects should be completed collaboratively between practitioners, researchers, CBOs and other stakeholders.

## Conclusion

These data suggest that obstacles to STD clinic-based HIV testing persist among some clients of CBOs providing medical, social and housing services. To make HIV testing more acceptable, clinic-based counseling and testing program staff should increase their familiarity with the barriers.

Clinicians may improve rates of HIV testing by explaining and maintaining patient confidentiality, understanding and addressing client perceptions about cost, and improving patient interactions with clinical and non-clinical staff. In addition, as stigma underlies many of the reported concerns, policies and implementation guidelines are necessary to support the provision of HIV testing in non-stigmatizing settings, such as the offices where general social services are provided.

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