

MOVING FROM APPREHENSION TO ACTION: HIV COUNSELING AND TESTING PREFERENCES IN THREE AT-RISK POPULATIONS

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This study sought to identify factors influencing HIV testing decisions among clients at a sexually transmitted disease clinic, gay men, and injection drug users. Focus group and intensive interview data were collected from 100 individuals. The AIDS Risk Reduction Model was adapted to describe factors that affect test decisions. Testing barriers and facilitators were grouped as factors affected by “Individual” beliefs, “System” policies and programs, “Testing” technology, and “Counseling” options. Individual factors (fear of death and change), system factors (anonymous test availability, convenience), and counseling and testing factors (rapid results, counseling alternatives) interact to determine whether an individual does not test (“apprehension”) or does test (“action”), and ultimately, tests routinely (“integration”). In conclusion, traditional HIV testing presents barriers to some populations at risk for HIV. These findings suggest several strategies to improve HIV test acceptance: acknowledge fears, address system barriers, utilize available test technologies, and expand counseling options.

Despite advances in HIV test technology and treatment, many persons at risk for infection do not seek testing (Berrios et al., 1993; Tao, Branson, Kassler, & Cohen, 1999). Data from three national surveys (Anderson, Carey, & Taveras, 2000) from 1995 and 1996 showed that only 22% - 30% of people with ongoing HIV risks had been tested in the past year. In addition, many who tested did not return for their results. Depending upon the site, 25%-33% of individuals tested in public programs, or a national average of 13.3% in 1995, did not learn their HIV serostatus after taking the time to get a test, and only 29% received posttest counseling. Explanation for the

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persistence of this pattern remains elusive (Burris, 1997). The addition of new HIV testing options and a greatly expanded pharmacopoeia for disease management have not been accompanied by correspondingly dramatic upsurges in testing by populations at greater risk of HIV infection (Peterman, Todd, & Mupanduki, 1996). While the number of test takers has remained relatively stable at around 2.6 million per year, the percentage of seropositives declined approximately three-fold from 1989 to 1996 (Centers for Disease Control and Prevention [CDC], 1998). Policy changes such as HIV surveillance have been instituted apace with technological trends, with an as-yet-unclear impact on testing behaviors. Recent analyses in a number of states with named HIV reporting concluded that little impact on testing behaviors has resulted (Nakashima et al., 1998; Osmond et al., 1999), whereas a small study in San Francisco found different levels of willingness to test (Woods et al., 1999), and an eight-state study found that name-based reporting may have contributed to delays in testing among injection drug users (Hecht et al., 2000). Currently it is estimated that 200,000 people in the United States remain unaware that they have been infected with HIV (Sweeney et al., 1997). A better understanding of the underlying factors that facilitate or impede HIV test uptake and result receipt among persons at risk for HIV infection is needed to enhance the testing strategies currently offered, and to provide guidance for innovative new approaches.

Specific factors that influence HIV testing vary from individual to individual, but some normative contexts regarding group values and behavioral patterns may be identifiable for specific subpopulations. Important variables can be uncovered by collecting ethnographic data using focus groups and interviews. These identified "context variables" help define the social and cultural determinants of behavior (Newman, Zierler, & Cheung, 1996), in this case, HIV testing attitudes and practices. The present study set out to examine determinants of HIV test-taking and to document preferences for HIV counseling and testing modalities among men who have sex with men (MSM), female and male injection drug users (IDU), and female and male sexually transmitted disease (STD) clinic clients. A primary goal was to understand from the participant's perspective the specific components of the testing process, with procedural and policy implications for HIV testing strategies.

METHOD

Attitudes about current and alternative HIV counseling and testing approaches were studied among three groups of individuals in Seattle, Washington: MSM patrons of three bathhouses, active IDU clients of a store-front needle exchange program, and clients at a public STD clinic. These populations were chosen because of documented epidemiologic risk, because "risk group" membership has been shown to influence preferences for HIV counseling and testing services (Paringer, Phillips, & Hu, 1991; Valdisseri, Holtgrave, & Bruckbill, 1993), and because these sites are a focus of health department-run HIV counseling and testing programs.

The AIDS Risk Reduction Model (ARRM) (Catania, Kegeles, & Coates, 1990), which integrates the Health Belief Model, self-efficacy theory, and stage of change research (Fisher & Fisher, 2000), helped inform and guide the data collection and analysis. As in the ARRM, we postulated that in order for individual behavior to change, or in this case, for one to decide to test, one must first acknowledge risk (labeling). To progress to the next stage one weighs the benefits and risks of the new behavior, testing, and decides to act upon the decision to test (commitment). The last stage involves

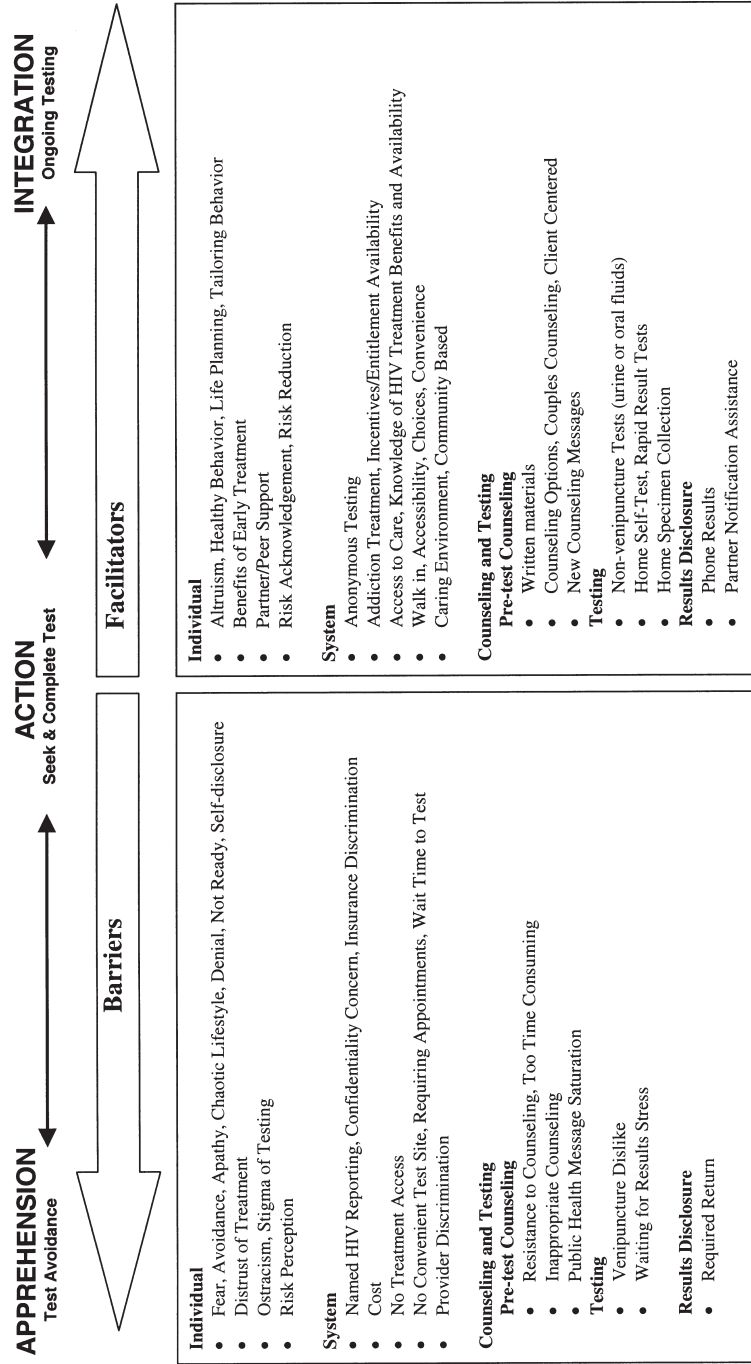
actually testing (enactment). As with all stage theories, change processes are not necessarily unidirectional or irreversible. After one test, one might decide that the risks of testing outweigh the benefits and not test again despite ongoing HIV risk, or a decision might be made to continue testing when new risks occur. In our study we sought to determine what factors affected movement through those stages. We developed a model (Figure 1) to describe the benefits ("facilitators") and risks ("barriers") to testing that are weighed as one progresses from a state of "apprehension" about testing to a state of "action" and finally "integration," where HIV testing becomes a routine health behavior after potential exposure.

Our model added to the ARRM theory in that we also considered the effect of external factors on decisions to test. We hypothesized that test-seeking or -aversion behavior may be driven by individual psychosocial factors interacting with health system-level variables such as how testing and counseling are offered, and perceived confidentiality of results. We sought to identify decision-making influencers at each of the several stages (Valdisseri et al., 1993) in the HIV-testing process. In our model the barriers and facilitators of testing were grouped into categories based on the levels at which these factors potentially could be modified, including through changes affecting "individual" motivation, "system" policies or programs, "testing" technologies, and "counseling" options.

A topic list was developed for initial focus group use and evolved over time to incorporate issues raised by participants in successive focus groups. The final semi-structured, open-ended instrument incorporated these changes and then was kept consistent during subsequent interviews. Trained interviewers surveyed respondents regarding the following topics: motivations for testing or postponing testing; reasons individuals do not return for their results and what factors undermine doing so; current HIV counseling and testing modality preferences; testing barriers; testing facilitators; testing location preferences; awareness of and preferences for alternative test technologies (urine, oral fluid, rapid, and home testing) and alternative counseling approaches (such as written materials, videos, telephone, and couples counseling); and the role of HIV testing as part of an individual's personal HIV risk-reduction strategy. Responses to open-ended questions were explored further with appropriate probes using ethnographic techniques to allow respondents to expound on their unique perspectives and experiences (Gorbach et al., 2000). Due to interview structure, the length of verbatim quotes ranged from short-answer (several words) to several sentences.

Potential participants at each site were recruited sequentially for participation by trained staff. Exclusion criteria included individuals who tested for HIV in the last 3 months, those who could not understand English, and those who were less than 14 years of age. The protocol was reviewed and approved by the University of Washington Institutional Review Board, and informed consent documented for each participant. Participants were paid \$20 for participation. Acceptance rates were 74% at the needle exchange program, 43% at the STD clinic, and 39% at the bathhouse site. After initial focus groups at each site, a decision was made based on participant preferences to collect subsequent data at the STD clinic and bathhouses through individual interviews. A total of five focus groups (three at the needle exchange, one at the STD clinic, and one at the bathhouse, $n = 34$ participants) and 66 individual interviews (14 at the needle exchange, 29 at the STD clinic, and 23 at the bathhouse) were conducted in the summer of 1998, for a total sample of 100 participants.

FIGURE 1. Conceptual Framework*: HIV Testing Decisions Model – Participant-identified Barriers and Facilitators of Testing
 (* Adapted from ARRMs [Cantania et al., 1990])



Focus groups were videotaped and individual interviews were audiotaped. No systematic differences were discernable between focus group and individual interview responses, so the data were pooled for analysis. Tapes were reviewed by a minimum of two staff persons, and relevant text fragments were transcribed. Concise text extractions were analyzed, and a third staff member synthesized coding for relevant topics. Overarching themes across and within the three groups were identified by three of the authors (Miles & Huberman, 1994).

RESULTS

The demographic profile of the 100 study participants (42 IDUs, 31 STD clients, and 27 MSM) is provided in Table 1. Approximately one third were women. The STD clinic population tended to be younger, and the IDUs older, than the overall mean age of 35 years. Bathhouse participants were more likely to be white (78%) and STD clinic participants least likely to be white (42%), with Hispanics most often represented in the STD group, and African Americans in the needle exchange group. MSM and STD participants were on the whole well educated, while most IDUs had a high school education or less. In contrast to MSM and STD subjects, few needle exchange clients lived in their own apartments. Most participants (89%) had been HIV-tested previously, though almost two-thirds had not tested within the past 6 months.

Figure 1 illustrates the common risks and benefits considered by persons who decide whether to HIV test. Barriers and Facilitators of testing were identified: *individual* factors such as fear of HIV diagnosis and the desire to protect loved ones; *system* factors such as policies regarding named reporting and availability of anonymous testing; *testing* technologies such as anxiety caused by the wait for result with standard testing, and availability of rapid testing; and *counseling* options such as dislike of face-to-face counseling and the option of written materials and telephone results. These barriers and facilitators interact to determine whether an individual does not test (stays in a state of “apprehension”), or is able to test (“action”), and, ultimately, incorporate ongoing HIV testing (“integration”) into a personal risk-reduction strategy. Detailed descriptions of these barrier and facilitator themes are illustrated in the Appendix through the words of study participants, who are identified by their demographic characteristics in the far right column.

BARRIERS THAT PREVENT PEOPLE FROM TESTING

Individual Barriers. Fear was the predominant individual barrier to HIV testing (see Appendix, HIV Testing Barriers). This included fear of receiving a positive result, fear of physical death and social discrimination, or fear of a radical change in one’s life should seropositivity be confirmed. Among the STD clinic clients, fear of testing positive and denial of risk stood out as primary reasons for why people said they avoided testing. Other commonly cited fears included anxiety about possible social ostracization, concern about transmitting HIV to others, and fear of dying from AIDS. MSM who postponed testing indicated they did so out of fear (especially of positive results), lack of support, and to avoid having to make life changes following a possible seropositive result. Additional issues included societal homophobia and confidentiality concerns. IDUs reported shame, denial, and stigma as significant impediments to HIV test seeking. Especially for this group, the desire to maintain what one participant called an “Ignorance is bliss” approach, and thus avoid experiencing attendant loss of control, more often predominated.

TABLE 1. Study Participant Characteristics

	Needle exchange (n = 42)	STD Clinic (n = 31)	Bath house (n = 27)	Overall (n = 100)
Age, mean years	38	27	36	34.9
Range	20 - 54	15 - 60	21 - 57	15 - 60
Sex, %				
Male	55	45	100	64
Female	45	55	—	36
Race, %				
White	52	42	78	56
Asian/Pacific Islander	—	3	7	3
Black	26	32	11	24
Hispanic	2	6	4	4
Native American/Alaskan Native	17	3	—	8
Other	2	13	—	5
Education, %				
Less than high school	45	29	4	29
High school	24	16	19	20
Some college	19	26	11	19
College	2	26	52	23
Professional degree	—	—	15	4
Residence, %				
Streets	21	3	—	10
Shelter	21	3	—	10
Hotel	2	—	—	1
Friends	19	13	7	14
Rent	7	—	—	3
Own condo/home	2	—	—	1
Private apartment	17	77	89	55
Last HIV Test, %				
Never	12	13	7	11
Over 1 year ago	26	29	26	27
7-12 months ago	12	13	37	19
1-6 months ago	43	52	33	43
Health Insurance, %				
Yes	26	55	78	49
No	62	39	22	44

Note. Totals not adding up to 100 either do not include missing data, or have been rounded.

System Barriers. The policies and programs that served to keep some people frozen in a state of apprehension were those that magnified, rather than reduced, these fears. Most respondents who talked about named reporting for HIV surveillance voiced serious concern about its impact as an impediment to HIV testing. Nearly half of MSM said they were concerned about named reporting and said they would only test if an anonymous option were maintained, fearing discrimination from friends, insurance companies, and employers. Some STD clinic respondents viewed named reporting as conditionally acceptable, but considered it to be punitive if it remained unconnected to services and support for people identified as HIV-positive.

Counseling and Testing Barriers. A large number of respondents across all three groups mentioned having to wait for the test result, and for a scheduled test itself, as specific dislikes. Participants described being unable to tolerate the feelings experienced during the wait for test results; this result delay was seen as adding tension to

lives that already are complicated. For IDUs, barriers included the profound anxiety of waiting, as well as logistical and practical factors (moved, no phone, incarceration, active addiction). Among the MSM, knowing that a recent sexual partner was HIV-positive often compounded this anxiety. Only a few STD participants specifically mentioned a dislike of the result wait as an impediment to getting test results. Participants next most frequently mentioned venipuncture as a dissatisfaction with the current testing system. This dislike cut across all three groups, but was especially pronounced among IDUs, given their difficulties with vein access.

FACILITATORS THAT MOTIVATE PEOPLE TO TEST

Individual Facilitators. An acknowledged risk history was a key factor in many people's decision to seek an HIV test (see Appendix, HIV Testing Facilitators). STD clinic clients tended to test because they wanted to know their HIV status, or because they had a risk history (generally sexually related). Most intravenous drug use did so because they had a history of either unprotected sex or IDU (about equally reported). MSM who sought HIV testing did so because of a history of risk exposure: nearly half had a current or previous HIV-positive sex partner. Other motivators for testing included encouragement from peers, especially among MSM. Several clients at the needle exchange were motivated to test to protect partners or children. Although we hypothesized that access to early treatment also would be a motivating factor for testing, only one person explicitly mentioned the benefit of accessing early HIV antiretroviral treatment as a reason to test. Several participants at the needle exchange site were not aware that they had access to early treatment.

The majority of participants did not appear to consistently use testing as an HIV prevention strategy, though substantial proportions in all three groups said that they incorporate testing as part of their personal prevention plan. Some individuals did appear able to integrate HIV testing on an ongoing or as-needed basis into their lives as part of their overall health maintenance. Many of the MSM respondents used testing as a reminder to reduce their risk and to practice safer sex. STD clinic clients often used testing as a way to initiate new relationships safely. Many people said that HIV testing serves as a concrete way to help them reduce their risk behaviors. For them, testing functioned as a kind of "reality check" and a consciousness-raiser, helping limit behaviors to those that are low-risk: what one participant labeled the "Makes me think twice" phenomenon. Some people said that testing has no role in their prevention approach, in that it does not change their behavior. Approximately equal numbers in each group said that they take fewer risks during the time they are waiting for a test result, while two people appeared equivocal about increased risk during this period. The role of HIV testing in terms of personal risk reduction was not as pronounced a theme with the IDU group as it was with the STD and MSM groups, among whom multiple reasons were given for the benefits of testing.

System Facilitators. Those individuals who contemplated moving into a state of action or who had already undergone HIV testing said they do so more readily when options such as walk-in testing at convenient tests sites and anonymous testing are available. The preservation of an anonymous testing option was seen as particularly important by the IDU participants, and as the single most important factor to facilitate testing by the MSM group. STD clinic participants recommended a larger number of test sites, and financial incentives including free testing. Some needle exchange clients also wanted monetary incentives offered with testing. Others felt that easier access to drug treatment would facilitate testing.

Participants stressed the importance of a convenient location and a respectful environment for testing. Many said they would like to test in doctor's offices and clinics. Support for HIV testing at culturally relevant sites such as the needle exchange program and bathhouses was divided, with some preferring this and others saying on-site testing threatens confidentiality (IDUs) and the mood of sexual freedom (MSM). Other participants at the needle exchange felt positive about exchanging needles because they were doing something good for their health. These participants preferred testing at the needle exchange, where they could privately request an HIV test, to testing at a nearby addiction outreach agency, where they are hesitant to climb the stairs in front of others when the announcement is made that HIV and STD testing is being offered.

More participants than not supported partner notification (assistance in informing sexual or needle-sharing partners of possible HIV exposure). Provider-assisted partner notification was seen as a way to make people who may not otherwise be reached aware of their risks. Many STD clinic clients emphasized the difficulty in contacting partners on their own. However, few participants were aware that assistance with anonymous partner notification was available from health departments.

Counseling and Testing Facilitators. Nonvenipuncture test methods, fast results, telephone test results, and overall choice in HIV counseling and testing emerged as clear themes. A number of participants said that access to a rapid test result was the key issue, while others cited peer support and other supportive elements.

The relative impact of pretest counseling on the HIV-test decision appeared to be minimal. Some participants expressed impatience with, while others were grateful for the support of, the pretest counselors. Satisfaction with current, traditional pretest counseling appeared mixed. On the one hand, many participants expressed the feeling that face-to-face counseling can be one of the most effective means of facing the pressure of the test-taking and result-disclosure process. On the other hand, many participants made it clear that they do not want to go through such in-person risk-reduction pretest counseling. This was particularly the case among MSM and IDUs, who saw pretest counseling as repetitive, unnecessary, and in need of new messages. Some IDUs were hesitant to discuss personal risk behaviors with counselors. A few among the STD clinic participants mentioned that they appreciated pretest counseling, seeing it as an opportunity to review their risks. Many respondents in all three groups said they prefer face-to-face counseling.

Participants expressed support for new counseling modalities, including brochures, telephone counseling, and to a lesser degree, videos and computer/Internet access options. IDU participants particularly liked the option of substituting written materials for the face-to-face pretest counseling, as pamphlets were felt to offer convenience and flexibility and allowed participants to avoid hearing repeatedly the "same messages." Support was strongest among STD clinic clients and MSM for the option of telephone counseling, which was appealing because of its convenience. Yet nearly as many MSM said they would not choose telephone counseling. Phone counseling, when associated with home specimen collection, was seen about equally among IDUs as an opportunity and as a threat. These perceived threats included confidentiality concerns (e.g., wire tapping, or caller ID) and the damaging psychological impact of a positive phone result. However, a number of others said that they would respond no differently to a test result given over the phone versus in person, and would access health care and other services in the same way given either test result delivery mecha-

nism. The STD group raised some of the same concerns, but was in general the most supportive of the phone-counseling concept.

Most participants indicated that they would be more willing to test if offered a rapid HIV test with same-day results, an oral fluid test, a urine-based assay, a home specimen collection kit or a home self-test, instead of the traditional serum testing. For a handful of people there appeared to be comfort in having their test done “the standard” way using a blood draw with a 1 - 2-week waiting period for test results. There was pronounced support for rapid HIV test availability across all three groups. Oral fluid (OF) and urine tests were the next most popular choices. Support for the home HIV specimen collection option was mixed. Some MSM were supportive, but others (especially in the STD and IDU group) were concerned about the potential for user error, and distrusted the mail. Clients were more positive about home self-test kits than home specimen collection kits, because of the increased anonymity and rapid results that the former provide. Several clients who preferred home self-tests indicated that they would follow up for confirmatory testing if positive results were received at home.

A consistent finding across the three groups was that few people had heard of or were talking about these new methods. Of the alternative test modalities mentioned, only the home specimen collection kit seemed known to some participants, because of earlier outreach efforts making free home specimen collection kits available to the needle exchange population.

DISCUSSION

This study identified a number of internal and external factors that impede or facilitate the decision to test for HIV. The relative importance of these factors varied somewhat by group, though there were many commonalities. The impetus to test may be related to an acknowledged personal risk history, especially with IDUs and MSM, and to relationship issues, as seen in the STD population. Legal and health system policies, and counseling and test technology modalities, can encourage or thwart people’s HIV testing decisions. Generally speaking, named HIV reporting policies did seem to be a greater concern for MSM than other groups. This echoes the CDC finding that among groups at risk for HIV, MSM most frequently choose anonymous over confidential testing in publicly funded facilities (Editor, 1999). Infrastructural conveniences such as walk-in testing and phone results were appreciated most by IDUs.

The ARRM provided a useful framework to identify the risks and benefits that one considers when making a decision to test. Yet the ARRM’s individual-level focus required expansion to consider the impact of those factors at the system and counseling and testing program levels. In fact, these latter factors proved as salient as, and are potentially more easily modified than, individual motivational factors.

Some of the factors that keep people from testing at all involve intrapersonal issues that may not be easily amenable to public policy interventions. Targeted test-promotion campaigns that specifically address individual and group identity-specific fears of social consequences and physical death may still be very relevant for many persons at high risk of HIV (Myers, Orr, Locker, & Jackson, 1993). Other studies that have focused on the HIV testing decision likewise have identified as barriers fear of not being able to cope with a positive result, and concern about the negative impact on economic/insurance benefits and on one’s relationships (Beardsell & Coyle, 1996).

Even though at the time of the study there was a plethora of media and community-based information regarding combination antiretroviral therapy efficacy, few participants seemed aware of the availability of early treatment for HIV. Nor did we see a trend of downplaying HIV infection in light of its “manageability” with highly active antiretroviral therapies. Here again may be an opportunity for targeted informational campaigns.

These data suggest that pretest counseling does not serve to convince people to test, but rather mainly to reassure (or distance) people who have already decided to take the test. Similar findings were seen in a qualitative study of mainly heterosexual low-risk individuals for whom pretest counseling affirmed “ownership” for a decision that had already been made, mostly for current relationship motivations (Coyle, Knapp, & O’Dea, 1996). Use of the test for negotiating sexual relationships that was seen with many participants in this study also was described in an Australian qualitative study (Lupton, McCarthy, & Chapman, 1995). The option of written pretest counseling may enhance the willingness of key populations (the “test-experienced” [Kalichman et al., 1997] and those who prefer not to talk to counselors about risk behaviors) to undertake initial or repeat testing. The impact on HIV prevention efforts of making counseling optional should be explored. Since both MSM and IDUs may be more often exposed to HIV prevention information, it is likely that a higher level of client-centered sophistication in counseling messages, or a more focused behavior change intervention (Kamb et al., 1998) is needed for some of the “test-experienced” among these populations.

While most study participants agreed that face-to-face post-test counseling is optimal for receiving test results, many of the same people expressed an eagerness for a phone results option. These data are consistent with other studies that have shown preferences for telephone counseling and HIV results disclosure among people at risk (Schluter et al., 1996; Spielberg et al., 2000). Despite an often-expressed concern in the HIV provider community (Spielberg et al., 2001), many of these at-risk, potential HIV testers say they are not concerned about adverse reactions to receiving a positive result by phone. It may be that some who are at different perceived HIV risk will “self-select” for one modality over the other. Since March 1998, all clients seeking HIV testing at Public Health-Seattle & King County sites have been offered telephone results; in the first year 76% overall of those offered, but only 65% of those who tested seropositive, accepted phone results (Goldbaum, 1999). Similar proportions of those who chose telephone or face-to-face counseling (89%) received test results. Among those who received results by telephone only 12% (2 out of 17) were lost to follow-up. In 1993 a panel of external reviewers recommended that the CDC develop guidelines for phone notification of results (Centers for Disease Control and Prevention, 1993). New revised guidelines for HIV counseling, testing, and referral have just been published (CDC, 2001) which recommend providing services that are responsible to client and community needs and priorities, including telephone counseling in some situations. Finally, a nearly universal preference was for choice - that is, offering all types of counseling and testing, to provide as many avenues as a variety of people might require.

LIMITATIONS

This study identified barriers and facilitators to testing that may be important for testing decisions among clients at high HIV risk in Seattle. However, given the relatively

low participation rates at the bath houses and STD clinic, these data may not be generalizable to all clients at these sites, or to other populations at high risk outside Seattle. Some generalizability to HIV testers, however, is supported by the fact that many themes were universally identified among participants at the needle exchange, the STD clinic and the three bathhouses. This study was not designed to identify differences based on racial/ethnic group, gender, or age. Additional evaluations should identify the relative importance of specific themes among various populations, as a necessary step in developing and refining population-specific programs to overcome the most prevalent impediments to testing.

PUBLIC HEALTH IMPLICATIONS

In the United States, provision of HIV counseling and testing has been an important strategy for prevention and early treatment. However, many high-risk individuals have not been reached through traditional HIV testing programs that utilize scheduled clinic visits, venipuncture, two visits for pretest and posttest face-to-face counseling, and a 1 - 2-week wait for test results. Focus group and interview data revealed several HIV counseling and testing barriers and preferences that may impact the effectiveness of HIV testing. Test promotion approaches that fail to take into account the influence of system-level factors such as service structure and policies, or that focus only on these issues and neglect intrapersonal affective elements such as fear, are likely to be insufficient. This study goes beyond previous work to identify clear preferences among specific populations at risk for HIV that may increase test uptake. Our findings indicate that MSM, IDUs and STD clinic attendees would prefer a variety of counseling and testing options, including rapid and nonvenipuncture tests and telephone test results. The revolution in rapid, client-controlled HIV testing technologies necessitates a reexamination of the way in which we offer HIV counseling and testing (Rotheram-Borus, Cantwell, & Newman, 2000). Expanding HIV counseling and testing options - literally "by all means necessary" - may improve testing rates and knowledge of HIV status among those most at risk.

APPENDIX: SELECTED VERBATIM QUOTATIONS FROM STUDY PARTICIPANTS

HIV Testing Barriers (Organizes by the Themes within the Four Factors)		
Factors	Qualitative Data	Age, Sex, Ethnicity, Site ^a
<i>Individual</i>		
Fear of results	"You don't want to know. You don't want to die."	40s, F, W, IDU
Avoidance of change	"The only reason why it's taken me a while to lead up to my first time, to get tested, ... it would require a big change in my life. I guess we're all kind of afraid of change."	30s, M, AA, MSM
Apathy	"I'm pretty much to the curb. My life has gone downhill. I'm a drug addict, I'm on the street. I'm out there running on the street. . . I'm just not caring. It doesn't matter to me much about HIV."	40s, M, W, IDU
Chaotic lifestyle	"They got other things on their mind to worry about than having to take the time to call for an HIV test - you know what I'm sayin'? They're dopesick, and they spend most of their time hustlin' their money to get well, so they got a lot on their mind."	40s, F,W, IDU

Denial "It took a friend of mine who died to bring me to my senses. After he died, I said I'm gonna go and try and be tested." 50s, M, AA, IDU

HIV Testing Barriers (Organizes by the Themes within the Four Factors)

Factors	Qualitative Data	Age, Sex, Ethnicity, Site ^a
Not ready	"The first time I took the test, it took me a while to go and do that because I knew that I had been doing things that I could've come up positive. And I wasn't ready to deal with that. So I postponed it as long as I could, and then I lost a friend of mine, a very close of friend of mine. That made me go ahead and be tested. I don't really know what she died from, but I know the way she died she possibly could have had AIDS. I know that me and her had done things together, shared needles, everything else. So I was afraid to get tested, what I would find out."	30s, F, W, IDU
Self-disclosure	"I didn't tell [the counselor] about that partner because he was using and I was embarrassed to admit I'd been with him. Besides, we weren't together anymore."	30s, F, W, STD
Distrust of treatment	"I think you're killing people with that crap. That's just my opinion. I think they're overloading people will all kind of pills. I think it's possible that some of these things are making people die earlier. I've seen these guys with all these pills that they have to take. They're skinny and they're always sick. Maybe if they'd stop taking those pills, they'd start feeling better. I just have a gut feeling about that."	40s, M, W, IDU
Ostracism	"AIDS, that's a touchy subject. 'Cause a lot of people, they don't even wanna walk down on the same side - some people that don't know a lot about it they don't even want to be around you, or touch you or nothin'."	30s, M, AA, IDU
Stigma of testing	"Stereotypes, labels, perceptions . . . It would be easier [to test] if there weren't such a negative image associated with it."	20s, M, AA, MSM
Risk perception	"Putting it off? I hate it. I still put it off. . . . I feel healthy. I do my work. I don't think I'm at much of a risk. I'm in a monogamous relations two years."	30s, M, W, IDU
<i>System</i>		
Named HIV reporting	"Name results can follow you the rest of your life - [reaching] your employer or neighbor." "It's still scary . . . the government may stick all positive people somewhere."	40s, M, W, IDU 20s, M, W, IDU
Confidentiality concern	"The President can't even get confidentiality, how's we gonna?"	60s, M, AA, IDU
Insurance discrimination	"Your insurance can get dropped if you get a test . . . [by testing] I'm doing a good thing, and you're knocking me for it."	30s, M, W, STD
Cost	"I wonder about the availability to people in rural areas. I don't know if they have the availability of free and anonymous testing to them, or do they have to go to private doctors, which is a whole different story? If you don't have a lot of money, it might be very expensive to go to a private place for testing."	50s, M, W, MSM
No treatment access	"A lot of people don't even have welfare, don't have no source of income. So why would they go get tested, cause if they do have it they don't have no way of treatment."	40s, M, AA, IDU
No convenient test site	"My only problem is, you know, I need people to reach me, come to me. I didn't know what resources or whatever was out there."	30s, M, W, IDU
Requiring appointments	"I never make an appointment - I can't even make a court date, let alone in the neighborhood!"	50s, M, AA, IDU
Wait time to test	"[My decision to test] absolutely could be affected if the wait was too long. Waiting a long time gives people an opportunity to see you, and for, you know, discretion and confidentiality to go."	30s, M, AA, STD

Provider discrimination	"I think that a lot of doctors and/or counselors if they see that you're a drug addict, in a bad way, homeless, dirty, they pass you on, they don't give you the medical attention you deserve."	40s, M, AA, IDU
Factors	Qualitative Data	Age, Sex, Ethnicity, Site^a
	"A lot of people think, this room here, this group of people, we're the scum of the earth. We're drug addicts, we're homeless, we're poor . . . and they judge us before we even open our mouths and it's a really sad state because I consider myself and some of these people first class people. We're educated. We're intelligent. I understand that we're drug addicts but these people are not the scum of the earth."	30s, M, W, IDU
<i>Counseling and testing</i>		
Pretest Counseling		
Resistance to counseling	"I'd rather just read about it. I'm not really into being forced into anything. Some of those nurses and stuff don't know any more than you do about stuff."	40s, F, W, IDU
Too time consuming	"It's all too much time-consuming."	30s, F, W, IDU
Inappropriate counseling	"This whole sort of notion of counselor as principal is I think kind of unfortunate and counterproductive. I don't think that the counselor should be there to discipline."	50s, M, W, MSM
Public health message saturation	"Except for advances in treatment it's the same spiel it was the first time." "I think if you have the black and white Surgeon General's warning, you just turn it off these days. I don't want to be bombarded with it."	30s, M, W, MSM 40s, M, W, MSM
Testing		
Venipuncture dislike	"I got small veins, and they always mess up my veins so I can't fix no more." "Never liked it . . . being stabbed by another person . . . too invasive . . . they are sucking out my blood"	40s, F, W, IDU 40s, M, W, MSM
Waiting for results stress	"It's like a burden, stress will bust a pipe no matter what. I don't care if it's a steel pipe, whatever, in time it will bust. We got enough crap in this room to be stressed out about . . . one time is all it takes." "I was sick with waiting one week, that's why I haven't tested again."	30s, M, W, IDU 30s, M, W, MSM
Results Disclosure		
Required return	"I'm not very good at just writing something down and going back to the calendar."	40s, M, W, MSM

HIV Testing Facilitators

Factors	Qualitative Data	Age, Sex, Ethnicity, Site
<i>Individual</i>		
Altruism	"It helps us by knowing to adjust our behavior, whether we're HIV positive or negative. If we are HIV positive, then we're in a different situation, in which we need to be thoughtful about our behavior with partners."	50s, M, W, MSM
Healthy behavior	"It's the responsible thing to do, plus it's good health-wise, I mean if you do become infected you need to know so you can take care of yourself" "I'm a grandmother now. It took that. I needed to know that I was healthy, so over the years I'd be there for my daughter and my grandchildren like my mother was there for me and my child. So those are the issues that came up. . . . It's more about family. I needed to know for my family. To know that I could clean up and be healthy and change my lifestyle."	40s, M, W, MSM 50s, F, AA, IDU
Life planning	"[Helps] to plan ahead so that you don't get to the stage where you may be in a bad way already."	20s, M, A, MSM
Tailoring behavior	"I go for a while and then I get tested and then I get scared. And then I say I'm going to be really good now . . ."	20s, M, AA, STD

“I just broke up with the girl I was with for three years. I was really afraid I might have given her that. I didn’t know whether I had it or not. I’d never been tested. That’s the reason I got tested, and it turned out I didn’t have it and I was real happy about that.”

HIV Testing Facilitators

Factors	Qualitative Data	Age, Sex, Ethnicity, Site
Benefits of early treatment	“It’s always good to know because if I did contract HIV I’d want to know as quickly as possible in order to start on all the different treatment programs and so on.”	30s, M, W, MSM
	“All the drugs they have now days, they slow it way down and if a woman gets pregnant, they have to treat it early so the baby won’t get it.”	30s, M, W, IDU
Partner/Peer support	“My boyfriend at the time got tested and he forced me to do it . . . I mean I was glad that I did it. I went and my boyfriend sat with me when I got tested.”	20s, M, W, MSM
Risk acknowledgement	“...we used to share outfits and we didn’t know nothin’ about no bleach and stuff and we used to share - one person would finish using it and pass it on . . . ”	30s, F, W, IDU
Risk reduction	“I use [testing] as a monitoring device to remind myself to play safe.”	30s, M, W, MSM
<i>System</i>		
Anonymous testing	“For me it’s not important, but I can still appreciate some others who have a job, career, and reputation to lose.”	50s, M, AA, IDU
Addiction treatment	“People are using, maybe put it together [treatment and testing], you know, say you come in maybe we can give you some [treatment] alternatives when you come in for your results.”	40s, F, W, IDU
Incentives/entitlement availability	“If I found out that I had it, I’d go to the SSI board and say, hey, I’m HIV positive and I can’t handle it and give me my money. I earned, I want it.”	40s, M, W, IDU
	“Incentives would help people to get their results, resources like money, a place to live, clothes.”	40s, M, AA, IDU
Access to care	“ . . . the only way [named reporting is] alright is if they’re going to help those people . . . give them up-to-date medicine.”	teens, F, AA, STD
Knowledge of HIV treatment benefits and availability	“Educate them about the disease without them just having the knowledge that HIV is a disease that will kill you, you know, letting them know they can live a long life if they change their lifestyle. Let them know what kind of medication that they could get and whatever this medication is going to cost them or is it going to be free.”	50s, M, AA, IDU
Accessibility	“If it wasn’t for a place like this here [the needle exchange program], I wouldn’t get tested. I think we need more places like this center around, cause there’s a lot of people like myself that would get tested but they don’t have no place to go and we’re not going to no hospital that’s out and we can’t afford no doctor . . . ”	30s, F, W, IDU
Choices	“By all means necessary, whatever it takes.”	30s, M, AA, IDU
Convenience	“I wish [testing were offered] a variety of times. Not everybody works nine to five. So it’s difficult for them to access it. It’d be nice if two or three times a week there were night hours.”	20s, M, W, MSM
	“The easier the better. If I walk into a Gay City event, or the Cuff, and someone’s there saying testing, and it’s been three months or more, my arm’s out, let’s go.”	40s, M, W, MSM
Walk in	“ . . . if sometimes you just get the urge or if a freak accident happens or something you want to just be able to go in.”	20s, F, W, STD
Caring environment	“For me the methadone clinic is the most convenient place to test and the people there know me and they wouldn’t be so cruel.”	30s, F, W, IDU

Factors	Qualitative Data	Age, Sex, Ethnicity, Site
Community based	"[Counseling should be offered] wherever your community is. People's community might be . . . from the bath houses to on Broadway to skateboarder kids to other parts of town. Done by the community in their community. Where they feel comfortable and connected and a part of, as opposed to the white-doctored coat coming in and the door slamming shut. You feel much better when it's somebody you actually see on the street."	40s, M, W, MSM
<i>Counseling and testing factors</i>		
Pretest counseling		
Written materials	"I'd rather just read about it."	30s, F, W, IDU
Counseling options	"Whatever makes people comfortable, 'cause everybody's different."	30s, F, AA, IDU
	"Different people respond to different things. The more options they have, the more likely the message will get out."	20s, M, W, MSM
Couples counseling	"It's a good idea but it usually doesn't get offered."	30s, M, W, MSM
Client-centered	"I need interactive situations to make things clearer."	40s, F, W, STD
	"[Counseling and testing] helped me realize exactly the scope of what I was doing and put it into perspective."	20s, M, W, STD
New counseling messages	"We need different counseling . . . get tired of hearing same thing over and over."	40s, F, W IDU
	"As far as pamphlets and such, I'm a real fan of cartoons. The packaging of the condoms with fun stuff like that is a really effective just to ward off complacency. Because I think if you have the black and white Surgeon General's warning, you just turn it off these days. I don't want to be bombarded with it, but if I am bombarded, I want it be enjoyable."	40s, M, W, MSM
<i>Testing</i>		
Non-blood tests	"It's better than blood. I got small veins and they always mess up my veins so I can't fix no more and I want something else."	30s, F, W, IDU
Home self-test	"It gives you a reason to go and get more professional help."	40s, M, W, IDU
Rapid result tests	"If a rapid test had been available, I might have been tested a while back. Getting rapid results in an hour or so, I might have been tested."	30s, M, W, IDU
Home specimen collection	"I like the home testing. I'd do that. I do all the work myself, then just send it in with an alias name, code, number, whatever, so my name's not linked. It's a privacy thing, and that way your name don't leak out."	40s F, W, IDU
Results Disclosure		
Phone results	"One of the best ways, certainly easier; assuming everyone is responsible with those results."	30s, M, W, MSM
Partner notification assistance	"It's really hard to tell someone . . . it would take the pressure off the person . . ."	20s, F, W, STD

^aAge estimated by interviewer or confirmed by questionnaire; F = female, M = male; W = White, AA = African American, A = Asian, AI = American Indian, PI = Pacific Islander; IDU = injection drug user, STD = sexually transmitted disease clinic attendee, MSM = men who have sex with men.

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