AIDS outside the United States—not one of his references comes from elsewhere—he might have recognized the sad irony that the western country with the highest caseload is also one of the least responsible in developing a national program of public education on the transmission of AIDS.

This comment probably sounds harsher than I would want to be about this particular article. Maybe the harshness is born out of a sense of frustration at both the academicism and the New York centrism of Seidman's approach. By concentrating so heavily on the media—indeed on the New York media—he seems to me to miss the political significance of the role of gay/AIDS community organizations in responding to the challenge of the epidemic, and their impact on both the lived experience and the discourse of sexuality.

NOTES


3. See R. Shilts, And the Band Played On (New York: St. Martin's Press, 1987), for a popular account of this theory.
The Motives of Gay Men for Taking or Not Taking the HIV Antibody Test*

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This paper analyzes the motives for taking or not taking the HIV antibody test among a sample of 120 gay men. The motives were forged from prevailing cultural constructions of the HIV test. The most commonly cited motives for taking the test were: to take medical treatments for HIV infection, to become motivated to make needed health and lifestyle changes, to clarify an ambiguous medical condition, to inform sexual decision making, and to relieve psychological distress associated with not knowing HIV status. The most frequently reported motives for not taking the test were: to avoid the adverse psychological impact of a positive test result, to avoid social discrimination and repressive governmental actions, to avoid an ambiguous or unreliable test result, and to avoid having to make undesired lifestyle changes.

The present paper explores the motives given by gay men for taking or not taking the HIV (Human Immunodeficiency Virus) antibody test. Following Mills (1940), we conceptualize these motives as reasons, explanations, or justifications for taking or not taking the test. Moreover, we also conceptualize HIV antibody testing as problematic behavior, mainly because of the momentous psychological and social risks and benefits associated with testing. As one noted chronicler of the AIDS (Acquired Immune Deficiency Syndrome) epidemic put it,

To test or not to test clearly would become the most important personal decision most gay men would make in their adult lives. To be tested meant learning that you might at any time fall victim to a deadly disease; it was a psychological burden few... could imagine. However, not to be tested meant you might be carrying a lethal virus, which you could give to others (Shils 1987:540).

Other risks include stigmatization, discrimination, and disrupted social relationships (Miller 1987). Among the benefits connected with testing are the opportunity to learn of one’s seropositive status and obtain available treatments, a reduction in the anxiety of individuals who test seronegative, the opportunity to plan more effectively for the future, and support for a differential diagnosis when HIV infection is suspected (Goldblum and Seymour 1987).

To date, not much is known about gay men’s motives for taking or not taking the test (Coates et al. 1988). What little data that are available indicate that gay men’s motives frequently refer to perceived consequences of learning test results or taking the test. For example, Lyter et al. (1987) used fixed choice mail questionnaires to investigate the reasons why participants in the Pitt Men’s Study (the Pittsburgh component of the Multicenter AIDS Cohort Study) did or did not ask to be informed about their antibody test results. These men had their blood tested as part of the research protocol. Out of a total of 2,047 gay and bisexual men, 61 percent chose to learn their results. The chief reasons offered for learning test results

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were curiosity about possible infection with HIV and the belief that knowledge about antibody status would help them cope with fears of AIDS and reduce high-risk sexual practices. Conversely, the primary reasons for not learning test results were concerns that positive results would be psychologically harmful (in the sense that it would increase anxiety, depression, and worry), and the belief that the test does not predict the development of AIDS.

Another study directly tapped motives for not being tested among a community sample (N = 213) of gay and bisexual men living in the San Francisco area (Research and Decisions Corporation 1986). About three-quarters (73%) of the respondents were untested. The major reasons reported for not taking the test included concerns about emotional reactions to the test, uncertainties regarding the utility and meaning of the test, and fears about the confidentiality of the test.

This paper expands our understanding of the motives of gay men for taking or not taking the antibody test. In what follows, we discuss the research methods used to collect our data on gay men's motives, report the motives cited by our respondents, and close with a discussion of how the major cultural definitions of the HIV test are reflected in the respondents' reports.

Method

The data presented below come from an ongoing qualitative study of sexual decision-making among gay men in the context of the AIDS epidemic. The study was undertaken in response to a recognition that, although self-identified gay men have participated in a number of survey studies concerning the extent to which the AIDS epidemic caused changes in their sexual lives and emotional well-being, there was a notable lack of research on the meaning of AIDS as it is phenomenologically and pragmatically experienced by the men themselves. The research was designed to address this gap in understanding by using a primarily qualitative methodology that includes participant observation, the use of a brief self-administered questionnaire, and relatively unstructured but focused group and in-depth individual interviews.

Respondents for the study were recruited through fliers distributed and posted at a variety of gay service, political, and social organizations (including the large Gay and Lesbian Community Center which serves the organized gay community in New York). In addition, recruiting announcements were run as advertisements in gay newspapers, as public service announcements on gay cable television, announced at various gay organizational meetings, published in a range of gay newsletters, and distributed through a constantly growing recruitment network.

To participate, respondents had to be between 18-65 years of age, live in the greater New York metropolitan area, have not used intravenous drugs in the past six months, and not have been diagnosed with AIDS. Seventeen men participated in initial group interviews. A total of 150 gay men eventually will participate in two, two-hour individual interviews. All interviews were conducted as relatively unstructured open-ended discussions led by the project's interviewer. Interview sessions began with a nine-minute videotape produced by the study team as a projective stimulus for discussion. The video contained five vignettes in which actors portray gay men articulating their diverse views about safer sex and AIDS. The vignettes included men who have adopted safer sex practices and express differing feelings about their choice as well as men who justify continuing to engage in risky sex. By presenting varying views about safer sex, the video was designed to give respondents permission to express themselves candidly (e.g., to acknowledge disagreement with safer sex recommendations or involvement in unsafe sexual practices). Interviews were audiotaped and transcribed verbatim.

The material presented here was derived from individual unstructured focused inter-
views (Merton et al. 1956) with a total of 120 men. Of these, 41 percent were untested, 22 percent were seropositive, and 37 percent were seronegative. One hundred and eleven of the respondents were white, four were Hispanic, three were black, and one was Asian. The mean age of the sample was 34.6 years and the median age was 33 years (range = 18 to 63 years of age). Eighty percent of the sample was between ages of 18 and 40 years. Respondents were well educated: 69 percent had at least a college education; about 26 percent had completed some college; and the remaining 5 percent were high school graduates. Approximately 22 percent of the respondents earned less than $20,000; 29 percent earned between $20,000 and $29,000; 19 percent earned between $30,000 and $39,999; and 30 percent earned more than $40,000. All interviews were conducted between May 1988 and May 1989.

The data reported below were either spontaneously volunteered by respondents or offered in reply to a general query by the interviewer asking them to discuss what led to their decision to or not to be tested. Because the interviews were unstructured there were no standardized probes as a follow-up to their responses. That is, the interviewer did not systematically probe about the possible importance of factors other than those reported by the respondent. In this way, we believe that we captured the respondent's subjective perceptions and definition of the situation and insight into what factors were personally most salient to him in arriving at his decision. For the purposes of exposition the reasons offered by men for their decisions are segregated. In reality, however, men frequently expressed more than one reason for their decision, and one reason would seem to potentiate another. All of the motives reported below for undergoing testing were cited by men who were actually tested. Similarly, all of the motives presented for not being tested were offered by untested respondents.

In presenting the findings we have pooled tested men regardless of their test results. Because the decision to be tested obviously temporally precedes knowledge of one's antibody status, the latter should not be causally implicated in explaining decisions about whether or not to be tested. Still, it must be recognized that, as reports regarding why one was tested are in fact retrospective accounts, it is possible that a respondent's test result influenced his reconstruction of his earlier decision to take the test. In describing the experiences of respondents who have been tested, their antibody status will be noted.

**Motives for Taking the Test**

The men who said they had taken the test told us they did so primarily because of the medical and health consequences they believed might follow from knowing their serostatus (whether positive, meaning that the HIV is present, or negative). In addition, they sought to know their test status in order to make more informed decisions about their sexual and social lifestyles. We have grouped their comments into five categories of motives: (1) to enable medical treatments for HIV infection, (2) to become motivated to make needed health and lifestyle changes, (3) to clarify an ambiguous medical condition, (4) to inform sexual decision making, and (5) to relieve the psychological distress associated with not knowing HIV status.

**To Enable Medical Treatments for HIV Infection**

Most men who underwent testing reported being previously opposed to taking the test. At first, they believed that nothing could be done to help HIV infected individuals or prevent the disease from running its inexorable course. In addition, they believed that learning that one was seropositive carried grave psychological dangers. In this sense, “ignorance was bliss” under conditions of helplessness. Some further rationalized not being tested on the grounds that they practiced only safer sex, and therefore did not place any partners at risk. They
viewed their decision not to be tested as socially acceptable rather than as selfish, self-protective, or irresponsible because they did not engage in practices that could potentially infect partners.

However, the perceptions of these men changed over time. Many came to believe that there were effective medical therapies for HIV diseases. These included prophylactic treatments (e.g., aerosol pentamidine) for some of the more common opportunistic infections and antiviral drugs (e.g., Azidothymidine or AZT) that slow the replication of HIV. Accordingly, they recognized that these treatments provided a means of exerting some control or influence over their future health and said or implied that this recognition motivated them to take the test. One 32-year-old seropositive man said,

Up until a few weeks before I took the test, which is in December, I had a couple of the opinions that I heard on your videotape. And that was, "No one really knows what they're talking about," and "There's nothing that can be done anyway." And I didn't hear this on the tape, but you know it's in line with that—ah, my feeling that the HIV test is just a blood marker and not an indication of whether or not one will get AIDS. I was thoroughly ignorant until December. And then I came upon information that was not consistent with what I had thought up until then. Someone told me that the HIV test is not just a marker any more. That is old information. Now there are prophylaxis measures that one can take if one tests positive, and you can keep, you can possibly keep your T4 cells from dropping. So I . . . got as much information as I can. And I found out that untreated HIV, the current wisdom is that untreated HIV will progress to AIDS in like 76 percent of the cases over six and a half to seven years time. And there's no other information . . . right now. That is the current wisdom, and things can be done. Things can be done to possibly halt the degeneration of one's immune system.

Another, 26-year-old, who was tested but had not yet received the results, said,

Until recently, for myself, I thought that . . . testing positive would just scare me. And that I was behaving, or trying to behave, you know, in my sex life, just as if I was positive and not putting other people at risk. And that I didn't see. I didn't see what I would gain from learning I was positive. Just seemed like there wasn't much I could do. You know unless I wanted to, you know, like go on a macrobiotic diet; or, you know, start swimming every day; or, you know, do general things which make me healthier—which, you know, if I had the will to do, I would do anyway. Ah, but just recently, it just seems like there's a lot more people can do. I mean whether it's, you know, taking low dose AZT when it's in a symptomatic stage, or whether it's getting your T-cells monitored and doing aerosol pentamidine. Ah, you know, as well as nutritional and general health maintenance things. It just seems like there's enough, enough that people can do that it seemed like a rational decision.

A seropositive man, 41 years old, told us that:

Up until recently, I didn't feel that there was any prophylactic treatment. And now I'm encouraging people to go get their diagnosis because I think now with aerosol pentamidine, and we're doing experiments with AZT being given to people with ARC. And there are a couple of new drugs on the market that are AZT analogues with less side effects that I think more and more is gonna become, it's becoming advantageous to be diagnosed earlier. But until recently, I don't think this was true.

Some men also recognized that early implementation of these treatments could prolong health and life. They felt that those who did not take prophylactic actions were likely to be diagnosed when it was "too late," at an advanced stage of the disease, with a poorer treatment outlook and consequently shorter survival time. One man, 40 and seropositive, said,

I feel that I'm better taken care of by my doctor. And the old saw, the old line used to be, "What difference does it matter if the doctor knows because there's nothing they can do." Well, now there are things they can do. Granted, not in terms of giving you ten years, but there are things they can do in giving you one and half years versus two years and a certain amount of quality time. Ah, someone who doesn't know whether he's HIV positive or not might very well go right up to getting a
full-blown case of AIDS, without any prophylactic medication whatsoever. And I think that's regrettable because then it is indeed much harder to treat the person.

And a 34-year-old seropositive respondent said,

I think gay men need to hear in a clear, concise, and convincing way that if their HIV status is known it could benefit them. It could in fact make the difference in years, added to or taken off of their life. 'Cause I believe that's the case. Ah, not knowing your HIV status, I think is very dangerous—psychologically as well as physically. I think it's a bad medical decision to have, if you're a homosexual and you've been sexually active over the past ten years, or maybe fifteen, you should have your status determined. . . . It's gonna, there are gonna be two situations. There will be those who, like myself, have sought help before they needed it. 'Cause I think in this it, when it's too late, it's too late. You wait too long and that's it. Ah, whereas those like myself who seek out the help, have their bloodwork done, and work with their health care professionals, and also work with their, work on their head too, you know, psychologically keep themselves healthy in every way, that they can influence—I think we can do quite well. Maybe I'll live to be 60 years old. You never can tell, but I think those on the other scenario, the other extreme, they're gonna die very quickly.

The diagnosis and subsequent rapid death of friends and acquaintances reinforced some men's perceptions of the medical benefits of early intervention. A few men previously felt they could adopt a "wait and see" stance, delaying the decision to take the test and/or the decision to take recommended medical treatments until the appearance of HIV-related symptoms. The experience of seeing untreated and seemingly healthy gay men suddenly become very sick and diagnosed with AIDS altered this stance and motivated them to be tested. Knowledge of their serostatus would allow them to take appropriate medical treatments. For example, a 51-year-old seropositive man told us:

I feel it's better to take it. If you know the results you can explore ways you can deal and cope with it. And there are support groups and so there someone can go for help. And then rather than not know about it, because there have been cases of friends of mine who did not take the test and suddenly were diagnosed and died instantly in about a few months. Whereas those who have taken the test a long time ago and have been practicing safe sex and using preventive measures, as well as vitamins, and a non—ah, antitoxic drugs have been able to survive and are doing very well.

A man, 26, recently tested but who had not gotten the results, said:

So I've been thinking for the past few months that I wanted to do it [get tested] and I was just a little nervous about actually doing it. Ah, but then, someone who I knew a little bit, a friend of a friend, just about three or four weeks ago, after I mean having no indication that he was HIV positive or had any health problem, you know. He had a cold which became a cough and it persisted. And it turned out he had pneumocystis pneumonia. And so, you know, he was diagnosed as having AIDS, just like that. And he is certainly someone with, you know, access to medical information and medical care. And, you know, like he could have been doing pentamidine, you know, if there was any reason for him to. Ah, and that sort of like jolted me into realizing that, you know. I really ought to do it.

Nearly all the men citing the possibility of medical treatments as the motive for undergoing testing, described their decision as one they made for themselves. Nevertheless, several reported that their personal physicians played an important role in influencing them. These men were obviously impressed that their doctors, who had previously shared their opposition to testing, had altered their stance in light of recent scientific data and clinical experience indicating the potential efficacy of available treatment options. One 29-year-old seronegative man commented:

When I saw him [my doctor] a year and a half ago he did not recommend taking the test. He recommended not taking the test. And then, then six months ago, it's really more like more like eight months ago. . . . I knew my former lover had ARC, so was positive—HIV positive. And I went to the doctor just for a general check up and told him this. He said at this point he was very insistent
that his patients, people who think that there might be the possibility or just for—you know, he recommends the test because he now feels with AZT if you’re symptomatic, but not diagnosed, there may be time to start treatment if necessary. . . . And he explained, he took out charts and he took, you know, he had articles about it and we talked about it. He was just, you know, he was very level-headed about what he was saying to me.

Another seronegative man, 34, said,

Yeah, it was actually a hard decision. And I, I thought about it for probably two or three years before I did it. Ah, I have a doctor who is gay, who treats a lot of people with AIDS. And he, a lot of my decision was based on his recommendations. Ah, there was obviously a natural curiosity all through the years. Ah, I think that only after I was convinced primarily through his telling me so, that there would be good, there could be good to come from having taken the test and finding out that you were positive, in terms of there being certain medical things that could be done. . . . Previous to that he was a strong proponent of not taking the test because medically there was nothing that could be done.

**To Become Motivated to Make Needed Health and Lifestyle Changes**

Some men said they took the test to become motivated to make desired health and lifestyle changes. Although aware of the desirability of safer sex, sound nutrition, reduced alcohol and drug consumption, they said they were insufficiently motivated to initiate and maintain these behaviors in the absence of knowing they were positive. They felt that a positive result would represent a concrete and certain threat to their health and to their partners, which would motivate them to make appropriate behavioral changes. For example, a 31-year-old seropositive man said, “I also knew that I was really not taking proper care of myself—physically, safe sex speaking, and just everything [like] nutrition . . . and somehow I thought that it might give me just the jolt I needed.” And a 28-year-old seronegative respondent said,

I defended my own reluctance to take the test by saying, much like one of the guys in here [on the videotape], “If I have it, I don’t want to know. And if I don’t have it it’s not gonna change anything about me anyway because I can’t, ah, there’s no cure. There’s nothing to do.” You know, I’m a sitting duck. And then some friends of mine . . . had taken the test and their doctors began to—they tested positive—and then the next step was to be, to have the T-4 cells counted and all this other stuff. And it became clear to me that, if in fact I was positive, there were things I could do to protect myself. I could give up the alcohol I was drinking. I could give up the marijuana I was smoking. I could worry more about my diet. I could, ah, be more honest with myself and my future. Ah, whatever future I would have. Ah, it became . . . really a question of honesty and courage. And, and protecting myself to the extent that I could.”

Another man, 51 and seropositive, believed a positive result would stimulate him to adopt holistic health practices:

I’d given it thought and I wanted to know whether I had the virus and that if I did, what I was going to do to help myself. And what preventative measures that it’s gonna take to protect my life. And this is exactly what I did. I’m exercising. I wake up at five to do some meditation for half an hour. I do the Hatha Yoga exercises. I eat macrobiotic food cause I feel that’s helped people in the past. [I take] minerals that inhibit the virus from manifesting itself, and I do megadoses of vitamin C like 10,000 grams per day.

**To Clarify an Ambiguous Medical Condition**

In some cases, the appearance of possible HIV-related symptoms motivated respondents to be tested. Where the prevalence of HIV infection is assumed to be high, as in New York City, physicians caring for gay men often consider this as a possible cause of an ambiguous
medical condition, since the symptoms of HIV infection are often similar to those of other illnesses. Therefore, to arrive at a definitive diagnosis of a patient's condition, physicians treating gay men may recommend antibody testing. This was commonly reported by our respondents. Nevertheless, in a few instances respondents took the initiative and proposed to their physicians that they be tested. A 26-year-old seropositive respondent said he took the test "because I got really sick with a kidney infection. And it did not clear up with the antibiotics right way. And I knew I was gay. I knew that my sexual activity would definitely put me in that risk group." Another man, 27, and also seropositive, said,

I had been seeing a physician for an unrelated problem [anal warts] that he was treating. And as he treated it, the recurrence he said was possibly indicative that I was HIV positive. . . . He said the recurrence of the warts were possibly had to do with HIV positive. I didn't believe him. I wanted to [take the test]. I wanted to find out and prove to him and myself that I was negative.

A man, seronegative and 44, said, in response to the question of why he decided to take the test,

Oh 'cause I think when I had I had this little basal cell carcinoma . . . I got very paranoid about it 'cause when it first showed up, it's this little red rash, Right on my clavicle. I was in St. Thomas when it happened. And I thought, "Oh well" and I ah—"Who knows what it is?" And then two weeks later it opened, you know, it bled, it ulcerated, it didn't close. And I thought, "Well, cancer." I knew enough about KS [Kaposi's sarcoma] to know that these lesions don't ulcerate that way. But it still, you know, the unconscious grip is much stronger than the rational one.

And a 36-year-old man who said he was seropositive commented:

I found out I had a form of muscular dystrophy, so I went to the doctor; went to the hospital for ten days to find out exactly what it was. 'cause I, at the same time, I had bruises and everything. I thought it might have been AIDS. Ah, I found out I was just anemic. I had low platelets, and muscular dystrophy and everything. About six months later he [my doctor] decided to, "Let's try it [the HIV antibody test], if you want. Let's try to take the test 'cause I want to know if this is gonna, if this is related or not."

**To Inform Sexual Decision Making**

Some men explained that they had taken the test so that they could make more informed and responsible decisions about their sexual behavior. There were two subgroups among these respondents. The first consisted of those who felt a negative result would allow them to expand their sexual activities, such as one 27-year-old seronegative man:

Well I did it [took the test] because I was in a relationship. The one that I'm in now. It's been going on for eleven months. And I just, I tested negative twice. And he tested negative twice. But he had just recently been tested negative. And I just, we were having, we were pretty much having safe sex. I mean we blew it a couple of times. And so we were trying to decide if we wanted to have unsafe sex. And we knew we wanted to be mutually exclusive. And so I just wanted to do it one more time to make sure.

Another 34-year-old seropositive man, citing similar motives, commented:

I was sure I was negative. . . . In [the] autumn of 1986, I had a boyfriend and this guy was very hypochondriac. He had the test at least twice and he was negative. But he set very strict sex rules for us. And I thought that one of the reasons of our problems was that he couldn't have a relaxed sexual life because of that. Turned out that I was wrong. But, I couldn't know that. I thought, well, if I take the test, too, and I, of course, I'll be negative, then we'll be both negative. We'll make a pact of mutual total fidelity, sexual fidelity. And so we will be able not to have, not to follow safer sex guidelines anymore."
And a seronegative man, 26, said, “I think it [a negative test result] allowed me to perceive myself as being at less a risk, and to have fewer qualms about having unprotected oral sex.”

The second subgroup was motivated to be tested because they wanted to know if their sexual activities presented any risk of infecting their partners. They believed that if they tested negative, they posed no risk to others, regardless of their behavior. One 27-year-old seronegative man said he took the test “for a variety of reasons. First off, I really thought I was going to be negative. But I also didn’t want to pass it on to anybody else. I mean I was having— I didn’t want to pass it on to anyone else.” Another man, 25 and who had tested negative, told us:

Well, what basically led up to it [getting tested] was in September I met my lover. And I felt something I had never really felt for anybody else before. And he told me I guess about a month into our relationship that he has been tested negative three times, because there was someone he had been with that told him afterwards that he had it. So he was quite upset from that. So he went and told me, you know, he took it three times. And he was negative all three times. And I just felt that this was something that was very important to me. And this was something that I really cared a great deal about. And I didn’t want to be in the dark about it and risk something happening at some point. Ah, so I decided, you know for myself, but also for him that I wanted to try it out [be tested].

Another respondent, also negative and 24, spoke of the “responsibility” he felt to others:

But anyway, the reason I got tested was mainly because I wanted to know. It’s a big responsibility. Ah, this is my counter to the argument of “I don’t want to get tested.” Because you have a responsibility to the person you are going to sleep with. You have a responsibility to make sure they are healthy when they leave you. And that’s something that I take very seriously. I mean in terms of whether or not you want to know for yourself, doesn’t hold up if you are going to endanger the life of somebody else. And that’s basically my argument. So I really wanted to know for that.

To Relieve Psychological Distress Associated With Not Knowing HIV Status

Virtually all respondents recognized that they may have been infected through past sexual behaviors. Even those who had consistently practiced safer sex during the last several years and expected they were negative realized that they could have acquired the virus through their earlier behavior. Furthermore, even those who had remained asymptomatic for several years after stopping unsafe behavior worried about infection because they knew that the disease had a long incubation.

The ambiguity of their status left them psychologically vulnerable to persistent fears and suspicions that any symptom might be HIV related. To relieve this psychological distress, some respondents were motivated to take the antibody test. A 30-year-old man who had taken the test, with negative results, about a year earlier said,

I knew about the test I guess since it’s been out. What was happening up until that point, you know, every time I’d be sick, I would think “is this AIDS?”... [And] for a long time I was able to live with that fear. What I realized was that, you know, the stress of every disease that was coming up, every common cold—anything—the stress that I would put myself through by not knowing if I was exposed to the virus was just outweighing me getting a positive result back. You know it came to that point where I finally realized that if I got a positive result back it’d probably be less stressful than not knowing. So I went and took the test at that point.”

For many men, learning that past partners or close friends tested positive or were diagnosed with AIDS heightened their own sense of vulnerability and finally raised their anxiety to an intolerable level. These men experienced a kind of “closing circle” effect as the illnesses of past partners and friends personalized the threat of the disease, making it harder to deny the immediacy of the peril to own health. A 63-year-old man who said he was seronegative described these feelings:
I was worried, I was very worried. . . . Ah, several partners, previous partners, got AIDS and died with AIDS which scared the hell out of me. . . . And each time I heard that someone got AIDS and subsequently died of AIDS, I used to say, "There but for the grace of God go I." Ah, then ah, anytime I'd see something on my skin or something unusual in my physical make-up, I'd get frightened. Uh oh, here's a symptom coming up. Ah, it was two years ago, I was on the beach in the, down in Florida in the wintertime. And I saw three spots on my calf I had never seen before. Holy shit! KS [Kaposi's sarcoma]. Ah, and I was living with those fears, and I just didn't like it. I felt if I was positive, I could cope with it, but I just wanted to know. Ah, I wanted to push paranoia aside or whatever.

A 28-year-old man with a seronegative test result said,

I had three good friends who died of AIDS. And it was all over the papers and all over everything. And I, in my mind I kept saying to myself, "Well, gee that it could be that chance that I have it." And it was just getting to me. And it was getting the best of me. And I don't usually let anything get the best of me, but it, it kind of was. And I said, "Well, fuck it. Let me go for my [test], just to see. And I did.

One 31-year-old respondent initially had chosen not to be tested, justifying his decision by saying that he felt that knowing he was positive would be like walking around with a "time bomb" inside of him. However, eventually he decided to be tested (obtaining a positive result) because he felt not knowing his status was equally psychologically distressing:

Then what happened was I, I think I started walking around with that anxiety and that time bomb feeling even without taking it [the test]. . . . AIDS was something I was always able to keep at a comfortable distance. You know even though I volunteered at GMHC [Gay Men's Health Crisis, a community-based AIDS service organization], I could still go home and forget about it. Ah, most of the people that I—all of the people that I knew that had become sick were acquaintances, not close friends. And over the past year and a half, it started to hit closer to home. Closer friends, just people in my social circle. And, ah, so I suppose I started feeling the time bomb syndrome anyway, and then really wanted, you know, the anxiety level was high and I wanted some affirmation either way.

**Motives for Not Taking the Test**

Respondents who had not taken the test spoke of the anticipated negative psychosocial consequences that a seropositive result might have. We organized these responses into four categories: (1) the desire to avoid the adverse psychological impact of a positive test result, (2) the desire to avoid social discrimination and repressive governmental actions, (3) the desire to avoid an ambiguous or unreliable test result, and, (4) the wish to avoid having to make undesired lifestyle changes.

**To Avoid the Adverse Psychological Impact of a Positive Test Result**

Respondents most frequently cited the wish to avoid negative psychological consequences as their reason for not taking the test. The men feared a devastating emotional impact if they learned that they were infected and expected they would become severely depressed and even potentially suicidal if confronted with that knowledge. Some said they would feel that their lives would "be over," "destroyed" by such an awareness. These fears were usually based on the belief that most, if not all, infected individuals would eventually develop AIDS and die and that available medical treatments could not prevent that eventual-ity. A 39-year-old said,

*As far as the test is concerned, I just feel for myself, I am not, I haven't taken it and I don't intend to.*
I sort of agree too, very much, that if you test positive, it seems now that just about everybody who tests positive is gonna get it, you know. And that if you know that, first of all your life, your life is destroyed; even if not physically, just as much destroyed.

And a man, 26, spoke of how knowing that he was positive would "destroy" him:

I would never get tested. I mean it. It would take a lot for someone to convince me to be tested. Ah, if I found out that I was positive, it would destroy me. Whether you could tell me I was gonna live for seventy or five hundred years. I think I would start, I would really feel, start to think really negatively. As it is, I think I probably have the HIV virus. But I don’t know. So it’s almost like it’s better for me living for me that way. I mean I go back and forth. It would be great to find out I was negative. But if I found out I was positive, it would be devastating. And that’s too great a risk for me to take. Basically, it’s—I feel that if I found out I was positive on a piece of paper, my life would be over. I would, I would think every day, “Well, I just wonder when it’s gonna happen.” Not if it’s gonna happen. When. I’d wonder if it will happen, you know, like a year from now, or two years. I mean it would totally wreak havoc.

Another, about the same age, said,

Ah, I know myself well enough to know that I’m not the sort of person who would respond well to that kind of information. So, ah I would rather not know. I don’t take it because I conjecture that I would be really debilitated by it. I wouldn’t be able to function well, knowing that I would worry, I would live a life of default. Ah, but at the same time, it’s hard not to know. I mean if I were in the circumstance and at that point were faced with no option, but to cope with it or kill myself, I don’t know. I don’t know which I would do.

Other men saw the immediate psychological impact as less acute and devastating, but felt knowing they were positive would become a chronic stressor which would significantly compromise the quality of their lives. They felt they would become morbidly preoccupied with their health and possible death if they knew they were infected. They expected they would be continually anxious about the specter of the appearance of the first HIV-related symptoms and be alarmed by even innocuous symptoms and ailments. Most described themselves as already riddled with anxiety about their antibody status and future health. They believed that the certain knowledge that they were infected would only serve to heighten their worries and fears.

One 38-year-old respondent, who described himself as already in a panic because a former live-in lover had died of AIDS, said if he found out he was positive he would “be even more frightened. I’d think of when it would come... What I would do... It’s a death sentence.” Another man of the same age said he thought about being tested “every single day... Will finding out I’m positive or not change what I do? No. Will it make me worry more? Yes... And I don’t need to worry more.” And a 19-year-old respondent also said he preferred not to know:

But I wouldn’t take the test because if, God forbid, the results were positive, I, I couldn’t take that. I’d feel like I’m a time bomb and I’m going to explode soon. I just wouldn’t want to know. If I have it, I have it. Ah, and I don’t—now I haven’t been doing any sexual practices that would, you know, harm anyone that I’m in sexual contact with.

Several men recognized that their past sexual behavior placed them at high risk for exposure to the virus, and even presumed themselves to be seropositive. Still, they felt that not having definitive knowledge that they were positive permitted them to maintain a modicum of hope that they were uninfected and that was psychologically protective. One 33-year-old man described the importance of this hope as something that could “sustain” him:

[If positive] I would worry, you know. I’m more, kind of a hypochondriac in a lot of ways. And I think that ah, I worry enough as it is. And that thing, that little point zero one percent hope that I might be negative, you know, may sustain you sometimes... I don’t want to deal with the fact that I’m probably positive.
When we asked him about the difference between assuming he is positive and knowing it, he responded, "Just that difference. That little bit of, you know, there's a little bit of hope there." Similarly, a 36-year-old man who said he assumed he was positive, spoke about how not knowing for sure gave him "that little five percent that says maybe I'm not. And so, ah, rather than be told, "Yes, you are", and having to deal with that." He preferred not to be tested.

A number of men felt that learning they were positive could have adverse physical consequences. These men believed that psychological stress damaged the immune system's functioning. A 39-year-old said, "I feel good. If it's gonna happen, it's gonna happen. Ah, if I got the test and it was positive, I would probably worry about it and make matters worse. So if I don't know, then I'm gonna proceed on a healthy way of life." A man, 36, said knowing he was positive could result in "damaging stress" to his immune system, and he thus avoided the test. One 27-year-old, who had gone to be tested in the midst of what he described as an "incredible anxiety attack" but decided not to return to learn the results, explained his decision this way:

At that time it seemed so certain that you were going to die very soon if you had it, that I just didn't want to face that information. And I guess I believe in the holistic idea that a healthy mind can help a healthy body. I do believe that ah, if you are infected, if you worry about it constantly, it's much more likely to sort of undermine your immune system than if you don't have worry about that very real solid fact.

To Avoid Social Discrimination and Repressive Governmental Actions

Another motive mentioned for not being tested was to avoid social discrimination and repressive governmental actions. Many men doubted that their test results would remain confidential or be truly anonymous and thus feared that testing positive, or even just taking the test, could result in loss of jobs, insurance coverage, and civil liberties. While the dangers of repressive government actions against infected individuals were typically discussed as something that could happen in the future, fears about loss of insurance or employment were usually based on stories they had heard of the past experiences of others and were perceived as an immediate threat. These men seemed to put little credence in assertions by various institutions or officials that results would be kept confidential or that testing was anonymous. Our respondents expressed distrust of public officials, employers, insurers, and even the general public. One 46-year-old man spoke of his fear of "getting on somebody's list":

You know, I think politically, I mean in pure politics, that we see our country frequently shifting into a real conservative bent. And when they are in power, there is nothing to stop them. And once you've been tested, I really think you're probably on somebody's list, whether it's the doctor's list or public health's list or something like that. . . . I'm also concerned about the insurance question, medical insurance. People being refused it or dropped. Ah, I don't trust the American public. Especially when something selfish comes, I don't trust any public . . . I just, I feel that panic that we've seen at times. And it will probably get worse because there are all indications that it's going to go into—it's broadening its spectrum in terms of the number of people and kinds of people that it's hitting. But I would be fearful of getting on some list.

Another man, 35, also doubted the anonymity of the test results:

I think of a few of the horror stories about test results, about test results being released to insurance companies, to employment agencies, to these kinds of things. Unfortunately I don't believe we are at a point where these things are totally anonymous. I don't feel I'm being overly cautious. If I felt it was something, that being tested was going to save my life, I wouldn't care. But the idea that somehow my insurance would be dropped or something based on the fact that some worker in a health department somewhere was convinced by an insurance company employee that for X amount of money that certain records could be left open or copies could be made. I've heard many horror
stories of men with AIDS who have been dropped from insurance programs, and it's pretty horrible. I don't think knowing whether I have the HIV virus or not is worth right now taking that risk.

A 26-year-old man who said he "worked in government relations" commented that he didn't trust public authorities with any kind of information regardless of what they say about confidentiality, including this. Public policy advocates will use information in any way that they can to advance their cause. And those advocates are not always going to be people who are sympathetic to those people who have taken the test. And even though right now the balance of power may be such that you have nothing to worry about now, that doesn't mean it will be so in the future.

**To Avoid an Ambiguous and Unreliable Test Result**

The perceived ambiguity of and/or unreliability of the antibody test results, the significance of HIV as a "cause" of AIDS, and the meaningfulness of a positive or negative test for anticipating future health were also offered as reasons not to be tested. These respondents seemed to feel that tolerating the uncertainty of not knowing their status was possibly no worse than submitting to the ambiguity of a potentially unreliable or inaccurate test result. A few men remained unconvinced that HIV was the etiologic agent in AIDS or that seropositivity was a useful predictor of future health. One man, 37, said he thought taking the test was "like flipping a coin":

I have friends who tested negative up until the day they died. . . . I have heard it's as high as 40 percent false positive, false negative, for example. 40 percent on the ELISA [an initial test to screen blood for HIV antibodies]. The Western Blot [a more precise confirmatory test for the antibodies] is 70 percent, fairly accurate. . . . [My roommate's second lover] hung himself in his hospital room. . . . One day his test was positive and the next day negative, right up until the end. And it was like, "Oh no, it's just lymphatic cancer you lucky dog." you know. Really, every couple of days it was "you've got it, you don't have it, you've got it, you don't have it," you know.

Another man, 24, spoke of his understanding that the test was not "100 percent accurate":

It doesn't mean that you don't have it [HIV infection] if it comes out negative. So I guess that would be the main thing. So what would be the sense of you taking it and then it coming out negative, and then having sex and end up catch, you know, contracting AIDS anyway.

The men recognized both the dangers inherent in a false sense of security that a "false negative" can provide and the psychological devastation that a "false positive" can bring. A respondent, 26, said,

So I get a negative? Great. Well, maybe it's a false negative. You know, who knows? Or then I have to go get tested again. If they come up with a sure-fire test that says, "you are definitely, 100 percent." Until then I don't really think it would do that much for me. And I think getting a positive, which again could be false, is actually worse than not being sure and sort of assuming you have it. I think that would be, that would be worse.

**To Avoid Having to Make Undesired Lifestyle Changes**

Other men had decided not to undergo testing because they felt a positive result would require changes in their lifestyle that they did not want to make. Ignorance of their status seemed to make it at least personally acceptable to maintain current practices. A man, 29, said,

I kind of like, well I do like the way I live now. And I know my personality. And if someone were to tell me that I tested positive for this, I wouldn't live my—I know I'm pretty sure I wouldn't live
my life the same way. I would worry. I'd be in fear. At the same time, if I tested positive it would probably be the end of my sexual activities.

Like this man, others said that learning they were positive would obligate them to modify their sexual behavior or lifestyle, something they did not feel compelled to do in the absence of certain knowledge they were positive. A man, 27, spoke of the "moral issue" involved:

if I found out I tested positive, it's not real for me to say that I would stop having sex. It's not real for me to say I would find a lover who has AIDS and only have sex with him. Ah, so I would continue to not practice safe sex, but I would continue to have sex—a great deal of anonymous sex. And that's wrong.

We asked him why he thought that was "wrong":

Because you know that you are in effect poisoning people. . . . I agree with the first person [on the videotape who said every person that has sex with you without asking you first [if you're infected] is taking a risk, and that's his responsibility, not yours. And it's an implied risk and so you're off the hook. Well yes, if you don't know you're going to contaminate this person. If you know you're infected, you know that you will contaminate him if what you do is unsafe. And that's, morally that's wrong. Worse [to me] than actually having the disease and dying would be to live the rest of my life and not be able to have sex with anyone or knowing I was killing whoever I was having sex with.

And finally, a 38-year-old man speculated about how knowing he was positive might affect his relationships:

I don't think that would necessarily stop me from having a relationship with another person. But I know that it would really curtail the sexual activity because of what I may contribute to the person's development. Who knows, it may be multiple infections or whatever, so it would probably be better not to have any, you know, contact with his semen. You know it would probably be bad for both of us.

Discussion

The motives our respondents offered for taking or not taking the HIV antibody test both reflect and constitute prevailing social constructions of the test. In this final section of the paper, we characterize these cultural constructions more broadly and comment on changes in the motives offered over time.

Within the broader culture there are three competing definitions of the HIV test, which can be labeled the public health, psychosocial, and medical constructions. The men we interviewed discussed their motives for taking or not taking the test by drawing on these definitions, applying them to their own circumstances, and thus revitalizing them as cultural constructions. An analysis of public health and gay literature shows that the first two, what we call the psychosocial and the public health definitions, emerged shortly after the development in 1984 and subsequent licensing in 1985 of a test for serum antibodies to HIV. The third, the medical definition, appeared following the growing recognition in 1987 and 1988 that HIV causes a spectrum of diseases that culminate in AIDS. All three constructions differ in regard to the meaning and anticipated consequences of the test.

The psychosocial construction of the test depicts it as a grave threat to individuals' basic human rights and psychological well-being. A perception of pervasive homophobia in the United States prompted gay community leaders and civil libertarians to become the main proponents of this perspective (Shilts 1987, Bayer 1988). According to this construction, all but anonymous testing procedures presumably are associated with the creation of registries of infected people or provide the potential for such registries to be established. Although assur-
ances of confidentiality may currently exist, it is recognized that future laws or court orders could overturn these protections. Subsequent breaches of confidentiality could be exploited by anti-gay interest groups, possibly leading to employment and housing discrimination against registered individuals as well as loss of their health and life insurance protection.

This construction also holds that test results may be emotionally and socially disruptive to individuals in a number of ways. First, positive results can have profound adverse psychological consequences, including depression, anxiety, suicide, and the disruption of social relationships. Second, the technical limitations of the test, including the existence of a period after infection during which antibodies cannot yet be detected, can lead to inaccurate or inconclusive results. False positive results can engender the same adverse emotional consequences as accurate findings, and, of course, false negatives can allow those infected to unknowingly transmit the virus.

The campaign against testing within the gay community in New York City conveyed the psychosocial construction. The leading gay newspaper and AIDS organizations published editorials, advertisements, and informational brochures discouraging gay men from being tested for technical, social, and psychological reasons (Shils 1987, Bayer 1988). A widely distributed GMHC pamphlet was typical of these campaign materials. Written in alarmist tones, this brochure warned gay men that test results were unreliable and ambiguous and could cause them to "lose their jobs or health insurance."

The motives cited in the interviews for not taking the test drew heavily upon the psychosocial definition. Most of the men reported avoiding being tested because they feared social discrimination, repressive governmental actions, and the adverse psychological impact of positive results. Many men feared that hostile groups would gain access to test results and use them for discriminatory purposes. In addition, they believed that a positive result, even if it was inaccurate, would leave them emotionally traumatized and devastated.

The medical construction views the test as a valuable tool for planning the most efficacious and appropriate clinical management of at risk individuals. AIDS clinicians, researchers, and treatment activists have been the major supporters of this perspective (Redfield and Burke 1988, Institute of Medicine 1988, Helquist 1989, Delaney 1989). In this definition, HIV is presumed to cause a sequence of disease conditions, ranging from acute infection to sero-positivity to chronic HIV infection and, finally, to AIDS. Furthermore, the antibody test is regarded as an acceptably reliable indicator of HIV status, with a positive result indicating the presence of the virus and infectivity. Therefore, a positive test result is considered to be grounds for initiating medical treatments. Moreover, it is presumed that if left untreated sero-positivity will inexorably progress to AIDS, and hence early intervention is considered central to prolonging health and survival.

Prominent gay clinicians and treatment activists began to articulate this definition in New York City in early 1988. At public forums and in articles in the gay press and the newsletters of AIDS organizations, they encouraged gay men to get tested in order to take advantage of emerging medical treatments for HIV infection. They recommended that seropositive men practice sound health maintenance, participate in holistic therapies, and take either antiviral drugs or medicines that can either boost the immune system or prevent opportunistic infections.

The men's motives for undergoing testing largely embodied the medical definition. Many of the men stated that they took the test in order to more effectively monitor their health status and plan medical interventions. Knowledge of their test results would allow them to determine whether or not they should take drugs that could either slow the replication of HIV or forestall opportunistic infections. Others stated that they needed this knowledge in order either to become motivated to lead a healthier lifestyle or to arrive at a definitive diagnosis of a problematic medical condition.

The public health definition views the test as an effective mechanism for controlling the
spread of the HIV epidemic. Public health officials and policy makers were the principal advocates of this construction, with most favoring widespread, voluntary, and confidential testing (Bayer 1988, Brandt 1987, Koop 1986, Centers for Disease Control 1986). According to this interpretation, the antibody test is an acceptably accurate and reliable indicator of HIV infection. Hence, individuals who test positive are regarded as being infected and presumably infectious.

Furthermore, testing, especially among high risk populations, is regarded as an effective strategy for reducing HIV transmission. First, testing is believed to locate infected individuals who are unaware of their status; these people can then be counseled to cease behaviors associated with the transmission of the virus and to adopt health maintenance practices. Second, some proportion of the asymptomatic infected population who are currently unaware of their status and unknowingly infecting others will learn of their seropositivity and be motivated to cease practices that spread the virus. Finally, widespread testing presumably provides more accurate surveillance data concerning the geographic and demographic spread of the virus, enabling more intensive educational efforts to be targeted to those regions and groups with high rates of infection.

The motives offered in the interviews for taking or not taking the test drew slightly from the public health construction. For the most part, the men saw little personal benefits in the public health rationale for testing. Some commented that the civil liberties and psychological risks associated with testing far outweighed the public health need for more accurate surveillance data. Others felt that education, not testing, was what was needed to motivate gay men to practice safer sex.

Only one of the motives cited for being tested reflected the public health construction. A few men reported that they took the test in order to alter current sexual practices. They felt that knowledge of their test results would allow them to either expand their range of sexual practices to include risky behavior or restrict their conduct to practices that posed no risk of infecting others.

The interviews indicate that over time there was a shift in men’s definitions of the consequences of the test. When testing initially became available, most respondents subscribed to the psychosocial construction of the test. Accordingly, they perceived it as having potentially far-reaching adverse social and psychological consequences while offering no meaningful benefits. With the emergence of the medical construction in 1987 and 1988 some men redefined their perception of the anticipated consequences of being tested. Testing came to be viewed as providing a means of learning one’s HIV status, and if infected, initiating medical treatments that could prolong health and life. Conversely, most of the respondents who have remained untested continue to adhere to the psychosocial construction of the test.

The respondents’ accounts suggest that the medical construction is likely to take on increasing importance in gay men’s motives for testing. For example, if evidence continues to accrue demonstrating the efficacy of treatments for HIV infection and the benefits of beginning treatments early, more men will be strongly motivated to be tested. Furthermore, as the data indicating that HIV infection is the first stage of a progressive disease that will culminate in AIDS proliferates, the value of learning early that one is seropositive is likely to be viewed as greatly increased. Nevertheless, the psychosocial construction continues to present formidable barriers to testing. As our study and others cited above indicate, anticipated psychological distress and discrimination are among the most frequently reported motives for not taking the test. To overcome these barriers, gay organizations, public health agencies, and AIDS commissions and community-based organizations have repeatedly called for the availability of anonymous testing procedures and laws safeguarding the confidentiality of and prohibiting discrimination against tested individuals (Bayer 1988, Institute of Medicine 1988). Without these protections, it seems likely that many gay men will continue to regard the risks of testing as unacceptable.
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