

Understanding Patients' Perspectives on Opt-Out, Incentivized, and Mandatory HIV Testing

Carey M Noland,⁽¹⁾ Nicole A Vaughn,⁽²⁾ Sirena Sun,⁽³⁾ Hans P Schlecht⁽⁴⁾

Associate Professor of Communication Studies, Northeastern University
204 Lake Hall, Boston, MA 02115, c.noland@neu.edu, 617-373-7261.⁽¹⁾

Assistant Professor, Dept. of Health Management & Policy, Drexel University School of Public Health,
3215 Market Street, Philadelphia, PA 19104, nicole.vaughn@drexel.edu⁽²⁾

Graduate Researcher, Dept. of Health Management & Policy, Drexel University School of Public Health,
3215 Market Street, Philadelphia, PA 19104.⁽³⁾

Assistant Professor of Medicine, Division of Infectious Diseases and HIV Medicine, Drexel University College of Medicine, Mail
Stop 461, 245 N. 15th Street, Philadelphia, PA 19102-1192.⁽⁴⁾

Abstract

Background: Currently, widespread HIV testing is the best preventive action against further spread of the HIV epidemic. However, over 40% of the U.S. population has never been tested for HIV and 25% of those with HIV have never been tested. To increase testing rates, in 2006 the CDC advised healthcare settings to conduct testing on an opt-out basis.

Methods: Qualitative, semi-structured interviews with ten seropositive patients and ten seronegative were conducted to address the lack of studies investigating patients' acceptance of and attitude towards this and more novel testing models, e.g. incentivized or anonymous mandatory testing. Participants were asked about their HIV testing history and attitudes towards opt-out, incentivized, and mandatory anonymous HIV testing.

Results: Major themes were identified using grounded theory data analysis. All participants were receptive to opt-out testing, and saw the removal of separate written consent as beneficial as long as patients were given the opportunity to consent in some form.

Conclusion: Ultimately, both mandatory and opt-out testing were equally indicated by participants as being the most effective testing model at increasing testing rates. A firm understanding of patients' perspectives allows for development of effective HIV testing initiatives that are patient-sensitive and can substantially reduce HIV infection rates.

Keywords: HIV testing, opt-out HIV testing, incentivized HIV testing, mandatory HIV testing, patient education.

Corresponding Author:

Carey M. Noland, PhD
Associate Professor,
Communication Studies,
Northeastern University,
204 Lake Hall, Boston, MA 02115,
Email: c.noland@neu.edu

Introduction

Currently more than 1 million people are living with HIV/AIDS in the United States. Moreover, every 9.5 minutes someone is infected with HIV. ⁽¹⁾ Every averted HIV transmission saves approximately \$379,688 (in 2010 US dollars) in medical expenses over a lifetime. With a projected \$16.6 billion in future medical care costs from new HIV infections occurring each year, greater investments are needed in evidence-based HIV prevention activities that can diminish this burden. ⁽²⁾ A fundamental means of reducing new infections and thus reducing treatment costs are to increase testing rates which would result in the identification of HIV infections in the early stages so that patients may start immediate treatment.

Throughout the course of the epidemic in the United States, the CDC has emphasized HIV testing as a method for reducing transmission of the disease. People who know they are seropositive are more likely to have protected sex; one study found that people who were unaware that they were HIV positive were 3.5 times more likely to transmit HIV than those who knew that they were seropositive. ⁽³⁾ Furthermore, proper antiviral treatment decreases HIV viral loads, making people less contagious, and decreases the long-term costs associated with HIV treatment. ⁽⁴⁾ However, one third of all new AIDS diagnoses are late (defined as a diagnosis made less than 12 months after an initial HIV diagnosis).⁽⁵⁾ Thus increased rates of HIV testing not only prevent new infections but also allow early detection, thereby preventing the consequences of late diagnoses. We explored participants' perceptions of various testing methods that may serve to increase testing rates and decrease late diagnoses. We examined patient perspectives on three currently used testing methods: opt-out, incentivized, and mandatory testing. Although these testing initiatives have been widely implemented, few studies have investigated patients' perspectives on these initiatives. ⁽⁶⁾

1.1 Opt-Out Testing

Voluntary counseling and testing (VCT) was first recommended by the CDC in 1987 ⁽⁷⁾ and targeted individuals involved in high-risk behaviors. VCT involved counseling and

testing and various forms of paperwork. ⁽⁸⁾ In 2006, the CDC shifted from risk-based VCT to routine "opt-out" testing to increase testing rates. In opt-out testing, patients undergoing a yearly physical examination or visiting the emergency department (ED) are informed that they will undergo an HIV test. ⁽⁹⁾ Consent is implied unless the patient specifically declines, or "opts out," of the test.

1.2 Incentivized Testing

In addition to opt-out testing, incentivized testing is a testing initiative in which a small incentive, such as a gift card or movie ticket, is offered upon completion of an HIV test to motivate individuals. For example, The California Prevention and Education Project offered \$10 grocery vouchers to individuals who completed an HIV test. ⁽¹⁰⁾ Currently literature has not addressed patients' attitude towards incentivized testing for HIV. The available research examined the efficacy of incentives in encouraging particular behaviors, such as following up on outpatient HIV testing referrals from the ED and encouraging adherence to HIV treatment regimens. ⁽¹¹⁾

1.3 Mandatory Testing

Mandatory testing has also emerged as a testing method for certain groups of individuals such as pregnant women, federal prisoners, active duty military personnel, and blood/organ donors. ⁽¹²⁾ Currently, 17 states have legislation requiring mandatory HIV testing for pregnant women. If the mother refuses, her refusal will be noted and the newborn will be tested despite parental consent. ⁽¹³⁾ Several states also have implemented laws mandating testing of prisoners. Exceptions are allowed on religious grounds.

1.4 Reasons People Get Tested and Theories of HIV Testing

Research shows that psychosocial factors such as gender, education, lack of awareness, risk perception, knowledge, and self-efficacy are significant factors in a person's decision to test. ⁽¹⁴⁾ However, traditional theories of testing (i.e., theories of uncertainty reduction and theories of planned behavior) may not pertain to the three testing methods that we studied here, because providers are asked to test everyone, regardless of symptoms or risk.

Traditional theories associated with VCT such as the theory of planned behavior and uncertainty reduction may not be applicable. While these three testing methods may reduce stigma associated with testing, they might not affect the stigma associated with a positive diagnosis. Therefore, stigma may still be a valid reason why some individuals decline opt-out, incentivized, and mandatory testing; they fear the result. Criminalization issues are also becoming pertinent.⁽¹⁵⁾ A study presented by the Sero Project at the 2012 International AIDS conference surveyed 2,000 people with HIV infection and found that 25% said they knew someone who refused testing for HIV because they feared they would be prosecuted if they tested positive and spread the disease, as a result of the criminalization laws in many states.

Truly understanding patients' perspectives is the most effective way to create fully informed testing initiatives that can effectively increase testing. Considering that the HIV/AIDS epidemic continues to be a substantial public health threat, all measures that can improve testing rates should be considered. Our objective was to assess patients' responses to opt-out, incentivized, and mandatory testing to identify factors that might motivate individuals to undergo testing in a pilot study. We reasoned that successful identification of these factors will lead to fully informed recommendations and guidelines for HIV testing initiatives that can better increase testing rates, raise awareness of serostatus, determine serostatus earlier in the course of infection, influence future HIV testing initiatives and policy proposals, and effectively reduce further spread of infection. Based on previous research, we posited the following research questions:

1. What are patient perceptions of opt-out, incentivized, and anonymous mandatory testing?
2. Are there thematic differences between seropositive and seronegative participants regarding the testing options?
3. What recommendations do participants have to increase testing and improve communication between patients and providers?

Participants and Methods

2.1 Participants

Criteria for inclusion in the seropositive group were being between the ages of 18 and 64 years; reporting a positive HIV diagnosis; and being available to complete an interview lasting 30 to 45 minutes. The ten seropositive participants were receiving care from a large comprehensive HIV care clinic affiliated with a medical school located in the U.S. HIV status was determined via patient self-reporting. Participants were recruited through their physicians to preserve patient anonymity. Physicians were approached and asked to broach the research topic with their patients and to provide an informational flyer. A convenience sample of the first 10 people from each group who contacted researchers and qualified for the pilot study were selected. Ten seronegative patients were recruited from an internal medicine clinic at the same institution. The study was approved by the university's institutional review board. Interview questions were developed by the co-authors prior to the study implementation. We conducted the face-to-face interviews using a semi-structured interview guide in a private room. All interviews were audio recorded. Upon completion, participants received \$10 in compensation for their time.

2.2 Data Analysis

We analyzed the data using grounded theory. The main goal of grounded theory is to ultimately produce a theory that explains observed phenomena.⁽¹⁶⁾ McCann and Clark⁽¹⁷⁾ describe a similar rationale for using grounded theory in their work focused on understanding how community mental health nurses work with clients. We chose this method because we wanted the data to guide us in developing an elementary theory to understand patients' decisions about testing. All of the authors analyzed the interview transcripts independently to identify major concepts.

Results

Ages of the seropositive participants ranged from 35 to 51 years. The average age was 43.6 years and the average length of time since diagnosis was 11.3 years. The average length of time from diagnosis to initiation of treatment was 9.27 years (range, 1 month to

15 years). Eight men and two women participated, including seven African Americans and three whites. The seronegative group included three men and seven women, with an average age of 48.8 years (range, 30 to 62 years). Seven were African American, two were Latino, and one was white. Half of the participants in the total sample ($n = 20$) were employed. The average annual income was less than \$30,000. Demographic differences between the two groups were small.

Four themes emerged from the data: (1) importance of getting tested and reducing barriers to testing; (2) the stigma associated with testing and with positive test results; (3) the likelihood that people will take the path of least resistance; (4) and the importance of normalizing HIV testing and making it routine.

3.1 Motivation to Test

Two categories of factors influenced individuals' decisions to get tested: intrinsic and extrinsic. Many of the participants had been tested during the era of VCT, rather than under current opt-out policies; two were tested in a setting where it was mandatory (incarceration). Half of the seropositive participants were first tested for HIV for intrinsic reasons. Participants described concerns over their physical health (prompted by either an illness or a desire to avoid catching or spreading disease) as their reason for testing. One subject stated, "I was feeling sick, I wasn't feeling so well so I went to the doctor to find out what was wrong." Another said, "It was more to see if I was okay, but I just didn't want to pass anything along to anybody."

Other participants said they got tested because they perceived themselves to be already at risk for contracting the disease. "One time I really took a test because I was sick. And, uh, I knew that in my mind I was being destructive and doing destructive behaviors, sexual behaviors, not protecting myself."

The other half of the seropositive participants reported extrinsic factors as their initial reason for HIV testing. These individuals did not proactively request an HIV test but found themselves in situations where HIV testing was being performed (in one

participant's case, as a requirement for donating blood). Others were tested either because they were incarcerated or as a requirement for participation in a research study. The third theme, mitigating resistance (to get tested, if that is the easiest thing) is present in these participant explanations.

The majority of seronegative patients sought testing as a result of intrinsic factors. They recounted getting tested on the spur of the moment, because rapid testing was available and they were already at a health care facility and it was easy. One participant summarized it nicely: "I don't know what happened, I got hurt and went to the hospital and while I was in there she asked me if I wanted to be tested so I agreed while I was in there and I wanted to know anyways." The fourth theme of routinization emerged as some reported testing during routine screening; two women were tested during their pregnancies and one man while serving in the military. One person got tested because her surgeon pricked herself with a needle and wanted to make sure the patient was seronegative.

Three of the 10 seronegative participants actively sought testing, but only because they were already being treated in a clinic or hospital. None reported going to a clinic to get tested. One woman said, "Well, she [the nurse] didn't actually offer. I was looking, I was reading posters I saw on the bulletin board I have been in a relationship for 15 years now but I wanted to know, to know my own body." For the seronegative patients, it is difficult to draw strict conclusions about intrinsic and extrinsic testing factors because many of them had been tested multiple times for different reasons. However, most did test for intrinsic reasons. The first, third and fourth themes are evident in both intrinsic and extrinsic reasons to test. The importance of easily available, rapid testing for both seropositive and seronegative patients was clear, even within VCT. None of the seronegative participants and few of the seropositive participants actively sought out a testing facility for the sole purpose of being tested. The circumstances of testing, ranged from incarceration to military service to being at a hospital or clinic for another health reason, confirm this conclusion.

3.2 Testing Barriers

Seropositive participants' responses regarding testing barriers fell into two general categories: the need for absolution of responsibility and lack of knowledge about HIV. Participants stated that individuals may not get tested for HIV because they are afraid of the consequences of a positive test result and do not want to have to deal with those implications. A participant stated, "There's a reason why they're not aware. They don't want to be aware as long as they feel okay, they're not going to say anything because of the stigma." Moreover, by avoiding testing, people do not have to cope with changing their lifestyle according to their serostatus. One participant explained that "being negative you get a lot more action." Another participant touched on the criminalization of HIV transmission. He stated:

"Say I have sex with a girl. And I don't know I have AIDS and I give it to her, right. Can I still be charged with attempted murder? No, right? I have to know I have it. So see that right there is a deterrence for some people."

Another reason people do not get tested is that they lack knowledge about the disease, and fear of the disease stems from their lack of knowledge. As one seropositive participant stated, "You gotta be closer to a cure for people to want to get tested. And, and have people realize that it's not a death sentence. You can live with it." People are also afraid to get tested because of the severe stigma that still surrounds the disease and the ostracization of HIV-positive individuals resulting from the public's lack of knowledge about the disease.

The seronegative participants were less focused on the potential stigma of a positive diagnosis, although many of them mentioned stigma briefly. Most focused on the procedural barriers that they felt prevented testing. For example, one said, "Too much talk and too much paperwork. Say what you have to say, just get right to the point. Don't make it where it's, you know, a debate thing. It's a need to know basis, treat it like that." Another said, "You get rid of that red tape. Because that's what turns people away." Both groups discussed the importance of removing barriers (theme 1) and decreasing stigma (theme 2) associated with testing.

3.4 Opt-Out Testing

All 20 participants were enthusiastic about opt-out testing and felt that this testing model would encourage people to test. All of the four themes are reflected in participants' comments regarding opt-out testing. Participants' positive responses to opt-out testing centered on the idea that any method that would streamline the testing process would help increase the number of people tested for HIV. One seropositive participant remarked about testing that "anything that makes it easier and more accessible is going to be helpful." Another seropositive participant explained that opt-out testing is beneficial because "it's much quicker where you won't have so much on your mind." Making HIV testing part of a routine physical examination was also appealing. Participants stressed the importance of removing barriers and making testing routine. A seronegative patient stated that opt-out testing just made sense, "The blood is already been drawn, they have the blood, they're testing it for other things...they're testing it for cholesterol they're testing it for diabetes, go ahead doc. You know, test me for HIV too, Bloods already drawn".

When we questioned participants about specific provisions of opt-out testing (e.g., elimination of the separate written informed consent requirement), all participants felt that eliminating paperwork would increase testing rates. As one seropositive participant described it, "That paperwork is aggravating, frustrating," and "All that paperwork really will make a person not want to be involved with it." As long as patients are given the opportunity to consent in some way, participants felt that verbal consent was sufficient.

One seropositive participant and four of the seronegative participants cautioned that although opt-out testing is beneficial because it makes testing easier, the individuals who do refuse to take the HIV test may be a challenge. A seropositive participant explained that "my first thought is anyone that would opt out of ...not wanting to be tested for HIV is someone that needs to be tested for HIV."

3.5 Incentivized Testing

Most participants felt that incentivized testing would increase testing rates, but they also found incentivization problematic for many reasons. Themes one and two, the importance

of getting tested and reducing barriers and decreasing stigma associated with testing emerged from these data. Participants' responses to incentivized testing fell into two categories: pragmatism and idealism. Participants explained that incentives work because a person would be willing to take a test as long as they are "getting something in return." One seropositive participant exclaimed that "it would spark my interest enough to go ahead and see about my health." A seronegative participant said, "That always works. That's like 99.9% of the time, you know I mean I'm receiving something for doing this, hey sure test me. Want to test me again, you know?"

All of the participants recognized that, as a seropositive participant stated, it was "a shame to have to pay people to be proactive and concerned about their own health." One seropositive participant exclaimed, "Why pay me to go take a test? It's for my health, it's for my benefit." All participants also stated that testing for HIV ideally should be free of coercion, and participants recognized that incentivized testing was still a form of coercion. Participants also noted that if incentivized testing is going to be used, incentives should be small amounts of money, about \$5 to \$10. Subjects advised, "Go the most inexpensive way" to avoid coercion. Also, many participants expressed concern that incentivized testing would not be effective because it would not encourage individuals with high-risk behaviors.

3.6 Mandatory Testing

We asked participants their opinions regarding mandatory testing. Surprisingly, all four themes were present in this category of responses as well. Participants felt that mandatory testing would increase testing rates, making testing routine, and would require little effort on the part of those getting tested (path of least resistance). They believed mandatory testing would also eliminate stigma associated with testing, as everyone would get tested. Although every participant was in favor of mandatory testing in some instances, when probed, most felt it would be too difficult to implement. Their responses fell into one of two categories: positive sentiment for mandatory testing owing to the need for desperate measures to contain the epidemic and

negative sentiment because of the need to respect individual autonomy. One seropositive participant's response captured the feeling that drastic measures would be required to curb the HIV epidemic. He exclaimed, "It's got to become a mandatory test. You want to end it? Make it a mandatory test." Another seropositive participant echoed the importance of getting tested when he explained that "people need to know if they're HIV positive or negative because it's an epidemic." Others described the need to get people to test for their health and the health of others.

Some seropositive participants supported mandatory HIV testing under certain conditions. One commented, "That should be mandatory for pregnant women because why give birth to a child that's going to live with HIV? You know, that's like ... it's not fair to the child. It's not." Another stated that "[tests] should be mandatory when you go to prison, and if you're going to rehab. If you're on any kind of government assistance." Mandatory testing was viewed as acceptable "as long as it's confidential."

And while participants stated why they thought testing should be mandatory, they expressed a tension because they also felt that mandatory testing violated patient autonomy. They felt that mandatory testing was "interfering with someone's rights." One seropositive participant stated, "It's their choice if they want to get tested or not. You know, do I agree with it? No. No, but it's their choice." The seronegative participants held similar opinions. Most said something similar to this participant: "I think everybody should have it done. I don't think they should even get permission to do it. You're trying to save their lives. So I think everyone should have that test done."

Even those who felt uncomfortable with mandatory testing agreed that it would be useful, especially in certain cases: "Nobody wants to be forced....But I'm glad they made it mandatory for those pregnant women having babies."

Seropositive people had fewer reservations about mandatory testing, but even the seronegative patients, while either personally uncomfortable with it or concerned about enforcement, were amenable to at least some forms of mandatory testing, and in general favored mandatory testing for everyone at least

once. One said, "Well, the disease is running rampant, it should be mandatory testing to control the disease, but it sounds like Nazi Germany to me."

3.7 Most Effective Testing Model

Of the three testing models that we asked participants about, both mandatory testing and opt-out testing were indicated as the most effective way to encourage people to get tested for HIV. Approximately 80% of the participants rated both of them equally, but when they were asked to pick one method, the majority chose opt-out due to perceived ease of implementation (Table 1).

Table 1. Most effective testing model

Testing Model	Number of Participants*		
	HIV +	HIV -	Total
Opt-Out	3	5	8
Incentivized	2	4	6
Mandatory	3	1	4

* Number of participants do not add up to 20. Two participants did not indicate which model was best.

Discussion

Many participants emphasized that awareness of HIV/AIDS is limited currently, compared with when they were first tested for the disease. All participants mentioned education campaigns when asked their opinions on alternative methods to increase testing. Their observations were reflected in a recent nationwide Kaiser Family Foundation survey ⁽¹⁸⁾ indicating that the percent of individuals who had personally seen, heard, or read about the problems of AIDS in the United States had fallen from 34% in 2005 to 14% in 2009. Health officials have recognized this increasing complacency.

An equal number of participants identified opt-out testing and mandatory testing as the best models to improve testing rates. Participants who preferred mandatory testing perceived that the HIV epidemic is severe enough to justify this and believed that desperate measures are needed to curb the spread of the disease. These participants also emphasized that it was extremely important for individuals to know their HIV status; individuals' lack of awareness about their status, they believed, increases transmission of this disease. Seropositive participants felt that the major reason individuals did not test was that they did not want to cope with the implications of a positive test result, including possible social isolation resulting from stigma. Seronegative participants felt that the biggest barriers to testing were procedural barriers, such as filling out paperwork, paying for a test, making a special trip to get a test, or having to receive counseling.

Our findings regarding patients' attitudes towards opt-out testing agree with existing studies indicating that patients are receptive to physician-initiated HIV testing.⁽¹⁹⁾ Patients trust their doctors in general, and most comply with physician-recommended actions. Participants also felt that elimination of separate written informed consent would ease the testing process and encourage more people to test, in agreement with the findings of Zetola et al.,⁽²⁰⁾ and with the intent of the 2006 CDC policy changes when these updated testing recommendations were created. Zetola et al. found that when the requirement for separate written informed consent was eliminated, the average monthly rate of HIV tests per 1,000 patients increased by 44% and the average monthly number of new HIV-positive test results increased by 67%. Finally, all participants were amenable to incentivized testing, and indeed incentives have been successfully used to encourage compliance with outpatient testing referrals.

The degree to which patients supported mandatory testing was unexpected. The number of participants choosing mandatory testing as the "best model" indicates that these participants recognize the urgency of the HIV epidemic and the importance of serostatus awareness, and the subsequent need for increased HIV testing. These patients' acceptance of mandatory testing may also be

influenced by their positive diagnosis and their previous experiences getting tested. Campaigns may evoke a similar sense of desperation to learning ones' status, thus increasing testing rates.

4.1 Toward a Theory of Opt-Out testing

Because HIV testing process can be offered more readily through noninvasive rapid testing, and because the CDC guidelines and ethical studies ⁽²¹⁾ support HIV opt-out testing, we and our research participants believe that opt-out testing is the most effective of the three options reviewed. Studies of VCT have been grounded in theories of planned behavior, uncertainty management, and stigma, focusing on HIV testing in the context of people's willingness to engage in risky behaviors. Theories that have been applied to traditional VCT may not be applicable to opt-out, because opt-out testing requires no planning prior to a medical visit and does not target individuals with perceived high-risk behaviors. In addition, most published HIV testing research has been atheoretical. In a meta-analysis of theory utilization in prenatal HIV-testing research, Delissaint and McKyer ⁽²²⁾ found that very few studies referred to theory. They called for more theory use and more theory building in HIV testing research.

Therefore, a theory to explain why people comply with opt-out testing is needed. We believe there are two significant factors in opt-out testing: patient inertia and provider routinization. When presented with the option of getting tested for HIV as part of a routine process, whether in an acute care setting or during a regular check-up, most people will comply or remain inert in the face of a routinely performed test, ⁽⁹⁾ especially if the process is explained by an expert medical professional, e.g. physician.⁽²³⁾ One participant summarized, "Yeah, I think I prefer this, just to make it normal routine to encourage people to do it every, just [like] you go normally ... like dental you have to go every 6 months." Early results indicate low rates of uptake for opt-out testing, ranging from 35% in a clinic setting⁽²⁴⁾ to 45% in an ED; ⁽²⁵⁾ however, the people who did get tested may have not have tested otherwise. To avoid HIV testing stigma, people may engage in nonstigmatized behaviors to conceal their interest in HIV testing.⁽²⁶⁾ Young, Monin, and Owens ⁽²⁷⁾ demonstrated that opt-out testing

reduces stigma associated with HIV testing; they found that in an opt-in system, getting tested draws suspicion regarding moral conduct, whereas in an opt-out system, not getting tested draws suspicion. They suggest that an opt-out policy may increase testing rates for stigmatized diseases and lessen the effects of stigma in people's reluctance to test.

Participants in our study indicated that opt-out testing would reduce stigma as well. Although opt-out testing in routine care settings would alleviate stigma associated with HIV testing, it might not reduce the stigma associated with a positive diagnosis. This may be a reason that people opt out. However, stigma did not play a significant role in recent studies of those who did opt out; most subjects cited low risk factors and recent testing as a reason to decline testing. The act of making testing a normal routine would result in increased testing and help decrease stigma associated with testing.

The second component that may explain compliance with opt-out testing is patient inertia, which has recently been applied to behavioral economics by Thaler and Benartzi ⁽²⁸⁾ to explain why people do not save adequate amounts for retirement. Organizations with automatic (opt-out) enrollment retirement plans have employees with much higher saving rates than those with plans employees must sign up for. Furthermore, once people sign up, they rarely make changes to their plan, thus demonstrating additional inertia. Can we also predict that once a person gets tested for HIV, he or she will do so at every annual appointment or in an acute care setting, especially if asked to do so by a physician? Will testing become part of the person's medical routine? Given that behavioral economists have successfully studied the inertia phenomenon ^(28- 30) when it comes to savings, it seems reasonable for them to recommend savings plans where the default is to join, unlike most plans where the default is not to join. ⁽³¹⁾ Likewise, opt-out testing makes the default to get tested, unlike with VCT where the default is not to get tested until one seeks it out. With opt-out testing, inertia might cause most people to comply with the recommendation of getting tested. In organ

donation research, Johnson and Goldstein⁽³²⁾ found that when participants had to opt in to being an organ donor, only 42 percent did so. When they had to opt out, 82 percent agreed to be organ donors. They also looked at the effect of the default on organ donation status in different countries. They highlight the difference in donation rates in Germany and Austria, two comparable countries. In Germany where people opt in to organ donation, 12 percent gave their consent and in Austria, with an opt out law, 99 percent of the people consented to be donors.⁽³³⁾ Unlike savings schemes and organ donation, HIV testing has the added persuasive factor that an expert, e.g. physician, personally asks the patient to take the test. As one participant summarized nicely, "Well, I know I've had unprotected sex before and they offered, you know, what was the harm?" Recall that few of the seropositive patients and none of the seronegative patients reported actively seeking out testing; rather for most participants testing was offered in another clinical setting and they decided to get tested because it was easy. As another participant stated, "They already have the blood, they're testing it for cholesterol, they're testing it for diabetes, go ahead doc. You know, test me for HIV too. Blood's already drawn."

Therefore a theory involving patient inertia and provider routinization could account for compliance with opt-out testing, the recommended method of HIV testing in our study. Because of inertia, some people will get tested simply because it is the path of least resistance, even for something as important and significant as HIV status. For patients who opt out and decline testing, traditional theories of avoidance would still apply. A cross-section of people know they are not at risk because they do not engage in behaviors associated with HIV transmission and they may opt-out. However, as the participants in the current study noted, there will also be an at-risk percentage that opt out. These are potentially the people who most need to be tested. Participants specifically spoke about this group, noting that these individuals may not want to know for legal reasons (those who knowingly transmit HIV may be legally responsible) or for psychological reasons commonly researched in HIV testing avoidance. This hypothesis of patient inertia

and provider routinization needs to be further tested so that these themes can potentially emphasized and leveraged to increase rates of HIV testing in the U.S.

4.2 Limitations

As this was a pilot study in an urban setting, the size and demographics of our sample limit the generalizability of our findings to other settings. The majority of participants were African-American men who had at most a high school education and annual family incomes of less than \$20,000, were unemployed, and were publicly insured. Self-selection of participants may also have biased the sample; participants whose strong feelings regarding HIV testing might not be representative of the general population or of the HIV-positive population may have been more likely to volunteer to participate in the study than others who were ambivalent towards HIV testing. Recall bias, subjects' misremembering of facts, and social desirability bias (the subjects' desire to not be viewed negatively by the interviewer) may also have skewed the findings. The current research project involved people who have been tested; therefore we cannot comment on why people opt out and/or do not get tested. Future research needs to address how to target the at-risk population who opt out and how to persuade them to get tested.

Conclusion

Since the epidemic began, HIV has been highly stigmatized, making it difficult to study the social and environmental factors influencing transmission and treatment-seeking behaviors. Recently, HIV infection has come to be seen as a chronic condition that can be managed like other chronic conditions (e.g., diabetes, asthma). As with other chronic conditions, public health practitioners must battle to encourage early testing to reduce and/or slow progression of the disease and its complications. Making communities aware of the threat while encouraging testing and treatment are difficult to do simultaneously. This is a delicate balance for public health professionals as more evidence mounts for treatment.

Current testing initiatives are heading in the right direction, but more must be done to ensure that more individuals are tested for this disease at least once in their lifetimes.

Nevertheless, all future testing initiatives must find a balance between encouraging widespread routine testing, ensuring confidentiality of results, linking patients to care, and guaranteeing informed consent. Our research provides insights into patients' decision making around HIV testing, perceptions of the testing experience, and deficiencies in current and proposed testing initiatives. Most participants strongly supported opt-out testing and mandatory testing, even though they recoiled at the same time from imposing anything mandatory. Consequently, these results indicate that the public may be more receptive to more drastic changes than most health experts believed possible. Hopefully opt-out policies will have legislative, financial, and media support that will result in lower transmission rates, decreased stigma, and early engagement in treatment.

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