Barriers and Facilitators to Routine HIV Testing in VA Primary Care

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BACKGROUND: Approximately 21% of the 1.1 million HIV-infected persons in the United States are unaware of their HIV status. The Centers for Disease Control (CDC) recommend routine opt-out HIV testing for all patients aged 13–64. Yet little is known about patient and provider perspectives on routine HIV testing.

OBJECTIVE: We sought to understand patient and provider perspectives on the adoption of routine HIV testing within the US Department of Veterans Affairs.

DESIGN: We conducted four focus groups with patients and two focus groups with primary care providers to explore perceptions of, communication about, and barriers and facilitators to routine HIV testing in primary care.

PARTICIPANTS: Convenience sample of patients and primary care providers at two geographically diverse Veterans' Affairs Medical Centers.

APPROACH: We conducted grounded thematic analyses of transcribed audio-recordings of focus groups to identify major themes, identifying similarities and differences between patient and provider perspectives.

MAIN RESULTS: Patients and providers concurred that implementation of routine HIV testing, treating HIV like other chronic diseases, and removing requirements for written informed consent and pre-test counseling were of benefit to patients and to public health. Patients, however, wished to have HIV testing routinely offered by providers so that they could decide whether or not to be tested. Veterans also stated that routinizing testing would help destigmatize HIV. Six steps to communicating about routine testing ("the 6 R's") were identified.

CONCLUSIONS: Patients and providers appear ready for implementation of routine HIV testing. However, providers should use patient-centered communication strategies to ease patients' concerns about confidentiality and stigma associated with HIV disease.

KEY WORDS: HIV/AIDS; screening; communication; qualitative research.
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INTRODUCTION

With the availability of effective medications, early diagnosis of HIV reduces mortality and is cost-effective^{1–3}. Patients diagnosed and treated for HIV avoid hospitalizations and can reduce risky behaviors, further reducing HIV transmission⁴. Despite longstanding guidelines recommending HIV testing, as many as 21% of the 1.1 million HIV-infected persons in the US are unaware of their status⁵. Consequently, in 2006 the Centers for Disease Control and Prevention (CDC) released new recommendations that *all* patients between the ages of 13 and 64 be offered opt-out HIV testing regardless of risk status⁶; these recommendations were recently endorsed by the American College of Physicians⁷. The guidelines suggest that providers routinely order HIV testing unless the patient declines. These guidelines differ from previous HIV testing practices in most jurisdictions, including the Department of Veterans Affairs (VA), in that previously HIV testing was only for patients at behavioral risk for HIV, or if patients requested a test. In addition, requirements for specified pre-test counseling and written informed consent have been, and remain, the policy in many places.

Routine 'opt-out' testing, in which patients are informed by the provider that they will be tested for HIV and assent is inferred unless the patients decline, is likely to reduce barriers to HIV testing⁸. Yet adoption of routine testing in general, and of opt-out testing practices in particular, may be challenging^{9–11}. We know little about how patients will respond to the routine offering of HIV testing or how providers view this extension in scope of their primary care responsibilities. The persistent stigma associated with HIV and patients' fear of the health and social consequences of the diagnosis have been identified as significant barriers to being tested^{10,12}. Many primary care providers find discussing the sensitive topics of HIV risk behavior and testing difficult and awkward^{13,14}. Therefore, routine discussions of HIV testing may be more complex than screening for other diseases.

We sought to identify, from patient and provider perspectives, facilitators and barriers to implementing routine HIV testing in the VA according to current CDC guidelines. The issue is of particular importance in the VA, where a change in policy will affect the care of over 5 million veterans. Veterans are subject to social and behavioral factors that put them at higher risk for HIV, including lower income, more substance

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abuse and other co-morbidities¹⁵. Thus, HIV prevalence rates are higher than in the general population¹⁶, and early HIV detection is of particular concern. Understanding the concerns and perspectives of both VA patients and providers is central to succeeding with implementation of routine testing in this large health-care system.

METHODS

We conducted a qualitative study using focus groups of primary care providers and patients at two VA Medical Centers, one in California, one in New England. We explored provider and patient attitudes towards routine HIV testing, perceptions about what effective communication about HIV testing should entail, and perceptions of barriers and facilitators to implementing routine HIV testing. Institutional review boards at both sites approved the study.

Participants

Patients were recruited using informational posters, post cards with a drop-box placed in primary care clinics and at patient orientation sessions. Recruitment materials stated we were conducting focus groups about talking with providers about sensitive issues. A research assistant contacted each interested patient and indicated that HIV would be discussed in the focus groups. Patients were eligible to participate if they responded negatively to the question, "Have you ever been told you have HIV disease?" This requirement ensured that participants had not been diagnosed with HIV disease, which might alter their perceptions of HIV testing. Patients were eligible regardless of previous HIV testing, to include patients with HIV testing experiences.

Providers were recruited at regularly scheduled staff meetings at each medical center by a project investigator. All primary care providers were eligible to participate, including physicians, nurse practitioners and physician assistants. Written informed consent was obtained from all participants.

Data Collection

Patient focus groups were conducted at the medical centers by a study investigator, lasted approximately 90 min and were audio-recorded. We used a semi-structured focus group guide, containing broad lead questions and focused follow-up questions, designed to elicit patient experiences with, and perspectives on, HIV testing. The guide was used flexibly to follow the flow of conversation among participants while addressing all topics. Patients also commented on draft CDC patient HIV testing educational materials.

Provider focus groups were conducted during regularly scheduled 45-min staff meetings. The semi-structured focus group guide elicited provider experiences with discussing HIV testing with patients, barriers to conducting HIV testing and routinizing HIV testing as recommended by the CDC. Providers also commented on draft patient and provider CDC educational materials.

Analysis

Audio-recordings were transcribed verbatim. Transcripts were analyzed qualitatively using procedures informed by grounded theory methodology^{17,18}, a systematic approach to deriving qualitative themes from textual data. Accordingly, we first conducted open coding in which an investigator identifies key concepts emerging from the language used by participants and assigns codes (descriptive phrases) to segments of text. NVIVO qualitative analysis software was used to facilitate data coding and sorting¹⁹. Coded text segments were reviewed by two investigators to condense broad codes into distinct themes. Themes that emerged in both patient and provider groups were examined for similarities and differences in perspectives in a process known as constant comparison analysis. Subsequently, prominent themes and quotes exemplifying each were presented to the research team and refined through discussion.

RESULTS

Of the 67 patients contacted, 10 refused participation, 3 were ineligible, and 26 were unable to participate, predominantly due to scheduling problems. The 28 patient participants in four focus groups—2 at each site—were all men aged 35–88, were predominantly low income and had mixed levels of education (Table 1). Of the 47 providers contacted, 20 providers consented to participate; however, 7 dropped out because of scheduling difficulties. Thirteen providers participated in two provider focus groups, one at each site, and two additional providers who were unable to attend a focus group participated in individual interviews. Seven of the providers were women, eight were physicians, six were nurse practitioners and one a registered nurse.

In the focus groups, patients and providers discussed key issues that help or hinder conversations about, and achievement of, HIV testing in primary care encounters. Themes centered around perspectives on HIV testing becoming routine, what information should be communicated to patients and how, and procedural issues that hinder HIV testing. We present below the major themes that emerged from analyses, highlighting some strikingly similar as well as important differences in patient and provider perspectives.

Table 1. Patient Characteristics*

<i>Age</i>	
Range	35–88
Mean	60
<i>Race (n)</i>	
White	13
African American	3
<i>Income** (n)</i>	
\$15,000 or less	4
15,001–20,000	4
20,001–40,000	5
40,001–60,000	2
<i>Educational status (n)</i>	
Some high school	1
HS graduate	4
Some college/ technical school	6
Completed college	3
Some graduate school	2

*Data missing for two patients

**One patient chose not to indicate income

HIV Testing Should Be Routine

Both patients and providers concurred that HIV testing should be routine because they thought it was (1) good for patients and (2) good for public health. The most salient reason for testing for both patients and providers was the value in knowing one's HIV status. Patients and providers advocated that HIV should be equated with other chronic diseases—such as diabetes and cholesterol—for which testing is routine.

"I'd like to see [HIV] become like everything else, diabetes, tuberculosis, anything else that we test for. When they do the blood screening, do the whole thing. It's a deadly disease." (*Patient*)

"I mean, why should [HIV] be any different, you know? I can order a CBC. I can order a PSA and somebody can come back with a PSA of 150 and I know he's got metastatic prostate disease. Why should this be any different?" (*Provider*)

Both groups stated the importance of learning results for chronic diseases/conditions—including HIV—in order to commence treatment as quickly as possible, or, as one patient put it, "nipping it [HIV] in the bud," before the disease progresses. In this respect, managing HIV was viewed as no different from managing other chronic health problems. Participants favored including HIV testing along with other routine blood work typically included in primary care visits.

Both patients and providers also evoked public health reasons for knowing one's HIV status. As a serious public health threat, HIV testing and subsequent treatment were viewed as effective means of stemming the spread of the disease and protecting sexual partners. Some patients were motivated by misunderstandings about HIV transmission, arguing that knowing one's status could protect others with whom they have even casual contact, such as kissing or sharing a glass.

Routine Testing May Decrease HIV Stigma

Patients and providers also asserted that testing for HIV routinely would likely reduce some of the stigma associated with the disease. Routinizing HIV testing would change an unusual screening into an ordinary event, rendering HIV testing "normal," thereby diminishing the stigma. This could be accomplished by associating HIV testing with screening for other chronic diseases that have much less discernible stigma, such as diabetes.

"If it was something that happens all the time, you could take the stigmatism [*sic*] out of it, maybe." (*Patient*)

One provider reflected that current processes make HIV testing anything *but* routine, and that routinizing testing would further decrease HIV stigma.

"My own feeling is that the stigma associated with it...it's certainly decreasing.... And it's almost like we're creating processes that make it different than routine care." (*Provider*)

Stigma as a Barrier to HIV Testing

At the same time, HIV stigma remained a barrier for patients as reflected in their concerns about confidentiality and the potential impact on the patient-provider relationship. Confidentiality was paramount to both patients and providers. Patients wanted guarantees that both the fact they were being tested, and the test results, would be confidential. One patient, stating that he didn't trust the VA or the government to maintain confidentiality, said that he might choose to be tested elsewhere.

Patients and providers indicated that a patient who trusts his/her provider would be more likely to agree to being tested. However, patients and providers alike were concerned about the impact raising this sensitive topic might have on the patient-provider relationship. Emphasizing the wish to be offered rather than told to have the test, one patient said that being told to be tested might lead someone to "walk out of [the doctor's] office and see another doctor." One provider stated that simply asking a patient to be tested could alter their rapport, affect the level of the patient's trust and negatively impact their future relationship.

Barriers to HIV Testing in the Clinical Encounter

Patients and providers described two important barriers to HIV testing that occur during the clinical encounter: obtaining written informed consent and pre-test counseling. Patients viewed signing consent forms as anxiety-provoking, intimidating and sometimes difficult to understand because of the dense legalistic language. They indicated that the documents rendered HIV different from other diseases, running counter to their desire to normalize HIV by equating it with other chronic diseases. Once HIV is construed as exceptional—somehow different from other diseases—patients noted they were likely to be more apprehensive about being tested because of fears of a positive result.

"They do all [other tests] over here, but [HIV testing] is different. This is 'Ooh, keep away from that.' You know, and that's what that form does, in my opinion." (*Patient*)

In addition, patients voiced concern about legal language in the consent forms indicating the possibility that test results might need to be released to "third parties." Because of fears of breached confidentiality, some patients expressed reservations about having to sign a consent form.

Providers agreed with patients that requiring written informed consent made HIV different from testing for other chronic diseases. In addition, the informed consent forms represented a formidable and time-consuming logistical obstacle. At one site, social workers conducted the consent process, but were not located in the primary care clinic, making, the providers said, the "whole situation so difficult, with the limited amount of time we have." Providers from the other site were encouraged to use computer-based consent forms and signature pads intended to streamline the process, but these were cumbersome in practice.

The second barrier to HIV testing was pre-test counseling, in which providers discuss the process of HIV testing, the potential implications of a positive test result and behaviors that may put individuals at risk for HIV. Patients viewed pre-test counseling as another process that rendered HIV excep-

tional, and therefore preferred not to participate in it. They noted that counseling would be likely to instill fear about HIV, and may even prevent them from being tested. Equating HIV once again with other chronic illnesses, patients said they wished to talk in-depth about HIV with a provider only if a test result were positive, at which time they would want information about the implications of a positive result and how best to manage the disease. For example, one patient, talking about routine TB testing, stated:

"It was automatic that we'd get tested. I didn't need an explanation at the time of the testing. However, if it came back positive, you'd best like some explanation".

Providers viewed pre-test counseling as an obstacle to HIV testing because it took up many "precious primary care minutes." One provider feared that talking with patients about HIV testing in depth would lead to a flood of patient questions and concerns, and yet others acknowledged the moral necessity of discussing potential ramifications of a positive test. Doing justice to such questions and concerns was viewed as taking away time from accomplishing other important tasks during clinical appointments.

Patients identified an additional barrier to getting tested—the wait time between being tested and receiving the results. Several patients stated that waiting for results made them anxious and depressed, and when they considered being tested again would delay the test. One patient even stated, "I'd be swallowing tranquilizers while I'm waiting for the phone to ring." Providers did not discuss this aspect of testing.

Communicating About Routine Testing

Although patients suggested HIV testing be handled as routine rather than unusual, they repeatedly stated that they wished to be *asked* if they would like to have an HIV test, rather than be *told* they were going to be tested or have it be done automatically without discussion. One man, after saying he would agree to be tested stated, "But I don't think it should be automatic. A lot of people might take umbrage at that." Others reported similar views, with statements such as:

"...as long as they use the word 'should,' and not 'have to.'" (Patient)

"I'm not against it, absolutely not. But again I just don't want something else shoved down my throat." (Patient)

Above all, patients desired the autonomy to be able to choose and consent to be tested for HIV. Some patients equated their wish for the autonomy to decide about testing with their fundamental "civil liberties," one stating that he wanted a choice in order to "preserve as much of my freedom as possible."

Patients stated they would be more likely to agree to be tested if providers communicated several key information points when raising the topic. First, patients wanted to be told, "We're going to test everybody, everybody," indicating the goal of making the test not only routine, but also universal.

Patients indicated that they needed to be reassured they were not being singled out to be tested based on clinical signs of the disease. One patient stated:

"If he suggested he wanted to test me for AIDS, he must have saw something in my crit [sic] counts or something like that, that are fallen enough that he wanted to do the research on me." (Patient)

Thus, patients who were asymptomatic and had no apparent risk factors wished to be told that HIV testing was being suggested as a general policy, not because of suspected HIV disease.

Patients found that learning that 25% of all HIV infected patients are unaware of their status, in combination with the test being 'offered,' would be influential in achieving testing (note that this figure has changed to 21% since the time of the focus groups). One man said it most succinctly:

I think any time you go see a doctor, it should be offered to you. "Would you like it?" And this information should be given to each patient, that a quarter of the people don't know they have it, and offer them, "Would you like to have an HIV test because of this information?" (Patient)

Providers similarly found that information from the CDC materials about HIV testing would be helpful in talking with patients, particularly the information noting that 25% of all HIV infected patients are unaware of their status. Several providers stated that they felt ill-prepared to raise the topic of HIV testing with patients. One even said that some sort of written script would be helpful. Others suggested that one way to routinize testing would be to inform patients that they would be tested for HIV just as they inform patients about blood tests for other health conditions, such as thyroid disease or elevated cholesterol. They argued that by making it completely matter-of-fact, patients would be more likely to agree to being tested. One provider stated that he would say the following to patients:

"I'm going to order a bunch of blood tests including cholesterol, kidney function, liver function. One of the tests that's now recommended is that we also check for HIV. I'm going to go ahead and order that." (Provider)

Veterans may be Different

The fact that the patients were veterans of the US Armed Forces is an important point that was raised by the patients themselves. They contended that veterans as a group are more likely than the general population to engage in unprotected sex and use drugs and alcohol, putting them at higher risk of HIV infection. Therefore, they said, veterans may be more open to being tested than civilians. One man stated:

"I was tested when I was in California the first time in '95 when I was in the Marine Corps. And, you know, I was nervous then, just because, you know, we had had unprotected sex with, you know, a female, and it was a

bunch of us and it was just crazy.... It was just really reckless." (Patient)

Another man stated:

"I think, you know, the veterans and stuff [who's] been around the lower side of life a little bit, could accept it more than somebody that goes to the Calvary Baptist Church every week." (Others laugh.) (Patient)

Although this man recognized that "being on the lower side of life," leads to a higher risk for HIV, the idea that anyone could become infected remained salient to him. Thus, he advocated for routine testing. Providers did not comment on the uniqueness of the veteran population regarding HIV risk.

DISCUSSION

Under rapidly changing accepted HIV testing recommendations, providers may take different approaches to discussing testing with patients. The CDC-recommended 'opt-out' approach to routine HIV testing is a dramatic change from typical past practices²⁰. At present, there is no clear consensus on exactly how providers should present 'opt-out' testing to patients, and no other studies have examined patient perspectives on routine testing. Patients and providers in our study expressed clear perspectives about how to best achieve routine testing. Our findings have implications for implementing the new CDC recommendations, supporting routine testing of all adults, eliminating written informed consent and reducing the time burden of HIV testing by eliminating extensive pre-test counseling.

We found that patients were open to being tested and supportive of testing as a routine aspect of regular care, similar to others' findings that hospitalized patients responded positively to an unsolicited HIV test¹⁰. However, our findings highlight veterans' wishes to be tested only after being given information to make an independent decision and provide verbal consent for testing. This is important for providers to note, especially as some of our providers, in line with the CDC 'opt-out' guideline, recommended informing the patient they would order an HIV test unless it was actively refused.

The concomitant perspective that both routine testing and this more 'opt-in' scenario are desirable for patients is understandable given the stigma associated with HIV disease²¹⁻²³. Although HIV is less stigmatized than in the past, patients remain concerned about the confidentiality of testing and results. Previous research shows that providers can effectively communicate and request routine testing with at-risk individuals, contributing to destigmatization of the disease²⁴. To conduct HIV testing in a patient-centered manner, we must consider patients' concerns alongside those of the medical and public health communities.

Barriers to testing noted by our providers, including concern about the patient-provider relationship, time constraints and the consent process, have all been noted by other studies in a variety of settings²⁵. Like most primary care providers, the providers in our study felt constrained by time limits imposed

on them for clinical appointments, and adding routine HIV testing to their responsibilities seemed onerous. Easing requirements for pre-test counseling and written consent should result in reduced provider burden. Providers can be patient-centered in ordering this sensitive test by *offering* the test to patients, reassuring patients that HIV testing is now routine for all adults, stating that patients are not exhibiting clinical signs of HIV, providing some basic information about HIV and asking patients if they would like to be tested.

Based on these findings, we developed the 6 R's for routine testing—six steps for providers to use in patient-centered discussions of HIV testing: (1) **R**aise the topic of HIV testing; (2) **R**eassure the patient that he/she is not showing clinical signs of the disease; (3) provide **R**ationale that many patients infected with HIV are not aware of their status; (4) **R**espond to any questions that the patient may have about HIV disease; (5) **R**esult permission to order the test; (6) tell the patient when he/she can expect to get the **R**esults. A sample script for using the 6 R's is provided in Table 2.

There are several limitations to our study. We conducted our study at only two VAs; patients and providers from other regions in the US may have different views not expressed here. All veteran patients enrolled in the focus groups were men, and women may have different perspectives about routine HIV testing¹⁰. As noted by the veterans themselves, veterans may be different from the civilian population. In addition, other studies have identified the costs of HIV testing and funding for HIV treatment as barriers to testing⁸. In the VA, cost is not a barrier because HIV testing and treatments are covered fully for most HIV-positive veterans or require minimal out-of-pocket expense. Approximately half of patients who were eligible were unable to participate in our focus groups due to scheduling constraints. Nonparticipating individuals may have different views. We also had a limited number of providers who participated in the focus groups, meaning that we may not have fully appreciated the range of perspectives of the providers at these sites. Finally, providers who choose to work within the VA system may differ in their perspectives about care for vulnerable patients from primary care providers elsewhere.

Using the 6 R's, we propose, may help providers discuss HIV testing with their patients, and make patients comfortable with being testing for HIV disease. In contrast to 'opt-out' testing, this communication strategy may alleviate the risk of patients' being tested without their knowledge, which could put them at additional psychological and social risk if they are positive.

Future research is needed to fully explore implementation of routine testing guidelines, examining both an opt-out ap-

Table 2. Sample Script for Using the 6 R's for Routine Testing

Raise	"We are now offering to test everybody for HIV just as we test for other things like diabetes or heart disease, through a simple blood test"
Reassure	"There's nothing I know about you or your health that makes me think you might have HIV"
Rationale	"It is possible to have HIV for a long time without knowing it. Of the people who have HIV as many as 25% of them don't know they have it"
Respond	"Lots of people have questions about HIV disease or getting tested. What questions do you have for me?"
Request	"Given what we've discussed, would you like me to test you for HIV along with your other blood tests today?"
Results	"It takes about 2 weeks for the results to come back. Waiting for the results can make people nervous. We will contact you as soon as we receive the results"

proach as proposed by CDC and the more patient-centered approach proposed here. Such research should examine the impact of these communication approaches on HIV testing rates, the impact on the patient-provider relationship and the cost-effectiveness of each approach.

Increasing the number of patients tested for HIV in the US is a high priority, to achieve earlier detection, earlier treatment and earlier secondary prevention through education about HIV transmission²⁶. However, the ultimate goal of early detection is to transition newly positive patients into care smoothly and rapidly. If routine HIV testing is achieved at the cost of weakening veterans' trust in the health-care system, this could lead patients to delay returning for test results, or it could lead to delayed transition into care after testing.

Putting an end to the 'exceptionalism' of HIV requires an ongoing effort to routinize and destigmatize HIV testing and the disease itself²⁰. In the hands of some doctors, a brief script in which HIV is embedded in a list of other needed blood tests may stifle opportunities for question-asking and fall short of standards for patient-centered communication. A patient-centered approach to streamlined HIV test discussion may improve the likelihood that patients accept testing and eventually lead to fully routine HIV testing in primary care.

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