

HIV Vaccine Knowledge and Beliefs among Communities at Elevated Risk: Conspiracies, Questions and Confusion

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An earlier version of this article was presented at the 2004 American Sociological Association meeting in San Francisco, CA.

Financial support: This study was supported by the University-wide AIDS Research Program through a grant to the UCLA California AIDS Research Center (CC99-LA-002) and the UCLA AIDS Institute and Pallotta Teamworks AIDS Vaccine Rides.

HIV vaccines offer the best long-term hope of controlling the AIDS pandemic. We explored HIV vaccine knowledge and beliefs among communities at elevated risk for HIV/AIDS. Participants (N=99; median age=33 years; 48% female; 22% African-American; 44% Latino; 28% white; 6% other) were recruited from seven high-risk venues in Los Angeles, California, using purposive, venue-based sampling. Results from nine focus groups revealed: 1) mixed beliefs and conspiracy theories about the existence of HIV vaccines; 2) hopefulness and doubts about future HIV vaccine availability; 3) lack of information about HIV vaccines; and 4) confusion about vaccines and how they work. Tailored HIV vaccine education that addresses the current status of HIV vaccine development and key vaccine concepts is warranted among communities at risk. Ongoing dialogue among researchers, public health practitioners and communities at risk may provide a vital opportunity to dispel misinformation and rumors and to cultivate trust, which may facilitate HIV vaccine trial participation and uptake of future HIV vaccines.

Key words: HIV/AIDS ■ HIV vaccines ■ conspiracy theories ■ African Americans ■ Latinos ■ IV drug users ■ qualitative research

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Forty-thousand persons are newly diagnosed with HIV each year in the United States.¹ Five million new HIV infections and 3 million AIDS deaths were estimated worldwide in 2002.² Despite concerted behavioral prevention efforts, HIV continues to spread at a devastating pace. The main technology for HIV prevention that is presently available, the male condom, is primarily under the control of men and needs to be used and negotiated at every sexual encounter, resulting in limitations to perfect and consistent implementation. Microbicides are a promising possibility as an addition to the HIV prevention armamentarium but are also likely to require frequent application and may not be acceptable or accessible to all persons at risk.³ HIV vaccines would be a tremendous boon to HIV prevention and represent perhaps the greatest hope in combating the epidemic. Nevertheless, it is likely that first-generation HIV vaccines will be only partially efficacious⁴ and may be neither universally acceptable nor accessible.⁵⁻⁷ Given the monumental challenges of preventing the spread of HIV and the shortcomings of any one prevention approach, the more technologies and options available, the better are the chances of controlling the AIDS pandemic.

Numerous clinical trials to test HIV vaccines are underway around the world.^{8,9} The first HIV vaccines to be tested in phase-III clinical trials, the last stage of testing before receiving U.S. Food and Drug Administration (FDA) approval, were found to be ineffective.^{10,11} However, these investigations demonstrated the feasibility of conducting safe and ethical human trials of HIV vaccines.¹² With ongoing trials of >20 different candidate HIV vaccines, many new products in the pipeline and a new phase-III trial in Thailand, it is estimated that first-generation HIV vaccines may be approved within the next decade.¹³

Nevertheless, the availability of a safe and efficacious vaccine does not ensure uptake. In fact, a UNAIDS-WHO report suggests that there is a gap between the projected need and likely uptake of initial HIV vaccines.⁶ As recommended by leading

international HIV/AIDS organizations, formative research is needed now to begin preparing for the challenges of future HIV vaccine dissemination.^{6,14,15}

Investigations of HIV vaccine clinical trial preparedness suggest that individuals generally have low levels of knowledge regarding vaccine trial concepts.^{16,17} Baseline knowledge of vaccine concepts (e.g., safety) and clinical trial concepts (e.g., randomization) was low among high-risk populations: only 8.4% of participants correctly answered at least 11 of 14 questions.¹⁶ Low levels of knowledge about HIV vaccine concepts (e.g., adverse reactions and vaccine-induced seropositivity) have been reported among men who have sex with men, male and female injection-drug users (IDUs), and women at risk of acquiring HIV via heterosexual transmission.¹⁷ Most strikingly, increases in knowledge of HIV vaccine trial concepts over time were associated with less willingness to participate in an HIV vaccine trial. The latter underscores the importance of adequate knowledge to enable potential trial participants to engage in appropriate decision-making and informed consent before enrolling in a clinical trial.¹⁴ The underrepresentation of African Americans, Latinos and women in the first major North American trial of an HIV vaccine (i.e., AIDSVAX 004)¹⁰ further suggests the importance of reaching out to racial/ethnic minority communities, in particular.

International studies have also explored people's knowledge and beliefs about HIV vaccine trials. For example, in a study of 1,182 Ugandan military men, low levels of baseline knowledge about vaccine trial concepts, such as "placebo", as well as confusion regarding the preventive versus curative nature of vaccines were identified.¹⁸

Beyond HIV vaccine clinical trials, very limited research has assessed what the general public thinks and believes about approved HIV vaccines that may be publicly available in the future. Greater vaccine efficacy, lower cost and increased social saturation (i.e., percentage of the population already vaccinated) were associated with greater intentions to accept a U.S. FDA-approved HIV vaccine among 549 (70% female, 80% white) midwestern college students.¹⁹ Among 318 adolescents (86% female, 72% African-American) recruited from public health clinics, HIV vaccine acceptability decreased after the adolescents were told that the vaccine would require several injections over a period of six months.²⁰ In a study conducted in northern Thailand, the site of several HIV vaccine trials, two-thirds-to-three-fourths of persons at high risk for HIV infection knew that efforts were underway to develop an HIV vaccine, yet a significant number of high-risk individuals remained unaware of HIV vaccine development efforts.²¹

Limitations of investigations of knowledge and beliefs about future HIV vaccines include both the

use of specialized populations, some of whom are not at high risk for HIV/AIDS (e.g., midwestern college students), and lack of qualitative data that may give expression to people's thoughts and beliefs about future HIV vaccines from their own perspectives. Qualitative investigations are particularly appropriate when investigating a new research domain, such as public reactions to future FDA-approved HIV vaccines, about which relatively little is known. Furthermore, qualitative methods are well suited to the study of patient reactions to HIV vaccines since they remain hypothetical; the phenomenon under study is exploratory. Gathering information from the unique perspectives of those at high risk for HIV may aid the research and public health communities in developing appropriate and effective educational campaigns, and in averting possible barriers to future HIV vaccine uptake, before initial HIV vaccines are ready for dissemination. This study explores knowledge and beliefs about future HIV vaccines among men and women at elevated risk for HIV infection.

MATERIALS AND METHODS

Participants

Nine focus groups were conducted with 8–13 participants per group (N=99). Participants were recruited from diverse settings in Los Angeles, CA using multisite, purposive, venue-based sampling.^{19,21} Selection criteria were implemented at the venue level and included the following: 1) having a high proportion of individuals at elevated risk for HIV/AIDS; 2) including racially/ethnically and sexually diverse communities, and 3) representing likely settings for future dissemination of HIV vaccines. Individuals were screened based on gender and age only; all participants were aged ≥ 18 . The youth group was screened on age only (18–24 years), as many of the male and female youth had previously participated together in a group at the venue. Individual screening was done by trained research staff onsite, immediately prior to the informed consent process.

Participants included: 1) Latino men attending a men-who-have-sex-with-men services program run in Spanish; 2) Latina women attending a community healthcare clinic that provides services in Spanish; 3) Latino men attending a community healthcare clinic that provides services in Spanish; 4) women attending a healthcare clinic serving African-American women; 5) males attending a needle-exchange site; 6, 7) two groups of women attending two needle-exchange sites; 8) men attending an STD clinic housed in a gay/lesbian services organization; and 9) young men and women (aged 18–24) attending a social service agency for lesbian, gay, bisexual and transgender street youth.

Potential participants were recruited in three ways: 1) they called in response to flyers posted at each of the venues, 2) they signed up with our research staff persons who were trained in recruitment and research ethics and visited the venues 2–3 times in the two weeks preceding the planned focus group, or 3) they wrote their name on a sign-up sheet left by the research staff with a designated staff person onsite. Flyers advertised a UCLA research study about “possible HIV/AIDS vaccines that may be available in the future.” The exact recruitment protocol was tailored to the operating procedures at each venue and the nature of the study populations. Many participants did not have stable housing or a phone; therefore, sign-up sheets removed obstacles to their involvement in the study. Since many of the clients at the recruitment sites were particularly concerned about confidentiality (e.g., IDUs at a needle-exchange program), workers at the sites handled the sign-up sheets for the study. That is, only they—and not the study’s research staff—had access to the names of the individuals on the sign-up sheets. Given this protocol, which was

implemented to encourage vulnerable populations to participate, information regarding the number of persons who signed up for the study but did not show up and participate in the focus groups is not available. The recruitment and focus groups occurred from March 2002 to February 2003.

The median age of focus group participants was 33 years, with a range from 18–56 years. Just over half (52%) of the participants were male. Most (44%) were Latino, with 28% white; 22% African-American; and 6% other race/ethnicity. Forty-three percent were heterosexual; 27% gay; 20% bisexual; and 3% lesbian. More than two-thirds (69%) of participants were single. Overall, about half (51%) of participants were unemployed, half (48%) reported total annual income of <\$10,000, half (51%) had no health insurance and one-third were homeless. Demographic characteristics of participants by focus group are reported in Table 1. Table 2 shows socioeconomic characteristics of participants by focus group.

Table 1. Sociodemographic characteristics of participants by focus group

Characteristic	Focus Group								
	1	2	3	4	5	6	7	8	9
Number of participants	12	10	10	13	13	12	8	8	13
Completed demographic form	11	8	10	13	11	12	6	8	10
Median age (years)	32.7	27.4	26.0	36.7	33.1	30.8	20.6	41.3	43.6
Age range (years)	24–39	18–41	18–50	20–48	20–45	22–39	18–23	30–56	30–53
<i>Gender</i> ^{1,2}									
Male	12	10	--	--	13	12	5	--	--
Female	--	--	10	13	--	--	3	8	13
<i>Sexual Orientation</i>									
Gay	9	--	--	--	4	10	1	--	--
Lesbian	--	--	1	--	--	--	--	2	--
Bisexual	2	1	5	1	4	1	2	--	2
Heterosexual	--	7	4	7	3	1	3	6	7
No response	--	--	--	5	--	--	--	--	1
<i>Ethnicity</i>									
African American	--	--	--	1	1	--	4	8	6
Latino	1	2	--	12	10	12	--	--	2
White	10	5	10	--	--	--	--	--	--
Other	--	1	--	--	--	--	2	--	2
<i>Relationship Status</i>									
Single	10	5	7	8	7	9	2	6	7
Partnered/married	--	3	1	5	1	3	4	1	2
Divorced	--	--	1	--	1	--	--	1	--
No response	1	--	1	--	2	--	--	--	1

1: 89 participants (90%) completed the sociodemographic questionnaire; 2: Gender percentage is based on a total of 99 participants; all other summary statistics are based on 89 respondents.

Data Collection

Focus groups were single gender by design, given the sensitive nature of some of the research questions about postvaccine sexual behaviors, except in the case of the youth group. The participants in the youth group were primarily recruited from a previously existing (mixed-gender) group at an agency at which they received services. Since these youth participants had a history of participating comfortably together in a group setting, the youth focus group was conducted as a mixed-gender (rather than single-gender) group.

Same-gender facilitators conducted the focus groups (one male, one female for the youth group) to encourage comfort and candor among participants. Focus groups were 75–90 minutes in duration. All focus groups were conducted in private conference rooms, and refreshments were provided. Participants were given a \$30 honorarium. The institutional review boards of University of California, Los Angeles and the University of Toronto approved the study.

Participants provided individual, written informed consent on-site immediately before joining the group. All persons who arrived for the focus groups agreed to participate. At the beginning of each group, trained facilitators used a scripted protocol to explain the purpose of the study and the ground rules for the focus group, including respect for diversity of opinion and confidentiality.

Facilitators used a semistructured interview guide with scripted probes.²² The interview guide was translated into Spanish, back-translated into English, and then revised in Spanish for the Span-

ish-language groups. The focus group guide began with questions that addressed participants' experiences with and knowledge and beliefs regarding vaccines in general. Focus group questions included: 1) "We would like to hear about what you know and what you may have heard about vaccines. What vaccines have you heard about or are you familiar with?" and 2) "What do you know about how vaccines work or what vaccines do?" Then brief, simple information was given regarding an HIV vaccine: "a vaccine to protect against HIV infection," followed by: 3) "Remember, we are talking about an as-if situation, so there are no right or wrong answers to the following questions about possible HIV/AIDS vaccines. What, if anything, have you heard about vaccines for HIV/AIDS?"

Participants were asked to give their own opinions or their perceptions of the opinions of their peers. To enhance the credibility of the data, respondent validation ("member checking") was utilized, first by having the facilitator periodically check in with participants to make sure he or she understood what had been said and, second, by feeding back emerging data and themes to participants in subsequent groups to elicit interpretations and responses from various community stakeholders.^{23,24} At the end of each focus group, participants were asked to complete a brief, anonymous sociodemographic questionnaire; 90% completed the questionnaire.

Each group was audiotaped and then transcribed verbatim. All surnames and other specific identifying information that was inadvertently mentioned

Table 2. Socioeconomic characteristics of participants by focus group

Characteristic	Focus Group								
	1	2	3	4	5	6	7	8	9
Number of participants	12	10	10	13	13	12	8	8	13
Completed demographic form	11	8	10	13	11	12	6	8	10
<i>Employment</i>									
Full-time	5	--	1	4	5	9	--	2	--
Part-time	3	--	2	3	2	2	--	--	2
Unemployed	3	8	7	5	2	1	6	6	7
No response	--	--	--	1	2	--	--	--	1
<i>Income (Annual)</i>									
<\$10,000	--	8	6	3	4	2	5	6	8
\$10,000–\$19,999	3	--	2	3	1	4	--	--	2
\$20,000–\$29,999	2	--	1	1	--	3	--	--	--
≥\$30,000	5	--	--	--	1	2	--	1	--
No response	1	--	1	6	5	1	1	1	--
Homeless ¹	0	6	5	1	2	0	5	4	6
No health insurance	5	8	6	4	5	3	4	4	6

1: Includes living in shelters and transitional housing

was deleted from the transcripts. Spanish-language focus groups were transcribed in Spanish and then translated into English for data analysis. In addition to the three questions about vaccine knowledge and beliefs—the focus of the present study—the larger study included other questions that addressed issues reported elsewhere, including perceived barriers and motivators in regard to hypothetical HIV vaccine uptake⁵ and possible behavioral responses to future HIV vaccine availability.²⁵ The present paper explores in depth participants' knowledge, beliefs and conspiracy theories regarding HIV vaccines.

Data Analysis

Ethnograph, a software program for computer-based text search and retrieval, was used to assist with data analysis. Research team members independently read the transcripts multiple times to identify major themes.²⁴ Next, a line-by-line review of the transcripts was performed and first-level codes (descriptors of important components of the interviews) were noted in the margins. All codes were then tagged to associated text segments in Ethnograph. Data corresponding to each of the first-level codes were printed and reviewed by ≥ 2 independent investigators. Using a method of constant comparison,²⁴ subcodes were developed to divide the first-level codes into smaller categories. Data source triangulation (comparing data across nine focus groups) and researcher triangulation (2–3 investigators independently read and coded the same transcripts) were used to ensure the reliability of the findings.²⁶

RESULTS

Four major themes were identified: 1) beliefs and conspiracy theories regarding the current existence of HIV vaccines, 2) ideas about the future availability of HIV vaccines, 3) lack of information about HIV vaccines, and 4) confusion about vaccines. Each of these themes is discussed in detail. Quotations provided are drawn from the focus groups. Table 3 provides an overview of the four themes.

Do HIV Vaccines Currently Exist?

Participants evidenced a wide range of beliefs about the current existence of FDA-approved HIV vaccines. Some participants believed that HIV vaccines do not yet exist. As a participant from the male IDU group stated, “There’s no vaccine anywhere.” Among participants who believed approved HIV vaccines do not yet exist, there were two main groups: those who did not have any information on HIV vaccines and those who realized that scientists were working to develop HIV vaccines but had not yet developed an efficacious vaccine due to the complexities of HIV/AIDS. A participant from the MSM group said an HIV vaccine is “a moving target” because of the multiple subtypes of HIV.

In contrast, other participants believed that HIV vaccines already exist but were being suppressed. A number of conspiracy theories were invoked to explain why HIV vaccines are not readily available, even though they exist. Participants reported that those who are in power in the government and corporate world have a stake in hiding HIV vaccines

Table 3. Overview of main themes

Theme	Overview
1. Current existence of HIV vaccines	<ul style="list-style-type: none"> • Beliefs ranged from HIV vaccines do not exist to HIV vaccines exist but are being withheld from the public • Economic and sociopolitical conspiracy theories were invoked to explain the withholding of HIV vaccines • Some participants believed HIV vaccines are available in other countries
2. Future availability of HIV vaccines	<ul style="list-style-type: none"> • Some participants believed an HIV vaccine would be available in the future; others believed it would not • Projected length of time before an HIV vaccine would be available ranged from 1–20+ years
3. Lack of information about HIV vaccines	<ul style="list-style-type: none"> • Lack of information regarding HIV vaccines in popular media & from healthcare professionals • Numerous questions regarding HIV vaccines (e.g., questions about testing, distribution, etc.)
4. Confusion about general and HIV vaccines	<ul style="list-style-type: none"> • Confusion regarding vaccines in general versus treatment • Confusion regarding preventive versus therapeutic HIV vaccines • Confusion about the meaning of vaccine efficacy

from the public. As a participant from the MSM group said, "All I'm saying is that they [HIV vaccines] are not necessarily out in the public eye." One focus of HIV vaccine conspiracy theories was pharmaceutical companies. Respondents reported that pharmaceutical companies were withholding HIV vaccines in order to continue reaping profits from HIV/AIDS medications. A participant from the male IDU group said, "They want to keep it from the public because they're making billions and billions of dollars keeping these [HIV-infected] people barely alive." Another man from this same group noted, "Pharmaceutical companies are going to lose out in billions of dollars every year and they don't want to do that. It's all a big money market scam."

Another focus of HIV vaccine conspiracy theories was the U.S. government. One particularly malevolent government-related conspiracy theory was tantamount to genocide. Respondents explained that the existence of HIV vaccines was being withheld from the public in order to allow HIV/AIDS to eliminate or diminish certain groups of "undesirable" people in the population. A participant from the female IDU group said, "They figured ... let's see if we can get rid of undesirables, like junkies, faggots, whores. Immoral people who are loose ... acceptable losses." Another woman from the same group stated, "It's a way of population control." From this perspective, "possibly once certain populations are down in percentages, then they would come out with a vaccine," as a respondent from the male IDU group noted.

A second government conspiracy voiced by respondents was along the lines of social control. Respondents explained that HIV vaccines were being withheld because those in political power feared the possible behavioral implications of allowing the public to be vaccinated against HIV. A participant from the female IDU group said:

If they do have a vaccine, they won't give it to you until later on because of the fact that maybe they think, 'Oh, it's going to make people behave more risky and it's going to defeat the whole purpose [people] might go back ... to not having family values anymore.'

In addition to the belief that HIV vaccines do not yet exist and conspiracy theories regarding pharmaceutical industry and government suppression of already developed HIV vaccines, a third school of thought posited HIV vaccine availability in countries other than the United States. As a participant from the Latino MSM group noted, "I heard that Europe already has a vaccine," and a man from the MSM group said, "France has one." Related to a

belief in the existence of HIV vaccines in other, particularly European countries, some participants voiced the belief that if one were rich enough, one could have access to the HIV vaccines available in other countries. A participant from the female IDU group said, "One of the basketball players, he had it. Now, he don't have it ... he's kicking around all healthy, wealthy and wise, and look at everybody else," noting a belief in the existence of a therapeutic vaccine or other curative measures that are only available to the rich.

Future Availability of HIV Vaccines

Among respondents who believed that HIV vaccines do not yet exist, some were optimistic that they would be developed in the future. A participant from the Latino MSM group said, "I am very optimistic." Similarly, a participant from the youth group said, "I think it will happen." Participants had different viewpoints about when HIV vaccines might be available to the public. Some participants believed scientists would perfect an HIV vaccine in as little as a year. A participant from the Latino MSM group said, "The only thing I heard is that we will have access to it in 2006." Other participants thought that it would take 10–20 years to develop a viable HIV vaccine. A man from the Latino group said, "It will be ready in 10 years." In contrast, some participants were more pessimistic, believing that it would take so long to develop an HIV vaccine that it would not happen during their lifetime. A participant from the youth group said, "I don't think I'll even be alive." These different theories about the future availability of HIV vaccines highlight the fact that, as noted by a participant from the MSM group, "different sources say ... different time periods," resulting in confusion for participants.

An alternate viewpoint among respondents was that it was unlikely that an HIV vaccine would ever be developed because it was much too difficult to create a vaccine for such a serious and complicated disease. Respondents likened HIV vaccine development to the quest to eliminate other serious diseases. A participant from the youth group said, "They can't even cure herpes. They can't cure cancer. They can't cure tuberculosis." An MSM group respondent stated, in regard to HIV, "I think a vaccine is a little bit farfetched."

Respondents suggested that one of the reasons why an HIV vaccine was unlikely to be developed was the problem of viral mutation in regard to HIV. A participant from the female IDU group said, "One of the things that I heard is that the few times they thought they have gotten closer to finding a vaccine, the disease seems to have mutated into different forms." Similarly, a participant from the Latino MSM group said, "I believe that it will be very diffi-

cult because the virus is always changing” and a participant from the MSM group said, “It [HIV] just cannot be contained.”

Lack of Information: “It Blows My Mind How Much We Don’t Know”

Respondents discussed that they, and their peers, were largely unaware of the status of HIV vaccine development as the popular media rarely covers this topic. As a respondent from the MSM group said, “It really blows my mind how much we don’t know. We don’t know what has been done. I watch the news every night.” Even when the popular media does address HIV vaccines, participants stated that they were left with unanswered questions. A man from the Latino group explained, “I heard it on the news, and I asked a doctor and the doctor left me with no answer. He said ... he knew nothing about that ... they never give you the information.” Not surprisingly, many participants were left with questions about HIV vaccines, including the following:

- “Who will get the vaccine? Is everybody getting it?” (Latina group participant);
- “Are they doing human testing?” (MSM group participant);
- “How are they going to distribute the vaccine for the virus?” (Latina group participant);
- “Are they going to try it in Africa or China?” (MSM group participant); and
- “How close are we? How far away are we?” (MSM group participant)

Highlighting this lack of information about HIV vaccines, some respondents simply answered “no” when the focus group moderator asked them if they had heard anything about HIV vaccines. A participant from the female IDU group complained, “They never put enough information out for people.”

Confusion about Vaccines: “There’s So Much Confusion”

In addition to lack of information, many respondents expressed confusion about HIV vaccines. A participant from the MSM group stated, “What’s interesting here is that ... we are all ... interested in this subject ... but still, there’s so much confusion.” Part of the confusion about HIV vaccines related to lack of knowledge and information about vaccines in general. Respondents from the youth group asked, for example, “What is a vaccine?” and “What is the difference between a vaccine and medicine?” One youth group respondent believed that vaccines are a type of medicine that work by helping a person “from getting too sick from whatever you have.”

Respondents also expressed confusion when oth-

er group members raised issues about the possible development of therapeutic as well as preventive HIV vaccines (a preventive vaccine would be targeted to those who are HIV-negative to avoid becoming infected, while a therapeutic vaccine might be appropriate for persons living with HIV to avoid or delay disease progression). A participant from the male IDU group asked, “So the vaccine wouldn’t help if you already have it?” When the moderator, in a scripted probe, specifically referred to and explained the project’s focus on preventive vaccines, many participants were still confused, as suggested by the following comments: “If I had it, I would try it” (female IDU group participant) and “A vaccine is like a cure” (youth group respondent).

Participants also exhibited confusion about the meaning of HIV vaccine efficacy. Participants suggested several ways to understand efficacy, such as how effective a vaccine is at protecting a particular individual against infection and the proportion of the population in which the vaccine confers immunity to HIV infection. Participants also conflated the concept of efficacy with the occurrence of serious adverse events, such as vaccine-induced HIV infection. A participant from the MSM group asked, “When you say it is effective, you are saying this is going to protect you from the exposure versus it accidentally makes you positive?”

Finally, participants expressed concerns and confusion about vaccine-induced HIV infection. As a respondent from the African-American women’s group asked, “By them actually shooting the virus into your system, it’s going to ... give it to you?” Some participants thought that people who received the vaccine might not be infected themselves but would still be able to transmit HIV to others. As a woman from the Latina group said, “If it’s active, then you can transmit it,” which may reflect concerns about getting vaccinated and then infecting sexual partners with HIV.

DISCUSSION

Participants in this study reported conspiracy theories, lack of knowledge, inaccuracies and confusion regarding future HIV vaccines. Our findings build on previous research conducted in the context of clinical trials that suggests misunderstandings about HIV vaccines^{16,17} as well as accurate knowledge that HIV vaccines do not yet exist, though research efforts are underway.²¹

HIV Vaccine Conspiracies

A variety of conspiracy theories were invoked to the effect that HIV vaccines do currently exist but are being withheld from the public by those in power. The various economic and sociopolitical conspiracy theo-

ries expressed by participants reflect a high level of mistrust among vulnerable communities at elevated risk for acquiring HIV. Several studies have similarly identified HIV/AIDS conspiracy beliefs among African Americans²⁷⁻³⁰ as well as among gay men.³¹

HIV vaccine conspiracies expressed by participants may be grounded in part by the Tuskegee Study of Untreated Syphilis (TSUS) and other unethical medical research.^{32,33} A number of investigations among African Americans suggest an association between awareness of the TSUS and both mistrust of medical research and low willingness to participate in medical research.³⁴⁻³⁷ The present study suggests that not only African Americans but also Latino/as, IDUs as well as some gay men may initially distrust a vaccine developed by the medical establishment, especially a vaccine for a disease as feared and stigmatized as HIV/AIDS.³⁸

The HIV vaccine conspiracies voiced by participants may also be grounded in the trend in the U.S. popular media to focus on adverse events related to vaccines. For example, media reporting of alleged links between the hepatitis-B vaccine and multiple sclerosis³⁹ and between the measles-mumps-rubella vaccine and autism⁴⁰ have persisted despite lack of scientific evidence. Media focus on negative allegations about vaccines may promote general distrust of vaccines.

Gaps in Knowledge/ Need for Education

Participants revealed gaps in knowledge regarding vaccines in general (e.g., some respondents believed vaccines were akin to medical treatments), as well as confusion generated by ongoing research to develop both therapeutic and preventive HIV vaccines.⁴¹ The fact that many existing vaccines do not prevent infection, but prevent the development of disease,⁴² suggests an additional basis for confusion about the nature of vaccines in general and the difference between a vaccine and treatment. Similar confusion regarding the preventive, versus curative, nature of vaccines has been reported among vaccine trial participants in the developing world.¹⁸

Participants also expressed confusion regarding the concept of vaccine efficacy, and defined and understood efficacy in different ways. In reality, both individual- and population-level perspectives are relevant to understanding overall vaccine efficacy. For example, a vaccine might be completely effective in certain people and ineffective in other people (“all-or-none effect”) or it may be partially effective in everyone (“leaky effect”).⁴³

In addition to building on previous research that suggests specific educational needs about HIV vaccine trial concepts among prospective clinical trial participants,^{16,17} the present findings suggest issues

that may need to be addressed in educational interventions to facilitate uptake of future FDA-approved HIV vaccines. Given the much larger populations that will be targeted for the dissemination of approved HIV vaccines as compared to more limited numbers of participants needed for clinical trials, the significance of public education is arguably greater and will be required on a much larger scale. Furthermore, a degree of skepticism would appear to be warranted in approaching a randomized, placebo-controlled trial of a candidate vaccine of unknown efficacy; similar levels of skepticism in response to vaccines that have been granted FDA approval may result in low vaccine acceptability, which has the potential to undermine the ability of an HIV vaccine to ameliorate the AIDS pandemic.^{7,44,45}

Education for Lay People and Healthcare Professionals

The prevalence of inaccuracies regarding HIV vaccines highlights the importance of better informing and educating the public, particularly communities at elevated risk, about HIV vaccine development. Few sources of information exist outside of the professional literature for those interested in learning about HIV vaccine developments. Previous research has documented inadequate information about common, approved vaccines, such as the pneumococcal and influenza vaccines among African Americans and Latinos who reported that their physicians do not routinely inform them about or offer vaccination.⁴⁶

A few participants reported trying to engage their physicians in discussions about HIV vaccines, but the physicians did not satisfactorily answer their questions. This suggests that even individuals who are savvy enough to pose questions about an HIV vaccine to traditional sources of health information, such as healthcare professionals, may not receive answers. Many physicians may also be unaware of ongoing developments in HIV vaccine research. Hence, there is not only a need to provide accessible information to consumers, but there is also a need to provide HIV vaccine information to primary care physicians and to encourage them to disseminate the information. Several studies have shown that patients trust and respect their doctors’ health information and recommendations.⁴⁷⁻⁴⁹

Community Forums as Part of a Multipronged Educational Approach

Given the questions and confusion about HIV vaccines identified in this study and participants’ general desire for information, it may be helpful to initiate community forums and to establish community advisory boards (i.e., outside of clinical trials)

to create an ongoing dialogue about HIV vaccines among researchers and the diverse communities at elevated risk for acquiring HIV. Limited investigations suggest that people are able to learn complex vaccine concepts, given appropriate information and education.^{17,50} Racial/ethnic minorities and women, in particular, are underrepresented in clinical trials of agents against HIV^{51,52} and may benefit from tailored community outreach and education.³⁴⁻³⁷

Community forums hosted by respected community agencies may allow researchers to present current and prospective HIV vaccine research, tailored to the community's cultural and educational background, and allow the community to voice their concerns and beliefs. Such forums not only may engage the public in the process of HIV vaccine development and serve to dispel rumors and mitigate conspiracy theories, but also may establish researchers' credibility and build trust among communities at risk and the public health and research communities. This process, in turn, may facilitate future HIV vaccine trial participation and ultimately, acceptability of an approved HIV vaccine.

As initial HIV vaccines are developed and become available to the public, a multidimensional approach may be needed to increase HIV vaccine awareness and acceptance among communities at elevated risk for HIV and the general public. A multipronged educational approach has been shown to be useful in increasing acceptance of other vaccines. For example, a study regarding parents' knowledge of and attitudes about the varicella vaccine found that media coverage was useful in spreading news about its availability; however, the provision of detailed information and a recommendation by a personal physician were crucial in helping parents make the ultimate decision about having their children vaccinated.⁵³ Formative research to discern empirically based audience segmentation, information needs and communication strategies may be crucial to appropriately tailoring HIV vaccine information to different communities.⁷

Study Limitations and Conclusion

The small nonrandom sample in this study limits the generalizability of the results. Additionally, 10% of participants did not fill out demographic sheets; providing the information was voluntary and some participants had concerns about confidentiality. We also do not know the number of persons who initially signed up, but did not show up, for the groups. While the primary purpose of this qualitative study was to explore in depth the perspectives of persons at elevated risk for HIV/AIDS, rather than to generalize to others, we recruited a diverse sample from seven different high-risk venues in order to increase the

breadth of our findings. Future studies should explore HIV vaccine knowledge and beliefs among racial/ethnic minorities in other locales to determine if the results found here prove to be robust in other settings.

The present findings suggest the importance of carefully planning and developing strategies designed to reach communities at elevated risk for acquiring HIV/AIDS in order to increase HIV vaccine knowledge, acceptability and trust and to dispel misinformation and undue fears in regard to future HIV vaccines. Ultimately, HIV vaccine acceptability may be crucial to the success of future HIV vaccines in controlling the AIDS pandemic.

ACKNOWLEDGEMENTS

The authors thank the following colleagues for feedback and support: Peter Anton, MD; Ned Bayrd; William Cunningham, MD; Faith Landsman; Mary Jane Rotheram, PhD; David Wood, PhD; and Gail Wyatt, PhD. The authors also thank Ella Kelly, PhD, Frances Nguyen, Dallas Swendeman and Andrea Witkin for their assistance in conducting field work; and Danielle Seiden and Lisa Kakinami for their assistance in preparing the manuscript. The authors also gratefully acknowledge the support of the study sites and the participation of the study volunteers.

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