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Journal

Journal of Interprofessional Care, 18(4)

ISSN

1356-1820

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Publication Date

2004

DOI

10.1080/13561820400011735

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To cite this article: Adeline Nyamathi, Deborah Koniak-Griffin, Louise Tallen, Evelyn González-Figueroa, Lisa Levson, Yvonne Mosley, Ernestina Dominick & Nancy Anderson (2004) Use of community-based participatory research in preparing low income and homeless minority populations for future HIV vaccines, *Journal of Interprofessional Care*, 18:4, 369-380, DOI: [10.1080/13561820400011735](https://doi.org/10.1080/13561820400011735)


To link to this article: <http://dx.doi.org/10.1080/13561820400011735>

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Use of community-based participatory research in preparing low income and homeless minority populations for future HIV vaccines

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Summary *We conducted Community-Based Participatory Research (CBPR), using a qualitative focus group design, to assess factors that might impact participation of high-risk impoverished adults in future HIV Vaccine Trials (HIVVTs). The participants were 40 homeless and low-income adults recruited from subsidized apartments and homeless shelters in Los Angeles. Findings revealed that the participants expressed both concerns and interest in future HIVVTs. Concerns centered on the impact of the vaccine on their physical health, the possibility of seroconverting and its associated stigma. While distrust of the government was pervasive, the participants were interested in receiving more information about the vaccine from the researchers. They also wished to have their voices heard by the researchers early in the design of the vaccines. Motivating factors were also discovered, and included altruism, compensation and access to care. Perception that risk behaviors might increase among some as a result of participation in a future HIVVT was likewise revealed. Implications of the study reveal that while impoverished populations are interested in participating in future HIVVTs, the researchers must address concerns early on. Moreover, the importance of ongoing education and counseling to warn about hazards of engaging in risky behavior while participating in a future HIVVT was critical.*

Key words: *Community-based; participatory; research; low income; homeless.*

Introduction

Since the Human Immunodeficiency Virus (HIV) was identified over 20 years ago, more than 19 million people have died and over 53 million people have been infected. Experts contend that while HIV treatments to date have prolonged lives, they remain complicated and require sophisticated infrastructures (National Institutes of Health, [NIH] 2001). Moreover, successfully tested behavioral interventions alone are not expected to stem the tide of HIV (Centers for Disease Control and Prevention [CDC] 2001). While the recent VaxGen investigation in Los Angeles (LA) has revealed overall non-significant findings, the question arose as to whether a protective capability of the vaccine was manifested among minority populations (Kahn, 2003).

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However, as the study had been conducted primarily among white gay, and non-drug using males (Brown, 2001), this finding could not be confirmed. Thus, little is known of the challenges that will confront researchers interested in assessing the efficacy of the dozen or more Phase II and Phase III clinical vaccine trials needed for impoverished seronegative populations who engage in high risk activities such as injection drug use (IDU), unprotected sexual activity with multiple partners, and who report recent sexually transmitted diseases (STD).

Currently, the disparities in incidence of HIV/Acquired Immunodeficiency Virus (AIDS) and the course of disease progression among African-Americans and other ethnic minority people as compared to whites is large and persistent despite continuing efforts at the national and international level to reduce these differences. Healthy People 2010 (United States Department of Health & Human Services, [USDHHS], 2003) directs the nation to eliminate disparities in infectious diseases such as HIV/AIDS by equalizing: the quantity and quality of services delivered; increasing community participation, and partnerships; and delivering new treatments and vaccines. Populations who disproportionately engage in these high-risk activities reside in low-income housing sites and homeless shelters. As underrepresented people of color comprise the majority of residents at these sites, engaging the residents in future HIV vaccine trials is of critical importance in order to decrease and eventually eliminate health disparities for HIV/AIDS among this group of low-income underrepresented people of color. These sites frequently serve as research sites; however, until recently, the residents have not been offered the opportunity to participate in the planning of research projects. As a result, many residents have developed mistrust and are reluctant to participate in research and clinical trials. Giving voice to persons at risk in preparatory studies could enable researchers to establish trust and subsequently influence their involvement in later clinical trials as well as increase the cultural appropriateness of trials for specific communities.

The purpose of this study was to conduct community-based participatory research (CBPR), using a qualitative design, focused on assessing factors that might impact future participation of high-risk homeless and impoverished adults of primarily racial/ethnic minorities in HIVVTs. Specifically, we sought to: (1) to describe the potential facilitators of, and barriers to, participation of low income and homeless persons in future HIVVTs; (2) to determine the type of information desired by homeless and impoverished adults when deciding whether to participate in a future HIVVT; and (3) to describe the potential impact of HIVVT participation on risky drug and sexual behavior among these persons. In this study, CBPR was used as a key strategy in improving the quality and validity of research by engaging the community as partners in the research to facilitate the development and implementation of population-specific HIV Vaccine Trial (HIVVT) intervention strategies.

Literature review

A limited body of research exists on the willingness to participate in preventive HIV vaccine trials, particularly among hard-to-reach at-risk homeless populations. The majority of past studies have been conducted on populations such as gay white men (O'Connell *et al.*, 2002; Strathdee *et al.*, 2000), college students (Liau & Zimet, 2000), and IDU (Koblin *et al.*, 2000; Seage *et al.*, 2001). Furthermore, a number of investigators have administered written or interview questionnaires rather than applied research methods designed to solicit the voices of the participants through ethnographic techniques.

HIV/AIDS among impoverished population

HIV/AIDS cases have increased among low income and homeless adults, IDUs, and gay and bisexual males in LA. The second highest number of HIV-infected persons in the US resides

in LA; an estimated 43,541 adults live with AIDS (NIH, 2001). The majority of reported AIDS cases in LA have been male (90%), with 42% white, 22% Black, and 33% Latino. Certain segments of the population are at high risk for HIV/AIDS and should be considered in future HIVVTs. For example, in LA, HIV seroprevalence is estimated at 8% among IDUs not in treatment (Longshore & Anglin, 1996) as compared to 1.4% in the general LA population (Los Angeles County Health Department [LACHD], 2002). Among homeless populations, HIV seropositivity was found to be as high as 8% (Zolopa *et al.*, 1994). Independent risk factors for HIV infection among homeless adults include young age, Black race, male homosexual contact, IDU, sharing needles, and selling sex. Rates of drug use and abuse range from two to ten times higher among homeless and low income populations than those in the general US population (Robertson, 1997), with over 20% of low income and sheltered homeless populations reporting injection drug use in the last 6 months (LACHD, 2002).

Barriers to and facilitators of participation in HIV vaccine trials among high risk populations

Vlahov (1994) found that 85% of IDUs initially expressed interest in participating in a future HIVVT. However, interest declined to 47% when participants were informed that the vaccine might result in a positive HIV test. While research does indicate altruism as a predominant factor in willingness (Strauss *et al.*, 2001), persons who perceived themselves to be at greater risk, those who received information that the vaccine had greater efficacy, and those who were given larger incentives (Ringwalt *et al.*, 1998) were more likely than their counterparts to be willing to participate in HIVVTs. A study conducted by Celentano *et al.* (1995) indicated that persons attending sexually transmitted disease (STD) clinics, and men discharged from the army, 25% voted to participate in a future HIVVT, and an additional 38% would elect to join if they received convincing information the vaccine would be safe. Barriers to participation included concerns about discrimination, and side effects, and a belief that partners would refuse to have sex with the participant.

Participation in HIV vaccine trials may have an impact on risky behavior

Vlahov (1994) likewise revealed that 37% of his IDU sample would not maintain safe behavior and would rely on the vaccine for protection. In a sample of sex workers from Kenya, 17% of men and 9% of women believed they would increase their risk behaviors after participating in a future HIVVT. Similar intentions were prevalent among youth (Webb *et al.*, 1999), military personnel (Hom *et al.*, 1997), and in high risk women (Jackson *et al.*, 1995). Yet little is known of the potential consequences of such vaccines.

Among a sample of 48 HIV-negative men and women enrolled in an actual phase I and II HIV vaccine study, a significant increase in insertive unprotected anal intercourse from 9% to 13% at 6 months, and 20% at 12 months was observed. A hope that the vaccine would be protective was one predictor of increased risk behavior (Chesney *et al.*, 1997).

Community-based participatory research methods

Community-Based Participatory Research (CBPR) embraces a collaborative approach whereby community members, community organizations and researchers contribute to the process of research (Israel *et al.*, 1998). Community members are involved in defining what is to be evaluated, designing the evaluation protocol, selecting assessment tools, implementing the evaluation, analyzing outcomes, and interpreting the results. Because of their active involvement, participants also serve as project advocates. A systematic approach to inquiry, CBPR incorporates basic principles from formative program evaluation and action research

methods (Rogers & Palmer-Erbs, 1994), as well as principles from other fields of inquiry such as feminist theory, cooperative inquiry, and anthropology. The outcome of CBPR is a greater understanding of the phenomenon of interest as a result of the communities' sharing their unique perspectives and experiences, and by their partnership in the research process to provide knowledge of the social and cultural dynamic of the community, and how as a team we can address complex problems. Successful employment of CBPR methods leads to empowerment of participants and communities through acquisition of knowledge and skills and building community capacity. Community-partnered research projects are increasingly being recognized as an effective method for reducing/eliminating health disparities.

Methods

Design

This study incorporated community-based approaches using focus groups with eligible and randomly selected high-risk homeless and impoverished adults residing in LA. Focus group methodology uses in-depth open-ended group discussions 1–2 h long centered around a specific set of pre-defined issues of limited focus (Robinson, 1999). This strategy has been successfully used to examine public attitudes related to health behaviors (Nyamathi *et al.*, 1999; Ritchie & McEwan, 1994). Ethnographic procedures outlined by Hymes (1974) were employed in this study.

Participants and setting

Homeless and impoverished men and women were recruited from low-income, Section 8 subsidized, LA County apartments and shelters in the Skid Row area of Los Angeles. These sites are known to attract a disproportionate number of at-risk persons of color who would meet the following eligibility criteria: aged 18–50; and engaging in one or more of the following high-risk activities within the past 6 months: IDU, and/or exchange of sex for money or other things with three or more partners, or with an HIV positive person; a diagnosis of an STD, and for males, unprotected sex with other men (MSM). Of the 48 persons screened as eligible to participate, 40 were randomly selected to participate in the study.

These participants were primarily African American (78%), White (15%), Hispanic (5%), Other (American-Indian) (2%), and reported the following risk factors: use of injection drugs (15%); unprotected sex with multiple partners (95%); unprotected sex with an HIV positive person (8%); males having unprotected sex with another man (8%); having a STD (60%). Twenty participants were recruited from a low-income housing project and 20 were recruited from one of two homeless shelters.

Procedure

Consistent with our University of California School of Nursing Center for Vulnerable Populations Research, the philosophy of fostering extensive community input was provided. A Community Think Tank on HIV Vaccine Trials attended by over 50 community-based and University academic researchers, administrators, community organizers and peer advocates provided far-reaching community perspectives on the research questions to be asked, the barriers to and facilitators of HIVVT experienced by low income and minority persons in LA; ways to promote cultural sensitivity in education and intervention programs; and the types of questions important to pose in a Semi-Structured Interview Guide (SSIG) for use in focus group sessions.

Based on this think tank, a draft of the SSIG was developed and a Community Advisory Board (CAB) was formed comprised of five members including a physician who directed a large homeless medical clinic in the Skid Row area of Los Angeles, two community workers with expertise in organizing intervention programs for high-risk populations, and a member of the community who provided peer education to the homeless population. Four members of the investigative team also joined the CAB. All CAB members were familiar with and had expertise in the identified high-risk groups and were interested in promoting HIV/AIDS prevention in their communities. The CAB members assisted the research team in refining the SSIG, in finalizing recruitment site selection, and in revising the SSIG in a culturally-sensitive and linguistically appropriate manner.

Within each selected site, flyers describing the study were posted in the lobby. All those interested in participating were asked to notify the research staff. After information was provided about the study, and written informed consent obtained, demographic data were collected by self-report, by research staff that read a questionnaire to the participants. Questions were asked regarding date of birth, age, gender, ethnicity, religion, education, country of birth, employment status, income assistance, marital status, and number of children. Questions were also asked about high-risk activities within the last 6 months such as use of injection drugs, unprotected sex with multiple partners or an HIV positive person, and having a STD.

After screening was conducted, all eligible persons within the selected sites were randomly selected and informed that focus group sessions would be initiated shortly, in private rooms at the sites, by a well-trained research facilitator. In addition, during each of the focus group interviews, a second trained research associate conducted observations of the participants' behaviors and interactions. Each session, which lasted about 75 min, included 6–8 participants. Participants were paid \$15 each for participating in the focus group discussions.

The SSIG, using open-ended questions, guided each session. The focus group discussions were audiotaped for subsequent transcription. Observations were recorded into field notes, followed by more detailed note writing, which was completed within 24 h of each session. These observations were guided by Johnson and Sackett (2000) for direct observation of behavior including descriptions of the setting, actors, verbal and nonverbal interactions, communication sequences and the specific words used. Upon completion of the focus group sessions, the investigators oversaw transcription and content analysis of the taped recordings. Following completion of all focus groups, a random sample of six participants was selected and asked to participate in a follow-up interview at a mutually agreed upon location. In this interview, participants were given clusters of data segments from the focus group transcripts and asked to identify which words and phrases accurately reflected their own experiences. Participants in these sessions validated the content of the earlier transcribed sessions. In addition, inter-rater reliability was assessed by independent review of three community health care professionals.

Data analysis

The audiotapes of each session were transcribed into computer files in preparation for data analysis. Data management and analysis methods developed by Hymes (1974) were employed e.g., reading and re-reading of field note data and transcriptions, coding and breaking down of information into data segments. These data were sorted into clusters according to emerging categories, reexamined and combined into themes. The Ethnograph Software was used for qualitative data storage, retrieval and sorting. Three independent coders assessed intercoder reliability. Participants in follow-up focus groups ensured trustworthiness, credibility, dependability, and confirmability of the data through data verification. Four major categories

resulted; each with subcategories: Willingness to Participate, My Issues of Concern, What I Want to Know, and How My Behavior Might Change. These terms were derived from both the participants (emic) and researcher's perspective (etic).

Results

As there were no significant response differences in background characteristics between homeless and low-income adults, the samples were combined for purposes of data analyses.

I. Willingness to participate in an HIVVT

Participants expressed many reasons for being willing to participate in an HIVVT including compensation for themselves and others, desire to help themselves and others, and desire to learn more. Only one participant indicated that he would not be willing to participate in an HIV vaccine trial because he was not HIV positive. Across the domains, participants expressed concern about trusting the government and/or researchers involved in a vaccine trial.

Compensation for family and self

As many homeless adults have experience in participating in research studies, it is not surprising that receiving compensation was a common idea—expressed by a majority of participants. In the Skid Row area of LA, over 85% of people are unattached and without families (Nyamathi, *et al.*, in press). Thus, individual compensation is important. This is exemplified by a 24-year-old, African-American man, living in a homeless shelter for parolees, who stated, 'I feel like if I put [in] my time, I should be getting paid for it'.

Moreover, a significant proportion of homeless and impoverished adults also have children who are in the custody of relatives. Desire for compensation for loved ones in case of an adverse reaction to the vaccine was also expressed. One 51-year-old, African-American woman, living in a low income hotel, expressed it this way, '... I have to be compensated in case something [does] happen to me; at least my family or loved ones would be taken care of ...'.

Desire to help others and self

Several participants expressed altruism as a rationale for their willingness to participate in a future HIVVT. Several participants were most interested in participating, if they, in fact, were HIV positive. Others were interested in participating because of their previous and/or current risk behavior.

A homeless, 40-year-old white man living in a parolee shelter described it this way, 'If I had HIV or AIDS and there was a vaccine and I could be of use to finding out if it works, man, yes, I would participate'. Another male, a 44-year-old, African-American, homeless adult, said, 'If I did have it [HIV], unfortunately that would be the bomb right there; I would go submit myself to a vaccine trial, yeah'.

For others, a willingness, or desire, to help others was their primary reason for being willing to participate in an HIVVT. For example, a 47-year-old African-American man, living in the parolee shelter expressed it eloquently, stating that if he was HIV positive, he would participate so he could help the entire human race. 'Yes, I would if it came to me, yeah. I would take it, because if I have AIDS, I would like to help the human race and what [do] I have to lose? I have nothing to lose. I have something to gain though. To help scientific progress in this trying to make a cure ... I would have something to gain for human society. You gonna go anyway, you know? So I might as well be helping.'

Desire to learn more

While less apparent, a number of participants were interested in learning all they could about the HIV vaccine, based on the number of questions they raised. As the aim of the sessions was to assess the participants' perspectives about participating in future HIVVTs, and not an educational forum on the HIV vaccine, the facilitator was trained to defer questions to an information session made available after the focus group session was completed. Nevertheless, it was not surprising that several participants expressed willingness to participate in an HIV vaccine trial just so they could learn more, or know more, about the vaccine. 'I would go for it, just the knowledge of learning more about it. 'Cause [AIDS] is a disease that is dangerous, so I would yeah, just the knowledge of knowing about it,' stated a 38-year-old Native American Indian man living in a low-income hotel.

Another reason participants were willing to participate in an HIV vaccine trial was to protect themselves. 'I would be interested in an HIV trial simply because I don't want to catch HIV and AIDS . . . I know how deadly it is . . . so anything out there is going to help me with reason not to catch HIV, I'm all for it,' stated a 43-year-old African-American man living in a low income hotel. 'I would be willing to just find out more about and keep myself from getting it.'

Still others worried that previous risk behavior put them at increased risk for AIDS, and thus, they would be willing to participate in an HIV vaccine trial. TY, a 38-year-old African-American woman living in a low income hotel, said, 'I'm like 5 years clean off of Crack, but, still, you now, I get tested once a year . . . but, still I might be subject cause I was like really out there . . . so, you know, I would go for it . . . because of my past'.

II. Issues of concern about participating in an HIVVT

When asked what concerns they might have about participating in a future HIVVT, a lively debate ensued in all of the focus groups, producing a wide variety of responses. Concern about government and/or researchers' involvement in an HIV vaccine trial, was followed closely by concerns about side effects and access to health care. Two other common concerns were worry about testing positive for HIV and worry about becoming infected with HIV. A few participants were concerned about the cost of participating in an HIV vaccine trial. Most people expressed concern about stigma if they tested positive for HIV after receiving the vaccine.

Government involvement

One participant echoed the feelings of many others when he expressed concern about possible government involvement in an HIV vaccine trial. 'I would trust the researcher more than I would trust the government. To me the government [cares] . . . more about money. The researcher is the one that's putting in all the work . . . so, I'm pretty sure that they got a little feeling in [their] heart . . .', said one participant. There were some, however, who argued that even if one did not completely trust the government, its involvement would be necessary for developing a vaccine. One 45-year-old white male living in a low-income hotel, argued, ' . . . I don't usually trust the government but I can't see it coming up with that without them'.

Side effects

Concern about side effects worried many participants in the focus group discussion, whether in the short or long term. 'Yes, I probably would be worried about some kind of side effects if not the virus, it would be something else, you know it's long-term, like cataracts or . . .

something might go to the liver or heart. I would be worried about it,' stated a 44-year-old African-American man living in a homeless shelter for parolees. A 43-year-old African-American man living in a low income hotel expressed his concerns about side effects, 'Yes, I'd be very concerned about the side effects. I'd be concerned if this [is] gonna work. I mean, is it safe, yeah, everything, whether I'm gonna grow another arm or something'.

Several participants expressed concern about access to health care. A 37-year-old African American man living in a low income hotel stated, 'I would say definitely, in order to have health care . . . 'cause you taking it for long, you want to make sure that you are in good health after you take the vaccine'. MO, a 51-year-old African-American woman living in a low-income hotel concurred with others in her focus group regarding health care, 'I have to agree with you that [access to health care] should be a major concern to all, after and before health care. It's very important being involved with a vaccine program'.

III. What I want to know

To probe further about the decision process the participants would use when deciding to join in an HIVVT, participants were asked what information they would want before deciding to enroll and with whom they would want to discuss their participation. Regarding the type of information desired, the two most common responses were information about side effects and how vaccine researchers were involved in the trial.

Many participants indicated a desire to know about side effects they might experience before deciding to participate in an HIVVT. Some wanted to know about immediate side effects while others wanted to know about possible long-term side effects. One participant expressed this sentiment. 'I would like to know what it's going to do to me; what reaction I'm going to have years after. You know, 'cause it (side effects) don't have to (become apparent) in two or three hours or a day. It could take years for the side effects to become [apparent]'.

Some participants wanted to talk to the researchers to find out the aims of the trial and to find out how successful the trial was when it was over. '[In] an HIV trial, you're really a guinea pig. The scientists are using you as part of their data to move their product forward. What information can you [the scientists] share with us,' asked a 41-year-old African-American man living in a homeless shelter. Another 46-year-old white man living in the parolee homeless shelter stated he would like to talk to the researchers involved in a trial to find out, 'what they hope to achieve and information after the trial to know if it's been successful or not'.

Regarding from whom they would attempt to seek information regarding participation in a vaccine trial, the three most common responses were medical personnel, vaccine researchers and family. A 30-year-old African-American living in homeless shelter stated he would want to talk to 'my doctor and my family [because] I'm diabetic'. Another participant eloquently described why he would want to talk to vaccine researchers: 'Who would I speak to? I would talk to the person making the vaccine . . . to find out about it and how they came up [with] this new dose. Find out the history of the medicine to see what it's about . . . ain't gonna talk to no church or no personal friend 'cause they can't do nothing for me, so I would talk to the person that's trying to prevent it you know, and see what it'll do . . .'.

IV. How my behavior might change after receiving an approved vaccine

Participants were asked several questions regarding possible risk behavior change if an actual HIV vaccine were available: whether behavior would change positively or negatively; what percentage of people would change their risk behavior; and how increased risk behaviors could be prevented. All but one participant believed risk behavior would change in a negative direction. Answers regarding the percentage of negative behavior change ranged from 30% to

97%; the most common response was 50%. All participants agreed the best way to prevent increased risk behavior was through education.

One participant felt his risk behavior would increase if a vaccine were available; 'I think that if I felt I had been vaccinated and I was protected against the disease, I'd think I would be more promiscuous and even more risk taking'. Another participant felt that while he wouldn't be concerned for himself, he worried that others' risk behaviors would increase; 'Myself . . . I'm very low risk, so I wouldn't be concerned for myself but I would be concerned for other people's behavior patterns, they might go back to the negative . . . more promiscuous sex, more sharing of dirty needles . . . because they would feel that there's no way they can contract the disease once they have a vaccination'.

All participants who responded agreed that education, broadly conceived, was the best way to prevent increased risk behaviors. One participant felt people would need to be educated and reminded to practice safe sex; 'I would say to keep promoting safe sex on the commercials and on the buses . . . using a condom . . . keep promoting, keep it in people's minds . . .'.

Discussion

Findings from this study contribute to the growing body of literature examining willingness to participate in an HIVVT and extend the literature to include a previously unstudied population of low-income and homeless adults of predominantly African American background. The participants represented a subset of a vulnerable population in the community who were interested in knowing that their words were being communicated to vaccine developers and others involved in vaccine trials. They expressed concerns about different factors relevant in HIVVT design and were related to the impact of the vaccine on their physical health, including seroconversion and other potential negative side effects. These concerns are consistent with findings from other hypothetical vaccine preparedness studies (Koblin *et al.*, 1998; O'Connell *et al.*, 2002; Strathdee *et al.*, 2000).

For many homeless and poor adults in this study, government distrust was pervasive and outweighed distrust of researchers, possibly reflecting the 'collective memory' of the community of the Tuskegee Syphilis study or other government-supported investigations involving African Americans. The data also indicate that poor adults may consent to participate in vaccine trials because of their desire to decrease personal vulnerability by gaining access to basic necessities such as money for self and family and short and long-term health care. These motivating factors reflect the life realities of the poor and should raise the consciousness of researchers about how incentives have the potential to serve as a coercive force in clinical research. However, compensation was not uniformly valued as a motivating factor among the impoverished adults in this study, dispelling perceptions commonly held among health care providers and researchers about reasons why these individuals participate in investigations. Findings from another multi-site national study involving homosexual men, male and female IDUs and non-drug injecting women demonstrated that participants who are uninsured or insured by public medical coverage were more likely to be willing than those with private health insurance to participate in HIVVT, possibly indicating an expectation that vaccine trials will pay for any health problems that occur during the trial (Koblin *et al.*, 1998). Research findings also indicate that socioeconomically disadvantaged gay and bisexual men express greater willingness to participate in HIVVT than those with greater financial resources (O'Connell *et al.*, 2002).

Although less frequently verbalized, an altruistic desire was expressed to help further knowledge about vaccine safety, particularly if HIV positive. In another study involving a vulnerable population, altruism was a main motivator for participating in efficacy trials, and monetary incentives were important to only a small proportion of participants (Koblin *et al.*,

1998). Similar findings have been reported in other investigations involving African Americans, IDUs, and gay men (Strauss *et al.*, 2001). Lack of knowledge about vaccines was widely evident among participants in this study and served as an additional facilitator for potential enrollment in clinical trials. These facilitators, barriers and concerns about participation in HIVVT were shared across ethnic/racial groups (e.g., African American and white participants).

Almost, unanimously, participants stated that high-risk behavior would increase if there were an HIV vaccine available. This is consistent with prior literature that has assessed perceptions of high-risk behavior and HIV vaccines (Jackson *et al.*, 1995; Vlahov, 1994). This finding may add challenges to behaviorists and prevention researchers and calls for a stronger link between behavioral change efforts and vaccine trials. Further, it illustrates the need for a variety of prevention approaches that respond to the subpopulations invited to participate and who lack knowledge about research processes and HIVVT.

A variety of educational approaches need to be employed within the community in order to address the concerns of vulnerable populations about future participation in HIVVT. For example, programs need to be tailored to specific knowledge levels about vaccines in general and more specifically about preventive HIV vaccines (e.g., basic vaccine trial concepts, safety issues, side effects). Similarly, risk for HIV needs to be addressed in relation to overall lifestyle behavior and post vaccine behaviors. Comprehensive counseling will be needed with frequent reinforcement during the course of clinical trials to prevent participants from engaging in high-risk behaviors for HIV because of assumptions about protection by the vaccine (either placebo or real without proven efficacy). In addition, participants will require information about the nature of HIV testing and the meaning of vaccine-induced seropositivity.

Significance of expected results

Findings from this study strongly support the need for clinical researchers to address adequately the perceptions of communities regarding participation in studies as many disenfranchised groups such as low income and homeless adults continue to question issues of beneficence versus malevolence in proposed trials. Using a CBPR approach is an important for confronting obvious tensions that may emerge. Vazquez (1999) describes the significance of including community representatives in trial design and implementation for assuring the creation of successful HIVVTs that consider the realities of community participants' experiences and facilitate enrollment. Furthermore, this type of partnership assures that community value systems are incorporated in developing criteria for enrollment, incentives and follow-up and builds participants' commitment in the successful outcome of the trial.

Despite the fact that HIV vaccines are being developed and need testing in the near future, there is a scarcity of systematic research on decision-making regarding HIV vaccine trial participation, or on consequences of participation among racial/ethnic populations who are IDUs, and/or engage in unprotected sexual activity. A major strength of this investigation was the employment of CBPR methods that establish a new path for assessing interest and willingness to participate in HIVVT. Application of CBPR methods reflects the investigative team's respect for the values of the community of homeless and low-income adults. The approach has facilitated development of a trusting relationship for future work that moves away from traditional methods of research that are often insensitive to the local culture and values of the community. Multiple strategies are necessary to build trust; effective approaches within this study included implementation of a Think Tank to gather information and problem solve, and organization of a CAB for guidance in the planning, implementation and evaluation of the study. By employing CBPR methods and advancing their use, coupled with education about the risks and benefits of trial participation, the notion of trust could be enhanced among

participants and researchers and among community-based organizations and academic institutions.

Eventual triangulation of data from qualitative and quantitative sources will assist in testing a meaningful conceptual framework for interest and willingness in HIVVT participation among these groups and will form the basis for culturally- and linguistically-appropriate intervention and prevention programs, inform HIV vaccine research and policy, and enhance participation in HIVVTs.

Study limitations

The results of this study are limited by the nature of the sample which represents a special subset of vulnerable populations and may not be generalizable to other high-risk groups. Discussions did not examine participants' feelings about specific vaccines or HIVVT protocols. A prospective assessment of willingness to participate in HIVVT would augment the validity of findings from this study.

Acknowledgements

Funded by the UCLA Center for Vulnerable Populations Research award and the UCLA Intramural Grant Award.

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