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Decisions to participate in research: views of underserved minority drug users with or at risk for HIV

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Abstract

Under-representation of minority populations, particularly African Americans, in HIV/AIDS research is problematic because African Americans bear a greater disease burden from HIV/AIDS. Studies of motivations for participating in research have emphasized factors affecting individuals' willingness to participate and barriers to participation, especially in regard to HIV vaccine research. Little is known about how underserved minority drug users perceive research and their decisions to participate. This study describes African American drug users' perceptions of research participation and their decisions to participate based on three kinds of hypothetical HIV/AIDS-related clinical studies. In-depth, qualitative interviews were conducted with 37 underserved, African American crack cocaine users, recruited from participants already enrolled in three different behavioral HIV prevention studies. Interviews were recorded, transcribed, coded for themes and sub-themes and analyzed using directed and conventional content analysis. Participants' decisions to take part in research often involved multiple motivations for participating. In addition, decisions to participate were characterized by four themes: a desire for information; skepticism and mistrust of research and researchers; perceptions of medical care and monitoring within a study; and participant control in decisions to participate or decline participation. Lack of adequate information and/or medical care and monitoring within a study were related to mistrust, while the provision of information was viewed by some individuals as a right and acknowledgement of the participant's contribution to the study. Participants perceived, rightly or wrongly, that medical monitoring would control some of the risks of a study. Participants also described situations of exerting control over decisions to enter or withdraw from a research study. Preliminary findings suggest that continuous communication and provision of information may enhance enrollment and adherence. Further exploration of decisions to participate in research will add to the understanding of this complex phenomenon and enhance the ability of individuals with HIV/AIDS to benefit from research.

Keywords

research participation; economically-disadvantaged African Americans/underserved minorities; drug users; decision making; HIV/AIDS; research ethics

Introduction

Economically-disadvantaged minorities disproportionately bear the disease burden of HIV/AIDS (Center for Disease Control and Prevention, 2000). Yet minorities at risk, African Americans, in particular, may lack access to or decline participation in research that could provide new treatments or preventive measures for HIV/AIDS (Djomand et al., 2005; Gifford

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et al., 2002; Stone, Mauch, Steger, Janas, & Craven, 1997; Sullivan, McNaghten, & Begley, 2007). Knowledge of how research participants perceive the experience of research and what motivates their participation can promote their enrollment and protocol adherence and enhance informed consent processes (Halpern, 2002). Furthermore, increased minority enrollment improves applicability of results, thereby increasing access of minorities to healthcare benefits derived from research (Gifford et al., 2002).

Research on participation in HIV/AIDS research has primarily dealt with barriers to participation (Mills, Cooper, & Guyatt, 2004) and individuals' willingness to take part in HIV vaccine trials. The focus on vaccine trials stemmed from the National Institutes of Health's initiative to develop a foundation for testing new HIV vaccines as soon as they became available (Koblin et al., 1998). However, over a 14-year period, enrollment of minorities in preventive HIV network vaccine trials in the US was only 17% (Djomand et al., 2005). A variety of potential influences on minority individuals' participation in research have been identified, including accessibility of information on research and HIV; skepticism about whether a vaccine exists; mistrust of research, researchers, government and related conspiracy beliefs; concerns about vaccine-induced infection, seropositivity, side-effects and social stigma; vaccine safety, efficacy and side-effects; study demands and inconveniences; altruism; incentives to participate; relationships with research staff; and post-study care (Allen et al., 2005; Buchbinder et al., 2004; Golub et al., 2005; Meyers, Metzger, Navaline, Woody, & McLellan, 1994; Newman et al., 2006; Priddy, Cheng, Salazar, & Frew, 2006; Roberts, Newman, Duan, & Rudy, 2005; Strauss et al., 2001).

Among the many potential influences on individuals' willingness to take part in research, trust and mistrust have been consistently identified as key issues affecting African Americans' views about research participation in general (Corbie-Smith, Thomas, & St. George, 2002; Shavers, Lynch, & Burmeister, 2002) and their willingness to participate in HIV/AIDS studies in particular (Sengupta et al., 2000). African Americans' mistrust is underscored by the prevalence of conspiracy beliefs about HIV, including perceptions that the government uses HIV infection as a means to discriminate against African Americans and marginalized groups such as drugusers. Conspiracy beliefs have been linked to pervasive racial discrimination and identified as significant barriers to African American participation in public health programs dealing with birth control and the prevention of HIV and other infectious diseases (Bird & Bogart, 2005; Bogart & Thornburn, 2005; Ross, Essien, & Torres, 2006). Conspiracy beliefs related to participating in vaccine research include the belief that the AIDS epidemic was created by the government as a means of genocide (Meyers et al., 1994; Priddy et al., 2006) and that an HIV vaccine or a cure for AIDS exists but is being withheld by the government (Allen et al., 2005; Meyers et al., 1994; Priddy et al., 2006; Roberts et al., 2005).

Studies of participation in HIV/AIDS clinical trials have noted that health professionals may influence individuals' decisions to enroll in clinical trials. Professional influences include the individual's physician (Ross & Jeffords, 1994), the work of a dedicated health research team (Madge et al., 2000) and participants' positive encounters with researchers (Mueller, 2004). However, attitudes of healthcare providers and investigators have been reported to adversely affect minority participation. Some physicians and researchers perceive difficulty in communicating with minority individuals about research or assume their lack of interest in participating in studies (Stone, Mauch, & Steger, 1998). Health professionals may also assume that minority individuals will have difficulty complying with a research protocol for a variety of social, cultural or economic reasons (Shavers-Hornaday & Lynch, 1997).

Some writers have noted that when actual participation has been measured by rate of consent by ethnic group, significant differences in participation between African American and white participants have not been demonstrated (Corbie-Smith et al., 2003; Wendler et al., 2006). This

finding suggests that access to, and availability of, research studies, rather than attitudes of individual participants toward research, may have a greater influence on minority decisions to participate (Wendler et al., 2006). Although one study (Stone, Mauch, Steger, Janas & Craven, 1997) found that minority participation in HIV/AIDS research remained low even when access to participation was available, a recent large-scale investigation showed that failure to offer enrollment was the most commonly reported reason for non-participation across gender and ethnic groups (Sullivan, McNaghten, Begley, Hutchinson & Cargill, 2007). Furthermore, African Americans may be under-represented in HIV/AIDS clinical trials, but they tend to be adequately represented in clinical research focusing on less stigmatizing diseases such as hypertension and cancer (El-Sadr & Capps, 1992; Shavers-Hornaday & Lynch, 1997).

While influences on minority participation in research have been identified in the literature, little is known about the decisions of drug users, especially non-injection drug users, to take part in research. The association of substance use, HIV and poor health outcomes is well-established. Among HIV-infected individuals engaged in different types of substance use, crack cocaine users were shown to have the poorest access to healthcare (Cunningham, Sohler, Berg, Shapiro, & Heller, 2006). More information is needed about the decision processes involved in the participation of minorities and marginalized populations in all kinds of clinical and preventive HIV/AIDS research. Understanding how underserved African American drug users view the experience of research and their decisions to participate in different kinds of studies can help clarify access issues and identify participant views of “best practices” regarding their recruitment and retention in research studies.

To explore motivations of underserved African American drug users to participate in research, a qualitative interview study was conducted among individuals already enrolled in minimal risk, HIV-prevention research. This paper examines views of African American drug users about decisions to participate in research.

Methods

The study methodology has been described elsewhere (Slomka, McCurdy, Ratliff, Timpson, & Williams, 2007). To summarize, from February to May 2006, in-depth interviews were conducted with 41 participants enrolled in three different minimal-risk, HIV prevention studies of economically-disadvantaged, African American crack cocaine users, with, or at risk for, HIV. Two primary studies tested behavioral interventions to prevent HIV; a third study was a hepatitis vaccine project developed as a model for an HIV vaccine study. A convenience sample of interviewees was recruited from participants in the primary studies who had given prior consent to be contacted about future qualitative studies. Participants were paid $20 for their time and travel. Semi-structured interviews lasting 30–45 minutes were conducted until theme saturation was reached. Interviews focused on participants’ views of research in general and on perceptions of risks, benefits, inconveniences and financial compensation using three hypothetical research scenarios. Each scenario presented an HIV-related study of differing risk level: (1) a study relating sleep disturbances to stress in persons with HIV, using a written questionnaire (adapted from Vosvick et al., 2004); (2) a randomized controlled trial of a medication; and (3) an HIV vaccine trial (adapted from Coletti et al., 2003). Because qualitative interviewing is both an iterative process and an attempt to understand the meaning of phenomena, participants’ views of actual experiences of research participation were elicited as well as their views evoked by the hypothetical research scenarios. As per standard qualitative interviewing technique, emerging new themes were explored using probe questions. Methods for establishing quality and credibility of data also followed standard qualitative methods (Patton, 2002). Verbal consent was obtained prior to each interview and participants were given an informational letter in lieu of signing a consent form. This study was approved by the Institutional Review Board of The University of Texas Health Science Center at Houston.

Interviews were transcribed verbatim, coded for themes and sub-themes and analyzed with directed content analysis (using pre-existing theoretical categories) and conventional content analysis (using categories derived from the data) (Hsieh & Shannon, 2005). Theoretical categories were drawn from the bioethics and research ethics literature and included topics of risk, benefit, privacy/confidentiality, therapeutic misconception, undue inducement, vulnerability and trust/mistrust.

Thirty-seven of 41 interviews were included in the analysis; two were excluded because of recording failure; one interviewee was not African American; and one interview was stopped by the researcher due to participant fatigue. Twenty (54%) of the interviewees were male whose ages ranged from 22–53 years with a median of 40 years. Fifteen participants (42%) had completed 7–11 years of schooling, 17 (47%) had a 12th grade education and four (11%) had 13–16 years of schooling. Thirteen (36%) had their own house or apartment, while 20 (56%) lived in others' homes. Three individuals (8%) had lived in temporary shelters or "on the streets". Only seven respondents (19%) had more than $600 income per month and five (14%) had no monthly income. Of those individuals who knew their HIV status, 6 (17%) were sero-positive; 14 (39%) were sero-negative; and 16 (44%) did not know their status or their status was not verified. Data, except for gender and age, were missing for one interviewee; percentages were rounded.

A second investigator reviewed transcripts for competing or alternative interpretations (Barbour, 2001). All investigators reviewed and refined data categories and interpretations. Differences were minimal and discussed by investigators to achieve consensus.

Results

Interviews with participants revealed that decisions to take part in research, both actual and hypothetical, were often multifaceted. The primary motivation for participating in research was monetary compensation, an issue examined in depth elsewhere (Slomka et al., 2007). Participants stated non-financial reasons for participating as the desire to help medical science and researchers and to help oneself or one's family, especially if affected by the disease being studied. Some respondents viewed the provision of medical tests as a benefit of participating in research, while others viewed such tests as neutral because they already had healthcare available to them. Access to new, better and/or free medications and learning about one's disease condition and the risks associated with HIV and drug use were also noted as motivations for participating in research.

The time needed to take part in a study, especially if it interfered with employment, the inconvenience of travel to a study site and concerns about being a "guinea pig" were noted as negative aspects of participation. Views about risks and potential harms of a research study were contingent on numerous factors, including type of study; participants' perceptions of risks of research are addressed in detail elsewhere (Slomka, Ratliff, McCurdy, Timpson & Williams, in press). Although participants expressed a multitude of views about research and reasons for participating and declining participation in research, overall, decision making was characterized by four themes: (1) a desire for information; (2) skepticism and mistrust of research and researchers; (3) perceptions of medical care and monitoring within a research study; and (4) participant control in decisions to participate or decline participation in research.

Desire for information

For most participants, research was associated with seeking or finding information, especially information about drug indications, side-effects and/or specific diseases. Both researchers and participants were seen as learning from the information derived from research. Some interviewees reflected the view that although they lacked knowledge about research, they still

needed information. Others expressed sentiments similar to the participant who said that he "just would like to know [about a research study testing a medication] … I'm just saying I wouldn't want to participate in nothing if I can't be told what it is. Why am I really taking it?"

One respondent wanted to know what medication was being tested in the medication study scenario in order to "read up on it" and learn about the drug's use and side-effects. This respondent, as well as others, implied that while researchers need to provide information, participants should also actively seek information about a study because "you're putting something in you that's not naturally in you". Another interviewee, when presented with the sleep disturbance study scenario, was asked what other kinds of information he would want before taking part in a minimal risk study. He replied:

> What are they trying to find out? … And when they find out about stress, okay, what are you trying to do? You're trying to find a way to suppress stress? Or you're trying to find a way to get some kind of medication for stress? What is you trying to do? Because I'm getting involved in your study, and I'm helping your research. So I need to know what you're trying to do.

This participant's response suggests not simply a desire for information, but a claim to information as a prerequisite to participation and as an acknowledgment of one's contribution to the research study.

In considering the medication study scenario, some individuals stated a willingness to participate without asking the name or kind of drug to be tested. More often, though, interviewees were adamant that they needed information and understood that they had a right to such information. Said one participant: "I would have to see what it [the study] was all about and everything, yeah, first. You can't just put me in a research. I would have to find out more about it." Another participant inquired about legal rights:

> Now also, when there's a study like this, would I be signing anything, as far as if anything happened to me when I was in it, or would I be able to make them liable or make them un-liable?

In discussing the medication study scenario, an interviewee admitted his unfamiliarity with medical terms and names of drugs. Yet he still acknowledged his right to information about the medication being tested. His comments also suggest that mistrust can be generated if information is not freely provided by research personnel. When asked if the name of the study drug was something he would want to know, he replied:

> To an extent, like I'd be worried. You can give me any name, any name on here, because I'm sure I'm not aware of the different ones that you have. But it would make a difference. I'd like to at least see that they're not trying to hide any information given.

Mistrust might make someone more leery or more inclined to ask for information. This same respondent diplomatically states his concern about the possibility of not being given adequate information about the hypothetical HIV vaccine study:

> Q: You think that there might be some long-term effects you think that they might not be telling you about?
>
> A: Well, not so much not telling me about. Maybe it could have been overlooked by them also … like I'm sure they go completely over it, but there's always room for error so I'd be really worried about that.

Most interviewees wanted additional information prior to participating in studies. Many would depend on research personnel to provide information, although a few said they would use a library or the Internet, or speak with a physician or nurse.

Skepticism and mistrust of research and researchers

Participants' remarks often revealed skepticism about motives or an outright mistrust of researchers and the research endeavor. Interviewees were wary if they sensed that risks or other information about a study were not being fully disclosed. Some respondents said they would participate to "find out what's going on, like why they doing this research". A discrepancy between the amount of financial compensation and perceived risk of the study could be a source of mistrust:

> Yeah, that's too much, that's just too much money ($500 for the minimal risk sleep disturbance study) … But that much money would make a person think, like, what kind of questions I've got to answer, you know, how personal, or whatever it is … Five hundred dollars, just for a questionnaire … Something don't sound right. You know, for an hour. I'd be trying to get all kinds of information before I would participate.

Participants expressed skepticism about research that involved taking pills or injections. Other expressions of skepticism and mistrust appeared to derive from research studies, apocryphal or real, that were perceived as harmful or enabling substance use:

> They've got a program right now, they let you snort crack … Well, they were trying to test some kind of synthetic drug or something. Then they'd try to see how a person reactions, you know, how he or she reacts when they should know, what type of, just what type of effect it takes on.
>
> Q: Why would they do a study like that?
>
> A: I don't know. That was a question I asked myself … I really can't say.
>
> Q: Because it sounds like – could that be harmful to the person?
>
> A: I would think so. To me, I think it – I could be wrong, but I'll say it anyway. I think you turn them more into a drug addict than just trying to send them to a rehab … What the hell is that, do they feed it to you for? … Don't break laws by trying, you know, to see what kind of examples you can make, or again, create in somebody.
>
> Q: Well, if there might be some harm to that study, why do you think people are participating in it?
>
> A: To get high.

Later, the interviewee said he would do a medication study for $2000. But not the crack study, which he felt was "suicide": "… Keep your crack; keep your $2000 …" he said. This participant interpreted a research study of a street drug as enabling or encouraging drug use and exploiting one's addiction. In general, mistrust of research and researchers could result if information about a study was misunderstood, misinterpreted or perceived as inadequately or insufficiently disclosed.

Perceptions of medical care and monitoring within a study

While interviewees viewed medical exams and diagnostic tests as both a benefit and an expected part of a clinical study, the provision of healthcare within a study was important for another reason. A common perception among interviewees was that the risk of harm in research studies was mitigated because participants were monitored for adverse reactions. One interviewee explained she would be comfortable participating in a medication study:

> Because they're giving you drugs. A new drug and the old drug. And you know what the old drug going to do for you. I mean, you come in every week. So even if you have any bad side-effects or anything, you can come right to the doctor. They can take you off of it and stop it right then and there or whatever.

Another respondent stated:

> Okay, I don't see any risks as long as they are drawing blood to test and all that there, to see what condition your body is in or maybe they figure you could withstand it, or you can't … Maybe you start to get some kind of reaction or something doesn't go right. They'll stop you from taking them.

One participant viewed a study of a drug for paranoid schizophrenia as higher risk, "But you'd be in a program, and you know, they gotta watch you night and day because you're taking pills and they want to see how you act, how you're doing …" Even though several respondents indicated discomfort with participation in psychotropic drug studies, the perception of monitoring appeared to provide some control over the risks of these medication studies.

When the hypothetical scenarios were presented as not providing any healthcare for research injury, interviewees sometimes expressed mistrust or resentment. This mistrust appeared to be rooted in the perception that researchers were not fulfilling their obligations to the participants as well as a misunderstanding of the research process:

> I wouldn't do this (medication) study at all … Because it's like they won't give you any medical care. I mean, like what if you have a side-effect or anything? They're not going to give you any pills. And then they don't know who took what drug until the end of the program. That wouldn't be something I'd want to be in. That's like a health risk or something. Hmm-mm. I wouldn't trust that.

Participants also expressed concern if they believed health information obtained in the course of a study, but unrelated to study data, would be withheld:

> When they say the people who take part in this study will not receive any other tests or treatments except for – so if there's something wrong – if they find something within the medical examination, are they going to treat it or they say they not going to treat it? … Because if I'm doing this study for them and they've given me all these drugs and they gave me a medical examination, maybe I haven't had one in a while and if they find something, I would appreciate it if they told me even though it's not a part of their study. They don't have to take care of the problem, just let me know that they seen the problem.

Whether this participant's concerns were rooted in a belief that the scientific goals of the study would take precedence over one's health or that the medical system in general is not to be trusted was not clear. The statement does imply, however, that informing the participant of an observed, though unrelated health problem would demonstrate an acknowledgement of the person and his or her contribution to the research study.

Overall, interviewees expressed views that medical exams and diagnostic tests provided as part of the hypothetical study scenarios were a benefit of research participation. Medical care provided within the study was also perceived as a means of monitoring the reactions of the participant to the study and controlling for risks. The lack of provision of healthcare resulting from injury within a study or the possible withholding of pertinent health information were viewed as concerns, both in terms of fairness and risk of physical harm.

Participant control in choosing and declining participation

Participants demonstrated the ability to exert control in research situations. Some participants controlled their time in the interview, either by making a polite excuse prior to the start of the interview or when an offer to stop was made by the interviewer once 30 minutes had passed. One participant, when asked if he would like to return for a second interview, asked for the interviewer's business card instead of answering directly.

Another participant believed a harmful study medication could be recognized, avoided and refused:

> It (the study medication) could cause you harm. But you ought to be able to tell. You know, you take the medicine, that it's doing you harm and tell whoever's in charge of it, I'm not going to take this anymore. Because your body is going to tell. You know, when I take it, it makes me feel like this, and when I don't take it, I don't feel like that … so you'll know if the medicine is making a difference or, you know, by the way you feel.

Another interviewee related the story of a friend who participated in a smoking study that she said neither of them understood:

> And I [the interviewee] don't even understand that one [the smoking study]. It was over in the Medical Center. But she [the acquaintance] didn't even finish that study … Because she wasn't too clear on what really was going on. What they was trying to get from her. So she just stopped.

Participants were asked about whether a family member or physician might influence their decision to participate in a research study. Some agreed that others might have an influence: "If a doctor told me, I would really go for it. I think, you know, I would trust his decision, his look at it. Family member, maybe, maybe. Yeah." A strong desire to decide for oneself was expressed by others. When asked if his doctor or a friend might influence his decision to participate in a study, this individual replied: "Right. I mean, I can picture myself already telling them, 'Okay, I'm thinking that's something I would look into', and in actuality never doing it."

Another interviewee was asked specifically about the influence of the outreach worker for the primary HIV prevention studies, who was highly-respected by many of the interviewees:

> A: No, no. No, it wouldn't make a difference in the person.
>
> Q: Or sometimes a doctor might ask you to participate in the study.
>
> A: No, I don't think it would make a difference. I think it could be my mother saying the same thing and probably my answer would be the same.

Participants exhibited control in choosing, declining or stopping participation in research situations. Reasons for withdrawing from studies included personal time limits, perception of physical harm and lack of adequate information about study procedures. Most participants viewed the decision to participate or decline participation as their own.

Discussion

Participants reported a variety of influences on decisions to participate in research, many of which have already been noted, primarily in studies of participation in HIV vaccine trials. In addition, decisions about participation were characterized by a tendency to seek information about a study; skepticism and mistrust of research and researchers; expectations that medical care and monitoring would be available during participation; and rejection or discontinuation of participation in a study if one was uneasy about it. These data expand upon some of the

findings of previous studies in the identification of African American attitudes, beliefs and barriers to participating in HIV-related research and research in general.

Economically-disadvantaged African Americans are often viewed as “vulnerable” research participants who require increased regulatory protections because of their presumed limited educational background that may interfere with their ability to provide informed consent; their economic position that implies undue susceptibility to offers of money and healthcare to participate in research; and their history of research abuse (Stone, 2003). Participants in this study did not demonstrate a passiveness toward research participation that such a view of vulnerability implies. Most participants’ desired information about a study and some perceived a claim to that information as a condition of participating and as acknowledgment of their contribution to the study. Participants wanted information even if they might not understand it and voiced concerns about whether all information related to a study would be provided.

Inadequate provision of information and lack of healthcare monitoring were related to perceptions of mistrust of research and researchers. While African Americans’ mistrust of healthcare and research is often attributed to the Tuskegee Syphilis Study, Gamble (1997) notes that this mistrust is rooted in more pervasive racism, occurring from the time of slavery when African Americans were non-consenting experimental subjects, to the present day of persisting disparities in access to high-quality healthcare. Some participants, familiar with clinical research, viewed healthcare and monitoring within a study as an expected part of research. Participants tended to believe, rightly or wrongly, that monitoring controlled some of the risks of research. They appeared less concerned about gaining access to healthcare through participating in research than in being monitored for adverse effects during a study, a view that could be attributed to knowledge of the healthcare “safety net” for the poor and availability of federal funds for treating individuals with HIV/AIDS.

Misunderstanding of drug abuse research could help to foster mistrust and conspiracy theories, as suggested by one participant’s perception of a crack cocaine study. Procedures for the conduct of ethical drug abuse research are well-known among investigators (College on Problems of Drug Dependence, 1995), but not the public. Public perceptions of HIV and drug abuse research are areas for further investigation.

Participants also described instances of themselves and others exerting control by declining participation or withdrawing from research studies. A desire for information and the ability to control one’s participation may suggest that participants who are skeptical or mistrustful about aspects of a research study may be more likely to ask for information or to walk away from the process if their needs are not met.

Limitations of this study are noted elsewhere (Slomka et al., 2007). They include the potential for selection bias involved in recruiting participants from on-going studies and a resulting inability to generalize to other populations. Participants in our study may have been more sophisticated in regard to healthcare and medical research than in other cities and regions of the country. The Texas Medical Center, a large consortium of institutions involved in healthcare, research and education, dominates the health scene in Houston, Texas and opportunities to participate in research studies are available.

The recruiting of participants only for a study may introduce bias because participants may differ in important ways from non-participants. But eliciting views of individuals who choose participation may be valuable to enable the design of future studies that will accommodate participant preferences and promote enrollment and retention (Halpern, 2002). Decisions to participate based on hypothetical scenarios are generally considered to be problematic in predicting actual research participation. However, Halpern, Metzger, Berlin and Ubel (2001) showed that those who were willing to participate in a hypothetical HIV vaccine study were

likely to enroll in the actual study. Our study investigated broad questions of participants' perceptions of research and decision making surrounding participation, rather than the specific question of willingness to participate. Therefore, we explored participants' views whether they related to the hypothetical scenarios, to their own experiences or to their knowledge of others' experiences.

Practical methods have been suggested for enhancing research participation of underserved minority populations by addressing potential participants' needs and concerns (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; El-Sadr & Capps, 1992). Our study described a population of "vulnerable" participants who had a fairly good knowledge of their needs and rights as research participants. Our study also demonstrated that meanings inherent in the provision of information and healthcare within a research study relate to trust and mistrust. An implication for health professionals in the research setting is that information provided during the consent process alone may be less effective in promoting enrollment and adherence than continuous information and communication during a study. Continued attention to individuals' perceptions and meanings associated with research decision making will help to enhance participation of minorities in research and enable those with HIV/AIDS to obtain optimal benefit from participation in research.

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