Perceptions of Financial Payment for Research Participation among African-American Drug Users in HIV Studies

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BACKGROUND: Financial compensation for participating in research is controversial, especially when participants are recruited from economically disadvantaged and/or marginalized populations such as drug users. Little is known about these participants' own views regarding payment for research participation.

OBJECTIVE: The objective of the study was to elicit underserved minority drug users' views about monetary payments for participating in research.

DESIGN: Semi-structured in-depth interview study of motivations for and perceptions of participation in research was used.

PARTICIPANTS: Thirty-seven adult, economically disadvantaged African-American crack cocaine smokers were the participants of the study.

APPROACH: Participants were recruited from among those taking part in three HIV prevention studies. Interviews were conducted at one of 2 research field offices located in underserved minority neighborhoods in Houston, Texas. Interviews lasting 30–45 min were recorded, transcribed, coded, and analyzed for categories and themes using both conventional and directed qualitative content analysis. This report addresses themes under the broad category of financial motivations for participating in research.

RESULTS: Participants viewed monetary payment for research as essential to attract participation and desirable to provide optional income. Payment for research participation was perceived as one potential income source among others. Participants considered self-determination a prerogative for themselves and others. They rejected the notion of payment for participation as encouraging drug use or as inducing risk taking.

CONCLUSIONS: Research regulators should consider participants' views of their desires and capacity for autonomous decisions about financial compensation for research rather than assume participants' diminished capacity due to poverty and/or drug use. Payment for research participation appears to be part of the "informal economy" that has been observed in underserved communities.

KEY WORDS: undue inducement; drug use; HIV/AIDS; underserved minorities; ethics of payment for research.

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INTRODUCTION

The offer of financial compensation is often used to recruit individuals to participate in research studies; yet the concept, method, and amount of payment to research participants remain controversial.^{1–11} Some writers argue that financial compensation for research should be avoided except under very limited circumstances.^{4,9} In practice, however, payment for participating in research is widespread, although researchers and Institutional Review Boards (IRBs) have yet to agree on the process and appropriate levels of payment.¹²

Little empirical information is available about the effects of financial compensation on research participation for individuals from low-income, uninsured, or marginal populations, such as those engaging in illicit drug use and/or at risk for HIV/AIDS. Such populations have been a focus of ethical concern because of perceptions that payment for their inclusion in research may make them vulnerable to excessive risk taking and exploitation, whereas their exclusion may deprive them of the benefits of research participation.^{13,14} This paper examines the views of economically disadvantaged African-American drug users participating in HIV prevention research. Participants' views about financial compensation for research participation can inform recruitment practices for research studies that have the potential for improving the prevention and treatment of HIV/AIDS and drug use in this population.

BACKGROUND

Ethical concerns about paying individuals to participate in research have focused on "undue inducement," defined as the provision of positive incentives at levels high enough to undermine potential participants' ability to act in their own best interests, thereby resulting in a risk of serious harm to individuals.¹⁵ Emanuel¹⁵ argues that even very large monetary payments to research participants are not "undue inducement" because adequate administrative ethical review of studies will preclude serious harms when participants are compensated according to market value. Others¹⁶ suggest that payment for research participation at the level of unskilled

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labor would obviate undue inducement by including paid research participation as one opportunity among others to obtain comparable wages. Research payment comparable to wages for unskilled labor might also increase the likelihood that individuals would choose research participation voluntarily and not simply for financial gain.¹⁶

Questions about the role of payment in enabling drug users' addictive and illegal behaviors have been noted, but not subjected to rigorous investigation.^{17,18} One recent study demonstrated that different levels of cash incentives to encourage research follow-up did not affect the rate of new drug use among participants in several substance abuse treatment programs.¹⁹ Furthermore, moderate financial incentives appear to be effective for recruiting drug users in health education projects¹⁷ and preventive research.²⁰

Research on payment to participants in other research populations has illuminated several aspects of the controversy. Money increased participants' willingness to participate in hypothetical research studies, but higher payment levels did not change perceptions of risks of harm.^{21,22} Higher payment levels had a greater influence on wealthy participants' agreement to participate in hypothetical research than on those of poorer participants.²¹ As well, increased monetary payments influenced participants to conceal low-risk information from investigators, but such concealment was considered less detrimental to the research participant than to the scientific integrity of the research.²²

Research participants themselves vary in their opinions about financial compensation for participation. For example, in a survey examining willingness to participate in a vaccine trial, less than half of the participants desired financial compensation, believing that payment could increase costs of research and introduce bias.²³ In a study of healthy participants' responses to a hypothetical hypertension clinical trial, respondents believed that large financial compensation would not prevent their consideration of research risks and that monetary rewards would induce others more so than themselves.²⁴ The populations in these studies had relatively high socioeconomic and educational levels. It is unknown whether the results apply equally to economically disadvantaged or marginal populations.

METHODS

Design. Semi-structured in-depth interviews were conducted to elicit participants' views of research and motivations for participation. Forty-one participants were recruited from 3 concurrent studies of African-American crack cocaine users, with or at risk for HIV infection. Two parent studies tested educational interventions to prevent HIV; the third provided hepatitis vaccination as a model for an HIV vaccine study. Of 41 interviews, 4 were excluded for methodological or technical reasons, leaving 37 for analysis. This study was approved by the IRB of the University of Texas Health Science Center at Houston. To enhance confidentiality, participants were given an informational letter in lieu of a signed consent.

Setting/Population. Participants were adult African-American drug users from parent studies who had given prior consent to

be contacted. Participants were drawn from two urban neighborhoods with large numbers of economically disadvantaged African-Americans. Interviews were conducted at 1 of 2 field offices designed for the parent projects. Demographic and population characteristics are listed in Table 1.

Focus of Interviews. Participants were questioned about their perceptions of research and attitudes and motivations for participating in research studies. Depending on time constraints, 2 or 3 hypothetical research scenarios were used to prompt specific discussion about perceptions of risks, benefits, inconveniences, appropriate levels of financial compensation, and additional information desired to inform decisions to participate.^{21,24,25} Summaries of scenarios are found in Table 2.

Data Collection. Interviews were conducted over a 3-mo period, between February and May 2006. To ensure consistency, all interviews were conducted by a single investigator (JS). General questions guided the interviews and "probe" questions (Can you say more about that?) were used to explore and cross-check new information and encourage participant elaboration.²⁸ Interviewees were paid \$20 for their time and travel costs. Interviews lasted 30–45 min and were audio-recorded and transcribed.

Table 1. Demographic and Population Characteristics^a

Age (years)	Range 22 to 53; median 40	Sex	Male Female	N 20 17	% 54 46
Education (years)	N	%	Monthly Income	N	%
7-9	7	19	None	5	14
10-11	8	22	<\$200	7	19
12	17	46	\$200-399	10	27
13-16	4	11	\$400-599	7	19
Housing			>\$600	7	19
Own house or apartment	13	35	Major sources of income		
Someone else's house or apartment	20	54	Jobs	6	16
Other (shelter, "on the streets or temporary housing)	3	8	Disability; public assistance	9	24
Considers oneself 'homeless'	7	19	Money from spouse, partner, family, friends	7	19
Employment			Trade sex for money	4	11
Unemployed	21	57	Illegal source of income	1	3
Unable to work due to disability	6	16	No major source of income	5	14
Regular full-time work	2	5	Other	4	11
Regular part-time work	3	8			
Other	4	11			

^aData on education, housing, homelessness, employment, monthly income and source of income were missing for 1 participant. Percentages do not add up to 100 due to rounding.

Table 2. Summaries of Hypothetical Study Scenarios

Research study	Summary
Study of sleep disturbances and stress	A one-time survey that takes approximately 90 min to complete. Participants are asked to complete 4 questionnaires measuring their present amount of stress; the amount of support from family, friends, a partner or health care professionals; the amount of pain they might be having; and their sleep habits. Investigators also obtain drug screening test results from the participant's medical record. (Based on a published study). ²⁶
Medication study	A randomized, double-blind, controlled trial of a new drug. The new drug plus standard treatment is compared against a placebo plus standard treatment. The study lasts for 3 mo. Participants receive a medical examination including chest X-ray, EKG and blood tests at the beginning and at the end of the study. Participants are required to attend a clinic appointment once a week during the study period.
HIV vaccine trial	A randomized, double-blind, controlled trial of an HIV vaccine with placebo control. Participants are recruited from those who are HIV-negative and at high risk for HIV infection, based on initial screening. The study lasts 12 mo. Participants receive a medical examination including chest X-ray, EKG and blood tests at the beginning and at the end of the study, and report for a clinic visit and blood test once a month. The possibility of decreased immunity, false positive HIV tests and protection from infection if the vaccine works (for those who receive the vaccine) are included in the scenario. (Based on a published study). ²⁷

Analysis. A single investigator (JS) coded and analyzed the data for thematic patterns using a combination of conventional content analysis, which derives categories from the data, and directed content analysis, which uses preexisting theoretical categories for analysis.²⁹ Individual data segments consisting of an idea or theme embedded in the text of a word, phrase, or narrative were coded and grouped under larger categories. Data segments relating to large thematic categories were further analyzed for subthemes.

Quality and credibility of data were established through rigorous and continuous review of tapes and transcripts to critique and improve interview methods and interpret the interviewer's effect on participants' responses. Trustworthiness of data was also verified through an interviewer assessment of participants' motives for providing information. Concepts and emerging data patterns were continuously cross-checked within and across interviews to confirm or negate participants' statements.^{28,30,31,32} A second investigator (EAR) reviewed the transcripts to identify competing or alternative interpretations.³³ All investigators participated in reviewing and refining data interpretation and analysis. Differences were minor, and discrepancies were negotiated to achieve agreement.

RESULTS

In examining participants' perceptions of financial compensation for participating in research, four themes were identified: (1) financial compensation as a prerequisite for research participation; (2) ethics of payments to impoverished drug

users; (3) research income as an aid to economic survival; and (4) poverty, drug use, and risks of everyday life.

Financial Compensation as a Prerequisite for Research Participation

All participants agreed in general with the provision of money for participating in research. No one declined financial compensation for participating in the study interviews. Several individuals noted that financial aspects were secondary to the educational benefits they believed they were receiving from HIV prevention studies, although they were initially attracted by the offer of money. A few also stated that research participants should not receive compensation for their participation because they were already benefiting by learning about drug use and HIV/AIDS risk. In general, money was seen by interviewees as a necessary incentive to attract research participants and as extra income for people in need (Table 3a,b,c).

Interviewees were open and explicit about their expectations and need for payment for participating in research. The belief that people are motivated by economic incentives was frequently expressed. For example, one interviewee observed that "A lot of these people come in just for the money. They don't give a damn about your research. I'm just putting it out there like it is." Another respondent advised telling potential participants about compensation immediately "...Because a lot of people won't even sit and listen to what you've got to say if you don't give them an amount up front."

In response to questions about monetary influences on risk assessment, some respondents said they would participate in a study if the price was right in spite of the risks, whereas others said they would decline certain risky studies no matter what amount of money was offered. Most respondents viewed the \$20 payment for participation in this and other behavioral research projects as an appropriate amount, whereas some suggested higher payment, comparing the use of their time to a day's pay at minimum wage. For the three hypothetical research scenar-

Table 3. Examples of Theme "Financial Compensation as a Prerequisite for Research Participation"

Examples	
a	(Money is) what first hit the mind. I say, well, let me go see. Because you know you want money, you need money, you're finding money...like me, I have four kids. I'm a single parent, and I just be needing money or something, you know, something extra. It always goes for something, so it brings the people to you and draws their attention.
b	But you're going to need some people to do it (research). And you won't maybe get as many as you would just volunteering. Because most people that do these things, research and stuff, need money. They're either homeless or you know, they need some financial help. You know—I have me a nice home, new books or whatever. Drive a Mercedes. Research. I don't know, research for what? Not me. You know, that's a hobby.
c	That's not enough money (\$5) to do nothing with, you know? Maybe ride a bus. Well, you could do that, maybe come in for some change or something like that. But you won't have your turnout like you want it, unless you have about \$20. And if it is a drug addict, he ain't going to do it for \$5. I mean—he wants some drugs. He wants to get \$20 and \$5 ain't getting it, you can't do nothing with that; \$10 would probably. But \$20, he can get him some beer, cigarettes and the dope.

Table 4. Examples of Theme of "Ethics of Payments to Impoverished Drug Users"

Examples	
a	Because, see, to me it's not using them (drug users) because it goes both ways. They say you're using them but they using you all too because they don't give a damn....Some of them don't care. They just doing it for the money. So they can't say that. It goes both ways....That's just like calling them a guinea pig. You paying them to be their guinea pig, so why be a broke guinea pig?
b	I think you are using people to get what you want. They're using you to get what they want. Because if you (the researchers) didn't have no money, they ain't going to do this (participate in research)....They're not going to—they don't care about your pills. They don't care about the EKG. I just want the money. So if you want to pay me to do your thing, give me your money. And if I don't feel like—I'm giving you my body, see? And if I don't feel like doing it then, I won't do it. Okay? That's how it is. So I think a fair exchange is no robbery.
c	...it's not only helping the one that's receiving the money, it's helping the ones that's issuing the money too...Because in order for y'all—y'all got to do something. It's a job, you know. So y'all got to search for whatever it is y'all are seeking for out there through us. And by y'all doing that, we get paid....it's good for both. If you don't do your research through a participant, you don't have a job. So you know, you got to survive too. So it goes both ways.
d	You're not encouraging me to go do no drugs. Because it's up to me whether I do them or not, with or without money. Like I say, people can know people out there in the street, don't have to spend not one thin dime on drugs...if a person's going to get high, they're going to get high anyway. Whether you give them money or not....There's not no 'enticing' to me. I'm not going to let you entice me into doing nothing. No way. I'm 40 years old. You know. And to me, if a person say, "Oh she enticed him to do that," (he) already wanted to do that anyway. He already wanted to do it so—that's just an excuse to say that person did it. That other person didn't do nothing. That was just his green light. That's all it was.

ios, those who perceived risks tended to view higher payments as appropriate compensation for increased risk.

Payment of \$20 was considered a minimum amount because less money would be a "waste of time" and compete with other income sources. Also, most interviewees believed that drug users with access to money were likely to use it to purchase street drugs. Based on this assumption, a number of participants believed that \$10, the minimum needed for a drug purchase, would be necessary to attract participants. Although some participants believed that drug users would accept compensation as low as \$5, payment in the amount of \$20 generally was considered appropriate: even if one did buy street drugs with the money, enough would remain for the purchase of necessities or luxury items. Whether or not they used the money for street drugs, a payment as little as \$5 or \$10 was considered ineffective as a recruitment incentive and unfair to research participants:

Ethics of Payments to Impoverished Drug Users

When asked to comment about concerns some researchers and IRBs have about "exploiting" or "using" impoverished drug users by paying them for research participation, interviewees expressed several different opinions. Some felt that both parties, researchers and participants, were using each other (a and b in Table 4). Others believed that if they were being "used" by investigators, it was to their advantage, given the

extra income and other benefits of research participation. Faced with the everyday reality of unemployment or lacking a consistent source of income, interviewees expressed views similar to one respondent who remarked, "Nowadays you got to do what you got to do to survive." This person viewed research as a "good thing...because they're helping you and you're helping them." Another participant opined that offering money for taking part in research was not exploitation because researchers also need to do their job to survive (c in Table 4). Other participants disagreed with the notion of exploitation, saying "I have a choice to say no," and by noting that people cannot be exploited against their will. One participant explained, "If you feel like you've been taken advantage of, don't do it. It's just that simple, you know. If I felt like I had been taken advantage of, I wouldn't have even come down anyway...."

Another issue of ethical concern for some researchers and IRBs is that monetary compensation for drug-using research participants would encourage them to use the money to purchase more illicit drugs or delay stopping drug use. While participants typically assumed that drug users with money would spend at least some of it on drugs, they disagreed with the premise that payment for research participation would encourage further drug use. Participants believed that drug users who take part in research should be paid. Money was not an incentive to use drugs because individuals could obtain drugs without money (d in Table 4). Respondents noted that "...you can't tell them what to use it (the money) for...what they do with it you have no control over that...you can't say if it's wrong or right because you don't know what they're going to do with the money." Overall, participants viewed themselves and others as free agents capable of determining for themselves the most appropriate ways to use money obtained as compensation for research participation.

To explore participants' views of "undue inducement", participants were asked about pharmaceutical companies or others willing to pay large sums for research participation. Interviewees viewed the offer of large amounts of financial compensation in different ways. According to some respondents, large financial incentives might raise questions for potential research participants about whether all the risks of a study were being disclosed. Others believed that if a large amount of money was offered, individuals would be more likely to provide false information to investigators and "say anything" to obtain the money. However, for minimal risk public health research, participants were concerned that relatively large payments for research participation (e.g., \$50 or \$100 instead of the usual \$20) would attract too many people, and "chaos" would ensue. One interviewee remarked that a \$50 payment should be the limit "So it won't be so hectic out there." Others remarked, "Y'all would have a line out the door" of people willing to participate in the research. Another predicted: "Yeah, well you'll have fights out there and everything...Or it would be big confusion out there...." Participants perceived appropriate levels of compensation as proportional to the study's level of risk of harm or inconvenience.

Research Income as an Aid to Economic Survival

According to interviewees, people continuously search for money for daily living expenses. Participation in research is one venue for obtaining needed cash to ensure everyday

survival (a in Table 5). One participant reiterated this view when asked about the sleep disturbance research scenario and whether people should be invited to participate in it without financial compensation. He replied that "...I'm trying to find not so much a hustle of some sort, but just some way to make money and keep it generating. So I'd be looking for that, and I'd overlook this (research study) if it were free." In regard to unpaid research participation, another person noted, "Why should I? I could be doing something else to try and make some money...."

Spending on drugs was considered secondary if a person needed food or if he or she had others depending on him or her. For example, when asked how they would spend the \$20 payment for their interview, some participants said they might spend part on drugs at a later time, but most replied that they would go immediately to a fast food restaurant or grocery store. As one interviewee said, "It's not drugs that was the first thing went in my mind. Closest thing on my mind was getting a hamburger or something." One woman explained that necessities such as food for her children and gasoline for their car would take priority over drug use (b in Table 5). Another

explained her decision to participate in a clinical trial for \$1500 was motivated by the need to pay household bills out of concern for her children (c in Table 5). During the latter clinical trial, this interviewee described another woman who had also enrolled in the drug study. According to the participant, the woman was employed, but had enrolled in the clinical trial to obtain extra cash for a rental deposit (d in Table 5).

For those with serious and chronic financial need, monetary compensation for research participation can be an important source of income for basic necessities and used only secondarily for drugs. Higher amounts of compensation for the so-called "underemployed" could make the difference between the independence of being able to rent one's own apartment or having to rely on others for housing. The stresses of being dependent upon relatives, the dangers of living 'on the street', and the cultural value of independence are other risks and benefits that are likely to be weighed against risk of research harm in decisions to participate in compensated clinical trials.

Poverty, Drug Use, and Risks of Everyday Life

Participants often referred to the difficulty of their lives. Many perceived drug use as a reaction to the stresses of poverty and the dangers of life in their neighborhoods. Accepting financial compensation for participation in research was viewed as an honest way to obtain income (a in Table 6). As one person put it, "...you're doing something honest. So you're out there doing some all kinds of stuff. So you see something that can benefit you and keep you out of harm's way, more power to you, right?" Another interviewee explained that for drug users desperately in need of a 'high', payment for research can provide income that might deter illegal efforts at gaining money (b in Table 6).

Table 5. Examples of Theme "Research Income as an Aid to Economic Survival"

Examples	
a	...a lot of people looking for the money. It's all about the money. A quick, fast hustle. You got a lot of people out here, they looking for things like this. That's how they make it. You know, they look up for things like this (research) every day. "Oh, I got to go over here tomorrow. I'm going to get \$30 from them. Yesterday I went over here. I got \$20 from them. Today I'm fixing to go get \$50." You know, that's how they make it.
b	...right now I'm on a 1/4 of a tank...Gas is three dollars a gallon.... And I stay all the way on the other side of town. So that (\$20) could fill my tank....I won't go to work until probably tomorrow night. So that means I don't have no money today. I got to pick up the kids from school. What if they hungry? I hate to say "Well, Mama don't have no money to get you nothing to eat....I look at it like this here, I may use drugs but every dime that I get my money (hands) on I can't put it on the drugs. I got other responsibilities and I do have that much sense to know....I can't do that....I got two children that look up to me and I can't fall or let them see me fail because then they not going to have nothing to live for or to work for. What they going to want out of life?...
c	But see, at the time when I did it (participated in a clinical trial), I was like, behind on my rent and my electric was due, and I had all these bills plus I have the kids. And I kept thinking, where can I get this money? I couldn't go to my family and borrow because I had already done that prior, the month before....I was scared (of the research), but I didn't know what I was going into, so it wasn't really as scary feeling at the time....It was really the money on my mind, getting these bills paid and that. These kids, I can't be on the street with them, so it made me go in....I'm willing to take that break-out (referring to a risk of skin rash from the trial drug) for them, even though I was on drugs, and when you have a drug habit, my kids will be the ones that break me down and say, you know what, it's time for me to chill out this time.
d	...I met one girl (also participating in the clinical trial). She wasn't on drugs. She didn't do anything. Sweet little girl, you know...they let her bring her baby because she only had one baby. She had just had a baby. And she was staying with her mom and her stepdad, and she just wanted to do it to get the money to try and get her own house and try to get herself together. And she had a little job and everything, but she just needed that extra boost. To help her get that deposit and rent. You know what I'm saying, go girl, that's good. You know, it's helping you....

Table 6. Examples of Theme "Poverty, Drug Use and Risks of Everyday Life"

Examples	
a	Everybody's trying to survive. So it's good y'all have this here (research) going on. It's helping a whole lot of people. Help a whole lot of people from doing wrong or whatever because they know they can get something out of it. So that's a blessing.
b	They ain't going to try to rob somebody, try to kill somebody for a little \$20 or \$30 that you know research will give them. I mean, they feel like they have somewhere to come to when they to their last...to their last point, you know where they don't know where they going to get the money, and they itch (for drugs) and they just got to get it. Oh, they think about the research. Let me go see if I can go and do a study or something and get the money. It's a better thing than going out, trying to rob somebody, take they purse or do anything else. You can come here and say, well, I'm going to the research and I'll get the money and go ahead and get my high.
c	They (research participants) got food, they got sleep, they got baths, they got clothes. And three weeks they stayed out (in hospital for a clinical trial), and then when they got out they got twenty-three, twenty-four hundred dollars. So how can you beat that? When you leave they take you to go cash the check, put the money in your hand...The same thing, it's like you spend 23, 24 days in jail. You're going to get out of there with nothing. This, you're getting out of there with something and you're sitting back watching T.V., just taking pills three times a day. People just watch you and see how you act, and this and that. I seen people that talk about it. I've seen that.

In addition to helping individuals avoid the risks inherent in criminal activity, payment for research participation can affect other risks of everyday life that indigent drug users face. One such risk is the possible necessity to trade sex for drugs, an exchange that increases the risk of sexually transmitted infection. Another risk faced by drug users is incarceration related to illicit drug use. When asked if a large sum might preclude consideration of research risks, one interviewee compared participation in a clinical trial with incarceration. He perceived that an on-site clinical trial was superior to prison not only because of the food and clothing provided but because the participant received financial compensation (c in Table 6). These participants viewed participation in research as having both economic benefits, in the form of monetary payment, and social benefits, in the form of obviating certain antisocial behaviors.

DISCUSSION

Participants in our study viewed payment for participating in research as essential to attract individuals to a study. Some participants expressed values of altruism in research, but most saw paid participation simply as another means of pursuing their livelihood. This finding suggests that impoverished individuals may not share the same values of those who promote volunteerism as the foundation for research participation. Our data suggest that economically disadvantaged individuals are unlikely to participate in research for altruistic motives alone if they have an alternative way of making money.

This study has limitations. Many participants were unfamiliar with actual clinical research participation and may have based comments about higher risk clinical research scenarios on perceptions rather than actual experience. Some respondents appeared to make socially acceptable statements or to present careful responses to the interviewer who differed in ethnicity, education, and socioeconomic level. Because participants were paid and desired payment for research, we reasoned that it would be unlikely that they would speak out against payment for research participation, a potential bias in the study. On the other hand, the transcripts included numerous contrary examples in which participants expressed negative sentiments such as cynicism and mistrust of research and researchers. The occurrence of sufficient participant statements that were negative or critical suggests that most participants spoke freely and did not feel constrained. In future studies, the possibility of bias or distortion in participants' responses could be minimized with repeated interviews over time.³⁴

In spite of limiting generalizability, a convenience sample was used because of difficulties in recruiting and following economically disadvantaged drug users who may have lacked a home, phone, or permanent address. We could not reach those who declined participation, nor avoid selection bias in recruiting participants who may have been favorably disposed to research participation; some who may have misconceived the research as a means of obtaining help for their drug use or health problems; and all of whom expected to obtain \$20 for their participation.

Because our study proposed to examine motivations for participating in research, we recruited individuals whose

perspectives would be informed by actual research participation. These kinds of studies—research on the research process itself—are becoming more widespread. Methodological problems of “piggybacking” an investigation of research processes onto ongoing research studies have been recognized.^{35,36} While participants' favorable attitudes toward the parent programs may have been a source of bias, such attitudes may also have facilitated the scope of experiences shared by participants who entered the study with a high comfort level.

Two aspects of our study contribute new knowledge to the sparse empirical literature on financial compensation for research participation in this population. First, in spite of their drug use, many respondents had a clear vision of themselves as autonomous individuals. Rather than providing a picture of an out-of-control addiction, several drug users described their use as manageable, e.g., using drugs only on the weekends or saving money to buy food for children. Participants' use of drugs on any given day appeared to be based primarily on contextual factors rather than on monetary payment for research participation.

The notion that paying participants for research participation would encourage their drug use or take advantage of them was unacceptable to most participants. Respondents stated that *other* drug users enrolled in research to obtain money for drug purchases, but none stated explicitly that they themselves would not use compensation to buy drugs. Even if the purchase of drugs was a primary motive for participating in research, autonomy was a larger issue for these participants. They rejected stereotypical views of themselves as unable to exert control over their behavior because of their drug use and/or desire for money. Our study suggests that research regulators should consider impoverished drug users' own views about their desires and capacity for autonomous decisions to participate in paid research and not assume that participants have diminished capacity or vulnerability to undue inducement resulting from poverty and/or drug use. Participants described themselves both as capable of acting in their own interests and as having the prerogative for decision making in regard to paid research participation.

A second contribution is the observation that payment for research participation appears to be a part of the “informal economy” in economically disadvantaged communities. The informal economy includes a variety of economic transactions that reside outside traditional employment as a means for obtaining a livelihood.³⁷ It includes legal transactions (e.g., odd jobs for pay), illegal ones (e.g., drug dealing, prostitution—referred to by some^{38,39} as the “underground economy”) and systems of barter.³⁸ Interviewees viewed participating in research as an alternative to other riskier ways of making money. The perception of everyday risks in this economy may provide a yardstick for assessing research risk from the perspective of economically disadvantaged drug users. When individuals in high-crime neighborhoods assess the risks and possible indignities of having to sell one's body for drugs and/or food and the prospect of having to serve time in a degrading and dangerous prison system, they may conclude that the “risks” of participation in a clinical trial are not all that great.

This observation suggests that participants from disadvantaged populations are “rational” and assess the various trade offs involved in making economic decisions. As such, the decision to participate in research may represent a comparatively lower level of risk, as well as an accompanying benefit of

financial gain. Some would argue that participants' risk-benefit assessments should not be considered in determining the risk-benefit ratio of a study. We suggest that while participants' perspectives may not be the sole determination, an understanding of participant views is an essential component of any dialogue about risk and benefit in research.

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