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ETHICAL ISSUES IN RESEARCH WITH HISPANIC DRUG USERS: PARTICIPANT PERSPECTIVES ON RISKS AND BENEFITS

MERRILL SINGER, GREG MIRHEJ, DERRICK HODGE, HASSAN SALEHEEN, CELIA B. FISHER, MEENA MAHADEVAN

There has been considerable discussion in the research ethics literature concerning special researcher responsibilities in studying vulnerable populations, including whether or not drug addicts, as a result of their health condition and craving for drugs, constitute a vulnerable group from a human subject perspective. In the assessment of ethical issues, researchers in recent years have begun to recognize the critical importance of hearing the subject's voice and learning the concerns and attitudes of those who participate in research. To date, however, despite a significant increase in studies of not-in-treatment drug users, little attempt has been made to determine the perspectives of drug users about participation in research, especially ethnic minority drug users, and in particular, Hispanic drug users. Based on recent findings of a study of drug user attitudes and perspectives on research, this paper reports on the perceived risks and benefits of participation in research of a subsample of Hispanic street drug users from Hartford, Connecticut

INTRODUCTION

Pervasive inequalities, cultural differences, and significant dissimilarities in experience separate researchers from research subjects (Gold 2003; Hoeyer, Dahlager, & Lynøe, 2005; Marshall, 2005; Turner, 2005). These distinctions raise important

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questions about how issues like communication, trust, inclusion, and coercion impact research relationships, the quality of data collection, and the consequences of involvement in research on study participants and their respective communities (Alvidrez & Arean, 2002; Armstrong, Crum, Rieger, Bennett, & Edwards, 1999; Freimuth et al., 2001; Molyneux, Peshu, & Marsh, 2005). While researchers have been active in the discussion of these issues, as Molyneux et al. (2005, p. 443) emphasize, "The voices of the people likely to be the subjects of research have been notably absent from the debate." Only in recent years have researchers begun to examine the views, attitudes, and concerns of prospective participants toward involvement in research (Brody, Gluck, & Aragon, 1997; Fisher, 2002; Fisher & Fyrberg, 1994; Fisher, Higgins-D'Allesandro, Rau, Kuther, & Belanger, 1996; Fisher & Wallace, 2000; Roberts, Warner, & Brody, 2000; Sugarman et al., 1998). While progress has been made in the inclusion of participant perspectives in research on cancer, aging, and several other health-related issues, much of this research has focused on White middle class participants. To the degree that ethnic minorities have been included in such research, the emphasis has been on assessing the attitudes toward and understandings of research among African Americans (most notably in light of the Tuskegee syphilis study), with relatively little examination of perspectives on research participation among Hispanics (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Napoles-Springer et al., 2002; Robinson, Ashley, & Haynes, 1996; Sengupta et al., 2000).

While research on drug use began during the 1930s, efforts were limited until the 1960s and 1970s, and it was only with a significant rise in funding in the late 1980s and early 1990s, primarily as a result of the AIDS epidemic, that the study of active, not-in-treatment drug users was fully established as an important domain of scientific investigation (Singer, 1999). Although a considerable body of research into causes, consequences, patterns, trends, risks, prevention, and treatment of drug use and abuse has accumulated over the last 25 years, despite important ethical issues raised in this research (Fry, Hall, Ritter, & Jenkinson, 2006; Kleinig & Einstein, 2006) most of this work proceeded without much direct input from drug users about their views of costs and benefits of research involvement, their reasons and motivations for research participation, and the nature and quality of their experiences as research subjects (Barratt, Norman, & Fry, in press; Fry & Dwyer, 2001). Of special importance in this regard are the particularly silent voices of minority drug users, a result of the triple burden of class location, socially devalued ethnic identities, and demonization as illicit drug consumers (Wright, Klee, & Reid, 1998). Those who also are infected with HIV/AIDS face a quadruple burden of social marginalization because of disease stigmatization. The lack of such research confirms the assertion by Anderson and DuBois (2007, p. 103) that "While the ethical issues that arise in

research conducted with potentially vulnerable participants who abuse substances are numerous and well-documented, the evidentiary base for addressing these issues is clearly inadequate.” Based on an ongoing study of attitudes and experiences of marginalized drug users, this article is intended to help clarify some issues of concern about research participation among not-in-treatment Hispanic women and men who use drugs. Specifically, the paper addresses Puerto Rican drug user attitudes about the risks and benefits of research participation in light of socio-cultural and socio-economic factors that shape their daily lives. In light of the topic of this paper, we provide a detailed discussion of the research methods used to collect data on participant perspectives on research.

METHODS

The data presented in this paper were collected as part of a larger, ongoing National Institute on Drug Abuse funded project entitled *Participant Perspectives on Drug Use/HIV Research Ethics* (# 1 R01 DA015649-01A1). This mixed-method study was designed to address limitations in current understanding of the experiences and attitudes of vulnerable illicit drug users by examining participant points of view on a range of issues, including risks and benefits of participating in research, informed consent, confidentiality, and use of incentives in the social and clinical sciences. The study unites the work on ethical issues in research by the Fordham University’s Center for Ethics Education in New York City with the community based substance abuse and HIV/AIDS research experience of the Hispanic Health Council in Hartford, Connecticut

The larger study is organized around three waves of data collection from each of the two sites using both qualitative and quantitative methods. Data from a series of focus groups—structured by ethnicity, gender, and sexual orientation—were collected from January 11 to September 12, 2006. This paper reports findings from the Hispanic focus groups held in Hartford, although some comparisons with non-Hispanic participants are included below to help describe the sociodemographic, health, and drug use characteristics of the Hispanic participants in the study. There were a small number of Hispanics in the minority sexual orientation focus groups held in New York City, but because these groups included participants of diverse ethnic identities, comments specifically of Hispanic participants cannot be extracted from the taped focus group narratives, so they are not analyzed in this paper.

FOCUS GROUP INTERVIEWING

In selecting a focus group approach, we were aware that participants would hold differing views and that individual perspectives might change in the course of group discussions (Fisher & Wallace, 2000). Indeed, it was the desire to capture

participants' "opinions in progress" (ibid.) that led to our selection of the focus group format as even heart-felt attitudes are often emergent and only achieve full coherence as they are articulated in social interaction. Focus groups are useful in ethics research because they have the potential to constitute quasi-ethnographic settings if participants feel comfortable and begin to partake in animated discussion with peers about meaningful issues of common concern. In constructing our approach to introducing ethical issues in research to participants and in facilitating group discussions of those issues, therefore, we were concerned that participants have the opportunity to consider all sides of an issue and that we not assume that there would be group agreement about the issues under discussion. Further, we were aware that the small sample size, unique characteristics of our focus group participants, and the particular approach that we took all influenced the course of the discussions and the comments of individual focus group members. Our goal, however, was not to document participant perspectives that would then be translated into specific ethical practices, but rather to provide insight on the emic perspectives that might challenge current ways of thinking about ethics-in-research issues among poorly understood, stereotyped, and vulnerable populations, especially populations like drug users whose voices are not often heard in the research discourse.

FOCUS GROUP SAMPLING AND RECRUITMENT

In New York, participants were clients of Housing Works, a community program that provides HIV/AIDS and health living services while emphasizing a harm reduction approach to lowering the spread of AIDS. In Hartford, where all of the Hispanic participants discussed in this paper were recruited, focus group members were recruited through street outreach by experienced, bi-lingual staff. Outreach targeted public venues known from past research in the city to be higher-density activity areas for street drug users, including illicit drug acquisition and use locations, sources of social services targeted to low income populations, and sites of service provision specifically targeted to populations at high risk for HIV/AIDS (e.g., street locations visited by the local syringe exchange program). Interaction with potential participants was initiated through walk-up introduction and a brief description of the project. Initial screening was conducted on the street to ensure that potential participants met project inclusion criteria. Individuals who expressed interest in participating and met enrollment requirements (e.g., active involvement in drug use and not currently in drug treatment) were provided with additional information and an appointment to attend a scheduled focus group (based on participant gender and ethnicity) at the centrally located offices of the Hispanic Health Council. The ethnic identification of participants used to assign them to focus groups was based on self-report.

Focus groups with Hispanic participants were conducted in Spanish and were facilitated by bi-lingual ethnographers. Discussions for the focus groups were stimulated by brief video-taped presentations of scenarios or "research vignettes" carefully designed to present participants with visual examples of ethical considerations and questions. Three approximately three to five minute vignettes featured professional male and female actors portraying researchers and drug users in the contexts of conducting a survey, an ethnographic study, and a double-blind placebo-controlled clinical trial, respectively. To account for the possibility that perceived differences in the versions might occur due to the ethnicity or gender of the actors, two versions were made for each vignette or research design, one version depicting a male researcher and a female drug user, the other a female researcher and a male drug user. Each version of a vignette was also made available in Spanish, for a total of 12 vignettes. A male or female drug user version was shown depending on the ethnicity of the focus group. The facilitator coordinating the focus group sessions introduced the vignettes to the participants one at a time, followed by guided focus group discussion of each vignette. While participants were not asked about their own behaviors, they often framed their comments in terms of personal experiences.

RESEARCH VIGNETTES

The vignettes presented a range of research methodologies for which ethnically diverse street drug users are recruited and about which ethical issues have been raised in the literature (Buchanan et al., 2002; Charland, 2002), as well as in the experience of research team members (Singer et al., 1999). The first vignette depicted a researcher engaged street outreach recruitment to enroll a drug user in a survey about his/her sexual behavior and drug habits as well as attitudes and beliefs about what spreads HIV and other infectious diseases that affect drug users. The narrator in the video explains that this information will help researchers understand what sex practices and drug-sharing behaviors transmit HIV and Hepatitis C in the community, and will aid policy makers to improve services that help people remain healthy. Viewers are encouraged by the narrator to pay specific attention to the recruitment procedures employed in the scenario and the interactions between the researcher and the participant.

The second vignette illustrates participation in an ethnographic study of the transmission of HIV in illicit drug using populations based on participant observation and street interviews. The narrator in this vignette explains to the focus group viewers that the ethnographer has spent several months with local drug users who have or are at risk of becoming infected with HIV/AIDS, in order to gain an insider's perspective on the conditions that lead them to share syringes and other drug injection equipment.

The narrator explains that the researcher usually gets to know one or two drug users very well and these individuals are asked to introduce the researcher to other drug users in the community. The narrator encourages viewers to pay particular attention to the nature of the relationship between the researcher and the participant and to any ethical dilemmas they see that might arise in such a relationship.

The third vignette depicts recruitment of a drug user for a double-blind placebo-controlled randomized clinical trial to test the efficacy of a new drug for reducing cocaine cravings. The focus groups were introduced to this vignette with an explanation that the research was designed to compare a group which will receive the experimental drug with another receiving a placebo. The researcher in this video explains to the potential participant that while both groups will have the option to receive psychological therapy and counseling, neither the researcher nor the participant would know the specific group to which she would be assigned. Viewers are told to pay specific attention to the risks and benefits of participating in such a trial.

Each focus group session, ranging from 60 to 120 minutes, was tape recorded, transcribed, and translated. The transcripts were first examined using participants' own words and concepts (emic codes) to generate a preliminary set of themes and sub-themes. A codebook was then developed according to the specific research questions used to frame the study (etic codes). The etic codes were then compared against the emic codes to generate a complete and comprehensive codebook. The final set of codes was catalogued in a software program (Atlas.ti) that was then used to code transcript segments. Code-based analysis for this study was therefore both deductive and inductive in nature.

CONSENT AND CONFIDENTIALITY

All participants gave informed written consent for their participation, noting the confidentiality of their responses within the focus groups and accepting that they could withdraw from the study at any time without reason or loss of services from Housing Works or the Hispanic Health Council (HHC). In order to further maintain confidentiality, focus group participants were given color-coded badges. They were instructed to identify themselves and each other by their badge colors. No names were used during the sessions, and when names were inadvertently uttered, they were not included in the transcript. The focus group phase of the study received approval from each site's Institutional Review Board (IRB). Participants were paid a \$25 cash incentive plus round-trip bus fare. These amounts were based upon previous work with the target population and were determined not to be coercive by the HHC's IRB in past studies. The fairness and non-coerciveness of this form of compensation was further evaluated by a Community Advisory Board consisting of

ethicists, drug abuse researchers, and community health activists who helped shape the focus group content, format, and materials prior to their implementation.

HISPANIC AND NON-HISPANIC SAMPLE CHARACTERISTICS

The total focus group sample was comprised of 100 participants. Within this larger sample, the Hispanic focus groups, of which there were four, included 36 participants, the majority (64%) of whom were men. The ages of participants ranged from 22 to 67 years (mean 43.3 years). Eighty-six percent of the Hispanic subsample self-identified as straight and 6% as bisexual, while the remaining participants declined to identify their sexual orientation. None had a full-time job, the majority (72%) being either unemployed or laid-off. A minority (13%) worked part-time. The remainder chose to not identify employment status. Forty-eight percent of participants in the Hispanic focus groups reported welfare or social security benefits as their only sources of income. Just over a quarter (28%) indicated that some form of hustling or selling drugs was a source of income. Notably, this compares to 9% for the non-Hispanics in the total multi-ethnic focus group sample. As to their living situations, only 31% of participants in the Hispanic focus groups reported living in their own home or apartment compared to 47% of non-Hispanics in the overall sample. Eleven percent of participants in the Hispanic focus groups reported that they were homeless, compared to 5% of non-Hispanics in the overall sample. In short, Hispanic participants tended to live under less secure, more risky circumstances and, as a result, may be more likely to face greater challenges of street life than their non-Hispanic counterparts in the study.

In the month prior to intake, participants in the Hispanic-specific focus groups reported drug use patterns that were noticeably different from and possibly more risky than those reported by non-Hispanics in the overall sample. Prevalence rates of drug use for both groups during this period were as follows:

- heroin (Hispanics: 81%, non-Hispanics: 26%)
- powder cocaine (Hispanics: 72%, non-Hispanics: 28%)
- alcohol (Hispanics: 31%, non-Hispanics: 25%)
- crack (Hispanics: 28%, non-Hispanics: 37%)
- embalming fluid/marijuana mixtures (Hispanics: 19%, non-Hispanics: 0%)
- marijuana (Hispanics: 17%, non-Hispanics: 32%)
- illicitly acquired anti-depressant pills (Hispanics: 14%, non-Hispanics: 9%).

While 67% of the participants in the Hispanic focus groups reported regular use of street drugs, this was true of only 35% of non-Hispanics in the total sample. Almost 70% of participants in the Hispanic-specific focus groups reported injecting drugs in the last 30 days; among non-Hispanics this was the case for just over half (51%). Participants in the Hispanic-specific focus groups were much less likely to report an HIV/AIDS diagnosis (14%) than non-Hispanics (49%) in the larger study. While most of the participants in the Hispanic subsample (81%) reported they had previously participated in a drug/alcohol survey or interview study, 53% indicated participation in an HIV/AIDS-related survey or interview study, and 64% had participated in a clinical trial to test a new drug or HIV treatment.

FINDINGS

In the analysis of Hispanic focus group narratives, we identified a dynamic tension within and between participants about the dangers and appeals of involvement in drug use and HIV-risk research. As discussed below, we found that participants in our Hispanic focus groups were particularly concerned about loss of confidentiality and resulting disruption of familial and community social support because of HIV/AIDS stigma. Yet they also viewed research participation as an available means of acquiring health knowledge, health services, and hard-to-come-by sums of money.

HIV/AIDS STIGMATIZATION: FEAR OF FAMILY AND COMMUNITY REJECTION

Fear about loss of confidentiality, especially in studies that include HIV testing, was a strong concern among the Hispanic participants in our study. Indeed, this was seen as a primary risk of partaking in social science research among Hispanic participants. Participants seemed to be particularly concerned that taking part in research could lead to family members learning their HIV statuses (or falsely believing they were infected just because of research participation). Worries about loss of confidentiality were closely tied by participants to their concerns about ever being marginalized or ostracized by their families, other kin and friends, and their peers.

As expressed in the following comments by Hispanic focus group participants, the primary fear was not of the virus per se and the physical threats it presents to the health of infected individuals, but rather of the social stigma attached to HIV/AIDS infection, and the insensitivities and painful rejection it can produce among significant others, especially family members. Participants felt that after learning about being HIV+ through a research project, when the need for family support would be greatest, would be the worst time for family members to “turn their backs” and leave the individual to suffer in isolation. Short of full rejection,

unfounded family fear about contagion can lead to hurtful interactions with family members. One source of negative family reactions, according to participants, is a grave apprehension that the wider community might learn about the infection, subjecting the family to social disparagement and loss of dignity.

The first thing ... is your family. Because if you don't know what I am suffering, I cannot be important to you. The relatives are the first ones to say that you are sick, that you cannot come in [the house].... They are the first one that say things that are hurtful to us.

Well depending on, let me use a bad word here, if you have a fucked-up family, they are going to only care about the stigma associated with knowing the fact that one of their relatives, especially if it is his son...that someone in their family has AIDS, and what this means for the family...you know, all this has to do with the stigma because they may think, "my son or my daughter has AIDS", that is on the streets. There are families like that. These are families that don't think in the person but rather in the stigma.

Some of the rejection described by participants might be due to medical misconceptions in the Hispanic community regarding possible contagion. Such misconceptions can operate in conjunction with the physical abandonment concerns discussed in the preceding quotes; such treatment is viewed by participants as a form of emotional rejection even if the drug user has not been physically ejected from the household. Consider the following quote in which a participant expresses fear of both kinds of rejection, followed by the statement of another who is concerned that a family might allow its misunderstandings to impede a nurturing and supportive relationship.

...with the situation they are referring to in the video, I think he will be helping his family [to find out his status], you know. That is, if they don't turn their back on him. Because very often the family is the one that turns its back on you, even when you need it the most. Because in a moment like that, when you find out that you are positive, that is when you really need support from all those 'round you...On the contrary, they turn their back on you; you go crazy because you learn that you are HIV positive and sometime you even feel like you want to commit suicide... and your family doesn't want to know anything about you. When you go to visit

them and you want to drink water, lets say, they give it to you in a disposable paper cup. They don't want you to use the silverware; they don't want you to use nothing.

For me, although she [actor in the vignette] is exposing her mother to risks, her mother may not have anything to do with that problem of drugs or whatever. Her mother may feel bad about it; she may be sorry because many families know it and they want to keep it covered. Because in some houses they only allow you to use certain things, because you may get things dirty, I mean, wherever you put your tongue. If you are going to serve yourself something, you have your own glass and whatever. Even today, there are some families that think that they can get infected by using your glass; they believe that. Those things still happen.

In addition to their fear of loss of family support as a result of unintended consequences of research participation, in the statements above there is expressed as well a degree of bitterness, perhaps reflecting participants' personal experiences with their own families.

Additionally, involvement with an organization that provides HIV/AIDS services or conducts HIV/AIDS research was seen as a cause for concern by participants because of erroneous conclusions some people in the community might draw. For instance, even though the Hispanic Health Council is a multi-service and research institute with various health education and support programs as well as research initiatives unrelated to HIV/AIDS, one participant stated that she was concerned that her mother would think she had AIDS and that she was even concerned about participating in the ethics research study:

But if someone who knows you finds out and go tell your family, for them, in my case, for my mom, it would be terrible. Because we are here now, and after this interview anyone who will see us leaving this place... they may say, "Oh, they are sick because they were at the Hispanic Council."

Similarly, other participants commented:

Eh, you know we face a risk... you know, because sometimes you are afraid... that if people get to know, if they find out, they are

going to say... they are going to recognize you, and very quickly they are going to say, "Look, she does have AIDS."
...when she [actor in the vignette] goes to an agency like this one and another person sees her entering, that person may say, "Ah, she was here the last time." And she may also say, "Oh that person has AIDS." And they will spread the word and tell other people... It is like that... There are many places where they are doing studies on AIDS, not just the Hispanic Health Council.

The consequences of family rejection are momentous according to participants, leading possibly, as we have seen, to "going crazy" or contemplating suicide. Another participant noted:

The thing is for the family to understand what he [participant in the vignette] is going through... Because in the video you can see that he is afraid of explaining it to them. And he knows he has the virus... And he doesn't know what to do... and not everyone in the family will understand... If you don't know what it is about, you cannot help yourself... You are alone in the world, you are lost.

As this comment suggests, without familial involvement and support, an individual lacks a social anchor or meaningful place in the world. This concern is magnified by possible rejection by the wider community, including fellow church members and co-workers, as indicated by the following participant:

But you know I still have this issue today, going to my family's church and telling them that I have it, but then again I feel like I'm going to be shunned once I tell them I have it. Like nobody, not even people at work, gonna want to know me no more, like get away from me, like I don't want to shake your hand no more. Then they could fire me...it happened to my friend once.

Participants also were concerned about other ways their private information collected in a study could be exposed, subjecting them not only to consequent family or community rejection, but legal actions as well. As one participant stated:

There is one thing and maybe I am wrong but I am going to say it. These [research] programs are good and they have their parts that are not that good too. I am going to explain why I see it this way.

This information that we give to them, for example, something happens, the court may request this information and they will have it the moment they want it. That is what I say. They [the researchers] cannot say that this is private information... It is not private, because with a warrant from the court, they come here and they take any information that they want and especially if it's Federal... So it is private because it is information they keep in their private files but at any moment that the Feds or any government person want this information, they will have to give it to them; they will give them the papers. They cannot refuse to give it to them because if they don't do so, they will be taken to jail... When we are doing these programs, we have to be very careful in the way in which we talk.

While it was explained to participants as part of the consent process that the ethics study, like many studies with drug users, was protected by a federal Certificate of Confidentiality from court order or police seizure of records, it is no doubt hard to believe that such certification could really stop a concerted law enforcement or court effort from gaining access to research files.

HEALTH BENEFITS OF RESEARCH PARTICIPATION

Despite being worried that their families and other might find out their HIV status because of their involvement in research, the Hispanics drug users in our sample nonetheless tended to see participation in research as generally beneficial. Importantly, the benefits that they believed could be found in being a research subject appeared to reflect a lack of other access to needed health information and services. Research, in short, was seen by many participants as a means of overcoming structural barriers to prevention information, health screenings, and referral to care. As one participant commented, by participating in research it is possible to gain access to health "information that he doesn't have right now and information that is going to be good for him, information that will be beneficial for him and for his family... [and] tests .. to know about his physical condition and how he is doing." Later, when assessing the risks of research participation, this individual added:

Risks of what? Risks are the ones he [actor in the vignette] faces every day on the street, using drugs and doing other things. Those are the risks... but to participate in the program, I don't see any risk on that... I mean, on the contrary, he is going to have knowledge that, most likely, he doesn't have right now.

Other participants commented:

The benefit that if he [actor in vignette] ever finds himself in the situation of being HIV positive they can refer him to a doctor... Also, the benefit that if he has hepatitis they will tell him, they will look for whatever disease he has, and if the disease is not too advanced, he will have the benefit of receiving help. He can help himself with early detection.

I think that it is beneficial [to participate] because in the same place you can get help if you are sick or any other type of help like clothing that one may need. They can offer that kind of help to us, you know. Because it's not only money... its help with medications.

When you are using drugs on the streets, many times you engage in things that may put you in danger, so ... if you submit to that ...survey and the physical exam, and you know if you don't have any disease. So that is a relief and from there you can start protecting yourself... He [actor in vignette] may say, "So far, this [HIV or other infection] has not happened to me so let me take better care of myself."

While many participants, as noted, fear that naïve family members could find out that they are HIV+, participation in a study, and being tested for HIV, was seen by others as a way to placate anxious and disgruntled family members who might falsely assume that their relative was infected (perhaps because they knew he/she was a drug user), as reflected in the following comments of a study participant:

The benefit for the family is to know if he [actor in vignette] has any kind of disease or not, because sometimes our family, when they know that we are doing drugs and they have no orientation in regards to that well they don't know anything about the drugs or anything. So many times they overwhelm you. They say, "You are lazy. You have this and that." In this case, they would get the benefit of knowing if he is clean [of HIV/AIDS infection].

In short, the Hispanic participants in our study see research participation as a two-edged sword, something that is simultaneously risky and potentially quite

beneficial. Ultimately, all of the individuals decided to participate in the ethics study, presumably because risks were seen as manageable. That most had participated in previous research as well suggests they have reached this conclusion on more than one occasion. Given the scarcity of resources available to marginalized drug users in the inner city, repeated research participation comes to be seen as a risk worth taking.

Without question, given their marginalized economic status, the financial incentives offered by research participation are an important motivator for not-in-treatment Hispanic drug users. As one participant explained,

Well I ... think that forty dollars [the amount of the incentive mentioned in the vignette] is a million dollars. That's what that is, you know. Especially when you are sick and you have no money and you don't have a job. Forty dollars is a million dollars.... But...the money is just money. He has to do the blood test, they are going to do a bunch of other things, and he is going to be there for two hours. For me, I think that is enough money because he is getting a benefit too.

Other participants added:

Let me tell that for example if you say to me that you are going to pay me, I will go for the money. Let's be honest.

So [is] he [drug user in the vignette] doing it for the money or [is] he is doing it driven by his own will or for getting the money? That is difficult to answer from the point of view of the addict. Because one can believe that you are doing it on a volunteer basis but in reality you are doing it for the [money]... I am here, I can say I am here voluntarily, but I also came for the twenty bucks, do you understand?

Ultimately, however, many participants felt that receiving help with drug abuse and with other needs would be the best research incentive and the greatest benefit of involvement in research.

The best way to compensate John [name of the drug user in the vignette] is to help him with a program. They can send him to detox and then they can give him orientation to see if he can go to a long-

term program so he can move on with his life.... And those forty dollars are gone in five minutes. But after that his life continues on. So for me it would be good if they offered a program, you know in-patient. You know, something that would benefit him.

I wanted to say the same, that ...there is information about many of the programs that are available today and many times we are not aware they exist, programs that can help you stay clean if you want to be clean, they help you find a job, they help you find a place to live.... So, the money is not the only thing. Sometimes the information helps you even more because you can get more than the forty dollars.

DISCUSSION

On the street, faced by multiple challenges and threats, drug users are forced to carefully sharpen their skills in assessing the costs and benefits of various courses of action. As described by Edward Preble and John Casey (1969, pp. 2-3) in their classic study of heroin addicts in New York, street drug users are

always on the move and must be alert, flexible, and resourceful. The surest way to identify heroin users in a slum neighborhood is to observe the way people walk. The heroin user walks with a fast, purposeful stride, as if he is late for an important appointment—indeed, he is. He is hustling (robbing or stealing), trying to sell stolen goods, avoiding the police, looking for a heroin dealer with a good bag (the street retail unit of heroin), coming back from copping (buying heroin), looking for a safe place to take the drug, or looking for someone who beat (cheated) him—among other things.

In the shadow of the AIDS epidemic, with a significant jump in the number and kinds of research focused on drug using individuals, participation in research emerged as a new component of the street drug user's social environment. Like other arenas in their world of concern, research was seen as presenting both threats and opportunities that had to be assessed in light of individual and group needs, sensitivities, understandings, and options.

It is evident from our focus group interviews with active drug users that they are fully prepared and able to cogently evaluate the risks and benefits of research participation. In this, they do not appear to bring an “all or none” philosophy into play but rather to keenly recognize that life as a drug addict requires that

they be prepared to accept significant risk in the pursuit of valued benefit. Among the Hispanic participants in our study, it is clear that underlying cultural values about the importance of family relations (Marin & Marin 1991; Sabogal, Marin, Otero-Sabogal, & Marin, 1987) shape their cost/benefits assessment of research involvement. On the one hand, research participation is quite risky, not—as researchers might assume—primarily because the police or other institutions of social control might gain access to information about criminal activities (although this is certainly a concern), but because potentially damaging personal information (e.g., HIV status, drug addiction) might reach an individual's family or his/her wider community. Fearing that family members do not really understand AIDS, a loss of confidentiality was seen as possibly leading to rejection, an outcome that would be so frightening that it could push some participants to consider suicide.

On the other hand, because of the limited resources available to active street drug users—both financial and in terms of access to health care—the risks of research participation routinely are outweighed by the benefits of participation. Indeed, it has been our sense over the last 16 years of conducting research with drug users that they are not only quite willing to participate in research, but they are also quite forthcoming about their behaviors, including risky and criminal activities (e.g., Hofman, 2004). Benefit, in the eyes of our Hispanic focus group participants, includes gaining access to desired health information, learning about available drug-related services, receiving health screenings (including HIV testing), and being assisted to enter treatment or other intervention programs. Access to effective and culturally appropriate treatment is a major challenge for participants in our study, a situation that has worsened over the years as access to longer term residential treatment for indigent drug users has all but vanished (Singer, 2004). Participants also see fiscal incentives as a valued benefit of taking part in research given their limited options for income generation. Considerable discussion has ensued in the ethics literature about whether paying drug using participants for research involvement is ethically problematic, with the general conclusion being that unless inducements are unusually high they are not unethical nor do they damage the quality of the data collected (Grady, 2001; Macklin, 1981; McNeil, 1997; Ritter, Fry, & Swan, 2003; Seddon, 2005; Wilkinson & Moore, 1999). Overall, Hispanic participant views of the benefits of research involvement appear to be strongly influenced by the significant barriers they face in gaining access to health, residential, and employment opportunities although they are tempered by fear of exposure and loss of one of the few sources they possess of emotional support, their families.

CONCLUSIONS

The focus groups examined in this paper included self-identified Hispanic male and female active drug users. The experiences of this urban, low-income Hartford sample cannot be taken as representative of other groups of Hispanic drug users at risk for HIV. It is possible, however, in qualitative studies like this one that the knowledge gained about underlying cultural attitudes and experience-based concerns may be transferable to Hispanic drug users in other contexts (Fisher & Wallace, 2000). Participants' poignant fears about loss of confidentiality and the potential consequences of family and community exposure to this information, for example, are likely shared by Hispanic drug users in other locations. Additional qualitative research with other Hispanic drug using populations, as well as longitudinal studies of participants' pre- and post-experimental experiences, will help to clarify common issues of concern about research participation among Hispanic drug users that are of value to both researchers and IRBs.

An example of why it is critical that Hispanic drug users' views on research participation be heard directly can be found by contrasting the sentiments of Hispanic drug users expressed in this paper with assertions about Hispanic participation found in the literature. Miskimen, Marin, and Escobar (2003, p. 100), for example, note that health related decisions among Asian Americans tend to be made by consensus and that:

the inclusion of family members, providing explanation on the procedures and agreement to participate, should be incorporated in the process of informed consent. We believe this approach might be also useful in the case of Latinos given their heavy reliance on family support.

While it is clear from the comments of our participants that these researchers are correct about the magnitude of importance of family support among Hispanics, even among socially marginalized Hispanic drug users, family involvement in informed consent, however, would hardly be welcomed by the participants in our study. Even from family, or more precisely, especially from family, some things must be hidden so as not to threaten access to critical social support.

Finally, while the use of video-typed hypothetical research scenarios provided our focus group participants with visual, easy-to-understand examples that they could discuss in light of their own experiences and attitudes, research is needed on participant reactions during actual recruitment and involvement in drug use and HIV research in order to test the extent to which focus group statements reflect actual reactions when members are involved in research procedures. The next

phase of the ethics project will test these preliminary focus group findings by speaking with drug users about their actual research experiences.

These limitations notwithstanding, our findings on Hispanic drug users' views of the risks and benefits of research point to the importance of designing protocols with a keen awareness of the perspectives of the subjects of the intended investigation. In research with impoverished Hispanic street drug users, special attention must be paid to concerns that information regarding their HIV or drug use status might inadvertently reach family members. Similarly, there is a need for thoughtful consideration of the incentives and resources available through research participation, consideration that seeks to balance pressing participant need and appropriate concern about coercive inducement.

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