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Ethical Considerations in HIV/AIDS Biobehavioral Surveys That Use Respondent-Driven Sampling: Illustrations From Lebanon

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Respondent-driven sampling is especially useful for reaching hidden populations and is increasingly used internationally in public health research, particularly on HIV. Respondent-driven sampling involves peer recruitment and has a dual-incentive structure: both recruiters and their peer recruits are paid.

Recent literature focusing on the ethical dimensions of this method in the US context has identified integral safeguards that protect against ethical violations. We analyzed a study of 3 groups in Lebanon who are at risk for HIV (injection drug users, men who have sex with men, female sex workers) and the ethical issues that arose.

More explicit attention should be given to ethical issues involved in research implementing respondent-driven sampling of at-risk populations in developing countries, where ethical review mechanisms may be weak. (*Am J Public Health.* 2009;99:1562–1567. doi:10.2105/AJPH.2008.144832)

RESPONDENT-DRIVEN SAM-pling is a relatively new technique that has been effective in sampling difficult-to-reach or invisible populations for which there is no sampling frame.[1–3] This chain-referral method—led by network peers—was developed to avoid many of the problems and biases of other such methods (e.g., snowball sampling). Respondent-driven sampling begins with nonrandomly selected seeds and proceeds in waves: the first wave of participants is referred by seeds from their social networks, the second wave by the first-wave participants, and so on. Critically, for ethical considerations, respondent-driven sampling operates with a dual-incentive structure in which a modest financial incentive is given to all who complete the survey (primary incentive) as well as to recruiters (secondary incentive).

Developed initially in the United States as a method for reaching injection drug users (IDUs),[4] respondent-driven sampling is being widely adopted in developing countries for HIV prevention research among a range of vulnerable groups and for other areas of public health research. This method has been used in more than 30 countries.[5] The literature includes papers about both the method itself[6,7] and findings from respondent-driven sampling studies,[8–12] but discussions of the ethical aspects of such studies have appeared only recently and only in relation to US contexts and studies of IDUs.[5,13] As Semaan et al. acknowledged, social and cultural factors may affect the ethical considerations of respondent-driven sampling studies in other countries.[5] Addressing these concerns is especially important when research is conducted in places where national ethical boards are weak or nonexistent.

We examined ethical concerns arising from an HIV biobehavioral study that used respondent-driven sampling with 3 population groups at high risk of HIV exposure in Lebanon: IDUs, female sex workers, and men who have sex with men (MSM). During the course of this study, which was approved by a university institutional review board, ethical dilemmas emerged. Here we review the recent international literature on ethical dimensions of respondent-driven sampling, describe the methodology of the Lebanese study, and discuss ethical issues we confronted that may be relevant to other respondent-driven sampling studies, particularly in developing countries.

ETHICAL IMPLICATIONS OF RESPONDENT-DRIVEN SAMPLING

In a review of ethical and regulatory considerations in HIV prevention studies that use respondent-driven sampling, coauthored by Douglas Heckathorn, originator of the method, Semaan et al. described 4 integral safeguards that help to prevent ethical

violations.[5] First, referral quotas, implemented through coupons, limit the number of participants each recruiter can enlist. These quotas serve to restrict the potential influence of any one recruiter on the study sample but also have the ethical consequence of capping the potential remuneration to recruiters.

Second, the level of remuneration is modest, although the criteria by which remuneration is set have not been extensively discussed in the literature and may be variable. Third, Semaan et al. argued that in respondent-driven sampling, unlike in studies that include finders' fees, whereby health care providers pay their patients to participate in clinical studies (a practice that is deemed unethical), recruiters and recruits do not share a clinical or consulting relationship and therefore do not have a financial or professional conflict of interest.[5]

Finally, the method is designed to minimize any pressure recruits may feel, by having study team members, not the peer recruiters, obtain informed consent and administer the survey. We detected a further safeguard in respondent-driven sampling: researchers are encouraged to ask participants why they participated in the study, information that may reveal any undue influences on participants regarding their recruitment.

Despite these safeguards, however, as in all HIV prevention research among stigmatized populations that involves outreach and payments, ethical dilemmas inevitably arise. Because respondent-driven sampling is increasingly becoming the method of choice to reach hidden populations, particularly in HIV research, exploring research participants' experiences is important.

In one of the few such studies published to date, Scott discussed participants' experiences in this type of research.[13] He reported on a 4-year independent qualitative research project in which respondent-driven sampling generated a local IDU sample in Chicago, Illinois. Two key issues were identified that were relevant to the use of this sampling method internationally among populations at risk for HIV. First, Scott found that an "underground stratified marketplace"[13] of coupons and study-related services emerged in the study areas. The same phenomenon has been observed in Serbia, where some IDUs sold coupons to peers, and in Cambodia, where some MSM waited to collect coupons for resale from those exiting from interviews.[14] Second, people who were eager to participate in the study for financial reasons quickly learned methods for getting around the study's screening procedures. Scott described such tactics as signing up for the study twice and falsely claiming to belong to a risk group. Similar behaviors have been reported elsewhere,[11] although it is not known how widespread they are.

Scott's findings have been questioned in a series of responses, which focus on, among other concerns, methodological deficiencies and his failure to compare the risks of involvement in a study with the risks such participants face in everyday life.[15–18] One critique argued that the ethical issues Scott raised were not new to respondent-driven sampling but apply to all outreach methods to hidden populations that involve payment.[15] Scott's article nevertheless highlights the importance of exploring respondents' experience of recruitment, even while acknowledging, as others have,[5,13] that respondent-driven sampling remains the best method for developing valid samples of hidden populations.

THE LEBANON RESPONDENT-DRIVEN SAMPLING STUDY

The Middle East and North Africa have a low estimated prevalence of HIV/AIDS, at 0.3% of adults.[19] Lebanon, where there had been no biobehavioral surveys before our study, has had 1172 reported cases of HIV, and adult prevalence is estimated at less than 0.1%.[20] As in the region as a whole, however, HIV/AIDS in Lebanon tends to be underreported because of the limitations of existing surveillance; the lack, until recently, of accessible voluntary counseling and testing services; and high levels of stigma surrounding infection with HIV. In Lebanon, as in the region as a whole, MSM, female sex workers, and IDUs are all highly stigmatized and hidden populations engaged in activities that are illegal. Lebanon is exceptional among Arab countries in that it has a nongovernmental organization (NGO) that advocates on behalf of MSM.

Because no biobehavioral survey data was available for Lebanon, our study's primary objective was to develop estimates of HIV prevalence among 3 at-risk populations: IDUs, female sex workers, and MSM. The behavioral survey, funded by the World Bank, focused on risk behaviors as well as the sociodemographic background of participants and their knowledge, attitudes, and beliefs about HIV. The study team in Lebanon comprised researchers at the American University of Beirut and staff members from 6 community-based NGOs serving the study populations. One of the study aims was to strengthen the research and counseling and testing capacity of the NGOs. All those involved in data collection received extensive training in the research instruments, respondent-driven sampling methodology, HIV testing, HIV awareness, communication skills, pre- and posttest counseling, and relevant ethical issues.

Fieldwork took place from August 2007 to July 2008 in the greater Beirut area, and the findings are under analysis. The team selected the seeds after establishing key criteria; we also developed a recruitment protocol. Seeds received 3 coupons for recruiting members from their networks. We conducted an oral informed consent procedure separately for the survey and blood tests. If a participant agreed to complete the survey but not undergo the blood test, we still proceeded with the survey. We screened for both group membership and study eligibility prior to the interview. Counseling was undertaken before and after the HIV test. Only dried blood spot samples were taken initially, but many participants did not return in 2 weeks for the test results. For ethical reasons, we therefore offered rapid HIV tests as well.

We did not have funds to rent separate premises for the interviews, which were conducted on NGO premises. Because of the potential stigma for some recruits in visiting the NGOs (IDUs were particularly reluctant to visit rehabilitation-related NGOs), we sent mobile interviewers to meet participants at independent sites. The profound stigma in Lebanon associated with HIV and with the specific population groups under study, as well as the fact that a blood test was involved, made it difficult to negotiate with other venues to host the interviews.

At the conclusion of the survey and test, participants were told when they could receive their test results, and those who opted for rapid tests as well were given their results immediately. They were given HIV prevention material tailored to their risk group, as well as information about referral and treatment in case they proved to be HIV positive. (The Lebanese government provides free treatment to anyone found to be HIV positive whose CD4 count warrants treatment.) At that time, they also received their primary incentive. They were then issued 3 coupons to recruit further contacts in their network and told that for each person recruited, they would receive a secondary incentive. Staff at the NGOs involved followed the recommended coupon management system for respondent-driven sampling.

Our research team worked within the ethical framework of the Belmont Report.[21] Several ethical issues arose as the study progressed; these could be broadly categorized as concerning autonomy or risks and benefits.

AUTONOMY

The principle of autonomy suggests that individuals have the right to make decisions that are free of pressure or undue influence after careful consideration of options.[21] We encountered several issues that related to maintaining participants' autonomy.

Informed Consent

Informed consent is one way to ensure that autonomy is maintained. A key overarching ethical issue concerning the use of respondent-driven sampling, as Scott pointed out, is that human participant protection is effectively delegated—at least initially—to peers.[13] It is difficult to regulate how the study is presented by peer recruiters except by careful training of these recruiters, as is recommended.

In respondent-driven sampling, the research team regains control of the process by administering the informed consent process once recruits come to the site to participate. In our study, we also checked comprehension of the details of participation.

Monetary Incentives

Ethical concerns about payment in the respondent-driven sampling method, which may restrict choice, need to be analyzed in each setting because they are specific to context and population groups.

No official guidance on remuneration exists for respondent-driven recruitment, but a widely used norm is to reimburse for time and transportation costs.[5] Considerable literature exists on the use of payments as compensation for research in public health studies in general and in HIV-related studies in particular.[22–28] The authors of most of these articles concluded that payments are ethical, so long as they are not so high as to coerce low-income participants into consenting to the study.[22,25,27] Semaan et al. argued that the risk of coercion or undue influence has not been shown to be substantial.[5] One study that assessed respondents' willingness to participate in research and the effects of financial incentives on participation levels found that higher payment levels did not affect participants' consideration of the potential risks of involvement but did increase willingness to participate in research projects.[24]

A sum of money that is carefully calculated is a sign of appreciation for the participant's time and effort employed in the study.[25] Clearly, however, there are subtle dividing lines between paying respondents for their time and transportation and paying them for information. Moreover, the question of whether payments induce nonmembers of at-risk groups to join should be explored.

Less discussed in the literature is the amount of the payment and the criteria that should be used for setting it. We determined the primary and secondary incentives at the beginning of our study through consultation with the NGOs and members of the populations being surveyed. Participants received the equivalent of US $6.60 after completing the survey and blood test and the equivalent of US $2 for each person they recruited. The research team followed the ethical principle of justice in agreeing that all groups should be given the same incentive because the sampling was conducted simultaneously for the 3 groups.

Because of difficulties in recruitment and because respondents were not returning for the secondary incentive, we increased this payment to US $3.50. After 7 months, it became clear that recruiting the full sample would be difficult and that the secondary incentive was still not being collected, so we raised the primary incentive to US $10 and the secondary incentive to US $6.60 per person recruited. However, increasing an incentive during the course of a study poses additional ethical dilemmas relating to justice in that participants from early phases of the study received less money, and because of anonymity in the study protocol, they could not be recontacted and compensated at the higher level.

We analyzed why participants reported enrolling in the study and found that payment was not their main reason for participating, which would indicate potential pressure or duress. The overriding reason for participating was the HIV test (37.6% of all reasons cited; Table 1). Of all the reasons given, only 11.8% pertained to the financial incentives, although this percentage increased for MSM and IDUs after we raised the primary and secondary incentive amounts.

Sequencing of Payment

By contrast to the growing literature about paying research

TABLE 1—Reasons for Participation in a Respondent-Driven Sampling Study, Before and After a Substantial Increase in Monetary Incentives: Lebanon, 2007–2008

Reasons Given by Participants	MSM		IDU		FSW		Total		
	Before, No. or No. (%)	After, No. or No. (%)	Before, No. or No. (%)	After, No. or No. (%)	Before, No. or No. (%)	After, No. or No. (%)	Before, No. or No. (%)	After, No. or No. (%)	Combined Before and After Responses, % or No.
Financial incentive	3 (3.2)	18 (22.5)	10 (13.7)	13 (26.5)	10 (18.9)	5 (3.3)	23 (10.5)	36 (12.8)	11.8
HIV test	27 (29.0)	23 (28.8)	39 (53.4)	21 (42.9)	22 (41.5)	56 (36.8)	88 (40.1)	100 (35.6)	37.6
Peer influence	21 (22.6)	23 (28.8)	2 (2.8)	4 (8.2)	9 (17.0)	84 (55.3)	32 (14.5)	111 (39.5)	28.6
Find study interesting/useful	38 (40.9)	14 (17.5)	17 (23.3)	7 (14.3)	10 (18.9)	6 (5.5)	65 (29.5)	27 (9.6)	18.4
To spend time	1 (1.1)	0 (0)	0 (0)	1 (2.0)	0 (0)	1 (0.7)	1 (0.5)	2 (0.7)	0.6
Other[a]	3 (3.2)	2 (2.5)	5 (6.8)	3 (6.1)	2 (3.8)	0 (0)	10 (4.5)	5 (1.8)	3.0
Total responses	93	80	73	49	53	152	219	281	500
Total participants	65	55	73	36	37	113	175	204	379

Note. MSM = men who have sex with men; IDU = injecting drug user; FSW = female sex workers. Percentages are rounded; a participant could cite more than one reason.
[a]Other reasons included to share experience, to help, to help in research; 53% of drug users cited seeking help/treatment as reason for participating in the study.

participants, insufficient attention has been paid to the sequencing of the dual payments involved in respondent-driven sampling, which has important ethical consequences. If, for example, the payments to recruiters are only made after a recruit completes the interview, the potential for pressure or duress is higher.

We addressed this ethical concern by paying recruiters once the recruits arrived at the site of the interview (where they still had the option to refuse to participate). On the other hand, if payment were made for recruiting without the assurance that the recruits would actually come to the interview, a study would risk losing potential participants.

Monetary Versus In-kind Incentives

Another ethical dimension linked to autonomy is how the monetary incentives are used by participants—an issue that arises in all studies involving payment, but particularly when drug users participate. Lebanese NGOs involved in our study were particularly concerned about remunerating IDUs because this might subsidize further drug use. The study team considered using in-kind incentives but ruled them out because they would not sufficiently compensate participants for travel costs within Beirut.

Semaan et al. noted that in-kind remuneration does not produce sufficient incentive to recruitment in respondent-driven sampling and that in the US context, studies have found that only a minority of drug users report using remuneration from study participation to buy drugs and that most use the money to meet various needs.[5] Some argue that paying IDUs in-kind incentives could compromise participants' autonomy, because it eliminates the recipient's right, integral to monetary compensation, to decide how to use the incentive.[5] In addition, it risks reinforcing negative stereotypes (e.g., being irresponsible or untrustworthy) of this population.[26] Given that dual payments are essential to the respondent-driven sampling method, these ethical questions need to be confronted.

RISKS AND BENEFITS SPECIFIC TO THE LEBANESE SETTING

The principle of beneficence suggests that all research must attempt to do no harm and is obligated to at least maximize benefit in relation to risk.[21] More explicit consideration of how researchers who use respondent-driven sampling strategize to maximize benefit over harm in specific cultural contexts would be useful in all reports on this type of research.

Risks

Stigma. The risks to participants in any HIV-related study in Lebanon, as in other highly stigmatized contexts, are high. The very nature of the respondent-driven sampling method, it can be argued, causes the research to intervene not only with individuals but also within social networks. We found in Lebanon, where HIV is highly stigmatized, particularly in relatively small networks of at-risk groups, the mere fact of participating in a study in which an HIV test is performed, and recruiting others to do the same, could affect individuals' reputation in their social networks. (We are grateful to J. Mokhbat, MD, president of the Lebanese AIDS Society, for emphasizing this point; personal communication, October 22, 2007.)

Indeed, although HIV testing was cited in more than a third of the reasons participants gave for participating in the study (Table 1), recruiting others to an HIV-related study is tantamount to confessing that one perceives oneself to be at risk for HIV, which may jeopardize social relations. The respondent-driven sampling method is unique in that recruiters not only recruit other individuals within their

networks but also learn whether those persons participate, because recruiters collect the secondary incentive only if their recruits follow through.

Political instability. Our study took place during a period of political instability in Lebanon that was marked by intermittent bombings. Such instability raises the risks to participants in any study. Study participants voiced reluctance to circulate during periods when there were threats of bomb attacks. Moreover, the very communities most affected by political instability tended to be those where groups at higher risk of HIV were concentrated.

Benefits

To maximize benefit and reduce risks, we provided health education materials specific to each target group, employed a psychologist to monitor and supervise counseling (because of concern about the quality of counseling being offered), and provided rapid tests to allay the stress of waiting for the results of the dried blood spot tests.

Increased outreach. Paradoxically, the benefits, as well as the risks, to participants in a respondent-driven sampling study may be greater in settings such as Lebanon than in contexts where HIV is less stigmatized and where there is greater political stability. For example, only 1 of the NGOs involved in our study was actively engaged in outreach to its target population; during the study, staff members discovered the benefit of developing outreach programs and identified new at-risk individuals. NGO staff also gained greater awareness about HIV and ways to address it. Many individual recruits who were not previously linked to NGO services learned about, and in some cases benefited from, these resources.

Location of study sites. An important consideration in decreasing risk and maximizing benefit was the choice of location for administering the biobehavioral survey. Although the NGO sites were the most convenient and contained, some participants (particularly MSM and IDUs) perceived stigma associated with entering them. We thus began exploring alternative sites.

Securing a confidential venue that our respondents were comfortable with was difficult, so we considered using a mobile van offered by one of the NGOs, which had the added advantage of increasing accessibility to participants. However, stigma could still attach to those entering the van, and the research team had further concerns about security and a possible police crackdown, so this venue was ruled out to avoid harm to participants. As a compromise, we had mobile interviewers ready to meet participants at agreed-upon locations.

RECOMMENDATIONS

The ethical issues encountered in the implementation of our biobehavioral HIV study in Lebanon may not arise in all contexts and with all at-risk populations. However, given the extensive use of the respondent-driven sampling method in public health research worldwide, including where ethical oversight may be weak, greater attention should be paid to ethical guidelines across varying cultural contexts. Particular emphasis is needed on maximizing benefit over risk as well as on the amount and sequencing of payments made to research participants.

As Simic et al. argued,[8] for ethical reasons alone it is important for researchers who use respondent-driven sampling to conduct formative research, even though this method has been promoted as requiring less formative research than other sampling methods. Ongoing research on participants' experience of recruitment is also necessary to understand the true risks and benefits. Finally, we fully endorse Semaan et al.'s recommendations—and their checklist of ethical and regulatory variables—that all published reports of studies that use respondent-driven sampling explicitly address the ethical issues involved. ■

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Contributors

J. De Jong led the writing of the brief with R. A. Afifi. All authors reviewed relevant literature, conceptualized ideas, made substantive comments, and recommended revisions to the brief. All authors were involved in the design and implementation of the study and deliberation on the ethical issues raised.

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Human Participant Protection

This study was approved by the American University of Beirut's institutional review board. Participants gave separate verbal consents for both the HIV test and the behavioral survey.

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Percent Total Attrition: A Poor Metric for Study Rigor in Hosted Intervention Designs

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Health behavior interventions delivered at point of service include those that yoke an intervention protocol with existing systems of care (e.g., clinical care, social work, or case management). Though beneficial in a number of ways, such "hosted" intervention studies may be unable to retain participants that specifically discontinue their use of the hosting service.

In light of recent practices that use percent total attrition as indicative of methodological flaws, hosted interventions targeting hard-to-reach populations may be excluded from consideration in effective intervention compendiums or research synthesis because of high attrition rates that may in fact be secondary to the natural flow of service use or unrelated to differential attrition or internal design flaws. Better methods to characterize rigor are needed. (*Am J Public Health.* 2009;99:1567–1575. doi:10.2105/AJPH.2008.134767)

EXAMINATION OF METHODO-logical rigor in behavioral intervention research is essential for the systematic identification of interventions that are empirically