



Published in final edited form as:

Subst Use Misuse. 2010 April ; 45(5): 700–716. doi:10.3109/10826081003591282.

Ethnographic Strategies in the Tracking and Retention of Street-Recruited Community-Based Samples of Substance Using Hidden Populations in Longitudinal Studies

Alice Cepeda and Avelardo Valdez

Department of Sociology and Center for Drug and Social Policy Research, University of Houston, Houston, Texas, USA

Abstract

The article presents practical and methodological strategies in the tracking and retention of a longitudinal community-based sample of 300 Mexican American noninjecting users of heroin. Presented are the ethnographic strategies the research team utilized to maintain high retention rates among this highly marginalized and hidden population. Findings indicate that these ethnographic strategies are the basis for a reliable method for subject retention among drug-using populations. Further, the strategies illustrate how qualitative methods can complement the collection of quantitative data. Discussed is how these strategies can be used to identify and engage similar populations in research studies.

Keywords

noninjecting heroin; hidden populations; retention; contextual factors; cross sectional research designs; health risk behaviors; longitudinal panel designs; tracking strategies

Introduction

Researchers have increasingly recognized the importance and strengths associated with implementing longitudinal panel designs in both clinical and social science studies. As has been documented in the past, the clear challenge in these types of studies is the retention of cohorts of individuals over various temporal contact points. The retention of subjects in longitudinal studies is crucial given that these rates may affect the measured frequencies of behaviors engaged in by those retained in the cohort over time versus those lost to follow-up (i.e., attrition) (Del Boca and Darkes, 2007; Robles, Flaherty, and Day, 1994). The problem of attrition becomes more acute when dealing with conventional study populations such as drug users, criminals, or other socially marginalized populations whose behavior is often highly stigmatized. These groups often engage in these behaviors in places and times hidden from conventional public scrutiny. Moreover, contextual factors associated with the communities of these types of populations are often distinct from others. These factors make it difficult to engage what we identify here as *hidden populations* in successful clinical and social longitudinal studies. This article will focus on barriers and strategies, which may

Copyright © 2010 Informa Healthcare USA, Inc.

Address correspondence to Alice Cepeda, Department of Sociology and Center for Drug and Social Policy Research, 110HA Social Work Building, Houston, Texas 77204-4013. acepeda2@uh.edu.

Declaration of interest: The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

affect the researcher's ability to maintain substance users in longitudinal studies based on our experience with Mexican American drug-using populations.

Studies on drug use and related topics such as health risk behaviors are routinely done using cross-sectional research designs. These studies focus on a cross section of the population at a single point in time. The reason that these cross-sectional research designs tend to be more common in the social sciences is that often they include large diverse samples that allow for more statistical power and generalizability. Because of the difficulty and expense of engaging study subjects at different points in time that characterize longitudinal studies, most research that relates to substance use(r) employs cross-sectional designs.

In recent years strategies of retaining participants in health care research have been identified (Robinson, Dennison, Wayman, Pronovost, and Needham, 2007). Much of this research has focused on participant retention in randomized controlled trial studies of diseases such as diabetes, heart disease, and cancer (Bailey, Bieniasz, Kmak, Brenner, and Ruffin, 2004; Froelicher et al., 2003; Katz et al., 2001; Parra-Medina et al., 2004). These study participants are often recruited from clinical settings in institutions where they are patients and thus highly accessible. The strategies to retain subjects in these studies are less problematic than current drug users because subjects may have different motivations to remain in the study. That is, in a conventional clinical study, a patient may continue their participation on the basis of the anticipated health benefits. The motivations and benefits for drug users in longitudinal epidemiological studies are less clear and often confounded by issues of income, education, race, and social capital particularly among minority groups.

Discussions of retention in longitudinal studies of substance users generally have been associated with treatment programs for alcohol and drug use (Craig, 1979; Fried and Watkinson, 1990; Mackenzie, Funderburk, and Allen, 1987). Longitudinal studies of nonintervention research are less common especially if it relates to street-recruited, community-based *hidden populations* of drug users. Hidden populations have been defined as a subset of the general population whose membership is not readily distinguishable or enumerated on the basis of existing knowledge and/or sampling capabilities (Morgan, 1996). Longitudinal studies among these subpopulations require the use of multiple innovative retention techniques. These techniques are specific to these individuals and their respective contexts given their involvement in socially sensitive and undesirable activities. Only a few studies have provided strategies in maintaining low rates of attrition when conducting longitudinal, epidemiological, community-based research among drug users (Dunlap and Johnson, 1999; Neaigus et al., 2006; Sterk, 1999). Therefore, there is little systematic discussion on how to successfully implement these strategies among a drug-using population. An assessment of these methodological strategies are necessary to advance the science of drug use and misuse. This is particularly important given that government funding agencies, such as the Substance Abuse and Mental Health Services Administration (SAMHSA), are requiring treatment and prevention grantees to have retention rates of at least 80% for their projects.

The challenge for those who use longitudinal designs is to develop tracking and retention strategies that engage these hidden populations into a methodological framework that can safeguard both internal and external validity. In this article we provide practical and methodological strategies in the tracking and retention of a street-recruited community-based sample of noninjecting users (NIU) of heroin that build upon previous studies. Specifically, the article presents six tracking and retention strategies that subsequently contributed to the development of six underlying principles for maintaining low attrition in a longitudinal study among a drug-using, hidden population.

Methods

“Project Brown” is a prospective cohort epidemiologic study of 300 recruited Mexican American noninjecting heroin users in San Antonio, Texas funded by the National Institute on Drug Abuse. The purpose of the study was to investigate the incidence and risk factors for making a transition to injecting and the prevalence and incidence for infection with bloodborne and sexually transmitted infections (HIV, HBV, and HCV). The study design consisted of a baseline interview with two follow-up interviews at six-month intervals. Participant inclusion criteria for the baseline cohort were: 16 years through 40 years of age for females, 35 years for males; self-reported and biological evidence of heroin use in the past 30 days; absence of drug injection history or no recent injection in the six months prior to enrollment; Mexican American ethnic background; no participation in formal drug-user treatment in 30 days prior to enrollment; and resident of the San Antonio metropolitan area.

Most importantly, it is important to recognize the research team working on the project. All of the Project Brown staff were residents of the study community. Three of these were middle-aged Mexican American men who grew up on the West Side of San Antonio and had extensive contacts in the community. Two of these men were the project outreach specialists who were responsible for identifying, accessing, and recruiting the respondents into the research project and the third was the project coordinator. Due to the sensitive nature of this research, combined with the gender composition of participants, it was critical to utilize female staff. Thus, a fourth staff member was a 50-year-old woman, also from the neighborhood, who served as the primary interviewer. She had over 20 years of experience working in community-based organizations with drug-using populations. Her extensive experience allowed her the ability to easily establish rapport as well as offer a deeper understanding of the social context of the lives of these respondents. Overall, having staff that were indigenous to the community was important in that it enhanced their ability to convey empathy and understanding without judgment that allowed for the elicitation of more truthful responses.

The West Side community in San Antonio is comprised predominantly of persons of Mexican origin living in one of the poorest urban areas in the United States (U.S. Bureau of the Census, 2000, 2002). In 2006, an estimated 22% of the Mexican American population was below the poverty line compared to 18% of the total general population (U.S. Bureau of the Census, 2005). According to the census data, the per capita income was \$5,098, and the median household income was \$14,352 for 22 census tracts that comprise this community. Fifty-five percent of the West Side families had children living in poverty, and only 23% of the families received public assistance (U.S. Bureau of the Census, 2001). The area of focus is near West Side (see map) consisting of eight census tracts with a population of approximately 50,000 persons (Brischetto, 2000). Neighborhoods in the study area are characterized as having the highest concentration of low income Mexican-origin persons in the city. This area has the highest unemployment rates, lowest educational attainment, high school dropout rates, teenage pregnancies, and delinquency (Brischetto, 2000).

The Project Brown field office was located in the heart of the West Side community in offices of a community-based social service agency. Although our offices were in this agency's complex, we had a separate entrance that provided us with the project's own identity. This agency has been providing services since the 1950s at this site and is well established and recognized by community residents. This nonprofit Mexican American organization is governed by a community-based board of directors, which endorsed the objectives of our research study. Respondents felt comfortable visiting our field office given its association with the agency. Moreover, the location of the field office facilitated

interviewing and the implementation of the tracking and retention strategies given its accessibility to the participants.

During the summer of 2001, the two male outreach specialists began identifying potential recruitment locations including heroin acquisition and using sites. During different times of the day and week, outreach specialists conducted regular sweeps of the neighborhoods identifying potential respondents, key informants, and contacts. In conducting this initial fieldwork, outreach specialists were able to establish “an ethnographic presence” and maintain a high visibility within the targeted neighborhoods to help legitimize the project in the community (Sifaneck and Neaigus, 2001). After this was accomplished, the outreach specialists began to make contacts with the noninjecting heroin users, gain their trust, and obtain access to their social networks.

Upon identifying potential respondents, outreach specialists would briefly describe the focus of the study as, “We are doing a health study and are interested in talking to people about their experiences with heroin use.” After consenting to participate, respondents were screened for eligibility criteria and scheduled to visit the field office for their first interview. The face-to-face interviews were administered in a private room in the field office by the primary interviewer. The interview was 2–3 hours in duration and participants were compensated \$35 for their time and effort.

Results

Study Follow-Up Rates

At the completion of data collection, the research team had a 98% follow-up rate. Specifically, the research team had a sample size of (numerator) 290 and 272 for follow-up 1 and 2, respectively. The denominator, excluding respondents who withdrew or were deceased was at follow-up 1 ($n = 295$) and 2 ($n = 279$). Given the highly stigmatized nature of the respondent’s behavior and high rates of residential mobility, the research team utilized several ethnographic strategies to maintain high retention rates that proved to be effective among the population. In implementing the following strategies, research staff were instructed when speaking about the research project to others in the community to always refer to it as a “health study.” This eliminated the loss of confidentiality for our respondents. Also, respondents provided consent for the research team to collect follow-up information and consent for permitting the disclosure of respondent’s name to potential study participants.

Tracking and Retention Strategies

Locator Form Documentation—The first strategy was the collection and documentation of data on detailed locator forms. Upon obtaining informed consent at the time of the baseline interview, outreach specialists asked respondents to provide detailed locator information so that they could be contacted for follow-up visits and interviews. Information collected on the locator form included the individual’s most current phone number(s), current address, driver’s license number, state identification number (SID), and social security number (used to search computerized databases). Collected as well were the respondent’s nicknames or street names, usual hangouts, physical description (i.e., tattoos), and information on other respondents they knew of participating in the study. Most importantly, similar locator information was collected for at least one stable relative (i.e., grandparent, aunt, uncle, etc.) of the respondent. This person would be someone who would serve as a contact person in case we needed to locate the respondent and could not find them using their own contact information. This latter data proved to be strategically significant given the sample was highly mobile during the course of the study.

Project staff made sure that the participant understood the importance of follow-up interviews being essential and integral to the research, a point that was highlighted in the informed consent procedure. Moreover, outreach specialists verified all locator data within one week of the baseline interview and at each follow-up interview. No respondent was excluded on the basis of not providing the requested locator information. However, staff did make sure there were sufficient data to relocate the respondent. In order to ensure the validation of specific locator information, outreach specialists verified phone numbers before the participant left the office.

Follow-Up Tracking Bulletin Boards—A second strategy was the creation of a “follow-up tracking bulletin board” that monitored the status of contacts made by the outreach specialists with each respondent during the time period between scheduled interviews. The bulletin boards displayed the respondent’s identification number (RESID), assigned outreach specialist identification number (STAFF ID), date of baseline interview, projected date of first follow-up, actual date of first follow-up interview, projected date of second follow-up, and actual date of second follow-up interview (see Table 1). Between each of the interview dates, outreach specialists documented the dates in which personal contact was made with each respective respondent. Personal contact included a phone conversation or face-to-face meeting in the field at which time any updated locator information was collected.

Table 1 provides an illustration of how the follow-up tracking bulletin boards worked. Sammy was a 19-year-old male who was recruited for the study and initially interviewed in April, 2003. The assigned outreach specialist maintained consistent contact with Sammy throughout the course of the study as seen by the dates below. This contact facilitated Sammy’s retention in the study and assured that follow-up interviews were on schedule. Moreover, at the time of the baseline interview Sammy provided us with his grandfather’s contact information (address and phone number) as an alternative in case we had problems relocating him. This proved to be helpful in that during the course of the study the outreach specialist made contact with Sammy several times through his grandfather.

The follow-up tracking boards were displayed in the outreach specialists’ office work area. These tracking boards would allow research staff to identify if there were any respondents who had not been recently contacted. Maintaining contact with respondents proved to be important with over 80% indicating the main reason they came back for follow-up interviews was because of the reminders they personally received from outreach specialists. In addition, every respondent had a personal file in which the outreach specialists would document specific fieldnotes about each of the contacts made with the respondent during the course of the study. These notes proved to be helpful in instances where a second outreach specialist would need to make contact with someone they had not originally recruited. For instance, Jose was a 24-year-old male with less than a high school education. Jose had been using noninjecting heroin for just over a year when he was recruited by outreach specialist 39 (OS39). The following field note describes Robbie’s (OS42) experience in finding Jose based on OS39’s notes.

Jose was initially recruited by OS39 and completed his initial baseline interview on April 16, 2004. At the time of his interview, he resided on the far west side of town with his mother. During the period between his baseline interview and his scheduled first follow-up interview (October 16, 2004) two contacts were made. Just prior to his follow-up, OS39 discovered that the home where they were living was empty. On speaking with neighbors, OS39 was informed that the mother had sold the house and moved to California. Reports indicated the Jose was left homeless. After numerous attempts, OS39 was unable to locate Jose.

I was assigned to continue the search for Jose. Since I was not familiar with him I looked into his folder and found information that led me on the same path. I began leaving my business card at the distinct addresses identified in his locator form in his folder. His father's address was listed, so that was the main target residence I visited. During one of my visits to his friend's house I was told that he had heard that Jose was employed at a restaurant on the southside of town. I drove to that location and asked to speak to the manager. A woman came up to me and I explained I was looking for Jose. She informed me that Jose had been employed there but had quit two weeks prior to my visit. According to the manager, Jose was homeless and they had no address on him.

Approximately 8 months from the time of his baseline interview, Jose called on my cell phone. Apparently, he finally got my card and messages I had been leaving with his father. I set up his first follow-up interview.

Appointment, Thank You, and Reminder Mailings—A third strategy implemented during the course of the study, was the utilization of bulk mailings to thank and remind respondents of their upcoming scheduled follow-up interview appointments. Before the mailings were initiated however, interview staff were instructed to distribute at the end of each interview (baseline or first follow-up), project appointment cards displaying the respondent's scheduled day and date for the follow-up interview. The appointment cards also included the address and phone number of the field office in case participant's needed to get in touch with the research staff.

The initial mailing consisted of sending "Thank You" cards one week after the baseline or first follow-up interview was conducted. The cards were mailed out to the most current address found on the respondent's locator form. This initial mailing helped the research team verify addresses given by the participants. Those that came back as "return to sender" were assigned to outreach specialists, who in turn would contact the respondent to get secondary valid addresses. The content of the Thank You card read:

We wanted to send you this thank you card for participating in the health study. We are thankful for your participation and enjoyed talking to you.

We look forward to seeing you at the next follow-up interview.

The flip side of the card read:

If your address or telephone number change, please call us so we can keep in touch with you. This will also help us let you know if you win the raffle.

[Office Address and Contact Info]

The next mailing was a Project Brown Reminder letter sent out to each respective respondent two weeks before their scheduled follow-up interviews. The letter would remind the participant of their engagement in the health study, the potential to win the project raffle (described later), and the day and date of their scheduled follow-up visit. Again, contact information for the field office was provided. The content of the letter read:

Dear « »,

Thanks for participating in the University of Houston health study. We enjoyed talking to you. We would like to remind you that it is now time for your six-month follow-up interview. When you come in for your follow-up interview you will be paid \$30.00 for your time and effort.

You will also be entered in a raffle at the time of your follow-up interview. The raffle prizes are: 1st prize is \$50.00 and we have five 2nd prizes paying \$10.00

each. Please ask how you are eligible. Remember we want to talk to you about anything that has happened in your life, since we last interviewed you.

Your follow-up visit is scheduled for _____, ___/___/____. If you complete your interview on your scheduled date you will receive a \$5 bonus. **Call us to schedule your interview by calling _____ or by stopping by our office before your scheduled interview.** We're open Monday–Friday from 8:00AM to 5:00PM.

We look forward to seeing you.

Birthday Card Mails—As part of the above mentioned mails, research staff sent one last mail that proved to be one of the most important. Two weeks prior to each respondent's birthday, individual cards were mailed out to each respondent who was still eligible for the follow-up interviews. The cards wished the respondent a Happy Birthday and informed them that if brought into the office, the cards were redeemable for a \$10 gift certificate to a local store. The objective of the birthday card was threefold: get respondents to come into the field office, maintain contact with them, and collect updated locator information. There were instances in which the outreach specialists would hand deliver birthday cards for those that were returned in the mail as undeliverable. Many participants expressed that this was the first birthday card they had ever received and were very appreciative of the gesture. Pedro, a 28-year-old male from the West Side of San Antonio, was one of the first noninjectors to be recruited into the study (August 2002) and thus one of the first to come into the office and redeem his birthday card (April 2003). Pedro had a ninth-grade education, was father of a 5-year-old and unemployed. Pedro recalls:

I don't think I ever got a card for my birthday. It was really nice. When I saw it in the mail I didn't know what it was. I opened it and there it was. I mean it's nice to get a gift certificate but getting the card was cool.

While the birthday cards were effective in getting participants to come into the office in-between interviews, they also assisted the outreach staff in gaining the trust of the respondents. That is, the cards reflected personalized attention and to a certain extent a sense of empathy from the research staff that many respondents had not previously experienced.

Project "Brown" Raffle—A final strategy used during the course of the study was what was known as the "Project Brown Raffle." Within a three-month period, every respondent who completed either a baseline or follow-up interview was eligible to participate in the raffle. At the completion of their respective interviews, respondents would receive a raffle ticket with a unique number printed at either end of the ticket. The respondent would keep half of it for their records while the other half was put into a raffle bowl kept in our field office. At the completion of the three-month period, the project staff would hold the raffle by drawing six winning tickets. Cash prizes included a first place winner of \$50 and five distinct second place winners each worth \$10. The strategy for the raffle was to encourage respondents to phone or come by the field office to get the raffle results. By getting them to do this, we were able to obtain any new updated locator information and maintain contact with the respondents.

According to data collected on the locator reconciliation form, during the first follow-up interview, approximately 50% of the respondents indicated that the raffle encouraged them to return to the field office. Of these, 42% felt that the raffle was "somewhat" or "very" important in their decision to visit the field office. These data demonstrate the extent to which the raffle was effective in motivating individuals to visit the field office.

Personal Visits/Phone Calls—Finally, throughout the course of the study, in particular when the above strategies did not yield results, outreach staff made phone calls and personal visits to homes. This strategy was particularly critical during the month’s in-between interviews. Phone calls were used in two ways. First, the day before the scheduled follow-up interview, outreach specialists would make reminder phone calls with those with valid numbers. Staff were instructed to follow the following script.

“Hello my name is _____. I am calling to remind you of your scheduled appointment with the University of Houston’s Health study. I would like to confirm that you will be able to come in to the office for the interview. I would also like to remind you that we will pay you for your time and effort and will be eligible for a raffle if you complete your follow-up interview.

[If respondent is unable to make appointment, attempt to re-schedule]

[*If respondent confirms appointment:*] “Thank you for participating in the study and we look forward to speaking with you tomorrow.”

Staff also implemented telephone reminders within one hour of a missed appointment. In some cases the respondent had forgotten the appointment and in others they were not available. If at all possible, interviews would be rescheduled for the same day. Phone calls were also used as a way to maintain contact with respondent’s in between interviews. This was especially the case for those that had valid phone numbers. Outreach specialists would not have to drive into the community to make a visit in person.

Personal visits were the primary alternative to phone calls. Of importance, personal visits contributed to the research team’s “street presence.” This street presence facilitated the process of maintaining trust and rapport with the population under study. Also, the location of the field office within the same geographical area where the recruitment was taking place contributed to the interaction of staff and respondents on a daily basis. For instance, the following note from OS1 describes his street persistence in finding a 29-year-old female respondent.

Rose was always living with her mother. She was in and out of jail during the course of our study. What I had to do was to find one of her relatives who were also enrolled in the study. The problem was that they were very mobile. For instance, during the study Rose’s two cousins lived in two different apartments. I soon found out on talking to people that they had become homeless and were living under the bridge. One of them transitioned to injecting heroin and was very difficult to locate. I finally found the other cousin and she took me over to where Rose was now living. It took time to find Rose’s cousin. It took about 7 to 10 attempts out in the field, but I finally found her. I took her in my car to show me the place. This example of being persistent paid off because I stayed on top of this network.

According to OS1, the key to maintaining contact with a respondent like Rose was the large network. That is, given that Rose had several cousins OS1 had established trust and rapport with made it easier to locate her through the network.

Supplemental Retention Strategies—There were two strategies that supplemented the above retention techniques. One, supplemental retention strategy used was the offering of referrals to appropriate social and medical services in the community if the respondent expressed the need. As part of another study the research team involved was funded by SAMHSA, and a *Family Resource Manual* was developed. The referral manual identified a comprehensive list of services for individuals and their respective families participating in the research. The manual includes pamphlets and descriptions of the services each agency provides, some of which include health, criminal justice, education, and legal services. On

many occasions, respondents would visit the field office seeking referrals. The most common reason for unscheduled visits by participants (mostly females) was for seeking referrals for assistance in paying water or electricity bills. During these visits the research team had the opportunity to collect updated locator information and remind participants of their upcoming follow-up appointments.

A second supplemental strategy was the implementation of *institutional data searches*. These searches were initiated if the outreach specialist's efforts to relocate participants did not yield rapid results. The searches facilitated the location of hard to find respondents who may have been incarcerated, deceased, and/or relocated to other parts of the country. Databases and information sources accessed included components of the local, state, and Federal criminal justice information systems, public health care facilities, and drug treatment providers. In the course of the study, the research team established linkages with the San Antonio Metropolitan Health District, the Bexar County Hospital District, and other institutions such as the Bexar County Juvenile Systems to access equivalent databases. Moreover, the research team also utilized the public services of the database Lexis-Nexis to obtain any updated locator information on participants who were difficult to relocate through the previously identified methods. These searches were only conducted among those respondents who gave the project consent to use institutional databases.

Principles Associated with Low Attrition Rates

Through the field experience of the staff and the implementation of the previously identified tracking and retention strategies, six principles were derived that we have identified to be of special importance in reducing the attrition rate in follow-up studies of heroin drug users (injecting and noninjecting). First among these is the *collection of adequate locator information up front*. Getting this information will prove to be key in maintaining contact with respondents and reducing the likelihood of attrition.

The second principle is that high follow-up rates in studies of deviant or socially marginal subjects ("hidden populations") are rarely achieved without *intensive utilization of indigenous paraprofessionals as field workers*. Properly selected and trained field workers in maintaining confidentiality tend to have "privileged access" (Griffiths, Gossop, Powis, and Strang, 1993) to closed or restricted social networks. For instance, as previously mentioned the project field staff were all Mexican Americans who grew up and were currently living in the research neighborhoods. Their social characteristics and life experiences matched, within practical limits, those of the target population. However, these persons should also have certain personality attributes in order to be maximally effective including good communications skills, tact, persistence, and problem-solving abilities.

The third principle is to *provide adequate, effective incentives* for subjects to enroll in the study and to make themselves available for repeated postbaseline measurements. The research team's previous experience has demonstrated that there is no ready substitute for cash incentives payable immediately following completion of each interview especially when dealing with a drug-using population. Cash incentives we have found are extremely cost effective.

Documentation is the fourth principle. All locator-relevant data received from or about each subject should be recorded in detail. For example; an outreach specialist runs into a street contact who knows subject X, who is due for a follow-up interview. The contact mentions that subject X has been seen on the day labor pool gathers near the overpass. "X" is not on this outreach specialist's wanted list but he passes this information on to the outreach specialist who is assigned to that respondent, and he enters it in a progress field note.

Access to prison population is important given that hidden study populations tend to be mobile due to unstable personal relationships, employment problems, and recurrent involvement with the criminal justice system. Thus, establishing a relationship with the local sheriff's department and gaining access to these potential respondents is critical.

Flexible procedures with some latitude in scheduling and conducting interviews with respect to both time and place are essential. Insistence on rigid adherence to appointment schedules is often counterproductive. Thus, the field office staff should be structured so that subjects who arrive for follow-up interviews at an unscheduled time can be accommodated within reasonable limits. Also, for some subjects, the site of the interview can be an issue. Therefore, if necessary, some follow-up interviews may be conducted at sites other than the field office.

Discussion and Conclusion

In drug use(r) research, hidden populations differ significantly from respondents recruited from treatment programs along such variables as accessibility, severity of psychological issues, residential and occupational instability, and legal status (Eland-Goossensen, van de Goor, and Garretsen, 1997). These characteristics prevent the use of standardized tracking systems used for retention that are implemented with more conventional populations. This may explain the reason that cross-sectional research designs are often selected by most researchers investigating populations with these characteristics. The ethnographic strategies and principles for tracking and study retention described in this article offer drug user researchers guidelines for designing successful longitudinal studies among these types of populations.

Most of the discourse on the methodology of hidden populations has been on how to gain access to the population and drawing representative samples (Griffiths et al., 1993; Heckathorn, Broadhead, and Sergeyev, 2001; Spreen, 1993; Thompson and Collins, 2002; Watters and Biernacki, 1989). The knowledge used to draw a good sample from a hidden population is very different from that which is needed to follow up the sample and to retain it in sufficient numbers in order to validly measure changes in study variables. Our tracking and retention methodology has been effective largely because it relies primarily upon the development of innovative and creative informational sources and procedures than are found in both sampling strategies for hidden populations as well as for longitudinal clinical studies. In this manner, our ethnographic field approach allows us to incorporate the "everyday" knowledge of our subjects by our research team into our methodology (Burawoy, 1998). This approach also facilitates a continuing and flexible contact process that is not dependent or restricted to requirements associated with a clinic, community social service center or other institutional setting.

We have found that much of the new ethnographic knowledge needed to sustain contact with hidden populations in a longitudinal study is contextual knowledge. This knowledge does not refer primarily to the individual characteristics of the subject, but more importantly to the subject's social environment. For example, in our study, the NIU participants were members of a relatively closed community that is characterized by persistent poverty and social isolation (Bauder, 2002). Even though our respondents exhibited serial residential mobility, they rarely left the geographical boundaries of the West Side community or interacted with persons outside of these neighborhoods. These closed contextual characteristics of the community informed the principles that emerged from our retention strategies. For instance, indigenous fieldworkers were employed because they had firsthand knowledge of the particulars of the culture and context of which the population was embedded. These staff, in addition to individual follow-up data and documentation, placed

respondents within specific personal networks and social environments that facilitated maintaining contact with them (Valdez, Neaigus, and Kaplan, In Press). Also, gaining access to the county jail\break population through good relationships with the sheriff's department emerged as a necessary methodological principle.

Social community characteristics also need to be considered in the development of tracking and retention strategies among drug-using populations. We found that the use of a raffle and a financial incentive of \$40–50 was an effective motivation for continuing in the research in particular given the economic status of the community. However, the use of material incentives such as the raffle has been found to be less of a benefit among more affluent groups (Latkin and Knowlton, 2000). Research in eastern Europe has also suggested that social background factors such as weak social networks and high levels of stigmatization of behavior can determine the appropriate use of monetary and nonmonetary incentives (Simic et al., 2006). Our findings support the call for a more full and open debate that takes into consideration the influence social background characteristics such as poverty and social isolation has on identifying appropriate incentives as well as the associated risks and harms that may arise from paying drug-using study participants (Fry, Hall, Ritter, and Jenkinson, 2006; Seddon, 2005).

In conclusion, quantitative studies have demonstrated how population differences can affect the internal validity of statistical techniques. Awareness of these differences require specific adjustments in quantitative methodology (Hook and Regal, 1995; Wickens, 1993). Our findings suggest that applying ethnographic tracking and retention methodologies will require particular adjustments that are fitted to both the context and social background characteristics of the population. For instance, strategies and principles applied to marginalized populations such as Mexican American heroin users will have to be modified compared to those more affluent and less socially isolated populations. Our main research conclusion therefore is that the internal validity of longitudinal studies of hidden populations of drug users would benefit from remembering earlier social science traditions that argued for a continuous combination of ethnography and quantitative methods in the conduct of community and social epidemiological drug-user research (Goor et al., 1994; Lambert, 1990).

Biographies



Alice Cepeda, Ph.D., is currently Assistant Professor in the Department of Sociology at the University of Houston (UH) where she is also Associate Director of the Center for Drug and Social Policy Research (CDSPR). Dr. Cepeda received her Ph.D. in Sociology from the City University of New York, Graduate Center. Her experience and research interest has been in substance use, crime, violence, prostitution, and urban health issues among the Mexican-origin (Mexican Americans and Mexicans) population. At the CDSPR, Dr. Cepeda is currently coinvestigator of a NIDA funded study focused on examining how disaster related experiences associated with Hurricane Katrina impact changes in substance use and abuse patterns. More recently, she has been working on a research project as part of a NIDA funded Minority Institute Drug Abuse Research Development Program focused on social networks of aging Mexican American injecting heroin users. Dr. Cepeda is also a recipient and scholar of the National Center on Minority Health and Health Disparities (NCMHD) Loan Repayment Program.



Avelardo Valdez, Ph.D., is currently a professor at the Graduate College of Social Work at the University of Houston and Director of the Center for Drug and Social Policy Research. He obtained his Ph.D. in Sociology at the University of California, Los Angeles. He was also a Fulbright Scholar at the Universidad Nacional Autónoma de México, Mexico City, D.F. A primary focus of his research has been on the relationship between substance abuse and violence and health issues among high-risk groups. His research projects have been among “hidden populations” such as youth and prison gang members, injecting and noninjecting heroin users and sex workers on the U.S./Mexico border. He is a recipient of federal research grants from the National Institutes of Health (NIH), Centers for Disease Control and Prevention (CDC), and Substance Abuse and Mental Health Services Administration (SAMHSA). He is currently working on a NIDA-funded grant focused on examining long term consequences of adolescent gang membership on HIV, hepatitis and STIs. Dr Valdez is a current recipient of a NIDA Minority Institution Drug Abuse Research Development Program grant. His most recent book is entitled “Mexican American Girls and Gang Violence: Beyond Risk” published by Palgrave/St. Martin Press (2007).

Glossary

| | |
|---|---|
| Contextual factors | Social and structural features of the environment that may affect and or motivate behaviors of members beyond individual characteristics. |
| Cross-sectional research designs | A methodological research design where respondents are assessed at one point in time. |
| Health risk behaviors | Behaviors individuals engage in that may potentially put them at risk for such health consequences as infectious diseases, personal injury, or psychological disorders. |

| | |
|-----------------------------------|--|
| Hidden populations | A population in which members are not readily distinguished, hard to identify and access, and often engage in behaviors that are stigmatized. |
| Longitudinal panel designs | A methodological research design where one or more cohorts of participants are assessed at several points in time. |
| Nonintervention research | Research in which individuals behaviors are observed or studied without interrupting the daily lives of the respondents. |
| Outreach specialist | An individual who is trained to identify and recruit persons in the community with specific characteristics and enroll them into research projects. Used interchangeably with field worker/recruiter in social science research. |

References

- Bailey J, Bieniasz M, Kmak D, Brenner D, Ruffin M. Recruitment and retention of economically underserved women to a cervical cancer prevention trial. *Applied Nursing Research* 2004;17:55–60. [PubMed: 14991556]
- Bauder, H. *Work on the West Side: urban neighborhoods and the cultural exclusion of youths*. Lanham, Maryland: Lexington Books; 2002.
- Brischetto, RR. Making connections on San Antonio's West Side: the neighborhood transformation/family development project. Baltimore, MD: The Annie E. Casey Foundation; 2000.
- Burawoy M. The extended case method. *Sociological Theory* 1998;16(1):4–33.
- Craig RJ. Locating drug addicts who have dropped out of treatment. *Hospital, Community and Psychiatry* 1979;30(6):402–404.
- Del Boca FK, Darkes J. Enhancing the validity and utility of randomized clinical trials in addictions treatment research: II. Participant samples and assessment. *Addiction* 2007;102(8):1194–1203. [PubMed: 17511752]
- Dunlap E, Johnson B. Gaining access to hidden populations: strategies for gaining cooperation of drug sellers/dealers and their families in ethnographic research. *Drugs and Society* 1999;14(1/2):127–149. [PubMed: 19809526]
- Eland-Goossensen A, van de Goor IA, Garretsen HF. Heroin addicts in the community and in treatment compared for severity of problems and need for help. *Substance Use & Misuse* 1997;32(10):1313–1330. [PubMed: 9286002]
- Fried P, Watkinson B. 36- and 48- month neurobehavioral follow-up of children prenatally exposed to Marijuana, cigarettes, and alcohol. *Journal of Deviant Behavior Pediatrics* 1990;11(2):49–58.
- Froelicher E, Miller N, Buzaitis A, Pfenninger P, Misuraco A, Jordan S. The enhancing recovery in coronary heart disease trial: strategies and techniques for enhancing retention of patients with acute myocardial infarction and depression or social isolation. *Journal of Cardiopulmonary Rehabilitation* 2003;23(4):269–280.
- Fry CL, Hall W, Ritter A, Jenkinson R. The ethics of paying drug users who participate in research: a review and practical recommendations. *Journal of Empirical Research on Human Research Ethics* 2006;1(4):21–36. [PubMed: 19385835]
- Goor, LAMvd; Garretsen, HFL.; Kaplan, C.; Korf, D.; Spruit, IP.; Zwart, WMd. Research methods for illegal drug use in hidden populations. *Journal of Psychoactive Drugs* 1994;26(1):33–40. [PubMed: 7913127]
- Griffiths P, Gossop M, Powis M, Strang J. Reaching hidden populations of drug users by privileged access interviews: methodological and practical issues. *Addiction* 1993;88:1617–1626. [PubMed: 8130701]
- Heckathorn DD, Broadhead RS, Sergeyev B. A methodology for reducing respondent duplication and impersonation in samples of hidden populations. *Journal of Drug Issues* 2001;31(2):543–564.

- Hook EB, Regal RR. Internal validity analysis: a method for adjusting capture-recapture estimates of prevalence. *American Journal of Epidemiology* 1995;142(9 Suppl.):48–52.
- Katz K, El-Mohandes P, Johnson D, Jarrett P, Rose A, Cober M. Retention of low income mothers in a parenting intervention study. *Journal of Community Health* 2001;26:203–218. [PubMed: 11478566]
- Lambert, EY., editor. *The collection and interpretation of data from hidden populations* (Vol. 98). Washington, DC: USGPO; 1990.
- Latkin CA, Knowlton AR. New directions in HIV preventing among drug users: settings, norms, and network approaches to aids prevention (Snaap): a social influence approach. *Advances in Medical Sociology* 2000;7:261–287.
- Mackenzie A, Funderburk F, Allen R. The characteristics of alcoholics frequently lost to follow up. *Journal of Studies on Alcohol* 1987;48(2):119–123. [PubMed: 3560947]
- Morgan P. Unknown, unexplored, and unseen populations: an introduction into the truly hidden worlds of drug and alcohol research. *Journal of Drug Issues* 1996;26(1):1–4.
- Neaigus A, Gyarmathy A, Miller M, Frajzyngier VM, Friedman SR, Don CDJ. Transitions to injecting drug use among noninjecting heroin users. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 2006;41(4):493–503.
- Parra-Medina D, D'antonio A, Smith S, Levin S, Kirkner G, Mayer-Davis E. Successful recruitment and retention strategies for a randomized weight management trial for people with diabetes living in rural medically underserved counties of South Carolina: the Power Study. *Journal of American Diet Association* 2004;104:70–75.
- Robinson KA, Dennison CR, Wayman DM, Pronovost PJ, Needham DM. Systematic review identifies number of strategies important for retaining study participants. *Journal of Clinical Epidemiology* 2007;60(8):757–757. [PubMed: 17606170]
- Robles N, Flaherty DG, Day NL. Retention of resistant subjects in longitudinal studies: description and procedures. *American Journal of Drug and Alcohol Abuse* 1994;20(1):87–100. [PubMed: 8192137]
- Seddon T. Paying drug users to take part in research: justice, human rights and business perspectives on the use of incentive payments. *Addiction Research & Theory* 2005;13(2):101–109.
- Sifaneck SJ, Neaigus A. The ethnographic accessing, sampling and screening of hidden populations: heroin sniffers in New York City. *Addiction Research and Theory* 2001;9:519–543.
- Simic M, Johnston LG, Platt L, Baros S, Andjelkovic V, Novotny T, et al. Exploring barriers to 'respondent driven sampling' in sex worker and drug-injecting sex worker populations in Eastern Europe. *Journal of Urban Health: Bulletin of the New York Academy of Medicine* 2006;86(6 Suppl):i6–i15. [PubMed: 17109206]
- Spreen, M. Sampling and analyzing in hidden populations. In: Bieleman, ADB.; Merlo, G.; Kaplan, CD., editors. *Lines across Europe*. Amsterdam: Swets & Zeitlinger; 1993. p. 185-204.
- Sterk CE. Building bridges: community involvement in drug and HIV research among minority populations. *Drugs and Society* 1999;14(1/2):107–121.
- Thompson SK, Collins LM. Adaptive sampling in research on risk-related behaviors. *Drug & Alcohol Dependence* 2002;68(1):S57–S67. [PubMed: 12324175]
- U.S. Bureau of the Census. Quick tables: QT-PL. Race, hispanic or latino, and age: 2000 for San Antonio city, Texas. 2000. Retrieved July 16, 2003, from <http://factfinder.census.gov/>
- U.S. Bureau of the Census. Annual demographic survey march supplement: Table 2. Age, sex, household relationship, race and hispanic origin by ratio of income to poverty level: 2001. 2001 Sep 23. 2002. Retrieved July 17, 2003, from http://ferret.bls.census.gov/macro/032002/pov.new02_001.htm
- U.S. Bureau of the Census. *Poverty in the United States: 2001, current population reports*. Washington, DC: U.S. Government Printing Office; 2002.
- U.S. Bureau of the Census. Quick tables: Qt-PI. Race, hispanic or latino, and age: 2000 for San Antonio City, Texas. 2005. (Publication no. from <http://factfinder.census.gov/>). Retrieved December 14, 2005, from <http://factfinder.census.gov/>

- Valdez A, Neaigus A, Kaplan CD. The influence of family and peer risk networks on drug use practices and other risks among Mexican-American non-injecting heroin users. *Journal of Contemporary Ethnography* 2008;37(1):79–107. [PubMed: 19337564]
- Watters JK, Biernacki P. Targeted sampling: options for the study of hidden populations. *Social Problems* 1989;36(4):416–430.
- Wickens TD. Quantitative methods for estimating the size of a drug-using population. Special issue: prevalence estimation techniques for drug-using populations. *Journal of Drug Issues* 1993;23(2): 185–216.



Map.

Table 1

Follow-up tracking bulletin board

| RESID | Staff ID | Baseline Int. | Contact 1 | Contact 2 | Contact 3 | Contact 4 | Contact 5 | Contact 6 | Second FU projected | Second FU actual date | | |
|-------|----------|---------------|-----------|-----------|-----------|-----------|-----------|-----------|---------------------|-----------------------|---------|---------|
| 141 | 39 | 4/24/03 | 6/3/03 | 8/14/03 | 10/27/03 | 10/24/03 | 10/28/03 | 12/04/03 | 3/25/04 | 4/25/04 | 4/28/04 | 4/26/04 |