

## Ethno-epidemiological research challenges: Networks of long-haul truckers in the inner city

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### **Abstract:**

Long-haul truck drivers and members of their social networks in urban locales constitute a hard-to-reach population at risk for acquiring and disseminating STIs/HIV. This paper focuses on the unique logistical, methodological, and ethical challenges faced by population health scientists while studying long-haul truck drivers and members of their sexual networks in inner-city neighborhoods of a major US metropolitan center and the innovative strategies developed to overcome the challenges. Formative research and focus groups with several trucker-centered populations (N = 28) led to in-depth interviews and serologies with 60 truck drivers and 24 sexworkers. Various difficulties encountered by the research team are discussed, followed by strategies devised to overcome them.

**Keywords:** hard-to-reach populations | truckers | social networks | ethno-epidemiological research | urban populations

### **Article:**

#### **Introduction**

The difficulty of investigating sexual and drug behaviors and their associated health ramifications among hard-to-reach or ‘hidden’ populations is well documented (Adler, 1990; Agadjanian and Zotova, 2012; Atkinson and Flint, 2001; Fashola, 2010; Festinger et al., 2005, 2008; Flanagan and Hancock, 2010; Johnston and Sabin, 2010; Platt et al., 2006; Potterat et al., 2004; Rothenberg et al., 2004; Seddon, 2005; Shaghaghi et al., 2011). Population health research in socioeconomically depressed urban settings, in particular, is entrenched with multiple

complexities and risks that arise during subject recruitment, sampling, and data collection involving hard-to-reach populations and their social partnerships (Adler, 1990; Agadjanian and Zotova, 2012; Atkinson and Flint, 2001; Fashola, 2010; Lee, 1995; Magnani et al., 2005; Van Maanen, 1988). These difficulties are often linked to their distrust of outsiders and fear of stigmatization, judgment, or fear of arrest, which are oftentimes-salient characteristics of marginalized populations (Agadjanian and Zotova, 2012; Goffman, 1963).

Hard-to-reach populations are comprised of associations of people for whom formalized lists do not exist. Members of these populations may be dispersed, may leave the immediate community due to frequent incarceration, may be distrustful of outsiders or may have a proclivity for privacy due to housing or financial circumstances they do not wish to express to people they are unfamiliar with, or may be bound by shared illicit behaviors (e.g. illicit drug use); specific characteristics may be undefined, and they are difficult to locate via an available sampling frame or known residential location (Adler, 1990; Fashola, 2010; Rothenberg et al., 2004). Some members are likely to be averse to research participation due to their involvement in illicit behaviors that define their membership in a hidden population (Adler, 1990; Johnston and Sabin, 2010), or as a result of previous negative experiences with researchers or healthcare service providers (Flanagan and Hancock, 2010). Field researchers who attempt to gain access to hard-to-reach populations by interacting with potential participants in their natural environments often risk negative association or stigmatization by outsiders, including law enforcement (Faugier and Sargeant, 1997). In other cases, researchers are not well matched to the populations and communities they are working with, in terms of community experience and education level (Nilan, 2002; Peritore, 1990; Rothenberg et al., 2004). Studies with hard-to-reach populations that involve collecting specimens for STI/HIV testing and sensitive personal data and identifiers present a multitude of ethical, legal, and operational difficulties (Klov Dahl et al., 1994; Rothenberg et al., 2004; Woodhouse et al., 1994). In some of these studies when researchers deemed it crucial to locate HIV-positive individuals within social networks, the option of confidential instead of anonymous HIV testing was preferred, although it increased concern on the part of participants (Rothenberg et al., 2004).

Long-haul truck drivers and members of their drug use and sexual networks in urban North American locales exemplify poorly investigated hard-to-reach and hidden populations. The trucking subculture, occupational stressors, and broad trucking milieu in inner-city neighborhoods create unique work and living conditions for long-haul truckers and their social networks that elevate their risk susceptibility (Apostolopoulos and Sönmez, 2006, 2007; Apostolopoulos et al., 2010, 2011, 2012, 2015). Consequently, studies involving these populations require particularly thoughtful research approaches. In view of the significance of reaching a better understanding of hard-to-reach and hidden populations for effective etiological intervention, in this paper we: (1) present a brief overview of key issues in drug/STI social and health science research with hard-to-reach and hidden populations; (2) discuss logistical and ethical challenges encountered while implementing *ethno-epidemiological* methodology to understand long-haul truck drivers and members of their social networks in US urban, inner-city neighborhoods; and (3) summarize key lessons learned and innovative solutions devised in response to challenges of data collection that have implications for population health research involving hard-to-reach and hidden populations in risk-enabling urban environments of industrialized countries. Ethno-epidemiological methodology refers to an '*emergent cross-*

*disciplinary health research methodology that combines the strengths of direct participant observation and other qualitative methods for understanding social meanings and contexts as practiced in medical anthropology with the design, sampling, data collection, and analytical strategies focusing on risk factors and disease outcomes developed in epidemiology'* (Darity, 2008).

This paper is based on the experiences of fieldworkers that were brought back to the research team, which led to a series of changes in study procedures. The fieldworkers were also debriefed over several meetings following the completion of the study, during which all issues were discussed. Extensive notes taken during those conversations served as the primary source for this paper, to explain the challenges encountered during various phases of data collection.

### **Trucker networks, substance use, and STIs: Design and methods**

The federally-funded Trucker Community Health Project was designed to examine connections between substance use, sexual behaviors, and risk for infection acquisition and transmission among long-haul truck drivers and members of their social networks in urban, inner-city neighborhoods of a major metropolitan area in the southeastern United States (Apostolopoulos and Sönmez, 2006). In the framework of social network studies (Wasserman and Faust, 1994), one of the key aims of this investigation was to better understand the assumption that network structure has consequences for its individual members and for the network as a whole over and above the effects of characteristics and behavior of individuals involved in the possible transmission of sexually transmitted (STIs) and bloodborne infections (BBIs), including HIV.

While members of truckers' social and risk networks are primarily hidden populations due to their involvement in illicit activities, long-haul truck drivers are considered hard-to-reach due to their constant mobility as well as hidden due to some drivers' substance use and risky sex transactions that can be profoundly detrimental for their employment security as well as their personal lives (Apostolopoulos and Sönmez, 2007; Apostolopoulos, et al., 2007, 2010, 2011, 2012, 2015). While a detailed description of sociodemographic segments of trucker social networks as well as study methods are beyond the scope of this paper, readers are referred to earlier publications for additional details (Apostolopoulos et al., 2007, 2010, 2015). There are roughly 3.5 million truck drivers in the US (American Trucking Association, 2014); however, the focus of this paper is on the risk-taking behaviors of a transgressive minority. The problem with this lies in the fact that drivers are perpetually mobile and can engage in risk behaviors with members of risk networks in a variety of environments. However small it might be, a subgroup of transgressive drivers has the potential to transmit STI/HIV across a number of states they drive through by repeating risky encounters. Research protocols were approved by the Institutional Review Board of the university where the study was implemented and all participants provided written informed consent while being permitted to remain anonymous, through the use of aliases. The Trucker Community Health Project went through three consecutive, progressive phases:

*Phase I* was ethnographic in nature and designed to identify the full gamut of populations and locations of interest, to introduce field researchers to the dynamics of these populations and locations, to initiate trust-building efforts, as well as to inform the next phase of the investigation

involving focus-group discussions. Formative fieldwork, which extended for a period of about three months beginning in the fall months, included sociospatial mapping, onsite non-participant observation, and informal discussions. During this phase the research team explored the spatial and social topography of trucking milieux spanning interstate highways, highway rest areas, socioeconomically depressed urban centers, and industrial sections of the selected metropolitan area. Sociospatial mapping illustrated the relationship between the spatial and social characteristics of research settings representing truckers' overall risk environment. Spatial characteristics of selected study sites included truckstops and trucking-related businesses, gas stations, fast food restaurants, bars, nightclubs, strip clubs, hotels and motels, informal brothels located in motels where rooms are rented by the hour, vacant lots, homeless shelters – all amidst a network of roads and highways funneling tractor trailers into the area (Apostolopoulos et al., 2012). In many of these establishments, drug and sex transactions were known to take place. Social characteristics included a loosely-formed community of truckers, female sexworkers, drug dealers, pimps and hustlers, homeless or transient persons, intermediaries who work at or near truckstops or gas stations either polishing chrome wheels or running errands for truckers, and often procuring drugs or female sexworkers for truck drivers, as well as members of local law enforcement who patrolled the area (Apostolopoulos et al., 2012). Observation was conducted at six different inner-city settings until three locations were selected as final study sites for subject recruitment and data collection – primary selection criteria included proximity to truckers and ample trucker-centered activities. Field notes covered approximately 970 hours of onsite observation and informal discussions with 105 individuals, conducted by seven field researchers with ethnographic training (Apostolopoulos and Sönmez, 2003). Managers of truckstops were notified of our research study and were told that observation and informal discussions would be conducted in their vicinity (outside in the parking lot or nearby). Study activities were kept outside of the truckstop to avoid interfering with business activities as well as to avoid any surveillance cameras that would make study participants uneasy.

*Phase II* involved five focus-group discussions with a total of 28 participants: 10 truckers, six drug suppliers, five female sexworkers, four intermediaries, and three gatekeepers (e.g. employees of local businesses, such as custodial staff or cashiers at the truckstop checkout who are comparatively more stable in the community and have greater familiarity with those going in and out of the site – both locals and drivers) who worked at nearby truckstops. The main objective of this phase was to utilize findings from focus groups to develop valid themes and questions for the next phase of in-depth interviews. Systematic sampling with a random start was used to sample every Nth (randomly selected number) trucker and gatekeeper at truckstops. Snowball sampling was used to recruit intermediaries, sexworkers working out of nearby motels, and drug dealers selling drugs to various members of truckers' risk networks in the area, including the drivers themselves. Following an explanation of the study and a series of basic screening questions, individuals were invited to participate in the focus groups. They were given rides by the field researchers to the focus-group location and were brought back upon completion.

Finally, *Phase III* included in-depth, face-to-face interviews with female sexworkers and intermediaries engaged in substance use and/or sales and sexual risk-taking with long-haul truck drivers, to fully delve into these behavioral risk patterns and their determinants as well as to obtain serological data on their STI/HIV status. In-depth interviews were conducted with 90

participants: 60 truckers, 24 female sexworkers, and six intermediaries and/or drug suppliers. Participants were recruited using respondent-driven sampling (RDS) procedures beginning with sexworkers or intermediaries often doubling as drug suppliers, identified as *indexes* (due to their relative stability in the community compared with the more transient drivers passing through), who led field researchers to their *contacts* (drivers with whom they engaged in drug and/or sex transactions). RDS, a variety of chain-referral sampling, has been used since the late 1990s in research involving hard-to-reach and hidden populations such as injection-drug users (Heckathorn et al., 2002; Stormer et al., 2006) and men who have sex with men (Yeka et al., 2006). RDS allows researchers to access hard-to-reach populations through their social networks and identify relationships among persons who tend to engage in the same behaviors as the *index* (Stormer et al., 2006). The *index* is at the center of a cluster of *contacts* comprising the social network, which s/he is connected to via sexual or drug transactions and/or relationships.

Informed consent was obtained with participant signatures for which all participants were permitted to use aliases to protect their anonymity, including street names or Citizen's Band (CB) radio 'handles' that are short but memorable nicknames used while broadcasting (e.g. Big Red, Gas Hog). At the conclusion of the interviews, blood and urine samples as well as vaginal swabs were collected, which were tested for HIV, syphilis, hepatitis B and C, chlamydia, gonorrhea, trichomoniasis, and genital herpes. All serological samples were identified with the aforementioned aliases and assigned study participant numbers; reports of completed assay results were returned to the project office with the same aliases and numbers, therefore no legal names were used at any time in order to protect participants' anonymity.

### **Ethno-epidemiological research with networks of truckers: Challenges and remedies**

A number of anticipated and unexpected logistical, methodological, and ethical concerns were encountered during the Trucker Community Health Project. Appropriate solutions were devised to overcome them in order to successfully complete the project. Regardless of how well planned an ethno-epidemiological study with hard-to-reach and hidden populations might be, researchers are likely to encounter unexpected challenges. Mid-course corrections to data collection methods have been reported in other studies involving similar methodological approaches (Potterat et al., 2004).

#### Logistical issues

The organizational structure of the research team was comprised of a principal investigator (PI), two co-investigators (Co-Is), a project director, one field supervisor and seven field researchers (later reduced to two). Constant communication between the PI, project director, and field supervisor provided ongoing oversight of all study-related activities. Preparatory steps taken by the research team prior to data collection were intended to minimize expected challenges associated with the nature of the study. Along with Institutional Review Board (IRB) approval of protocols to protect human subjects (e.g. informed consent), a federal Certificate of Confidentiality (CoC) was obtained to protect the confidentiality of information anticipated from study participants. The CoC, issued by the National Institutes of Health (NIH), helps researchers protect participants enrolled in biomedical, behavioral, clinical, or other forms of sensitive research and protect compulsory legal demands (e.g. court orders, subpoenas) for identifying

information or identifying characteristics of a research participant (NIH, 2002). While the CoC permitted the research team to protect the identities of study participants from law enforcement for any illegal activities, it also prevented research team members from notifying authorities in the case of a truck driver or any member of his social network using illegal substances. This process was essential for trust- and relationship-building to ensure the highest quality of data.

To avoid potential legal issues for the research team that would eventually compromise the study's integrity, area police precincts were contacted prior to the start of research and were provided with a letter from the PI on university letterhead explaining the nature of the study as well as the location and times the research team would have a presence at the sites belonging to their jurisdiction. Letters included copies of field researchers' photo-identification cards in order to avoid their possible arrest while spending extensive time with drug contacts, sexworkers, and transient individuals, during trust building and data collection efforts.

A detailed ethnographic field manual was developed during this period to clarify in detail all study procedures and to be used as a training and reference guide for field researchers and project staff (Apostolopoulos and Sönmez, 2003). Seven public health graduate students were hired as field researchers. All had taken at least one advanced research methods course, demonstrated theoretical understanding of qualitative and epidemiological research, and expressed excitement over involvement in a project that would give them valuable field research experience. Once hired, they received extensive training on study procedures, populations and types of activities of interest, trust-building methods, and procedures for conducting non-participant observation, methods for taking field notes, procedures for sociospatial mapping, tips on initiating informal discussions, participant screening and recruitment, human subject protections, informed consent procedures, as well as phlebotomy. All field researchers obtained IRB certification before beginning fieldwork. Key study investigators monitored fieldwork and debriefed field researchers on their experiences as well as difficulties they encountered during the course of their work.

Difficulties of using RDS to recruit members of a study population deemed hard-to-reach or hidden were exacerbated by the addition of mobility/absence of fixity. *Indexes* believed at first to be permanent in the communities used as study sites were later discovered to also move in and out of those communities quite a bit, due to transience or incarceration. This issue became particularly problematic when field researchers needed to reach them to report lab results and extremely urgent for positive STI/HIV cases. Unlike truck drivers who have mobile phones and can be reached regardless of their movement, many of our *indexes* who used street names, had no stable addresses, lacked mobile phones as a result of dire financial situations, and thus were particularly hard to reach and needed to be tracked down through multiple tries. Field researchers were required to have precise and regularly updated records of contact information for all study participants.

A particularly critical logistical issue emerged as the study team approached the phase of recruiting participants for focus groups, when the physical location planned for this phase became a problem. Focus-group discussions were originally set to be conducted at the university offices located in downtown (about 9 miles from study sites); but during the recruitment process it became evident that alternative arrangements were required to keep study participants in their

comfort zones. None of the potential participants were willing to travel to the downtown area where the university was located, despite the offer of rides to and from the university. As a result, a meeting room was rented at a hotel located within a few minutes of one of the primary study sites to conduct the focus groups. A large sign was placed in the lobby with the university emblem, indicating the room where Trucker Community Health Project focus groups were being held. This location eliminated the discomfort of study participants while it increased the convenience of holding all focus groups within a two-day period; however, transportation needed to be arranged to and from the hotel even though it was only minutes away from the usual hangouts of participants.

Similarly, original plans to conduct in-depth interviews and serologies at the university had to be revised. To accommodate the participants while ensuring their privacy during the interviews and to assure an acceptable level of hygiene while collecting blood and urine samples and vaginal swabs, it became apparent that data would best be collected at the hotel rooms out of which the female sexworkers conducted their transactions and where they felt safe. Because the sexworkers knew the intermediaries, their interviews as well as the interviews with their trucker contacts were also conducted in hotel rooms. In those situations where sexworkers or intermediaries did not already have hotel rooms, field researchers rented a room to be able to conduct the interviews. This arrangement, although more costly, was more desirable for all study participants, including the truckers, and would not have been possible with the original team of researchers (discussed further below). Field researchers informed hotel managers of their research activities in the rooms in order to get their permission as much as to increase their personal safety. In order to increase study participants' comfort level, field researchers often conducted interviews in rather difficult circumstances such as prolonged exposure to smoke from study participants' crack pipes or sitting with scantily clad or partially nude participants immediately following a sex transaction. Because the interviews often required several days to arrange due to difficulties in reaching identified participants and the occasional disappearance of some of these individuals due to incarceration or loss of housing, it was not possible for the field researchers to seek ideal circumstances in which to carry out their work. The study team's response to this logistical challenge turned out to increase the success of focus group and in-depth interview discussions; however, getting the collected serological samples back to the university lab at very late hours following data collection added additional unavoidable inconvenience to field researchers.

Methodological issues

### ***Sampling procedures***

Participant recruitment and sampling presented assorted challenges for different members of truckers' risk networks and across study phases, including focus groups and interviews. Using information from and relationships built during the lengthy period of onsite observation in Phase I, the research team finalized the recruitment and sampling strategies that varied slightly by subgroup of truckers' networks.

As noted earlier, systematic sampling using a random start to select every Nth individual was used at selected urban inner-city locations, to recruit truckers and gatekeepers for focus-groups

discussions to follow. The recruitment process involved approaching selected individuals and engaging them in informal discussions, asking key screening questions, describing the nature of the research project, explaining the voluntary and confidential nature of participation, and providing information on incentives and study locations. Following informed consent, which included an explanation of the need for recording the conversation for later transcription, and being permitted to use CB handles or aliases of their choice rather than actual names, the truckers were quite forthcoming in their discussions.

Given the illegal activities of certain members of the truckers' social networks – intermediaries, female sexworkers, and drug suppliers – snowball sampling was used to recruit an index – a type of contact-tracing which begins with the index who then leads researchers to his/her contacts (members of his/her social network) in the process of recruiting participants for focus-group discussions. A copy of the CoC was presented to members of these groups to assure them that their identities would not be revealed. Additional reassurances were made that they would not be turned over to law enforcement and that they would be permitted to use only their aliases, rather than legal names, before they agreed to participate. While the intermediaries and sexworkers were extremely forthcoming to the questions of the focus group moderator, drug dealers were not at all so until they felt comfortable some time after understanding that the discussion was being recorded only for transcription purposes, that no names would be used on the recording, and that the recordings would be destroyed following transcription.

Due to specific behaviors of interest (e.g. sex, drug use), an RDS approach was used to recruit indexes and their sex and/or drug contacts for individual interviews in Phase III. Using word-of-mouth, field researchers sought out sexworkers and drug dealers who had engaged in sex and/or drug transactions (or use) with truck drivers. The challenges included locating individuals who were not only connected to each other through these transactions but who were willing to reveal their contacts to researchers and also helping to locate truckers who might have previously driven through the city but were not currently accessible. The reason our RDS procedures selected sexworkers and drug dealers as indexes, rather than drivers, is that researchers were certain (from prior informal discussions and focus groups) that truckers would be unlikely to admit to engaging in commercial sex or drug transactions for fear of risking their jobs, and it provided greater certainty of the credibility of the relationships within the social network. There is a level of trust established between truck drivers and their contacts who are sexworkers or drug dealers; therefore, drivers are much more willing to discuss these relationships when prompted by the sexworkers or drug dealers themselves rather than when approached by a researcher. The field researchers had succeeded in earning the trust of sexworkers and drug dealers who also had a great deal to lose. The fact that these individuals felt comfortable enough with the researchers to lead them to truck drivers who were their drug and/or sex contacts allowed the drivers to also feel more comfortable participating in the interviews. Very few driver contacts continued to demonstrate reluctance to talk with field researchers once identified by their drug and/or sex contacts (our indexes).

The intensive relationship-building carried out during Phase I was critical to the success of field researchers when they began to screen potential study participants – particularly when identifying sexworkers and intermediaries as indexes and also for locating their truck driver's sex and drug contacts. Indexes were given a nominal cash incentive to put their trucker contacts

in touch with field researchers. Most sexworker and intermediary indexes were found to engage in fairly regular communication with truck drivers who were their regular clients. Truckers often give their mobile phone numbers or CB handles to the individuals with whom they develop such a level of trust so they can meet during the drivers' next stopover in town. The selected indexes were asked to communicate with the truckers, explain their involvement in the study, assure them that their participation would not bring them any harm, and to invite the truckers to talk with field researchers. Once the contacts (truckers) were communicated with, field researchers went through a detailed vetting process to confirm that the indexes and contacts actually knew each other and had engaged in either a drug or sex transaction (or both) as claimed, before enrolling the drivers for interviews. Also challenging in this process was the field researchers' responsibility for managing the intricate balance of membership in trucker networks because conflicts frequently erupted between female sexworkers, pimps, drug dealers, and truck drivers over money, territory, or relationship jealousies.

### *Data collection*

The primary challenge to data collection that emerged was on matching field researchers to study populations across the three phases of the study. Selecting the right field researchers who can work together and who have the right combination of qualifications, education, and life/street experience is critical to the success of this type of research (Nilan, 2002; Peritore, 1990; Rothenberg et al., 2004). As the study progressed, it quickly became evident that the initial team of male and female, white and African-American field researchers in their mid-20s was not well matched with the study's particular characteristics involving potentially dangerous study sites with populations engaged in illegal activities. For the field researchers to be able to observe naturally-occurring phenomena relative to our research questions, they were required to work in these environments when the study population was accessible (late night until early hours of the morning), which meant working into the evening hours to have at least partial access. Field researchers expressed growing discomfort at being immersed in the study settings, described earlier, especially after dark. Because the fieldwork began in the fall, days were getting shorter, with nightfall beginning as early as 4–5 pm.

Researchers were given explicit and repeated instructions on situations to avoid for their own safety, such as not getting into a vehicle or truck cab while having discussions with truck drivers or other study participants. In one case, a female researcher decided against her better judgment and ignored explicit instructions, by agreeing to conduct an informal discussion with a truck driver inside the cab of his truck parked at a truckstop. After a period of time passed, the researcher became increasingly uncomfortable over the explicit discussion of sexual transactions, left the truck cab, and phoned another field researcher to meet her. Although no harm came to her, she was duly shaken by the experience. This is one example of questionable judgment and naïveté on the part of the field researchers. The vastly different life experiences between them and study populations contributed to a lower than expected comfort level among the field researchers. The field researchers, all graduate students attending a top tier private university, came from middle/upper-middle class families. They had previously come into contact neither with the types of locations of our study sites nor with members of the study population. Their selection may be attributed to the research team's overconfidence in how their academic experiences and qualifications (e.g. knowledge of advanced research methods) would translate to

their effectiveness in the field – in other words, an incorrect recruitment strategy. In hindsight, it is quite understandable why these graduate students were not well matched with their assigned tasks and felt unsafe in the study sites. Not unlike experiences in similar studies, field researchers' safety concerns greatly diminished their effectiveness (Nilan, 2002; Peritore, 1990; Rothenberg, et al., 2004). Initial efforts to ease their discomfort included pairing up field researchers; however, dispatching two researchers to the same study site created logistical problems of matching schedules and made members of the study population feel outnumbered during the interview and less willing to talk. These efforts to improve the situation were quickly abandoned and the PI replaced the original team of field researchers in order to avoid compromising their personal safety as well as the study.

The second wave of researchers differed greatly from the first; two African-American men in their late-40s who could be described as 'street wise' were hired. Both had extensive experience in both ethnographic and epidemiological research with hard-to-reach populations in inner-city environments from numerous other federally funded projects conducted at the university (at both schools of medicine and public health), and both were certified phlebotomists. Peritore (1999: 369) has noted that 'street knowledge must supersede ideological or cultural assumptions for the researcher's own safety'. The gender, maturity, race, and much more relevant life experiences of these two men assured their substantially greater level of comfort working at selected study sites regardless of time of day. Because the majority of our study population was African-American, the ethnicity of these two field researchers created a higher degree of comfort among study participants when broaching sensitive topics. Additionally, these field researchers were able to access the study population much more effectively by conducting the majority of their fieldwork in the evening. Their abilities to communicate with members of the truckers' social networks using appropriate colloquialisms, demonstrate common sense approaches to solving problems and sound judgment when confronted with difficulties or unexpected situations, and especially to read and avoid hazardous situations were essential for recruiting participants for in-depth interviews and serologies. A new period of trust building was thus initiated in order to assure continuity of the work started by the first group of field researchers and to ease the new researchers into the study settings by building rapport with the study population. The new field researchers' extensive experience expedited these efforts and helped to build relationships with members of the study population in the form of their own social network quite rapidly, leading to successful recruitment and data collection in the next phase, as they maintained regular contact with key informants (Peritore, 1990). In addition to the foregoing efforts, the empathy and lack of judgment with which the field researchers approached study participants and the manner in which they conveyed the research team's genuine interest in understanding and alleviating their health risks were the foundation for the building of the level of intimate trust and genuine human relationships that permitted not only the collection of sensitive information during the interviews but also the serological data (blood, urine, vaginal swabs).

### Ethical issues

Several ethical issues emerged related to the witnessing of illegal activities such as sexwork and drug transactions, protection of participant confidentiality and anonymity when informing participants of their STI results, and paying cash incentives to participants known to be involved in illicit activities. The research team acknowledged that illegal activities would be taking place

at the study sites but they were under no obligation to report them to law enforcement, with the exception of child abuse. The CoC provided additional protection to members of truckers' social networks by assuring that their illegal activities would not be revealed to law enforcement. Without this document, it would have been much more difficult for the research team to gain the confidence and trust of participants. Ethnographic studies have pointed out that field researchers gain 'guilty knowledge' when studying deviant or illegal behaviors and inevitably breaking the law in order to acquire valid data from study participants (Fetterman, 1983; Polsky, 1969). In its most innocuous form, this occurs when researchers gain knowledge of illegal activities or make 'guilty observations' by being present at the scene of a crime (Adler, 1990). Ethnographers have also been described as having 'dirty hands' because they do not emerge innocent of wrongdoing as a result of their 'guilty knowledge' (Fetterman, 1983). In our study, field researchers were faced with the ethical dilemma of witnessing illegal activities, such as drug and sex transactions by study participants during the course of data collection. For the research team, however, the value of gathering valid data that would benefit members of the study population remained a constant priority and guideline for the fieldwork.

The nature of the study warranted the protection of study participants' identities; however, allowing participants to use their aliases created challenges when 'anonymous' participants were to be notified of their STI/HIV test results. In one study with different populations, level of education and age were found to play a role in drug users' willingness to return for their HIV-test results (Ziek et al., 2000). In our case, we tried to minimize any discomfort associated with getting STI/HIV test results by using participant identification numbers instead of actual names to reconnect with study participants in order to provide results. In order to identify participants to provide their test results in a private and confidential manner, each interviewed participant was issued a unique number. With the exception of truckers, most study participants did not have a contact number where they could be easily reached. Field researchers provided all study participants with their business cards labeled with the project name, researcher's name, and mobile phone number. Truckers were asked to call the field researchers on their mobile phones at an appointed date and time, provide their alias and participant identification number, and answer several screening questions regarding their interviews in order to get their test results. For sexworkers and intermediaries who remained in the local area, field researchers delivered their test results in person. Any individual who tested positive for an STI or HIV was provided with supplemental information on local healthcare and social service facilities where they could seek treatment.

The research team tried to balance issues of practicality and research ethics with regard to subject incentives; the primary 'currency' on the street was found to be cash and, to a lesser degree, food. Various incentives were used to facilitate informal discussions, participant recruitment, and data collection, ranging from food and beverage purchases from nearby fast food restaurants and convenience stores to more substantial cash incentives of \$20 for participation in focus groups and \$40 for in-depth interviews and serologies. Additional monies were paid to sexworker and intermediary/drug dealer indexes to provide researchers with information that would lead to their truck driver sex and drug contacts, payable upon confirmation. These fees were set at a nominal \$5 to avoid the suggestion of coercion; however, one sexworker or intermediary/drug dealer was able to receive \$40 for being interviewed and up to an additional \$30 or \$40 for their network contacts, depending on the number of confirmed

contacts they yielded. Free STI/HIV testing of serological samples served as an additional incentive for individuals who would not otherwise easily get tested. Field researchers provided study participants with additional incentives such as free condoms, safe-sex literature, and information on local free medical services, resources for drug rehabilitation, and a number of other local social services. Although the research team was aware that the cash paid to study participants could be used to procure substances, the close communication that developed between participants and field researchers also revealed that the cash incentives were mostly used to cover basic needs, such as food or a hotel room for many participants who were homeless or unstably housed.

## **Lessons learned**

Some of the key issues discussed included the difficulties experienced by researchers with overall spatial and social characteristics of research settings, extensive time required for trust-building with populations at risk involved in illicit activities (e.g. sexwork, drug dealing, using drugs while driving commercial vehicles), difficulties in recruiting study participants, appropriate matching of field researchers with study settings and populations, and problems with the logistics of data collection such as selecting appropriate locations for qualitative data and serological sample collection, challenges of informing study participants of their STI/HIV test results while assuring their anonymity, and ethical considerations of paying cash incentives to study participants involved in sexwork and drug transactions. Key lessons learned and how they fit into the larger drug/STI literature related to hard-to-reach and hidden populations are discussed below.

### **Logistical lessons**

Thorough pre-study planning is an essential component of working with hard-to-reach and hidden populations and helps to anticipate potential issues for study subjects and researchers. In this case, the federal CoC helped researchers to protect study participants' anonymity as well as the integrity of the data collected. Also, informing local law enforcement of the identities of field researchers served to protect them against any suspicion that might have arisen from the extensive amount of time they spent with members of the study population involved in illicit activities in questionable environments at various times during the day and night.

Meticulous record keeping of any and all individuals the study team came into contact with, keeping track of constantly changing aliases, addresses, and telephone numbers as well as the quickly and often loosely formed relationships among the study population, allowed field researchers to maintain contact with these individuals. We also found it very useful for field researchers to make occasional appearances at study sites, even on those days when data were not being collected, to maintain established relationship and become a regular part of study participants' environments. Finally, the study team's flexibility in logistical matters helped greatly. By adjusting the environment in which data were collected from what was convenient and logical for the research team to what was comfortable and perceived safer for the study population, we were able to accommodate the needs of study participants and continue the study without interruption. These adjustments also conveyed to field researchers that although the

process was fluid, the major priority was to achieve study objectives rather than get stuck in details, with the caveat that rigor and quality were not compromised.

### Methodological lessons

Cultivating a working relationship between field researchers and members of hard-to-reach populations is of utmost importance because mutual trust and respect are critical for successfully engaging individuals in the research (Flanagan and Hancock, 2010), and for preventing challenges documented by other researchers while working with similar populations. Thus, in order to engage members of hard-to-reach study populations, researchers need to remain flexible and consider innovative approaches to their sampling, recruitment, and data collection procedures in order to ensure high-quality, reliable data.

Research with injecting drug-users has largely used recruitment methods of chain referral, snowball, or convenience sampling to gain access to individuals closely connected to the target population through current or former drug use. Researchers have also recruited drug-using individuals to function as indigenous fieldworkers who then recruit others as study participants (Platt et al., 2006). It is important to note that snowball sampling techniques may be prone to certain types of bias, such as selection bias, because members of the population who are not connected to associates of the targeted social network may be excluded or gatekeeper bias, because intermediaries feel protective of their contacts and may hesitate to refer them as members of the study population (Atkinson and Flint, 2001). RDS offers an alternative to snowball sampling with potential to increase generalizability of study results to other populations (Johnston and Sabin, 2010).

As noted above, the first phase of the Trucker Community Health Project was designed to increase our knowledge of the research settings and for trust building. A primary component for successful data collection focused on relationships between field researchers and populations of interest, for early ethnographic data collection and index solicitation. Successful subject recruitment in this type of research requires a certain level of trust between researchers and potential participants. Having carefully cultivated these types of relationships, the research team relied on both snowball and RDS sampling and recruitment techniques to delve deeper into the social, sexual and drug networks of truckers. RDS has proved a particularly useful method in identifying indexes and recruiting contacts involved in sex and drug transactions (Fashola, 2010; Platt et al., 2006; Stormer et al., 2006). A series of studies involving injecting drug-users in Eastern European countries compared the two sampling methodologies of chain-referral sampling using 'indigenous fieldworkers' and RDS and found the latter to enable faster recruitment and to better address staff safety considerations, but also to cost significantly more (Platt et al., 2006). Challenges of RDS include incorporating an incentive that is enticing enough to motivate participants to refer others to the study (Fashola, 2010), yet modest enough to prevent participants from referring others unrelated to the target population in order to earn more money (Platt et al., 2006).

Once the sampling strategy was established, recruitment of participants and data collection details became the key focus of the study. In the Trucker Community Health Project, physical locations selected for data collection, in particular, became a concern for recruiting study

participants. This problem emerged during both focus-group discussions and in-depth interviews and had to be resolved before researchers could move forward. Addressing participants' feelings of discomfort when asked to leave their natural environments to participate in research activities led to movement of data collection locales from the university campus to hotel rooms located at the study sites. The renting of hotel rooms for data-collection purposes created an unanticipated but necessary expense for the study and may be an option with hard-to-reach populations, but serious matters of personal safety and security need to be considered. Each field researcher became somewhat of a 'regular' at the hotels, where they spent increasingly more time as the study progressed. A rapport was established between them and hotel employees, leading to a positive feeling on the part of the hotel staff as well as study participants that they were playing an important role by contributing to research conducted by a group of health researchers that actually cared about their community. These experiences confirmed the critical importance of the training and experience of the research team to be well matched to the needs of the study population for successfully accessing, engaging with, and collecting data from study participants. They also confirmed the importance of daily communication between the PI, project manager, and field researchers to have an up-to-the-minute grasp of what was happening in the field, in order to make necessary changes.

Finally, it is very important to build in sufficient time to studies taking place with similar populations in order to give the field research team the opportunity to get to know the community. These types of studies cannot take place without the community's trust in the researchers, which can only be earned through their repeated presence over a lengthy period of time (Rothenberg et al., 2004). In this study, field researchers established relationships with both permanent (local business owners, e.g. hotels, lingerie shops, gas stations, fast food restaurants) and transient members of the communities that comprised our study population. The researchers gave their business cards to all those they communicated with, which included the university name and study title, their mobile telephone, as well as the name of the principal investigator and numbers for the research office in case they had questions. In a manner of speaking, the study became a community effort of sorts, with everyone doing their part. Furthermore, the sensitivity and respect with which field researchers approached each individual contributed greatly to validating the worth of each and every individual they interacted with. The importance of this behavior – particularly for marginalized populations who were accustomed to ill treatment and to being judged at multiple levels – was repeatedly emphasized to field researchers. Stigmatized persons have been described as being reduced 'from a whole and usual person to a tainted and discounted one' (Goffman, 1963: 3). Our study participants included homeless individuals, sexworkers, drug dealers, drug users, as well as truck drivers, each of whom were accustomed to ill treatment by the rest of society (Apostolopoulos et al., 2012, 2015). Primarily for ethical and secondarily for pragmatic reasons, it was critical for field researchers to approach and treat study participants as individuals worthy of respect and consideration.

During the colder months in particular, members of the research staff organized a clothing drive to gather warm clothing, which was then distributed by the field researchers to the members of the study population. It is strongly believed by the research team that these front-heavy community building efforts that took place for months at the start of the project and continued throughout the study, resulting in good will, is the primary reason for the field researchers'

success, not only in getting names of drug and sex contacts but also in getting extremely personal and sensitive information regarding sexual and drug use behaviors.

### Ethical lessons

Given the not uncommon practice of illicit behaviors (e.g. drug use, sexwork) among some members of hard-to-reach and hidden populations (Fashola, 2010), reluctance to participate in research is understandable (Flanagan and Hancock, 2010; Johnston and Sabin, 2010). Accordingly, the research team weighed a number of ethical concerns in approaching the study. First and foremost, it was important to protect the anonymity of participants through the use of aliases and the CoC. The research team's commitment and responsibility to inform study participants – often transient and/or involved in illegal activities – of their STI/HIV test results was made more difficult by the commitment and responsibility to protect their anonymity. The research team delivered STI/HIV results in person to local participants and communicated via telephone with the drivers who were on the road. The effectiveness of this approach depended on the field researchers' ability to maintain the trust of study participants so that they were willing to share their contact information with the researchers for communication later on. An important consideration for future studies will be to identify effective mechanisms by which to link individuals who test positive for STIs/HIV with healthcare services. As a result of this study, a number of participants were informed of available resources (e.g. drug rehab programs, women's assistance programs) in the community that they were unaware of.

Another serious consideration was justifying the payment of cash incentives to participants who were known substance users without expressing any type of judgment. Paying cash incentives to study participants involved in illicit activities clearly raises ethical considerations. Cash incentives could be viewed as a reward for or enabling of illicit behavior; however, appropriating different types of incentives for participants based on their behaviors may be construed as discriminatory (Seddon, 2005). In one study that enrolled clients of drug abuse treatment centers, varying amounts (\$10, \$40, \$70) of cash and gift certificate incentives for participation were compared and it was found that cash incentives neither coerced study participation nor promoted new drug use (Festinger et al., 2005, 2008). Instead, higher incentives and cash (instead of gift certificate) payments were associated with higher rates of follow-up, reduced the amount of time and money researchers spent tracking participants, and improved participant satisfaction with the study – suggesting that higher incentive payments, particularly in cash, may be effective strategies for improving participation without the risk of increasing new drug use or fostering perceptions of coercion (Festinger et al., 2005, 2008).

Additionally, there is concern that paying cash incentives may endanger the personal safety of field researchers in certain types of study settings, if community members suspect the researchers of carrying cash or vouchers with them (Seddon, 2005). Having learned a great deal about study participants during the early phases of this project, field researchers were often privy to information on how some of the monies were spent (e.g. rent of hotel room, food, other necessities). There were instances where incentives paid to sexworkers for data collection meant they had to seek one or two fewer clients that day. Overall, it was determined that the benefits of collecting data outweighed other concerns regarding how incentive monies might be spent.

On several occasions, sexworkers requested assistance from field researchers to deal with their traumatic experiences and, more importantly, to get out of sexwork permanently, and several others requested assistance to deal with their drug addiction. When these were reported back to the research office, appointments were made with local social work bodies, women's organizations, and drug rehabilitation centers for the individuals who requested help. Only as much information was shared as to permit identification in the community (street name, personal descriptors, mobile number when available) but without violating their anonymity or privacy. Members of the research office staff followed up after a reasonable amount of time had passed, to assure that the individuals who requested assistance were indeed contacted by the organizations. As with earlier described community-building efforts, these instances of responding to study population members' calls for help created the sense among them that they were not simply being used to gather information but that they mattered to the research team, they were respected and valued, and that their contribution had meaning.

**Table 1.** Examples of considerations for working with hidden or hard-to-reach study populations.

Logistical	<ul style="list-style-type: none"> <li>• Keep meticulous records of members of the study population (names, aliases, hangouts, relationships, contact information), which oftentimes change.</li> <li>• Develop detailed research protocol for training and guiding field researchers; however, maintain flexibility in research procedures (e.g. locations of data collection) to accommodate needs of study participants.</li> <li>• Obtain any and all possible documents (e.g. Certificate of Confidentiality) to protect research team and study participants.</li> <li>• Inform local police precincts of study, field researchers, and the general community that will be involved to assure as much cooperation as possible.</li> <li>• Conduct sociospatial mapping of research environment and include potential data collection sites that are in the comfort zone of study participants and provide convenience for them as a priority.</li> </ul>
Methodological	<ul style="list-style-type: none"> <li>• Build sufficient time into study procedures for field researchers to understand (through non-participant observation) the community in which the study will take place and for extensive trust-building with community members.</li> <li>• Assure solid match between study participants and field researchers (e.g. maturity, race, life experiences).</li> <li>• Maintain daily communication between PI, project director, and field researchers to understand any issues as they arise.</li> <li>• Consider building in a period of time before and after the study to engage study population, to understand their needs and for follow-up to determine if social services they have been informed of have been located or delivered. This is particularly important to lay the foundation of good will and cooperation for subsequent studies taking place in the same environments.</li> <li>• Assure field researchers carry only small amounts of cash on them for their own safety when they spend extensive periods of time in precarious environments.</li> </ul>
Ethical	<ul style="list-style-type: none"> <li>• Build genuine relationships with study participants to prevent any feeling that they only serve the purpose of being study subjects. Efforts can include responding to some of their needs for clothing, food, shelter, and information on available health/social services).</li> <li>• Assure that incentives (in magnitude and form) are not viewed as coercive.</li> </ul>

## Conclusions

This paper addresses the unique logistical, methodological, and ethical challenges encountered and solutions that emerged from a study involving a series of qualitative phases, using ethno-

epidemiological methodology for engaging with hard-to-reach populations, specifically long-haul truck drivers and members of their sexual and drug networks in urban, inner-city locales in the southeastern United States. Key recommendations for overcoming (un)anticipated challenges address study logistics, sampling, recruitment, data collection, incentives, communicating with mobile network members, and informing subjects of their serological test results while assuring their anonymity. These lessons provide useful insights for approaching drug and STI research not only with long-haul truck drivers and their risk contacts in urban, inner-city locales but also with hard-to-reach and hidden populations in industrialized nations, in general. Experiences from this study have implications for other etiological research and interventions targeting hard-to-reach populations or marginal groups involved in illicit activities and highly susceptible to STIs. Incorporating the lessons learned into methodology and field staff selection and training may help to increase the quality of field methods and data collected. Some important considerations to keep in mind when working with hidden or hard-to-reach study populations are summarized in Table 1.

In conclusion, this study suggests that there are exciting opportunities to not only conduct action research with marginalized communities by engaging their members in a collaborative effort but also to bring needed services to underserved populations, by continuing relationships established during earlier phases of work. The study team through various means – lengthy trust-building, CoC, encouraging anonymity, collecting serological samples for testing in participants’ own environment, reporting back results, and offering guidance on what to do in case of positive results – engaged not only truck drivers but also members of their social and risk networks, each elusive for their own reasons. This reveals that epidemiological research with members of society who need assistance has greater potential for success when study participants are given the opportunity to play an active role; once they agreed to provide serological samples, our study participants were critical in changing our approach to collecting them. Using a community-building approach with genuine compassion and sensitivity to help members of marginalized, hard-to-reach populations, dealing with individuals with respect and validation and, whenever possible, providing assistance in response to calls for help comprise a humanitarian approach that this type of research can greatly benefit from. The study team felt very fortunate about the cooperation we received from study participants – partially due to our lengthy trust building efforts, but to a greater extent due to participants’ very human need for recognition and respectful treatment.

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