



Short Communication

A rural/urban comparison of privacy and confidentiality concerns associated with providing sensitive location information in epidemiologic research involving persons who use drugs



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HIGHLIGHTS

- To examine the risk environment, surveys collect sensitive location data from PWUD.
- Participants' privacy/confidentiality concerns may vary by setting or by approach.
- Locations considered to be sensitive differed in rural and urban settings.
- Interviewer rapport and confidentiality were more important to rural participants.
- Changes to the study protocol and the data collection approach can reduce concerns.

ARTICLE INFO

Keywords:

Research ethics, Rural
Urban
Risk environment
Substance use
Persons who use drugs

ABSTRACT

Background: Analyses that link contextual factors with individual-level data can improve our understanding of the “risk environment”; however, the accuracy of information provided by participants about locations where illegal/stigmatized behaviors occur may be influenced by privacy/confidentiality concerns that may vary by setting and/or data collection approach.

Methods: We recruited thirty-five persons who use drugs from a rural Appalachian town and a Mid-Atlantic city to participate in in-depth interviews. Through thematic analyses, we identified and compared privacy/confidentiality concerns associated with two survey methods that (1) collect self-reported addresses/cross-streets and (2) use an interactive web-based map to find/confirm locations in rural and urban settings.

Results: Concerns differed more by setting than between methods. For example, (1) rural participants valued interviewer rapport and protections provided by the Certificate of Confidentiality more; (2) locations considered to be sensitive differed in rural (i.e., others' homes) and urban (i.e., where drugs were used) settings; and (3) urban participants were more likely to view providing cross-streets as an acceptable alternative to providing exact addresses for sensitive locations and to prefer the web-based map approach.

Conclusion: Rural-urban differences in privacy/confidentiality concerns reflect contextual differences (i.e., where drugs are used/purchased, population density, and prior drug-related arrests). Strategies to alleviate concerns include: (1) obtain a Certificate of Confidentiality, (2) collect geographic data at the scale necessary for proposed analyses, and (3) permit participants to provide intersections/landmarks in close proximity to actual locations rather than exact addresses or to skip questions where providing an intersection/landmark would not obfuscate the actual address.

1. Introduction

Geographic Information Systems methods are used in HIV/HCV and substance use research to link contextual factors with individual-level data to understand how the “risk environment” influences behaviors

(Beletsky, Arredondo, Werb, et al., 2016; Brouwer, Weeks, Lozada, & Strathdee, 2008; Gaines, Beletsky, Arredondo, et al., 2015; Gaines et al., 2016; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005). For analyses to be informative, locations must be both accurate and contextually-relevant. Interviewer-administered surveys which

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collect participant-reported addresses/cross-streets are subject to recall bias, response bias, and data entry errors. These errors can influence the percentage of successfully geocoded addresses, and in turn reduce the sample size, introduce sampling bias (i.e., if participants selectively disclose some locations but not others), and diminish statistical power (Cayo & Talbot, 2003). Even web-based surveys which use Google Maps APIs to facilitate data entry and eliminate the need for geocoding (Rudolph, Bazzi, & Fish, 2016) remain susceptible to recall and response biases. This study aims to identify and compare privacy and confidentiality concerns associated with two interviewer-based survey methods that (1) collect self-reported addresses/cross-streets and (2) use an interactive web-based map to find/confirm locations (i.e., live/sleep, buy/use drugs) among persons who use drugs (PWUD) in urban and rural settings (i.e., a Mid-Atlantic city and a small rural Appalachian town) within the United States.

2. Methods

Study sites were selected for their elevated risk of comorbidities (including HIV and Hepatitis C) among PWUD, yet diverse social contexts which could influence privacy and confidentiality concerns related to participation in research studies, and particularly those that collect the locations of illicit behaviors/activities. For example, our two sites were distinct in terms of population size (622,271 vs. 5453), population density (7687 vs. 764 people/mi²), and demographics (63% vs. 2.1% African American/Black; median age 34.5 vs. 43.4) (United States Census Bureau, 2014). They also differed with respect to the type (s) of drugs used most often (prescription opioids in rural Appalachia (Brawley, Sanders, & Miracle, 2016; Jonas, Young, Oser, Leukefeld, & Havens, 2012; National Center for Health Statistics, Centers for Disease Control and Prevention, 2014) vs. heroin, crack, and cocaine in the Mid-Atlantic city (Buchanan & Latkin, 2008; Latkin, Knowlton, & Sherman, 2001; Williams & Latkin, 2007)).

Methods for recruiting participants in the Mid-Atlantic city are described elsewhere (Rudolph et al., 2016). Briefly, fifteen Mid-Atlantic city residents who reported drug use (past 6 months) were enrolled between November 2014 and April 2015. Between November 2015 and March 2016, twenty persons who reported drug use (past 6 months) were purposively selected for diversity on age, gender, arrest history, injection status, and type(s) of drug(s) used from an ongoing longitudinal study of PWUD in rural Eastern Kentucky (i.e., 'SNAP', described elsewhere (Young, Rudolph, Quillen, & Havens, 2014)). All study procedures and materials were reviewed and approved by Institutional Review Boards at The Pacific Institute for Research and Evaluation and Boston University. All participants provided written informed consent to complete an hour-long in-depth interview.

A semi-structured interview guide was developed for the mid-Atlantic city (Rudolph et al., 2016) and adapted for rural Appalachia. The guide used open-ended questions to explore concerns informed by the International Ethical Guidelines for Biomedical Research Involving Human Subjects (Sciences CfI OoM, 2002). Interviewers first described each method, showed an example question, and then explored issues relating to beneficence, confidentiality, and privacy. Of note, locations in the web-based map survey screenshot (Rudolph et al., 2016) were location-specific and recognizable to participants in each setting. For each method, participants were also asked whether they thought any of the concerns mentioned would influence anticipated study compliance or the accuracy of responses provided. Finally, interviewers explained that when researchers have obtained a Certificate of Confidentiality (CoC) from the National Institute of Health for data collected in the United States, they cannot be forced to provide identifying information about participants in any legal proceeding. Participants were then asked how knowing that the research was protected by a CoC would influence any of their concerns.

Demographic and behavioral data were collected in a short survey following each interview to provide additional context. All interviews

were recorded and transcribed verbatim using only unique identification numbers. The PI first reviewed all transcripts to develop a broad understanding of the content. Transcripts were then coded using the domains from the interview guide and other emergent themes using MAXQDA software (MAXQDA, 1989). All a priori and emergent codes were organized in a codebook and reviewed by another co-author. Discrepancies in code application were discussed and resolved. Themes were analyzed with respect to similarities and differences in participants' perspectives for each data collection method and across settings.

3. Results

As reported previously (Rudolph et al., 2016) the median age of the urban sample was 49 (IQR:43–52), 73% were male, 87% were Black, and 87% had a prior drug-related arrest. In the last 30 days, 27% reported injecting drugs and a majority reported using crack (73%). The rural sample's median age was 39.5 (IQR:34.5–42), 50% were male, 100% were white, 45% had a prior drug-related arrest, and 90% reported using at least one prescription opiate in the last 30 days. The samples were statistically significantly different on age, gender, race, types of drugs used, prior history of drug-related arrests, and self-reported HIV status (Table 1).

3.1. Interviewer rapport

Rural participants were much more likely to note that their

Table 1
Sample characteristics (N = 35), 2014–2016.

	Small Rural Appalachian Town		Mid-Atlantic City		P-value
	N = 20		N = 15		
	N	%	N	%	
Age (median, IQR)	39.5	34.5–42	49	43–52	0.0004
Male	10	50	11	73	
Race					< 0.0001
White (non-Hispanic)	20	100	2	13	
Black/African American (non-Hispanic)	0	0	13	87	
Drug use in the past 30 days					
Heroin	1	5	7	47	0.004
Crack	1	5	11	73	< 0.0001
Cocaine	6	30	5	33	0.83
Methamphetamine	5	25	0	0	0.04
Other	20	100	4	27	
Marijuana	8	40	2	13	0.08
Xanax	7	35			
Neurontin	5	25			
Klonopin	1	5			
At least one prescription opiate ^a	18	90			
Injected drugs in the past 30 days	8	40	4	27	0.23
Ever arrested for a drug related offense ^b	9	45	13	87	0.01
Ever been told by a healthcare professional that he/she was HIV positive	0	0	10	67	< 0.0001

^a Includes Suboxone (n = 11), IR30 (Roxicod) (n = 2), Oxycodone (n = 2), Percocet (n = 3), Ultram (n = 1), Lorcet (n = 3), Methadone (n = 4), Hydrocodone (n = 1), and Morphine (n = 1). The numbers do not sum to 18 because some participants reported using more than one opiate.

^b Those who had previously been arrested for a drug-related offense in both settings were significantly more likely to worry about the police getting access to the data (P = 0.0277).

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