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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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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

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Contributors: A.E.R. conceived the study design and research question, conducted in-depth interviews with participants at the urban site, analyzed data from all interviews (both sites), drafted and revised the manuscript, and approved the final version. A.M.Y. supervised participant enrollment and interviews conducted at the rural site and the adaptation of the interviewer guide to the rural context, contributed to the analysis, assisted with the interpretation of study findings, provided feedback on multiple drafts, and has reviewed and approved the final version of this manuscript. J.R.H. designed the SNAP study and directed its implementation, including quality assurance and control, revised the manuscript critically for intellectual content, and approved the final version. None of the authors are affiliated with any organization with a direct or indirect financial interest in the subject matter discussed in the manuscript.

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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.

Keywords

research ethics; rural; urban; risk environment; substance use; persons who use drugs

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.¹⁻⁵ For analyses to be informative, locations must be both accurate and contextually-relevant. Interviewer-administered surveys which 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.⁶ Even web-based surveys which use Google Maps APIs to facilitate data entry and eliminate the need for geocoding⁷ 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. 5,453), population density (7,687 vs. 764 people/mi²), and demographics (63% vs. 2.1% African American/Black; median age 34.5 vs. 43.4).⁸ They also differed with respect to the type(s) of drugs used most often (prescription opioids in rural Appalachia⁹⁻¹¹ vs. heroin, crack, and cocaine in the Mid-Atlantic city¹²⁻¹⁴).

Methods for recruiting participants in the Mid-Atlantic city are described elsewhere.⁷ 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 elsewhere¹⁵). All study procedures and materials were reviewed and approved by Institutional Review Boards at [Blinded Institutions]. 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 city⁷ 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.¹⁶ 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 screenshot⁷ 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.¹⁷ 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,⁷ 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 willingness to participate and provide truthful responses in a research study was dependent on interviewer rapport and trusting that the research staff would keep their responses confidential (See Table 2 for representative quotes). Many rural participants explained that their willingness to participate in the current study was based on the rapport that they had already developed with the interviewers over time. Many also recalled initial skepticism about participating in a research study, which subsided as they became more comfortable with the research staff.

3.2. Willingness to participate and provide truthful responses

In both settings, participants indicated that their willingness to provide truthful responses to an interviewer would be influenced by whether the researchers had a CoC. Rural participants referred to the CoC as a “trust agreement” and “a legally binding document that my information is private” which provided “freedom to talk without having to worry about it getting back to the wrong person”. Most urban participants were willing to participate in studies regardless of whether researchers had obtained a CoC,⁷ but were more willing to be truthful when one had been obtained. Among urban participants, willingness to participate in studies was related more to their anonymity as research participants.

3.3. Confidentiality of locations

Locations considered to be “sensitive” also differed in rural (i.e., locations of others' homes) and urban (i.e., where drugs were used) settings; the location where drugs were purchased was considered “sensitive” in both settings. Among those uncomfortable providing exact addresses for sensitive locations, urban participants were more likely than rural participants to view providing intersections/cross-streets as an acceptable alternative. Urban participants worried primarily about police gaining access to location information. Other concerns among urban participants included: losing their drug connections if providing this information led to their dealer's arrest, being considered a snitch, and fear of retaliation from a dealer or other PWUD for providing this information. The primary concern among rural participants was that others (i.e., law enforcement, social services, dealers, or employers) might get access to the data collected and use it against them or others at those locations. Because drugs were often purchased in others' homes, some feared that providing this information could “mess up [their] connection” (see Table 2). Although rare, one 40-year old rural male stated, “Either the police would know where it was, or somebody would find out that I pointed at their house on a map and kill me”. In each setting, those with a prior drug-related arrest were more likely to worry about the police getting access to this data ($P=0.0277$).

4. Discussion

In both settings, participants were concerned about providing addresses for locations where illegal activities occurred; however, there were contextual differences. While most urban participants who were uncomfortable providing exact addresses were comfortable providing intersections, few rural participants viewed this as an acceptable alternative. Further, many urban participants preferred the web-based map because it allowed them to identify nearby

cross-streets or approximate locations rather than exact locations. Differences in population density may partially explain this difference, as addresses and intersections provide less anonymity in rural settings (i.e., several urban apartments may share the same address but this is not as common in rural Appalachian towns). Similarly, providing the nearest intersection for an apartment, townhome, or storefront provides greater anonymity in more densely populated urban centers.

Second, rural participants worried more about providing other peoples' home addresses, which may reflect differences in where drugs were purchased in each setting. For example, a few urban participants noted that the police already knew where the drug areas were; however, many rural participants indicated that drugs were purchased in others' homes. A greater sense of community in rural Appalachia and differences in the composition of rural and urban drug use networks may also partially explain this finding. For example, compared with similarly recruited PWUD in urban settings, drug use networks in the larger PWUD cohort study in rural Appalachia were comprised of more family members;¹⁵ the close interpersonal bonds that characterize Appalachian families¹⁸ may partially explain the greater priority that rural participants placed on protecting the locations of others' homes.

Third, more urban than rural participants worried about providing the locations where drugs were used. This may reflect the fact that more urban participants (i.e., 87% of urban vs. 45% of rural participants) reported a prior drug-related arrest. Of note, rural participants who were unwilling to provide location information and who worried about police getting access to this data were significantly more likely to have a prior drug-related arrest ($P=0.0277$ and $P=0.0072$, respectively).

This study revealed potential privacy and confidentiality concerns from participants' perspectives and contextual differences in these perspectives. Below are measures that researchers can take to reduce these concerns without compromising analyses. First, obtaining a CoC was important in both settings and alleviated concerns about police gaining access to data. Among rural participants, having this certificate influenced willingness to participate in research and provide truthful responses. Among urban participants, it only influenced willingness to answer questions honestly. Of note, rural participants viewed trust in the research team as something that needed to be earned, whereas this trust was implied for most urban participants. While researchers conducting work in the United States previously had to apply for a CoC, in accordance with the 21st Century Cures Act, CoCs will soon be automatically provided for NIH-supported research.^{19,20}

Researchers should also consider the level of accuracy required to successfully carry out the study aims and design data collection instruments that collect only the relevant information. As researchers often aggregate location information and analyze it on a different scale (i.e., census tract or block-group), data collection tools could be developed that collect and store data only at the smallest unit needed for analyses. For analyses which aim to calculate distances between participant locations and health centers, collecting cross-streets rather than exact addresses should be considered, particularly in urban settings. Finally, participants should always have the option to skip questions or to provide approximate rather

than exact locations; this is particularly important in rural contexts, where providing an intersection may do little to obfuscate the actual address and could evoke privacy concerns.

5. Conclusions

The concerns expressed by participants differed more between settings than between methods, which likely reflects contextual differences. For example, rural participants placed more value on interviewer rapport and the protections in place by the CoC, which may reflect the fact that participants in the urban sample had more prior experience in research studies and were more likely to implicitly trust that their responses would be kept confidential. Further, where drugs are purchased/used, perceptions about whether these locations are already known to police, and having a prior drug-related arrest appeared to influence which locations were regarded as sensitive. Finally, urban participants were more likely to view providing cross-streets as an acceptable alternative to providing an exact address for sensitive locations and were consequently more likely to prefer the web-based map, which may reflect differences in population density. Importantly, many of the concerns raised can be reduced by minor changes to the study protocol or the data collection approach. For example, future studies can (1) obtain a CoC, (2) collect only the geographic data needed and at the scale necessary for proposed analyses, and (3) allow 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 effectively obfuscate the actual address.

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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

Sample Characteristics (N=35), 2014-2016

Table 1

	Small Rural Appalachian Town N=20			Mid-Atlantic City N=15			
	N	%		N	%		P-Value
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 ¹	18	90					
Injected drugs in the past 30 days	8	40		4	27		0.23
Ever arrested for a drug related offense ²	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

¹ Includes Suboxone (n=1), 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.

² 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).

Table 2

Comparison of Themes Identified among Participants in a Small Rural Appalachian Town and a Mid-Atlantic City (2014-2016).

		Theme	Qualitative differences in perspectives of rural and urban participants	Representative Quotes
Both Methods	Confidentiality concerns	Importance of obtaining a certificate of confidentiality	<ul style="list-style-type: none"> • Important for both study participation and for providing truthful responses among rural participants. • Important for providing truthful responses, but not a pre-requisite for being willing to participate in a study among urban participants. 	<ul style="list-style-type: none"> • “[With a certificate of confidentiality] I’d be 101% more comfortable... That means everything to us as people walking through the door. That is very, very important for someone to know that they are not going to get locked up for going to a certain house and buying a pill” (40-year old rural female) • “I think [having a certificate of confidentiality] puts the individual at ease and gives them more willingness to share information and be truthful” (52-year old urban male)
		Concerns associated with providing the locations for illegal activities (i.e., using and buying drugs)	<ul style="list-style-type: none"> • Rural participants were more concerned about providing locations where drugs were purchased than where drugs were used. Of note, drugs were more often purchased in others homes in the rural setting. • Urban participants were equally concerned with providing location information for buying and using drugs. 	<ul style="list-style-type: none"> • “I wouldn’t really want to say where I get my stuff at” (42-year old rural male) • “I would hate to have that location marked by someone...going to buy drugs would be my only concern” (45-year old rural female) • Due to privacy concerns, a few indicated that they would answer the questions despite some discomfort; others refused and said, “I don’t think I could do that” (41-year old rural female), “that’s crossing the line” (29-year old rural female), or “there’s no way” (33-year old rural female). • “From personal experience, I’m not

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		Theme	Qualitative differences in perspectives of rural and urban participants	Representative Quotes
				going to tell nobody where I buy no drugs at or use drugs at" (43-year old urban female)
		Importance of interviewer rapport	<ul style="list-style-type: none"> Mentioned by the majority of rural participants but only by a few urban participants. This difference likely reflects differences in prior experience as a research participant. While many urban participants had participated in research studies for many years, most rural participants had only participated in one prior study. <ul style="list-style-type: none"> "I've been doing studies for about 20 years." (44-year old urban male). 	<ul style="list-style-type: none"> "The first couple times...I thought that this place was setting people up--that they were going to have a big drug bust...after two or three times and nothing didn't happen, I gained trust in you... [Now] I [would] tell you [anything] because I know that it would be confidential 'cause I've told you all some stuff through the years that would probably put me in jail if the wrong people got a hold of it." (52-year old rural male). "It's all about trust...you've gained trust in a lot of people here... it's all about how the person treats you and how you feel around them" (51-year old rural male). "If you feel comfortable with them, you will probably give them the information. But if you're not feeling that person, you probably wouldn't...at [urban study location], you feel like they have a genuine interest in you...that they do generally care... but other studies that I've been in, you don't feel it" (43-year old urban female).
	Privacy concerns	Willingness to provide the locations of others	<ul style="list-style-type: none"> The majority of rural participants but only a few urban participants mentioned concern about providing the 	<ul style="list-style-type: none"> "That's their business. It's what they want to do... and that wouldn't be my place to put

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		Theme	Qualitative differences in perspectives of rural and urban participants	Representative Quotes
			locations of others' homes.	<p>that out" (42-year old rural female)</p> <ul style="list-style-type: none"> "I wouldn't give the addresses. I would give generalized locations" (39-year old urban male)
	Accuracy of location information provided	Likelihood of being honest about the location(s) where drugs were purchased	<ul style="list-style-type: none"> In both samples, a majority of participants indicated that they would either not answer this question or that they (and others) would not answer it honestly. 	<ul style="list-style-type: none"> "They're definitely not going to want to tell you where they get [drugs]... they're going to lie to you anyway. You realize that 9 times out of 10 what they're telling you is really not the truth." (52-year old rural male) "As far as where they purchase drugs...I don't think anybody would tell the truth about that" (43-year old urban female)
		Likelihood of being honest about the location(s) where drugs were used	<ul style="list-style-type: none"> More urban than rural participants were reluctant to provide this information in an interview. 	<ul style="list-style-type: none"> "I don't think people are going to want to tell you where they're actually doing the drugs because they're afraid somebody would walk in and catch them." (52-year old rural male) "I don't think I would be inclined to give an exact address, but a cross street would be easier for me to provide" (43-year old urban male)
	Confidentiality concerns	Concern that police might get access to the data	<ul style="list-style-type: none"> This was the primary concern in both settings. Rural participants were more concerned about disclosing the locations of others and the potential legal consequences for both themselves and others. Urban participants were primarily concerned with the 	<ul style="list-style-type: none"> "The police is mainly who everybody'd be concerned about" (40-year old rural female) "You're just used to not telling people that... plus, you don't want to get anybody in trouble. If it's illegal they can get in trouble" (40-year old rural male).

		Theme	Qualitative differences in perspectives of rural and urban participants	Representative Quotes
			legal consequences for themselves.	<ul style="list-style-type: none"> I'm not going to tell you where I use thinking somebody going to send the police there, and it's going to interrupt me while I'm using" (43-year old urban female) "[The police could] put a raid on where I live at" (62-year old urban male)
Web-based map only	Privacy and Confidentiality Concerns	Not wanting to pinpoint locations on a map due to fear that (1) they would be seen as a "rat" or (2) once entered into the internet, it could be accessed by others	<ul style="list-style-type: none"> Two rural participants and one urban participant expressed discomfort with "pin-pointing" locations on a map. 	<ul style="list-style-type: none"> "I think if you go there on Google maps... somebody records that and can go back and find it...that would worry me. Don't ever make me point it out on a map" (40-year old rural male). "I just don't like the fact that you pinpoint a drug area" (52-year old urban male)
	Accuracy	Perceive the web-based map to be helpful in finding some locations	<ul style="list-style-type: none"> More urban participants preferred this method. Many noted that this tool unlike the first method, allowed them to use the map to find nearby cross-streets which were preferable to exact addresses. Of note, most urban participants (but none in rural Appalachia) had experience with this data collection method. 	<ul style="list-style-type: none"> "I believe it would be a helpful tool because I know there's plenty of places that I have used before or have bought drugs before that I couldn't really tell you the name but I know what the place looks like and I know what's close by and stuff like that." (32-year old rural male) "Sometimes. I don't know the exact address. I just know how to get there." (54-year-old urban female)

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