


“He’s under oath”: Privacy and Confidentiality Views Among People Who Inject Drugs Enrolled in a Study of Social Networks and Human Immunodeficiency Virus/Hepatitis C Virus Risk

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Abstract

Despite the promise of social network research, this method raises important ethical questions regarding privacy and confidentiality. Although researchers and bioethicists have considered research obligations in relation to marginal or vulnerable populations, the views of people who inject drugs (PWIDs) have not been sufficiently considered. To elicit participants' views of research obligations, we conducted in-depth interviews with a subset ($n = 40$) of active PWIDs enrolled in a large social network study. Findings suggest participants have an expectation of confidentiality but believe this obligation need not be absolute and can be waived if a participant violates community norms or place others at risk. Ethics boards should recognize that marginalized populations are able to articulate complex moral views about privacy and confidentiality. Engaging participants in dialogue about the responsible conduct of research presents an opportunity to correct under- or overestimations of research vulnerabilities when such decisions are restricted to the perspectives of investigators or Institutional Review Board members.

Keywords

social networks, community-based research, ethics, privacy, anonymity, confidentiality, people who inject drugs, Puerto Rico

Introduction

In recent decades, social networks research has contributed to important gains in knowledge critical to programs designed to decrease the spread of infectious diseases (i.e., hepatitis C virus [HCV], human immunodeficiency virus [HIV], and other sexually transmitted diseases [STIs]) to chronic conditions (i.e., tobacco use and obesity) (Flath et al., 2018; Maddox et al., 2014; Morris, 2004; Rothenberg et al., 1998; Valente & Pitts, 2017; Valente et al., 2004; Williams et al., 2019; Wu et al., 2018). The relational data collected through social network analysis (Tubaro, 2014) are particularly important for epidemiological research, mapping how a virus or infectious diseases spread from one person to another within a particular group (Smith & Christakis, 2008).

Social network studies have been particularly critical in demonstrating how the sharing of drug injection equipment contributes to HIV risk among people who inject drugs (PWIDs) (Bogart et al., 2018; Ghosh et al., 2017; Latkin et al., 2018). Other social network studies have demonstrated that PWIDs were more likely to share needles and injection equipment with those users with whom they were strongly socially connected, rather than with mere

acquaintances or those with whom they had weak connections (De et al., 2007; Rudolph et al., 2017).

Recently, studies have shown that similar social network dynamics underpin the emergence of an HCV epidemic among PWIDs (Hellard et al., 2014; Pilon et al., 2011; Rolls et al., 2013). Social network analysis has been employed not only to illustrate how individual and structural factors can contribute to HIV and HCV risk behaviors in this group, but also to model the evolution of HIV and HCV epidemics among PWIDs and to formulate evidence-based prevention and treatment strategies (Mateu-Gelabert et al., 2018). One important contribution of social network health research to behavioral, epidemiological, or qualitative HIV research is the ability to understand the social pattern of infectious diseases within impoverished and marginalized communities.

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In turn, the relational quality of social network research, which is one of its main strengths, also presents particular ethical challenges. As detailed by Borgatti and Molina (2005), conducting social network research is different from traditional research, where participants report on themselves. Instead, participants in network studies report not only on themselves but also on others, who in turn provide the names of other individuals in their social network. Thus, social network research raises unique privacy, confidentiality, and anonymity challenges because there is no clear mechanism for securing the consent of individuals named by participants. This also presents challenges for Institutional Review Boards (IRBs), because traditional requirements for informed consent of “named” participants could bring this scientifically critical type of research to a halt (Klov Dahl, 2005).

The ethical challenges regarding privacy protections in social networks research continue to evolve with the emergence of new technologies. Social networks health research involving social media has prompted renewed concerns about privacy, confidentiality, and anonymity (Hibbin et al., 2018; Lunnay et al. 2015; Samuel and Buchanan, 2020; Sellers et al., 2020).

Researchers and bioethicists tend to interpret privacy and confidentiality by taking into consideration only their own obligations. However, an account of how study participants understand privacy and confidentiality or the role these considerations play in their decision-making process is lacking. While the research experiences of PWIDs have received some examination (Davidson & Page, 2012; Scott, 2008), to the best of our knowledge this is the first empirical study documenting how PWIDs involved in a social network study understand ethical obligations derived from their participation. By drawing on the experiences of PWIDs previously enrolled in a large-scale study of social networks and HIV/HCV risk in rural Puerto Rico, this paper explores the participants’ perspectives on privacy and confidentiality. Understanding how vulnerable populations perceive norms around HIV disclosure within their social network will contribute to the conduct of research in a way experienced as acceptable for participants. One strength of this study is that its participants’ views are shaped by their actual experience of having been enrolled in a social network study. Using qualitative methods involving 40 semistructured interviews with active PWIDs 18 years old and older, we documented participants’ views regarding the privacy and confidentiality issues raised by their engagement in social network research.

Methods

Aims

Data presented in this paper were from measures embedded in a larger study, in which participants’ views on research trust and attitudes toward financial compensation were

also examined (Abadie et al., 2018, 2019). This study focuses on how PWIDs view confidentiality and disclosure obligations when individuals within their social network are perceived as violating community norms. The purpose of this research is to (1) identify community norms on HIV disclosure in the course of social network studies with PWIDs, (2) motivate ethical deliberation around these issues, and (3) inform best research ethics practices through consideration of study participant’s values.

Participants

This study was nested within an ongoing, multi-year NIH/NIDA funded parent project on social networks and HIV/HCV risk among PWIDs residing in the localities of Cidra, Cayey, Aguas Buenas, and Comerio, in rural Puerto Rico. Data collection for the social network study was conducted between April 2015 and April 2017 and included $N=360$ active PWIDs ≥ 18 years old. Details about the methodology, including recruitment strategy and sample composition, have been published elsewhere (Abadie et al., 2016, 2017). To document participants’ views about confidentiality, we conducted semi-structured interviews ($N=40$) with a subsample of participants in the social network study. This was a convenience sample, with all the attendant limitations, but the broad inclusion criteria helped ensure sampling of participants from different sociodemographic backgrounds and substance abuse profiles. Since PWIDs in rural Puerto Rico are overwhelmingly men, we decided not to include women in our convenience sample. We address the effects of this selection in the limitation section.

We secured approval from two IRBs for the present research. Participants provided written consent prior to enrollment in the study. To protect confidentiality, participants were identified through the same identification and coupon number assigned for the parent study, which also facilitated linkage of participant data to data gathered through the parent study (e.g., demographics, HIV/HCV status, polysubstance and injection drug use, and injection risk behaviors). A Community Advisory Board (CAB) of eight active PWIDs who had participated in the parent study was established prior to the commencement of data collection. The input of the CAB was sought in drafting the recruitment, consent, and interview procedures to ensure their cultural appropriateness and sensitivity to our study population.

Interview Format

With the permission of participants, all semistructured in-depth interviews were audio-taped at the research office site in Cidra, a location already familiar to study participants. The first section of the semistructured interviews collected demographic data such as age, education, income,

costs of acquiring drugs, frequency of drug use, and access to health care. We also collected data about HIV/HCV status and injection risk behaviors. To explore participants' attitudes toward confidentiality as well as their views of disclosure obligations when somebody in their social network violates social or community norms, we asked them to respond to a vignette asking participants how the principal investigator of a study should proceed if he/she learned that an HIV positive participant in his/her study shared injection materials with other participants in the study. One of the strengths of this vignette is that it presented a realistic scenario for respondents because all had previously enrolled in the parent social network study that had tested them for HIV/HCV and had also gathered data on who had injected or shared injection equipment with whom.

Data Analysis

Interviews were transcribed, and all personal identifiers were removed. Codes were developed to convey the wide array of themes present in the narratives. An audit trail was maintained to keep track of how and why analytic decisions were made, and a codebook was developed to describe and define all study codes. These codes were iteratively revised and regrouped until they eventually represented a set of higher-level axial codes comprehensively describing participants' understandings of confidentiality and disclosure obligations in the context of social network health research.

Results

Demographic Information

The sociodemographic profile of participants enrolled in the current study shows that all are male participants with a median age of 42.4 years and a median number of 22.5 years spent injecting drugs. Only one in 20 (5%) were HIV-seropositive; a large majority were HCV-seropositive (78%). All participants reported having previously experienced incarceration, and the majority were unemployed (87.5%). Only half had a high school or greater level of educational attainment. Approximately half had never been married, and all participants in our sample self-identified as heterosexuals. Finally, a little more than half injected four times or more a day (55%), and one-third injected two to three times a day (30%). Few reported having participated in a research study other than the parent study from which they had been recruited (7.5%).

Major Themes

"This is between you and me.": Investigator confidentiality obligations

Participants express strong views about protecting their confidentiality as research subjects. In contrast to PWIDs in urban areas where interactions can be more impersonal or even anonymous, PWIDs in rural areas have very deep personal, and in some cases even familiar connections with each other. In this context, the confidentiality of HIV and HCV results becomes paramount since the lack of confidentiality can impact not only an individual but also everybody involved in his or her network, something Flaco Pablito (not his real name. All names reported in the results are pseudonyms) is very aware of:

If they tell me that it is confidential, we'll go everywhere, you know, but if it is not and it leaks to a third, a fourth, a fifth that might have the opportunity to learn things one tells you for example, or the results [of the tests], that is not right. This is between you and me.

Confidence that confidentiality would be protected was not assumed but was a result of the participant's experience sharing their information with investigators.

I trusted you because you conducted the tests and it didn't go out there, it stayed there. If the result was positive, it stayed there, if it was negative, it stayed there, it didn't go out there, nobody knew this information. I trusted you because what we said in the office stayed there, it was confidential. The fact that it was confidential made me trust your study more. (Miguelito)

Despite the fact that most participants have not engaged previously in community health research, they demonstrated a good understanding of the meanings of confidentiality: "nobody else knows" the tests results:

Yes, yes, it was very important [confidentiality] it was an additional layer of reassurance that you are giving me that [survey responses and test results] are confidential, nobody else knows them. (Vitin)

For some, the understanding of confidentiality was not necessarily shaped by previous research engagements, but through their experiences navigating the health care system, where most were very familiar with the Health Insurance Portability and Accountability Act (HIPAA), protection of patient medical information:

Right now, you go to a hospital and none of them can divulge... [your medical record], they can't say anything else. That's HIPAA law, if they divulge anything then you can sue them, you can do a lot of things. I think that his study is like that and it gives me peace of mind. (Papo)

"He's under oath": Attitudes toward disclosure of HIV status.

To explore the meanings of confidentiality in this population, we provided a dilemma adapted from Fisher (2010):

“A researcher knows that an HIV positive participant in his study is sharing syringes/works with another participant in the study without disclosing this information to him/her. Should the investigator tell the other participant or not?”

The responses were divided into two distinct camps. One group of participants felt that confidentiality was paramount and should not be broken under any circumstances, while the other group felt that the HIV+ participant was placing others at risk and that this fact justified the elimination of confidentiality. Yet, participants’ reasoning went beyond the yes or no answer, both groups recognized the complexity of the issue and came up with potential solutions to the problem or further elaborated their views, illustrating the multiple dimensions behind the disclosure of confidential results that reflected both responsibilities of the investigator and participants.

Miguelito presents a straightforward answer to this question.

The investigator should not intervene. It’s the participant that needs to be upfront and tell the other: “Look, I have this, I can’t share anything [with you]. You’ve been warned, now if you want to share that’s on you. The participant that has HIV has to speak clearly, and if he doesn’t then it is something that both will need to sort out...”

Landi espouses a more restricted view that of confidentiality being an absolute principle that should be respected because “that’s the way it should be”: *“No, because if it is confidential, then it’s confidential. The researcher can’t say anything. [...] But the researcher should not intervene, it is confidential, and that’s the way it should be. He can’t tell.”*

Papo agrees with the latter view and understands the predicament the researcher is in—that, being bound by the confidentiality requirements, he should not disclose information that might save participants’ lives. The researcher, in his view, is “like a priest” during confession, who “can’t say anything because he’s under oath”:

P: If you see that the person is not going to say anything and it’s f..king up the other and the researcher knowing this... if I were the researcher, I would tell because if not the other will keep hurting other people.

I: But you know that the researcher promised everybody that the test results are confidential.

P: But if you see that the person is not helping. You see that it is hurting, I would break the promise because I wouldn’t see that he keeps hurting and hurting. Then, this one comes and fucks one, and then another one and then he keeps going... he’s going to keep hurting others. The researcher might get into trouble by violating the confidentiality. It is like a priest, you go and confess and then he can’t say nothing because he’s under oath.

I: You think the researcher is like a priest?

P: Yes, it has to be kept secret.

On the other hand, another group of participants felt that confidentiality protection should be lifted if participants’ health and well-being were at risk. Cesar illustrates this position, though noting that lifting confidentiality arrangements would be “sad and regretful”:

Yes. If the person with the condition is not been direct and is exposing somebody’s else health for the rest of his life. It is confidential, but the person is been widely imprudent and when you are not taking care of yourself or others, I understand that the researcher should intervene. It is sad and regretful, and I understand that it is an invasion of privacy, but the person has been irresponsible.

El Viejo also believes that the investigator should break confidentiality to avoid serious harms and that this intervention is ethically justified because the HIV patient is acting unethically. Furthermore, since HIV-positive PWIDs can share drugs safely, there is no reason not to disclose their status, providing a further justification to break the confidentiality agreement.

The investigator should approach the exposed participant and tell him: “Look, this guy has this, just in case he didn’t tell you.” I think that the investigator should tell because he would not be violating anybody’s right. The person that is in the wrong is the patient that is sick and wants to kill the other. In some U.S. states, it is a crime if an HIV-positive person knowingly transmits the disease to another one. The investigator should intervene to save a life. Let me tell you something, when I was in jail, I saw somebody share injection equipment with his nephew without telling him that he had AIDS. The nephew was insisting, insisting, and at the end, he says, “OK! Get the damn syringe,” and he gave the infected needle to his own nephew!

If the investigator tells the participant (that the injection partner is HIV positive) and, as a result, he kills the other, that is not the investigator’s fault. It is because he (the participant) felt used. If the other had disclosed his status, nothing would have happened. Do you remember Angel? He would tell everybody, and if somebody did not know about his status, he would tell them: “no, I would go first, gave me my dose first and then you throw away that needle. I have the condition.”

Luis initially agrees with the notion that the researcher should disclose the HIV status of a study participant, but when reminded of the researcher’s obligation to maintain confidentiality, he advances a creative solution to the problem that enables the researcher to maintain confidentiality obligations while also safeguarding the well-being of study participants:

I. Should the researcher disclose the HIV status? Why?

Luis. Yes. To save a life.

I. But keep in mind that the researcher tells everybody that results are confidential.

Luis. Confidential. Well, then the best would be that you call the person that has an HIV-positive result and tell him, with all due respect, you know that this is confidential, you know that your test result is positive, if you are going to do a “caballo” sharing drugs with others, why don’t you tell him the truth, that you have “la condicion,” HIV, so he can take care? Instead of the researcher telling the other person, he has a conversation with whoever tested positive. It stays confidential.

I. And if you were the person that is sharing drugs with the participant that tested HIV positive and the researcher does not tell you anything, how would this make feel?

L. I wouldn’t change my view of him because when one enters here the first thing that one is told is that everything is confidential. And you can’t divulge the lives of others.

Discussion

The narratives of PWIDs in this study demonstrate that participants’ value and expect investigators to honor obligations of privacy and confidentiality as a requirement for their enrollment in social network health research. Participants worry that confidential HIV tests’ results might become known by others in their social network or those in the community at large. Disclosure of HIV status or other confidential information within a tight social network can have serious consequences, from reinforcing stigmatization to retaliatory violence (Conroy & Wong, 2015; Hammett et al., 2015; Yonah et al., 2014). Yet as participants’ responses to the vignette illustrates, PWID approach ethical dilemmas faced by investigators through their own moral lens suggesting that privacy and confidentiality requirements might be waived if community norms have been violated or in order to protect the health and well-being of their members. As Luis’s response shows, study participants can adopt a pragmatic approach, taking contextual factors into consideration to produce a creative solution that simultaneously allows the researcher to maintain confidentiality obligations while also reducing the risk of HIV transmission and associated harms. This ability for moral lens should not be surprising; other studies confirm that lay members and, in particular, economically marginalized people who use drugs can engage in complex ethical deliberations (Fisher, 2010; Fisher, & Goodman, 2009).

The empirical examination of privacy and confidentiality issues arising from social network research among PWID can be framed within a goodness-of-fit ethical framework (GFE) that conceptualizes participant protections in terms of the extent to which ethical procedures are fitted to the needs of the participant population (Fisher, 2015; Fisher & Goodman, 2009). The GFE’s

conceptualization of confidentiality risks shifts judgments regarding ethical procedures away from an exclusive focus on the privacy vulnerabilities faced by PWID in their daily life and toward the implementation of specific ethical practices that minimize privacy risks, maximize privacy protections, and best advance science to inform population-sensitive interventions. This approach also suggests that researchers and bioethicists need to consider not only researcher obligations toward participants but, critically, the ways that study participants perceive confidentiality and privacy obligations. Failure to do so might be perceived as violating important community norms, resulting in a potential lack of trust.

PWIDs expect that the researcher in the study will preserve their privacy and confidentiality unless there is an overwhelming reason to break this obligation. Yet, as studies on research trust have shown, trust building is not an event, like the signing of the consent form, but a social process in which both the researcher and the subject become aware of each other’s goals and can share some kind of common good. As research on trust has shown, research participants perceive trust as part of a reciprocal relationship, where both participants and researchers help each other in the pursuit of their particular goals (Abadie et al., 2018; Collins et al., 2017; Guillemain et al., 2016; Morgan et al., 2015; Zamudio-Haas et al., 2016). In this context, research participants might support limiting privacy to preserve community norms or avoid larger harms. This is particularly important in social network studies which might require to identify not only participants’ names or identifiable information, but also non-anonymized data of alters in the social network. During HIV testing for the social network and HIV/HCV risk study, we conducted hundreds of tests, with an HIV prevalence close to 5%. Frequently, we knew all the participants who had shared injection equipment with the HIV-positive participant. While maintaining participants’ confidentiality, our staff provided the standard safe injection recommendations but in addition suggested that HIV-positive participants refrain from sharing if possible. If avoiding sharing injection equipment was not feasible, participants were advised to disclose their HIV status to their partners if they had not done so already. This approach, which is very similar to the one suggested by one of our participants, preserved our obligation toward maintaining participants’ privacy and confidentiality while also minimizing community harms.

By documenting how PWIDs understand privacy and confidentiality in the context of social network research, this study contributes to larger debates about research ethics with marginalized populations. Findings suggest that participants understand that some constraints may exist regarding the protection of privacy and confidentiality in social network research but that they are willing to participate if trust in the researchers is present, if the study is perceived to contribute to the social good, and if it does not oppose community norms.

Limitations

While one of the strengths of this study is that participants' views on privacy are based on their previous engagement in a large study of social networks and risk in Puerto Rico, we acknowledge that the sample size, while standard for qualitative inquiry, might produce more robust results were it larger and randomly selected. Another limitation is that, given the convenience sampling strategy employed, results cannot be generalized beyond this population. The fact that this study has not collected data about how women who inject drugs understand privacy in the context of the social network is another limitation. Our sample composition is entirely male; this choice reflects not only the demographic background in our parent study but also a more general distribution among PWIDs, who tend to be extremely gendered, with many more men than women choosing intravenous drug use, at least in the United States and Western countries. This study only enrolled PWIDs who had participated in the parent study. It is possible that this selection could have introduced some selection bias: those prospective participants with serious privacy concerns might have refused to enroll in the parent study, and, therefore, their views would not have been taken into consideration in this study. It is possible that this bias might have eliminated more extreme privacy views in our sample. Finally, this study assumed that conducting social network studies with this vulnerable population was desirable, but it did not ask participants if they agreed with that assessment—for example, if they considered that the benefits of the study outweighed the risks. Finally, this study shows complex moral reasoning on privacy and consent among its participants, but it is possible that they might have benefited from the fact that they were responding not to hypothetical situations but from their actual experiences as research subjects.

Best Practices

Results show that PWIDs value and expect privacy and confidentiality in the course of social network studies research but might be willing to see investigators lift certain privacy rights in certain circumstances. Researchers and study participants might harbor different expectations around the perceived obligations related to the disclosure of HIV test results. To avoid conflicts or misunderstandings, confidentiality expectations about HIV/HCV test results should be clearly addressed during the consent process. Participants should be informed of the procedures adopted to maintain the privacy and confidentiality of medically sensitive information. The potential for conflicting perceived obligations between the researchers' duty to maintain confidentiality and participants' expectations that privacy might be lifted to protect participant well-being in accordance with community norms should be addressed. While social network studies

involving PWIDs are a small fraction of all epidemiological and community-based studies conducting HIV testing with vulnerable populations, researchers in these fields should be mindful of community norms around HIV disclosure. Clear communication of expectations about this issue is critical to secure and maintain research trust.

Research Agenda

Our findings, which are based on a sample primarily of men who inject drugs in poor, rural settings in Puerto Rico, might not be generalizable to other populations. While some concerns about privacy and confidentiality in social network studies might be shared by PWIDs in urban settings or by users from different ethnic backgrounds or in a different gender composition where women are more prevalent, more research is needed to document such continuities and changes. In addition, while this study focuses on the particular ethical issues raised by social network studies among PWID, the question of whether other vulnerable populations enrolled in similar studies might share the same concerns requires further attention.

Educational Implications

Research findings suggest that researchers conducting social network studies, those involved in community-based research with PWIDs, and IRBs need to be aware of study participants' views around privacy and confidentiality. Engaging participants in dialogue about the responsible conduct of research presents an opportunity to correct under- or overestimations of research vulnerabilities when such decisions are restricted to the perspectives of investigators or IRB members (Fisher, 1999).

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Authors' Contributions

All authors contributed to the development of the concepts used in this article. Celia contributed to the study design and commented on drafts of the article. Kirk contributed to the conceptual analysis of the article and commented on drafts of the article. Roberto contributed to the study design, conducted the interviews, analyzed the research data, and wrote the first draft of the article.

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