



Research methods

A qualitative analysis of peer recruitment pressures in respondent driven sampling: Are risks above the ethical limit?



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ABSTRACT

Background: This paper examines peer recruitment dynamics through respondent driven sampling (RDS) with a sample of injection drug users in Hartford, CT to understand the strategies participants use to recruit peers into a study and the extent to which these strategies may introduce risks above the ethical limit despite safeguards in RDS.

Methods: Out of 526 injection drug users who participated in a mixed-method RDS methodology evaluation study, a nested sample of 61 participants completed an in-depth semi-structured interview at a 2-month follow-up to explore their experiences with the recruitment process.

Results: Findings revealed that participants used a variety of strategies to recruit peers, ranging from one-time interactions to more persistent strategies to encourage participation (e.g., selecting peers that can easily be found and contacted later, following up with peers to remind them of their appointment, accompanying peers to the study site, etc.). Some participants described the more persistent strategies as helpful, while some others experienced these strategies as minor peer pressure, creating a feeling of obligation to participate. Narratives revealed that overall, the probability of experiencing study-related risks remains relatively low for most participants; however, a disconcerting finding was that higher study-related risks (e.g., relationship conflict, loss of relationship, physical fights, violence) were seen for recruits who participated but switched coupons or for recruits who decided not to participate in the study and did not return the coupon to the recruiter.

Conclusions: Findings indicate that peer recruitment practices in RDS generally pose minimal risk, but that peer recruitment may occasionally exceed the ethical limit, and that enhanced safeguards for studies using peer recruitment methods are recommended. Suggestions for possible enhancements are described.

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Introduction

Respondent-driven sampling (RDS) is a participant-driven recruitment method that involves participants recruiting peers from their social networks into studies and provides statistical adjustments to overcome sampling bias introduced from non-random sampling associated with peer recruitment (Abdul-Quader, Heckathorn, Sabin, & Saidel, 2006b; Heckathorn, 1997, 2002, 2007; Heckathorn, Semaan, Broadhead, & Hughes, 2002; Magnani, Sabin, Saidel, & Heckathorn, 2005; Salganik, 2006; Salganik & Heckathorn, 2004; Semaan, Lauby, & Liebman, 2002;

Semaan, Santibanez, Garfein, Heckathorn, & Des Jarlais, 2009). RDS has become widely used in public health surveillance because it provides a means for reaching “hidden” populations that tend to be wary of participating in studies due to their engagement in illegal or stigmatized related risk behaviors (Heckathorn, 1997). The recruitment process begins with a very small sample of recruiters (seeds) who are selected by study staff based on representations of population subgroups. Each seed is given a small fixed number of coupons (typically three) to pass on to peers in their network that fit the study criteria. Seeds who successfully recruit an eligible peer into the study receive a small cash recruitment incentive, separate from the survey incentive, after the recruit returns the coupon or enrolls in the study. Eligible recruits who become study participants are given the same number of coupons to pass on to the second wave of recruits with the same reward structure, and so on, until the desired sample size is reached. Sampling bias is reduced as the number of recruitment waves increase.

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With the growing popularity of RDS worldwide, ethical considerations are increasingly relevant and important. Ethical concerns and study-related risks associated with peer recruitment generally, and RDS in particular because of the dual-incentive structure, have been actively debated in the literature with steps taken by many researchers to address concerns and potential risks (Heckathorn & Broadhead, 1996; Margolis, 2000; Semaan et al., 2009; Simon & Mosavel, 2010; Tiffany, 2006). During the past decade, researchers have developed ethical frameworks and regulatory procedures to address emergent concerns, such as the responsibilities of investigators for informing participants of their HIV discordant partnerships, and protections against undue inducement associated with payment for participant-driven recruitment and peer coercion related to overzealous recruitment by peer recruiters (Abdul-Quader et al., 2006a; Broadhead, Heckathorn, Grund, Stern, & Anthony, 1995; Broadhead et al., 1998; Des Jarlais et al., 2007; DeJong, Mahfoud, Khoury, Barbir, & Affi, 2009; Heckathorn et al., 2002; Hughes, 1999; McKnight et al., 2006; Robinson et al., 2006; Semaan et al., 2009).

In a review of ethical and regulatory considerations in studies involving RDS to recruit injection drug users (IDUs), Semaan and colleagues (2009) described four most commonly reported methods used in RDS studies to protect against potential ethical violations that may arise due to peer recruitment and to provide procedures for mitigating risks and monitoring the recruitment process to ensure that any developing problems are promptly addressed. First, RDS procedures limit compensation levels by limiting the number of recruits any one participant can refer to a study. This form of coupon rationing is designed to help protect against peer coercion through participants trying to earn income as a recruiter. Second, research staff obtain recruits' informed consent before they can participate. This is designed to correct any potential misinformation given by peers and to mitigate against peer coercion. Third, the confidentiality of participating peer recruits is protected by not disclosing information on which peer recruit participated. Recruiters meet with study staff to obtain the referral payment for each coupon that has been redeemed. Fourth, monitoring and reporting requirements ensure that adverse events are reported promptly to project personnel so remedial actions can be taken (Abdul-Quader et al., 2006a, 2006b). Despite these protections, ethical dilemmas may still occur in the efforts to reach hidden populations. It is therefore critical to explore the experiences of participants of peer recruitment methods to minimize risk.

A small body of literature has explored participants' experiences with peer-driven recruitment qualitatively and has made important contributions to date (DeJong et al., 2009; Scott, 2008a; Simon & Mosavel, 2010). These studies have highlighted a number of potential risks that could be mitigated by additional safeguards. Two published studies with IDUs found an "underground stratified marketplace" where some participants sell coupons to intermediary recruiters who distribute and resell coupons to recruits (Johnston, Malekinejad, Kendall, Iuppa, & Rutherford, 2008; Scott, 2008a). Scott's (2008a) ethnographic study documented peer recruiters using coercive recruitment strategies to pressure recruits to participate in the study, and found that all 17 interviewees had experienced threats, arguments, or actual physical violence over coupon non-redemption.

However, critiques of Scott's study are numerous with two primary concerns focused on methodological limitations associated with a small and biased sample and his failure to disclose the quality assurance protocols used to monitor and mitigate risks that emerged during the study (Broadhead, 2008; Lansky & Mastro, 2008; Ouellet, 2008; Prachand & Benbow, 2008). Despite significant concerns about Scott's findings, the article made an important

contribution, as it prompted lively debate concerning the need for additional RDS safeguards to mitigate study-related harms and risks to participants and to confidentiality breaches (Fry, 2010; Scott, 2008b). Recommendations for additional safeguards that have emerged in the literature include providing recruiter training (DeJong et al., 2009; Lansky & Mastro, 2008) and careful consideration of the timing of the secondary payment to reduce the potential for duress (DeJong et al., 2009; Emanuel, Wendler, Killen, & Grady, 2004; Semaan et al., 2009; Semaan, Heckathorn, Des Jarlais, & Garfein, 2010).

Ethical concerns related to potential problems of peer coercion are of course not unique to RDS and are relevant to all studies using peer-driven recruitment and local intermediaries to recruit participants (Broadhead, 2008; Festinger, Dugosh, Croft, Arabia, & Marlowe, 2011; Semaan et al., 2002; Simon & Mosavel, 2010). In peer-driven recruitment, some amount of peer influence in recruitment practices is expected and even considered beneficial to a study because peers can recruit individuals who are more difficult to reach and who would participate as a favor to a friend (Heckathorn et al., 2002; Magnani et al., 2005). However, the balance between risks and benefits is not always clear. The key to protecting participants typically lies in researchers' judgment of the critical *ethical threshold*, which refers to the line at which the probability and magnitude of study-related harms are not greater in and of themselves than those ordinarily encountered by participants in their daily life (see 45 CFR Part 46 in NCPHS, 1979). The principles of autonomy, beneficence, and justice constitute the basis for defining this threshold. Research that protects *autonomy* of potential participants is free of controlling influences and pressures to participate and gives each person the respect, time, and opportunity to make his or her own decisions about whether or not to enter a study. *Beneficence* obligates the researcher to secure the well-being of all study participants by protecting them from harm and by ensuring that they experience the possible benefits of involvement. *Justice* means that both benefits and risks of research are fairly distributed among people, and that certain groups or persons should not be selected to participate in a study simply because of their availability, their compromised position, or their manipulability (NCPHS, 1979).

The ethical threshold has been an important area of debate for researchers (Levine, 1988) for some time, particularly among those working with vulnerable populations. Some researchers reason that establishing a standard threshold is not appropriate when the risks of daily life are different for different populations (Freedman, Fuks, & Weijer, 1993; Kopelman, 1989), particularly for vulnerable populations involved in research. Much of the peer recruitment process places the burden on participants to identify and recruit others; thus, the recruitment challenges, strategies used, and benefits and risks can be unknown to researchers who are not present at the time of recruitment. This raises important questions regarding the ethical threshold of peer pressure in recruitment and whether the current safeguards in RDS protect against risks of peer coercion. Understanding participants' experiences with peer recruitment are vital to identifying the contexts and recruitment practices that may heighten risks and benefits and exceed the ethical limit.

This paper qualitatively explores the range of strategies used by a sample of IDUs to recruit peers into an HIV-related study, and the extent to which peer recruiters use certain strategies to exert pressure on their peers to encourage participation. The paper responds to the call by researchers to contribute to developing an evidence-based ethics for RDS through collecting and reporting data on variables related to the process of participant-driven recruitment (Halpern, 2005; Miller & Rosenstein, 2002; Semaan et al., 2009).

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