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Participant and Staff Experiences in a Peer-Delivered HIV Intervention with Injection Drug Users

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Abstract

We explore ethical issues faced by investigators as they conduct research as part of a peer-delivered HIV/AIDS risk reduction program for injection drug users (IDUs). Staff and participant experiences in peer-delivered interventions among IDUs have come under scrutiny by ethics researchers because of their potential to inadvertently and negatively impact participant rehabilitation due to continued engagement with drug-using networks during the course of outreach. This study explores whether enhanced communication of participant concerns and experiences with clinic and research staff helps to reduce inadvertent malfeasance in peer-delivered drug treatment interventions. Results contribute to the development of patient support infrastructure in peer-delivered risk reduction programs involving IDUs.

Keywords

HIV prevention; peer-delivered prevention; prevention in clinics; ethics; program support; participant experience

Since early in the epidemic, peer-delivered approaches to HIV risk and harm reduction have been successful in extending positive health messages and information about harm reduction to hard-to-reach drug users, aiding in the recruitment of drug users into treatment services and improving drug treatment outcomes among patients (Boyd et al., 2005; Kalichman et al., 2001; Lauby et al., 2000; Needle et al., 2005; Wingood et al., 2004). Researchers (e.g., Raja et al., 2008; Convey et al., 2010; Dickson-Gomez et al., 2009; Weeks et al., 2009) have argued that participating in peer-delivered programs not only reduces risk for HIV/STIs, but also confers psychosocial benefits, including increased self-esteem, efficacy, and sense of purpose as a result of adopting positive new roles as health advocates within the community, and increased knowledge about harm reduction techniques to aid in their own health enhancement, treatment entry or retention, and recovery process.

While an overwhelming majority of peer-delivered interventions have demonstrated positive outcomes, it is imperative that investigators conducting intervention research take measures to minimize risks for participants with substance use problems in the community. While substance use investigators typically focus on mental health outcomes and incorporate informed consent and confidentiality, as well as referral and data safety monitoring directly related to drug/alcohol use behaviors, interventions that include community engagement confront ethical challenges relevant to participant rights and welfare that go beyond a focus on reducing symptomology. Intervention studies that engage community members as central agents in disseminating health information to their peers constitute a unique form of community-engaged research (CEnR), in that participants themselves become community educators and health advocates, taking on new roles in the community and undergoing transitions and transformations as a result of their participation. Investigators guiding participants in these transitions and researching their effects must be sensitive to ethical challenges that arise across multiple geographic settings (clinic, community) and stakeholders (hired staff, patient/participants, community members). Research is needed that illuminates ethical issues faced by investigators as they conduct their research, and by extension, those challenges faced by research participants as they disseminate health information to their peers. The study of ethical concerns among both investigators and participants in CEnR can better inform researchers regarding how to mitigate harm and ensure that participants' ethical concerns are effectively addressed.

In their broad overview of ethical considerations in CEnR, Anderson et al. (2012) pointed out that community partners (organizational staff as well as clientele participating in research activities) may experience "moral distress" owing to emotionally challenging encounters with other community members in the name of research. They cite Simon and Mosavel (2010) in explaining that "moral distress can arise when community partners learn certain information about their communities ... and become concerned with whom they interact." Other researchers (e.g., Fisher et al., 2012; True, Alexander, & Fisher, 2012) have further argued that moral distress can be heightened in contexts where individuals perceive themselves to be unable to provide assistance to other community members in need, due to limited resources. Another study by Fisher et al. (2013) adds that the empirical finding research staff who are on the "frontline"—engaging in face-to-face interaction with marginalized and vulnerable groups—experienced greater moral distress primarily when they perceived lower levels of support and commitment from their own community organizations and research partners. Ethical issues can also arise when frontline workers are recovering drug users themselves, when their interactions with current drug users can heighten their risk for relapse and secondary trauma (Simmons & Koester, 2003; Singer et al., 2001), and when their "dual role" as research agents conflicts with their role(s) as community members and peers (Anderson et al., 2012). Other researchers have argued that ethical dilemmas exist—including potentials for coercion or exploitation—when community members are enlisted as participant recruiters (Scott, 2008; Semaan et al., 2009; Whittle et al., 2010). Confidentiality can also be an ethical concern, particularly in research projects where breaches to confidentiality (e.g., with regard to sero-status) among peers can involve significant stigma (e.g., Fisher, 2011).

The studies cited above address ethical considerations when working with organizations and individuals in community settings; however, no studies to date offer a qualitative examination of psychosocial, emotional, and practical challenges that may be faced by drug users in treatment as a result of engaging in peer-delivered interventions. For example, to what extent do participants experience stress, depression, and stigma as a result of peer-delivered outreach activities, and/or encounter salient triggers while continuing their interactions with drug-using peers?

This paper presents a unique set of findings from a qualitative study of positive and negative impacts on participants of a peer-delivered HIV risk and harm reduction program for recovering drug users in a methadone maintenance treatment program (MMTP) in inner-city Hartford, Connecticut. Findings are triangulated from both patient/peer and program staff perspectives. The paper discusses the rationale for a peer-delivered approach with clinic patients and explores ethical issues raised by their participation in both the research trial of the intervention and the program itself as peer health advocates, as well as recommendations for minimizing potential harm and sustaining patient recovery and participation in outreach activities.

RATIONALE FOR PEER-DELIVERED INTERVENTION IN CLINIC SETTINGS

Previous studies have demonstrated the efficacy of peer-delivered interventions to diffuse risk reduction information through networks of active drug users, resulting in significant reduction in illicit drug use and drug-related risk behaviors among trained peers and their untrained drug-using network members (Weeks et al., 2009a, 2009b; Li et al., 2012). Exposure to peer-delivered interventions has been associated in both groups with entry into drug abuse treatment, improved attitudes toward risk reduction and health promotion, and increased empowerment and engagement in risk/harm reduction efforts among peers (Convey et al., 2010; Dickson-Gomez et al., 2006). The program described in this paper, called the Risk Avoidance Partnership (RAP), is a peer-delivered program that has been translated for implementation in drug treatment clinics with clinic patients. Clinics constitute "one of the few social institutions that actively seek out and maintain involvement with drug users" (Metzger, Woody, & O'Brien, 2011), making them a logical place to situate and sustain HIV, hepatitis, and STI prevention and health promotional interventions for addicts (Raja et al., 2008). Situating interventions in this setting was intended to offer the multiple benefits of reducing HIV/STI related risks in trainees and their peers, and increasing intervention recipients' attachment to, retention in, or entry/reentry into drug treatment.

THE ROLE OF ETHICS IN RESEARCH ON PEER-DELIVERED INTERVENTION CONDUCTED BY DRUG USERS IN TREATMENT

While peer-delivered interventions have been established as an efficacious way to reduce overall risk and to diffuse health and harm reduction information through networks of drug users, no studies have explored the potential ethical challenges of involving recovering drug users in treatment as central agents in intervention. Two key ethical principles of beneficence and nonmalfeasance are particularly relevant to peer-delivered HIV risk and harm reduction intervention trials with drug users. As outlined by the HIV Prevention Trials

Network (Mayer et al., 2003) as well as a number of national and international entities (e.g., UNAIDS, 2009; WMA, 1983), participation in HIV research programs should not result in harm or injury to participants, either through acts of commission or omission. Though HIV prevention studies are intended to reduce HIV risk and provide benefits to participants and the larger community, ethical dilemmas are introduced when the proposed risks potentially outweigh the benefits of participation.

Consistent with ethical guidelines outlined in the Belmont Report (NCPHS, 1974), the potential harm of disrupting an individual's drug rehabilitation, treatment success, personal safety, and reputation for the sake of disseminating harm reduction information may not be justifiable if these harms outweigh the potential personal and public health benefits of participation. While most researchers try to anticipate and prevent any harm to participants, the design stages of prevention/intervention programs do not always include plans for building in participant support structures (Fisher, 2011; Fry et al., 2006; Raja et al., 2008). This is partly because participant perspectives and experiences of risk versus reward are not always well understood (Fisher, 2008, 2009; Fry, 2010; Oransky et al., 2009). A number of peer-delivered programs (e.g., Colón et al., 2010) report a lack of communication between staff and clients regarding participant experiences and concerns. An ethics-based approach can help researchers to better understand the role and impact of prevention and intervention programs on participants' well-being and recovery, as well as contribute to the creation of new channels of support and communication for addressing participant risks and concerns in future peer-delivered interventions (Slomka et al., 2008).

OVERVIEW OF THE RISK AVOIDANCE PARTNERSHIP PROGRAM

The Risk Avoidance Partnership (RAP) was a successfully tested community-based program that trained not-in-treatment drug users to become peer interventionists, who delivered prevention information and materials to other drug users in the community. RAP was translated for clinic implementation in order to train clinic patients to deliver the peer outreach program to not-in-treatment drug users in their networks and neighborhoods. A pilot test of the translated RAP conducted in an MMTP clinic context took place in four cycles over an eight-month period from January to August 2012 in partnership with two branch clinics of the Hartford Dispensary. Eligible patients volunteered to be trained as "peer health advocates" (PHAs) over a total of nine sessions in groups of 3–5 patients per cycle. For the first three sessions, PHAs-in-training met in a clinic with trained Facilitators employed by the Hartford Dispensary who were experienced with street outreach. In these training sessions, patients learned harm reduction strategies, including drug safety and prevention of HIV/STI transmission through awareness of needle-sharing risks and/or unprotected sex with partners, and strategies for communicating these risks to out-oftreatment peers and others at risk in their networks. In the remaining six sessions, PHAs-intraining, accompanied by clinic staff facilitators, practiced delivering harm reduction information, materials, and demonstration of their use in real-world community settings where congregation of drug users is common. This apprenticeship format was designed to encourage supervision and support of PHAs-in-training as they learned to conduct outreach intervention. After completion of the training program, participants are certified as PHAs, and are then encouraged to continue outreach activities on their own as well as in groups

with other PHAs, using the techniques they learned in the program. This observational pilot study was designed to test both the process of PHA training conducted by clinic staff who participated in the research project, as well as the process and preliminary outcomes of the program on clinic patient research participants who received the training and implemented the peer-intervention program.

Methods

As a smaller study embedded within the RAP clinic translation pilot, the current research focused specifically on ethical considerations in peer-delivered outreach programs among patients in treatment. Qualitative in-depth interviews (IDIs) were conducted by research staff to collect data about stressors and ethical challenges introduced to patients as a result of their participation in the RAP program, and also to collect data about clinic staff perceptions and awareness of patient concerns, experiences, and risks as PHAs. All participating PHAs-in-training and a sample of clinic staff were asked to share their opinions on existing and/or preferred channels for mutual communication within the organizational structure of the RAP program and the treatment facility, and about any perceived risks or benefits as a result of participation in the program. Additionally, a small group of not-in-treatment drug users from the study community were asked about their perceptions and attitudes toward PHAs conveying harm reduction messages to peers outside of the clinic.

Participant Recruitment and Eligibility

Clinic patients were referred to clinic RAP staff by their drug treatment counselors at the Hartford Dispensary, based on a mutual negotiation between counselor and patient, using patient interest, willingness, and perceived readiness (in terms of their own level of recovery) to participate. PHAs were eligible to participate if they were at least 18 years old, Hartford residents, an active Hartford Dispensary patient, had been in drug treatment for at least one month, and self-reported that they could successfully bring in two eligible Contact Referrals (CRs) prior to start of the training for a baseline survey. CRs were eligible to participate if they were at least 18 years old, Hartford residents, identified by a PHA as a member of that PHA's social network (broadly defined), had some history of drug use over the previous year or were current drug users, and were not active patients at the Hartford Dispensary. Recruitment of clinic staff participants for IDI in the present study was done by the research staff, who also conducted all IDIs. Eligible participants were asked to schedule an appointment to return to the dispensary to provide written consent and to complete an IDI. PHAs and CRs were offered \$25 as an incentive for their participation in the 1.5-hour IDIs. All participation was strictly voluntary and information shared by participants was kept confidential. All protocols were reviewed and approved by an institutional review board at the authors' research institution.

Data Collection and Analysis

Out of a total of 14 Peer Health Advocates and 26 Contact Referrals participating in the RAP pilot program in the clinic, the research staff completed in-depth interviews with 14 PHAs and 8 CRs, as well as 4 clinic staff, for a total of 26 participants. Demographic characteristics of the sample include 3 Latinos, 10 Latinas, 5 Latino/Puerto-Ricans, 3 Latina/

Puerto-Ricans, 3 white men, and 2 white females. All completed IDIs were audio-recorded and transcribed in Microsoft Word for storage and analyzed using Atlas.ti Version 7 software (Muhr, 2004). A codebook was developed collaboratively among the authors and with the input of other research staff. All IDIs were coded and reviewed for patterns and variations at the domain, factor, and inter-factor levels (Schensul, Berg, & Nair, 2012) and exemplar quotes were identified. Analysis of research questions was iterative, using preliminary findings to modify subsequent IDI protocol questions and to refine ongoing interrogations of the data (Polkinghorne, 1994).

Results

The following key themes emerged around three main research questions: (1) What are the perceived benefits and risks of participation in peer-delivered outreach programs across groups of clinic patient PHA participants, their not-in-treatment CRs, and clinic staff participants? (2) To what degree do patients who participated in the pilot study feel they have adequate support from program staff and clinic administration to address concerns and experiences that arise as a result of their participation in the RAP program? and (3) What suggestions do PHAs, CRs, and staff have to improve future implementation of RAP in clinic settings and peer-delivered outreach programs more broadly? Findings below are organized in the order of these questions.

Emotional and Psychosocial Benefits

A number of PHAs reported that their involvement in the program as PHAs helped them to face their own psychosocial challenges, including low self-esteem, depression, and anxiety. Like other drug-using populations, a disproportionate number of clinic patient PHAs suffer from chronic depression or anxiety. Many PHAs in this study said that participating in the program helped them to keep their minds off of their anxieties by providing a positive activity to pass the time and opportunities to work in a group of peers toward a common goal. Participants said that by learning to do outreach "you learn about yourself as well." Learning to conduct outreach teaches PHAs to develop self-esteem and pride, in turn motivating them to sustain their own recovery. For example, one PHA (52-year-old Latina female) shared:

I got a lot of time in my house, sitting there and thinking, and when I'm over here with the group, I laugh. I make jokes. I help somebody.... You start being a positive influence on others, and you get a feeling of pride.... I think [the program] makes my rehabilitation stronger.... It was very good for me.... There was this guy and he said, "Oh, my God, you changed so much. I'm so proud of you. Look what you doing." I said well, you can do it too. ...So I think it was real, real good for me, this experience. And I feel stronger, too ... it don't cross my mind, not even in my wildest dream to go back.

Another PHA, a 46-year-old white female, said:

It was good for me. It was good to get me out there ... and it made me feel good, you know. It makes you feel good to help people ... give out some information ...

and in positive ways, you know. It makes me feel good about my sobriety ... with me being more assertive.

Other people in the community who knew PHAs before and after their participation in the experimental program reported seeing significant improvements in attitude and demeanor. As one CR, a 46-year-old Latina, communicated about her friend who completed the PHA training:

He used to ... snap, at any little thing. He's actually more calm now, he goes to sleep early ... his way of expressing himself, the way he talks now, you know, he's, it's amazing because he's a total different person and he speaks, instead of speaking like the street language, he's actually talking more professional, more like, like he's making sense. And when he talks, it's like you could see the light in his face, it lights up, see the difference. And taking care of himself, you know, he's healthier.

Participation in the program can also lead to a positive change in social role, a shift from feeling over-looked and marginalized to feeling like active role models in the community. One PHA, a 48-year-old Latino male, said,

I really didn't never have a purpose to do anything. And this has given me a purpose to do something ... to help, you know, people to live better.... They, like, giving us respect, which is one thing that I never had ... 'cause being an addict or being in a gang.... I wasn't getting that "God bless you" stuff, or whatever. On the streets, you know. Yes, I got "God bless you" from people that love me and church people and stuff like that ... but addicts saying that to me; it's different.... A big difference.

Equipped with new health knowledge to apply in their own lives and to pass along to other community members, PHAs reported feeling a new satisfaction and outlook on life that helps them in their own process of rehabilitation and sobriety. A Latino male PHA said about his participation in the program during the pilot study:

I learned so much from it, you know. It just helped me even more staying clean. You know with all the information that you learn ... and not only about what I learned but I get to pass it on to others.

Another PHA, a 46-year-old white female, related:

It helps me with my sobriety.... It just keeps, you know, it helps me to feel good about my sobriety... and it gives me another reason to stay on track.

These testimonies suggest that many participants attributed positive changes in their pride, self-esteem, social skills, and personal outlook and recovery to their participation in the study.

Practical Challenges and Barriers to Participation

As with many other prevention/intervention programs involving low-income populations, participation in RAP pilot study for clinic patients introduced a number of practical challenges. A minority of individuals mentioned that the lack of private transportation

occasionally hindered them from full participation. While public transportation was available, some potential PHAs view it as a nuisance. For example, one PHA, a 52-year-old Latina, said:

I didn't have no transportation, so I decided not to go.... And there's people [in the clinic] complaining about, you know, they don't got some services, like bus fare.

Likewise, another PHA, a 38-year-old Latina, said:

A lot of people, they like to do stuff but they don't want to walk, you know? Like why would I walk all the way down there? So they should offer those people at least a token to make it to especially the first groups we do, the first four weeks.

Other PHA study participants report having medical problems such as diabetes, problems with their feet or legs, and/or overall problems with bodyweight, creating challenges for walking around for long periods. These physical constraints can be exacerbated by bad weather, which tends to be a barrier to conducting outreach in general (e.g., "We had to cancel a few times 'cause of the weather ... it was gonna rain."). While this challenge is indeed a real one, a majority of PHAs reported having very few issues with transportation. However, other issues, such as employment and legal responsibilities, can also prevent people from attending all sessions and/or from continuing to do PHA work after completion of the training program. PHAs' job responsibilities, classes, court appointments, or other personal obligations were reported to interfere with their availability to conduct outreach as part of the study.

Psycho-Social and Emotional Challenges

A number of other issues were cited as challenges to PHAs' motivations to participate. Factors that reduced group cohesion among PHAs together also decreased motivation and added to anxieties about conducting outreach. For example, being in a different stage of recovery than others in the cohort can reduce levels of rapport and add to the challenges of conducting outreach. For example, a 43-year-old white male PHA says of the other PHAs in his group:

I would talk with them ... but we all seem to be in different phases, I think, in our process.... I think, being early on, it's important for me to hang around with people that are doing the [treatment] work ... outside of going out [to do outreach]. Like if they're not going to meetings and doing things like that.

Not only rapport with other PHAs in the study but also with community members can influence outreach experiences and motivation. PHAs who are not from the area and do not know many people in the town where they are conducting outreach may experience greater levels of anxiety about doing outreach. For example, a 45-year-old Latina related:

I'm not from [the areas we do outreach in], so I didn't know none of those people. So, if I do [outreach] here it would be more because I know more people here. I'm from here so I know people around. It make me feel more comfortable.

While PHAs were encouraged to conduct outreach only in areas of their choosing, two PHAs mentioned that they had conducted outreach in areas where they felt racially

incongruent with community members, and that this made them feel uncomfortable and lowered their motivation to conduct further outreach there. A 52-year-old Latina PHA shared:

You know, in the north side, I don't go different places because, you know, there's a lot of.... There's not hardly Puerto Ricans over there.... So I'm scared that they gonna.... I don't get in that park ... because that park is dangerous.

In addition to PHAs' discomforts about conducting outreach in socially or culturally unfamiliar areas, many PHAs carried with them the burden of chronic psychological and emotional troubles, including social anxiety and depression. The wide prevalence of mental health issues render this population more likely than others to suffer negative emotional reactions to challenging situations that may arise during outreach. Venturing into the community and approaching strangers can be very intimidating and requires a level of confidence and practice. One staff member, a Latina woman, said,

They're very scared to go out. You know, when you start talking about: When we go out into the community, right away you can see like ... the fear in their eyes.

While this and other comments revealed a level of anxiety among participants in response to conducting outreach, these anxieties did not seem in excess of a typical "stage fright" and are not clearly associated with any mental health issues prevalent among this population. A small number of cases, however, suggested that doing outreach can be emotionally taxing when PHAs encounter individuals who have suffered significant trauma, or when PHAs feel uncertain about how to help someone. Below are two longer quotes to illustrate in greater detail the types of encounters that PHAs cite as emotionally difficult. The first is from a 52-year-old Latina woman who conducted much of her outreach on public buses. She shared:

If I'm in the bus and I see somebody, [I'll say] "I'm a health advocate, and can I give you this information?" and then they start talking to me. Like this girl ... she was 18, and she was using heroin, and I said well, you're so young, and I bet you anything that you very smart girl. If you need anything, I give her my phone number, and I told her where to go. She said that her mother throw her out. She don't have no place to stay. It was hard. She start crying and everything. I can see here the mark on her neck, and she was so pretty. My granddaughter is 17, the other is 16. It breaks my heart, because I was like that too. I was young ... and I wish that somebody approached me and talked to me.... It's something that told me talk to that girl.

PHAs can also encounter ethical dilemmas during outreach that require difficult decisions about how best to respond to encounters with community members. For example, a 52-year-old Latino PHA described:

You know, it could be a person that's been out there for a while, hustling like quarters or something, and they short maybe \$2.00 or \$.75 to get their fix, so they see you or they'll give you that minute ... and the moment you say ... I don't have \$1.00. Well, what do I have, what I have is info. They're gone. One guy tell me in Spanish, yeah, *te infermo*, *te infermo*. He's like, "I'm sick, man, all I need is, I'm trying to get my wakeup." And I'll say, "Well I can't help you there," and [he] took

off.... You put yourself in his place, but I can tell if they're really, really sick. ... Now, if I'm walking and I see the guy on the floor and he's cramped up and he's like, "Oh man, I'm short \$1.00"... I know 'cause I've been there, I might give that guy the \$1.00 at least so he can get back on his feet, you know? So that's, that's the decision we have to make, you know?.... Do you give someone a dollar to cop if they're looking like they're on their deathbed with heroin sickness?

While patients who participate in the experimental program are trained to distribute information and materials to their peers and other community members, some of the situations that PHAs encounter may fall outside of this realm, requiring them to draw upon their own personal judgments in deciding how best (and whether) to help certain individuals in the community who may be more difficult to reach. Participants rely on support from clinic staff on the study and from their drug-treatment counselors to help address the psychosocial and ethical challenges that arise during these encounters.

Environmental Dangers

Two potential environmental dangers were discussed, including exposure to "triggers" such as people, places, or things that might incite a relapse into drug use, and exposure to dangerous environments, including "hot spots" where individuals are using or selling drugs. While conducting outreach where drugs are prevalent can be both physically and psychologically dangerous, the degree to which PHAs and CRs in this study perceive them as risks to their own rehabilitation was minimal. As one CR, a 44-year-old white male, said:

The only time that you'll actually ever really be truly safe of relapse is when you go to your grave.

However, a 52-year-old white female PHA offered a different perspective:

I didn't even think of that at all. I mean ... you don't even think about your recovery, because you're doing something for another human being.

For those who do have potential problems with triggers, project staff and counselors tried to remain aware of where PHAs felt comfortable conducting outreach without encountering any major challenges to their own recovery and well-being. A core component of RAP is that PHAs led and planned outreach agendas and routes according to their own preferences. A majority of PHAs reported feeling safe during outreach because they went to familiar places. A 52-year-old Latina PHA said:

I don't mind. I don't want to jeopardize, my recovery. Some may have a "flash" or something like that coming back. But [the clinic training staff] say oh no, no, no. You don't have to go in there, because I thought if that's where we gonna go, to a place where the addicts are there, they gonna be there. But she explained about it. And that, I think that's the best decision that I made [not to go there], because I love it. I really love [doing PHA work].

PHAs also reported that they felt safer conducting outreach when accompanied by other PHAs and clinic staff on the project. For example, a 45-year-old Latina PHA described her first time doing outreach:

I felt a little strange, not that I was scared because I don't know people around but I felt safe because we were with one of the counselors. They were walking with us so, I felt safe.... I don't want to do it alone, I need to be with somebody.... I think there's more support being in a group.

In rare situations where PHAs did perceive some danger, either because they were in the proximity of triggers, drug deals, or potentially dangerous community members, PHAs were trained by project staff to "not escalate the situation" and to "walk away." A majority of PHAs, however, were acutely aware of community "hot spots" and had a commonsense knowledge of where outreach could be conducted safely. One PHA explains that "even if I know that I need to go by there, you know, I try to be careful, or avoid it."

Psychosocial Support for PHAs

A number of informal support structures exist for PHAs who encounter difficulties during the course of their participation in the clinic-based RAP pilot study. These informal supports include casual "debriefings" with clinic project staff before and after outreach sessions, consultations with their drug treatment counselors in response to anxieties or concerns, and developing friendships with other PHAs participating in the study. Clinic RAP staff and drug treatment counselors are central sources of support for PHAs in the study, and all staff suggested that PHAs needed support as they were learning to conduct outreach. One staff member (Latina) suggested:

For the majority of the PHAs, I think the staff needs to be present. It gives them a boost. It gives them a little bit more self-esteem. 'Cause we tell them we're not doing your work as a PHA, but we're there to support you. We're their safe line.

For some PHAs with limited social networks and/or disrupted family ties, program staff are among the few people available to turn to for support. A 37-year-old Latina PHA shared:

I don't have anybody that I can talk to unless I can call [the program staff] but, other than that, no.

A majority of the PHAs view clinic staff who participated in the study as training facilitators as a source of social support, encouragement, and respect. A Latino male PHA said of the staff:

[They] were very encouraging. When I started working, oh my god, you know, it was like, "We're so happy, you know, that you here, you doing so good." I mean they were all very encouraging.... Whatever I needed or didn't need, they was always there.... And when I met [the Dispensary Director], I love that guy, you know, and [the Associate Director], they're really into helping the people here, the ones that need the help. They make sure that they get it ... and I say that we are treated with respect ... and our needs our needs are met.... We got the psychiatrist, we got the dental program, you know, we got primary care and stuff.

Drug-treatment counselors, who were not part of the clinic-based RAP study design but are essential players in the clinic context, were also viewed by many PHAs as central sources of support and caretakers of their general well-being. For this reason, counselors were often the

first to monitor and assess the readiness of their patients for eligibility to participate in RAP and to conduct outreach on an ongoing basis. As one 43-year-old white male shared:

[My counselor] is just like someone like me but he's got a little more time in the, in AA and he's done the 12 steps and he's actually bringing me through the work, like step 1, 2, 3, 4, 5, you know, things like that. I think you have to be adult enough to manage how you're feeling and, you know, get some advice quickly before you go out that day. And that's what was important for me. That's what my [counselor] wanted me to do is before I went out to call him and, you know, he wanted to make sure that I was okay before I went out.

Other PHAs stated that not only RAP clinic staff but also other PHA patient participants were sources of social support in helping to face challenges in recovery and provide a sense of camaraderie. For example, a 50-year-old Latina PHA related:

I'm so beyond the point of saying that I'll relapse again.... I don't mean I'll never relapse again, but I'm not scared anymore as far as thinking that just because I see people that are using I'm gonna relapse. It doesn't faze me at all. I know some of the other girls [were] a little concerned with going back into that street but we all stayed together as a group and I think that helped us. You know, the knowing that we weren't there by ourselves and we had to ... answer back. Nobody ever tried to leave the group ... we were all like really committed and I think that was really nice.

Another PHA (Latino) said of himself and other PHA participants in his training cohort:

We were able to vent with each other, which made a big difference ... not to mention, you know, if I had to I could always walk over there and, you know, talk to my counselor.

Some PHAs befriended one another during the course of their training and kept in touch after the end of the training program, sometimes even continuing to conduct outreach together, cultivating bonds with other PHAs who were facing many of the same challenges. PHAs offered each other support and increased their comfort going out into the community after the end of their training, which is anticipated as one of the outcomes of the pilot intervention program. A 50-year-old Latina PHA stated:

I actually asked the people in our group for their phone numbers. Everybody gave it to me so we can keep in contact. We all want to keep working at it.... I don't want to go out by myself. I think it's better when you have someone else. At least one more person to talk to on the way so that the people feel more comfortable when they see you. So, we thought it was better to keep safe 'cause we all want to still do it so we would keep in touch and go out there and do this some more.

While a majority of PHAs developed bonds with others in their training cohort, rapport and cohesion among PHAs varied from group to group. Factors that appeared to positively affect rapport include having meals together and calling each other on the phone occasionally to check on each other's well-being. A 52-year-old Latina PHA said of her cohort:

We're all planning to do [outreach] I hope tomorrow if it's not raining, [and] we gonna go eat all together. Usually, after we do the hour [of outreach], we always go eat a sandwich, a hot dog, anything.... I think we are a close group. And if one of us don't come, you know, we worry what happened. Like me last week, my back.... I couldn't walk, so, you know, they called me to see how I was doing.

Other PHAs tried to form support groups with other members of their training cycle, but these attempts could be thwarted by lack of interest or availability of other PHAs, as well as social dynamics of the group. One PHA, a 37-year-old Latina who tried to form her own support group with other women in her group, described:

The ladies that were in there, we were trying to go out and do the group ourselves, you know, have a cup of coffee. We go to the library, but it's not the same and it's not working as well as I thought. Not having a leader or person ... because everybody wants to be the leader ... to have the rules in their hands and say this is what we're going to do today and ... it doesn't work. It's not working.

For this reason, some PHAs have suggested that the RAP program provide more structure and supports for PHAs to respond to their social and psychological needs as they participate in outreach.

Suggestions for Improving PHA Experiences

A number of suggestions were made by both PHAs and RAP clinic staff to help reduce anxieties associated with conducting peer-delivered outreach as part of the pilot intervention. Among these were to allow more time for PHAs to solidify the information they learned in the training sessions and to practice role-playing in different scenarios they might encounter during outreach. A 37-year-old Latina PHA said:

It was very helpful, but I think we could use more time to, you know, focus on the information that we're getting, because it was a very short time to get all that information in your mind and to keep it there.

This opinion was echoed by staff as well. For example, one staff member (Latina) said:

How can you go through something when you only have 15 minutes to do each section? I think that's a big barrier in it ... and we're teaching some heavy duty stuff.... But there are pluses and minuses to [extending the length of training] because ...who's going to invest two weeks in it?.... But at the same time, if you do it too fast you might not get it all.... But I do honestly feel we have to ... incorporate more time into it.... I don't feel it's sufficient for them to go out there and feel confident.

A number of PHAs expressed that they would like to see more role-playing incorporated into the training component of the intervention design in order to enhance their comfort and learn how best to react in various outreach scenarios. A 53-year-old white female PHA explained:

I learned a lot from the group.... I felt that role playing could have had more emphasis. They had ... two people stand up and role play three times, you know,

with a casual person, with a person they knew, and with a person they didn't know. And that was it.

One staff member (Latina) further elaborated:

For the patients, they've never done it before ... and you're just giving them less than five or ten minutes to try something out. You know, do different scenarios, like, really get into them going out into the community [where] all kinds of behaviors come at you, because they need to know how to react.... And they still—not all—have some negative behaviors that we don't want them to take out in the community. Someone comes off at them, and what they gonna do ... throw a punch? I think a little bit more role playing would be excellent, that kind of practical side of it.

In addition to curriculum considerations, another important concern mentioned primarily by PHAs was what to do after the official training period of the study ended. While many certified PHAs were highly motivated to continue outreach on their own time in their own communities, no structure was in place during the pilot to guide them or to connect them with other PHAs who might have wanted to conduct outreach together as a team. As one 52-year-old Latina PHA suggested:

Now we gonna finish. They're gonna start a new group, right? And I don't know what happened with those people who finished. They don't come back and, you know, support. They already [onto] a new group and stuff like that. They should have all the groups together and go out.

Bringing together PHAs into larger groups can help to create formal or informal support networks for PHAs, providing a forum for "debriefing" by sharing stories, experiences, and concerns. One staff member (Latina) said:

I feel like there should be something in place for them. Like, once a month ... where they can just come and talk ... about how things are going. I feel they should have a time with their staff member to debrief how they felt. How was it for them, where they felt [something] lacking ... where they need help? You know, 'cause just: "Okay, let's come. Let's go out. Okay, bye, see you next time".... I don't think it develops the relationship that it should develop. How do they stay involved with the project afterwards? There has to be always continuity to something 'cause otherwise, it's just ... not even a relationship.

Other PHAs who completed the program had concerns about what would come from their participation in the program in terms of their own personal rehabilitation, employment, or continued engagement within a positive community dynamic. A 52-year-old Latino PHA shared:

Right now, I keep myself occupied, the PHA stuff, it's something I like doing. It's something I feel like I have a purpose for and it blocks all the other stuff away right now, but eventually ... something's got to come out of it.

Likewise, another PHA, a 37-year-old Latina, described what she hoped to get out of participating in the study program:

Maybe get a job [laughs], to help because I really love it.... And I would really like to ... help people and, and be around people more.... And it will, will help me personally, you know, with everything. With my depression, with my bills, with everything.

Another PHA, a 27-year-old Latino, offered a similar statement:

If something came out [of this], like work, some job, you know. Through training or something. I'm willing to do that ... if some position came out or something, even voluntary, you know, a couple of hours a week or what, to talk to people.... I want to do that ... 'cause you never know from there you might get something better.

Discussion

This study was driven by the central question of whether the benefits outweigh the potential harms for drug treatment clinic patients with regard to participation in an experimental peerdelivered outreach program that was based in their treatment clinic. The overwhelming response pattern among clinic patient and staff participant testimonies suggests that peerdelivered outreach by clinic patients can involve certain psychosocial discomforts and challenges, but that the particular challenges encountered in the RAP program, when conducted in clinics, are outweighed by positive impacts on participants' knowledge, selfesteem, attitude, demeanor, and overall emotional health. In contrast to some of the criticisms that have been directed toward other peer-driven interventions and sampling procedures tested in community settings (e.g., respondent driven sampling—RDS), patients in this pilot study did not convey that their participation in RAP conducted in the clinic entailed any stigma or significant risks to their sobriety, personal health and safety, mental health and well-being, or the integrity of their social networks. Instead, these interviews revealed that patients experience a manageable set of anxieties associated with transitioning into their new role as community educators and that upon initiating outreach, they quickly experienced responses from intervention recipients that provided positive social supports for their continued delivery of the peer program.

Best Practices

The major recommendation from patients is that they want to feel supported by program staff at every step during this transition. They received informal support from their drugtreatment counselors, clinic staff on the study, as well as other PHAs. The ethical imperative suggested by their narratives regarding this pilot intervention is to channel program resources into the creation of more structured and well-developed support networks that enhance patients' feelings of emotional support, confidence, and morale, and thereby motivate both participants and clinic staff to sustain peer-delivered outreach past official training "end-dates" and into the future.

Patients and study staff at the clinic identified specific challenges associated with participation in the RAP pilot in drug treatment clinics, including learning how to approach people during outreach, deciding where to conduct outreach so that participants in the

training feel comfortable and safe, and deciding how to respond to community members experiencing significant problems or trauma. Rather than describing these challenges as disincentives, however, participants tended to characterize them as positive occasions for exploring self-improvement through helping others. The availability of outreach staff and counselors to help participants manage these concerns was cited as a major buffer of stress and anxiety related to outreach activities and personal recovery.

A small number of participants in the pilot study discussed potential threats to physical safety and recovery, and exposure to dangerous settings and "triggers." However, there was almost unanimous agreement that threats to personal safety and recovery are very rare, and are buffered by the protective feature of conducting outreach in groups, and more importantly, by the program's focus on observing participant preferences in deciding how and where to conduct outreach. This central component of the RAP intervention design minimizes the likelihood of physical danger and threats to recovery, as participants voluntarily avoid outreach settings they perceive to be dangerous.

Participants also said that a major concern is what to do after the experimental training program ends. Aside from a nominal monetary incentive, all participation in the pilot study was voluntary. For a majority of participants, entering into the project's intervention training program constituted a significant and positive life change. However, the momentum of this change was threatened by the looming "end" of the training program, despite that participants were encouraged to continue outreach activities on their own. Without the proper guidance and structure to continue these activities, participants' ongoing engagement and the benefits to their recovery may plateau or even decline. Furthermore, many participants expressed a wish that their participation in the study could lead to practical benefits in the long-term, including income-generating employment. Peer-delivered outreach programs like RAP may benefit from building in support structures that help participants to transition into employment or other forms of social and economic reintegration.

Research Agenda

The continuity of participant outreach activities past the end of the program training period depends on the level of continued leadership. Collaborations between research and program staff in the clinic as well as clinic administrators to develop these structures from the start can help to organize group outreach activities among trained PHAs who may not have the capacity to organize and maintain these structures for themselves. In future research, attention should be paid during the early stages of project design and implementation to train program clinic staff and advise drug treatment counselors in what to expect and how to respond to patient concerns at different stages of the training and outreach, as well as their transition into more sustained outreach activities. While one-on-one consultations with counselors and staff during the study period appeared to constitute a basic level of support, participants and staff also stated that the inclusion of more structured group-level supports, including group "debriefings" with other PHAs and cultivation of a connected network of peer-outreach workers across training cohorts, would further help to mediate psychosocial stresses generated by program participation and encourage continued efforts. Establishing clinic groups and peer-to-peer contact forums may help to promote a growing network of

peer outreach workers, motivate participation in group outreach sessions, and enhance the enjoyment and sustainability of peer-delivered outreach.

While the first training cycles of the pilot study to implement RAP in the clinic were ongoing, no formal supports had yet been put in place to guide patients or address any psychosocial concerns. Subsequently, results from this study led clinic staff to establish ongoing support structures, including monthly Community Advocacy Group (CAG) meetings, in which patient participants can share their experiences with other PHAs, receive more training, debrief, and simply "hang out" with other PHAs and clinic program staff. Additionally, clinic staff and patients have also begun to organize group outreach opportunities for trained PHAs to regather and conduct outreach together, both to sustain their efforts and to provide mutual support.

Educational Implications

Exploring and incorporating patient study participant feedback in the early stages of this pilot was an important part of the startup process and a necessary step in creating supports in the intervention design that are specific and relevant to participants' experiences and concerns. Researching the ethical considerations for investigators as they conducted this research helped to mitigate risk and reduce harm to study participants in the subsequent stages of the study. Because the needs of participants are likely to shift from person to person, as well as from cohort to cohort, psychosocial supports must be dynamic and able to adapt to meet the specific needs of individuals and groups of participants in the training program over time. Future peer-delivered outreach intervention models tested in clinics should regularly elicit and incorporate participant feedback as a way to continually improve program dynamics, to ensure that participant needs are being met, and to help to sustain patients' outreach activities and personal recovery into the future.

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References

- Anderson EE, Solomon S, Heitman E, DuBois JM, Fisher CB, Kost RG, et al. Research ethics education for community-engaged research: A review and research agenda. Journal of Empirical Research on Human Research Ethics. 2012; 7(2):3. [PubMed: 22565579]
- Boyd M, Moneyham L, Murdaugh C, Phillips K, Tavakoli A, Jackwon K, et al. A peer-based substance abuse intervention for HIV positive rural women: A pilot study. Archives of Psychiatric Nursing. 2005; 19(1):10–17. [PubMed: 15765367]
- Colón RM, Deren S, Guarino H, Mino M, Kang SY. Challenges in recruiting and training drug treatment patients as peer outreach workers: A perspective from the field. Substance Use & Misuse. 2010; 45(12):1892–1908. [PubMed: 20380554]
- Convey MR, Dickson-Gomez J, Weeks MR, Li J. Altruism and peer-led HIV prevention targeting heroin and cocaine users. Qualitative Health Research. 2010; 20(11):1546–1557. [PubMed: 20639354]
- Dickson-Gomez J, Hilario H, Convey M, Corbett AM, Weeks M, Martinez M. The relationship between housing status and HIV risk among active drug users: A qualitative analysis. Substance Use & Misuse. 2009; 44(2):139–162. [PubMed: 19142817]
- Dickson-Gomez J, Weeks M, Martinez M, Convey M. Times and places: Process evaluation of a peer-led HIV prevention intervention. Substance Use & Misuse. 2006; 41(5):669–690. [PubMed: 16603454]
- Fisher, CB. Decoding the ethics code: A practical guide for psychologists. Thousand Oaks, CA: Sage;
- Fisher CB. Addiction research ethics and the Belmont principles: Do drug users have a different moral voice? Substance Use & Misuse. 2011; 46(6):728–741. [PubMed: 21073412]
- Fisher, CB.; True, G.; Alexander, L.; Fried, AL. Moral distress and the responsible conduct of community-based drug use research. Paper presented at Quest for Research Excellence Conference; Washington, DC. March 15–16; 2012.
- Fisher CB, True G, Alexander L, Fried AL. Moral stress, moral practice and ethical climate in community-based drug use research: Views from the frontline. American Journal of Bioethics: Primary Research. 2013; 4(3):27–38.
- Fry CL. Ethical implications of peer-driven recruitment: Guidelines from public health research. American Journal of Bioethics. 2010; 10(3):16–17. [PubMed: 20229407]
- Fry CL, Hall W, Ritter A, Jenkinson R. The ethics of paying drug users who participate in research: A review and practical recommendations. Journal of Empirical Research on Human Research Ethics. 2006; 1(4):21–36. [PubMed: 19385835]
- Kalichman SC, Rompa D, Cage M, DiFonzo K, Simpson D, Austin J, et al. Effectiveness of an intervention to reduce HIV transmission risks in HIV-positive people. American Journal of Preventive Medicine. 2001; 21(2):84–92. [PubMed: 11457627]

Lauby JL, Smith PJ, Stark M, Person B, Adams J. A community- level prevention intervention for inner city women: Results of the women and infants demonstration projects. American Journal of Public Health. 2000; 90(2):216–222. [PubMed: 10667182]

- Li J, Weeks MR, Borgatti SP, Clair S, Dickson-Gomez J. A social network approach to demonstrate the diffusion and change process of intervention from peer health advocates to the drug using community. Substance Use & Misuse. 2012; 47(5):474–490. [PubMed: 22428816]
- Mayer K, Karim S, Kelly C, Maslankowski L, Rees H, Profy A, et al. Safety and tolerability of vaginal PRO 2000 gel in sexually active HIV-uninfected and abstinent HIV-infected women. AIDS. 2003; 17:321–329. [PubMed: 12556685]
- Metzger DS, Woody GE, O'Brien CP. Drug treatment as HIV prevention: A research update. Journal of Acquired Immune Deficiency Syndromes. 2010; 55(Suppl 1):S32. [PubMed: 21045597]
- Muhr, T. ATLAS.ti (Version 5.0)[Computer software]. Berlin: Scientific Software Development; 2004
- Needle RH, Burrows D, Friedman SR, Dorabjee J, Touzé G, Badrieva L, et al. Effectiveness of community-based outreach in preventing HIV/AIDS among injecting drug users. International Journal on Drug Policy. 2005; 16:45–57.
- Oransky M, Fisher CB, Mahadevan M, Singer M. Barriers and opportunities for recruitment for nonintervention studies on HIV risk: Perspectives of street drug users. Substance Use & Misuse. 2009; 44(11):1642–1659. [PubMed: 19938935]
- Polkinghorne DE. Reaction to special section on qualitative research in counseling process and outcome. Journal of Counseling Psychology. 1994; 41(4):510.
- Raja S, Teti M, Knauz R, Echenique M, Capistrant B, Rubinstein S, et al. Implementing peer-based interventions in clinic-based settings: Lessons from a multisite HIV prevention with positives initiative. Journal of HIV/AIDS & Social Services. 2008; 7(1):7–26.
- Schesnul, JJ.; Berg, MJ.; Nair, S. Using ethnography in participatory community assessment. In: Israel, Barbara A., et al., editors. Methods for community-based participatory research for health. 2. San Francisco: Jossey-Bass; 2012. p. 161-188.
- Scott G. They got their program, and I got mine?: A cautionary tale concerning the ethical implications of using respondent-driven sampling to study injection drug users. International Journal of Drug Policy. 2008; 19(1):42–51. [PubMed: 18226516]
- Semaan S, Santibanez S, Garfein RS, Heckathorn DD, Des Jarlais DC. Ethical and regulatory considerations in HIV prevention studies employing respondent-driven sampling. International Journal on Drug Policy. 2009; 20(1):14–27. [PubMed: 18243679]
- Simmons J, Koester K. Commentary hidden injuries of research on social suffering among drug users. Practicing Anthropology. 2003; 25(3):53–57.
- Simon C, Mosavel M. Community members as recruiters of human subjects: Ethical considerations. American Journal of Bioethics. 2010; 10(3):3–11. [PubMed: 20229402]
- Singer M, Scott G, Wilson S, Easton D, Weeks M. "War stories": AIDS prevention and the street narratives of drug users. Qualitative Health Research. 2001; 11(5):589–611. [PubMed: 11554190]
- Slomka J, Ratliff EA, McCurdy S, Timpson S, Williams ML. Perceptions of risk in research participation among underserved minority drug users. Substance Use & Misuse. 2008; 43(11): 1640–1652. [PubMed: 18752165]
- True, G.; Alexander, L.; Fisher, C. Addressing ethical challenges in urban drug addiction research: Lessons from community research workers. Paper presented at Quest for Research Excellence Conference; Washington, DC. March 15–16; 2012.
- UNAIDS. AIDS epidemic update: December 2009. WHO Regional Office Europe; 2009.
- U.S. Department of Health and Human Services. The Belmont report: Ethical principles and guidelines for the protection of human subjects of research. 1979. Retrieved from www.hhs.gov/ohrp/humansubjects/guidance/belmont.html
- Weeks MR, Convey M, Dickson-Gomez J, Li J, Radda K, Martinez M, Robles E. Changing drug users' risk environments: Peer health advocates as multi-level community change agents. American Journal of Community Psychology. 2009; 43(3–4):330–344. [PubMed: 19326208]

Weeks MR, Li J, Dickson-Gomez J, Convey M, Martinez M, Radda K, Clair S. Outcomes of a peer HIV Prevention program with injection drug and crack users: The risk avoidance partnership. Substance Use & Misuse. 2009a; 44(2):253–281. [PubMed: 19142824]

- Weeks MR, Li J, Dickson-Gomez J, Convey M, Martinez M, Radda K, Clair S. Outcomes of a peer HIV prevention program with injection drug and crack users: The risk avoidance partnership. Substance Use & Misuse. 2009b; 44(2):253–281. [PubMed: 19142824]
- Whittle J, Fletcher KE, Morzinski J, Ertl K, Patterson L, Jensen W, Schapira MM. Ethical challenges in a randomized controlled trial of peer education among veterans service organizations. Journal of Empirical Research on Human Research Ethics. 2010; 5(4):43–51. [PubMed: 21133786]
- Wingood G, DiClemente R, Mikhail I, Lang D, McCree D, Davies S, et al. A randomized controlled trial to reduce HIV transmission risk behaviors and sexually transmitted diseases among women living with HIV. Journal of Acquired Immune Deficiency Syndromes. 2004; 37(2):S58–S67. [PubMed: 15385901]

World Medical Association. Declaration of Geneva. Geneva: WMA; 1983.