Agents of Change: Peer Mentorship as HIV Prevention Among HIV-Positive Injection Drug Users

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This paper presents a qualitative investigation of peer mentoring among HIV seropositive injection drug users in a randomized controlled trial, the INSPIRE study. Qualitative analyses of 68 in-depth open-ended interviews conducted in 2005 in Baltimore, New York, Miami, and San Francisco revealed that these individuals conceptualized themselves as change agents through the identity of peer mentor at the three related domains of individual, interpersonal, and community-level change. Implications for program development and future research of peer mentoring as a mechanism for HIV prevention are discussed. This study was funded by the Centers for Disease Control and Prevention and Health Resources and Services Administration (HRSA).

Keywords: change agent, identity, peer mentor, risk environment, social context, social identity, HIV prevention, HIV-positive, injection drug user

INTRODUCTION

HIV prevention approaches that engage HIV-positive (HIV+) injection drug users (IDUs) in the context of social-structural “risk environments” (Rhodes, 2009) are critical to stemming the transmission of HIV. Peer-based interventions comprise one approach to HIV prevention that locate the individual in the context of his or her social environment and have been demonstrated as an effective approach to HIV prevention among drug users (Des Jarlais et al., 2007; Dickson-Gomez, Weeks, Martinez, & Convey, 2006; Garfein et al., 2007; Latkin, Hua, & Davey, 2004; Latkin, Sherman, & Knowlton, 2003; Sherman et al., 2009). Based on social network and empowerment theories (Broadhead et al., 1998; Friere, 1973; Gottlieb, 1985; Zimmerman, 2000), peer mentoring approaches to HIV prevention draw from the shared experience and social status of members of a specific group (e.g., HIV status, drug user status, housing status, gender, race/ethnicity, age, sexual orientation) as a means for the communication
of health-promoting messages among peer networks, as well as to effect positive change on the behaviors of the peers themselves. While there has been evidence of positive results of peer mentoring on HIV-related outcomes for the mentor, including reduction of unsafe injection practices (Latka et al., 2008; Latkin et al., 2009), reduction in drug use (Sherman et al., 2009), and increase in condom use (Sherman et al., 2009), the mechanisms through which peer mentoring operates have not been adequately understood.

A risk environment has been defined as “the space – whether social or physical – in which a variety of factors exogenous to the individual interact to increase the chances of HIV transmission” (Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2005, p. 1027). The framework of the risk environment is predicated on an understanding of the necessary interplay between the micro, meso, and macro levels of environmental influences and underscores the importance of HIV prevention measures that are “locally produced,” or based in specific communities and environments (Rhodes et al., 2005, p. 1028). Drawing on the framework of the risk environment allows for a way to identify the social context of peer mentoring at the three distinct but interrelated levels of the individual, the interpersonal, and the community in which the peer mentor operates.

Responding to the call for greater understanding of the processes of peer mentoring (Dickson-Gomez et al., 2006; Hilfinger Messias, Moneyham, Vyavaharkar, Murdaugh, & Phillips, 2009), this paper explores how HIV-positive IDUs in a peer mentoring intervention articulated the effects of peer mentoring as a vehicle for change in their lives. Peer mentoring in this study emphasized the ability to non-judgmentally approach and communicate HIV prevention and care messages through informal, street-based discussions with other HIV-positive IDUs as well as other community members. This qualitative analysis aims to shed light on whether and how HIV-positive IDUs conceptualize themselves as change agents through the identity of peer mentor at and across the three related domains of individual, interpersonal, and community-level change.

METHODS

We conducted analysis of in-depth post-intervention interviews with 68 HIV-positive heterosexual active IDUs who participated in the INSPIRE (Intervention for Seropositive Injectors – Research and Evaluation) study. INSPIRE was a randomized controlled trial of a 10-session peer mentoring intervention, designed to assess the four primary outcomes of sexual risk, injection-related risk, use of HIV care, and adherence to HIV medications. Eligibility criteria included having had an opposite-sex partner in the three months prior to the study and having injected in the 12 months prior to the study. The study was conducted in four US cities (Baltimore, Miami, New York, and San Francisco) between 2001 and 2005 (see Purcell et al., 2004). In addition to the more standard cognitive-based theories of behavior change (Bandura, 1986; Fishbein & Ajzen, 1975; Janz & Becker, 1984), INSPIRE integrated key concepts of empowerment theory into an HIV prevention intervention (Purcell et al., 2004). The experimental condition consisted of seven group sessions, two individual sessions and one peer volunteer activity. The control condition comprised eight small-group video-and-discussion sessions on topics relevant to participants’ lives, such as employment/work, discrimination, drug use and abuse, and basic HIV prevention information. Participants in both conditions reported significant reductions in sexual and injection HIV risk behavior, with no statistically significant difference between the groups (Purcell et al., 2007).

Based on a harm reduction framework, participants in the intervention were trained to discuss safer sex, drug use, medical care, and adherence to medications with their peers; to discuss disclosure of HIV serostatus; and to address consistent condom use, sterile needle use, or other risk reduction strategies as appropriate. Peer mentors were given up-to-date information about HIV risk reduction techniques, health care and treatment, and resources in their local communities. The training emphasized concrete skills-building techniques that addressed how to approach peers and open conversations about sensitive topics, and how to listen to peers and provide resources when needed. Participants engaged in exercises to practice these skills and then attended a one-time peer volunteer activity at a local community site, where they were given the opportunity to experience peer mentoring in a service setting. In the peer volunteer activity, participants took part in activities such as handing out condoms at needle exchange sites, handing out food at an HIV/AIDS organization, and interviewing a panel of outreach workers. It is important to note that for some participants, disclosure was not desired in familial, sexual, drug-using, and/or community relationships and that the intervention did not encourage or require participants to disclose to anyone. Participants could choose to opt out of the peer volunteer activity or were given an option of an activity that did not involve the disclosure of their HIV status. The role of peer mentor in the intervention condition was intentionally framed as a less formal social identity than that of peer educator. This ensured that mentors were distinct from the peer educators in the community-based organizations. For more details on the intervention, see Purcell et al., 2007.

In order to understand how INSPIRE was experienced by participants, each study site conducted qualitative interviews in 2005. A total of 116 people were interviewed, 68 participants from the experimental condition and 48 from the control condition. Participants were eligible for inclusion in the qualitative substudy if they had completed at least four group sessions and the 12-month follow-up survey. This paper focuses on data from the 68 participants from the peer mentoring intervention condition. The socio-demographic characteristics of this subsample are presented in Table 1, which indicates that this subsample was representative of the larger study sample (Purcell et al., 2004).
Data Collection

Trained site interviewers at the four study sites conducted the in-depth semi-structured interviews 12–24 months after participants had completed their last group session. All participants provided written informed consent specifically for the in-depth interview. Using interview guides developed to capture participant experiences with INSPIRE, interviews ranged from 45 to 90 minutes. Participants were reimbursed $25. All interviews were audio-taped and transcribed and analyzed using ATLAS.ti 5.0 qualitative software (Scientific Software Development, Berlin). Interview topics included general and specific impacts of the INSPIRE program and the experience and the impact of the peer mentoring component, including the peer volunteer activity (for experimental condition participants). All 68 participants who had participated in the peer mentoring training were asked to reflect on what they had learned from INSPIRE about being a peer mentor; what being a peer mentor meant to them; what, if any, impacts being a peer mentor had on their lives; if they had continued to draw on these skills; and how they perceived themselves in relation to their peers and community; and were asked to describe their experience with the peer volunteer activity.

Analysis

Our analytic approach was based in grounded theory, which seeks to develop knowledge based on information and insights provided by the people who experience a particular phenomenon (Strauss & Corbin, 1990). We used contextualizing and categorizing strategies to analyze the data (Patton, 1990; Strauss & Corbin, 1990). First, the transcripts were summarized in a “digest” that identified the major themes of the interview. In addition, a contextualizing strategy of describing the social and cultural context of each research site was included in the digests. Using ATLAS.ti, we conducted coding of the data in three steps. First, based on the summaries and transcripts read by the cross-site analytic team, a list of analytic areas represented in the data were composed and given a code (from a “closed code” list). Second, each site analyst re-read the transcripts and identified blocks of text to be given a descriptive label (either a label from the closed code list or a novel one, termed an “open code”). Third, the data under the code “peer mentoring” in the 68 experimental interviews were re-read and re-coded into subcategories that emerged from the data in order to refine the analytic categories used (Strauss & Corbin, 1998). These subcodes included “peer mentoring-acceptance,” “peer mentoring-disclosure,” and “peer mentoring-community.”

In our results, we present quotations from the peer mentoring primary and secondary-level codes that illustrate the five primary themes that emerged, identifying the age, race/ethnicity, and sex of the participant, as well as study site.

RESULTS

Five key themes are highlighted here that emerged from the qualitative data on peer mentoring: (1) construction of the peer mentoring identity, (2) individual change, (3) interpersonal or relationship change, (4) community change, and (5) challenges with the peer mentoring identity.

The Construction of the Peer Mentor: “Show Versus Tell”

The construction of an identity as a peer mentor in these data was based on participants’ narratives of the authority of their experiences as HIV-positive IDUs. Peer mentoring allowed participants to draw on their life experiences, experiences that are typically marginalized by dominant societal structures. In the words of one participant: “These are my brothers and sisters, folks who other people probably don’t have time for” (52-year-old African American female, NY). The sense of shared histories often included incidents of social exclusion and/or estrangement from individuals and institutions, thereby precluding meaningful interaction that the mentoring role then gave them.
opportunities to bridge. Many discussed the importance of life—versus book—knowledge, alongside the lack of social value attributed to this form of knowledge. “Living the experience” became the central tenet of peer mentoring:

It’s like, who can best teach a dope addict about pills, but a dope addict (chuckles)? If you’re livin’ an experience, who better to help someone, other than the person who’s livin’ the experience? (48-year-old African American male, NY)

In the face of the social stigma surrounding injection drug use that participants described experiencing in HIV/AIDS organizations as well as organizations working with drug users, the peer user then becomes a trusted source of knowledge, in the words of one man, “someone I can believe in and trust” (50-year-old African American male, Miami). The logic of experience equaling expertise coupled with the felt effects of stigma served to call into question other forms of knowledge:

I’m a drug addict you know? You can’t understand it—you know, the train of thought. One addict to another is on a parallel … it’s like outside communication doesn’t even exist. Because we in the mix, you know? All this here [movements to office papers], it’s like a foreign language man. (49-year-old African American male, San Francisco)

Beyond the accumulated life history and specialized knowledge that mentors described as integral to the identity of peer mentor, peer mentorship was constructed as being a form of action. In this regard, the role of peer mentor is predicated on shared experience but takes place through the actions of the mentor as well as those of the mentee. The following participant points to the ways in which his being a peer mentor to young family members is based on his own actions, and the importance of “show” versus “tell”:

I knew that I had contracted [HIV], but … maybe it was the drugs I was usin’, you know, I was givin’ myself a whole lotta excuses. I shot enough narcotics, that’ll suppress it, you know? I had great nieces and nephews. That … (sighs) … I gotta be there for ‘em like they were there for me. It’s my turn to step up and I gotta be more or less show it than tell it. Tellin’ it—bullshit, you know? If you ain’t stackin’ up, then that’s goin’ right over their head, you know? (53-year-old African American male, Baltimore)

Inherent in peer mentoring is a call to change—for the mentee and for the peer mentor him or herself. The following discussion will address the ways in which mentors experienced peer mentoring as a vehicle for change in their lives by acting at and across the levels of the individual, interpersonal, and community.

“It’s All Gonna Come Back to You”: Individual Change

Many participants described that the most significant form of personal change that they experienced in relation to peer mentoring was coming to greater acceptance of their HIV status. Participants frequently talked about the way in which their mentoring of others necessitated change in and was most useful for themselves. As one man pointed out:

I think it [peer mentoring] even had more impact in helping me than helping out other people. Because if I wasn’t able to better myself, and the issues that I was dealing with, I wasn’t—I wouldn’t be able to pass on the good influence to other people. (44-year-old white male, Miami)

Another participant touched on the accountability that he felt as a peer mentor to embody in his actions what he was discussing with others:

I: And what impact has being a peer mentor had on you?
R: It makes me want to stay straight.
I: (Pause) How so?
R: Because I can’t preach one thing, and do another. How can I tell this person not to eat apples, and I’m goin’ around the corner eatin’ apples? (53-year-old African American male, Miami)

In this regard, peer mentoring serves as a form of personal accountability through its role of accountability to others. The following participant touched on the ways in which his role as peer mentor supported personal change by giving him a new perspective on himself:

The only way I can keep what I have is by giving it away. You know, because I could have something and sit on it. But if I have something and get up off of it, I can, I can see it as well as give it away … It really reinforces what it is I need to do to take care of myself. (44-year-old African American male, San Francisco)

He later discussed the impact that seeing people in an HIV/hepatitis C co-infection support group had on him, in particular as a motivator for his own self-care practices. Many participants similarly described their role as peer mentors as initiating self-evaluation. By acquiring knowledge of their peers and the varied situations facing them, individuals described being able to situate and come to a new understanding of themselves, including the fact of having HIV.

The following woman described how HIV stigma and shame, as well as a history of sexual trauma, affected the ability of a young female injector on the streets whom she knew was HIV-positive to “remember,” let alone accept, her HIV status:

[Some people] are ashamed to go to anybody. Ashamed to tell, AFRAID and ashamed, ‘cause of all the past violence towards HIV—didn’t let anybody know. And then some of ‘em even just forget that they have it. You know, literally forget! Put it out of their head, that they’re HIV. Say, “Well, if I thought about it all the time, I’d be dead. So I just forgot all about it. Oh, man! You just reminded me! Why’d you do that for?” (Chuckles) I say, “Well, I think it’s good that I reminded you.” “Oh yeah!” You know, they’ll be lookin’, like a dead gaze into nowhere. And I say, “All right, come, snap out of it, Where ARE you?” Shake her up a little bit, and she said, “I’m not here. I’m not here.” She was doin’ a daze, where she didn’t have HIV, “HIV?” “Yeah, remember you told me?” (53-year-old American Indian female, San Francisco)

This passage illustrates the extent of the dissociation that can accompany living with HIV/AIDS as an IDU, given continued experiences of HIV stigma and subsequent fear of violence, and the resultant challenges to integrating HIV status. These experiences are often managed
as well as exacerbated by drug use. In the face of these significant barriers to acknowledging HIV status, this peer mentor describes serving as a most basic reminder that this young woman has HIV. The participant goes on to describe how she would watch over for this young woman by bringing her condoms and encouraging her to use them, as an attempt to support her in taking measures to protect herself and her sex partners.

Participants described both individual and group encounters with peers that facilitated reflections on having HIV that they framed as coming to accept the virus. The participant who attended the HIV/hepatitis C co-infection support group described how he was able to use his peer mentoring skills to talk with group participants about a number of issues, from navigating correctional systems to approaching safer sex because he had “worked through it.” He describes his experience with peer mentoring in the following passage:

I: So when you were doing the peer counseling in the group, what do you feel like it did for you? Describe a little bit about that.

R: “Peace. It put me at peace with . . . (pause) . . . the fact of having HIV, because so many others were there discussing their issues . . . Some person’s conditions was worse, and some people’s conditions were better. So it gave me a broader perspective of what the possibilities are. But it just makes you more self-aware you know, the whole peer counseling process . . . it just makes you more aware. It made me more conscious of my behavior, and how I approach individuals. (44-year-old African American male, San Francisco)

This participant describes how his peer mentoring group experience gave him a new perspective on his health and, indeed, his sense of coming to “peace” with having HIV. This group was also significant because he chose to disclose his HIV status to the group, representing the first time that he had publicly disclosed. Many participants echoed the following statement from a man who, reflecting on his experience with the INSPIRE training, stated that the group “opened my eyes to that I know I got this disease” (45-year-old African American male, Baltimore).

That participants framed their experience with the peer mentoring training so frequently around coming to accept their HIV underscores both the challenges to and critical importance of the integration of HIV status for positive IDUs, as well as the ways in which the adoption of a peer mentor identity can harness these very challenges, through shared experience, toward facilitating acceptance of their own HIV status. The salience of HIV acceptance for these participants provides evidence that peer mentoring can facilitate personal change through contextualizing the individual in light of a spectrum of life experiences. In the words of one man, “eventually, it’s all gonna come back to you” (48-year-old African American Male, NY).

Interpersonal Change: “It’s My Place to Let Ya Know”

At the interpersonal level, the experience of being a peer mentor was often discussed in relation to HIV disclosure. The role of peer mentor facilitated a sense of changed social identity for some peers through supporting them to explore disclosure in their lives. This discussion addresses disclosure as a process that is both affected by and impacts upon individuals’ identities as HIV-positive IDUs (Frye et al., 2009), as well as a dynamic interplay between the individual and his/her social environment. The experimental condition of the INSPIRE training explicitly addressed skills-building around disclosure and gave peer mentoring participants various opportunities to disclose their status to others both within and outside the group, as well as in the peer volunteer activity (for more analysis of disclosure in the INPSIRE study, see Frye et al., 2009).

This analysis considers the ways in which adoption of the peer mentor role was articulated in relation to disclosure in key relationships in participants’ lives. Many participants reported that adopting the role of peer mentor enhanced their ability to disclose their HIV status in their personal relationships and/or publicly because it gave them both the opportunity and the skills to do so. Mentors described enhanced communication skills with individuals and institutions as a result of the peer mentoring training.

Bridging individual and interpersonal levels of change, the following participant links coming to an understanding of his HIV with disclosure of his status:

I: What has your role of peer mentoring been like in HIV prevention?

R: [Peer mentoring] make me understand I have HIV, that I care about other people . . . I’ll go tell a person, you know, that I’m HIV. And if after I tell you, you either respect me or you don’t, you know, life goes on. Just got to deal with it” (37-year-old African American male, Baltimore).

As with data presented in the prior section, this participant points to the ways in which he now “understands” that he has HIV and links this to his role as a peer mentor caring for other people and disclosing his status to others.

In addition to facilitating the acceptance of HIV status, these data suggest that peer mentoring in this study may have supported disclosure by offering a new social role—that of peer mentor—as well as a concrete training in the development of communication skills to support this role. Participants’ identities as peers to other HIV-positive IDUs were predicated on their sharing of those joint social experiences with people whom they were mentoring. The importance of the peer experience to the peers themselves is underscored in the following comment by a woman in response to the question of what being a peer mentor means to her: “From day one, it felt like a burden lift up off me when I found out it was other people out there like me, and we all in this class” (52-year-old African American female, Baltimore). This woman, like many participants, discussed the extent of the isolation she felt as an HIV-positive IDU, often described in retrospect as hiding or keeping a secret: “All your secrets is right here in you. And you ain’t tellin’ nobody nothin’, you know, that’s a lonely place to be” (52-year-old African American female, Baltimore). Another woman reflects on the impact of peer mentoring in her life:
I: So what kinda impact do you think peer mentoring has had on you?

R: The impact it had on me, like uh, just tellin’ other people. Just tellin’ other people about it [HIV] and everything. As a matter of fact one of my girlfriends . . . I told her I was sick. (Chuckles) . . . And she was like “Wow! Why you pick me to tell me that?” . . . like I said I didn’t use to tell nobody that I was sick. Or anything like ‘at . . . Since I been comin’ here I done told my family (chuckles) and I told a couple of my girlfriends, you know. I feel like it was just . . . I ain’t gonna hide it no more. You know? (53-year-old American Indian female, San Francisco)

Participants had varied approaches to engaging with disclosure, often coming up with creative strategies for keeping themselves and others protected in risky sexual and/or injection scenarios. One participant described his new approach to making sure that he protected himself and the women he had sex with:

At one time I’s scared to tell people, you know, young ladies anyway, that I had it. But I always tell and—I always come up and tell ‘em you know. “I don’t know if you got it and I don’t know if I got it, but I wanna protect myself.” And then I use a condom. I protectin’ both of us, “cause I don’t know if she had it or not. (45-year-old African American male, Baltimore)

While some participants discussed disclosure in their personal relationships, many participants addressed the ways in which assuming the role of peer mentor allowed them to feel comfortable—and, even, a sense of responsibility toward—disclosing to other HIV-positive IDUs whom they did not know on the street, bus, in groups, and/or in other public places.

Participants reflected on the specific elements of the peer mentoring training that contributed to their comfort in disclosing. As a way of countering isolation, disclosure to select members of their family and social networks often built on positive experiences of disclosing in the INSPIRE group as well as the one-time peer volunteer activity. In response to a question asking whether the peer mentoring part of the INSPIRE program was useful to him, one participant discussed the fact that while a lot of the people he knows are HIV-positive, most of them do not know how to disclose their status to others. He continued to reflect on specific components of the peer mentoring training as he discussed his newfound ability to disclose in his own life:

I’m followin’ a lot of things they [INSPIRE] said. You know, you have to pick, certain places and times and stuff, when you discuss things with ‘em. And let them know. And they reinforced it in me, because . . . (pause) . . . there was a time when I first was diagnosed—I wouldn’t tell anybody. But after goin’ like this, oh yeah. Now, I have no problem. (48-year-old African American Male, NY)

Having specific communication skills to support the practice of peer mentoring, as well as the identity changes that adopting this new social role created, combined to support meaningful changes in participants’ interpersonal relationships. These changes were primarily articulated around experiences of disclosure. In the words of one participant:

Well, it [INSPIRE] makes it easier for me to just . . . tell people. Whereas a lotta times I wouldn’t ‘say nothin’. You know, I feel like it’s my place to let ya know. (49-year-old African American Male, San Francisco)

In the above statement, the language of place underscores the ways in which the identity of peer mentor locates the individual in his or her social environment through the creation of a literal and figurative space for building, and changing, social relationships.

Community Change: “I Wanna Leave a Legacy Behind”

Assuming the identity of peer mentor created a role through which HIV-positive IDUs could become agents of change and take action in their communities. This re-orientation to other HIV-positive IDUs extended beyond interpersonal relationships fostered through peer mentoring to a broader re-conceptualization of themselves in relation to the larger community of HIV-positive IDUs. This was particularly significant in light of the high levels of isolation reported by individuals.

Participants drew on their understandings of the peer mentor as both an identity and a form of action as they discussed how peer mentoring allowed them to give back to others what they felt they had received by way of support and resources as HIV-positive IDUs from both individuals and organizations. This was a strong motivation for people, and provided a great source of pride in themselves and their ability to contribute at the collective level. For some individuals, the role of peer mentor fostered newfound relationships with community members and providers. Several participants discussed going back to volunteer at their peer volunteer site, and had done so from one to several times; however, maintaining a long-term volunteer relationship without structured support proved to be difficult. For some, the role of peer mentoring allowed them to see themselves in a more formal relationship while working in their communities. The following participant discussed how since his involvement in INSPIRE, he had applied for continued work as a peer outreach worker at the harm reduction organization at which he did his peer volunteer activity, saying:

Sometimes I feel like it’s time for me to give a little back. ‘Cause INSPIRE made me feel good about who I am, and what I got—so, yeah. It’s time to give a little back. (48-year-old African American male, NY)

Many framed their mentorship of other HIV-positive IDUs in terms of “saving a life,” drawing on their personal experiences in receiving social support from others as a way to understand the significance of this role in their peers’ lives. As one woman said:

That was my main object is to save a life. Somebody told me how I can live longer, and saved my life, so I can do the same. (40-year-old African American female, San Francisco)

Participants took seriously the potential impact of their peer mentoring, understanding it in terms of HIV prevention through their ability to bring their shared experience...
and knowledge to helping others with disclosure, identifying needed health and social services, and managing drug use and sexual risk. One woman, echoing many mentors’ sense of responsibility to youth, discussed handing out condoms to the “little fellas on the corner” as well as to her female friends turning tricks:

Sometimes I know that they’re infected, and I know that they’re not passin’ it [HIV] on, and I know it was because of me. That I just saved somebody’s life, you know? (50-year-old African American female, Baltimore)

Several participants expressed a strong desire to apply their mentorship skills and increased knowledge of HIV/AIDS to working as advocates for their community. The following woman discussed the need for collective advocacy to address the lack of funding and resources for HIV prevention and harm reduction services for HIV-positive IDUs, and described the ways in which peer mentoring had allowed her to acquire the information she felt she needed as well as the skills to advocate for her community:

It’s made me stronger in my fight … gotta fight for resources, some of us can’t speak for ourselves. (56-year-old African American female, New York)

This participant touches on the critical importance of peer involvement to understand the key issues facing other HIV-positive IDUs but also to advocate for those within the community who are not able to do so themselves.

Attendant to participants’ engagement with and taking action on the part of their communities, they described key changes in how they conceptualized themselves in relation to their communities. Peers articulated a sense of empowerment with the sense that they could play a key role in others’ lives, and in so doing, reflected on how this ultimately affected their lives as well. As one woman said:

It [peer mentoring] would make somebody feel empowered. Like they were doing something not just for themselves, but for the community. That is teaching people who are HIV positive, especially people who are just finding out they were positive, how to empower themselves, is really important, and it’s the difference between people taking their medication and not. It’s the difference between people going on a bender, or, or relapsing, and having no desire to change. Because, you know, it’s like “what’s the point? I have no power.” (42-year-old African American female, Baltimore)

This statement indicates how peer mentoring can empower mentors to make change in their own lives as well as in their communities, pointing to this participant’s perception of how supporting a sense of empowerment among those who feel that they have no power can contribute to HIV prevention for these individuals. Peer mentoring as a tool for empowerment extends both to the mentor, those individuals who are being mentored, and to their communities. Underscoring the importance of their conceptions of the peer mentor role as a critical role for community change, the following woman referenced historical precedents in social movements as a backdrop for her desire to continue her community engagement:

I’m only one person. I can’t do it all by myself, but I’m not gonna stop! One person can make a difference … like Rosa Parks difference. She didn’t get off that seat! So that gives me hope. If one person can make a change—one person could at least do it and that’s me. I willin’ to be another Rosa Parks. You know. Not just Rosa Parks but another Harriet Tubman if I have to be, you know? When they was lookin’ for her, she was right under they nose and didn’t catch her … I wanna leave a legacy behind. (40-year-old African American female, San Francisco)

The Challenge of Change: “Staying Strong”

While participants articulated that the changes they felt in their personal and social identities were overwhelmingly positive, some participants also raised challenges they experienced as peer mentors. All participants were asked if they had felt challenges in being a peer mentor, and two thirds of the participants responded that they had faced some level of challenge during their experience. The main challenges that they discussed were: (1) being rejected and/or experiencing resistance from their peers, (2) pressure to be a role model, including staying clean, and (3) self-disclosure of their HIV status. These challenges underscore the individual, interpersonal, and community identity changes that participants were experiencing as they built a new social role in their lives and communities. They also demonstrate that the experience of becoming a change agent through the peer mentor role for HIV-positive IDUs involves a process, rather than a static event, unique to each individual mentor.

The main challenge that participants identified in assuming the peer mentor role was negotiating their peer interactions, in particular with people who do not want help or who “throw up attitude” either related to HIV or more generally around being mentored (46-year-old African American male, NY). Often, participants talked about how difficult it was to engage a peer who did not want help from them, and the subsequent rejection they felt. Asked what she felt the biggest challenge of peer mentoring was, one woman reflected:

For other people to accept that YOU can talk about it … to accept you for sayin’ it … They’re still in denial, so, you know, they throw things at you. You know, it kinda hurts. ‘Cause, and then you have to accept that hurt, because you already been there too, so you know that emotion. ‘Cause sometimes, to accept some of the things they say to you isn’t easy … for you, yourself. (38-year-old African American female, Miami)

While this woman touches on the rejection she has felt as a peer mentor, she also draws on her own experience as an HIV-positive IDU to try to understand the reason why people may be resistant to being mentored. Other discussions of resistance to peer mentoring reflected a similar openness to reflecting on shared experience as peers. The following woman speaks to the denial of people she was trying to mentor, responding to the interviewer’s question of what has been challenging about peer mentoring by saying:

People in denial … There’s a lotta people in denial. There’s so many people who … most of the time they just wanna consume
Another mentor framed the resistance he encountered:

Uh, closed minds. That’s the biggest challenge. Cause it’s always a wall. Some people don’t wanna hear that shit, you know? Sometimes the truth is so hurtful, and is so unlike what we want— we are doing, and what we’re tryin’ to achieve that we don’t wanna hear it! And that’s the biggest challenge. Tryin’ to put the truth in places where it don’t wanna be. (50-year-old African American male, San Francisco)

Some participants discussed feeling pressure in their new role of peer mentor, both in terms of the responsibility that they felt to embody the social characteristics of the mentor role—such as being strong, social, and motivated—and in terms of sustaining behavioral changes that they felt they should keep up to be good role models, in particular getting or staying clean. These data underscore the ways in which while the experience of being a peer mentor instigated change for the mentor himself or herself, inherent in the experience of change in mentors’ personal and social relationships was the sense that they had to sustain their ability to be a role model. The feeling that they had to maintain themselves in certain ways took on many forms, including their overall sense of physical and emotional presence for their peers. One participant commented that he felt he should carry himself as someone who cares about himself, which included maintaining “how you look and the condition you are in” (Miami male 3353). Another participant reflected that:

One of my biggest challenges is … keepin’ myself strong. (Pause) … And you know, keep on that right path. (46-year-old African American female, Miami)

For this woman, as well as for some others, the “right path” as a peer mentor included drug use management. Some participants felt that they should be clean, or manage their drug use, in order to be a peer mentor to other HIV-positive drug injectors. The role of peer mentor acted as a motivator and support for these changes, and yet this change was sometimes hard to sustain. The following interview excerpt is with a woman who was struggling to stay clean:

I: In your experience, what are the biggest challenges of being a peer mentor?
R: (Pause). Staying clean.
I: How is that a challenge for you?
R: If I can do it, someone else can do it. (Pause).
I: All right. And does being a peer mentor make it hard for you to stay clean?
R: No. That’s inspired me to stay clean much more.

This participant touched on the ways in which the role of peer mentor served as a motivator for her to stay clean, echoing an understanding of how peer mentoring works, which many participants articulated— “If I can do it, someone else can do it.” She also indicated that it was a challenge for her to stay clean. Even as the peer mentor role supported personal change related to their identities as well as, for some, behaviors, it was not necessarily easy for participants to sustain this change.

Several participants raised disclosure of their HIV status as a challenge they faced as peer mentors. While the peer mentoring training did not require that participants publicly disclose their status, participants still felt that the shared identity of the peer mentor was premised on their being open about their status. The following participant reflects on how talking about HIV, as well as his own HIV status, was a challenge for him as a peer mentor:

To me, the biggest challenge would be … HOW to approach somebody that HIV—you know, discussin’ it. Once you get past that, probably the biggest part of [it was] discussin’ that you [have] HIV, especially if the person ain’t never been open about it. But I always been open ‘bout my HIV. I don’t SCREAM that I got HIV, but if somebody asks me, I’ll show ‘em I ain’t ashamed to tell ‘em that I’m HIV positive. (50-year-old African American male, Miami)

This participant discussed disclosing his status as a peer mentor, feeling that it was important to show his peers who asked him that he was not ashamed of being HIV-positive, but at the same time being selective about disclosure. When asked if there had been anything that had been difficult about peer mentoring, another participant responded: “Well, the difficult thing is me telling people that I have HIV” (50-year-old African American male, Miami). Disclosure was a salient component of this participant’s experience with INSPIRE. He discussed how he had disclosed his HIV status to his family since the INPSIRE training, and the relief he felt in their response: “If anything, it was off my conscience” (50-year-old African American male, Miami). For some, the selection of their one-time peer volunteer activity was based on their ability to maintain their privacy in relation to community members by either not disclosing their status or selecting a site where they felt they would not be recognized. Others who wished to claim a public identity as an HIV-positive IDU peer mentor intentionally picked their community placement in a known setting, discussing their feelings of pride in being seen as a peer mentor.

DISCUSSION

Public health has increasingly recognized the need to develop HIV prevention interventions that address the social and structural context of vulnerability among drug users (Bourgois, 1998; Rhodes et al., 2005; Sumartojo,
2000), as well as to engage HIV-positive individuals as actors in ending the spread of the epidemic (Gilliam & Straub, 2009; Shriver, Everett, & Morin, 2000). In the face of continued stigmatization of drug use, it is particularly important to develop effective mechanisms for engaging drug users in mobilizing themselves and members of their communities to prevent HIV/AIDS and drug-related harm (Friedman et al., 2004). Prior research has suggested that peer mentoring constitutes an effective mechanism for HIV prevention among drug users, focusing primarily on its effects on behavioral outcomes. In order to gain insight into the mechanisms through which peer mentoring operates, it is important to develop an understanding of the process of peer mentoring among HIV-positive IDUs. Responding to increased calls for HIV prevention interventions at the social and structural levels (Blankeneship, Friedman, Dworkin, & Mantell, 2006; Latkin & Knowlton, 2005; Rhodes et al., 2005; Sumartoyo, 2000), these findings provide support for building peer mentoring HIV prevention programs that engage drug injectors as change agents to build upon the resiliency and strengths within their communities.

This consideration of the social context of HIV prevention among HIV-positive IDUs suggests that peer mentoring can function as a salient strategy of HIV prevention for HIV-positive IDUs, through connecting personal experiences to emerging conceptions of community and shared identity as a stigmatized population. Framing peer mentoring within the risk environment allows for an understanding of the process of mentoring as it affected participants’ personal and social identities, including their understanding of themselves as change agents in their lives and in the lives of those around them. These data find that peer mentoring engendered a sense of identity, agency, and social engagement at and across three domains of environmental influence, from reflections on the most proximate forms of behavior change and social interaction at the micro level to a contextualizing of the mentor as an agent of change within the broader community (at the meso level) and to acting upon and within the constraints of structural determinants at the macro level. At the individual level, mentors described the instrumental role of peer mentoring in facilitating acceptance of their HIV status. At the interpersonal level, mentors discussed how the adoption of the role of peer mentor enhanced their ability to disclose their HIV status, if desired. At the community level, mentors described enhanced communication skills with individuals and institutions, as well as a newfound sense of collective identity as a stigmatized population. Peer mentoring activities were motivated by also built users’ sense of community affiliation, and were often accompanied by a sense of shared history and shared experiences of structural discrimination.

Assuming the identity of peer mentor allowed users to re-configure how they conceptualized themselves in relation to institutional structures, re-interpreting dominant discourses in relation to power, agency, and knowledge in these interactions. Moore (2009) discusses the ways in which the attributes of self-reliance, autonomy, and inde-

pendence are often denied to drug injectors in their interactions with service staff (Moore, 2009). Many participants in the peer volunteer activity discussed the identity shift they experienced, literally and figuratively, in sitting “on the other side of the table,” and discussed continuing to mentor other HIV-positive IDUs beyond the intervention and their one-time peer volunteer activity.

While all participants in the INSPIRE study knew of their HIV status, a striking component of peer mentoring discussions was the ways in which many participants described their mentoring experiences in relation to acceptance of their HIV status. The median length of time since INSPIRE participants in this qualitative sample had been diagnosed HIV-positive was 6.9 years, with a range of 1 month to over 19 years since diagnosis. Research has found that the integration of an HIV diagnosis into one’s life, identity, and practices does not simply follow from the fact of HIV diagnosis (Baumgartner & David, 2009; Tewksbury & McGaughey, 1998). Among drug users, learning of one’s HIV status can instigate a phase of “going underground,” involving a period of increased drug use as a mechanism for “forgetting” about HIV/AIDS (Knight et al., 2000). Often, individuals re-emerge into integrating HIV after a significant life event, such as a sickness or the death of a loved one, which serves as a “wake-up call” (Knight et al., 2000). These data suggest that peer mentoring approaches to HIV prevention may support the integration of HIV status among HIV-positive IDUs and facilitate change at the individual level for this population.

Disclosure of HIV status by HIV-positive injectors is a complex issue that has been explored in the literature as a critical component of HIV prevention (Frye et al., 2009; Knight et al., 2005; Parsons, VanOra, Missildine, Purcell, & Gomez, 2004; Valle & Levy, 2009). As an identity based on the development of social relationships and predicated on shared experience as an HIV-positive IDU, the peer mentor role gave participants new possibilities, tools, and a social role to support disclosure. The training provided a supportive environment in which to try new ways of communicating. In the face of years of isolation from people both in their personal lives and in their broader communities, often related to having HIV and being a drug injector, participants came to reflect on HIV disclosure as a vehicle for building supportive social relationships. Having a sense of “place” to disclose reflects how adopting the identity of peer mentor and the skills-building of the INSPIRE training resulted in interpersonal change through newfound explorations of disclosure.

Through adopting the social role of peer mentor, individuals often described a new sense of collective identity and community affiliation, positioning themselves in relation to the larger HIV-positive and/or IDU community. Through a re-orientation to the collective experience of HIV-positive IDUs that offered a new role in their communities. Through a re-orientation to the collective experience of HIV-positive IDUs that offered a new role in their communities.
an identity of change. Participants expressed that their presence in the community underscored the importance of HIV prevention at the community-wide level, through the involvement of peers on the streets, in SROs (single-room occupancy residences), and other places where newly diagnosed HIV-positive IDUs in particular are found.

Even as these data provide support for the peer mentor role as an identity of change, it is critical to understand the need to support all elements of the experience of change, including its challenges. The challenges that participants experienced included: others’ resistance to being mentored, pressure to be a role model, and HIV disclosure. Participants’ reflections on the challenges of peer mentoring underscore the need for HIV prevention programs to create infrastructure to support peer mentors as they enact this new social role, in order to better understand the ability of the peer mentor role to sustain these forms of change over time. The varied experiences that participants had with disclosure as a part of becoming peer mentors indicate the importance of adopting a harm reduction approach that can meet mentors where they are with regard to their HIV status, while supporting the change they wanted to initiate in their lives related to disclosure.

Mentors’ motivations to enact change in their own lives were reinforced by—and reinforced—their desire to create positive change in the lives of community members and their community at large. Conceptualizing peer mentoring as a social-level intervention allows HIV prevention approaches to draw on the interplay between the individual, his or her social relationships, and the structural-level factors in which drug injectors become vulnerable to HIV/AIDS. Individuals are not merely constrained by structural factors and their social environment; it is as actors within and against this context, that they become agents of change.

LIMITATIONS

There are several limitations to these findings. These data represent the perspectives of a self-selected group of HIV-positive IDUs in four urban areas in the United States who participated in a peer mentoring intervention where they had to disclose their HIV status and drug use to study staff and to a group of strangers, and who later agreed to enroll in an interview study about intervention experiences. Peer mentoring did not lead to differential risk reduction or health-seeking behavior between experimental and control participants, indicating that the control condition also provided HIV-positive IDUs a place to meet with their peers. This may have led them to have some of the same identity development as participants in the peer mentoring condition. The data were collected between one and two years after the end of the study, likely affecting participants’ ability to recall details and specific events related to peer mentoring. These discussions of peer mentoring may reflect only the most profound and lasting effects of this peer mentoring intervention.

CONCLUSION

These findings provide support for continued development of and research on sustained, peer-driven mentoring programs for HIV prevention among HIV-positive IDUs as one mechanism for creating change in the conjoined individual, social, and structural context in which IDUs continue to be vulnerable to HIV/AIDS. The following participant articulates that what is at stake here is not merely a matter of identity, or the changes that mentors spoke of experiencing in their own lives and in affecting others’ lives as change agents. She reflects that what is at stake here is life itself: “[A] peer mentor—to me—lets you know that there IS life after bein’ diagnosed HIV” (46-year-old African American female, Miami). And that, as agents of change, HIV-positive IDUs can and must continue to remain at the forefront of efforts to curb the spread of HIV/AIDS among their communities.

Declaration of Interest

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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GLOSSARY

Change agent: A process through which individual-level and social change is brought about and sustained by individuals in and across communities.

Empowerment theory: Theory of the processes through which individuals, communities, and societies build their social power amidst societal inequities.

Environmental influences: Environmental influences constitute facilitators and barriers to HIV prevention and are considered across four types (physical, social, economic, and policy) and across three levels – micro-, meso- and macro-level influence (Rhodes et al., 2005). The micro level concerns interpersonal relationships, the meso level refers to group or social interactions, and the macro level concerns the structural-level determinants of law, policy, social inequities, and cultural norms that interact with the micro and meso levels of influence.

HIV prevention: The primary and secondary prevention of HIV (Human Immunodeficiency Virus) transmission through structural, behavioral, and/or biomedical means.

Peer mentor: An individual who draws from shared experience and social status as a means for the communication of health-promoting messages among networks who share social experiences based on membership within a specific group (e.g. HIV status, drug user status, housing status, gender, race/ethnicity, age, sexual orientation).

Risk environment: The social or physical space in which “a variety of factors exogenous to the individual interact to increase the chances of HIV transmission” (Rhodes et al., 2005, p. 1026).

Social context: The social environment (including institutions, and cultural norms and identities) which structures the interactions of individuals and the communities in which they live.

Social identity: The sense of self held by individual as an actor within social context.

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