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Affirming incarcerated women of color as HIV experts: Feminist insight into the possibilities of HIV education and participatory action research

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Using ethnographic, interview, and analytic response data from the Jailed Women and HIV Education (JWHE) study, I explore the pedagogical possibilities found at the intersections of incarceration, participatory research methods, and sexuality education with and for women of color. My analysis demonstrates the need to expand traditional HIV education to include discussions of structural inequalities including racism, sexism, and heterosexism, and to acknowledge and affirm incarcerated women of color as experts in their own lives. Such expansion will allow feminist educators and researchers to expose HIV as a community and social issue and not perpetuate the racist and sexist blame typically located on individuals.

Racist and sexist institutions such as the prison industrial complex vilify the sexualities of women of color (Cohen, 1997); further, queer female sexualities are often absent in HIV prevention and sexuality education. It is imperative that HIV prevention pursue alternative discourses of agency. Such action would honor the lived experiences of incarcerated women of color as well as promote meaningful change in the individual and community approaches to HIV prevention and sexuality education.

Working with incarcerated women of color yields new theories of HIV prevention education that bridge the divide between a traditional model of knowledge as means to preventing HIV and a model of agency, engagement, and affirmation as paths to healthy sexuality. Including participants' expertise and experience allows women of all races and sexualities new access into HIV education.

I will first discuss the rates of incarceration and HIV/AIDS infection to demonstrate the particular need to form better HIV prevention interventions for incarcerated women of color. Next, I will describe the Jailed Women and HIV Education research project as a whole. Finally, using data from the study, I will highlight two particular workshop exercises that our team used

to honor and value the expertise of incarcerated women of color. These exercises promoted meaningful sources of knowledge and a positive learning environment.

In the United States, over one million women are under the supervision of the criminal justice system; this includes women on parole or probation (The Sentencing Project, 2007). California's incarcerated population is also on the rise. As California has gotten "tough on crime," the number of women of color in state correctional facilities has dramatically increased. In California, 72% of the prison population is comprised of racial and ethnic minorities as compared to 53% of the overall state population (Petersilia, 2006). Despite the disproportionate rates of incarceration for people of color, society does not acknowledge this disparity of incarceration as evidence of racism within our society (Davis, 2000).

Similar to the disproportionate incarceration rates of people of color, HIV/AIDS diagnoses show clear trends along race lines. Data from the 2005 Census show that, despite African American and Latino women comprising 24% of the female population, they accounted for 82% of the AIDS diagnoses for women. Furthermore, HIV is the primary cause of death for 25-34 year-old African American women and women are also less likely to receive the most effective HIV treatment (Centers for Disease Control and Prevention, 2007). The rates of incarceration and HIV/AIDS diagnosis both reflect the disproportionate impact on people of color in the United States; the HIV/AIDS data for African American and Latino women show their particular vulnerability.

Methodology

Participatory action research (PAR) is at the heart of this project. PAR is a methodological and epistemological perspective that actively involves participants in the formulation of research questions, data collection, and data analysis. PAR encourages

investigators to work *with* rather than for research participants. This form of research recognizes “that knowledge is produced in collaboration and in action” (Fine et al., 2001, p. 173).

Participants become collaborators whose knowledge is indispensable to making the research stronger, more valid, more accessible to communities, and socially just (Cahill, 2007; Schensul, 1999). Thus, our team considers the incarcerated participants as “incarcerated researchers” and the non-incarcerated researchers as outside researchers” (Fields, González, Hentz, Rhee, & White, forthcoming). This process challenges the power/privilege differential inherent to most projects in which researchers make decisions and guide the process and findings while the participants have less influential roles on data collection and analysis as well as research design. The study design created a way to introduce incarcerated women of color to the research process and train them in research skills as a way to increase their agency and meaningfully incorporate their expertise in HIV prevention programs.

The project consisted of 16 workshops (four cycles comprised of four different workshop topics) conducted weekly from January through June 2007. Jessica Fields, San Francisco State University Sociology professor and co-investigator, and Isela González, San Francisco Department of Public Health HIV educator and co-investigator, conceived, planned, and secured funding for the project. The overall study objectives, as Jessica and Isela identified and defined in the original study design are to explore (1) The ways incarcerated women experience HIV/AIDS risk and infection; (2) The obstacles incarcerated women confront when trying to implement HIV/AIDS prevention strategies; and (3) The feasibility and impact of jailed women, health educators, and university researchers collaborating to study HIV/AIDS risk and prevention. The workshops encouraged incarcerated and outside researchers to think critically about HIV prevention and sexuality while providing training to incarcerated researchers on

research skills. These skills included conducting peer interviews, analyzing emerging data, providing feedback on the process of data analysis, and creating workshop content. Workshops occurred weekly, and incarcerated researchers attended a maximum of four workshops. At this point, they graduated from the workshops to allow new women an opportunity to participate. Each workshop built on the lessons learned in previous workshops and incorporated the input of incarcerated co-researchers (See Appendix 1).

New Approaches to HIV Prevention and Sexuality Education

Sexuality education and HIV prevention are potential sites for alternative lessons – not simply for risk reduction, pregnancy planning, and STD/HIV prevention, but also for asset-based, positive sexuality that promotes desire, comprehensive education, and sexual awareness.

Liberatory education is flexible with the type of “knowledge” being learned and shared. It addresses the conflict between two different ways of knowing: legitimized knowledge and community and individual truths (Freire, 1986). It is not only *how* information is known (the learning and the telling), but *what* information is available to us (fact-based, faith-based, honest). Dismantling the validity and idea of one truth into a more pluralistic vision of truths recognizes individual and community subjectivities and access to information (such as HIV status) to help challenge the rhetoric of one truth. The unraveling of universal and individual truths creates the potential for agency. When we claim our own truths, we then call others to be accountable to their truths as well. It is in this view that I call for an expansion of who we see as HIV experts and that we affirm incarcerated women of color as experts in their own lives.

Jailed Women and HIV Education workshops are an example of what health education can look like when we see participants as experts and educators expressing lived experiences—not solely as passive learners. In addition, bringing in a discourse of desire allows for

conversations that do not traditionally exist in HIV prevention settings (Fine, 1988; Fine & McClelland, 2006). A discourse of desire is not an optional addition to sexuality education; it is a necessary fundamental. That distinction is crucial. Fine and McClelland (2006) offer an empowerment model as a way to address the sexism, heterosexism, and overall lack of desire in sexuality education. Individual empowerment is one aspect of a successful model, but we also need to look beyond individual responsibility to the larger context of social inequalities.

The research process made it possible for incarcerated researchers to envision HIV education *with* outside researchers. By validating their input and encouraging their participation throughout the workshops (as educators, interviewers, interviewees, and experts), the incarcerated researchers could participate in many capacities not only in a rhetoric of health promotion and HIV prevention. Instead, participants had many ways of connecting to one another and the discussions had both direct and indirect connections to HIV prevention.

Co-researchers: A Diversity of Roles

One of the most successful exercises that created opportunities for the incarcerated researchers to claim various roles was the use of a handout that described the myriad roles that incarcerated and outside researchers can claim during the workshop. The handout, "RISE, member's roles," (see Appendix 2) invited incarcerated researchers to see the possibility of claiming active (i.e. not passive research participant) roles in the workshop. Often, researchers and participants alike see formal guidelines between who is the educator, interviewer, researcher, and expert (traditional researcher roles) and student, interviewee, and participant (traditional research participant roles). However, the handout facilitated a process of deconstructing the traditional assignment of roles and provided opportunities for outside and incarcerated researchers to claim roles outside of traditional expectations.

The “RISE, member’s roles” exercise demonstrates one way to actively call incarcerated researchers into the otherwise privileged circle of researchers and experts. In one workshop when we used the exercise there was excitement in the room, Jessica, an outside researcher, noted that “hands went up, and almost everyone shared. The conversation was invigorating to participate in. I felt fantastic as I listened to the women claim their knowledge and curiosities.” When presented with the handout and asked about what roles the incarcerated researchers claim, Karli¹ says she wants to be “an interviewer because I enjoy sharing life experiences.” Beth shared that she’s “an expert,” Marilyn said, “student, so that I can learn more to be a researcher so that I can be educated and do interviews so that I can become an expert,” and Hayley said she’s “an educator.” I insisted that everybody has the potential to claim each of the roles and that all people can be an expert without traditional schooling. The fluidity of being able to assert many traditional and alternative roles in one workshop as well as witness the many ways incarcerated researchers claimed these roles demonstrates the potential of exercises that invite a sharing of expertise. This excitement is an example of the liberatory and erotic that hooks (1994) and Lorde (1984) promise.

Incarcerated researchers also discussed their roles in an analytic feedback session. In this activity, outside researchers developed emerging analyses to present to the incarcerated researchers for their responses. In response to the prompt “Working as an educator makes me feel...” incarcerated researchers responded: “empowered and aware. I love knowing about subjects that directly affect my life and the lives of those around me. That I can really make a difference,” “very, very special and helpful to me,” “helpful to others. And at the same time, teaches me all about the protection that’s needed,” and “makes me feel helpful because

¹ All incarcerated researchers names are pseudonyms.

sometimes others really do not know where to go for help. Personal experiences help others.”

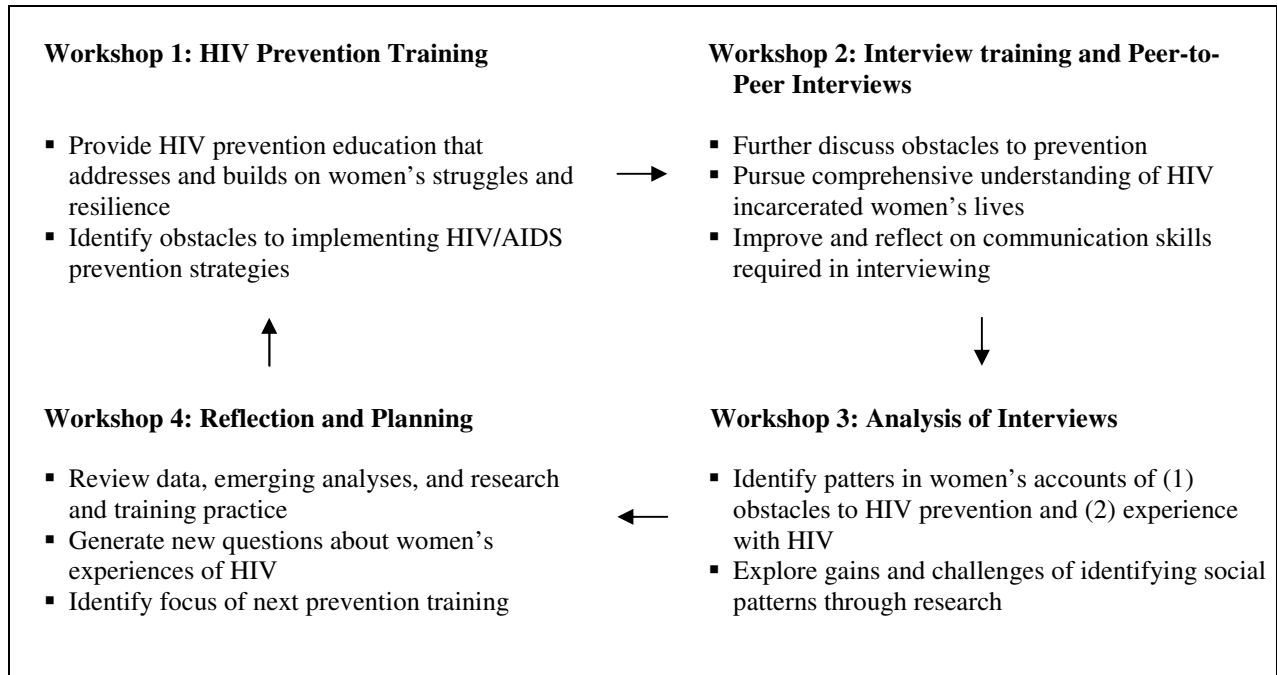
The answers illuminate how claiming the role of educator feels as well as what it enables incarcerated researchers to accomplish for their own lives as well as their peers.

Asking women to view themselves as experts in this setting is liberating for both incarcerated and outside researchers; identifying incarcerated women as experts in a humanizing workshop stands in stark contrast to the typical expectations of the setting. Discussing pleasure and sexuality allows for more holistic understandings of the lives of incarcerated women of color. When society silences desire, pleasure, and the expertise of already underprivileged groups, we not only deny opportunities for these important conversations, we also mute and devalue lived experiences. This is a double disservice.

Participatory projects that engender a positive health outlook, sexual communication and negotiation, and do not focus on traditional health education models of HIV prevention validate the expertise of underprivileged populations. The progress of HIV prevention necessitates conceptualizing other empowerment models already in place, be them activist, community building, or volunteering. Through this research, I show the resiliency and expertise that incarcerated women of color possess in terms of their sexuality and relationships.

Appendix 1

Illustration of one cycle of four workshops



This diagram has helped the team throughout the project to illustrate the constantly changing series of workshops.

Appendix 2

RISE

Members' roles

Our project involves many people in many roles. We all fill more than one role, and our roles change from day to day. Sometimes we know a lot about a topic, and we're **experts**. In order to help others become experts, we may become **educators** and share our knowledge. Sometimes we learn from others; at those times, we're **students**. Below are some of the roles we all play in this project. Which roles do you play? Which roles would you like to play?

Educator: a teacher; person who shares information with other people; someone who inspires others to learn more about the world

Student: person who learns from others; someone who observes and pays attention

Interviewer: someone who asks other people questions about their lives and experiences

Interviewee: someone who has agreed to share information about her or his life or experiences in an interview

Researcher: someone who gathers information in order to learn more about the world

Research assistant: person who helps out on research projects and, in the process, gains new skills

Research participant: person who agrees to be part of a study in order to increase the understanding about the world

Expert: someone with special knowledge and skills

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