

San Francisco Bay Area Study Staff

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Main Study Findings

- HIV positive injection drug users (IDUs) continued to report unprotected sexual encounters with HIV negative partners and partners of unknown HIV status.
- Sexual risk behavior occurred with both intimate partners and drug/sex exchange partners.
- IDUs continued to use injection drugs after becoming HIV infected, and employed various drug use management strategies to keep healthy.
- The vast majority of HIV positive IDUs reported having access to care, but less than half the sample was currently on HIV antiretroviral medication.

Background

New HIV infections are decreasing among IDUs.¹ This decrease has been related to the practice of injection risk reduction among IDUs such as the use of needle exchange programs where available. However, recent research has found that sexual risk behavior among IDUs may account for more new HIV infections than injection practices.² We need to know more about the sexual practices of IDUs.

To date, most HIV prevention efforts have focused on how HIV negative people can stay negative. This has overlooked the important role that HIV positive individuals can play in the prevention of new HIV infections. HIV positive people also need support to not spread the virus and to keep themselves healthy (avoid STDs, Hepatitis C, abscesses, etc.). The need for prevention efforts targeting HIV positive individuals has only recently been addressed.³

Why this project?

The Seropositive Urban Drug Injectors Study (SUDIS), known in the Bay Area as the VENUS Study, was a descriptive multi-site study of HIV positive IDUs in the San Francisco and New

York metropolitan areas. SUDIS was conducted to fill a gap in the knowledge about sexual transmission risk among HIV positive IDUs. In SUDIS, we explored drug use practices and sexual risk behaviors among a group of injectors who were already HIV infected. In addition, we explored the social factors that affect sexual risk-taking and specific sexual encounters that HIV positive injectors had with HIV negative or unknown-status partners.

The goals of the study were to:

- Describe the sexual and drug-injection practices of HIV positive IDUs in the San Francisco Bay Area and New York City;
- Identify demographic, psychosocial, and contextual factors that help or hinder serostatus disclosure and reduction of HIV transmission risk among HIV positive IDUs;
- Identify strategies to promote safer sexual and drug use practices among HIV positive IDUs.

Why is it important to study the prevention needs of HIV positive IDUs?

HIV positive persons are a unique group because they need support for both HIV prevention and HIV care. For HIV positive people, prevention and care are linked. There are very few programs that target prevention to HIV positive people, especially HIV positive IDUs.

IDUs have to focus on sexual *and* drug use prevention. Life circumstances and histories of drug use and addiction can make HIV positive IDUs more vulnerable than the general population of HIV positive people. Many have had experiences with the criminal justice system that profoundly affect their lives and HIV coping. Experiences of drug use stigma and discrimination can impact the health care utilization of HIV positive IDUs, as many have had negative encounters with service and health care providers. Many HIV positive IDUs also experience difficulties accessing appropriate HIV medications and taking them as prescribed. All of these circumstances make it important to work with HIV positive IDUs.

A brief description of SUDIS

SUDIS was a study of 161 HIV positive IDUs who had reported sex with an opposite-gender partner and used injection drugs within the previous three months. We recruited participants from street locations frequented by IDUs and AIDS service organizations in the San Francisco Bay Area: Richmond, Oakland, East Palo Alto, and San Francisco; and in greater New York, the Lower East Side of Manhattan, and Jersey City, New Jersey. Data collection took place during 1998-1999.



Some members of the VENUS Study team

For each participant, we conducted a 1-2 hour interview and a survey. The interviewer asked for information on the role and meaning of sex for HIV positive IDUs, how partners were chosen, disclosure of serostatus, and ideas for intervention programs for HIV positive IDUs.

In addition, participants were asked to describe recent specific sexual episodes, including instances that were considered “safe” and instances that were considered “risky” for transmitting HIV. In talking to people about sex and drug use, we hoped to learn about the kinds of experiences which helped or stopped people from telling a partner that they were HIV positive. We also wanted to know about people’s experiences in getting HIV care.

Conducting Community-Based Research with Drug Users

In addition to finding out about what was happening in the sexual lives of HIV positive IDUs, one of our motives was to come up with meaningful findings that could be used to help guide the development of prevention programs for HIV positive IDUs. For the San Francisco Bay Area site, we approached this study as a collaborative working project between community providers and the research staff.

We asked for input from community members during study design, recruitment, data collection, and data analysis. We held meetings throughout the study with our Community Advisory Boards (CABs) made up of community based organization (CBO) staff in Oakland, Richmond, San Francisco, and East Palo Alto. At the end of the study, the research staff met with the CAB

members in each community to present that community’s findings and discuss how these findings could be most useful in program planning.

Partnering with CBOs helped the research study access, approach, and find participants, and informed study staff of specific stigma issues. We wouldn’t have been able to work at all if not for CBO involvement.

What did we learn in the VENUS Study?

We heard a lot of stories about people’s experiences of finding out they were positive, and how being a person with HIV affected their intimate relationships. These stories were very powerful. For many people, it was the first time someone had asked them about how HIV had affected their sexual relationships and how they dealt with those feelings.

HIV positive IDUs expressed a strong desire to translate their experience with HIV prevention and care into something valuable for another HIV positive IDU. Many study participants were motivated to be peer mentors or outreach workers, particularly to newly diagnosed drug users.

“[There’s] a lotta people in my community that has this disease, this virus... I want to be able to help ‘em...with the acceptance...gettin’ resources... I want to be an outreach worker... That’s my goal... I figure if I take what has gone on with my life and apply it to what I want to do professionally, it will work.”

Sex

- Most HIV positive IDUs were in long-term sexual relationships, many with partners who were HIV negative or untested.
- HIV positive IDUs reported unprotected sex with HIV negative and unknown-status partners.
- For some HIV positive IDUs, the desire to preserve intimacy in their relationship outweighed their ability to have protected sex. Some felt pressure from their HIV negative partners to have unprotected sex.

“At first it used to bother me. Because I didn’t wanna get him sick or nothin’ like

that....He said, 'I ain't...used no condom before, I'm not gonna use one now... If you go out that way, I'm goin' out that way with you. I love you and...I don't wanna use no condom with you.' You know, he chose that."

- Some HIV positive IDUs exchanged sex for drugs and had to manage disclosure and prevention in those chaotic settings where there wasn't a lot of opportunity for communication.

Drug Use

- Study participants continued to inject drugs after finding out they were HIV positive, often increasing their drug use initially in order to try and escape the reality of the diagnosis.
- After this higher risk period, HIV served as a "wake up call," motivating many HIV positive IDUs to access social services and to develop drug management strategies for their HIV health.
- Drug management strategies included reducing the number of times one injected, drug substitution, injecting alone, abstinence from alcohol and stimulants, and methadone maintenance.
- There was a high level of concern about the interaction between HIV medications and street drugs, and many HIV positive IDUs expressed a need for information in this area.

"I've always been hooked. I just now recently stopped since my health's been really bad. [I'm trying] to seek some help, you know? To get on the methadone, but I'm still...fixin' in between. That's not doin' me no good. And now I'm really gonna have to stop 'cause I caught a case, and I might be goin' to the pen, so... But now my doctor says I'm gonna have to quit, because I'm really too sick to, you know, I need to strictly stay on my medicine, the medicine. And I cannot afford...to be usin' on a regular basis."

HIV Care

- Almost all participants reported having access to care, and the majority had seen a provider in the previous six months.
- HIV positive IDUs were very concerned about the impact of their drug use choices on their overall HIV health and on other health concerns such as Hepatitis C.
- HIV positive IDUs related previous negative experiences with health care providers that

included perceived discrimination based on drug use status and inability to manage social service systems effectively. This affected their current willingness to access care.

- Participants who reported positive experiences with their providers reported that they felt respected and cared for by their providers regardless of their use of drugs.

Recommendations

1. Study participants who were currently using drugs were not necessarily interested in stopping all drug use, but were very interested in finding out more about how best to manage their drug use. Many also wanted information about the effects of specific street drugs on HIV progression.
 - IDUs should be supported in developing drug use management strategies.
2. The majority of HIV risk behavior occurring among HIV positive IDUs was sexual.
 - Sexual risk reduction must be emphasized in all HIV education and prevention efforts for HIV positive IDUs.
3. Most HIV positive IDUs had never talked to anyone about their sex lives. For many, the study interview was one of the first times they had been asked about their sexual relationships.
 - Programs that empower drug users to talk about their sexual lives and be active participants in developing strategies to prevent HIV transmission are needed.
4. Study participants reported barriers to accessing regular and consistent care because of their drug use.
 - IDUs should have access to medical care and HIV medications regardless of their drug use.

Next Steps

Informed by the SUDIS findings, we are developing an exciting new program for HIV positive IDUs in the San Francisco Bay Area. To get involved, or for more information, please call 1-877-55-VOICE (86423).

References

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Materials Available

A presentation which highlights the findings from SUDIS can be heard on the Web at: <http://hivinsite.ucsf.edu/InSite?doc=2098.4615>.

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