

(The Gender Centre advise that this article may not be current and as such certain content, including but not limited to persons, contact details and dates may not apply. Where legal authority or medical related matters are cited, responsibility lies with the reader to obtain the most current relevant legal authority and/or medical publication.)

A Plague Undetected

Did Shady Backroom Hormone Treatments and Dirty Needles Cause a Killer Outbreak of H.I.V. in the Transgender Community?

by Nina Siegal, Urban Life Reporter, Bloomberg News - [Salon.com](#) 

Article appeared in Polare magazine: May 2001 Last Update: October 2013 Last Reviewed: February 2014



Did shady backroom hormone treatments and dirty needles cause a killer outbreak of H.I.V. in the transgender community?

Fourteen years ago, when Barbara Cassis was a twenty-four-year-old man, she asked a family physician to give her hormones so she could become a woman. He prescribed a visit to a psychiatrist instead.

... this so-called doctor would set up shop in a bathroom stall for hours, injecting possibly hundreds with a single needle.

Undeterred, Cassis, now a towering blond with swimming pool blue eyes and a C-cup chest, entered an underground economy of fake doctors and self-appointed medical gurus who were willing to help her make the transformation she desired. She didn't know at the time that she was putting herself at risk for AIDS.

At transgender clubs in Hell's Kitchen, she asked the convincing looking girls where to start. One gave her a business card for a hormone home delivery service. Another, she recalls, told her about a doctor who administered treatments in the bathroom of Sally's, a popular Hell's Kitchen bar catering primarily to transgender patrons.

According to Cassis and outreach workers who are familiar with the transgender scene in New York, this so-called doctor would set up shop in a bathroom stall for hours, injecting possibly hundreds with a single needle, without sterilizing it between shots.

"You could just walk in there, pay him \$30 and he injected you in your butt," says Cassis, with an anguished expression on her face, because she now knows the risks associated

with such activity.

"They had the needles packaged, so it looked like they were new, but the tops of the packets were always open. I don't have any doubt that they were being reused."

Hormone needle sharing has not been identified as a major risk factor for H.I.V. transmission among transsexuals, but a growing number of physicians and AIDS outreach workers believe it may be the cause of hundreds of cases in the United States and abroad.

Very little is known about the health care issues facing transgender people — an umbrella term for anyone who does not identify with the sex they had at birth — because research focused on transgender people is scarce.

Recently, however, public health officials across the United States have begun to explore transgender health needs, and they are particularly concerned about high rates of H.I.V. infection in this population.

"Due to the lack of tracking, there might be an epidemic out of control and we don't know about it, nor do we have the resources to address it if we need to," warns Jason Farrell, executive director of the Positive Health Project, an AIDS outreach program in New York.

"Some advocates think that the rates of infection may be going up in the transgender community, but there's no way to know because there's no tracking whatsoever of transgender people now."

In the last ten years, H.I.V. prevalence rates amongst intravenous drug users have dropped dramatically, according to David A. Hansell, associate commissioner for H.I.V. services for the New York Department of Health, and many researchers believe outreach to drug users and widespread use of needle exchange programs have been partially responsible for the decline.

But rates of transmission in the transgender population have remained staggeringly high, and may be continuing to rise, according to recent health studies.

Researchers are now asking whether black market hormones could be at least partly responsible for high H.I.V. infection rates.

"Clearly, sharing of hormone needles is a possible route of transmission because with any injection there's a possible risk," Hansell says. "It's one of the risks that people need to be educated about so they avoid it."

Health departments in New York, Los Angeles, Boston and San Francisco are exploring the issue. Finding that the rates of infection in the group were phenomenally high in Los Angeles County, the city's Community H.I.V. Prevention Planning Committee recently designated the transgender population as one of its highest priorities for H.I.V. prevention efforts.

Dr. Paul Simon, a medical epidemiologist with the Los Angeles County Department of Health Services, is one of several researchers who conducted a survey of 244 male-to-female transsexuals in 1998 and 1999. The results of the study were published in a December 2000 issue of the journal *AIDS*.

The findings stunned Simon and his researchers. 22 percent of those in the study group were H.I.V.-positive (while only a fraction of one percent of the general population in the United States is thought to be H.I.V.-positive today). They conducted a follow-up study and determined that in a group of a hundred transsexuals, the chance of getting infected was over three percent.

"That's as high as what we were seeing among gay and bisexual men in the 1980s at the peak of the epidemic," says Simon. "It's a very high rate of H.I.V. infection."

As a group, transsexuals face several risk factors. Although most transgender people do not think of themselves as gay, most engage in anatomically homosexual sex. And among male-to-female transsexuals, the group reported a high rate of unprotected anal sex (47 percent reported having unprotected receptive anal sex in the last six months).

Recent public health studies also reveal that sexual partners of transsexuals tend to identify as straight, providing anecdotal evidence that safe-sex education that is widely available in the gay community may not be reaching them.

When asked about needles, 69 percent reported that they had injected hormones at some point in their lives; 44 percent in the previous six months alone. Of those who had recently injected hormones, 72 percent said they got their needles off the streets.

But Simon says it is unclear what role black-market needles played, since unsafe sex and drug use are also dangers (eight percent reported using intravenous drugs in the last six months).

Sharing hormone needles may be less risky than sharing drug needles, he added, because transsexuals do not typically draw blood directly back into the needle, as drug users do.

Female and male hormones come in various forms — pills, patches and liquid — but many transsexuals prefer injections to the other methods because liquid hormones supposedly take effect faster. Hormone needles are about twice the length and width of the needles used to shoot heroin, which is usually diluted with water before it is injected. But just like drug syringes, hormone needles are not readily available in pharmacies without a prescription, and are sometimes even harder to come by than clean drug needles on the streets.

The San Francisco and New York health departments have both studied H.I.V. risk factors in the transgender population. Of 94 transgender people surveyed for the 1999 'Transgender Needs Assessment' for the New York City H.I.V. Prevention Planning Group, 90 percent of respondents said they had a history of using hormones. Of those, forty percent said they had gotten them off the black-market.

"A small number reported sharing, but when people are accessing hormones from the black-market there's no way of knowing if they're using syringes that have been used before," says Kelly McGowan, author of the report. "It was definitely discussed as a perceived risk factor, particularly amongst female-to-males."

In San Francisco, however, researchers found little needle sharing. Out of 500 transsexuals surveyed, only three men who were taking hormones to become women, and one woman trying to become a man, reported sharing needles in the last six months.

Of the transgender people who inject hormones, 84 percent reported that they had obtained their needles from safe sources in the last six months.

Kristen Clements, an epidemiologist with the San Francisco Department of Public Health and the chief investigator for that city's report, says the divergence might reflect the two cities' different approaches to needle exchange and transgender lifestyles.

In San Francisco, several health clinics provide free hormone syringes and free and low cost hormone therapy in a safe, medical setting, with hours set aside exclusively for transsexuals.

"I can guarantee you that if someone is grappling with gender identity, they're going to get hormone needles off the street," Clements says. "But we take that seriously here, and we provide needles."

By comparison, the *1999 Gay and Lesbian Health Report* by the New York City Department of Public Health found that "members of the transgender community report barriers to accessing body altering drugs and procedures."

When asked if he knew of any clinics in New York City that offer low cost or free hormone therapy for transitioning adults, Farrell just laughed, shaking his head. "That's San Francisco," he says.

(Indeed, San Francisco is currently considering a proposal to add sex changes to the list of medical procedures covered by city employees' health plans.) Farrell adds that he knew of only two needle exchange programs in New York that specifically do outreach to the transgender community — his own and 'Street Works', a program for adolescent transsexuals.

However, on 1st January, New York State implemented a new policy of needle deregulation. For three years, it will make syringes available to adults without a prescription, through licensed pharmacies, healthcare facilities and certain healthcare practitioners who

voluntarily register with the state.

But the sea change in New York and progressive politics in San Francisco will do little for transgender people like Barbara Cassis, who is already H.I.V.-positive. Cassis didn't think much about the potential of getting infected by sharing hormone needles. But she is H.I.V.-positive, and says that other AIDS risk factors don't apply to her. She has never injected illicit drugs, she says, or worked as a prostitute. She assumes she got H.I.V. from unsafe sex or sharing hormones.

Though Cassis has no way of determining the origin of her H.I.V., it's hard to imagine that she, or her friends, weren't putting themselves at risk. In the 1980s and early '90s, she recalls, one so-called doctor parked a grey van in front of popular transgender clubs in New York, from about 10:00pm until 2:00am, and later near the Chelsea Piers where transgender prostitutes waited for johns.

People lined up for \$30 to \$40 shots, administered assembly line style, climbing in through the van's back door and exiting through the side door, says Cassis. When hormones were delivered to her house, she remembers, the situation was no more sanitary. "You might get one or two needles with a vial of hormones," she says. "But they were always open. I didn't think about it much at the time, because I was so excited to get the hormones. I remember taking my needle and shooting my girlfriend up, and just rinsing it out with water. I never thought about it."

But now she thinks about it a lot. "Probably hundreds of girls were infected that way, from about 1979 to about 1991 or 1992. Now, the transgender community in New York is small, but there used to be hundreds of girls who would come to the city, get their hormones that way and leave. A lot of them are dead now," she says.

Unsafe sex was another major risk activity for H.I.V. transmission. In the beginning of the epidemic, many transsexuals didn't think they had to worry about safe sex as gay men did. "Everyone thought of AIDS as a gay man's disease," she explains. "And we weren't gay."

Cassis stopped buying hormones on the street, and found an above-board physician who is now helping her manage her transition. She's also active in the transgender community, and works as an administrative assistant at the Positive Health Project, one of only a few AIDS programs in New York that gives out hormone needles in its needle exchange program. She and several other transsexuals on the group's staff educate others about needle sharing.

They also helped to design an unusual pamphlet, *Safety Guidelines for Injecting Hormones*, as well as a small brochure, *Calling All Girls: Transgender people and H.I.V.*, which warns about the risks of hormone-needle sharing.

Jason Farrell is Cassis' boss at the Positive Health Project. A H.I.V.-positive former intravenous drug user, Farrell set up the needle exchange program in 1994 in the heart of Hell's Kitchen. While canvassing the neighbourhood to assess the needs of the population he hoped to serve, he discovered that most AIDS education and outreach programs had largely overlooked transsexuals.

But the stories he heard in transgender bars and clubs worried him.

"If what has been told to me is in fact true, I can only assume that sharing hormone needles was leading people to getting H.I.V.," he says. "It would be no different from me having a shooting gallery in my house and having everyone share syringes. I assume these guys would have infected a lot of people."

Yet despite widespread efforts to educate people about the dangers of sharing needles of any kind, Cassis says she still knows transgender girls who buy their hormones on the black market and reuse syringes or shoot-up their friends.

And that's because of the lack of specific efforts to educate the transgender community about H.I.V. risk. "It's obvious that it's a risk factor," says McGowan of the New York City H.I.V. Prevention Planning Group.

"And it's obvious that we can do something about it. Hormone needle exchange is a very simple precautionary tool that can be easily implemented and should be."

Polare Magazine is published quarterly in Australia by The Gender Centre Inc., which is funded by the Department of Family & Community Services under the S.A.A.P. program and supported by the N.S.W. Health Department through the AIDS and Infectious Diseases Branch. Polare provides a forum for discussion and debate on gender issues. Unsolicited contributions are welcome, the editor reserves the right to edit such contributions without notification. Any submission which appears in Polare may be published on our internet site. Opinions expressed in this publication do not necessarily reflect those of the Editor, The Gender Centre Inc., the Department of Family & Community Services or the N.S.W. Department of Health.

The Gender Centre is committed to developing and providing services and activities, which enhance the ability of people with gender issues to make informed choices. We offer a wide range of services to people with gender issues, their partners, family members and friends in New South Wales. We are an accommodation service and also act as an education, support, training and referral resource centre to other organisations and service providers. The Gender Centre is committed to educating the public and service providers about the needs of people with gender issues. We specifically aim to provide a high quality service, which acknowledges human rights and ensures respect and confidentiality.