HIV among transgendered people

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Abstract This study explores HIV status and HIV-related risk factors among transgendered people. A needs assessment survey developed with the help of transgendered people was used to conduct face-to-face interviews with 81 transgendered persons, 49 male-to-females (MTFs) and 32 female-to-males (FTMs). The findings indicate that HIV/AIDS is a serious health concern facing the transgender community. The majority of respondents engaged in at least one high risk sexual activity during the past three months, were willing to have high risk sex in the future and did not believe they were susceptible to infection. FTMs have a significantly lower level of AIDS knowledge than MTFs (p < 0.01). Over half (56.7%) of FTMs have not been tested for HIV/AIDS. Efforts to prevent the spread of HIV/AIDS among the transgendered community are urgently needed. HIV/AIDS prevention must specifically target transgendered people, including FTMs who, despite being at risk, have been largely ignored.

Introduction

Societal discrimination of transgendered people is not new (MacKenzie, 1994) and such discrimination has resulted in adverse public health outcomes, including HIV/AIDS, facing the transgendered community. 'Transgender' has been used as an umbrella term to describe people who do not follow traditional gender norms and may include transgenderists, drag queens, cross-dressers, intersex persons and transsexuals (Green & Brinkin, 1994; Lombardi *et al.*, 1998). Transgendered people commonly use the terms male-to-female (MTF) and female-to-male (FTM) to describe their gender identity. MTFs are people who are assigned a male gender at birth, but identify as female. FTMs are people who are assigned a female gender at birth, but identify as male. Available research, though limited, seems to indicate that there is a high HIV seroprevalence rate among transgendered people and that transgendered people are at high risk for HIV infection (Clements *et al.*, 1998; Elifson *et al.*, 1993; Gattari *et al.*, 1991; Kok *et al.*, 1990; Modan *et al.*, 1992; Pang *et al.*, 1994).

Gattari et al. (1991) reported that among 22 transgendered prostitutes (11 transvestites and 11 transsexuals) who were attending a drug dependency unit in Rome, 86% tested positive for HIV. Elifson et al. (1993) found that 68% of a sample of 53 male transvestite prostitutes in Atlanta, Georgia were HIV-1-positive. In another study, almost half (47.6%) of 25 MTFs were HIV-positive (Nemoto et al., 1999). Additionally, higher seroprevalence rates were found among transgendered people than among non-transgendered groups, including IV drug users (Gattari et al., 1991), female prostitutes (Modan et al., 1992) and male sex workers (Elifson et al., 1993).

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There is evidence that HIV infection among transgendered people may be the result of high risk sexual activity including lack or inconsistent use of protection (Clements *et al.*, 1998; Gattari *et al.*, 1991; Kok *et al.*, 1990) and high numbers of sexual partners (Clements *et al.*, 1998; Nemoto *et al.*, 1999). In addition, high levels of sexually transmitted diseases (STDs) among transgendered people have been reported (Clements *et al.*, 1998; Elifson *et al.*, 1993; Kok *et al.*, 1990).

Transgendered people's risk for HIV/AIDS from IV drug use is also a concern; however, the extent to which IV drug use is a factor in the transmission of HIV in the transgender community is not clear. For example, Gattari *et al.* (1991) found that about 73% of their sample (n = 22) occasionally used IV drugs. Nemoto *et al.* (1999), on the other hand, found that about one-fifth (22.2%) of 25 MTFs used IV drugs, while Elifson *et al.* (1993) found that only 6% of 53 transvestite sex workers had injected drugs. Additionally, among a sample of 392 MTFs and 123 FTMs, Clements *et al.* (1998) found higher levels of IV drug use among MTFs (34%) than FTMs (18%). Gattari *et al.* (1991) suggest that HIV infection might be the result of a combination of IV drug use and sexual activity. It is very likely that alcohol and drugs are being used to decrease one's inhibition to engage in high-risk sexual activity (Bockting *et al.*, 1998).

Lack of AIDS knowledge may also be a risk factor for HIV infection among transgendered people. The amount of information available is limited, but research seems to suggest that transgendered people have lower levels of AIDS knowledge than other non-transgendered groups (Kok *et al.*, 1990; Nemoto *et al.*, 1999). Compounding the risks for HIV infection are barriers to services. Research reports the difficulties transgendered people have in accessing HIV services as due in part to the lack of service providers that are knowledgeable about transgender issues (Kammerer *et al.*, 1999).

In general, research on HIV among transgendered people focuses predominately on MTFs. Only scarce attention has been given to FTMs and their risk for HIV/AIDS. Therefore, information on a broader segment of the transgendered community including FTMs is needed. In addition, there is a lack of information in the literature about the racial/ethnic background of the study samples. This study aims to address some of the gaps in the literature by exploring HIV status and HIV-related risk factors among both MTFs and FTMs. Racial background of the study sample is reported. Differences between MTFs and FTMs are explored.

Methods

Participants

The data presented in this paper are based on a needs assessment study conducted in Philadelphia in 1997. A Philadelphia-based AIDS service agency was given funding to study transgendered people. The agency, in collaboration with another social service agency and a local university, conducted a needs assessment of a community-based sample of transgender people in the Greater Philadelphia area. Snowball sampling was used to recruit respondents.

There were 81 transgendered persons in the sample, including 49 (60.5%) MTFs and 32 (39.5%) FTMs. Table 1 presents the demographic information of the respondents. Among the 78 respondents who answered the question on race, 53 (67.9%) were African-American, nine (11.5%) were multiracial, seven (9.0%) were biracial and nine (11.5%) were 'other', which included Hispanic and White. The average age of the respondents (n = 62) was 28.0 years (SD = 6.3), ranging from 19 to 67 years of age. The average number of years of schooling among respondents (n = 75) was 11.7 (SD = 1.5).

Sexual orientation was explored by asking respondents 'Which of the following terms

| Variable | MFT (<i>n</i> = 49) | FTM (<i>n</i> = 32) | Total (<i>n</i> = 81) |
|--|-------------------------|-------------------------|---------------------------|
| Age (M) | 29.1 | 26.4 | 28.0 |
| Race (%) | | | |
| African-American | 72.9 | 60.0 | 67.9 |
| Multiracial | 10.4 | 13.3 | 11.5 |
| Biracial | 6.3 | 13.3 | 9.0 |
| Other (including Hispanic and white) | 10.5 | 13.4 | 11.5 |
| Highest grade attended (M) | 11.4 | 12.1 | 11.7 |
| Sexual orientation (%) | | | |
| Homosexual | 34.7 | 84.4 | 54.3 |
| Heterosexual | 36.7 | 12.5 | 27.2 |
| Bisexual | 16.3 | 3.1 | 11.7 |
| Other (including asexual and don't know) | 12.2 | 0.0 | 7.4 |

Table 1. Sample characteristics

best describes your sexual orientation right now? Forty-four (54.3%) of them were homosexual; 22 (27.2%) heterosexual; nine (11.1%) bisexual; and six (7.4%) were 'other', which included asexual and don't know. More variability in sexual orientation was found among MTFs than FTMs (see Table 1).

Instrument

The needs assessment survey instrument was developed with the help of transgendered people, and was piloted before interviews were conducted. The perspectives of transgendered people were the foundation of the survey instrument. The main topics, many of the questions and the wording of questions were derived from two focus groups and two discussion groups with MTF and FTM transgendered people. Questions on HIV/AIDS status, attitudes and knowledge were adopted from the National Health Interview Survey, 1992: AIDS Knowledge and Attitudes Supplement (US Department of Health and Human Services, 1993). The needs assessment covered a wide variety of health and social service needs of transgendered people. This paper reports results relevant to HIV/AIDS.

Procedure

Data were collected through face-to-face structured interviews by eight transgendered interviewers (six MTF, two FTM) trained to administer the needs assessment survey. Interviews lasted about one hour. Respondents were administered the needs assessment survey in places of their choosing (e.g. apartments, boarding homes, restaurants) so they would feel as safe and comfortable as possible.

Results

HIV status

HIV status was determined by the question, 'As far as you know are you HIV-positive?' Of the 48 MTFs who answered the question, nine (18.8%) were HIV-positive, 37 (77.1%) were HIV-negative and two (4.2%) said don't know/no answer. Among HIV-positive MTFs, five (55.6%) were taking medicine to treat the virus. All FTMs (n = 32) reported they were HIV-negative.

HIV test

Respondents were asked, '(Except for blood donations since March 1985) have you had your blood tested for the AIDS virus infection?' About three-quarters (77.8%) of the 45 MTFs who answered the question said they had been tested. On the contrary, more than half (56.7%) of the 30 FTMs who answered the question had not been tested.

Respondents who said they had been tested for HIV/AIDS were then asked when they were last tested. The question was open-ended and was coded in months. Respondents who said they were HIV-positive or said 'no answer' to the question on HIV status are not included in order to explore testing among respondents who may be at risk for HIV infection. The average time from last test to the interview among the 22 MTFs who answered this question was 5.5 (SD = 3.3) months, ranging from a low of 0.5 months to a high of 12 months. The average time from last test to the interview among the 12 FTMs who answered this question was 8.2 (SD = 13.0) months, ranging from a low of 0.25 months to a high of 48 months.

High-risk sexual activity

Current risk. A series of questions about sexual activities during the past three months was asked. Respondents were considered to be at risk for HIV infection if they engaged in one or more of the following activities without using a condom or a dental dam during the three months prior to the interview: vagina-penis, anal-penis, oral-penis, oral-vagina, oral-anal or vagina-vagina sex. In addition, they were considered to be at risk if they had sex while drunk or high or sex with someone known to be HIV-positive during the three months prior to the interview. Almost three-quarters (71.4%) of MTFs (n = 49) and almost all (90.6%) of FTMs (n = 32) had engaged in at least one high risk sexual activity during the three months prior to the interview (p < 0.05). Among 37 HIV-negative MTFs, 70.3% were at current risk for HIV infection. Among nine HIV-positive MTFs, 77.8% were at current risk for reinfection.

Future risk. Respondents' future risk was determined by their reported willingness to engage in one or more of the following high-risk sexual activities in the future: sex without a latex barrier such as a condom or dental dam; sex with multiple partners at the same time or non-monogamous sex; sex while drunk or high; or sex with someone who was known to be HIV-positive. Over half (59.2%) of MTFs (n = 49) and more than three-quarters (78.1%) of FTMs (n = 32) said they would engage in at least one of these high-risk sexual activities in the future. Over half (56.8%) of HIV-negative MTFs (n = 37) and over two-thirds (66.7%) of HIV-positive MTFs (n = 9) would take this risk.

Specifically, the willingness to engage in sex without a latex barrier, such as a condom or dental dam, in the future was significantly higher among FTMs than MTFs (p < 0.05). Almost two-thirds (62.5%) of FTMs (n = 32) said they would have unprotected sex in the future as opposed to only about one-third (35.6%) of MTFs (n = 45).

Drug and needle use

Respondents were asked 'Have you ever injected any drugs?' Among respondents who reported injecting drugs, there was a follow-up question: 'Do you think you have ever used a needle that wasn't new and clean?'

The majority (84.4%) of the 77 respondents who answered the question on IV drug use had not injected drugs. Among the 12 respondents who reported injecting drugs at some

point during their lifetime, 83.3% were MTF. Two-thirds (66.7%) of these 12 respondents (all MTFs) said they had used a needle that wasn't new and clean. In addition, all of the 12 respondents who reported a history of injecting drugs had engaged in at least one high-risk sexual activity during the three months prior to being interviewed.

Respondents were also asked whether or not the needles used for hormones, silicone and electrolysis were clean. Since none of the FTMs reported having hormone or silicone injections or undergoing electrolysis, the data apply to MTFs only. Most (90.0%) of the 40 respondents who answered the question on hormones thought the needles used for hormone injections were clean. Also, most (93.3%) of the 15 respondents who answered the question on silicone injections were clean. More than two-thirds (78.6%) of the 14 respondents who answered the question on electrolysis thought the needles used for electrolysis were clean.

Sexually transmitted disease (STD)

Respondents were asked, 'Have you ever been tested for a sexually transmitted disease (STD), except HIV/AIDS?' The majority (83.7%) of MTFs (n = 49) and about one-third (34.4%) of FTMs (n = 32) had been tested for an STD other than HIV.

Respondents who said they had been tested for an STD were then asked when they were last tested. The average time among the 30 MTFs who answered the question was 11.4 (SD = 21.8) months prior to the interview. The average time among the 11 FTMs who answered the question was 8.4 (SD = 6.0) months prior to the interview.

History of an STD was determined by the question, 'As far as you know, have you ever had an STD?' A large percentage (40.8%) of MTFs (n = 49) said they had been diagnosed with an STD as opposed to only 6.3% of FTMs (n = 32).

Perceived AIDS knowledge

Respondents were asked, 'How much would you say you know about AIDS—a lot, some, a little, or nothing?' Of the 79 who answered, 54.4% said a lot, 29.1% said some, 15.2% said a little and 1.3% said nothing. FTMs felt they had a lower level of AIDS knowledge, compared to MTFs. Almost three-quarters (74.5%) of MTFs (n = 47) as opposed to only one-quarter (25.0%) of FTMs (n = 32) felt they knew a lot about AIDS.

AIDS knowledge

Respondents were read 11 statements about AIDS from the National Health Interview Survey, 1992: AIDS Knowledge and Attitudes Supplement (see Table 2 for the list of statements). After each statement, respondents were asked to indicate whether the statement was true, false or that they didn't know if the statement was true or false. Respondents' AIDS knowledge score was based on the number of correctly answered questions.

A significant difference (p < 0.01) in AIDS knowledge score was found between MTFs (M = 8.8, SD = 1.7) and FTMs (M = 7.4, SD = 3.1). Overall, a higher percentage of MTFs than FTMs answered each of the 11 questions correctly. In particular, significant differences between MTFs and FTMs were found on two questions. First, MTFs seemed to have a better understanding of the impact AIDS can have on their body. The majority (83.7%) of the 49 MTFs said it was true that AIDS can damage the brain as opposed to only half (50.0%) of the 32 FTMs (p < 0.01). Second, MTFs seemed to be more informed about the meaning of AIDS than FTMs. Almost all (98%) of the 49 MTFs said it was true that AIDS for the 49 MTFs said

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AIDS can reduce the body's natural protection against disease. AIDS can damage the brain. AIDS is an infectious disease caused by a virus. A person can be infected with the AIDS virus and not have the disease AIDS. Any person with the AIDS virus can pass it on to someone else through sexual intercourse. A pregnant woman who has the AIDS virus can give it to her baby. A person who has the AIDS virus can look and feel well and healthy. There are drugs available which can lengthen the life of a person infected with the AIDS virus. Early treatment of the AIDS virus infection can reduce symptoms in an infected person. There is a vaccine available to the public that protects a person from getting the AIDS virus. There is no cure for AIDS at present.

Note. From the National Health Interview Survey, 1992: AIDS Knowledge and Attitudes Supplement.

Perceived current HIV/AIDS risk

Respondents were asked, 'What are your chances of *having* the AIDS virus; would you say high, medium, low or none?' Most MTFs and FTMs did not believe they were at high risk for HIV/AIDS. Of the 35 MTFs who answered the question, only 5.7% thought their chances of having AIDS were high. The rest thought their chances were low (51.4%), medium, (22.9%), none (14.3%) and 5.7% refused to answer the question. Of the 31 FTMs who responded to this question, none thought their chances were high. They thought their chances were none (71.0%), low (35.5%), medium (16.1%) and 12.9% refused to answer the question.

Perceived future risk

Respondents were asked, 'What are your chances of *getting* the AIDS virus; would you say high, medium, low or none?' Most MTFs and FTMs did not seem to believe they were at risk of getting AIDS in the future. Of the 27 MTFs who answered the question, only 7.4% thought their chances of getting AIDS were high. The rest thought their chances were low (48.1%), medium (25.9%), none (14.8%) and 3.7% refused to answer the question. Of the 16 FTMs who answered the question, only 6.3% thought their chances of getting AIDS were high. The rest thought their chances of getting AIDS were high. The rest thought their chances of getting AIDS were high. The rest thought their chances of getting AIDS were high. The rest thought their chances of getting AIDS were high. The rest thought their chances were none (43.8%) or low (25.0%) and 25.0% refused to answer the question.

Discussion

Before discussing the implications of these findings, several limitations of this study should be addressed. First, the non-probability sampling method employed does not allow the results of this study to be generalized beyond the study sample. Second, it should be noted that this study asked about IV drug use and did not ask specifically about injecting illicit drugs. Therefore, the type of drug use (i.e. illicit or other) is unclear. Third, this study reports whether or not respondents have been tested for an STD, average length of time since last STD test, and incidence of an STD among the study sample, but information regarding the specific types of STD was not available. Future studies can provide respondents with a list of STDs and ask them to check-off those for which they tested positive, as a means to understanding the relationship between STDs and HIV infection. Despite these limitations, findings from this study indicate that HIV/AIDS is a serious health concern facing the transgender community. Both MTFs and FTMs are at risk for HIV infection. MTFs were found to be at risk from high-risk sexual activities and a willingness to engage in high-risk sexual activities in the future. Although MTFs were at risk for HIV infection, the majority did not believe their chances of having, or getting, HIV/AIDS were high.

Although the percentage of the sample that was HIV-positive was lower than reported by previous studies, the majority of FTMs had not been tested. In addition to lack of testing, FTMs were found to be at tremendous risk for HIV/AIDS through a combination of high-risk sexual activities, willingness to engage in high-risk sexual activities in the future, lack of knowledge about HIV, and a belief that they are not susceptible to the disease. These findings are alarming due to the lack of attention to HIV risk among FTMs in the literature. These findings also indicate the urgent need for HIV education and prevention efforts targeting FTMs. For an example of an FTM-specific HIV prevention programme, see Hein and Kirk (1999).

Although this study supports the low levels of injection drug use found by Elifson *et al.* (1993), the combination of IV drug use and high-risk sexual activities, particularly among MTFs, indicates a need for strategies which target multiple high-risk behaviours. In addition, although use of unclean needles for hormone and silicone injections and electrolysis among respondents who were going through some degree of medical treatment was not found to be a major problem in this study (most respondents had not used unclean needles as reported in the Results section), it is still a concern. For example, in an effort to maintain or modify their appearance, transgendered people without access to proper health care may resort to sharing needles to inject hormones and risk HIV infection in the process.

Respondents' risk for HIV infection from high-risk sexual activities demonstrates the need for HIV prevention education targeted specifically towards transgendered people. Messages should take into account the uniqueness of transgendered people's bodies (Bockting *et al.*, 1998). For example, there may be an increased risk of HIV transmission for MTFs who have had vaginoplasty to construct a new vagina, due to the vagina's fragile lining (Modan *et al.*, 1992).

HIV risk assessments should not only take into account the uniqueness of transgendered people's bodies, but also their sexual experiences. This study (as well as many previous studies) assessed HIV risk through questions of high-risk sexual activities that are based on standard conceptions of female and male anatomy. As such, the breadth of information that can be reported about the sexual activities experienced by the respondents may be limited. For example, FTMs may answer the sexual activities questions based on having male anatomy even if they had not undergone gender-related surgery. Additionally, these questions fail to capture sexual activities among those whose bodies are changing due to hormone use or gender-related surgery. HIV/AIDS risk based on sexual activities commonly associated with non-transgendered people may not be applicable to transgendered people.

HIV prevention efforts must also take into consideration the complexity of their sexual orientation. Sexual orientation of transgendered people is not well documented in the literature and at times seems to be confused with gender identity. The term transgender pertains to the gender, not the sexual orientation with which a person identifies, transgendered people can be gay or lesbian, heterosexual, bisexual, asexual, etc. (MacKenzie, 1994). Although traditional categories of sexual orientation that are based on anatomy are used to discuss the sexual orientation of transgendered people, these categories may need to be defined differently when applied to this group. For example, some transgendered people may base their definition of sexual orientation on their gender identity, while others may identify their sexual orientation based on their anatomy.

One unexpected benefit of the study was that some FTMs reported learning about HIV/AIDS from participating in the survey. Interviewers reported that once the interview was complete they would go over the correct answers to the 11-item AIDS knowledge test with respondents who did not know all of the answers. Although the needs assessment survey was not intended to be an HIV education tool, the fact that some FTMs learned from it was a very positive aspect of the study.

In conclusion, this study demonstrates the need for HIV prevention interventions for transgendered people. Intervention strategies need to address the needs of both MTFs and FTMs. Furthermore, this study points out that in order to accurately assess HIV/AIDS risks specific to transgendered people, it is critical to develop questions about sexual activities that are sensitive to the complexities of transgender identity.

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References

- BOCKTING, W.O., ROBINSON, B.E. & ROSSER, B.R.S. (1998). Transgender HIV prevention: a qualitative needs assessment. AIDS Care, 10, 505-526.
- CLEMENTS, K., MARX, R., GUZMAN, R., IKEDA, S. & KATZ, M. (1998). Prevalence of HIV infection in transgendered individuals in San Francisco. Poster session presented at the XII International Conference on AIDS, Geneva Switzerland.
- ELIFSON, K.W., BOLES, J., POSEY, E., SWEAT, M., DARROW, W. & ELSEA, W. (1993). Male transvestite prostitutes and HIV risk. *American Journal of Public Health*, 83, 260–262.
- GATTARI, P., REZZA, G., ZACCARELLI, M., VALENZI, C. & TIRELLI, U. (1991). HIV infection in drug using transvestites and transexuals [letter to the editor]. *European Journal of Epidemiology*, 7, 711–712.
- GREEN, J. & BRINKIN, L. (1994). Investigation into discrimination against transgendered people. (Available from the Human Rights Commission, City and County of San Francisco, 25 Van Ness Avenue, Suite 800, San Francisco, CA 94102–6033.)
- HEIN, D. & KIRK, M. (1999). Education and soul-searching: the enterprise of HIV prevention group. *International Journal of Transgenderism* [On-line], 3(1 + 2). Available: http://www.symposion.com/ijt/hiv_risk/hein.htm
- KAMMERER, N., MASON, T. & CONNORS, M. (1999). Transgender health and social service needs in the context of HIV risk. *International Journal of Transgenderism* [On-line], 3(1 and 2). Available: http://www.symposion.com/ijt/hiv_risk/kammerer.htm
- KOK, L.P., HO, M.L., HENG, B.H. & ONG, Y.W. (1990). A psychosocial study of high risk subjects for AIDS. Singapore Medical Journal, 31, 573–582.
- LOMBARDI, E.L., WILCHINS R.A., PRIESING, D. & MALOUF, D. (1998). Gender violence: transgender experiences with violence and discrimination. Paper presented at the annual meeting of the American Sociological Association, San Francisco, CA.
- MACKENZIE, G.O. (1994). Transgender nation. Bowling Green, OH: Bowling Green State University Popular Press.
- MODAN, B., GOLDSCHMIDT, R., RUBINSTEIN, E., VONSOVER, A., ZINN, M., GOLAN, R., CHETRIT, A. & GOTTLIEB-STEMATZKY, T. (1992). Prevalence of HIV antibodies in transsexual and female prostitutes. *American Journal of Public Health*, 82, 590–592.
- NEMOTO, T., LUKE, D., MAMO, L., CHING, A. & PATRIA, J. (1999). HIV risk behaviours among male-to-female transgenders in comparison with homosexual or bisexual males and heterosexual females. *AIDS Care*, *11*, 297–312.
- PANG, H., PUGH, K. & CATALAN, J. (1994). Gender identity disorder and HIV disease. International Journal of STD & AIDS, 5, 130–132.
- US DEPARTMENT OF HEALTH AND HUMAN SERVICES (1993). National health interview survey, 1992: AIDS knowledge and attitudes supplement [machine-readable data file]. Hyattsville, MD: US Dept. of Health and Human Services, National Center for Health Statistics, producer, Ann Arbor, MI: Inter-university Consortium for Political and Social Research, distributor.