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AIDS CLINICAL RESEARCH CENTER

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AIDS MENTAL HEALTH TRAINING PROJECT

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January 1, 1987

Dear WHAT TO DO ABOUT AIDS authors:

Congratulations on a fine book. I hope you have gotten your copies of the book in the mail from UCPress by now. You can find out about ordering more books using your authors discount by calling UCPress at 415 642 4247.

There will be a book signing party at Walt Whitman Bookstore in San Francisco on Friday January 23. A number of copies of the invitation letter are enclosed for you to distribute to your friends and colleagues. There will be refreshments and celebration. The party occurs on the evening of the first day of a conference we are sponsoring on AIDS at the University of California Berkeley, so many faculty and participants from that conference should also be there.

I hope you can come and join in the celebration of the fine work you have done.

Sincerely yours,

A handwritten signature in cursive script, reading "Leon McKusick".

Leon McKusick, PhD
Project Director

PHONE MEMO

TO

Nancy Shaw

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August 30, 1986

Dear Author;

The book What to Do About AIDS will be released by UCPress in October. When it is available, you will receive a copy. Meanwhile, here is a copy of the page proofs of your contribution, the table of contents, and the title page.

Thanks for helping make this a great book!

Sincerely yours,

Leon McKusick

WHAT TO DO ABOUT AIDS

*Physicians and Mental Health Professionals
Discuss the Issues*

Edited by

Leon McKusick

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Women and AIDS

NANCY SHAW AND LYN PALEO

In 1983 the first brochure on women and AIDS was produced. Since then a great deal has happened. With the growing awareness that women can contract AIDS has come the realization of needs: that specialized services should be provided to them and that health care providers will increasingly come into contact with women who have some kind of AIDS concern. Some women may have been exposed to AIDS, others have close friends or family members who are ill. Additionally, many of the health care personnel providing AIDS services are women.

Women At Risk: Epidemiology

AIDS in women presents a different epidemiological pattern from that found among men. The most prevalent risk category is IV drug use (53 percent), according to CDC AIDS activity reports. The next category, or group of women with AIDS, is one for which no root of transmission has been identified, referred to as "none/other" by the CDC (20 percent) (1986). Included in this risk category are women from countries where a higher proportion of the population has AIDS or ARC or may be seropositive. This includes women diagnosed in the United States who immigrated here from Haiti and Zaire. For many of the women (including the nonimmigrants) in the "none/other" category, the probable risk factor was heterosexual contact with a man who was infected with the virus but is not in an identified risk group. His infection may have been through a person that he did not know to be in a risk category (for example, his wife, who had a blood transfusion prior to his meeting her).

Another grouping of women in the "none/other" category is composed of those who were diagnosed late in their illness or only at au-

topsy. Because men and their health care providers are more aware of the possibility of contracting AIDS, male diagnoses may take place at earlier stages. This allows more time for adequate investigation into the source of infection. If more women are diagnosed only at autopsy, risk factors will be more difficult to determine. Systematic research has not yet been conducted into this issue. It is striking, however, that in only a very small percentage of male AIDS cases is "none/other" listed for patient groups.

Another aspect of surveillance that may affect the female "none/other" category is that the questions listed on the CDC surveillance form are not designed to elicit special data on female risk groups. Data are collected on "homosexuality," for example, but the word "lesbian" is not used. Many health care providers are not aware that their female patients may be lesbians. Consequently, this risk factor may be overlooked. In a similar vein, questions are not asked about donor insemination, although clinical reports demonstrate clearly the possibility of viral transmission via insemination.

The third risk category is heterosexual contact. Even though many more men than women have AIDS, for about five times as many women as men is heterosexual contact the suspected route of infection, according to the CDC. One reason for this difference is that, regardless of initial route of infection (for example, gay activity, hemophilia, drug use, transfusion), there are more males currently carrying the virus than females. This means that in terms of heterosexual contact, more males are capable of transmitting the virus.

A second consideration may be that AIDS is more readily transmissible from males to females than vice versa. Additionally, some heterosexual contact includes anal intercourse, an important risk factor for virus transmission. Research in *types* of heterosexual activity and virus transmission has yet to be completed. Within the heterosexual risk category, the partners of the women were predominantly IV drug users (72 percent); bisexual men as partners are a much smaller group (19 percent) (Hardy 1985).

The fourth risk category for women is transfusions with blood or blood products, according to the CDC. It accounts for 9 percent of all female cases. New cases from earlier transfusions will continue to appear, but the risk of transfusion-related transmission is currently near zero.

A fifth risk category for women is "hemophiliac/coagulation disorder." Four adult females were in this category in 1986. Women *do* have coagulation disorders for which they receive the same types of blood products as are prescribed for hemophiliacs. As with transfusions,

the current risk associated with Factor VII blood products is essentially zero.

In California, women's risk factors are somewhat different from the national ones. Transfusion-related AIDS is a more common cause of infection than drug use. Drug use and heterosexual contact are the second most important risk factors (California Health Services 1986). Of the California women who contracted AIDS through heterosexual contact, two of them had partners who were both IV drug users and bisexual. One had a partner who was an IV drug user, one had a partner who was homosexual/bisexual, one partner was a hemophiliac, and about two we do not have adequate data. In California, as of September 1985, two lesbians were identified with AIDS diagnoses. One contracted it through a transfusion, the other via IV drug use (Miller 1985).

These data refer to AIDS cases only. We estimate that there are ten times as many ARC cases and one hundred times as many women who are infected.

In California, female AIDS cases are concentrated in several of the larger metropolitan areas: Los Angeles, San Francisco, and Alameda County, for example. Although surveillance figures are *supposed* to refer to the county of *residence*, they actually represent the county of *diagnosis*. In some cases, but not all, the county of residence is the same. This fact should be taken into account when services are being developed and when city and county budgets are being prepared.

There is no evidence that prostitutes constitute a special risk category. The CDC documented this, as has preliminary research being done in San Francisco (Wofsy et al. 1986, Schultz et al. 1986, Wykoff 1986). Some prostitutes do get AIDS. To the extent that researchers have been able to isolate prostitution and/or multiple sexual contacts from such issues as IV drug use, however, neither the number of sexual contacts nor the receipt of money for sex (by sex therapists, prostitutes, call girls, and the like) seems to put women at a higher risk for getting AIDS. Many women who are in paid sexual activity were concerned about sexually transmitted diseases even before the AIDS epidemic. They protected themselves and continue to protect themselves by being somewhat alert to new medical developments in sexually transmitted diseases and how to avoid them. They may be better protected than the typical woman who is "just going to a bar" or a woman who thinks of herself as not sexually active but who "just happens to have this relationship." They may be more aware than women who are involved in serial monogamy or those whose self-image is "I'm not at risk so I'm not going to learn more about it."

Transmission and Its Prevention

Prevention of HIV transmission for women is essentially the same as it is for gay men and will be described below. The safe sex guidelines, now in use with gay men, can, with a little creativity, be revised to apply to women. AIDS is caused by a virus transmitted in some, but not all, bodily secretions. It can be *found* in probably every bodily secretion, including blood, spinal fluid, semen, saliva, sweat, and tears. But that does *not* mean it can be transmitted via all these routes. The concentration varies significantly from fluid to fluid. The highest concentrations are in blood, spinal fluid, and semen. Even when traces of the virus are found in other fluids, saliva, for instance, they may be in a nontransmissible or poorly transmissible form. The concentration may also be too low for effective transmission.

The virus *can* be transmitted through blood, as epidemiological data indicate, and through semen. Those are the two main bodily fluids to be wary of. Blood can appear in a variety of places. One could have blood in her saliva; in that case, then, her saliva might be an effective transmission route. Blood often passes through the colon as a matter of course, without any illness being present. It is often in feces and there may be fecal contact in sexual activity, either advertently or inadvertently. Blood is also present in menstrual fluid, which can be in smaller or larger amounts in vaginal and/or cervical secretions.

Although numerous studies about transmission of the virus during sexual activities between men are in progress, little research has been completed on sexual transmission and women (with either a heterosexual or lesbian focus). Finding HIV in vaginal secretions does not answer the question of vaginal transmission. For that we need an epidemiological study. One epidemiological study addressing this issue is the AWARE study at UCSF, under the direction of Constance Wofsy and Judith Cohen (1986). Very few of the participants thus far have positive antibody test results, indicating infection. All these women, however, were IV drug users in addition to being at risk through sexual contact. The study (ultimately of 500 women at risk) will give us extensive data concerning virus transmission.

A second epidemiological study of women and AIDS in San Francisco, conducted by Nancy Padian, focuses on the female sexual partners of gay and bisexual men (1986). The men's blood has been analyzed for seroconversion since 1980. The female partners of a sample of the men are being tested for HIV antibody positivity.

The third San Francisco epidemiological project on AIDS transmission and women is the Lesbian Insemination Project (LIP), affiliated

with the AWARE study (Pies 1986). LIP's purpose is to gather more information about semen as a transmitter of the virus when the factor of sexual intercourse is removed. The subjects in this study have a very low rate of sexual activity with men, but they have been exposed to semen through donor insemination. The project investigates antibody positivity in the women and, in some cases, their children.

Research results are important to educators and health care providers who wish to provide accurate information to their clients concerning transmission and prevention of AIDS. Our approach—in this field where so little is known—is to base our education on as much knowledge as we can and to make conservative recommendations, erring on the side of safety.

For most sexual activity—vaginal intercourse, anal intercourse, and fellatio—the most important AIDS transmission risk is semen entering the body. The best prevention method is condoms. Condoms do seem to act as an effective barrier to the virus, just as they act as a barrier to almost every other virus. Condoms can be used in any kind of intercourse and in fellatio by mutual agreement or, in fact, without it. Many prostitutes and other women in the sex industry use condoms without their clients knowing it. The woman holds the condom in her mouth until she performs fellatio and, with a learned skill and ease, puts it on the man and takes it off after the act is finished. He never knows.

Transmission may also occur when sex toys are shared. Any item (dildo or vibrator, for example) should *not* be used internally by both partners. If it is, it should be cleaned with bleach, alcohol, or hydrogen peroxide.

Previous exposure and current sexual activity are two separate factors. If two people are at very "high risk" because of their previous practices, they still could be presently engaging in very safe sexual activities, including use of condoms. Conversely, they may be two people whose sexual activities have been very limited, or they may have been monogamous for years. They do not *have* a sexual risk factor, yet they are very worried: "Well, everyone's pointing the finger at us, saying we're going to get AIDS, because we engage in anal intercourse, and *they* say that's how the gay men get it."

Another aspect of risk is dose. Researchers believe that repeated doses of the virus are sometimes necessary for infection. One might have a brush with the virus, some contact with it, and not *necessarily* become infected. But infection *could* also occur after only one exposure.

An effective lubricant, gel, or spermicide to use with a condom is nonoxynol-9, which kills HIV in laboratory settings (Hicks et al.

1985). This does not necessarily guarantee that it will kill the virus in other settings. Home use is different from clinical studies. We cannot say categorically to a client, "If you use nonoxynol-9, you will be safe." It will, however, lower the risk of transmission. Nonoxynol-9 lubricants can be applied both inside and outside a condom. Some condoms are also prelubricated with spermicide. Using a condom appropriately, without user error, breakage, and so forth, *will* prevent the virus from entering the body during ejaculation (Conant et al. 1985). So, in terms of intercourse, even fellatio, the condom is a very effective protective device.

Basically, safe sex boils down to one concept: "Do not allow one person's semen, blood, feces, vaginal secretions, or, in the case of lactating mothers, mother's milk, into another person's body." That might mean using condoms; it might mean not ejaculating. Vaginal secretions may also transmit the virus. If a woman were infected, cunnilingus *might* transmit the virus to her partner.

To prevent a partner's exposure to her menstrual blood and/or cervical secretions, a woman can use a diaphragm and nonoxynol-9, and have her partner use a condom. Such activity reduces, but does not eliminate, the risk of transmission.

Another aspect of sexual transmission is saliva and kissing. Saliva poses a difficult question for the health educator and mental health care provider. It is quite easy to prove that something does transmit a virus; all you need is one case in which it has. It is much more difficult to prove that it does not. In all likelihood, saliva does *not* transmit the AIDS virus, unless there is blood mixed in with it. Brushing your teeth or having cuts or sores in your mouth can produce blood. If the virus is in the blood, it is then "in" the saliva. But saliva itself (or with minute amounts of blood) has never been implicated in a case of HIV transmission. The viral concentration is apparently too low. Some comparisons have been made between HIV and the hepatitis B virus, which is, similarly, transmitted primarily through blood and semen. Hepatitis B virus is also found in saliva, but in thirty years of research not one case has been linked to salival transmission. As health care providers, we must be alert to the client who says, "Oh well, saliva's probably risky, and so is semen, and I'm not going to stop kissing, so I might as well not stop intercourse without a condom." Semen is *known* to transmit the virus.

Levels of Risk

Communities and populations have variable rates of virus exposure. In the case of a community like the gay male community of San Francisco (with a 50 percent infection rate) or the New York IV drug user community (with as many as 80 percent of the community exposed), the basic public health goals should be that everybody engage only in safe sex, for protection of self and others. Community survival will require major behavioral changes.

In a community where the incidence of infection is below 50 percent, perhaps only 1 percent, the average person is less likely to want to use condoms. How can one mandate safe sex for *everyone*? If one follows the risk reduction guidelines in all cases, there would be no pregnancies. One aspect of sexual counseling for the lower risk population is education on decision making and risk evaluation. The client should be asked, "What level of risk are you willing to take?" Some people feel that they have very little risk of exposure and that their partner has little or no risk. They feel safe, or safe enough to do "everything." Some people review their pasts and those of their partners. Others take antibody tests and then decide about sex. Still others take the attitude that if there's any risk at all, they would rather avoid sex. Some risks are more acceptable than others to an individual. One person will drive drunk, but always use a condom. Another is the reverse. Partners negotiate to what degree each wishes to take some sort of risk.

Pregnancy and Pediatric Issues

Most pediatric AIDS patients (77 percent) contracted the illness via a parent with AIDS or at increased risk for AIDS, as of June 1986, 224 infants, 114 male and 110 female (CDC 1986). Although there is a chance of the fetus being exposed to the virus through transplacental transmission *in utero*, not every baby will be born infected (Scott et al. 1985). In some cases, infected women who have given birth to infected children have later delivered noninfected, healthy children. We cannot predict whether a specific infant will be born infected. Additionally, some children who have had positive results on the AIDS antibody tests remain in good health. Transmission of the virus can also occur via breast milk. A clinical report from Australia identified one infant who became antibody-positive after its mother received a tainted

blood transfusion postnatally and then nursed her child over a period of months (Ziegler et al. 1985).

If a woman is infected at the start of a pregnancy, what are her chances of developing the symptoms of ARC or AIDS during the course of pregnancy? Pregnancy may accelerate the course of illnesses associated with AIDS and ARC and perhaps also the underlying syndrome itself. Counseling women who are already pregnant, and at the point when abortion is feasible, is a complex and difficult task (San Francisco Public Health Department 1986).

And lastly, donor insemination. No women who received semen via donor insemination have yet contracted AIDS. One study in Australia demonstrated that the virus is transmissible via insemination. Freezing the sperm may make transmission less likely. Screening programs similar to those in use in blood banks are the major technique for preventing transmission via insemination. Typically, a sexual and social history of the donor, blood tests, and other screens are used. HIV antibody tests are in routine use at licensed sperm banks.

Testing for the antibody to HIV is a screening strategy that is being increasingly applied as a protection even beyond the blood banking community. Sperm banks use it. Some doctors recommend it for their patients considering pregnancy. Some people want it to feel secure about their sexual activity. While the test is relatively accurate, it is not 100 percent perfect. Since we are dealing with a potentially deadly illness, the imperfections of the test are very important to understand.

The consequence of a false-negative result is that a woman may *wrongly* think that she is not carrying the virus and spread it inadvertently or misunderstand her real symptoms of AIDS or ARC. In most testing systems, negative test results are not a signal to retest and the result is treated as "true." Any woman in a high-risk group who gets an initial negative result should consider a retest for certainty.

The consequence of a false-positive result can be unnecessary stress, anxiety, and fear. Because almost all testing programs include retests of positive specimens, any woman with an initial positive test is likely to have her blood retested automatically. Retesting significantly reduces the risk of a false result.

Women's Unique Issues

First, there is the problem of maternal transmission, already described. Women at risk for infection are going to be counseled about preg-

promiscuous women. Prostitutes were described as "a reservoir of infections" (Schultz et al. 1986, Wykoff 1986, Redfield et al. 1986). Just as gay men are stigmatized for their sexual activity, so women who cannot prove that they contracted the virus from their husbands or from blood transfusions are also going to be stigmatized and criticized and blamed for their (imagined) sex life and morals.

Women as Health Care Providers

Numerically, women constitute the bulk of the care-giving population for those who have AIDS. Persons with AIDS are primarily men. The medical care system itself is dominated by men. This situation mirrors women's family role of filling others' physical and emotional needs and being responsible for their daily maintenance. Many of us are in the situation of providing extensive service but receiving inadequate recognition. We have the role (which we have filled for centuries) of caring for the sick, handling emotional problems, handling issues of nurturance, doing the daily work, doing the dirty work, handling everybody's waste materials in one form or another, being exposed. The AIDS epidemic makes our nurturing roles more necessary while simultaneously reducing our self-worth. If we begin to complain about, for example, sexism or lack of recognition, we are told, or may tell ourselves, that we are dealing with a very serious epidemic, we're talking about people dying, and after all, I am a woman who is not at much risk. "I'm healthy, what right have I to ask for anything?"

We experience this criticism externally and internally. On the one hand, women have frustrations about status in the hierarchical structures of medicine; and on the other hand, they feel that they should not complain. Therefore, meeting the challenges of the AIDS epidemic may include addressing the role of women health care professionals as well as the needs of women at risk of illness.

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nancy, abortion, breastfeeding, contraception, and antibody tests. They are going to be encouraged to share information about their antibody status with obstetricians, labor room staffs, and pediatricians. Some may even be told to delay pregnancy indefinitely "until more is known." How will women react to such advice?

In some cities, women in high-risk groups are being encouraged to have antibody testing prior to pregnancy. It is entirely possible that women, or subgroups of them, and not gay men, will be the first population to face mass screening for the AIDS virus antibody.

A second aspect of AIDS that is unique to women is the social role of mothering: From this role flow two important consequences. First, when a woman becomes ill with ARC or AIDS, her role as a primary care-giver to a child or children or to other adults in the household is immediately affected. The family is severely disrupted, and she herself will have to make many adjustments. Her children may also be indirectly affected by her diagnosis and forbidden to go to school. She has to deal with a life-threatening illness, and she also has to deal with the impact on her family, and this is a very serious matter. As stated earlier, 53 percent of women with AIDS contracted it through IV drug use. A significant number got it through heterosexual contact, most often with a drug user. Demographic studies of such women indicate that they are likely to have young children and also to be the sole support of these children.

A second consequence of the social role of motherhood is care of the child with AIDS. With AIDS, as with other sicknesses, it is ordinarily the mother who is expected to care for or manage the care of the child. But since most pediatric AIDS cases are the result of maternal transmission, the mother may herself be ill. Her illness and responsibility may be compounded by illegal survival activity, incarceration, poor health (caused by drug use and illnesses associated with its life-style), and the threat of foster care or child abuse proceedings. These are parenting issues that men rarely face.

If the mother is healthy enough to care for her child, she must still handle the complex issues of medical and home care, research investigations, school access, friends, and family stress. CDC recommends that every child be evaluated individually to provide quality care for a child who either is infected with the virus or is ill (Education and Foster Care 1985).

Resources for Women

Because the total number of women infected with HIV is much smaller than the number of men, the general resources available for women and those that deal with particular problems of women are much more limited. Let us look briefly at the area of drug rehabilitation services—necessary to combat AIDS transmission via shared needles. Both in absolute numbers, and in proportion to need, fewer drug programs exist for women than for men (Shaw 1985). Residential programs have fewer spaces available for women than for men. In addition, most of the programs will not take women who are pregnant, and those that will take women who are pregnant will not take them when they are more than twenty-one weeks pregnant. None will house a woman with a child.

The only residential substance abuse program in San Francisco that will take women who are pregnant and/or have children is the Women's Alcoholism Center, which requires that the woman's primary problem be alcohol, not drugs. As a consequence, a woman with a drug problem who is at risk for AIDS and has children is forced to leave her children in order to be treated in a residential program. She probably will not be able to have visitors, including her children, for at least two months. Such rules are standard in many residential programs. These programs are designed to meet men's needs, not those of women.

Women need AIDS services as well. Many AIDS-focused organizations have no women's support group or people who are particularly sensitive to women's issues. Organization members, clinic staff, and health department employees may be sensitive to the issues of AIDS in a general way, but many are not trained to understand those problems specific to women.

Another aspect of resources and services for women is the need for ethnic diversity in staff and programs. Most female AIDS cases are black or Latino women. Effective educational programs require culturally sensitive and linguistically appropriate materials, combined with active outreach. This is not happening so far any place in the United States. Work with local ethnic health and civic organizations can be an important step in raising community awareness of AIDS and preventive techniques and assist those affected. Most women with AIDS are from poor backgrounds. As a whole, they are probably poorer than men with AIDS. This means that more resources are going to be needed for women than for men.

At the 1985 International Conference on AIDS in Atlanta, many researchers discussing sexuality would refer to sexually active men and

Wykoff, R. F. 1986. Letter to the editor. *JAMA* 255:1704-5.

Ziegler, J. B., D. A. Cooper, R. O. Johnson, et al. 1985. Postnatal transmission of AIDS-associated retrovirus from mother to infant. *Lancet* 1:896-98.

Substance Abuse as a Cofactor for AIDS

BARBARA G. FALTZ AND SCOTT MADOVER

It becomes apparent when we look at the connection between substance abuse and AIDS that they are linked in five ways.

The first and most obvious link is the direct transmission of the AIDS virus through the sharing of hypodermic needles, syringes, and paraphernalia used in "shooting up" drugs. According to the CDC, IV use is the primary risk factor for 17 percent of persons with AIDS. In addition, 11 percent of the gay and bisexual men report a history of IV drug use, making a total of 28 percent of those with AIDS IV drug users (CDC 1985).

The second link of substance abuse with AIDS is the transmission of the virus by infected IV drug users to their sexual partners in either heterosexual or homosexual contact. Of those reported cases of heterosexual transmission of the disease in the United States, the overwhelming preponderance has been in women (CDC 1985).

Third, infected women who are IV drug users or who are sexual partners of IV drug users can transmit the virus during the neonatal period.

In cohort studies, a correlation between the use of volatile amyl and butyl nitrites (poppers) and the development of KS has been demonstrated (Newell et al. 1985). Although they are not directly linked to AIDS, alcohol, marijuana, cocaine, and amphetamines have been demonstrated to be immunosuppressant. We feel that persons who have been exposed to the AIDS virus by their sexual partners or through IV drug use need to reexamine their use of immunosuppressant drugs—particularly their use of poppers.

Finally, there is the factor of increased sexual and needle-using behavior while under the influence of alcohol or drugs. In a report prepared for the San Francisco AIDS Foundation, the Research and Decisions Corporation (1985) cited the following findings:

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SAN FRANCISCO, CALIFORNIA 94143

Nancy;

You are a hard one to get ahold of. Between the two of us, we could play phone tag for months. So I am messengering this to you in the interest of our June 23 final final deadline. All the papers have been reviewed and accepted for publication. Those with medical information had to be further analyzed for accuracy and yours passed that hurdle. However, it still needs to be referenced. I don't know this literature. I have gone through your paper and have highlighted those statements that are data based. Thus, you or Lynn need to cite references and perhaps update these statements if any new data has emerged.

I have enclosed an envelope with Jane Duells address on it. She will need to do one final go-over between June 20-23.

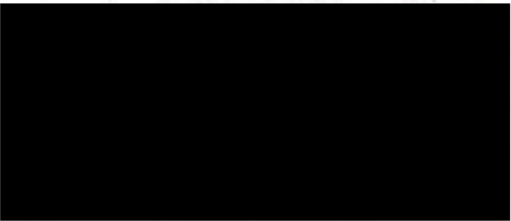
so please get it to her by then (Portage is
only for a small amount of paper. Please copy
your section out of the manual + send).

Your paper is very good. UC Press loves it.
We want to be sure to include it.

I also have not reviewed your signature
on release of the paper. Yours is the last one,
and UC Press wants these right away. I have
provided you an envelope. Please mail it
today!

I hear from someone on my answering phone
(of all places) that you ~~are~~ have won a tenure
battle at UCSC. Congratulations. I will be
putting on an AIDS Mental Health Conference
then this fall. Perhaps you'd like to
join in.

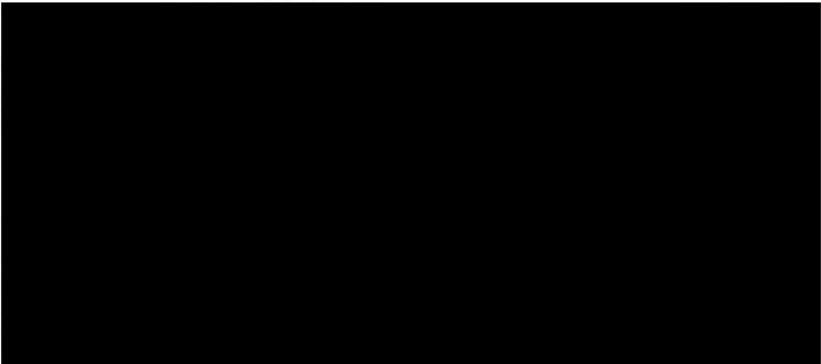
Thank for your help,
Jim



Publications
Jean Duell

Home:





PK in driveway
Slot next to door
— Ring bell —

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UNIVERSITY
OF California
PRESS

10995 Le Conte Avenue, Suite 613 • (213) 825-3018

Mail Address: 405 Hilgard Avenue, 613 UNEX Building, Los Angeles, California 90024

April 10, 1986

To: *Nancy Shaw*

This letter, when countersigned by you, will indicate your consent that your article(s),

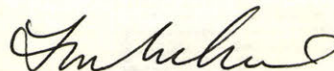
"Women and AIDS"

appear in the volume edited by Leon McKusick, entitled

WHAT TO DO ABOUT AIDS: MENTAL HEALTH PROFESSIONALS AND PHYSICIANS
DISCUSS THE ISSUES

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Sincerely,



Leon McKusick
AIDS Behavioral Research Project
UCSF, 4326 18th Street
San Francisco, CA 94117

Nancy Shaw

Signature

5/7/86

Date

AIDS Behavioral Research Project
4326 18th Street
San Francisco, California 94117
(415) 552 - 6356

February 7, 1986

Dear AIDS Mental Health Authors;

Thank you for working with Jeanne Duell to produce the manuscript from the AIDS Mental Health Conference. Today I am sending this manuscript to UC Press in Los Angeles to be reviewed for publication. The process is slow and iffy, but we may have a book based on these papers by the end of the year.

The first step is the review. At the end of that I will be receiving comments and criticisms and will have a chance to re-edit or respond to their suggestions. Enclosed are the draft that went to LA and the previous draft of your paper, as well as the table of contents for the book. If you have any grammatical or typographical editing suggestions, I will take them when the manuscript returns from the reviewers. Regrettably some of the papers from the workshops were lost due to the poorness of the recording devices in some of these sessions. I invited additional papers to round out the topic coverage.

Please do not submit your paper elsewhere for publication in its current form. If we are accepted UC Press will contact you for signature later this year.

For those of you who have not given a professional biography to either Jeanne or myself, I would appreciate your sending them to my office, or you can call the information onto my answering machine 415 552 6356. We basically need a degree check, current position, previous AIDS related positions, AIDS related publications.

Please copy and distribute this paper and letter to your co-authors.

Again, thank you for your help. Believe it or not, this has been a fairly easy and enjoyable process for me so far, and I believe that we have a comprehensive and informative book as a result. That is a testament to the quality of your efforts.

Sincerely yours,

Leon McKusick

Leon McKusick, Ph.D.
Project Director

*Many,
Thanks for your
help. J*

AIDS AND MENTAL HEALTH :
POLICY, ADMINISTRATION, TREATMENT

Leon McKusick, PhD, Editor
AIDS Clinical Research Center, University of California San
Francisco

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Barbara Faltz

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Marc Gold, MSW
Neil Seymour, MA
Jeffrey Sahl, PhD



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MEMO FROM

NANCY STOLLER SHAW, PH.D.
Education Department

Notes that table

① Rephrase tables into
sentences where possible

Jan. 22
goal

→ UCSF
Jean Duell

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SAN FRANCISCO, CALIFORNIA 94143

Nancy and Lyn;

Our deadline is January 7.

If you could produce a draft
(don't bother to type it, use this one + cut
+ paste, if possible) before Christmas
and then get it to Jean Duell in the
enclosed envelope, everything will
go on schedule.

Sorry about the short notice.

Tables
Tables, provided separately,
much appreciated.

a Brief Biography of each of you
including degrees, schools, AIPS related
work and relevant Publications
would be appreciated also. See

AIDS AND MENTAL HEALTH

POLICY ADMINISTRATION TREATMENT

PRODUCED BY

University of California, San Francisco, AIDS Clinical Research Center

FUNDED BY

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City and County of San Francisco, Department of Public Health

AIDS AND MENTAL HEALTH:
POLICY, ADMINISTRATION, TREATMENT

Papers resulting from a conference
at the University of California San Francisco

September 13 - 14, 1985

sponsored by

The AIDS Clinical Research Center

Co-Chairs

Marcus Conant, MD
Leon McKusick, PhD

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Women and AIDS

by Nancy Shaw, PhD, and Lyn Paleo

In 1983, the first brochure on women and AIDS was produced. Since then a great deal has happened. With the growing awareness that women can contract AIDS has come the realization that specialized services should be provided to them and that health care providers will increasingly come into contact with women who have some kinds of AIDS concern. Some patients may have been exposed to AIDS, others have close friends or family members who are ill. Additionally, many of the health care personnel providing AIDS services are women.

Women At Risk: Epidemiology

AIDS in women presents a different epidemiological pattern from the one found among men. National data show that the most prevalent risk category is IV drug use (53 percent).^{*} The next category, or group of women with AIDS, is one for which no root of transmission has been identified, referred to as "none/other" by the Centers for Disease Control (CDC) (22 percent). Included in this risk category are women from countries where a higher proportion of the population has AIDS or AIDS-related complex (ARC) or may be virus seropositive. This includes women diagnosed in the U.S. who immigrated here from Haiti and Zaire. For many of the women (including the nonimmigrants) in the "none/other" category, the probable risk factor was heterosexual contact with a man who was infected with the virus, but is not in an identified risk group. His infection may have been through a person that he did not know to be in a risk category (e.g., his wife, who had a blood transfusion prior to his meeting her).

Another grouping of women in the "none/other" category is composed of those who were diagnosed late in their illness or only at autopsy. Because men and their health care providers are more aware of the possibility that males get AIDS, male diagnoses may take place at earlier stages. This allows more time for adequate investigation as to the source of infection. If more women are diagnosed only at autopsy, risk factors will be more difficult to determine. Systematic research has not yet been conducted on this issue. It is striking, however, that in only 5 percent of male AIDS cases is "none/other" listed for patient groups at the present time.

Another aspect of surveillance which may affect the female "none/other" category is that the questions listed on the CDC surveillance form are not designed to elicit special data on female risk groups. Data are collected on "homosexuality," for example, but the word "lesbian" is not used. Many health care providers are not aware

^{*}Data are drawn from the CDC AIDS Activity Report for December 30, 1985.

that their female patients may be lesbians. Consequently, this risk factor may be overlooked. In a similar vein, questions are not asked about donor insemination, although clinical reports demonstrate clearly the possibility of viral transmission via insemination.

The third risk category is heterosexual contact. In absolute numbers, 151 women are in this category. Even though many more men than women have AIDS, for only 28 males was heterosexual contact was the suspected route of infection. What are the reasons for this reversal in absolute numbers when it comes to AIDS transmission via heterosexual contacts? One factor is that, regardless of initial route of infection (e.g., gay activity, hemophilia, drug use, transfusion), there are more males currently carrying the virus than females. This means that in terms of heterosexual contact, more males are capable of transmitting the virus.

A second factor may be that AIDS is more readily transmissible from males to females than vice versa. Whereas semen is a proven route of virus transmission, the virus has not yet been cultured from vaginal secretions. Additionally, some heterosexual contact includes anal intercourse, an important risk factor for virus transmission. Research on types of heterosexual activity and virus transmission has yet to be completed. Within the heterosexual risk category, the partners of the women were predominantly IV drug users (72 percent) and secondarily bisexual men (19 percent).*

The fourth risk category for women is "transfusions with blood/blood products." This category accounts for 10 percent of all cases. New cases from earlier transfusions will continue to appear, but the risk of transfusion-related transmission is currently near zero.

A fifth risk category for women is "hemophiliac/coagulation disorder." There are four adult females in this category. Women do have coagulation disorders for which they receive the same types of blood products as are prescribed for hemophiliacs. As with transfusions, the current risk associated with Factor VII blood products is essentially zero.

Maternal Transmission

Seventy-five percent of all pediatric AIDS patients contracted the illness via a "parent with AIDS/or at increased risk for AIDS." As of December 30, 1985, there were 172 infants in this category, 87 male and 85 female.

Infection can occur in utero via transplacental transmission. It might also occur at birth, although this has not yet been demonstrated. The percentage risk to a child of becoming virus-infected when the

*Data from CDC, as of September 9, 1985.

mother is already carrying the virus cannot yet be stated; in some cases, women who have given birth to infected children have later delivered noninfected, healthy children. Transmission of the virus can also occur via breastmilk. A clinical report from Australia identified one infant who became antibody-positive after its mother received a tainted blood transfusion postnatally and then nursed her child over a period of months.

In California, women's risk factors are somewhat different from the national ones.* Transfusion-related AIDS is a more common cause of infection than drug use. Drug use and heterosexual contact are the second most important risk factors. Of the California women who contracted AIDS through heterosexual contact, two of them had partners who were both IV drug users and bisexual. One had a partner who was an IV drug user, one had a partner who was homosexual/bisexual, one partner was a hemophiliac, and about two we do not have adequate data. In California, as of September, 1985, two lesbians were identified with AIDS diagnoses. One contracted it through a transfusion, the other via IV drug use.

These data refer to AIDS cases only. We estimate that there are ten times as many ARC cases and one hundred times as many women who are infected. Nationally, this would be 10,000 women with ARC and 100,000 infected. In California, it would be an estimated 690 women with ARC and 6,900 estimated to be infected as of December 31, 1985.

In California, female AIDS cases are concentrated in several of the larger metropolitan areas: Los Angeles, San Francisco, and Alameda County, for example. Although surveillance figures are supposed to refer to the county of residence, they actually represent the county of diagnosis. In some cases, but not all, the county of residence is the same. This fact should be taken into account when services are being developed and when city and county budgets are being prepared.

There is no evidence that prostitutes constitute a special risk category. The Centers for Disease Control have documented this, as has preliminary research being done in San Francisco. Some prostitutes do get AIDS. To the extent that researchers have been able to isolate prostitution and/or multiple sexual contacts from such issues as IV drug use, however, neither the number of sexual contacts nor the receipt of money for sex (by sex therapists, prostitutes, call girls, etc.) seems avoid them. They may be better protected than the typical woman who is "just going to a bar" or a woman who thinks of herself as not sexually active but who "just happens to have this relationship." They may be more aware than women who are involved in serial monogamy or those whose self-image is "I'm not at risk so I'm not going to learn more about it." to put the woman at a higher risk for getting AIDS. Many women who are

*Data from California Department of Health Services AIDS Activity Office.

involved in paid sexual activity were concerned about sexually transmitted diseases even before the AIDS epidemic. They protected themselves and continue to protect themselves by being somewhat alert to new medical developments in sexually transmitted diseases and how to

Transmission and Its Prevention

Prevention of human T-cell lymphotropic virus type III (HTLV-III) transmission for women is essentially the same as it is for men, with some minor adjustments. The "safe sex guidelines," now in use with gay men, can, with a little creativity, be revised to apply to women. AIDS is caused by a virus transmitted in some, but not all, bodily secretions. It can be found in probably every bodily secretion, including blood, spinal fluid, semen, saliva, sweat, and tears. But that does not mean it can be transmitted via all these routes. The concentration varies significantly from fluid to fluid. The highest concentrations are in blood, spinal fluid, and semen. Even when traces of the virus are found in other fluids, e.g., saliva, they may be in a nontransmissible or poorly transmissible form. The concentration may also be too low for effective transmission. The virus can be transmitted through blood, as epidemiological data indicate, and through semen. Those are the two main bodily fluids to be wary of. Blood can appear in a variety of places. One could have blood in her saliva; in that case, then, her saliva might be an effective transmission route. Blood often passes through the colon as a matter of course, without any illness being present. It is often in feces and there may be fecal contact in sexual activity, either advertently or inadvertently. Blood is also present in menstrual fluid, which can be in smaller or larger amounts in vaginal and/or cervical secretions.

Although numerous studies are in progress concerning transmission of the virus during sexual activities of men and men, little research has been completed on sexual transmission and women (with either a heterosexual or lesbian focus). Current clinical research includes several attempts to culture the HTLV-III in vaginal secretions. Is the virus in vaginal secretions? By analogy, we assume that it is. Simply finding it there will not answer the question of vaginal transmission. For that we need an epidemiological study. One epidemiological study addressing this issue is the AWARE study at UCSF, under the direction of Constance Wofsy and Judith Cohen. Of 200 women for whom data have been analyzed, about 10 have positive antibody test results, indicating that they were infected with the virus. All these women, however, were IV drug users in addition to being at risk through sexual contact. A detailed questionnaire provides data on all the subjects (ultimately 500 women at risk). The study will give us extensive data concerning virus transmission.

A second epidemiological study on women and AIDS is being conducted by Nancy Padian. This study focuses on the female sexual partners of gay and bisexual men. The men's blood has been analyzed for

seroconversion since 1980. The female partners of a sample of the men are being tested for HTLV-III antibody positivity.

The third San Francisco epidemiological project on AIDS transmission and women is the Lesbian Insemination Project (LIP), affiliated with the AWARE study. LIP's purpose is to gather more information about semen as a transmitter of the virus when the factor of sexual intercourse is removed. The subjects in this study have a very low rate of sexual activity with men, but they have been exposed to semen through donor insemination. The project investigates antibody positivity in the women and, in some cases, their children.

Research results are important to educators and health care providers who wish to provide accurate information to their clients concerning transmission and prevention of AIDS. Our approach--in this field where so little is known--is to base our education on as much knowledge as we can and to make conservative recommendations, erring on the side of safety.

Sexual Transmission Issues

For most sexual activity--vaginal intercourse, anal intercourse, and fellatio--the most important AIDS transmission risk is semen entering the body. The best prevention method is condoms. Recent research indicates that condoms do act as an effective barrier to the virus, just as they act as a barrier to almost every other virus. Condoms can be used in any kind of intercourse and in fellatio by mutual agreement or, in fact, without it. Many prostitutes and other women in the sex industry use condoms without their clients knowing it. The woman holds the condom in her mouth until she performs fellatio, and with a learned skill and ease, puts it on the man and takes it off after the act is finished. He never knows.

Transmission may also occur when sex toys are shared. Any item (dildo or vibrator, for example) should not be used internally by both partners. If it is, it should be cleaned with bleach, alcohol, or hydrogen peroxide.

Previous exposure and current sexual activity are two separate factors. If two people are very "high risk" because of their previous practices, they still could be presently engaging in very safe sexual activities, including use of condoms. Conversely, they may be two people whose sexual activities have been very limited, or they may have been monogamous for years. They do not have a sexual risk factor, yet they are very worried. "Well, everyone's pointing the finger at us, saying we're going to get AIDS, because we engage in anal intercourse, and they say that's how the gay men get it." It's as if the person thinks that AIDS is a function of spontaneous combustion.

Another aspect of risk is dose. Researchers believe that repeated doses of the virus are sometimes necessary for infection. One might have a brush with the virus, some contact with it, and not necessarily become infected. But infection could also occur after only one exposure.

An effective lubricant, gel, or spermicide to use with a condom is non-oxynol-9, which kills HTLV-III in laboratory settings. This does not necessarily guarantee that it will kill the virus in other settings. Home use is different from clinical studies. We cannot say categorically to a client, "If you use non-oxynol-9, you will be safe." It will, however, lower the risk of transmission. Non-oxynol-9 lubricants can be applied both inside and outside a condom. Some condoms are also prelubricated with spermicide. Using a condom appropriately, without user error, breakage, and so forth, will prevent the virus from entering the body during ejaculation. So, in terms of intercourse, even fellatio, the condom is a very effective protective device.

Basically, "safe sex" boils down to one concept: "Do not let another person's semen, blood, feces, vaginal secretions, or, in the case of lactating mothers, mother's milk, into another person's body." That might mean using condoms. To another couple it might mean not ejaculating.

Vaginal secretions may also transmit the virus. We do not know whether they are an effective means of transmission. If a woman were infected, cunnilingus might transmit the virus to her partner.

To prevent a partner's exposure to her menstrual blood and/or cervical secretions, a woman can use a diaphragm, non-oxynol-9, and have her partner use a condom. Such activity reduces, but does not eliminate, the risk of transmission.

Another aspect of sexual transmission is saliva and kissing. Saliva poses a difficult question for the health educator and mental health care provider. It is quite easy to prove something does transmit a virus; all you need is one case in which it has. It is much more difficult to prove that it does not. In all likelihood, saliva does not transmit the AIDS virus, unless there is blood mixed in with it. Brushing your teeth or having cuts or sores in your mouth can produce blood. If the virus is in the blood, it is then "in" the saliva. But saliva itself (or with minute amounts of blood) has never been implicated in a case of HTLV-III transmission. The viral concentration is apparently too low. Some comparisons have been made between HTLV-III and the hepatitis B virus, which is, similarly, transmitted through primarily blood and semen. Hepatitis B virus is also found in saliva, but in thirty years of research not one case has been linked to salivary transmission. As health care providers, we must be alert to the client who says, "Oh well, saliva's probably risky, and so is semen, and I'm

not going to stop kissing, so I might as well not stop intercourse without a condom." Semen is known to transmit the virus.

Levels of Risk

Some communities and populations have a high rate of virus exposure. Others are much lower. In the case of a community like the gay male community of San Francisco (with a 50 percent infection rate) or the New York IV drug user community (with as many as 80 percent of the community exposed), the basic public health goals should be that everybody engage only in "safe sex." This is the only way that people can protect themselves and others. Community survival will require major behavioral changes.

On the other hand, in a community where the incidence of infection is below 50 percent, perhaps only 1 percent, the average person is less likely to want to use condoms. How can one mandate safe sex for everyone? If one follows the risk reduction guidelines in all cases, there would be no pregnancies. One aspect of sexual counseling for the lower risk population is education on decision making and risk evaluation. The client should be asked, "What level of risk are you willing to take?" Some people feel that they have very little risk of exposure and that their partner has little or no risk. They feel safe, or safe enough to do "everything." Some people review their pasts and that of their partner. Others take antibody tests and then decide about sex. Still others take the attitude that if there's any risk at all, they would rather avoid sex. Some risks are more acceptable than others to an individual. One person will drive drunk, but always use a condom. Another is the reverse. Partners negotiate to what degree each wishes to take some sort of risk.

Pregnancy Issues

Although there is a chance of the fetus being exposed to the virus through transplacental transmission in utero, not every baby will be born infected. In one study, a mother with several children passed the virus on to one but not to a later child, even though she herself continued to be infected. At present, we cannot predict whether a specific infant will be born infected. Additionally, some children who test positive on the AIDS antibody tests remain in good health.

If a woman is infected at the start of a pregnancy, what are her chances of developing the symptoms of ARC or AIDS during the course of pregnancy? There is some evidence to suggest that pregnancy can accelerate the course of illnesses associated with AIDS and ARC and perhaps also the underlying syndrome itself. Counseling women who are already pregnant, and at the point when abortion is feasible, is a complex and difficult task.

And lastly, donor insemination. No women who received semen via donor insemination have yet contracted AIDS. One study in Australia demonstrated that the virus is transmissible via insemination. Freezing the sperm may make transmission less likely. Screening programs similar to those in use in blood banks are the major techniques for preventing transmission via insemination. Typically, a sexual and social history of the donor, blood tests, and other screens are used. HTLV-III antibody tests are in routine use at licensed sperm banks.

Antibody Testing Issues

Testing for the antibody to the HTLV-III is a screening strategy that is being increasingly applied as a protection even beyond the blood banking community. Sperm banks use it. Some doctors recommend it for their patients considering pregnancy. Some people want it to feel secure about their sexual activity. While the test is relatively accurate, it is not 100 percent perfect. Since we are dealing with a potentially deadly illness, the imperfections of the test are very important to understand.

There are both false-positive and false-negative results. In a population with a high rate of virus infectivity (e.g., gay men or IV drug users) there will be more false negatives. In a population with a low rate of infectivity (e.g., the general population), there will be a higher rate of false positives.

The consequence of a false negative is that a woman may wrongly think that she is not carrying the virus and spread it inadvertently or misunderstand her real symptoms of AIDS or ARC. In most testing systems, negative test results are not a signal to retest and the result is treated as "true." Any woman in a high risk group who gets an initial negative result should consider a retest for certainty.

The consequence of a false positive, on the other hand, can be unnecessary stress, anxiety, and fear. Because almost all testing programs include retests of positive specimens, any woman with an initial positive test is likely to have her blood retested automatically. Retesting significantly reduces the risk of a false result.

Women's Unique Issues

First of all, there is the problem of maternal transmission, already described. Women at risk are going to be counseled about pregnancy, abortion nursing, planning pregnancy, contraception, and antibody tests. They are going to be encouraged to share information about their antibody status with obstetricians, labor room staffs, and pediatricians. Some may even be told to delay pregnancy indefinitely "until more is known." How will women react to such advice?

In some cities, women in "high-risk" groups are being encouraged to have antibody testing prior to pregnancy. It is entirely possible that women, or subgroups of them, and not gay men, will be the first population to face mass screening for AIDS virus antibody.

A second aspect of AIDS that is unique to women is the female social role of mothering: From this role flow two important consequences. First, when a woman becomes ill with ARC or AIDS, her role as a primary caretaker to the child or children or to other adults or persons in the household is immediately affected. The family is severely disrupted, and she herself will have to make many adjustments. Her children may also be indirectly affected by her diagnosis and forbidden to go to school. She has to deal with a life-threatening illness, and she also has to deal with the impact on her family, and this is a very serious matter. Fifty-three percent of women with AIDS contracted it through IV drug use. A significant number got it through heterosexual contact, most often with a drug user. Demographic studies of such women indicate that they are likely to have young children and also to be the sole support of these children.

A second consequence of the social role of motherhood is care of the child with AIDS. With AIDS, as with other sicknesses, it is ordinarily the mother who is expected to care for or manage the care of the child. But since 75 percent of all pediatric AIDS cases are currently the result of maternal transmission, the mother may herself be ill. Her illness and responsibility may be compounded by illegal survival activity, incarceration, poor health (caused by drug use and its life style associated illnesses), and the threat of foster care or child abuse proceedings. These are parenting issues that men rarely face.

If the mother is healthy enough to care for her child, she must still handle the complex issues of medical and home care, research investigations, school access, friends, and family stress. CDC recommends that every child be evaluated individually to provide quality care for a child who is either infected with the virus or is ill.

Resources for Women

Because the total number of women infected with HTLV-III is much smaller than the number of men, the resources available for women in a general sort of way and those that deal with particular problems of women are much more limited. Let us look briefly at the area of drug rehabilitation services--necessary to combat AIDS transmission via shared needles. Both in absolute numbers, and in proportion to need, there are fewer drug programs for women than there are for men. There are fewer residential programs with spaces available for women than there are for men. In addition, most of the programs will not take women who are pregnant, and even if they will take women who are

pregnant, they will not take them when they are more than 21 weeks pregnant. None will house a woman with a child.

The only residential substance abuse program in San Francisco that will take women who are pregnant and/or have children is the Women's Alcoholism Center, and this center requires that the woman's primary problem be alcohol, not drugs. As a consequence, a woman with a drug problem who is at risk for AIDS and has a drug problem, and has children, is forced to leave her children in order to be treated in a residential program. She probably will not be able to have visitors, including her children, for at least two months. Such rules are the standard in many residential programs. These programs are designed to meet male needs, not those of women.

Women also need AIDS services attentive to their needs. Many AIDS-focused organizations have no women's support group or people who are particularly sensitive to women's issues. Organization members, clinic staff, and health department employees may be sensitive to the issues of AIDS in a general way, but many are not trained to understand those problems which are specific to women.

Another aspect of resources and services for women is the need for ethnic diversity in staff and programs. Over 70 percent of all female AIDS cases are black or Latino women. Effective educational programs require culturally sensitive and linguistically appropriate materials, combined with active outreach. This is not happening so far in any place in the United States. Work with local ethnic health and civic organizations can be an important step in raising community awareness of AIDS and of the techniques to prevent its spread and assist those affected. Women with AIDS are from poor backgrounds. As a whole, they are probably poorer than men with AIDS. This means that more resources are going to be needed for women than for men.

At the International Conference on AIDS in Atlanta, 1985, many researchers discussing sexuality would refer to sexually active men and promiscuous women. Prostitutes were described as "a reservoir of infections." Just as gay men are stigmatized for their sexual activity, so women who cannot prove that they contracted the virus from their husbands or from blood transfusions are also going to be stigmatized and criticized and blamed for their (imagined) sex life and morals.

Women as Health Care Providers

Numerically, women constitute the bulk of the caretaking population for those who have AIDS. Persons with AIDS are primarily men. This situation mirrors women's family role of caretaker of others' physical and emotional needs and their daily maintenance. The medical care system itself is dominated by men. Many of us are in situations of providing extensive service but receiving inadequate recognition. As

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We experience this criticism externally and internally. On the one hand, women have frustrations about status in the hierarchical structures of medicine; and on the other hand, they feel that they should not complain. Therefore, meeting the challenges of the AIDS epidemic may include addressing the role of women health care professionals as well as the needs of women at risk of illness.



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MEMO FROM

NANCY STOLLER SHAW, PH.D.
Education Department

Dear Jean-

Our postnotes are
enclosed. If you have
questions, please call Lyn
Paleo or me.

Thanks,
Nancy Shaw

cc to me

Orig. to

Nancy

NS' copy

6/2/9



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Women and AIDS

by Nancy Shaw, PhD, and Lyn Paleo

In 1983, the first brochure on women and AIDS was produced. then a great deal has happened. With the growing awareness that women can contract AIDS has come the realization that specialized services should be provided to them and that health care providers will increasingly come into contact with women who have some kinds of AIDS concern. Some patients may have been exposed to AIDS, others have close friends or family members who are ill. Additionally, many of the health care personnel providing AIDS services are women.

Women At Risk: Epidemiology

20% | AIDS in women presents a different epidemiological pattern from the one found among men. National data show that the most prevalent risk category is IV drug use (53 percent).^{* (1)} The next category, or group of women with AIDS, is one for which no root of transmission has been identified, referred to as "none/other" by the Centers for Disease Control (CDC) (27 percent).⁽¹⁾ Included in this risk category are women from countries where a higher proportion of the population has AIDS or AIDS-related complex (ARC) or may be virus seropositive. This includes women diagnosed in the U.S. who immigrated here from Haiti and Zaire. For many of the women (including the nonimmigrants) in the "none/other" category, the probable risk factor was heterosexual contact with a man who was infected with the virus, but is not in an identified risk group. His infection may have been through a person that he did not know to be in a risk category (e.g., his wife, who had a blood transfusion prior to his meeting her).

Another grouping of women in the "none/other" category is composed of those who were diagnosed late in their illness or only at autopsy. Because men and their health care providers are more aware of the possibility that males get AIDS, male diagnoses may take place at earlier stages. This allows more time for adequate investigation as to the source of infection. If more women are diagnosed only at autopsy, risk factors will be more difficult to determine. Systematic research has not yet been conducted on this issue. It is striking, however, that in only 5 percent of male AIDS cases is "none/other" listed for patient groups at the present time.

Another aspect of surveillance which may affect the female "none/other" category is that the questions listed on the CDC surveillance form are not designed to elicit special data on female risk groups. Data are collected on "homosexuality," for example, but the word "lesbian" is not used. Many health care providers are not aware

~~*Data are drawn from the CDC AIDS Activity Report for December 30, 1985.~~

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that their female patients may be lesbians. Consequently, this risk factor may be overlooked. In a similar vein, questions are not asked about donor insemination, although clinical reports demonstrate clearly the possibility of viral transmission via insemination.

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The third risk category is heterosexual contact. In absolute numbers, 151 women are in this category. Even though many more men than women have AIDS, for only 28 males was heterosexual contact was the suspected route of infection. What are the reasons for this reversal in absolute numbers when it comes to AIDS transmission via heterosexual contacts? One factor is that, regardless of initial route of infection (e.g., gay activity, hemophilia, drug use, transfusion), there are more males currently carrying the virus than females. This means that in terms of heterosexual contact, more males are capable of transmitting the virus.

A second factor may be that AIDS is more readily transmissible from males to females than vice versa. Whereas semen is a proven route of virus transmission, the virus has not yet been cultured from vaginal secretions. Additionally, some heterosexual contact includes anal intercourse, an important risk factor for virus transmission. Research on types of heterosexual activity and virus transmission has yet to be completed. Within the heterosexual risk category, the partners of the women were predominantly IV drug users (72 percent) and secondarily bisexual men (19 percent).*

The fourth risk category for women is "transfusions with blood/blood products." This category accounts for 10 percent of all female cases. New cases from earlier transfusions will continue to appear, but the risk of transfusion-related transmission is currently near zero. 1(2)

A fifth risk category for women is "hemophiliac/coagulation disorder." There are four adult females in this category. Women do have coagulation disorders for which they receive the same types of blood products as are prescribed for hemophiliacs. As with transfusions, the current risk associated with Factor VII blood products is essentially zero.

Maternal Transmission

Seventy-five percent of all pediatric AIDS patients contracted the illness via a "parent with AIDS/or at increased risk for AIDS." As of December 30, 1985, there were 172 infants in this category, 87 male and 85 female. 224 114 110 1(1)

Infection can occur in utero via transplacental transmission. It might also occur at birth, although this has not yet been demonstrated. The percentage risk to a child of becoming virus-infected when the

*Data from CDC, as of September 9, 1985.

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mother is already carrying the virus cannot yet be stated; in some cases, women who have given birth to infected children have later delivered noninfected, healthy children. Transmission of the virus can also occur via breastmilk. A clinical report from Australia identified one infant who became antibody-positive after its mother received a tainted blood transfusion postnatally and then nursed her child over a period of months.

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In California, women's risk factors are somewhat different from the national ones.* Transfusion-related AIDS is a more common cause of infection than drug use. Drug use and heterosexual contact are the second most important risk factors. 4 Of the California women who contracted AIDS through heterosexual contact, two of them had partners who were both IV drug users and bisexual. One had a partner who was an IV drug user, one had a partner who was homosexual/bisexual, one partner was a hemophiliac, and about two we do not have adequate data. In California, as of September, 1985, two lesbians were identified with AIDS diagnoses. One contracted it through a transfusion, the other via IV drug use. 5

These data refer to AIDS cases only. *country use model* We estimate that there are ten times as many ARC cases and one hundred times as many women who are infected. Nationally, this would be 10,000 women with ARC and 100,000 infected. In California, it would be an estimated 690 women with ARC 840 and 6,900 estimated to be infected as of December 31, 1985. *APR 130, 1986* (4)
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In California, female AIDS cases are concentrated in several of the larger metropolitan areas: Los Angeles, San Francisco, and Alameda County, for example. Although surveillance figures are supposed to refer to the county of residence, they actually represent the county of diagnosis. In some cases, but not all, the county of residence is the same. This fact should be taken into account when services are being developed and when city and county budgets are being prepared.

There is no evidence that prostitutes constitute a special risk category. The Centers for Disease Control have documented this, as has preliminary research being done in San Francisco. *6, 78* Some prostitutes do get AIDS. To the extent that researchers have been able to isolate prostitution and/or multiple sexual contacts from such issues as IV drug use, however, neither the number of sexual contacts nor the receipt of money for sex (by sex therapists, prostitutes, call girls, etc.) seems to avoid them. They may be better protected than the typical woman who is "just going to a bar" or a woman who thinks of herself as not sexually active but who "just happens to have this relationship." They may be more aware than women who are involved in serial monogamy or those whose self-image is "I'm not at risk so I'm not going to learn more about it." to put the woman at a higher risk for getting AIDS. Many women who are

*Data from California Department of Health Services AIDS Activity Office.

data previous

involved in paid sexual activity were concerned about sexually transmitted diseases even before the AIDS epidemic. They protected themselves and continue to protect themselves by being somewhat alert to new medical developments in sexually transmitted diseases and how to

Transmission and Its Prevention

Prevention of human T-cell lymphotropic virus type III (HTLV-III) transmission for women is essentially the same as it is for men, with some minor adjustments. The "safe sex guidelines," now in use with gay men, can, with a little creativity, be revised to apply to women. AIDS is caused by a virus transmitted in some, but not all, bodily secretions. It can be found in probably every bodily secretion, including blood, spinal fluid, semen, saliva, sweat, and tears. But that does not mean it can be transmitted via all these routes. The concentration varies significantly from fluid to fluid. The highest concentrations are in blood, spinal fluid, and semen. Even when traces of the virus are found in other fluids, e.g., saliva, they may be in a nontransmissible or poorly transmissible form. The concentration may also be too low for effective transmission. The virus can be transmitted through blood, as epidemiological data indicate, and through semen. Those are the two main bodily fluids to be wary of. Blood can appear in a variety of places. One could have blood in her saliva; in that case, then, her saliva might be an effective transmission route. Blood often passes through the colon as a matter of course, without any illness being present. It is often in feces and there may be fecal contact in sexual activity, either advertently or inadvertently. Blood is also present in menstrual fluid, which can be in smaller or larger amounts in vaginal and/or cervical secretions.

Although numerous studies are in progress concerning transmission of the virus during sexual activities of men and men, little research has been completed on sexual transmission and women (with either a heterosexual or lesbian focus). Current clinical research includes several attempts to culture the HTLV-III in vaginal secretions. Is the virus in vaginal secretions? By analogy, we assume that it is. Simply finding it there will not answer the question of vaginal transmission. For that we need an epidemiological study. One epidemiological study addressing this issue is the AWARE study at UCSF, under the direction of Constance Wofsy and Judith Cohen.⁶ Of 200 women for whom data have been analyzed, about 10 have positive antibody test results, indicating that they were infected with the virus. All these women, however, were IV drug users in addition to being at risk through sexual contact. A detailed questionnaire provides data on all the subjects (ultimately 500 women at risk). The study will give us extensive data concerning virus transmission.

A second epidemiological study on women and AIDS is being conducted by Nancy Padian.⁹ This study focuses on the female sexual partners of gay and bisexual men. The men's blood has been analyzed for

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seroconversion since 1980. The female partners of a sample of the men are being tested for HTLV-III antibody positivity.

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The third San Francisco epidemiological project on AIDS transmission and women is the Lesbian Insemination Project (LIP),⁽¹⁰⁾ affiliated with the AWARE study. LIP's purpose is to gather more information about semen as a transmitter of the virus when the factor of sexual intercourse is removed. The subjects in this study have a very low rate of sexual activity with men, but they have been exposed to semen through donor insemination. The project investigates antibody positivity in the women and, in some cases, their children.

Research results are important to educators and health care providers who wish to provide accurate information to their clients concerning transmission and prevention of AIDS. Our approach--in this field where so little is known--is to base our education on as much knowledge as we can and to make conservative recommendations, erring on the side of safety.

Sexual Transmission Issues

For most sexual activity--vaginal intercourse, anal intercourse, and fellatio--the most important AIDS transmission risk is semen entering the body. The best prevention method is condoms. Recent research indicates that condoms do act as an effective barrier to the virus, just as they act as a barrier to almost every other virus. Condoms can be used in any kind of intercourse and in fellatio by mutual agreement or, in fact, without it. Many prostitutes and other women in the sex industry use condoms without their clients knowing it. The woman holds the condom in her mouth until she performs fellatio, and with a learned skill and ease, puts it on the man and takes it off after the act is finished. He never knows.

Transmission may also occur when sex toys are shared. Any item (dildo or vibrator, for example) should not be used internally by both partners. If it is, it should be cleaned with bleach, alcohol, or hydrogen peroxide.

Previous exposure and current sexual activity are two separate factors. If two people are very "high risk" because of their previous practices, they still could be presently engaging in very safe sexual activities, including use of condoms. Conversely, they may be two people whose sexual activities have been very limited, or they may have been monogamous for years. They do not have a sexual risk factor, yet they are very worried. "Well, everyone's pointing the finger at us, saying we're going to get AIDS, because we engage in anal intercourse, and they say that's how the gay men get it." It's as if the person thinks that AIDS is a function of spontaneous combustion.

Another aspect of risk is dose. Researchers believe that repeated doses of the virus are sometimes necessary for infection. One might have a brush with the virus, some contact with it, and not necessarily become infected. But infection could also occur after only one exposure.

An effective lubricant, gel, or spermicide to use with a condom is non-oxynol-9, which kills HTLV-III in laboratory settings. (1) This does not necessarily guarantee that it will kill the virus in other settings. Home use is different from clinical studies. We cannot say categorically to a client, "If you use non-oxynol-9, you will be safe." It will, however, lower the risk of transmission. Non-oxynol-9 lubricants can be applied both inside and outside a condom. Some condoms are also prelubricated with spermicide. Using a condom appropriately, without user error, breakage, and so forth, will prevent the virus from entering the body during ejaculation. So, in terms of intercourse, even fellatio, the condom is a very effective protective device.

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Basically, "safe sex" boils down to one concept: "Do not let another person's semen, blood, feces, vaginal secretions, or, in the case of lactating mothers, mother's milk, into another person's body." That might mean using condoms. To another couple it might mean not ejaculating.

Vaginal secretions may also transmit the virus. We do not know whether they are an effective means of transmission. If a woman were infected, cunnilingus might transmit the virus to her partner.

To prevent a partner's exposure to her menstrual blood and/or cervical secretions, a woman can use a diaphragm, non-oxynol-9, and have her partner use a condom. Such activity reduces, but does not eliminate, the risk of transmission.

Another aspect of sexual transmission is saliva and kissing. Saliva poses a difficult question for the health educator and mental health care provider. It is quite easy to prove something does transmit a virus; all you need is one case in which it has. It is much more difficult to prove that it does not. In all likelihood, saliva does not transmit the AIDS virus, unless there is blood mixed in with it. Brushing your teeth or having cuts or sores in your mouth can produce blood. If the virus is in the blood, it is then "in" the saliva. But saliva itself (or with minute amounts of blood) has never been implicated in a case of HTLV-III transmission. The viral concentration is apparently too low. Some comparisons have been made between HTLV-III and the hepatitis B virus, which is, similarly, transmitted through primarily blood and semen. Hepatitis B virus is also found in saliva, but in thirty years of research not one case has been linked to salivary transmission. As health care providers, we must be alert to the client who says, "Oh well, saliva's probably risky, and so is semen, and I'm

not going to stop kissing, so I might as well not stop intercourse without a condom." Semen is known to transmit the virus.

Levels of Risk

Some communities and populations have a high rate of virus exposure. Others are much lower. In the case of a community like the gay male community of San Francisco (with a 50 percent infection rate) or the New York IV drug user community (with as many as 80 percent of the community exposed), the basic public health goals should be that everybody engage only in "safe sex." This is the only way that people can protect themselves and others. Community survival will require major behavioral changes.

On the other hand, in a community where the incidence of infection is below 50 percent, perhaps only 1 percent, the average person is less likely to want to use condoms. How can one mandate safe sex for everyone? If one follows the risk reduction guidelines in all cases, there would be no pregnancies. One aspect of sexual counseling for the lower risk population is education on decision making and risk evaluation. The client should be asked, "What level of risk are you willing to take?" Some people feel that they have very little risk of exposure and that their partner has little or no risk. They feel safe, or safe enough to do "everything." Some people review their pasts and ~~that~~ ^{those} of their partner. Others take antibody tests and then decide about sex. Still others take the attitude that if there's any risk at all, they would rather avoid sex. Some risks are more acceptable than others to an individual. One person will drive drunk, but always use a condom. Another is the reverse. Partners negotiate to what degree each wishes to take some sort of risk.

Pregnancy Issues

Although there is a chance of the fetus being exposed to the virus through transplacental transmission in utero, not every baby will be born infected.¹³ In one study, a mother with several children passed the virus on to one but not to a later child, even though she herself continued to be infected. At present, we cannot predict whether a specific infant will be born infected. Additionally, some children who test positive on the AIDS antibody tests remain in good health.

If a woman is infected at the start of a pregnancy, what are her chances of developing the symptoms of ARC or AIDS during the course of pregnancy? There is some evidence to suggest that pregnancy can accelerate the course of illnesses associated with AIDS and ARC and perhaps also the underlying syndrome itself. Counseling women who are already pregnant, and at the point when abortion is feasible, is a complex and difficult task.¹⁴

And lastly, donor insemination. No women who received semen via donor insemination have yet contracted AIDS. One study in Australia demonstrated that the virus is transmissible via insemination. Freezing the sperm may make transmission less likely. Screening programs similar to those in use in blood banks are the major techniques for preventing transmission via insemination. Typically, a sexual and social history of the donor, blood tests, and other screens are used. HTLV-III antibody tests are in routine use at licensed sperm banks.

Antibody Testing Issues

Testing for the antibody to the HTLV-III is a screening strategy that is being increasingly applied as a protection even beyond the blood banking community. Sperm banks use it. Some doctors recommend it for their patients considering pregnancy. Some people want it to feel secure about their sexual activity. While the test is relatively accurate, it is not 100 percent perfect. Since we are dealing with a potentially deadly illness, the imperfections of the test are very important to understand.

There are both false-positive and false-negative results. In a population with a high rate of virus infectivity (e.g., gay men or IV drug users) there will be more false negatives. In a population with a low rate of infectivity (e.g., the general population), there will be a higher rate of false positives.

The consequence of a false negative is that a woman may wrongly think that she is not carrying the virus and spread it inadvertently or misunderstand her real symptoms of AIDS or ARC. In most testing systems, negative test results are not a signal to retest and the result is treated as "true." Any woman in a high risk group who gets an initial negative result should consider a retest for certainty.

The consequence of a false positive, on the other hand, can be unnecessary stress, anxiety, and fear. Because almost all testing programs include retests of positive specimens, any woman with an initial positive test is likely to have her blood retested automatically. Retesting significantly reduces the risk of a false result.

Women's Unique Issues

First of all, there is the problem of maternal transmission, already described. Women at risk are going to be counseled about pregnancy, abortion nursing, planning pregnancy, contraception, and antibody tests. They are going to be encouraged to share information about their antibody status with obstetricians, labor room staffs, and pediatricians. Some may even be told to delay pregnancy indefinitely "until more is known." How will women react to such advice?

In some cities, women in "high-risk" groups are being encouraged to have antibody testing prior to pregnancy. It is entirely possible that women, or subgroups of them, and not gay men, will be the first population to face mass screening for AIDS virus antibody.

A second aspect of AIDS that is unique to women is the female social role of mothering: From this role flow two important consequences. First, when a woman becomes ill with ARC or AIDS, her role as a primary caretaker to the child or children or to other adults or persons in the household is immediately affected. The family is severely disrupted, and she herself will have to make many adjustments. Her children may also be indirectly affected by her diagnosis and forbidden to go to school. She has to deal with a life-threatening illness, and she also has to deal with the impact on her family, and this is a very serious matter. Fifty-three percent of women with AIDS contracted it through IV drug use. A significant number got it through heterosexual contact, most often with a drug user. Demographic studies of such women indicate that they are likely to have young children and also to be the sole support of these children.

A second consequence of the social role of motherhood is care of the child with AIDS. With AIDS, as with other sicknesses, it is ordinarily the mother who is expected to care for or manage the care of the child. But since 75 percent of all pediatric AIDS cases are currently the result of maternal transmission, the mother may herself be ill. Her illness and responsibility may be compounded by illegal survival activity, incarceration, poor health (caused by drug use and its life style associated illnesses), and the threat of foster care or child abuse proceedings. These are parenting issues that men rarely face.

If the mother is healthy enough to care for her child, she must still handle the complex issues of medical and home care, research investigations, school access, friends, and family stress. CDC recommends that every child be evaluated individually to provide quality care for a child who is either infected with the virus or is ill. 10

Resources for Women

Because the total number of women infected with HTLV-III is much smaller than the number of men, the resources available for women in a general sort of way and those that deal with particular problems of women are much more limited. Let us look briefly at the area of drug rehabilitation services--necessary to combat AIDS transmission via shared needles. Both in absolute numbers, and in proportion to need, there are fewer drug programs for women than there are for men. 17 There are fewer residential programs with spaces available for women than there are for men. In addition, most of the programs will not take women who are pregnant, and even if they will take women who are

pregnant, they will not take them when they are more than 21 weeks pregnant. None will house a woman with a child.

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In 1983, the first brochure on women and AIDS was produced. Since then a great deal has happened. With the growing awareness that women can contract AIDS has come the realization that specialized services should be provided to them and that health care providers will increasingly come into contact with women who have some kinds of AIDS concern. Some patients may have been exposed to AIDS, others have close friends or family members who are ill. Additionally, many of the health care personnel providing AIDS services are women.

Women At Risk: Epidemiology

AIDS in women presents a different epidemiological pattern from the one found among men. National data show that the most prevalent risk category is IV drug use (53 percent).⁶* The next category, or group of women with AIDS, is one for which no route of transmission has been identified, referred to as "none/other" by the Centers for Disease Control (CDC) (22 percent). Included in this risk category are women from countries where a higher proportion of the population has AIDS or AIDS-related complex (ARC) or may be virus seropositive. This includes women diagnosed in the U.S. who immigrated here from Haiti and Zaire. For many of the women (including the nonimmigrants) in the "none/other" category, the probable risk factor was heterosexual contact with a man who was infected with the virus, but is not in an identified risk group. His infection may have been through a person that he did not know to be in a risk category (e.g., his wife, who had a blood transfusion prior to

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his meeting her).

Another grouping of women in the "none/other" category is composed of those who were diagnosed late in their illness or only at autopsy. Because men and their health care providers are more aware of the possibility that males get AIDS, male diagnoses may take place at earlier stages. This allows more time for adequate investigation as to the source of infection. If more women are diagnosed only at autopsy, risk factors will be more difficult to determine. Systematic research has not yet been conducted on this issue. It is striking, however, that in only 5 percent of male AIDS cases is "none/other" listed for patient groups at the present time.

Another aspect of surveillance which may affect the female "none/other" category is that the questions listed on the CDC surveillance form are not designed to elicit special data on female risk groups. Data are collected on "homosexuality," for example, but the word "lesbian" is not used. Many health care providers are not aware that their female patients may be lesbians. Consequently, this risk factor may be overlooked. In a similar vein, questions are not asked about donor insemination, although clinical reports demonstrate clearly the possibility of viral transmission via insemination.

The third risk category is heterosexual contact. In absolute numbers, 151 women are in this category. Even though many more men than women have AIDS, for only 28 males was heterosexual contact was the suspected route of infection. What are the reasons for this reversal in

*Data are drawn from the CDC AIDS Activity Report for December 30, 1985.

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absolute numbers when it comes to AIDS transmission via heterosexual contacts? One factor is that, regardless of initial route of infection (e.g., gay activity, hemophilia, drug use, transfusion), there are more males currently carrying the virus than females. This means that in terms of heterosexual contact, more males are capable of transmitting the virus.

A second factor may be that AIDS is more readily transmissible from males to females than vice versa. Whereas semen is a proven route of virus transmission, the virus has not yet been cultured from vaginal secretions. Additionally, some heterosexual contact includes anal intercourse, an important risk factor for virus transmission. Research on types of heterosexual activity and virus transmission has yet to be completed. Within the heterosexual risk category, the partners of the women were predominantly IV drug users (72 percent) and secondarily bisexual men (19 percent).*

The fourth risk category for women is "transfusions with blood/blood products." This category accounts for 10 percent of all cases. New cases from earlier transfusions will continue to appear, but the risk of transfusion-related transmission is currently near zero.

A fifth risk category for women is "hemophiliac/coagulation disorder." There are four adult females in this category. Women do have coagulation disorders for which they receive the same types of blood products as are prescribed for hemophiliacs. As with

*Data from CDC, as of September 9, 1985.

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transfusions, the current risk associated with Factor VII blood products is essentially zero.

Maternal Transmission

Seventy-five percent of all pediatric AIDS patients contracted the illness via a "parent with AIDS/or at increased risk for AIDS." As of December 30, 1985, there were 172 infants in this category, 87 male and 85 female.

Infection can occur in utero via transplacental transmission. It might also occur at birth, although this has not yet been demonstrated. The percentage risk to a child of becoming virus-infected when the mother is already carrying the virus cannot yet be stated; in some cases, women who have given birth to infected children have later delivered noninfected, healthy children. Transmission of the virus can also occur via breastmilk. A clinical report from Australia identified one infant who became antibody-positive after its mother received a tainted blood transfusion postnatally and then nursed her child over a period of months.

In California, women's risk factors are somewhat different from the national ones.* Transfusion-related AIDS is a more common cause of infection than drug use. Drug use and heterosexual contact are the second most important risk factors. Of the California women who contracted AIDS through heterosexual contact, two of them had partners who were both IV drug users and bisexual. One had a partner who was an IV drug user, one had a partner who was homosexual/bisexual, one partner was a hemophiliac, and about two we do not have adequate data. In

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California, as of September, 1985, two lesbians were identified with AIDS diagnoses. One contracted it through a transfusion, the other via IV drug use.

These data refer to AIDS cases only. We estimate that there are ten times as many ARC cases and one hundred times as many women who are infected. Nationally, this would be 10,000 women with ARC and 100,000 infected. In California, it would be an estimated 690 women with ARC and 6,900 estimated to be infected as of December 31, 1985.

In California, female AIDS cases are concentrated in several of the larger metropolitan areas: Los Angeles, San Francisco, and Alameda County, for example. Although surveillance figures are supposed to refer to the county of residence, they actually represent the county of diagnosis. In some cases, but not all, the county of residence is the same. This fact should be taken into account when services are being developed and when city and county budgets are being prepared.

There is no evidence that prostitutes constitute a special risk category. The Centers for Disease Control have documented this, as has preliminary research being done in San Francisco. Some prostitutes do get AIDS. To the extent that researchers have been able to isolate prostitution and/or multiple sexual contacts from such issues as IV drug use, however, neither the number of sexual contacts nor the receipt of money for sex (by sex therapists, prostitutes, call girls, etc.) seems

*Data from California Department of Health Services AIDS Activity Office. avoid them. They may be better protected than the typical woman who is "just going to a bar" or a woman who thinks of herself as not sexually active but who "just happens to have this relationship." They may be more aware than women who are involved in serial monogamy or those whose self-image is "I'm not at risk so I'm not going to learn more about it."

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to put the woman at a higher risk for getting AIDS. Many women who are involved in paid sexual activity were concerned about sexually transmitted diseases even before the AIDS epidemic. They protected themselves and continue to protect themselves by being somewhat alert to new medical developments in sexually transmitted diseases and how to

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Transmission and Its Prevention

Prevention of human T-cell lymphotropic virus type III (HTLV-III) transmission for women is essentially the same as it is for men, with some minor adjustments. The "safe sex guidelines," now in use with gay men, can, with a little creativity, be revised to apply to women. AIDS is caused by a virus transmitted in some, but not all, bodily secretions. It can be found in probably every bodily secretion, including blood, spinal fluid, semen, saliva, sweat, and tears. But that does not mean it can be transmitted via all these routes. The concentration varies significantly from fluid to fluid. The highest concentrations are in blood, spinal fluid, and semen. Even when traces of the virus are found in other fluids, e.g., saliva, they may be in a nontransmissible or poorly transmissible form. The concentration may also be too low for effective transmission. The virus can be transmitted through blood, as epidemiological data indicate, and through semen. Those are the two main bodily fluids to be wary of. Blood can appear in a variety of places. One could have blood in her saliva; in that case, then, her saliva might be an effective transmission route. Blood often passes through the colon as a matter of course, without any illness being present. It is often in feces and there may be fecal

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contact in sexual activity, either advertently or inadvertently. Blood is also present in menstrual fluid, which can be in smaller or larger amounts in vaginal and/or cervical secretions.

Although numerous studies are in progress concerning transmission of the virus during sexual activities of men and men, little research has been completed on sexual transmission and women (with either a heterosexual or lesbian focus). Current clinical research includes several attempts to culture the HTLV-III^{virus} in vaginal secretions. Is the virus in vaginal secretions? By analogy, we assume that it is. Simply finding it there will not answer the question of vaginal transmission. For that we need an epidemiological study. One epidemiological study addressing this issue is the AWARE study at UCSF, under the direction of Constance Wofsy and Judith Cohen. Of 200 women for whom data have been analyzed, about 10 have positive antibody test results, indicating that they were infected with the virus. All these women, however, were IV drug users in addition to being at risk through sexual contact. A detailed questionnaire provides data on all the subjects (ultimately 500 women at risk). The study will give us extensive data concerning virus transmission.

A second epidemiological study on women and AIDS is being conducted by Nancy Padian. This study focuses on the female sexual partners of gay and bisexual men. The men's blood has been analyzed for seroconversion since 1980. The female partners of a sample of the men are being tested for HTLV-III antibody positivity.

The third San Francisco epidemiological project on AIDS

transmission and women is the Lesbian Insemination Project (LIP), affiliated with the AWARE study. LIP's purpose is to gather more information about semen as a transmitter of the virus when the factor of sexual intercourse is removed. The subjects in this study have a very low rate of sexual activity with men, but they have been exposed to semen through donor insemination. The project investigates antibody positivity in the women and, in some cases, their children.

Research results are important to educators and health care providers who wish to provide accurate information to their clients concerning transmission and prevention of AIDS. Our approach--in this field where so little is known--is to base our education on as much knowledge as we can and to make conservative recommendations, erring on the side of safety.

Sexual Transmission Issues

For most sexual activity--vaginal intercourse, anal intercourse, and fellatio--the most important AIDS transmission risk is semen entering the body. The best prevention method is condoms. Recent research indicates that condoms do act as an effective barrier to the virus, just as they act as a barrier to almost every other virus. Condoms can be used in any kind of intercourse and in fellatio by mutual agreement or, in fact, without it. Many prostitutes and other women in the sex industry use condoms without their clients knowing it. The woman holds the condom in her mouth until she performs fellatio, and with a learned skill and ease, puts it on the man and takes it off after the act is finished. He never knows.

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Transmission may also occur when sex toys are shared. Any item (dildo or vibrator, for example) should not be used internally by both partners. If it is, it should be cleaned with bleach, alcohol, or hydrogen peroxide *and then ~~cleaned~~ rinsed with water.*

Previous exposure and current sexual activity are two separate factors. If two people are very "high risk" because of their previous practices, they still could be presently engaging in very safe sexual activities, including use of condoms. Conversely, they may be two people whose sexual activities have been very limited, or they may have been monogamous for years. They do not have a sexual risk factor, yet they are very worried. "Well, everyone's pointing the finger at us, saying we're going to get AIDS, because we engage in anal intercourse, and they say that's how the gay men get it." It's as if the person thinks that AIDS is a function of spontaneous combustion.

Another aspect of risk is dose. Researchers believe that repeated doses of the virus are sometimes necessary for infection. One might have a brush with the virus, some contact with it, and not necessarily become infected. But infection could also occur after only one exposure.

An effective lubricant, gel, or spermicide to use with a condom is non-oxynol-9, which kills HTLV-III in laboratory settings. This does not necessarily guarantee that it will kill the virus in other settings. Home use is different from clinical studies. We cannot say categorically to a client, "If you use non-oxynol-9, you will be safe." It will, however, lower the risk of transmission. Non-oxynol-9

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lubricants can be applied both inside and outside a condom. Some condoms are also prelubricated with spermicide. Using a condom appropriately, without user error, breakage, and so forth, will prevent the virus from entering the body during ejaculation. So, in terms of intercourse, even fellatio, the condom is a very effective protective device.

Basically, "safe sex" boils down to one concept: "Do not let ^{one} ~~another~~ person's semen, blood, feces, vaginal secretions, or, in the case of lactating mothers, mother's milk, into another person's body." That might mean using condoms. To another couple it might mean not ejaculating.

Vaginal secretions may also transmit the virus. We do not know whether they are an effective means of transmission. If a woman were infected, cunnilingus might transmit the virus to her partner.

To prevent a partner's exposure to her menstrual blood and/or cervical secretions, a woman can use a diaphragm, non-oxynol-9, and have her partner use a condom. Such activity reduces, but does not eliminate, the risk of transmission.

Another aspect of sexual transmission is saliva and kissing. Saliva poses a difficult question for the health educator and mental health care provider. It is quite easy to prove something does transmit a virus; all you need is one case in which it has. It is much more difficult to prove that it does not. In all likelihood, saliva does not transmit the AIDS virus, unless there is blood mixed in with it. Brushing your teeth or having cuts or sores in your mouth can produce

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blood. If the virus is in the blood, it is then "in" the saliva. But saliva itself (or with minute amounts of blood) has never been implicated in a case of HTLV-III transmission. The viral concentration is apparently too low. Some comparisons have been made between HTLV-III and the hepatitis B virus, which is, similarly, transmitted through primarily blood and semen. Hepatitis B virus is also found in saliva, but in thirty years of research not one case has been linked to salival transmission. As health care providers, we must be alert to the client who says, "Oh well, saliva's probably risky, and so is semen, and I'm not going to stop kissing, so I might as well not stop intercourse without a condom." Semen is known to transmit the virus.

Levels of Risk

Some communities and populations have a high rate of virus exposure. Others are much lower. In the case of a community like the gay male community of San Francisco (with a 50 percent infection rate) or the New York IV drug user community (with as many as 80 percent of the community exposed), the basic public health goals should be that everybody engage only in "safe sex." This is the only way that people can protect themselves and others. Community survival will require major behavioral changes.

On the other hand, in a community where the incidence of infection is below 50 percent, perhaps only 1 percent, the average person is less likely to want to use condoms. How can one mandate safe sex for everyone? If one follows the risk reduction guidelines in all cases, there would be no pregnancies. One aspect of sexual counseling for the

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lower risk population is education on decision making and risk evaluation. The client should be asked, "What level of risk are you willing to take?" Some people feel that they have very little risk of exposure and that their partner has little or no risk. They feel safe, or safe enough to do "everything." Some people review their pasts and that of their partner. Others take antibody tests and then decide about sex. Still others take the attitude that if there's any risk at all, they would rather avoid sex. Some risks are more acceptable than others to an individual. One person will drive drunk, but always use a condom. Another is the reverse. Partners negotiate to what degree each wishes to take some sort of risk.

Pregnancy Issues

Although there is a chance of the fetus being exposed to the virus through transplacental transmission in utero, not every baby will be born infected. In one study, a mother with several children passed the virus on to one but not to a later child, even though she herself continued to be infected. At present, we cannot predict whether a specific infant will be born infected. Additionally, some children who test positive on the AIDS antibody tests remain in good health.

If a woman is infected at the start of a pregnancy, what are her chances of developing the symptoms of ARC or AIDS during the course of pregnancy? There is some evidence to suggest that pregnancy can accelerate the course of illnesses associated with AIDS and ARC and perhaps also the underlying syndrome itself. Counseling women who are already pregnant, and at the point when abortion is feasible, is a

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complex and difficult task.

And lastly, donor insemination. No women who received semen via donor insemination have yet contracted AIDS. One study in Australia demonstrated that the virus is transmissible via insemination. Freezing the sperm may make transmission less likely. Screening programs similar to those in use in blood banks are the major techniques for preventing transmission via insemination. Typically, a sexual and social history of the donor, blood tests, and other screens are used. HTLV-III antibody tests are in routine use at licensed sperm banks.

Antibody Testing Issues

Testing for the antibody to the HTLV-III is a screening strategy that is being increasingly applied as a protection even beyond the blood banking community. Sperm banks use it. Some doctors recommend it for their patients considering pregnancy. Some people want it to feel secure about their sexual activity. While the test is relatively accurate, it is not 100 percent perfect. Since we are dealing with a potentially deadly illness, the imperfections of the test are very important to understand.

There are both false-positive and false-negative results. In a population with a high rate of virus infectivity (e.g., gay men or IV drug users) there will be more false negatives. In a population with a low rate of infectivity (e.g., the general population), there will be a higher rate of false positives.

The consequence of a false negative is that a woman may wrongly think that she is not carrying the virus and spread it inadvertently or

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misunderstand her real symptoms of AIDS or ARC. In most testing systems, negative test results are not a signal to retest and the result is treated as "true." Any woman in a high risk group who gets an initial negative result should consider a retest for certainty.

The consequence of a false positive, on the other hand, can be unnecessary stress, anxiety, and fear. Because almost all testing programs include retests of positive specimens, any woman with an initial positive test is likely to have her blood retested automatically. Retesting significantly reduces the risk of a false result.

Women's Unique Issues

First of all, there is the problem of maternal transmission, already described. Women at risk are going to be counseled about pregnancy, abortion nursing, planning pregnancy, contraception, and antibody tests. They are going to be encouraged to share information about their antibody status with obstetricians, labor room staffs, and pediatricians. Some may even be told to delay pregnancy indefinitely "until more is known." How will women react to such advice?

In some cities, women in "high-risk" groups are being encouraged to have antibody testing prior to pregnancy. It is entirely possible that women, or subgroups of them, and not gay men, will be the first population to face mass screening for AIDS virus antibody.

A second aspect of AIDS that is unique to women is the female social role of mothering: From this role flow two important consequences. First, when a woman becomes ill with ARC or AIDS, her

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role as a primary caretaker to the child or children or to other adults or persons in the household is immediately affected. The family is severely disrupted, and she herself will have to make many adjustments. Her children may also be indirectly affected by her diagnosis and forbidden to go to school. She has to deal with a life-threatening illness, and she also has to deal with the impact on her family, and this is a very serious matter. Fifty-three percent of women with AIDS contracted it through IV drug use. A significant number got it through heterosexual contact, most often with a drug user. Demographic studies of such women indicate that they are likely to have young children and also to be the sole support of these children.

A second consequence of the social role of motherhood is care of the child with AIDS. With AIDS, as with other sicknesses, it is ordinarily the mother who is expected to care for or manage the care of the child. But since 75 percent of all pediatric AIDS cases are currently the result of maternal transmission, the mother may herself be ill. Her illness and responsibility may be compounded by illegal survival activity, incarceration, poor health (caused by drug use and its life style associated illnesses), and the threat of foster care or child abuse proceedings. These are parenting issues that men rarely face.

If the mother is healthy enough to care for her child, she must still handle the complex issues of medical and home care, research investigations, school access, friends, and family stress. CDC recommends that every child be evaluated individually to provide

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quality care for a child who is either infected with the virus or is ill.

Resources for Women

Because the total number of women infected with HTLV-III is much smaller than the number of men, the resources available for women in a general sort of way and those that deal with particular problems of women are much more limited. Let us look briefly at the area of drug rehabilitation services--necessary to combat AIDS transmission via shared needles. Both in absolute numbers, and in proportion to need, there are fewer drug programs for women than there are for men. There are fewer residential programs with spaces available for women than there are for men. In addition, most of the programs will not take women who are pregnant, and even if they will take women who are pregnant, they will not take them when they are more than 21 weeks pregnant. None will house a woman with a child.

The only residential substance abuse program in San Francisco that will take women who are pregnant and/or have children is the Women's Alcoholism Center, and this center requires that the woman's primary problem be alcohol, not drugs. As a consequence, a woman with a drug problem who is at risk for AIDS and has a drug problem, and has children, is forced to leave her children in order to be treated in a residential program. She probably will not be able to have visitors, including her children, for at least two months. Such rules are the standard in many residential programs. These programs are designed to meet male needs, not those of women.

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Women also need AIDS services attentive to their needs. Many AIDS-focused organizations have no women's support group or people who are particularly sensitive to women's issues. Organization members, clinic staff, and health department employees may be sensitive to the issues of AIDS in a general way, but many are not trained to understand those problems which are specific to women.

Another aspect of resources and services for women is the need for ethnic diversity in staff and programs. Over 70 percent of all female AIDS cases are black or Latino women. Effective educational programs require culturally sensitive and linguistically appropriate materials, combined with active outreach. This is not happening so far in any place in the United States. Work with local ethnic health and civic organizations can be an important step in raising community awareness of AIDS and of the techniques to prevent its spread and assist those affected. Women with AIDS are from poor backgrounds. As a whole, they are probably poorer than men with AIDS. This means that more resources are going to be needed for women than for men.

At the International Conference on AIDS in Atlanta, 1985, many researchers discussing sexuality would refer to sexually active men and promiscuous women. Prostitutes were described as "a reservoir of infections." Just as gay men are stigmatized for their sexual activity, so women who cannot prove that they contracted the virus from their husbands or from blood transfusions are also going to be stigmatized and criticized and blamed for their (imagined) sex life and morals.

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Women as Health Care Providers

Numerically, women constitute the bulk of the caretaking population for those who have AIDS. Persons with AIDS are primarily men. This situation mirrors women's family role of caretaker of others' physical and emotional needs and their daily maintenance. The medical care system itself is dominated by men. Many of us are in situations of providing extensive service but receiving inadequate recognition. As women, we are also in roles (which we have filled for centuries) of caring for the sick, handling emotional problems, handling issues of nurturance, doing the daily work, doing the dirty work, handling everybody's waste materials in one form or another, being exposed. The AIDS epidemic makes our nurturing roles more necessary while simultaneously reducing our self-worth. If we begin to complain about, say, sexism or lack of recognition, we are told, or may tell ourselves, that we are dealing with a very serious epidemic, we're talking about people dying, and after all, I am a woman who is not at much risk. "I'm healthy, what right do I have to ask for anything?"

We experience this criticism externally and internally. On the one hand, women have frustrations about status in the hierarchical structures of medicine; and on the other hand, they feel that they should not complain. Therefore, meeting the challenges of the AIDS epidemic may include addressing the role of women health care professionals as well as the needs of women at risk of illness.

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