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Women and AIDS-Related Concerns:

Roles for Psychologists in Helping the Worried Well

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Abstract

Acquired Immunodeficiency Syndrome (AIDS) has important implications for the practice of psychology. As the epidemic continues, the role of behavior change and psychosocial factors in the spread and transmission of Human Immunodeficiency Virus (HIV) infections assumes increasing significance. Psychologists, as behavior change experts, have a special and challenging role to play in educating the public, particularly women, about AIDS. This article examines AIDS- and HIV-related concerns in women with a focus on the personal dilemmas for the practicing psychologist, problems in health behavior advocacy, and methods and pitfalls in modifying sexual behaviors.

The appearance of Acquired Immunodeficiency Syndrome (AIDS) in this country introduced not only a new behaviorally transmitted disease into the population, but also a psychosocial force toward change. As with discovery of oral contraceptives over 20 years ago, women are again rethinking their intimate relationships with men and with their own bodies. Articles in popular women's magazines (e.g., Edwards, 1987; Greenberg-Adair, 1987; Weber, 1987) underscore this new source of anxiety for dating women. In recent years, several books have been published with advice on how to date safely in the now uncertain world of premarital sexuality (e.g., Douglas & Pinsky, 1987; Everett & Glanze, 1987; Mandel & Mandel, 1986; Ulene, 1987).

For psychologists, too, AIDS presents a unique and complex challenge. Although AIDS is a physical disease, in most instances its transmission and spread is dependent on the volitional behaviors of people (Ward, Hardy, & Drotman, 1987). AIDS is not inadvertently "caught" by contact with airborne germs or contaminated food products. Instead, the majority of individuals who contract Human Immunodeficiency Virus (HIV) infection do so through participating in behaviors that involve intimate contact with HIV-infected bodily fluids, such as blood, semen, and possibly vaginal secretions (Friedland & Klein, 1987). This infectious contact can be prevented. Even though biomedical science has made dramatic strides in our understanding of HIV and its endstage manifestation, AIDS, behavioral science contributions to prevention efforts have come more slowly (Clarke & Sencer, 1987; Des Jarlais, Tross, & Friedman, 1987). With scientists predicting an uncertain timespan before

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an effective AIDS vaccine is developed (National Academy of Sciences, 1988), the importance of prevention efforts through behavior change is clear (Osborn, 1986). Psychologists have a special role to play in developing these interventions.

In this article, we will examine AIDS- and HIV-related issues pertinent to women in psychotherapy. In doing so, our focus will be on the personal dilemmas faced by some psychologists, problems in health behavior advocacy, and methods and pitfalls in modifying sexual behaviors. First, however, a brief review of the incidence and prevalence of AIDS in women may be helpful.

Epidemiology of AIDS in Women

Although a primary focus here will be on the concerns of women in psychotherapy, the truth is that women who are most likely to be at risk for acquiring an HIV infection generally are not those who can afford to seek treatment in a private practice setting (Centers for Disease Control Public Use AIDS Data Tape, January 2, 1989). In contrast, the women at highest risk for an HIV infection are among the least advantaged groups in society: poor, urban ethnic minority women (Mays & Cochran, 1988). To date, women and female children with AIDS are predominantly Black (52%), and most women with AIDS were infected from intravenous (IV) drug use (52%). More often than not, when these women do come into treatment it is likely to be as a result of seeking medical care in settings where psychological services are ancillary. This is normally in such treatment facilities as prenatal care centers, substance abuse programs, correctional facilities, and hospital settings.

In Table 1, we present data from the Centers For Disease Control Public Use AIDS Data Tape, dated January 2, 1989, on reported female AIDS cases. For White women, the majority of cases implicated intravenous drug use as a primary means of HIV transmission, followed by blood transfusions, and then heterosexual contact with an HIV-infected individual. With reduction in the risk of HIV-contaminated blood entering the blood supply through blood screening procedures now in place, it is expected that occurrence of new cases in this category will significantly drop over time. For Black and Hispanic women, infection through receiving contaminated blood products has never been a major source of infection.

If women continue to constitute approximately 9% of the cases of AIDS, with no changes in relative risk, it is projected that over 20,000 women nationally will have been diagnosed with AIDS by 1991 (Macdonald, 1986). Although it is clear that a majority of these cases will occur among ethnic women due to higher rates of IV drug use in ethnic minority communities (Gary & Berry, 1985), estimates for nonethnic women are more difficult to gauge because less is known about the prevalence of HIV outside of established higher-risk groups (Macdonald, 1986).

The long incubation period between infection with HIV and symptomatic AIDS-Related Complex (ARC) or AIDS (Lifson, Ancelle, Brunet, & Curran, 1986) means that the statistics presented in Table 1 track a path of infection that may not reflect what is currently happening. Many of the current heterosexual cases are referred to as the second generation of AIDS (Redfield, 1987). The first generation was among intravenous drug users. The

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second occurred when HIV-carrying IV drug users infected their sexual partners. The third generation will be sexual partners of individuals who have been infected through sexual contact themselves. With each new wave, the circle widens, both increasing the number of individuals at risk and obscuring the boundaries of who is at risk and who is not. It is toward this third wave, and the fourth wave beyond it, that most of our comments are directed.

Although the majority of practitioners are not likely to see women at highest risk for AIDS for the reasons noted above, they are likely to encounter women who are called the "worried well." The worried well are individuals who perceive themselves to be at some risk for HIV infection but are currently not infected. This includes both those who have concerns based on realistic appraisals of personal vulnerability and those who inaccurately estimate their own risks.

Studies such as the one by Masters, Johnson, and Kolodny (1988) fuel the fears of low-risk heterosexual women that they may inadvertently contract the disease. Indeed, many women hold fairly inaccurate beliefs about the epidemiology of AIDS. The 1987 National Health Interview Study, using a cross-sectional probability sample of the civilian noninstitutionalized population, found that 36% of women believed AIDS could be transmitted by insects or mosquitoes, 32% thought it "somewhat" to "very likely" that one could contract AIDS from toilet seats, and only 19% knew that it was not possible to get an HIV infection from donating blood (Dawson, Cynamon, & Fitti, 1987). Others (Gould, 1988) may mislead women as to the actual risks of contracting AIDS from sexual contact by providing advice at odds with current epidemiologic and biomedical knowledge (Friedland & Klein, 1987). In the midst of this public concern and misinformation, many practitioners will eventually (if they have not already) find themselves confronting issues associated with AIDS within their own offices, no matter who their clientele.

Dilemmas of the Practicing Psychologist

For practicing psychologists, AIDS introduces new responsibilities, sometimes perplexing and often disturbing, but responsibilities nonetheless. Most important, therapists are obligated to educate themselves about AIDS, whether or not they anticipate ever working with an individual directly affected by the epidemic. One truth is that we are all affected by this epidemic. Another truth is that AIDS is a disease of intimate behavior, whether between sexual partners, IV drug-using partners, or mother and child, and therapy is one of the few societally sanctioned relationships where intimate behavior can be openly discussed. Psychologists, therefore, are in a unique position to act as health educators. To do so, it is necessary to know not only how the virus is transmitted but also the multifaceted psychological world of AIDS and HIV infection. This includes the immediate and long-term psychological reactions to HIV testing (Cleary et al., 1986; Cochran, 1987; Dlugosch, Gold, & Dilley, 1986; Green, 1986; McCombie, 1986), the impact of AIDS infection on families and individuals (Cohen, 1987; Deuchar, 1984; Durham & Hatcher, 1984; Miller & Green, 1985; National Institute of Mental Health, 1986; Nichols, 1985), possible neuropsychological sequelae (Navia & Price, 1986; Perry & Jacobsen, 1986), the emotional repercussions of AIDS/ARC-related discrimination (Cassens, 1985; Cohen, 1987), and the complexities of fertility and reproductive decisions that HIV-infected women must make

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(Mantell, Schinke, & Akabas, in press; Murphy, 1987). There are also special issues for women who are caregivers for those with AIDS, for those who have lost friends or former sexual partners to AIDS, and for mothers who must confront their sense of responsibility and fear in the case of a drug-addicted or sexually active child, including those with gay male sons. Anxieties, denial, fear, grief, and bereavement are all psychological aspects associated with AIDS and the spectrum of HIV infections—aspects that clinical psychologists are often trained to treat within the psychotherapeutic context. Finally, as educators, it is also necessary to have a fairly good understanding of the physical manifestations of the disease in order to provide accurate information to anxious clients.

AIDS Anxiety: The Worried Well

Although the psychological and psychiatric conditions associated with HIV seropositivity and the diagnosis of AIDS/ARC have been well identified (see Miller & Green, 1986), less study has focused on the psychological concerns of the "worried well," individuals who are not HIV-infected but concerned about their risk of being infected. Even less is known about the reactions of women (Mantell et al., in press).

The risk of HIV infection for any individual depends not only on the occurrence of at-risk behavior, but the performance of this behavior in an environment where HIV is present. The earliest documented AIDS case in the United States so far occurred in 1968 (Garry et al., 1988). For those women who were sexually active, particularly during the 1970s, an era of sexual experimentation, their AIDS anxiety may have a real, though relatively unlikely, basis. The possibility of infection is influenced by several factors, including the woman's geographic region (nearness to an AIDS epicenter), use of IV drugs where sharing of drug "works" (paraphernalia) occurred, number of sexual partners (number of potential sources of infection), and types of sexual practices (riskiness of behavior). It is important to help women assess their own relative risk realistically, because for most this will very quickly allay anxiety. Unfounded perceptions of risk, based on misinformation or a personal tendency to catastrophize, create unnecessary worry. Similarly, denial of present potential risk exposure is counterproductive to the maintenance of physical and psychological well-being.

Extrapolating from what is known about gay men's reactions, the clinical presentation of the worried well may include acute or chronic anxiety with panic attacks, agitated depression, obsessional thoughts involving morbid preoccupation with AIDS symptoms, and hypochondriacal reactions to autonomic anxiety symptoms that can appear like AIDS symptoms, for example, loss of appetite and weight, sweats, rashes, or lethargy (Miller, 1986). These women may be worried as a result of past sexual behavior with suspected bisexual, gay, or intravenous drug-using men, previous blood transfusions, artificial inseminations, or proclivities in their personalities to worry. The manifestations of emotional distress of worried-well women may appear much like those of individuals with HIV infection, including those with ARC or AIDS. Like those with an HIV infection, there is a sense of uncertainty (Miller, 1986). The worried well fret, worry, and are dominated by obsessional concerns about their actual contact with HIV. They may experience guilt over

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whether they have infected others. This guilt is particularly acute if they are concerned about having infected their own children.

Some worried-well women's perception of vulnerability to HIV infection may be perceived as distorted and therefore may not be taken seriously. However, the source of their perhaps unfounded concern may emanate from previous relationships or distrust of men's honesty about past incriminating sexual or substance abuse behavior. Anxiety about men's dishonesty is not entirely unrealistic. In an informal survey of college age men conducted by a student of Cochran, the extent of the "dating game lies" men readily admitted to provides support for women's suspicions. When asked what lies they have told women in order to have sex with them, these young men reported lying about their feelings, future intentions, relationship status, and previous sexual involvements. Presumably, these issues of trust and honesty go both ways. We must assume that women, too, will lie to men.

The following case illustrates some of the complexities that can occur with worried-well women.

> A 38-year-old woman from a low socioeconomic and fundamentalist religious background was seen at a community-based AIDS organization by Mays for information and counseling for HIV antibody testing. She was extremely distraught and tearful. She reported the following history: On a visit to a prior boyfriend she noticed that he had lost a considerable amount of weight. He denied that he had AIDS. Yet, he lived in an area of the city where there was a high prevalence of intravenous drug use. His denial did not ease her worries because "he lied about other things." Since then she had developed a variety of somatic complaints that were for the most part consistent with an early HIV infection, including fatigue, weight loss, swollen glands, head-aches, fever, and sweats. Her extensive phone calls to local AIDS projects requesting information had only further convinced her that she had AIDS. On one occasion, she had requested HIV testing after presenting with flu-like symptoms at the emergency room of her health maintenance organization (HMO). The emergency room physician told her that it was very unlikely that she had AIDS and sent her home without HIV testing being performed. Her attempts to obtain anonymous testing at a county testing center were unsuccessful due to their then-limited resources. As the interview progressed, it became clear that the woman's tears resulted from feelings of guilt that she had some-how infected her pre-adolescent son. Although Mays counseled her about HIV infection and issues involved in HIV antibody-testing, it was diagnostically evident her emotional state was so fragile that the first intervention necessary was short-term psychological counseling. Referral to Cochran was made. Upon further assessment, it was determined she was suffering from a delusional process. At that point, a request was made to speak with her father with whom she lived. He believed his daughter's assertion that she had AIDS, was also extremely distressed, and wished to avoid public exposure of his daughter's illness by keeping her at home. He denied a previous history of psychiatric disturbance in his daughter, although he acknowledged that she had frequently sought help for a variety of problems on an emergency basis at her HMO. With the daughter's permission, the

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> father was advised to first seek psychiatric help for his daughter at the HMO in order to avoid further deferrals of care. He was also informed of the issues surrounding HIV testing and was advised, upon stabilization of his daughter's psychological status, to proceed with HIV antibody counseling prior to testing, if that was the desired course of action. The crisis was resolved when this emergency psychiatric care was sought.

This case illustrates not only the extent to which women can worry about AIDS, but many of the dilemmas faced by psychologists who must sort through the especially intense anxieties of clients and their families when the topic is AIDS. Although this case occurred early in the AIDS epidemic, many of the issues raised continue today.

AIDS Anxiety: The Practitioner's Side

Psychologists, themselves, are not immune to anxieties precipitated by AIDS-related issues. Some of these have to do with feeling a lack of needed competence to cope with this new role as health educator. Some feel awkward or reluctant to discuss the graphic intimacies of "safer sex" with clients, whom themselves are often reticent to disclose such intensely personal information. Many are not especially well-versed to tackle the broad range of topics associated with AIDS. And when the topic is women and AIDS, there are some answers not immediately known, even by those who work in the area of AIDS, because so little still is known about how AIDS affects women psychologically. Yet psychologists will be increasingly forced to confront AIDS-related issues, because AIDS is not just a physical disease to be left to the care of physicians. Rather, it is a behaviorally transmitted disease and psychologists are experts when it comes to human behavior.

There are other personal dilemmas psychologists acting as AIDS health educators will face. Recently, a colleague confessed to one of us that he felt great discomfort advising his clients to use condoms, which he did, when he himself found them personally intolerable and that he was relieved to be monogamously married. This attitude harkens to the early discomfort of "safer sex" advocators within the gay male community (Hirsch & Enlow, 1984). Such concerns were partially resolved when gay men began to redefine their schemas of sexuality and condom usage. Psychologists can reenact this process by coming to understand what would be involved, personally, in practicing safer behaviors. This can be done no matter what the circumstances of our own lives. In the process, it is possible to learn useful information to pass on to clients.

Ethical Perplexities

One basic issue involves the level of advocacy that the practicing psychologist adopts with clients. For example, many therapeutic approaches are nondirective, making the role of psychologist as "safer sex" advocator inconsistent with current practice. Some approaches highly value the importance of client-centered decision making. Yet, is it ethical to avoid advocacy for theoretical notions of growth and development? On the other hand, is it therapeutically destructive to be too directive? Are we to advise a particular course of action with the pregnant HIV-positive client who is trying to decide whether or not to abort? At present, it is estimated that less than one third to one half of such women opt for abortion despite the fact that their offspring run a 50% or greater risk of HIV infection (Pinching &

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Jeffries, 1985) and their own lives are threatened by the physiological stress of the pregnancy (Rogers, 1987). Such issues are not easily resolved, underscoring another reality of this disease: With AIDS there are very few easy decisions or simple answers.

Many other ethical dilemmas will arise for the psychologist. For example, what are the duties of the practicing psychologist when a sexual intimacy planned during the course of therapy involves the risk of transmitting a fatal disease? More perplexing is the question of what is the appropriate role of the psychologist when a woman chooses from a position of low self-esteem or powerlessness to have unprotected sexual contact with either a spouse or sexual partner who is infected or at high risk for HIV infection. Is this client a danger to herself? Is there a duty to warn or protect when a psychologist learns of unsafe sexual or unsafe IV drug use behaviors by an individual? All of these questions reflect the ways in which AIDS will complicate the practice of psychotherapy.

Issues in Health Behavior Advocacy

One of the recent advances in thinking about the epidemiology of AIDS has been to move away from the notion of high risk groups and to talk instead about high risk behaviors. But in advocating the avoidance of high risk behaviors we need to be concerned with at least two issues. First, is the advice understandable in terms of appropriate behavior? Second, is the advocated behavior reasonable given the circumstances of a woman's life?

The first concern is whether the behavioral advice that women are given makes sense to them. As an example, in the June 1987 issue of the *Reader's Digest* one specific instruction for "safe sex" is: "Avoid having multiple sexual partners" (p. 60). What are multiple sexual partners? When AIDS researchers compare the number of sexual partners within high risk samples looking for differences in rates of infection, the numbers of sexual partners are often far different from average behavioral patterns. In a not unusual case, researchers studying low and high status prostitutes from Nairobi reported that one group had 922 partners per year whereas the other had 143 partners per year (Kreiss et al., 1986). When one of us asked this same question of young heterosexual college students during a class, they responded that having multiple sexual partners means several "one-night stands" where there is no emotional involvement in a short period of time. For them, multiple sexual partners seems to be a euphemism for promiscuity. But one's perception of being promiscuous or not may have little to do with how many sexual partners one has. Does one new partner a year constitute multiple sexual partners? What about 3 or 4—or 20? Does reducing the number from 6 to 2 have any practical effect? Obviously this question can be interpreted differently by young adults, as opposed to prostitutes, or by a woman who feels determined to date and find a suitable marriage partner.

Much of AIDS education is based on experiences of gay men, for whom the advice to avoid multiple partners may have more readily apparent meaning. It is important that AIDS education not only be gender appropriate but also consistent with women's social reality. One such context is the social influences on women's relationship choices. For women facing a sex ratio imbalance where eligible males are scarce (Bureau of the Census, 1983), should our warning about avoiding multiple partners be one more reason for women to

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remain in safe but unsatisfying relationships when, in fact, multiple partners may not have the same meaning for women as for gay men?

In understanding how women construe this issue of defining risk, the role of intention may be an important arena for psychologists to examine with their clients. Women who approach sexual activity with a commitment to their partner may not be as likely to view having had several serially monogamous encounters as having multiple partners. This schema is influenced by women's perspectives on relationship development. Studies examining women's and men's orientations and values in entering heterosexual relationships show distinct gender differences (see Rubin, Peplau, & Hill, 1981, for a review). Women tend to be more cautious, practical, and realistic than men when selecting a mate. It is this very caution in their selection process that may influence their interpretation of the term "multiple partners." For some women, a committed monogamous relationship, that is, a safe relationship, may be one that lasts more than a few months and where there is simply the intention that it will continue.

Social psychologists (Perloff, 1987; Perloff & Fetzger, 1986) know that individuals have a great capacity to perceive themselves as uniquely invulnerable to the negative consequences of external events. We must help clients to clarify for themselves what their personal risks actually are by translating behavioral advice into personally meaningful information. Unfortunately, little guidance has been offered on the most gender-appropriate strategies with women.

The second concern in health behavior advocacy is whether the advice can be implemented. For instance, when poor women are told to use condoms and they barely have enough money to purchase food, what are they to do? Food stamps cannot be used to purchase condoms or spermicides, and Medicaid does not cover the cost of them. Free condoms can probably be obtained through family planning clinics, but is this a reasonable expectation when utilization of these services is characteristically low in this group of women (Silverman, Torres, & Forrest, 1987)? Some ethnic women report experiencing verbal and physical abuse as a result of advocating condom usage by their sexual partners. The social context of a request for condom use not only can convey a message about suspicions of past sexual behaviors or drug use, but also represents a possible change in the power and decision-making balance in the relationship. One author (Fox, 1988) suggested, "If your partner starts using a condom, don't question the decision—be glad, not suspicious" (p. 98). This advice ignores the social meaning of such unexpected behavior change. In advising women, care must be taken to devise strategies sensitive to the sociological and psychological realities of their lives.

Problems in Modifying Behavior

Currently, most psychology practitioners are in contact with the worried well, women who are not HIV infected but are worried about AIDS, and the unworried well, women who are engaging in risky behavior but do not perceive themselves to be at risk. As discussed, for the former, clarification of current risk and methods to reduce risk can often reduce anxiety. For the latter group, confronting the denial can lead to exploration of the possible underlying self-devaluation.

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In a survey of young sexually active adults (Cochran & Peplau, 1989), factors that led to risk reduction for women and for men were compared, and clear differences were observed. Women who had altered their sexual behavior were more sexually experienced than those women who had not reduced their risk. The best predictor was a history of being previously treated for a sexually transmitted disease. Women, apparently, learn their vulnerability from personal experience. For men, predictors of behavior change were more cognitive, for example, their perceptions of being at risk and their level of homophobia, although their actual sexual experiences did not predict risk reduction. These results suggest that underscoring the extent of sexual experiences may facilitate behavior change for women but not necessarily for men.

As is well known, women often enter psychotherapy with longstanding problems in effectively negotiating interpersonal interactions. Sexuality is, perhaps, one of the most difficult interpersonal situations in which to be assertive. With the threat of AIDS, women are being asked to be assertive and insist on “safer sex.” The topic can become a focus for questioning the relative importance of one’s self-worth, and the question may be “Am I important enough *to me* to want safety at the risk of being rejected by a man?”

Sometimes women will try to avoid this basic issue with a cloak of magical external protection. One method is to try to follow the advice of the *Reader’s Digest:* “Abstain from sex with people whose activities put them in a high-risk group” (p. 60). So women will ask men certain questions. For example, in some urban cities one method employed by women to reassure themselves that unprotected sex is safe is to bring up the topic of AIDS on one of the first dates and to query whether their partner has had the AIDS test. At this point, he may reassure her that he has had the test and that he tested negative. It is, most probably, a he, but lying is not new on the dating scene (Cochran, 1988). Nor perhaps is the believing of the lie. It is only that the lie and its believing now seem a little more dangerous than other pretenses so common when two people meet. It is important to help women to see past these potential fictions to the very real need to protect themselves.

We, too, need to protect our clients as much as possible from the trauma of AIDS. This can be done by addressing the issues of self-worth, sexuality, and drug use directly in therapy and by recognizing that such profound behavior changes require time—time to try, to fail, to try again. This is why psychologists have a unique opportunity to contribute to stopping the spread of AIDS by intervening now, before the prevalence of AIDS in women escalates. For a woman who may not value herself or her own needs very much, there are skills that need to be acquired in raising the issue of using a condom or alternative methods of sexuality. There are skills a woman needs to rebut a partner’s refusal, should it occur. Even more skill is needed to learn how to choose partners whom she can trust. All of this lies at the heart of psychotherapy. As psychologists rehearse with their clients scenarios for assertively negotiating safer sex encounters, fundamental assertion skills are taught. As women expand their consciousness to expect “safer” sexuality with their partners, self-esteem must necessarily be enhanced as well. It just may be that by confronting the issues of AIDS in their clinical practices, psychologists will better help women to achieve what they came into therapy for in the first place.

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Table 1

Total Number of Female AIDS Cases by Transmission Categories for Each Ethnic/Race Group, United States, January 2, 1989

	White		Black		Hispanic/Latina		Other		Total	
	N	%	*N*	%	*N*	%	*N*	%	*N*	%
Intravenous (IV) drug user	787	38	2,082	53	728	48	25	34	3,622	48
Heterosexual contact	482	23	1,106	28	466	31	19	26	2,073	27
Blood transfusion	511	25	148	4	71	5	17	23	747	10
Hemophilia/coagulation disorder	16	<1	6	<1	0	0	0	0	22	<1
Other/unknown	152	7	262	7	95	6	10	14	519	7
Children (under age 13)	118	6	347	9	141	9	2	3	608	8
Total cases	2,066	100	3,951	100	1,501	100	73	100	7,591	100

Note. Data are from the Centers for Disease Control AIDS Public Access Data Tape, January 2, 1989. Percentages in each transmission category are calculated within each ethnic group.

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