

# FOCUS A GUIDE TO AIDS RESEARCH

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## Integrating AIDS Prevention Into Clinical Practice

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The threat to public health posed by the increasing number of AIDS cases in all segments of the population requires physicians and mental health professionals to become involved with AIDS prevention. This prospect makes many health professionals uncomfortable since few have received any training in human sexuality or sexuality counseling.

To become familiar with the counseling issues related to AIDS prevention, health care providers need to address three basic areas of concern:

- (1) the means of HIV transmission and how safer sex practices can reduce the risk of transmission;
- (2) the nature of one's personal biases about sexual orientation (heterosexual, homosexual, and bisexual);
- (3) the variety of human sexual practices.

Often physicians and therapists do not ask patients questions about areas that make them feel uncomfortable or those about which they are uninformed or biased. As a result, the physician or therapist may ignore or overlook the fact that a patient might be engaging in sexual behavior that could lead to HIV exposure.

Especially relevant to Western societies is Kinsey's research that sexual orientation is often not a fixed entity, and that it varies throughout a person's life (Kinsey, Pomeroy, and Martin, 1948). In other cultures, the predominant heterosexual spread of HIV makes it clear that all sexually active individuals need information and counseling about HIV risk reduction. An ideal opportunity to address these issues for many health care providers is when treating an individual for a sexually transmitted disease, when prescribing birth control, or when beginning a counseling relationship.

### Misconceptions About Risk

The assumption that a couple's current state of monogamy protects them from exposure to AIDS must be examined closely. Often the idea of monogamy is more popular than the reality. Kinsey's research in the 1940s and Hunt's research in the 1970s (Hunt, 1974) demonstrated that more than 50% of supposedly monogamous heterosexual couples in the United States were in fact not sexually exclusive. Even for those couples who currently relate sexually only to each other, monogamy does not protect them from experiences each other may have had prior to entering into the relationship. Few people can be absolutely

certain about the drug use or sexual history of their sexual partners. Since the HIV incubation period for HIV can be several years long, unknowing transmission or exposure to HIV may have occurred, leaving individuals erroneously believing that they are not at risk since they are currently monogamous.

To assess whether a patient or client is at risk for AIDS, the practitioner needs to determine the nature of both current and past sexual practices. Simply asking, "Are you gay?" or "Do you have a history of sexually transmitted diseases or drug use?" is not sufficient. For example, health care professionals cannot assume that a patient who is not openly gay has not engaged in sex with other men. Many men who have sex with men do not label themselves as homosexual; they certainly do not identify as part of the gay community.

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Questions regarding sexual practices need to be asked in an accepting, nonjudgmental, and gentle manner that does not incorporate the use of labels. For example, the physician or therapist can ask, "As an adult have you ever had any sexual contact with another man?" If the answer is "yes," then asking "When was the last time?" can provide useful and pertinent data about this individual's risk for being exposed to HIV.

In discussing high risk behaviors, many professionals have counseled patients to reduce the number of their sex partners. This, in and of itself, is not particularly helpful or even accurate advice. An individual may be the receptive partner in unprotected vaginal or anal intercourse with one exclusive partner who is HIV seropositive and, as a result, be at high risk for infection. On the other hand, safer sex activities with several different partners would place this individual at a comparatively low risk. May AIDS educators have begun talking about high-risk behaviors rather than high-risk groups; a similar shift emphasizing behaviors instead of numbers of partners would also be appropriate and more accurate.

Safer sex is necessary for all sexually active people, regardless of their age or antibody status. In many nations health authorities have issued guidelines that advise individuals to avoid sex with persons with AIDS or members of "high-risk groups." This suggestion, if followed, would mean that anyone who has AIDS, ARC, or HIV infection, who is a current or past intravenous drug user, a hemophiliac, or who is a gay man should not have sex. Obviously, this is impractical and unrealistic; it also ignores the variety of sexual behaviors that do not place individuals at risk.

Some clients respond to such guidelines by entering a period of "enforced celibacy." This is called "enforced" because

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# Clinical Practice . . .

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the person feels trapped into choosing celibacy as the only method of avoiding AIDS. These people have reported that when they cease to remain celibate they often engage in high-risk sexual behaviors (Palacios-Jimenez and Shernoff, 1987). This kind of "diet/binge" sexual activity has obvious negative physical and emotional ramifications for the individual.

If two people follow the guidelines for having low-risk sex there is no reason why they cannot enjoy a creative and healthy sex life, despite their antibody status, potential risk, or current health status.

## Counseling Issues

Physicians and therapists need to ask their patients, "What are you doing to protect yourself and your sexual partners from possibly becoming infected with AIDS?" Therapists can initiate discussions by asking questions such as these: "How did you feel when you first realized that you might have to change your sexual behavior because of AIDS?" and "What thoughts and feelings do you have when you think about safer sex?"

For therapists there are reasonable concerns about introducing this topic into treatment. Questions about whether the interview content will become overstimulating or inappropriately eroticized have to be judged on a case-by-case basis. Patients may also be uncomfortable with discussions of sexuality and may feel intruded upon or angered by this subject.

Questions about AIDS often raise profound feelings for clients, including anger and, at times, relief. The anger may occur because any discussion of AIDS shatters their denial that this disease can touch them. The anger can also be due to transference issues stemming from the individual's perception of the question as a negative parental injunction. An exploration of these negative transference feelings can lead to important discussions of sex and sexuality in general, taking care of one's self, self-image, and the consequences of impulsive behavior. When relief is expressed, it is usually because this highly charged issue can finally be discussed with the therapist or physician.

Once the shock or anger dissipates, the next step is to elicit from clients their feelings about the changes in sexual behavior that will be required. Asking what specific behaviors they will miss and how they feel about this loss has proven very useful to clients in individual and group therapy sessions. Therapists need to encourage clients to be very specific about sexual behaviors in this discussion. Frequently it is helpful for the client to hear the therapist validate feelings of sadness, anger, and mourning that can accompany any exploration of this issue.

An additional tool that has proven helpful in both therapeutic and instructional settings is a chart that illustrates the spectrum of sexual practices grouped from low to high risk. This can be a useful technique for the physician or therapist who is not comfortable asking patients exactly what sexual practices they engage in.

## Eroticizing Safer Sex

To integrate safer sexual behavior into their lives, people must discover that low-risk sex need not be boring, dull, or limited. There are several helpful verbal exercises that professionals who have not been trained as sex therapists can have their clients practice (Palacios-Jimenez & Shernoff, 1986).

Ask clients to reflect upon very specific erotic ways that they like to touch or be touched, ways that will not put them or their partner at risk for AIDS. If verbally reporting this information to the therapist produces too much anxiety or discomfort, the individual should be given the option of simply writing a list and keeping the contents private. But the feelings that arise from doing the exercise need to be discussed.

When this exercise is discussed, people invariably report that what they thought about was a variety of ways to have

foreplay that they have always enjoyed. If they have a sexual partner, patients can be encouraged to practice these behaviors. The next step is to ask the client to imagine, discuss, or write a list of erotic but low-risk ways of doing specific sexual acts such as mutual masturbation, oral sex, intercourse, and eroticizing condom use.

## Condoms

Research has demonstrated that the proper use of condoms can reduce the risk of transmitting HIV during intercourse (Conant, 1986 & Goldsmith, 1987). Feelings about condom use need to be elicited. Practitioners should acknowledge the loss of some sensitivity due to condom use but should encourage clients to consider how condoms can be incorporated into foreplay.

It is critical that physicians and therapists remind patients and clients that using condoms cannot guarantee absolute safety and protection. Clients should recognize that options are available. For example, clients can be reminded that they can refrain from engaging in anal or vaginal intercourse completely if that makes them feel more relaxed. Some people use two condoms at the same time; others practice withdrawal even while wearing a condom.

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Physicians and therapists need to become familiar with the steps for correctly using a condom. If it appears not to be appropriate treatment to discuss the specifics of condom use with the individual directly, then literature should be provided which carefully explains how to use a condom.

## AIDS Prevention for Women

Helping women protect themselves and their sexual partners from HIV infection involves several special issues. Statistics show that the majority of women with AIDS in the United States are poor minority women from inner cities. Many of these women report that sex has usually not been enjoyable for them, thus helping them eroticize safer sex is not the issue. Risk reduction programs for these women have focused on both assertiveness training and how to get their men to use condoms.

Some women face particular difficulties; some have been raped within their relationships while others have been threatened with the loss of their relationships when they have tried to get their men to use condoms. Colleagues who work with women suggest use of multiple forms of barrier contraception that always employ nonoxynol-9, a spermicide that *in vitro* has been found to kill HIV.

## Conclusion

A satisfying sex life is one hallmark of the well-adjusted human being, and AIDS need not infringe on sexual fulfillment. While AIDS has understandably and appropriately caused many people to examine their patterns of sexual behavior, all people, and especially health care professionals, need to be concerned about stopping the spread of AIDS. We have the opportunity to fight the fear with the facts about how AIDS is transmitted. With this information, physicians and therapists are in a unique position to help their patients and clients make responsible and intelligent choices about expressing their sexuality in the face of AIDS.

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## Diagnosis/Treatment/Prevention

### Care for the Caregivers

Sandra Jacoby Klein, MA  
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The informal network of family and friends who have taken the role of caring for people with AIDS or HIV infection have become valuable resources in the effort to provide essential services. This discussion will address the needs of these caregivers who, while not being trained health care professionals, nevertheless have become integral members of the treatment team. Our intent here is to outline ways in which the health care professional can best utilize the services of these newest members of the treatment team.

Previous studies have identified the general needs of individuals who are caregivers. These include the need to:

- (1) feel accepted and not stigmatized,
- (2) feel helpful and a part of the caregiving team,
- (3) be assured of the patient's comfort,
- (4) be able to express emotions in an accepting, non-judgmental atmosphere,
- (5) receive comfort and support from family members,
- (6) receive support and acceptance from health care professionals,
- (7) receive religious and spiritual support,
- (8) be referred to outside resources, and
- (9) obtain respite time and help in setting limits for themselves.

The AIDS epidemic has brought additional caregiver issues to the attention of health professionals. These include fears of contamination and isolation, concern about confidentiality, possible discrimination, and the effects of homophobia.

One of the first tasks for the practitioner is to identify the unique stresses experienced by the patient's caregivers. Ideally, the best way to assess these needs is to communicate with the patient and his or her support group soon after diagnosis. Private physicians and hospital care providers should take time to listen, explain, educate, and answer questions about diagnosis and treatment. This discussion might best be repeated during a follow-up visit since the initial shock of hearing the diagnosis frequently renders patients and their caregivers incapable of hearing anything else that is conveyed. They can be invited to return with a list of questions to encourage further discussion of their needs.

For the mental health practitioner, initial discussions may focus less on the medical aspects of the diagnosis and more on the psychosocial dimensions. For all practitioners it is important to see how the illness fits into the lives of the patient and the caregivers. How have they coped with crises previously in their lives? What personal strengths do they bring to the current crisis? It is important also for the practitioner to determine the extent of the patient's support structure and the nature of the relationship among the patient and the caregivers.

The assessment process will be ongoing during the course of the illness, and changes may occur in the patient's relationships. Do caregivers have the opportunity to express their own frustrations? If the disease has progressed, have family members or friends begun to withdraw from the patient, leaving the primary caregiver alone to cope? Are there patterns of substance abuse? Have overt conflicts emerged between the patient and the caregivers or among the caregivers?

Some of the stumbling blocks practitioners encounter in trying to understand the needs of caregivers relate to their own prejudices and misperceptions, for example, their attitudes toward people of color, people of varying ages, gay men and lesbians, people with chronic illnesses and I.V. drug users. Health

care workers first need to understand their own anxieties and expectations if they are to provide support and assistance to patients and their caregivers.

#### Interventions for Caregivers

People with AIDS and their caregivers may benefit most from working with a multidisciplinary health care team including a physician, nurse, social worker, psychologist or family therapist, home care agency staff, spiritual advisor, and an agency representative who provides volunteer support. Supportive interventions can be undertaken by any of these team members.

Caregivers have identified the following interventions as being helpful:

- (1) to be familiar with the recommended treatment and to be kept current when changes occur;
- (2) to be assigned a contact person familiar with the case who can answer questions and intervene during crises;
- (3) to learn how to administer medications, change dressings, and maintain infection control in the home;
- (4) to learn about proper nutrition to help promote the patient's maximum health;
- (5) to receive help and support in organizing a non-professional caregiving team, one that can share the burdens of caring for the patient;
- (6) to learn communication skills so that they may be effective patient advocates;
- (7) to develop active listening skills, helping them learn to just "be there" with their loved one;
- (8) to be encouraged to express their feelings of anger, guilt, helplessness, shame, fear, grief, and frustration;
- (9) to be given information about social services and other resources available locally and nationally.

For practitioners these interventions may sound demanding and time-consuming. Instead we have found that these efforts can reduce the professional's time involvement and can lessen the burden for the patient's caregivers.

#### Conclusion

As the AIDS epidemic continues to broaden, the health care system will be hard-pressed to meet the social and medical needs of people with AIDS. Community support systems such as volunteer organizations and informal groups of caregivers will be required to provide essential patient care. These non-professional caregivers can also help patients remain in their homes during much of their illness.

Health care professionals need to be aware of the specific concerns of caregivers who offer support and assistance to people with AIDS and HIV infection. The specific interventions above can help assure that these caregivers develop the skills and obtain the resources necessary for operating as successful members of the care-giving team.

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#### Resources for Caregivers

The following books and pamphlets may be helpful to individuals who have become caregivers for someone with AIDS, ARC, or HIV infection:

"The Family's Guide to AIDS", a handbook published by the San Francisco AIDS Foundation (333 Valencia Street, 4th Floor, San Francisco, CA 94103).

"AIDS: A Self-Care Manual", edited by Betty Clare Moffatt, MA, Judith Spiegel, MPH, Steve Parrish, Michael Helquist. A paperback book published by AIDS Project Los Angeles and IBS Press (2339 28th Street, Santa Monica, CA 90405), 1987.

"The Healing Family" by Stephanie Matthews Simonton; Bantam Books, New York, NY.

"When Someone You Know Has AIDS: A Practical Guide," by Leonard J. Martelli with Fran D. Peltz, CRC and William Messina, CSW; Crown Publishers, Inc., New York, NY, 1987.

## BRIEFS

### Recent Reports

**Survey Finds Physicians Need AIDS Education.** Many patients may not be receiving adequate information about how to avoid infection with HIV due to their physicians' lack of knowledge about AIDS, according to a recent article in the *American Journal of Public Health* (July 1987). In a random statewide survey of 1000 California physicians, Dr. Charles Lewis of the UCLA Department of Medicine and Sociology found that 65% of the respondents did not take sexual histories of their patients, and only 44% knew more than three symptoms of AIDS-related complex. Lewis also noted that many physicians reported a high degree of discomfort in treating and counseling gay patients.

The same issue of the medical journal reported findings from a related study of 500 physicians in three medium-sized American cities: Columbus, Phoenix, and Memphis. They were asked to respond to written profiles of two patients with similar backgrounds. One patient was diagnosed with leukemia while the other was a gay man with AIDS. Dr. Jeffrey Kelly of the University of Mississippi found that in general the physicians considered the AIDS patient to be more responsible for his illness, more deserving of its consequences, to be in more pain but less deserving of sympathy and understanding, more dangerous to others, and more deserving of quarantine. Several respondents also expressed concern that HIV is casually contagious.

**Time interval to seroconversion for HIV antibody.** How long does it take for a person to develop detectable antibodies to HIV? This is a very relevant question for those who test negative and want to be sure that they were not tested during the "window" period between infection and seroconversion. From a compilation of studies and observation of other viral diseases, most clinics have asserted that the time interval between actual infection and the first positive HIV antibody tests is from 2 to 12 weeks and possibly up to 6 months.

The difficulty in being more definitive is in pinpointing exactly when a person became infected. This has been possible only in cases of transmission by a single event, such as a needle-stick or transfusion. Even in these cases, if specimens are not collected frequently, the time to seroconversion may appear longer than it actually is. For example, if the first specimen is not taken until three months after the infecting event, a positive test shows only that the seroconversion took place some time during three months.

A report from Finland published in *The Lancet* September 12, 1987 (Ranki, Krohn, Allain, et al.) has prompted many questions. The authors state that it may take 18 months or longer to develop positive HIV antibody tests by the usual screening ELISA test. There are several problems with this study, and it warrants a closer look at the data.

1. All of the subjects in the study had *ongoing* sexual relationships with a person who was seropositive. Therefore, pinpointing the time the subject actually became infected is extremely difficult.

2. In order to define the interval between infection and seroconversion, the study must show when the person actually became infected. This study used evidence from antigen testing and Western blots to indicate early markers of infection. The results can be interpreted differently than they were in this report:

(a) Antigen testing. Tests for antigen are research methods which can be non-specific. There is a neutralization test for confirmation which was not done.

(b) Western blots. These tests are designed to show typical patterns of bands which correspond to the antibody response to the major components of the HIV virus. Results are unequivocal when there is a response to viral proteins representing the core, the polymerase, and the envelope of HIV. Quite frequently, uninfected people will react on Western blots to the core proteins only. The blots shown as evidence for early indication of infection in the subjects in this study had patterns that are termed "core antibody only" and are commonly seen as non-specific reactions in uninfected blood donors as well as in early infection. Western blot alone cannot distinguish between these possibilities. Even if a person eventually develops a true positive reaction, the initial tests may not have indicated infection at the earlier time.

3. Specimen collection. The specimens were collected 3 to 6 months apart. As explained earlier, seroconversion could have taken place at any time during these intervals.

4. ELISA Tests. "Seroconversion" was defined as "positivity by ELISA." There are seven manufacturers licensed by the FDA to produce HIV ELISA kits in the United States and several more in Europe. Most of the manufacturers have greatly improved the sensitivity of the assays in the last two years. The ELISA test used in the study was never identified, and it may have been a first generation test lacking sensitivity.

Until this study is validated, it seems reasonable to continue to say that we expect that most people will develop antibody within 2 to 12 weeks, although it may take as long as 6 months. We must, however, be sensitive to people's fears and accept the fact that some will not feel comfortable without a re-test even a year or two later.

Contributed by **Judith C. Wilber, PhD**, virologist, San Francisco Department of Public Health.

## Next Month

In the January issue of **FOCUS**, **John David Dupree, PhD** and **Glen Margo, MSW, DrPh** will consider how homophobia affects the response of governments and individuals to AIDS programs and to people with AIDS. They will review how the fear and hatred of homosexuality influence the work of health care providers, and they will suggest how health professionals can determine and change their own homophobic attitudes. Both Dupree, a co-founder and education specialist for the AIDS Project of the East Bay, and Margo, formerly the Bureau Chief of the Office of Health Promotion and Education for the San Francisco Department of Public Health, have taken positions in Washington, DC with AIDSCOM, a new federally funded, AIDS prevention program directed to developing countries. Margo will be Director and Dupree will be Program Officer for Training.

Also in the next issue, **Chuck Frutchey**, Assistant Director of Education for the San Francisco AIDS Foundation, will discuss how AIDS educators can address homophobia in their prevention messages. He will also examine how current prevention programs address sexuality and homosexuality.

## FOCUS A GUIDE TO AIDS RESEARCH

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The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. The goal of **FOCUS** is to place the data and medical reports in a context that is meaningful and useful to its readers.

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