

# FOCUS A GUIDE TO AIDS RESEARCH

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## Communicating about AIDS

Mark Hochhauser, PhD

Limited progress towards a vaccine and effective treatments has made prevention crucial to stopping the AIDS epidemic. Despite repeated recommendations from health care professionals that education should be the focus of this effort, very little is known about effective techniques to provide information that will change behavior.

The challenge of educating the public is so great because misinformation about the threat of HIV and its routes of transmission is far more widespread than the virus itself. A December 1987 National Health Interview Survey (NHIS)<sup>1</sup> of 5,597 adults in the United States found considerable misunderstanding about AIDS, particularly among those with less than 12 years of education—an estimated 41 million Americans.

Among those in the study at this educational level, 68 percent said that they knew little or nothing about AIDS. Many incorrectly thought HIV could be contracted through a variety of routes: 34 percent by donating or giving blood, 35 percent by using public toilets, 39 percent by being coughed or sneezed upon by someone with AIDS, and 38 percent by being bitten by mosquitoes or other insects.

These individuals—the poorly educated and the functionally illiterate, as well as the mentally ill and the homeless—may represent significant “high-risk” groups for transmission of HIV. Their lack of information about AIDS will not prevent them from contracting or transmitting the virus.

Educational programs for this group, as well as other sectors of the general public, must go beyond the crude risk group categories identified by the Centers for Disease Control (CDC)—gay and bisexual men, I.V. drug users, hemophiliacs, and sexual partners of members of other risk groups—in order to be effective. These programs must consider key demographic characteristics such as education, socioeconomic status, and cultural factors. They must also acknowledge the fact that cultures seen as uniform, such as Native Americans, Blacks or Asians, are not, and may differ in a variety of ways, including country of origin, language, values and religion.

### Information Techniques

The most common method for providing information about HIV transmission is anonymous distribution, in which there is no direct contact between the source and the recipient of the information. Television, radio, brochures, pamphlets and booklets, for example, have become primary sources of information. While these methods are convenient, there is little evidence to show that they are, in fact, effective in changing behavior. Information may play a role in increasing knowledge, and perhaps in affecting attitudes, but information alone appears to

have little impact on behavior change. A national health education campaign in Great Britain, based on whole-page newspaper advertisements in the national press, caused some increase in information, but no change in misconceptions about AIDS or alteration in attitudes or behaviors.<sup>2</sup>

The NHIS found that most people in the United States report getting AIDS information from television (84 percent). Other sources were considerably less influential: newspapers (55 percent); magazines (28 percent); radio (10 percent); brochures (9 percent). Only about 6 percent of the sample reported getting most of their information about AIDS from a doctor or health provider. Sources in other countries may vary considerably, for example, radio may play a major role in health communication in developing countries.

Brochures, despite the fact that they have been widely

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distributed and may be effective informational tools for specific groups such as gay men, have had little impact upon the knowledge of the general public. In order to reach this constituency, educators must emphasize television and newspapers as sources of AIDS information.

### AIDS Brochures: Separating Fact from Fiction

Despite their limited use up to now in educating the general public, brochures may be particularly effective when targeting a specific audience. In these cases, however, information must be clear, accurate, unambiguous, relevant to this targeted group and geared toward their reading level.

Relatively little has been published about the evaluation of AIDS educational efforts. A recent review<sup>3</sup> of selected AIDS programs by the congressional Office of Technology Assessment found virtually no documentation of evaluation of the behavioral change that might result from these programs. It should be noted, however, that most early prevention campaigns in the United States were developed before the government started to provide funding for education and evaluation.

A review of 22 safe sex brochures from the United States, that evaluated 13 areas, identified significant limitations in the content of specific educational materials. These included: lack of a rationale for why a particular practice was considered risky; focus on prevention of AIDS, without mention of other sexually-transmitted diseases; evocation of fear as a way to encourage preventative measures, without advice on how to deal with the fear; and ambiguous recommendations to “reduce or limit” the number of sex partners without specific numbers.

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# Communicating . . .

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In those studies that have reported significant changes in sexual behavior among gay men, the motivation for such changes often cannot be identified. These changes have occurred in environments where knowledge of AIDS has come from a variety of sources, including discussion among peers and the personal experience of knowing people who have died of AIDS. Written materials clearly have some role in promoting behavior change. The challenge is trying to identify the specific impact of particular interventions. The conclusion is that we do not yet know what information presented in which ways works for whom to change what behaviors.

Two tools are helpful in developing and evaluating brochures: readability formulas and focus groups. Readability formulas assess characteristics of the text of a brochure including: word length and mix, sentence length, use of common words, and the unnecessary use of difficult words. From this data, an index of reading difficulty is calculated and expressed as the reading grade level required to understand a particular document.

In a review last year of 16 AIDS educational brochures from the United States, Hochhauser<sup>4</sup> found that the average reading level of these brochures was grade 14 (second year of college), with some written as high as grade 17 (first year graduate school). Some of these brochures are likely to be beyond the understanding of large segments of the population. The recent "Understanding AIDS" brochure, published by the U.S. Public Health Services and mailed this summer to every household in the United States, was written at an eighth-grade reading level.

There are approximately 40 readability formulas and their results are not always consistent. Experts suggest that three or four formulas should be used together to make a determination. Critics say that readability formulas produce materials that are readable, but which may also be choppy, oversimplified, condescending and boring. In the end, readability formulas should be used as one, but not the only tool in developing brochures.

While readability formulas have many limitations, the concept of "readability" is an important one in AIDS education. Without addressing issues of readability, much AIDS information is likely to be misunderstood by much of the public. As an alternative to overemphasizing readability formulas, focus groups can be used to pre-test written materials and ensure that the information and its presentation is relevant and understandable to the intended audience.

A focus group is comprised of eight to 12 people who represent this audience. With the help of a moderator, the group

discusses the topic in question and offers researchers answers to questions such as: What kind of information about AIDS do you want to know? Does this brochure provide this information? Is it understandable? What do you understand? What don't you understand? Is this brochure persuasive? Would you change your behavior if someone gave it to you?

Focus groups must be carefully planned. The moderator should be knowledgeable about the topic and the audience, and should be clear about the goal of this particular focus group, the areas it will cover, and how much time will be spent discussing each area. There should also be a plan as to how information gained in the focus group will be organized for analysis. It is wise to involve people trained in marketing in these efforts.

## Facts about AIDS

The presentation of AIDS information is often inaccurate. Much of what passes for AIDS information, particularly in the mass media, is incorrect or at best misleading. The following concepts are misrepresented most often.

**The AIDS test.** There are a number of tests that detect the presence of HIV or are correlated to a suppression of the immune system. The most common among these is a test for the presence of antibodies to HIV, to which the media consistently refers as the "AIDS test." Not surprisingly, the NHIS found that 40 percent of the general public believe that the HIV antibody test reveals whether a person has AIDS, despite the fact that a person can be asymptomatic for years after infection with HIV. Combining "AIDS" with "test" compresses in the minds of many the time frame for the development of AIDS from an average of seven years to however long it takes to get the test results back. One can only guess the number of Americans who have not been tested because they do not want to find out if they "have AIDS."

**"Getting" AIDS.** AIDS is a clinical description based on the presence of certain opportunistic infections and cancers, and usually, but not always, a positive HIV antibody test. Strictly speaking a person does not "get AIDS"; he or she contracts HIV. References to "getting AIDS" are too similar to "getting a cold," and may help perpetuate the myth that HIV can be spread through casual contact.

**The AIDS virus.** AIDS is only one of the manifestations of infection by HIV, the virus believed to cause AIDS. The mass media emphasis on the end stage disease (AIDS) rather than the beginning stage cause (HIV) implies that AIDS itself is infectious. AIDS is not communicable; HIV is.

**High-risk groups.** Despite the efforts of many, some brochures still refer to high-risk groups, rather than high-risk behaviors. The danger in this representation is that as long as people do not identify with those "groups," they may not perceive themselves at personal risk for HIV infection.

## Some Practical Suggestions for Developing Educational Materials

**Objectives.** What do you want the materials to accomplish? Do you want to change knowledge, attitudes or behaviors? Can this be accomplished in a single brochure or booklet, or might a series of materials be more appropriate? How will you evaluate the impact of your materials?

**Marketing Tools.** Produce materials that are intriguing, readable and understandable to your target audience. Consult with marketing experts and become familiar with basic marketing and advertising terminology and practices. Instead of assuming that you know what your audience needs to know, ask your audience what they want and try to meet that need. Work closely with representatives from your intended audience and use formal focus groups to test messages. Ask yourself, focus group members and other advisors, such as experts in AIDS, communication and education: What are the benefits and risks of this material? Does it empower the listener? Does it complement previous messages?

**Identify barriers.** Political factors may dictate the content of your materials and require compromises. The most common barrier is reluctance to approve sexually-explicit information. One way to answer this objection is to emphasize the life and death nature of AIDS and ask, "What is more offensive, sexually-explicit material or death?" Another way is to marshal support for your materials from well-respected individuals, including public health officials, physicians, health educators and government administrators.

**Recognize developmental differences.** The presentation of information for 16-year-olds should be different from the presentation for 26-year-olds. Knowing how your audience thinks is vital. For example, one of the most difficult problems in educating adolescents and young adults is their perception of immortality: their belief that illness and disease happen to other people. Developmental differences among various cultural, socioeconomic, and ethnic groups may complicate this even more.

**AIDS carriers.** People with AIDS do not carry AIDS; they are infected with HIV. Some politicians are concerned about irresponsible individuals who they say are spreading AIDS to the general public. This suggests that the virus is more communicable than is actually the case. More importantly, it omits the fact that it takes one person to contract the virus as well as one to transmit it. Political solutions that overemphasize incarcerating transmitters of HIV, without acknowledging the responsibility of the potential receivers of the virus, again mislead the public.

These points are more than an exercise in semantics. As long as misinformation about HIV and AIDS is disseminated to the public, individuals will not be able to make truly informed choices about their behaviors. At the very least, people will be confused by the contradictory messages they receive.

**Mark Hochhauser, PhD** is the former Director of Health Education at the University of Minnesota student health service and is now a consultant on AIDS issues.

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## Diagnosis/Treatment/Prevention

# The Effect of AIDS Education on Mental Health Professionals

**Thomas M. Irish, PhD and Nancy Gourash Bliwise, PhD**

A survey of mental health practitioners before and after a training workshop conducted by the AIDS Health Project showed a positive shift in the attitudes of participants toward people with AIDS, I.V. drug users and gay men. At the same time, it demonstrated an increase in participants' concerns about dealing with sexually-explicit material, death and dying and the stress of working with people with AIDS.

Results such as these are particularly significant as the numbers of AIDS educational programs for health professionals grow. This report documents both the positive and negative effects of the workshop and offers insights into the way educational efforts must be packaged to be most beneficial.

#### Survey of Participants at AHP Training

In the fall of 1987, the AIDS Health Project conducted an intensive, three-day training workshop for clinicians from a southeastern state department of mental health. Seventy-four clinicians attended the training. The workshop presented a comprehensive overview of HIV-related health care and mental health issues.

Using both didactic and experiential components, the training covered the following areas: basic medical information about AIDS, including a description of HIV disease and how it is treated; the epidemiology of AIDS; how to prevent transmission; the relationship of substance abuse to the spread of HIV; how to take a sexual history; and the psychiatric assessment of clinical syndromes such as AIDS dementia. The workshop also provided training in pre- and post-test AIDS antibody-test counseling.

Psychological issues discussed by participants included stages of coping with AIDS, stigmatization, family issues, and typical reactions of people affected by AIDS. The training made

use of many small group discussions, in which clinicians were asked to express their personal feelings about death and dying, drug use, homosexuality, and human sexual behavior. These exercises led to the exploration of the key issue of clinicians' countertransference reactions and the importance of being aware of these reactions when providing AIDS care.

An attitudes survey developed by the authors was administered directly before and after the workshop. The survey assessed clinicians' attitudes towards populations at highest risk, contagion, sexuality, death and other AIDS-related issues, using an 80-item self-report questionnaire. Subjects chose one of six responses ranging from strongly agree to strongly disagree. Among the statements tested were: I would not mind counseling the lover of an AIDS patient; I.V. drugs users only waste time and resources; Hispanics and Blacks should be especially concerned about catching AIDS because it is all around them; My fear of catching AIDS would keep me from working with AIDS patients.

#### Results of Attitudes Survey

The results of the survey indicated that a significant change in attitude did occur over the course of the workshop. The pre- and post-training surveys showed that clinicians' attitudes shifted significantly toward greater acceptance of gay people. Twenty percent changed their answers from disagreement to agreement in response to the statement, "I would feel at ease at a party where many guests were homosexual." Thirty percent changed from agreement to disagreement in response to, "Homosexuality is not as good as heterosexuality." Other shifts in attitude included greater confidence in counseling the lover of a person with AIDS and a greater agreement with the idea that people with AIDS often have close interpersonal relationships.

The survey also revealed that clinicians became significantly less afraid of physical contact with people with AIDS and of contracting HIV while working with AIDS patients. Clinicians also saw I.V. drug users as more deserving of professional time and 23 percent changed their answers from agreement to disagreement in response to the statement, "It is difficult to be sympathetic to I.V. drug users." Racist attitudes towards Blacks and Hispanics also decreased during the workshop.

Of equal importance are the areas about which clinicians' anxieties significantly increased. Some saw themselves as less likely to work with people with AIDS because of the stress involved in patient care. This anxiety also increased when clinicians discussed sexually-explicit matters. Twenty-seven percent changed their answers from disagreement to agreement in response to the statement, "It is hard for me to ask patients about their sexual practices." Clinicians also expressed a disinclination to discuss the subject of death with a dying person, and 29 percent changed their answers from disagreement to agreement in response to, "I am very much afraid to die."

#### Conclusion

The survey indicated that the workshop had a significant impact on the attitudes of practitioners working in more rural states where AIDS is not as prevalent as it is in cities such as New York or San Francisco. Their concerns about contagion and negative attitudes towards those groups at risk for AIDS decreased as clinicians considered individuals at-risk less as stereotyped external threats and more as people in an understandable and dire situation. As these fears decreased over the course of the workshop, however, personal and internal fears increased.

It should be remembered that this training addressed an audience of clinicians who had little experience in providing AIDS care. Most in attendance were probably hearing the concrete details of AIDS care for the first time and probably felt anticipatory anxiety when they imagined themselves faced with the real-life experience of working with AIDS. In addition, such intimate, personal concerns as sexuality and mortality are still beyond the comfort level of many professionals.

Educators should consider these reactions when planning workshops and should expect that initial trainings, while reducing

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some fears, may actually accentuate others. While AIDS trainings can force professionals to confront, perhaps for the first time, issues such as sexuality and working with the dying patient, educators and administrators should be aware that becoming comfortable with these issues is a process that requires time and experience. After some experience is gained, additional, long-term educational strategies can be developed to help professionals improve their skills in these areas.

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## BRIEFS

### In Review

**Strategies for Survival: A Gay Men's Health Manual for the Age of AIDS.** Martin Delaney and Peter Goldblum, PhD, MPH, with Joseph Brewer. St. Martin's Press, New York, NY, 1987; 320 pages, paperback, \$10.95 U.S.

The AIDS crisis has placed gay men in a new relationship to the medical profession. Already a marginal population whose health concerns fall outside the sphere of traditional medicine, gay men now find themselves dependent upon a professional group that often cannot provide them with clear or unbiased answers. Some medical providers question the gay lifestyle, mix facts with fiction, or unwittingly give homophobic advice under the guise of "safer sex" counseling.

*Strategies for Survival* provides a gay-affirmative "insider's" approach to the issues confronting gay men today and validates gay male sexuality in the face of existing dangers. Coping, making choices, evaluating one's approaches to the variety of decisions that need to be made—these are some of the tools offered in this manual directed at gay men and written by gay men. The authors use a broad definition of health that considers physical, intellectual, social and emotional well-being. They take the concept of exposure to HIV and use it as an opportunity to discuss various layers of gay identity and sexuality.

In general, the book avoids the *whys* and focuses on the *hows*. How can I build an integrated health plan? What goals should I set for myself? Which goals for myself are currently outdated or self-destructive? How do I achieve these goals? This approach implies that some control over the health crisis can be attained. But, the book makes no false promises, and places responsibility for behavior change and for making informed choices onto the reader's shoulders and not in the hands of the doctor.

The authors recognize the powerful role of internalized homophobia in shaping responses to the epidemic, and shun stereotypic morality, providing instead a refreshing chorus of self-acceptance. Facts, commentary and workbook exercises are interwoven through each of the chapters.

Occasionally, the book lapses into a cookbook tone such as, "Listen to your friends more." No mention is made of the significant, fledgling, self-help movements for sex and love

addicts, and an insufficient amount of the book addresses the subgroups of gay men who continue to put themselves and others at risk in spite of knowing the facts. A few more *whys* are in order. These are minor faults, however, in a book that encourages gay men to re-examine old assumptions and to transcend aspects of the epidemic.

**James Fishman, LCSW** is the Coordinator of Men's Services at Operation Concern, San Francisco's gay and lesbian mental health agency and is also a psychotherapist in private practice.

## Recent Reports

**HIV Infection and Genital Ulcer Disease.** A marked increase in the risk of HIV infection occurs among gay men with genital ulcers caused by herpes simplex and syphilis, according to scientists at the University of Washington School of Medicine.

The study, published in the *Journal of the American Medical Association* (September 9, 1988), included two populations of gay men: 200 patients who presented with acute rectal or gastrointestinal infection at a sexually transmitted diseases (STD) clinic and 111 who sought HIV-antibody testing and counseling from a local health department. The STD subjects were tested for a variety of infections including HIV disease, herpes simplex and syphilis. The HIV-antibody test subjects were also tested for herpes and syphilis.

The study concluded that historical or serologic evidence of herpes simplex or syphilis, the two most common causes of genital ulcers among gay men, resulted in a threefold to eightfold increased risk of HIV infection. These statistics persisted even after adjustment for amount and type of sexual activity and are supported by prior research on female prostitutes and heterosexual men, both in Kenya. The study also concluded that a history of non-ulcerative STDs, such as gonorrhea and chlamydia, was not associated with HIV infection.

## Next Month

As a greater consensus forms about the utility of HIV-antibody testing and as experts advocate its wider use, counselors are confronted more often by clients who ask for help in deciding whether to be tested. In the November issue of **FOCUS**, **Peter Goldblum, PhD, MPH** will discuss the pros and cons of antibody testing and the approach a therapist should take with clients who are trying to make this decision. The article will cover issues such as the significance of testing, the accuracy of the test and the importance of anti-discrimination measures. Goldblum is a therapist in private practice, the former Deputy Director of the AIDS Health Project, and a member of the AIDS Task Force of the Pacific Graduate School of Psychology.

Also in this issue, **Judith Wilber, PhD**, a virologist at the San Francisco Department of Public Health, will review from a scientific perspective the variety of tests that are used to study HIV infection, including antibody tests, DNA amplification (PCR), antigen tests and T-cell assays.

## 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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