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THE IDENTITY POLITICS OF BIOMEDICAL RESEARCH: Clinical Trials, Medical Knowledge, and the Female Body

Mary Beth Caschetta

INCLUDING WOMEN IN SCIENTIFIC RESEARCH: A Change in Name Only?

Teresa McGovern, Esq.

APPLYING HARM REDUCTION TO SEXUAL AND REPRODUCTIVE COUNSELING: A Health Provider's Guide to Supporting the Goals of People with HIV/AIDS

Risa Denenberg, FNP

OUT OF THE QUESTION: Obstacles to Research on HIV and Women who Engage in Sexual Behaviors with Women

Nancy Warren, MPH

THE TRUTH ABOUT LATEX CONDOMS: A SIECUS Fact Sheet

HIV/AIDS: An Annotated Bibliography of Print Material

Carolyn Patierno

THE IDENTITY POLITICS OF BIOMEDICAL RESEARCH

Clinical Trials, Medical Knowledge, and the Female Body

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In the Spring of 1993, the Food and Drug Administration (FDA) announced that it will lift a 16-year-old ban that prohibits women from participating in early experimental drug trials. However, the FDA's revision of the discriminatory policy has been received with criticism, since new guidelines to govern pharmaceutical companies and other research practices fall short of ensuring women's full participation in early scientific research. The importance of such participation is evident; not only is there a current absence of knowledge about female biology, but oftentimes drug trials are the only access to potentially life-prolonging treatments for women with life-threatening illness, such as AIDS. In fact, women's HIV health activists and advocates have worked particularly hard in applying political pressure to ensure the equal treatment of women in science and medicine. Most commentators have expressed the belief that, in its 1993 revision of scientific policy, the FDA has not come far enough. Nonetheless, it is noteworthy that this slight alteration in the scientific research protocol represents one of the few basic changes in the system since the late 1700s when the first six British sailors were enrolled for the testing of experimental scurvy medicine.

The National Research Council of the National Academy of Sciences was not the first to observe that in the face of AIDS our social systems have generally failed.[1] But examples like the recently discovered treatment failures of nucleoside analogues like AZT have made us newly aware of the limitations of science. The scientific shortcomings of HIV research, especially where women are concerned, have facilitated what can be called the identity politics of biomedical research. Identity politics is the common name for the current trend in which we as a society are moving toward increasing fragmentation with the creation of more and more isolated identities. The formation of new and distinct identities, such as African-American, Latino, gay or lesbian, person with AIDS, serves a political purpose for those who have traditionally been considered outsiders. Thus by organizing around a new identity, people can fight against societal oppression and strive for more power within the political economy. For instance, the identity "women of color" was recently formed for political, cultural, and liberating purposes. Additionally, "lesbians with AIDS" is an emerging political identity formed by women who have been excluded from epidemiological, medical, and political consideration within the political framework of the epidemic. Thus, in the identity politics of biomedical research, demands are made on researchers that scientific trials be designed to yield information about people with particular identities. In this way, scientific researchers are being pressured by different contingents to consider biology by ethnicity, race, gender, age, etc. Do infants born to urban Latina mothers have a better chance of survival than those born to urban Caucasian mothers? Do diseases act differently in women than men? Does an African-American body metabolize some medicine differently than a Caucasian body or an Asian body? How does identity affect disease prevalence and progression? Should older Americans demand specific trials to gather information about diseases and the aging process? These and other questions are newly being asked and addressed for the first time by biomedical researchers. Pressures from people with AIDS are foremost in leading to such a dramatic change in science and medicine.

Because of these trends, and because of at least a spoken commitment toward changing social systems to better respond to the needs of people with AIDS, we may now be better situated to see that medical knowledge is inseparable from social relations and experience. Due to its highly specialized practice and discourse, medical research has always been given a technical status that has allowed it to seem removed from other intellectual and social activities. In fact, western medicine has traditionally been viewed as a natural system of objective observation, not bound by societal rules, but invested with autonomy and authority.[2] "Science is power, God is dead," Nietzsche wrote during the early reign of western medicine, science, and technology. However, the demise of medical science as the new God — because of its increasingly undeniable association with and dependence upon social relations — now seems imminent. This article takes a closer look into the history of women's participation in medical research with a special emphasis on women and HIV/AIDS to better illustrate the social relations of medical science. First, it will be helpful to explain briefly the structure of U.S. drug testing.

Drug Testing and Changing Scientific Categories

When an experimental therapy is under investigation for its efficacy and safety as an intervention into a specific disease, it must be tested in a series of required experiments. Each candidate drug is first observed in the laboratory in test tube experiments in order to make sure that it has activity against the specific disease-causing organism it is meant to treat. The drug is then tested in preclinical trials, sometimes called animal models. In this phase of scientific research, the drug is tested in mice, rats, cats, dogs or monkeys. The next phases include experiments with humans and are referred to as "clinical trials." Phase I trials enroll a small homogeneous group of people in order to establish rate of absorption, safety, and the best dosage according to minimum toxicity. Phase II and III trials are larger and meant to show how effective the experimental agent is against a specific disease compared to the control (in most cases, standard treatment or no drug at all, which is sometimes called placebo). If the drug is proven safe and effective, it is submitted to the Food and Drug Administration (FDA) for licensing. If the data from all of these research experiments are accepted as sound, the drug becomes available to the general public in pharmacies with a doctor's prescription. Follow-up research is mandated in the form of phase IV studies, which document long-term effects of the drug in a very large group of people and are usually conducted after the drug has been approved.

This rigorous process is governed by the Department of Health and Human Services (DHHS) and is required for all experimental treatments tested by the federal government. Governmental research in AIDS is mostly funded by the National Institutes of Health (NIH) which oversees a group of approximately 50 research centers around the country (hospitals mostly) that make up the AIDS Clinical Trials Group (ACTG). While technically the DHHS regulations — for example, the guidelines that exclude fertile women from phase I and II trials — apply only to federally funded projects, in practice, almost all institutions that conduct research, regardless of funding source, have adopted these rules and regulations. Additionally, many nations worldwide follow the lead of the DHHS and employ similar, if not identical, processes for drug approval. This method of research is regarded as "purely scientific." However, a closer examination of research and women produces the opposing view that the categories of scientific research are bound quite closely to social relationships.

An example of this phenomenon is the emergence of the social and political category "population subset" as a medical research entity. The FDA proposal for the inclusion of women in clinical trials clearly evidences this new trend as follows:

> Documented subgroup pharmacodynamic differences are fewer, but have been observed, including increased sensitivity to beta-blockers in Asians, decreased sensitivity to beta-blockers in the elderly, decreased responsiveness to the blood pressure-lowering effects of adrenocortical extract (ACE) inhibitors and beta-blockers in African-Americans, and increased sensitivity to the central nervous system effects of midazolam in older people.[3]

Previously, the biological individuation of affected patients unless indicated epidemiologically (and sometimes not even then) in accordance with race, ethnicity, socio-economic status, age, or gender was unheard of. The idea is relatively new that people of different ethnicities and races may respond differently to drugs and disease. The FDA statement above asserts that the concentration of a drug in the blood or other tissues over time (pharmacokinetics) or the body's response to a given concentration of a drug (pharmacodynamics) may differ according to whether a body is Asian, African-American, or Caucasian. The same has been asserted according to whether the body is female rather than male or older rather than younger.

The overriding principle for trial participant enrollment has been homogeneity, and populations studied (sometimes regardless of disease prevalence within that population) are almost invariably young and middle-aged Caucasian men, unless significant factors indicate otherwise, as in the case of sickle cell anemia. Scientific research theory, for the most part, has been so intent on homogeneity that body mass, weight, and water gain differences even among white male trial participants are not usually factored into the research design. The establishment has been blind to difference in favor of similarity. But it seems that the current political tenor, which demands that social systems attend to differences on all levels, whether by race, gender, or socio-economic status, has begun to affect even medical research. Slowly, therefore, we have witnessed changes in underlying philosophies of scientific research that lean toward embracing individual difference and seem to correspond with the identity politics of the day.

Exclusion of Women From Scientific Research

It is best to begin the history of women's exclusion from scientific research with a current-day illustration from a corner drug store. A woman suffering from depression enters her local pharmacy in order to fill a prescription for a common antidepressant medication. She feels secure that this drug has been proven safe and effective, which is, after all, the promise of medicine as relayed to her by her doctor. She will feel better, more like herself, her doctor says, by taking the prescribed drug. This is, after all, the modern magic of medical science.

However, what this woman does not know is that all of the original human research for antidepressant drugs was conducted on a group of people unlike her, to be specific, on a group of young white men. The drug has never been tested in female bodies, which are, regardless of essentialist vs. constructionist debates, different in some undeniable aspects from men's bodies. For instance, women have smaller body mass, more fat, different hemoglobin levels, and varying hormonal levels due to their menstrual cycles. The original researchers of antidepressant medication did not anticipate these differences; in fact, they did not even ask the question.[4] The result is unfortunate: in women the usual dose of prescribed antidepressant drug is sometimes too high or too low, depending on the natural hormonal changes during the menstrual cycle.[5] In fact, the drug may actually cause additional problems in the regulation of a woman's illness that — depending on the experience of her doctor — may or may not be detected or aptly managed.

These problems, until very recently, had not been brought to light and are still only a marginal part of medical discourse. According to much of modern science, women and men are biologically the same, and therefore clinical trials, which have insisted upon a homogeneous group of study subjects, have been conducted for the most part with white men. In general, the problem that the woman in the pharmacy faces in choosing a medication that has not been tested in the female body has only recently been identified. The information culled from almost all medical research has been and still is comfortably and routinely extrapolated from white men to women and people of all ethnicities, who are referred to as "the general population."

A stunning example is the original research on the ability of aspirin to prevent coronary artery disease which was done exclusively on men, although it had been known for some time that heart disease is a leading killer of women.[6] Other examples of this kind of extrapolation abound. Gender-related differences for a number of drugs have only recently been discovered. For instance, Propranolol, a hypertension-reducing treatment for heart disease, is metabolized more slowly in women than in men, probably because of differences in sex hormones which seem to help metabolize the drug.[7] Lower rates of excretion from the body of acetaminophen (an aspirin-like anti-inflammatory), several benzodiazepines (hypnotic drugs), lidocaine, aspirin, ondansetron, and mephobarbital (a barbiturate) in women have also been described.[8] The exclusion of females from medical research is so institutionalized that even female rats (except in reference to reproduction) are commonly excluded from early basic research on which many scientific decisions rest.[9]

Obviously the impact of the exclusion of female bodies from medical research is great. For instance, more women than men die from heart disease each year, yet women with heart trouble are less likely to receive treatment, even when symptoms clearly indicate severe cardiac trouble.[10] And while lung cancer is the number one cancer killer of women, they are twice as likely as men *not* to be tested for lung cancer.[11] Additionally, while AIDS is a leading killer of women in many urban areas, the official definition of AIDS has until recently excluded female-specific HIV-related conditions. And the latest definition of AIDS, revised this past January, includes only severe cervical cancer. Cervical neoplasia, pelvic inflammatory disease, and chronic, severe vaginal candidiasis remain largely unexamined. Essentially, it still holds true that what is known about HIV disease is derived from research on men.[12] AIDS in women is generally regarded as a male disease in female bodies.

Women and HIV/AIDS Research

In particular, AIDS research has a disproportionately low number of women participating in experimental drug, observational, and other scientific trials. As of January 1992, 1,151 women were enrolled in the U.S. AIDS Clinical Trial Group (ACTG), including 154 pregnant women who are enrolled in trials which aim to stop HIV transmission to the fetuses of HIV-positive mothers. During the same time period 13,628 men were enrolled. Women's enrollment in trials nationwide has increased only slightly since 1990, when increased efforts to recruit women were said to have become a priority. The percentage of female enrollment from 1990 to 1992 increased from 6.5% to 7.8%.[13] Researchers from the Women's Health Committee of the ACTG report that in order for a large clinical trial of 2,000 participant to yield significant gender differences in toxicity or response to therapy, greater than 15% of trial participants must be women.[14]

In the case of AIDS, much activist and advocate pressure has been applied to urge clinical researchers to conduct female-specific trials. Many have pointed out the ethical, legal, scientific, and moral problems with the exclusion of women from existing clinical trials. However, the message has had a difficult delivery. For example, in the summer of 1992, the VIII International Conference on AIDS convened a most prestigious and wide-ranging panel of researchers, policy experts, government officials, clinicians, social workers, activists and advocates, and people with HIV from around the world. At a conference session about the ways in which HIV disease manifests different symptoms in men as compared to women, researchers discussed emerging knowledge about women and AIDS. The disease, they asserted confidently from their data, is the same in men as in women.

However, upon closer examination of the trial designs that yielded such data, a universal phenomenon was called to attention by women in the audience. The researchers had neglected to gather data on all the biological areas where men and women differ. For example, no gynecological data was collected, nor were hormone levels, reproductive impacts, or changes in menstruation noted during the trial. Essentially, then, the scientists categorized women as men and studied them only in accordance with their biological similarities to men. Their conclusions were easy and expected: men and women are the same as far as HIV disease is concerned. In this case, the disease was studied as a male disease in female bodies that were in fact treated throughout the research as male bodies.

The medical community has recently recognized that women are underrepresented in clinical research in large part due to concern over possible harm to a potential fetus (teratogenic effects) resulting from experimental drug testing. Despite the 16-year-old guidelines excluding women from early scientific research, an escape clause has always been maintained, allowing women with life-threatening diseases access to experimental therapies and clinical drug testing. The underlying principle of this escape clause is that women who might otherwise die have the right to decide their own treatment and fate, regardless of harm to their reproductive abilities and offspring. Nonetheless, women with HIV disease, a life-threatening illness, continue to be excluded from clinical trials of experimental HIV treatment, unlike, for instance, women with cancer, who are routinely granted the use of experimental cancer treatments, even those thought to be harmful to a fetus. The discrimination against women with HIV disease in this particular situation is undeniable.

History of Recent Policy Changes

In 1983, the Assistant Secretary for Health established a Public Health Service Task Force on Women's Health Issues. The Task Force presented a two-part report, the first of which recommended that "biomedical and behavioral research be expanded to ensure emphasis on conditions and diseases unique to, or more prevalent in, women in all age groups."[15] To carry out such a mandate, the NIH in 1986 developed and published a policy statement urging applicants to include women in clinical studies.[13]

Additionally, an inventory was conducted of the research activities supported by the National Institutes of Health (NIH) in 1987. This inventory found that NIH spent approximately $778 million on women's health issues, approximately 13.5% of the budget. The following criteria were used to determine that a particular health problem was a "women's" issue:

- diseases or conditions unique to women or some subgroup of women;
- diseases or conditions more prevalent in women;
- diseases or conditions for which the risk factors are different for women or some subgroup of women;
- diseases or conditions for which the interventions are different for women or some subgroup of women.[16]

In 1990, with pressure from Congresswoman Patricia Schroeder, Co-Chair of the Congressional Caucus for Women's Issues in the House of Representatives, the General Accounting Office (GAO) reported to Congress about the NIH policy and practices in this area. The GAO report found a non-uniform implementation of policy throughout the agency.[17] Although the NIH announced its policy encouraging the inclusion of women in research study populations in 1986 and guidance for implementation was published in 1989, its policies were not applied consistently at all. Further, NIH officials had taken little action to encourage researchers to analyze study results by gender. Due to the usual lack of coordination among governmental agencies, the FDA during the same period, accepted new drugs into the market without proper gender analysis. To date, no labeling mandate from the FDA requires pharmaceutical companies to inform consumers that for the most part the effects of approved drugs in women are unknown.

The problems with NIH's implementation of gender research policies were the subject of congressional hearings. Thereafter, in September, 1990, the Office of Research on Women's Health of the National Institutes of Health was established as a means to strengthen the effort of the NIH to improve the prevention, diagnosis, and treatment of illness in women and to enhance research related to disease and conditions that affect women. Women's health activists have since questioned whether the functioning of this office is true or effective. A second investigation on the matter was reported in 1992 by the General Accounting Office, and a request was put forth by members of Congress regarding the inclusion of women as research subjects in NIH-sponsored studies.[18]

The 1992 GAO report found that while a 1989 guideline recommends to drug manufacturers that they test new drugs on representative patient populations, it does not define "representative." In fact, 25% of drug manufacturers report that they do not deliberately recruit representative numbers of women as participant in drug trials. Further, more than 50% of drug companies claim that they have not been asked specifically to include women in drug trials. The GAO report confirmed earlier findings that women were generally underrepresented in the trials surveyed. And although there were enough women enrolled in some trials to detect gender-related differences in response, the data were not analyzed to determine if women's responses to the drug under investigation were different from men's.[19]

How Women Have Been Excluded

The lack of research in women has been justified in a number of ways. Because menstrual cycles were said to constitute a separate variable affecting test results, researchers have used menses as a reason to exclude women from research.[20] A woman's period "muddies" research data, so to speak. Additionally, medical experts have been reluctant to perform studies on women of childbearing capacity because experimental treatments or procedures may affect their reproductive capabilities and/or a potential fetus.[21] The most common excuse used by the pharmaceutical companies is that they wish to avoid being sued by women who suffer damage to unborn children during trial participation. However, a review of legal documents clearly shows that pharmaceutical manufacturers have not faced substantial litigation by clinical-trial participants.[22] In fact, liability litigation is more likely to occur after a drug has been approved and used in a population in whom it had not been systematically studied in clinical research, as in the famous case of Thalidomide in the 1960s.[23]

While the "fetal hazard" principle has effectively excluded women from clinical drug testing, the FDA, nonetheless, maintains an escape clause for life-threatening illness, allowing women faced with fatal disease to decide for themselves whether to enter drug testing and possibly risk harm to a potential fetus or to reproductive function. As mentioned earlier in the case of cancer, women have been generally allowed access to experimental therapies. The key vehicle to protect both women seeking treatment and the companies conducting the experiments is the informed consent document. In 1981, the FDA issued regulations that assure subjects in clinical trials be fully informed in an unbiased manner about the findings from animal studies of an experimental drug. The purpose of informed consent in clinical research is to educate participants about potential risks and benefits and allow for informed decisions concerning participation. The principle that a woman has the right to make her own decision based on full information concerning the risk and benefit about her pregnancy has been upheld by the Supreme Court. For example, the Pregnancy Discrimination Act of 1978 was interpreted in the recent *United Automobile Workers v. Johnson Controls* case, which prohibits a blanket exclusion of women from jobs they are qualified for solely because working conditions might pose potential risks to fetuses.[24]

Genuine informed consent is of the utmost importance when considering the inclusion of women in clinical trials and respecting the autonomy and decision-making ability of women. However, in a preliminary review of such trial documents, no consistent, logical approach is in place that sufficiently addresses such important matters as fetal exposure and full informed consent.[25] This review of the informed consent documents of 36 AIDS clinical trials from a major medical center in New York City shows that the quality and amount of information given to the potential female trial participant is alarmingly insufficient. Pregnant women, for instance, were generally excluded from participation but on inconsistent grounds. Exclusion based on potential teratogenic risk (harm to a fetus) was vaguely defined. Specific risks, when identified, were either scantily described or described in prohibitively technical language, thus precluding genuinely informed consent. This matter warrants further exploration so that problems can be addressed and full informed consent can be ethically delivered.

It is also important to note that at least in some cases, harm to a fetus due to exposure to experimental drugs has been traced to alterations in male sperm.[26] These findings have been interpreted to mean that men with reproductive potential might also cause harm to their potential offspring by participating in clinical trials. However, it is more logical and efficient to inform both men and women about known risks to offspring than to exclude all people of reproductive potential from scientific research.

Pregnant Women and AIDS Clinical Trials

Much attention has been focused on HIV-antibody testing of pregnant women for the purpose of preventing transmission of HIV infection from a pregnant woman to her unborn child. Fewer systematic research efforts have been directed toward the successful treatment of the HIV-positive pregnant woman herself. Exclusion of women from clinical trials is particularly dramatic in the case of pregnant women, and much effort and energy has gone into such exclusion. Minkoff and colleagues assert, however, that "the potential for teratogenicity is not in itself a sound basis for excluding a pregnant woman who could theoretically benefit from an experimental medication."[27] In fact, the authors go on to explain that in a non-research context, HIV-infected women, including those who are pregnant should be informed about and prescribed (if they so chose) standard treatment for HIV disease, although risk of fetal harm associated with the treatments is unknown. However, it seems clear that for the most part, unlike with other life-threatening diseases, pregnant women with HIV/AIDS are generally not given the option of deciding treatment regimens for themselves.

Asking the Questions

The summer of 1993 has been described as the end of an era in HIV/AIDS research and the bleakest season in the history of the epidemic. Perhaps for the first time there is agreement from all parts; the development of a cure or even a reasonably effective treatment for HIV in the near future is unlikely. Reports from this year's International AIDS Conference in Berlin dispelled quite thoroughly the notion that HIV/AIDS could become a "chronic and manageable" disease for many people. Even the media, usually bent on ferreting out a topic worthy of hysteria — deep kissing transmission one year, HIV-negative AIDS the next — remained quiet. The data from several large studies showed convincingly that nucleoside analogs like AZT, ddI, and ddC are at best only slightly effective for short periods of time. Additional scientific hopes were dashed over a number of previously promising drugs that yielded unpromising data, and many conference-goers came home disillusioned.

However, knowledge that an experimental treatment — like AZT — is less effective than originally hoped is an important contribution to medical understanding and care. Knowing what we don't know — even 13 years later — can be a useful lesson in flexibility, creative thinking, and the limitations of scientific study. However, life-and-death situations lead to despair when answers do not become readily available. Should doctors still prescribe the drug because it seems to be better than nothing? What should testing counselors and educators say to clients who have just found out their serostatus? Should people with AIDS alter their treatment plans? What new scientific approaches are logical to stop the proliferation of HIV in the body? These questions are difficult, but there is no doubt they will be asked and explored by many of us in the coming years, including those in the scientific and medical communities.

What is a normal T4 count for women? How does HIV affect the menstrual cycle? Will drugs available in the pharmacyone day say whether or not they've been tested in women? Should pregnant women with AIDS be allowed to decide what drugs to take? These questions may not be as eagerly asked or addressed by the scientific communities in the near future, although activist, advocate, and congressional pressure is currently high. Nonetheless, well-respected clinicians and male-focused AIDS activists still complain aloud that even asking scientific questions is expensive. J. Claude Bennet from the Institute of Medicine wrote in a recent issue of the *New England Journal of Medicine*:

> The detection of significant differences among relevant subgroup generally requires clinical trials that are prohibitively large, time consuming, and expensive.[28]

Continued discrimination against women and people of color, including people who live in poverty, is no longer excusable. Time and money are not valid excuses for unequal treatment. It is clear in the above statement and the situation of women in clinical research that the social organization of medicine often fosters patterns of oppression that are antithetical to medicine's more humane purposes. These patterns within medicine mirror and reproduce oppressive features of the wider society.[29] This is demonstrated in the scientific (mis)treatment of female bodies as subjects of medical research and the resulting lack of medical knowledge concerning women.

Medical sociologist Irving Kenneth Zola has aptly noted that medicine "is becoming the new repository of truth, the place where absolute and often final judgments are made by supposedly morally neutral and objective experts." It is critical that we approach medical science as a social system, which is susceptible to social judgments, political opinions, and morally charged categories such as drug user, prostitute, homosexual, female. Anthropologist Jean Comaroff urges a close examination of these matters. Failure to do so, she writes, "dooms us to reproduce our cultural order rather than explain it."[30]

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INCLUDING WOMEN IN SCIENTIFIC RESEARCH
A Change in Name Only?

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In December, 1992, the HIV Law Project, joined by the National Organization of Women's Legal Defense Fund and the American Civil Liberties Union, filed an administrative Petition challenging a 1977 guideline "General Consideration for the Clinical Evaluation of Drugs" regulated by the Food and Drug Administration (FDA). The FDA 1977 Guideline excluded women of childbearing potential from participating in Phase I clinical trials. The guideline also based female participation in phase II and III on both the completion of animal teratogenicity (harmful effects of a drug in laboratory animals) and the female portion of animal fertility studies which determine the effect of an experimental drug on pregnancy and reproduction in animals before it is tested in humans. The 1977 FDA Guideline noted an exception for women with life-threatening illnesses; however, in many actual instances this exception was ignored, and women with HIV/AIDS were denied participation in research trials with potentially life-prolonging drugs.

The Petition not only challenged the 1977 Guideline as unconstitutional gender-based discrimination, but also pointed out an overall failure to monitor the inclusion of women in trials, the discriminatory protocol criteria, and the administration and results of required animal reproduction studies. The Petition further noted discriminatory practices due to an emphasis on studying only the female-mediated effects of a drug in animal reproduction research, despite strong evidence that harmful effects of experimental drugs may be mediated through the reproductive capacities of men. In other words, an experimental drug may affect male sperm so as to cause harm to future offspring.

The Petition requested that the FDA mandate that these animal reproduction studies be undertaken prior to human testing, in order that information about the potential harm of experimental drugs to future offspring be fully known and that the FDA monitor these results. Most importantly, the Petition requested that informed consent be delivered in an unbiased manner, regardless of the results of animal reproduction studies, in order that persons with life-threatening illnesses be allowed to decide whether to participate. Furthermore, the Petition requested that pregnant women with life-threatening illnesses be allowed to participate where a special justification such as life-prolonging treatment requires participation as long as informed consent is provided. Additionally, the FDA should monitor the informed consent process.

On July 22, 1993 the FDA published for notice and comment in the *Federal Register* a new guideline entitle "Guideline for the Study and Evaluation of Gender Differences in the Clinical Evaluation of Drugs." While the 1993 guideline (the revision) announces a change in the earlier policy which excluded women, in reality the participation of women in clinical trials will remain hindered even after the revision goes into effect. The FDA states in the *Federal Register* that the revision will not have a binding effect on any person or organization. This means pharmaceutical companies can and most likely will continue to exclude women from participation in a clearly discriminatory manner because it is faster and cheaper to do so. The FDA publicly abdicates all responsibility for monitoring the process by stating that the "FDA's policy will not, by itself, cause drug companies or Institutions Review Boards (IRB) to alter restrictions they might impose on the participation of women of childbearing potential."

Moreover, the revision still countenances unconstitutional gender-based exclusion. Specifically, the revision mandates only women to participate in appropriate pregnancy prevention and risk counseling. Additionally, substantive and updated informed consents are required for only female participants. The revision provides "in general, it is expected that [animal] reproductive toxicity studies will be completed before there is large-scale exposure of women of childbearing potential, i.e., usually by the end of phase II and before any expanded access program is implemented." No such treatment is expected for male participants. Such gender classifications may preclude women from participating in drug studies where the pharmaceutical companies do not perform, or want to perform, toxicity studies. As the Petition pointed out, because the FDA does not monitor this process adequately, require male toxicity studies, or make male participation dependent upon the completion of these tests, the revision still allows gender discrimination.

The closest the revision comes to a requirement that women of childbearing potential be included in certain drug studies is in the provision that "there may" in some cases be a basis for requiring women in early studies. The revision states that when the disease under study is serious and affects women and when it is made available rapidly under an expanded access program or an effect on survival has been documented, it is medically important that both men and women receive the drug. The revision states that "under these circumstances, clinical protocols should not place unwarranted restrictions on the participation of women." The revision does not discuss methods of monitoring the enforcement of this provision, thereby rendering the statement relatively ineffectual. Who at the FDA will make the decision that women's participation is required? When will the decision be made? Will protocols be halted when they violate this provision? All these vital questions are left unanswered.

APPLYING HARM REDUCTION TO SEXUAL AND REPRODUCTIVE COUNSELING

A Health Provider's Guide to Supporting the Goals of People with HIV/AIDS

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HIV-positive individuals sometimes enter the health care system only to face widespread bias concerning their sexual orientation and practices. This bias is especially evidenced when HIV-positive people express an interest in conceiving, bearing, and raising children. Professionals who work with clients and families living with HIV/AIDS often admit to feelings of discomfort when sexual behaviors that put the client or his or her partner and family at risk are acknowledged. Unfortunately, providers often react to their own discomfort with admonitions or anger directed toward the client along with a tendency to inflate the client's intent. The result, not infrequently, is a growing distance within the client/provider relationship. Sometimes, after facing such attitudes, the client does not return.

Unsafe behaviors that put an individual and a partner at risk must be contextualized in order to be fully addressed. It is helpful to acknowledge that we all engage in risk-taking behaviors. In fact, in many situations, risk-taking is a healthy, adaptive response to challenges. Adolescents and young adults must take risks to achieve goals appropriate to their developmental growth such as asserting a sexual identity, choosing partners, becoming independent from the family of origin, creating a chosen family, and raising children.

The public response to HIV-positive individuals who put others at risk for infection mirrors and augments the response of most health care providers. An HIV-positive person is bombarded with messages not to engage in activities which have previously been considered normal. The slogan "living" with AIDS becomes a cruel joke to persons burdened with such strict proscriptions.

In part as a result of this professional and public attitude, adult clients with HIV experience stress and self-consciousness. Along with other factors, this can lead to sexual dysfunction. Clients sometimes decide that denying their normal interest in sexual activities and childbearing is an appropriate response. The client is often unable to find assistance in reasserting a healthy sexual and reproductive response. Supporting the sexual and childbearing goals of clients is not only ethically imperative, but it is the most practical way of offering helpful interventions and preserving the provider-client relationship.

Harm Reduction Model

Using a harm reduction model will facilitate the provision of support for achieving healthy sexual and reproductive responses in HIV-positive clients. This process is similar for female and male clients. For the sake of simplicity, the female pronoun will be used throughout this article where appropriate. Harm reduction is a philosophy wherein the professional health care provider sets aside all judgments in order to meet clients at their own level regarding a problem or crisis. In doing so, the professional also commits to assist the client with technical information toward achieving the client's goal. This model is utilized most often with injection drug users. Once judgments about drug-use are set aside, the client's goals can be elicited in an unbiased manner. For example, a client may wish to continue to shoot heroin without risking HIV infection, while arranging for a family member to care for her children. The goal may change from continuing drug use to stopping drug use, especially after child-care arrangements are made, and the client feels committed to entering a drug rehabilitation center. Harm reduction philosophy acknowledges that the client has good and logical reasons for her goals and strives to limit the amount of harm that might occur while she is attaining such goals. This particular client might be referred to a needle exchange program to cut down on the possibility of reusing unclean needles, as well as to a counseling center, to family outreach programs and other social service agencies.

A harm reduction model for the achievement of childbearing goals must also assume that clients have good and logical reasons for their desired goals. General admonitions regarding safer sex may not take into consideration that couples may engage in unprotected intercourse for the purpose of procreation. This may be an individual or mutual goal within a couple. Single heterosexual women and lesbians also may engage in unprotected sexual intercourse in order to get pregnant. Further, communities of color often understand proscriptions against unprotected sexual intercourse as a public statement supporting their genocide.

Harm Reduction Model in Sexual Counseling

The harm reduction model can be utilized in sexual counseling as well as in reproductive counseling. However, in sexual counseling it is far more complicated. For instance, it is fairly straightforward to ascertain a person's childbearing goals by asking "Do you plan to have children?" Asking a client what her goals are for her sexual life is far more complex and somewhat unprecedented. To use the harm reduction model, all judgments must be put aside in order to support a client's goal and provide technical information. It is helpful to start by acknowledging that we as individuals don't always know what we want or what we might do in a given sexual situation. For the following complicated reasons, sexual goals are difficult to ascertain:

- Our sexual fantasies are private, but sometimes difficult to separate from our desired sexual actions.
- Our sexual relationships are shared, and therefore not entirely subject to individual planning.
- Many of us have unresolved issues concerning our own sexuality which may inhibit our ideal sexual responses.
- Drugs and alcohol often affect our sexual behaviors.

Taking a comprehensive sexual history is the critical underlying task. It is essential to ask clients if they have experienced sexual abuse, incest, or rape. This question is asked first, since childhood sexual abuse often precedes voluntary sexual activity. The professional must, of course, be prepared to respond appropriately when sexual abuse is disclosed. The client should be reassured that the abuse was not her fault. She may express a desire or need for counseling, for which she can be referred promptly. Further, it is possible that the client or her children are at risk for current abuse, since women who were abused as children may choose an abusive partner as an adult. Here, immediate attention is required. Finally, recent studies show that a history of unresolved sexual abuse often leaves a client vulnerable in sexual situations, rendering her more likely to experience adolescent pregnancy, substance abuse, domestic violence, and HIV infection. Advising that these clients "negotiate safe sex" may be an ineffectual intervention. Other more thoughtful interventions which are geared toward bolstering the client's self-esteem and initiative to seek counseling in order to resolve the symptoms of childhood sexual abuse may be more helpful. [*For more information see the* SIECUS Report, *Vol. 21, No. 4.*]

All clients should also be asked if they have had sexual relations with men, women, or both; if they have exchanged sex for money or drugs (survival sex); if they have any current sexual partner(s); and how they feel about their current sexual situation. A current sexual situation can be explored by assessing specific sexual acts, sexual satisfaction, discomforts associated with specific acts, use of contraception, and use of barriers for protection from STDs.

Applying the Technique

Once a thorough history is obtained, certain tentative "goals" can be formulated with the client. This is an opportunity for the client to "try on" various ideas which are presented by the professional. The client is guided to articulate what fits her best. The underlying assumption is that clients have good and logical reasons for their behaviors but will be able to modify behaviors to increase personal safety if basic goals are not obstructed.

For the professional, the sticky part of this exercise is learning to eliminate judgment about sexual goals and behaviors, while holding on to values that protect others from harm. Most professionals tend to agree that a child at risk of sexual abuse by an adult requires investigation and protection. However, consensus may be more difficult regarding partner notification of HIV for consenting adults. It is important to spend adequate time discussing these difficult concerns and doing value-clarification exercises. Naming behaviors allows the client to compare a description of what she is doing with what she believes she might want to be doing. After taking a history, the counselor may say something like this: "So, you and your partner both want to have intercourse without using condoms but for different reasons. He doesn't believe that he can contract HIV by having intercourse without a condom. And you don't like the irritation you feel when he wears a condom. But neither of you really wants to have a baby right now. Is that right?" If the client finds this an acceptable assessment of her goals and plans, two interventions can be offered: counseling her partner so that he can more accurately understand his risk and suggesting an alternative barrier methods such as a diaphragm, sponges or foam. Contraceptive counseling should be offered as well in this case, since the client might like additional protection from pregnancy, such as the pill.

In another example, the counselor may say, "So you want to hold on to your boyfriend, and you're afraid to tell him that you are positive because he may leave you. You try to avoid sex with him as much as possible, but you still want to have sex with other men occasionally. Your boyfriend doesn't want to use condoms because he wants you to have his baby. Is that right?" This situation is more difficult. One obvious intervention is to assist the client to use barriers with any liaison outside of the primary relationship. This reduces the risk of STDs and HIV transmission, and is not in conflict with other goals. The more difficult intervention is to guide the client through a discussion of the inevitable confrontation with her partner. It is reasonable to ask her directly how she would feel if her partner contracted HIV from her, or if she got pregnant in the next few months.

Of course the client may not agree that the counselor has correctly described her goals and plans. This, too, offers an opportunity to fine-tune the discussion in order to look closely at what is really going on. If the woman in the second example responds by saying, "I don't want to tell him, but not because he would leave me. I just don't want to tell him everything I've done in the past. And he has done things too. He could have the virus for all I know." In this case, the client may agree to couples counseling so that she can disclose her serostatus in a supportive situation. Then the couple could be assisted in defining their sexual and reproductive goals as a couple. The client could be assured that her confidences to the counselor will be respected in this and all situations.

There are many possible situations that may be encountered in sexual counseling of individuals and couples. Individuals may be gay, lesbian, bisexual or heterosexual. Couples may be concordant or discordant in their HIV status, or the status of one or both partners may be unknown. Clients may need technical information about potential transmission of HIV for specific sexual acts. Some clients practice unsafe sex consensually; others may practice unsafe sex without discussing the consequences with their sexual partners. Many individuals, regardless of HIV status, practice a variety of sexual acts, in which some would be considered safe, and others unsafe. In most situations, however, by using the sexual history and techniques which clarify sexual goals, interventions can be planned with the clients that reduce risks without interfering with sexual autonomy.

Initiating Discussions Regarding Childbearing Goals

Sexual and reproductive counseling can be accomplished in many settings. As a family nurse practitioner working with people with AIDS, I have found it imperative to take a comprehensive sexual and reproductive history. Once this is initiated, a portrait of individual and family goals can be painted, and interventions that will be particularly useful can be introduced. It matters how questions are posed to the client. What information is provided before and during the history-taking session is crucial. Support and a sincere offer to help clients achieve personal goals builds trust into the client-provider relationship. Taking an appropriate and comprehensive sexual and reproductive history allows the provider many opportunities to educate, support, and intervene. On the other hand, it becomes a crisis between the client and the professional if a pregnancy occurs before the topic has been broached and thoroughly discussed, so that goals are understood and supported.

Counseling is an important part of assisting clients to articulate and achieve goals. This can often best be accomplished by a social worker, psychologist, or counselor who can work with the individual or couple regularly over time. In most settings a team approach is best. A medical provider may, for example, take a sexual history and refer a client for immediate counseling and intervention. Or a social worker may uncover a motivation for behavior about which the medical provider is unaware. In either case the social worker and the provider will want to have a discussion about the best integrated intervention for the client. Sexual and reproductive questions should be a part of any psychosocial history that is taken by a professional working in the area of HIV/AIDS. Privacy, inclusion of partners, and uninterrupted time are the primary components which allow for information to be exchange and trust to be built over time.

The HIV-positive client or couple who wish to have children can be assisted through an open-ended discussion on various topics. This need not occur in the course of a single visit. For example, clients should be asked about their fertility and any problems they have had in the past achieving a pregnancy. The current health status is reviewed and specific information can be given about the obstetrical risk to the individual. The risk to the pregnant woman who is HIV-positive, but asymptomatic with good CD4 counts, is considered to be similar to the obstetrical risks of an HIV-negative woman who is matched for parity, socio-economic status, drug-use, etc. However, for the symptomatic woman with little immune reserve, the risks to the mother are much greater. Risk of viral transmission to the fetus during the pregnancy is often overestimated by clients and professional. The risk for transmission from mother to child is approximately 25%.[1]

For individuals or couples who express a current desire to conceive and bear a child, a more focused discussion must be initiated. Once a trusting relationship is built and the client can expect her goals to be supported, the following questions can be addressed and not be perceived by the client as obstructing her intent:

- In some situations there will be the risk of HIV transmission to an uninfected partner. Is the couple willing to assume such a risk?

- Is the couple interested in learning strategies to minimize the risk or do they wish to eliminate risk altogether?

- Often the uninfected partner is more willing to have unprotected sexual intercourse than the HIV-positive partner. Both partners in the couple should be able to explore the difference for the whole family of having two instead of one infected parent.

- What are each partner's strengths and weaknesses as parents?

Many clients want a child to replace children they have lost, either due to their own inability to provide a stable environment or a death from AIDS or other causes. Some couples want to parent a child together, even though one or both already have had children with a previous partner. This is rocky but important terrain to cover. Identification of the skills and resources needed to become successful at parenting may assist clients to attain their goals or to modify them. For example, if a woman receives support and counseling for her desire to regain custody of her child, she may find renewed energy to work to that end and her desire to achieve a new pregnancy may diminish.

Finally, prospective parents must be offered an opportunity to discuss their feelings and uncertainties. Will the parents be able to accept if the child becomes HIV-infected, become ill, or die? Can the parents imagine how they might feel during the first few months after the child is born when there is no way to know for sure if the child carries the virus? How will they feel about the possibility that the HIV-positive parent (or both parents) might not live long enough to raise the child? What are the family support systems and extended family network that will be able to help in the event of illness or death of a parent?

Each situation is unique and brings challenges to consider. The following interventions are offered to address situations that are frequently encountered in the clinical setting.

Interventions For Heterosexual Couples

If both partners are HIV-positive, they may feel no need to practice safe sex. Unfortunately, no data exists concerning the likelihood of re-infection from sexual intercourse between two HIV-positive individuals. The medical model leans away from the possibility of re-infection because antibodies, produced soon after HIV-infection occurs, work to fight off similar viral strains. Nonetheless, many clinicians continue to advise against unprotected sexual intercourse between two HIV-infected individuals, in part to reduce the likelihood of transmission of additional STDs. For a couple that has used protection but now desires a pregnancy, teaching fertility awareness may allow the couple to limit unprotected sexual intercourse to the fertile times of each month until pregnancy is achieved. In this way, exposure and re-infection may be limited.

For the discordant-status couple (couples in which one partner is HIV-positive and the other is HIV-negative), other strategies may be useful. If the woman is HIV-positive and her partner is not, alternative insemination (previously referred to as artificial insemination) is a possibility. The couple can inseminate the man's semen and reduce his risk of contracting HIV from unprotected intercourse. This can be done at home with simple instructions and without medical intervention. Reducing the male partner's risk of contracting HIV infection may increase the likelihood that the child will have at least one healthy parent. If the couple finds this unacceptable and is willing to risk transmission to the male, the partners can learn fertility awareness and limit the number of episodes of unprotected intercourse in order to reduce the likelihood of exposure.

For the couple in which the male partner is HIV-positive and the female is not, they can consider other options for parenting, such as adoption or alternative insemination with sperm from bank or known donor. This reduces the woman's risk of contracting HIV from her partner. If this option is unacceptable to the couple, fertility awareness may be used to limit risk of transmission.

Single Women/Lesbians

Single women (both lesbian and heterosexual) may have the same desire as coupled women to bear and raise children. Single women who are HIV-positive may choose to have unprotected intercourse with a stranger or acquaintance in order to achieve their goals. Indeed, few other options are generally available. These women will need a very strong, informed advocate in order to utilize the services of a sperm bank. In particular, single women, lesbians, and women with health problems may experience difficulty accessing such programs. Additionally, alternative insemination is often prohibitively expensive. It is imperative to be familiar with the facilities available in the community, including issues of access. It will be easier for the professional to break through the barrier than it will be for the client herself. Other options may be considered on a more informal basis. Any prospective sperm donor should be evaluated for STDs, HIV, and hepatitis before donating sperm.

Lesbian Couples

When lesbians want to rear a child together as a couple, some additional concerns may arise. First, who is going to bear the pregnancy? If only one of the women is HIV-positive, it seems logical to consider the HIV-negative partner for pregnancy. However, the complete health status of both women must be considered fully, not just HIV serostatus. A referral for legal advice is also a good idea, since there is currently legal precedent for a lesbian to legally adopt a child to whom her lover has given birth.

Single Men/Gay Men

Single men and gay couples can consider adoption, co-parenting, or other arrangements for meeting their desires to be involved in child rearing. Yet for the most part men's options are extremely limited. Our society punishes men when they fail to support and provide for their children, but offers little in the way of support to men who desire to parent successfully. In counseling men who express a desire to father and parent children, professionals must offer a realistic picture. Men facing a life-threatening illness are often quick to recognize how limited their options are, but often need support to express their sadness and grief.

As professionals, we must keep abreast of news regardingsperm washing techniques, such as those reportedly used in Italy, which may render semen still potent, yet uninfected with HIV. Studies seem to indicate that partners of HIV-infected men may still become HIV-positive although the sperm is processed or washed. However, according to one small study no children have become HIV-positive as a result of fertilization with washed semen.[2] Further it is as yet unclear if the use of AZT lowers the viral burden of HIV in semen.[3] If so, HIV-positive men who wish to father children could decrease likelihood of HIV transmission with its use. Limited information is currently available regarding these options.

In a gay couple where one partner is HIV-positive, the other partner might consider locating a surrogate mother to carry a pregnancy with his sperm. However, these arrangements are often fraught with conflict and difficulty.

Infertility Work-ups

Questions about sexuality and reproduction are often addressed by clients as general concerns regarding their fertility. In fact, when questions are raised regarding fertility, it does not always indicate a desire to procreate. Often, when clients ask if they "can still have children" it indicates a need to understand and have control over their own future. These questions should be answered and explored fully. Infertility services, when offered in a supportive setting, help a client or couple face the reality of the situation at hand. In fact, the proper goal to an infertility work-up is not the delivery of a baby, but the honest evaluation of the individual or couple's capacity for conception. While such services are usually geared toward helping couples achieve a pregnancy, they are more likely to give a couple or an individual solid information suggesting that fertility problems cannot always be easily solved. Providing information about the process of an infertility work-up may engage the client to test the strength of her desire to become a parent. Infertility work-ups include sperm analyses, menstrual and temperature charting, post-coital tests, salpingograms to determine if a woman's tubes are blocked, exploring the use of fertility drugs, and other interventions. Complying with the required procedures, record keeping, and appointments can be grueling, and the process itself often helps the client to clarify desires and values.

Male and female HIV-positive clients can be assisted in the process of an infertility work-up including fertility awareness, sperm counts, post coital tests, salpingograms, fertility drugs and other interventions. These interventions should not be conducted based on HIV status alone, and the message that those with HIV-infection should not reproduce is not the appropriate response to clients' questions about fertility.

Many individuals have infertility problems. If the problem turns out to be that the male partner has a very low or non-viable sperm count, the couple has to come to grips with this fact and turn to other options for parenting. During such a process, they may also accept that there is no good reason for them to have unprotected intercourse and begin to use condoms. Or if the woman has tubal infertility and needs time to discuss the option of surgical repair with its risks and limited likelihood of success, she may postpone efforts to conceive until she has determined the best course of action. While infertility work-ups and services result in a reasonable percentage of pregnancies, their main point is to provide solid information and a chance to explore the sometimes difficult solutions to obstacles.

Conclusion

When conception and childbearing are very important to an individual or couple, supportive fertility services should never be denied on the basis of socioeconomic status, sexual orientation, marital status or HIV status. HIV-positive adults and couples must have access to the same support, technology and information as all individuals who enter the health care system with requests for information about achieving personal goals of childbearing. Using harm reduction techniques improves the client/provider relationship and allows an opportunity for intervention. Assisting clients in evaluating, understanding, modifying, and often achieving childbearing and sexual goals can be extremely rewarding for the health care professional.

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OUT OF THE QUESTION

Obstacles to Research on HIV and Women Who Engage in Sexual Behaviors with Women

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In general, most doctors, researchers, and service providers assume that women who are HIV-positive are exclusively heterosexual. Lesbian invisibility and disenfranchisement have contributed to this assumption. However, responsibility also lies with researchers who need to ask questions concerning all female sexual activity, institutions that often refuse to sponsor such research, and journals that judge articles on the topic too controversial or insignificant to publish.

Despite these facts, unpublished studies and anecdotal information indicate that many HIV-positive women have sex with other women.[1] Additionally, a number of other studies indicate that a high percentage of intravenous drug-using women have had female sexual partners,[2] and women who have had female partners may be more likely to engage in high-risk behaviors that lead to HIV infection, such as using intravenous drugs and exchanging sex for money.[3] These women, in particular, may be more likely to be HIV-positive than women who have had only male sexual partners.[4] Studies conducted by the Centers for Disease Control (CDC) document a lack of information about the population of women who have sexual contact with other women, and indicate there is little transmission of the virus between women.[5] However, no study has looked closely at the unique problems faced by this population, particularly regarding access to HIV-related medical services, social services, drug treatment, prevention education, and transmission.

Drug-Use, HIV, and Women

According to recent unpublished research, the number of HIV-infected women who engage in sexual behaviors with other women is higher than was originally presumed. Preliminary data from Bronx Lebanon Hospital in New York City found that over 30% of female HIV-symptomatic patients have had a female sexual partner.[6] Similarly, preliminary data from Montefiore Medical Center at Rikers Island Jail in New York City found that over 40% of HIV-infected inmates have engaged in sexual behaviors with other women at some point during their lives.[7] One small unpublished study of drug users entering treatment in Seattle found that women who had engaged in sexual behaviors with women were five times more likely to be seropositive (or 5.1, 95% CI: 1.8 to 14.7) than women who had only male sexual partners.[8] Very similar findings were obtained from a New York City sample.[9]

Some published studies reporting HIV-related risk from intravenous drug use, or from exchanging sex for drugs, reveal high numbers of women who are or were once sexually involved with other women. CDC data show that 50% of women with AIDS nationally and 60% of women with AIDS in New York City have a history of intravenous drug use.[10] A 1993 study examining the risk of sexual transmission of HIV among injection drug users reported that 19% of 72 women had a female partner within five years of the interviews.[11] No special analyses were conducted on the bisexual women in this study, although they comprised a significant minority of those interviewed. A recent Australian study on sexually transmitted diseases (STDs) found that 32% of 325 female intravenous drug users were either bisexual or lesbian.[12] Another study of drug-using women in California found that 21% of 711 women interviewed regarded themselves as bisexual, and 3% identified as exclusively lesbian.[13] The majority (69%) of these women were black; 41% had injected drugs, and 32% had used crack.

Homophobia in Medicine: An Additional Difficulty

These surprising data are even more stark, considering that HIV-symptomatic women who have sex with women face hostility and discrimination from medical providers. Studies reveal that most lesbian and bisexual women are unwilling to disclose their sexual orientation and behaviors to providers.[14] In one study, 70% of black lesbians and 82% of black bisexual women reported that they did not reveal their sexual orientation to physicians.[15] Thirty-eight percent of lesbian and bisexual women interviewed in another study believed that revealing their orientation would adversely affect the delivery of their health care.[16] Studies documenting negative attitudes among health providers toward lesbian and bisexual women support these data.[17] A 1991 study found that more than 50% of nursing students found lesbians "unacceptable" and 15% thought lesbian sexual behavior should be made illegal.[18] Seventy-two percent of lesbians described negative responses from health care providers concerning sexual orientation, including inappropriate treatment, refusal of care, and sexual harassment.[19] Finally, a survey of health care literature found that in the few articles (n = 59) which mention gay men and lesbians, the majority of them (61%) reflected negative attitudes and images.[20]

Surveillance Methods

CDC and other surveillance data reports about women with AIDS have systematically excluded women's sexual activity with other women. University-based, hospital-based, and drug treatment-based studies have also been remiss in covering a full range of female sexual activity. Few published seroprevalence studies and no studies of women with AIDS that report women's sexual behavior with female partners can be found. As Cole and Cooper pointed out three years ago, the "no identified risk" category for women was twice that of men in the New York City Department of Health surveillance report on AIDS Cases and may have been a category where lesbian and bisexual women with AIDS were classified.[21] The category name has been changed to "other," but the situation remains the same. In fact, for women "other" makes up 11% of reported cases, and for men it comprises only 5%. Lesbian and bisexual women remain uncounted and are then told that evidence about HIV-infected women who have sex with women does not exist.[22]

This phenomenon is even more striking when compared to the thorough investigation of male sexuality, which has been integrated with its unique complexities into data collection methods. Questions that are routinely asked of men — including number and gender of sexual partners, exact sexual activities with partners, and discrepancies between sexual identity, orientation and behavior — have not been asked of women. Motivated, no doubt, by the urgency of HIV transmission among men, HIV research has spearheaded groundbreaking studies on male sexual identity, orientation, and behavior. These important studies empirically document a significant minority of the general male population being studied, including:

- bisexual men;
- men who do not identify as gay or bisexual but who engage in sexual behavior with other men on a regular or occasional basis;
- men who identify as heterosexual but engage in sexual behaviors with other men to obtain money or crack;
- men who identify as gay but occasionally have sex with women.

The results of such research have led to important HIV-related campaigns designed to target each of these specific male populations for education, prevention and service delivery.

In contrast, such thorough research methodology has not been extended to women. A CDC retrospective review of national surveillance data for lesbian AIDS cases concluded that nearly 1% of female AIDS cases were lesbian.[23] However, it must be noted that the accuracy of data gathering regarding women's sexual orientation is severely compromised since the CDC relies on state and city health departments to gather this information from hospital charts and private doctors. Hospitals do not routinely ask questions about the sexual orientation of their HIV-positive female patients, nor is there a federal requirement that they do so. Recently, the CDC amended its standard vehicle for data collection and added a space on the questionnaire form that allows hospital personnel to fill in whether the patient has engaged in sexual activity with men or with women. Presumably, then, if the patient is female, the interviewer should inquire whether she has engaged in same-gender sexual activity. In reality, the chance that such a question will be skipped over is fairly great, given that many personnel may not inquire about lesbianism and may not consider sexual behavior between women a risk factor for HIV infection.

Some researchers have tried recently to rectify this lapse of information by incorporating one question in surveys that attempt to identify female risk for HIV infection. For instance, in a meta-analysis of data from 960,000 female blood donors, CDC researchers found no women whose only HIV risk factor was sex with other women. They documented only three HIV-infected women who had sex with women, and these women also had sex with men, and an intravenous drug-using history.[24] From this data they concluded there was no evidence for female-to-female transmission. However, despite its large sample size, this study design is not appropriate for determining the likelihood of HIV transmission between women. The population studied by definition has a low prevalence of HIV, since prospective blood donors are discouraged from donating if they have reason to believe they are currently at risk for HIV. Therefore, it is not surprising that only three of the HIV-infected female subjects of the 960,000 donors were intravenous drug users. As is shown in other unpublished studies, most women who have sex with women engage in multiple risk activities.

Another CDC national survey interviewed 15,685 women who were testing for HIV antibodies at public-funded women's health clinics (WHC) and sexually transmitted disease clinics.[25] Of the 511 women who reported having sex with women, 2.5% were HIV-positive, 92% were classified as bisexual, and 8% were classified as lesbians. Conducted as part of the agency's national survey of risk behavior, this survey included only one question pertaining to women's sexual experience with other women. It read as follows:

> Since January 1978, were the people you had sex with: 1) only men; 2) women only; 3) both, mostly men; 4) both, mostly women.

Multiple questions about women's specific sexual behaviors were asked; however, these refer exclusively to heterosexual behaviors. Additionally, as discussed earlier, even women who are open about their sexual identity may be reluctant to share such information with their health care providers. Clients may experience STD clinics as punitive, and women may be even less likely to reveal details about their sexual behaviors in such a setting, fearing that it may lead to repercussions in their care. Finally, it needs to be recognized that women's health clinics offer abortion, family planning, and/or prenatal services as opposed to general gynecological care. Thus the sample of women who attend these clinics may be more likely to be heterosexual.

The problems in these studies reflect a larger societal confusion between sexual identity and sexual behavior. Saying that women's risk is due to heterosexual behavior is not the same as saying that only heterosexually defined women are at risk for HIV. Information about women who have sex with women — whether they identify as lesbian, bisexual, or straight — is crucial to construct coherent provision of services, as well as prevention and education efforts. By doing so, sexual behaviors with women will be studied on equal par with sexual behaviors with men and be more accurately characterized for HIV transmission risk.

Conclusion

Despite major research obstacles, some useful information has been culled from studies about drug use and HIV that have included questions about women's sexual orientation. In fact, new research documents significant minorities of HIV-infected women who have engaged in sexual behavior with women, as well as lesbian and bisexual women who are at high risk for HIV. However, too few efforts have been devoted to the complicated but important topic of female sexual behaviors with other women. The few studies that are published are cursory at best. Research studies designed to collect information on women must include questions about female sexual behaviors with other women. A guideline that mandates that all federally funded researchers ask such questions would further the scientific agenda immensely. It should be noted that one question in an otherwise heterosexually oriented questionnaire is not adequate. The questions and questioners must be sensitive to those who feel that exposing their sexual experiences will be another excuse to discriminate against them.

Clinical reports confirm woman-to-woman transmission of HIV.[26] Women who have sex with women exist in all ethnic and behavior groups that have struggled for recognition within the HIV/AIDS epidemic including African Americans, Native Americans, Latinos, and Asians, as well as current and former injection drug users. As research has shown, cultural sensitivity is central to the effective provision of medical treatment and other HIV-related services.[27] This strategy may be the key to encouraging women to feel comfortable in discussing the full range of their sexual behavior, including sexual activities with other women.

Nancy Warren is a research consultant and a writer. She has conducted research in jails and clinics in New York City concerning HIV-related issues.

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LET THE WOMEN SPEAK
Testimonies by Lesbians with AIDS*

- **About living with AIDS**
  "I'm a gay woman, living with AIDS. Nobody out here believes I'm real," says Marlene, the mother of three, who has recently been released from jail. "I'm starting to doubt it myself."

- **About assumptions**
  "We have a population of women not counted with high numbers of us already infected with the virus. I'm one of them," writes Shiela, an incarcerated HIV-positive lesbian. "We must learn to educate ourselves because due to our minority status and our society, women who sleep with other women exist in every community in this country, no less the world [but are invisible]."

- **About drug treatment programs**
  "I stopped going to that place [drug treatment] because I didn't know what they would say in the group when I started talking about my [female] lover," Iris says. "For a while, I just sat there, saying nothing." She is living on the streets, using injection drugs again. After being recently released from a detention center, she dropped out of an HIV-positive support and drug treatment group for women because she was afraid to come out as a lesbian.

- **About woman-to-woman transmission**
  Angela does not usually reveal that she became HIV-infected ten years ago through sexual activity with an HIV-positive female lover that involved a lot of blood. "It's difficult to tell people," she says. "But it's always the first thing people ask me when they find out I'm an HIV-positive lesbian, or when they find out that my lover, a woman, died of AIDS."

- **About other lesbian-specific education**
  "Some of us are forced to go back on the streets (to sell sex for money) for survival," says Blossom, an HIV-negative inmate whose lover of many years is HIV-positive. "We need the education to know how to keep ourselves healthy."

- **About the lack of information**
  "There's no category for lesbian women with HIV," says Gloria, an HIV-positive lesbian. "Like we don't exist. Nobody's looking at lesbian couples with one HIV-positive and one HIV-negative to see if the virus is passed. It's like our lives don't matter"

- **About the lesbian experience with health care**
  One woman from an HIV-positive woman's group said: "If I go to get GYN care — that is, if I can get it after waiting all day, or after being told I got to wait two months — and if I tell her I'm a lesbian, she won't even look up there. They all think lesbians don't pass anything, can't get anything. Then I say, 'I'm positive;' so off they go to the other room to have a conference. Meanwhile, there I am with my legs in the air waiting to find out about these problems I got."

- **About humanity**
  "I didn't used to think I deserved anything," Peaches said at an HIV-positive Lesbian group. "Because why? Because I'm a lesbian? Because I got AIDS? Because I've had a hard life? I never want to think that way again."

These testimonies are excerpted from a briefing report prepared by the Women's National Network of the AIDS Coalition to Unleash Power (ACT UP) for a meeting that took place on April 23, 1993 at the Office of the U.S. Department of Health and Human Services with a group of15 HIV-positive lesbians, AIDS activists, and advocates, the Secretary of Health and Human Services, Donna E. Shalala, and other HHS agency directors. The report is entitled "Briefing Report: Lesbians Living with HIV/AIDS Deserve Health Care Not Death Care." The names in the document and this excerpt have been changed.

SIECUS Fact Sheet
Comprehensive Sexuality Education

THE TRUTH ABOUT LATEX CONDOMS

The Centers for Disease Control and Prevention recently released an update report on the effectiveness of condoms in the agency's weekly publication Morbidity and Mortality Weekly Report (MMWR) *on August 6, 1993 (Vol 42, No. 30). The updated information confirms the federal government's 1988 recommendations for using condoms to prevent the transmission of HIV and STDs, plus provides new compelling information about consistent and correct condom use as well as the female condom. SIECUS is publishing highlights from that report plus other empirically based information about condoms in an easy question-and-answer format.*

ARE THERE NEW STUDIES ABOUT CONDOM EFFICACY?
Yes, good news about condoms was released in the summer of 1993 in the form of two clinical studies. The research shows that latex condoms are highly effective against the sexual transmission of HIV when used consistently and correctly during sexual intercourse.

WHAT ARE THESE NEW STUDIES ALL ABOUT?
Both studies monitored people at extremely high risk for HIV infection by studying heterosexual couples in which one person was HIV-positive and the other was uninfected. With repeated exposures to HIV, condoms proved to be highly effective for couples using condoms consistently and correctly.

WHAT ARE THE SPECIFICS OF THE FIRST NEWLY RELEASED STUDY?
In the first study called the European Study on Heterosexual HIV Transmission, 123 heterosexual couples, in which one was HIV-positive and the other was HIV-negative, were followed by scientific researchers from 1987 to 1991. None of the HIV-negative partners in couples who used condoms consistently and correctly became infected. However, in a separate control group, of the 122 couples who inconsistently used condoms, 10% (12 of 122) became infected.[1]

WHAT ABOUT THE SECOND NEWLY RELEASED STUDY?
The second of the studies was conducted in Italy and involved the female partners of HIV-infected men. In a group of 171, only three (or 2%) of the women whose male partners always used condoms during sexual activity became infected. However, 15% (8 of 55) of the women whose male partners used condoms inconsistently became infected.[2]

WHAT DOES "CONSISTENT USE" OF CONDOMS MEAN?
Consistent use of condoms means using a condom with every act of sexual intercourse from start to finish.

WHAT DOES "CORRECT USE" OF CONDOMS MEAN?
Correct use of condoms means the following:

1) A new condom is used every time a person has sexual intercourse, whether it is anal, oral, or vaginal intercourse.

2) The condom is put on after the penis is erect and before it touches any part of a partner's mouth, anus, or vagina. (If the penis is uncircumcised, the foreskin is pulled back before putting on the condom.)

3) The condom is put on by pinching the reservoir tip, then unrolling it all the way up the shaft of the penis from head to base. (If the condom does not have a reservoir tip, pinch the tip enough to leave a half-inch space for the semen to collect after ejaculation. Air must not be allowed in the tip, otherwise the condom might break).

4) If the condom breaks during sexual intercourse, the penis should be withdrawn immediately, and a new condom should be put on the penis.

5) After the ejaculation and while the penis is still erect, the rim of the condom should be grasped between the fingers, and the penis with the condom on should be removed carefully so no semen is spilled.

6) Water-based lubrication should be used to prevent condoms from breaking; oil-based lubricants such as cooking or vegetable oils, baby oil, hand lotion, or petroleum jelly should never be used with latex condoms. They can cause the condom to break.

7) Condoms should be stored in a drawer or closet, somewhere cool, dry, and out of direct sunlight. Changes in temperature, rough handling or age can make the latex brittle or gummy. Never use condoms that are damaged or discolored, brittle, or sticky. Do not store them in a wallet or car glove compartment for a long time.

WHAT ABOUT OTHER STUDIES THAT INDICATE CONDOMS HAVE A HIGH CONTRACEPTIVE FAILURE RATE?

None of the studies which indicate a high condom failure rate distinguishes between consistent and inconsistent condom use. Additionally, the most recent study which considers the difference between consistent and inconsistent condom use shows that pregnancy rates are estimated to be as low as 2% for couples who use condoms consistently and correctly.[3]

WHAT ABOUT THE RECENT MARIPOSA STUDY WHICH FOUND SEVERAL BRANDS OF CONDOMS LEAKED VIRUSES SIMILAR TO HIV?

The implications for this study are unknown. Representatives from the Centers for Disease Control and Prevention and the Food and Drug Administration (FDA) have criticized this study on a number of counts. First, the study was conducted in 1988 when condom manufacturing was notably less controlled. At that time, the FDA had just started a program to sample condoms, test them, and prevent sale of any batch with over four defective condoms per 1,000. This FDA program has now been in operation for six years and has had significant effect on the quality of condoms. In addition, formulation of latex has since been improved. Further, there is no information about the storage and the expiration dates of the condoms used in this study. Lastly, leakage of virus particles was measured after 30 minutes using a coital simulating instrument. In actuality, then, leakage would most likely occur thirty minutes after ejaculation while continuing sexual intercourse. Used correctly, condoms are carefully removed immediately after ejaculation.

PEOPLE WHO ARE OPPOSED TO EDUCATION ABOUT SAFER SEX ALWAYS ARGUE THAT CONDOMS BREAK ALL THE TIME. IS THAT TRUE?

Condoms rarely break. When they do break, it is almost always related to user error rather than condom quality. Using out-of-date condoms is a leading cause of breakage. Other common reasons for breakage include fingernail tears, exposure to heat or sunlight, reusing condoms, or unrolling the condom before putting it on. Mineral oil, the leading ingredient in oil-based lubricants such as baby oil, petroleum jelly and hand cream can cause a 90% decrease in condom strength after as little as 60 seconds exposure.[4]

IS IT REALISTIC TO THINK THAT PEOPLE WILL USE CONDOMS CONSISTENTLY AND CORRECTLY?

Yes. The two new studies and several others clearly demonstrate that consistent and correct condom use is possible if the couple is highly motivated.[5]

HOW ARE CONDOMS TESTED AND REGULATED?

Condoms are classified as medical devices, regulated by the Food and Drug Administration (FDA), and manufactured according to national standards. Every condom sold in the U.S. is tested by the manufacturer electronically for defects, including holes or thin areas before it is packaged. During the manufacturing process, condoms undergo stringent quality testing. In addition, the FDA randomly tests condoms using the water-leak test, in which a condom is fill with 300 ml. of water. If the FDA finds that more than four per 1000 condoms leak, the lot is not allowed to be sold in the U.S.[6]

WHAT ABOUT MICROSCOPIC HOLES IN CONDOMS THAT MIGHT ALLOW HIV TO PASS THROUGH?

Laboratory studies prove that sperm and disease-causing organisms cannot pass through intact latex condoms. Sperm has a diameter of 3 microns (.003 mm). STD-causing organisms are much smaller — from 1/4 to 1/90 the size of sperm. Still, laboratory tests show that none can penetrate tan intact latex condom. This includes HIV.[7] Condoms are required to undergo demanding tests, including tests for holes before they are sold. If any holes are found, the condoms are discarded.

WHAT IS THE FEMALE CONDOM?

The female condom is the first barrier method of contraception approved by the FDA that is within the control of the female partner and provides some level of protection against pregnancy, STDs, and HIV. It is a lubricated polyurethane sheath with a ring at each end that is inserted into the vagina.

ARE THERE NO OTHER FORMS OF BIRTH CONTROL USED BY WOMEN AND NOT MEN THAT PROTECT AGAINST HIV? WHAT ABOUT THE USE OF NONOXYNOL-9?

Laboratory studies indicate that while nonoxynol-9, a foam spermicide, kills HIV and other sexually transmitted pathogens, there is no evidence that using it without the use of a condom is effective for preventing sexual transmission of HIV.[8] Further one randomized controlled trial among women identified as sex workers in Kenya found no protection against HIV infection with the use of a vaginal sponge that has a high dose of nonoxynol-9.[9] None of the other barrier methods used by women, such as a diaphragm, a cervical cap, or the sponge has been proven effective against HIV. The birth control pill has also not been proven to prevent HIV-infection.

HOW EFFECTIVE IS THE FEMALE CONDOM (BRAND NAME: REALITY)?

The female condom is about 74% effective at preventing pregnancy.[10] As a very new product, however, limited studies have been conducted to assess its effectiveness against STDs and HIV. Additional studies are being conducted, and other methods within women's control are being explored.

ISN'T ABSTINENCE THE ONLY FOOLPROOF WAY TO PREVENT HIV INFECTION?

Refraining from intercourse with infected partners is the most effective HIV prevention strategy. This is an especially important message for young people. Periodic abstinence, however, carries risk for HIV infection. A 1988 National Survey of Family growth found that 26% of people who believed they practiced abstinence did not actually practice it consistently (i.e. they had intercourse). This fact has been interpreted as meaning that even abstinence has a 26% failure rate.[11] Like condoms, for effective protection by using abstinence as a method, consistency is key.

SO CONDOMS ARE CONSIDERED BY THE PUBLIC HEALTH SERVICE TO BE AN EFFECTIVE FORM OF PROTECTION?

The two new scientific studies discussed above show that condoms are more effective than previously thought and that spermicides may be less effective than had been hoped. The Centers for Disease Control strongly support condom use for the prevention of pregnancy, STD and HIV infection.

WHY DID THE FEDERAL GOVERNMENT RECENTLY RELEASE RENEWED COMMITMENT TO ITS RECOMMENDATION FOR CONDOM USE? AREN'T PEOPLE ALREADY USING CONDOMS?

Actually most sexually active people are not using latex condoms every time they have sexual intercourse. For example, a national study of heterosexual adults with multiple sexual partners found that only 17% of those surveyed reported using condoms all the time.[12]

WHAT ABOUT EDUCATION PROGRAMS ABOUT CONDOMS?

A 1992 study reported in Family Planning Perspectives found that AIDS education and sexuality education for adolescents results in decreases in the number of sexual partners and the frequency of intercourse.[13] Having received education was also associated with more consistent condom use. Unfortunately, as SIECUS has discovered in a review of state-wide comprehensive sexuality education programs in the schools, most programs are not very comprehensive and need to be improved greatly.[14]

WHY WOULD THE FEDERAL GOVERNMENT PROMOTE CONDOMS WHEN THEY ARE NOT 100% FOOL PROOF?

The CDC states that consistent and correct condom use substantially reduces the risk of HIV infection during vaginal, anal, and oral sexual activity. The government promotes many other health behaviors that significantly reduce risk, but may not entirely eliminate it. Additionally, research has provided definitive evidence that using a condom is 10,000 times safer than not using a condom.[15]

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HIV/AIDS

A SIECUS Annotated Bibliography of Print Materials

This annotated bibliography profiles HIV/AIDS resources — both those have recently been released and those which have stood the test of time and are still useful. Resources which have appeared in SIECUS' earlier HIV/AIDS bibliographies are marked with an asterisk (*). This bibliography has been prepared by Carolyn Patierno, director of SIECUS' AIDS Initiative, and is funded through a cooperative agreement with the Centers for Disease Control and Prevention. It can be reproduced, as long as SIECUS is acknowledged. (Please send a copy to the Publications Department for our records.) A single copy can be obtained, free upon request, with a self-addressed, stamped, business-size envelope by writing to: Publications Department, SIECUS, 130 West 42nd Street, Suite 2500 New York, NY 10036.

Resources for PWAs and Health Care Providers

*AIDS AND ALCOHOL/DRUG ABUSE: Psychosocial Research

Dennis Fisher, PhD, editor

The relationship between HIV and substance abuse is considered in this collection of papers by drug-abuse researchers. The collection also examines issues involved in conducting HIV/AIDS research with various racial and ethnic communities. The book focuses on aspects of HIV infection that have received little attention elsewhere such as injection drug use in Alaska, and little-known facts that relate substance use to HIV infection in American Indian/Alaskan Native populations. 1991, 97 pp., $24.95 hc, $14.95 pb.

The Harrington Park Press, 10 Alice Street, Binghamton, NY 13904; 800/342-9678.

*AIDS AND THE HOSPICE COMMUNITY

Madalon O'Rawe Amenta & Claire Tehan

This book documents facts and addresses issues of concern in current AIDS hospice care. It presents an authoritative commentary about many common misperceptions of HIV/AIDS. Research projects and findings that detail these and other effective barriers to AIDS hospice care are described. Additionally, the authors give examples of hospices that have entered into AIDS patient care and show that such programs can be extremely successful for everyone involved. This book will help agency administrators plan AIDS policies and programs and promotes further research by identifying specific areas in need of study. 1991, 196 pp., $19.95, pb.

The Haworth Press, Inc., 10 Alice Street, Binghamton, NY 13904; 800/342-9768.

AIDS IN THE WORKPLACE: Legal Questions & Practical Answers

William F. Banta

This resource reviews all the laws potentially applicable to HIV/AIDS in the workplace on federal, state, and local levels. The author analyzes various HIV/AIDS employment issues in a practical fashion, identifying the pros and cons of alternative approaches and recommending courses of action that are both consistent with legal cases and protective of legitimate business interests. It includes a very good overview of the issue. 1993, 422 pp., $35.00.

Lexington Books, 866 Third Avenue, New York, NY 10022; 800/235-3565.

COURAGE TO CARE: Responding to the Crisis of Children with AIDS

Gary R. Anderson, editor

This book is a fundamental resource for those seeking a comprehensive review of the implications of AIDS on individuals, families and society. Its diverse topics address better care for the sick, the young, and the disabled; better education for a range of concerned audiences; and preservation of human rights. It includes a good section on training strategies. 1990, 416 pp., $24.95 hc/ $15.95 pb.

Child Welfare League of America, Inc., 440 First Street, NW, Suite 310, Washington, D.C. 20001; 202/638-2952.

*COUNSELING CHEMICALLY DEPENDENT PEOPLE WITH HIV ILLNESS

Michael Shernoff, editor

This collection of writings about HIV and drug use begins with a story by a man living with AIDS who is a recovering alcoholic and drug user. Articles include: "What Drug Treatment Professionals Need to Know About Medical Aspects of HIV Illness"; "Counseling Chemically Dependent HIV Positive Adolescents"; and "Effective AIDS Prevention with Active Drug Users: The Harm Reduction Model." 1992, 172 pp., $32.95/hc, $19.95/pb.

Harrington Park Press, 10 Alice Street, Binghamton, NY 13904; 800/342-9678.

DYING AT HOME: A Family Guide for Caregiving

Andrea Sankar

Dying at Home is a very practical and useful information coupled with personal stories from caregivers who experienced the process with a loved one. Topics include a historical overview of dying at home, social support, the well-being of the caregiver, demystifying death and life after the death of a loved one. Written in an extremely caring and supportive tone. 1992, 257 pp., $22.95.

Johns Hopkins University Press, 701 W. 40th Street, Baltimore, MD 21211; 800/537-5487.

*EARLY CARE FOR HIV DISEASE: Second Edition

Ronald Baker, PhD, Jeffrey Moulton, PhD, John Tighe

Divided into two parts, this book covers early medical care and psychological well-being. The authors effectively deliver the message that HIV-positive individuals will benefit greatly from seeking medical care and psychological support as soon as possible after learning their HIV antibody status. 1992, 144 pp., $9.95 + $4.00 shipping/handling.

Impact AIDS (Distributor), 3692 18th Street, San Francisco, CA 94110; 415/861-3397. Produced by the San Francisco AIDS Foundation.

*FOR THOSE WE LOVE: A Spiritual Perspective on AIDS (2nd Edition)

The Archdiocese of St. Paul & Minneapolis

This workbook offers good, practical, and simple suggestions for both PWAs and the people who love them. There is a particularly wonderful section by a PWA about talking with young people about AIDS. 1991, 121 pp., $9.95 + $3.50 s/h.

The Pilgrim Press, 700 Prospect Avenue East, Cleveland, OH 44115; 800/537-3394.

*GETTING THE WORD OUT: A Practical Guide to AIDS Materials Development

Ana Consuelo Matiella, editor

This practical guide for developing effective HIV/AIDS education materials offers insights and recommendations about how to develop culturally sensitive and relevant HIV/AIDS education materials for diverse communities. Chapters include: Using Focus Group Interviews to Design Materials; Developing Low-Literacy Materials; Adapting and Translating Materials; Producing Comic Books and Photonovels; and Developing Relevant Materials on a Low Budget. 1990, 232 pp., $19.95 plus 15% p/h.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 800/321-4407.

GYNECOLOGICAL CARE MANUAL FOR HIV-POSITIVE WOMEN

Risa Denenberg, FNP

This text will serve as a much needed reference, allowing those at the frontlines of care for HIV disease to enhance and incorporate gynecologic skills into their clinical practice. The handy tome also directs the health care provider's attention to mechanisms of support for patients that will offer an extended and improved level of care. 1993, 171 pp., $12.95.

Essential Medical Information Systems, Inc., P.O. Box 1607, Durant, OK 74702-1607; 800/225-0694.

*HIV INFECTION AND DEVELOPMENTAL DISABILITIES: A Resource for Service Providers

Allen Crocker, Herbert Cohen, and Theodore .Kastner

The authors of this guide examine medical social, legal, and educational issues involved in the effort to provide appropriate services to people with developmental disabilities and HIV infection. This book "aims to ensure that developmental services will be included as needed in the complex of care provided for persons with HIV infection." 1992, 292 pp., $49.95.

Distributor: National Professional Resources, Inc., P.O. Box 1479, 25 South Regent Street, Port Chester, NY 10537;914/937-8879.

*HOMOPHOBIA: How We All Pay the Price

Warren Blumenfeld, Editor

Inviting sexual minorities and heterosexuals to become allies in the fight against homophobia, the contributors in this anthology explore how homophobia colludes with sexism by forcing people into rigid gender roles; how homophobia causes unnecessary pain and alienation in family relationships; how it works against health-care policy and arts administration that would otherwise benefit all members of society; and how homophobia leaves the promise of religious institutions unfulfilled. The book includes a section about how to run an anti-homophobia workshop. 1992, 308 pp., $30.00 cloth, $17.00 pb.

Beacon Press, 25 Beacon Street, Boston, MA 02108; 617/742-2110.

IMMUNE POWER: A Comprehensive Treatment Program for HIV Combining Holistic & Standard Medical Therapies Into the Optimal Treatment Program

Jon Kaiser, MD

This healing program for HIV includes an integration of three basic approaches: nutritional support; psychological support; and standard medical therapies. Chapters include Viral Dormancy, Private Practice Data, Natural Therapies, Emotional Healing, Standard Medical Therapies, and Case Histories: Examples of Viral Dormancy. 1993, 240 pp., $18.95.

St. Martin's Press, 175 Fifth Avenue, New York, NY 10010;800/458-8341.

*LATINA AIDS ACTION PLAN AND RESOURCE GUIDE

National Hispanic Education and Communications Projects (HDI)

This guide covers the critical issues that must be addressed in order to implement successful HIV/AIDS prevention programs and to develop policies that will empower women and support women's leadership in public health decision-making. Contains a resource guide which covers model programs, a bibliography targeting Latinas and children, and a listing of HIV/AIDS testing and counseling sites and organizations providing HIV/AIDS services to Latinas. Spanish translations of the major sections are provided. 1990, 195 pp., $15.00.

HDI Projects, 1000 16th Street, NW, Room 504, Washington, DC 20036; 202/452-0092.

NO TIME TO WAIT: A Complete Guide to Treating, Managing and Living with HIV Infection

Nick Siano with Suzanne Lipsett

This book is designed to bring the full range of treatment information to HIV-positive people and their caregivers. It explains a range of AIDS-related diseases in layperson's language, and provides prevention information about drugs and alternative therapy options. 1993, 367 pp., $12.95.

Bantam Books, 1540 Broadway, New York, NY 10036; 800/223-6834.

*PREVENTING AIDS: A Guide to Effective Education for the Prevention of HIV Infection

Nicholas Freudenberg

This guide is divided into two sections: Planning AIDS Education Programs and How to Educate Specific Population Groups about HIV/AIDS. Each chapter includes tables that provide clear information and guidelines for the most effective and creative means for program development. 1989, 217 pp., $28.50, $19.95, APHA member.

American Public Health Association, 1015 15th Street NW, Washington, DC 20005; 202/789-5600.

RISK & RECOVERY: AIDS, HIV & Alcohol -- A Handbook for Providers

Marcia Quackenbush, MFCC, J.D. Benson, MFCC with Joanna Rinaldi

This guidebook provides essential knowledge about the connections between alcohol-use and HIV disease. It offers valuable advice to private practitioners, alcohol counselors, treatment staff, and AIDS service providers, including information about how these connections affect alcohol recovery. Finally, the book affirms the importance of maintaining recovery while dealing with a second life-threatening disease. 1992, 242 pp., $16.95.

UCSF AIDS Health Project, P.O. Box 0884, San Francisco, CA 94143; 415/ 476-6430.

SUPPORT GROUPS: The Human Face of the HIV/AIDS Epidemic - A Handbook for Health Care Providers, PWAs, Their Loved Ones & the Community-at-Large
Gail Barough, PhD

This how-to manual for providing support groups provides information on various support groups including those for PWAs, substance-free PWAs, caregivers, bereavement groups for families, caregivers and friends, bereavement groups for partners and spouses, and support/supervision groups for other support group facilitators. Each section begins with a participant's story and then maps out the format of that particular group. 1992, 91 pp., $10.00.

Long Island Association for AIDS Care, Inc., P.O. Box 2859, Huntington Station, NY 11746; 516/385-2451.

***THE AIDS BENEFIT HANDBOOK: Everything You Need to Know to Get Social Security, Welfare, Medicaid, Medicare, Food Stamps, Housing, Drugs and Other Benefits**
Thomas McCormack

McCormack discusses programs that are available by cutting through the complexities of the benefits system and summarizing in practical and concise terms what benefits are offered, who is eligible for them, where and how to apply, how to appeal and other key information. 1990, 257 pp., $30.00/hc, $11.00/pb.

Yale University Press, 92A Yale Station, New Haven, Ct 06520; 203/432-0940.

WOMEN & HIV/AIDS: An International Resource Book
Marge Berer with Sunanda Ray

"If we want to end the epidemic of HIV, a virus which has, above all, taken advantage of how all of us across the world live our sexuality, it is our relationships that we must start to question and transform." So begins this resource book. Thoughtful and practical, the authors discuss various creative possibilities for reaching women with prevention messages as well as truly supporting women living with the disease. 1993, 383 pp., $22.00.

Pandora Press, 77-85 Fulham Palace Road, Hammersmith, London, England W6 8JB.

***WOMEN, AIDS AND ACTIVISM**
The ACT-UP/New York Women and AIDS Book Group

This resource advances research by and about women involved with the HIV/AIDS crisis, provides information about women's particular needs, analyzes the impact of AIDS on women's lives from a feminist perspective, and promotes grassroots activism. It includes articles on a wide range of topics including: Testing and Legal Issues for HIV-Positive People; Unique Aspects of HIV Infection in Women; Race, Women and AIDS; Lesbian in the AIDS Crisis; Teenagers; Reproductive Rights and AIDS; Bisexual Women and AIDS; and Prostitution and HIV Infection. 1990, 295 pp., $9,

South End Press, 116 St. Botoloph Street, Boston, MA 02115;800/533-8478.

***WOMEN, AIDS AND COMMUNITIES: A Guide for Action**
Gerry Pearlberg

This book provides an overview of the HIV epidemic's impact on women in the U.S. and some ways concerned organizations can help women address the issue. It is clearly and gently written with practical suggestions. The author provides guidelines, not step-by-step plans, and includes an excellent section on testing. 1991, 141 pp., $27.50 hc, $19.50 pb.

Scarecrow Press Inc., PO Box 4167, Metuchen, NJ 08840; 800/537-7107.

HISTORICAL OVERVIEWS OF THE PANDEMIC

AIDS, THE WINTER WAR
Arthur D. Kahn

This is a two-part account of the reawakening of lesbian and gay activism in the mid-1980s to force recognition and action on behalf of the AIDS epidemic and the resulting governmental response to this pressure. It is an important historical perspective. 1993, 236 pp., $27.95.

Temple University Press, Broad & Oxford Streets, University Services Building, Room 305, Philadelphia, PA 19122; 800/447-1656.

A GLOBAL REPORT: AIDS in the World
Jonathan Mann, MD, Daniel Tarantola, & Thomas W. Netter, editors

This book has a clear mission to provide information about the current status of the pandemic and the global response to it, as well as to stimulate discussions and to help shape understanding for the sake of action yet to come. This first edition contains both a retrospective and current analysis of the pandemic's dimensions, shape and impact, as well as the range of societal responses. 1992, 1037 pp., $45.00/hc, $22.95/pb.

Harvard University Press, 79 Garden Street, Cambridge, MA 02138; 617/495-2600.

***THE AIDS AGENDA: Emerging Issues in Civil Rights**
Nan Hunter & William Rubenstein, editors with the AIDS Project of the American Civil Liberties Union

This book examines the legal system's response to HIV/AIDS and analyzes the increasingly complicated questions related to AIDS litigation. It attempts to help legislators and others concerned with health care policy chart a more coherent and humane course in the coming years. 1992, 301 pp., $27.95.

The New Press, 450 W. 41st Street, New York, NY 10035; 800/233-4830.

PERSONAL STORIES

AS REAL AS IT GETS: The Life of a Hospital at the Center of the AIDS Epidemic
Carol Pogash

Randy Shilts, author of *And the Band Played On*, writes in the forward of this book "The stories reveal that sometimes we have behaved well in the face of AIDS, and sometimes we have behaved poorly, and always we have behaved as humans, for better or worse." This book tells the stories of the staff of San Francisco General and their struggles at the beginning of the pandemic. 1992, 253 pp., $18.95.

Birch Lane Press, 120 Enterprise Avenue, Secaucus, NJ 07094; 201/866-8159.

POSITIVE WOMEN: Voices of Women Living with AIDS
Andrea Rudd and Darien Taylor, editors

An international collection of writing by women who are living with AIDS, this book is "not about despair; rather it's an amazing spectrum of writing by women who shatter myths, take control of their lives and find their own power in the challenge of living with AIDS." 1992, 269 pp., $14.95.

Second Story Press, 760 Bathurst Street, Toronto, Canada M5S 2R6;416/ 537-7850.

WISE BEFORE THEIR TIME: People From Around the World Living with AIDS and HIV Tell Their Stories
Ann Richardson & Dietmar Bolle, editors

The personal stories of women and men from around the world living with HIV and AIDS. The reader becomes acquainted with various voices and the outlook in various countries. Valuable for educators in personalizing their HIV/AIDS information. 1992, 144 pp., $9.00.

HarperCollins, 77-85 Fulham Palace Road, London, England W6 8JB; 800/328-3443.

AIDS & THE POPULAR CULTURE AND THE ARTS

A LEAP IN THE DARK: AIDS Art, & Contemporary Cultures
Allan Klusacek & Ken Morrison, editors

In this international anthology, essays by historians and anthropologists present a historical context for AIDS while contributions from artists, writers, art critics & AIDS activists describe the multifaceted involvement of the artistic community in the fight against AIDS. 1992, 320 pp., $16.95.

Vehicule Press, P.O. Box 125, Place du Parc Station, Montreal, Quebec, Canada H2W2M9.

MUSES FROM CHAOS AND ASH: AIDS, Artists & Art
Andrea K. Vaucher

The author explores the impact of AIDS on the work of artists living or having died of AIDS-related illnesses. Through interviews, artists from the worlds of dance, theater, music, film and the visual arts discuss the effects of HIV/AIDS on their own artistic evolution and on the creative process. 1993, 260 pp., $22.50.

Grove Press, 841 Broadway, New York, NY 10003; 800/937-5557.

FOR YOUNG PEOPLE AND THOSE WHO CARE FOR THEM

***AIDS: TRADING FEARS FOR FACTS — A Guide for Teens**
Karen Hein, MD & Theresa Foy DiGeronimo

The authors, writing especially for teens, are sensitive to the needs, fears, and concerns of young adults. Pronunciations of medical terms are given as the terms are introduced in the text for discussion, and photographs are effectively used. The book includes a resource directory. Third Edition, 1993, 240 pp., $4.95 + $.50 p/h.

Consumer Reports Books, 9180 Le Saint Drive, Fairfield, OH 45014;800/272-0732.

***ALEX, THE KID WITH AIDS**
Linda Walvoord Girard

For grade school children ages 6-10, this is the story of Alex, a new student who is living with AIDS. While Alex's friendship with another boy in the class grows, he comes to understand Alex's illness. Alex tries to get away with as much mischief as he can by playing up the fact that he has AIDS. The story demystifies the life of a child living with AIDS and offers insight into the schoolmate's response. 1991, 35 pp., $13.95/hc, $5.95/pb.

Albert Whitman and Co., 6340 Oakton Street, Morton Grove, IL 60053; 708/581-0033.

***BE SMART ABOUT SEX: Facts for Young People**
Jean Fiedler & Hal Fiedler

This book, containing anecdotal information from young people, fosters a better understanding of the realities of HIV/AIDS. Chapter topics include: Expressing Sexual Feelings; Thinking About Sexual Decisions; Facts About AIDS; and Four Rules for Safer Sex. 1990, 128 pp., $17.95.

Enslow Publishers, Bloy Street & Ramsey Avenue, Box 777, Hillside, NJ 07205; 908/964-4116.

***CHILDREN AND THE AIDS VIRUS: A Book for Children, Parents, and Teachers**
Rosemarie Hausherr

Utilizing beautiful black-and-white photos, this book explains the facts about HIV and its transmission. Large print is used for younger children, and in-depth discussions in smaller print are included at the bottom of the page for older children. 1992, 48 pp., $14.95/hc; $5.95/pb.

Clarion Books, 215 Park Avenue South, New York, NY 10003; 212/420-5800.

***COME SIT BY ME**
Margaret Merrifield, MD & Heather Collins

This book about understanding and dealing with HIV/AIDS is written for children ages four to eight and their caregivers. The story concerns a young girl who finds out that one of her schoolmates is living with AIDS. Beautifully illustrated, sensitive, and realistic. 1990, 30 pp., $6.95.

Women's Press, 517 College Street, Suite 233, Toronto, Ontario M6G 4A2, Canada; 416/921-2425.

***LOSING UNCLE TIM**
Mary Kate Jordon

Beautifully written and illustrated, this book deals with the loss, grief, and fear children can experience after losing a family member or friend to AIDS. Daniel experiences his Uncle Tim's illness in the beginning of the story and his subsequent death toward the end, as well as his funeral and the reading of his will. An important book, as there are more and more children are having to deal with the emotional ramifications of death and dying due to HIV/AIDS. For ages 4-8. 1989, 26 pp., $13.95/hc, $5.95/pb.

Albert Whitman and Co., 6340 Oakton Street, Morton Grove, IL 60053; 800/255-7675.

***RISKY TIMES, HOW TO BE AIDS-SMART AND STAY HEALTHY: A Guide for Teenagers**
Jeanne Blake

This attractive, easy-to-read book includes chapters such as, How You Can and Can't Get Infected; Condoms; Decisions; and Questions. Six teenagers provide personal insights into each of the issues presented. Quotations from famous entertainers and athletes appear throughout the book. A companion guide for parents accompanies the book. This companion guide was written by syndicated columnist Beth Winship ("Ask Beth"). 1990, 158 pp., $5.95.

Workman Publishing Co., Inc., 708 Broadway, New York, NY 10003; NY, 212/254-5900, elsewhere, 800/722-7202.

***RYAN WHITE: My Own Story**
Ryan White & Ann Marie Cunningham

This personal account of this outstanding young man's life — both joyous and difficult — is told with much humor. The autobiography is amazing, interesting, and moving. Many photographs are included. Although enjoyable for people of all ages, this autobiography is especially useful for teenagers learning about HIV/AIDS. 1991, 277 pp., $16.95.

Dial Books, 120 Woodbine Bergenfield, NJ 07621; 800/526-0275.

*TALKING WITH KIDS ABOUT AIDS: A Program for Parents and Other Adults Who Care

Jennifer Tiffany, Donald Tobias, Arzeymah Raquib, & Jerome Ziegler, Illustrations by Marcia Quackenbush

This resource is actually a training manual that includes a resource manual and a teaching guide. This three-session training will better prepare parents and other adults who care for young people "to work as a group to clarify any confusion they have felt about AIDS and to learn to offer AIDS information to young persons in increasingly effective ways." The resource manual is provided to participants of this workshop. The material is well-organized and beautifully illustrated, and the information is clearly and sensitively presented. 1991, Resource Manual: 86 pp., Teaching Guide: 47 pp., $9.50.

Parent AIDS Education Project, Department of Human Service Studies, Cornell Cooperative Extension, Cornell University Resource Center, 7 Business and Technology Park, Ithaca, NY 14850; 607/255-1942.

*TEACHING AIDS: A Resource Guide on Acquired Immune Deficiency Syndrome

Marcia Quackenbush & Pamela Sargent

An updated version of this curriculum is for educators to use with teenagers. It provides seven teaching plans, ready-to-use worksheets, teacher background information, and a 10-question quiz about HIV transmission and prevention. New sections have been added and include: a preface about the evolving language of the AIDS epidemic, new information on the changing patterns of high-risk behavior among teens, practical recommendations for more effective HIV/AIDS prevention education, and a glossary. Third edition. 1990, 163 pp., $19.95.

Network Publications, PO Box 1830, Santa Cruz, CA 95061; 800/321-4407.

*TEENS WITH AIDS SPEAK OUT

Mary Kittredge and Julian Messner

Written for teens, this book seeks to fill gap between knowing the facts about HIV and AIDS and what it actually means to be living with the disease. It includes a glossary of terms. 1991, 119 pp., $8.95.

Simon & Schuster, Prentice Hall Bldg., Englewood Cliffs, NJ 07632; 201/592-2000.

*WHAT YOU CAN DO TO AVOID AIDS

Earvin "Magic" Johnson

Likely to be a popular choice among teens, this book actually begins with a message for parents asking them to talk with their children about HIV/AIDS in order to help protect kids from HIV-infection. There are several personal stories from young people that make for interesting reading, plus a very good section on condoms, and an overall personal, warm tone. Also available in Spanish. 1992, 193 pp., $3.99; in audio cassette (in English) $5.99, English book and cassette combo., $9.95

Chronicle Books, 275 Fifth Street, San Francisco, CA 94103; 415/777-7240.

WHISPER, WHISPER JESSE, WHISPER, WHISPER JOSH: A Story About AIDS

Eileen Pollack

This book is for children ages 5 and up. Jesse's Uncle Josh is living with AIDS, yet neither his parents nor his uncle come out and tell the boy. Jesse knows that something is wrong and hears it in the adult's whispers, which give the book its title. Because many adults find that AIDS is difficult to talk about, young children are often left in the dark as painful events unfold. All children would benefit from reading this story. "The widespread experience of coping with loss from this sad epidemic will betoken a new generation." 1992, 30 pp., $5.95.

Advantage/Aurora Publications, P.O. Box 881, Kendall Square, Cambridge, MA 02141; 617/721-1064.

*Z's Gift

Neal Starkman

This book tells the story about how a young boy responds to the news that his teacher is living with AIDS, and how he teaches the adults and children around him the meaning of compassion and rationality. Written for 8 - 12 year olds, this story has lovely and simple illustrations. 1988, 52 pp., $7.00.

Comprehensive Health Education Foundation, 22323 Pacific Highway South, Seattle, WA 98198; 800/323-2433.

How to Talk to Your Children About AIDS
An Updated SIECUS brochure

This indispensable and much-needed comprehensive booklet, designed to help parents talk with their children about AIDS, has been updated with the most current information and will be available in December. The brochure offers basic information about AIDS and age-appropriate guidelines for preschoolers, young children, preteens, and teenagers. More than one-half million copies of this precise and thorough booklet have been distributed to individuals and organizations across the United States.

"I heartily recommend ... *How to Talk To Your Children About AIDS.*
It is written in plain, easy-to-understand language." --Dear Abby.

One copy free with a self-addressed, stamped, business-size envelope; 2-49 copies/$1.00 each, 50-100 copies/$.80 each, multiples of 100/$65.00 per hundred copies, multiples of 1000/$400 per thousand copies.

• AUDIO-VISUALS • AUDIO-VISUALS • AUDIO-VISUALS •

SEX EDUCATION IN AMERICA: AIDS AND ADOLESCENCE

60 Minutes, Distributed by Media Works, Inc. P.O. box 15597 Kenmore Station, Boston, MA 02215800/600-5779, $29.95

Sex Education in America: AIDS and Adolescence powerfully illustrates the components of the current controversy over sexuality education and the unfortunate outcome of increasing numbers of teens who are becoming infected with HIV. The video is framed by interviews between news correspondent Jeanne Blake and four teens living with HIV/AIDS. These four young adults are committed to breaking through adult and peer denial by discussing their experiences openly.

Against this poignant backdrop, the video examines the debate between comprehensive and abstinence-only approaches in providing sexuality education. Five different sexuality education programs are examined: three comprehensive (*Reducing the Risk*, *Postponing Sexual Involvement*, and *Skills for Life*) and two abstinence-only (*Sex Respect* and *Teen Aid*). Portions of a lesson from each program highlight the differences between the two types of approaches. For instance, The *Reducing the Risk* instructor is shown describing various birth control methods and students in the class engage in role-playing exercises that model ways of refusing to engage in sexual activity. *Skills for Life* footage includes students talking openly about the pressures to have sexual intercourse and a demonstration about how to use a condom.

In contrast, the Teen Aid instructor is attempting to scare students out of pre-marital sexual behaviors. "Guys, let me tell you something," the instructor says. "If you get a girl pregnant you have to pay child support. If you're in school and unable to pay child support, your parents will have to pay child support. I don't care if she's slept with ten guys. And if they can't pay that child support, they're going to jail." In the *Sex Respect* classroom, junior high student receive a lesson about AIDS that includes the false information that kissing transmits HIV. A student sums up the (mis)information by saying, "Pecks are okay, but if you go deep [when you kiss], you have a good chance of getting AIDS."

The video also includes comments from Dr. James Curran of the U.S. Centers for Disease Control and Prevention, Surgeon General Dr. Jocelyn Elders, and researcher Dr. Douglas Kirby. Emotional appeals from community members on both sides of the issue (comprehensive and fear-based) present the most common arguments for their approach to sexuality education. One weakness of the video is its strict focus on local church involvement in promoting abstinence-only programs. The national movement by Far Right organizations to replace accurate effective programs with fear-based programs is not mentioned, nor are some of the ways in which sexuality education is used as a wedge issue for promoting larger right-wing agendas within the public school systems.

Nonetheless, this video is an excellent overview of the issues surrounding sexuality education to date. The documentary may indeed go a long way toward developing awareness about the current controversy and inspiring community members, parents, students, administrators, and teachers to get involved. The program is extremely balanced and objective in its portrayal and could certainly be used to educate school boards and policy makers about the issues. The documentary has aired on some PBS stations and will be shown in additional areas if sufficient interest is demonstrated. For more information about how to facilitate the showing of this documentary on a local PBS station, contact media works at 800/600-5779.

Reviewed by Leslie M. Kantor, M.P.H., SIECUS Directory of Community Advocacy.

AIDS AND ADDICTION

Spirits Alive, 20 minutes, 1992, PO Box 6074, $65.00 Minneapolis, MN 55406.

The issue of HIV/AIDS and addiction is one with which many professionals do not feel comfortable. *AIDS and Addiction* profiles the lives of four individuals who are in recovery and who are also living with AIDS. Each shares his and her own experience with previous drug use, subsequent treatment and recovery, and finally the impact of HIV on sobriety.

This twenty-minute video is comprised of five segments: Diagnosis, Relationships, Recovery, Relapse, Experience in Treatment, Support, and Living with HIV. The video is thorough, insightful, and an important resource for AIDS educators and counselors who have little or no experience with chemical dependency. It may also be used as a discussion-starter and a supportive tool for those who are in treatment or involved in various twelve-step programs. For those working in other educational and therapeutic settings, the video is informative and moving.

The PWAs featured in the video reveal vital information about each of the topics. For example, Bobbie explains that although he felt afraid when he learned of his diagnosis, he realized it was more a fear of rejection than of death. Barb was 16 when she tested HIV-positive. Now a young woman in recovery, a lesbian, and the mother of two, she articulately reveals the breadth of her experience growing up in foster care, and how it influenced her to give up her own children. Carlton asserts that his sobriety made living with HIV easier. Ironically, friends in the program often tell him, "If I were you, I'd be using [drugs]." Carlton confides that "one of the best ways to disrupt the group process is to disclose that you're HIV positive."

The four HIV-positive people in this video reveal painful experiences — at least initially — in treatment programs. Barb recalls hearing AIDS jokes made by the counsellors and being advised not to talk about her HIV status in treatment groups. The overriding assumptions in treatment settings seems to be that everyone is HIV-negative, and the goal most discussed is how not to become infected. Barb shares that she was also restricted from revealing and exploring the implications of her sobriety and her lesbianism. In fact, for these two important reasons her early treatment experience was unsuccessful, and she left after a month.

Barb shares that she feels like she is fighting for her life in two ways, for sobriety and for life despite HIV — a feeling which is echoed by the others. Carlton addresses the fact that what is especially difficult about living with both is the chronic nature of these diseases. "People are always becoming infected or dying. It's like relapse - losing people to the bottle or needle. Some come back and some don't." He concludes this video by expressing a wish that what he'd really like to do is "take all my friends with AIDS and give them the day off. We're going to the park!" This simple wish is one that so many PWAs often express. Just one day of not having to think about it, deal with it, take medication, talk to health care providers, argue with insurance companies, social services ... on and on.

AIDS and Addiction is produced in a clear and poignant style and never loses sight of its main point. It provides viewers with a succinct peek into the lives of the very remarkable people living in recovery and with HIV/AIDS. The video is a wonderful tool for anyone seeking self-improvement or working in AIDS to help others.

Reviewed by Carolyn Patierno is the Director of the National AIDS Initiative at SIECUS.

WHERE ARE THE INFORMATION GAPS?

A Needs Assessment of 133 HIV/AIDS Service Organizations and Programs

Through the National AIDS Initiative Program at SIECUS, a survey was distributed in March 1993 to nearly one thousand AIDS Service organizations and programs across the U.S. to assess gaps in information about sexuality and HIV/AIDS education and information. A total of 133 agencies responded to this SIECUS questionnaire, representing most geographic regions and a spectrum of services to diverse communities. The following is a report of the findings:

Who Responded

Of those responding to the questionnaire, 84% conducted client HIV/AIDS education, 74% were involved in providing direct HIV/AIDS services, 68% worked on the policy aspects of HIV/AIDS, and 66% produced an HIV/AIDS publication. Since many of the respondents worked in different aspects of AIDS, the percentages are greater than 100. These respondents served a variety of communities, including adolescents, gay men, people of color, and people living with HIV/AIDS. A minority of respondents reported serving migrant workers, new immigrants, and senior citizens.

Interestingly, those agencies conducting direct services were more likely to serve gay men, homeless youth and homeless adults, injection drug users, people in recovery and PWAs. Those agencies reporting that they engaged in client education were more likely to serve adults rather than adolescents, people of color, lesbians, gay men, bisexuals, injection drug users, people in recovery, sex workers and PWAs. Agencies targeting college students were likely to be involved in producing HIV publications. Advocacy work was not associated with any particular community.

How Sexuality Information is Used

Respondents were asked how sexuality information and HIV/AIDS information fit into their particular program. Ninety-five percent reported that they included sexuality information in their HIV/AIDS resources. Seventy-three percent also reported that they conducted staff trainings on sexuality issues. Among direct service organizations, 79% reported providing sexual counseling and sexuality education to clients. However, 10% of those agencies who provided sexual counseling, reported that they did not provide information about safer sex within a context of sexuality education. There were no regional differences in the likelihood of including safer sex in sexuality education programs.

Identifying Gaps in Information

Respondents were asked where they perceived their agency had gaps in information regarding HIV/AIDS education. The following gaps were most commonly reported:

Sexuality through life	(58%)
Homophobia	(53%)
Sexual Behavior Research	(52%)
HIV issues for women	(51%)
Sexual abuse	(48%)
Sexual Orientation	(47%)
Alcohol and Drug use	(46%)
Adolescent sexuality	(43%)

The areas that seem to be adequately covered by the responding agencies and for which adequate information exists are transmission of HIV, condom efficacy, and techniques for safer sex.

Those who reported gaps of information in adolescent sexuality were also likely to report gaps of information in sexual orientation, homophobia, condom efficacy, sexual behavior research and women. Those respondents who reported gaps in information concerning homophobia also were likely to report that they lacked information about transmission of HIV and condom efficacy. Further, those who reported that they lacked information about alcohol and drug use also lacked information about women's issues.

Conclusion

Although the majority of agencies surveyed report that they offer sexuality information and provide staff trainings, significant gaps exist in HIV/AIDS programs. HIV/AIDS educators, advocates, and service providers in general perceive that information concerning sexuality throughout life, homophobia, sexual behavior research and HIV issues for women is lacking in their programs. Sexual abuse, sexual orientation, alcohol and drug use, and adolescent sexuality also lack adequate coverage and information in these agencies. Clearly there remains a need for greater coverage of sexuality issues in HIV/AIDS programming.

Sex Information and Education Council of the U.S. Instructions for Authors

SIECUS REPORT

Now nearing its 30th year anniversary, SIECUS continues a tradition of excellence in the publication of the *SIECUS Report,* a journal of contemporary thought and research from the field of sexuality and education. In each issue of the report, groundbreaking articles and commentary by leaders and workers in the field are featured along with news, special bibliographies on varied topics, book and audiovisual reviews, recommended resources, and advocacy updates. All of this comes to members and interested subscribers six times a year. Articles, book and audiovisual review submissions should adhere to the following guidelines to assist in expediting the publication. The SIECUS Report is prepared using a Macintosh desktop publishing system.

Preparation of Articles, Book, and Audiovisual Reviews

If possible: all submissions should be on disk, with one copy printed-out (all articles, book, and audiovisual reviews should be submitted on 8^1/2x11 paper, double-spaced, with paragraphs indented):

Ideal — Macintosh hard disk. Hard disks should be sent only for a Macintosh Apple Computer. Others are non-compatible.

Acceptable — floppy disk. We can translate almost all later models of computer floppy disks (IBM PC, IBM-compatible machines, etc.) .

On all disk labels (hard or floppy) include the following clearly written information: Title of article and author's name, the type of computer/word processor used (IBM PC, Macintosh) type of software used (Word, Word Perfect).

If you do not have access to a computer, send a typewritten copy.

- **Article format:**

The article should include (all centered) at the beginning: the title, all caps; the subtitle, upper and lower case; the author's name, upper and lower case, with professional degree(s) (all caps, no periods between letters); author's title(s) and current affiliation, upper and lower case. Example:

HOMOPHOBIA
A Weapon of Sexism
Suzanne Pharr
Founder, Women's Project, Little Rock, Arkansas

Articles may incorporate sidebars, special resources, and factual information of interest; chart information should be incorporated into the body of the article if possible, or if indispensable in chart form, be submitted camera-ready for printing. It is helpful if captions/headings are used to demarcate different sections, as we normally end up dividing the article into separately headed sections; however, sometimes this is not applicable.

- **Book review format:**

The beginning of book reviews should include the following information (not centered): title of the book, author(s) or editor(s), what city and state it is published in, publishing company, year of copyright, number of pages, and price for hardcover and/or paperback editions. Example:

THE INVISIBLE EPIDEMIC: THE STORY OF WOMEN AND AIDS, Gena Corea, Harper Collins, 365 pp., $23.00.

- **Audiovisual review format:**

The editor is open to discussion of creative ideas for presentation of book and audiovisual reviews — multiple reviewstogether, interviews, summaries of topical subject areas, etc. Example:

FIVE OUT OF FIVE
Executive Producer, New York Women Against Rape; produced and written by Fatima Cortex & Pat Beaupre; and directed by Ayoka Chenriza. 1987, 7 mins., color video. Rental, $35, purchase, $100. Women Make Movies, Inc., 225 Lafayette Street #211, New York, NY 10012, 212/925-0606.

References — if included in the above:
At the end of the manuscript, all references should be listed numerically as they appear in the manuscript as per our style.

Example:

- **Book citations:**
  Coles, R. & Stokes, G. Sex and the American teenager (New York: Harper & Row, 1985).

- **Chapter in book citations:**
  Faro, S. Sexually transmitted diseases, In RW Hale & JA Krieger, eds. Gynecology: A Concise Textbook. (New York: Medical Examination Publishing Company, 1983), 198-214.

- **Journal article citations** (Vol. 7, No. 4 of the Journal Family Life Educator):
  Young, M. Self-esteem and sexual behavior among early adolescents. *Family Life Educator* 7(4):16-19, 1989.

- **Conferences, seminars, etc.:**
  Conway, G & Hooper, EY. Risk of AIDS and HIV infection in American Indians and Alaskan Natives. Poster session presented at the Fifth International Conferences on AIDS, Montreal, Quebec, Canada, June 4-9, 1989.

- **Personal communication, unpublished:**
  Cairns, KA. Computer-assisted learning program for adolescent sex education. Unpublished manuscript. University of Calgary, Calgary, Alberta, Canada, 1987.

  Rowell, R. Warning Signs: Intravenous drug use among American Indians/Alaskan Natives. Drugs and Society 5(1,2), 1990 (forthcoming)

Length: Varies for submissions. Feature articles are usually 3,000 - 6,000 words. Book and Video reviews range from 200 - 600 words.

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CALL FOR SUBMISSIONS

Following is a schedule of themes for the *SIECUS Report* to be published in the coming year (Volume 21). If you are interested in submitting an article, related book or video review, or a critical analysis of the issues, send a draft manuscript, by the dates specified, to SIECUS Editorial Office, 130 West 42nd Street, New York, NY 10036.

SIECUS Report, Dec 1993/Jan 1994
Culture and Sexuality
Deadline: 10/1

SIECUS Report, Feb/Mar 1994
Parent Education
Deadline: 12/1

SIECUS Report, Apr/May 1994
30th Anniversary Issue
Deadline: 2/1

SIECUS Report, Jun/Jul 1994
Sexuality and Morality
Deadline: 4/1

SIECUS Report, Aug/Sept 1994
Female Sexuality
Deadline: 6/1

SIECUS Report, Oct/Nov 1994
HIV/AIDS Education
Deadline: 8/1