The Paris AIDS Conference: Psychosocial Research

Judy Macks, MSW, LCSW

With the AIDS epidemic striking more than 90 nations, the Second International Conference on AIDS easily attracted researchers and health professionals from around the world. Nearly 3500 participants attended the three-day conference held in Paris and sponsored by the Pasteur Institute and the French government. The participants were challenged to screen and assimilate more than 1000 scientific papers and poster sessions from the fields of virology, immunology, clinical research, psychiatry, and public health.

The vast majority of psychosocial presentations centered on four topical areas: (1) the psychosocial response to AIDS spectrum disorders among high risk populations and health care providers, (2) neuropsychiatric complications in AIDS, (3) group interventions, and (4) HIV antibody testing and counseling.

Psychosocial Response: Gay and Bisexual Men

Three psychosocial researchers reported on longitudinal studies measuring psychosocial distress among persons with AIDS and ARC. Susan Tross, PhD of Memorial Sloan-Kettering Cancer Center in New York found a descending level of distress in the preliminary analysis of data collected on the first 236 men participating in the study. Criteria for DSM III diagnoses were met by 78% of the men with ARC, 56% of those with AIDS, and 39% of healthy gay male controls. The most common diagnoses, accounting for 67% overall, was adjustment disorder with depressive, anxious, and mixed features. (Note: DSM III is a published guide used by mental health professionals to determine diagnoses.)

In University of California San Francisco (UCSF) studies conducted by Lydia Temoshok, PhD and Jeffrey Mandel, PhD, MPH, persons with ARC scored higher than persons with AIDS on several self-report measures of distress. This again points to the considerable psychosocial stress experienced by people with ARC. In both studies reported by Temoshok and Mandel, the data suggested that psychosocial distress is significantly correlated with the following variables: attributing the cause of disease to oneself, attributing possible health improvements to oneself or others, significant beavior changes had been made, particularly a reduction in high risk sexual practices. Risk reduction programs on these behavior changes.

Intravenous Drug Users

All the scientific presentations about intravenous (IV) drug users clearly indicated the seriousness of the epidemic among this population and emphasized the need for research, psychosocial services, and prevention programs directed to this group.

A study conducted by the New York City Department of Health documented a significant increase in the mortality rate reported that the constellation of coping characteristics measured by Kobasa's "hardiness" scale, including commitment, challenge, and control, may be the most significant variables in preventing dysphoria.

In addition to research on psychosocial aspects of coping with AIDS and ARC, several papers dealt with the psychosocial problems encountered among men at risk of contracting AIDS. For example, several researchers presented findings on men at high risk who suffer from AIDS Anxiety, a condition with the following characteristics: (1) repeated physician visits with no reassurance of being healthy, (2) obsessional thoughts, (3) recurrent fears of dying and ego-dystonic reactions, and (4) a fixed belief of an AIDS diagnosis in high risk persons with non-specific symptoms. Clinical reports suggested that AIDS Anxiety may partially result from the displacement of psychosocial conflicts and that short-term psychotherapy can be successful in treating the syndrome.

"Investigators agreed that the incidence of neurologic impairment is extremely high among AIDS patients . . . of 108 patients with AIDS Related Dementia, 25% had neurologic dysfunction as their first AIDS presentation."

Anti-gay sentiment among the public sector had increasingly become a concern for 950 gay and bisexual men, according to the data obtained by the Coping and Change Project in Chicago and Ann Arbor. During the 15 months preceding September 1985, 5% of this cohort indicated that fears of job discrimination, quarantine, and possible violence were directed against them as gay men impacted their lives significantly. During the last quarter of 1985 these concerns increased among the sample to 15% of the men.

Data from several reports suggested that among gay men in New York, Houston, San Francisco, and other metropolitan areas, significant behavior changes had been made, particularly a reduction in high risk sexual practices. Risk reduction programs among this population appeared to have impacted significantly on these behavior changes.
mental health

V)

through casual contact, (2) 20% believed AIDS can be spread by transmission, (3) more than half said they would wear a mask and gown when caring for a person with AIDS, (4) 25% reported spending less time with AIDS patients. Fred Gordin, MD and his colleagues found that accuracy anticipated the increased availability of sterile needles may be successful preventative interventions among this population.

Women

Monnie Callan, MSW, a social worker from Montefiore Medical Center in New York, presented the only data specifically focused on women and AIDS. She identified the following seven areas of psychosocial concern for these women: (1) economics, (2) childbearing and child rearing, (3) women's social role as caretakers, (4) child care, informing children about the diagnosis, custody challenges, (5) physical appearance and feminine image, (6) inadequate social support systems, (7) isolation and stigma due to the perception of AIDS as a male disease. Callan said that a multidisciplinary and family-oriented approach to the care of women with AIDS best meets the needs of this population.

Health Care Workers

The Veterans Administration Medical Center in Washington, D.C. and the National Institute of Health conducted a survey in January of 1986 of 1194 hospital employees in a large urban hospital in the nation's capitol. Significant findings included the following: (1) 50% believed that AIDS can be spread through casual contact, (2) 20% believed AIDS can be spread by coughing and sneezing, (3) more than half said they would wear a mask and gown when caring for a person with AIDS, (4) 25% avoided public places such as swimming pools out of fear of HIV transmission, (5) 49% reported spending less time with AIDS patients, and (6) 35% actively avoided involvement with AIDS patients. Fred Gordin, MD and his colleagues found that accurate knowledge about AIDS was significantly correlated with low anxiety, willingness to work with AIDS patients, and appropriate professional behavior toward AIDS patients.

Two studies measured health care workers' attitudes toward homosexuals. Thomas P. Kalman, MD from Cornell University reported that of 37 medical house staff and 91 registered nurses, mean scores on the Index of Homophobia scale measured in the low-grade homophobic range for both groups. Having a gay friend or relative was significantly correlated with more positive attitudes and feelings toward homosexuals. Of this sample 10% believed that persons with AIDS were getting what they deserved. This finding was corroborated in a study conducted by William A. Barrick, RN, MSN with 250 registered nurses living in San Francisco.

Neuropsychiatric Complications

A large number of presentations focused on the most common neuropsychiatric complications with HIV infection; namely, AIDS Related Dementia, a condition characterized by cognitive, motor, and behavioral deficits. Investigators at Memorial Sloan-Kettering Cancer Center and Cornell University Medical College extensively described these deficits in terms of symptomatology and incidence. Bradford Navia, MD and Richard W. Price, PhD reported that of 108 patients with AIDS Related Dementia, 25% had neurologic dysfunction as their first AIDS presentation. Early complaints of cognitive impairment typically included decreased concentration, recent memory loss, mental slowing, unsteady gait, incoordination, social withdrawal, and apathy. John Sidtis and Susan Tross found in a sample of 43 recently diagnosed AIDS patients that neurologic impairment was most commonly characterized by psychomotor slowing, decreased spontaneity, and poor cognitive flexibility. These typical presentations may be overlooked or misdiagnosed as depression in the early stages of dementia. Price described severe dementia as characterized by mutism, incontinence, paraplegia, and rudimentary intellectual functioning. Investigators generally agree that the incidence of neurologic impairment is extremely high among AIDS patients with approximately 70% experiencing cognitive impairment ranging from mild to severe dementia. Additionally, case reports of persons with ARC or HIV infection with mild to moderate cognitive impairment were also discussed.

Group Interventions

Psychoeducational groups designed for persons with AIDS and ARC, survivors and others affected by this disease were presented by mental health practitioners from Memorial Sloan-Kettering, the UCSF AIDS Health Project, AIDS Project Los Angeles, and others. Each center identified consistent group goals which included increasing social support, skills training, stress reduction, increasing adaptive coping skills, exploring psychological and emotional themes, and providing information.

Antibody Testing and Counseling

Researchers and practitioners reported very little disagreement on issues related to antibody testing including motivation for taking the test, impact of receiving antibody results on risk reduction among gay and bisexual men and I.V. drug users, and the effectiveness of counseling. In two reports from the UCSF AIDS Health Project and the UCSF Department of Medicine, concern for infecting others and decreasing anxiety were the most frequent reasons cited for taking the antibody test.

Various studies agreed that counseling for recipients of test results is helpful in increasing knowledge about AIDS and risk reduction behaviors, interpreting the meaning of the test, coping with the psychosocial impact of results, and developing adaptive coping strategies.

Researchers from Johns Hopkins University, California State University Hayward, and other research centers studied the impact of the antibody test on sexual behavior. Findings indicated a decrease in number of sexual partners prior to receiving results and a decrease in number of sexual partners after learning of a positive test result. No comparable reduction in the number of partners reported was documented among persons receiving a negative test result. However, whether there was a similar reduction in high risk sexual behaviors among either group remains speculative.

The impact of antibody testing on high risk behavior among I.V. drug users was studied at the Montefiore Methadone Maintenance program in New York. Fifty percent of those who tested positive stopped sharing needles, and 75% of this group changed high risk sexual behavior.

Summary

Overall, psychosocial research data presented at the Second International Conference on AIDS supported the clinical experience of direct care providers. The studies discussed in Paris also revealed the gaps in current efforts. Much of the psychosocial research to date has looked at the impact of AIDS on gay and bisexual men. However, the effect of the epidemic on I.V. drug users, women, children, and people of color has not been studied to a degree that corresponds with the incidence of AIDS among these groups. Their psychosocial needs — as well as the appropriate interventions and prevention strategies geared to them — await researchers' attention.

Judy Macks, MSW, LCSW is the coordinator of mental health training at the UCSF AIDS Health Project in San Francisco.
Diagnosis/Treatment

AIDS Therapies: Update from Paris

Michael Helquist

Virologists and other researchers have developed three major theories about the underlying mechanisms that govern immune suppression and disease progression with AIDS. Briefly stated, these are: (1) that infection with HIV, the AIDS virus, is sufficient in itself to damage the immune system and trigger the disease progression to AIDS; (2) that AIDS is an opportunistic disease itself, taking advantage of an immune system suppressed by uncertain co-factors; and (3) that AIDS results from HIV infection plus an autoimmune response. Each of these theories was discussed, disputed, and left unresolved at the Second International Conference on AIDS in Paris.

HIV: A Primary Role

Ever since Robert Gallo, MD and his colleagues at the National Cancer Institute identified and described the virus they called HTLV-3 in 1984, they have maintained that infection with the virus is the primary cause of immune system damage and development of AIDS. In Paris Gallo once again presented the extensive scientific data that supports his theory. He added that treatment research is now at a less-haphazard stage, allowing scientists to follow rational approaches in attempts to interrupt viral processes.

Anthony S. Fauci, MD, director of the National Institute of Allergy and Infectious Disease (NIAID), described the ideal antiretroviral agent as one that (1) can completely eliminate the virus from the host; (2) can cross the blood-brain barrier; (3) can be taken orally; (4) can produce its effect with a limited course of therapy; and (5) is non-toxic. The primary experimental drugs that researchers hope will inhibit the action of HIV and meet some of these above criteria are AZT (also known as Compound S), the relatives of AZT, ribavirin, and foscamet.

AZT

Preliminary trials with azidodeoxythymidine or AZT have indicated that the antiviral can block replication of the AIDS virus and can also pass through the blood-brain barrier to fight viral infection of the brain. Samuel Broder, MD of the National Cancer Institute reported in Paris that the Phase I study with AZT revealed a partial restoration of some immune functions for the subjects involved. (Note: Phase I studies of experimental drugs involve human subjects and look at drug toxicities and their relationship to medication doses.) Currently multi-center trials involve 260 American AIDS patients in double-blind, placebo-controlled, six-month study.

Broder added that two relatives of AZT, named dideoxyctydine and dideoxyadenosine, have also blocked replication of HIV in laboratory experiments. Both have been shown to be "orally absorbable," an important consideration for drugs that may need to be taken for an indefinite period of time. Broder said he hoped to have dideoxyctydine ready for Phase I clinical trials sometime in the next few months.

The federal researcher asserted that he believed it was important to challenge AIDS in its fulminant stage. His studies involve subjects diagnosed with full-blown AIDS. He concluded, "I believe AIDS itself is a curable disease."

Ribavirin

Ribavirin is an antiviral drug that has been legally administered in several countries, but not in the United States, for many years. Clyde S. Crumpacker, MD, associate professor and physician at Beth Israel Hospital in Boston, presented the key results of a Phase I study on 10 patients with AIDS and 5 with ARC. After an 8 week period, 7 of the subjects became virus-negative; but when the drug was discontinued, all but two subjects showed evidence of the virus again. Crumpacker emphasized that the toxicity of this drug at the prescribed doses was remarkably low. He also noted that ribavirin does enter the central nervous system. He cautioned, however, that prolonged treatment may be necessary to accumulate an adequate level of the drug in the cerebrospinal fluid.

Foscamet

Foscamet is an antiviral drug manufactured by a Swedish pharmaceutical firm; it has been used experimentally with cytomegalovirus (CMV) patients who are immunosuppressed. A recent pilot study designed by C.F. Farthing, MD provided subjects with a continuous I.V. solution for three weeks. Sixteen subjects were selected for the study: 12 were treated and four were untreated controls. Four subjects had AIDS; seven had ARC.

The researchers found that foscamet is a well-tolerated drug. Clinically nine patients reported feeling better. There were, however, no significant immunologic changes; for example, there was no change in helper T cell counts. The four AIDS subjects are still alive, five months after treatment. Four of the seven ARC subjects went on to develop AIDS.

Farthing concluded that for a more useful clinical and immunological analysis, foscamet must be used for longer periods of time. However, as a practical treatment for large numbers of people, foscamet, now available only by I.V. administration, is not feasible.

HPA-23

Dominque Dormont, MD of the Pasteur Institute reported that 12 AIDS patients, 2 patients with lymphadenopathy, and 4 seropositive patients had received HPA-23 during a long-term treatment protocol (4 to 16 months). The study showed that HPA-23 is effective in vitro as an antiviral drug. In vivo, the drug inhibits the replication of the virus but only on a temporary basis. He concluded that when an antiviral is used, it should be combined with other therapeutic methods, such as immunostimulants or immunosuppressors, for clinically confirmed AIDS patients. Dormont explained that an immunosuppressor might be necessary to "freeze" any autoimmune activity involved in AIDS and thus prevent the body's immune system from attacking itself.

Bone Marrow Replacement

Dr. Fauci of NIAID announced in Paris that one of his patients with an immune system severely damaged by AIDS had apparently regained his normal health and has been able to return to work. The treatment involved a combination of bone marrow transplants, transfusions of healthy lymphocytes, and suramin. (The use of suramin predated the finding that the drug is ineffective and too toxic.) The combination therapy was successful for only one in three subjects, and practical applications of the treatment are severely limited since the most successful transplants occur between identical twins.

Autoimmune Theory

Luc Montagnier, MD is one of the major proponents of the autoimmune theory. He is the director of the Virology Department of the Pasteur Institute and is credited with the discovery of the AIDS virus in 1983. Montagnier summarized his position in an interview with Le Monde newsmagazine (June 25, 1986) conducted during the Paris conference.

"We are currently working on the model of a secondary autoimmune disease," Montagnier stated. "The patient is able fairly well to endure the more or less long first phase of the viral infection (positive test result with little or no clinical signs). Then for reasons we still do not understand, the body's system abruptly goes haywire: the virus starts to destroy the lymphocyte system, after which the lymphocyte system self-destructs. At this stage, the virus plays nothing more than a secondary role."

Cyclosporine

Three French researchers working at Laennec Hospital in
Paras also subscribe to the theory that AIDS is a viral-induced autoimmune disorder. Drs. J.M. Andrieu, P. Even, and A. Venet said during the Paris conference that they believed the drug cyclosporine would be an appropriate therapeutic agent because it can inhibit T-4 helper cell activation, thus preventing viral replication and the triggering of an autoimmune response.

The researchers have administered cyclosporine to 23 patients; several of them appear to have benefited from the drug. The primary benefit is an increased and sustained level of T-4 helper cells. The researchers believe that cyclosporine holds more promise for people with ARC and asymptomatic AIDS viral infection than it does for those with AIDS itself.

Controversies

Close observers of the development of different AIDS treatment strategies recognize the dynamic give-and-take among researchers who often do not agree on theories or therapies. This was certainly the case in Paris: while one prominent researcher advanced the autoimmune and co-factor theories, another dismissed them as not based on hard data. Noting the debate surrounding some of the experimental treatments, Broder of the NIH offered this solution: "These studies should be conducted by true believers and should be analyzed by true skeptics."

Finally, as the number of people infected with HIV continues to climb in every country, the controversies over the limited number of openings and the use of placebos in clinical drug trials has intensified. A few researchers spoke out in Paris about a need for more drug trial openings and called for governments to provide adequate funding.

Michael Helquist is the editor of FOCUS.

BRIEFS

RECENT REPORTS

Tuberculosis As A Manifestation of AIDS. Observers have been puzzled that more people with AIDS have not developed tuberculosis. To combat and control TB, an individual needs a well-functioning cell-mediated immune system, something lacking in people with AIDS. During the last year and a half physicians have reported a new trend: more and more diagnoses of TB that appear related to the increasing incidence of AIDS. Morbidity and Mortality Weekly Report (July 18, 1986) noted that in 1985 the number of new TB cases was essentially the same as it had been in 1984, thus reversing a 32 year old decline in the number of cases reported.

Researchers from University Hospital in Newark, New Jersey recently published data (JAMA, July 18, 1986) from their study of 48 cases of mycobacterial diseases among a group of 136 adult patients with AIDS. Twenty-nine had severe and unusual manifestations of disease due to Mycobacterium tuberculosis. These patients included 24 men, 5 women, 19 male intravenous drug abusers, 4 gay men, 4 male Haitians, and 1 man with no known risk factor. All five women were parenteral drug abusers; one was also a prostitute.

Gnana Sunderam, MD and colleagues noted that TB was more common among Haitians and I.V. drug users than among gay men who were not I.V. users. In fact, none of the non-I.V. using gay men developed TB. In contrast, the incidence of Mycobacterium avium intracellulare appears to strike individuals no matter what their risk factors.

The researchers hypothesized that AIDS may reflect and magnify cell-mediated diseases that are endemic to a certain area. They added that "the aggressive behavior of tuberculosis in many of our AIDS cases suggests that AIDS may make usually pathogenic tuberculosis organisms behave in an even more virulent manner, somewhat like an opportunistic pathogen behaves in a compromised host."

AIDS Prevention: The Amsterdam Approach. The Netherlands has taken an aggressive approach to preventing the spread of AIDS among drug addicts, incorporating measures that are only at the discussion stage in the United States. Members of the Municipal Health Service in Amsterdam outlined their efforts in a recent letter to THE LANCET (June 21, 1986).

Like AIDS educators in other nations, the Dutch developed a campaign to inform workers at drug clinics and I.V. drug users themselves about the risks of sharing needles. In 1984 the health service worked with the Association of Drug Addicts to establish a strict needle and syringe exchange program. The Dutch worried that people might inadvertently prick themselves with discarded needles if the government were simply to distribute free needles. Officials also did not want to appear to encourage I.V. use. E.C. Buning and colleagues note in the journal correspondence that 100,000 syringes and needles were exchanged in 1985; they report that there has been no increase in accidental needle sticks among the general population. More significant, the authors claimed that the number of addicts who use I.V. drugs did not increase in 1985. Drug clinics reported that more clients than ever before were seeking treatment, and the number of addicts in Amsterdam has stabilized at 7000 to 8000 individuals.

The authors emphasized the context for Amsterdam's approach to its drug problem. They explained that previous attempts to discourage addiction by drug-free treatment programs were ineffective. In the late 1970s the Dutch undertook a "more pragmatic, non-moralistic approach." "The principle is that if it is impossible to cure a drug addict one should at least try to create a situation that greatly reduces the risk that the addicted harms himself or his environment," they wrote. This philosophy led to an extensive outreach program that is estimated to have reached 60% to 80% of the city's drug addicts in 1985. When the first cases of AIDS appeared, an outreach system had already been established. This same approach to health care prompted authorities to distribute free condoms among prostitutes that are I.V. drug users.

The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. This newsletter represents an attempt to place much of the data and press reports in a context that will prove meaningful and useful to its readers. Suggestions and comments are welcome and encouraged. Please address correspondence to Editor, AIDS Health Project; 333 Valencia Street, 4th Floor; San Francisco, CA 94103. For information about the other AIDS Health Project programs, call (415) 626-6637.

NEXT MONTH

The epidemiological data has never supported the notion that AIDS is a "white man's disease," and yet the considerable impact of AIDS on ethnic populations has been largely unreported in the mainstream and medical media.

In the October issue of FOCUS, Amanda Houston-Hamilton, DMH will present the current status of AIDS in ethnic populations. Houston-Hamilton, a faculty member of the Department of Psychiatry at UCSF, serves as the chair of the Black Task Force on AIDS and is coordinator of Third World Outreach for the UCSF AIDS Health Project.

In addition, Sala Udin, executive director of the Multicultural Prevention Resource Center in San Francisco, will discuss AIDS awareness in the black community and the issues that affect risk reduction campaigns.