Here in the United States, researchers, service providers and activists are shouting that “AIDS isn’t over” and fighting to counteract the lack of interest and urgency reflected in our national media and the general public. But in other developed countries, researchers and service providers are taking a closer look at how advances in treatment have affected the AIDS epidemic and at the impact of these changes on HIV prevention and education.

At the 4th International Conference on the Biopsychosocial Aspects of HIV Infection (also known as the AIDS Impact Conference), in Ottawa Canada, the impact of HIV treatment advances was a major topic of discussion and debate. Changes in HIV course and progression achieved by highly active antiretroviral treatment (HAART) have influenced the services of many AIDS service organizations. Some AIDS agencies are switching their efforts from focusing for the most part on physical health to addressing mental health concerns of HIV-positive gay men as these men learn to live with HIV disease. Many agencies are beginning to discuss targeting HIV-positive people for prevention efforts. Much effort is being focused on helping HIV-positive persons adhere to strict drug regimens. New treatments have also affected issues such as partner notification, names reporting, and client confidentiality.

This article covers several issues presented at the AIDS Impact Conference. One caveat: although the conference was billed as an international conference, funding for scholarships became unavailable at the last minute. As a result, most of the presenters from developing countries were unable to attend. The seminars presented, therefore, while interesting, mainly represented the epidemic as it affects developed countries and gay men.

AIDS = Life

At the opening plenary on Friday, July 16, Robin Gorna of the Australian Federation of AIDS Organizations talked about the radical difference in HIV treatment strategies in poor and rich nations.

Rich nations, she said, are currently experiencing a sense of optimism combined with a need to understand the challenges involved with HAART. Some of the challenges include: planning for the future, adherence to complicated drug regimens, the sometimes debilitating side effects of HAART drugs, the possibility of taking drug “holidays,” negotiating sexuality, and addressing mental health issues.

“In Australia, among gay men, there has been a shift in thinking from ‘AIDS equals death’ to ‘AIDS equals life,’ ” Gorna said. “We are planning for the future now, and gay mental health issues are a major priority.” Gorna discussed a new Australian advertisement campaign called “Getting Things in Focus,” which addresses gay men’s concerns in a “post-AIDS” world. The campaign explores some of the complexities of taking antiviral therapies over a lifetime, for example, adherence and managing side effects, and addresses the need to find a purpose or goal for the future. The campaign also addresses drug holidays, maintaining safer sex, and substance use.

On the other hand, in poor countries, 90 percent of people with HIV live without any kind of drugs. Treatment in poorer countries has mainly involved prevention,
with a focus on preventing HIV transmission from women to their newborns. In many poor countries, a health services infrastructure is absent. Doctors are not available or knowledgeable, there is no follow-up for patients, and HIV testing and counseling does not take place. In addition, basic treatments for many diseases, such as cancer, tuberculosis, and malaria, are unavailable. There is often no clean drinking water to use to take antiviral drugs were they available. Drugs to stop opportunistic infections such as *Pneumocystis carinii* pneumonia (PCP) and tuberculosis are cheap and can significantly reduce mortality from AIDS, yet they are also unavailable.

**A Different Picture in Africa**

Precious Alawuru, head of the Nigeria AIDS Education and Research Organization and physician at the University of Benin Teaching Hospital, argued that in Nigeria, advocating for access to HAART is the wrong direction to take in fighting the epidemic [7/16: 2-3:30]. Alawuru cited many of the structural barriers to effective administration of HAART, from the very basic such as lack of clean water, electricity, and health facilities, to the more specific, such lack of equipment or laboratories to conduct viral load and CD4+ cell tests. “In the South we have only now begun to talk about prevention, and now the North wants to give us drugs. A lot of things will have to change before then. By just giving us drugs with no means of monitoring the effect, the aim is defeated,” said Alawuru. Alawuru gave the example of a patient with end-stage AIDS who came into the hospital and was taking ritonavir combined with Chinese herbs, having sold his car to afford the treatment. The man asked about combination therapy. Alawuru asked him, “Will you now sell your house to afford three drugs? Why? You will die anyway and then your family will be refugees, living on the street.” She said that it would be better to counsel the man on “positive living,” focusing on good nutrition, stress reduction, and healthy family relationships.

Alawuru suggested that instead of focusing on antiviral drugs, public health efforts in Nigeria should focus on building health care infrastructure, treating other infectious diseases such as tuberculosis and malaria, and strengthening HIV prevention. In addition, Alawuru stated that it is imperative that international organizations such as UNAIDS and the World Bank step in and control the money that is supposed to go to public health. “The North is allowing our leaders to rob their countries blind.”

**Prevention among HIV-Positive People**

The situation is quite different in richer countries, where seropositive people for
Findings from one study highlight the urgent need for interventions for HIV-positive injection drug users that focus as much on sexual behaviors as on drug-using behaviors.
Another study at St. Stephen’s Centre in London found that there is no “magic bullet” to improve adherence. Among these patients, 19 percent said they took fewer than 90 percent of their doses. The most common reasons for this were timing of meals (38 percent), oversleeping (36 percent), forgetting (35 percent), and being in a social situation (31 percent). Reasons for non-adherence varied widely not only among participants but also for any single participant over time. As the number of reasons for missing doses increased, overall adherence decreased. The study recommended that clinicians develop individualized programs to increase adherence for each patient. Focusing on a single solution for any patient, for example, providing medication timers, will likely be ineffective.

A Change of HAART

Several presentations addressed topics of HAART “backlash” among people infected with and affected by HIV. Researchers examined topics of the true cost-effectiveness of HAART and why some patients have chosen not to take combination therapy.

Recent studies have highlighted the potential short-term cost savings associated with HAART, arguing that it reduces costs of hospitalization and treatment of opportunistic infections. To determine the real cost savings, the Center for AIDS Intervention Research, Medical College of Wisconsin, developed a model to predict the long-term economic impact of new treatments [7/17 11-12:30]. The model showed that preventing progression to severe HIV disease, while an efficient use of resources, is not likely to result in cost savings over the course of a patient’s life. Even with treatment advances, the cost of caring for someone with HIV is substantial. The study found that the most cost-effective strategy remains preventing people from becoming infected in the first place.

In Australia, it is estimated that 40 to 45 percent of people living with HIV are not on HAART. A Deakin University study of 270 HIV-positive gay men not currently on antiviral drugs, asked participants their reasons for not taking combination therapy [7/16 4-5:30]. The most common reason for not going on antiviral therapy was fear of side effects that would interfere with day-to-day living. Other important reasons were the belief that antivirals are poison and that it would be better to wait until improved drugs became available. Many participants were defensive about their decisions and resented perceived pressure to use treatment. A majority were monitoring their health through regular CD4+ cell and viral load tests.

AIDS Impact Conference Information

Audiotapes of the 1999 AIDS Impact Conference can be ordered for about $7.75 (U.S.) or $11.30 (Canada) per tape, shipping included. To learn more, contact Conference Tape, 8 Woodburn Drive, Ottawa, Ontario K1P 5H3, Canada; 613-824-2583; 613-824-2584 (fax); contape@cyberus.ca (e-mail).

Conference program and abstract books are available for about $14.00 (U.S.) or $20.00 (Canada) each. To learn more, contact Canada Psychological Association, 205–151 Slater Street, Ottawa, Ontario K1P 5H3, Canada; 613-237-2144. Visit the official conference web site at: http://www.aidsimpact.com to view final abstracts.

Future Conferences

November 29, 1999, Baltimore, Maryland: Women’s Issues in HIV. To contact organizers, write: Jennifer Walter, Office of Continuing Medical Education, Turner 20, 720 Rutland Avenue, Baltimore, MD 21205-2195; 410-614-6181; 410-614-7315 (fax); jwalter@jhmi.edu (e-mail); http://www.med.jhu.edu/cme (web site).


January 10-13, 2000, Lake Buena Vista, Florida: Multicultural Adolescent
The Role of Community Research
Pamela DeCarlo and Ellen Goldstein, MA

Even the best research has little impact on the HIV epidemic if it is not translated and used by those working in the front lines. Yet researchers and service providers have traditionally not worked together to share ideas and expertise or to make sure that the findings of one influence the work of the other. To address this problem, researchers, advocates, and research managers at the AIDS Impact Conference in Ottawa held a satellite meeting of the Community-Based Research Group, whose goal is to strengthen and promote HIV-related community based research.

Community-based research is conducted by researchers in a community setting, by community-based organizations (CBOs), or collaboratively between CBOs and researchers. The term community-based research also refers to research developed with community advisory board input and participation. In Ottawa, presentations introduced four different models of community-based research, including disseminating research findings, strengthening CBOs, evaluating impact and outcomes of programs, and working collaboratively with researchers and service providers.

Using Findings

The first model is an innovative example of how a research group makes its data available to community organizations in order to answer their questions. A program at the University of British Columbia in Canada, hired a Community Liaison Researcher to help disseminate findings from an ongoing study of economic factors affecting HIV-positive people [7/18: 11-12:30]. The study has enrolled more than 600 people who are interviewed every three months and has completed more than 2,000 interviews.

“Because our participants and community agencies have been key to the success of the project, they felt it was important to find a way to help community agencies and their clients access the information that they helped provide,” said liaison Steven James. Any CBO in British Columbia can request data on education, income, housing, health status, viral load and medication usage, among other factors, from the study’s database. James begins the process by helping the community organization define the question it wants answered. He then consults researchers to learn if the question can be answered using the study’s data. If so, James analyzes the data and discusses the findings with CBO staff, refining or redefining the questions as needed. Finally, he publishes a report of the analysis on the internet.

Organizational Development

The second model shows how strengthening community organizations helps to guarantee the health of programs and agencies [7/18: 11-12:30]. Organizational development is key to community research, because agency health and capacity is necessary for conducting research. The AIDS Bureau of Canada’s Ontario Ministry of Health established an Organizational Development Program (ODP) in 1994 in response to requests for training to strengthen community based organizations. ODP provides analysis and needs assessments, on-site facilitation, and connections to other resources. AIDS coordinator Frank McGee summed up the role of ODP: “Given the complexity of issues relating to HIV/AIDS, it is imperative that employees and volunteers in CBOs are

HIV/AIDS Prevention Conference. To contact organizers, write: University of South Florida, Continuing Education, 12901 Bruce B Downs Boulevard, Tampa, Florida 33612-4799; 888-873-2674 ext. 2, 813-974-7860 (fax); conted@hsc.usf.edu (e-mail).
February 19-21, 2000, St. Louis, Missouri: Ryan White National Youth Conference on HIV and AIDS 2000. To contact organizers, write: RWNYC 2000, Sara Leedom, 1413 K Street, NW, 7th Fl, Washington, DC 20005-3442; 202-898-0414 ext. 126; 202-898-0435 (fax); sleedom@napwa.org (e-mail).
February 24-25, 2000, Washington, DC: 2000 National Conference on African-Americans and AIDS. To contact organizers, write: Jennifer Walter, Office of Continuing Medical Education, Turner 20, 720 Rutland Avenue, Baltimore, MD 21205-2195; 410-614-6181; 410-614-7315 (fax); jwalter@jhmi.edu (e-mail); http://www.med.jhu.edu/cme (web site).
provided with the organizational support and skills necessary to create and maintain stable and effective organizations."

By its third year of activity, the number of community organizations ODP served grew to 51, or 84 percent of CBOs in Ontario. The most frequently requested types of services have been help with board development (roles, responsibilities, and recruitment) and strategic planning and evaluation for agencies. Because CBOs receive funding and have reporting requirements from both federal and provincial sources, collaboration between the two sections of governments was essential to the success of the program.

Working Together

The third model of community-based research addresses the link between CBOs and program evaluators, presenting guidelines for developing working relationships [7/17: 11-12:30]. "As health care delivery systems adopt more integrated models of care, strategies are needed to improve partnerships between service and evaluation efforts," said Thomas Soto, of the CORE Center in Chicago. His workshop, presented with Michelle Pillen, outlined factors associated with conducting program evaluation in social service and primary care settings.

Finding the right evaluator to work with is key, and is a personal choice, similar to finding the right therapist. Other essential factors include time and budget and staff participation and buy-in. Agency staff must be involved in identifying and framing the evaluation questions as well as collecting and analyzing the data. Service providers should be clear about what they want and do not want from the evaluation results, and the evaluator should not overwhelm the agency with too much data.

Finally, evaluators and service providers should work together to disseminate the findings using multiple strategies. Soto advises that evaluators define a clear end to the work relationship and acknowledge all the different levels of staff who participated. "This is the most critical piece for buy-in for future evaluation and research efforts," he said.

A fourth model also addresses the relationship between community organizations and research collaborative partners, focusing on theoretical framework for understanding these working partnerships [7/17: 2-3:30]. The workshop led by Ellen Goldstein and Olga Grinstead of the UCSF Center for AIDS Prevention Studies (CAPS), used cross-cultural communication theory to improve the relationship between researchers and service providers, emphasizing that such collaborative relationships are often filled with power struggles, misunderstandings, and unmet expectations.

The cultures of research and community service differ in terms of language, time frames, resources, education and training, incentives, and the shape of a typical day. Culture shock, power imbalances, and diversity can further affect communication. For example, in regard to issues of time, service providers are often consumed with the goal to respond to immediate client needs such as housing, drug treatment, or medical care, while researchers are involved with long-term issues such as multi-year projects and extended publication timetables. Both groups may be overwhelmed by grant writing, concerns about job security, and emotional and spiritual fulfillment in their work. Goldstein and Grinstead recommended choosing collaborative partners carefully, making time and financial commitments to each other, and defining the research task together using both scientifically rigorous and community-appropriate criteria.

Way of the Future

Community-based research is becoming more important and widely recognized in the United States and across the world as service providers and some researchers advocate for including patients and agencies as equal partners in research. In addition, CBOs in the United States are being required by funders to base new programs on research findings and to evaluate existing programs. As many AIDS Impact Conference presentations demonstrated, however, knowledge and capacity still lag far behind both for service providers and researchers. The Community-Based Research Group hopes to fill that gap by promoting and providing training in all aspects of community research.
Recent Reports

The following reports are based on abstracts of presentations at the AIDS Impact Conference. For more information on viewing final abstracts or purchasing the conference program and abstract book, refer to the Clearinghouse in this issue of FOCUS.

**Disclosing HIV Infection to Children**


Disclosing HIV infection to children: The paths families take to truth telling. (The Hospital for Sick Children, London; AIDS Saskatoon; Newfoundland and Labrador AIDS Committee.)

Trust—in one's children, parenting ability, family unit, and social network—is essential for adults faced with disclosing HIV infection to their children, according to Canadian researchers who interviewed families in which parents had disclosed their HIV infection to their children. Failure to trust may delay or prevent an adult from making a disclosure to a child and can have negative consequences for family relationships and well-being.

The study consisted of “in-depth” interviews with members of 44 families—51 adults and 54 children who had learned of a parent's HIV infection. Researchers found that gender, the HIV status of the child, and parenting styles were important influences in adults' decisions to disclose. Personal and relational coping styles, children's ages, spirituality, and family circumstances were also factors adults identified as affecting their decisions to disclose.

Adults disclosed to female and HIV-infected children at a younger age—10 years versus 11 years—than male and non-infected children. Researchers found that children's feelings toward knowing the status of family HIV varied between male and female children. Female children were more likely than male children to show anger, wish they did not know the parent's HIV infection status, and avoid talking with parents about HIV. Fifteen percent of all children "wished" they did not know, but all children stated they believed it was important to have been told. Ninety-one percent of children said the disclosure was made to them in a "good" way. Non-infected children were less likely than infected children to mention that they received emotional support from parents following disclosure.

Researchers suggested that adults' disclosure decisions were influenced by the "meaning" they attach to children and their role as parents. They concluded that being aware of unique meanings of various influences in deciding whether or not to disclose one's HIV infection can help foster supportive family and professional relationships.

**Pre-Release HIV Prevention for Inmates**

Grinstead, O. Evaluation of a pre-release HIV prevention program for HIV-seropositive male prison inmates. (University of California, San Francisco.)

Reducing sexual and injection drug-use risk behavior and increasing the use of community services by HIV-infected male inmates who are about to be released from prison would be enhanced by pre-release HIV prevention programs, according to the results of a recent study. The purpose of the study was to develop an HIV prevention program for HIV-seropositive inmates and to evaluate its effectiveness as an educational device for such men as they return to sex- and needle-sharing partners in the community.

Within three months prior to release, study participants took part in a two-week intervention consisting of interactive group sessions led by community service providers. Group session topics included sex, drug use, recovery, nutrition, and HIV-related legal issues. Study participants received individual interviews prior to the intervention to assess pre-incarceration behavior. Follow-up telephone interviews were conducted two to three months after participants were released from prison.

A total of 125 participants agreed to follow-up—100 of whom received the intervention and 25 from a comparison group that did not receive the intervention. Fifty-four percent of those who agreed to follow-up were African-American, 69 percent reported that they had previously injected drugs and 94 percent of these said they had shared an injection drug-using needle in the past. Those receiving the intervention were less likely to have had sex, injected or shared needles, or used drugs or alcohol. Men in the intervention group who had engaged in sex following their release were more likely than those...
not receiving the intervention to have used a condom during their first intercourse after release from custody, and these men were more likely to have seen a health care provider since their release. Researchers suggested that the results indicate that pre-release HIV prevention programs can benefit HIV-seropositive inmates in reducing risk behavior and increasing the use of community resources following prison release.

Methadone in Prisons

Burchell A, Calzavara L, Slossberg J, et al. Would methadone programs reduce IDU in provincial correctional centres? Results from an Ontario-wide survey. (University of Toronto and Ontario Ministry of Health.)

Among a group of prison inmates who reported injecting drugs while in custody, most would use methadone as an alternative to heroin if it were available in correctional facilities. Canadian researchers randomly selected 458 men and 159 women being held at six Canadian correctional facilities; 89 percent of these chose to participate. Forty-six percent of participants reported a history of injection drug use and 7 percent reported injecting drugs inside prison. Seventy-seven percent of participants expressed positive attitudes about making methadone available, while 26 percent expressed negative attitudes. Injection drug users had fewer negative attitudes toward methadone availability than non-injection users. Ease of heroin withdrawal symptoms was the most frequently cited reason in support of methadone availability.

Among injection drug users, 60 percent believed that methadone would reduce injection drug use in prison and 74 percent of inmates injecting inside prison stated they would use methadone as an alternative to injecting. Women, those who had injected opiates outside prison in the year prior to incarceration, and those who reported drug use inside prison in the past year reported that methadone availability would decrease injection drug use.

HIV Education on the Internet

Price B, O’Callaghan S, Patterson P, et al. Surfing safely: Delivering the HIV/AIDS education message in a new and innovative way. (The Alfred Hospital, Melbourne.)

The internet can be used to heighten young people’s awareness of services related to sexual health, injection drug use, and HIV, according to Australian researchers who conducted a health education contest on the internet.

An Australian HIV, hepatitis, and STD resource center held the competition during AIDS Awareness Week in 1998 in response to research suggesting complacency among young Australians’ attitudes towards HIV. The internet competition, which was promoted through a radio station and secondary schools, tested young people’s knowledge about HIV testing, risk behaviors, and services available in the state of Victoria. Participants could find answers to questions by following computer "links" to web pages of the resource center and other community agencies. Once participants found correct answers, they were eligible for a drawing for surfing-related prizes.

Ninety people successfully answered the questions and entered the prize drawing, and many more people accessed the web site without entering the competition. The average age of entrants was 16 years; 53 percent of participants were from rural areas. Researchers suggested that the competition itself raised awareness of HIV as a current issue in both rural and metropolitan areas.

Next Month

The relationship between “developing” and “developed” countries is complex, no more so than in the context of the HIV pandemic. The assumption is that it is the industrialized nations that have lessons for their poorer cousins. In the November issue of FOCUS, Alan Greig, an international AIDS consultant based in New York, discusses this assumption and looks at lessons that developing countries may be able to offer industrialized ones in particular around the concept of vulnerability.

The most hopeful approach to stemming HIV in the non-industrialized world is a preventive vaccine. Also in the November issue, Joe Wright, a San Francisco community educator who works with vaccine trials, discusses the challenge of implementing a vaccine should a safe and effective prototype be approved.
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