Although "Bridging the Gap" was the theme of the 12th World AIDS Conference in Geneva, most of the conference's plenary sessions highlighted the fact that treatment advances had actually expanded the gap, and presenters demonstrated this fact in financial, prevention, care, and social science studies. The gap refers to the difference in resources, in prevalence among groups, within countries and between countries, between providers and receivers, between rhetoric and action, and between advances and cure. These gaps were clearly highlighted by the fact that more than 200 presentations looked at adherence to treatment despite the fact that for the majority of people worldwide access to treatment is not available. More than 5,000 presentations were crammed into five busy days as 13,624 participants tried to grasp this theme and all of its implications.

In a fitting, yet uncomfortable, closing plenary, Richard Horton observed the gap even in the behavior of conference delegates. He suggested that the willingness of participants from developed nations to leave sessions when the presentations switched to developing nations indicated a failure to tolerate and listen to voices from outside their own spheres of reference.

The conference also proved that, contrary to the popular myths, the Swiss are not as efficient as their reputation implies—and neither is combination therapy. The key fact to emerge from the conference was the ongoing endorsement of the medium-term efficacy of combination antiviral therapies coexistent with major challenges to sustain these effects over time. At the same time, concerns relating to new side effects emerged. Among these were low level diabetes [179/41177, 12308, 12327, 12377, 12387, 60148], abnormalities of body fat distribution [12319, 336/32173], drug resistant strains of HIV, and the challenges of complex, demanding, and lifelong drug regimens [281]. This article focuses on these findings and their counseling implications.

**Adherence to Treatment**

High levels of adherence to combination therapies are necessary for maximum drug effectiveness. It is important to note that many of the conference presentations—266 in all—focused on this topic, and while this research is necessary, some participants expressed concerns that this attention excluded discussion of other topics.

A large number of studies found a high proportion of adherence, systematically noting subgroups with no recorded lapses, but consistently including a group that forgot or failed to take medication for a variety of reasons. It is notable that while homeless individuals were less likely to be prescribed protease inhibitors, when they were, their adherence was relatively good [389/32406]. Similarly, those with an injecting drug use history had equally good adherence [391/32366], and providing support enhanced their adherence [393/32336]. Finally, during pregnancy, women maintained high adherence to zidovudine, but after pregnancy adherence suffered [31/23280].

Many of the difficulties people have with adherence result from practical day-to-day issues, such as forgetting, taking in combination with sleeping and eating, and being distracted, rather than from personality or other mental health issues. A busy lifestyle, including the resumption of pay-
Editorial: Cultural Competence

Robert Marks, Editor

“This conference was about bridging the gap. Why was it then that . . . whenever a speaker from a developing world country rose to talk about an issue central to ‘bridging the gap,’ seats emptied?”

Thus rang the rebuke by Richard Horton, editor of the British journal, The Lancet. Horton’s observation was emblematic of the frustration that delegates felt about the difficulties of moving through a cross-cultural event: witnessing vast differences in the wealth of nations, powerlessness in the face of the enormous political and economic forces, and wide disparities in the type and quality of presentations.

At an international conference, we have an international opportunity to share ideas. What interferes with this might be called “cultural incompetence,” to borrow a concept from cross-cultural studies, the inability of a person to communicate and understand beyond his or her parochial experience. To bridge cultural gaps, conference organizers are best served by creating structures that prepare presenters and participants to translate experience, not simply language.

Being competent does not require fancy slides or complex statistical analyses or flawless scientific method. But most presentations were either so basic as to be uninformative or so focused and complex as to be stifling.

Technical Assistance

It seems that presenters from anywhere are rarely prepared to talk about the wider implications of their work or to clarify how their conclusions might be applied to other situations. This synthesis remains absent after all these years and it remains the responsibility of the organizers to help delegates develop presentations that go beyond the constraints of a particular study, region, or subpopulation to help the audience understand the broader implications of a presentation. This may require more than written instructions; it may require technical assistance to help presenters develop a perspective that can be productively shared, fewer presentations overall, and greater resources to help in the preparation of presentations. (This conference did create limited opportunities for interdisciplinary sharing, and I don’t mean to dismiss these efforts.)

This second article in this issue of FOCUS highlights one presentation that was successful in making this cultural leap. In discussing global epidemiology, Quarraisha Abdool Karim found ways to reconceive the industrialized/developing world split. Her creative approach not only succeeded in describing the pandemic in ways that suggest prevention interventions, but also enabled participants to see how vastly different cultures face remarkably similar challenges.

Competent presentations like Abdool Karim’s are crucial, but must be matched with competent reception. This, of course, requires being present. As important, we must strive to imagine how a radically different experience might be useful. The conference itself must create a way to help those of us with flawed imaginations and suffering from information overload to bridge the gap among our experiences.
government policy [460/42210]. Physicians’ beliefs in the patient’s ability to adhere may well affect their willingness to prescribe combination therapies [446/32335]. Hernando Knobel showed that the involvement of pharmacy workers who worked intensely with physicians in providing support for people on complex regimens had a significant impact on adherence [388/32322; see also 390/32323]. An Australian presentation with notable adherence levels (72 percent of the sample reported total adherence and the remainder reported levels of adherence in excess of 80 percent) found that providing support, clear information, and a thorough briefing at initiation are key elements of maximizing rates of adherence.

In a moving presentation, Agnes Harley explored the discourse surrounding adherence and highlighted the need to approach drug regimens with a sensitivity to the medication and its complexity, the condition of the client and the client’s personality and desires, provider motivations background and biases, and market forces in terms of funding, costing, profit, and progress [638/34212]. This analysis was immediately helpful in expanding the “adherence” versus “compliance” debate. Some have suggested that compliance, the older term, lays a value judgment on behavior. It presumes that medical opinion is beyond question and client behavior should focus on complying. Adherence is more neutral, and makes no assumptions of blame, guilt, ability, or motivation. Michael Bartos further stressed the need to be sensitive to the potential negative effects of blame, and the resulting guilt, when clients have trouble adhering to treatment regimens [641/23402].

Conference presentations put forward many practical suggestions to improve or sustain adherence, but few of these had been the focus of long-term trials and most were not theoretically derived. Until the development of more “client-friendly” antiviral drugs, which would require less strenuous schedules, the challenge is to understand more completely how adherence can be integrated into daily life, the ways in which different people confront different barriers, and what facilitators, both internal and external, can minimize problems and ensure the success of seemingly horrendous regimens.

It is important to recognize that although adherence is an important issue, it is essentially irrelevant to the vast majority of people with HIV who do not have access to treatment. Presenters demonstrated that the gap was not only between industrialized and developing countries, but also between advantaged and disadvantaged people within industrialized nations. Several poster presentations discussed inmates, members of minority groups, and substance users as disadvantaged, at high risk for infection, and with limited access to treatment.

**Psychosocial Implications of Treatment**

The focus on adherence should not overshadow the many other psychosocial ramifications of the new treatments. Among the issues covered at the conference were questions of who gets treatment, how are decisions made to initiate or stop treatments, and how the availability of new treatments impacts relationships, social functioning, and prevention. “It is not simply a matter of taking treatments and then having everything else in life easily sort itself out,” Bill Whittaker said [326]. The range of concerns around treatment, Whittaker added, include doubt: guilt; rethinking death and illness; operating in a decimated friendship network; treatment failure for those who do not reach “undetectable viral load” and viral breakthrough; the resurgence of problems such as discrimination, racism, and poverty; practical obstacles to treatment; and confidentiality and privacy.

There is ongoing medical debate surrounding the protocol for monitoring treatment success and prescribing and new treatments. Bruce Walker suggested that emphasis on viral eradication was unnecessary and stressed the need to continue studying immunity in people who stop antiviral therapy [425]. The question about starting new therapies must also include a debate about when, how, and whether or not to cease treatment and the long-term impact of these decisions. Once an individual commences combination therapy, he or she faces a limited number of options in the case of intolerance or resistance. This plus the lifelong burden of antiviral therapy and the need for strict adherence require careful decision making. This issue requires further study as is clear from an article published by Jay Levy after the conference.1

Integrating new treatments into everyday life—including dealing with adherence—is a major challenge about which little is known, and counselors need to
provide clients with sensitive support. Studies seemed to suggest that this effort should focus on family and social support as well as on the client. Initial explanation and understanding of the compounds and the regimens were seen as crucial. The use of alternative support avenues such as counselors, nurses, family members, and pharmacists all proved useful. Direct communication and a close partnership seem to be the vital ingredients for progress, not only between people on treatments and their supporters, but among them, medical providers, and medical science.

**Impact of New Treatments on Behavior**

A series of papers provided insight into the complex impact of new treatments on sexual behavior. This topic has been controversial because of the assumption that increased risk-taking and unsafe sex will follow in the wake of perceptions that improved treatment makes HIV less threatening and that “undetectable” viral load levels translate to reduced risk of transmission. Some conference presentations found that study participants held neither of these beliefs and that increases in risk were unrelated to the new treatments. Others found that for some populations, some subgroups, and some behaviors, increases in risk were indeed related to such beliefs.

For example, both Jonathan Elford [644/23106] and Phillipe Adam [642/34107] reported that in large studies of gay men, beliefs that the new treatments are effective were associated with increased sexual risk behavior. Alternately, Michael Bartos found that the belief that treatment prospects are better correlated to increased condom use and that there was no evidence that participants equated an undetectable viral load with noninfectiousness (641/23402).

A clearly emerging pattern was one of more informed and rationalized decision making about sexual practice, especially among gay men. The practice of negotiated safety—the agreement between partners of similar serostatus to participate in unprotected sex under specific circumstances—has become more prevalent and the need for relationship dialogue is emerging as a key area of study, support, and progress. In a study of 1,040 gay men in regular relationships for at least six months, June Crawford found that 83 percent had negotiated safety agreements, the minority of which were “unsafe” agreements [25/23105]. Having established three groups—concordant HIV negative-couples, discordant couples, and those with unknown status—the study found that those in the first two groups were more likely to have agreements concerning their sexual behavior. She also reported that a disproportionate amount of risk behavior occurs among men with unsafe agreements or no agreements at all.

**Conclusion**

The conference seemed to point to a number of new challenges for the future, as the ongoing despair becomes tinged with hope. But many of these come at a time when there are growing numbers of new infections in both the developing and the developed worlds, growing divisions between the have and the have nots throughout the world and within industrialized countries, and continued political and economic constraints. Despite recent progress, there is yet a way to go. The poignant closing comments by Hoosen Coovadia, chair of the long awaited 13th World AIDS Conference in Durban, the first in Africa, mirrors the hope and challenge still faced by a world grappling with HIV.
Compared to the feeling of optimism portrayed after the 11th World AIDS Conference two years ago in Vancouver, the feeling after this year’s 12th World AIDS Conference in Geneva was markedly guarded. The news about the magnitude of the global epidemic was sobering. “There is news so devastating that few in this room could have predicted or imagined it a decade ago,” Peter Piot, executive director of the Joint United Nations Program on AIDS (UNAIDS), told the opening plenary session in Geneva.

Starting Statistics
According to UNAIDS, the total global estimate now stands at more than 30 million people living with HIV and 16,000 becoming infected each day. For the first time, AIDS has become the world’s most common cause of death by infectious disease. Over the past three years, HIV infection rates have more than doubled in 27 countries, including almost every Asian nation. In several Eastern European countries, the increase has been six-fold or more.

The epidemic continues to progress at an exponential rate in many impoverished regions of the planet. Sub-Saharan Africa and the developing countries of Asia are home to 89 percent of all people living with HIV. Yet these two regions account for less than 10 percent of the global total of gross national products.

“We continue to confront an epidemic which, in many parts of the world, is wiping out the development gains that so many have worked so hard to achieve over many decades,” Piot said.

The region most affected by the epidemic is the area of Africa south of the Sahara desert, with an estimated 21 million people living with HIV at the beginning of 1998. In Botswana and Zimbabwe, 25 percent of all adults are infected with HIV. South and Southeast Asia, meanwhile, report 5.8 million HIV cases. Latin America and the Caribbean follow with 1.6 million cases. In North America (860,000), Western Europe (480,000), Australia and New Zealand (12,000), and North Africa and the Middle East (210,000), HIV cases have remained steady for the past few years. While total numbers of infections are still relatively low, the epidemic is spreading rapidly in China and East Asia (420,000), as well as in Eastern Europe and Central Asia (190,000).

Three Alarming Patterns
In her plenary address on the current understanding of HIV epidemiology, Quarraisha Abdool Karim described three alarming patterns of HIV transmission that have taken shape throughout the world: “explosive,” “masked,” and “emerging” [160].

For the first time, AIDS has become the world’s most common cause of death by infectious disease.
Her presentation was notable because it defined the epidemic by its behavior rather than the behavior—heterosexual, homosexual, or needle sharing—of its populations and went beyond the gross economic classifications of “developed” or “developing.” In this way, it put the United States and other industrialized nations into a context that made clear distinctions among them and meaningful connections between them and non-industrialized nations.

Explosive epidemics are those in which HIV spreads rapidly once it surfaces and achieves a high percentage maximum prevalence of infection before leveling off. The region of Southern Africa and the country of Cambodia are currently experiencing explosive HIV epidemics. Political and social turmoil, high levels of sexually transmitted diseases, high population mobility, and ubiquitous denial of the threat of HIV are ingredients of these and other explosive epidemics.

In another presentation on South Africa, Helen Schneider echoed these comments, observing that implementing AIDS prevention in a state that has been in transition is difficult, that the greater political commitment of the South African government cannot solve the problem alone, and that productive conflict can help the process move along [147 plus related poster 24141]. She noted that between 1990 and 1997, seroprevalence in antenatal clinics jumped from 0.5 percent to 16 percent.

In countries with masked epidemics, HIV infection rates appear to be stable, but transmission continues to increase at alarming rates in subpopulations. Declining HIV incidence in one population may camouflage increasing incidence in another. Such is the case in the southern and eastern United States, where decreases in HIV infection among White gay men are offset by increases among African Americans, Latinos, women, and injection drug users. In Rwanda, the casualties inflicted during the recent genocide and a shift of infection from urban to rural areas have masked the continued rapid spread of HIV despite apparent stabilization in the national seroprevalence rates. Masked epidemics may be a feature of complacency; countries with stable or declining HIV prevalence must be vigilant in their surveillance of the epidemic, particularly among marginalized populations, in order to avoid a masked epidemic.

In Geneva, the U.S. Centers for Disease Control and Prevention (CDC) unveiled a campaign entitled “Combat Complacency,” a reminder that the AIDS epidemic is not over in the United States. The CDC is working to increase tracking and reporting of instances of HIV infection in addition to AIDS cases. Because it can take several years before HIV infection progresses to CDC-defined AIDS, focusing on HIV infection rates instead of AIDS cases will give a more accurate view of which populations are at greatest risk today. UNAIDS has also launched an effort to improve HIV surveillance and data collection about HIV-related behaviors. It has developed Epidemiological Fact Sheets that combine HIV infection and AIDS prevalence and incidence statistics with behavioral data. More than 140 countries responded to the first round of data collection.

Emerging HIV epidemics occur in areas characterized by low levels of infection plus conditions conducive to rapid spread of disease. In regions with emerging epidemics, HIV incidence is high in small sub-groups, and infection is unevenly distributed geographically. The term “emerging” has most often been associated with the HIV epidemics in India, Russia, and the Ukraine. In the Ukraine, the epidemic is occurring mainly among injection drug users. In 1995 the Ukraine reported only 44 HIV infections, but by 1996, the number skyrocketed to more than 12,000, and in 1997 there were another 15,000 new infections. In India, the overall infection rate for the country

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**Tribute to Jonathan Mann**

Lorraine Sherr asked us to dedicate her article to Jonathan Mann, who was among those who died in the Swissair jet accident last month. Mann’s wife, vaccine researcher Mary Lou Clements-Mann, also died in the crash.

Jonathan Mann, the founding Director of the World Health Organization Global Programme on AIDS and founding director of Harvard School of Public Health’s Center for Health and Human Rights, was among the most effective and inspiring cross-cultural thinkers and communicators. His death requires us to be even more creative to make up for the loss of a leader whose mind and imagination were potent enough to make connections among the experiences of people from all over the world and confront the complex ethical and policy issues the epidemic raises.
is less than 1 percent of the total adult population, which is considered to be a fairly low rate. However, in some populations and regions, the rates are increasing dramatically. In Madras, HIV rates among truck drivers increased four-fold from 1.5 percent in 1995 to 6.2 percent in 1996. In Manipur, the epidemic is skyrocketing among male injection drugs users, and in 1996, the HIV rate among client populations of some drug clinics was as high as 73 percent.

Given that AIDS has been identified in every country on earth, areas that do not yet fit the descriptions of explosive or masked could be fairly labeled as emerging. China and the Middle East—home to a quarter of the world's population—should be included in this group. In emerging epidemic regions, accurate data on risk behaviors and large-scale health education are essential. Emerging epidemics may be explosive epidemics waiting to happen, which would represent a missed prevention opportunity of catastrophic proportions.

Areas of Success

While this overview of current epidemiology may appear grim, there have also been many success stories in HIV prevention world-wide. According to Piot, HIV infection rates are decreasing not only in industrialized nations like Switzerland and Australia, but in some developing countries as well. Community responses in Brazil, Senegal, Thailand, and Uganda have helped to lower infection rates, and in some regions of Tanzania, strong prevention efforts have reduced rates among young women by more than 50 percent.

According to Werasit Sittitrai, HIV infection is increasing especially quickly in young people throughout the world [4]. But young people have begun to mobilize to protect and educate themselves. In Thailand, a program offering opportunities for schooling and employment helped reduce the number of young girls from rural areas beginning commercial sex work. Young people are also working as peer educators to increase awareness among their age group. In Brazil, Ronaldo, international star of the Brazilian soccer team, has joined the campaign against AIDS and against child labor.

Conclusion

Sadly, although there are many effective programs for stemming the tide of the AIDS epidemic, and although there are countries that have been successful in reducing HIV infections, there are many more countries that have not or cannot learn this lesson. In many countries, political and economic crises have relegated AIDS care and prevention to the back burner. Marina Mahathir of India spoke of funding crises in Southeast Asia, where HIV prevention programs have suffered due to enormous economic changes [491]. She noted that even as countries begin to recover from their economic crisis, the AIDS epidemic will be a burden to complete recovery. As has always been true, prevention efforts remain more cost-effective than treatment.

In other countries, religious beliefs or political ill will continue to block HIV prevention. Valeriy Chervyakov noted that although economic problems in Russia and countries of the former Soviet Union have been severe, it is a unique alliance between conservative political and religious groups that has had a greater negative impact on dealing with the HIV epidemic [148]. In Russia, pro-life organizations, communi-ist politicians, and the Orthodox church have banded together to reduce funding of family planning centers, ban safe sex promotion campaigns in Moscow, and forbid condom promotion in some regions.

“This epidemic is out of control at the very time when we know what to do,” Piot declared. The world cannot simply wait for a vaccine, a cure, equitable access to antiviral drugs, or for the epidemic to burn itself out. Proven HIV prevention efforts have not been fully implemented where they are needed most.

“We have the tools,” Piot concluded. “Now we must build the political will to use them.”
Review of Clinical Care

Below is an excerpt from a broad summary of clinical presentations given at the end of the Geneva AIDS conference by Richard Horton, editor of the British medical journal The Lancet.

The good news at this conference is that we now seem clear about our goal—maximum suppression of viral load. But the issues have shifted. Our notions of eradication have been modified; more sensitive viral load assays have been developed; and there are now more options in HIV therapy.

Attempts to eradicate virus have so far been thwarted by the existence of HIV in reservoirs of latently infected resting memory cells. But David Ho reported data this week showing that this pool is vulnerable to attack with antiretroviral therapy . . .

Currently, we have 11 approved antiretrovirals. Soon we will have 15, once efavirenz, amprenavir, adefovir, and abacavir are licensed. That means 204 possible triple combinations and 1028 four-drug combinations. Not all of these regimens can be tested and there is sharp disagreement about how to proceed. One person argued that there is no need for clinical trials end-point studies for every regimen, while another believed that practice must be driven by data, not intuition. There are many trial issues that still remain to be settled: which end-points; which method of analysis; . . . the meaning of standard of care; generalizability of results; and getting the right balance between the ethics and enthusiasm of doing drug trials.

Data on efavirenz were especially intriguing. We heard that a 24-week phase III study showed that efavirenz plus indinavir was equivalent to the now-standard three-drug regimen of indinavir, AZT, and 3TC. Efavirenz [a non-nucleoside reverse transcriptase inhibitor (NNRTI)], AZT, and 3TC work better than either of these two combinations, allowing for an effective protease-inhibitor-sparing regimen. It seemed to me that this result is likely to change clinical practice most quickly.

But there was bad news as well.

Despite the increased [choices that we now have], toxicity, resistance, adherence, and cost have all combined to produce a quite striking about-face in the views of opinion leaders on treatment.

The “hit hard, hit early” approach has been tempered. Now, caution is emphasized with the option of deferring therapy if a person is asymptomatic with a low risk of progression . . .

One reason for this dramatic pull-back from the aggressive positions of the past is our understanding of the serious adverse effects [including low-level diabetes and abnormal fat distribution, among others] of the drugs we are using. All of which raises the urgent question of how drug regulatory authorities exert power—perhaps by issuing only provisional licenses—to demand that drug companies collect long-term safety data on products that go through accelerated approval.

Horton completed this part of his speech by listing future issues regarding treatment, including: optimal timing of therapy; the definition of drug failure; adjuvant therapies; clinical validation of resistance testing; access and cost; improving palliative care; immune reconstitution; and developing new drug targets. He went on to discuss issues related to the developing world, noting, “What are the prospects for the developing world, where 800 million people lack access to health services. . . . Robert Hogg calculated that the worldwide cost of triple antiretroviral therapy would be $35.5 billion, of which two-thirds would have to be spent in Africa.”

Cross-cultural counseling is often portrayed as a process of preparation, the result of studying the ethnography of culture. While such knowledge can lead to insight, it can lead to an oversimplification of culture and of a client’s personal experience. In the November issue of FOCUS, Mindy Thompson Fullilove, MD, Associate Professor of Clinical Psychiatry and Public Health at Columbia University, discusses stigma and the counseling process, focusing on the development of stereotypes and their manifestation in therapy.

Also in the November issue, Amanda Houston-Hamilton, DMH, a clinical psychotherapist in San Francisco, discusses ways of “working downhill,” that is, using culture to further counseling goals.
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