HIV/AIDS and Aging:
Emerging Issues in Research, Care, Treatment, and Prevention

Thanks to better HIV treatments—and the efforts of treatment advocates—people are living longer with HIV. As HIV-positive people get older, and as increasing numbers of people acquire HIV at an older age, the medical, emotional, and social issues typically associated with aging are compounded by HIV-related challenges.

This official satellite session of the XVIII International AIDS Conference, held July 19, 2010, in Vienna, Austria, was designed to explore the intersection of HIV and aging. The session included a series of presentations on current epidemiology and research, followed by a panel discussion with older HIV-positive individuals and a dialogue with audience members. The event was co-sponsored by San Francisco AIDS Foundation; amfAR, the Foundation for AIDS Research; and Gay Men’s Health Crisis.

Dr. Judith Auerbach, Vice President of Science & Public Policy at San Francisco AIDS Foundation, opened the session with a brief introduction. The presenters were introduced by Dr. Sean Cahill, Managing Director for Public Policy, Research, and Community Health at Gay Men’s Health Crisis. Dr. Rowena Johnston, Vice President and Director of Research at the Foundation for AIDS Research (amfAR), gave the audience an epidemiological overview of HIV/AIDS in older individuals around the world. She was followed by Dr. Amy Justice, Associate Professor of Internal Medicine at Yale Medical School and Principal Investigator for the Veterans Aging Cohort Study, who offered a framework for understanding the multiple co-morbidities that affect people aging with HIV. Dr. Glenn Treisman, Director of the AIDS Psychiatry Program at Johns Hopkins University School of Medicine, spoke on the interactions between HIV disease and psychiatric conditions. Finally, Ms. Siphewe Hlophe, Founder and Director of Swaziland Positive Living (SWAPOL), a national grassroots organization advocating for the rights and recognition of people affected by HIV, discussed the effect of HIV and AIDS on aging caregivers in Africa.

After these presentations, Dr. Auerbach moderated a discussion between HIV/AIDS advocates who are themselves over the age of 50 and living with HIV. Dr. Michael Siever, Director of Behavioral Health Services at San Francisco AIDS Foundation, and Ms. Sylvia Young, Peer Advocate Program Manager at Women Organized to Respond to Life-threatening Disease (WORLD) in Oakland, California, were joined by Ms. Hlophe, who was one of the first women in Swaziland to publicly declare her HIV-positive status. The session was then opened for audience questions and dialogue.

Following is a summary of key questions and issues addressed during the presentations and the panel and audience discussions.

Epidemiology of HIV and Aging

“As antiretroviral therapy becomes more widely available, the proportion of people with HIV who are over 50 will absolutely grow.”

—Rowena Johnston

Increasing numbers of people living with HIV are over the age of 50. In her overview presentation, Dr. Rowena Johnston explained that in the United States, 28% of new HIV diagnoses in 2006 were among people over 45 years old, and modelers suggest that half of all HIV-positive individuals in the U.S. will be over 50 by the year 2015.

Data collected by UNAIDS define “adults” as those between 15 and 49 years of age, making it difficult to find information about HIV infection in people over 50 outside the U.S., but one study suggests that approximately 7% of the world’s HIV-positive population (roughly 2.3 million people) is 50 or older. As antiretroviral therapy becomes more widely available around the globe, the number of individuals growing older with HIV will increase proportionately. Already, Johnston said, there are significant populations of older adults living with HIV in Kenya, Jamaica, India, and parts of East Asia.

Where data about HIV are available, they tend to reflect prevalence rather than incidence of HIV infection, making it unclear whether HIV was acquired earlier in life or after the age of 50. This gap in knowledge may hinder the provision of adequate HIV care and treatment, as the clinical needs of individuals newly infected with HIV in older age tend to differ from those of older adults who have lived with the virus for many years.

There is also a great need for HIV prevention efforts among older populations. Older individuals are...
rarely targeted for HIV prevention messages because of a common assumption that they don’t have sex—a misconception flouted by a recent study showing that 73% of people aged 57 to 64 years are sexually active. “I think that probably comes as a surprise to a lot of people,” said Johnston. Sexually active older adults are more likely to have HIV or other sexually transmitted infections, yet older adults often do not consider themselves at risk for HIV; Johnston cited an Australian study suggesting that few older adults use condoms or seek HIV testing.

As antiretroviral therapy becomes more widely available and HIV-positive people live longer, Johnston concluded, more information on the epidemiology of HIV and aging is needed to adequately address the HIV treatment and prevention needs of older adults around the world.

Comorbidities Associated with HIV and Aging

“The question really is, ‘What’s the total burden of disease, and how do we try to minimize its effects on people’s quality of life and survival?’”

—Amy Justice

Between 20% and 75% of deaths among HIV-positive individuals on antiretroviral treatment are now due to causes other than the AIDS-defining conditions specified by the Centers for Disease Control and Prevention. Dr. Amy Justice cited data from a host of studies showing that major causes of death in the setting of HIV are attributable to alcohol use, liver disease, cardiovascular disease, cancer, and renal disease (although these comorbidities, while not considered AIDS-defining conditions, are not necessarily unrelated to HIV disease).

Differences in HIV-related mortality between younger and older age groups cannot be explained by age alone. “Clearly, folks who have HIV infection—and people who have lived an extended period of time exposed to HIV infection—are biologically older than people who are newly infected or are not infected,” explained Justice, and life expectancy is not “normal” even among optimally treated individuals.

At one time, researchers assumed that antiretroviral drug toxicities accounted for the continued excess morbidity and mortality among treated patients. But results from the Strategies for Management of Antiretroviral Therapy (SMART) study showed that individuals who interrupted treatment when their CD4 counts exceeded a set threshold still had more deaths and more AIDS-defining and non-AIDS-defining conditions than their counterparts who received continuous treatment, suggesting that long-term exposure to the virus itself is to blame for the higher rates of illness and death seen among HIV-positive individuals. In short, there is an ongoing effect of the virus.

Today, researchers believe that HIV increases the risk of many “non-AIDS conditions.” Although the relative risk contributed by HIV infection is modest compared with other established risk factors for these conditions, the effect of HIV increases over time: the longer an individual has HIV, the greater his or her risk for such conditions compared with a non-infected person.

The list of comorbidities associated with HIV grows with nearly every new publication in the HIV literature and includes diseases of the lungs, liver, kidneys, and vascular system, as well as neurological conditions and bone diseases. Many patients who access care through Veterans Administration clinics, said Justice, deal not only with HIV infection but also with hepatitis B, hepatitis C, and substance use (including illegal drugs, alcohol, and tobacco). Justice suggested that these three conditions together conspire to cause a host of illnesses that act in tandem, leading to “incremental depletion in organ system reserve, and eventually functional decline, organ system failure, and repeated hospitalizations, nursing home placement, and finally death.”

Clinicians caring for patients with HIV need to carefully monitor for early signs of these non-AIDS conditions, she said; being equipped to accurately predict where people are in terms of their HIV disease progression can help providers intervene and improve life expectancy and quality of life for their patients. For example, some comorbid conditions may justify earlier antiretroviral therapy, and conditions such as anemia may become important indicators of HIV disease progression. Justice also noted that it is important to carefully consider which markers of disease progression are most useful for managing care in lower-income countries, where viral loads and CD4 cell counts may not be universally available, and how to incorporate them in a way that is cost effective.

Justice also acknowledged that drug toxicities complicate treatment for HIV-positive individuals with comorbid conditions, and stressed that individualized care is becoming increasingly important. “We have a balancing act,” she said. “If someone already has renal injury, we probably want to avoid drugs that are going to add to that renal injury, but all else equal, those drugs may actually help reverse some of that injury. So, it’s getting more complicated, in the sense of the balance that we need to make and the tailoring that we need to do for each individual patient who comes in.”

Mental Health and HIV

“If you treat psychiatric disorders, [HIV] patients do better.”

—Glenn Treisman
Drawing on his work at Johns Hopkins, Dr. Glenn Treisman explained how mental health, including psychiatric disorders, and HIV disease interact and intensify one another. Treisman focused on three key mental health issues that influence—and are influenced by—HIV disease: depression, cognitive impairment, and substance use, all of which may increase with age, and, in turn, affect treatment adherence, viral load and CD4 cell counts, inflammation in the central nervous system (CNS), and CNS infection.

Depression, Treisman said, is a key morbidity in the setting of HIV infection. Major depression, a clinical diagnosis, occurs in about 4% of the general population and is likely to be significantly higher in older age groups. However, HIV patients have a dramatically higher risk for depression—between six- and ten-fold higher in aging HIV-infected patients compared with the general population, Treisman estimated.

Unfortunately, depressed patients tend to be less adherent to prescribed treatment and less likely to seek care. Depression can also worsen cognitive function, and vice versa, he observed, and exacerbates substance use disorders.

There is also good reason to believe that the virus itself can cause depression, Treisman explained, citing studies that link HIV-induced cytokine activity and CNS inflammation to depression in a large subset of patients. HIV and depression thus perpetuate one another: as Treisman put it, the virus “inflames your brain [and] causes depression. As you get depressed, you don’t take your HIV medicines, and as you don’t take your HIV medicines, your depression gets worse.”

Another issue often faced by people aging with HIV is cognitive impairment. HIV-related dementia persists despite antiretroviral treatment, Treisman noted: “So, even though we’re treating people, we still see them getting cognitively impaired—it’s just more subtle forms of cognitive impairment…and the onset is more variable.” People with HIV dementia may experience a general slowing of their thought processes, along with movement difficulty and depression. Although older patients tend to be more adherent to treatment in general, cognitive impairment has a greater effect on treatment adherence in older people than in younger adults.

An elevated viral load in the CNS is associated with a greater likelihood of HIV-associated dementia. New research is assessing whether antiretroviral regimens that better penetrate the CNS may decrease the risk for HIV dementia, even in people who have low levels of virus in the CNS. Treisman cited a study showing that better CNS penetration of antiretroviral drugs is also correlated with improved mood. With drugs that better reach HIV in the CNS, said Treisman, “not only do we prevent dementia, but we may be preventing depression—which isn’t a surprise to those of us who subscribe to the ‘cytokine idea’ that depression is caused by elevated cytokines in your brain.”

Substance use and addiction represent another mental health issue that disproportionately affects people aging with HIV, Treisman observed. Elderly patients with addictions have greater morbidity and mortality than younger patients, which can partially be attributed to the lack of recognition among health providers that substance abuse is an issue among older patients. In addition, abuse of opiates and other narcotics is a growing problem among older people with HIV. Chronic use of opiates such as OxyContin may not be considered “addiction,” but it profoundly affects cognition and negatively influences HIV health outcomes, said Treisman.

Substance-use treatment is a cost-effective intervention but is chronically underfunded, and Treisman suggested that “the reason we’re not spending the money is that drug addiction is unpopular.” But in order to more effectively respond to the HIV epidemic, we must recognize and address all of the comorbidities that present barriers to treatment, to diagnosis, and to stopping the spread of HIV.

“We can get people better—all of the things I talked about tonight are treatable,” concluded Treisman. “Demand more resources for your patients, and raise a little hell when people say, ‘They’re old anyway.’”

HIV, Aging, and Caregiving in Africa

“Of the estimated 40 million people living with HIV and AIDS, the vast majority are adults in their prime working years. But as this generation dies of AIDS, a generation of young people and a generation of the elderly, aged 50 and older, are left behind.”

—Siphiwe Hlophe

Sub-Saharan Africa accounts for only 11% of the world’s population but nearly 70% of people globally living with HIV/AIDS, as Ms. Siphiwe Hlophe reminded her listeners. In her initial presentation, Johnston reported that 600,000 to 900,000 older individuals across Africa are living in a household that doesn’t have prime-age adults to look after them, and 140,000 to 323,000 are left to raise grandchildren orphaned by AIDS. Family structures are being up-rooted, said Hlophe, as the elderly, who traditionally relied on the support of working-age adults, become the caregivers.

As hospitals become overloaded, Hlophe continued, doctors encourage families to take relatives suffering from AIDS home to “die peacefully.” Particularly for an older women living with HIV herself, this is a tremendous burden: in addition to managing her own health and caring for her grandchildren, she must now nurse her adult children, as well. Without a reli-
Getting Older with HIV: Challenges and Resiliencies

“It’s a very odd thing now to be thinking about—because I never thought I would have to worry about this—who is going to take care of me as I get older. What’s going to happen to me if I become frail and need long-term care? How is that all going to work, as an older person with HIV?”

—Michael Siever

Following the presentations, panel participants discussed some of the challenges they experience as they get older with HIV. Dr. Michael Siever prefaced his comments by acknowledging that, being a white male from a wealthy country and having been fortunate enough receive and respond well to antiretroviral treatment, he speaks from a position of privilege and is extremely lucky and grateful to have lived long enough to face these challenges. Then he summed up some of the confusion faced by HIV-positive people experiencing health problems as they get older: “Is it age or AIDS?”

It’s a common question among HIV-positive people as they begin to experience memory loss, declining stamina, and other health changes. Researchers are grappling with the same question about the interactions of HIV, HIV drugs, and aging, but it is unclear just what the study findings mean to older HIV-positive people. Siever spoke of the difficulty interpreting the flood of new research findings on HIV and aging, particularly around HIV-induced inflammation. As he put it, “sometimes too much knowledge is not very helpful.”

Young shared that the challenges she encounters as she ages with HIV can feel unrelenting. She related that a diagnosis of oral cancer the previous year led to three surgeries and loss of speech for two weeks, which in turn led to depression. She battled the depression with exercise, until the exercise caused debilitating fatigue. “It’s one thing after another,” said Young.

All three panelists also focused on the stigma older HIV-positive people encounter. As a gay man living with HIV, Siever deals with homophobia, ageism, and HIV stigma—and, he observed, many stigmatizing attitudes come from within the gay community itself. “There’s an incredible amount of ageism in the gay community, where we are, unfortunately, all expected to be young and beautiful and have rippling abs and all kinds of impossible things to have when you’re 60.” In his clinical work, Siever sees increasing numbers of older gay men turning to alcohol and drugs to cope with stigma. He finds it especially painful when older men who have recently “come out” turn to substance use to ease the transition into the gay community, or feel that they can only secure sex partners if they offer drugs.

In her work with SWAPOL, Hlophé sees intimate partner violence as a reaction to stigma around HIV. “The most important thing [is] disclosure to your partner,” she said, because male partners often blame women for acquiring HIV. Her organization teaches women to fight stigma in the home and in their communities, as well as in health clinics, where SWAPOL-trained “lay counselors” help HIV-positive women better manage their health and get adequate care as they age. Through SWAPOL, women gain the resilience to overcome stigma and live longer with HIV. “We empower women on the issues of HIV and AIDS,” Hlophé explained, “especially those over 60, who have started...
their income-generating project, so that you don’t think about the disease—you think about what you are doing now in order to earn a living.”

Young offered a similar view: “In my work at WORLD, as a peer advocate working with women who are over 50 and HIV positive, I have seen challenges, but I also see resilience.” She noted that working with a peer advocate helps older HIV-positive women strengthen relationships with their health care providers and get better attention to their unique needs—such as starting menopause in their early forties, or dealing with arthritis and incorporating pain medication into their daily treatment regimen for HIV. “I have seen peer advocacy change the lives of positive women,” said Young.

Conclusions: Moving Forward

“The good news is, we have to think about HIV and aging.”

—Amy Justice

Having covered the current state of the science on HIV and aging and discussed the lived experience of getting older with HIV, the next question for the participants and audience members followed naturally: What should advocates, providers, and individuals be doing now to prepare for and meet the needs of an increasingly older HIV-positive population around the world?

Siever, Young, and Hlophe agreed that advocates need to help overcome the misconception that HIV does not affect older people, and address the larger issues of poverty, racism, sexism, and ageism that hinder efforts to prevent new HIV infections and improve the health and wellness of those already living with the virus.

Treisman returned to the topic of mental health, noting that providers hesitate to offer antidepressant medications to elderly patients because older persons tend to experience more side effects and are generally more resistant to taking psychiatric drugs. He and Dr. Justice concurred that, rather than following a single “recipe” for treating all HIV patients regardless of age, providers should tailor care for each individual. HIV often trumps other health issues in the doctor’s office; Treisman encouraged providers to look beyond a patient’s HIV to ensure that other conditions don’t go untreated.

In a similar vein, Justice suggested that providers and individuals draw on resources outside of HIV medicine—specifically, the field of geriatrics. She offered falls prevention (such as removing throw rugs and other tripping hazards) as one proactive step: “We should be thinking about bone mineral density and thinking about medications, but we also ought to think about the living environment that this person is in, and can we help them prevent having a fall rather than treating it after it occurs, when they have a fracture?”

Justice and Treisman agreed that other fairly simple measures—including maintaining familiar environments to minimize disorientation, promoting activities for mental stimulation, and switching to clothing with Velcro fasteners rather than buttons—can help aging HIV-positive individuals prepare for and cope with cognitive impairment. “There are lots of resources for elderly patients that are going to be necessary in somewhat younger HIV patients,” Treisman concluded.

In terms of what individuals can do, one audience member made a simple yet poignant suggestion: “It’s time to take care of each other again.” He recalled the early days of the HIV epidemic in the U.S., when members of the gay community assumed caretaking responsibilities for their sick and dying friends. His remarks echoed Hlophe’s from her discussion of SWAPOL’s mission: “We continue with the social support...at a community level. We make sure that we support each other, come together, share our experiences.” Hlophe recalled plain but powerful words she uses to reassure women facing older age with HIV: “You will be living with the virus.”