Global Survey: Stigma, Isolation and Discrimination Still Pervasive

July 28, 2010 By Tim Horn

HIV-associated stigma, isolation and discrimination remain pervasive problems in the United States and other parts of the world and continue to have profound effects on people's willingness to disclose their serostatus to key individuals in their lives. This is the finding of a global survey of 2,035 people living with HIV conducted by the International Association for Physicians in AIDS Care (IAPAC) on Thursday, July 22, at the XVIII International AIDS Conference in Vienna.

Suniti Solomon, MD, director of the YR Gaitonde Center for AIDS Research and Education in Chennai, India, presented the survey results on behalf of IAPAC. The survey found that stigma, isolation and discrimination are first among unique obstacles facing people living with HIV around the world. There is no shortage of research indicating that they affect HIV prevention and testing efforts, along with initiatives to link and retain people diagnosed with HIV in care and on treatment.

"An environment of tolerance in which an individual can take an HIV test and live with an HIV diagnosis is of paramount importance to effective HIV prevention and treatment programs at local and national levels," Solomon said. "Health care providers bear the responsibility of ensuring compassionate and nonjudgmental care of patients.

"Society—or all of us—have a responsibility to break down the barriers of stigma, isolation and discrimination that persist almost 30 years into the global HIV pandemic," she added.

Indeed, the IAPAC survey results illustrate that HIV-associated stigma, isolation and discrimination remain pervasive issues all over the world.

The AIDS Treatment for Life International Survey (ATLIS 2010) was conducted in the same manner as a similar survey reported in 2008 at the XVII International AIDS Conference in Mexico City, which found that people living with HIV around the globe still live in fear of the societal stigma that surrounds the disease, and that some are so concerned about side effects of medication that they have chosen to stop their antiretroviral (ARV) drug regimens.

The ATLIS 2010 data reported in Vienna were based on Internet, telephone and face-to-face interviews conducted with 2,035 HIV-positive adult men and women residing in five global regions: 201 people residing in North America, 201 in Latin America, 1,133 in Europe, 200 in Asia and the Pacific and 300 in Africa. A second set of results from the survey, evaluating patient-physician

communication, was also reported in Vienna.

The survey was conducted with support from Merck.

According to ATLIS 2010, Solomon reported, the emotional toll of HIV/AIDS is still considerable. More than one third of respondents (37 percent) reported strong feelings of isolation, with the highest prevalence rates in North America and Asia-Pacific. Depression was also prevalent.

Societal and cultural stigmas also continue to affect people living with HIV around the world. According to Solomon, 38 percent of respondents felt as if others were judging them. What's more, nearly half of respondents had encountered someone who was afraid to have casual contact with them—25 percent reported that someone would not share food or drink with them, and 24 percent reported that someone would not kiss them, simply because they are living with HIV.

Forty-two percent of ATLIS 2010 participants also reported "strong concerns" about others learning their HIV status. Seventy-nine percent, for example, cited social discrimination as a reason for their reluctance to disclose. Other drivers included the impact on establishing future relationships (46 percent), impact on current relationships (42 percent), reputation (42 percent), risk of losing job (36 percent) and risk of losing family or friends (35 percent).

Though 96 percent of respondents reported having disclosed their HIV status to at least one person, Solomon's team made some sobering discoveries. For example, 17 percent of respondents in long-term relationships had not disclosed their HIV status to their spouse or partner. In addition, 16 percent of Asia-Pacific respondents and 8 percent of Latin-American respondents had never told anyone about their HIV status.

Understandably, many respondents stressed the need for more public education around stigmas. The three most common stigmas in need of combating, Solomon reported, are: a person with HIV has or does engage in risky behavior, people with HIV or AIDS should be avoided, and HIV is easily transmitted through normal everyday activities.

"Despite great strides, 29 years into the HIV pandemic, HIV-associated stigma, isolation and discrimination persist," Solomon said in her concluding remarks. "Addressing these challenges can benefit individual, community and public health."

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