

Stigma, Fear of Side Effects, Keep Many off Treatment

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People living with HIV around the globe still live in fear of the societal stigma that surrounds the disease, and some are so concerned about side effects that they have chosen to stop their antiretroviral (ARV) drug regimens, according to a new survey released by the International Association of Physicians in AIDS Care (IAPAC) at the XVII International AIDS Conference in Mexico City.

IAPAC worked in collaboration with a marketing research firm to conduct the AIDS Treatment for Life International Survey (ATLIS) of 2,968 HIV-positive adults—919 of whom were women—in 18 countries. To mirror the actual population with HIV, both treatment-experienced and treatment-naïve patients were recruited.

The study was funded by Merck and was conducted between March and May 2008.

One survey finding is that stigma remains an issue for HIV-positive patients, particularly with regard to disclosing their HIV status. Fifty-four percent of those surveyed are “very” or “somewhat” concerned about others knowing their HIV status, with 83 percent claiming this is predominantly due to concern of social discrimination and stigma. Respondents also expressed concern about specific repercussions, including loss of family and friends (41 percent), the impact on their ability to establish future relationships (37 percent), the risk of losing their jobs (36 percent) and the impact on their reputation (36 percent).

African respondents had fewer concerns about revealing their condition as opposed to respondents in other regions. Asian/Pacific respondents were more concerned about the risk of losing family and friends, as well as the potential impact on their current relationships. Respondents in North America were most concerned that their HIV-positive status could damage their reputation.

A second major finding of the survey is that many are concerned about ARV side effects and, as a result, avoid or stop HIV treatment. Overall, 26 percent of the respondents reported that they had elected not to seek treatment because they believe that ARV therapy causes too many side effects, with responses from Europe (42 percent) and South Africa (29 percent) being most prevalent. What’s more, 34 percent of treatment-experienced survey respondents discontinued ARV therapy primarily because they believe it caused too many side effects.

Side effects that survey respondents are most worried about include lipodystrophy, lipoatrophy and other body-shape changes (58 percent of survey respondents); gut-related problems such as nausea and diarrhea (54 percent); fatigue or anemia (54 percent); and liver disease (54 percent).

Respondents in Latin America and North America voiced significantly more concern about many potential side effects than respondents from other regions, while African respondents voiced significantly less concern.

Female respondents in most regions, especially those in Europe, worried more than male respondents in their respective regions about bone loss and face or body shape changes.

“ATLIS results indicate there is still a strong need to educate HIV-positive patients and the world around them. The findings demand an increase in global HIV and AIDS literacy,” said José Zuniga, PhD, president and CEO of IAPAC. “It is critical that we empower HIV-positive patients to take an active part in the management of their disease by educating them on the importance of adhering to their treatment and teaching them about the innovations in treatment that could improve their overall quality of life.”