



Survey: Most People With HIV Lack Mental Health Services

The results are in on a groundbreaking survey detailing the mental health and substance use problems faced by people living with HIV. Confirming that both problems are all too common and frequently untreated, the survey is now being analyzed by the American Psychological Association for advocacy efforts to increase the availability of affordable mental health services for people with HIV. But first, we provide a glimpse at the data POZ and AIDSmeds readers and NAPWA members provided.

April 28, 2009 By David Evans

The majority of people with HIV experience depression, anxiety, thinking and memory problems and substance abuse—but they're not getting the mental health services they desperately need. That's the verdict from a survey of 2,052 HIV-positive people, conducted jointly by AIDSmeds, POZ, the National Association of People with AIDS (NAPWA) and the American Psychological Association (APA) this winter.

The groups joined forces to give HIV-positive people a voice in describing their challenges with mental health and substance use. Survey results will help seed educational programs for HIV-positive people and health care providers. In addition, the data will be a valuable tool in convincing Congress that mental health support needs to be funded as an integral component of HIV prevention and treatment services.

More people than anticipated responded to the survey, which highlights the fact that psychological and cognitive problems are commonplace. In fact, only 4 percent of those surveyed said they had not experienced psychological problems since they were first diagnosed with HIV.

What's more, three quarters of the respondents say they told their primary health care provider about their mental health concerns—but only two thirds of those were referred to a mental health specialist. This is kind of statistic worries Janet St. Lawrence, PhD, a professor of psychology at Mississippi State University in Meridian, and one of the partners in developing and analyzing the survey. She says untreated or under-treated mental health, cognitive and substance use problems—over and above the suffering endured by those afflicted—results in poorer physical health and medication adherence.

John Anderson, senior director of the Office on AIDS at the APA, and another partner in the study, says he is excited by the collaboration between the groups and sees the survey as an important

first step in improving mental health and substance use services for people with HIV. According to Anderson, not only does the survey give people a voice to speak about mental health and substance use—which can be just as stigmatizing as HIV itself—but it also can serve as a catalyst for changing the health care system and what gets funded.

“[We’re going to] translate those findings into both policy recommendations in terms of funding for services and service delivery systems up on Capitol Hill,” Anderson says. He adds the survey results will serve as a foundation to “[train] mental health workers and primary health care providers in terms of what they need to be doing differently to be more responsive to the needs of people living with HIV who have mental health and substance abuse problems.”

Partnering to Give People With HIV a Voice

The survey is not the first time researchers have explored how commonplace mood disorders and substance use problems are among people with HIV. A large nationwide study by the HIV Cost and Services Utilization Survey (HCSUS) found nearly 50 percent of people with HIV in the study suffered from depression and anxiety and that 12 percent were screened as being drug dependent.

The partnership between the APA, NAPWA, AIDSmeds and POZ, however, represents one of the first times a group representing mental health professionals has teamed up with groups led by people with HIV to make HIV-positive people such an integral part of exploring and defining their mental health needs.

People with HIV were recruited to complete the survey, maintained by POZ.com, through newsletters, e-mail blasts, blogs and website banner ads. Nearly two thirds of those who responded had an income of less than \$35,000 per year. About half were working full- or part-time; 34 percent were on disability; and 14 percent were unemployed. Forty percent had private health insurance; 6 percent had no health insurance; and the rest relied on Medicare, Medicaid or AIDS drug assistance programs.

“The magnitude of people who were reporting difficulties—that was heartbreaking,” said St. Lawrence, who crunched the numbers on the survey. She revealed 89 percent of the respondents said they had experienced some degree of depression since their diagnosis. Seventy-eight percent reported having felt anxious, afraid or consistently worried about the future, and 65 percent reported problems with thinking and memory. Sixty-seven percent said they’d had trouble coping with their HIV diagnosis.

St. Lawrence was also “alarmed” that 32 percent said they’d felt unsafe in their homes or relationships. “That’s very troubling,” she says.

Drug use was also fairly common among the people surveyed. Though most reported alcohol or marijuana use, 18 percent reported having used crystal meth, 10 percent had used crack, and 3.5 percent had used heroin. Nearly 7 percent had injected drugs. Thirty-one percent reported not

having used drugs or alcohol since being diagnosed.

What moved St. Lawrence most, however, were the reports people gave of their struggles to find treatment for mental health and substance use problems. Six percent of people, she says, felt too embarrassed to tell their provider, and another 6 percent feared being judged. One respondent wrote about deciding not to tell a provider because the 15 minutes allotted with the provider “isn’t long enough for personal problems.” Another wrote, “No point bringing it up. I can’t afford to treat it.” A third wrote, “I was ashamed.”

Of the 1,500 people who were courageous enough to raise the issue with their health care provider, nearly 28 percent were not referred to a mental health specialist. Unfortunately, of those who saw a professional for their problems, 30 percent said they were not satisfied with the care they received. Of those who weren’t satisfied, many said their mental health care provider had no experience dealing with HIV or did not understand their situations. A substantial number of comments from survey respondents complained about the cost of mental health care being prohibitive; as one person wrote: “Poverty and loneliness can’t be treated with a pill.”

Moving Forward

Anderson and St. Lawrence acknowledge the data from the survey are not as rigorous as those in a study choosing random sample of people who are representative of the overall population of people living with HIV in the United States. Also, the survey did not allow for people to answer the kind of screening questions most often used to formally diagnose clinical depression, anxiety and cognitive or substance use disorders. Anderson and St. Lawrence, however, are very interested in doing follow-up surveys, and they believe the completed survey is an excellent beginning.

Working closely with NAPWA, one of the nation’s leading federal advocacy groups for people living with HIV/AIDS, and other organizations, APA hopes the survey will help yield important policy changes. “The survey is very helpful,” says Daniel Dawes, the senior legislative and federal affairs officer at APA’s Public Interest Government Relations Office, “not only for folks on the hill—especially the champions on HIV and AIDS—but also for the coalitions we work with, with different organizations, with different alliances we have. It sort of arms them with this knowledge and helps them realize, ‘Oh my gosh, this is what actually is coming out of our community.’”

Anderson wants policymakers to realize that resources for mental health and substance use disorders are an absolute necessity, not just in terms of treating those disorders, but also in minimizing their impact on the physical health of people living with HIV. “To put energy or funding into [HIV prevention and primary care] without addressing the mental health issues is undercutting our ability to be successful in those endeavors,” Anderson says.

He would like to see additional resources for mental health and substance use services devoted to people living with HIV, but he also wants to improve training for primary care providers and mental health and substance use providers. The data from the survey clearly point to problems in both areas, with primary providers not offering referrals and mental health providers not being

experienced in dealing with HIV, both of which are key. He says in addition to seeing providers deal with mood and substance use disorders, he'd like them to be aware that many HIV-positive individuals may have cognitive or "information processing" problems that need to be addressed. He notes people with serious mental illnesses, such as bipolar and psychotic disorders, have some of the highest rates of HIV/AIDS in the country.

"It is well past time for everyone to realize good health care for people with HIV/AIDS [requires] practical integration of primary care, mental health care and substance abuse treatment," Anderson says. "Although many people have been calling for this type of integration for years, the investment of money, time and effort has not occurred on the scale required." He hopes the completion of the survey will be a much-needed step in the right direction.

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