The HIV Mental Health Generation Gap

Are younger people living with the virus worse off than the older ones, contrary to popular belief?

February 3, 2014 By Benjamin Ryan

It is a truth universally acknowledged that older people with HIV are more stressed and isolated and suffer from a greater prevalence of mental health problems than the younger set.

Or is it?

Contrasting the findings of past research, a recent paper out of Case Western Reserve University in Cleveland, Ohio, came to the conclusion that it is in fact the members of the under-50 demographic who are struggling with greater levels of stress and isolation.

Past researchers have found that the stress of dealing with getting older, particularly with the age-related health and cognitive problems that HIV may spur, can result in declining mental health. Such psychological strain becomes particularly critical for people with HIV, because depression has been linked to worse HIV-related cognitive and physical functioning, as well as worse treatment side effects.

“People with HIV are under a lot more pressure than the general population,” says Christian Grov, an associate professor in health and nutrition sciences at Brooklyn College who has conducted research on the mental health of the older HIV population. “Stress, depression and anxiety can negatively impact health. So it can be a downward spiral.”

As the HIV population ages, researchers are striving to get a handle on the precise nature of the older faction’s needs. The urgency is high, with 2014 expected to be a watershed year: Half of HIV-positive Americans will be older than 50, compared with just a third in 2009 and a sixth in 2001.

Publishing their findings in the journal AIDS Care, the Case Western researchers studied 102 HIV-positive men and women during 2011 and 2012, investigating links between stress, isolation and age. The study participants ranged between 18 and 64 years old. Reflecting the demographics of the HIV population in the Midwest, the typical participant was African American, 48 years old, had been living with the virus for about 14 years and was low income, with just 17 percent reporting an income above $12,000.

The investigators found that those younger than 50 suffered from greater disconnection from

family and friends than the older cohort. HIV stigma appeared to play a major role; the researchers speculated that the peers of the younger group don't identify as well with someone who is living with a chronic health condition. The paper's authors also posited that blame game was also possibly at play: Young people with HIV may feel that others both fault them for acquiring the virus and try to avoid them because they perceive them to be sick. The older group, on the other hand, experienced less stress, possibly because they had developed support systems through social networks developed over the years.

"The reason we wanted to do the study was because there's so much evidence that older people are more isolated, they're more at risk," says Allison R. Webel, RN, PhD, an assistant professor of nursing at Case Western and the study's lead author. "In our small sample here in northeast Ohio, we didn't really see evidence of that."

Considering that Webel's study sample was indeed quite small, was taken from an area of low HIV prevalence in Ohio, and had a much higher concentration of African Americans than the U.S. HIV population at large, her team's findings are not necessarily applicable to all adults living with the virus. Judith G. Rabkin, PhD, MPH, a professor in the department of psychiatry at Columbia University, says the study's findings are also limited because the Case Western researchers did not establish an HIV-negative sample group to serve as a comparison.

Nevertheless, the paper does open a window into the nuances of how living with HIV during different stages of life, as well as in different parts of the country, may affect mental health.

Stephen E. Karpiak, PhD, the senior director for research and evaluation at the ACRIA Center on HIV and Aging in New York City, says that for HIV-positive individuals' mental health, "so much is dependent on time and place. And therefore stressors develop around those."

Part of the reason why younger people may have uniquely difficult challenges, Karpiak points out, and as the Case Western paper also illuminates, is that there is a generational schism within the HIV population. Those younger than middle age don't tend to interact with anyone over that hump and who possibly would have beneficial wisdom to share.

Furthermore, Karpiak is keen to suspect that the persistently uncertain economic outlook for the millennial generation plays heavily into the kind of global pressure young people living with the virus suffer as they weather stigma and rejection as a result of their HIV status.

In a 2010 paper looking at the resilience of people with HIV older than 50, Brooklyn College's Christian Grov found that the older members of this set were less likely to be depressed than those closer to 50.

"Perhaps people over time develop this sense of resilience," Grov says. "So if you were diagnosed in your 30s and you spent 10, 15 years coping with it, once you've made it past that milestone you're in a much better place."

For those who are suffering from mental health problems, Columbia's Judith Rabkin cautions against falling into the trap of thinking that it is perfectly natural to feel depressed when dealing with difficult health conditions. She recalls conducting trials of antidepressants in the early days of the epidemic, when HIV was essentially a death sentence.

"It was taken for granted that you'd be depressed," she says. "Doctors would say, 'Of course they're depressed. I'd be depressed. I'd jump out the window.'"

Nevertheless, those with HIV who received treatment for depression in those trials got better at the same rate as the HIV-negative members of the studies.

Outside of the direct treatment of depression, a fundamentally important factor researchers point to as the key to mental health is social connectivity.

Karpiak, who is also on faculty at the New York University College of Nursing, says that when he and his research colleagues have asked all ages of people with HIV what it is they want most, "The thing that comes to the top of the list, always, is socialization." Contrasting the Case Western study results, he says that older HIV-positive people often "find themselves very socially isolated, and that only feeds the depression worse. Let's face it, if you have HIV, and I don't care what age you are, you perceive yourself as the odd person out."

Irrespective of an HIV-positive patient's age, Webel says that clinicians should do a better job of looking out for their mental health. Unfortunately, however, when it comes to mental health assessments, clinics are not required to ask about those all-important social networks.

"All of these things are related," Webel says. "When people are more connected, less stressed, they probably will engage in better behaviors, and they probably will have better health in the long term."

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