8% of Teens With HIV Had AIDS-Defining Illnesses After Transitioning to Adult Care

Immigrants and girls had worse HIV outcomes in this study.

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Even after staying in adult HIV care, 8% of young people living with HIV experienced a new AIDS-defining illness or died within five years, according to a retrospective analysis in HIV Medicine.

The findings highlight the urgent need to engage young people in HIV care prior to transitioning to adult care and to implement practices that engage them in care long term. In general, teens are less engaged in HIV care than their adult counterparts. Lots of clinics are trying to find ways to stop that slip and improve teens' ability to achieve an undetectable viral load and reap the health and HIV prevention benefits that come with it. But this new study among young people living with HIV in the United Kingdom found that engagement in care isn't always enough.

Hibo Asad, a PhD candidate at University College London, and colleagues reviewed the charts of 474 young people living with HIV who were at least 13 years old at the end of 2015 and had participated in both the Collaborative HIV Pediatric Study and the adult UK Collaborative HIV Cohort. Asad's team then reviewed what happened as those patients transitioned from pediatric to adult care, looking specifically for diagnoses of AIDS-defining illnesses and deaths.

Just over half of the participants were young women, 80% were Black and 60% were immigrants. The participants' median age was 18, and they had been on HIV medications for half their lives. At the time of leaving pediatric care, 89% had a prescription for antiretroviral treatment, 60% had a viral load below 400 and the median CD4 count was 471—that is, they were pretty healthy.

But over a median of three years of follow-up in adult care, 25 developed AIDS-defining illnesses, such as Pneumocystis pneumonia or Kaposi sarcoma. Fourteen died, though HIV was not the cause of death for all participants. Just three had advanced HIV disease as their cause of death, two had respiratory disease (tuberculosis was one of the AIDS-defining diagnoses the researchers uncovered), one had kidney failure, one had progressive multifocal leukoencephalopathy and one died by suicide. Four causes of death were unknown.

What was known was that most of the young people were immigrants, women or both. And while

the median time in adult care was three years, the AIDS cases and deaths came a median of one year later. Ten of the 14 participants who died were still on antiretroviral treatment, and four had a viral load of 400 copies or less. But the median CD4 count in this group was 150, indicating overall poor health.

It's worth noting, however, that the median year when participants transitioned to adult care was 2011, and the median year of death was 2010. That's before the more effective and safer HIV medications came out and before many innovations designed to improve the transition from pediatric to adult care were underway. Most of these participants weren't doing well before their transition to adult care; participants who'd had AIDS-defining illnesses in pediatric care were more than two and a half times more likely to have one again after transition.

"Our findings highlight the clinical complexities of this cohort, with nearly 1 in 10 people experiencing an AIDS-defining event or dying by five years follow-up in adult care," wrote Asad and colleagues. "The mortality rate in our study, of 0.6 per 100 person-years, is more than 12 times higher than the mortality rate in the general population of people aged [less than] 25 in the U.K., highlighting the ongoing vulnerability of our cohort despite widespread [antiretroviral treatment] access."

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