Dutch Teens With HIV May Be Better Adjusted Than Their HIV-Negative Peers

Supporting universal access to care and quality-of-life check-ins may be associated with better quality of life for teens with HIV.

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Where are teens living with perinatally acquired HIV better adjusted than their peers? The Netherlands, according to a small study published in the journal AIDS Care.

This study looked at data from the NeurOlogical, Visual and Cognitive performance in HIV-infected Children (NOVICE) trial, which, overall, found no statistical difference in health-related quality of life between young people who acquired HIV perinatally and their peers without HIV. But it did find a few statistically nonsignificant decreases in quality of life in the children living with HIV. So this small study was meant to use a different health-related quality-of-life scale, the Pediatric Quality of Life Inventory (PedsQL) 4.0, to see whether it could replicate NOVICE's findings and see how they might change over time. Health-related quality of life is a measure of how a health condition like HIV might affect things like physical health, memory, emotions and social interactions.

This follow-up study was small. Just a fraction (about 45% in both groups) of NOVICE's original participants agreed to participate in the follow-up study—a total of 32, of whom 15 were living with HIV. The median age at the start of the new study was 13, and the researchers followed them for five years. The participants were slightly more likely to be girls than boys; transgender status was not reported. Most of the participants (73%) were Black, one in five was in foster care and one in five met the criteria for AIDS. All were on antiretrovirals (ARVs), most had been on them their whole lives (a median of 14 years) and 87% had an undetectable viral load.

Interestingly, at baseline and at follow-up, teens living with HIV reported generally higher health-related quality of life, which was statistically indistinguishable from the Dutch population at large. But compared with the HIV-negative teens in the study, the teens with HIV were statistically more likely to have a high quality of life when it came to emotional functioning at baseline.

At follow-up five years later, the teens living with HIV not only had a significantly higher rate of functioning at school than their peers without HIV but also better school functioning than Dutch teens in general. The other measures of health-related quality of life—like emotional, social and

physical functioning—were statistically similar between the teens with HIV and the general public. However, when the researchers looked at how the HIV-positive teens fared compared with their HIV-negative peers in the study, they noticed that the HIV-negative teens fared worse than the teens with HIV in terms of physical and emotional functioning.

Because this was a small study, the results may be specific to these particular teens living with HIV. Indeed, the authors suggested that it could be that only teens who were doing well decided to participate in the follow-up study. But they said they suspected the findings may also be the result of the system of care in the Netherlands, which universally offers rapid ARV starts and follow-ups every three to four months that allow clinicians to regularly check in with teens about their emotional well-being. Their HIV-negative peers may have no such support.

“In our center, children [with perinatally acquired HIV] are asked to fill out several questionnaires via the online KLIK [patient-reported outcome measures] portal, including the PedsQL before every hospital visit,” wrote A.M. ter Haar, MSc, of the Amsterdam University Medical Centers, and colleagues. “Like patients [with perinatally acquired HIV], their socioeconomic status-matched peers have a higher risk of a [health-related quality of life] below the Dutch national average due to their low socioeconomic status, yet they do not receive extra guidance from professionals.”

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