

How Does Trauma-Informed Care Improve Outcomes for Youth With HIV?

By Sony Salzman From TheBodyPRO



Kistin Nolan, M.P.H., is an HIV nurse who loves working with teens and young adults. But when she joined the Johns Hopkins University specialty infectious disease practice, she quickly realized young people living with HIV were falling through the cracks.

"We had a 70% no-show rate of young people with HIV in our clinic in 2012," said Nolan, speaking at the 2018 Association of Nurses in AIDS Care (ANAC) conference in Denver.

Nolan and her colleagues, including HIV physician Allison Agwu, M.D., helped pilot a retention program designed to accommodate the emotional turmoil that makes it more difficult for young people with HIV to successfully navigate the health care system.

Though Nolan didn't have the words to describe it at the time, she was helping move Johns Hopkins toward a "trauma-informed" model of health care. Trauma-informed care is a framework in which providers try to understand how trauma has impacted their patients, and then build clinical protocols around that understanding.

Trauma-informed care is especially important for young people living with HIV, said Brian Dentoni-Lasofsky, M.S.N., M.S.W., PMHNP-BC, of the Pediatric Psychiatry Consultation-Liaison Service at UCSF Benioff Children's Hospital. That's because people with HIV are more likely to have experienced trauma at a young age, said Dentoni-Lasofsky, also speaking at ANAC.

"Violent trauma is more common than nonviolent trauma in HIV-positive individuals," said Dentoni-Lasofsky. Overall, "trauma is associated with poorer medical outcomes."

Though trauma-informed care is a relatively new idea, it has a strong scientific rationale, Dentoni-Lasofsky explained.

"It's kind of this hip, novel thing out there," he said, but there's evidence to suggest that young adults with HIV do better in clinical settings that employ a trauma-informed framework.

According to the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA), any program that practices trauma-informed care:

1. "Realizes the widespread impact of trauma and understands potential paths for recovery;
2. Recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system;
3. Responds by fully integrating knowledge about trauma into policies, procedures, and practices; and
4. Seeks to actively resist re-traumatization."

In addition to employing a trauma-informed framework, HIV clinics can do a lot to make their facilities more youth-friendly. That includes an inviting waiting room area, longer visit times, staff training in adolescent health, and flexible hours.

There is "pretty convincing research" that these measures can dramatically improve outcomes for youth -- even those who seek care at an adult clinic, said Adam Leonard, M.S.N., M.P.H., of Community Health Programs for Youth at the San Francisco Department of Public Health.

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Success at Johns Hopkins

In 2012, Nolan and others at Johns Hopkins set up a new program they called Accessing Care Early (ACE) -- a carve-out within the adult clinic that would cater to people ages 18 to 29.

"Prior to this, we had a pediatric HIV clinic and an adult HIV clinic, and there was no room in between for adolescents," she said. Interestingly, the ACE team decided not to focus on viral load as a primary measure of success for the program. Rather, they focused on retention in care.

"We had goals, but our first goal wasn't viral load suppression," said Nolan. "We had to get them in the door, and we're not going to get them virally suppressed until we get them in the door again and again and again."

Patients were referred to the ACE program from one of three places: 18-year-olds who aged out of their pediatric care, young people who had been recently diagnosed, or young people who had a prior diagnosis and were not showing up to their appointments at the adult clinic.

To qualify for the program, patients also had to have a dual diagnosis, such as a mental health disorder, housing instability, or a substance use disorder. Once enrolled, patients were set up to meet with a nurse within three days -- key to keeping their attention, Nolan said.

Those visits were ideally about 30 minutes and ended with a warm introduction to the social

worker and psychiatrist working in the ACE program. "We didn't use the word psychiatrist," Nolan said, because it might dissuade patients from taking advantage of that aspect of ACE's services.

The final step was a visit with the physician, usually scheduled for within two to four weeks. Throughout the program, the care team met in weekly rounds over the phone.

The ACE program has been a success, Nolan said.

"The cohort has grown from 40 patients in 2012 to 140 patients now," she said. According to an analysis of the ACE program from 2012 to 2014, ACE patients had better retention in care than young people receiving care in the adult HIV clinic (49% versus 26%).

There was a lower rate of patients lost to follow-up in the ACE program compared with young people in the adult clinic (16% versus 37%). ACE patients were also more likely to use the social worker, psychiatry, and other services than their peers in the adult clinic. Both of those metrics were statistically significant.

Though they didn't focus on viral load, Nolan recognized that viral load is an important outcome. And, disappointingly, the ACE cohort didn't have better viral suppression rates, on average, than non-ACE patients (60% versus 89%).

However, Nolan pointed out that the viral suppression achieved by the ACE program (60%) was better than the average viral load suppression in the city of Baltimore for young people ages 20 to 29 (44.4%).

"That's not statistically significant," Nolan said, "but it is data."

The ACE program will be summarized in a forthcoming *Journal of AIDS Care* paper titled "Impact of a youth-focused care model on retention and virologic suppression among young adults with HIV cared for in an adult HIV clinic."

Ultimately, the goal of the ACE program is to help young adults transition into a typical adult

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clinical setting. "We want them to be independently successful in our own complex health system," Nolan said.

For any nurses or physicians hoping to replicate ACE's success in their own HIV clinics, Nolan offers this advice: Start small.

"We have this great robust program now," she said, "but it was built in steps."

Sony Salzman is a freelance journalist reporting on health care and medicine, who has won awards in both narrative writing and radio journalism. Follow Salzman on Twitter: @sonysalz.