Still Here

Young long-term survivors continue to face challenges.

August 17, 2020 By Reed Vreeland

In the 1980s and ’90s, UNTOLD U.S. infants AND children with HIV died of AIDS. When effective HIV medications became available, thousands survived, thanks to a heroic effort to create pediatric HIV regimens and to provide services for physical and mental health. But that’s not the full story.

Today, these long-term survivors—now in their 20s and 30s—are facing the effects of decades of living with HIV and of being on different antiretroviral regimens. They have higher than normal mortality rates and a higher risk of certain physical and mental health conditions, so what does the future look like for long-term survivors who have been living with HIV since childhood?

The Kids Are Not All Right

In April 2017, POZ magazine published an article titled “The Kids Are All Right,” featuring interviews with five young people born with HIV. Most of the cover story focused on the praiseworthy HIV education efforts of interviewees Jake Glaser and Hydeia Broadbent, but buried halfway through the article was a quote from Marc D. Foca, MD, a specialist in pediatric infectious diseases at Columbia University Medical Center. He said that in his practice he had found that people with HIV who have taken meds since childhood have a higher rate of heart disease and diabetes, and at younger ages. Broadbent shared her own experience with depression, her virus’s resistance to certain medications and her difficulties over the years adhering to HIV regimens.

The POZ article focused mainly on positive stories that matched the cover's title, "Forever Young," instead of folding the concerns of Foca and Broadbent into a look at the research on people who have lived with HIV since birth. What that research has found is that, far from being "forever young," these long-term survivors are "prematurely old" in many ways.

Some face serious physical and mental health conditions decades before their usual age of onset. And the abundance of resources that was there for them when they were children is now nowhere to be found.

Aging Out of Pediatric Care

"The transition from pediatric to adult care for a person who has been living with HIV since childhood can be an extremely challenging process," explains Lori Wiener, PhD, who spent many years at the National Institutes of Health (NIH) working with children and young people in the pediatric AIDS unit. She is now codirector of the Behavioral Health Core at the National Cancer Institute.

"In most cases, the transition to adult care is dependent on age limits rather than developmental milestones, so young people might be required to transition when not being necessarily ready to do so," she explains. When NIH's Pediatric AIDS Unit was phased out in 2005 and closed in 2006, Wiener helped develop a transition scale to determine the needs of young people with HIV who were being moved to adult care. The measure surveyed how ready a teen was to handle a higher level of autonomy in adult care. For example, it asked if the teens knew their HIV diagnosis, medications, dosages, CD4 count, viral load and comorbidities.

Some young people had not been told they had HIV until their teens and so had relied on their parents and providers to manage their treatment, without understanding the basics of HIV.

The measure also looked at whether the young person was able to schedule doctors' appointments on their own, had a basic understanding of insurance, had an adult health care provider and had access to transportation.

Unfortunately, despite pediatric health providers who were well intentioned, many young long-term survivors (YLTS) were pushed out of pediatric care because of their age, not because they were ready to switch to adult care.

Creating a Smoother Transition

"The transition to adult care hasn't gone well when a person doesn't have a provider they can really talk to and work with, and this can lead to poor HIV medication adherence and poor health outcomes," Wiener explains.

The National Alliance to Advance Adolescent Health and the Maternal and Child Health Bureau have partnered to create GotTransition.org, an online resource dedicated to improving the transition to adult care for many health conditions. This resource center can be used by young people with HIV who have not yet made the transition to adult care.

YLTS who have already transitioned to adult care but are unsatisfied with it can also use GotTransition to evaluate their own needs and get information about how to move to a new provider. Doctors providing care to YLTS should be aware of the research on liver, kidney and bone health in this group and the elevated risks for certain comorbidities, and they should take extra

time to ensure that mental health and substance use services are in place and meet their needs.

Doctors caring for YLTS can also look to NIH's COPE study (Clinical Outcomes for Persons with HIV Acquired Early in Life) for recent findings. Colleen Hadigan, MD, the principal investigator, discussed a recent article that investigated coronary blood vessel wall thickness in this group. "Using MRIs, we could see that the coronary walls were thicker in YLTS [compared with young people without HIV]," which could predispose them to developing plaque, raising the risk of heart attacks and strokes. This is an area that the study will continue to monitor as they age.

The good news is that, despite the difference in coronary wall thickness, no one with HIV had coronary artery narrowing or cardiovascular disease. "Even in adults with HIV, careful screening following standard cardiovascular guidelines for the general public should be adequate," Hadigan says. "The low-hanging fruit that we can do something about includes identifying people who are smoking, counseling them and monitoring weight gain—as well as identifying and addressing obesity and high blood pressure."

The relatively small COPE study of approximately 65 individuals with HIV since early in life will continue to track a number of health issues in this group. "Our thinking on cancer and other less common health concerns is that if we suddenly see several cases of a relatively rare illness, we would ring the bell and mobilize other networks to start looking for this in similar but larger HIV cohorts. Thus far, we have not seen conditions such as cancer that are alarming or out of the ordinary of what we would've expected," Hadigan says.

Mental Health and Social Support

Mental health and social well-being must also be considered when looking at the transition to adult care. Wiener explains that many of the YLTS she worked with had lost family members to AIDS, and their primary support had come from their pediatric HIV team. "The new adult care team might not know the family member they lost—leaving the pediatric program might be experienced as another loss," she adds. A young person may not have had the opportunity to grieve for parents who died, and their new adult care provider might not understand this bottled-up grief. Wiener explains that it's also important for providers to screen for cognitive impairment that might feel or look like depression.

Sadness, anger, depression, anxiety, PTSD, social isolation, cognitive challenges, worry about the future—these are all common among YLTS. "Being able to have individual psychotherapy is important, as is meeting other people who are also living with HIV and doing well," Wiener says. It's important for YLTS to have people in their lives who are aware of their diagnosis and whom they can talk to about their physical and mental health, sexuality and emotional well-being.

Wiener has found that for some YLTS, HIV is an all-consuming part of their lives, while others have not come to terms with it or even deny it. This creates a barrier to forming relationships and getting close to people. She has seen that YTLS who do the best are the ones who accept HIV as part of their life but don't let it define them. "Bottom line, the most important thing is human attachment and how we make meaning in our life. We need to balance connection to others while

understanding what the future may bring. I'm very much alive today, and I can make the most out of today. None of us knows what tomorrow is going to bring," she says.

Adherence and Viral Load

In 2017, JAMA Pediatrics published an analysis of the health data of 1,446 people born with HIV and found that those between the ages of 13 and 30 had higher viral loads and lower CD4 counts compared with adults with HIV who had not had the virus since childhood. They were also more likely to have AIDS-related illnesses and were more likely to die.

According to Wiener, "Adherence is a huge issue for any teenager who feels invincible. It's hard for people who are healthy to complete even a two-week course of antibiotics."

This is further complicated when HIV regimens need to be followed during adolescence—the time of life when obeying rules is often challenged.

The good news from the study is that serious health problems were rare among people who had sustained viral suppression, according to study leader Anne Neilan, MD, MPH, of Massachusetts General Hospital in Boston. This means that maintaining an undetectable viral load more or less eliminates the heightened incidence of opportunistic infections and mortality.

But adherence and viral load suppression seem to be especially difficult for YLTS. A 2019 study in the American Journal of Managed Care followed 381 young people who were born with HIV and found that the likelihood of adherence goes down with age. When children born with HIV aged from preadolescence (ages 8 to 11) to young adulthood (18 to 22), their rate of nonadherence increased from 31% to 50%, and the likelihood of having a detectable viral load increased from 16% to 40%. This should be an alarm bell, and it requires attention and resources that follow the principles of meaningful involvement and leadership for YLTS.

Plan for the Future. Demand Attention. Learn From one Another.

As YLTS age out of pediatric care and are isolated from others like themselves, how can they get the help they need? Demand to be acknowledged and learn from others with shared experiences is the answer of Grissel Granados, who directed a 2015 documentary called We're Still Here. It focused on the lives of YLTS. After holding screenings when it was first released, she made the full documentary free to view on YouTube; search for "We're Still Here (2015)—Official."

As a person born with HIV, Granados grew up in the Los Angeles area and participated in summer camps for kids with HIV. As an adult, she felt she was well adjusted but noticed that she didn't see herself reflected in spaces discussing HIV or in the data and research she found.

"Where are all of these other people I grew up with?" she asks. When she met people and told them about being born with HIV, they were often shocked. They hadn't heard anything about kids with HIV since the early '90s.

"I guess they assumed we died," she says. "No, some of us didn't die—we're still here, lost in the

adult system."

Granados started the documentary project trying to find other people who were born with HIV who had experiences similar to hers. "I learned about myself and my little community: the 10,000 people born with HIV living in this country. But we're all so separated and in small numbers in any jurisdiction. We grew up very isolated," she says. Granados also found that parents had a big influence on whether a YLTS met or socialized with other people with HIV, how they thought about their HIV status and who knew about it. There were significant differences in experiences, but also some similarities.

Granados was raised to be optimistic by her mother (who was also HIV positive), and she began by looking for positive stories that supported her own narrative. But when she started conducting interviews, she instead found that many people were struggling. "I don't think it's that the kids are all right or that the kids are screwed. I thought I was going to find that the other kids are all right, but I learned it's not that black and white," she explains.

Another realization she had while making the documentary was that the optimism that had served her well as a coping mechanism while growing up was actually hurting her as an adult. "It is really hard for me to sit with sad feelings. It's hard for me to sit with people's pain. It's something as an adult I'm trying to unlearn, so I can sit with feelings and connect with people when they're struggling or when I'm struggling," she shares. She discovered that what had been a successful coping mechanism at one age was now leaving her a little emotionally stunted. Creating the documentary forced her to reevaluate the coping mechanisms she'd used and to look at them as an adult, still living with HIV but with a different set of circumstances.

Granados points out that there are many similarities between older long-term survivors and YLTS but that the main difference is age. There are many things in common, such as dealing with sickness, side effects, medications, fear of your mortality, losing parents and friends to AIDS, the trauma of surviving. But the age at which these experiences occurred was different. "Loss in this population is pretty deep, because we experienced it as children and to this day," Granados explains. "In general, whenever there is someone from my small community who deteriorates and passes away, there is a voice in my head that says that could happen to me," she adds, thinking of a young HIV-positive poet who had died recently.

Many YLTS didn't expect to live to 18 or 21. "They were living their lives as though they were going to die—for some it became a crisis. Now they are adults and have not been preparing for adulthood," Granados observes. She sees YLTS in their 20s and 30s just starting to prepare for adulthood and considering their future, exploring the question: What does my lifetime look like now?

A lot of the conversations about long-term survivors begin with the assumption that they're in their 50s or older, so Granados has open questions about what being a long-term survivor means when you're in your 30s. "We hear that HIV ages you faster, but what does that mean for me? What about menopause? Should I be checking my bones?" These questions and many others

crossed her mind as she tried to understand what the research says about her near- and long-term future.

In many cases, people who have lived with HIV since early childhood barely know a world in which HIV and its treatment was not in their lives. “Medication fatigue is real,” Granados emphasizes, “particularly when you’re a young adult and want to live your best life and go on with your developmental milestones.” She explains that it is important to consider and not dismiss when people are not adherent. “We should support people’s bodily autonomy, while also recognizing that this can be a sign people are struggling,” Granados says. She added that it’s important not to shy away from a conversation about adherence and not to impose any shame, instead coming from a stance of openness and understanding.

This summer, Granados and a number of other YLTS in Los Angeles took it upon themselves to connect and formed a support group. Another group is forming in Puerto Rico.

“We’ve started doing grassroots little meet-ups. I’m still meeting people today who say, ‘You’re the first person I’ve met [who was born with HIV or acquired it early in life].’” Strangely, 20 people in the Los Angeles group went to the same pediatric HIV clinic growing up but never met before. “There were a lot of missed opportunities of people who were growing in isolation,” she says.

Now, as adults, they are meeting on their own time, without resources, to support these groups and are starting to build small networks of folks. “We’re taking it upon ourselves to start connecting,” Granados adds.

Back to Activism School

We have much to learn from the response to the pediatric AIDS epidemic in the United States. Now, a second wave of worldwide pediatric AIDS activism has made it possible to end all mother-to-child HIV transmission in the near future. But YLTS and current HIV-positive babies, children and teens will still be here long after that goal has been achieved. Ending mother-to-child transmission of HIV is quite different from extending and improving the lives of YLTS, which must be pursued with equal resources and determination.

What Granados and other YLTS have beautifully demonstrated is that the interventions most likely to save and improve the lives of YLTS will be developed by them. But that doesn’t mean they can get their plans off the ground without support. There needs to be a third wave of activism that is unafraid of the things that happen when kids with HIV grow up—and that starts by bringing together people eager to have those conversations.

Reed Vreeland is a YLTS and is director of New York City community mobilization at Housing Works. Titled “Young Long-Term Survivors: Still Here, Still Facing the Challenges,” this article was reprinted from Achieve, a publication of ACRIA @ GMHC. Go to acria.org/achieve to learn more. This text has been edited.

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