Women with Early Acquired HIV

While HIV transmission to babies has dropped dramatically, there are still many adults with HIV today who acquired HIV early in life. Learn more about the challenges and strength of young female long-term HIV survivors.

November 10, 2020 By The Well Project

This post originally appeared on and can be read in its entirety at The Well Project.

Young Female Long-Term Survivors of HIV

Rates of HIV transmission to babies during pregnancy, birth, breastfeeding, or through medical interventions have dropped significantly in recent years. This success is due to progress in research, treatment, and testing for women; screening of donated blood products and organs; and the continued expansion of access to these advances worldwide. Still, there are many adults living with HIV today who acquired HIV at birth or as young children. They, too, are long-term HIV survivors, with issues that are similar to older adults who have lived with HIV since its earliest days, as well as their own unique concerns. At last count, at the end of 2018, there were more than 12,000 people in the US living with early acquired HIV; fewer than 2,000 were less than 13 years old. (That number globally is more difficult to gauge.) But there is very little information available about their lives and experiences, particularly for women. These young people often get "lost in the mix" of HIV statistics, rather than being seen as a group and a community unto themselves.

Women with early acquired HIV may face challenges stemming from their childhood, and growing into adulthood, as a person with HIV. These may include trauma related to their diagnosis (including the death of parent(s), upheaval, or potential secrecy around their HIV status); managing medication adherence (taking medicines as prescribed) at a young age and for the entirety of their lives; shifting care from pediatric to adult settings; dating, sexuality, and reproductive health; and the visible and invisible impacts of life-long medication on their bodies.

Despite numerous obstacles, many of these young long-term survivors are sustaining full lives; choosing to build families; contributing to communities; in some cases, making history; and sharing profound wisdom and vital information based on their experiences.

HIVictorious, A Girl Like Me

“I would like to be supportive to other HIV positive people and be an example that you can have a long prosperous life even with an HIV positive status. I also want to bring light to the fact that not all long-term survivors are older people. The kids that were born HIV positive are long-term survivors and we are thriving.” – from "Intro - HIVictorious," on A Girl Like Me

Some Language to Know

There are several terms with similar meanings that are used to describe HIV transmission at birth or early in life, and those who acquired HIV this way. Some terms come from the community itself, while others are more clinical – and some may be considered stigmatizing.

It may be confusing for those who do not share this experience to know what term they ought to

use. If in doubt, an important guideline when talking to or about any person living with HIV is to use people-first language (phrasing that puts the person before their diagnosis or label – as in "woman living with HIV" rather than "HIV-positive woman"). If you want to read more about language and HIV, please see our fact sheet Why Language Matters: Facing HIV Stigma in Our Own Words.

- Early acquired HIV: Acquiring HIV in the first decade of life.
- Long-term HIV survivors: People who have been living with HIV for many years – typically more than 10 years. "Longest-term survivors" are those who have lived with HIV since the epidemic's early days, before effective treatment was available – a group that includes people who acquired HIV at birth or early in childhood that are now adults. Please see our fact sheet on long-term survivors of HIV for more information.
- Mother-to-child transmission of HIV (MTCT): Consider avoiding this term, though it is still widely used by the World Health Organization (WHO) and other global health entities. Describes transmission to a baby during pregnancy, labor, delivery or breastfeeding. Often used in relation to preventing these transmissions, though the term promotes stigma against pregnant and parenting people with HIV.
- Perinatal HIV transmission: Clinical term for transmission to a baby during the perinatal (immediately before and after birth) period
- Perinatal infection, perinatally infected: Recommend avoiding these terms. Refers to HIV acquired in the perinatal period, but the word "infection" or "infected" applied to a person is stigmatizing.
- Perinatal acquisition, perinatally acquired: Also refers to becoming HIV-positive immediately before or after birth. Preferred to the term above, but may be overly formal or complicated for some settings.
- Vertical HIV acquisition: Becoming HIV-positive via transmission by a parent.
- Vertical HIV transmission: Transmission from a parent to their offspring. Also a clinical term, though some advocates living with vertically acquired HIV have reclaimed this term and refer to themselves and others who share this experience as "verticals."

Individual and Social Challenges

- Disclosure
- Limited Support Systems
- Mental Health
- Substance Use and Sexual Risk
- Violence
- Intersectional Experiences of Oppression

As often noted in this fact sheet, many of the concerns below affect most people with HIV, but may be made even more difficult by the challenges of managing young adulthood with a chronic health condition that may affect not just them, but members of their family as well.

Disclosure

Porchia, A Girl Like Me

“Disclosure has been one of the scariest things to navigate in my experience. You don’t know how people will react–what they’ll say, or if they’ll freak out.” – Porchia Dees, from "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care" on A Girl Like Me

Telling others (disclosure) can be one of the hardest decisions that young people with HIV make. Women who acquired HIV early in life may be afraid to tell their friends and partners that they have HIV, for fear of being rejected or treated badly due to HIV stigma. They may also have negative associations with finding out their own HIV status.

Finding out HIV status

Some young women may not be told that they are living with HIV by parents of guardians until they are older – or ever. Advocate Lolisa Gibson-Hunte acquired HIV as an infant, but found out as a teenager when she got tested on her own. By the time they are adolescents, young people may already have formed negative opinions about people with HIV based on HIV stigma in the community and society around them, before finding out their own HIV-positive status.

Knowing their own HIV status is an important first step for a young person to begin to manage their own HIV care (discussed more below), and being told their HIV status is associated with staying connected to care in some studies among adolescents. Decisions about when a child ought to be told their HIV status may have to do with concerns around family privacy and stigma, caregivers' beliefs about what that disclosure would do to the child's mental health, or caregivers' own internalized HIV stigma. Disclosure to young people with HIV has also been shown to be delayed in areas of the world where there are high levels of social rejection due to HIV status. For more information, please see our fact sheet on talking with your children about your HIV status, or theirs.

Dating and sex

Lynnea, A Girl Like Me

“Growing up positive added its own layers of difficulty to the [dating] equation. I used to describe myself as poison ivy. I let the negative viewpoints of society and the stigma that I felt whenever people indirectly insulted me by joking about HIV alter the way I perceived myself.” – Lynnea, from "My Cup of Tea," on A Girl Like Me

“I started experiencing my first real feelings of exclusion from the rest of society when I started becoming interested in dating and learning about sex.” – Porchia Dees, from "Growing Up Poz & Dating" on A Girl Like Me

Dating and navigating sex can be tricky for anyone – especially young people who are just beginning to mature socially and explore their sexuality. Research has shown that adolescents

who acquired HIV at birth or as infants start having sex later than young people without HIV – especially if their adult caregiver is also living with HIV.

Limited Support Systems

Across the globe, many young people with early acquired HIV have experienced the death of one or more of their primary caregivers. Caregivers who have survived may be struggling with their own health. These conditions can be extremely stressful for young people, who may use methods to cope with stress that may help them feel a sense of control in the moment, such as not taking their HIV drugs – but may not be healthy for them. It is important for the places and teams that provide HIV care to young people to be "medical homes" that provide not just medicines and tests, but also the social support, emotional caregiving, and help with learning to cope with stress that young people may not be able to get in their homes.

Mental Health

Mental health challenges are not addressed at the level that they need to be anywhere in the world. Concerns such as depression, anxiety, anger, post-traumatic stress, social isolation, cognitive issues, worries about the future, and other mental health conditions are common among people who acquired HIV early in life. While there have not been many studies looking at differences in rates of mental health concerns between those who identify as female or male, some research suggests that young women are at higher risk.

HIV stigma, as well as other related forms of stigma, can have a strong impact on the mental health and quality of life of young people with HIV. The move from adolescent to adult HIV care, discussed more below, can also be a source of stress, anxiety, and loss for young people. In addition to leaving a setting where they may feel supported and cared for, there is the added stress of having to disclose HIV status and traumatic past experiences to a new group of providers.

Survivor guilt, while discussed more among older-adult long-term HIV survivors, is also a concern for people with early acquired HIV, and may have an impact on mental health. Survivor guilt is common among survivors of traumatic events. It refers to the feeling that they have done something wrong in surviving when others did not. People who acquired HIV early in life are likely to have lost parents or friends who were also positive. Many of the programs and camps they attended as children to combat depression, stigma and isolation may eventually lead to those very conditions, when so many of the other participants that they knew and loved have died.

Substance Use and Sexual Risk

Like many young people around the world, young people with early acquired HIV may explore sex and/or substance use. One study looking at use of alcohol, marijuana, and cigarettes found that, while young people with early acquired HIV did not use these substances at higher rates than the average for their age group in their country, the negative effects of substance use on the health of these young people were likely to be greater. Findings were similar regarding risky sexual activity: Youth with early acquired HIV were less likely to have had sexual intercourse recently and had fewer sexual partners overall. However, sex without condoms or other prevention methods was

common among those who were sexually active, even though this meant they could potentially acquire sexually transmitted infections (STIs) that could compromise their HIV health – or risk HIV transmission to partners if their viral loads were detectable.

“Even as I went through my little rebellious and experimenting adolescent stage the fact that I was conditioned to having to go get tested on an every six month basis, and had to encourage all my partners to go get tested, as well, forced me to be much more aware of the status of all my partners. The fact that I was exposed to a variety of information about treatment for HIV and STIs early in life, and that I knew how treatment for HIV and other STIs worked gave me a greater understanding on how to navigate hooking up and having sex in our society …” - Porchia Dees, from "Sexual Freedom" on A Girl Like Me

“I know women living with HIV often have this perception that they already have the worst STI, and are nonchalant about contracting any of the other ones. … I believe that we tend to start off thinking that we will not find anyone who will be accepting of us and our status. This leads us to be accepting of things that we shouldn’t be accepting of, more so than usual. Sometimes putting us in really vulnerable situations, like abuse, substance use, rape, prostitution, contracting other STIs, etc.” – Porchia Dees, from "Spotlight on Porchia Dees: Women Making a Difference"

There is a lot more to learn about how to support young people with early acquired HIV in making decisions that help them lead their own healthiest possible lives, including safe and fulfilling sexual experiences. Among young people, having sex, smoking or taking drugs, and not taking their HIV drugs as prescribed, may be ways to show independence or be accepted by other young people. The awareness that substance use can impact viral suppression, and that they cannot transmit HIV to sexual partners if their HIV drugs are working and their viral load stays undetectable (undetectable=untransmittable, or U=U), may encourage young people with HIV to better care for their health, in part by taking their HIV drugs regularly (discussed more below).

Violence

Kim Canady, Community Advisory Board Emerita

"I think it's important to talk about sexual violence in intimate partner relationships as a barrier to being in a relationship while being positive. Being born with HIV can impact how you feel about yourself, but also what you might believe you deserve." - Kim Canady, Emerita member of The Well Project's Community Advisory Board

Violence against women and girls is a worldwide epidemic, and studies have shown that women with HIV are more likely to experience violence than the general population of women. Intimate partner or domestic violence can take many forms, from physical or sexual harm to name-calling, controlling, threats, and much more. Among women with HIV, studies have also shown that trauma and violence are associated with lower HIV drug adherence and poorer health.

Important: If you are feeling threatened right now, call 911 in the US or the National Domestic Violence hotline in the US at 800-799-SAFE [1-800-799-7233; or 1-800-787-3224 (TTY)]. You can also search for a safe space online at Domestic Shelters.

Intersectional Experiences of Oppression

It is very important to note that the structural factors that affect people's lives and health outcomes also impact young people's experiences of living with HIV. These include systemic racism, sexism, classism, transphobia, ableism (bias against people with disabilities), and other intersecting, overlapping forms of oppression against vulnerable and marginalized communities that young people with early acquired HIV are more likely to be part of. Continue reading...

The Well Project is a non-profit organization whose mission is to change the course of the HIV/AIDS pandemic through a unique and comprehensive focus on women and girls. Visit their website, www.thewellproject.org, to access fact sheets (English and Spanish), blogs, and advocacy tools, and to join a global community of women living with HIV.

© 2026 Smart + Strong All Rights Reserved.
http://beta.docker.poz.com/blog/women-early-acquired-hiv