Women Survivors

A blog post from The Well Project titled “Medical Concerns for Women Lifetime Survivors of HIV” explores the challenges of women living with HIV who acquired the virus early in life. Below is an edited excerpt.

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Recent decades have seen great progress in HIV research and treatment; testing, especially of pregnant women; screening of donated blood products and organs; and the continued expansion of access to these advances worldwide.

As a result, rates of HIV transmission to babies during pregnancy, birth, breast/chest feeding or through medical interventions have dropped significantly overall.

Still, many adults living with HIV today acquired HIV at birth or as young children. They are lifetime survivors of HIV, meaning they have lived with HIV for their entire lives. They may have medical and other issues similar to those of older adults who have lived with HIV for many years as well as their own unique concerns.

At the end of 2021, nearly 13,000 people in the United States were living with early acquired HIV; fewer than 2,000 were under 13 years old. (That number globally is more difficult to gauge.) But very little information is available about their lives and experiences, particularly about women.

Women lifetime survivors may face challenges stemming from their childhood, and growing into adulthood, as people with HIV. These may include 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 lifelong medication on their bodies.

Many lifetime survivors have been taking HIV drugs for most or all of their lives. Adolescence (roughly the time between ages 10 and 19) is an especially rough time to have to think about taking medications of any kind.

There are many reasons young people may not take their HIV drugs at the times or in the amounts prescribed. These pertain to structural factors around systems and access, the person themselves or their provider, the drugs or HIV itself or a combination of these—and these factors may change over time.

A key reason HIV drug adherence is so important for staying healthy is that levels of HIV drugs in a person's body can drop too low when they are not taken as prescribed, causing their virus to change and the drugs to become less effective against it (known as developing drug resistance). Resistance to HIV drugs can keep a person's HIV regimen from controlling the virus and reduces a person's options for HIV drugs in the future.

Lifetime survivors over 18 are more likely to have drug resistance than those under 18 who were born with HIV.

HIV drug regimens have become easier to take and pose a lower risk of resistance, and those who are under 18 living with HIV are more likely to have been taking these newer regimens all along. When their virus is not controlled, it is more likely due to low levels of the drugs in their bodies because of low adherence, not because of drug resistance.

Lifetime survivors of HIV who were born earlier in the epidemic may have treatment histories as complex as those of long-term survivors who acquired HIV as adults, often involving outdated and more toxic HIV drugs. They also may have been exposed to HIV treatment in the womb, increasing their chances of resistance.

Luckily, today's many classes of HIV drugs allow for designing powerful regimens that can be relatively easy to take and can work well even for young people with long treatment histories and drug resistance.
