Women with Early Acquired HIV

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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 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 about 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.**
"I would like to be supportive to other people living with HIV 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 - HInvestigious [3]," on A Girl Like Me

Some Language to Know

Some terms come from the community itself, while others are more clinical – and some may be considered stigmatizing.

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"). To learn more about language and HIV, please see our fact sheet Why Language Matters: Facing HIV Stigma in Our Own Words [4].

- **Early acquired HIV:** Acquiring HIV during the first ten years 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 who are now adults. Please see our fact sheet on long-term survivors of HIV [5] 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 [6], labor, delivery or breastfeeding. Often used in reference to preventing these transmissions, though the term promotes stigma against pregnant and parenting people who are living with HIV. See vertical HIV transmission.
  - **Perinatal HIV transmission:** Clinical term for transmission to a baby during the perinatal (immediately before and after birth) period.
  - **Perinatal infection, perinatally infected:** Consider avoiding these terms. Refers to HIV acquired in the perinatal period, but the word "infection" or "infected" applied to a person is stigmatizing. See perinatal acquisition.
  - **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 living 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**

"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 [7]" on A Girl Like Me

Telling others (disclosure [8]) can be one of the hardest decisions that young people living with HIV make. Women who acquired HIV early in life may be afraid to tell their friends and partners that they are living with HIV, for fear of being rejected or treated badly due to HIV stigma [9]. 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 or 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 living with HIV based on HIV stigma in the community and society around them, before finding out their own HIV 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 some studies among adolescents have shown that being told their HIV status is associated with staying connected to care. 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 living 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 [10] about your HIV status, or theirs.

Dating and sex

"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 [11]," 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 [12]" on A Girl Like Me

Dating [13] 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 who are not living with 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 [14], 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.

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.

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 living with HIV. The move from adolescent to adult HIV care, discussed more below, can also be a source of stress [15], 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 whom 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 the 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 [16] (STIs) that could compromise their HIV health – or risk transmitting HIV to their 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 [17]" 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 [18]"

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 medications as prescribed (adherence), may be ways to show independence or be accepted by other young people. Knowing that substance use can affect 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 [19]) may encourage young people living with HIV to better care for their health, in part by taking their HIV drugs regularly (discussed more below).

**Violence**

"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 [20], Member of The Well Project's Community Advisory Board

Violence against women and girls [21] is a worldwide epidemic, and studies have shown that women living 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 [22] and violence are associated with lower treatment 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 [23].

**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 [24], sexism, classism, transphobia [25], 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.

**Treatment Experience and Challenges**

- Adherence
- Drug Resistance
- Transition from Pediatric to Adult Care
"I know my HIV medication is keeping me alive. I know how important it is. I know it's working against my virus and keeping me from getting sick. But like most people I had to grow up and learn the hard way....

"Taking my medicine was a reminder that I wasn't like everybody else—that something was wrong with me. I struggled with the acceptance of my HIV status because it came with so many different misconceptions. Subconsciously, taking my medications made feel like I wasn't normal, and it felt like an interruption to the life I was leading. It served as a reminder that I'm HIV-positive and all the negative stigma attached to it." – Porchia Dees, from "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care [7]" on A Girl Like Me

Many women who acquired HIV early in life have been taking HIV drugs for most or all of their lives. Adolescence (roughly the time between age 10 and 19 years) is an especially rough time to have to think about taking medications of any kind. There are many reasons that may lead young people not to take their HIV drugs at the times and amounts that they were prescribed (adherence [26]). These reasons can have to do with structural factors around systems and access; things having to do with the person themselves or their provider; things having to do with the drugs or HIV itself; or a combination of factors – and these factors change over time.

Adherence

Low adherence to HIV drugs is especially common among young people living with HIV. It is the number-one factor to consider when a person's HIV drugs stop working. There are many issues affecting adherence that are similar whether a young person is growing up in a resource-limited or resource-rich area of the world. These include concerns like busy schedules filled with school and other adolescent activities, forgetting to take your HIV drugs, falling asleep or leaving drugs at home before a scheduled dose. Young people may also stop taking HIV drugs as prescribed if they are feeling well (which is linked to taking the drugs regularly), or if they are worried that others will find out they are living with HIV if they are seen taking the medications.

Another important factor in adherence that some people with early acquired HIV have identified is the relationship with their providers.

Furthermore, after taking medications for many years, young people may simply be tired of taking them (treatment fatigue). They may also be taking a complex regimen of HIV drugs that involves a lot of pills taken at different times (when a drug is not taken correctly, it may stop working and a more difficult regimen may be needed – see the "Resistance" section below). The pills may also be too big or taste bad.

Particularly in high-resource areas of the world, having little confidence that they could adhere to their HIV drugs (self-efficacy), or not believing that HIV drugs have good effects (outcome expectancy), has been strongly linked with individuals not taking HIV drugs as prescribed. Young people experiencing systemic injustices like lack of medical providers or insurance, unstable housing situations, lack of transportation to provider appointments or to pick up HIV drugs, concerns related to caring for family members, and other factors related to poverty, may also struggle with adherence.

Physical factors like rapid growth and change in adolescents' bodies can affect how HIV drugs work. Uncomfortable HIV drug side effects like gut problems, headaches, or even changes in appearance [27] (much less common with newer HIV drug regimens) may lead young people not to take their drugs.

Disclosure-related concerns also have an impact on adherence in particular ways for young people. Those who have not been told their HIV status by caregivers may start to question why they are taking the drugs, or experience treatment fatigue. At least one study has shown that young people with early acquired HIV who shared their HIV status with at least one friend were less likely to hide that they were taking HIV drugs, which was related to higher CD4 numbers, an important marker of
immune system health [28].

Some people with early acquired HIV have identified the relationship with their providers as an important factor in adherence. Provider etiquette, rapport, dialogue, and discussion about adherence can have an impact on young people's ability to take medications and attend appointments as prescribed. Young people may be at risk of lapses in care as a result of challenges in their relationship with a provider, team, or with the institution where they go for care – whether it is with administration, appointment times, ethics and compassion of the staff, ineffective case managers, or the providers themselves.

It is important to remember that adherence is among the absolutely most important factors in managing HIV, especially among young people – which is why it is so vital to find the set of circumstances that works for a person to support them in taking their HIV drugs on time and as prescribed.

**Drug Resistance**

A key reason why HIV drug adherence is so important for staying healthy is that levels of a drug in a person’s body can drop too low when HIV drugs are not taken as prescribed, causing their virus to change and the medicine to become less effective against it (developing drug resistance [29]). Resistance to HIV drugs can keep a person's HIV regimen from controlling HIV and reduces the options a person has for HIV drugs in the future.

Just like many long-term HIV survivors regardless of age, people who acquired HIV early in life and are now adults are more likely to have drug resistance than those under 18 who were born with HIV. HIV drug regimens have gotten easier to take and have a lower risk of resistance, and those 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 drug resistance.

Young adults with early acquired 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. This includes in many cases less modern and more toxic HIV drugs – or taking one or two drugs by themselves, which we now know is not ideal – which play a role in their higher rates of drug resistance. They also may have been exposed to HIV treatment in the womb, increasing their chances of resistance. However, adherence is also a factor in these situations, since it gets more difficult through later adolescence to keep taking HIV drugs regularly.

HIV providers with experience caring for people who acquired HIV early in life recommend that regimens be as simple as possible (for instance, single-pill regimens) so that taking HIV drugs is more convenient and adherence easier for young people with so much else going on in their lives and their bodies. However, as young people get older and have taken different HIV drugs, low adherence and resulting resistance may make it hard for them to avoid more complicated regimens, continuing the cycle of adherence challenges. Luckily, today there are more classes of HIV drugs that 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.

**Transition from Pediatric to Adult Care**

"Transitioning out of pediatric care was a very significant—and extremely difficult—moment in my life. Entering into adult HIV care felt cold and distant. That transition made it easy for me to fall out of care in my young adulthood. I had built such a strong bond with my pediatrician that anything less than that was hard to accept. He always talked to me about more than just my numbers—he was concerned with what was going on in my life and how I was doing with my meds. He was like a dad to me. I mean he practically took care of me my whole life. Having a provider who cares and is able to connect with you on a more personal level is important." – Porchia Dees, from "Attention Health Care Providers: Insight into Why Young People May Be Not Consistently Engaging in HIV Medical Care [7]" on A Girl Like Me
The transition period has been shown to lead to young people falling out of HIV care, which can lead to worse health.

People between the ages of 18 and 25 transition from pediatric (child-specific) to adult care because providers have different training and institutions have different policies regarding where people of certain ages must get their care. There is a growing amount of research showing that adolescents' transition from pediatric to adult medical care settings can be a difficult process.

This is especially true for young people living with HIV, particularly those who have lived with HIV since early in life as they may have built community and friendships among the kids at their clinic, and/or a deep bond with their doctor and other members of their care team for virtually their entire lives. These bonds may be even stronger when providers are aware of a young person's family history, which can often be painful and include the death of parents or other caregivers within their family; and young people may dread having to explain all this to a new provider. The transition period has been shown to lead to young people falling out of HIV care, which can lead to worse health.

Research and personal reflections from community members have repeatedly shown that it is critical for young people living with HIV to have providers who not only understand the complexities of HIV care and services for young people, as well as the unique needs and challenges of people with early acquired HIV, but who take a real, dedicated interest in the lives of young people. This includes creating a nonjudgmental, family-like environment that validates young people's experiences and feelings, and working with young people as experts in their own care and needs.

Sexual Lives and Reproductive Health

"I'm now 34 years old, healthy, unashamed, single, and in love with the woman I am. I've been loved, I've been heartbroken, I've been desired, and I've been denied. My fear of passing HIV to another has caused me to experiment with my sexuality, and my fear of being alone has caused me to tolerate domestic violence, because I thought I deserved the abuse, and I thought I couldn't do better. Through it all, I have found me. I am a strong, brave, positively beautiful Queen!" – Lynnea, from "My Cup of Tea [11]," on A Girl Like Me

Women with early acquired HIV can and do nurture full and fulfilling sexual lives – and become parents to healthy, happy children if they choose to.

"Young women must be able to access HIV care with providers that are able to treat women holistically, instead of just looking at viral loads and CD4 counts. The full sexual lives of young women must be acknowledge by providers. ... I have met young women born with HIV who have grown up in such fear of themselves as sexual beings that they cannot even fathom dating, much less having healthy children someday." – Grissel Granados, from "Resources and Reproductive Justice for Young Women Living with HIV [30]" on PWN-USA's blog

While there ought to be more research to support women and their providers in this aspect of their journey, the voices of community members are clear: Women with early acquired HIV can and do nurture full and fulfilling sexual lives – and become parents [31] to healthy, happy children if they choose to.

When they engage with prenatal and postpartum services, many women with early acquired HIV may experience some similar challenges to women who acquired HIV later. As discussed above, the chances of a baby acquiring HIV during or soon after birth can be lower than one in 100 when the woman is taking HIV drugs that are working well. Research has shown that even women born with HIV who had drug resistance and needed to take complex HIV drug regimens in order to keep their HIV under control during pregnancy still had HIV-negative babies and no more complications than...
other women living with HIV who gave birth. In the same study, almost all the women born with HIV were having their babies with partners who were not living with HIV [32].

Unfortunately, however, women living with HIV may still experience stigma and ignorance around their family-building choices. This often occurs when women living with HIV seek information about breastfeeding [33] their babies. In the United States and other resource-rich areas of the globe, the official recommendation is that women living with HIV never breastfeed, the idea being that formula is available and safe in these areas, and the risk of a baby acquiring HIV outweighs the benefits of breastfeeding. In resource-limited regions where clean water, refrigeration, and money for formula are scarce, the opposite is true: the recommendation is that women living with HIV breastfeed exclusively. Research from these areas shows the risk of HIV transmission to be extremely low when the breastfeeding parent is taking effective HIV drugs – roughly as low as the risk of transmitting HIV during birth, though far more research is needed in this area. Still, women living with HIV in resource-rich areas may wish to breastfeed for many reasons, or at least make an informed decision, and are routinely shamed if they ask or punished if they try.

Claire Gasamagera, who was born with HIV, experienced anguish and physical pain at not being able to breastfeed her sons. Adding to her frustration was the fact that, in East Africa, where she is from and where she was an activist for years, she has known numerous women living with HIV who were encouraged to breastfeed, in keeping with HIV guidelines for that area of the world. Now that she lives in the US, the opposite is true. Gasamagera has a great relationship with her obstetrician, but still felt shut out of the decision-making around how she would feed her babies. "I didn't feel room for asking questions," she said in a 2019 panel discussion on the topic [34].

It is vital that there be more research into breastfeeding among women living with HIV, and that providers be informed enough about the data we do have to support people in making their own empowered, informed choices. Toward this goal, there has been some recent guidance in the US and other resource-rich regions to support providers of women living with HIV who wish to breastfeed. For more information on these guideline changes and more, please see our fact sheet on infant feeding and HIV [33].

Other HIV-Related Medical Challenges

"I want to add so much about body image and self-esteem but there's no studies to support all of the physical issues and concerns expressed by my peers. I listen to so many of my perinatal friends that complain about physical deformities that stem from early antiretroviral use. Even dental concerns, things that affect the quality of everyday life.

"Even I, myself, struggle with feeling good about the image in the mirror. The shingle scars riddled across my chest, back and arms. The scars on my face, barely visible, thanks to my grandmother getting them treated. But, even then, it's hard to love the person I see. I never knew a day without HIV, neither has my body; and we all struggle with the truth of what it has done and continues to do to our physical appearance." - Ieshia Scott [35], founder, Positive Support [36]

Many of the challenges discussed below apply to the wider community of people living and aging with HIV, but there may be unique concerns for women who have lived with HIV for their whole lives and throughout their development. The main difference between older long-term survivors [5] and
young long-term survivors who acquired HIV early in life does appear to be age. The health conditions and serious considerations that others are having as seasoned adults, young long-term survivors may have encountered in their childhood, teenage, and adolescent years. It is very important to continue to monitor these factors in young people who acquired HIV early in life, throughout their lives.

Liver health [37]: In a large study, young people born with HIV had significantly higher scores on tests for indirect (noninvasive) markers that can indicate potential future liver disease, particularly when HIV was not controlled.

Bone health [38]: While in one study rates of low bone mineral density (BMD), a test for potential bone problems, were relatively low among children born with HIV, they were higher than among the general population. These differences were explained in part by differences in body size among the young people in the study. However, most of the children born with HIV had not yet reached the increased growth period of puberty at the time of the study. Factors related to low BMD could increase with the growth spurt of puberty and could lead to greater risk of more serious bone problems in adulthood.

Dental health [39]: Poor oral health, cavities, and gum disease were found to be common in one study among young people who acquired HIV early in life. This is particularly troubling considering how frequently these young people engage with medical care, and highlights the need for medical providers to discuss and monitor dental health in their young clients.

Cardiovascular health: A study of how fat is distributed [27] on the bodies of young people who acquired HIV at birth showed that while these young people had lower total body fat than young people who had been exposed to HIV during birth but were HIV-negative, the fat was more likely to be distributed in a pattern linked to cardiovascular (heart [40] and blood vessels) disease risk. This difference may be due to the young people taking specific, older HIV drug regimens. Another study in the same cohort (group) of young people showed that those who acquired HIV at birth also had higher levels of biomarkers for problems with the heart and blood vessels, related in part to unfavorable fat (lipid [41]) levels and HIV not being under control. Additionally, emerging data on integrase inhibitors, a newer class of HIV drugs that many young people living with HIV are now taking, suggests that they may contribute to weight gain – and to a greater degree for women than men.

Neurocognitive [42] concerns: Several studies have shown that young people with early acquired HIV, and particularly those who have had an AIDS-defining condition in the past, may be at greater risk for challenges with learning and memory.
"I'm 30 and HIV don't control nor worry me. I live in the life as a mother of a negative 4-year-old son, a sister, an aunty, a daughter, a Warrior, a strong believer, a child of GOD. I am RAVEN LOPEZ not HIV!!!! HIV is human – so yup that's me.

"Sometimes I even forget I have HIV! I have so many other things to do, I'm not really thinking about it – besides at night when I pop my pill – but otherwise, HIV is not my life. I refuse! I have too much else to think about and do. And I am loving the mom life!" – Raven Lopez, public speaker and longtime advocate

Researchers and community members have noted over and over again that a connection with others who share their unique experience and advocacy around some effort larger than their individual lives is a vitally important aspect of life for women with early acquired HIV. Women have talked about finding such communities to be life-changing.

The global HIV community as a whole has a long way to go in understanding the potential impacts of having acquired HIV early, and unique issues that may occur. Far more research is needed on best practices for supporting this community of women to live their best and healthiest lives on many levels. However, beyond studies and data, what is needed is more listening, more opportunities and
spaces for women who acquired HIV early to connect – and more following the lead of women who have spent a lifetime figuring out, with few models, what they need in order to live and thrive.

While women who acquired HIV at birth or early in life do face many challenges, they also are a unique community with amazing resiliency and strength. These young long-term survivors are sustaining full, rich lives; their experiences and voices are critically important and need to be heard.

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long-term survivor HIV young [43]
young long-term survivor AIDS [44]
MTCT [45]
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perinatal infection HIV [48]
Vertical HIV transmission [49]
perinal HIV transmission [50]
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AIDS survivor syndrome [52]
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Additional Resources
Still Here (Achieve, via POZ) [55]
Born with HIV (Terrence Higgins Trust) [56]
Pediatric HIV/AIDS Cohort Study (PHACS) [57]
For Children Born with HIV, Adhering to Medication Gets Harder with Age (AIDS) [58]
In World First, HIV-Positive Woman Donates Kidney to HIV-Positive Recipient (CNN) [59]
Born Free (Positively Aware) [60]
What Are the Outcomes for Adults Who Were Born with HIV? (aidsmap) [61]
Medical Mentorship for Young People Living with HIV (Advocates for Youth; PDF) [62]
Born Free (POZ) [63]
Resources and Reproductive Justice for Young Women Living with HIV (Positive Women's Network - USA) [64]
Health Risks Grow as Kids Born with HIV Age (WebMD) [65]