

Perspectives on ART-Related Weight Change from People Living with HIV in a New York Medicaid Plan: A Qualitative Study

The association between HIV disease, HIV treatments, and healthy weight has been a concern since the early days of the epidemic. In the early antiretroviral treatment (ART) era, weight gain was seen as a “return to health” and linked to improved survival and immune recovery.

Newer ART meds are associated with greater weight gain than older meds, and being overweight or obese may pose a greater risk for mortality, disability, and chronic health problems. But other things affect weight change among people living with HIV.

This study aimed to better understand how individuals experience effects such as weight change in their daily lives and how they feel about their body image. We also examined how weight change was related to taking ART as directed. The study was not designed to prove a connection between ART use and weight change.

We interviewed 61 people living with HIV about their feelings about weight change in their daily lives:

- Many had gained weight since their HIV diagnosis.
- Some people welcomed their weight gain and saw it as a return to health.
- Others were unhappy about their weight, usually because they wanted to weigh less.
- Some people wanted to gain weight or size but were not able to.
- Several had problems with fat redistribution, or lipodystrophy. Lipodystrophy can include fat loss in the face, arms, or legs, and fat gain in the belly, neck, breast, and upper back.
- Some people did not report any weight changes.

Participants often thought their HIV medication was at least partly responsible for weight changes. In some cases, people had changed medications and experienced a weight gain or loss at that time.

Sometimes weight change had to do with the side effects of the medications. Some said they had lost weight because of nausea, diarrhea, or lack of appetite, or they had gained weight because of the need to eat a meal with their medication.

Nearly all were engaged in care for HIV and reported taking their medications as directed, at least most of the time. For a few people, side effects, including weight gain or loss, made them want to stop taking ART or take it less often.

Some participants had weight changes but did not think their medication had anything to do with it:

- People often blamed themselves, either their eating habits or lack of exercise, or both.
- Those with a history of drug use or smoking experienced weight changes when they quit or got sober.
- In some cases, non-HIV medications had an effect on weight.

Participants wanted to be healthy, and many saw weight as an important factor. Everyone knew they should exercise and follow a healthy diet, but many participants struggled to do so. Depression or anxiety were common challenges to lifestyle change.

Most people reported walking regularly, sometimes walking a lot. But some found it hard to exercise because of physical conditions or simply lack of motivation. The COVID-19 pandemic shutdowns also kept many people at home.

When people talked to their doctors or nurses about weight problems, providers tended to focus on their patients' diet and exercise, which was sometimes helpful, but not always.

Body image satisfaction varied widely:

- Some felt distress due to weight problems or lipodystrophy. Controlling their viral load was most important, but it was frustrating when body changes felt out of their control.
- Others felt good about their health and appearance and what they were doing to take care of themselves.
- Some individuals weighed more or less than they wanted to, but they had accepted it.

Conclusion

Antiretroviral medications for HIV may lead to weight changes, especially weight gain. Weight gain may pose challenges for people living with HIV, especially if they are struggling with side effects of ART, other physical and mental health conditions, and feelings that they lack control of their health. These factors are often related.

While viral suppression is the priority in care of people living with HIV, maintaining an undetectable viral load can be a burden.

Health care providers should be alert to the effects that weight gain may have on body image and health behaviors. Some individuals would benefit from greater support to achieve the healthy weight they seek and to regain a sense of control.

For more information, visit <https://brookdale.org/projects/hiv-patient-perspectives-on-weight-change-and-healthy-weight/>