

# Perspectives of people living with HIV on ART-related weight change and healthy weight

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## Background

Some current HIV antiretroviral therapy (ART) regimens have been associated with changes in weight, especially weight gain.

Weight gain may be part of a return-to-health phenomenon. Yet an increasing number of individuals are overweight or obese at the time of HIV diagnosis.

Individual reactions to weight gain vary. There is limited research on how perceptions of weight change affect health behaviors among people living with HIV (PLWH).

## Study Aims

This qualitative study asked PLWH in a New York City Medicaid plan:

- how they experience weight change in their daily lives
- how they feel about their body image
- how that influences health behaviors, including ART adherence

## Methods

PLWH were recruited through Amida Care, a Medicaid managed care organization in New York City, and screened to ensure a diverse sample (N=61).

- We conducted semi-structured one-to-one telephone interviews during fall 2021.
- Interviews were recorded and transcribed.
- We used Atlas.ti v.22 for the analysis.
- We used an inductive thematic approach to coding.
- After naming, defining, and grouping concepts in the data, we identified patterns and developed themes.

## Results

Research questions focused primarily on the relationship of weight changes and body image to ART usage and adherence. Experiences and perceptions varied widely, but five main themes emerged.

Characteristic	n	%
Age group		
23–49 years old	31	51
50–65 years old	30	49
Gender identity		
Cisgender male	31	51
Cisgender female	22	36
Transgender/nonbinary	8	13
Sexual orientation		
Gay/bisexual/queer men	22	36
Heterosexual men	9	15
Heterosexual women	23	38
Gay/bisexual women/nonbinary individuals	7	11
Race/ethnicity		
Non-Hispanic Black	34	56
Hispanic	19	31
Non-Hispanic White	3	5
Asian/Asian American	2	3
Mixed race	3	5
Body mass index (BMI)		
Normal weight/underweight	15	25
Overweight	17	28
Obese	29	48

Themes	Selected Participant Quotations
<b>Unwanted weight gain was attributed to ART and other factors</b>	<i>When I was diagnosed back in 2016, the medication that they put me on . . . made me gain a lot of weight and I was very unhealthy. So I got my medication changed two years ago . . . and my weight has dramatically changed. And I don't have any, I don't have any of those health problems anymore. The high blood pressure, the pre-diabetes, I don't have that anymore.</i> —37-year-old cisgender woman
<b>Weight gain was desired by some</b>	<i>When I was diagnosed, I was at the lowest weight that I've been at. . . I looked kind of gaunt. My appetite wasn't there. . . But within six months [after starting ART] I gained approximately 50 pounds. And I felt healthy.</i> —44-year-old transgender woman
<b>Body image satisfaction was linked to feeling in control of one's health</b>	<i>And now that I'm on a new regimen, they're telling me that that can cause weight gain, weight loss, weakness, this, that. . . The way I look, the way I feel, I don't think I'm attractive anymore, I don't think I'm worthy anymore.</i> —57-year-old cisgender man
<b>Side effects of ART were a burden</b>	<i>I don't know not one person who doesn't have a, doesn't go through anything, mental health crisis, because the medications alone cause those types of side effects and it changes the way you think about stuff. And sometimes you could just be one way and the minute you're like, what is wrong with me? And I know it's because of that.</i> —58-year-old cisgender man
<b>Weight was seen as an individual responsibility</b>	<i>I'm a very emotional eater. . . I wish I could control my thoughts when it comes to food, but I have a lot of work to do. . . I just gotta really . . . discipline myself, which is extremely hard to do when you're so used to eating, eating recklessly, recklessly like I do.—54-year-old cisgender woman</i>

- Many participants had gained weight since their HIV diagnosis.
- Many attributed weight change at least partly to ART initiating or switching.
- Other cited causes were eating habits, lack of exercise (exacerbated by the COVID-19 pandemic), other medications, ending drug use, and depression/anxiety.
- Some, especially long-term HIV survivors, interpreted “weight change” as referring to lipodystrophy.
- Body image satisfaction varied widely across the sample but was tied to a sense of control.
- Some seemed to have responded to the HIV diagnosis by focusing on healthful habits, but others struggled with weight and other health issues, including ART adherence.

## Conclusions

- Experiences and perceptions varied widely, but weight changes are a concern among PLWH, whether or not they attribute the changes to ART.
- Some PLWH may grapple with a loss of control in terms of managing weight and weight change.
- Achieving and maintaining viral suppression is the priority, but for some participants HIV treatment was associated with health and body image problems they felt forced to accept.
- It is important to consider a patient's desired weight and provide information about potential weight changes associated with ART initiation or switching.

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