

# WEIGHT CHANGES MAY AFFECT SENSE OF CONTROL AMONG PEOPLE WITH HIV ON ANTIRETROVIRAL THERAPY

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## RESEARCH OBJECTIVE

- While the role of antiretroviral therapy (ART) regimens in weight change is the subject of other research, people living with HIV may perceive a relationship between ART and their own weight fluctuations or weight gain.
- Individual reactions to weight gain vary, and there is limited research on how perceptions of weight change affect health behaviors among people living with HIV.
- This study aimed to learn how weight change and its association with body image affected ART adherence and other health behaviors.

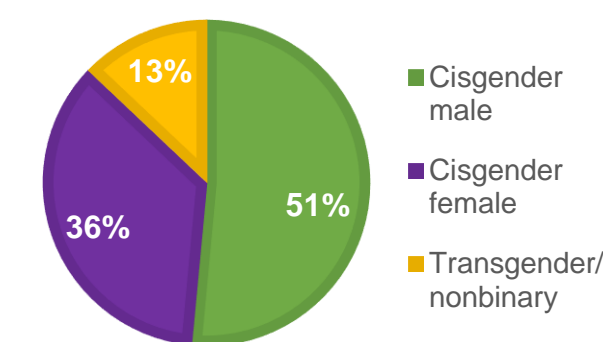
## STUDY DESIGN

- We recruited participants through a Medicaid managed care organization in New York City in fall 2021 (N=61).
- English-speaking adults with an HIV diagnosis and a history of ART usage were eligible.
- We conducted and recorded semistructured interviews by telephone. Topics included participants' stories of weight changes, if any, especially in relation to ART initiation and switches; perspectives on healthy weight; and approaches to maintaining physical and mental wellness.
- Participants received a \$50 gift card as compensation.
- We coded the transcripts and generated themes using inductive thematic analysis.
- The study protocol was approved by the City University of New York Institutional Review Board.

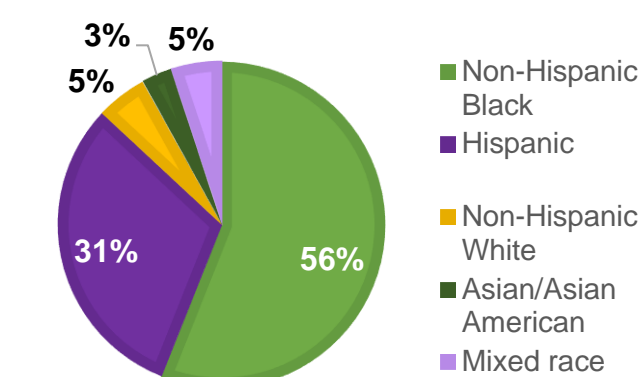
## PARTICIPANT CHARACTERISTICS

AGE: Range 23-65 years; mean 47.9 (10.97); 30 (49%) were 50 or older.

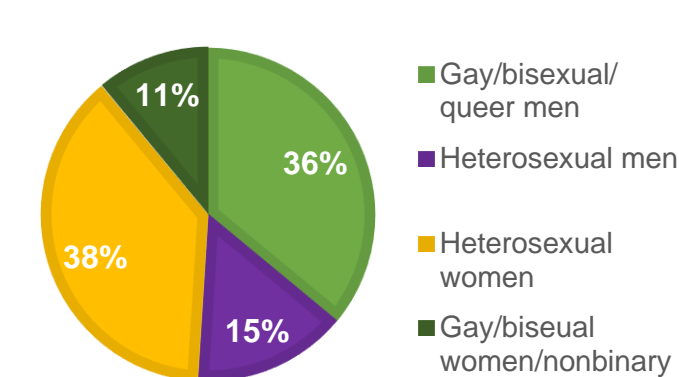
### GENDER IDENTITY



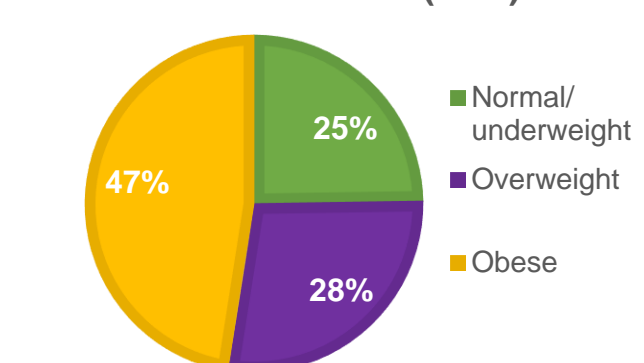
### RACE/ETHNICITY



### SEXUAL ORIENTATION



### BODY MASS INDEX (BMI)



## PRINCIPAL FINDINGS

Among those who struggled with weight changes or side effects of ART, many expressed frustrations and a sense that they lacked control over their health.

### THEMES AND ILLUSTRATIVE PARTICIPANT QUOTATIONS

#### Weight gain, loss, and fluctuations were attributed to ART and other factors

- Weight gain or fluctuations were sometimes attributed to ART
- Other health conditions, especially depression, seemed to play a role in weight changes
- Participants blamed their own health behaviors for weight gain

When I was first diagnosed with HIV and I started the antiviral medication, I ballooned up to almost 350 pounds. And I was never in my life that big, always been a slim, slim, grew up all my life. (Ella, 55)

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. (Annabelle, 44)

Being HIV positive and having to change the way you live altogether doesn't make life worth living. So I just ignored that part and proceeded with what I wanted to do. So, I got, you know, bigger. I had to, like, lose weight and I made it all the way up to 200 pounds once. Just eating and yeah. (George, 46)

#### Weight management was seen as an individual responsibility

- Individuals generally believed they should be able to control their weight through nutritional and exercise behaviors
- Providers tended to reinforce the emphasis on diet and exercise
- Failure to control weight was a source of frustration

The nurse and the nutritionist ... reminded me with that medication, you have to be careful what you're eating because of increasing fat cells or something. (Zora, 57)

I'm a very emotional eater. I like to eat so that's the problem. ... I wish I could control my thoughts when it comes to food, but I have a lot of work to do. ... Oh, boy, I eat all the wrong things. I mean, I really do. But I also successfully, successfully ate the proper way, the healthy way, once upon a time. So I could actually do it, 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. (Ursula, 54)

#### Body image satisfaction was linked to feeling in control of one's health

- Body image was linked to the participant's sense of being able to achieve a "healthy weight"
- Long-term survivors often had lasting health and body image problems due to HIV or ART

I'm overweight. But I look good. I don't look sloppy. ... I've been at 260 for a long time. And then I lost 20 pounds. So I'm like 237. So I lost 20 pounds and that makes me feel good. That makes me feel like I'm doing something right. (Tanya, 54)

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. (Louis, 58)

#### Sense of control influenced health behaviors in divergent ways

- Low sense of control could lead to stress and depression, resulting in poor health behaviors
- Some long-term survivors focused on controlling what they could control
- Some participants regained a sense of control as they made lifestyle changes that worked

I've always had a long period of adjustment [to a new regimen]. ... I was sad, you know, like, why am I always still not feeling good? ... You know, my friend is food. ... I would eat, eat and sleep, and I was fine. So I thought. ... When I found out I was diabetic, my weight shot up. It really, really depressed me. (Jackie, 57)

I walk a lot. ... And I think that that helps me feel like I'm at least evoking some level of control. I don't know how effective that is. I don't feel as though it's effective. But I feel as though ... I'm making some effort at it. (Michael, 40)

For many, many, many years, I felt very unpowerful and only until recently, I'm just starting to believe in myself and know that things are gonna get a little better and that, you know, taking my medications is good for me. So believe in yourself and things will be all right. (Ivan, 47)

Note: All names are pseudonyms.

## CONCLUSIONS

- Some people living with HIV may grapple with a loss of control in terms of managing weight along with other health conditions.
- Achieving and maintaining viral suppression is the priority for this population, but for some participants HIV treatment was associated with health and body image problems they felt powerless to change.
- Providers have an opportunity to offer support that increases patients' sense of agency and to offer solutions to help patients meet weight management and other health goals.

## IMPLICATIONS FOR POLICY AND PRACTICE

- Justifiably, healthcare providers prioritize viral suppression for their patients with HIV. However, the burden of maintaining viral suppression should not be overlooked. Health care providers should be alert to the effects that weight gain or loss may have on body image and health behaviors among people living with HIV.
- Informing patients about the possibility of weight changes with ART initiation and regimen switches, and helping them manage such changes, could bolster patients' sense of control about their health.
- The participants appreciated access to nutritionists and other resources that helped them take control of some aspects of their health. Resources that address structural barriers to healthy behaviors, such as free gym memberships, would be beneficial for Medicaid recipients.
- Some people living with HIV need a greater level of support to achieve the healthy weight they strive for, to find ways to address negative feelings about their bodies, and to regain a sense of control. HIV care practices should consider how they might make such support available to patients who are struggling.

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