

# Stigma in older people with HIV: disclosure concerns and self-image do not change over time in older AGEhIV Cohort Study participants with HIV

## INTRODUCTION

- Stigma remains a barrier jeopardising the HIV care continuum
- Negative self-image (or self-stigma) and disclosure concerns are associated with:
  - depression, anxiety, non-adherence to HIV treatment, less engagement in care, and reduced quality of life
- AGEhIV Cohort Study is a prospective, observational study in older people with and without HIV in the Netherlands with 10 years of follow up
- In 2022, patient-reported outcomes were introduced as part of routine clinical care at Amsterdam UMC. (Moody K et al, BMJ Open 2023)

## METHODS

### Participants

- AGEhIV cohort participants who completed the Berger HIV Stigma Scale (HSS) between October 2012-October 2014 (T0) and May 2023-May 2024 (T1)

### Measurements

#### Berger HSS - Dependent variables

- T0: 40-item version; T1: 12-item version
- Domains analysed: negative self-image (3 questions) & disclosure concerns (3 questions) common to each version
- Scale:
 

Strongly disagree	Disagree	Agree	Strongly agree
1	2	3	4
- Total score per domain: 3 to 12

### Statistical analysis

- Mean change in disclosure concerns and negative self-image (paired sample t-test)
- Factors associated with absolute changes in disclosure concerns and negative self-image over time (T0-T1, linear regression)
- Factors associated with higher or lower scores (mixed linear effects model with random intercept for individuals)
- Modelling: backwards stepwise selection, including all variables with a p-value <0.20 in univariable analysis and removing all those with a p-value ≥0.05
- Covariates in models
  - Demographic: age, sex, ethnicity, years since HIV diagnosis, route of transmission, education, marital/relationship and work status
  - Lifestyle: smoking, alcohol, drug consumption, household size
  - HIV-related: CD4 & CD8 counts, HIV-1 RNA, prior AIDS event
  - Self-reported depressive symptoms: T0: PHQ-9 or CES-D; T1: PROMIS CAT

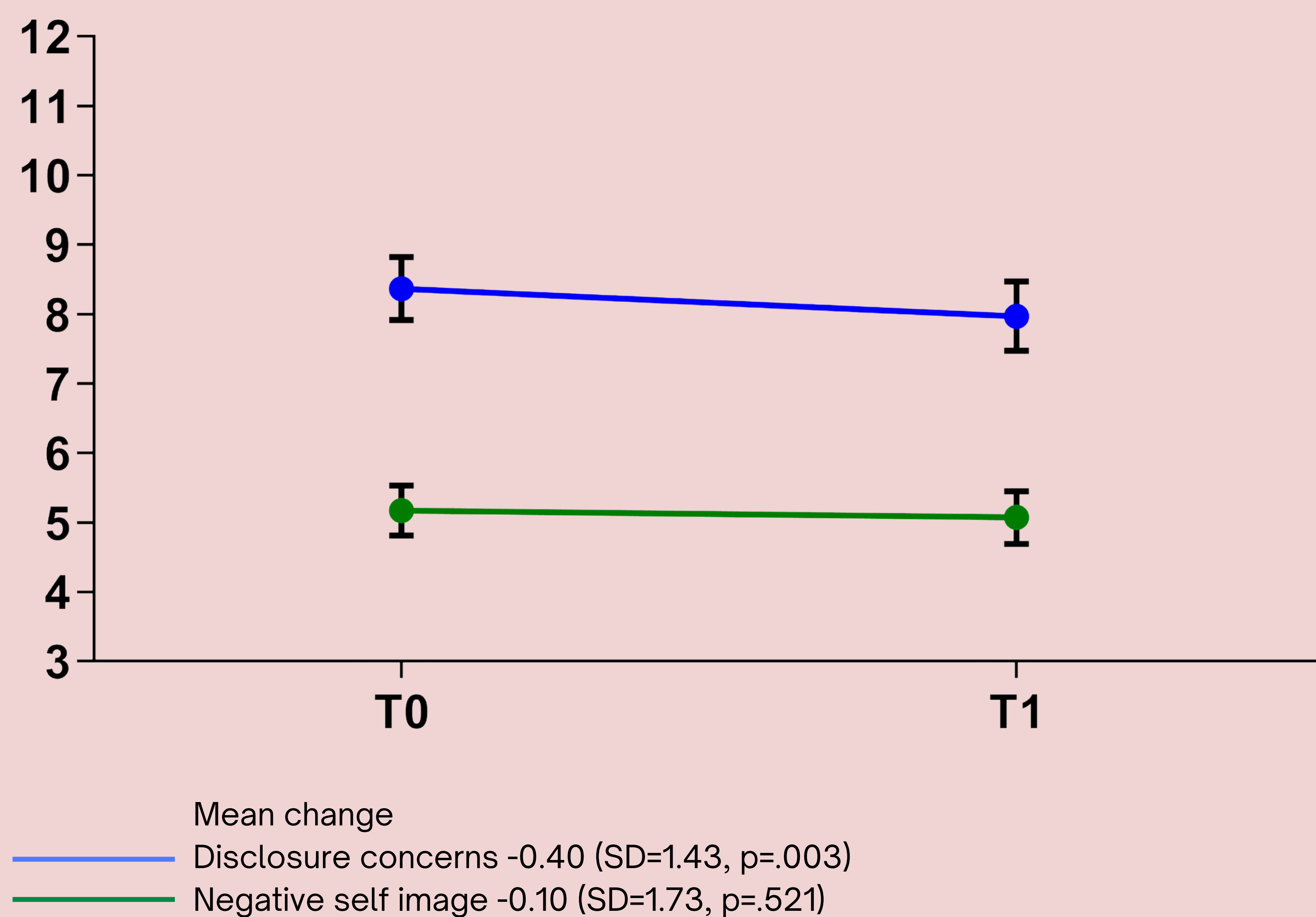
## STUDY AIM

- Do negative self-image and disclosure concerns change over time?
- Which factors are associated with these changes and with high or low stigma scores over time?

## RESULTS

**Participants included:** 116 people (93.1% male; 98.3% white); median age of 55.5 years (IQR 50.9-60.5). 95.7% had an HIV-1 RNA < 200 c/ml; median CD4 cell count was 650 (IQR: 510-830); median time since HIV diagnosis was 14.5 years (IQR: 8.3-20.8), median time on ART was 12.1 years (IQR 5.8-17.0); 28.4% were previously diagnosed with AIDS

### Mean (CI95%) disclosure concerns and negative self-stigma: 10-year follow up



### Factors associated with disclosure concerns

- Change in disclosure scores: None
- Higher or lower score
  - Lower disclosure concerns: more years since HIV diagnosis
    - (-1.10 [95%CI, -1.70 to -0.49], p<.001)
  - Higher disclosure concerns: Households greater than 3
    - (+1.28 [95%CI, +0.15 to +2.40], p=.027)

### Factors associated with negative self-image

- Change in negative self-image: Female
  - (+1.32 [95%CI, +0.08 to +2.56] p=.037)
- Higher or lower score
  - Lower negative self-image: more years since HIV diagnosis
    - (-0.72 [95%CI -1.10 to -0.35], p<.001)
  - Higher negative self-image: Bisexual
    - (+1.86 [95%CI, +0.63 to +3.09], p=003)
  - Higher negative self-image: Depressive symptoms
    - (+1.86 [95%CI, +1.20 to +2.53], p<.001)

## CONCLUSIONS

- In this population of largely well-treated Dutch white men, stigma has not changed despite U=U and other biomedical advances in the last 10 years
- Further inquiry into the relationship between U=U and stigma is needed
- It is crucial to prioritise research into stigma in women, bisexuals, people in large households and those with depression to drive meaningful change
- Since stigma has a negative impact on quality of life beyond viral suppression, there is a need for more accessible and effective interventions

### AUTHORS

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