

## HIV as a chronic condition

*Experienced burden of living with HIV today among men who have sex with men in the Netherlands*

Ward P.H. van Bilsen

# Disclosure of speaker's interests

- No conflicts of interests



# × × × Background

- **HIV history**
  - From fatal disease to manageable chronic disease
- **Psychosocial impact**
  - Acute mental stress associated with dying in pre-ART era
  - More complex and on-going distress associated with living with HIV in ART era



# Background



- **HIV history**
  - From fatal disease to manageable chronic disease
- **Psychosocial impact**
  - Acute mental stress associated with dying in pre-ART era
  - More complex and on-going distress associated with living with HIV in ART era
- **Little is known about psychosocial impact in the context of recent developments**
  - Early ART initiation
  - ART regimens with less side-effects
  - Introduction of biomedical interventions (PrEP)
  - U=U campaigns



# ××× Background

- Research question

*What is still perceived as a burden of living with HIV among MSM in the Netherlands?*



# Methods



## ■ Mixed-method study

### • Qualitative phase:

- Semi-structured in-depth interviews
- 18 MSM diagnosed with HIV between 2014-2018
- Living in urban and non-urban settings
- Recruitment at three Dutch HIV treatment centers & Amsterdam STI clinic





# Methods



## ■ Mixed-method study

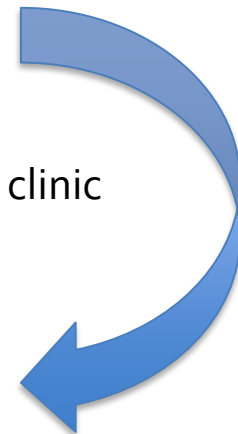
### • Qualitative phase:

- Semi-structured in-depth interviews
- 18 MSM diagnosed with HIV between 2014-2018
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### • Quantitative phase:

- Questionnaire with 7-point Likert scale items to measure burden\*
- Distribution at gay (dating) sites/apps among HIV-positive MSM



\* Burden was categorized in low burden (score 1-2), neutral/medium burden (score 3-5) and high burden (score 6-7)



GGD  
Amsterdam

**Wat denk jij dat het betekent om hiv te hebben?**

De gevolgen van een hiv-infectie zijn door medische ontwikkelingen sterk veranderd. Is jouw mening over hiv ook veranderd? Laat het ons weten via deze korte vragenlijst.

OK

GGD  
Amsterdam

**'Ik schrok van het nieuws dat ik hiv heb, maar het voelde ook als een opluchting.'**

Hoe denk jij over hiv?

[Geef je mening](#)



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HIV





# Results



## ■ Identified burdensome aspects during qualitative phase

- Medicalization of life
- Emotions
- HIV-identity
- Stigma
- Disclosure
- Sexual experiences

} **subsiding versus persistent burden**

## ■ Positive experiences:

- Living more consciously, closer bond with family/friends, not having to use a condom, lower perceived burden of pill taking due to PrEP

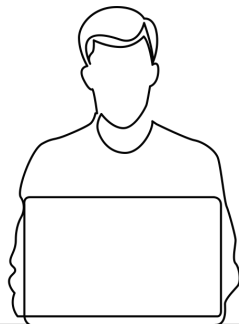


# Results



## ■ Questionnaire data

- 446 HIV-positive MSM
  - Median age 50 [IQR 41-57] years
  - 88% born in the Netherlands
  - 56% college degree or higher
- 
- HIV-related outcomes
    - 98% using ART
    - 98% undetectable HIV VL





# Results



## ■ General burden

- 31% reported living with HIV as burdensome
  - Associated with younger age, not having another chronic condition and not knowing other HIV-positive individuals
- 67% accepted their HIV status
- 74% reported no impact on quality of life
- 82% reported relief if HIV could be cured





# Results



## ■ Medicalization of life

### ■ Subsiding burden

- Initial burden related to medical investigations, hospital visits and pill taking
- Decreased over time, due to trust in health care providers and ART





# Results

## ■ Medicalization of life

### ■ Subsiding burden

- Initial burden related to medical investigations, hospital visits and pill taking
- Decreased over time, due to trust in health care providers and ART



- 59% comfort in regular health checks
- 71% habituated to HIV-related hospital visits
- 71% integrated pill taking in daily routine
- 67% no difficulty remembering pill taking





# Results

## ■ Medicalization of life

### ■ Persistent burden

- Not in control of own health, feeling a “patient”, dependent on pills
- Difficulties with pill taking in presence of others





# Results

## ■ Medicalization of life

### ■ Persistent burden

- Not in control of own health, feeling a “patient”, dependent on pills
- Difficulties with pill taking in presence of others



- 66% relieved if ART was not needed anymore
- 50% relieved if hospital visits would not be needed anymore



# Results

## ■ Disclosure

- Reported to be most burdensome
  - Persistent dilemma of disclosing vs. not disclosing, no win situation
    - If you disclose: (fear of) stigmatization and rejection
    - If you do not disclose: struggle with being dishonest/withholding info
  - Resulting in difficulty initiating sex or engaging in relationships







# Results



## ■ Disclosure

### ■ Reported to be most burdensome

- Persistent dilemma of disclosing vs. not disclosing | no win situation
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- Resulting in difficulty initiating sex or engaging in relationships



↓  
32%

44%



↓  
39%



# Results

## ■ Emotional aspects



- |                            |     |
|----------------------------|-----|
| ■ Anger                    | 14% |
| ■ Sadness                  | 18% |
| ■ Stress                   | 19% |
| ■ Feelings of inferiority  | 16% |
| ■ Loneliness and isolation | 17% |
| ■ Shame                    | 26% |
- 
- Difficulties with lack of knowledge on HIV in society



# Results

## ■ Sexual aspects

### ■ Subsiding burden (when detectable)

- Fear infecting sex partners -> less sex and sexual pleasure



### ■ Persistent burden (when undetectable)

- Persistent fear of infectiousness
- Difficulty initiating sex due to disclosure dilemma and feelings of inferiority



# Results

## ■ Sexual aspects

### ■ Subsiding burden (when detectable)

- Fear infecting sex partners -> less sex and sexual pleasure



### ■ Persistent burden (when undetectable)

- Persistent fear of infectiousness
- Difficulty initiating sex due to disclosure dilemma and feelings of inferiority



- 88% trusted U=U message
- 23% worried about becoming detectable
- 10% feared infecting sex partner



# Conclusion



- **The experienced burden changes over time**
  - After diagnosis, participants struggled with aspects of medicalization of life, emotions and HIV-identity -> this subsided over time due to trust in health care system, ART, U=U and acceptance of being HIV positive
  - Later in time, burden related to stigma, disclosure and sexual experiences emerged and persisted



# Conclusion



- **The experienced burden changes over time**
  - After diagnosis, participants struggled with aspects of medicalization of life, emotions and HIV-identity -> this subsided over time due to trust in health care system, ART, U=U and acceptance of being HIV positive
  - Later in time, burden related to stigma, disclosure and sexual experiences emerged and persisted
- **Recent medical developments lowered the psychosocial burden**
- **However, several burdensome aspects remain and highlight the importance of cure research, stigma reduction and psychosocial guidance/counselling**



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HIV



# H-TEAM acknowledgements



Professor Joep Lange



## Partners



DC Klinieken



MC Slotervaart



Radboudumc



SOAIDS



## Funding support





# Acknowledgements

## GGD Amsterdam

- Hanne Zimmermann
- Udi Davidovich (PI)
- Dieke Martini
- Titia Heijman
- Maarten Bedert

## SOA AIDS Nederland

- Arjan van Bijnen
- Wim Zuilhof

## Hiv Vereniging

- Tomas Derckx

## Amsterdam UMC

- Annouschka Weijnsfeld
- Marc van der Valk

## Noordwest Ziekenhuisgroep Alkmaar

- Frieda van Truijen

## Medisch Centrum Leeuwarden

- Sandra Faber



**SOAIDS**  
Nederland



*All interviewees &  
all questionnaire respondents!*

