

HIV prevention needs after PrEP discontinuation in the Netherlands



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Introduction

Albeit initially being introduced as a temporary form of HIV prevention, during “seasons of risk” (WHO policy brief 2015) PrEP use is currently often promoted without a clear exit strategy and mainly under the auspices of increasing uptake. Furthermore, MSM often prefer non-daily regimes (Elsesser et al. 2016) and can experience longer periods of PrEP non-use.

Reasons for discontinuation are often linked to:

- Side effects
- Financial/insurance hurdles
- Stigma



Additionally, there is evidence that PrEP discontinuation, without a decrease in HIV risk, increases the risk of an HIV infection (Jonas & Yaemim, 2018).

In sum, a needs assessment is necessary to map out the optimal HIV prevention strategies and tailored counseling following temporary and permanent PrEP discontinuation.

How do MSM experience HIV prevention after discontinuation of PrEP?

Methods

- 12 MSM living in the Netherlands that stopped using PrEP were interviewed face-to-face and online. One interviewee was interviewed twice.
- Interviews were content coded.

Post-PrEP HIV prevention: Knowledge – Communication-Choice Model (Jonas & Yaemim, 2018)

- **Knowledge** about all alternative HIV prevention possibilities
- **Communication skills** to address HIV status and prevention options with sex partner(s)
- **Choice behavior**, i.e., the ability to make and maintain informed choices regarding risk practices and sex partners

In particular, information about the potential protection due to PrEP use of sex partners. While this third party-driven strategy is not providing optimal levels of protection, it still offers some levels of vicarious protection, given adequate PrEP adherence/HIV negative status of the PrEP-using sex partner(s).

Furthermore, information about the protection based on the UVL status of PLHIV partners.

Results

Accepting higher HIV risk

Q: ok. So now, while you are not on PrEP. What do you do?

S: at first I was like, no sex at all, cause I am not protected. But now I am not always thinking about it. It kinda went into the background a bit

Q: so you used condoms again?

S: I mean, can't you read? I like it up my ass. I have never used condoms in my life.

Q: I am sorry. I just wanted to explore how you protect yourself against HIV

S: not, mum

S: 21, had to stop with PrEP due to kidney function/use of other nephrotoxic substances

Q: so how would you rate your HIV risk now?

M: High, I guess, but as I said before, I am ok with it. If I am lucky I am not catching it, and if not, so be it. It's like when you are 40 you have 30 more years to live, but I am in my late 50ies now. Imagine I'll catch it with 60 or so. I won't die from that, and I'll be shitting my pants for other reasons till it gets bad.

Q: Do I understand you correctly that you are using no protection now and just take the risk?

M: if you want to put it that way, yes. It does not sound nice. I would say I select my partners wisely.

Insufficient health care provider knowledge

S: No, not at all. Like my doc has no real clue.

S: I m a guinea pig, haha

P: Yes and no. It should be more, but it is difficult. I think this is really a shortcoming. They tell you to stop with PrEP but they don't tell you what to do then.

Q: did you talk to your GP about your prevention after stopping with PrEP, or did he talk to you about it?

M: haha, he put on this stern look and said, M, you know that you have to use condoms again now. And I looked him in the eyes and said, do you really think so?

Condom use and feeling “left out”

Q: Kun je beschrijven wat jouw de beste manier lijkt om mannen die gaan stoppen met PrEP voor te lichten? (vanuit jou ervaring, zijn er dingen die je graag had willen horen)

X: Ik moet eerlijk zeggen dat ik zelf (let op: zelf) geen behoefte heb aan voorlichting over het stoppen. Althans, ik heb geen voorlichting gehad maar zou ook niet weten waarom dit nodig is. Immers, is het mij duidelijk dat je, als je stopt met PrEP, je weer een condoom nodig hebt bij het hebben van seks. Maar dat lijkt mij nogal straight forward

X: 29, intermittent user, stopped due to a new relationship

Q: did you talk to your GP about your prevention after stopping with PrEP, or did he talk to you about it?

M: haha, he put on this stern look and said, M, you know that you have to use condoms again now. And I looked him in the eyes and said, do you really think so?

M: 56, had to stop with PrEP due to kidney function

Q: do you use condoms now?

P: Yes and no. It should be more, but it is difficult. I think this is really a shortcoming. They tell you to stop with PrEP but they don't tell you what to do then.

P: 54, had to stop with PrEP due to kidney function and skin rash

T: no one wanted to have sex with me. This was in Berlin. A guy told me Opa, wennde sex willst musste schon bare machen (Grandfather, if you want to have sex then you have to do it bare)

Q: that is rough. What did you do?

T: I let him fuck me without a condom.

Q: What else did your doctor tell you?

T: Condoms, condoms, condoms. But he just does not understand. I think something went really wrong here. They promoted a drug without thinking about side effects and what to tell people like me. Everybody is just so happy about PrEP. But there are people left behind. I guess this is typical for our society these days. If you don't fit into the mainstream you are left behind.

Q: Can you explain that a bit more, please?

T: The Pharmaindustrie [pharmaceutical industry] wants to sell their products. Do not misunderstand me PrEP is great, but it seems that nobody thought about the few cases that cannot take it. And they do not have a good message for us. Going back to condoms is ridiculous, especially when you did not use them before, or when you stopped using them.

T: 60, discontinued PrEP because side effects (nausea etc.) did not stop

Conclusion

We found that predominantly older MSM are overrepresented in a group individuals that discontinue PrEP for reasons of side effect experience. Financial hurdles are not mentioned often in the Netherlands and in this sample besides by a young MSM with a Global North migration background. Other reasons to stop range from medical indication (risk of nephrotoxic effects), to low subjective HIV risk. Stigma is hardly mentioned.

The main common theme found is the lack of adequate counseling by health care providers and the confrontation with prevention messages that do not fit their prevention needs („use condoms again“).

Respondents also revealed a striking acceptance of a higher HIV risk post PrEP use.

Some individuals also expressed pharmaceutical conspiracy given a lack of alternatives.

Health care providers need to improve their post PrEP counseling offers and also make (beginning) PrEP users aware of the possibility of a discontinuation. Counseling models like the KCC approach (Jonas & Yaemim, 2018) can facilitate transition phases.