The influence of HIV-related stigma on PrEP disclosure and adherence over time among AGYW in HPTN 082

HPTN 082/HERS

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PrEP as HIV prevention for AGYW

• Daily oral PrEP is effective when taken with high adherence
• Open-label and demonstration projects have found that women want oral PrEP but have trouble sustaining PrEP use over time
  – Undermines public health impact of PrEP

Van Damme 2012, van der Straten 2014, Bekekr 2018, Gill 2018
Stigma as a potential barrier to PrEP use

Types of stigma:
- Anticipated
- Experienced
- Internalized
Qualitative questions

• How is stigma **described** and **experienced** among AGYW using PrEP in South Africa and Zimbabwe?
  – How is stigma related to **disclosure** about PrEP and PrEP **adherence**?
  – Do stigma experiences **change over time**?
### Study sample

<table>
<thead>
<tr>
<th>HPTN 082/HERS (PIs: Celum, Delany-Moretiwe)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design:</strong></td>
</tr>
<tr>
<td><strong>Years:</strong></td>
</tr>
<tr>
<td><strong>Location:</strong></td>
</tr>
<tr>
<td><strong>Population:</strong></td>
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<tr>
<td><strong>Study aim:</strong></td>
</tr>
</tbody>
</table>

Celum  
Delany-Moretiwe
Methods

- **Serial in-depth interviews** (n=67 women)
  - After Weeks 13 and 26
  - Barriers to adherence, product disclosure, HIV risk perceptions, perceived stigma

- **Constant comparative** method
  - Thematic analysis: Coding, analytic memos, diagramming
  - Case-based analysis: Matrix approach
  - Differences by site and demographics

Qualitative coding workshop, Johannesburg
Description of the HPTN 082/HERS sample

• 95% accepted PrEP at enrollment
• 49% reported at least one IPV experience in past year
• High rates of STIs and elevated HIV risk score (VOICE score)
• Four key themes
Stigma related to sexual behavior and HIV:

- "Guys take it that you are this whore, you are sleeping around that is why you are going to protect yourself…My ex-boyfriend was saying I am a whore, why am I taking PrEP?" Zimbabwe, age 24, 1st interview

- "The thing is, you see this bottle that they give us, it’s the same bottle as those of ARVs, some people will think that you are lying, she is taking the AIDS pills, you see. So I also feel bad that eish and it’s not easy to prove for a person.” Johannesburg, age 25, 1st interview
Theme 2: Stigma as a barrier to disclosure and PrEP use

Theme 1: HIV-related and sexual stigma

Anticipated stigma
- Fear
- Shame

Experienced stigma
- Name calling
- Loss of friends
- Loss of partners
- Eviction

Theme 2

PrEP use disclosure and community knowledge about PrEP use
- Accidental
- Intentional

PrEP use
- Pill storage
- Daily dosing
- Traveling with PrEP
- PrEP stops
Theme 2: Stigma as a barrier to disclosure and PrEP use

• Bidirectional relationship between stigma and disclosure
  – Anticipated stigma prevented participants from disclosing and resulted them in delaying disclosure, refusing PrEP, or not traveling with their PrEP
  – Intentional/unintentional disclosure related to experiencing stigma

• Impact of stigma and related disclosure issues on participants’ lives, relationships, and ability to use PrEP early on:

  “When I started taking pills for the first time, I stopped taking them. When I had taken them for some time, my [PrEP bottle] was seen by others and I was laughed at by others in the community… I felt quite low. I came and told the staff, ‘I want to stop’.” Zimbabwe participant, age 23, 1st interview

  “If I were to tell him that I’m using PrEP; he would not understand. He would shout. He would swear at me and say that I have AIDS and you are taking these pills and so on. So that is why I chose not to tell him and just leave take the pills in secret.” Cape Town participant, age 18, 1st interview
Theme 3: Disclosure to combat stigma

- PrEP use disclosure and community knowledge about PrEP use
  - Accidental
  - Intentional

- PrEP use
  - Pill storage
  - Daily dosing
  - Traveling with PrEP
  - PrEP stops

- Theme 2

- Theme 3

- Theme 1: HIV-related and sexual stigma
  - Anticipated stigma
    - Fear
    - Shame
  - Experienced stigma
    - Name calling
    - Loss of friends
    - Loss of partners
    - Eviction
Theme 3: Disclosure to combat stigma

- Disclosure allowed some participants to get ahead of rumors and explain PrEP before people they lived with found out:
  - “I told him that we were now being given pills in the program because it would have been tricky if he were to see the pill container and then ask me what that was. It was better for me to tell him first.” Zimbabwe, age 23, 2nd interview
  - Language around PrEP and justification to use differed by site
- Proactive discussions of PrEP in communities (“PrEP ambassadors”):
  - “I want to be the change. I want to announce it (PrEP) so that many people can know about it and feel there’s a need for them to take PrEP.” Cape Town, age 22, 2nd interview
- Disclosure changed community levels of stigma around PrEP
Theme 4: Opportunities for intervention

Interview 1

- Accidental PrEP disclosure
- Experiences of HIV-related and sexual stigma related to PrEP use
- Break-ups with partners
- Fears of not finding another partner
- Eviction
- Loss of friends and community status
- Discrimination

Interview 2

- Increased community understanding and knowledge about PrEP
- Confidence in skills around disclosure
- Confidence in skills around hiding product use or taking PrEP discreetly
- Increased self-efficacy to use PrEP
- Supportive others in the community, study clinic, and study participant population

HPTN 082 activities: Adherence clubs, outreach, educational materials

National activities: PrEP roll-out campaigns
“At adherence clubs, we meet, share our experiences, get ideas. If I share that I was laughed at by people saying I have AIDS, someone will say, ‘No, being laughed at is common, just ignore it’ you see. We are giving each other advice. When you are home you will still be in pain that people laughed at you and can actually think of stopping the pill. But you hear someone encouraging you…there are many who testified that they were also being laughed at. Ignore what other people say.” Zimbabwe, age 23, 2\textsuperscript{nd} interview
Theme 4: Opportunities for intervention

- Educational conversations with staff
- Community outreach campaigns

“The young men in our community were prohibited [from asking her out] and would be told, “Brother you will die for nothing. We saw her pill bottle dropping here.” So, you will just feel ah--., as an individual you will just get hurt even if you know that you do not have the disease [HIV]. It’s just painful.”

Harare participant

Interview 1
Summary

• High PrEP uptake and desires for PrEP
• Sexual and HIV stigma around PrEP use:
  – Stigma was a barrier to disclosure and PrEP use particularly early on
• Disclosure became a powerful way to combat stigma over time
• There remains a need for social support and community outreach intervention approaches to empower women around disclosure, PrEP use, and coping with stigma
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