Stigma, non-disclosure/denial and pill burden: the tri-factor challenge for ART adherence in adolescents and young people living with HIV (AYPLHIV)

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• ART has changed the course of the HIV epidemic and has saved millions of lives.

• Adherence is the strongest predictor of treatment success.

• Understanding ART adherence barriers can improve treatment programmes for clients living with HIV.

• This is even more important when considering AYPLHIV, which is the only age group experiencing increased HIV related mortality and morbidity.
What makes it difficult for AYPLHIV to adhere to ART?
Methods

- Qualitative data was collected.
- Thematic coding used to identify central themes.

Cross-sectional survey

- 42 Peer Supporters
- 30 Health Providers
- 11 sub-Saharan Africa countries
Participant Demographics: Peer supporters (n=42)

Gender
- Female: 61%
- Male: 39%

Country of origin
- East Africa: 50%
- Southern Africa: 45%
- West-Central Africa: 5%
Results

Participant Demographics: Health providers (n=30)

Gender:
- 60% Female
- 40% Male

Profession:
- 59% Doctor
- 31% Nurse
- 10% Counsellor

Country of origin:
- East Africa: 58%
- Southern Africa: 35%
- West-Central Africa: 6%
Common factors affecting ART adherence
## Results

Health provider and peer supporter top barriers to ART adherence

<table>
<thead>
<tr>
<th>ART barriers</th>
<th>Health providers</th>
<th>Peer supporters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma</td>
<td>50%</td>
<td>60%</td>
</tr>
<tr>
<td>Non-disclosure</td>
<td>37%</td>
<td>19%</td>
</tr>
<tr>
<td>Pill burden</td>
<td>43%</td>
<td>17%</td>
</tr>
<tr>
<td>Denial of status</td>
<td>7%</td>
<td>14%</td>
</tr>
</tbody>
</table>
## ART adherence barriers as reported by health providers

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma</td>
<td>50%</td>
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<tr>
<td>Pill burden</td>
<td>43%</td>
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<td>Non-disclosure</td>
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<td>Peer pressure</td>
<td>17%</td>
</tr>
<tr>
<td>Time</td>
<td>13%</td>
</tr>
<tr>
<td>Poor nutrition</td>
<td>7%</td>
</tr>
<tr>
<td>Denial of status</td>
<td>7%</td>
</tr>
<tr>
<td>Lack of knowledge</td>
<td>7%</td>
</tr>
<tr>
<td>Lack of support</td>
<td>3%</td>
</tr>
<tr>
<td>Side effects</td>
<td>3%</td>
</tr>
<tr>
<td>Fear</td>
<td>1%</td>
</tr>
</tbody>
</table>
ART adherence barriers as reported by peer supporters

- Stigma: 60%
- Non-disclosure: 19%
- Pill burden: 17%
- Denial of status: 14%
- Time: 12%
- Lack of support: 12%
- Fear: 10%
- Peer Pressure: 7%
- Poor nutrition: 7%
- Lack of knowledge: 5%
- Cultural beliefs: 5%
- Side effects: 2%
- Religious beliefs: 2%
- Transport costs to the facility: 2%
• Treatment adherence is not just about taking a tablet.
• The different factors influencing adherence to ART are complex and dynamic.
• Multiple holistic interventions are needed at a social, systematic and individual level.
• Interventions from a health facility or a community level need to take into account the PSS support and mental wellbeing of adolescents and young people.
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