People Living with HIV Stigma Index 2.0: Stigma and Discrimination Experienced by People Living with HIV in Portugal

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CENETO ANTI-DISCRIMINAÇÃO VIH E SIDA

CAD

Training and Awareness

Advocacy

Documentation centre

Legal support

Research

GAT

Grupo de Ativistas em Tratamentos

Membro da Coligação Internacional Sida
Internacional Project

- Implemented in more than 100 countries
- Standardized tool
- Measure stigma and discrimination experienced by PLHIV and advocate for the promotion of their rights
- Developed and applied by PLHIV

In Portugal....

- Implemented in 2013 and 2021/22
- 1095 questionnaires
- Collected in:
  - 15 hospitals
  - 18 Civil Society Org.
  - Snowball
- Oct. 2021 to March 2022
Sample

- Ratio Men / Women of 1.6
- Half over 50 years old
- 60% live with HIV for more than 10 years
- 40% concluded primary School and 36% secondary school
- 39% have full-time job; 33% are unemployed
- 73% belong to (at least) one key or vulnerable population

Gender
- n=1083
- CIS Women: 38%
- CIS Men: 60%
- Trans: 2%

Age
- n=1095
- 20-24: 49%
- 25-29: 17%
- 30-39: 29%
- 40-49: 4%
- 50+: 1%

Key/Vulnerable Population

- PWUD: 37.0%
- MSM: 24.5%
- Migrants: 21.9%
- SW: 16.2%
- Trans people: 2.4%
### Internalized Stigma & Self-Discrimination

- **90%** identify some form of internalized stigma
- **More in Mig (95%) and SW (92%), and Women**

- **30%** report at least one self discrimination behaviour in last 12M
- **More in SW and Trans (40%), and Women (34%)**

#### Internalized Stigma

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I hide that I have HIV</td>
<td>81.4%</td>
</tr>
<tr>
<td>I feel worthless because I have HIV</td>
<td>15.5%</td>
</tr>
<tr>
<td>I feel shame for having HIV</td>
<td>27.2%</td>
</tr>
<tr>
<td>I feel guilty about having HIV</td>
<td>30.5%</td>
</tr>
<tr>
<td>Having HIV makes me feel &quot;dirty&quot;</td>
<td>15.7%</td>
</tr>
<tr>
<td>It’s hard to say I have HIV</td>
<td>82.1%</td>
</tr>
</tbody>
</table>

#### Self-Discrimination, last 12M

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decided not to have sex</td>
<td>16.8%</td>
</tr>
<tr>
<td>Have isolated myself from my family/friends</td>
<td>14.8%</td>
</tr>
<tr>
<td>Decided not to seek social support</td>
<td>5.1%</td>
</tr>
<tr>
<td>Decided not to apply for a job</td>
<td>8.1%</td>
</tr>
<tr>
<td>Avoided going to health services</td>
<td>8.0%</td>
</tr>
<tr>
<td>Decided not to attend events</td>
<td>8.7%</td>
</tr>
</tbody>
</table>
38% had some S&D experience (8.5% in last 12M)

More in vuln. pop (42%), (specially SW, Trans and PWUD), that in general pop. (27%), and in Women (40%)

9% experienced structural S&D, namely the denial of health/life insurance (7%)

15% suffered some violation of their rights, namely non voluntary discloser

81% didn’t adopt any action
### S&D in Health Services related to HIV, last 12M

<table>
<thead>
<tr>
<th>Event</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoided physical contact/extreme precautions</td>
<td>5.9%</td>
</tr>
<tr>
<td>Advised against sexual intercourse</td>
<td>4.2%</td>
</tr>
<tr>
<td>Revealed HIV status without consent</td>
<td>3.8%</td>
</tr>
<tr>
<td>Made negative comments</td>
<td>3.3%</td>
</tr>
<tr>
<td>Verbally assaulted</td>
<td>2.5%</td>
</tr>
<tr>
<td>Refused to provide health services</td>
<td>2.0%</td>
</tr>
<tr>
<td>Physically assaulted</td>
<td>0.6%</td>
</tr>
</tbody>
</table>

**N=1084**

### S&D in Health Services not related to HIV, last 12M

<table>
<thead>
<tr>
<th>Event</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avoided physical contact / extreme caution</td>
<td>10.9%</td>
</tr>
<tr>
<td>Made negative comments</td>
<td>5.0%</td>
</tr>
<tr>
<td>Revealed HIV status without consent</td>
<td>4.1%</td>
</tr>
<tr>
<td>Verbally assaulted</td>
<td>3.8%</td>
</tr>
<tr>
<td>Advised against sexual intercourse</td>
<td>3.6%</td>
</tr>
<tr>
<td>Refused health services</td>
<td>2.1%</td>
</tr>
<tr>
<td>Refused dental treatment</td>
<td>2.0%</td>
</tr>
<tr>
<td>Physically assaulted</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

**N=560**

### S&D in Health Services

- **30%** were tested without their knowledge
- **33%** avoided care for HIV, and **15%** missed ART in last 12M, for fear someone discover HIV status.
- **22%** report some form of S&D in last 12M, by HCP
- More in SW (41%) and PWUD (28%), and Women (34%)
- Less frequent in HIV Health services (11%), that other (16%)
- **9.5%** say confidentiality is not assured
- **4%** were advised not to have children, in last 12M
- **9%** of women were advised to interrupt pregnancy
Conclusions

- Internalized Stigma (90%) and Self-Discrimination (30%) are still very high in Portugal.
- Social S&D (38%) and structural discrimination (9%) persists.
- S&D are higher in Healthcare Services (22% last 12M).
- People belonging to key / vulnerable populations and women experience more S&D.
- PLHIV show little knowledge about their rights and action to defend them.
- Big limitations to compare data from 2013 and 2021/22.
From 2013 to 2021/22...

**Improved**
- Guilt and Shame
- Self-discrimination
- S&D in Workplace
- S&D in Health services

**Same or worse**
- Decision not to have sex
- Social S&D
- Test without consent
- Confidentiality of medical records
- Taking action

- ✓ Improve laws and regulations
- ✓ Disseminate knowledge and change behaviours
- ✓ Empower PLHIV
Thank You!