Treatment Refusal in South Africa in an Era of Expanded ART Availability

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* Joint Senior Authorship
Disclosure

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Adult HIV prevalence (15–49 years), 2013
By WHO region

Prevalence (%) by WHO region

- Western Pacific: 0.1 [0.1–0.1]
- Eastern Mediterranean: 0.1 [0.1–0.1]
- Americas: 0.5 [0.4–0.6]
- South-East Asia: 0.3 [0.3–0.4]
- Europe: 0.4 [0.3–0.4]
- Africa: 4.5 [4.2–4.7]

Global prevalence: 0.8% [0.7–0.8]
ART Coverage in Sub-Saharan African Countries, 2010

Adults Presenting For VCT In Soweto

Total Adults Presenting for VCT: 7287

- HIV Infected: 2562 (35%)
- HIV Negative: 4725 (65%)

ART Ineligible: 743 (29%)

Initiated ART: 595 (80%)
- Refused ART: 148 (20%)

Reasons for Refusal:
- Feeling Healthy: 38%
- Unable to Disclose: 23%
- Side Effects: 17%
- Unable to Adhere: 11%
- Cultural Beliefs: 10%
- Stigma: 1%

Katz IT et al, AIDS, 2011
Perceived Risks

Losing health or beauty
Stigma
Financial burdens

Protective Factors

Life-saving

Social Support

Katz IT et al, AIDS Behav, 2015
Research Objective

- **Primary**: To determine the rate of ART refusal at the point of testing in the current era of expanded ART eligibility in South Africa

- **Secondary**: Identify correlates associated with ART refusal

- **Hypothesis** – Social factors would be more important drivers of ART decision-making than structural factors in an urban population
Study Sites:
Soweto & Gugulethu
Design

- **Design: Cross-sectional survey**
- Administered a survey with detailed psychosocial measures to individuals presenting for CD4 results
Analyses

• Bivariate analyses were performed to identify patient factors associated with ART refusal based upon our prior research
  • Covariates with p<0.1 were included in the multivariable model

• Primary Outcome:
  • ART refusal
Participants

• 400 ART-eligible adults presenting for VCT between July, 2014 – May, 2015
  • 200 participants at each site

• ART Eligibility: South African guidelines
  • CD4 < 350 cells/mm$^3$ before Jan 1, 2015
  • CD4 < 500 cells/mm$^3$ after Jan 1, 2015

• Excluded: pregnant women, children < 18 yrs
Predictor Variables

- Socio-demographic characteristics
- Structural barriers to HIV care
- Mental health, stress and coping
- Self-assessment of health and quality of life
- Sexual and substance use risk factors
- Social support
- Stigma
- Knowledge, attitudes and beliefs
## Participant Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total n = 400</th>
<th>Soweto n = 200</th>
<th>Gugulethu n = 200</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median Age</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>0.37</td>
</tr>
<tr>
<td>Female</td>
<td>63 %</td>
<td>58 %</td>
<td>68 %</td>
<td>0.05</td>
</tr>
<tr>
<td>Median CD4</td>
<td>238</td>
<td>205</td>
<td>266</td>
<td>0.0003</td>
</tr>
<tr>
<td>Unemployed</td>
<td>58 %</td>
<td>60 %</td>
<td>56 %</td>
<td>0.36</td>
</tr>
<tr>
<td>Repeat testers</td>
<td>67%</td>
<td>68%</td>
<td>66%</td>
<td>0.75</td>
</tr>
<tr>
<td>Repeat testers with a prior positive test</td>
<td>60%</td>
<td>68%</td>
<td>52%</td>
<td>0.002</td>
</tr>
</tbody>
</table>
Baseline Rate of ART Refusal

- 7% refusal rate at point of learning ART-eligibility
- Soweto: 10%
- Gugulethu: 4%
## Fatalism was Significantly Associated ART Refusal

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unadjusted</th>
<th></th>
<th></th>
<th>Adjusted</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Odds Ratio</td>
<td>95%CI</td>
<td>Odds Ratio</td>
<td>95%CI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td>1.19</td>
<td>0.99 – 1.44</td>
<td>1.09</td>
<td>0.87 – 1.37</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td>1.28</td>
<td>1.04 – 1.58</td>
<td>1.16</td>
<td>0.93 – 1.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatalism</td>
<td>1.16</td>
<td>1.02 – 1.32</td>
<td>1.21</td>
<td>1.04 – 1.40</td>
<td></td>
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</table>
Social Support Moderates Fatalism

<table>
<thead>
<tr>
<th>Variable</th>
<th>Low Social Support (n=28)</th>
<th></th>
<th></th>
<th>High Social Support (n=370)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AOR</td>
<td>p-value</td>
<td>AOR</td>
<td>p-value</td>
<td>AOR</td>
</tr>
<tr>
<td>≥ High school education</td>
<td>1.48</td>
<td>0.64</td>
<td>0.40</td>
<td>0.22</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>1.07</td>
<td>0.92</td>
<td>1.04</td>
<td>0.94</td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td>1.37</td>
<td>0.09</td>
<td>1.24</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Fatalism</td>
<td>1.49</td>
<td>0.01</td>
<td>1.12</td>
<td>0.15</td>
<td></td>
</tr>
</tbody>
</table>
Implications

- Fatalistic world view associated with ART refusal
- Social support modifies the effect of fatalism on ART refusal
- Potential interventions:
  - Cognitive behavioral therapy or Motivational Interviewing
  - Increased social support
Follow-up Study

- Rates of ART refusal lower than expected
- Retrospective study to evaluate pre-ART losses between HIV testing and return for CD4 results
- Reviewed intake forms for all ART-eligible individuals who presented for testing but failed to return for CD4
Pre-ART Losses

881 ART Eligible Adults

270 (31%) Lost After HIV Testing

Soweto: 54%
Gugulethu: 20%

611 (69%) Present for CD4 Testing

Soweto: 10%
Gugulethu: 4%

43 (7%) Refused ART Upon Learning CD4

568 Initiate ART

Attrition: > 35% lost before starting ART

Median CD4: 274 cells/mm³
Impact of our findings on the continuum of decision making

65% repeat testers --> Aware of Status

- Sustained Refuser: Data Pending 2016
- False Accepter: Up to 30% Losses
- Initial Refuser: Up to 7% Losses
- True Accepter: <65% of testers
Limitations

• Self reported ART initiation
  • NHLS data pending

• Longitudinal data pending

• Limited data in our retrospective analysis
  • Unable to fully characterize how this sample differs from refusers on key psychosocial factors
Conclusion: A Cascade of Losses

- > 2/3 of individuals presenting for testing are repeat testers; 60% report prior positive test
- >30% of individuals who test positive for HIV are lost after testing
- 7% refuse to initiate ART at the point of learning they were eligible for treatment
Future Directions

• Further characterize patients at each point of loss in pre-ART care continuum in order to design effective interventions to promote uptake of ART

• Understand how forces such as fatalism may be influencing decision-making and how to optimize social support in this population
Acknowledgements

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To the patients who share their lives and choices with us