Psychosocial Barriers to HIV Care in Kampala, Uganda

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Outline

• Background
• Methods
• Results
• Further Work
• Conclusions
• Acknowledgements
Background

-HIV treatment has been successfully rolled out in sub-Saharan Africa
-20-25% of patients still present with advanced HIV disease
Background

• Late Presenters with HIV
  – Higher Mortality Rates
  – Higher Morbidity
  – Incur higher medical costs
  – Lower Life expectancies

• People continue to present late
  – Delayed diagnosis
  – Loss to Follow up
Background

• In Uganda - some causes known
  – Care outside of medical facility
  – Male gender
  – Unmarried

• Other Causes Uninvestigated
  – Psychosocial causes in particular
Design

• Primary objective:

Evaluate **psychosocial factors** which affect the **timing of presentation** to HIV care
-both early and late presenters
-factors important for the rollout of test-and-treat

using both in-depth interviews and surveys in a mixed methods study.
Semi-Structured In-Depth Interviews

• Health Care Workers (HCW) at the same HIV clinics as the patients
• People Living with HIV (PLWH)
  – 1) antiretroviral therapy (ART) “defaulters”
  – 2) ART naïve CD4 count<100 cells/uL “late presenters”
  – 3) ART naïve CD4 count>350cells/uL “early presenters”
Sampling

- Point person at each clinic
- Purposeful Sampling of People recently enrolled into clinic (in last 3 months)
- Sampled according to CD4 count
- 20 participants in each category
  - Healthcare workers
  - Early Presenters
  - Late Presenters
  - Defaulters
Semi-Structured In-depth Interviews

- Interview topics included:
  a) barriers for HIV care
  b) facilitating factors
  c) mental illness
  d) drugs and alcohol
  e) stigma
  f) social support
Analysis

- Theme Content Approach
Results

• Between May and August 2017
• At 5 HIV clinics (IDI and 4 KCCA clinics, Kisenyi, Kawaala, Kitebi, Komamboga)
• 21 HCW were interviewed
• 58 PLWH were interviewed
  – 24 Early Presenters
  – 19 Late Presenters
  – 15 defaulters
Note

• Universal Test and Treat was Rolled out during this time
• In beginning of study some HCW at IDI could not explain and by then end most patients at KCCA clinics could explain Universal Test and Treat
Results

• Healthcare Workers
  – stigma as the primary barrier for HIV testing and care.
  – Denial of diagnosis
  – time-consuming clinic appointments
  – lack of transport funds were other barriers
Results

• Healthcare Workers
  – Alcohol abuse contributed to men not engaging in care
  – Fear of abandonment or domestic abuse contributed in women
  – Barriers around clinics being inefficient and lacking privacy were also themes
### Demographics of Patients

<table>
<thead>
<tr>
<th></th>
<th>Overall</th>
<th>Late Presenters</th>
<th>Early Presenters</th>
<th>Defaulters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>33</td>
<td>11</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>Female</td>
<td>25</td>
<td>13</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Age, Median(range)</td>
<td>32 (20-55)</td>
<td>32 (23-55)</td>
<td>27.5 (22-50)</td>
<td>36 (20-50)</td>
</tr>
</tbody>
</table>
Results

• Late presenters
  – Stigma a major theme
  – Nearly all waited until they were ill/symptomatic.
  – Many had been diagnosed previously
  – A major theme among men and some women was alcohol abuse
  – Several women reported fearing being thrown out of house by their husbands
Late Presenter

- Okay you told me before coming to ART you were in denial how long did that take?
- “It was a year back I wasn’t believing the results and I was scared to tell my husband and how to start the medication that year. I was always getting sick so when I came here they tested me and gave me the medicine immediately and they advised me to take it as soon as possible before I start losing weight and getting sick of other infections because my CD4 was so low so I had to start.”

-28 year old female
Results

• Early Presenters
  – Stigma less strong
  – Incidental HIV testing during febrile illness
  – After a partner develops AIDS or partners are non-monogamous
  – Many noted a friend/family member who encouraged them to engage in care
  – A few tested for HIV to check on the status of their health
Early Presenter

• *Tell me how you came to be diagnosed with HIV?*
• “As I had told you before I came to be diagnosed with HIV after knowing that my wife was cheating on me with other men I came to the hospital to know my status because I was feeling insecure with my health so when I tested I was diagnosed with HIV.”

-42 year old Male
Results

- **Defaulters** reasons for not engaging in care:
  - Denial of diagnosis, stigma, and/or alcohol use
  - Lost ART card

- Most had a major life event, which interrupted their care
  - Unexpected travel, incarceration, or neighboring country civil wars.
Defaulters

• *Now have you ever defaulted on taking drugs and for what length of time and what reasons did you default?*

• “I missed out on drugs not deliberately but because of challenges. This happened for one year. I missed out because I had lost my card and also lack of transport and on coming I was told by the counselor to go and find some one bigger than me to come and stand in as a reference for me. I failed to get some one and having been bounced for several times by the health workers at the hospital, I got fed up. I decided to go and do without, I was determined for any situation that would come. Later after one year, I was called by a health worker called Julius to come and we agree on the way forward. So I came back.”

-27 year old Female
Domestic Violence and HIV

- Togo study: those with HIV were more likely to have experienced domestic violence
- Prevalence of lifetime physical and sexual violence among HIV-infected women vs. uninfected (63.1 vs. 39.3%, p<0.01 and 69.7 vs. 35.3%, p<0.01, respectively).
- Not found in Zambian Study
Domestic Violence

• Unexplored as cause for late presentation for HIV care

• Added quantitative questions to my survey
Mental Illness

- Not Major Theme
- Not Conceptualized in Biomedical Model
Conclusions

- Interventions to:
  - Reduce stigma
  - Reduce alcohol abuse
  - Educate the community, ART myths, etc
  - Screen for and reduce domestic violence
  - Decentralize care
  - Contact tracing and partner disclosure helpful
Conclusions

• Improving clinic efficiency and privacy would be useful.
• Strong Evidence for Point-of-Care HIV testing (for anyone in a healthcare facility)
• Encouraging healthy individuals to have periodic HIV tests would likely help reduce late presentation of HIV.
Limitations

• Only in Kampala so limited generalizability
• More work to be done to assess for mental illness in this context
Next Steps

• This is a 2 part study
• Quantitative Questionnaire will be completed
  – Measure Depression
  – Measure Internalized and Externalized Stigma
  – Measure Social Support
  – Ask question related to the timing of presentation
Next Steps

• 88-103 Early Presenters and Late Presenters will be recruited
• Hope to complete study by end of 2018
  – Caveat that those with CD4 <100 hard to find
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Questions?

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References


References


References


