

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 > 350 cells/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

	Overall	Late Presenters	Early Presenters	Defaulters
Male	33	11	10	12
Female	25	13	9	3
Age, Median(range)	32 (20-55)	32 (23-55)	27.5 (22-50)	36 (20-50)



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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