

# Barriers to Care among People Living with HIV in South Africa: Contrasts between Patient and Healthcare Provider Perspectives



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# HIV in South Africa



- ~5.6 million (11% of population) living with HIV
- Only 1.79 million receiving antiretroviral treatment (ART) in 2011
- Half of newly-diagnosed patients fail to obtain CD4 count results promptly after diagnosis
- Most deaths occur before patients start ART

(UNAIDS, 2011; Johnson, 2012; Losina et al., 2010; Fairall et al., 2008)



# Research Goals



- To use qualitative methods to identify barriers to and facilitators of linkage to care among people with HIV who had not yet initiated ART in Durban, KwaZulu-Natal, South Africa



# Methods: Study Setting



- Jan-March 2010 at McCord Hospital (semi-private)
- HIV prevalence was 48% among people tested in McCord's outpatient testing program in 2007



McCord Hospital  
outpatient department



# Methods: Patient Focus Groups & Interviews



- 8 focus groups, 60-90 min (N=41; 19 men, 22 women)
  - Patients visiting clinic to obtain CD4 count results or ART psychosocial readiness assessments
- 60-min semi-structured interviews (N=10; 5 men, 5 women)
  - Delayed returning for CD4 count results/readiness assessments
- Patient eligibility:
  - Not yet taking ART
  - English or Zulu speaking
  - $\geq 18$  yrs old



# Methods: Provider Interviews



- 60-min semi-structured interviews with McCord healthcare providers (N=11)
  - 5 medical providers (physicians and nurses)
  - 6 social service providers (e.g., counselors)



# Qualitative Protocol: Barriers to Care



- Psychosocial barriers
  - Stigma
  - Lack of support
  - Lack of disclosure
- Tangible barriers
  - Lack of transportation
  - Clinic too busy or not open at convenient times
  - Cost of HIV medical care



# Qualitative Data Analysis



- Preliminary analysis identified themes
- Two coders double-coded themes in 20% of transcripts for inter-coder consistency (all Kappas >0.72)
- Examined and compared themes within and across participant groups





# Results: Psychosocial Barriers



- Providers and patients agreed that stigma was the main barrier to care, but disagreed on patient responsibility for overcoming internal stigma
- Patients discussed issues in the clinic setting related to disclosure and confidentiality



# Results: Psychosocial Barriers



- Internal stigma: denial

It took me a very long time to accept. I felt as if I could not mix with other people. I was the first person to discriminate against myself.

31-year-old Female (Interview)

There's nothing you can do with external stigma, but you can do something with internal stigma...internal comes from not accepting yourself and when you are not accepting yourself, you think that other people are not accepting you too.

Counselor



# Results: Psychosocial Barriers



- External stigma: Involuntary disclosure

This woman came with the child [to the clinic]...After this woman left, the one left behind [says]...‘this child lost her mom and...she’s also taking treatment.’...she’s telling people she doesn’t know...By the time you leave here, your neighbor will be talking about you...

Female patient (Interview)



# Results: Tangible Barriers



- Patients and providers had different perspectives on tangible barriers
  - Patients were concerned about:
    - ✦ Quality of care
    - ✦ Inconvenient clinic hours
    - ✦ Long clinic queues
    - ✦ Not being able to get to appointments
    - ✦ Disrespect from staff
  - Providers felt that tangible barriers were surmountable



# Results: Tangible Barriers



- Transportation and Cost

## Barrier

When I arrived in town, I must get a taxi...[to the hospital]...I do not have food. I only have transport money to get into the hospital. This is the major challenge for many people...they have money to get here, but they do not have money to buy something to eat while they are here.

## Not a barrier

There are numerous taxis...and buses and trains coming from every point. I don't think transportation is a problem...I worked in a rural hospital and people used donkey carts to get to my ARV clinic, so I don't think transportation should be a barrier. It's just a stupid excuse.

Doctor

41-year-old Male Patient (Interview)



# Results: Tangible Barriers



- Patient experience: Queues

## Barrier

Sometimes you sit in a wrong queue because you do not know where to sit. You find that when it is your turn to be seen, they tell you that you are in a wrong queue, and that breaks your heart. Sometimes it breaks your heart in such a way you just decide to go home and tell yourself that you will come back some other time.

44-year-old Female Patient (Interview)

## Not a Barrier

...number one, [getting an appointment is] not a problem. Number two, if you are on treatment...and you do want to see a doctor then you are allowed to make an appointment...if you can't, there are always government [clinics], provincial hospitals, private doctors.

Doctor



# Results: Tangible Barriers



- Patient experience: Staff

Some people get annoyed and stop going to the clinic as they feel that...health care workers talk in a nagging way...It could be better if they can stop scolding at patients...I think the doctors should be more caring.

44-year-old Female Patient (Interview)

There is a lack of communication between the clinic staff and patients...we could be...waiting in the queues and we see staff members passing by...they only say...next patient, or they say you must wait for a few minutes we have a tea break...Sometimes, you wait for a very long time and then you decide to go back home because they are not helping you. And you do not even understand why you did not get help.

Male Patient (Focus Group)



# Discussion



- Patients and providers agreed that HIV stigma is a critical barrier
- Mismatch between patient and healthcare provider perceptions of barriers
  - Providers seemed to minimize or not be aware of patients' concerns
- Limited by small sample in one semi-private clinic in Durban





# Implications for Intervention



- Raise awareness about the effects of HIV on communities, how discrimination is harmful to community fabric
- Target healthcare providers to reduce stigma
- Implement more efficient systems to handle patient flow



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