



# 'Maybe my husband is on ARVs, but I cannot tell him that I am on them': Gendered patterns of HIV disclosure and treatment experience in urban and rural Uganda.

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## INTRODUCTION

Advances in access to HIV/AIDS care and treatment continue to improve the lives of those living with HIV/AIDS around the world. There is urgent need to better understand the range of factors influencing access to care so as to ensure ongoing access across the HIV spectrum.

Research in medical anthropology shows that health care/treatment seeking is a process that unfolds within an intricate web of social, cultural, and economic factors; affecting both individual decisions regarding treatment seeking and outcomes of the treatment seeking process.

With regard to HIV/AIDS, consideration of the context of care seeking should include examination of stigma and perceived consequences of disclosing one's HIV status. As part of an ongoing longitudinal study of the social context of HIV treatment in urban and rural Uganda, we report patterns of disclosure in men and women receiving HIV treatment and the impact of disclosure on treatment seeking.

### STUDY OBJECTIVES:

- To identify and examine treatment seeking practices and barriers to accessing care which influence:
  - initiation of HIV treatment seeking
  - long term adherence to care and treatment.

- To describe and compare these experiences for patients at two sites.

- To contribute to development of recommendations regarding efforts to de-stigmatize HIV treatment seeking.

### BACKGROUND AND RATIONALE:

UNAIDS estimates are that 940 000 [870 000 - 1 000 000] people are HIV infected in Uganda, of which 480 000 [440 000 - 540 000] are women aged 15 and up. Today, AIDS remains the leading cause of adult deaths in Uganda (UNAIDS, 2008).

Given the millions of HIV+ persons in need of HIV medications now and over the long term, it is clear that procurement of more or newer drugs tells only part of the story.

To successfully achieve the goal of universal treatment we must understand who seeks HIV care, when, where, and why they do so.

One factor that is important in HIV care seeking is disclosure of HIV status to social network members who may provide assistance in various forms. Studies have shown that disclosure is affected by perceived or anticipated stigma and that women experience more stigma than men do.

For this reason, examination of gendered patterns of perceived stigma and of disclosure helps to understand treatment seeking patterns.

### METHODS:

This study utilizes semi-structured interviews at baseline, with follow-up scheduled at 6, 12, and 24 months. This presentation reports data from the baseline interviews only.

#### Design:

The study is a longitudinal study of 800 men and women receiving HIV treatment at two sites in Uganda.

#### Study sites:

Urban Uganda, represented by the Joint Clinical Research Centre (JCRC) in Kampala.

Rural Uganda, represented by Mbarara Hospital in Southwestern Uganda.

#### Inclusion criteria:

- 18 years and above
- Attending JCRC and Mbarara hospital for HIV care
- Consent to be interviewed at baseline, 6, 12 & 24 months.

#### Data collection:

##### Semi-structured interviews to measure:

- Demographic data
- Illness history
- Treatment experience and adherence
- Health care seeking decisions
- Disclosure and non-disclosure decisions
- Experienced barriers to access and remaining in care



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## RESULTS

Table 1: Socio-demographic characteristics (N = 816)

Median age in Years (range; SD)	38 (18-65; 8.5)
<b>Marital Status</b>	<b>N (%)</b>
Married	435 (53.3)
Separated or Divorced	114 (14)
Single	80 (9.8)
Widowed	187 (22.9)
<b>Median number of children (range; SD)</b>	<b>3 (0-18; 2.6)</b>
<b>Number of Children</b>	<b>N (%)</b>
No children	72 (8.8)
1 to 3 children	412 (50.5)
4 to 6 children	243 (29.8)
Above 6	89 (10.9)
<b>Median Number Living in Household (range; SD)</b>	<b>5 (1-26; 3.1)</b>
<b>Number Living in Household</b>	<b>N (%)</b>
1 to 3	242 (29.7)
4 to 6	336 (41.2)
> 6	238 (29.2)
<b>Level of Education</b>	
Primary	436 (53.4)
Secondary	277 (33.9)
Tertiary	97 (11.9)
Others	6 (0.7)
<b>Religion</b>	
Catholic	263 (32.2)
Protestant	341 (41.8)
Muslim/Islam	105 (12.9)
Born Again Christian	93 (11.4)
Seventh Day Adventist	10 (1.3)
Orthodox	1 (0.1)
No religion	1 (0.1)
Others	2 (0.2)

### STUDY POPULATION:

440 women and 376 men receiving HIV treatment at JCRC (n=441) and Mbarara hospital (n=375). The participants are described in Table 1 above.

### ILLNESS NARRATIVES:

Participants' illness narratives reveal several cross cutting themes as well as several themes which are gender specific. We examine three of these themes:

#### Theme 1: Experiences of perceived stigma

Women report more frequently than men experiences or fear of social isolation including perceptions of being avoided.

*"... I kept it a secret to my self. I live with my aunt, I know her, she would treat me so badly – torture and would spread the news all over the place."*

Female, Kampala

*".....they distanced themselves from me."*

Female, Kampala

Whereas both men and women reported concern about the impact of discussing their HIV status with others, women's narratives reveal that they felt embarrassed due to their status.

*"...I didn't inform my neighbors because they would laugh at me"*

Female, Kampala

#### Theme 2: Reasons for disclosure of HIV status

There are differences between men and women in likelihood to disclose partly due to the perceived impact of disclosure.

Women who have recently begun treatment are less likely to report disclosing to their partners, families, or friends, primarily in fear of social isolation;

*"....they would discriminate upon me and never use a cup or plate I had used."*

Female, Kampala

*"I fear telling my employer because he can sack me."*

Female, Mbarara

However, among females who reported willingness to disclose, their narratives revealed the motivation to disclose to a confidant being influenced mainly by an intention of accessing social support.

*"So that they can support me when I fall sick."*

Female, Mbarara

*"Because I wanted them to know and be able to get more help from these people."*

Male, Mbarara

But, many women continue to fear decreased social status that they anticipate may result from being HIV positive.

*"...Some people like workmates are so rude and arrogant that they abuse me in front of our customers."*

Female, Kampala

Whereas both men and women have gone out into the community as 'expert clients' to share their experience of living with HIV/AIDS, men overall report less fear of disclosure;

*"I am an outreach specialist and I have used my situation to encourage so many people to test. We have been on radio and television sensitization groups."*

'Expert Client'

From above, there appear to be differences between men and women in perceived stigma. Narratives suggest fewer males than females being ashamed of their status, worried about potential negative impact on their relationships and family life.

### Theme 3: Importance of 'expert clients' in HIV care spectrum

Importantly, a common reason given for having initiated treatment was hearing the personal experiences of "expert clients" or other confidants on ARVs.

*"She was already positive so I knew she would help me get treatment since she was also receiving it."*

Female, Kampala

*"I was told by a friend that there were trial studies and that I would receive free ARVs if I had accepted."*

Female, Kampala

This underscores the importance of patient participation in de-stigmatizing HIV, as a means to encourage HIV infected persons to seek treatment.

### DISCUSSION:

Because the logistics and cost of HIV/AIDS treatment seeking requires socio-economic and social support from partners, other family members, and perhaps even co-workers, fears of disclosure become significant barriers to accessing care.

For women, the barriers to accessing care are more complex than for men, and include the need for support programs;

## CONCLUSIONS

This preliminary analysis demonstrates that gender differences in experiences of perceived stigma, particularly affecting willingness to disclose one's illness, remain a challenge to improved HIV care access.

Women appear to bear a greater burden of stigma than men, and are, therefore, less likely to disclose their status. Fear of disclosure of sero-status remains a bigger barrier to get into treatment and to remain in treatment for women.

HIV prevention and treatment programs should enhance gender equity in access to HIV care by:

- incorporating and encouraging women-friendly disclosure support programs;
- including focused efforts to use "expert clients" to de-stigmatize HIV treatment seeking.

#### Reference:

UNAIDS (2008) *Epidemiological Fact Sheet on HIV and AIDS, 2008*, UNAIDS/WHO/UNICEF, Geneva; accessed July 16, 2009 at: <http://www.unaids.org/en/CountryResponses/Countries/uganda.asp>

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