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Differences in Reasons for Late Presentation to HIV Care in Uganda Among Men and Women

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Abstract

Late presentation to HIV care, i.e., presenting with < 200 CD4 cells/mL, is associated with higher mortality and worse outcomes. Despite that, a quarter of people living with HIV in Uganda still present late to care. We surveyed Ugandans living with HIV who enrolled in clinic ≤ 90 days prior. We compared groups who presented 'late' with CD4 < 200 and 'early' with CD4 > 350, stratifying by sex. We found men who presented late had higher externalized stigma than early presenters. Thirty-six percent of the entire cohort were depressed. Social support was stronger in late presenters versus early, although weak overall. Social support was inversely correlated with depression, with social support dropping as depression increased. Interventions to improve clinic privacy, reduce stigma, improve social support, and help women disclose their HIV status to male partners are needed to reduce late presentation to HIV care.

Keywords HIV care · Late presentation · Sex differences · Universal test and treat · HIV stigma

Introduction

Late presentation to HIV care results in higher mortality rates [1, 2], lower life expectancies [3], and higher medical costs [4]. Nevertheless, people in Sub-Saharan Africa continue to present late to care with advanced HIV for various reasons. These include stigma [5], delayed diagnosis [6], and loss-of-follow-up [7, 8]. As universal test and treat (a policy to start everyone with HIV on antiretroviral therapy to prevent illness and spread to others [9, 10]) has been rolled

out, information targeting high-risk groups such as late presenters are essential for success.

Demographic factors such as male sex, non-pregnant women, age > 30, lack of formal education, and Muslim faith are known associations with delays in HIV care [11–13]. Poor mental health, stigma, and using traditional medicine have been previously described [13–16]; however, interpersonal and intrapersonal factors related to delays in HIV care remain less well known overall.

Prior qualitative work has demonstrated a variety of reasons why individuals present late for HIV care—with stigma, both internalized (shame and expectation of discrimination) and externalized (experiencing unfair treatment) [17], being most salient [18]. Themes surrounding the lack of empowerment of women have also been recognized [19], with many women having cited concerns surrounding stigma and disclosure as reasons why their male partners kept them from seeking/obtaining HIV care. Some women have documented that male partners may become violent, deny transport funding for testing and treating HIV, or throw away their HIV medications. Since routine prenatal HIV testing is standard of care globally [20], many women are diagnosed with HIV early while they are asymptomatic. Prevention of mother-to-child transmission programs reduce

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late presentation to HIV care among women [21, 22], but this reduced late presentation is not seen in their male partners [21].

Psychosocial information specific to men is limited. For example, a mixed-methods study from Malawi found that men were likely to be tested for HIV only after showing physical signs of illness [23]. In the same study, men reported ignoring radio messages and other public health campaigns about HIV and had concerns about appearing weak or being laughed at by friends. Further work to better understand male barriers to HIV care would help their and their potential partners' care.

To further explore these issues, we conducted a quantitative survey as part of a mixed-methods study to explore individual modifiable factors on why people with HIV present late to HIV care in Uganda.

Methods

People living with HIV (PLWH) who recently presented to HIV clinic within the last three months were surveyed using a questionnaire. We grouped participants into two groups: (1) ART naïve CD4 count < 200 cells/μL "late presenters" or (2) ART naïve CD4 count > 350 cells/μL "early presenters." The cutoff for > 350 was selected because the 2009 WHO guideline followed by Uganda had a cutoff of < 350 CD4 as ART start criteria, and also, these participants have relatively less risk and are likely to feel well [24]. We used a convenience sample and enrolled sequentially. A questionnaire collected demographic and social information. We also used several validated tools, including the Patient Health Questionnaire (PHQ-9), previously validated in Uganda [25]. This depression measure has nine questions on a 4-point Likert scale. We further evaluated internalized stigma with the HIV internalized stigma scale, validated in Uganda [26], and used the HIV/AIDS Stigma Instrument, validated in Tanzania [27] and used in Uganda [28], to measure externalized stigma. These tools utilized a 4-point Likert scale with 16 questions from the HIV internalized stigma scale and 14 questions from the HIV/AIDS Stigma Instrument.

Finally, we used the Medical Outcomes Study Social Support Scale, which evaluates emotional, tangible, and affectionate support and positive social interaction [29, 30]. This scale has 19 questions and uses a 5-point Likert scale. All scales can be found in Supplementary Tables 1–3.

Approvals

This study was approved by the Joint Clinical Research Centre (JCRC) Institutional Review Board (IRB), the University of Minnesota IRB, and the Kampala Capital City Authority (KCCA) central office. All participants consented both verbally and in writing. Surveys were performed in the participants' native language of Luganda and entered into the study database by native Luganda speakers.

Data Analysis

Data were collected in the University of Minnesota's version of the database RedCAP or Research Electronic Data Capture [31]. The data were analyzed using Excel (© Microsoft 2018) and SPSS (® IBM 2019). Frequencies and percentages for discrete variables and medians and standard deviations for continuous variables were used to summarize socio-demographics and study outcomes by early or late presentation and sex. Mann–Whitney-U and Chi-square were used for continuous and categorical variables. PHQ-9 had a cutoff for mild depression of 5 and major depression of 10 [32]. We coded the male responses as positive or negative with details described in the Supplemental Material. We compared positive and negative answers (for men encouraging or discouraging their female partner from seeking treatment) with depression, internalized stigma, externalized stigma, and social support using Mann–Whitney-U. Further, we used a linear regression analysis to compare how depression, internalized stigma, externalized stigma, and social support interact. Finally, we wanted to compare social support to other studies in the literature. Following a similar article [33], we transformed our scores to a 0–100 scale, multiplying our values by this formula: $100 \times \left(\frac{Observed\ score - minimum\ possible\ score}{Maximum\ possible\ score - minimum\ possible\ score} \right)$. This transformation allowed us to compare our study to others focused on chronic illness. [33]

Results

Between September 2017 and January 2019, we enrolled 187 participants (88 late presenters and 99 early presenters) from three government clinics in Kampala, the capital of Uganda.

Combined Demographics and Social Factors

We found that women were significantly more likely to be early than late presenters when compared to men (55% vs. 74%, p = 0.006). Late presenters were older than early presenters (median 34 vs. 30 years, p = 0.014). Further, late presenters were less likely to reside in Kampala district (66% vs. 81%, p = 0.021) and lived farther from the clinic (5 versus 3 km p < 0.001) (Table 1). Late presenters were more likely to have only one sexual partner when compared to early presenters (64% vs. 32%, p < 0.001). The frequency

Table 1 Demographics and social factors associated with late presentation to HIV Care, by biological sex

	Overall			Women			Men		
	Late presenter CD4 < 200 N = 88 Median IQR or N %	Early presenter CD4 > 350 N = 99 Median IQR or N %	p	Late presenter CD4 < 200 N = 48 Median IQR or N %	Early presenter CD4 > 350 N = 73 Median IQR or N %	p	Late presenter CD4 < 200 N = 40 Median IQR or N %	Early presenter CD4 > 350 N = 26 Median IQR or N %	p
Women	48 (54.5%)	73 (73.7%)	*0.006*						
Men	40 (45.5%)	26 (26.3%)							
Age	33.5 (8.1)	30.4 (8.6)	*0.014*	30 (27.3–37.8)	27 (23–33.8)	*0.007*	34 (29–40)	34 (28–43)	0.828
Kampala district	58 (65.9%)	80 (80.8%)	*0.021*	33 (68.8%)	59 (80.8%)	0.128	25 (62.5%)	21 (80.8%)	0.115
Married vs other	51 (58%)	45 (45.5%)	0.088	20 (41.7%)	28 (38.4%)	0.716	31 (77.5%)	17 (65.4%)	0.280
Works outside home	53 (60.2%)	54 (54.5%)	0.724	19 (40.4%)	32 (43.8%)	0.870	34 (85%)	22 (84.6%)	0.966
Unemployed or Monthly Income < 100,000 Ugsh (~$30)	35 (39.8%)	36 (36.4%)	0.632	30 (62.5%)	32 (43.8%)	*0.044*	5 (12.5%)	5 (19.2%)	0.304
Distance from clinic median km	5 (2–11.3)	3 (2–4)	*< 0.001*	4.8 (2–9.7)	3 (1.6–4)	*0.002*	6.0 (2.3–12.9)	3.6 (2.0–4.0)	*0.022*
0–1 Lifetime partner (spouse)	57 (64.8%)	32 (32.7%)	*< 0.001*	35 (72.9%)	22 (30.6%)	*< 0.001*	22 (55%)	10 (38.5%)	0.189
Alcohol frequency > 5 drinks a week or former drinker	58 (65.9%)	70 (70.7%)	0.481	38 (79.2%)	53 (72.6%)	0.157	20 (50%)	17 (65.4%)	0.219

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

of alcohol of more than five drinks a month or being a former drinker was similar between early and late presenters (71 versus 66% p = 0.261). Traditional healer or traditional herb use was not significant between groups, with only eight participants (4%) having ever visited a traditional healer and 11 (6%) having used herbs. All participants identified with a religion, with 21% identified as Anglican, 24% Muslim, 19% Pentecostal, and 36% Catholic. There were no differences in religion between those presenting early and late (p = 0.551).

Mental Illness

Next, we asked about mental illness. Previous screening for mental illness was inconsistent per the participants. Only four reported that they were previously diagnosed with depression; no participants had been diagnosed with anxiety, bipolar disorder, mania, or psychosis. Four participants had had a suicide attempt; however, none had ever been diagnosed with depression. Five reported a spouse with a suicide attempt.

Depressive Symptoms, Externalized Stigma, Internalized Stigma, and Social Support

As seen in Table 2, rates of depression in the sample were high, with 31% and 41% of late and early presenters experiencing depression (PHQ-9 score > 9, p = 0.128). Although there was not a significant difference in rates of depression between early and late presenters by sex, women reported higher rates of depression than men overall, with early presenting women having the highest rates of major depression (45%). The median score for internalized stigma was 13 for late presenters and 14 for early presenters (p = 0.459). The median score for externalized stigma was 6.5 for late presenters and 2 for early presenters (p = 0.193). Finally, the median score for social support was 53 for late presenters and 40 for early presenters (p < 0.001). Thus, our social support scores were 51(normalized 42) for late presenters and 45 (normalized 34) for early presenters.

Correlation Between Tools

Next, we ran a linear regression model comparing the four scales for depression, internalized stigma, externalized

Table 2 Sex difference in depressive symptoms, stigma, and social support in those presenting early and late

	Overall			Female			Male		
	Late presenter CD4 < 200 N = 88 Median IQR or N %	Early presenter CD4 > 350 N = 99 Median IQR or N %	p	Late presenter CD4 < 200 N = 48 Median IQR or N %	Early presenter CD4 > 350 N = 73 Median IQR or N %	p	Late presenter CD4 < 200 N = 40 Median IQR or N %	Early presenter CD4 > 350 N = 26 Median IQR or N %	p
Depression PHQ-9	7 (5–10)	7 (3–14)	0.861	7 (5–10)	7 (4–15)	0.473	7 (5–10)	6 (1–13)	0.311
Major depression (PHQ-9 > 9)	27 (31%)	41 (41%)	0.128	16 (33%)	33 (45%)	0.193	11 (28%)	8 (31%)	0.195
Internalized stigma	13 (8–18)	14 (7–19)	0.459	12 (7–16)	15 (8–20)	*0.065*	14 (9–20)	12 (4–17)	0.171
High internalized stigma (> 14)	39 (44%)	55 (56%)	0.125	19 (40%)	44 (60%)	***0.026***	20 (50%)	11 (42%)	0.541
Externalized stigma	6.5 (0–15)	2 (0–16)	0.193	3.5 (0–16.8)	4 (0–18)	0.956	7 (2–13)	0 (0–9)	***0.007***
High externalized stigma (> 3)	50 (57%)	45 (45%)	0.121	24 (50%)	37 (51%)	0.941	26 (65%)	8 (31%)	***0.007***
Social Support Scale	53 (44–59)	40 (33–55)	***< 0.001***	53.5 (47.3–59.8)	39 (32.3–52.8)	***< 0.001***	53 (40–57)	45 (33–60)	0.397
Low social support (< 48)	26 (30%)	66 (67%)	***< 0.001***	12 (25%)	50 (68%)	***< 0.001***	14 (35%)	16 (62%)	***0.034***

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

stigma, and social support. As seen in Table 6, depression was significantly correlated with internalized stigma (Pearson correlation 0.182, p = 0.013) and externalized stigma (Pearson correlation 0.289, p < 0.001) and was inversely correlated with social support (Pearson correlation −0.435, p < 0.001). On the other hand internalized stigma was not significantly associated with externalized stigma or social support, but externalized stigma and social support were significantly inversely correlated (Pearson correlation −0.333, p > 0.001).

Questions About Presenting to Clinic and HIV Testing

Next, we asked questions about why participants decided to present to clinic now and why they were tested for HIV. Late presenters were more likely to be newly HIV-positive (57% vs. 33% p = 0.001) and were less likely to report encouragement from a family member or friend for presenting to clinic than early presenters (10% vs. 22% p = 0.028 for a family member, 3% vs. 14% p = 0.011 for a friend). Late presenters were more likely to report family or a healthcare worker encouraging HIV testing than early presenters (34% vs. 18% p = 0.013 for family, 50% vs. 31% p = 0.009 for a healthcare

worker). Compared to late presenters, early presenters were more likely to delay enrolling in clinic because they did not feel sick (28% vs. 51%, p = 0.002), as depicted in Table 3.

Stratification of Timing of Presentation and Biological Sex

We stratified by sex to see if the reason for the timing of presenting to HIV care was different between men and women. Employment was disparate between sexes, with 1/46 (2%) of men unemployed. In contrast, twenty-nine women (24%) were unemployed, with women who presented late being much more likely to be unemployed compared to those who presented early (18 [37.5%] vs. 11 [15.1%], p = 0.038), with more detail in Table 1.

Next, we compared depression, internalized and externalized stigma, in addition to social support by early and late presentation with sex stratification. Low social support was significantly higher in early presenters than late presenters for women (late 12 [25%] vs. early presenters 50 [68%], p < 0.001) and men (late presenters 14 [35%] vs. early presenters 16 [62%], p = 0.034) (Table 2). We found no difference between depression, internalized stigma, externalized stigma, and social support scales by sex. Women who presented late had significantly

Table 3 Reasons people living with HIV present to clinic by sex

	All			Women			Men		
	Late Presenter CD4 < 200 N = 88 Median IQR or N %	Early Presenter CD4 > 350 N = 99 Median IQR or N %	p	Late CD4 < 200 N = 48 Median IQR or N %	Early CD4 > 350 N = 73 Median IQR or N %	p	Late CD4 < 200 N = 40 Median IQR or N %	Early CD4 > 350 N = 26 Median IQR or N %	p
Why did you come to clinic Now? (check all that apply)									
I just tested positive	50 (56.8%)	33 (33.3%)	*0.001*	28 (58.3%)	23 (31.5%)	*0.003*	22 (55%)	10 (38.5%)	0.189
I was sick	33 (37.5%)	32 (32.3%)	0.458	17 (35.4%)	24 (32.9%)	0.773	16 (40%)	8 (30.8%)	0.446
Family member or friend or acquaintance encouraged me	10 (11.2%)	31 (31.3%)	*0.001*	5 (10.4%)	25 (34.2%)	*0.003*	5 (12.5%)	6 (23.1%)	0.260
Healthcare worker encouraged me	28 (31.8%)	38 (38.4%)	0.348	19 (39.6%)	28 (38.4%)	0.892	9 (22.5%)	10 (38.5%)	0.162
Why did I test for HIV?									
Partner has HIV	30 (34.1%)	38 (38.4%)	0.542	12 (25%)	24 (32.9%)	0.354	18 (45%)	14 (53.8%)	0.482
Media/advertisement	23 (26.1%)	37 (37.4%)	0.100	14 (29.2%)	30 (41.1%)	0.182	9 (22.5%)	7 (26.9%)	0.682
Friend/family encouragement	30 (34.1%)	18 (18.2%)	*0.013*	16 (33.3%)	15 (20.5%)	0.115	14 (35%)	3 (11.5%)	*0.033*
HCW encouragement	44 (50%)	31 (31.3%)	*0.009*	25 (52.1%)	26 (35.6%)	0.073	19 (47.5%)	5 (19.2%)	*0.020*
My child has HIV	3 (3.4%)	12 (12.1%)	*0.029*	2 (4.2%)	11 (15.1%)	0.058	1 (2.5%)	1 (3.8%)	0.755
The doctor tested without asking	3 (3.4%)	9 (9.1%)	0.114	1 (2.1%)	7 (9.6%)	0.104	2 (5%)	2 (7.7%)	0.654
Positive for > 3 months before enrolling in HIV clinic									
Yes	28 (31.8%)	40 (40.4%)	0.290	15 (31.3%)	29 (39.7%)	0.343	13 (44.8%)	11 (42.3%)	0.548
If yes, why?									
Not sick	25 (28.4%)	50 (50.5%)	*0.002*	12 (25%)	37 (50.7%)	*0.005*	13 (32.5%)	13 (50%)	0.155
Afraid Meds would make me sick	3 (3.4%)	11 (11.1%)	*0.046*	0 (0%)	8 (11%)	*0.018*	3 (7.5%)	3 (11.5%)	0.577
Afraid people would find out I had HIV	12 (13.6%)	22 (22.2%)	0.129	6 (12.5%)	18 (24.7%)	0.101	6 (15%)	4 (15.4%)	0.966
No money for transportation	7 (8%)	14 (14.1%)	0.181	6 (12.5%)	13 (17.8%)	0.432	1 (2.5%)	1 (3.8%)	0.755
Someone told me not to go	2 (2.3%)	8 (8.1%)	*0.078*	0 (0%)	5 (6.8%)	*0.064*	2 (5%)	3 (11.5%)	0.327

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

more social support than women who presented early, but men did not have such differences (Table 2). Women who presented late were less likely to have internalized stigma than those who presented early (19 [40%] vs. 44 [60%], p = 0.026). Men who presented late were more likely to have externalized stigma than those who presented early (late presenter 26 [65%] vs. 8 [31%], p = 0.007).

Questions About Timing for Presentation and HIV Testing by Sex

We asked if participants had tested positive for HIV more than three months before coming to clinic. We found that 68 individuals reported they had been positive for more than three months but had not established care, which was not significantly different between early and late presentation or by biological sex (Table 3).

Different Questions by Sex Around Disclosure

A theme in our qualitative research was that the lack of female empowerment was related to late presentation to HIV care. Unfortunately our study was not powered to detect differences in men's and women's answers, but we did collect preliminary data. We asked male participants if they would encourage or discourage their partner from getting HIV care. Less than half (32, 48%) of men recommended their partner seek HIV treatment. Twenty men (30%) said they would encourage their partner to take ART as they need it, while

five (8%) felt they should stop their partner from going to clinic (Table 4).

Next, we coded the male participants' responses as opposing (negative answers) or encouraging (positive responses) their female partners from receiving HIV care. Of the 65 men, 16 (25%) had only negative reactions, 41 (63%) had only positive, and 8 (12%) had both. When we compared any negative response (n = 24) with only positive responses (n = 41), we found higher PHQ-9 was associated with any negative (median PHQ-9 7.5, IQR 0–16) vs. only positive responses (median 6.0, IQR 0–12.5, p = 0.018). Lower social support was significantly associated with any negative response (median 15, IQR 0–31.5) vs. only positive responses (median 36, IQR 22.5–49, p < 0.001). Neither internalized stigma nor externalized stigma was associated with negative or positive responses.

Of the 119 female participants who responded, 25 (21%) reported having ever been injured by a partner. Five (4%) women said their partner had stopped them from attending HIV clinic. Seventeen (14%) reported their partner took their HIV medications away.

We next asked if women had disclosed their HIV status to their partner(s). Of responding women, 58/118 (49%) reported disclosing while 60/118 (51%) denied disclosing (although 49% of these reported being newly diagnosed with HIV). Details of reactions from partners for those who disclosed and did not disclose are in Table 5. Finally, Table 6 compares the four scales for depression, internalized stigma, externalized stigma, and social support.

Table 4 Male specific questions around encouraging or discouraging their female partner to engage in HIV care

	Yes	Late CD4 < 200 N = 40 Median IQR or N %	Early CD4 > 350 N = 26 Median IQR or N %	p
Men only N = 66				
If partner with HIV- Tell them not to go to clinic as someone might think I had HIV	11 (17%)	6 (6.8%)	5 (5.1%)	0.608
Partner with HIV- Stop them from going to clinic as someone might think I had HIV	5 (8%)	2 (2.3%)	3 (3%)	0.749
Partner with HIV- Stop them from taking ART because might disclose me	3 (5%)	2 (2.3%)	1 (1%)	0.493
Partner with HIV- Let them go to clinic but only far away one	11 (17%)	6 (6.8%)	5 (5.1%)	0.608
Partner with HIV- Let them go to clinic but make them pay transport	2 (3%)	2 (2.3%)	0 (0%)	0.132
Partner with HIV- encourage them to go to clinic as soon as possible as they need treatment	32 (48%)	15 (17%)	17 (17.2%)	0.982
Partner with HIV- Encourage them to take ART as they need treatment	20 (30%)	13 (14.8%)	7 (7.1%)	*0.089*
Partner with HIV- would go to clinic with them for support	7 (11%)	5 (5.7%)	2 (2%)	0.188
Would it be different if partner is wife? Yes	14 (7.5%)	9 (10.2%)	5 (5.1%)	0.179
Would it be different if partner is wife? No	54 (28.9%)	32 (36.4%)	22 (22.2%)	***0.033***

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

Table 5 Women specific questions around disclosure

Woman disclosed HIV status to male partner?		Late CD4 < 200 N = 48 Median IQR or N %	Early CD4 > 350 N = 73 Median IQR or N %	p
Yes		19 (39.6%)	39 (53.4%)	0.136
Had disclosed N = 58				
Angry and left me	3 (5.2%)	2 (10.5%)	1 (2.6%)	0.158
Angry and discouraged treatment	6 (10.3%)	0 (0%)	6 (15.4%)	
Angry and encouraged treatment	13 (22.4%)	6 (31.6%)	7 (17.9%)	
Sad but supportive	19 (32.8%)	5 (26.3%)	15 (35.9%)	
No reaction	16 (27.6%)	5 (26.3%)	11 (28.2%)	
Other	1 (1.7%)	1 (5.3%)	0 (0%)	
Had not disclosed N = 60*				
Afraid partner would hurt her	5 (8%)	1 (2.1%)	4 (5.5%)	*0.035*
Afraid partner will stop her from attending clinic	1 (2%)	0 (0%)	1 (1.4%)	
Afraid partner would leave her and had financial concerns	15 (24%)	3 (6.3%)	12 (16.4%)	
Afraid partner would consider her unfaithful	9 (14%)	6 (12.5%)	3 (4.1%)	
Just diagnosed and still thinking	31 (49%)	18 (37.5%)	13 (17.8%)	
Would disclosure assistance help a woman who was newly diagnosed?				
Yes	49 (40.5%)	12 (25%)	37 (50.7%)	*0.011*
Which is true?				
It would be better if someone told my partner that a partner of theirs has HIV	9 (7.4%)	0 (0%)	9 (12.3%)	***< 0.001***
It would be better to disclose alone	64 (52.9%)	36 (75%)	28 (38.4%)	
It would be better to have a doctor help me disclose	20 (16.5%)	7 (14.6%)	13 (17.8%)	
It would be better to have a nurse counselor help me disclose	28 (23.1%)	5 (10.4%)	23 (31.5%)	

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

*Three did not respond

Discussion

We analyzed demographic and psychosocial factors by the timing of presentation to HIV care as well as depression, stigma (both internalized and externalized), and social support in Kampala, Uganda. Our data demonstrated that the reasons people present late to HIV care vary by sex. In addition, we found demographic differences and differences in social support and externalized stigma. For example, rates of depression among all groups were high and social support was low. In addition, we found that less than half of men felt that their partners should seek care as soon as possible, given concerns about disclosing their own possible HIV status to the community. Finally, when we asked women about disclosing their HIV status to their partners, about half had disclosed, and issues surrounding power and fear of or actual strife from partners were essential factors.

Our sample had high rates of depression, with > 30% having major depression (PHQ-9 score > 9). This rate is higher than the general population globally (5%) [34, 35], including those with HIV in Sub-Saharan Africa (26%) [36]. Similarly, the rate of social support in our study population was low. Our mean social support scores were 51 (normalized 42) for late presenters and 45 (normalized 34) for early presenters. A review paper has previously reported a range of mean overall normalized scores of 57–83 among adults worldwide [33]. The authors of this work also documented a mean (non-normalized) score of 62 from U.S. adults living with HIV and who had ART adherence challenges. Thus, our participants had less social support than similar populations and were also more depressed. Additional studies examining the influence of depression and social support in HIV populations in Uganda overall could help determine barriers to care.

Poor social support was previously associated with late presentation to HIV care in Sub-Saharan Africa [14, 37]. Our findings also demonstrated that social support was significantly different between groups, but late presenters had *higher* social support than early presenters, which was an unexpected finding. This difference drove the difference in women who again had higher social support in

Table 6 Correlations between depression, internalized stigma, externalized stigma, and social support

Correlations

		PHQ9 score	Internalized Stigma Score	Externalized Stigma Score	Social Support Scale
PHQ9 score	Pearson Correlation	1	0.182	0.289	− 0.435
	Sig. (2-tailed)		*0.013*	*0.000*	*0.000*
Internalized Stigma Score	Pearson Correlation	0.182	1	0.088	− 0.083
	Sig. (2-tailed)	*0.013*		0.233	0.257
Externalized Stigma Score	Pearson Correlation	0.289	0.088	1	− 0.333
	Sig. (2-tailed)	*0.000*	0.233		*0.000*
Social Support Scale	Pearson Correlation	− 0.435	− 0.083	− 0.333	1
	Sig. (2-tailed)	*0.000*	0.257	*0.000*	

Values in bold italics indicate p < 0.01

Values in italics indicate p < 0.05

late presenters. We considered perhaps there was selection bias as our participants were newly enrolled in clinic. The majority of late presenters had just tested positive (57%), and late presenters were more likely to have a friend or family member encourage their testing (34%) vs. early presenters (18%, Table 3). Perhaps without this social support, the late presenters in our sample would not have presented at all but may have died instead.

High internalized stigma was more common in early presenting women than late presenting women, but not in men in our study. Turan et al. showed that depressive symptoms, loneliness, and low perceived social support mediated the association between internalized stigma and adherence issues in women with HIV [38]. Parcesepe et al. showed that men showed worse function scores and quality of life compared to women [39]. Internalized and externalized stigma as associated with a higher likelihood of poor life satisfaction and function in both men and women.

We found differences in externalized stigma, but only in men. Men who presented late were more likely to have higher externalized stigma than men who presented early. No differences in externalized stigma were seen in women early or late presenters. This discrepancy in externalized stigma between men and women has been seen before in Mozambique, with men showing higher rates of stigma [40]. This consistent finding suggests that interventions focused on addressing men's concerns about externalized stigma could influence the timing of presentation to care.

In evaluating the interactions between depression, stigma, and social support, we found that depression is highly correlated with all. Social support is also strongly correlated with externalized stigma. Our data are not clear on how depression may impact actual vs. perceived stigma and social support. Further studies are needed to evaluate this correlation in more detail; however, this could indicate that treatment of depression would reduce externalized stigma.

When we asked men about their likelihood to be supportive of HIV care for their female partners, about half of men reported that theoretically, women need care. However, only 30% of men would actively encourage their female partners to seek HIV care. In contrast, 8% of men would actively oppose their female partners from attending care because they were concerned others would think they (the male partner) had HIV. Concerns about public shaming and gossip about HIV have been described in multiple other communities and countries [41]. Reducing HIV stigma is paramount in counteracting this.

While many studies have shown HIV stigma negatively impacts health outcomes [42, 43], interventions to reduce stigma have disappointing efficacy [44]. Work to target stigma in the community and among people living with HIV is still needed; however, some of these issues may be targeted with clinic changes. Changes to make clinic more patient-centered and efficient have been advocated for years [45]. Interestingly, the Covid-19 crisis has forced changes to reduce daily clinic volume. Clinics have shifted to calling each patient to check-in, sending drugs in larger quantities for longer durations via motorcycle taxis, scheduling clinic visits (time slots) to reduce clinic volume, and have reduced barriers to transferring clinics or obtaining drugs from patients' non-primary clinic in the event of travel. A byproduct of these changes is increased privacy. If clinics remain more private, HIV clinic could be less stigma-inducing and improve outcomes.

Overall, our data show apparent differences in why men and women present to HIV care. Stigma, depression, and social support were important factors determining when people presented to care. Lack of empowerment among women is a substantial barrier to care due to delays in disclosure between partners after women are commonly diagnosed in antenatal clinic [46]. Interventions targeting externalized stigma would likely mitigate these concerns as men with higher stigma are likely to present later than those with lower stigma. Similarly, women are less likely to disclose their HIV status if they have higher stigma than those with lower levels of stigma. Interventions that increase social support, such as community accompaniment (treatment buddy) [47], starting at HIV testing, may also help reduce late presentation to HIV care. Social support, which is highly correlated with depression and externalized stigma, may improve outcomes overall. Finally, direct interventions that help women disclose their HIV status would likely help both men and women obtain and stay in care.

Limitations

Our data are limited by a relatively small sample size, especially when comparing men and women alone. In addition, articipants were those in care and not those not yet in care. The survey was done in Kampala, Uganda, and it may not generalize to rural areas or other countries.

Conclusions

We evaluated why people who are living with HIV present late to care. We found significant differences between the reasons men and women present late. Social support and stigma are essential in modifying barriers to care. Both men and women expressed that women are frequently blocked from coming to care, which impacts the disclosure of HIV status between partners. Interventions to improve disclosure, reduce stigma, and improve social support are needed to reduce late presentation to HIV care.

Data Availability Data will be available on request.

Code Availability N/A.

Declarations

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval This study was approved by the Joint Clinical Research Centre (JCRC) Institutional Review Board (IRB), University of Minnesota IRB, and the Kampala Capital City Authority (KCCA) central office.

Consent to Participate All participants consented both verbally and in writing. Surveys were performed in participants' native language of Luganda and entered into the study database by native Luganda speakers.

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