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Antiretroviral therapy availability and HIV disclosure to spouse in Rakai, Uganda: a longitudinal population-based study

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Abstract

Background—A decade after the rollout of antiretroviral therapy (ART) in sub-Saharan Africa, the effects of this structural change on social aspects of HIV such as rates of HIV disclosure to partners remain largely unmeasured. We evaluated whether the introduction of ART was associated with disclosure of HIV diagnosis to spouses in Rakai, Uganda, using longitudinal, population-based data.

Methods—We identified individuals in marital/cohabitating unions who were newly diagnosed with HIV in Rakai Community Cohort Study (RCCS) surveys between 2000 and 2008, where antiretroviral therapy (ART) was introduced in mid-2004. Using discrete-time survival analysis, we assessed the hazard of self-reported HIV disclosure to spouse after diagnosis pre- and post-ART rollout, adjusting for individual and union characteristics. Disclosure in the ART period was further stratified by ART initiation.

Results—The analysis included 557 married adults, 264 of whom were diagnosed with HIV before ART was available (2000-2004) and 293 diagnosed after ART was introduced (2005-2008). The cumulative incidence of self-reported disclosure was 75.2% in the post-ART period, compared to 58.3% before ART availability ($p<0.001$, adjusted hazard 1.46 [95% CI 1.16, 1.83]). In the post-ART period, observed disclosure rates were 39% (72/184) among those not in HIV care, 65% (82/126) among those in pre-ART care, and 85% (64/75) among persons on ART ($p<0.001$).

Conclusions—Treatment availability and use, especially ART initiation, was associated with increased self-disclosure of HIV diagnosis to partners. ART access may facilitate the prevention of transmission to uninfected partners and linkage to treatment for infected couples.

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Keywords

HIV/AIDS; disclosure; stigma; antiretroviral therapy; HIV counseling; discrete-time survival analysis

INTRODUCTION

Disclosure of positive HIV serostatus to spouses and other sexual partners is an important step in the pathway of transmission prevention through sexual risk reduction and uptake of prevention, treatment, and support services. However, individuals consider potential positive and negative consequences of sharing their positive HIV results with their spouse. Disclosure might stress or lead to the dissolution of the relationship if the partner responds with rejection, blame, or anger, though most studies have found that severe negative consequences such as violence and separation are relatively uncommon (1-3). Before communities in sub-Saharan Africa had access to ART, individual benefits of disclosure to one's spouse centered on emotional and instrumental support (4;5), improved mental health (2), ability to initiate safer sex practices within the relationship (2), and spousal support to access available medical care and short course ART regimens to prevent mother to child transmission (PMTCT) (4;6). Access to antiretroviral therapy (ART) in low and middle income countries increased 16-fold since 2003 (7). This structural change may have motivated disclosure among people with HIV directly—in order to openly seek ART and to enable one's potentially infected partners and children to benefit from treatment—and indirectly, by changing attitudes and reducing HIV-related stigma and discrimination (8).

Prior to ART availability, prospective studies found that less than half of HIV-infected women in antenatal care had disclosed their status to their sexual partner within 2 years after diagnosis in Cote d'Ivoire (9) and within 4 years in Tanzania (6). A systematic review found that on average, 49% of HIV-infected African adults reported disclosing their infection to their sexual partner, compared to 79% in high income countries (10). The lack of affordable treatment at the time may have contributed to the lower disclosure rates reported in Africa.

In contrast, several cross-sectional studies conducted after ART rollout reported disclosure rates to sexual partners of 62% to 79% in diverse populations attending HIV care and support groups in Uganda, Kenya and South Africa (2;11-13). However, these estimates are limited by their cross-sectional design, lack of data on pre-ART disclosure rates, variable recall time since HIV diagnosis, and participant self-selection into these programs. Longitudinal data on the effect of ART availability and initiation on HIV disclosure in a general African population remain limited. In this analysis, we use longitudinal population-based data collected between 2000 and 2008 to evaluate the association between ART availability and disclosure of newly diagnosed HIV infection to spouses by men and women in stable unions in rural Rakai district, Uganda. ART was introduced in this population in mid-2004, and was widely available through fixed and mobile clinics by 2005.

METHODS

Study Setting and Population

Since 1994, the Rakai Health Sciences Program (RHSP) has enrolled all consenting residents aged 15-49 in 50 villages in Rakai District, southwestern Uganda, into the Rakai Community Cohort Study (RCCS) (14). The RCCS administers behavioral questionnaires and collects venous blood for HIV-1 testing from participants approximately every 18 months. Approximately 94% of residents present in the community agree to participate in each survey round, and approximately 95% of participants provide a serologic sample for HIV testing. Between 2000 and 2008, participants were offered their HIV results through free post-test counseling, provided by trained RHSP counselors in participants' homes or other venues of choice (15;16). Although RHSP promotes receipt of results and counseling, testing and receipt were voluntary as per contemporaneous Ugandan Ministry of Health guidelines. Participants could choose to receive their HIV results individually or with their partner, and the protocol for returning new seropositive test results did not change over the study period.

In June 2004, ART first became available in Rakai, delivered by RHSP with funding from the USA President's Emergency Plan for AIDS Relief (PEPFAR). ART was initiated for those with a CD4 cell count $<250/mm^3$ or WHO stage IV disease. The program continued to provide cotrimoxazole prophylaxis, general healthcare, and other supportive services for those who did not meet ART eligibility criteria. With rapid scale-up and outreach, by 2005, less than one year after ART services were introduced, 87% of the community reported knowing where to access treatment.

The analytic sample included all RCCS participants in marital or consensual unions who received a new diagnosis of HIV infection from 2000 to 2006 (survey rounds 7-11). The study followed these participants and measured disclosure through 2008 (survey round 12). We included a participant regardless of whether his or her spouse participated in the survey.

Measurements

Participants who seroconverted between survey rounds or who tested positive at their first HIV test were classified as newly diagnosed once they reported receiving their HIV results. Participants' sera were tested for HIV-1 at each survey round with two enzyme immunoassay (EIA) tests (Vironostika HIV-1, Organon Teknike, Charlotte, NC, USA and Cambridge Biotech, Worcester, MA, USA) and confirmed positive or discordant EIA results by Western blot (HIV-1 Western Blot, Bio-Merieux-Vitek, St. Louis, MO, USA).

At each survey round, participants were interviewed regarding disclosure of HIV results to their spouse in the period between survey rounds. The disclosure outcome combined the response categories of disclosure through couples counseling and self-reported individual disclosure. For this analysis, we assessed cumulative rates of disclosure within up to three survey intervals following diagnosis (encompassing approximately 5 years). All observations were administratively censored after 2008.

ART availability, the primary predictor, is time-varying based on the year of the survey round. We defined the pre-ART period as the three survey rounds from 2000-mid-2004 and the post-ART period as the two survey rounds from mid-2004-January 2008 (Figure 1). As an external variable, ART availability was defined uniformly for all participants and was not dependent on self-use of ART. We compared these rounds, which were most proximal to ART rollout, to minimize the influence of secular changes that could affect disclosure. In addition, ART availability at diagnosis, a fixed variable, was used to stratify and compare the cumulative disclosure estimates.

Individual-level and union-level covariates were reported in the RCCS interview; the variables most likely to change due to disclosure were drawn from the interview prior to the visit (lagged) in which the disclosure outcome was measured. The individual characteristics included gender, age category, education level, wealth, formal labor force participation, religion, extramarital sex partners (lagged), alcohol consumption, attitude toward intimate partner violence (IPV), AIDS symptoms (lagged), and being bedridden within 30 days prior to the interview (lagged). Household wealth was based on an index of the quality of the roof, walls, and floor materials of the home, grouped into tertiles. Respondents with clerical, teaching, government, service industry, or trading/vending jobs were classified as part of the formal labor force. AIDS symptoms were substantial weight loss, diarrhea for longer than one month, fever for longer than one month, Kaposi sarcoma, herpes zoster, oral thrush, or tuberculosis.

Union-level covariates included polygamy, union type (married vs consensual), spousal age difference, union duration, and the report of verbal or physical abuse by spouse (females) or toward spouse (males). For males in polygamous unions, all union-level covariates refer to the wife with whom they reported the most recent sexual activity (self-reported disclosure to multiple wives was consistent in 79% of observations).

We linked RHSP HIV treatment program data to the RCCS community data by unique study identification number to assess whether a participant had accessed pre-ART care or initiated ART, as a secondary analysis.

Analysis

Means and proportions were calculated and t-tests or Chi-square tests were used to compare differences between individuals newly diagnosed with HIV prior to ART availability and those diagnosed after ART became available.

We use a discrete-time proportional hazards model (17). The hazard can be interpreted as the probability of disclosing one's HIV results to one's spouse in a given inter-survey interval, conditional on not having disclosed by the start of that interval. A generalized linear regression model with a complementary log-log specification was used to assess the association between ART availability and disclosure.

We fit the baseline discrete-time survival model with follow-up interval (time), stratified by ART availability at diagnosis, to estimate total and gender-stratified cumulative disclosure incidence for the pre-ART and post-ART periods. Bivariate models were fitted with each

potential predictor and time to estimate unadjusted hazards of disclosure. For the multivariable model, in addition to time-varying ART availability and the gender of the disclosing partner, we included and all predictors with unadjusted hazards with p-values < 0.10. We tested for a multiplicative interaction between gender and ART availability in the multivariable model. A secondary analysis, limited to the post-ART period, assessed the association between use of HIV treatment and disclosure —one pathway through which community-level ART availability could affect disclosure—by Chi-square test and a multivariable proportional hazard model. All analyses used Stata versions 9.1 or 12.0 (Stata Corp., College Station, TX).

Ethics statement

The AIDS Research Subcommittee of the Uganda National Council for Science and Technology, the Uganda Virus Research Institute, Science and Ethics Committee, and the Western Institutional Review Board (Olympia, WA) reviewed and approved this secondary data analysis and the RCCS and clinic data collection. The study team obtained written informed consent at enrollment and at each annual follow-up, and participants could opt-out of any part of the study. Patients attending RHSP care and treatment centers provided written informed consent to have their clinical data base linked to RCCS data. Personal identifiers were stripped from the databases prior to our use.

RESULTS

From 2000 to 2006, 557 RCCS participants in marital unions were newly diagnosed with HIV, contributing 725 person-intervals of observation. More than three quarters of individuals contributed only one interval of observation because they disclosed their diagnosis in the same interval in which they received results (n=317), didn't participate in the subsequent survey round (n=66), or were administratively censored after survey round 12 (n=51). Two hundred sixty-four (47%) participants were diagnosed before ART became available and 293 (53%) after it became available. Missingness was less than 3% for any variable, and multivariable analysis was limited to the 703 of 725 (97%) person intervals with non-missing data. Individuals diagnosed in the pre-ART years who had not yet disclosed by ART introduction contributed person-time both in the pre- and post-ART periods.

Participants diagnosed in the pre-ART period were comparable on most characteristics to their counterparts diagnosed after ART was available (Table 1). However, participants diagnosed in the post-ART period were significantly more likely to be female and to be in a consensual union compared to formal marriage. A minority of the population reported serious illness during the study visit when they received their results; 9% reported AIDS-associated symptoms and 11% reported being bedridden in the past month. Receipt of couples counseling among the newly diagnosed was similarly low (10%) between the two periods.

By the end of the second interval after diagnosis, disclosure increased from an estimated 58% in the pre-ART period to 75% in the post-ART period (p <0.001) (Figure 2). Stratified by gender, disclosure increased after the ART rollout among both men (63% pre-ART vs.

78% post-ART) and women (55% pre-ART vs. 73% post-ART). The rate of disclosure was highest within the first follow-up interval after HIV diagnosis (Figure 2). 127 of the 139 disclosures in the pre-ART period (91.4%) and 190 of the 198 disclosure in the post-ART period (95.9%) occurred within the first follow-up interval.

The adjusted hazard of disclosure was 46% higher in the post-ART period relative to the pre-ART period (adjHR: 1.46 95% CI 1.16-1.83, p<0.001) (Table 2). Women were 20 percent less likely to disclose their HIV diagnosis to their partners than were men over the entire period of follow-up (adjHR 0.79, 95% CI 0.62-1.00, p=0.046), and the effect of gender on disclosure was not statistically significantly modified by ART availability (interaction term not included in the final model due to lack of statistical significance).

Over the entire period, the hazard of disclosing to one's spouse was significantly increased with longer duration of the relationship (adjHR 1.30, 95% CI 1.13-1.49) and the presence of AIDS-associated symptoms prior to disclosure (adjHR 1.56, 95% CI 1.09-2.24). The likelihood of disclosure was lower among adults who reported alcohol use (adjHR 0.73, 95% CI 0.57-0.93) and with higher levels of education (adjHR 0.81, 95% CI 0.72-0.91). Other covariates were not significantly associated with disclosure.

In the post-ART period, disclosure to a spouse was strongly associated with utilization of HIV treatment services. Among the 385 person-intervals observed after ART availability, disclosure rates were 39% (72/184) among those who had not sought HIV care, 65% (82/126) among those on pre-ART care, and 85% (64/75) among those on ART (p<0.001) (Figure 3). In a discrete time survival analysis limited to the post-ART period, the adjusted hazard of disclosure was 3.26 (95% CI 2.16-4.92; p<0.001) when participants were on ART and 2.09 (95% CI 1.48-2.95; p<0.001) when participants were enrolled in pre-ART care, compared to those not in care.

DISCUSSION

We found a significant increase in disclosure of HIV infection to a spouse (from 63% to 78% among men, and from 55% to 73% among women) after the introduction of an ART program in a rural African community. To our knowledge, these are the first disclosure estimates reported from a general population in sub-Saharan Africa that directly quantify the change in disclosure after ART rollout.

Additionally, in the ART era, enrollment in ART or pre-ART care was strongly associated with disclosure to a spouse. Operations research in Rakai documented the desire to access ART as a motivating factor to disclose one's HIV diagnosis to one's spouse (Neema Nakyanjo, personal communication, 2006), a finding also reported in another study of disclosure in Uganda (2). Self-interest in preserving one's health and concerns for one's spouse's health or HIV status could thus outweigh fears about disclosure. This is consistent with studies that have found disclosure to be positively associated with ART uptake (18-20) and adherence (21;22), though in some contexts, preserving one's health through ART use has been reported as a strategy to avoid disclosure (23). Initiating treatment without disclosing to a spouse could lead to unintended disclosure because it would be difficult to

conceal treatment, including frequent clinical visits, from a cohabitating partner. More positively, a study in Uganda found that both men and women used their treatment as an opportunity for indirect (but intended) disclosure, by leaving their medications or health records in a place where their spouse would see them (2). Models of HIV testing and/or care can themselves facilitate disclosure, notably couples counseling and family-centered clinical care. The RHSP clinical program recommends and supports disclosure, and patients are encouraged to select a treatment companion to support their drug adherence. Spouses served as treatment companions for 71% of married men and 49% of married women on ART. Therefore, the need for treatment support may motivate the disclosure of HIV status to the spouse, particularly among men, either before or after initiating ART.

Knowledge of ART availability and its effectiveness for improved survival, which was high in this population, might have also contributed to higher rates of disclosure by reducing stigma. Though this pathway was not evaluated in our study, its plausibility is supported by studies that have found lower levels of self-reported stigmatizing attitudes or behaviors after ART rollout (24), in areas with greater ART access compared to those without (25;26) and among people with knowledge of how to access ART (25;27).

These findings provide insight into predictors of disclosure in a general population with access to HIV care. The lower probability of disclosure by HIV-infected women compared to men throughout the period of observation suggests that despite the availability of treatment, women may continue to anticipate more negative consequences of disclosure, which numerous studies have demonstrated as the most significant barrier to disclosure for women in sub-Saharan Africa (3;4;6;28). Our finding that disclosure is more likely in longer established relationships is consistent with previous findings in Tanzania (6), although the inverse association with education differed from a study in Nigeria (29). The reasons for the lower rates of disclosure among those with higher levels of education are unclear, but it is plausible that status loss associated with stigma is more acute for those with a higher social standing.

Despite relatively high disclosure among people with HIV in Rakai, a substantial subset of adults diagnosed with HIV had not shared this knowledge with their partner. While we hope that intensive programs for serodiscordant couples, disclosure support, and the reduction of violence against women launched in Rakai since this study period have further increased disclosure rates, HIV programs must continue to develop innovative models to facilitate safe disclosure. Our findings suggest that men and women in newer relationships may require additional support around disclosure, and that the integration of motivational interviewing and other interventions to address high-risk drinking within HIV testing or care and support programs may also benefit disclosure.

Several factors limit the conclusions that can be drawn from this study. First, it is possible that other factors coincided with ART introduction and influenced disclosure, although RHSP was the main provider of HIV counseling, testing, and other preventive services in all RCCS villages during the period of analysis, and did not implement any substantial changes in these interventions in this time period. The time period of observation was purposively restricted to three survey rounds pre-ART and two rounds post-ART to further reduce the

chance of secular changes. Second, the non-informative censoring assumption underlying the proportional hazards survival method could be violated if out-migration or marital dissolution was associated with disclosure. Third, this analysis does not account for the HIV status and disclosure behavior of the spouse, but we favored individual-level over couple-level analysis to avoid exclusion of couples where one partner was unavailable during a survey round. Finally, self-reported disclosure outcomes should be interpreted with caution, since a perception that non-disclosure would be negatively judged by the interviewer could introduce social desirability bias and inflate self-reports of disclosure. Interviewers were unaware of respondents' HIV status, and such bias is unlikely to differ between the two periods, however. Our community cohort design reduces the self selection that can occur in samples drawn from clinical, VCT, or couples counseling programs, and increases the generalizability of our findings. Cohort and HIV testing procedures and the characteristics of newly diagnosed HIV+ participants were comparable before and after ART introduction, so it is unlikely that the distribution of unobserved confounders would differ between the periods and affect results. The longitudinal design enabled us to observe individuals from the time they were diagnosed until the time they disclosed their results or were censored, reducing potential prevalence/incidence bias and recall bias. Time-varying measurement of predictors allowed us to account for changes in exposure over time. Since many of the studies that prospectively measured HIV disclosure were limited to women, our study adds a direct gender comparison of disclosure rates.

In summary, we demonstrated that ART availability was associated with disclosure of HIV infection to a spouse in a setting where free HIV testing and counseling are available. Disclosure within couples, in turn, facilitates linking infected partners to care, accessing PMTCT services, and preventing sexual transmission to uninfected partners through sexual risk reduction and treatment-centered prevention approaches. As the knowledge of HIV status in sub-Saharan Africa increases rapidly with expanded access to testing and counseling (7), the availability of ART in communities and supportive models of care will continue to be important factors to increase disclosure and facilitate HIV transmission prevention.

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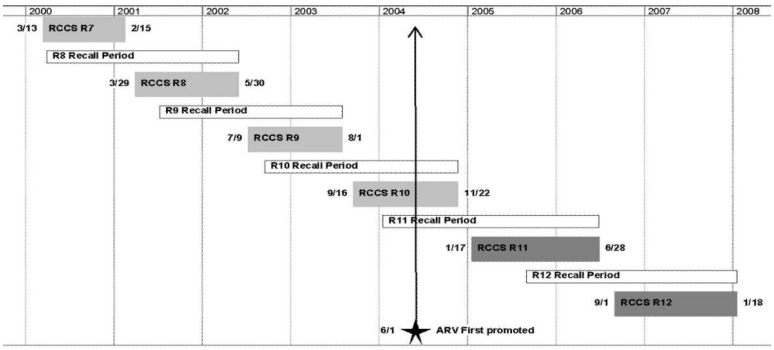


Figure 1. Timeline of ART rollout relative to RCCS survey rounds (R7-R12) in Rakai, Uganda, 2000-2008

Legend: ART was first provided in Rakai Uganda clinics in June 2004, toward the end of Round 10 of the Rakai Community Cohort Survey (RCCS). Rounds 8-10 are thus classified as pre-ART rounds, because the majority of the recall period for Round 10 respondents occurred before ART access, and diffusion of knowledge about ART availability likely took several months to reach the 87% knowledge of ART access reported by community members in RCCS Round 11.

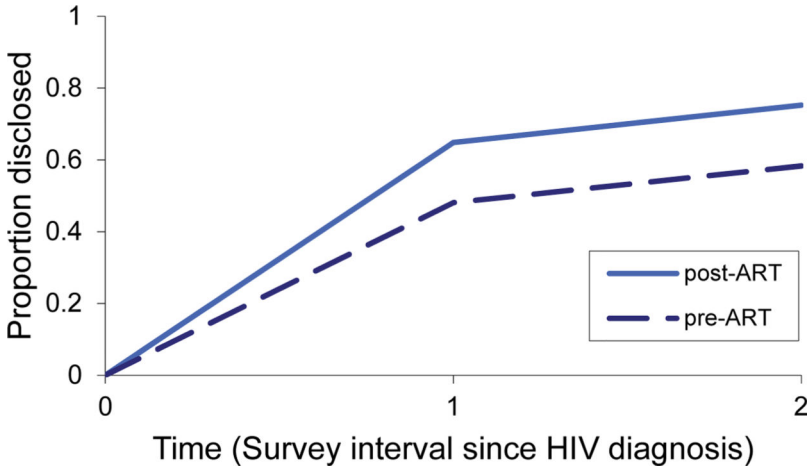
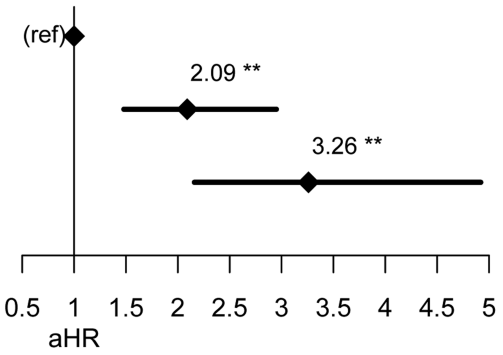


Figure 2. Cumulative incidence of HIV serostatus disclosure among HIV-infected adults in stable unions in Rakai, Uganda, by ART availability at the time of diagnosis

Legend: By the second survey round after diagnosis, 75% of adults reported disclosure to their spouse in the post-ART period, compared to 58% in the pre-ART period.

HIV Care Status	N (intervals)	Percent Disclosed (in total)	Percent Disclosed (a) (in first interval)
No HIV Care	184	39.1%	48.9%
Pre−ART Care	126	65.1%	70.4%
ART Care	75	85.3%	90.3%
Total	385	56.6%	64.9%



ART=antiretroviral therapy, CI=confidence interval.(a) Limited to the first survey interval after HIV diagnosis. Regression model adjusts for gender, education, polygamous union, union duration, alcohol,verbal abuse by husband, and HIV symptoms.
**p<0.001

Figure 3. Disclosure of HIV diagnosis to spouse by HIV care status, among HIV-infected adults in stable unions in Rakai, Uganda in the post-ART period (2004-2008)

Legend: Abbreviations: ART=antiretroviral therapy, CI=confidence interval.(a) Limited to the first survey intervals after HIV diagnosis. Regression model adjusts for gender, education, polygamous union, union duration, alcohol, verbal abuse by husband, and HIV symptoms. **p<0.001

Table 1

Baseline descriptive characteristics of 557[a] adults in married or consensual unions receiving HIV diagnosis before and after ART was available in Rakai, Uganda, 2000-2008

	Diagnosed with HIV pre-ART (n=264)		Diagnosed with HIV post-ART (n=293)		
	n	proportion	n	proportion	p-value
Sex					
Female	144	0.55	187	0.64	0.03
Male	120	0.45	106	0.36	
Mean age (SD)	30.2yrs	(0.4yrs)	30.8yrs	(0.4yrs)	0.31
Education[b]					
None	21	0.08	22	0.08	0.25
P1-P4	72	0.27	72	0.25	
P5-P7	109	0.41	130	0.44	
S1-S4	40	0.15	56	0.19	
>S4	22	0.08	13	0.04	
Wealth					
Low	120	0.45	104	0.35	0.05
Medium	77	0.29	98	0.33	
High	67	0.25	91	0.31	
Labor force participation	96	0.36	85	0.29	0.06
Union type					
Married	180	0.68	148	0.51	<0.001
Consensual	84	0.32	145	0.49	
Union duration (yrs)					
0-4	118	0.45	114	0.39	0.27
5-9	79	0.30	90	0.31	
>=10	66	0.25	89	0.30	
Extramarital partner in past year	61	0.23	67	0.24	0.77
HIV symptoms in past year	21	0.08	26	0.09	0.60
Bedridden (last month)	30	0.12	34	0.12	0.81
HIV test results delivery					
Couples	29	0.11	24	0.08	0.26
Individuals	235	0.89	269	0.92	
Accepting Attitude toward IPV	167	0.78	211	0.83	0.17

[a] 57 respondents were missing data on IPV attitudes, 21 participants were missing data on HIV symptoms and being bedridden; 16 participants were missing data on extramarital partner, and 1 participant was missing data on union duration.

[b] P1-P7 are primary school grades 1-7; S1-S4 are secondary school grades 1-4 (equivalent to US high school); Beyond S4 includes Advanced level (S5-S6), diploma programs, and technical school or university.

Table 2

Relative hazards of HIV serostatus disclosure to spouse among men and women in married or consensual unions, by ART availability and other predictors, Rakai, Uganda, 2000-2008

	Unadjusted HR 95% CI	Adjusted HR 95% CI
Period of ART availability	**1.56*** (1.26,1.94)**	**1.46*** (1.16,1.83)**
DEMOGRAPHIC CHARACTERISTICS		
Female	**0.89 (0.72,1.10)**	**0.79* (0.62,1.00)**
Age category	**1.06 (0.96,1.17)**	
Education level	**0.83** (0.74,0.92)**	**0.81*** (0.72,0.91)**
Wealth tertile	**0.96 (0.85,1.09)**	
Labor force participation	**0.85 (0.68,1.07)**	
Religion		
Muslim	**1.00 (REF)**	
Christian/Other	**1.07 (0.79,1.46)**	
UNION CHARACTERISTICS		
In polygamous union	**0.80 (0.63,1.03)**	**0.86 (0.66,1.11)**
Union type		
Marital union	**1.00 (REF)**	
Consensual union	**0.85 (0.68,1.06)**	
Union duration (category)	**1.27*** (1.11,1.44)**	**1.30*** (1.13,1.49)**
Spousal age difference (category)	**0.98 (0.87,1.11)**	
BEHAVIORAL		
Extramarital partner	**0.89 (0.66,1.20)**	
Alcohol in past 30 days	**0.72** (0.58,0.89)**	**0.73* (0.57,0.93)**
Accepting attitude of IPV	**1.10 (0.82,1.48)**	
Verbal abuse by husband	**0.82 (0.65,1.02)**	**0.90 (0.71,1.14)**
Physical abuse by husband	**0.89 (0.68,1.15)**	
HIV MORBIDITY		
Any AIDS symptom	**1.64** (1.16,2.32)**	**1.56* (1.09,2.24)**
Bedridden	**0.99 (0.71,1.37)**	

HR=hazard ratio, p-values

* <0.05

** <0.01

*** <0.001