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## Disclosure of HIV Status Between Spouses in Rural Malawi<sup>1</sup>

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### Abstract

Disclosure of HIV status after HIV voluntary counseling and testing (VCT) has important implications for the spread of the HIV epidemic and the health of individuals who are HIV positive. Here, we use individual and couples-level data for currently-married respondents from an ongoing longitudinal study in rural Malawi to (1) examine the extent of HIV status disclosure by HIV serostatus (2) identify reasons for not sharing one's HIV status with a spouse, and (3) evaluate the reliability of self-reports of HIV status disclosure. We find that disclosure of HIV status is relatively common among rural Malawians, where most have shared their status with a spouse, and many disclose to others in the community. However, there are significant differences in disclosure patterns by HIV status and gender. Factors associated with non-disclosure are also gendered, where women who perceive greater HIV/AIDS stigma and are HIV positive are less likely to disclose HIV status to a spouse, and men who are worried about HIV infection from extramarital partners are less likely to disclose their HIV status to a spouse. Finally, we test the reliability of self-reported HIV status disclosure and find that self-reports of HIV positive men are of questionable reliability.

### Keywords

HIV; sub-Saharan Africa; Malawi; stigma; VCT

### Introduction

With the rapid expansion of access to HIV voluntary counseling and testing (VCT) throughout sub-Saharan Africa (UNAIDS/WHO, 2008; WHO, 2007), the behavioral response to learning one's HIV status becomes an increasingly important factor in determining the course of the AIDS epidemic. One such response to VCT is the extent to which individuals disclose their HIV serostatus to others after VCT. Disclosure of HIV positive status gives any potential or current sexual partners the opportunity to adopt behaviors that protect them from HIV infection. Conversely, if HIV positive individuals do not share their HIV test results, sexual partners are instead forced to rely on subjective assessments of a spouse or potential partner's HIV status, and these assessments are often unreliable (Anglewicz et al., 2009).

HIV status disclosure *between spouses* is particularly relevant for the spread of HIV/AIDS in sub-Saharan Africa (SSA). HIV discordant couples now represent the majority of HIV-infected couples in SSA (de Walque, 2007), and a large proportion of new HIV infections in

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this region occurs within discordant couples in long-term stable partnerships (Hudson, 1996; Robinson et al., 1999). Because HIV is often transmitted between spouses, communication of HIV test results between spouses is critical for individuals to be fully aware of their risk of HIV infection and have the opportunity to take action to prevent infection.

Disclosure is also important for health of HIV infected individuals. It is often necessary for HIV positive men and women to inform others of their condition in order to receive necessary emotional and physical support (Antelman et al., 2001). For some, it is necessary to disclose an HIV positive status to a spouse in order to facilitate access to anti retroviral HIV treatment (Farquhar et al., 2000). Also, the act of disclosure itself may also have beneficial effects for individuals, as depression is higher for some HIV positive individuals who have not disclosed their status (Bennetts et al., 1999).

Despite the importance of status disclosure, research has shown dramatically varying rates of disclosure across settings. In Burkina Faso only 18% of HIV positive women reported sharing their HIV test results with their partners, and 32% of all women to husbands or partners (Issiaka et al., 2001). Similar low rates have been found in Barbados (29%) (Kumar et al., 2006), Kenya (32%) (Gaillard et al., 2000), Tanzania (22%) (Antelman et al., 2001), Thailand (44%) (Bennetts et al., 1999). In contrast, several other studies have found that the majority of individuals report disclosing their status after testing, in Kenya (Farquhar et al., 2000), Rwanda (Keogh et al., 1994), South Africa (Simbayi et al. 2007; Wong et al. 2007) and Tanzania (Maman et al., 2002). Reviews of research on disclosure of HIV status can be found in Arnold et al., 2008 and Medley et al., 2002.

The barrier to disclosing HIV test results is often generally described as “fear”. However, the specific fear of disclosure varies across settings. Divorce is higher among HIV positive individuals (Keogh et al., 1994; Porter et al., 2004), and fear of divorce or abandonment precludes HIV status disclosure in some instances (Antelman et al., 2001; Maman et al., 2001; Medley et al., 2004). Gender-based violence is often closely associated with HIV risk for women in SSA (Dunkle & Jewkes, 2007), so it is not surprising that fear of physical abuse prevents women from sharing their HIV status (Antelman et al., 2001; Kumar et al., 2006). Stigma, either real or perceived, also inhibits disclosure, as some fear social isolation and discrimination that could result from sharing one’s HIV status (Antelman et al., 2001; Daftary, Padayatchi, & Padilla, 2007; Keogh et al., 1994; Lie & Biswalo, 1996; McGrath et al., 1994; Schoepf, 1993; Simbayi et al. 2007). While fear of the consequences may inhibit disclosure in some cases, the decision not to share one’s HIV test result could also simply be a matter of a “need for privacy” (Wong et al., 2007).

We have three goals in this paper. First, we investigate the extent to which rural Malawians communicate their HIV test results to their spouse and others, by actual HIV status. Next, we identify reasons why individuals do not share their HIV status. Finally, we evaluate the reliability of self-reported HIV status disclosure by comparing self-reported disclosure with confirmatory reports from a spouse or partner. We expand on previous research by including disclosure of HIV status to range of individuals (spouse, other sexual partners, family members, and friends), and by comparing reports of disclosure by gender and actual HIV status. Furthermore, while the literature consistently shows that disclosure of HIV status is a sensitive issue for many, previous research has rarely evaluated the reliability of self-reports of HIV status disclosure (an exception is Katz et al. 2009), as we do here.

## Methods

### Study Setting and Sample

We use data from the Malawi Diffusion and Ideational Change Project (MDICP). Since 1998, MDICP has collected longitudinal data from married men and women in three rural sites in Malawi. MDICP was designed as a couples' survey, targeting a sample of approximately 1,500 ever-married women aged 15–49 and 1,000 of their husbands (regardless of age) in each of the three regions of Malawi: Mchinji (Central region), Rumphi (Northern), and Balaka (Southern). After the first wave of data collection in 1998, MDICP conducted follow up interviews with the same respondents in 2001, 2004 and 2006. MDICP was approved by the University of Pennsylvania in the United States and the National Health Sciences Research Committee in Malawi. More details about the MDICP sample can be found in Watkins et al. 2003 and Anglewicz et al. 2009.

In addition to survey interviews, MDICP collected HIV biomarkers for all consenting respondents, starting in the third wave of data collection (2004), and again in the fourth wave in 2006. MDICP did not offer HIV testing to respondents in 1998 or 2001. Written informed consent was obtained from all respondents who agreed to be tested for HIV, and less than 10% of MDICP respondents refused HIV testing in both 2004 and 2006. All respondents who consented to HIV testing received counseling at the time of HIV testing, in which all respondents were told that the decision of disclosing HIV test results was entirely up to them; they were not advised to disclose or not disclose their HIV test results to others. In 2006 MDICP used rapid results HIV test kits, and individuals trained in HIV counseling and testing carried out two separate rapid-results HIV test kits, by Unigold and Determine. After the tests were run, each respondent was given the opportunity to learn their HIV test results and received post-test counseling. In order to ensure confidentiality of survey responses and HIV test results, all husbands and wives were interviewed separately in private locations.

### Data analysis

We begin the analysis by tabulating percentages of respondents who reported disclosing their HIV test results to a spouse and others in their community in MDICP 2006, and we compare differences in reported HIV status disclosure by actual 2006 HIV serostatus. Next, we examine individuals' reports of whether their spouse told their HIV test result to others. We compare disclosing one's HIV status by actual HIV status using chi squared tests.

After examining the extent of HIV status disclosure, we next identify the characteristics associated with not disclosing one's HIV test result to a spouse. To do so, we run logistic regressions by gender, in which the dependent variable is an indicator of not telling their HIV test result to a spouse. Independent variables in these regressions are informed by the literature, and include background characteristics (age, education, economic status, and region of residence), and actual HIV status. We also include a set of marriage-related characteristics: polygamy, whether the respondent is most worried about HIV infection from other partners (compared to a spouse or other sources), and acceptability of condom use within marriage. Finally, as measures of female autonomy, we use measures of acceptability for a woman to (1) go to the local health center without the permission of her husband, and (2) refuse sex with her husband if she thinks he is HIV positive.

To account for the influence of HIV stigma on status disclosure, we use five stigma questions from MDICP 2006 (shown in Table 1) to create a 6-item index measure. Each of these stigma variables is coded as a binary indicator for stigma, and are then added together to create an index of stigma that ranges from 0 (representing no stigma) to 5 (representing a positive response to stigma for all five questions).

The validity of survey responses to sensitive questions can be affected by biases (Anglewicz et al., 2009; Bignami-Van Assche et al., 2007; Cleland et al., 2004). Because disclosure of one's HIV status is a potentially sensitive issue, individuals may incorrectly report having disclosed their HIV status to their spouse. Thus, we evaluate the reliability of self-reported disclosure of HIV status to a spouse. To verify claims by respondents that they shared their HIV test result with their spouse, we create tables that show the percentages of respondents who said their spouse told them their HIV test results for respondents who claim to have shared their HIV test result with their spouse, and we compare these reports by HIV status using chi squared tests.

## Results

In total, MDICP interviewed and HIV tested 2,424 currently married respondents in 2006. For our analysis, we are interested in reported disclosure of HIV status from prior HIV testing experience (i.e. prior to the time of interview in 2006); and we therefore limit our sample to respondents who had been tested for HIV and received their test result prior to the time of MDICP interview in 2006. Of the 2,424 respondents surveyed and tested by MDICP 2006, 916 women and 636 men were tested for HIV and received their test results prior to the 2006 MDICP survey, which represents the sample for the present analysis. Descriptive statistics for this sample are displayed in Table 1, including HIV prevalence, which was 7.6% for women and 4.6% for men in 2006.

Table 2 shows that only 15.6% of women and 8.1% of men did not share their HIV test result with their spouse. Disclosure was not limited to a spouse: more than one third of men and women report having told their HIV status to a relative and a friend. Only approximately 4% of women and 1% of men didn't tell anyone their HIV status.

There are differences by gender in disclosing HIV status. Although most MDICP respondents shared their HIV status with someone else, women who were HIV positive in 2006 were significantly less likely to report disclosing their status to their husbands (chi squared significant at  $p < 0.01$ ), and were significantly more likely not to tell anyone ( $p < 0.10$ ).

Why do individuals not disclose their HIV test results to their spouse? For women, HIV status is an important factor: HIV positive women were significantly more likely to not tell their HIV status to a spouse (OR=2.97, CI 1.65–5.34), as shown in Table 3.

As with actual HIV status, there are several important differences by gender in not disclosing one's HIV status to a spouse. First, there is regional variation for women: female respondents from the Central region are significantly more likely to disclose than women from the South (OR=1.77, CI 1.11–2.82). Finally, stigma is also important: women who report higher scores stigma index scores were significantly more likely to not disclose their HIV test results to their spouse (OR=1.22, CI 1.05–1.42).

There are, however, some similarities between men and women. Men and women who think it is acceptable for their wife to go to the health center without his permission were significantly more likely to not disclose their HIV status to their spouses (women OR=1.74, CI 1.01–2.99; men OR=2.08, CI 1.06–4.09). Also, higher economic status is associated with a lower likelihood of not disclosing: women who own a radio (OR=0.54, CI 0.35–0.83) and men who own a bicycle (OR=0.30, CI 0.15–0.61) were less likely to not share their HIV status with their spouse.

Finally, Table 4 displays results for the reliability of reports of HIV status disclose to one's spouse. Of the 916 and 636 women and men in the above analysis, 391 women and 423 men

had spouses who were tested for HIV prior to 2006 and interviewed by MDICP in 2006. Of these respondents, 4.3% of wives and 2.8% of husbands did not verify that they were told their spouse's HIV test result. Only 4.3% of men have wives who disagree with their husband's claim, but this percentage is significantly higher for HIV positive men: 15.4% of HIV positive men did not have their wife's confirmation, compared with 3.9% of HIV negative men (chi squared significant at  $p < 0.01$ ). A higher percentage of HIV positive women's husbands similarly disagree, but this difference is not significant at  $p < 0.10$ .

## Discussion

This research shows that the vast majority of rural Malawians disclose their HIV status to others in the community, particularly to a spouse. While other studies have found that the majority of their sample disclosed their HIV test results, relatively few (Farquhar et al., 2000; Keogh et al., 1994; Maman et al. 2002) have found disclosure to be as widespread as in rural Malawi. Similar to other studies, we find that rural Malawians who are HIV positive are less likely to disclose their HIV status than are HIV negative individuals (Maman et al. 2002). HIV positive women are significantly less likely to share their HIV status with their spouse than are men, and are more likely to not disclose their HIV status to anyone. We also find differences by gender in disclosure patterns, as often found in status disclosure research (Farquhar et al 2000; Katz et al. 2009). HIV positive status and perceived HIV stigma in the community are important correlates of HIV status disclosure for women, as often found in the literature (Antelman et al., 2001; Daftary, Padayatchi, and Padilla, 2007; Keogh et al., 1994; Lie & Biswalo, 1996; McGrath et al., 1994; Schoepf, 1993). It's less common to identify the correlates of HIV status disclosure for men, and we find that age and fear of infection from extramarital partners are more important inhibiting factors for men than women.

This research also shows that self-reports of HIV status disclosure can be of questionable reliability. Results in Table 4 show that men who are HIV positive are less likely to disclose their status to a spouse, a similar result to Katz et al (2009). Among possible reasons for this discrepancy is social desirability bias: HIV positive men might not intend to share their test results, but may feel the need to claim that they did. Alternatively, HIV positive respondents might feel compelled to disclose their HIV status but may ultimately find that the reality of telling their spouse is more difficult than expected.

This research has important implications for HIV policies and programs in sub-Saharan Africa, where a balance between individual rights to not disclose HIV status and a partner's right to be aware of their risk continues to be an important issue. There is evidence that individuals are avoiding HIV infection by divorcing spouses who they believe are HIV positive (Reniers, 2008; Watkins, 2004), and therefore HIV status disclosure is important in enabling individuals to reduce their risk of HIV infection. However, there is also evidence which suggests that HIV positive women who disclose their status to a spouse could be suffer from domestic violence (Dunkle & Jewkes, 2007), and keeping their HIV status secret could protect some women. Fear of stigma and discrimination also prevents women from disclosing their status (Antelman et al., 2001; Daftary, Padayatchi, and Padilla, 2007; Keogh et al., 1994; Lie & Biswalo, 1996; McGrath et al., 1994; Schoepf, 1993). Policies that both encourage disclosure of HIV status and reduce stigma and domestic violence would be useful, but such a compromise is likely difficult to attain.

This study has several limitations. Because we tabulate respondents disclosing their HIV test result for a test prior to 2006 by HIV status in 2006, it is possible that some respondents who were HIV positive in 2006 disclosed an HIV negative test result prior to 2006, which would occur if an individual sero-converted to HIV positive between 2006 and prior HIV testing.

This is, however, very unlikely given the very low incidence rate in the MDICP sample (incidence rate 0.7 per 100 person years) (Obare et al., 2009). Also, although spouses' confirmatory reports allow us to verify that individuals told their spouse an HIV status, we do not know if the individual told their spouse the correct HIV status- some HIV positive individuals could have told their spouse that they are HIV negative, and since our results show that HIV positive individuals are less likely to disclose their HIV status, such a scenario does not seem unlikely. These cases, however, do not change the conclusions reached about questionable reliability for HIV positive individuals (it seems very unlikely that an HIV negative individual would tell their spouse that they are HIV positive). Finally, we were limited by relatively few questions on HIV stigma in the MDICP survey; preferably we would use a measure that captures a wider range of stigma-related beliefs and experiences.

Since the future course of the HIV epidemic will be partly determined by the extent to which HIV positive individual infect others, efforts should be made to create an environment that encourages HIV status disclosure without negative consequences. It is therefore necessary to address reasons why the HIV positive do not share their HIV test results- particularly perceived HIV stigma- and to create or encourage support systems for HIV positive individuals in rural African communities. In addition, since our results show that self-reports of disclosure are sometimes unreliable, caution should be exercised when conducting analysis involving self-reported disclosure patterns.

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**Table 1**

Descriptive statistics for characteristics and behaviors among currently married couples interviewed and tested by the MDICP<sup>I</sup> 2006

	Women	Men
	Percentage or mean	
Age (mean)	35.2	40.3
<b>Education</b>		
No education	29.3	14.8
Primary	61.3	64.4
Secondary or higher	9.4	20.8
<b>Region of residence</b>		
South	34.4	29.5
Central	26.4	29.0
North	39.2	41.5
<b>Economic status</b>		
Bicycle	54.2	61.5
Radio	72.7	81.8
Iron sheet roof	13.8	13.7
<b>Marital characteristics</b>		
Polygamous	5.7	14.9
Condom use with spouse is acceptable	80.1	76.7
Worried about HIV/AIDS infection from other partners	14.3	30.0
<b>Autonomy</b>		
Acceptable for wife to attend health center without permission from husband	11.4	19.8
Acceptable for wife to refuse sex if she thinks husband is HIV positive	67.5	69.8
<b>Stigma</b>		
Most people in village are <b>not</b> comfortable around someone who is HIV positive	18.9	13.5
Most in village believe HIV positive individuals got what they deserve	48.8	48.5
Religious leaders believe HIV positive individuals got what they deserve	40.8	39.5
Would <b>not</b> buy vegetables from HIV positive individuals	9.3	4.3
An HIV positive teacher should <b>not</b> be allowed to teach	6.9	1.4
AIDS stigma index (mean of 6-point scale, 0–5)	1.2	1.1
<b>HIV positive</b>	7.6	4.6
N=	916	636

<sup>I</sup> Malawi Diffusion and Ideational Change Project (MDICP)

**Table 2**

Chi squared test of differences in disclosure of HIV test results by 2006 HIV serostatus for MDICP men and women, 2006 MDICP<sup>1</sup> data

Shared HIV test results with:	Women			Men		
	HIV Negative	HIV Positive	Total	HIV Negative	HIV Positive	Total
Spouse	85.8%	66.7% <sup>**</sup>	84.4%	92.1%	90.0%	91.9%
Other sexual partners	1.3%	2.9%	1.4%	2.5%	0.0%	2.3%
Relative	41.8%	50.7%	42.5%	37.6%	40.0%	37.8%
Friend	33.1%	26.1%	32.5%	39.4%	56.7% <sup>‡</sup>	40.3%
Nobody	4.1%	8.7% <sup>‡</sup>	4.4%	0.8%	3.3%	1.0%
N=	847	69	916	606	30	636

<sup>1</sup>Malawi Diffusion and Ideational Change Project (MDICP)

Chi<sup>2</sup> difference between HIV positive and HIV negative significant at  $p < 0.10$ <sup>‡</sup>,  $p < 0.05$ <sup>\*</sup>, Value significant,  $p < 0.01$ <sup>\*\*</sup>

**Table 3**

Odds ratios for results of multivariate logistic regression analysis of disclosing HIV test results to a spouse, for currently married MDICP men and women, MDICP<sup>i</sup> 2006

	Odds Ratio	95% CI	Odds Ratio	95% CI
Age	1.01	(0.99- 1.03)	0.79**	(0.70- 0.90)
Age squared	---	---	1.00**	(1.00- 1.00)
<b>Education</b>				
No education (ref)	---	---	---	---
Primary school level	0.83	(0.52- 1.32)	0.60	(0.25- 1.48)
Secondary level or higher	0.82	(0.34- 2.00)	0.64	(0.20- 2.06)
<b>Region of residence</b>				
South (ref)	---	---	---	---
Central	1.77*	(1.11- 2.82)	1.86	(0.86- 4.03)
North	0.84	(0.46- 1.53)	0.52	(0.20- 1.36)
<b>Economic status</b>				
Bicycle	0.69	(0.45- 1.05)	0.30**	(0.15- 0.61)
Radio	0.54*	(0.35- 0.83)	0.81	(0.39- 1.69)
Iron sheet roof	1.36	(0.75- 2.47)	1.26	(0.42- 3.77)
<b>Marital characteristics</b>				
Polygamous marriage	0.44	(0.15- 1.28)	1.78	(0.71- 4.42)
Condom use with spouse is acceptable	0.71	(0.45- 1.12)	1.90	(0.83- 4.35)
Worried about HIV/AIDS infection from other partners	1.56	(0.96- 2.53)	1.75	(0.93- 3.31)
<b>Autonomy</b>				
Acceptable for wife to attend health center without permission from husband	1.74*	(1.01- 2.99)	2.08*	(1.06- 4.09)
Acceptable for wife to refuse sex if she thinks husband is HIV positive	0.83	(0.55- 1.24)	0.60	(0.30- 1.21)
<b>HIV</b>	2.97**	(1.65- 5.34)	2.26	(0.61- 8.45)
<b>Stigma index</b>	1.22**	(1.05- 1.42)	0.97	(0.70- 1.33)
Pseudo R2	0.10		0.15	
N=	916		636	

Malawi Diffusion and Ideational Change Project (MDICP)

P-value for odds ratio significant at  $p < 0.05$ \* Value significant,  $p < 0.01$ \*\*

**Table 4**

Chi squared tests of differences in percentages of respondents who claim that they disclosed their HIV status to their spouse whose report is confirmed by their spouse, MDICP<sup>i</sup> 2006

	Husband told wife his HIV test result		
	Husband HIV Negative	Husband HIV Positive	Total
Wife states that husband didn't disclose HIV status	3.9%	15.4% *	4.3%
Wife states that husband disclosed HIV status	96.1%	84.6% *	95.7%
Sample size	410	13	423
	Wife told husband her HIV test result		
	Wife HIV Negative	Wife HIV Positive	Total
Husband states that wife didn't disclose HIV status	2.7%	6.7%	2.8%
Husband states that wife disclosed HIV status	97.3%	93.3%	97.2%
Sample size	376	15	391

<sup>i</sup>Malawi Diffusion and Ideational Change Project (MDICP)

Chi<sup>2</sup> difference between HIV positive and HIV negative significant at  $p < 0.05^*$ , Value significant,  $p < 0.01^{**}$