

To Tell or Not to Tell: Disclosure of HIV Status Among Rural Malawians

Philip Anglewicz

Abstract

With growing access to HIV testing throughout sub-Saharan Africa, the reaction to learning one's HIV status becomes an increasingly important factor in determining the course of the AIDS epidemic. A growing number of studies reveal action being taken by individuals to prevent becoming infected with HIV, and an important component of such behavior change is to know one's own HIV status and the HIV status of a spouse. In this paper, I use data from rural Malawi to examine an aspect of VCT that is relevant to both behavior change and divorce in sub-Saharan Africa: to what extent do couples share their HIV test results after VCT? To what extent do individuals share their HIV test results with others in the community? In addressing these questions, I investigate whether differences in disclosing HIV status are associated with actual HIV status and with gender.

Background

Although access to HIV voluntary counseling and testing (VCT) is limited for most residents of sub-Saharan Africa, UNAIDS and WHO recently announced intentions to dramatically expand VCT access throughout the region (UNAIDS/WHO 2007). As the number of people who know their HIV status increases, the reaction to learning one's HIV status becomes an increasingly important factor in determining the course of the AIDS epidemic. For example, some suggest that learning one's HIV status leads to the adoption of safe behaviors that prevent the HIV infection (Coates 2000). Others have shown that divorce often occurs among HIV-discordant couples in Africa (Porter et al 2004). In this paper, I use data from rural Malawi to examine an aspect of VCT that is relevant to both behavior change and divorce in sub-Saharan Africa: to what extent do couples share their HIV test results after VCT? To what extent do individuals share their HIV test results with others in the community? In addressing these questions, I investigate whether differences in disclosing HIV status are associated with actual HIV status and with gender.

Disclosing HIV status is important for several reasons. First, because HIV is often transmitted between spouses (de Zousa, Sweat and Denison 1996; Heise and Elias 1995; King et al 1993; McKenna et al. 1997), communication of HIV results between spouses is critical for individuals to be aware of their risk of HIV infection and have the opportunity to take action to prevent infection. In addition, in order to receive treatment and care for HIV infection, it may be helpful to have the support of a spouse to ensure that treatment is adhered to and proper support is provided. Similarly, some communities may have home-based care groups that provide assistance to HIV positive individuals who have declared their HIV status. Also, research has shown that reducing stress is particularly important for individuals infected with HIV/AIDS, and keeping their condition a secret (particularly from a spouse) may contribute to unhealthy levels of stress.

Finally, in addition to individual benefits, disclosing one's HIV status may be important to communities as a whole. An important component of HIV risk perception is perceived HIV prevalence in the community (Anglewicz and Kohler 2005). Knowledge of the HIV status of others in the community presumably informs perceived HIV prevalence. If HIV positive individuals are less likely to disclose their HIV status then perceived prevalence may be biased.

Despite the importance of HIV status disclosure, particularly for HIV positive individuals, there are several barriers that prevent widespread disclosure, including fear of divorce or abandonment (Maman et al 2001, Medley et al 2004), fear of physical abuse from spouse (Kumar et al), or fear of stigma and discrimination in the community (Kumar et al 2006, Lie et al 1996), or social isolation.

Goals of the paper and research questions

1. To investigate the extent to which MDICP respondents communicate their HIV test results to their spouse, and whether this varies by gender, and by actual HIV status. What percentage of MDICP men and women report that they *would* tell their spouse if they were HIV positive? What percentage of MDICP respondents report *actually disclosing* their HIV status to others, particularly their spouse?
2. To verify reported claims of disclosing HIV status to a spouse with the spouse's report of having been told their spouse's HIV status. Given the sensitive nature of many survey questions related to sexual behavior, individuals often do not accurately report their behavior (Pool et al 1996). Similarly, the literature indicates that disclosure of HIV status is also a sensitive topic for some (examples). Several studies examine rates of HIV result disclosure, but none have confirmed reports of disclosure with spouse's report that they were indeed told the HIV status of their husband or wife. For respondents who say they have disclosed their HIV test result to a spouse, for what percentage is this report confirmed by the spouse?
3. To identify reasons why some MDICP respondents do not disclose their HIV test results to their spouse or to others in the community, and examine whether this varies by gender or actual HIV status. Why do respondents not tell their HIV status to others? Does disclosure to a spouse vary by economic status, age or duration of marriage? Is perceived stigma in the community an important determinant of HIV status disclosure?
4. To investigate the extent of diffusion of HIV test results within a community by finding out the number of individuals who disclosed their HIV test result to MDICP respondents. To what extent do MDICP respondents report that others in the community told them their HIV test results?

Data and methods

The data for this analysis come from the Malawi Diffusion and Ideational Change Project (MDICP), a panel survey that examines the role of social networks in changing attitudes and behavior regarding family size, family planning, and HIV/AIDS in Malawi. Since 1998, MDICP has collected data in three areas of rural Malawi, representing each region of the country: Rumphi in the northern region, Mchinji (central) and Balaka (south). MDICP conducted its first wave of data collection for 1,541 ever-married women and 1,065 of their spouses in 1998, and subsequent waves of MDICP took place in 2001 and 2004. A detailed description of the data and an assessment of MDICP data quality is available in Bignami, Reniers and Weinreb (2003) and Anglewicz et al (2007).

For this analysis, I utilize three features of MDICP data that are particularly relevant to marriage and HIV status disclosure in rural Malawi. First, MDICP data is merged by spouse, which allows me to conduct this analysis at the level of the most at risk of contracting HIV in rural Malawi: currently married men and women (Bracher et al 2003). By merging MDICP data by spouse in 2004 and 2006, I can estimate the percentage of

individuals who agree and disagree with their spouse's claim that they disclosed their HIV status after being tested.

In addition, HIV biomarkers are also available for men and women in the MDICP sample. In 2004 and 2006, HIV biomarkers were collected for all MDICP respondents in the sample who consented to be tested (Bignami Van-Assche et al 2004). This allows me to investigate if there are differences by HIV status in (1) the intention to disclose HIV test results to a spouse, and (2) reported actual disclosure of HIV status. Then, if HIV positive respondents are less likely to disclose their HIV status to others in the community (particularly the spouse), I identify reasons for this secrecy. To do so, I run logistic regressions to estimate the effect of covariates on respondents' reports of having disclosed their HIV test result to a spouse versus keeping their HIV test result secret. I focus on differences by gender: are HIV positive women less likely to reveal their HIV status to their husbands than HIV negative women? Are HIV positive women less likely to disclose their HIV status to their spouse than HIV positive men? Are HIV positive women less likely to tell anyone their HIV test results? If so, is this due to fear of divorce, fear of HIV stigma in the community, or another reason?

Finally, since MDICP collected longitudinal data for HIV biomarkers and HIV status disclosure information, I can compare the intention of disclosing HIV test results in 2004 with actual reporting of HIV status disclosure in 2006, to see if MDICP respondents fulfill their stated intention to disclose their HIV status after HIV testing. HIV prevalence was 4.4% and 6.1% for men and women respectively, in 2004; and increased to 5.5% of men and 7.6% of women in 2006. Thus the vast majority were negative. Since it is no surprise to find, as I do, that the negatives were more likely to disclose their results than the positives, I focus here on the disclosure by the positives. I give equal weight, however, to disclosure to a spouse and disclosure to others in the community. The extent of HIV test result diffusion within a community is an important issue, since MDICP research has shown that perceived HIV prevalence is an important determinant of perceived HIV risk (Anglewicz and Kohler 2005).

Preliminary Results

1. **Table 1:** Before being tested for HIV in 2004, what percentage of MDICP men and women report that they *would* tell their spouse if they were HIV positive?
 - 88% of women and 89% of 2004 women and men interviewed in 2004 state that they would tell their spouse if they were HIV positive. It is interesting that there are no differences by gender in reporting the intention to tell a spouse if one is HIV positive.
 - This percentage increases for both men and women by 2006: approximately 94% of both men and women state that they would tell their spouse if they were HIV positive.
 - Is this different by HIV status?
 - There are no significant differences in the intention to tell a spouse if one is HIV positive by actual HIV status in 2004, for either men

or women. By 2006, HIV positive men are significantly more likely to state that they would tell their spouse if they were HIV positive than men who are HIV negative. There are no significant differences by HIV status for women.

2. **Table 2:** What percentage of MDICP respondents report *actually disclosing* their HIV status to others, particularly their spouse?
- Disclosing HIV test result to a spouse:
 - Overall, of MDICP men and women who were tested for HIV and received their HIV test result, approximately 86% of women and 92% of men report disclosing their HIV test result to their spouse by 2006.
 - It is interesting that the percentage of respondents who report that they *did* disclose their HIV test result to their spouse is smaller than the percentage of respondents who state that they *would* disclose their HIV test result to a spouse in 2004 and 2006.
 - Are there differences in reporting of disclosure by HIV status?
 - There are significant differences in disclosing HIV test result by actual HIV status for women. Women who are HIV positive are significantly less likely to tell their spouse: 67% of HIV positive women told their test result to their spouse, compared with 86% of HIV negative women.
 - There are no significant differences by HIV status for men- over 90% of both HIV positive and HIV negative men reported disclosing their test result to their spouse.
 - To what extent do MDICP respondents disclose their HIV test results to others in the community?
 - Approximately 40% of men and women also report disclosing their HIV status to a relative. 33% of women and 42% of men report telling their HIV status to a friend. 4.5% of women and 1% of men report not telling their HIV status to anyone.
 - There are differences in test result disclosure by actual HIV status for these other categories as well. Women who are HIV positive were significantly less likely to tell their status to a friend, and were significantly more likely to not tell anyone their HIV status. However, women who are HIV+ are significantly more likely to tell a traditional healer. There are no significant differences for men in disclosing HIV status by actual HIV status.
 - **Table 3:** Spouse disclosure of HIV status. Respondents were asked with whom their spouse shared their HIV test results, including the respondent themselves.
 - 91% of women and 95% of men report that their spouse told them their HIV test results. As with respondent's reports of disclosing their own HIV test result, telling a friend and relative were the most frequent categories, besides the spouse: 28% of women and 39% of men report that their spouse told their HIV status to a

relative, and 20% of women and 23% of men state that their spouse told their HIV test result to a friend.

- There are significant differences in spousal reporting of HIV status by actual HIV status. Women who are HIV positive were significantly less likely to state that their spouse told them their HIV test result. Women who are HIV positive were significantly more likely to state that their spouse didn't disclose their HIV status to anyone. Men who are HIV positive were significantly more likely to state that their wife told their HIV status to a traditional healer.
- There are interesting discrepancies between Table 2 and Table 3. First, 86% of women state that they told their spouse their HIV status. However, 95% of men claim that their wives told them their HIV status.
- Comparing spousal reports is closer for disclosure for husbands: 92% of men state that they disclosed their HIV test result to their spouse, and 91% of women state that their husband told them their HIV test result.

3. **Table 4:** For respondents who say they have disclosed their HIV test result to a spouse, for what percentage is this report confirmed by the spouse?

- Table shows the percentage of spouses who confirm and disagree with their spouse's claim that they disclosed their HIV status, by actual HIV status.
- First, nearly all spouses confirm that their spouse did indeed tell them their HIV test result. Among men who state that they disclosed their HIV status to their wife, only 4.4% of the wives disagree, and claim that their husband didn't tell them. Among women who state that they told their HIV test result to their husband, only 2.3% of husbands disagree.
- Does this vary by HIV status?
 - There are differences in confirmation by HIV status. A larger percentage of HIV positive respondents disagree with their spouse's claim that their spouse told them their HIV test result. For example, approximately 11% of HIV positive women disagree with their husband's claim that he told them his HIV test result, compared with 4.2% of HIV negative women who disagree with their spouse. Similarly, 5.9% of HIV positive men disagree, compared with only 2% of HIV negative men. Perhaps due to small sample sizes, these differences are not statistically significant, however.

4. **To do:** Why do respondents not tell their HIV status to others?

- Is this associated with perceived HIV stigma in the community?
- Is disclosing to a spouse associated with women's autonomy in marriage, or gender roles- or primarily due to fear of divorce among women?

5. **Table 5:** In addition to respondent's claims of telling their HIV status to others in the community, it is also interesting to see how many people MDICP respondents say have disclosed their HIV status to them. To what extent do MDICP respondents report that others in the community told them their HIV test results?
- How many people have told our respondents that they were tested, and how many disclosed their HIV test results?
 - Knowledge of HIV testing experience and HIV status of others in the community is common among MDICP respondents. Both MDICP men and women report an average of approximately 6 people in their community who they know were tested for HIV.
 - Of these people, an average of 2.4 disclosed their HIV status to female respondents and 2.7 disclosed their HIV status to male respondents. Only approximately 12% of men and women state that no one in the community disclosed their HIV test result to them, and over 22% of both men and women claim that more than 10 people told them their HIV test result.
 - Although there are some differences by HIV status in reported number of people known tested and who told the respondent their HIV test result, these differences are not statistically significant for either men or women. So whereas HIV positive women were less likely to disclose their HIV status to others, HIV positive respondents were not less likely to learn the HIV status of others.
 - Comparing the number known tested with the number of people who disclosed their HIV test results to MDICP respondents, 40% of people who MDICP women know were HIV tested told them their HIV test results, and 44% of individuals who male respondents know were HIV tested disclosed their test results to them.
 - **To do:** For what percentage of social network partners do respondents report being told HIV test results and discussions about HIV testing?

Table 1: If you found out you were HIV positive, would you tell your spouse or partner?

	Women				Men				
	2004 HIV+	2004 HIV-	Total	2006 HIV-	2006 HIV+	Total	2004 HIV-	2004 HIV+	Total
Wouldn't tell spouse if HIV+	10.1	12.0	11.9	6.3	6.3	6.3	10.8	16.1	11.2
Would tell spouse if HIV+	89.9	88.0	88.1	93.7	93.7	93.7	89.2	83.9	88.8
N=	89	994	1229	111	1343	1343	771	62	833
				1232				48	
				92.8				100.0	
				94.0‡				94.0‡	
				6.0‡				5.7	
				94.3				94.3	
				862				862	
				910				910	

Difference between HIV positive and HIV negative significant **at 1% *at 5% ‡ at 10%

Table 2: Disclosure of HIV test results by 2006 HIV status for MDICP men and women: 2006 MDICP data

Shared HIV test results with	Women			Men		
	HIV Negative	HIV Positive	Total	HIV Negative	HIV Positive	Total
Spouse	86.0%	66.7%**	85.7%	91.8%	92.9%	91.8%
Other sexual partners	1.3%	1.5%	1.2%	2.0%	0.0%	1.9%
Relative	41.5%	50.0%	42.3%	39.6%	39.3%	39.6%
Friend	33.0%	21.2%*	32.9%	41.4%	53.6%	42.0%
Doctor/traditional healer	0.3%	3.0%*	0.5%	0.9%	3.6%	1.0%
Nobody	3.7%	9.1%*	4.5%	0.9%	3.6%	1.0%
N=	751	66	817	558	28	586

Chi² difference between HIV positive and HIV negative significant **at 1% *at 5% ‡ at 10%

Table 3: Spouse disclosure of HIV test results by 2006 HIV status for MDICP men and women: 2006 MDICP data

Spouse disclosed HIV test result to:	Women			Men		
	HIV Negative	HIV Positive	Total	HIV Negative	HIV Positive	Total
Respondent	91.3%	80.9%*	90.7%	95.6%	92.6%	94.5%
Other spouses	12.5%	4.3%‡	12.0%	1.3%	0.0%	1.2%
Other sexual partners	2.0%	2.1%	2.0%	0.9%	0.0%	0.9%
Relative	28.2%	25.5%	28.0%	38.7%	44.4%	39.0%
Friend	20.7%	12.8%	20.2%	22.9%	22.2%	22.8%
Doctor/traditional healer	0.6%	0.0%	0.5%	0.4%	3.7%*	0.5%
Nobody	2.5%	8.5%*	2.9%	0.9%	0.0%	0.8%
N=						

Chi² difference between HIV positive and HIV negative significant **at 1% *at 5% ‡ at 10%

Table 4: For respondents who claim that they disclosed their HIV test result to their spouse, what percentage is confirmed by their spouse's report

	Women		Total
	HIV Negative	HIV Positive	
Wife says husband didn't disclose HIV status	4.2%	10.5%	4.4%
Wife agrees that husband disclosed HIV status	95.8%	89.5%	95.6%
N=	386	19	405

	Men		Total
	HIV Negative	HIV Positive	
Husband says wife didn't disclose HIV status	2.1%	5.9%	2.3%
Husband agrees that wife disclosed HIV status	97.9%	94.1%	97.7%
N=	378	17	395

Table 5: Disclosure of HIV test results to MDICP respondents from others in the community

	Women		Men		Total
	HIV Negative	HIV Positive	HIV Negative	HIV Positive	
Mean number known tested and received results	6.1 (6.9)	5.1 (5.4)	6.2 (7.7)	6.8 (8.4)	6.2 (7.7)
Mean number told results to respondent	2.4 (2.4)	2.3 (2.8)	2.6 (3.0)	3.2 (4.8)	2.7 (3.1)
Number told results					
No one disclosed results to respondent	12.1%	16.3%	12.5%	10.6%	12.4%
1-4 disclosed results	37.8%	43.6%	41.8%	38.3%	41.6%
5-9 disclosed results	25.9%	20.9%	23.3%	25.5%	23.4%
10+ disclosed results	24.1%	19.1%	22.4%	25.5%	22.5%
N=	1218	110	845	47	892

Notes: standard deviations are in parenthesis

T-tests were used to compare differences in means in disclosure of results to respondents. Difference between HIV positive and HIV negative significant **at 1% *at 5% † at 10%

References

Anglewicz P., and H.P. Kohler (2006). "Overestimating HIV infection: the construction and accuracy of subjective probabilities of HIV infection in rural Malawi." Paper presented at the Annual Meeting of the Population Association of America, April 27-30, Los Angeles, CA, USA.

Anglewicz, P., J. Adams, F. Obare, S. Watkins, and H.-P. Kohler (2007). The Malawi Diffusion and Ideational Change Project 2004–06: Data collection, data quality and analyses of attrition. Unpublished working paper, Population Studies Center, University of Pennsylvania, Philadelphia, PA. Available online at <http://www.malawi.pop.upenn.edu>.

Bignami-Van Assche, Simona, Georges Reniers, Alexander A. Weinreb. 2003. "An Assessment of the KDICP and MDICP Data Quality" *Demographic Research* S1(2): 31-76.

Bracher, M, Santow, G., & Watkins, S. C., 2003. A microsimulation study of the effects of divorce and remarriage on lifetime risk of HIV/AIDS in rural Malawi. Paper presented at the Annual Meeting of the Population Association of America, Minneapolis, MN.

Bignami-Van Assche, Simona et al. 2004. "Protocol for biomarker testing in the 2004 Malawi Diffusion and Ideational Change Project" SNP Working Paper No.7, Philadelphia: University of Pennsylvania.

UNAIDS and WHO press release, 2007. Available at: <http://www.who.int/mediacentre/news/releases/2007/pr24/en/index.html>

de Zoysa, I., Sweat, M.D. and Denison, J.A., 1996. "Faithful but fearful: Reducing HIV transmission in stable relationships". *AIDS*, **10** Suppl. A, pp. S197–S203.

Heise, L.L. and Elias, C., 1995. "Transforming AIDS prevention to meet women's needs. A focus on developing countries". *Social Science and Medicine* **40** 7, pp. 931–943.

King, R., Allen, S., Serufilira, A., Karita, E. and Van de Perre, P., 1993. "Voluntary confidential HIV testing for couples in Kigali, Rwanda". *AIDS* **7**(10), pp. 1393–1394.

McKenna, S.L., Muyinda, G.K., Roth, D., Mwali, M., Ng'andu, N., Myrick, A., Luo, C., Priddy, F.H., Hall, V.M., von Lieven, A.A., Sabatino, J.R., Mark, K. and Allen, S.A., 1997. "Rapid HIV testing and counseling for voluntary testing centers in Africa". *AIDS* **11** Suppl. 1, pp. S103–S110.

Maman S et al. Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary testing and counselling. *AIDS Care*, 2001; **13**:595-603.

Lie GT, Biswalo PM. HIV-positive patient's choice of a significant other to be informed about the HIV-test result: findings from an HIV/AIDS counselling programme in the regional hospitals of Arusha and Kilimanjaro, Tanzania. *AIDS Care*, 1996; 8:285-296.

Antelman G et al. Predictors of HIV-1 status disclosure: A prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *Aids*, 2001; 15:1865-1874

Medley, Amy, Claudia Garcia-Moreno, Scott McGill, & Suzanne Maman (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization* | April 2004, 82 (4).

Kumar, Alok, Ira Waterman, Geeta Kumari, Anne Carter (2006). Prevalence and Correlates of HIV Serostatus Disclosure: A Prospective Study Among HIV-Infected Postparturient Women in Barbados. *AIDS PATIENT CARE and STDs*. Volume 20, Number 10.