



Published in final edited form as:

AIDS Care. 2012 ; 24(9): 1173–1180. doi:10.1080/09540121.2012.699669.

Factors Associated with Pregnant Women's Anticipations and Experiences of HIV-related Stigma in Rural Kenya

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Abstract

Pregnant women who fear or experience HIV-related stigma may not get care for their own health or medications to reduce perinatal transmission of HIV. This study examined factors associated with anticipating and experiencing HIV-related stigma among 1,777 pregnant women attending antenatal care clinics in rural Kenya. Women were interviewed at baseline, offered HIV testing and care, and a sub-set was re-interviewed at 4–8 weeks postpartum. Women who were older, had less education, whose husbands had other wives, and who perceived community discrimination against people with HIV had significantly greater adjusted odds of anticipating HIV stigma. Over half of the HIV-positive women interviewed postpartum reported having experienced stigma, much of which was self-stigma. Women experiencing minor depression, and those whose family knew of their HIV status had significantly greater adjusted odds of experiencing stigma. Lack of women's empowerment, as well as depression, may be important risk factors for HIV-related stigma and discrimination.

Keywords

HIV; stigma; pregnancy; Kenya; empowerment

Introduction

In Kenya in 2009, approximately 1.3 million adults were living with HIV and 58% of them were women (UNAIDS & World Health Organization, 2010). The advent of antiretroviral (ARV) medications has transformed HIV into a chronic illness for many people (Gifford & Groessl, 2002), allowing them to live longer and healthier lives after an HIV diagnosis, as well as reducing the risk of perinatal transmission (The International Perinatal HIV Group, 1999). Although the physical health outlook for people living with HIV has improved in recent years, the issue of stigma remains as an important factor adversely affecting health and quality of life.

Since HIV/AIDS was first identified, the disease has been surrounded by stigma and discrimination. People who are infected, or even suspected of having HIV, have experienced emotional, physical, and structural abuse (Dlamini et al., 2007; Kohi et al., 2006), and the fear of experiencing such stigma can become a substantial barrier for HIV testing and treatment (Pulerwitz, Michaelis, Weiss, Brown, & Mahendra, 2010). In many countries of Africa, women are disproportionately affected, not only by the disease itself, but also by the related stigma and discrimination (Bond, Chase, & Aggleton, 2002). Women who experience or fear stigma may be less likely to access health care services, and research has shown that pregnant women who anticipate HIV-related stigma are less likely to get tested for HIV (Turan, Miller, Bukusi, Sande, & Cohen, 2008). The result is that pregnant women may not be aware of their HIV-positive status, may not get the care that they need for their own health, may infect sexual partners, and may not receive medications to reduce the risk of perinatal transmission of HIV (Desrees-du-Lou et al., 2009).

Having a greater understanding of the characteristics of women most likely to fear or experience HIV-related stigma may help health care workers identify women at risk and provide more appropriate advice and services. This may be particularly important for pregnant women, with whom there has been relatively little research on the issue of stigma. The purpose of this study was to identify factors associated with anticipating and experiencing stigma among pregnant women attending antenatal care clinics in rural Kenya.

Methods

The data and analyses presented here are part of a larger longitudinal study conducted by the University of California, San Francisco (UCSF) and the Kenya Medical Research Institute (KEMRI), who jointly run the Family AIDS Care and Education Services (FACES) program in Kenya. The general objective of the larger study (the Maternity in Migori and AIDS Stigma (MAMAS) Study) was to examine the effects of HIV-related stigma on use of maternity and HIV services by pregnant women (Turan et al., 2011). The institutional review boards of KEMRI and UCSF reviewed and approved the study. After receiving an explanation about the study, those who chose to be in the study gave their consent to participate and to have their HIV test results abstracted from their medical records.

Sample

Women were recruited for the MAMAS study from nine health facilities in rural Nyanza Province, Kenya (Turan, et al., 2011). They were eligible to participate if they were 18 years of age or older, in the first seven months of pregnancy, appearing for their first antenatal care (ANC) visit of their current pregnancy, and did not know their current HIV status (never tested or tested negative more than 3 months ago). Participants were interviewed by a trained interviewer in local languages (Dholuo, Swahili, and English) before their ANC visit. During the ANC visit, they were offered HIV testing and counseling as per Kenyan national guidelines.

Of the 1,777 women with baseline data, 598 were selected for participation in subsequent follow-up interviews. All of the women who tested positive for HIV or who refused HIV testing after the baseline interview were automatically selected for follow-up. In addition, a random sample of those who tested HIV-negative was also selected, using a computer-based random number generator. Our analyses of experienced stigma focus only on the 411 women (69% of those selected for follow-up) who could be located and participated in the follow-up interview 4–8 weeks after the birth. Of these 411, 154 tested HIV-positive at baseline (68.1% of HIV-positive women selected for follow-up), 165 tested negative at baseline (72.7% of those selected), 52 refused HIV testing at baseline (61.2% of those

selected), and 40 did not have HIV testing services available on the day they visited the ANC clinic at baseline (66.7% of those selected).

Independent Variables

Socio-demographics—These included age, ethnicity, religion, education, reading ability, marital status, whether the husband had other wives, reproductive history, the woman's main contribution to support of the household (housework, selling things, farming/agriculture, other), and household ownership of goods as a proxy of wealth (electricity, radio, television, landline telephone, cell phone, refrigerator). Age was dichotomized into <25 years and 25+ due to the lack of normal distribution, and because peak fertility in Kenya occurs around age 25 (Kenya National Bureau of Statistics (KNBS) & ICF Macro, 2010). Since the vast majority of participants were Luo, ethnicity was not included as a variable in the multivariable analysis. Religion was excluded because of the very wide range of religions reported.

HIV Knowledge—Two questions were assessed: “Do you think a healthy-looking person can be infected with HIV, the disease that causes AIDS?” and “Can the HIV virus be transmitted from mother to child during delivery?”

HIV Status—If the woman agreed to HIV testing during her initial ANC visit, her HIV status was obtained from her medical record, per her consent. If she was not tested for HIV at the initial ANC visit, she was asked her status at the follow-up interviews, though she may have declined to state.

Disclosure—At the postpartum interview, women were asked whether they had disclosed the results of their HIV test and to whom. They were also asked who knew about their HIV status, in order to identify situations in which she did not herself disclose.

Perceived Stigma (Genberg et al., 2009; Genberg et al., 2008)—This is a 22-item instrument, rated on a Likert scale from 0–3. It assesses (1) the respondent's own negative attitudes toward people living with HIV/AIDS (PLHA), (2) the respondent's perception of discrimination that PLHA experience in the community, and (3) the respondent's opinions about equity that PLHA should have. The scale has been tested in Tanzania, Zimbabwe, and South Africa and Cronbach's alpha reliability scores of .86, .82, and .81 have been obtained for the sub-scales (Genberg, et al., 2009). In the multivariable analysis, the equity sub-scale was excluded because of low reliability (Genberg, et al., 2009). The negative attitudes sub-scale was excluded due to collinearity with the perceived discrimination sub-scale. We dichotomized the perceived discrimination sub-scale variable by whether or not the woman answered yes to any of the items.

Edinburgh Postpartum Depression Scale (Cox, Holden, & Sagovsky, 1987; Pop, Komproe, & van Son, 1992)—The 10-item EPDS was originally designed to screen women for postpartum depression. The items ask about the woman's experiences in the past seven days, and responses are coded on a Likert scale from 0–3. When validated among pregnant women, the reliability scores by trimester were .82, .83 and .84 (Bergink et al., 2011). A cut-off of 13 is recommended for probable major depression and a cut-off of 10 is recommended for probable minor depression (Matthey, Henshaw, Elliott, & Barnett, 2006).

Outcome Variables

Anticipated Stigma Scale (Wolfe et al., 2006)—This 9-item scale measures whether or not a person anticipates experiencing stigma or discrimination from various sources if one

is found to be HIV-positive and one's HIV-positive status is disclosed to others. In this study, this construct was measured at baseline, when none of the women knew their current HIV status. The instrument was developed and tested in Botswana (Cronbach's $\alpha = 0.77$) (Wolfe, et al., 2006). We dichotomized the scale into those who anticipated 0–2 forms of stigma, and those who anticipated more than two forms of stigma. In this way, we were able to identify those who anticipated a substantial burden of stigma.

HIV/AIDS Stigma Instrument-PLWA (HASI-P) (Holzemer et al., 2007)—This 33-item instrument measures experiences of stigma among people living with HIV, and consists of six subscales (Cronbach's $\alpha = .76$ to $.91$): verbal abuse, negative self-perception (self stigma), healthcare neglect, social isolation, fear of contagion, and workplace stigma. On a scale of 0–3, participants rate how often various stigmatizing events have happened to them in the past few months, because of their HIV status. The HASI-P was developed and tested in Lesotho, Malawi, South Africa, Swaziland and Tanzania (Holzemer, et al., 2007). Both total and subscale experienced stigma scores at postpartum were dichotomized because of low reports of experienced stigma, possibly due to low levels of disclosure by this point.

Analysis

Bivariate logistic and linear regression methods were used to examine factors that were *a priori* considered to be associated with the outcomes based on the literature. Variables that were associated with the outcomes ($p < .10$) were entered into multivariable regression models in order to identify significant predictors of anticipated and experienced stigma. We adjusted these analyses for clustering by clinic, using mixed models. All analyses were conducted using Stata 11 (StataCorp, 2009).

Results

At baseline, the mean age of the 1,777 participants was 24 years (Table 1), and most had only primary education or less. Most were married and currently living with a male partner and, of these, 27% had husbands who had other wives. Among the women who were selected for follow-up, only radio ownership (as a proxy for wealth) and number of living children were significantly different between those who could be located and participated in a postpartum interview, and those who were lost to follow-up.

Anticipated HIV-related stigma

Anticipated stigma was measured at baseline, when none of the participants knew their current HIV status. Women 25 years or older had 1.4 (95% CI 1.0, 2.0) greater adjusted odds of anticipating substantial stigma than younger women ($p=.03$), after adjustment for other variables in the model (Table 2). Similarly, women who had primary education or less (Adjusted Odds Ratio (AOR)=1.8; 95% CI 1.2, 2.8; $p=.004$), who could read only with difficulty (AOR=1.60; 95% CI 1.2, 2.1; $p=.001$), and whose husbands had other wives (AOR=1.5; 95% CI 1.2, 2.0; $p=.002$) had greater adjusted odds of anticipating substantial stigma. Women who perceived discrimination in the community against PLHA had 10.2 greater adjusted odds of anticipating substantial stigma for themselves if they were to become HIV-positive ($p<.0001$). Conversely, women who knew that HIV can be transmitted during delivery had lesser adjusted odds of anticipating substantial stigma (AOR=.5; 95% CI 0.3, 0.8; $p=.003$). Similar results were obtained in analyses using the different sources of the anticipated stigma as the outcomes (partner, family, community) (data not shown).

Experienced HIV-related stigma

Experienced HIV-related stigma was measured only at follow-up, and only among women who had tested positive for HIV. At the postpartum visit, over half (55.8%) of the HIV-

positive women reported experiencing any stigma in the past few months, due to their HIV status. This was largely driven by the 45.5% of the women who said they had experienced self-stigma, but women experienced a range of types of stigma: verbal abuse (6.1%), healthcare neglect (7.9%), social isolation (4.9%), fear of contagion (3.0%), and workplace stigma (11.5%). Women who anticipated more stigma at baseline were no more likely to actually experience stigma than other women, although levels of anticipated and experienced stigma were substantial.

Using an EPDS cut-off score of 13, women experiencing probable major depression at the postpartum visit tended to be more likely to have experienced any HIV-related stigma, as were women whose families knew their HIV status (data not shown). Using the lower EPDS cut-off score of 10, however, women experiencing probably minor depression and those whose family knew their HIV status had had significantly greater adjusted odds of having experienced stigma in the past few months (Table 3). Other factors associated with experienced stigma in the bivariate analyses were not found to be significant in the multivariate analysis. Looking at just self-stigma, women who were experiencing probable minor depression at postpartum had 4.6 times greater adjusted odds (95% CI 1.7, 12.9; $p=.003$) of experiencing HIV-related self-stigma, compared to women without depression. No other factors were found to be independently associated with self stigma.

Discussion

Women who were older, had less education, whose husbands had other wives, and who perceived community discrimination against people with HIV had significantly greater adjusted odds of anticipating HIV stigma for themselves if they were to test HIV-positive in the future. Pregnant women who were married to men who had other wives (in a polygynous relationship) were particularly likely to anticipate HIV/AIDS stigma at baseline. It may be that women in polygynous relationships lack power and stability, resulting in concern about the consequences of their HIV status being disclosed to others. Muldoon and colleagues (Muldoon et al., 2011) report higher levels of sexual risk behaviors among men in polygynous relationships, and a trend toward men having greater control over decisions regarding sex in such a relationship. Bove and Valleggia describe polygyny as a situation of “co-operative conflict,” where women benefit from cooperating with their co-wives, but also must compete with them for affection and resources of the husband (Bove & Valleggia, 2009). In such a situation, disclosure of HIV status may put a woman at a disadvantage in her relationships with both her husband and co-wives, making her less likely to disclose and get the care she needs.

Although lack of education and HIV knowledge may be associated with being in a polygynous relationship, both showed independent effects on the anticipation of stigma, and both may be related to an overall lack of empowerment. As Bond, Chase and Aggleton explain, “HIV and AIDS-related stigma, being linked to power and domination in the community as a whole, plays into, and reinforces, extant social inequalities” (p.348) (Bond, et al., 2002).

Women who perceived more HIV-related stigma in their communities also anticipated stigma for themselves if they tested positive for the disease and their status were disclosed. Both experiences of stigma and fears of stigma can have negative effects on health behavior and health outcomes. Stigma has been shown to be associated with psychological distress and with negative health outcomes (Quinn & Chaudoir, 2009), and has also been shown as a substantial barrier to uptake of HIV testing and other health services (Kalichman & Simbayi, 2003; Meiberg, Bos, Onya, & Schaalma, 2008; Turan, et al., 2011; Turan, et al., 2008; Yang et al., 2006).

Over half of the HIV-positive women interviewed at postpartum reported having experienced some HIV-related stigma, much of which was self-stigma. Women whose family knew about their HIV status had experienced somewhat more stigma in the past few months compared to other women. While not surprising, it is unclear why disclosure to other sources (friends, health care workers, etc) showed less of an association with actual experiences of stigma. This may be because 33% of the women had not disclosed their HIV-positive status to anyone by the postpartum interview, or because expectations are worse than reality for these women.

Experienced stigma was also associated depression at the postpartum interview. It may be that women are depressed because of the stigma they had experienced, or that because of their depression they were more likely to view people's actions negatively and assume that they were related to her HIV status. Prior research from South Africa and the US has shown significant associations between internalized stigma and depression among both women and men (Lee, Kochman, & Sikkema, 2002; Simbayi et al., 2007; Vyavaharkar et al., 2010), and research in Canada has demonstrated an association between stigma and psychological distress among women of reproductive age (Wagner et al., 2010). This association could also be related to the recent birth of a child, which may have increased depression as well as perceptions of stigma among the women. At the postpartum visit, women who were experiencing depression were also more likely to experience self-stigma, but as these were both measured at the same visit, it is not possible to identify whether one predicts the other.

This study had several limitations. First, participants were recruited using convenience sampling, and selection bias through differential refusal to participate may have affected the results. However, the refusal rate among eligible antenatal clients was only 3.3% (Turan, et al., 2011). Second, we were not able to examine the role of religious affiliation because of the plethora of different religions reported. The emergence of polygynous relationships as an important predictor of anticipated stigma was unexpected, and a more in-depth understanding of wife rank/order, as well as other measures of women's empowerment, would be particularly useful in understanding stigma.

Finally, there was a 30% loss to follow-up for the postpartum interview, which although relatively low for a prospective study of pregnant women conducted in rural Africa, may have affected the validity of the results, and also left a fairly small sample of HIV-positive women for the analysis of experienced stigma. Those lost-to-follow up were very similar to those who were not lost-to-follow up, with the only significant socio-demographic differences being household ownership of a radio and number of children. Radio ownership is unlikely to have affected the results, but number of children may be an important factor. In Kenya, bearing children is expected, and having more children may bring more status and familial power for a woman. Thus, this difference may have had an impact on the results.

Conclusions

These results emphasize the complex nature of HIV-related stigma. Anticipated stigma was positively associated with the partner having other wives, low education, low HIV knowledge, and perceptions of discrimination in the community. For pregnant women with these characteristics, health care workers providing HIV counseling and testing services may consider additional counseling and interventions to reduce the impact of anticipated stigma on the women; to facilitate counseling, testing and treatment; and to ensure that women get the care that they, their male partners, and their children need.

Experienced stigma was associated with both disclosure and depression. Counseling women about the risks and benefits of disclosure, and interventions focused on safe disclosure could

help mitigate the impact of stigma on women's lives, and their decisions about accessing testing and care. Early screening of pregnant women for depression may also be warranted to reduce the effect of stigma.

When discussing stigma, most researchers simply refer to Erving Goffman's 1963 definition of "a deeply discrediting attribute." Goffman went on, however, to explain that stigma "requires a language of relationships," by which he meant that stigma is socially constructed. More recent theorists have built on this by emphasizing the essential role of differential power relationships in creating and perpetuating stigma. This research provides evidence to support these theories. The women who were most affected by stigma were those who were most disempowered within society. Though interventions may reduce the problem of stigma somewhat, larger social changes may be needed (Deacon, 2006; Link & Phelan, 2001; Parker & Aggleton, 2003).

Acknowledgments

This publication was supported by NIH/NCRR/OD UCSF-CTSI Grant TL1 RR024129. The MAMAS project was supported by NIH/NIMH Grant K01MH081777. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the National Institutes of Health.

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Table 1

Demographic, Health and Stigma Characteristics of Study Participants at Baseline (n=1,777)

Characteristic	Mean ± SD (or) # (%)
Age, years, mean ± SD, median	23.6 ± 5.4, 22.0 (range: 18–49)
Level of education completed	
Primary or less	1,483 (83.2%)
Secondary or more	294 (16.5%)
Literacy	
Read easily	764 (43.0%)
Read with difficulty	728 (41.0%)
Do not read at all	285 (16.0%)
Ethnicity (Luo)	1,641 (92.4%)
Religion	
Roman Catholic	331 (18.6%)
Seventh Day Adventist	583 (32.8%)
Other	863 (48.6%)
Marital Status	
Single (never married)	150 (8.4%)
Married	1,554 (87.5%)
Separated or Divorced	19 (1.1%)
Widowed	53 (3.0%)
Currently living with male partner (yes)	1,546 (87.1%)
Husband has other wives (yes) (valid n = 1,556)	439 (28.4%)
Woman's contribution to support of the household	
Housework	402 (22.6%)
Selling things	355 (20.0%)
Farming/agriculture	742 (41.8%)
Other	274 (15.6%)
Ownership of Household goods	
Electricity	64 (3.6%)
Radio	1,330 (74.9%)
Television	187 (10.5%)
Landline telephone	23 (1.3%)
Mobile phone	839 (47.2%)
Refrigerator	17 (1.0%)
Number of pregnancies, including current pregnancy (mean ± SD, median)	3.2 ± 2.0, 3.0 (range: 1–16)

Characteristic	Mean ± SD (or) # (%)
Number of live births (mean ± SD, median)	2.2 ± 2.0, 2.0 (range: 0–15)
Has living children (yes)	1,328 (74.7%)
HIV Knowledge Index (mean percent correct)	87.9%
HIV Status after first ANC visit	
HIV-positive	257 (14.5%)
HIV-negative	1,204 (67.8%)
Refused HIV Testing	99 (5.6%)
Testing Service Not Available	203 (11.4%)
Missing Result in Records	14 (0.8%)
Anticipated any stigma (valid n = 1,687)	1,136 (67.3%)
From partner (yes) (valid n = 1,582)	627 (39.6%)
From family (yes) (valid n = 1,686)	621 (36.8%)
From community/others (yes) (valid n = 1,608)	1,051 (65.4%)
Perceived any stigma	
Negative Attitudes (yes)	1,065 (61.5%)
Perceived Community Discrimination (yes)	782 (45.2%)

Table 2

Predictors of Anticipating More than Two Forms of HIV Stigma at Baseline (n=1,687)*

	OR (95% CI; p-value)	Adjusted OR** (95% CI, p-value)
Age		
< 25 years	(ref)	(ref)
25	1.3 (1.1, 1.6; p=.02)	1.4 (1.0, 2.0; p=.03)
Number of pregnancies		
1–3	(ref)	(ref)
4+	1.3 (1.0, 1.5; p=.03)	0.8 (0.6, 1.1; p=.16)
Education		
Primary or less	2.0 (1.5, 2.7; p<.001)	1.8 (1.2, 2.8; p=.004)
Secondary or more	(ref)	(ref)
Literacy		
Read easily	(ref)	(ref)
Read with difficulty	1.7 (1.3, 2.1; p<.001)	1.6 (1.2, 2.1; p=.001)
Not at all	1.8 (1.3, 2.4; p<.001)	1.2 (0.8, 1.8; p=.30)
Marital Status		
Single/Never married	(ref)	(ref)
Ever married	1.8 (1.2, 2.6; p<.01)	0.7 (0.2, 3.3; p=.65)
Husband has other wives	1.6 (1.3, 2.0; p<.001)	1.5 (1.2, 2.0, p=.002)
Lives with male partner	0.7 (0.5, 1.0; p=.03)	(excluded because of collinearity)
Woman's major contribution to support of the household is housework vs. other types of contribution	0.8 (0.6, 1.0; p=.03)	1.0 (0.7, 1.3; p=.83)
Ownership of Household goods		
Electricity	0.9 (0.5, 1.5; p=.64)	
Radio	0.9 (0.7, 1.1; p=.23)	
Television	1.0 (0.7, 1.3; p=.86)	
Landline telephone	0.8 (0.3, 1.0; p=.64)	
Mobile phone	0.8 (0.7, 1.0; p=.08)	1.0 (0.8, 1.2; p=.78)
Refrigerator	1.0 (0.3, 2.7; p=.95)	
Know that healthy-looking people can have HIV	0.6 (0.4, 0.8; p<.001)	0.9 (0.6, 1.2; p=.52)
Know that HIV can be transmitted during delivery	0.6 (0.4, 0.8; p=.01)	0.5 (0.3, 0.8; p=.003)
Has partner been tested for HIV (woman's report)		
Yes	(ref)	
No	0.9 (0.7, 1.2; p=.55)	
Don't know	0.8 (0.6, 1.1; p=.13)	
Know partner's test result		

	OR (95% CI; p-value)	Adjusted OR** (95% CI, p-value)
HIV-positive	(ref)	
HIV-negative	1.2 (0.5, 3.1; p=.67)	
Don't know	1.5 (0.5, 1.6; p=.48)	
Perceives any community stigma (yes)	5.1 (4.1, 6.3; p<.0001)	10.2 (7.1, 14.7; p<.0001)

* Sample size for adjusted odds ratios is 1,440.

** Analyses for adjusted odds ratios take into account clustering by site (clinic) using random effects logistic regression (mixed model).

Table 3

Final Model for Predictors of HIV-positive Women Experiencing any HIV-Related Stigma in the Past Few Months (n=147)

	OR (95% CI; p-value)	Adjusted OR* (95% CI, p-value)
Age (< 25 vs. ≥ 25)	1.0 (0.5, 2.0; p=.97)	0.5 (0.2, 1.3; p=.17)
Woman's major contribution to support of the household is housework	4.0 (1.4, 11.0; p=.01)	1.6 (0.4, 6.2; p=.5)
Family knows HIV-positive status	4.0 (1.3, 12.3; p=.02)	4.4 (1.0, 19.7; p=.05)
Perceives any community stigma on full scale (yes)	0.5 (0.3, 1.0; p=.04)	0.6 (0.2, 1.5; p=.23)
Depression (EPDS score of 10 or more)	4.9 (2.2, 10.9; p<.0001)	4.6 (1.5, 14.0; p=.01)

* Analyses for adjusted odds ratios take into account clustering by site (clinic) using random effects logistic regression (mixed model).