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Factors Affecting Disclosure in South African HIV-Positive Pregnant Women

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Abstract

To provide understanding of social and psychological factors that affect disclosure of HIV status among women diagnosed HIV-positive in pregnancy, 438 HIV positive women attending antenatal clinics in Pretoria, South Africa were invited to participate in a longitudinal study. A total of 293 (62%) women were enrolled from June 2003 to December 2004. Questionnaires assessing sociodemographics and psychological measures were administered during pregnancy and at 3 months postdelivery. At enrollment, 59% had disclosed to their partners and 42% to others. This rose to 67% and 59%, respectively, by follow-up. Logistic regression analysis identified being married (adjusted odds Ratio [AOR] 2.32; 95% confidence interval [CI] 1.20–4.47), prior discussion about testing (AOR 4.19; CI 2.34–7.49), having a partner with tertiary education (AOR 2.76; CI 1.29–5.88) and less experience of violence (AOR 0.48; CI 0.24–0.97) as factors associated with having disclosed to partners prior to enrollment. Better housing (AOR 1.26; CI 1.06–1.49), less financial dependence on partners (AOR 0.46; CI 0.25–0.85), and knowing someone with HIV (AOR 2.13; CI 1.20–3.76) were associated with prior disclosure to others. Increased levels of stigma at baseline decreased the likelihood of disclosure to partners postenrollment (AOR 0.91; CI 0.84–0.98) and increased levels of avoidant coping decreased subsequent disclosure to others (AOR 0.84; CI 0.72–0.97). These results provide understanding of disclosure for women diagnosed as HIV positive in pregnancy, and identify variables that could be used to screen for women who require help.

Introduction

Individuals diagnosed with HIV often have substantial difficulty telling others that they are infected and may not disclose their status to anyone. Presently, because of efforts worldwide to decrease perinatal HIV transmission, increasing numbers of women are being tested during pregnancy that can have unique implications regarding disclosure. A woman who finds out in pregnancy that she is HIV positive has only a relatively short period of time before the birth of her child to cope with her diagnosis and yet hiding her diagnosis may put her child at risk of HIV infection, if, fearing exposure, she feels unable to take her antiretroviral prophylaxis or choose a safe method to feed her baby.

A number of studies have documented that rates of disclosure are generally low, although they vary substantially in different populations. In a review of 17 studies from developing countries—15 from Africa—rates of disclosure 2 weeks to 4 years after diagnosis ranged from 16.7% to 86%. Studies done in South Africa have also reported similarly low rates of disclosure, 1,6,7 for example, only 36% of a rural sample of 55 women had disclosed their status 5 months after diagnosis. 8

Prior research has identified the many complexities that impact on disclosure to partners. Demographic variables associated with increased likelihood of disclosure to partners include younger age, lower socioeconomic status, ^{9,10} and a lower level of education. ¹¹ Barriers to disclosure include factors such as

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fear of accusations of infidelity, abandonment, rejection, discrimination, and violence, \$4.7,12-14\$ and most of all, fear of loss of economic support from a partner. Women in longstanding relationships and those reporting trust and love as part of their relationships are more likely to disclose than women in relationships of shorter duration or women who have had multiple sexual partners. Table 16 In a Tanzanian study, women's fear of their partners' reactions and communication in decision-making were important in affecting disclosure. It was easier for a woman to disclose her status to her partner if he had also tested, or if there had been prior discussion of testing.

The stigma associated with HIV disease also affects disclosure. In a study involving both men and women, stigma and fear of discrimination were the main reasons for nondisclosure.¹⁷ In some African communities people are reported to be more fearful of the social consequences of AIDS than of the disease itself.¹⁸ There is a complex relationship between an individual's psychological state and feelings of being stigmatized. After diagnosis, levels of anxiety and depression are often high¹⁹ and the extent of this emotional reaction can be affected both by the degree to which the individual feels stigmatized and the social support available from others.^{20–23} Bauman and colleagues²⁴ reported that women who felt more stigmatized, had poorer self-esteem, and more symptoms of depression were less likely to disclose their diagnosis. Other studies have shown that women who feel more supported by others in their circle, feel less stigmatized, and are more likely to disclose.8,22,25,26

Disclosure has been described as a process that involves decisions about timing, to whom, how, and under what conditions.⁴ Clearly, timing is an important factor; in a French study, 42% of the subjects disclosed immediately after diagnosis, 21% in the month after diagnosis, and 24% waited more than a year to disclose to someone.²⁷ However, little is known about this process when a woman finds out in pregnancy that she is HIV positive. There has also been little attention to what it means to disclose to one's partner as compared to others in one's circle of support. Obviously, hiding the diagnosis from a partner avoids discussion of sexual behavior and possible infidelity, but may continue to put the partner at risk of HIV through sexual transmission. A woman who is financially dependent on her partner might be less likely to disclose to him because of fears of abandonment, while a woman who lives with her family might be more likely to turn to family members for support.

Therefore, the purpose of this study was to provide a greater understanding of disclosure among women who test HIV positive in pregnancy and to determine what factors are associated with a woman's ability to disclose her diagnosis. We wished to identify why some women disclose HIV seropositivity shortly after receiving their diagnosis, while others are still not able to disclose, even months after giving birth. Recognizing that disclosure to partners might be very different than disclosure to others, we specifically examined these two separately. We hypothesized that factors that pertain to the relationship and economic dependence would affect a woman's ability to disclose to her partner, particularly in the early time period after receiving the diagnosis, whereas psychological factors and feelings of being stigmatized by the diagnosis might affect her ability to disclose to others, and that these factors would be especially important for those women who find it difficult to disclose their status.

Methods

Procedures

Women were enrolled in the study during pregnancy, shortly after testing HIV positive (mean gestational age 28 weeks) and participated in interviews at the time of study enrollment and again 3 months after giving birth. Women who had tested positive prior to the pregnancy were excluded from the study. Subjects were recruited from four antenatal clinics in two urban townships in Tshwane (Pretoria), South Africa. Trained HIV counselors, employed by the clinics, provided posttest counseling using standard procedures. The counselors informed women about the study and invited them to meet with a research assistant who provided further explanation and obtained consent. A separate appointment was then made for the baseline interview. Women were recruited to the study from June 2003 to December 2004. During this time, the treatment for prevention of mother to child transmission included single doses of nevirapine given to mothers and their infants at the time of birth. Treatment with highly active antiretroviral therapy (HAART) for those with more advanced disease was first initiated in the region in April 2004 but during the time of the study this treatment access to this treatment was limited. Institutional Review Board approval for the study was obtained from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, South Africa and the Human Investigation Committee of Yale University School of Medicine, New Haven, Connecticut.

Data collection

Sociodemographic data included questions on whether the participant lived with her partner and was receiving financial support from him. A "housing score" of zero to five was developed by assigning one point for each of the following: if the home had running water, a flushing toilet, electricity, a refrigerator, and was constructed of brick or concrete. Additional questions included whether the woman knew anyone else with HIV, and whether she and her partner had discussed testing before it was performed. At both interviews, data were gathered on whether the woman had disclosed her HIV status and to whom. For purposes of analyses disclosure that had already occurred prior to the baseline interview was labeled as "prior disclosure" and disclosure that occurred between the baseline interview and the follow-up interview was labeled as "post-enrollment disclosure." Data were collected at the 3-month interview on whether the mother and infant had received nevirapine for the prevention of mother-to-child transmission (PMTCT) and whether or not the woman had initiated HAART.

Measures of psychological variables and past experience of violence

Psychological measures included internalized HIV stigma, coping and self-esteem, depression, and level of social support. Established measures were adapted for the South African context and are summarized in Table 1.^{28–33} Information on the subject's past experience of violence (emotional, physical, and sexual abuse, and financial withholding) was obtained using questions from a survey of women's experience of violence in South Africa.³⁴ In initial analyses, the

TABLE 1. DESCRIPTION OF PSYCHOLOGICAL VARIABLES

Construct	Scale	Comments	No. of items	Cronbach α (present study)
Internal stigma	Perceived stigma of HIV/AIDS: Personal view	Adapted from scales developed by Westbrook and Bauman ²⁸ [Visser, Kershaw, Forsyth & Makin et al., Development of an HIV scale. unpublished]	12	0.75
Support	Multidimensional Social Support Inventory (MSSI) ²⁹	Two aspects positive and negative		
Positive		Scale created using "practical, affirmational and emotional support"	9	0.87
Negative		Excluded one item	3	0.56
Self-esteem	Rosenberg Self-Esteem Scale ³⁰	Minor changes in wording for cultural appropriateness	10	0.75
Depression	Center for Epidemiologic Studies Depression (CESD) ³¹	Excluded somatic items which are confounded by medical symptoms as recommended by Kalichman, Rompa and Cage ³²	15	0.88
Coping	Brief Cope ³³	Fifteen items from original scale included with minor wording changes. 9 items added to make the measure more HIV-specific. An exploratory factor analysis identified two factors—positive and avoidant		
-		Two separate scales then created		
Positive Avoidant			13 8	0.75 0.54

experience of multiple different types of violence appeared to be more important than the experience of any single category of violence. To avoid complexity in the analyses, those who had experienced two or more different types of violence were compared with those who had experienced less than two types.

Statistical analyses

As it was hypothesized that disclosure to partners would be associated with different variables than disclosure to other persons, each of these outcomes was analyzed separately. Because some women had already disclosed prior to enrollment in the study and it would not be possible to know whether any psychological differences might have contributed to these disclosures or were, in fact, the result of having disclosed, we conducted two separate sets of analyses: the first were cross-sectional analyses examining associations between variables obtained at baseline and prior disclosure; and the second were longitudinal analyses in which we assessed which variables obtained at baseline might be predictors for disclosure occurring in the interval between enrollment and follow-up at three months post-partum ("postenrollment disclosure"). In analyses examining postenrollment disclosure to partners we excluded subjects who had already disclosed to their partners prior to study enrollment but retained in the analyses all those who had already disclosed to someone other than their partner. Similarly for the analyses examining postenrollment disclosure to others, subjects with prior disclosure to their partners were retained.

SPSS® Version 13 for Windows {SPSS Inc., Chicago, IL) was used for data analyses. Associations between independent variables and disclosure were examined using the χ^2 test for categorical data and the Student's t test for continuous data. Factors associated with disclosure at a p value of less than 0.1 were subsequently entered into backward stepwise logistic regression models to determine which factors were independently associated with disclosure.

Results

Four hundred thirty-eight recently diagnosed HIV-positive women were invited to be part of the study and 293 (62%) agreed to participate. Data could not be collected on those who did not agree to participate, however, the proportion of nonparticipants was the same for each of the clinics. The median time from diagnosis to interview was 1 week. The sociodemographic characteristics are shown in Table 2. The majority 290 (99%) of women were black. The majority 233 (80%) were not married, but 200 (85%) of these women had partners. Of the women who had partners, the majority 138 (53%) were living with their husbands or partners. Only 171 (24%) of the women had a regular income, but the majority 202 (78%) of their partners did have regular incomes and provided the women with money. Almost one third, 95 (32%) of women reported experiences of emotional abuse in the past, with fewer women reporting other types of abuse. One hundred five women (36%) reported knowing someone who was HIV positive and 76 (72%) of these were persons who were not related to the women. Thirty-one percent of women had discussed testing with their partner before being tested.

Table 2. Participants' Baseline Characteristics (n = 293)

Baseline Characteristics Parity (median) Gravidity (median)	1
	2
Sociodemographics	
Age in years (Mean [SD])	26.5 (5.07
Marital Status	_0.0 (0.07
Single, with partner	68%
Married	21%
No partner	11%
Housing	
Electricity	80%
Flushing Toilet	67%
Fridge	63%
Made of brick or concrete	30%
Running water indoors	30%
Housing score (Mean [SD])	2.9 (1.8)
Household Income	` /
Subject has regular income	24%
Partner has regular income	78%
Partner provides money	82%
Subject's education level	
	0.9%
	5.4%
Tertiary 1	3.7%
Partner's education level	
None/primary	11%
Secondary	71%
Tertiary	18%
Experience of past violence	
Emotional	32%
Financial withholding or control	19%
Physical	14%
Sexual	8%
Two or more types of violence	21%
Other characteristics	
Interval since HIV test done	
< 1 week	27%
1–4 weeks	47%
> 4 weeks	26%
Discussed with partner before testing	31%
Knows someone who is HIV-positive	36%
Relative	17%
Non-relative	26%

SD, standard deviation.

Disclosure prior to enrollment

By the time of the baseline interview, 173 (59%) of the women had disclosed their HIV status to at least one person. Of the 260 who had partners, 124 (48%) had disclosed to their partners and 89 of the total group of women (30%) had disclosed to others. These included 35 who had disclosed to parents, 43 to other family members and 30 to friends. Of the 173 women who had disclosed, 120 (69%) had disclosed to only one person, 33 (19%) had disclosed to two people, and 20 (12%) had disclosed to three or more people.

Univariate analyses to identify factors associated with prior disclosure

Factors associated with disclosure prior to enrollment are shown in Table 3. Women who had disclosed to their partners had significantly higher household incomes and more often were married. Their partners were more likely to have a tertiary-level education and a regular income and more of the couples had discussed the test prior to testing. Women who had experienced two or more types of violence in the past were significantly less likely to have disclosed to their partners. None of the psychological variables were associated with early disclosure to partners.

The variables associated with prior disclosure to others were different than those associated with disclosure to partners. Those who had disclosed to others had a significantly higher housing score, but fewer of their partners had regular incomes and fewer provided money. Significantly more women who had disclosed to others knew someone who was HIV positive and had been tested more than a month prior to the interview, compared to those who had not disclosed. Unlike disclosure to partners, disclosure to others was associated with psychological variables. Those who had disclosed felt less stigmatized, had higher levels of active coping and lower levels of avoidant coping, greater self-esteem, and increased social support.

Logistic regression analyses to identify factors associated with prior disclosure

Logistic regression analyses were performed to control for possible confounding effects, and as seen in Table 5, only four variables remained significantly associated with disclosure to partners and three variables were associated with disclosure to others. Disclosure to a partner was more likely to have occurred if the couple was married, if they had discussed the test prior to testing, and if the partner had a tertiary education. Disclosure was less likely to have occurred if the woman had experienced two or more of the different types of violence. In the model examining variables associated with prior disclosure to others, a higher housing score and knowing someone who was HIV positive were associated with an increased likelihood of prior disclosure, while women whose partners supported them financially were less likely to have disclosed to others. None of the psychological measures remained significant.

Follow-up interviews (three months post-delivery)

Interviews were conducted with 198 women (67.6%) three months post-delivery. Those who were lost to follow up were more likely to have indicated they would stay with someone else after delivery (27% versus 19%, p=0.01), be living with their partners (57% versus 42%, p=0.02), and have lower housing scores (2.3 versus 3.2, p<0.001). Only 27% percent knew someone who was HIV positive compared to 41% of those who returned for follow-up (p=0.02). Both 94% of the women and 94% of their children had received Nevirapine at the time of delivery, but only two women had started on HAART, and both of these women had disclosed their HIV status.

Change in disclosure between enrollment and follow-up three months post-delivery

By three months post-delivery, 132 (81%) of the 198 women remaining in the cohort had disclosed their diagnosis to someone: 59% had disclosed to others and 67% of

Table 3. Univariate Analyses Identifying Factors Associated with Prior Disclosure

		Disclosure to partner			Disclosure to others	
	Disclosed (n = 124)	$Not disclosed \\ (n = 136)$	*p valueª	Disclosed (n = 89)	Not disclosed $(n = 204)$	*p value ^a
Sociodemographics						
Continuous variables (Mean [SD])	(10))10	000	e e	674	750	2
Monthly per-capita income Housing score	\$70 (01) 3.0 (1.8)	\$36 (30) 2.8 (1.7)	0:02	3.5 (1.4)	\$62 (61) 2.7 (1.8)	0.97 < 0.001
Age	27.1 (4.9)	26.4 (5.1)	0:30	26.4 (5.1)	27.1 (4.9)	0.93
Categorical variables (%)						
Married,	30%	17%	0.01	20%	21%	0.94
Living with partner	28%	46%	0.11	40%	49%	0.14
Living with other family members	73%	%62	0.25	85%	75%	0.02
Subject with tertiary education	14%	13%	0.91	13%	14%	0.95
Partner with tertiary education	22%	12%	0.03	10%	17%	0.14
Subject has regular income	20%	28%	0.14	29%	22%	0.19
Partner has regular income	84%	73%	0.02	61%	73%	0.04
Partner provides money	87%	%62	0.02	63%	%62	0.01
Past experience of violence (2+)	14%	26%	0.02	15%	23%	0.12
Other characteristics (%)						
Know someone who is HIV-positive	37%	33%	0.49	52%	29%	<0.001
Know someone HIV-positive in family	20%	14%	0.18	26%	13%	0.01
Know someone HIV-positive outside family	24%	26%	0.77	38%	21%	<0.001
Discussed with partner before testing	20%	21%	<0.001	36%	28%	0.19
Interval since test ≥ 4 weeks	27%	24%	0.57	35%	23%	0.03
Psychological measures (Mean [SD])	į	;	,	,	į	
Internalized stigma	28.0 (5.3)	27.8 (5.2)	0.00	26.9 (4.9)	28.3 (5.2)	0.04
Active coping	31.5 (4.4)	30.7 (4.4)	0.19	31.9 (3.9)	30.8 (4.4)	90.0
Avoidant coping	16.0(2.6)	16.5 (2.8)	0.11	15.8 (2.7)	16.4 (2.7)	0.05
Self-esteem	32.1 (3.9)	31.5 (3.8)	0.23	32.4 (3.8)	31.4 (4.0)	0.04
Depression	16.1 (11.6)	14.6 (10.7)	0.31	16.1 (13.0)	15.0 (10.5)	0.43
Positive social support	19.4 (6.0)	18.7 (6.0)	0.32	19.8 (3.9)	18.3 (4.4)	90.0
Negative social support	1.8 (2.4)	2.3 (2.4)	0.10	1.8 (2.3)	2.1 (2.4)	0.31

 $^{\rm a}{\rm Bold}~p$ values indicate variables entered into logistic regression models. SD, standard deviation.

	Disclosure to pa	rtner	Disclosure to o	thers
Variables retained in models	Adjusted odds ratio (95% CI.)	p value	Adjusted odds ratio (95% CI)	p value
Early disclosure				
Married	2.32 (1.20, 4.47)	0.01		
Discussed test with partner	4.19 (2.34, 7.49)	0.00		
Partner with tertiary education	2.76 (1.29, 5.88)	0.01		
Past experience of violence	0.48 (0.24, 0.97)	0.04		
Housing score	,		1.26 (1.06, 1.49)	0.01
Partner provides money			0.46 (0.25, 0.85)	0.01
Know someone who is HIV-positive			2.13 (1.20, 3.76)	0.01
Late disclosure				
Internalized stigma	0.91 (0.84, 0.98)	0.04		
Married	5.31 (1.25, 22.58)	0.02		
Age			0.91 (0.84, 0.97)	0.01
Avoidant coping			0.84 (0.72, 0.97)	0.02

Table 4. Logistic Regression Analyses Identifying Baseline Factors Associated with Prior and Postenrollment Disclosure to Partners and Others

CI, confidence interval.

those who had partners had disclosed to their partners. The follow-up group contained 88 women who, at baseline, had not disclosed to their partners, but by three months post-delivery, 31(35%) of these women had disclosed to their partners. Similarly, 132 of the women who attended the follow-up interview had not disclosed to others at baseline but by follow-up, 51(39%) of these women had now disclosed to others.

Univariate analyses identifying baseline factors that contribute to post-enrollment disclosure

As was found with early disclosure, post-enrollment disclosure to partners occurred more frequently if the couple was married, if they had discussed the test before HIV testing, and if there was a higher per capita household income (Table 4). Unlike with early disclosure, however, psychological measures at baseline were associated with an increased likelihood of disclosure to partners after enrollment. Those who felt less stigmatized, and those with higher levels of coping and increased social support were more likely to disclose to their partners. For disclosure to others, the only baseline variables that were significantly associated with late disclosure were, knowing someone outside the family who was HIV positive and having a lower level of avoidant coping.

Logistic regression analyses to identify baseline factors that contribute to post-enrollment disclosure

When variables were entered into logistic regression models to identify those factors that contributed to late disclosure (Table 4), a higher level of internalized stigma decreased the likelihood of a woman disclosing to her partner, while being married increased the likelihood she would disclose to her partner by approximately fivefold. Younger women and those with lower levels of avoidant coping were more likely to disclose to others.

Discussion

Despite the common perception that people diagnosed with HIV often do not tell others about their HIV status, the majority (81%) of the women in this study had disclosed their diagnosis to at least one person by three months following the birth of their child, and in fact, 59% had disclosed their diagnosis early, while they were pregnant and before they were first interviewed. As would be expected, the women disclosed selectively, with the majority disclosing to only one person, most often their partner.

We found that a woman's decision to disclose her HIV status to her partner early after being told her diagnosis was primarily impacted by issues that relate to the couple's relationship. In concurrence with the findings of Antelman et al.,¹⁵ women who were married and had discussed HIV testing prior to the test more often disclosed their diagnosis to their partner. It is notable, however, that a woman's choice about who she disclosed to, was not influenced by who she was living with; living with a partner did not make it more likely she would disclose to him. As has been reported in other studies,^{4,7,12} past experiences of violence also decreased the likelihood that women would disclose their HIV status to their partners. This illustrates one way in which violence against women and their ongoing fears of violence can contribute to women's experience of HIV.

Prior research has identified demographic factors that also impact disclosure to a partner. P-11 Our findings support the link between education and disclosure. While a woman's education had no impact on whether she disclosed, she was more likely to disclose if her partner had tertiary education. Previous research has also found that a lower socioeconomic status is related to an increased likelihood of disclosure to partners. Our findings support this association, as income was a significant factor in our univariate analysis. However, in the multivariate model, income ceased to be an independent predictor of disclosure.

Table 5. Univariate Analyses Identifying Baseline Factors that Contribute to Postenrollment Disclosure

		Disclosure to partner			Disclosure to others	
Variable	$Disclosed \\ (n = 31)$	Not disclosed $(n = 57)$	p value ^a	Disclosed (n = 51)	$Not \ disclosed \\ (n = 81)$	p value ^a
Socio-demographics						
Continuous variables [mean (SD)] Monthly per-capita income	(09) 22\$	\$46 (45)	0.01	\$71 (67)	\$50 (45)	0.13
Housing score	3.4 (1.8) 26.3 (4.9)	3.0 (1.6) 26.4 (5.1)	0.31	3.1 (1.8)	2.9 (1.8) 27.3 (5.2)	0.52
Categorical variables (%)						
Married	79%	2%	0.02	16%	17%	0.81
Living with partner	20%	39%	0.31	45%	46%	0.88
Living with other family members	84%	%62	0.58	%82	%08	0.80
Subject with tertiary education	16%	11%	0.51	14%	11%	0.65
Partner tertiary education	19%	11%	0.33	20%	16%	09:0
Subject has regular income	35%	23%	0.20	24%	20%	0.61
Partner has regular income	81%	%89	0.09	73%	%29	0.47
Partner provides money	%28	72%	0.11	%92	%2/	0.89
Past experience of violence	32%	28%	89.0	33%	22%	0.16
Other characteristics (%)						
Know someone who is HIV+	42%	35%	0.53	41%	26%	0.02
Someone in family HIV+	23%	12%	0.21	14%	12%	0.81
Someone else outside family HIV+	35%	28%	0.47	33%	19%	0.05
Discussed with partner before testing	31%	12%	0.05	29%	27%	0.78
Interval since test > 4 weeks	23%	32%	0.38	22%	28%	0.38
Disclosed to others prior to baseline	26%	28%	0.82	4/ /٥	41./0 NA	0.40
Psychological measures, [mean (SD)]	25.4 (6.1)	28.4 (4.2)	600	(0.7.7.7.0)	78 5 (5 1)	0.38
niteritatized sugnia Active coping	32.6 (4.0)	26. 4 (4 .2) 30.4 (4.0)	0.02	31.59 (3.7)	30.6 (4.8)	0.25
Avoidant coping	15.2(3.0)	16.8 (2.6)	0.02	15.8 (2.7)	16.8 (2.7)	0.03
Self esteem	32.2 (3.9)	31.1 (3.7)	0.20	30.4 (4.2)	31.5 (3.6)	0.10
Depression	14.8 (12.2)	14.5 (10.2)	0.92	16.5 (10.6)	15.0 (10.6)	0.43
Social support	20.7 (5.2)	17.3 (7.0)	0.02	18.4 (6.7)	17.3 (6.5)	0.35
Negative support	2.4 (2.4)	1.9 (2.1)	0.33	2.3 (2.2)	1.7 (2.4)	0.18

^aBoldface P value indicates variables entered into logistic regression models.

Not surprisingly, the factors that contribute to a woman's decision on whether or not to tell others about her HIV status are different from those involved in disclosing to her partner. Our findings show that disclosure to others was mainly related to economic factors; those who lived in poorer housing and were more reliant on their partners for providing money were less likely to disclose to others early. Indeed, fear of loss of economic support from a partner has previously been cited as a barrier to disclosure.⁴ Other studies have shown an association between age and disclosure to partners, 9,10 and although we found that younger women were more likely to disclose to others, this was not true for disclosure to partners. Similarly, knowing someone else with HIV infection did increase the likelihood a woman would disclose her status to others, but did not affect the likelihood that she would disclose to her partner which contrasts with the findings of Antelman et al. 15 that knowing someone else who is HIV-infected did increase the likelihood of disclosure to a partner.

A strength of this study is that we not only identified differences between women who had already disclosed their diagnosis and those who had not, but also examined what factors impede a woman from disclosing her diagnosis up to 3 months postdelivery. Failure to be able to confide in others during this period might make it less likely that a woman can more effectively avoid postnatal HIV transmission by either choosing to formula feed or exclusively breast feeding. The results elucidate the impact of HIV-related stigma on disclosure. While stigma was not important in determining whether or not women had told their partners shortly after receiving the diagnosis, it was important over time, as those who felt more stigmatized were still unable to tell their partners over the subsequent months. Similarly, those who were more likely to cope with adversity by avoiding issues and using denial were less able to disclose their HIV status to others over subsequent months. We had hypothesized that other psychological factors, such as depression, low self-esteem and a lack of support, might also impede a woman's ability to disclose her diagnosis, particularly as time progressed. However, these factors did not remain significantly associated with disclosure in the multivariate analyses.

Because HAART only became available during the period in which this study took place, we were unable to assess the possible effect that access to treatment might have on disclosure. Women initiating HAART are strongly encouraged to disclose to a treatment support person and/or a partner³⁵ Also because the medication regimen used for PMTCT at the time only included the taking of Nevirapine at delivery, it is unlikely that this would unduly influence women to disclose their HIV status. This approach, however, is changing in a number of countries and more prolonged courses of prophylactic antiretroviral treatment (usually from 28 weeks' gestation) are recommended. Because this treatment is more difficult to hide, disclosure might become even more critical to the success of PMTCT programs.

There are a number of limitations to this study. First, the distinction between "prior disclosure" and "postenrollment disclosure" is somewhat arbitrary and depends to some extent on when the first interview occurred in relation to the HIV testing. It would have been unethical, however, to interview subjects just after they had been told their HIV sta-

tus and therefore it is expected that some subjects will have disclosed prior to being interviewed. A second limitation is the potential for enrollment bias that might have occurred if women who had already disclosed their status were more likely to participate in the study. This would serve to overestimate the proportion of women who had disclosed their status early after diagnosis, but is unlikely to have affected the results pertaining to the associations with disclosure after enrollment. Also it is not known whether differences in those lost to follow-up may have introduced some bias in the results found with postenrollment disclosure.

This study only focused on disclosure of HIV status during pregnancy and in the early postnatal period. We thus did not assess factors that might affect a woman's decision later on when issues that have been identified by other researchers such as the desire to have another child.³⁶

Implications

Disclosure after diagnosis has been identified as an important goal in decreasing HIV transmission, and use of a screening tool has been advocated for identifying those least likely to disclose their diagnosis to others and thus those who may require further help.⁴ Previously, these recommendations have lacked impact, as understanding of factors relating to disclosure was sparse. However, the results of this study help identify issues which should be addressed in posttest counseling of HIV-positive persons, increasing the effectiveness of this service, and allowing resources to be spent on those who most need assistance.

As illustrated by the results of this study, women can benefit from knowing someone else who is HIV positive, and there are now a number of interventions that utilize the approach of bringing women who are HIV positive together in groups or pairs.37–40 Interventions for women who are unable to disclose their diagnosis despite the passage of time should include an approach that focuses on reducing the individual's sense of being stigmatized and promotes more positive coping. Providing support to women around disclosure should be an important component of any program designed to prevent HIV transmission from mother to child. Through providing such support and increasing disclosure, there potentially could be a significant effect on decreasing HIV transmission, both perinatal transmission to children and sexual transmission to others.

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