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Association between maternal HIV disclosure and risk factors for perinatal transmission

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Abstract

Objective—To determine whether maternal disclosure of HIV serostatus is associated with uptake of perinatal HIV transmission prevention interventions.

Study Design—Retrospective cohort study of women living with HIV enrolled in a perinatal HIV clinic. Women who disclosed their HIV serostatus to sexual partner(s) prior to delivery were compared to non-disclosers. Multivariable logistic regression was performed.

Results—Of 209 women, 71.3% (N=149) disclosed. Non-disclosers were more likely to attend <10 prenatal visits, demonstrated worse antiretroviral therapy adherence, required more time to achieve virologic suppression, and were less likely to have an undetectable viral load. On multivariable analyses, disclosure status did not remain associated with these factors. However, compared to non-disclosers, disclosers had lower odds of preterm delivery (OR 0.43, 95% CI 0.19–0.94) and greater odds of postpartum visit attendance (aOR 5.10, 95% CI 1.65–15.72).

Conclusions—Non-disclosure of HIV status to sexual partner(s) during pregnancy may be a risk factor for preterm birth and poorer postpartum visit attendance.

Keywords

disclosure; human immunodeficiency virus; perinatal HIV transmission; prevention of maternal to child transmission; vertical transmission

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INTRODUCTION

Each year an estimated 9,000 women living with HIV give birth in the United States.(1) Elimination of maternal to child transmission of HIV infection, defined as “reducing perinatal transmission to an incidence of <1 infection per 100,000 live births and to a rate of <1% among HIV-exposed infants,” is a goal of the Centers for Disease Control and Prevention.(2) Although this goal is achievable in high resource settings, where early identification and treatment can reduce the risk to <1%(2–5), it requires uptake of intensive antenatal and postpartum interventions, including preconception planning, multiple health care visits, and strict adherence to antiretroviral therapy to achieve virologic suppression.(2) Furthermore, obstetric complications such as preterm birth can increase the risk of perinatal transmission; preterm neonates are at increased risk for acquisition of HIV, likely due to shorter exposure to antenatal antiretroviral therapy and a less mature immune system.(6–9) Understanding how best to support women to meet these complex recommendations has not been fully elucidated.

Prior work has suggested non-disclosure of HIV serostatus to sexual partners may be associated with risk factors for perinatal transmission. Specifically, in the international setting, non-disclosure of HIV serostatus has been associated with late initiation of care, detectable viral load at delivery, and failure to comply with neonatal prophylaxis.(10) Yet, it is not clear if or how these findings translate to resource-rich settings with different social, cultural and economic implications of HIV infection. Existing data among reproductive-aged women in the United States (U.S.) suggest non-disclosure rates vary widely, with rates ranging from 10% to 80% in different populations.(11, 12) One report quantifying disclosure in an U.S. cohort of pregnant women living with HIV identified that 92% of women with a serodiscordant partner and 68% of those with unknown partner status disclosed their HIV serostatus to their sexual partner prior to the pregnancy.(12) Data on the association of HIV serostatus disclosure and uptake of perinatal transmission prevention interventions in the U.S. are sparse.

Understanding the relationship between disclosure status, health services utilization and associated outcomes during pregnancy is critical to optimization of care for women with HIV. The objective of this study was to determine whether antenatal disclosure of HIV serostatus to sexual partner(s) is associated with risk factors for perinatal transmission and uptake of perinatal transmission prevention measures. Given the international data and our clinical observations that women who do not disclose their HIV serostatus have weaker social support systems during pregnancy, we hypothesized HIV disclosure to sexual partner(s) may be associated with fewer risk factors for perinatal transmission and improved uptake of maternal health interventions and other measures with perinatal transmission prevention.

METHODS

This is a retrospective cohort study of pregnant women living with HIV who were receiving specialty perinatal care at a single multidisciplinary clinic between 2007 and 2014. The Women’s HIV Program at Northwestern Memorial Hospital provides coordinated care for

women living with HIV who desire preconception, prenatal, postpartum and interconceptional care. Perinatal care includes coordinated treatment by specialists from maternal-fetal medicine, infectious diseases, pharmacy, social work, psychology, and nursing. As a standard of care, all women in this program underwent an evaluation by a clinical psychologist or licensed clinical social worker during prenatal care; during this evaluation, disclosure status to sexual partner(s) was elicited. All patients were offered assistance and support with disclosure per patient request. Partner confirmation of disclosure status was not performed.

Inclusion criteria for the study included enrollment in this program for perinatal care with documentation of HIV infection. Women who were less than 18 years of age or who had unknown disclosure status to her sexual partner(s) (i.e., for whom records did not state whether she had disclosed) were excluded. Social work, psychology and medical records were reviewed in detail to assess disclosure status. Women were categorized as having disclosed or not disclosed regardless of the gestational age at disclosure as long as disclosure occurred prior to delivery.

The medical records were reviewed for maternal demographic and baseline clinical characteristics as well as maternal and neonatal outcomes. Demographic data included maternal age, self-reported race/ethnicity, immigrant status, marital status, employment status, primary source of medical payment at first visit, and maternal education. Clinical factors included parity, number of years since HIV diagnosis, perinatally acquired HIV infection (i.e., the mother herself had been infected at birth), new HIV diagnosis during index pregnancy, and CD4 count at time of initiation of prenatal care. Outcomes investigated included prenatal visit adherence (defined both as a continuous measure and dichotomized as fewer than 10 completed visits), self-reported antiretroviral medication adherence (number of missed doses), time to virologic suppression, presence of a detectable viral load at 36 weeks of gestation, viral load at delivery, and preterm birth (<37 weeks gestational age). We additionally examined postpartum visit attendance, which was defined as returning for obstetrical and HIV medical care within 12 weeks of delivery. Postpartum visit attendance was investigated as a perinatal transmission prevention measure because this time period represents a final window of opportunity to reinforce adherence to neonatal prophylaxis and follow up testing as well as retention in HIV care for the mother.(13–15)

Maternal characteristics and outcomes were compared between disclosers and non-disclosers using bivariable analyses. Chi-squared and Fisher's exact tests were utilized for categorical variables, and Student's t-test and Mann-Whitney U test were used for continuous variables. Potential confounders ($p < 0.05$ on bivariable analyses) associated with disclosure were then retained in multivariable logistic regression models for each of the examined outcomes. Analyses were performed with Stata version 13 (StataCorp, College Station, TX). All tests were two-sided and $p < 0.05$ defined statistical significance. This study was approved by the Institutional Review Board of Northwestern University.

RESULTS

Of 215 women receiving specialty perinatal HIV care during the study period, 209 (97.2%) had a documented sexual partner disclosure status and constituted the analyzable sample. Disclosure to partner(s) prior to delivery occurred for 149 (71.3%) of women. Compared to women who did not disclose, women who disclosed their HIV serostatus were more likely to be married, employed, and privately insured (Table 1). Women who disclosed were less likely to have a late presentation to prenatal care. There were no differences in maternal age, self-reported race/ethnicity, or immigrant status between groups. Regarding maternal clinical characteristics, we identified no differences by disclosure status for parity, CD4 count at first visit, HIV diagnosis during index pregnancy, perinatally acquired HIV, or number of years since HIV diagnosis (Table 2).

In bivariable analyses, women who had disclosed their HIV serostatus to their sexual partner(s) were less likely to attend fewer than 10 prenatal visits and more likely to report no missed doses of antiretroviral medication (Table 3). They additionally required fewer weeks on antiretroviral medication to achieve viral suppression and were more likely to have an undetectable viral load at 36 weeks. Women who disclosed were also less likely to experience a preterm birth and more likely to attend their postpartum appointment.

On multivariable logistic regression controlling for marital status, employment status, primary source of medical payment at initiation of care, and trimester at presentation, there were no statistically significant associations between disclosure and attendance at fewer than 10 prenatal visits, self-reported antiretroviral adherence, time to viral suppression, or detectable viral load in the third trimester or at birth. However, after adjustment for potential confounders, the odds of preterm birth remained significantly lower in women who disclosed (aOR 0.43, 95% CI 0.19-0.94) compared to women who did not disclose. Disclosure additionally remained associated with increased odds of postpartum visit attendance (aOR 5.10, 95% CI 1.65-15.72).

DISCUSSION

In this population of pregnant women living with HIV, the majority of women disclosed their HIV serostatus to their sexual partner(s), with a disclosure rate comparable to others reported in the U.S.(12) Importantly, maternal disclosure was associated with a lower frequency of preterm birth, a known independent risk factor for perinatal HIV acquisition(6–9) and with better postpartum visit adherence. The potential impact of these findings is significant for neonatal health and the woman's health, longevity, HIV control and potential outcomes of future pregnancies. The postpartum visit represents an important opportunity for both adherence to neonatal HIV prophylaxis and follow up testing as well as maternal retention in HIV care.(13–15) Recent data have shown that if antiretroviral therapy is started prior to conception, perinatal transmission risk approaches zero,(16) highlighting the critical need to engage a woman in care before her next pregnancy. Accordingly, the postpartum visit is considered an additional measure for prevention of perinatal transmission as it is the gateway to interconception care. As evidence accumulates that perinatal transmission can be

eliminated, efforts to understand the complex psychosocial factors associated with transmission, such as disclosure, will be critical.

Disclosure of HIV serostatus has been described as an important facilitator of uptake of the World Health Organization's four-pronged prevention of mother-to-child transmission recommendations: prevention of HIV transmission in reproductive-aged women, prevention of unintended pregnancies in women living with HIV, reduction of perinatal transmission via antenatal and neonatal prophylaxis, and provision of lifelong treatment and support for pregnant women and positive family members.(17, 18) Indeed, in developing countries, HIV non-disclosure has been associated with poorer health services utilization, such as not birthing in a health facility, and reduced adherence to antiretroviral therapy, while disclosure has been associated with improved adherence to recommended maternal and infant care.(17–20) In these settings, disclosure may raise awareness of HIV in the family, allow mothers to freely participate in perinatal transmission prevention measures, and empower women to make good health decisions for themselves and their infants.(18) However, aside from retention in early postpartum care, we did not identify the same protective relationship between disclosure and care adherence, suggesting women's ability to disclose may play an important but different role in the transmission prevention process in U.S. women. Of note, the raw data on differences in prenatal care attendance and medication adherence all favored better engagement in care for women who disclosed their HIV serostatus, but findings did not retain statistical significance on multivariable analyses, likely due to small sample sizes. Future work in larger U.S. cohorts is needed to understand the potential association of disclosure with adherence.

Disclosure of HIV serostatus has important social and psychological implications and likely serves as a marker for quality of social support and level of perceived or internalized stigma. (17) Although the mechanism for the association between disclosure and preterm delivery is unknown, one potential explanation may be that stress mediates the relationship between disclosure and preterm birth.(21, 22) Prior literature suggests disclosure may be associated with increased social support(23–26) and decisions for non-disclosure have been associated with fear, violence, stigma, and depression.(18, 27) HIV-related stigma appears to moderate relationships between social support and health outcomes, such as antenatal depression and linkage to HIV care.(28, 29) Although reasons for women's non-disclosure are myriad, anticipated HIV-related stigma (from the family, partner, or community members) and fear of intimate partner violence have been associated with non-disclosure.(17) Further work is required to understand other potential drivers of disclosure decisions in the U.S.; for example, although not statistically significant, trends in this study suggest there may be differences in disclosure frequency by maternal race and ethnicity, although findings were limited by the small sample size. We propose that in-depth qualitative work is needed to understand the social determinants of disclosure and how multisectoral individual, family, and community-level factors influence women's decisions to disclose. Such work will help elucidate the pathway from decision making about disclosure to subsequent health outcomes.

International data have demonstrated both disclosure(30, 31) and non-disclosure(32) to be associated with intimate partner violence during pregnancy and the postpartum period. In

concert with our findings, these data suggest that disclosure should be discussed in routine antenatal care for women living with HIV due to implications regarding maternal health outcomes, health care seeking behaviors, and risk of violence. Although disclosure may not be a safe or acceptable option for all women, it is important for clinicians to address the issue of disclosure with patients; this discussion and potential facilitation of disclosure when desired may benefit individual retention in care. Such discussions should occur in private and with support from psychosocial professionals when possible, and additionally should consider the woman's own readiness; for example, women with a new diagnosis of HIV may have a different readiness for disclosure than women who have been living with HIV for many years. Further, addressing disclosure concerns represents an important opportunity for clinicians to engage with patients surrounding issues of stigma, violence, stress and social support that may have important implications for perinatal transmission and long-term maternal health.

Our study has a number of limitations. First, this study is underpowered to demonstrate associations between disclosure and many perinatal transmission prevention measures. In our cohort, maternal disclosure of HIV serostatus was not independently associated with a number of known perinatal transmission prevention markers including prenatal visit attendance, antiretroviral medication adherence, time to virologic suppression, or viremia at delivery. This lack of association may be driven by lack of statistical power due to the relatively small cohort of non-disclosers. For example, with approximately 30% of the cohort not disclosing, an estimated sample of 474 women would be required to achieve 80% power to detect a statistically significant difference in the identified proportions of women with an undetectable viral load at 36 weeks. Similarly, our small sample size precluded analysis of maternal factors that may influence disclosure, such as maternal race and ethnicity or time since HIV diagnosis. Second, as a retrospective study, data such as self-reported adherence and disclosure status may be misrepresented; it was not possible to confirm reported disclosure status nor to characterize specific reasons for non-disclosure. Similarly, although we attempted to account for potential confounders using multivariable models, there are likely unmeasured social or biological confounders that mediate the relationship between disclosure and preterm birth. Furthermore, we were unable to characterize the serostatus of sexual partners in this population, and it is possible that knowledge of partner serostatus is associated both with HIV disclosure and perinatal transmission risk factors. Prior work has demonstrated that disclosure is more common in known serodiscordant couples than in couples where the partner has an unknown serostatus. (12) Further, further work is required to investigate other types of disclosure; for example, it is unclear whether disclosure to a sexual partner is the most important type of disclosure or whether disclosure to other supportive persons may also play a role. Finally, this cohort received multidisciplinary medical, social, and psychological care during pregnancy at a single tertiary care center; women additionally were beneficiaries of a robust system of social support services during pregnancy. Thus, although a diverse population, the experiences of these women may not be generalizable to a broader population.

This study is notable for its diverse and well-characterized population of pregnant women living with HIV who had detailed medical records available for review, particularly since discussion of disclosure is a routine component of clinical care. Moreover, few studies

directly examine associations between disclosure to sexual partners and engagement in perinatal transmission prevention in a resource-rich setting. This evaluation suggests further exploration of disclosure support as a potential marker of social support and target for reducing perinatal transmission is warranted. Qualitative analyses designed to deepen understanding of women's decisions for non-disclosure may yield valuable insight into how disclosure status is both driven by and alters a woman's social support and ability to fully engage in perinatal HIV care. While further work is required to fully elucidate these relationships, our findings suggest disclosure may be associated with maternal and neonatal health outcomes related to HIV. Pregnant women who do not disclose their HIV serotatus to their partner(s) represent an important and vulnerable group who require further study and support.

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Table 1

Patient characteristics stratified by disclosure status to partner(s)

	Did not disclose (n=60)	Disclosed (n=149)	p value
Age, years	28.7 ± 6.6	29.9 ± 6.1	0.209
Race/ethnicity			0.180
White	3 (5.0%)	19 (12.8%)	
Black	46 (76.7%)	103 (69.1%)	
Hispanic	11 (18.3%)	22 (14.8%)	
Asian	0 (0.0%)	5 (3.4%)	
Married	2 (3.3%)	68 (46.3%)	<0.001
Foreign-born	21 (35.0%)	62 (42.5%)	0.321
Employed	19 (33.3%)	74 (50.0%)	0.032
Educational level (n=167)			0.051
Less than high school	10 (21.7%)	21 (17.4%)	
High school graduate graduate/GED	24 (52.2%)	48 (39.7%)	
Some college	10 (21.7%)	25 (20.7%)	
College graduate or beyond	2 (4.4%)	27 (22.3%)	
Insurance status (at first prenatal visit)			<0.001
Uninsured	9 (15.0%)	18 (12.1%)	
Public	49 (81.7%)	94 (63.1%)	
Private	2 (3.3%)	37 (24.8%)	
Trimester of presentation to care			0.004
No prenatal care	2 (3.3%)	1 (0.7%)	
1st trimester	24 (40.0%)	91 (61.1%)	
2nd trimester	19 (31.7%)	43 (28.9%)	
3rd trimester	15 (25.0%)	14 (9.4%)	

Data presented as mean ± standard deviation, n (%), or median (interquartile range)

GED = general education development (high school equivalency)

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Table 2

Maternal clinical characteristics stratified by disclosure status

	Did not disclose (n=60)	Disclosed (n=149)	p value
Nulliparous	20 (33.3%)	58 (39.0%)	0.449
CD4 count at first visit, cells/mm ³			0.169
<200	10 (16.7%)	32 (21.5%)	
201–350	20 (33.3%)	33 (22.2%)	
351–500	15 (25.0%)	29 (19.5%)	
>500	15 (25.0%)	55 (37.0%)	
New HIV diagnosis during pregnancy	21 (35.0%)	42 (28.2%)	0.332
Maternal HIV perinatally acquired	3 (5.0%)	13 (8.7%)	0.566
Years since HIV diagnosis	2.5 (0–6)	4 (0–8)	0.088

Data presented as n (%), or median (interquartile range)

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Table 3

Association between HIV disclosure and measures to prevent perinatal HIV transmission

	Non-disclosers (n=60)	Disclosers (n=149)	p value
Number of prenatal visits (n=188)	10 (6–13)	11 (9–13)	0.086
Fewer than 10 visits	23 (45.1%)	39 (28.5%)	0.031
Self-reported missed ARV doses (n=191)			0.001
None	24 (47.1%)	85 (60.7%)	
1–5 doses	9 (17.7%)	39 (27.9%)	
>5 doses	18 (35.3%)	16 (11.4%)	
Number of weeks of ARVs until suppression	14 (9–17)	7 (0–15)	0.005
Undetectable VL by 36 weeks gestation	41 (68.3%)	121 (81.2%)	0.044
VL at delivery, copies/mL	0 (0–0)	0 (0–52)	0.015
Preterm birth (<37 weeks)	19 (31.2%)	28 (18.8%)	0.044
Attended postpartum visit	47 (78.3%)	141 (95.3%)	<0.001

ARV = antiretroviral; VL = viral load

Data presented as n (%) or median (IQR)