Shame, Guilt, and Stress: Community Perceptions of Barriers to Engaging in Prevention of Mother to Child Transmission (PMTCT) Programs in Western Kenya

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Abstract

While global scale-up of prevention of mother-to-child transmission of HIV (PMTCT) services has been expansive, only half of HIV-infected pregnant women receive antiretroviral regimens for PMTCT in sub-Saharan Africa. To evaluate social factors influencing uptake of PMTCT in rural Kenya, we conducted a community-based, cross-sectional survey of mothers residing in the KEMRI/CDC Health and Demographic Surveillance System (HDSS) area. Factors included referrals and acceptability, HIV-related stigma, observed discrimination, and knowledge of violence. Chi-squared tests and multivariate regression analyses were used to detect stigma domains associated with uptake of PMTCT services. Most HIV-positive women (89%) reported blame or judgment of people with HIV, and 46% reported they would feel shame if they were associated with someone with HIV. In multivariate analyses, shame was significantly associated with decreased likelihood of maternal HIV testing (Prevalence Ratio 0.91, 95% Confidence Interval 0.84–0.99), a complete course of maternal antiretrovirals (ARVs) (PR 0.73, 95% CI 0.55–0.97), and infant HIV testing (PR 0.86, 95% CI 0.75–0.99). Community perceptions of why women may be unwilling to take ARVs included stigma, guilt, lack of knowledge, denial, stress, and despair or futility. Interventions that seek to decrease maternal depression and internalization of stigma may facilitate uptake of PMTCT.

Introduction

INTERVENTIONS TO PREVENT MOTHER-TO-CHILD transmission (PMTCT) of HIV are remarkably efficacious,¹⁻⁴ the success of which has inspired a global plan to eliminate 90% of new pediatric HIV infections by 2015.⁵ While scale-up of PMTCT services has been expansive, the World Health Organization (WHO) estimates that in sub-Saharan Africa, where >90% of HIV-infected pregnant women reside, only 57% of pregnant women receive effective antiretroviral regimens for PMTCT.⁶

Health behavior theories cite cultural and environmental factors, including social norms, attitudes, and expected social acceptance as motivators or barriers to uptake of health services.^{7,8} Literature about sub-Saharan Africa demonstrates a

combination of health systems barriers to uptake of PMTCT, as well as widely perceived HIV-stigma and social or family influences.⁹⁻¹³ While much of the HIV literature describes stigma and discrimination as a single concept, Nyblade et al. specified four distinct domains of stigma: fear of casual contact; moral values of shame, blame and judgment; discrimination; and disclosure.¹⁴ Understanding which stigma domain is affecting PMTCT uptake may be critical in targeting interventions to the appropriate underlying cause.

In sub-Saharan Africa, few quantitative measures of HIV discrimination are available, and little is published about the prevalence of HIV-related abuse or domestic violence, and to what extent these occurrences factor into uptake of services.

Understanding the social and contextual landscape of PMTCT uptake from a community perspective is necessary

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to design appropriate theory-based interventions that address the primary drivers of health behavior within a cultural or regional context. In this study, we aim to evaluate social factors influencing uptake of PMTCT in a region of Western Kenya quantitatively and qualitatively, including sources of referral to care, community acceptability of services, and perceptions of barriers to uptake. We further aim to assess associations of two stigma domains (moral values and discrimination) with outcomes of uptake of services along the PMTCT cascade.

Methods

Study design

In order to assess the contextual environment of access to (and uptake of) PMTCT services in Western Kenya, we conducted a cross-sectional community-based survey during early 2011 of mothers who had recently delivered an infant and who were residents in the KEMRI/CDC Health and Demographic Surveillance System (HDSS) area.

Study location and population

The HDSS covers 385 villages in in Western Kenya with a population of approximately 220,000.¹⁵ All regions in the HDSS are rural, and a resident is defined as having lived in the area continuously for at least 4 months. The sampling framework utilized pregnancy information, as well HIV status from recent but incomplete home-based testing campaigns, available in the HDSS dataset. Given a regional 8% HIV prevalence, a larger random community sample than budget allowed would have been required to enroll sufficient HIV-positive women, thus we generated two samples to assess uptake of services targeting women in the community generally as well as HIV-positive women specifically. These included a random sample of women aged 14 and older who had delivered within the previous year (January to December, 2010) and a comprehensive sample of HIV-positive women in areas where home-based counseling had previously taken place. In the random sample, we surveyed 405 women, of whom 43 reported being HIV-positive. Among 275 women in the HDSS database known to be HIV-positive through previous home-based testing, 247 consented to participate, though only 173 women self-reported as HIV-positive to new interviewers. As HIV status was measured via self-report in both populations, and regions were demographically similar, we combined data from the random sample and the oversample to total 216 self-reported HIV-positive women.

Data collection

Quantitative and qualitative information were collected in face-to-face interviews by trained fieldworkers. In addition to questions of socio-demographics, uptake of health services, and knowledge of PMTCT, women were asked to describe their perceptions of why women in the community do or do not engage in PMTCT care. Eligible women were asked to respond to open-ended questions, which were entered in handheld PDAs. Multiple answers were accepted. Prior to disclosing HIV status, women were additionally asked hypothetical questions such as “if you were diagnosed with HIV, would you seek care at the same facility for your next

pregnancy?” Fieldworkers were blinded to prior HIV test results of participants, thus participant self-reported HIV status was used.

Stigma questions were also asked prior to disclosure of HIV status and focused on the community-level indicators derived from a validated toolkit within the domains of moral values of shame and blame/judgment, and enacted stigma or discrimination.¹⁴ To assess shame, participants were asked if they would feel ashamed if they were HIV-positive or if they were associated with someone who was HIV-infected. Blame and judgment was assessed through statements such as “HIV is a punishment from God” or “People with HIV are promiscuous.” To assess discrimination, women were asked if they had ever known *someone* in the community that had any of a list of discriminatory acts happen to them because of HIV/AIDS in the last year. A yes or agree response to any of the questions within each type of stigma (shame, blame/judgment, or discrimination) counted as an affirmative response. Questions on known domestic violence and abuse were included, but women were not asked to disclose whether they personally experienced abuse or violence.

Outcomes of interest along the continuum of PMTCT services included uptake of antenatal care, HIV testing among women attending antenatal care (ANC) who were not previously known to be HIV-positive, and uptake of maternal and infant antiretrovirals (ARVs) and of infant HIV testing among HIV-positive women.

Data analysis

Data were collected and managed using Pendragon Forms (Pendragon Software, Chicago, IL). Quantitative information was analyzed using STATA SE version 11 (STATA Corp, College Station, TX). Proportions were assessed using chi-square tests of significance with Fisher’s exact tests. Wilcoxon rank-sum tests were used for comparing distributions of linear data. Stigma outcomes were further assessed using generalized linear models to detect prevalence ratios adjusting for variables hypothesized *a priori*. Qualitative responses were translated from the local Dholuo language to English by the study team fluent in both languages, then coded into themes and validated by the lead author and a Kenyan social scientist.

Ethical considerations

Written informed consent was obtained from all participants, both to participate in the study and also to have their data from these surveys linked to their HDSS record. HDSS residents who were sampled using HBTC results had previously consented to allow use of their data for sampling. The study was approved by the University of Washington Institutional Review Board (#36022) and the Kenya Medical Research Institute Ethical Review Committee (#1714).

Results

Social factors influencing access to care

Source of referral to care. Among women in the random sample, there was high uptake of any ANC (94%) and moderate to low uptake of facility delivery (42%). Most common influences for attending any ANC were having seen advertisements (36%), friends or relatives (31%) or because

it was the same facility accessed in a previous pregnancy (31%). Few (<5%) chose an ANC facility based on health worker referral. Referrals for seeking care for labor and delivery services (either facility or home-based) were 31% via advertising, 31% based on experiences during a previous pregnancy, 23% by a friend or relative, and 15% by a health worker referral. HIV-positive women and the community sample were similar with respect to referrals to care.

Acceptability of services. Among women who responded to survey questions regarding acceptability of services ($n=395$ in the community sample and $n=213$ in the HIV-positive sample), there was high reported acceptability of PMTCT (Table 1). Almost all (>95%) of women in both the random community sample and in the HIV-positive group stated that they would opt for pregnancy care at a facility that offers HIV testing and would accept HIV testing if it was offered. A substantial number of women (33% in the random sample and 47% of HIV-positive women) reported that they would want to get pregnant again if they were told that they had HIV. Most (>90% in the community sample and >95% in the HIV-positive sample) reported that if they were pregnant and HIV positive, they would go to the same ANC and delivery provider and would be willing to take medicine to prevent the baby acquiring HIV. Women who did not have skilled care during delivery, such as those who had assistance from a family member or traditional birth attendant, were equally likely prefer to return to the same person for support/care during delivery compared to women who sought care from a skilled provider.

Among the 10 women out of 405 in the community sample (3%) who reported that they would be unwilling to take ARVs for PMTCT, issues of stigma and confidentiality ($n=6$), fear of medication ($n=4$), logistical issues of cost and time ($n=4$), and lack of social acceptability either by hus-

bands ($n=3$) or others in the community ($n=1$) were reported. Among the two HIV-positive women who said that they would be unwilling to take ARVs for PMTCT, one woman was willing to provide a reason. She cited stigma and confidentiality as a barrier and also stated a sense of futility, in that, "Life has now been shortened by being HIV-positive, and as such, there's no need helping this child because it will suffer (after its mother's death)."

Perceived barriers to uptake

Prior to disclosing their own HIV status, all women were asked to identify reasons that they thought HIV-positive women in their community might choose not to get tested for HIV, might not want their babies to get tested, or might choose not to take ARVs for PMTCT. Several cross-cutting themes were identified, summarized quantitatively and qualitatively in Tables 2 and 3, respectively.

Stigma or fear of disclosure. Stigma and fear of disclosure of one's HIV status was cited most frequently as a response to each of the three questions. Women reported both a sense of shame as well as concern over confidentiality as potential barriers to uptake. They also noted not just that "people will know status," but also a fear of gossip and "guilt of how people talk."

Denial. Denial, or not wanting to know one's status, was frequently cited as a perceived reason not to test both the mother and infant, ranking second only to stigma and fear of disclosure. However, it was not commonly endorsed as a reason to not take ARVs for PMTCT.

Concerns over family or husband acceptance. Both women in the community sample and HIV-positive women reported perception of fear that a woman's husband would

TABLE 1. SOCIAL HYPOTHETICAL QUESTIONS RELATED TO ACCEPTABILITY OF CARE AMONG RECENT MOTHERS RESIDING WESTERN KENYA (2011)^{a,b}

	<i>Random community N=395</i>	<i>HIV-positive women N=213</i>
<i>Would choose facility with HIV testing</i>	383 (97.0)	211 (99.1)
If you could choose between a facility which offered HIV testing and one which did NOT offer HIV testing, which would you choose?		
<i>Would accept HIV testing</i>	389 (98.5)	213 (100.0)
If you became pregnant again and were offered HIV testing during pregnancy, would you accept it?		
<i>Would want to get pregnant</i>	132 (33.4)	99 (46.5)
If you were told you have HIV, would you want to get pregnant?		
<i>Would seek care from same person/facility</i>	368 (93.2)	209 (98.1)
If you were told you had HIV, would you go to the same health care provider for ANC in the next pregnancy?		
<i>Would seek care from same person/facility</i>	375 (94.9)	211 (99.1)
If you were told you had HIV, would you go to the same health care provider for delivery in the next pregnancy?		
<i>Would be willing to take medicine for PMTCT</i>	385 (97.5)	211 (99.1)
If you were pregnant and HIV+, would you be willing to take medicine to prevent the baby getting infected?		

^aQuestions asked prior to disclosure of HIV status; ^b10 in random sample and 3 in HIV-positive sample excluded for missing data.

TABLE 2. PERCEIVED BARRIERS TO UPTAKE OF TESTING AND PMTCT AMONG RECENT MOTHERS IN WESTERN KENYA (2011)

	<i>Random community</i> N = 405	<i>HIV-positive women</i> N = 216
<i>Why do you think some women... Choose not to get tested for HIV</i>		
Stigma or fear of disclosure	260 (64.2)	161 (74.5)
Denial/don't want to know	230 (56.8)	144 (66.7)
Husband would not like it	61 (15.1)	56 (25.9)
Lack of knowledge	42 (10.4)	23 (10.7)
Despondency or despair	23 (5.7)	12 (5.6)
Feel guilty	12 (3.0)	3 (1.4)
Logistical concerns (cost/time)	6 (1.5)	2 (0.9)
Worried about medications	0 (0.0)	4 (1.9)
Fear of family break-ups	1 (0.0)	0 (0.0)
<i>Who are HIV+ do not want to test their babies for HIV</i>		
Stigma or fear of disclosure	197 (48.6)	120 (55.6)
Denial/don't want to know	193 (47.7)	118 (54.6)
Feel guilty	111 (27.4)	63 (29.2)
Lack of knowledge	65 (16.1)	34 (15.7)
Husband would not like it	48 (11.9)	34 (15.7)
Logistical concerns (cost/time)	11 (2.7)	3 (1.4)
Despondency or despair	3 (0.7)	1 (0.5)
<i>Who know that they have HIV choose not to take medicine to prevent the baby getting infected</i>		
Stigma or fear of disclosure	164 (40.5)	100 (46.3)
Fear of or difficulty with medication	116 (28.6)	53 (24.5)
Logistical concerns (cost/time)	14 (3.5)	5 (2.3)
Feel guilty	4 (1.0)	2 (0.9)
Lack of knowledge	18 (4.4)	5 (2.3)
Denial	3 (0.7)	0 (0.0)
Despondency or despair	10 (2.5)	2 (0.9)
Husband would not like it	46 (11.4)	28 (13.0)
Health worker advice	1 (0.0)	0 (0.0)

not approve of HIV infant testing or treatment. While the majority of women specified a fear of partner disapproval, one woman also specified a "fear of family break-ups" more generally, related to uptake of maternal HIV testing. Another indicated potential abandonment by families, in that "you can be sent away after the test result".

Lack of knowledge. A lack of knowledge was also commonly cited as a barrier to HIV testing of both the mother and infant. The theme consisted of three similar but distinct concepts, which included ignorance or lack of belief in, or awareness of, interventions to prevent transmission to infant ("some believe that there is no way they can prevent the baby from being infected"); lack of appreciation for the perceived benefit of the intervention to themselves ("not aware of the benefits they get from taking drugs"); and also having a lower level of education.

Logistical concerns. Logistical concerns such as cost or time required to access testing and medication were not commonly reported, particularly for maternal HIV testing. Just under half of women in the community (48%) and HIV-positive women (45%) reported knowing the cost of an HIV

TABLE 3. SAMPLE QUOTES FROM RECENT MOTHERS IN WESTERN KENYA, GROUPED BY THEME

<i>Maternal HIV testing</i>	
Stigma, discrimination, and fear of disclosure	Wants to be secret Confidentiality is not guaranteed Fear of discrimination A lot of shame
Lack of knowledge	Ignorance They don't know the benefits
Despondency or despair	To avoid stress Afraid of the stress of the outcome Fear of shock Stress of soon she will die Stress of awareness of child survival
Worried about medication	Afraid of medicine
Family relationships	Bring problems in the family
<i>Infant HIV testing</i>	
Stigma, discrimination, and fear of disclosure	Fear of stigmatization Can be sent away after test result
Lack of knowledge	Depends on peoples understanding Believe it's for adults Ignorance Fear the blood test can cause their babies to have insufficient blood
Despondency or despair	Fear of death The child will still die even if it is tested
<i>Maternal ARVs for PMTCT</i>	
Stigma, discrimination, and fear of disclosure	People will know status Guilt of how people talk
Difficulty with medication	Medicine requires a balanced diet which they cannot afford The medicine needs a lot of food Taking drugs is a problem Size of medicine
Lack of knowledge	Not aware of the benefits they get from taking drugs Some believe that there is no way they can prevent the baby from being infected
Denial	They do not want to accept the fact that they have HIV
Despondency or despair	Stress Too much thoughts Some prefer ending their lives, not caring about the child they are carrying Prefer dying to taking medicine Even if they take medicine, they will still die People's emotional strength varies

Participants asked why do you think some women in your community do not accept the following services.

test (it is free in public facilities), though most HIV-positive women (98%) and women in the community (90%) who did not know the cost of a test suspected that it was free.

Despondency, stress, and despair. Several women reported themes of despondency or emotional despair. These included concepts of stress and worry about implications of a positive test result, survival of mother and child, as well as family relationships. There was a clear awareness of the linkage between the well-being of the mother and the long-term survival of the child. In regards to uptake of maternal HIV testing, women reported “stress” over a child’s survival if the mother was found to be positive. A perceived fatalism was also described related to uptake of PMTCT. One statement was, “even if they take the medicine, they will still die” or “some prefer ending their lives.” Others said that some women may “prefer dying to taking medicine” or that women may find “death to be the only solution for both the mother and child.” Perceptions of despondency and despair were reported at a similar frequency among both HIV-positive women and women in the community sample.

Difficulty with or fear of medications. Difficulty taking or a fear of medications was reported by approximately a quarter of HIV-positive women (24%) and somewhat over a quarter of women in the community (29%). Women reported both a fear of harm to the mother and/or child, awareness or concern about side effects or size of the pills, and a concern that women who are very poor may not be able to afford food to take with the medication.

Guilt. Guilt was primarily described as a perceived factor influencing women who do not want to test their baby for HIV. Twenty-seven percent of women in the community

sample and 29% of HIV-positive women cited guilt as a reason they thought women would refuse infant HIV-testing.

Stigma: Discrimination

Proportions of women reporting knowledge of discrimination and abuse are detailed in Table 4. Twenty percent of women in the community and 28% of HIV-positive women reported knowing someone that has experienced at least one of the forms of discrimination related to HIV in the past year. The most commonly cited forms of discrimination were verbal with 19% of women in the community sample reporting knowing people with HIV who were gossiped about, and 12% reporting knowing people with HIV who were teased or sworn at. Among HIV-positive women, 27% knew someone who was gossiped about, and 10% knew someone who was teased or sworn at because of HIV. Twenty-three percent of women in the community sample, and only one-third of women who later reported being HIV-positive, reported knowing someone with HIV. Among those who knew someone living with HIV, the majority knew of someone that had experienced discrimination because of their HIV (86% in both groups).

Knowledge of discrimination was not significantly associated with decreased uptake of ANC: among those who did and did not access ANC, 19% reported knowledge of discrimination (Table 5). Among women who attended ANC and did not previously know their HIV status, knowledge of discrimination was more common among those who accessed maternal HIV testing (20%) than those who did not (8%) and this difference approached statistical significance. Among all HIV-positive women, report of known discrimination was similar among those who accessed any maternal ARVs for PMTCT (28%) and those who did not (29%). There was also

TABLE 4. KNOWLEDGE OF SOMEONE WITH HIV/AIDS WHO EXPERIENCED ABUSE OR DISCRIMINATION IN THE LAST YEAR^a

	<i>Among all in community random sample (n = 405) n(%)</i>	<i>Among those in community sample who know someone with HIV (n = 92, 23%) n(%)</i>	<i>Among all HIV-positive women (n = 215) n(%)</i>	<i>Among HIV-positive women who know someone with HIV (n = 69, 32%) n(%)</i>
<i>Knowledge of HIV-related discrimination or abuse in the community</i>				
<i>Discrimination</i>				
Excluded from social gathering	16 (4.0)	16 (17.4)	7 (3.3)	7 (10.1)
Lost customers or lost a job	15 (3.7)	15 (16.3)	5 (2.3)	5 (7.3)
Abandoned by family/sent away	16 (4.0)	16 (17.4)	8 (3.7)	8 (11.6)
Abandoned by spouse or partner	30 (7.4)	30 (32.6)	15 (7.0)	15 (21.7)
Teased or sworn at	48 (11.9)	48 (52.2)	22 (10.2)	22 (31.9)
Lost respect or standing within the family	21 (5.2)	21 (22.8)	10 (4.7)	10 (14.5)
Lost respect or standing within the community	22 (5.4)	22 (22.8)	6 (2.8)	6 (8.6)
Gossiped about	78 (19.3)	78 (83.7)	57 (26.5)	57 (81.4)
Total measure ^b	79 (19.5)	79 (85.9)	60 (27.9)	60 (85.7)
<i>Abuse or mistreatment</i>				
Mistreated by spouse or partner	24 (5.9)	24 (26.1)	14 (6.5)	14 (20.0)
Physically harmed by spouse partner	14 (3.5)	14 (15.2)	4 (1.9)	4 (5.7)
Physically harmed by other person	10 (2.5)	10 (10.9)	2 (1.0)	2 (2.9)
Isolated within the household	20 (4.9)	20 (21.7)	7 (3.3)	7 (10.0)
Total measure ^b	35 (8.6)	35 (38.0)	16 (7.4)	16 (22.9)

^aAmong Recent Mothers Residing in Western Kenya (2011).

^bCalculated if selected any of the above indicators.

TABLE 5. STIGMA AND UPTAKE OF CARE ALONG THE PMTCT CASCADE AMONG RECENT MOTHERS RESIDING IN WESTERN KENYA (2011)

	No uptake n(%)	Uptake n(%)	p Value
<i>Attendance at ANC (n=405)^a</i>	26 (6.4)	379 (93.6)	
Judgment or blame	25 (96.2)	337 (88.9)	0.34
Shame	14 (53.9)	174 (45.9)	0.54
Known or observed discrimination	5 (19.2)	74 (19.5)	1.00
Known or observed mistreatment or abuse	2 (7.7)	33 (8.7)	1.00
<i>HIV testing (n=362)^b</i>	48 (13.3)	314 (86.7)	
Judgment or blame	45 (93.8)	279 (88.9)	0.45
Shame	30 (62.5)	137 (43.6)	0.02
Known or observed discrimination	4 (8.3)	64 (20.4)	0.05
Known or observed mistreatment or abuse	2 (4.2)	28 (8.9)	0.40
<i>Any maternal antiretrovirals for PMTCT (n=216)^c</i>	39 (18.1)	177 (81.9)	
Judgment or blame	31 (79.5)	154 (87.0)	0.21
Shame	18 (47.4)	56 (31.6)	0.09
Known or observed discrimination	11 (29.0)	49 (27.7)	0.85
Known or observed mistreatment or abuse	4 (10.5)	12 (6.8)	0.49
<i>Complete course^d of maternal antiretrovirals for PMTCT (n=216)^c</i>	99 (45.8)	117 (54.2)	
Judgment or blame	83 (83.8)	102 (87.2)	0.56
Shame	42 (42.9)	32 (27.4)	0.02
Known or observed discrimination	24 (24.5)	36 (30.8)	0.36
Known or observed mistreatment or abuse	9 (9.2)	7 (6.0)	0.44
<i>Infant HIV testing (n=216)^c</i>	37 (17.4)	176 (82.6)	
Judgment or blame	29 (78.4)	154 (87.5)	0.19
Shame	19 (51.4)	55 (31.3)	0.02
Known or observed discrimination	6 (16.2)	53 (30.1)	0.11
Known or observed mistreatment or abuse	3 (8.1)	13 (7.4)	1.00
<i>Infant Antiretrovirals for PMTCT (n=216)^c</i>	43 (20.2)	170 (79.8)	
Judgment or blame	36 (83.7)	147 (86.5)	0.64
Shame	19 (44.2)	55 (32.6)	0.16
Known or observed discrimination	11 (25.6)	49 (29.0)	0.71
Known or observed mistreatment or abuse	3 (7.0)	13 (7.7)	1.00

^aAmong 405 women in the random community sample; ^bAmong 362 women with previously unknown or negative HIV status in random sample; ^cAmong 216 self-reported HIV-positive women; ^dDefined as ARVs during antenatal, perinatal, and postpartum time points.

no significant difference in uptake of maternal ARVs at all three time points (antenatal, during labor, and postpartum), infant HIV testing, or infant ARVs associated with known or observed discrimination.

Household or partner violence and abuse

Knowledge of mistreatment or abuse was not uncommon among those who knew someone with HIV (Table 4). Thirty-eight percent of women in the community sample and 23% of HIV-positive women who knew anyone with HIV reported that they knew someone who had experienced mistreatment or abuse because of their HIV status. Mistreatment by spouse other than physical violence (26% community, 20% HIV-positive) and isolation within the household (22% community, 10% HIV-positive) were the most commonly cited forms of abuse in each population.

Knowledge of violence or abuse was not associated with uptake of ANC (9% among those who accessed ANC and 8% among those who did not) (Table 5). Among women who accessed ANC and did not previously know their HIV status, 9% of those accepting HIV testing and 4% of those not accepting HIV testing reported knowledge of abuse ($p=0.44$). Among all HIV-positive women, there was also no significant association between knowledge of abuse and

uptake of maternal ARVs, infant testing, or infant ARVs for PMTCT.

Blame, judgment, and shame

Values-based stigma was high in the region, with 89% of women overall reporting blame or judgment of people with HIV and 46% indicating that they would feel shame if they were associated with someone with HIV. Levels were slightly lower among HIV-positive women, with 86% indicating blame or judgment of people with HIV, and 34% indicating they would feel shame if associated with someone with HIV. Stigma indicators related to feeling shame if they were associated with someone with HIV were significantly associated with decreased likelihood of maternal HIV testing (63% among women who did not test vs. 44% among women who tested, $p=0.02$), decreased uptake of maternal ARVs (43% among women who did not complete a course of maternal ARVs vs. 27% among women taking ARVs at all three time points, $p=0.02$), and infant HIV testing (51% among women who did not have their child testing vs. 31% of women who did, $p=0.02$) (Table 5). Blame or judgment was not significantly associated with uptake of any of the outcomes. In multivariate models adjusted for covariates of age and education, shame remained significantly associated with

uptake of maternal HIV testing (Prevalence Ratio 0.91, 95% Confidence Interval 0.84–0.99), a complete course of maternal ARVs (PR 0.73, 95% CI 0.55–0.97), and infant HIV testing (PR 0.86, 95% CI 0.75–0.99).

Discussion

This mixed-methods landscape analysis provides insight into the social context, perceived notions, and sources of information related to uptake of PMTCT; prevalence of stigma, discrimination, and abuse related to HIV; and social barriers to HIV services for pregnant women with and without HIV in a region of Western Kenya.

Despite the high reported acceptability of engagement in HIV services in this population in western Kenya, actual rates of uptake of skilled delivery and PMTCT services was lower. Women reported willingness to return to their care provider for services if they were found to be HIV-positive; however, more than half of these women received delivery care from unskilled providers outside of health facilities, suggesting that in addition to barriers to attending health facilities, there may be perceived benefit to care received outside of health facilities. Given that facility delivery has been associated with higher uptake of maternal ARVs during delivery,⁹ increasing uptake of facility delivery or expanding PMTCT services to include unskilled providers may be necessary to increase peripartum maternal ARV uptake.

Many women reported selecting their care provider as a result of advertising. Approximately one-third of women said that they were prompted to seek ANC and delivery providers through advertisements. Mass media campaigns have shown promise in increasing uptake of HIV testing¹⁶ and uptake of condoms,¹⁷ as well as reduction of stigma,¹⁸ and may help to further improve uptake of skilled delivery and PMTCT.

Stigma frameworks and corresponding measurement tools have been increasingly discussed specific to the African setting.^{19,20} Turan et al. developed a model where psychosocial effects of stigma and discrimination (shame, guilt, and denial) lead to behavioral consequences (lack of disclosure, avoidance of ANC, or lack of adherence), and ultimately result in negative health outcomes for mother and child.²¹ We found that stigma measures, both externalized and internalized, were prevalent in this community-based survey. Intriguingly, the prevalence of judgment and blame was similar among women living with HIV (86%) as in the general sample of women (89%). Shame about HIV was less prevalent than judgment and blame, but it appeared to exert more influence on women's decisions and adherence to ARVs and was significantly associated with being less likely to get HIV tested or take ARVs. This may be consistent with other stigma frameworks described in the field of mental health in the United States, where *awareness* of a negative belief about a group precedes *agreement* with that belief (blame), followed by *application* that the negative belief applies to oneself (shame) and subsequent loss of self-worth.²²

Shame is experienced when a person is judged as defective or inferior; or when a perceived negative social judgment is internalized as a negative self-evaluation.^{23–25} The resulting sense of worthlessness and powerlessness can overwhelm and debilitate, resulting in inability to act. Persons et al. describe a theoretical model in which HIV-related shame manifests as avoidant behavior, negative self-image, and

poor mental health functioning; leading to avoidance of health care or other social support networks, decreased motivation for self-care, and feelings of inadequacy in managing one's own health.²⁶ This theoretical model is supported by literature demonstrating similar findings between shame and other HIV-related health behaviors such as condom use,²⁷ retention in care,^{28,29} and adherence to medication.^{30–33} This also suggests that shame, unlike more culturally or socially rooted values of stigma, is potentially modifiable and should be a target for intervention at the individual level.³⁴

Discrimination was also highly prevalent in this population. However, having observed discrimination did not correlate with decreased uptake of ANC and PMTCT services. This suggests that observation or knowledge of discrimination, though often measured together with individual-level stigma, is distinct from actually internalizing feelings of shame, which appear to be more influential in PMTCT uptake. This is consistent with findings in Zimbabwe in which internalized stigma was significantly associated with decreased HIV testing, while observed discrimination and knowing someone with HIV was associated with increased uptake.³⁵ A study in South Africa also found that internalized stigma decreased after initiation of ART, despite increased experiences of discrimination over time.³⁶ Our observation of a trend for increased uptake of maternal HIV testing associated with discrimination could be explained by the cross-sectional nature of the study, in which women accessing care may have been more likely to observe or experience acts of discrimination.

Stigma and discrimination have been associated with decreased uptake throughout each step of the PMTCT cascade,²¹ suggesting a need for large-scale stigma-reduction initiatives in addition to simplification of the cascade. There are few rigorous evaluations of stigma-reduction interventions,³⁷ but there appears to be promise in media campaigns, as well as cognitive behavioral and mentor mother program delivery.^{18,38} Social marketing campaigns and counseling interventions advocating for uptake of PMTCT may gain effectiveness if they specifically target messages to decrease internalized values of stigma such as shame.

Considering the high prevalence of HIV in Nyanza Province, it was surprising how few women reported knowing someone with HIV, particularly the HIV-positive women. This could be related to stigma in either not wanting to acknowledge knowing someone with HIV, or knowing someone who has not disclosed their HIV status, indicating both a reluctance of disclosure as well as likely isolation and an absence of peer support. The need for peer support may also be reflected in the comments related to despondency and despair as perceived barriers to uptake of PMTCT services.

The concept of stress was frequently endorsed. While reports of severe depression were not common, the fatalism and despair reflected in some comments, particularly those who expressed ideas that nothing could be done for the mother or child so death was a better option, were striking. A qualitative study in Malawi noted similar responses as barriers to uptake of infant HIV-diagnosis and treatment.³⁹ Respondents stated that they believed some women do not seek care, or even hasten the death of their infant, citing complex sociological conditions where survival is tempered with extreme poverty and high baseline infant mortality. Our analysis supports this, but could also suggest two other important concerns. One is a potential prevalence of mental health concerns that may not

be currently addressed within the current care system. Studies in Africa have found high rates of depression among postpartum women,^{40,41} and a systematic review found lower rates of adherence during the postpartum period and a correlation between postpartum depression and non-adherence.⁴² However, assessment and care of postpartum depression is not integrated within MCH or PMTCT services. A second concern is that there is likely still some lack of awareness or belief in the efficacy, accessibility, and tolerability of PMTCT interventions.

Another community-wide issue was the perceived difficulty with medication and the interactions between food/nutrition and ability to take medication, especially in conditions of poverty where access to food is challenging. Fear of medication side-effects was widely perceived, and preemptive conversations about the tolerability of medications on the part of health care workers at time of testing and referral may help to alleviate some fears.

There were several strengths and limitations of this survey. The community-based platform allowed for assessment of opinions and behavior of both women who did and did not engage in formal health care services, thus providing more generalizable information within the region. The mixed-methods approach helped to both quantify prevalence of discrimination and abuse, as well as to understand more nuanced perceptions of barriers to care. A limitation is the cross-sectional nature of the study, thus the inability to assess the temporal relationship between measured factors and uptake of PMTCT services. Additionally, a substantial number of HIV-positive women declined to reveal their status to the field team, thus views from those who may be the least willing to engage in care may not be reflected.

This analysis identifies the social landscape and perceived barriers to uptake of PMTCT and subsequent elimination of mother-to-child transmission. Our findings highlight perceived needs and opportunities for social support of mothers accessing PMTCT services in order to enable them to engage in care. Opportunities include peer support, mental health services, advertising or marketing, and social awareness campaigns. Interventions that seek to decrease maternal depression and internalization of stigma may facilitate uptake of PMTCT services.

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