



Maternal Decision-Making and Uptake of Health Services for the Prevention of Mother-to-Child HIV Transmission: A Secondary Analysis

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Published online: 18 July 2018

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Abstract

Objectives We investigated whether a woman's role in household decision-making was associated with receipt of services to prevent mother-to-child HIV transmission (PMTCT). **Methods** We conducted a secondary analysis of the PEARL study, an evaluation of PMTCT effectiveness in Cameroon, Cote d'Ivoire, South Africa, and Zambia. Our exposure of interest was the women's role (active vs. not active) in decision-making about her healthcare, large household purchases, children's schooling, and children's healthcare (i.e., four domains). Our primary outcomes were self-reported engagement at three steps in PMTCT: maternal antiretroviral use, infant antiretroviral prophylaxis, and infant HIV testing. Associations found to be significant in univariable logistic regression were included in separate multivariable models. **Results** From 2008 to 2009, 613 HIV-infected women were surveyed and provided information about their decision-making roles. Of these, 272 (44.4%) women reported antiretroviral use; 281 (45.9%) reported infant antiretroviral prophylaxis; and 194 (31.7%) reported infant HIV testing. Women who reported an active role were more likely to utilize infant HIV testing services, across all four measured domains of decision-making (adjusted odds ratios [AORs] 2.00–2.89 all $p < .05$). However, associations between decision-making and antiretroviral use—for both mother and infant—were generally not significant. An exception was active decision-making in a woman's own healthcare and reported maternal antiretroviral use (AOR 1.69, $p < 0.05$). **Conclusions for Practice** Associations between decision-making and PMTCT engagement were inconsistent and may be related to specific characteristics of individual health-seeking behaviors. Interventions seeking to improve PMTCT uptake should consider the type of health-seeking behavior to better optimize health services.

Keywords Women · Prevention · Children · PMTCT cascade · Decision-making · Infant HIV testing

Significance

Women reporting higher levels of empowerment have been shown to engage more frequently in health care across a range of settings. We investigated whether an HIV-infected woman's role in decision-making—one aspect of empowerment—was associated with use of prevention of mother-to-child HIV transmission (PMTCT) services during pregnancy. Our findings suggest that active decision-making may differently influence engagement along the PMTCT cascade

and this may depend on characteristics of health behaviors and the context in which they are carried out. Such insights may inform the design of new interventions to optimize PMTCT programs globally.

Introduction

Prevention of mother-to-child HIV transmission (PMTCT) is a pillar of global AIDS control efforts and the growing availability of PMTCT services has dramatically reduced the pediatric HIV burden worldwide (Joint United Nations Programme on HIV/AIDS 2016). In order to be effective, PMTCT programs must engage women and their families at various points through the course of pregnancy, a critical

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path or “cascade” (Stringer et al. 2008) that includes HIV testing, collection of positive HIV results, initiating maternal antiretroviral treatment or prophylaxis, providing antiretroviral prophylaxis to infants exposed to HIV, and HIV testing of HIV-exposed infants (Chi et al. 2015; McNairy et al. 2015). When women engage in each of these steps, the HIV transmission rate can be as low as 1–2% (Fowler et al. 2016; Kesho Bora Study Group 2011; Shapiro et al. 2010). However, due to a variety of factors at the individual, health system, and societal level, the actual transmission rate is much higher in “real world” settings (Barker et al. 2011).

Engagement in healthcare is influenced by many individual, family and community factors. A women’s level of empowerment—the control she has over her life, body and environment (Kishor and Subaiya 2008)—has been shown to influence aspects of health-seeking behavior. In numerous studies, women reporting higher levels of empowerment were more likely to engage in health care across a range of services, from family planning to HIV testing (Bashemera et al. 2013; Mutowo et al. 2014).

To date, the evidence linking women’s empowerment to PMTCT service utilization remains limited. In interviews with women who failed to sustain virologic suppression at 24 months following delivery, Ngarina et al. reported the lack of empowerment as a significant barrier to long-term adherence (Ngarina et al. 2013). Similarly, a qualitative study from Malawi and Uganda found that a lack of agency (i.e., the ability to act or exert power) was commonly reported by women who did not adhere to PMTCT or who were lost to follow up (Flax et al. 2017). In a previous study, our team also investigated the relationship between women’s decision-making and PMTCT uptake in rural Zambia. Although trends in increased infant HIV testing were observed, ultimately the study may have been underpowered to provide definitive results (Ford et al. 2017).

In this report, we investigate how a woman’s role in decision-making may be associated with health behaviors in the context of PMTCT in a larger, multi-country population. We hypothesized that women with an active role in decision-making would have higher levels of engagement within PMTCT services.

Methods

The *PMTCT Effectiveness in Africa: Research and Linkages to Care Study*, also known as the “PEARL” study, was a four-country evaluation of PMTCT program effectiveness conducted in Cameroon, Cote D’Ivoire, South Africa, and Zambia (Ekouevi et al. 2012; Stringer et al. 2010, 2013). The community-based component of PEARL—the focus of the present analysis—comprised a household survey across 26 clinic catchment areas. The survey methods have been

reported elsewhere (Stringer et al. 2013). In brief, households were selected through a two-stage sampling technique specific to each country. All countries randomly selected PMTCT health facilities for inclusion in sampling. Once selected, the catchment area was defined for each facility via satellite imaging (South Africa, Zambia) or local maps (Cameroon, Cote d’Ivoire). The households were selected through a subdivision of evaluation areas. These areas were ranked in random order with a “rank probability proportional to size” technique and areas were visited in sequence until the community-level sample sizes were reached.

Sampled households were screened and deemed eligible if a child was born in the 24 months prior to the study visit. Study staff administered a three-part questionnaire that included: (1) an eligibility form to the head of household for identifying information on the household members, (2) a maternal questionnaire to the biological mother or caregiver (if the mother had died) addressing household, demographic and obstetric characteristics as well as HIV knowledge and perceptions, and (3) an infant questionnaire to the biological mother or caregiver (if the mother had died) addressing the healthcare engagement of the index pregnancy. Additionally, all participating mothers were tested for HIV, either at the time of the participant interaction (Cameroon) or batched for anonymous testing at a local reference laboratory (Cote d’Ivoire, South Africa, Zambia). The infants of those mothers found to be HIV-infected (i.e., HIV-exposed infants) were tested for HIV infection via DNA PCR. Before the questionnaire or HIV test was performed, informed consent was obtained from the participant. The information in the consent was customized to the procedure and the requirements of the ethics boards of the specific country. For illiterate participants, a non-biased literate witness was present for the informed consent. Approval was obtained from the institutional review boards at the University of Alabama at Birmingham (Birmingham, Alabama, US) and the US Centers for Disease Control and Prevention (Atlanta, Georgia, US), as well as the local research ethics review boards within each country.

In this secondary analysis, we included women who tested HIV-positive and only data from their most recent pregnancy was considered. The maternal questionnaire, given to the biological mother or caregiver (if the mother had died), included four questions on who in the family made specific decisions on maternal healthcare, large household purchases, schooling of children, and healthcare of children. These questions were adapted from the empowerment evaluation from the Zambia Demographic and Health Surveys (Central Statistical Office [Zambia] et al. 2015), but with an added emphasis on decision making in the context of the child’s health. Possible responses were “you,” “you and your husband/partner,” “someone else,” “respondent and husband/partner” (i.e., for cases where the primary caregiver was was

not the mother), and “decision not made/not applicable.” We categorized these responses for each decision into “active role in decision-making” (i.e., you, you and your husband/partner) or “no active role in decision-making” (i.e., someone else, respondent and husband/partner).

Our primary exposures were the woman’s role (i.e., active or not active) in household decision-making in each of these four domains. Our primary outcomes included healthcare engagement at three steps of the PMTCT cascade: maternal initiation of any antiretroviral regimen during pregnancy, infant initiation of antiretroviral drugs for prophylaxis (i.e., zidovudine or nevirapine), and HIV testing of the HIV exposed infant. All were based on the mother’s or caregiver’s self-report.

Demographic characteristics were compared according to the women’s role in decision-making domains. Using Pearson’s Chi-squared tests, we tested for associations between decision-making and self-reported uptake of each of the three PMTCT cascade steps. The demographic characteristics found to be significant at $p < 0.05$ in univariate analyses were included in multivariable logistic regression. We fitted a multilevel model with facility as a random effect and the country as the fixed effect to adjust for clustering at the facility and country levels. At the individual level, we adjusted for maternal age, parity, employment, and marital status.

We stratified women according to the degree of active decision-making reported across the four domains (i.e., maternal healthcare, large household purchases, schooling of children, healthcare of children). Participants were categorized as follows: women reporting no active role in any domain, women reporting an active role in one to three domains, and women reporting an active role in all four domains. These categories were chosen based on the distribution of responses. Relatively few women reported having an active role in one, two, or three domains, making it difficult to consider this as a continuous exposure variable. We included this variable in separate multivariable, multi-level models for each of the three programmatic outcomes. All statistical analyses were conducted using Stata version 14.1 (Stata Corporation, Texas, TX, USA).

Results

Between May 2008 and May 2009, 28,942 households were approached across the participating sites. 9348 households were found to be eligible and 7985 mother–child pairs were enrolled from these households. Of these, 1106 (13.9%) were HIV-infected mothers and HIV-exposed infants. 613 (55.4%) mother–child pairs completed at least one of the questions about PMTCT services and were thus included in this analysis. Overall, 272 (44.4%) women reported taking antiretroviral medication during pregnancy, 281 (45.9%) reported

giving their infant antiretroviral prophylaxis, and 194 (31.7%) reported taking their infant for HIV testing.

Women’s Role in Decision-Making

The proportion reporting an active role in decision-making was similar across all domains: 336 (54.9%) for their own healthcare; 311 (50.8%) for making large household purchases; 289 (47.2%) for the schooling of children; and 324 (53.2%) for children’s healthcare. Demographic and socioeconomic characteristics, stratified by decision-making role, are presented in Table 1. Of note, there were statistically significant differences in decision-making roles with respect to maternal age, parity, marital status, employment, and country. Country differences ranged from Cote d’Ivoire reporting of 5.6% for an active role in a women’s own healthcare to Cameroon reporting of 63.4%. Similar trends were noted with the other decision-making questions.

Active Decision-Making Within Domains and Program Outcomes

In Table 2, we show the associations between active maternal decision-making and our targeted PMTCT engagement points. In unadjusted logistic regression, active decision-making in one’s own healthcare was associated with maternal antiretroviral use (odds ratio [OR] 1.68, 95% CI 1.18–2.40) and infant antiretroviral prophylaxis (OR 1.73, 95% CI 1.05–2.88). However, other types of active decision-making (i.e. large household purchases, children’s schooling, and children’s healthcare) were not associated with maternal antiretroviral use or infant antiretroviral prophylaxis. We observed a significant association between an active role in decision-making across all domains and the outcome of infant HIV testing.

We fitted multivariable logistic regression models, which included maternal age, parity, marital status, employment, and country (Fig. 1). The association between decision-making for one’s own healthcare and maternal antiretroviral use remained significant (AOR 1.61, 95% CI 1.15–2.48; AOR 2.59, 95% CI 1.61–4.18, respectively); however, the association with infant antiretroviral prophylaxis was no longer significant (AOR 1.61, 95% CI 0.93–2.81). In contrast, significant associations between active decision-making and infant HIV testing remained consistent across all domains. Although direct comparisons were not made, the magnitude of the effect appeared to increase slightly when we adjusted for potential confounders (Table 2; Fig. 1).

Degree of Active Decision-Making and Program Outcomes

We aggregated individual responses across all four domains to assess global decision-making. Of those in our analysis

Table 1 Household and demographic characteristics of women reporting an active role in decision-making across four domains

	Own healthcare		Household purchases		Children’s school		Children’s healthcare	
	Active role in decision-making <i>n</i> = 336	<i>p</i>	Active role in decision-making <i>n</i> = 311	<i>p</i>	Active role in decision-making <i>n</i> = 289	<i>p</i>	Active role in decision-making <i>n</i> = 324	<i>p</i>
Maternal age at time of survey, in years		< 0.01		< 0.01		< 0.01		< 0.01
15 to < 25 years	89 (41.0%)		77 (35.5%)		70 (32.4%)		82 (32.3%)	
25 to < 35 years	201 (61.7%)		191 (58.6%)		181 (55.4%)		197 (60.2%)	
35 years or older	28 (73.7%)		25 (65.8%)		23 (60.5%)		26 (70.3%)	
Parity		< 0.01		< 0.01		< 0.01		< 0.01
0	105 (42.9%)		98 (40.0%)		89 (36.5%)		102 (42.0%)	
1	157 (59.0%)		145 (54.1%)		133 (49.8%)		148 (55.6%)	
2 or more	74 (73.3%)		68 (68.7%)		67 (66.3%)		74 (74.0%)	
Marital status		< 0.01		< 0.01		0.05		< 0.01
Married/cohabitating	258 (59.3%)		238 (54.8%)		217 (49.7%)		248 (57.3%)	
Other	75 (43.4%)		71 (40.8%)		70 (40.7%)		74 (42.8%)	
Educational level		0.74		0.21		0.39		0.38
Primary or less	192 (55.3%)		183 (52.9%)		169 (48.6%)		190 (54.6%)	
Secondary or higher	142 (54.0%)		126 (47.7%)		118 (45.0%)		132 (51.0%)	
Currently employed		< 0.01		< 0.01		< 0.01		< 0.01
No	167 (48.3%)		150 (43.5%)		139 (40.4%)		161 (47.1%)	
Yes	168 (63.4%)		160 (60.2%)		149 (55.8%)		162 (60.9%)	
Institutional delivery		0.65		0.90		0.35		0.69
No	17 (51.5%)		16 (50.0%)		13 (39.4%)		16 (50.0%)	
Yes	310 (55.6%)		286 (51.2%)		267 (47.9%)		298 (53.6%)	
Country		< 0.01		< 0.01		< 0.01		< 0.01
Cote d’Ivoire	3 (5.6%)		4 (7.4%)		4 (7.4%)		5 (9.3%)	
Cameroon	111 (63.4%)		113 (63.8%)		110 (62.5%)		117 (66.1%)	
South Africa	56 (51.4%)		52 (47.7%)		49 (45.0%)		52 (48.6%)	
Zambia	166 (60.6%)		142 (52.2%)		126 (46.2%)		150 (55.4%)	

cohort, 256 (42.5%) reported no active role in any domain, 79 (13.1%) reported an active role in one to three domains, and 268 (44.4%) reported an active role in all four domains. When we compared women with no active decision-making, those with an active role in at least one domain were more likely to report infant antiretroviral prophylaxis (adjusted OR 1.56, 95% CI 1.03–2.32) and infant HIV testing (adjusted OR 2.93, 95% CI 1.79–4.80). Maternal antiretroviral use also appeared higher among women who reported active decision-making in at least one domain; however, this was not statistically significant (adjusted OR 1.44, 95% CI 0.81–2.53). The crude and adjusted odds ratios for our stratified analysis are shown in Table 3.

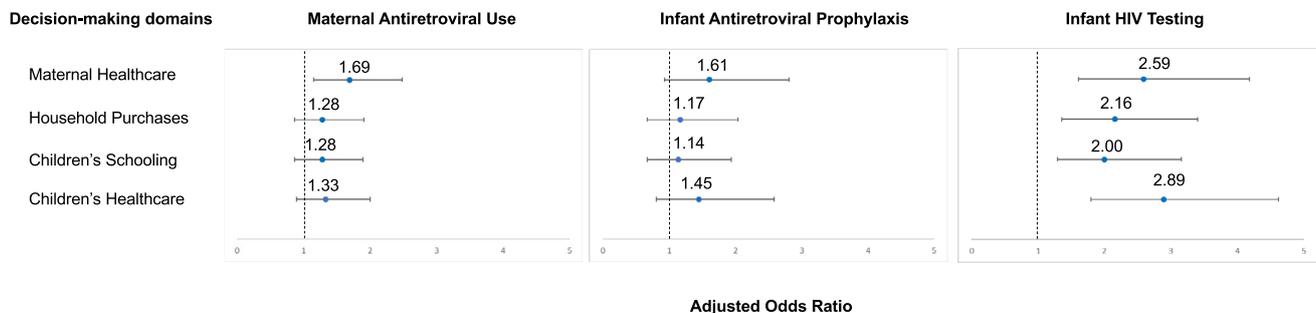
Discussion

In this secondary analysis, we found that a woman’s role in decision-making was associated with some key health-seeking behaviors along the PMTCT cascade. This association was strongest with infant HIV testing and remained robust even after adjusting for potential confounders. The associations between decision-making and antiretroviral use, both for mother and infant, were weaker and less consistent.

The PMTCT cascade has been used in various ways to describe PMTCT health service engagement (Chi et al.

Table 2 Association between maternal decision-making indicators and PMTCT cascade clinical points in four sub-Saharan African countries

	No active role		Active role		Crude OR ^b (95% CI)
	N	Proportion (95% CI) ^a	N	Proportion (95% CI) ^a	
Maternal antiretroviral use					
Own healthcare	93	40.3% (33.1–47.9)	179	56.1% (51.0–61.1)	1.68 (1.18–2.40)
Household purchases	111	44.7% (37.7–51.9)	161	54.2% (49.4–59.0)	1.28 (0.90–1.82)
Children's school	122	44.4% (37.4–51.6)	151	54.9% (49.2–60.5)	1.33 (0.94–1.88)
Children's healthcare	105	43.8% (36.2–51.8)	167	54.6% (49.6–59.5)	1.33 (0.93–1.89)
Infant antiretroviral prophylaxis					
Own healthcare	100	60.6% (44.0–75.1)	181	73.0% (64.0–80.4)	1.73 (1.05–2.88)
Household purchases	119	64.3% (47.5–78.2)	164	71.6% (63.8–78.3)	1.45 (0.88–2.40)
Children's school	128	63.7% (47.1–77.5)	155	72.8% (65.0–79.4)	1.49 (0.92–2.43)
Children's healthcare	110	64.0% (46.0–78.7)	172	71.7% (63.0–79.0)	1.65 (0.97–2.83)
Infant testing					
Own healthcare	66	24.5% (11.7–44.4)	128	38.6% (24.1–55.3)	2.20 (1.42–3.41)
Household purchases	76	25.9% (12.2–46.6)	117	38.1% (24.7–51.6)	1.81 (1.19–2.76)
Children's school	83	26.3% (12.5–47.1)	112	39.3% (26.1–54.3)	1.78 (1.18–2.69)
Children's healthcare	67	24.0% (10.4–46.3)	126	39.5% (26.7–53.9)	2.35 (1.52–3.64)

^aStandard errors for proportions adjusted for clusters^bMultilevel model, using facility code as random effect and country as fixed effect**Fig. 1** Adjusted odds ratio of active decision-making across different domains at three steps along the prevention of mother-to-child HIV transmission (PMTCT) cascade

2015; McNairy et al. 2015; Stringer et al. 2008). We have included three steps of the cascade in our analysis: uptake of maternal antiretroviral medication during pregnancy, uptake of infant antiretroviral prophylaxis, and infant HIV testing. In our analysis, 44.4% reported taking antiretroviral medication during pregnancy and 45.9% reported giving their infant antiretroviral prophylaxis. These rates are lower than several recent reports (Granato et al. 2016; Woldesenbet et al. 2015), which may reflect the efficiency of newer and simplified approaches such as “Option B+” (i.e., universal lifelong antiretroviral therapy for pregnant and breastfeeding women) (Chimbwanda et al. 2013). Infant HIV testing (31.7%) was also lower than rates reported in recent reports (Granato et al. 2016; Wettstein et al. 2012). This may be attributed to the expansion of such services globally since our study was conducted

(2008–2009), including in our target countries (Joint United Nations Programme on HIV/AIDS 2016).

We found that women’s decision-making was associated with infant HIV testing, but not uptake of antiretroviral drug regimens for mother or infant. Although these results require elaboration including through qualitative studies, they highlight a potentially important but overlooked aspect of the PMTCT cascade. The health-seeking behaviors needed to move from one step to the next may be inherently different in nature. As such, they may be influenced by different behavioral characteristics and contextual drivers. It is unlikely that a “one-size-fits-all” approach will be effective in such circumstances. Instead, such features should be carefully considered in the design of combination interventions to improve movement along the PMTCT continuum of care.

Table 3 Association between degree of active decision-making and PMTCT cascade clinical points in four sub-Saharan African countries

	Crude odds ratio (95% confidence interval) ^a	Adjusted odds ratio (95% confidence interval) ^b
Maternal antiretroviral use		
No active role in any domain	Ref	Ref
Active role in 1–3 domains	1.42 (0.82–2.46)	1.68 (0.94–3.01)
Active role in all 4 domains	1.54 (1.05–2.26)	1.51 (0.99–2.32)
Infant antiretroviral use prophylaxis		
No active role in any domain	Ref	Ref
Active role in 1–3 domains	1.13 (0.52–2.43)	1.51 (0.65–3.53)
Active role in all 4 domains	1.73 (1.00–3.00)	1.42 (0.78–2.56)
Infant testing		
No active role in any domain	Ref	Ref
Active role in 1–3 domains	2.45 (1.27–4.72)	3.67 (1.85–7.28)
Active role in all 4 domains	2.23 (1.40–3.56)	2.73 (1.63–4.57)

^aMultilevel model, using facility code as random effect and country as fixed effect

^bMultilevel model, using facility code as random effect and country as fixed effect, adjusted for maternal age, parity, employment, and marital status

Women's decision-making was associated with infant HIV testing across all four domains (i.e., own healthcare, large purchases, children's schooling, children's healthcare). These findings are similar to work by Bashemera et al., which demonstrated links between women's empowerment, combining a woman's role in decision-making with attitudes on domestic violence and the right to refuse sexual intercourse, and rates of adult voluntary counseling and testing for HIV (Bashemera et al. 2013). It is also consistent with our work in rural Zambia, where HIV-infected women reporting an active role in decision-making had a higher likelihood of infant HIV testing (Ford et al. 2017). We hypothesize that specific characteristics of this behavior may be more conducive to a woman's decision-making capacity. Infant HIV testing, for example, provides important prognostic data about the child's survival. A positive test is actionable, with available interventions (e.g., antiretroviral therapy) that can improve child survival (Violari et al. 2008); a negative result is reassuring. Infant HIV testing is a discrete event that is timed according to regular postpartum and well-child visits. It is also health-facility based, particularly in the first year of life, when simple antibody testing is not possible. In South Africa, Groves et al. found that, for antenatal HIV testing, women were strongly influenced by the recommendations of their healthcare providers. Some respondents did not feel they had a choice in deciding to test for HIV (Groves et al. 2010). Similar findings were noted in other sub-Saharan African countries (Mitiku et al. 2017; Musheke et al. 2013). It is possible such dynamics are present in the context of infant HIV testing as well.

Antiretroviral uptake, for either mother or infant, was not associated with decision-making capacity. Again, we contend that specific features of this health behavior may play

a role in this null finding. In contrast to infant HIV testing, adherence to antiretroviral regimens is a repetitive behavior that must occur at least daily; it occurs mostly, if not entirely, outside of health facilities. The risk for accidental disclosure—and its consequences for stigma and discrimination—could be an important disincentive to maternal or infant antiretroviral use (Ambia and Mandala 2016; Burgeyeya et al. 2017). Patients may also have different interpretations of what it means to start or stay on antiretroviral drugs in pregnancy. In Malawi, nearly 20% of women who received an initial dispensation of antiretroviral drugs were lost to follow up by 6 months after initiation (Haas et al. 2016b). The probability of maintaining adequate adherence declined significantly over time (Haas et al. 2016a). Additionally, the healthcare system can influence adherence through the availability of medications and access to trained healthcare workers (Finocchiaro-Kessler et al. 2016; Naburi et al. 2016), but these factors are not influenced by a woman's decision-making capacity. Interestingly, the findings appear to differ from the studies in the family planning literature, where measures of women's empowerment have been associated with the uptake of analogous health services (Corroon et al. 2014; Mutowo et al. 2014). These differences may relate to the formulations of certain family planning methods (i.e., long-acting) and the fact that there may be less stigma surrounding contraception, though this requires further investigation.

Although we explored decision-making across different domains, women reporting an active decision-making role in one domain were very likely to report a similar role in other areas. Nevertheless, we observed some heterogeneity in the odds ratios across the different domains. This was most apparent with maternal antiretroviral use, but such trends

were present with all three programmatic outcomes (Fig. 1). We conducted exploratory analyses that considered an aggregated assessment of individual decision-making; however, we were unable to delineate a simple dose–response relationship between the degree of active decision-making and uptake of specific PMTCT services.

Our analysis has several strengths, including its broad representation of African settings and its population-based sampling. We also acknowledge limitations. First, we did not have a sufficient sample to study site differences among the four countries. Each site has different social and cultural norms that could affect the relationship between decision-making capacity and health behavior. Second, there is always a risk of reporting bias in household surveys like ours, and significant missingness in the PMTCT cascade engagement. Participant responses may be influenced by social desirability, though we sought to minimize this bias by conducting interviews outside of the facility setting. Nevertheless, this potential remains and could be differential among the health behaviors measured. Third, data about partner characteristics would be highly informative in our multivariable analysis; however, such information was not routinely collected in the parent study. Women’s decision-making should be viewed in the context of broader partner relationships and this should be considered in similar future work. Fourth, although we adapted our questions from the Zambia Demographic and Health Survey, we recognize that this provides only a crude measure of household decision-making. There is likely greater nuance around the quality and context of decision-making and such factors should be considered in future studies. Finally, the study was conducted prior to the scale-up of the Option B+ strategy, in many ways a different era of PMTCT. Despite the different context, we believe that the relationships between women’s decision-making and PMTCT utilization still remain relevant.

Conclusion

We identified a positive association between women’s decision-making and infant testing of HIV. A similar association was not consistently observed with our other two programmatic outcomes: maternal antiretroviral use and infant HIV prophylaxis. These results suggest that an increased role in decision-making may exert influence differently at steps along the PMTCT cascade. Our findings suggest that efforts to increase women’s empowerment—which can strengthen women’s social, cultural, and economic standing—may have important benefits in health as well. This type of nuanced understanding of health behavior deserves further research and could help to optimize interventions that target uptake, retention, and adherence in the context of PMTCT services.

Acknowledgements The Zambia, South Africa, and Cote d’Ivoire work was supported by contract T0906150021 from the US Centers for Disease Control and Prevention Global AIDS Program. The Cameroon work was supported by a Grant from The Bill & Melinda Gates Foundation (351-07), which was awarded through the Elizabeth Glaser Pediatric AIDS Foundation. Additional trainee and administrative support was provided by the U.S. National Institutes of Health (T32 HD075731, R25 TW009340, K24 AI120796, P30 AI050410). None of the funding agencies were involved in the design, conduct, or interpretation of this analysis, nor did they participate in the preparation, review, and approval of the manuscript.

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