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'I did not feel like a mother': The success and remaining challenges to exclusive formula feeding among HIV-positive women in Brazil

Sarah MacCarthy, ScD, MSc.[1], **Jennifer J.K. Rasanathan, MD, MPH.**[2], **Amy Nunn, ScD, MS.**[1], and **Ines Dourado, PhD, MPH**[3]

[1]Alpert Medical School of Brown University and The Miriam Hospital, 164 Summit Avenue, Providence, RI 02906 USA

[2]Department of Family and Social Medicine, Montefiore Medical Center, 111 East 210th Street, Bronx, New York 10467 USA

[3]Institute of Collective Health, Rua Basilio da Gama, s/n – Campus Universitario Canela, Cep: 40.110-040, Salvador – BA, Brazil

Abstract

Exclusive and safe formula feeding can eliminate the risk of vertical HIV transmission due to breastfeeding. Therefore many countries advise all HIV-positive women to avoid breastfeeding their infants. However, little research explores the experiences of women attempting to exclusively formula feed (EFF) in countries with free and universal access to HAART. This article examines the success of Brazil in supporting HIV-positive women as they EFF their infants. We conducted in-depth interviews with 30 HIV-positive women receiving care at the primary facility for HIV/AIDS in Salvador, Brazil about their attitudes and practices related to EFF as well as challenges with adhering to EFF. All interviews were recorded, professionally transcribed and translated, and then analyzed. Our results showed that one woman reported both breastfeeding and formula feeding her infant; all others reported EFF. Postpartum counseling regarding the risk of HIV transmission through breastfeeding was the primary motivation for EFF. Challenges included difficulty reconciling their perceptions that breastfeeding is an important maternal responsibility, trouble accepting that breastfeeding can cause potential to harm their infants, confronting HIV-related stigma associated with EFF, and unexpected financial burdens due to EFF. We conclude that HIV-positive women adhered to national guidelines recommending EFF; this phenomenon has likely contributed to declining rates of vertical transmission in Brazil. Despite this success, many women experienced challenges with EFF. Greater support services may enhance Brazil's success in empowering HIV-positive women and eliminating vertical HIV transmission via breastfeeding.

CORRESPONDING AUTHOR: Sarah MacCarthy, sarah_maccarthy@brown.edu, tel: 011.703.447.3353, fax: 011.401.793.4534.

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Keywords

HIV/AIDS; exclusive breast feeding; exclusive formula feeding; Brazil

INTRODUCTION

Exclusive and safe formula feeding can eliminate the risk of vertical transmission due to breastfeeding (Iliff PJ et al., 2005), while access to antiretroviral prophylaxis when formula is unsafe or unavailable decreases the risk of transmission via breast milk to less than one percent. (Chasela CS et al., 2010; Jamieson DJ et al., 2012) In contrast, non-exclusive breastfeeding (mixed feeding) has been shown to more than double the risk of seroconversion (Coovadia HM et al., 2007; Iliff PJ, et al., 2005; Kuhn L et al., 2007) but continues to occur (Ladzani, Peltzer, Mlambo, & Phaweni, 2011; Maman S et al., 2012; Maru et al., 2009; Shapiro RL et al., 2003) despite global guidelines recommending either exclusive formula feeding (EFF) or exclusive breastfeeding (EBF) with ARVs for the first six months of life where replacement feeding is unsafe. (World Health Organization, UNAIDS, UNFPA, & UNICEF, 2010; World Health Organization, UNICEF, UNAIDS, & UNFPA, 2003; World Health Organization, UNICEF, UNFPA, & UNAIDS, 2006, 2007) These guidelines call for national health authorities to adopt country-specific HIV and infant feeding policies.

In Brazil, where antiretroviral medicines (ARVs) have been free and universally available since 1997, national HIV and infant feeding guidelines recommend avoiding breastfeeding by all HIV-positive mothers, regardless of their living conditions. (Ministerio da Saude, Secretaria de Vigilancia em Saude, & Departamento de DST, 2010) Brazil's Health Ministry also provides free infant formula to all HIV-positive mothers. (Ministerio da Saude, et al., 2010) As the HIV epidemic was taking root and expanding in Brazil in the past 30 years, (Bastos & Szwarcwald, 2000; Berkman, Garcia, Munoz-Laboy, Paiva, & Parker, 2005; Szwarcwald, 2008) nation-wide campaigns to promote breastfeeding among all women have effectively increased breastfeeding rates and duration. (Cardoso, Vicente, Damiao, & Rito, 2008) As such, Brazilian women living with HIV are advised and encouraged to adopt EFF in a social setting that strongly favors breastfeeding. Data from Brazil demonstrates that substantial progress has been made as a result of ARVs, coupled with polices to support EFF: 1019 cases of vertical transmission were reported in 1998 whereas 104 cases were reported in 2011. (Ministério da Saúde, Secretaria de Vigilância em Saúde, & Departamento de DST, 2012)

Given the substantial reductions in vertical transmission with EFF, many countries advise all HIV-positive women to avoid breastfeeding their infants. (Iliff PJ, et al., 2005) However, little research has explored the experiences of women who attempt to EFF in countries with free and universal access to HAART. This article therefore examines the attitudes, practices and challenges of HIV-positive women who engage in EFF through in-depth qualitative interviews.

METHODS

This qualitative study among 30 HIV-positive women was conducted in Salvador, the capital city of Bahia state and one of the poorest regions of Brazil. Issues related to EFF as highlighted in the peer-reviewed literature informed the semi-structured interview guide. Further, a team of local experts provided input to develop open-ended questions about attitudes, practices and challenges regarding breastfeeding. The interview script underwent extensive field-testing, and researchers met weekly to review the test interviews for clarity in questions asked and quality of information collected. Women were recruited for the study at the primary facility for HIV/AIDS care in the state of Bahia. All interviews were recorded and then professionally transcribed and translated from Portuguese into English. In addition, interviewers submitted field notes summarizing their impressions from the interview.

The following steps were taken to analyze translated interview transcripts: Transcripts and related field notes were reviewed; based on barriers highlighted in peer-reviewed literature, potential challenges were identified through deductive coding. Next, inductive coding was used to distinguish new factors that may not have been previously identified; all codes were discussed between two researchers and further refined. As challenges related to EFF were identified, data was pulled from relevant interviews to identify the scope of evidence available, and exemplars were identified to further illuminate the challenges highlighted from each interview. Finally, discrepant cases, those experiences that deviated from the majority of women in the sample, were also examined.(Bernard, 2006)

RESULTS

Demographic characteristics of all women included in the study are summarized in Table 1. With respect to infant feeding practices, the vast majority of women (97%) reported EFF, and only one woman engaged in mixed feeding. Several women (N=14) cited the comprehensive post-partum HIV counseling they received as a primary factor influencing decisions to EFF, as it taught them about the risks of vertical transmission and helped them cope with the psychological shock many felt upon hearing they should not breastfeed.

Most women (N=29) were able to successfully EFF; challenges women encountered in their efforts to EFF were not insurmountable in most cases. Nonetheless, more than half of women (N=18) reported barriers to EFF. Women’s challenges in attempting to comply with EFF comprised four broad themes: difficulty reconciling their perceptions that breastfeeding is an important maternal responsibility, trouble accepting that breastfeeding can cause potential to harm their infants, confronting HIV-related stigma associated with EFF, and unexpected financial burdens due to EFF. Quotes from interviewees illustrating these themes are captured in Table 2.

DISCUSSION

Qualitative data from this study demonstrate that, overall, HIV-positive women in our sample are able to successfully EFF. Importantly, a growing literature has documented that mixed feeding increases the risk of infant morbidity and mortality, including HIV seroconversion.(Ladzani, et al., 2011; Maman S, et al., 2012; Maru, et al., 2009; Shapiro RL,

et al., 2003) Our results reflect the success of current public health programming for infant feeding by HIV-positive women in Salvador, Brazil.

Although 97% of women living with HIV were able to successfully EFF, participants identified four major challenges that they faced – and successfully overcame – in their efforts to EFF. Barriers limiting women's ability to EFF have been identified in other national contexts, (Maman S, et al., 2012; Oladokun, Brown, & Osinusi, 2010; ÿstergaard LR & A., 2010; Sibeko, Coutsoudis, Nzuza, & Gray-Donald, 2009; Thairu, Pelto, Rollins, Bland, & Ntshangase, 2005) including Brazil, (Hebling EM & Hardy E, 2007) and are further corroborated by this study. As evidenced by these HIV-positive Brazilian women, comprehensive counseling enabled them to forgo breastfeeding despite identified personal, social and economic challenges to doing so. Studies in Nigeria, (Brown, Oladokun, & Osinusi, 2009) South Africa, (Bland RM et al., 2007; Nor et al., 2009) Burkina Faso, Cambodia and Cameroon (Cames et al., 2010) have similarly identified the need for counseling to provide women with the skills to successfully formula feed.

Women's infant feeding practices experiences with counseling and persistent challenges to EFF described here reflect the components of infant feeding counseling currently provided to HIV-positive mothers and pregnant women. They also highlight the positive impact of counseling and the potential for pre- and post-partum HIV-positive women to maintain and further progress in the prevention of HIV transmission from mother-to-child. While most women successfully EFF, this study suggests that additional counseling services are needed to support pregnant or post-partum HIV-positive women as they encounter social norms and experience personal infant feeding desires that conflict with medical advice. Specifically, services should acknowledge and support women to overcome their emotional and psychological challenges. Counseling should seek to empower women with skills and strategies to navigate conflicting pressures, social norms, stigma and any negative interactions with their partners, families, physicians and communities. Further, discussions about transportation, childcare and other factors that may limit access to free infant formula are needed.

The main limitation of this study is that the qualitative data only captures women already in contact with the health system and may not have reached the most marginalized individuals. The qualitative interviews and the sample, therefore, cannot represent the whole of Salvador and may not generalizable to entire population of breastfeeding mothers. The amount of time between the completion of infant feeding and the interview varied among the sample and may also result in some recall bias. Additionally, data on infant HIV seroconversion were not collected, so results are not correlated with HIV transmission. Finally, women may have reported EFF in effort to give a socially desirable response. Still, this study expands the body of knowledge related to the challenges associated with EFF. In other middle and high-income countries that promote EFF, this level of success with dedicated infant feeding counseling could serve as a benchmark or model for context-specific replication.

CONCLUSION

Brazil has achieved substantial success in the reduction of vertical transmission over the past 15 years. Women's successes with EFF documented here underscore the potential for health care providers to empower women to EFF, reduce persistent social and economic barriers to EFF and contribute to the elimination of vertical transmission via comprehensive medical *and* psychosocial counseling. Counseling services should extend beyond providing information on HIV transmission to include psychological support and coping strategies, while formula distribution services should consider the costs of EFF more broadly. Simultaneous, ongoing work to reduce HIV-related stigma may shift the social perception of HIV-positive mothers who avoid breastfeeding from being perceived as "bad mothers" to conscientious mothers acting in their infants' best interests. These efforts will maintain and enhance Brazil's success in empowering HIV-positive women and eliminating vertical HIV transmission via breastfeeding.

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Table 1

Demographic characteristics of women in the sample (n=30)

VARIABLES	n	percentage
Civil status		
Married or live with someone	19	63%
Single, divorced, or widowed	11	37%
Age[*]		
20 – 25 years	6	20%
26 – 31 years	15	50%
32 – 37 years	6	20%
38 years or older	3	10%
Race / ethnicity[**]		
White	1	3%
Brown	11	37%
Black	13	43%
Other	5	17%
Residence		
Outside of metropolitan Salvador	10	33%
Salvador	20	66%
Employment status		
Unemployed	21	70%
Employed (formally or informally)	9	30%
Monthly income		
Minimum wage or below	6	67%
Above minimum wage	3	33%

[*] The women reported their age at the time of the interview, which was not necessarily their age at the time of breastfeeding.

[**] Race and ethnicity in Brazil is complex and is commonly referred to as ‘color’ to reference the phenotype (physical appearance) and not one’s ancestry (origin).

Table 2

Quotes illustrating key themes highlighted in the qualitative interviews (n=30)

THEMES	Quote illustrating the key theme
Reported no challenges associated with EFF and highlighted the role of comprehensive counseling from the health care worker.	***Interviewer:*** *What about the news that you cannot breastfeed? How was that for you?* ***Woman:*** *Ah, that part I did not like.* ***Interviewer:*** *Why?* ***Woman:*** *Because I wanted to breastfeed. I wanted to know what the feeling [of breastfeeding] is like… But after I talked to the social worker, and she explained it all to me, I don't feel like that anymore.*
Difficulty reconciling their perceptions that breastfeeding is an important maternal responsibility (n=8)	***Woman:*** *I did not feel like a mother… At first, I didn't breastfeed, I didn't feel that [my baby] was mine because I had not breastfed.*
Trouble accepting that breastfeeding can cause potential to harm their infants (n=6)	***Woman****: "Because… it is a bond between mother and son [that], unfortunately, you do not have. You can't have! Because you want to protect your baby anyway. You know that with a gesture of affection you can transmit a virus! A disease to your children! I get kind of sad that I couldn't care [for my] child in that way!"*
Confronting HIV-related stigma associated with EFF (n=8)	***Interviewer:*** *"What about breastfeeding, talk a little bit about when you heard the news."* ***Woman****: "Oh! A knife, right? It's hard! When I'm in the hospital, half of the people [are] breastfeeding and I will not be able to breastfeed my child. Will someone ask, "Why aren't you breastfeeding?" So? It is embarrassing! It [is] a big concern! I do not know…if [I will] be in a group or in a specific room only for those with HIV."*
Unexpected financial burdens due to EFF (n=4)	***Interviewer:*** *"So, how was it for you at the time the doctor told you? Either in the maternity [ward] or here…How was that for you?* ***Woman:*** *It was bad, right? I soon started thinking "My God, I'm unemployed, no husband…how [am I] going to feed this boy?"*