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The Stigma of Exclusive Breastfeeding Among Both HIV-Positive and HIV-Negative Women in Nairobi, Kenya

Beryne Mikal Odeny,[1] James Pfeiffer,[1–3] Carey Farquhar,[1,4,5] Emmy Kageha Igonya,[6] Ann Gatuguta,[7] Florence Kagwaini,[8] Ruth Nduati,[9] James Kiarie,[10] and Rose Bosire[11]

Abstract

Background: Exclusive breastfeeding (EBF) means giving only breast milk to an infant. Although it is the optimal mode of feeding for infants younger than 6 months, its prevalence is low in HIV-endemic regions. Extensive promotion of EBF for 6 months in prevention of mother-to-child HIV transmission (PMTCT) programs could inadvertently result in stigma due to women's perceived association of EBF with HIV infection. In this qualitative study, we describe how stigma impacts the uptake of EBF among HIV-positive and -negative women.
Methods: Pregnant and postpartum women and their male partners were recruited to participate in a total of 22 focus group discussions (FGDs). Transcripts were analyzed using ATLAS.ti. Codes were identified both *a priori* and inductively using the open coding approach. Major themes and subthemes were identified.
Results: There was a broad and strong consensus among some FGD participants that HIV-related stigma was a barrier to EBF. EBF was perceived as a practice for HIV-positive women. Thus, fear of discrimination deterred both HIV-positive and -negative women from EBF. However, with health education, peer counselor, and male partner support, some women were able to breastfeed exclusively regardless of opposing social norms.
Conclusion: Stigma related to HIV poses a formidable barrier to EBF in HIV-endemic regions. There is an urgent need to widely target all women with EBF information and support EBF practices regardless of maternal HIV infection status. The lessons learned from this study indicate that vertical programs can hinder promotion of infant health interventions and therefore negatively affect child survival.

Introduction

Exclusive breastfeeding (EBF) means giving an infant breast milk only. It is recognized as the optimal mode of feeding for the first 6 months of life regardless of HIV exposure status.[1,2] Supporting EBF for 6 months is a low-cost and high-impact strategy for promoting healthy infant growth, development, and survival.[3] However, mixed feeding, which means giving foods or fluids in addition to breast milk before 6 months, is the cultural norm in many African countries.[1,4] Mixed feeding increases risks of infant death and morbidity, including diarrhea and respiratory infections and mother-to-child HIV transmission.[5]

In HIV-endemic settings, such as Kenya with HIV prevalence of 6%, prevention of mother-to-child HIV transmission (PMTCT) efforts have influenced infant feeding practices and EBF has largely been promoted among HIV-positive women.[2,4,6–10] The social implications of increased awareness of EBF as an HIV prevention strategy pose significant obstacles to its practice.[11] In some settings, EBF has been stigmatized and labeled as a practice for HIV-positive women.[12,13] The stigma results in a woman weighing up the benefits to the infant of EBF for 6 months versus the social harm experienced from loss of dignity and reputation in the community. Since EBF is beneficial to all babies regardless of HIV exposure, stigma created by focusing EBF promotion on HIV-positive women could be mitigated by embracing strategies that are inclusive of both HIV-negative and -positive women.[12]

In Kenya, the current prevalence of EBF for 6 months is 61%.[14] The most prevalent barriers to EBF include maternal

Departments of [1]Global Health, [2]Anthropology, [3]Health Services, [4]Epidemiology, and [5]Medicine, University of Washington, Seattle, Washington.
[6]Vreje University, Amsterdam, the Netherlands.
[7]School of Public Health, Kenyatta University, Nairobi, Kenya.
[8]Kirwara Sub-County Hospital, Murang'a County, Kenya.
Departments of [9]Pediatrics and Child Health and [10]Obstetrics and Gynecology, University of Nairobi, Nairobi, Kenya.
[11]Centre for Public Health Research, Kenya Medical Research Institute, Nairobi, Kenya.

attitudes and beliefs, cultural practices, societal pressures, maternal employment, food insecurity, and lack of breastfeeding education. [15–21] Although a number of barriers have been identified, stigma related to HIV and EBF as a barrier has not been sufficiently explored. The threat of this stigma cannot be underestimated as it has significant implications on infant feeding choices and practices.[11,13]

We carried out a qualitative study to understand how stigma manifests and impacts EBF. This study was conducted as part of a larger quantitative pre–post-trial that looked at the use of intensified breastfeeding counseling to improve EBF among HIV-positive women. The trial compared the impact of intensive, structured, and regular counseling with standard counseling on EBF. In the nested qualitative study, we describe the manifestations and impact of stigma on EBF, mitigation of stigma, and offer future recommendations.

Methods

Ethical review

Ethical approval was obtained from the Ethics Review Committee of the Kenya Medical Research Institute (KEMRI).

Study design

Between 2009 and 2012, we recruited pregnant and postpartum trial participants and their male partners to participate in focus group discussions (FGDs). Eligible postpartum participants were up to 18 months postpartum. Additionally, we conducted FGDs with HIV-negative pregnant and postpartum women who were not trial participants, but were seeking antenatal or postpartum services at the trial sites. FGDs were conducted before and during the larger trial's intensified counseling intervention. A trained social scientist and study investigator conducted FGDs to explore beliefs around EBF, manifestations of stigma, impact of stigma, and strategies to overcome the stigma.

Setting

This study was conducted in four major city council clinics within Nairobi, Kenya: Kangemi, Riruta, Baba Dogo, and Dandora II. Clinics were selected on the basis that they served densely populated low- to middle-income populations. The clinics also service high numbers of HIV-positive and -negative women.

Participants

We purposively selected participants using quota sampling. Criteria for selection included pregnant or postpartum (up to 18 months) women, over 18 years of age, and able to speak Kiswahili and provide written consent. They had to be antenatal or postnatal clinic attendees. We included both HIV-positive women, who were participating in the larger parent trial, and HIV-negative women. We also recruited male partners of female trial participants attending the clinic. Men were partners of HIV-positive women, had to be over 18 years, able to speak Kiswahili, and provide written consent. The subjects were recruited during trial or clinic visits.

Instrument development

Our FGD guide was designed to probe for information on seven topics: prevalent infant feeding practices; factors that influence infant feeding decisions; women's perceptions of hindrances to achieving EBF, including stigma; strategies for dealing with hindrances; timing of and circumstances that trigger mixed feeding; perceptions and attitudes toward EBF, including stigma; and the role of peer counseling, psychosocial support, and health education. Topics and questions were written in English, translated in Kiswahili, and back-translated to English to confirm accuracy of translation.

Data collection

We conducted 22 FGDs, each consisting of 6–11 participants. We conducted 12 FGDs with HIV-positive women, 5 with HIV-negative women, and 5 with male partners of HIV-positive women. Female FGDs comprised participants with same HIV-1 infection status to maintain confidentiality. Before FGDs, women did not object to potential disclosure of HIV status by being in an all HIV-positive FGD. Due to a lower number of male participants, male FGDs comprised both HIV-positive and -negative men. After individual discussions with men about potential HIV status disclosure during FGD participation, only those who had no concerns about disclosure were recruited. Participants provided written informed consent and were assigned identification numbers by which they were referred to during FGDs. Participant demographic information was collected on a separate form. All FGDs were audiotaped and transcribed verbatim. All discussions were conducted in a confidential space within each trial clinic. Written transcripts were compared with audio recordings to fill in missing data.

Data analysis

Transcripts were translated to English and validated by comparing with original transcripts and audio recordings. English transcripts were imported into qualitative analysis software, ATLAS.ti, version 7.0.92 (Berlin, Germany), for analysis. Transcripts were summarized by time point (before or during larger parent trial), participant characteristics, and clinic. Two coders, the qualitative analyst and principal investigator, were directly involved in data analysis. The coders read over the transcripts several times to acquaint themselves with the data. The qualitative analyst was the primary coder who developed the general coding scheme. The principal investigator, a secondary coder, went over the coding scheme, reviewed segments of coded transcripts, and assisted in fine-tuning themes and codes. Both coders wrote individual memos of their interpretation of data. Memos were discussed to harmonize perspectives and analytical conclusions. Research team meetings were held regularly to discuss the analysis with other investigators who provided feedback that shaped final codes and themes. Codes were developed both *a priori* and inductively using the open coding approach. Coding involved assigning thematic words to segments of transcripts that conveyed a certain meaning. We developed categories into which various segments of the data fit. We categorized major themes and subthemes. We selected some verbatim quotes to illustrate the findings below.

Results

Participant characteristics

A total of 153 women and men participated. Literacy rates were high: 57% of the HIV-positive women and 71% each of

the HIV-negative women and men had some high school education. All HIV-negative women, all men, and 78% of the HIV-positive women were married. Most men (92%), 24% of HIV-negative women, and 39% of HIV-positive women earned >$3.50 per day.

We present six themes that describe stigma related to EBF: exclusive breastfeeding and stigma (broad theme), manifestations of stigma, promoters of stigma, inaccurate assumptions, avoiding stigma, and mitigating stigma.

EBF and stigma

The study identified lack of maternal knowledge, attitudes, illness, employment, maternal time demands, and stigma as barriers to EBF. There was no difference in barriers experienced by HIV-positive and -negative women. This article focuses on HIV-related stigma as a barrier to EBF. There was a strong consensus among participants that stigma was a challenge to EBF. Mixed feeding was deeply engrained in communities. Therefore, infant feeding practices, which were contrary to community norms, sparked questions and curiosity particularly around a woman's HIV status. According to some, EBF was recognized among clinic attendees as a practice for HIV-positive women. Similarly, the community interpreted strict adherence to EBF as a potential indication of HIV infection. This fostered discriminatory attitudes and stigma against women who exclusively breastfed. Illustrative quotations are presented in Box 1. There were reports of women who attributed the remarkable health and growth of exclusively breastfed babies to antiretrovirals. This further compounded the pervasive misconception that only HIV-positive women breastfed their babies exclusively (Box 1).

This stigma affected not only HIV-positive women but also HIV-negative mothers. In some instances, HIV-negative mothers were labeled as HIV positive, further contributing to women's demotivation to exclusively breastfeed (Box 1). While stigma demotivated some women, HIV-positive and -negative mothers who had experienced negative effects of mixed feeding—such as infant diarrhea and frequent hospitalizations—were convinced to practice EBF (Box 1).

Box 1. Exclusive Breastfeeding and Stigma

Exclusive breastfeeding and stigma

''People say that those who exclusively breastfed for six months are infected with HIV. You try to tell such people that even if you are negative, you have to breastfeed for six months, but they will not believe you.'' [HIV-positive woman]

''They will force you to give the baby some porridge. If you happen to decline, they start thinking that you are suffering from something, so the stigma starts.'' [HIV-positive woman]

''They (neighbors) kept asking me questions until I had to disclose to them my status. I told them, 'I am positive and that is why I am breastfeeding. I am not supposed to give the baby other food.' I told them because I was tired of being asked questions all the time.'' [HIV-positive woman]

HIV-negative women and stigma

''If you exclusively breastfeed for six months, someone just thinks that you are sick.'' [HIV-negative woman]

''They say that you were told to breastfeed exclusively because you are sick and on medication.'' [HIV-negative woman]

''She will ask why I am not giving my child water. She will ask if I am sick. Neighbors really probe you. If you are giving the child other foods, they will take it that you are normal.'' [HIV-negative woman]

Antiretroviral drugs and weight gain in infants

''The baby of an HIV positive mother is fat because of the ARVs the mother is taking.'' [HIV-negative woman]

Negative consequences of mixed feeding

''The child had diarrhea when he ate other foods…The food I gave him caused the diarrhea. Every month I would take him to the hospital because of diarrhea and vomiting.'' [HIV-negative woman]

Manifestations of stigma

Women experienced both enacted and felt stigma. Enacted stigma refers to behaviors and perceptions of others toward an individual who is perceived as different. Felt stigma is the internalized perception of being devalued, or not as good as, by an individual.[22] For example, gossip about women who were exclusively breastfeeding (enacted stigma) and avoiding health education sessions in the presence of others who could potentially judge (felt stigma). Some respondents highlighted that fear of suspicion impacted their infant feeding. These women felt they were constantly under the watch of others who scrutinized or judged them. Quotes are provided in Box 2.

Promoters of stigma

Some women noted that health education and counseling on EBF done in MCH clinics were primarily targeted at HIV-positive women and that HIV-negative women were not always actively included. One contributor to this selectivity was the strong presence of peer counselors who were HIV positive (mother-to-mother mentors) and were mandated to provide supportive counseling to HIV-positive women. HIV-negative women were not given the same support. Overall, EBF messaging to prevent vertical transmission, separate counseling sessions, and exclusive peer counseling distinguished HIV-positive women. These activities could have initiated and promoted stigma toward EBF. Quotes are shown in Box 2.

Inaccurate assumptions

When asked, ''Who should exclusively breastfeed for 6 months?'' some respondents stated that EBF was mandatory for HIV-positive women, but optional for HIV-negative women since they have no concerns about HIV transmission. A minority stated EBF was recommended for all women. This indicates inaccurate processing of health messages or inconsistencies in the delivery of health information. It is possible that intensive EBF counseling and increased EBF literacy among HIV-positive women unintentionally conveyed the message that EBF was mainly recommended for HIV-positive women. Quotes are provided in Box 3.

BOX 2. MANIFESTATIONS OF STIGMA; PROMOTERS OF STIGMA

Manifestations of stigma

''When I came back, I found she was backbiting me saying that I exclusively breastfeed because I am HIV positive.'' [HIV-positive woman]
''For example, you tell your house-help not to give your baby water and she sees that you are always expressing your breast milk. Immediately after you leave, she will go around gossiping about you. This becomes stressful.'' [HIV-positive woman]
''My cousin asked, 'You are not feeding the baby porridge because you are waiting for six months, are you sick?' This question shocked me.'' [HIV-positive woman]
''There is fear that maybe someone will come to the house and ask you why you are not giving food to the baby.'' [HIV-positive woman]

Promoters of stigma

''Nowadays, they (community) take it that way. Before, it was known that HIV-positive mothers do not breastfeed and now they are told to breastfeed for six months. If you exclusively breastfeed for six months, someone just thinks that you are sick.'' [HIV-negative woman]
''I thought about what those women at the clinic said that those who were sick were the ones who were being taught.'' [HIV-positive woman]
''In most cases, the people who are talked to (health education/counseling) are the ones who are HIV positive.'' [HIV-positive woman]
''I delivered my first child (in a private clinic) and they did not tell me anything. They just gave me the baby.'' [HIV-negative woman]

BOX 3. INACCURATE ASSUMPTIONS AND AVOIDING STIGMA

Inaccurate assumptions

''It will depend on the mother, whether she is positive or negative. If she is negative, even at day one, she is allowed to give the baby water. But, if she is positive, she should not give the baby anything else except the breast milk. It will depend on her status.'' [HIV-positive woman]
''If a mother is HIV+, she should only give the baby other drinks after six months, and if HIV negative, she can give these after two weeks.'' [HIV-positive woman]
''If someone is negative, she can exclusively breastfeed for the duration she wants. But, if you are positive, you have to do it for six months'' [HIV-positive woman]
''You see, if you are HIV positive, you must listen carefully to the doctor's instructions so that you do not infect the baby. But, if you are negative, then you can continue with your life as you wish.'' [HIV-positive woman]

Avoiding stigma

''So, I normally cheat him (husband) by saying that I am giving the baby other foods.'' [HIV-positive woman]
''I was forced to stay away from my relatives and social events...'' [HIV-positive woman]
''You end up giving the baby other foods. You dare not disagree with your mother-in-law. You want to protect your place in that house.'' [HIV-positive woman]
''I know the reason why I cannot give the baby food, but I cannot disclose my status to her because she will go and spread it out there.'' [HIV-positive woman]

Avoiding stigma

HIV-positive women feared inadvertent disclosure of their status and HIV-negative women were worried about being mistaken to be HIV-positive if they exclusively breastfed. Avoidance of stigma was an important driver of their infant feeding choices. Women had to choose between EBF and facing the social consequences or mix feeding to avert suspicion. Women used different strategies to avoid stigma. For example, they stayed away from family and friends or social events (social exclusion interferes with social support), lied that they mix fed, and some succumbed and resigned themselves to mixed feeding. Quotes are in Box 3.

Mitigating stigma

Despite the burden of stigma, some women and men mentioned that EBF education and peer counselor or male partner support enhanced adherence to EBF. This demonstrates the critical role peer counselors and male partners have in alleviating the impact of stigma and empowering women to be intrepid about their infant feeding decisions.

Peer counseling. Women mentioned the value of peer counseling and support. Peer counselors were easily accessible by mobile phone and provided women with the social support and education to exclusively breastfeed. The knowledge gained through peer counseling motivated women to firmly adhere to EBF in spite of external pressures to mix feed and potential stigmatization. Some women had the boldness to openly disclose their status to justify their preference for EBF (Box 4).

Education received from healthcare workers. Education was a major source of empowerment for women who were torn between EBF and mixed feeding. Women had high regard for health workers and their medical advice. Women referred to breastfeeding education from nurses, doctors, or clinical officers when they faced significant barriers to EBF (Box 4).

Male partner involvement. Both male and female participants recognized the role of men in mitigating stigma against EBF. Explaining to women in the community that EBF is the male partner's choice of feeding for his child would counteract the social pressure to mix feed. Men motivated women to ignore external pressure and some relocated their wives when pressure was significant (Box 4).

Discussion

While EBF for 6 months is the optimal mode of feeding infants, its practice at the grassroots level is challenging. This is due to the disparity between recommended and normative community infant feeding practices such as mixed feeding. A strong focus on infant feeding promotion by public health systems is thus warranted. However, in the spirit of elimination of mother-to-child HIV transmission (eMTCT), infant health messaging has largely been promoted from a PMTCT

Box 4. Mitigating Stigma

Mitigating stigma

1. Peer counseling and support
   ''We appreciate having peer counselors who are in the same state as ours. They can understand us better.'' [HIV-positive woman]
   ''Most of them are HIV positive and everyone talks about their challenges. You get encouragement; it cuts off stigma and you realize that life must continue.'' [HIV-positive woman]
2. Education received from healthcare workers
   ''I told them that I was taught to breastfeed the baby for six months… I told them that I would follow the instructions from the doctor.'' [HIV-negative woman]
   ''It is hard, but you must tell them that the doctor said that you should breastfed for six months. They do not have to know your status.'' [HIV-positive woman]
3. Male partner support
   ''He told me that we should breastfeed the child for six months because of the teachings that we had received.'' [HIV-negative woman]
   ''I told my wife to take the porridge my mother made for the child and go to our house and drink it. She used to drink that porridge and breastfeed the child.'' [HIV-positive male partner]
   ''He told me that we should adhere to the doctor's instructions.'' [HIV-positive woman]
   ''The neighbors would say that I am starving the baby and should start giving him other foods. But, I refused to listen and the father of the baby also supported me by telling me not to give the baby other foods.'' [HIV-negative woman]
   ''The neighbors accused me of starving the baby and insisted that I start giving him pumpkin… But, I refused and the father of the baby also supported me. I have therefore exclusively breastfed my baby for six months.'' [HIV-negative woman]

standpoint. This approach can result in unintended consequences such as stigma toward EBF. Kenya recently adopted PMTCT Option B+ and there is sustained emphasis on EBF to prevent maternal HIV transmission.[23] The current Kenyan Strategic Framework for eMTCT mentions EBF as a key PMTCT intervention that should be supported.[24] There is need for policy makers and health programs to be sensitive to presentation of EBF messages and avoid messaging that biases EBF as an HIV prevention strategy.

Looking back at the evolution of breastfeeding policies, HIV emerges as an important driver for global recommendations around infant feeding in low-resource HIV-endemic regions.[9] An array of interventions to prevent mother-to-child HIV transmission was proposed and tried, including use of ARVs, shortening breastfeeding duration, and promotion of EBF or exclusive replacement feeding (ERF).[1,2,25] As a result, global guidelines have been revised progressively to currently promote EBF with use of ARVs.[26] Each change and recommendation has contributed to the confusion and stigma associated with EBF, especially when implemented with inadequate support of health education.[12]

In this study setting, women's accounts of their breastfeeding experiences reveal possible causes and manifestations of stigma toward EBF. Targeting EBF counseling at HIV-positive women could have led to the inaccurate assumption that HIV status was a criterion for EBF counseling and practice. The resultant judgmental attitudes, labeling, and discrimination challenged EBF. Women reported fear and avoidance as emotions and/or reactions that could have played a role in their infant feeding choices. Both HIV-positive and -negative women faced similar stigma. Often, those who had experienced an adverse event precipitated by mixed feeding had the fortitude to withstand stigma.

Prevailing perceptions were that HIV-negative women were free to mix feed as they had no PMTCT goal. However, mixed feeding outside the context of HIV is associated with increased infant morbidity and mortality. In the context of HIV, it is associated with increased risk of HIV acquisition.[2] Despite the stigma, there were women who succeeded in EBF. Peer counseling, health education, and male partner support were important motivators of EBF.[27,28] These three factors supported women in resisting high degrees of stigma.

Based on these findings, we can draw lessons and recommendations for infant feeding programs in low-resource HIV-endemic settings. The first lesson is the potential introduction of stigma resulting from vertical focus of health programs on HIV prevention. This phenomenon has been identified in a previous study in which aspects of PMTCT that promote stigma were assessed.[12] Public health planners should consider potential unintended consequences of health interventions and plan to avert or deal with them. The second lesson is that peer counseling and health education alongside male partner support can be helpful in reducing stigma toward EBF.

Based on these lessons, approaches that destigmatize EBF are necessary. While policy documents and educational materials address all women, it is important to ensure that health providers' focus and implementation of EBF support are all-inclusive and equally target HIV-negative women. Currently, HIV-positive women receive support through mentor mothers (peer counselors). Moving forward, the recommendation should be to provide similar support to HIV-negative women and public education for all. This will reduce the discrimination particularly in communities where infant feeding practices are less autonomous. At an individual level, peer counseling, health education, and male partner involvement support women where stigma related to EBF is prevalent. Peer counseling could be further modified to strengthen counseling against stigma by providing women with tools that enable them to manage stigma tactfully and confidently; for example, phrases they could use when confronted about their choices to exclusively breastfeed. On a broader level, more effort is required to reduce HIV-related stigma, which in turn will diminish stigma toward EBF.

Conclusion

While promoting EBF for PMTCT in both program and research settings, it is important to apply strategies that minimize the stigma toward HIV and EBF. Dissemination of infant feeding messages that are inclusive of HIV-negative women may avert stigma and provide a safe environment for all women to exclusively breastfeed. The lessons learned from this study indicate that vertical programs can hinder promotion of infant health interventions and therefore negatively affect child survival.

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Disclosure Statement

R.B. and C.F. designed the study and participated in data analysis. B.M.O. performed the analysis with guidance from J.P. R.B., E.K.I., and C.F. contributed to data collection. The primary author, B.M.O., is responsible for the completeness and accuracy of the data presented, as well as adherence of this report to the study protocol. A.G., F.K., R.N., and J.K. contributed to the writing and review of this article. All authors contributed to writing of the manuscript and approved the final draft.

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Address correspondence to:
Beryne Mikal Odeny, MBChB, MPH
Department of Global Health
University of Washington
325 9th Avenue #359909
Seattle, WA 98104

E-mail: bodeny@uw.edu