A qualitative study exploring attitudes and perceptions of HIV positive women who stopped breastfeeding at six months to prevent transmission of HIV to their children

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Abstract

Aim

The study explored knowledge, attitudes and practices of HIV positive women who were instructed to stop breastfeeding at 6 months to prevent the transmission of HIV to their children.

Methods

We used qualitative methods consisting of key informant interviews (KII), critical incidence narratives (CINs), focus group discussions (FGDs) and observations for data collection. The subjects were recruited at regular PMTCT clinics after consenting to participate in the study.

Results

Some women had a fair understanding of exclusive breastfeeding and its role in preventing the transmission of HIV from the mother to the child. However, uptake of services and adherence to exclusive breast feeding (EBF) were hindered by social stigma, discrimination, misconceptions, and fear of rejection by spouses.

Conclusion

Addressing social stigma, discrimination, misconceptions and male involvement should be part and parcel of PMTCT programming in order to ensure success. The recent introduction of option B+, in which all pregnant HIV positive women will be started on anti-retroviral treatment, regardless of their CD4 cell count, will perhaps encourage women to adhere to EBF and weaning at six months.

Introduction

Malawi has one of the highest levels of HIV infection in the world, with acquired immune deficiency syndrome (AIDS) being the leading cause of deaths among adults 15-49 years old[1]. In 2010, it was estimated that 910,000 adults and children were living with HIV and AIDS. The national adult prevalence rate among 15-49 year olds was 10.6 %, with 8.9% prevalence in rural areas and 17.4% prevalence in urban areas. Every year, 68,000 adult and child deaths are due to AIDS. Young women are disproportionally affected, with approximately one-half of new infections occurring in individuals 15-24 years old, and 9% of the overall total belonging to women in this age range (compared to 2% of men). In addition to adult mortality, approximately 150,000 children were living with HIV in 2010 and over 610,000 were orphaned due to AIDS-related deaths.[2]

Transmission of HIV to children can occur in utero, during birth and postpartum through breastfeeding[4]. If there is no intervention, 15 to 30% of infants of HIV-positive mothers are infected before or during delivery, or after birth through breastfeeding[5]. The standard WHO policy to curtail HIV transmission through breastfeeding is that HIV-infected women should breastfeed exclusively for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants. This recommendation is supported by research-based evidence demonstrating that exclusive breastfeeding (EBF) for up to six months is associated with a three to four fold reduction in risk of transmission of HIV from the mother compared to mix-feeding[6].

Breastfeeding remains the natural and best source of nutrition for the newborn and children.. It greatly improves the quality of life for infants and young children through its nutritional, immunological, psychological, and contraceptive benefits[7]. The Malawi Ministry of Health policy promotes and supports all mothers, with known and unknown HIV status, to exclusively breastfeed for the first six months.[8]

Purpose

The purpose of this qualitative study was to explore knowledge, attitudes and practices of HIV-positive women when advised to cease exclusive breastfeeding at six months postpartum.

Objective

The objective of the study was to identify potential barriers to successful adherence to exclusive breastfeeding recommendations.

Rationale for the study

Very little qualitative research has been conducted to explore the main factors that may influence the response to this policy by HIV positive mothers. Our search only found one published qualitative study done in Malawi assessing the role of health workers in explaining the WHO recommendations on breastfeeding to HIV positive.[4] Some studies have cited the lack of adequate replacement feeding as a barrier to explicitly following advice on breastfeeding[9]; however, few have reported on the psychosocial factors.

Methods

Qualitative approaches consisting of key informant interviews (KII), critical incidence narratives (CINs), focus group discussions (FGDs) and observations were used to collect data. All interviews and discussions were conducted by two social scientists and trained research assistants. Coordinators of prevention of mother-to-child transmission (PMTCT) services from the two health facilities served as key informants.

Using semi-structured and open-ended individual interviews, 61 incidence narratives of HIV positive mothers were conducted at the each health facility. The interviews focused on (i) attitudes of HIV-positive breastfeeding women towards the advice to exclusively breastfeed until the child was six months of age, (ii) perceived and real psychosocial barriers to adhering to the advice (iii) breastfeeding behavior if any, of the HIV positive women after the six months of EBF (iv) areas where specific HIV and breastfeeding knowledge was lacking among HIV-positive breastfeeding women and those who stopped breastfeeding.

Each CIN lasted approximately 40 minutes. Using guided tools, 7 FGDs of 5–9 participants per group were conducted with mothers, with underone child. Out of 7, 3 FGDs were with breastfeeding mothers and 4 were with non-breastfeeding mothers. The mothers at both locations were screened by their providers and who asked them to join the study based on their HIV status. There were 5 pregnant women in each FGD group. The content of the FGD guide was similar to that in the critical incidence narratives. Each FGD session lasted approximately 45 minutes.

There was one focus group at each study site with 5 and 6 participants at Thyolo and Mdeka respectively. The interviews with health workers were held in English while interviews with mothers were held in Chichewa. All interviews or discussions were tape recorded, transcribed, and coded.

Study Population:

The study population was made up of HIV-positive breastfeeding and non-breastfeeding women at Thyolo District Hospital and Mdeka Rural Health Center, located in Blanytre district. The facilities were selected because of their high HIV prevalence of more than 15% among women attending antenatal clinics, and also because of their proximity to the Malaria Alert Center at the College of Medicine to minimize travel expenses.

Ethical considerations

This study was approved by the Loma Linda University Institutional Review Board (IRB) and the College of Medicine Research and Ethical Committee (COMREC). Written and verbal consent was obtained from all the participants and their HIV serostatus was unknown until they consented to joining the study

Data analysis

The unit of analysis for the KII and CINs was the individual and it was the whole group for the FGDs. The data were analyzed using Nvivo 8. All the transcribed transcripts were exported into Nvivo software and analyzed by grouping similar thoughts together and generating themes. The following 7 themes emerged through this process:

Results

Knowledge of PMTCT services, access and uptake

Overall, the women's understanding of exclusive breastfeeding was adequate. Many participants were aware of the aim of the programs, "to prevent the transmission of HIV from the mother to the baby through breastfeeding". They were able to name services provided at the PMTCT clinics including voluntary counseling and testing, CD4 cell count, weight and growth monitoring, provision of ART and supplementary feeding.

Male involvement was very low, making adherence to ART for the women. This was true at both sites. In very few cases among discordant couples, husbands supported their wives.

"My husband was the first to be tested for HIV, he tested negative3 times . When I tested positive and I told him about exclusive breastfeeding, he encouraged me to follow the instructions." (CIN with breastfeeding mother - Thyolo)

Some women reported that their spouses refused to be tested or to accept their results. Others did not tell their husbands for fear of being be blamed or divorced.

The quote below demonstrates how male involvement affects PMTCT:

"Most mothers do not come for their CD4 results which determine if we should initiate antiretroviral treatment. Secondly, when husbands are not involved, adherence to ART becomes very difficult for the women." (The PMTC Coordinator for Thyolo district)

The majority of HIV positive pregnant women reported accessing PMTCT services.. More women accessed services in Thyolo than at Mdeka. This was probably because of the intense follow-up support provided by Médecins Sans Frontières (MSF Belgium). MSF also provided incentives such as baby blankets and clothes; soap, transport and plumpy nut, a nutritional supplement.

Perceptions of mothers towards exclusive breast-feeding

Most women, both breastfeeding and non-breastfeeding, viewed the EBF policy positively. The following quotes illustrate this.

"I understand quite well that breast milk is the only reliable food for the baby, because it boosts the baby's immunity and is readily available". (CIN,)

"I heard that the child's intestines are not yet mature enough at this age and giving him supplementary foods puts the child at risk (CIN,)

They also knew the importance of weaning the baby at 6 months or not breastfeeding at all if one can afford infant milk formulae.

"I will wean my child immediately after six months because I have learned that weaning will prevent my child from being infected."(CIN, breastfeeding mother)

"My first child, whom I breastfed for 2 years, was often sick and eventually died of HIV infection. I realized then that indeed a child can get infected. So when I learned that children that are exclusively breastfed do not catch the virus, I strictly followed the instructions and indeed my child is HIV negative." (FGD, non-breastfeeding mother)

The study also coincidentally found that the survival of a child increased fertility intentions as illustrated by the quote below.

"Every woman who is HIV positive is advised not to have more children, but I intend to have another one because my child is negative and I am allowed to have a maximum of two children." (FGD, non-breastfeeding mother)

Women who did not adhere to EBF felt that the milk was not adequate for the baby and it was culturally unacceptable to not give the child supplemental foods such as phala .

Challenges during breastfeeding and after weaning

Many women faced challenges , in the course of weaning and after weaning. Frequent illnesses caused many to stop breastfeeding before six months.

"I weaned my baby before 6 months because I was hospitalized for a long period of time with TB. My sister took care of the child." (FGD, non-breastfeeding mother)

"I fell ill several times while breastfeeding. I got better after I stopped breastfeeding." (CIN, non breastfeeding mother)

They mentioned inadequate food intake as the cause of inadequate lactation and their own poor health.

"I cannot exclusively breastfeed because I do not produce enough milk for the baby. This is because we are no longer getting the soya flour which helps us produce more milk. "

(CIN, breastfeeding mother)

Some women reported pressure from relatives to supplement other food.

"My child cried almost all the time and I was under a lot of pressure from relatives to start giving him supplementary food. I kept telling them that this was not the best time for the child." (CIN, breastfeeding mother)

In a few instances, lack of understanding of the reasons for exclusive breastfeeding led to non-compliance with the policy.

"Some women do not comply because they do not understand while others are just stubborn and believe that if they are on ARV's, the baby will also be on ARV's."' (CIN with breastfeeding mother - Mdeka).

Concerns and psychological stress

Both breastfeeding and non-breastfeeding mothers expressed concerns about how and where to get food.

"I am mainly concerned about feeding the child after weaning. I wish the government could assist us with food supplements." (FGD, breastfeeding mother)

"If I stop breastfeeding where and how will I be able to find adequate food for my child so he can thrive., I am really worried that my child will be malnourished and not grow." (CIN, breastfeeding mother)

Although they expressed these concerns, most participants said they would wean.

In some instances, women seemed confused and gave conflicting responses. The quotes below depict this:

"Weaning is good but I feel that my baby may fall sick due to lack of adequate good food, so maybe I will not wean my child." (CIN, breastfeeding mother)

"I am terribly stressed when I consider that the baby will be crying a lot and become difficult and this may force me to continue breastfeeding." (FGD, breastfeeding mother)

Women cited intense psychological stress when children were ill. This influenced them to re-evaluate their decision to wean the child.

"When the child got ill with oral sores or cough, I received treatment at the hospital. However when he was not improving, I asked myself if it was right to wean him."(CIN, non breastfeeding mother)

Other psychological stress emanated from fear of stigmatization once their positive status was known.

"People don't know I am HIV positive. When I don't breast feed when the baby cries, they conclude that I am positive. I am afraid of being laughed at and being ashamed and therefore mentally stressed." CIN, breastfeeding mother)

Because the breast is also used as a pacifier when the child cries, many breastfeeding mothers expressed concern that weaning a child will make them look like women who did not love their children..

I will feel like I do not love the child because when he cries I will not breastfeed him. He may fall sick because of lack of love and newly introduced foods. I also fear that if I wean him, he may be malnourished and I may lose him". (CIN, breastfeeding mother)

Many women lamented over broken marriages and other significant relationships following the weaning. They emphasized how stressful this was as this quote below depicts.

"My husband deserted me, yet he is the one who infected me. None of his relations was on my side either. I am unable to find adequate food for myself so I can produce adequate milk for the baby." (CIN, breastfeeding mother)

ke informed decisions." (FGD, breastfeeding mother)

Coping strategies and Support Mechanisms

Women reported developing various coping strategies in the face of stigma and discrimination. Turning a deaf ear to what others said about them was one way of coping. They pledged to be religiously adherent to EBF because that was the only way they would ensure that their children would be HIV negative.

"People say all sorts of things because of ignorance. They themselves don't know their HIV status and yet want to pose as knowledgeable people. So we just let them talk and ignore them." (FGD, non-breastfeeding mother)

"As for me, stigma is what encouraged me to even go a step further to making a decision that I should stop bearing children…" (FGD, non-breastfeeding mother)

Women cited other sources of support such as health care workers, extended family members, husbands and support groups; especially those made up of women who previously exclusively breastfed and weaned their children. They reported that "these women's children were strong and healthy, not sickly at all." This was a great motivator for them to embrace exclusive breastfeeding and wean after six months.

Women also cited the benefits of adhering to exclusive breastfeeding for their own health and their children's.

"The insults and whatever people say about me, simply encourage me to even do better in adhering to the exclusive breastfeeding practice. This is so because I am alive today because of strictly following instructions given by doctors and by the grace of God. I don't care what people say because I know by following medical advice I will be able to make informed decisions." (FGD, breastfeeding mother)

Misconceptions about exclusive breastfeeding, weaning, and HIV

Several misconceptions about EBF persist. For instance, many women are still afraid to breastfeed their infants immediately after birth because they believe that colostrum is not good for the babies.

Breastfeeding a child for up to two years is practiced by many because it is believed that as long as there is lactation, the child must breastfeed. Culturally, a child is supposed to suckle for not less than 2 years and weaning is regarded as a taboo.

"Yes, people believe that the child should suck until there is no milk left in the breasts." (FGD, non breastfeeding mother)

In addition, a breastfeeding mother believes that she should wean immediately upon realization that she is pregnant to protect the child.

"Once a breastfeeding mother becomes pregnant, she should wean the child because if this child continues, he or she will get sick with 'tsempho' and not thrive." (FGD, mother)

Some women both from CINs and FGDs stated that a baby is supposed to be given porridge before six months to mature him/her.

"Babies should be given porridge for strength." (CIN,

Breastfeeding mother)

There are also prevailing beliefs that if a child is not breastfed for a day, the breastmilk goes bad and one is then supposed to breastfeed only the next morning.

"When a woman goes somewhere and she comes back late , she is told not to breastfeed the child for the rest of the night until the next morning because by the time she comes home the milk is sour and the child will get ill if he is breastfed ." (FGD, ANC mother)

There is a belief that if the woman drinks kachasu , it will kill the HIV making breastfeeding safe for the baby.

"Some women believe that if they drink kachasu it will make the virus drunk too and consequently it will die hence they cannot transmit the virus to the child even if they observe the usual breastfeeding and provision of food to the child."

Discussion and conclusions

Our study found that some women had a fair understanding of exclusive breastfeeding and its role in preventing the transmission of HIV from the mother to the child. They were also quite conversant with the services offered at the health facilities related to PMTCT. However, uptake of services and adherence to EBF were hindered by social stigma, discrimination, misconceptions, and fear of rejection by spouses.

The fact that some men refuse to be tested even when their spouses are positive, indicates the powerlessness of women to demand that their husbands be tested. Women attending antenatal clinics accept HIV testing because they want to preserve their own health and that of their unborn children. Couple HIV counseling and testing should be encouraged for all women attending antenatal care in settings where HIV prevalence is very high. Women who had their husbands' support were more likely to adhere to EBF and ART. In cases where the husband walked out on the wife or ordered the wife to leave, the woman was left destitute with no adequate support to maintain her own health let alone that of her child. Some women were forced to look for work or to rely on the financial support of family members who were also struggling.

Social stigma is so deep rooted that support groups established to provide psycho-social support to people living with HIV and AIDS were making very little progress.

We also found that the resulting survival of children who have tested negative for HIV encouraged women to desire more children. This raises the question of fertility intentions and unintended consequences of family planning in PMTCT services. Comprehensive couple counseling for both family planning and fertility intentions should be included in all PMTCT programs.

Participants cited socio-cultural barriers that hindered them from adhering to exclusive breastfeeding even though they knew this would prevent their children from contracting HIV. For instance, wherever possible, the majority of Malawian women will breastfeed for two years or longer.

Challenges during the post weaning period

Table 1 below summarizes and illustrates the main challenges that the women faced after weaning.

Challenges	Illustrations
Psychological stress coupled with poverty:	"I cannot feed the child ad equately because I cannot afford to get the type of foods that they say I must eat always. I cannot even afford to buy soap to wash my baby's nappies." "What to do when there is no money to buy milk, I can afford only Sobo . That is why he is not growing well." "What to give at night? I needed milk and I had no money to buy milk. During the day he was eating nsima . My husband managed to buy him small sachets of milk at times."
Refusing to eat new food Baby losing weight	"The child refused eating the porridge since she was so used to the breastmilk." "The child was crying of hunger always as he had never come to terms with the foods I started giving him. He refused to eat anything."
Children suffering from Diarrhea	"My child got very sick with diarrhea. I assumed it was because he was not used to the new food. I was admitted to the hospital several times.The child is now well.." "The baby cried a lot at night, refused [cow]milk, had diarrhea, and was treated here.
Lack of support from spouses and relatives	"I have a sister who is a nun in the Roman Catholic Church. She could be supporting me but because I disobeyed her by getting pregnant and running away from home she doesn't help me.""When I told my husband about it, he seemed to be happy and he was very supportive. Later, he just disappeared. Since he was the bread winner , it has not been easy for me to find food to enable me to breastfeed adequately. " "I walked out of my marriage because my husband never accepted to go for HIV testing. It was better for me to take care of my life and that of my child rather than suffering because of marriage." "I don't have a husband; my husband deserted me because I tested positive."
Stigma	"…when they see the baby suckling bottled milk, people make conclusions that you are HIV positive." "People were curious as to why I was not breast feeding anymore.. People said a lot about me despite the fact that they did not go for testing themselves."
Discouragement from fellow HIV	"Some women encourage us to go on breast feeding but I feel they want to mis lead us. I will not do what they say because what the doctors say is always right."
positive mothers	"People say from the time of our fore fathers, children have been breastfed for more than 6 months and there is no sense for some to come in the name of health care to break that tradition."

Early weaning makes relatives and neighbours question the mother as to why she is not breastfeeding. The Ministry of Health and NGOs are continuing efforts at both facility and community levels to address these issues through appropriate behavioral change communication messages. The scaling-up of antiretroviral treatment programs will enhance adherence to exclusive breastfeeding.

Poverty was cited as a cause for women's inability to purchase enough appropriate food for the child after weaning, resulting in continued breastfeeding after six months. The mix feeding often resulted in diarrheal diseases and malnutrition. The women felt that the government should distribute supplementary food such as plumpy'nut for the children more often.

While the MSF's supplementary feeding programs were intended to be, in fact, a supplement to an everyday diet, participants agreed that the supplementary programs did not meet their needs and thus should be a daily food service. These services failed to meet the needs of the populations in Thyolo, and even more so in Mdeka, as a result food shortage. In Mdeka, women were observed mix feeding their children. When asked why, they replied that they did not have enough money to purchase appropriate food. It must be pointed out however that in many cases, in spite of the barriers, many women did adhere to exclusive breastfeeding especially if their older child was HIV negative. We did not inquire if any of these women were on ART as this was not part of our study. In retrospect, we should have asked if there were some women on treatment as this might have influenced their adherence to exclusive breastfeeding.

Conclusion and Recommendations

Exclusive breastfeeding remains the best way to prevent mother-to-child transmission of HIV in resource poor settings. Recently, the Malawi Ministry of Health has adopted the policy of putting all HIV-positive pregnant women on ART regardless of their CD4 cell count. One hopes that this will enhance adherence to exclusive breastfeeding as well as preserving women's health and that of their children.

Programs specifically designed to address socio-cultural issues, especially for men as decision makers, should be deployed in order to encourage men to be tested, regardless of their partner's status. . It is crucial for healthcare providers to be trained in couple-counseling. This will encourage men to be tested as well as support their partners when they test positive.

Issues such as irregular supply of food should also be addressed. Currently, the food programs do not meet the needs of Mdeka and Thyolo residents.

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