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Free formula milk in the prevention of motherto-child transmission programme: voices of a peri-urban community in South Africa on policy change

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Background: In 2001, South Africa began implementing the Prevention of Mother-to-Child

Transmission of HIV (PMTCT) programme. This programme included distribution of free formula milk for infants up to 6 months of age at all public health facilities. Effective from 1 January 2011, KwaZulu-Natal became the first province to phase out free formula milk from its PMTCT programme. On 23 August 2011, the South African National Department of Health adopted promotion of exclusive breastfeeding as the national infant feeding strategy and made a decision to withdraw free formula milk from the PMTCT

programme.

Objective: To explore the perceptions and understanding of households at community level

on the policy decision to phase out free formula milk from the PMTCT

programme in South Africa.

Methods: An exploratory qualitative study was conducted amongst women enrolled in a

community randomized trial known as Good Start III. Focus group discussions were held with grandmothers, fathers and teenage mothers; and in-depth interviews were performed with HIV-positive and HIV-negative mothers. Data

were analysed using thematic analysis.

Results: Identified themes included: (1) variations in awareness and lack of under-

standing of the basis for the policy change, (2) abuse of and dysfunctional policy as perceived reasons for policy change and (3) proposed strategies for

communicating the policy change.

Conclusion: There is an urgent need to develop a multifaceted communication strategy

clearly articulating the reasons for the infant feeding policy change and promoting the new breastfeeding strategy. The communication strategy should take into account inputs from the community. With a supportive environment and one national infant feeding strategy, South Africa has an opportunity to reverse years of poor infant feeding practices and to improve the health of all

children in the country.

Keywords Formula feeding, policy change, HIV, community perceptions, qualitative

research, focus group discussions.

KEY MESSAGES

- There are major variations in understanding by different members of the community as to why the free formula milk policy was phased out.
- There is an urgent need for a multifaceted communication strategy that clearly articulates the reasons for the change in policy and describes the role of households and communities in supporting, promoting and protecting breastfeeding.

Background

Since 1992, policy makers have grappled with the dilemma of developing appropriate guidelines to assist HIV-positive mothers with optimal infant feeding choices. The World Health Organization (WHO) has developed and/or revised at least 16 guidelines (Moland et al. 2010). The 1992 WHO guidelines recommended breastfeeding by all women including HIVinfected women (WHO 1992). Key recommendations in the revised guidelines of 1998/2001 were replacement feeding, including home modified animal milk or commercial infant formula milk, for HIV-infected mothers who chose not to breastfeed their infants. Second, HIV-infected mothers were to be supported in their infant feeding choices. Later, to address the local social, cultural and economic variations, avoidance of all breastfeeding by HIV-infected mothers was recommended only when replacement feeding was acceptable, feasible, affordable, sustainable and safe (AFASS). Otherwise, exclusive breastfeeding (EBF) for the first few months of life was recommended (WHO 1998). Based on this, the Botswana and South African governments introduced free formula milk in their Prevention of Mother-to-Child Transmission of HIV (PMTCT) programmes through public health facilities to assist women who otherwise would not have been able to afford formula milk. United Nations Children's Fund (UNICEF) responded by providing formula milk to several PMTCT sites in Africa. However, following a review of its use UNICEF decided to stop this provision (Linkages 2004).

From 2002 to 2011, the infant feeding options for South African HIV-infected mothers were either exclusive formula feeding for the first 6 months of life where AFASS criteria were met, or EBF. However, the interpretation of AFASS has been problematic at provider-client level (Doherty et al. 2007; Leshabari et al. 2007; Buskens and Jaffe 2008), and consequently many women ended up mixed feeding. Coutsoudis et al. (2002) argue that mixed feeding, rather than compliance with formula feeding, was the result of easy access to formula milk. Concerns about HIV transmission have led to more women choosing formula feeding, which may have caused a 'spill over' effect of formula feeding in the general population. South African has seen no improvement in national breastfeeding rates with the emergence of the HIV epidemic largely due to the provision of formula milk for PMTCT and mixed messages from healthcare workers (National Department of Health South Africa 2003: Tylleskar et al. 2011: Doherty et al. 2012).

The revised 2006 WHO guidelines (WHO 2007) were prompted by evidence from three large cohort studies conducted in South Africa, Cote d'Ivoire and Zimbabwe, which showed that EBF for up to 6 months was associated with >50% reduction in the risk of transmission of HIV compared with non-EBF (Iliff *et al.* 2005; Becquet *et al.* 2006; Coovadia *et al.*

2007). Evidence from these settings showed that the combined risk of HIV infection or death at 18 months of age was similar in infants who were formula fed from birth compared with infants who were breastfed for 3 or 6 months (Lockman *et al.* 2006; Thior *et al.* 2006; Leroy *et al.* 2008; Rollins *et al.* 2008).

The amendments to the 2006 WHO guidelines (WHO 2009) incorporated evidence showing that antiretroviral (ARV) administration to either the HIV-infected mother or HIV-exposed infant during the breastfeeding period could significantly reduce the risk of post-natal transmission of HIV (Bedri et al. 2008). In the revised 2009 guidelines (WHO 2010), WHO recommended that national authorities in each country should decide which single infant feeding practice to recommend and that this would be primarily promoted and supported by Maternal and Child Health services (WHO 2010). By then, the 2010 South African clinical guidelines were aligned with the WHO guidelines in terms of provision for expanded ARV regimes, including highly active ARV therapy for mothers, or nevirapine prophylaxis for infants for the duration of breastfeeding (up to 12 months of infant age; National Department of Health and South African National AIDS Council 2010). However, the continued provision of free formula milk in the South African 2010 PMTCT guidelines caused great concern amongst public health and child health researchers and clinicians (Doherty et al. 2011).

KwaZulu-Natal was the first provincial department of health in South Africa to comply with the WHO 2010 guideline by discontinuing the distribution of free formula milk through public health facilities and promoting breastfeeding (UNICEF 2011). In August 2011, the South African National Department of Health convened a national breastfeeding consultative meeting where the decision was taken to adopt breastfeeding promotion as the national infant feeding strategy (National Department of Health South Africa 2011a,b), after 10 years of provision of free formula milk through the PMTCT programme.

EBF is rarely practiced for the recommended period of 6 months in South Africa. The South African Demographic Surveys of 1998 and 2003 showed that only 10% (National Department of Health South Africa 1998) and 12% (National Department of Health South Africa 2003) of infants aged 0–3 months were exclusively breastfeed. Data from a recent sub-Saharan multi-country cluster-randomized trial of EBF promotion, PROMISE-EBF, showed South Africa to have the lowest prevalence of EBF (10% in the intervention arm and 6% in the control arm) at 12 weeks of age (Tylleskar *et al.* 2011).

The new breastfeeding policy creates opportunities not only to promote EBF amongst HIV-infected mothers but also to all mothers regardless of their HIV status. However, understanding household and community perceptions of this policy change is critical in crafting appropriate messages for informing and supporting households to protect breastfeeding. We undertook

a qualitative study to explore the perceptions and understanding of households at community level on the phasing out free formula milk policy in South Africa.

Methods

This qualitative study was a sub-study of a randomized controlled trial known as Good Start III, being implemented in Umlazi Township, KwaZulu-Natal province (ISRCTN41046462). The township has an estimated population of 1.2 million people (Ethekwini Municipality 2008). HIV prevalence is estimated at 44% in antenatal clients attending public health facilities (National Department of Health South Africa 2011a,b). The goal of the trial was to develop, evaluate and cost an integrated and scalable home visit package delivered by community health workers, targeting pregnant and postnatal women and their newborns, to provide essential maternal/newborn care and support for access to PMTCT.

Study design

We used a qualitative study design, which included focus group discussions (FGDs) and in-depth interviews based on developed guides. These were conducted by two experienced interviewers and FGD facilitators, fluent in Zulu and English.

Study sample

We purposively selected 11 HIV-positive mothers and 9 HIV-negative mothers who were exclusively or predominantly formula feeding infants under 6 months of age, their 14 grandmothers, 14 fathers of their babies and 14 teenage mothers aged 19 and below (see Figure 1). The grandmothers and fathers were related to the 11 HIV-positive and 9 HIV-negative mothers. All mothers were participants in the Good Start III trial.

Data collection

Interviewers explained the purpose of the study to each of the 20 mothers. Upon agreeing to participate in the study they were

visited by the interviewers and requested to give contact details of their grandmothers and fathers of their babies. Interviewers telephonically contacted all the 20 grandmothers and 20 fathers related to the above HIV-negative and HIV-positive mothers. Out of the above 20 grandmothers and 20 fathers, 14 of each (i.e. seven for HIV-exposed, seven for non-HIV-exposed grand-children and babies, respectively) who agreed first to participate were selected for the study. The 14 teenage mothers who were exclusively or predominantly formula feeding infants under 6 months of age, half of whom were HIV-positive, were purposively selected from a pool of Good Start III participants to take part in the FGDs.

All interviews and FGDs were carried out by the two interviewers at the same venue in Prince Mshiyeni Memorial Hospital, between March and May 2011. The first author, who is not conversant with the Zulu language, attended all interviews and FGDs as an observer and gained insight into the interviews and FGDs through the body language expressions, such as silence, eagerness, attentiveness sighs, laughter and giggling, which were recorded and referred to during data analysis. Interviews lasted between 50 and 90 min and FGDs lasted between 90 and 180 min.

Ethical considerations

We obtained Ethical approval (10/09/29) from the University of Western Cape Senate Research and Ethics Committee and acquired informed consent for all FGDs and interviews. To preserve anonymity, codes were used to identify individuals in FGDs and in-depth interviews. For the in-depth interviews, the code denotes the participant's identification letters, the HIV status and age in years. For the FGDs, the code denotes the category of the group, the number, the identification letter for the individual in the group and the age in years. For the teenage mothers, their HIV status was used to identify the group.

Data analysis

Data analysis was a continuous process. After each interview or FGD, the interviewers met with the first author to reflect on the

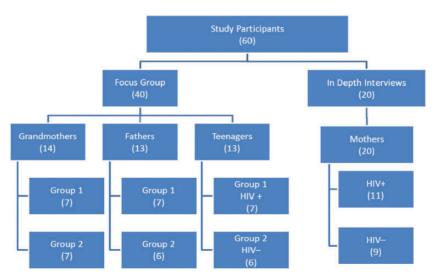


Figure 1 Participants' profile.

findings. Gaps and new emerging questions identified were included in subsequent interviews and FGDs.

The voice recorded interviews and FGDs were transcribed verbatim, and translated into English. Both Zulu and English versions were read several times by the interviewers/FGD facilitators to ensure that the content of the FGDs and interviews was retained after translation. The English versions were read twice by the first author to ascertain that the meaning of the text remained unchanged. One of the co-authors (T.D.) also read several of the transcripts to confirm emerging themes.

A thematic analysis method described by Braun and Clarke (2006) was used to analyse the data. The following questions were asked for each theme: What does it mean? What are the implications? Why these responses, and how do the responses in the different themes contribute to the whole story? Transcripts were coded, collated and grouped into themes.

Trustworthiness

Multiple strategies were used to ensure trustworthiness of the research findings. First, triangulation where two methods, in-depth interviews and FGDs, were used to collect data in this study and the data were compared across data collection methods. In addition, four groups of participants were included (mothers, fathers, grandmothers and teenage mothers) and data were compared across these four groups. Finally, themes were identified independently by the first author and T.D., one of the co-authors.

Results

Characteristics of participants

The majority (95%) of mothers who participated in the in-depth interviews were 20 years old or above. However, \sim 24% of the women who participated in the Good Start III trial were teenagers. To address this gap we recruited 14 teenage mothers to participate in two FGDs. One group comprised seven HIV-positive mothers and the other group comprised six HIV-negative mothers (one teenage mother declined to participate). The ages of the mothers who participated in the in-depth interviews ranged from 17 to 34 years, while fathers were aged between 24 and 46 years, and the grandmothers between 50 and 75 years.

Themes

Three themes, mostly relating to confusion about the free formula milk policy change, were identified from the data. Where they were encountered, comparisons are made of the views of the different groups.

Variations in awareness and lack of understanding of reasons for the policy change

Some participants from all groups except the grandmothers confirmed that they had heard that free formula milk was being phased out, mainly from the radio or their local clinics:

"Yes, there is something I heard from the radio that the Government is now suspending this formula milk because mothers fail to feed (breastfeed) their babies". (FFG2F41)

"I heard that government will no longer give Pelargon because government wants everybody to breast feed". (TFGC-19)

Even those who were aware of the phasing out of the free formula milk policy did not know why it was being phased out. Consequently, many had their own interpretation of why government had taken such a decision. Interpretations ranged from having too many mothers who depended on the formula milk, to formula milk not being delivered to the clinics, to the desire for mothers to breastfeed and to prevent mothers falling pregnant to receive free milk.

"...government is failing to provide this milk because of the increasing number of mothers who have to be given this milk...then decided to stop issuing it from January". (NG-21)

"Government wants them to get back to breastfeeding; they will be discharged without formula milk and when they get home they won't get it because as the grandmother I will not buy it either". (GMF1G58)

Some participants, particularly fathers and grandmothers, felt that certain unintended negative consequences of the free formula policy, such as enticing teenage girls to fall pregnant early and have many babies, were reasons for the policy change:

"...government decided to suspend the free formula milk because...it was contributing to people's indulgence to unsafe sex,...they know that if they get pregnant and eventually bear children, they will be provided with free formula milk". (FFG2E28)

Abuse of and dysfunctional policy as perceived reasons for change

Inappropriate use of free formula milk by both healthcare personnel and HIV-positive mothers was identified as a major concern by all groups except the HIV-negative mothers. They linked the mismanagement and abuse of the free formula milk as the reason for phasing it out. In addition, many viewed the change as a good thing. Fathers were more vocal than the other groups and narrated how they know people, including nurses, who have stolen not only formula milk but also other foods meant to be given to malnourished children, HIV and TB patients:

"...Most of the food will be sold...I know some of those people who sell the food,...people who need it are the ones who buy it...so this food does not reach the person who desperately needs it...people are rich because of this food,...I do not support this and I'm not happy about it". (FFG2C25)

"It is the nurses themselves who steal the food ... They steal the food and sell it outside of the clinic to boost their pocket money, transport money and it becomes a trend". (FFG2A40)

"...The Government should have put people in place that will ensure that this food reaches the intended people. Corruption is still

high that is why the government decided to suspend it, even if one report this fraud is not easy to follow...". (FFG2B46)

This selling of free formula milk was confirmed by a quote from an HIV-positive mother regarding her friend's experience in accessing it:

"My friend was getting it from the clinic but now she has changed it because she was saying they buy it from the clinic for R70". (SN+20)

One grandmother had this to say about some recipients of free formula milk, who sold it to make some cash for personal needs:

"Some who get this free formula milk are not getting it for their babies...but they sell it to their neighbours and use the money to make ends meet or buy alcohol and drugs, some mothers are not mothers...then they will feed their babies tea or porridge". (GMF1A58)

A grandmother questioned the criteria used in issuing free formula milk and other foods to target groups:

"It's difficult to know what they do with formula milk that is left at the clinics...because there are people who even get maize meal from the clinic whereas people who qualify to get the maize meal do not get it, they tell them it is finished". (GMF1D57)

HIV-positive mothers expressed disappointment at the lack of clear and transparent procedures in distributing free formula milk. Free formula milk seems to have been 'personalized' by some of the nurses and they treated it as their own commodity rather than a public service. One mother discussed how she was turned away because she did not go with her baby to collect it, while another indicated how she received formula milk once and was turned away the second time; others simply do not collect it:

"...you do not collect it without bringing the baby, they give you when they see your baby or they turn you away". (PN+34)

"Soon after giving birth they gave me six tins once, refused to give me more. I have rights, government says when something has been given to people they must get it". (TFGA+19)

"I do not collect it but the nurses pretend as if it is the money that comes from their pockets". (TFGB+18)

"I have seen that they do not treat us well...they do as if they have bought it". (TFGD+16)

The challenges faced by these mothers were confirmed by a grandmother working as a community health worker at one of the local clinics. She discussed how HIV-positive mothers frequently sought her counsel on how to access required monthly rations of formula milk for their babies because they had failed to do so through the standard clinic distribution system.

"I would say they give those that they know or like a lot like a monthly supply and they give others one tin or not give them at all when they see that is not going to be enough for those that they like. It becomes painful because people go to the clinic to seek assistance". (GMF1C67)

Some HIV-positive mothers viewed the clinic as an unreliable supplier of free formula milk; this shortfall forced them to make contingency plans for feeding their babies:

"You do not have to trust too much on the supply from the clinic because at times you do not get it when it is finished. Therefore, you must have something on the side beside the milk you get from the clinic". (ZK+31)

Proposed strategies for communicating the policy change

Participants made recommendations for how the information regarding phasing out the free formula milk policy could be communicated to them. It was interesting to note that they were conversant with the principles of the social marketing approach to communication. They indicated how people were different and that one channel of communication may not appeal to all. In view of this, they proposed a multifaceted information dissemination strategy. They recommended the use of the following communication channels: television, radio, pamphlets, notices, newspapers, billboards, posters and meetings:

"...the clinics and the hospital doctors should issue pamphlets to be distributed to tuck shops and public places. They should also use newspapers, TV and radio...". (GMF2F58)

They also identified different venues from which this information could be communicated. These include: clinics, labour wards, streets and street poles, schools, tuck shops and stores, taxi ranks, community halls, churches and homes:

"There must also be people at transport stations (taxi ranks) to issue pamphlets because stations are always crowded". (TFGC+19)

"...announced on the radio...Most of the time you find mothers at the clinic...can be informed at the clinic...and churches that the free formula milk has been suspended, because these are the most used institutions, and the schools can also be used because most people use schools, meetings can...be asked to inform people". (FFG1A35)

One HIV-positive mother said that communication should not be for pregnant women only, but should target all:

"Ok this means you should not target only pregnant women therefore everybody should be involved ... know the disadvantages of mixed-feeding babies". (SN+20)

Discussion

This article addresses the recent discontinuation of free formula milk in the PMTCT programme. It is the first study to describe community perceptions of this major policy change affecting child health in South Africa. We found that, although people were aware of the policy change, there were differing opinions as to the reasons with some seeing it as a temporary change resulting from an insufficient supply of formula milk, which could be resolved. Some viewed the policy change as positive,

as the distribution of the free formula milk was seen to be abused. They attributed the stoppage as addressing a dysfunctional system in which stealing and selling free formula milk diverted taxpayers' money. Fraud and corruption is an ongoing endemic challenge in South Africa including in provincial Departments of Health (Bateman 2011) and this may have influenced the views of participants to consider corruption as a reason for phasing out the free formula milk. Furthermore, the powerful status of nurses in acting as gatekeepers to health care has also been well described (Doherty *et al.* 2006; Wood and Jewkes 2006; Everett-Murphy *et al.* 2011).

Free formula milk was seen to be encouraging more teenage pregnancies and discouraging breastfeeding. While the association of free formula milk and increases in teenage pregnancy has not been substantiated through research this was a strong perceived view in the Umlazi community particularly amongst fathers and grandmothers.

The fact that there were different interpretations of the reasons for the discontinuation of the free formula milk policy is indicative of lack of appropriate and adequate communication about the change at the community level. Dorfman *et al.* (2005) argue that public health advocates, before determining what to say, must determine specifically what they want to change and know how to create change. They also need to identify the steps to the solutions and then frame the messages for change. Dorfman (2005) recommends that messages for social change should reinforce and activate values since values are motivators. Hence, it is critical to strengthen messages that articulate core values that motivate people to change. Furthermore, each message should answer three key questions: (1) What is wrong? (2) Why does it matter? (3) What should be done about it? (Dorfman *et al.* 2005).

In addition, the communication strategy should include explicit messages for household members to understand what EBF is, its value and the dangers of mixed feeding even in formula fed babies. Specific messages should be developed to address the needs of HIV-negative and HIV-positive pregnant women, men, grandmothers and the broader community for optimal support of the policy change. A recent study in Malawi indicates that women enter the PMTCT programme with pre-existing views on the best ways to feed their babies, therefore adequate counselling and clear communication of medico-scientific rationale for the recommended practices are crucial, and where mothers need resources for maintaining EBF, they should be assisted (Levy et al. 2010).

The community voices in this study indicate optimism in wanting to know more and engage better with the health system in understanding the reasons for phasing out free formula milk. This provides a chance to start a dialogue to address misinformation and confusing messages, which cause fear and deter women from breastfeeding, and to build trust between healthcare workers and the community. Research done in other countries indicates that when women are provided with accurate information, professional and social support, they are more likely to breastfeed (Horton *et al.* 1996; Susin *et al.* 1999; Dulon *et al.* 2003), contrary to when they are given directive messages.

However, the public health policy change terrain is complex and requires more than sound scientific evidence (Agyepong

and Adjei 2008). Activism and commitment to social change by public health practitioners who share the same ideology are core requirements for successful public health interventions (Bryant 2002). There are examples of successful policy change such as tobacco control (Malan and Leaver 2003), fluoridation of water and iodation of salt (Fielding et al. 2002) and antimalarial drug policy change (Mubyazi and Gonzalez-Block 2005). Certain processes and actions seem to have played a role in bringing about successful policy change. These include: policy analysis to understand past policy failures and successes, which are then used to plan for future policy implementation (Oliver 2006; Walt et al. 2008); supportive leadership and political commitment (Austin and Overholt 1988; Shiffman 2007), achieved through lobbying, advocacy and social mobilization; regular, precise, clear and understandable feedback to policy makers by researchers on incremental changes in policy implementation (Austin and Overholt 1988; Oliver 2006; Shiffman 2007): adequate resources for policy implementation: and strategies for engaging all stakeholders including the community and media in all policy change processes (Bryant 2002; Mubyazi and Gonzalez-Block 2005; Oliver 2006).

A recent study on responses to the 2006 HIV and infant feeding policy change in Malawi (Chinkonde et al. 2010) indicates that health workers found it difficult to advise women about the policy change due to lack of consensus on WHO guidelines. Health workers were worried that they could lose the trust of PMTCT clients and the population. However, support to HIV-infected women was noted in PMTCT programmes where health workers were multi-skilled, co-ordinated their efforts and had functional multidisciplinary task teams and involved communities. This study concluded that policy change is a slow process and it entails soliciting consensus amongst stakeholders, providing upto-date information about the change, training health workers on the policy change, providing supportive supervision, and investing more resources and developing contextualized easy-to-follow guidelines for policy implementation. There is a need to draw on these lessons in creating collaboration between policy implementers and communities and to build on communities' knowledge on breastfeeding, as well as training healthcare workers to communicate similar messages to households and communities.

Participants identified a multifaceted communication strategy similar to the multi-pronged message dissemination strategy used in social marketing described by Mattson and Basu (2010) as an effective way of communicating this important policy change. This will need commitment at all levels of the health system to craft and disseminate relevant culturally and scientifically sound messages using multifaceted communication strategies proposed by the study participants. These should inform current planning in South Africa for a communication strategy.

Limitations

We explored community perceptions on phasing out the free formula milk policy. It is crucial to also explore the health workers' perceptions, particularly those who are involved in counselling of mothers and communicating the policy change. Understanding their views is crucial to getting their buy-in, identifying training gaps, harmonizing the messages, and building linkages and trust between the health system and the community. This study only captured the perceptions of urban individuals; rural dwellers may have differing views on this policy change. Our sample, typical of qualitative research, was small; however, the setting, a township settlement on the outskirts of a major city, is typical of many settings in South Africa and neighbouring countries and these findings could therefore provide insights of relevance to similar high HIV prevalence settings.

Conclusions

The removal of free formula milk through the PMTCT programme following 10 years of provision is a major health policy change in South Africa. There is an urgent need for a well-developed and clear communication strategy articulating the reasons for the change and to support the renewed promotion of breastfeeding. With a supportive environment and one national infant feeding strategy, South Africa has an opportunity to reverse years of poor infant feeding practices and to improve the health of all children in the country.

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Conflict of Interest

None declared.

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