

## Community Support and Participation with HIV + Mothers and Infant Feeding in Semi-urban Societies, Cameroon

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### ABSTRACT

Replacement feeding is a known way of feeding babies born of HIV infected mothers in order to curb Mother-to-child transmission (MTCT). The reactions of family members and other neighbours towards HIV infected mothers who cannot breastfeed their babies poses a challenge to public health as a whole. This is because heeding to health education on appropriate actions to reduce or stop MTCT of HIV/AIDS through avoidance of breastfeeding may be fruitless as the mothers may be stigmatized. In communities with infant feeding groups or HIV support groups, the story may be different and will lead to better baby outcomes. In conditions where the family and the community understands and are supportive or in favour of replacement feeding, the chance of child survival is certainly higher. In sub urban areas like the study site where the prevalence (11.9%) of MTCT of HIV has been found to be highest in the whole nation, MTCT transmission through breastfeeding could be possible. Thus this survey was to find out the support and community participation in curbing HIV transmission through breastfeeding by the use of replacement feeding. A cross-sectional research design was used and the variables described. In both approaches (quantitative and qualitative methods) of data collection were used. The quantitative arm recruited 112 women in three facilities using convenient sampling and a WHO structured questionnaire was administered, and the qualitative components sourced 16 women from eight community-based associations for in-depth interviews. Microsoft Excel and Strata statistical software version 10 were used for creating data-base and analysis respectively. Community support on infant feeding was low. The results could be used in intensifying the health education on PMTCT of HIV/AIDS.

### Introduction

HIV+ mothers always stand a risk of transmitted the virus to born children requiring that enough counseling and support are provided during the postpartum period. The counseling service must be part of each follow-up visit to support mothers to decide on a safe feeding option for their newborn baby particularly where replacement feeding has been prescribed. Counseling, education and support in infant feeding can be provided during antenatal and postnatal care. This could be based on the national protocol; on the individual situation of a woman as well as on her habits and beliefs. It should include education on feeding options, empower women with abilities to enable them to safely breastfeed their babies, encourage involvement of the partner or the family in the choice of type of feeding and support women to reveal their HIV status to loved ones (MOH,2008). In the process, the following are involved: welcoming the client, offering her a seat, introducing oneself, enquiring about the pregnancy; checking her knowledge on the methods of mother-to-child transmission of HIV, specifying the risk of transmission of HIV through breast milk and /or breastfeeding, specifying the advantages of breastfeeding for the child, listing the risk of artificial milk, giving the advantages of formula feeding, and presenting the dangers of mixed feeding.( MOH,2008)

To assist the mother make informed decisions, there is a review of the risks and benefits of breastfeeding, the risks and benefits of formula feeding, client's understanding, making client choose an option, and making sure the client understands the option very well.

Should the client choose replacement feeding, the following five criteria (AFASS) must be assured:

**Acceptability** means no cultural pressures with regard to this option, no pressure from the partner and acceptance by the latter with respect to this option

**Feasibility** means the mother understands solutions and can prepare a feeding bottle; that there is time for adequate preparation of the substitute (at least eight times per day) and that adequate preservation is possible.

**Affordability** means the mother or family can pay for the cost of formula.

**Safe** means the method does not endanger the life of the child. (potable water is available, medical follow-up and transport for consultation could be ensured).

**Sustainability** means the artificial milk is always available.

The AFASS criteria must always be reviewed and checked for family and community participation and support particularly as the following foods are required:

**Energy giving foods (starches, cereals and grains):**

These includes maize, flour, millet, sorghum, cassava, bread, sweat potatoes, rice, pasta and pumpkins. Give the baby the foods found at the home. This group of foods makes up the bigger part of the food that the baby eats. These foods give energy and some proteins to the body.

**High energy foods (oils and fats):** They provide more energy to the body. This can be gotten from cooking oil, butter and margarine. Do not add too much oil because it can make the baby too fat.

**Protective foods (fruits and vegetable):** these give the baby vitamins and minerals, which protect the body from disease and help the body to work well. Give the baby fruits and vegetables of different types and colours: Dark green. Orange and red vegetables and fruits are the best for the body.

**Body building foods (meat, poultry, fish, beans, and nuts):** this group of food includes eggs and milk; the foods give proteins for the growth, development and repairs of body parts. These foods also provide vitamins and minerals which help to make the immunity of the body strong.

**Water:** give the water during every meal and whenever the baby wants water. Give water which has been boiled and left to cool. As from 6 months water is needed for basic metabolic processes in the body. (CBC Health board, 2010)

**Community support to PMTCT activities****What can men do?**

Though it is usually referred to as mother to child transmission, it does not mean men are not involved. Moreover men hold power in their homes and in the community giving them a leading role in promoting health behaviours like prevention of mother-to-child transmission of HIV, infant and young child feeding in the context of HIV, men who care: stick to one sex partner, practice safe sex, go for counseling and testing to know their HIV status, encourage their sex partners to go for counseling and HIV testing, encourage friends to act and avoid the spread of HIV, discuss and act to stop the spread of HIV and AIDS, in the family, among friends and in the community (LINKAGES, 2004). Non-Governmental Organizations (NGOs), associations and international organizations also have a lot to do in the fight against mother-to-child transmission of HIV. They can intervene in the following areas: Donations of diagnostic, treatment and care of equipments e.g. CD4 machines, HIV prevention and VCT, operational research, capacity building of health professionals, promotion of condom use, training of community organizations, youth organizations, and peer educators on adequate feeding methods in the context of HIV. (ibid)

**What community relay agents and health committees can do**

Community relay agents are liaison persons between the technical team in the health facility and the community while the health committee represents the community in the health care system. The relay agents and the dialogue structure have much to do in the context of mother-to-child transmission of HIV and infant feeding option for instance information, education and communication (I.E.C) in the community for behaviour change, reinforcing healthcare at the family and community level, working in close collaboration with the medical team, reinforcement of voluntary counseling and testing activities at community level, support people living with HIV/AIDS (PLWHA) to adhere to their treatment, clarify misconceptions, encourage pregnant women and their spouse to go for PMTCT services, encourage PLWHA to join support

groups and ensure psychological support to reduce stigma and discrimination that may be associated with a feeding options (ibid).

**Infant Feeding Recommendations in Cameroon**

Information from the Cameroon, 2008 prevention of mother-to-child transmission of HIV among other issues emphasized that:

Healthcare providers and social workers should inform HIV-positive mothers of the risk of transmission of HIV to their child during breastfeeding.

Healthcare providers and social workers should inform all HIV-positive mothers about the advantages and disadvantages of the various options of infant feeding in the context of HIV, and informed choice will be made with the involvement of the partner.

Healthcare providers and social workers should see to it that HIV-positive mother avoid breastfeeding when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS). No commercial pressure should influence this choice.

If the AFASS conditions are not met, exclusive breastfeeding is recommended during the first six months of life.

At any moment during the first six months of life if the AFASS conditions are met, it is recommended to move from exclusive breastfeeding to replacement feeding.

Healthcare providers and social workers should inform HIV-positive mothers that the duration of breastfeeding should not exceed six months.

Healthcare providers should let the HIV-positive mothers understand the danger of associating breastfeeding with replacement feeding.

Healthcare providers should train the HIV-positive mother in fast weaning (at most two weeks). Weaning should take place at the age of five months and half.

Healthcare providers should inform HIV-positive mothers of the existence of support groups and the need to discuss about her status with the partner of family. Healthcare providers should also support the HIV-positive mother in her choice of infant feeding option.

Healthcare providers and social worker should ensure that children fed with domestic preparations containing animal milk are giving supplements containing iron, zinc, vitamin A, C and folic acid in compliance with the approved protocol (MOH, 2008).

**Statement of Problem**

Community support in favour of replacement feeding options are a necessary way by which mothers can feel comfortable replacing breastfeeding with formula feeds. Reactions of family members, neighbours and perceptions of stigma could pose problems to mothers and consequently affect the feeding and wellbeing of their children. Where there are favourable actions, the zeal for replacement feeding is built and the baby is safe from MTCT through breast feeding. But where the reverse is true breastfeeding can continue even when counter indicated for fear of being stigmatized. The lack of infant feeding support groups and other support groups for people living with HIV (PLWHIV) further compounds the problem.

**Research question**

What is the reaction of family members towards HIV infected mothers who breastfeed their babies?

What is the reaction of neighbours towards HIV infected mothers who breastfeed their babies?

What is the perception of stigma in the community?

What infant feeding and PLWHIV support groups exist?

### Hypotheses

A positive community support of the HIV+ mothers may result to the use of a safe infant feeding method in the context of HIV.

### Specific objectives

To assess family members' reactions towards HIV infected mothers who breastfeed their babies.

To assess the reaction of neighbours towards HIV infected mothers who breastfeed their babies.

To assess the perception of stigma in the community.

To identify the existence of infant feeding and PLWHIV support groups.

### Materials and methods

A cross sectional descriptive study of key informants in community-based associations was used and employed the use of both quantitative and qualitative technique. An interview with a structured questionnaire was used during the in-depth interview of key informants in eight community-based associations.

The population of the study was women irrespective of their serological status in the selected communities. The non-probability sampling method was adopted. It entailed the systematic recruitment of volunteers in the communities who met the inclusion criteria of being a mother. For the qualitative phase of the study a purposeful sampling method was used and women were selected from the eight associations by the presidents of the group but who must meet the inclusion criteria. Data was collected in two phases, the first with the use of a structured questionnaire used on all informants and the second by an in-depth interview technique used on the samples women from the various community-based associations since they were the most appropriate (having been trained) when dealing with sensitive issues. The interview guide included both closed and open-ended question and probe for reasons behind different responses to specific questions. The main sections of the guide were factors of feeding options, community's facilities that could favour replacement feeding, and community support. The reason for using both tools was to increase the validity and reliability of the quantitative data. The following steps for conducting interviews were used.

**Pre-interview:** The principal investigator went into the communities, contacted the chiefs, the community relay agents in the communities who help him to identify and map-out the associations to be interviewed. Letters were sent to the presidents of the associations to inform the general assembly, and then to choose key- persons to be interviewed, venue, date and time of interview was also set. The community relay agents were charged with the responsibility to give a feedback to the researcher on the date, time, and place of the interview. Interviews were conducted at the meeting premises or at the interviewee's residence.

The letter to the presidents of associations contained the following information: an introduction of the research, purpose of the study, type of information to be collected, that the interview will be recorded, permission and authorization to conduct research, estimated length of the interview and provided contact information

**The interview:** The researcher introduced himself. Thanked the interviewee for her time and willingness to share her views. Create an atmosphere in which the interviewee freely tells his story in her own way. Briefly explained the purpose

and scope of the study and collected demographic characteristics of the interviewee. He started with a simple question that is important but not too specific. In our case the question, "in your opinion how soon after delivery should a baby start feeding?" was used. Each question was asked followed by the other once the question had been satisfactorily exhausted. The interview was closed by further thanking the interviewee.

**Recording the interview:** The interview was recorded using a Digital Voice Recorder, Mark: OLYMPUS, Reference N° : VN-2100. The researcher jotted down only important points.

### Reporting the interview

Soon after the interview, the information recorded was transcribed into a word document using Microsoft Word 2007. This was done for each interview and a final summary document for all the interviewees' views and perceptions was produced.

### Data processing and analysis

Data collected from the field were kept by the principal investigator who ensured work was done in accordance with schedule, data was cleaned manually by reviewing and checking of filled questionnaires from the field and observation of data collectors as they conducted the interviews, unfilled and unanswered questions were not included. Open-ended questions from the interview guide were coded as they came from the field, and range and consistency error during data collection were checked. The data was entered into the computer and analyze using two statistical software packages- Microsoft Excel version 2007 and Strata statistical software version 10.

Template for data entry was created in MS Excel and exported to strata for statistical analysis.

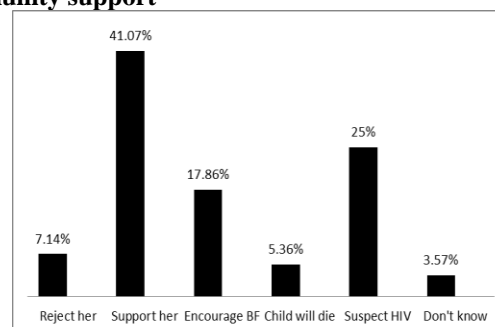
The ethical principles used were from Bonita et al (2006) thus:

Informed consent was obtained from the respondents either by reading and signing the consent form for literate respondents or orally for illiterate respondents.

### Results

Generally, the individual women who were administered the questionnaire fell within the age range of the 25 -45 years with a mean of 35 years. A majority of them were married while one quarter of them were single. One of them was a widow while one had divorced with the husband. Moreover almost half of them were business women, one quarter of them involved in farming. However, there was one teacher, a house wife, a student and a hair dresser each (n=112).

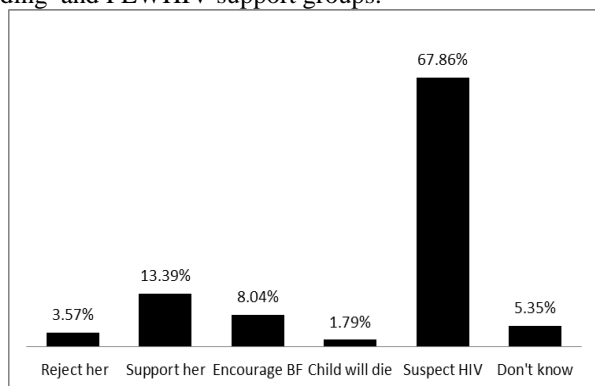
### Community support



**Figure 1. Reaction of family members towards an HIV-infected member practicing replacement feeding.**

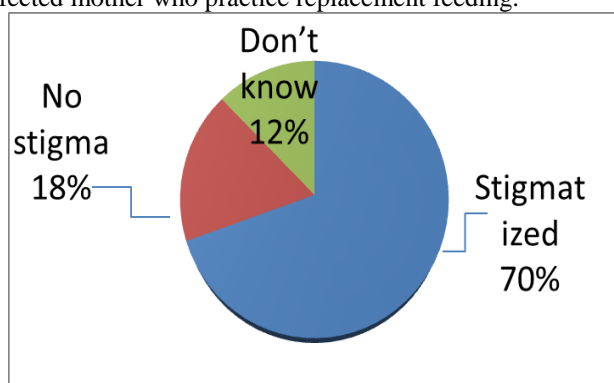
At the family circle there was a 41.07% support as oppose to 25% suspicion of HIV status for a member who practiced replacement feeding.

At level of the community associations 26 members were interviewed. The results have been presented following the objectives of the study: community support under reactions of family members, neighbours, perception of stigma, infant feeding and PLWHIV support groups.



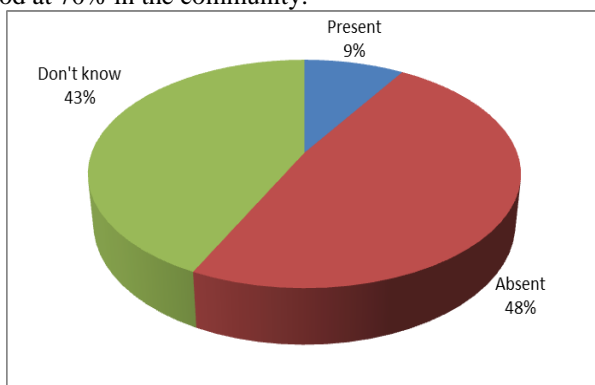
**Figure 2. Reaction of neighbours towards an HIV-infected mother practicing replacement feeding**

Within the community there was a 67.86% suspicion of HIV status as oppose to just 13.39% support for an HIV-infected mother who practice replacement feeding.



**Figure 3. Perception of stigma in the community**

Perception of stigma towards an HIV-infected mother stood at 70% in the community.

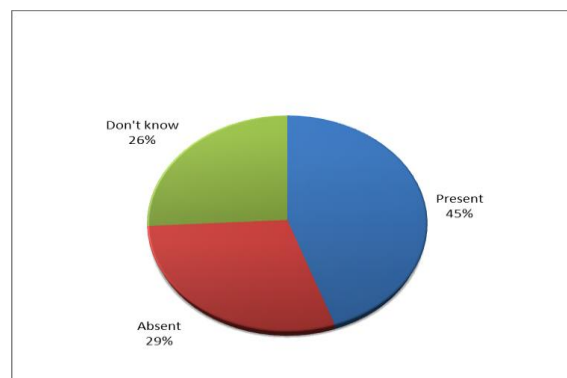


**Figure 4. Infant feeding support groups in the community.**

More than 90% of respondents acknowledge the absence of infant feeding support groups in the community.

Only 45% of respondents acknowledge the presence of support groups for people living with HIV.

The qualitative data from the interviews produced two distinct results: community's facilities like source of water, cooking fuel and waste disposal; while support for replacement feeding were not available but women would love to belong if created.



**Figure 5. support groups for PLWHIV.**

#### Community's facilities in favour of replacement feeding

For the sources and quality of drinking water most of the interviewees used public taps and spring water particularly those in rural areas while close to half of them use public taps only, three use tap water and mineral water when taps do not flow.

With regards to sources and availability of cooking fuel, three quarters used firewood while one quarter made use of kerosene or gas. Support facilities for sanitary conditions and waste disposal were available particularly with the coming of HYSACAM (a cleaning company) to the study area. However more than one quarter of the community members still dispose their waste in community dumping pits or streams which could be a source of contamination to infant feeds.

#### Community's support

No infant feeding support group was found in the communities. However about half of the women said if such a group were created they will be prepared to join. This was same for breastfeeding support group, but interviewees accepted to join such groups if created to empower them. With regards to HIV/AIDS support groups, three women confirmed the existence of such groups. While closed to three quarters of the women did not know of the existence of such a group. For those who knew of a group, they said the groups were based at hospital level not at community level. Another woman said she heard of it in the church. However there were conflicting ideas to join support groups. About one quarter of the women said if such groups are created in the community, they don't know if people will join because people are ashamed, but if created in hospitals people may join. While a few of them said they will be happy if such a group were created even at community level.

#### Discussion

Respondent's age-range in the quantitative study was 21 to 46 years, with a mean age of 32.17 years. In the qualitative phase the age range was from 24 to 45 years with a mean of 35 years. This age range is within the age range of those mostly affected in Cameroon, 20 to 39 years (MOH, 2010) and also falls between the reproductive age ranges of 15 to 49 years.

Community support in the context of PMTCT of HIV in general and using a safe infant feeding option in the context of HIV in particular can be effectively achieved by involving male spouse, other family members, opinion leaders, NGOs and community support organizations (CSOs), social networks, health committees, and community health workers or relay agents. (LINKAGES, 2004)

In the study respondents' opinions towards family support to a mother who practice replacement feeding was 41.07% against 25.00% who suggested that the woman will be suspected of having HIV and 17.86% who revealed that

family members will only encourage her to breastfeed. The results are slightly low as compared with the qualitative study where half of respondents acknowledge the fact that family members will support their HIV-infected sister to practice replacement feeding.

Results further demonstrated that 67.86% of community members will only suspect such a woman of having HIV as against 13.39% who revealed community support for a woman who practice replacement feeding. Contrary to the results, the qualitative study showed that half (50%) of community members will support a woman who practice replacement feeding.

They also acknowledge a high proportion of stigma (69.64%) associated to HIV-positive non-breastfeeding women in the community.

Finally respondents' opinions on the availability of infant feeding, breastfeeding and community services or support groups for people living with HIV/AIDS were 8.93%, 4.46%, and 44.64% respectively. These results are opposing to that of the qualitative study that revealed no infant feeding or breastfeeding support group but a few women who confirmed the availability of support groups for people living with HIV/AIDS.

### Conclusion

The community still has a negative perception about HIV, and community support and participation remains low. However they acknowledge joining support groups if created.

### Recommendations

Creation of community-based organizations that will ensure:

1. Application of behaviour change communication strategies on infant feeding like planning, advocacy and partnership with community leaders, NGOs, and social networks;
2. Ensure capacity building in group dynamics, HIV and infant feeding counselling, and measurement of progress of interventions.
3. Social mobilization on infant feeding using TV, Radio, press, Bill boards, and Posters.
4. Integration of infant feeding activities to those of Health committees and other social networks.
5. Encourage communities to ensure support facilities are available for replacement feeding

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