

BOTTLE MILK OR BREASTFEEDING?

**A QUALITATIVE RESEARCH ON MOTIVES OF FEEDING DECISIONS
AMONG HIV POSITIVE MOTHERS IN CAMEROON.**

Bachelor Thesis

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ABSTRACT

This research was done for the organization Give Milk Stop Aids that promotes artificial bottle-feeding among HIV-positive mothers. In this study, the motives towards feeding options of HIV-positive women in Cameroon were investigated. The WHO recommends HIV-positive women to either exclusively breastfeed, or give artificial bottle-feeding to their child, while a mixture of both feeding options is the norm in Cameroon. Give Milk Stop Aids works with a program that distributes free artificial milk and promotes giving artificial bottle milk to exclude the child from HIV-contaminated breastfeeding, and to protect children from contacting the virus through the mother. This program is located at three health care clinics in Cameroon; one hospital and one health clinic in rural areas and one hospital in the largest city of Cameroon. The program has been a success in the city, but this does not count for the programs in the rural area. This research consists of 2 studies. Study 1 aims to explain through which determinants women choose their feeding options. It also aims to explain why the Give Milk Stop Aids program is a success in the city, but not in the rural areas. 26 HIV-positive women who almost delivered or delivered recently were interviewed by a semi-structured questionnaire. The participants were divided into 3 groups. The first group were women who intended non-bottle-feed and lived in rural areas ($n=9$). The second group were women who intended to non-bottle-feed and lived in the city ($n=12$). The third were women who intended to bottle-feed and lived both in rural areas and the city ($n=5$). Analysis of results led to the conclusion that HIV-positive women who are aware of the fact that breast milk is contaminated with HIV, primarily choose to feed their baby artificial milk. Women that prefer to breastfeed believe strongly in the nutritious value of breast milk. The difference in success of the program between city and rural areas can be explained by differences in attitudes about stigma and coping strategies. Women in rural areas perceive stigma together with great consequences for their personal life, because revealing an HIV-positive status might lead to rejection from their relatives, which means that they lose their social safety net. Women in the city are more often employed and depend less on their relatives. The level of coping with HIV influences the willingness to give bottle-feeding. Women from rural areas cope slightly worse with the HIV diagnosis than women from the city, because they do not know much about HIV, except that it kills. Their bad coping strategies might influence their dismissive attitude towards bottle-feeding. Study 2 expressed the experiences of the health workers, working for Give Milk Stop Aids. In this

study, the health workers told about their experiences with the Give Milk Stop Aids program, the participants of the program and the women who refused to join the program. The answers of the health workers have been compared with the results of Study 1.

PREFACE

In the period of November 2011 to April 2012, I went to Cameroon to do my bachelor research about HIV and AIDS for the Dutch organization Give Milk Stop Aids. Two Dutch medical students founded this organization in 2004. They examined HIV positive pregnant women during their internship in the Apostolic Hospital Banga Bakundu, a rural area in Cameroon. HIV is present in the breast milk and for that reason it was better for the pregnant women to give bottle-feeding, according to the medical students. These pregnant women were generally poor and couldn't afford the milk. That is why the two interns founded Give Milk Stop Aids.



Front of the hospital Banga Bakundu

The Give Milk Stop Aids program runs in three areas in Cameroon; Douala, a large city of two million inhabitants, and two small rural villages where approximately 500 to 1000 people live: Banga Bakundu and Munyenge. The program that Give Milk Stop Aids designed for the hospitals in Cameroon exists partially of the free provision of formula milk for HIV positive women. Other aspects of the program are the organization of support group meetings for all HIV positive mothers and psychological counselling to cope with the HIV positive status. The program offers poor HIV-positive women to give artificial bottle-milk, even when they cannot afford it themselves.

The aim of this research

Although the number of participating women in the program has increased over the years, the management team of Give Milk Stop Aids has noticed that there is a large amount of HIV-positive women who refuse to join the program and decide to breastfeed their child. This phenomenon especially occurs with the programs in the rural areas. The management team has sent me to Cameroon to find out why women refuse to join. I will present the results of my research in the following report.

Acknowledgements

Before I start to present the results of my research, I would like to thank all the people who supported and helped me to realise this research. At first I would like my Cameroonian colleagues; Lorraine Tanga and Hannah Ebob, who guided me and helped me to perform my research in the Cameroonian hospitals. Without them I would be lost in Cameroon. I would like to thank the Apostolic Church in Cameroon, for receiving me and letting me perform my research in their hospitals. I would like to give my thanks to the management team of Give Milk Stop Aids, who provided this internship to me. Specifically Wendie Botjes, who was my Dutch supervisor at Give Milk Stop Aids. Living in a country that is so different from what you are used to is not always easy and she got me through the tough times during my stay. I would also like to thank my first tutor of the University of Twente, dr. Henk Boer. He was closely involved with the process of my report and was always prepared to give me feedback in order to present my research as clear as possible. I would like to thank my second tutor, dr. Marcel Pieterse as well.

Chapter 1

Introduction

INTRODUCTION

Impression of Cameroon

The Republic of Cameroon is located in the west of Central Africa. The country is called “Africa in miniature” for its geological and cultural diversity. The official languages are French (78%) and English (22%), but there are 24 major African language groups and 250 ethnic groups with their own dialects. Around 40% of the inhabitants practice indigenous beliefs. Another 40% is Christian and the left over 20% are Muslim. Cameroon has approximately 19.700.000 inhabitants (July 2011). Although Yaoundé (1.8 million inhabitants) is the capital of the country, Douala (2.1 million inhabitants) is more important because of its economic importance. About 58% of the people live in the cities of Cameroon. The other 48% lives in rural areas. Approximately 76% of the Cameroonians are literate. Among females, 32% is illiterate. Children receive on average 10 years of education (Central Intelligence Agency, 2012).



Economic facts

Because of its modest oil resources and favourable agricultural conditions, Cameroon has one of the best-endowed primary commodity economies in sub-Saharan Africa. Still, it faces many of the serious problems confronting other undeveloped countries, such as stagnant per capita income, a relatively inequitable distribution of income, a top-heavy civil service, endemic corruption and a generally unfavourable climate for

business enterprise. The national GDP is €1850, which is the equivalent of an average salary of €154 per month per employed person. Cameroon knows an unemployment rate of 30%. 48% of the households live below the standards of the poverty line (Central Intelligence Agency, 2012).

1.1 Health in Cameroon

The life expectancy in Cameroon is 54.39 years. 5,3% of the inhabitants are infected with the Human Immunodeficiency Virus (HIV). In numbers, this equals 610.000 people. Around 37.000 people per year die due to the consequences of HIV/AIDS. Only 25% of the infected people have access to antiretroviral therapy (Give Milk Stop Aids, 2010). Ways to transmit the virus are through body fluids like blood and sperm, but also through breast milk. Ziegler (1985) detected HIV (Human Immunodeficiency Virus) in mother milk of HIV-positive women and therefore it is certain that transmission of the virus can occur via breastfeeding. Transmission through breast milk infects at least 30% to 50% of the infants. This means that when no measures are undertaken, one out of two/three children delivered by an HIV positive woman will become positive without being able to prevent it. (De Cock, Fowler, Mercier, Vincenzi, Saba, Hoff et al., 2000; Bequet, Castebon, Viho, Ekouevi, Bequet & Ehouo, 2005)

An estimated total of 5,3% of the inhabitants of Cameroon are carrying the HIV virus (Central Intelligence Agency, 2012). The acquainted percentage among pregnant women is even higher. 15,9% of the pregnant women is diagnosed HIV positive (PMTCT Statistics, 2012). These numbers can be explained by the fact that every pregnant woman has been sexually active. Besides that, every woman is obligated to undergo an HIV test, while the general prevalence percentage is based on voluntary tests by voluntary participants.

In order to protect children from getting infected with HIV (protection from mother to child transmission), the World Health Organization (WHO) recommends that HIV-positive women choose between two feeding options before they deliver. The first and most preferable option is that they avoid breastfeeding entirely and shift to bottle-feeding. Option two is to practice exclusive breastfeeding entirely and eliminate all sorts of other food, like pap. The option of bottle-feeding is preferred when replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) for the circumstances those

women live in. This means that women have to be able to afford and prepare the bottle milk. This option is preferable because, when the milk is prepared well, children will not contract HIV. When women are not able or not willing to meet the AFASS criteria, the WHO recommends another option, namely exclusive breastfeeding in combination with prophylaxis for four to six months instead. This option is more risky concerning HIV, but is more nutritious than poorly prepared bottle milk (World Health Organization, 2009).

1.2 Feeding decisions: cause of stress

There are three options to feed a newborn baby. These options are: breastfeeding, bottle-feeding with artificial milk and a combination of breastfeeding and other foods like artificial milk and water, known as mixed feeding. Every woman has to think about what kind of feeding option she wants to practice. For women diagnosed with HIV it is especially important to decide upon a feeding option before her baby is born.

The phenomenon of 'mixed feeding' is the norm to feed a baby in Cameroon. Women introduce other foods besides breastfeeding after two or three months. This is not an option for HIV positive mothers, because mixed feeding is dangerous to their babies. A combination of breastfeeding and other foods results in a higher chance of transmission of the HIV virus (WHO, 2009). In order to prevent the occurrence of mixed feeding, it is important that the mother understands the dangers of mixed feeding and the dangers of practicing it. After that, it is important that the mother carefully decides upon either exclusive breastfeeding or formula feeding and sticks with this way of feeding; she must not ever combine breastfeeding with other foods. This is to decrease the chance of transmission of the virus.

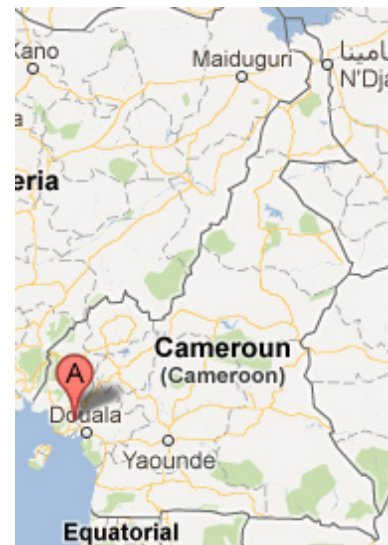
In short: pregnant women are certainly sexually active and therefore exposed to the risk of HIV infection. Therefore, there is a higher HIV prevalence among pregnant women than the rest of the Cameroonian population. In order to prevent the baby for mother to child transmission, the mother cannot practice the 'standard' mixed feeding. She has to choose between the preferred bottle-feeding and the riskier option of exclusive breastfeeding.

An HIV positive diagnosis for pregnant women is the cause of great stress during the antenatal period, especially when it comes to infant-feeding decisions. Mothers have

to choose between two options of exclusive feeding, while “neither exclusive breast-feeding nor exclusive non-breastfeeding are the cultural norm in most African settings”. (Doherty, Sanders, Goga, & Jackson, 2010). This means that HIV positive women who want to prevent their babies from the virus, need to choose between two options that are both not the norm. Some women may think that practicing an alternative feeding mode will reveal their HIV positive status.



Douala



Banga Bakundu

1.3 Give Milk Stop Aids

Since 2004, the foundation “Give Milk Stop Aids” works in Cameroon with a program according to the recommendations of the WHO. Aim of the program is to prevent transmission of HIV from mother to child. This is possible during and after pregnancy. The most important aspect of the program of “Give Milk Stop Aids”, is to provide artificial milk for free. Through this free distribution they want to promote bottle-feeding. The program exists of the following parts: detection of HIV-positive pregnant women, provision of prophylaxis during pregnancy and labour to prevent transmission of HIV during the prenatal stage, free provision of artificial milk to mothers who choose to practice exclusive formula feeding, free medical health check-ups for both mother and child during the first two years of the baby, mothers are able to buy medicines with a discount of 50% (Give Milk Stop Aids provides the rest), free hospitalization when necessary, education about HIV, AIDS and health on annual events like International Women’s Day and World AIDS Day. Another very important aspect of the program is the monthly “Support

Group Meeting” that the Cameroonians employees of “Give Milk Stop Aids” host. During these meetings the mothers are able to share their experiences and to give each other psychosocial support. (Give Milk Stop Aids, 2010)

The health workers of “Give Milk Stop Aids” support both women who choose to breastfeed and those who choose to bottle-feed. They explain advantages and disadvantages of both options and explain the danger of mixed feeding. They let the women decide what to choose. In this way they try to diminish the influence of their state as health worker on the women. They do not promote bottle-feeding exclusively, because they do not want the women to practice bottle-feeding involuntary. Whenever a woman chooses her favourite option, they support the woman to maintain this choice, in order to avoid mixed feeding.



The program exists in three hospitals at this moment. One hospital is located in francophone Douala, the largest city of Cameroon. The other two hospitals are located in the anglophone South-West region, in rural Banga Bakundu and rural Munyenge. The program in the city runs well. Every year more women want to join. The programs in the rural area have stabilized over the years. The program is not able to grow there. (Give Milk Stop Aids, 2010)

This leads to the question what determinants are exactly of influence. What motives are relevant when HIV positive women choose between their two feeding options; practicing bottle-feeding and side food or exclusive breastfeeding? Why do women take a risk of transmitting their baby when they practice exclusive breastfeeding? And why is it that the program of Give Milk Stop Aids is running better in the city than in rural areas?

Chapter 2

Determinants in feeding decisions

DETERMINANTS IN FEEDING DECISIONS

There are different determinants that influence feeding decisions. Chisenga, Siame, Baisley, Kasonka and Filteau (2011) mention some key categories that determine the infant feeding choice by mothers in Zambia. Some of these categories are: cost of the artificial feeding, influence from health workers, influence from relatives and stigma (not disclosing HIV results). According to these categories, mothers choose the best feeding decision for their situation. Cost of formula and influence from health workers are not of influence on women in the Give Milk program. In the next paragraphs this will be explained.

2.1 Costs of artificial feeding

Besides the program of Give Milk Stop Aids, there are more Cameroonian charity programs that provide formula feeding for free. HIV prophylaxis and medicines are provided for free by the Cameroonian government. This makes the option to choose exclusive formula feeding independent of costs that are normally involved to buy tins of formula milk. These costs are an equivalent of €3,50. Most women cannot afford tins of artificial milk for this price. By providing the tins for free, women can choose to breastfeed or bottle feed without having to take costs into account. This is not a relevant factor in this research.

2.2 Influence from health workers

African tradition knows a certain hierarchy between doctor and patient. People go to hospitals, get diagnosed, receive proper medication and are supposed to leave the hospital again. Most times there is no room for questions that a patient might have. Women who are pregnant and HIV-positive are often advised by their doctors to either breastfeed or practice artificial feeding, without having the option to think over which feeding option they prefer themselves. The nurses working for Give Milk Stop Aids are trained to start a dialogue with their HIV-positive patients. They explain all the feeding options together with their advantages and disadvantages and let their patients free to choose their favourite option. The women are able to overthink it as long as they need to. The Give Milk Stop Aids nurses make sure to put no pressure on their patients and to diminish their influence on the patients. They will explain more about this in Study 2 (Chapter 3: Method and Chapter 5: Results of Study 2).



2.3 Knowledge

An important determinant is the amount of knowledge women have about HIV, AIDS and feeding options. What women know about breastfeeding and artificial bottle-feeding is of influence in feeding decisions. (Doherty, Chopra, Nkonki, Jackson, & Greiner, 2005). Receiving an HIV positive status means that doctors and nurses will overload the patient with information and advice about HIV/AIDS. Not every doctor is updated or education at the same level. This results in a cocktail of all kinds of information and advice that a patient receives. Mothers are confused by all different sorts of guidelines about protecting themselves and the baby.

In the past few decades, the World Health Organisation has changed the recommendations for prevention of mother-to-child transmission often. Where the mothers used to have to stop breastfeeding entirely, today giving breast milk is allowed until the child is twelve months, under the condition that the mother uses prophylaxis.

The government, church or individuals manage hospitals in Cameroon. The hospitals do not cooperate with each other. Every hospital practices its own 'school of thought', which means that every hospital chooses its own way of treating patients. Patients in Cameroon do not visit the same hospital over and over again, but attend different hospitals at the same time. For this reason, patients contact different 'schools of thought'. An HIV positive mother might receive the advice to practice exclusive breastfeeding in hospital one, where hospital two tells her to exclude breastfeeding entirely. In the study of Chisenga et al. (2011) the diverse advice they got confused the mothers. The rela-

tionship between mother and health workers is in developing countries often based on power and hierarchy (Doherty, Chopra, Nkonki, Jackson, & Greiner, 2005). Mothers are not comfortable to ask more clarity about feeding options. Due to traditional myths, women believe that breast milk is healthier than artificial bottle milk. "The entrenched knowledge that 'breast milk is best' outweighed the perceived risk of transmission through breast milk."

2.4 Disclosure and coping with HIV

Receiving an HIV positive diagnosis has effect on the quality of life of a person. Holmes (2005) defined quality of life in several determinants with terms as illness or disease status, social support and overall life satisfaction and happiness. Vyavaharkar et al. (2011) state that "Quality Of Life is especially important in the context of chronic diseases since individuals are forced to change or adapt to new circumstances and demands of living with their disease on a daily basis." Kinsler et al. (2007) add the dimension of stigma related to HIV that affects the quality of life. Effects of noticed stigma result in interference in daily routine as well as the ability and intention a person has to attend and use health care services. Another study has shown that the quality of life of women is more affected by receiving an HIV positive diagnosis than the quality of life of men (Campsmith, Nakashima, & Davidson, 2003).

Coping (defined as the continuous process of cognitive and behavioural efforts to manage stress) is related with quality of life. Coping of a chronic disease can be processed in two ways: problem-focused coping and emotion-focused coping (Lazarus, 1993). Examples of problem-focused coping are the adaptive way of dealing with an HIV-positive status, making efforts to actively accept the disease and try to stay positive. This type of coping is associated with the improvement of quality of life, whereas emotion-focused coping is associated with a decrease in quality of life. The emotion-focused coping strategies involve denial of the disease, avoidance of facing the disease the state and a negative attitude towards accepting the disease (Moskowitz, Hult, Bussolari, & Acree, 2009). The way to develop a coping focus when receiving an HIV-positive diagnosis can be divided into four phases of psychological coping (Miller & Belak, 1993). In the first phase, right after receiving the HIV-positive diagnosis, a person will develop a feeling of shame, guilt and stigmatization. This feeling causes people to not disclose their status to anyone. In the second phase, the person develops a feeling of helplessness, which results

into an overruled feeling of depression. In the third phase, denial is important. A person consciously or unconsciously avoids seeking appropriate care. In the fourth and last phase, people are able to accommodate their HIV status. They are able to start to accept they live a life with HIV, so they can begin with coping and seeking appropriate care. In this phase, the person is able to easily disclose the HIV-positive status to other persons. It is preferable that a person quickly processes all the phases to end in phase four soon afterwards starting in phase one. In this way, the person will quickly develop a coping strategy. This is especially important to pregnant women, since appropriate health care is important to them to help them choose the right feeding option for their baby.

Ways of coping with an HIV positive diagnosis influence the acceptance of the status. Coping strategies could be translated into disclosure of the status. The more a person accepts his or her status, the higher the chance of disclosure. When a person accepts his or her positive status, he is more willing to fight the virus with medication and prevent others from HIV, than a person who denies the positive status. The level of acceptance of the status is for this reason a determinant of feeding decisions (Moskowitz, Hult, Bus-solari, & Acree, 2009). To prevent other from HIV includes protection of mother to child transmission, by choosing the safest feeding option.

2.5 Avoiding HIV and AIDS-related stigma

The psychosocial impact of receiving an HIV positive diagnosis in Africa is life changing and often received to be a death sentence. Reasons for this perception are because although treatment is available, a cure is still not found. The HIV positive persons are seeing others dying with AIDS prematurely and get frightened. They see others dealing with the progressive nature of illnesses that come along with HIV/AIDS (Cherry & Smith, 1993). Sharing an HIV positive status with others could cause anxiety and perceived threats to the well being on a personal level (Rodkjaer, Sodemann, Ostergaard, & Lomborg, 2011). Jha & Madison (2009) state: “the general perception is that AIDS happens to people who seek sexual intercourse outside marital relationships, or those who have intercourse with prostitutes”. One participant in the study of Rodkjaer et al. (2011) states: “People have so many prejudices because it has to do with your sexuality, and they think you have lived a promiscuous life.”

Women who choose to practice bottle-feeding face many difficulties in the African environment. Breastfeeding (in combination with other foods) is seen as a feminine domain and the number one source in nourishment. Over the years people started to notice that women who give bottle feeding only, often are sick of diseases like cancer or HIV. To choose this option makes a mother vulnerable to suspicion of HIV by her environment (Desclaux & Alfieri, 2009).

Anticipated stigma, being “the anticipation that one will personally experience specific types of stigma or discrimination if one is found to be HIV-positive and one’s HIV-positive status is disclosed to others” (Turan, Bukusi, Onono, Holzemer, Miller, & Cohen, 2011) is a major cause in the decision to keep an HIV-positive status to oneself, or even avoid an HIV-test at all. It often happens that a pregnant woman is the first member in the family tested on HIV. This means that being tested positive could cause accusations of other family members of bringing the virus into the family (Bond, Chase, & Aggleton, 2002).

Receiving an HIV-positive status is in almost every case a traumatic event (Leserman, et al., 2002). Stevens and Doerr (1997) state: “even those who suspect they are infected with HIV do not accept the diagnosis easily”. The difficulty of acceptance is associated with prevalent stigma of having HIV or AIDS (Van Der Kolk, McFarlane, & Weisaeth, 1996).

2.6 Research question

This thesis is divided into 2 studies. For the first study, literature has shown that some determinants are important to investigate among the HIV-positive mothers in Cameroon. These determinants are “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure of HIV status” and “HIV stigma”. To map the general perception of women about these determinants, I designed a semi-structured questionnaire based on these five topics. The qualitative aspects of these interviews are of special importance, because through this way I am able to reflect the unpolished attitude of HIV-positive pregnant women towards feeding decisions.

Through this qualitative research (Study 1) I would like to answer the following main research question: “What are the motives of HIV-positive pregnant women with regard to choose a certain feeding option?” I would like to answer this question via two sub-questions. The first sub-question of this study is: “What determinants influence HIV positive women in choosing a feeding option to feed their child?” The second sub-question of this study is: “Why does the Give Milk Stop Aids program run better in the city than the rural areas?” I would like to find out if there are noticeable differences in the answers of women in rural areas and urban areas, because the Give Milk Stop Aids program runs better in the city than in rural areas. In order to answer this question completely, I performed the research in rural areas (Banga Bakundu and Munyenge, both comparable of size and living conditions) and an urban area (Douala, Cameroon’s largest city). I asked both bottle-feeders and non-bottle-feeders to cooperate in this research to see if their motives on choosing a feeding option differ.



Through Study 2 I would like to map the experiences and ideas of the health workers, working for Give Milk Stop Aids. This research was designed to measure the influence of health workers on HIV positive women in making a feeding choice. I would like to map the ideas of the health workers concerning the following six topics: “Statistics of HIV positive pregnant women attending antenatal care in the participating hospitals”, “Counselling”, “Realities of artificial feeding according to the health workers”, “Protection of mother to child transmission”, “Perceived stigma” and “Influence of health workers”. Results of this study are needed to answer the third sub-question: “What influence practice hospital staff on HIV positive women with regard to choosing a feeding option?”

Chapter 3

Method

METHOD

3.1 Study 1: Research among HIV positive women

Participants

A total of 26 participants complied in this research. The participants were placed in three groups: non-bottle-feeders in rural areas (n=9), non-bottle-feeders in the city (n=12) and bottle-feeders (n=5). These groups were designed to compare results between city and rural areas, but also to compare results between non-bottle-feeders and bottle-feeders. The non-bottle-feeders from rural areas and the city did not want to join the Give Milk Stop Aids program. They all met the criterion of giving- or planning to give breastfeeding for at least three months, starting right after birth. The bottle-feeders were already participating in the Give Milk Stop Aids program, and were therefore feeding their child with artificial bottle milk. They were all interviewed through the same questionnaire.

I chose to create the research groups in three formations (non-bottle-feeders in rural areas, non-bottle-feeders in the city and bottle-feeders) because I want to research two things through this study. First I would like to compare results of the questionnaire between bottle-feeders and non-bottle-feeders to determine what factors influence feeding decisions. Secondly, I would like to compare results of the non-bottle-feeders between rural and city areas, to determine why the Give Milk Stop Aids program runs better in the city than in rural areas. The next sections will include a description of the three research groups.

Non-bottle-feeders from rural areas

The non-bottle-feeders from rural areas were coming from Banga Bakundu and Munyenge. Five of them were living in a small village called Banga Bakundu. It is located around a paved highway. Around 500 residents are living here. This village has facilities like a well, electricity wires and a market with fresh food twice a week. Banga Bakundu hosts a hospital that is the only health care service in a distance of forty kilometres. People can visit this hospital for health consults, surgery and delivery. People living in Banga Bakundu are mostly farmers, employed by the hospital or teacher. Houses are mostly built of iron plates and an average house is approximately ten square metres.

Families share beds and house. There is a fireplace outside of the house communities where they are able to cook their food in open air.

The four remaining rural participants in this study were living in Munyenge. This village is a two-hour drive from the nearest small village through a dirt road. There is no electricity in Munyenge, nor running water. The well is a ten-minute walk outside of the village. One health centre is located in the centre of the village. Although limited tools are accessible, the employees of the hospital perform surgery and deliveries. Houses in Munyenge look like slums. They are made of clay or waste. The access to Munyenge is difficult, but there is a fresh food market once a week.

Non-bottle-feeders from the city

The non-bottle-feeders from the city (n=12) were living in the biggest city of Cameroon: Douala. This city exists of almost two million residents. Most houses have private tap water, electricity and television access, but house rent is expensive. Internet is available at every corner of the street in Internet cafes. Douala is a vibrant city, where shops and market are opened from five AM to seven PM. Lots of other places like bars are open always. People living in Douala exercise all kinds of jobs, except for farming while there is no proper soil to cultivate. The business-, entertainment- and touristic industry creates many jobs. It is common that women work. Most of them sell foods on the street to make money.

Bottle-feeders

The bottle feeders (n=5) were coming from the same places as the non-bottle-feeders. Three of the bottle-feeders were living in Banga Bakundu, two were living in Douala. I chose not to distinguish the bottle-feeders by town, because this is not relevant for the research.

Questionnaire

This semi-structured qualitative questionnaire is designed to map ideas and thoughts of HIV-positive women concerning five topics. These topics are: "Knowledge of HIV", "Knowledge of HIV transmission", "Choosing between bottle-feeding and breastfeeding", "Disclosure of HIV status" and "HIV stigma". The questionnaire is based on these five topics as previous research shows that these determinants are of special influence

on feeding decisions among HIV positive women (Chisenga, Siame, Baisley, Kasinka & Filteau, 2011; Doherty, Chopra, Nkonki, Jackson & Greiner, 2005).

The topic of “Knowledge of HIV” measures general knowledge of women about HIV and AIDS. They have been asked what they knew about HIV and AIDS, the difference between the two and where they have learned all this. They were asked if they thought that HIV can be cured, and if so, by who. Examples of this topic are: “Can you tell me what you know about HIV?” and “Do you think HIV or AIDS can be cured? By whom?”

The “Knowledge of HIV transmission” topic was designed to measure the women’s knowledge about ways to transmit another person with HIV. They were also asked how to prevent others from HIV. This topic also includes questions about (prevention of) mother to child transmission, to measure if women think that breast milk is a way of transmitting HIV. Examples include: “Do you know how to prevent others from getting infected?” and “Is there a risk of transmission through breast milk?”

The “Choosing between bottle-feeding and breastfeeding” topic tried to map attitudes of HIV positive women towards artificial bottle milk and breast milk. This topic investigated advantages and disadvantages of both feeding options, perceived by the women. It tried to trace beliefs of women about feeding options. Examples of this topic are: “What is your association with breastfeeding? And artificial milk?” and “Did anyone give you advice about feeding your baby?” to find out if others were influencing the perception of feeding options of the women.

The topic of “Disclosure of HIV status” tried to map the strategies women were using to cope with an HIV-positive diagnose. Disclosure of the status is an important factor in coping strategies. This topic tried to summarize the difficulties and obstacles around dealing with an HIV-positive diagnose. Examples of this topic are: “How did you react when you heard you were HIV positive?” and “Do you know how you got the virus?”

“HIV Stigma” was included in this questionnaire to map anticipated stigma by the women. How they thought others would treat them if others knew the women were HIV positive. This topic tried to explain why HIV is seen as a disease that you should be ashamed of. This topic tried to sketch a ‘general perception of HIV among Cameroonians’. Ques-

tions include: “Do you know anyone who is HIV-positive? How did you react on the disclosure?” and ‘What is the general opinion of Cameroonians about HIV and AIDS?’

Procedure

The Give Milk Stop Aids health workers recruited all participants. They were reached by telephone and an appointment was made to participate in the research. The participants came to the office of the health worker or I visited them at their home. Most women were able to communicate in English. In the cases where women spoke another language (French or Pidgin, a dialect) there was a translator. This translator also explained misunderstandings due to cultural differences between Africa and Europe. By misunderstandings I mean differences in explaining things verbally, like expression or different choice of words. Every interview was recorded except for one. During this interview, the recording device failed. I chose to include this interview in the study.

Seven out of nine participants spoke Pidgin in the rural areas. The other two spoke English. In Douala, eleven out of twelve was Anglophone. The last one was speaking French. Another five of the same interviews (two in the city and three in the province) were held with mothers who decided to start artificial feeding right after birth. In the province, two were speaking Pidgin, one was speaking French. All three participants in Douala spoke English.

Interviews lasted between thirty and fifty minutes. Differences in lasting time mainly depended on their willingness to cooperate. Informed consent was verbally agreed upon before the start of every interview. The participants agreed that their answers were used for scientific purpose. They were made very clear that their answers would not have any effect on their social lives, since the answers were treated confidentially. They were offered to reject participation in the research, but nobody did. Permission was asked to record the interview digital. The digital audio recordings were transcribed verbatim. All participants received an appreciation of 2.000CFA (\pm €3).

Analysis

The data has been treated and analysed according to the definition of Bogdan and Biklen (1982): “working with data, organizing it, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned, and deciding what you will tell others”.

The data analysis was conducted manually without use of any computer program. Every transcript was marked manually with five different kinds of coloured markers to highlight quotes about the five topics: “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure of HIV status” and “HIV stigma”. After finishing the highlighting, all the quotes regarding one topic were brought together. The quotations were divided into three groups: non-bottle-feeders from the rural area, non-bottle-feeders from the city and bottle-feeders. After that, the general conclusion per topic per area was determined and compared between the three groups. The analysis and interpretations depend on one reader.

Statistical information was reported through analysis in SPSS18.

3.2 Study 2: Research among health workers at Give Milk Stop Aids

Participants

This research was done among two health workers, both working for the Give Milk Stop Aids program. The research consisted of the performance of a semi-structured interview among the Give Milk Stop Aids health worker in Banga Bakundu: Lorraine Tanga, and the Give Milk Stop Aids health worker in Douala: Hannah Ebob.

Lorraine was the responsible employee for the Give Milk Stop Aids program in the Apostolic Hospital Banga Bakundu. She was 28 years old at the time of the interview. She performed a full-time job for Give Milk Stop Aids that consisted of performing antenatal care in the hospital. She was the one who disclosed HIV-positive statuses to contaminated persons. She introduced feeding options to HIV-positive pregnant women and offered them to subscribe them into the program. Every last Saturday of the month she organised support group meetings for HIV-positive mothers that joined the Give Milk Stop Aids program. Every meeting had a different theme. The meetings I attended were covering “stigma around HIV” and “Raising a small food selling business on the streets”. She provided tins of artificial bottle milk to women that joined the program and was responsible for the stock of the milk. Lorraine received approximately 18 women per month to collect

Hannah was the health worker responsible for the Give Milk Stop Aids program in Douala. She was 29 years old. Her tasks resembled those of Lorraine. She was the Give Milk Stop Aids program coordinator in Douala, where she subscribed new members and supported members that already subscribed. She distributed the tins of milk and was responsible for the stock. Every first Saturday she organised a support group meeting for HIV-positive mothers that had joined the program. She introduces a saving system for the women to save money to afford an annual CD4-count. That is a test to count white blood cells, to check the viral load in the blood.

Aim

This second research was done for two aims. The first aim was to map and summarize the opinions of the health workers about five topics: “Statistics of HIV positive pregnant women attending antenatal care in the participating hospitals”, “Counselling”, “Realities of artificial feeding according to the health workers”, “Protection of mother to child transmission” and “Perceived stigma” The second aim was to investigate the influence of the health workers on HIV positive women on feeding choices. This was researched in the sixth topic: “Influence of health workers”.

“Statistics of HIV positive pregnant women attending antenatal care in the participating hospitals” was included in this questionnaire to give insight in the global size of the Give Milk Stop Aids programs in Banga Bakundu and Douala.

“Counselling” was included to summarize the counselling strategies that the health workers use to deal with disclosing an HIV-positive status. This especially concerned HIV-positive pregnant women that had to choose to either join the Give Milk Stop Aids program, or to refuse the program.

“Realities of artificial feeding according to the health workers” was included because literature showed that practicing bottle-feeding was not safe in some cases in Zambia and South-Africa. This means that in these studies the option of breastfeeding was more preferred. (Bond, Chase, & Aggleton, 2002; Doherty, Chopra, Nkonki, Jackson, & Persson, 2006) The Give Milk Stop Aids program promotes artificial bottle-feeding, but this is only preferred when the artificial milk is acceptable, feasible, affordable, sustainable and safe. This topic was included to prove that the artificial milk of Give Milk Stop Aids met these criteria.

“Protection of mother to child transmission” was included to map the opinion of the health workers about why HIV-positive women choose to join or refuse the Give Milk Stop Aids program.

“Perceived stigma” was included to give insight in the opinion of the health workers about what kind of stigma HIV-positive mothers experience when practicing bottle-feeding. The topic also summarized the general opinion of Cameroonians towards HIV, according to the health workers.

“Influence of health workers” was included because according to literature about feeding decisions among pregnant HIV-positive women, health workers can influence the women in their personal preferred feeding option (Chisenga, Siame, Baisley, Kasonka, & Filteau, 2011; Doherty, Chopra, Nkonki, Jackson, & Greiner, 2005). The health workers of Give Milk Stop Aids tried to diminish their influence on women as much as possible. This topic summarized how the health workers tried to diminish their influence.

Procedure

The interviews with Lorraine and Hannah lasted approximately one hour and were held at the Give Milk Stop Aids office in Banga Bakundu (Lorraine) and Douala (Hannah). The health workers spoke English and did not get an appreciation for the interview. The health workers were explained about the purpose of the interview and were asked for permission verbally. The interviews were recorded and transcribed verbatim.

Analysis

The data analysis was conducted manually without use of any computer program. The two transcripts were marked manually with six different kinds of coloured markers to highlight quotes about the six topics: “Statistics of HIV positive pregnant women attending antenatal care in the participating hospitals”, “Counselling”, “Realities of artificial feeding according to the health workers”, “Protection of mother to child transmission”, “Perceived stigma” and “Influence of health workers”. The quotations were brought together per topic. Every topic was analysed and described by one reader.

Chapter 4

Results Study 1

RESULTS STUDY 1

Research among HIV-positive women

In the next sections the findings of the interviews will be discussed. The interviews are organised by the following themes: "*Knowledge of HIV*", where I will summarize the general knowledge of the women living in the rural area and the city about HIV. Then, in "*Knowledge of HIV transmission*" I will summarize the women's statements about knowledge concerning transmission of the HIV virus. Opinions about breastfeeding and bottle-feeding, together with their advantages and disadvantages, will be summarized in the section of "*Choosing between bottle-feeding and breastfeeding*". "*Disclosure of HIV status*" will be about the difficulties concerning disclosing an HIV positive status. In "*HIV stigma*", the summary of quotes about stigma will be gathered. First I will start with a description of the participants in this research.

Description of participants

In the following table there will be an oversight of demographic features of the women who participated in this study.

Table 1 Baseline characteristics of interviewed women

		Non-bottle-feeders		Bottle-feeders
		Rural Area	City	
n		9	12	5
Age		24,5 ± 3,25	28,9 ± 3,7	29,8 ± 3,2
n children		2,3 ± 1,2	2,6 ± 0,8	1,9 ± 1,3
Marital status (%)	married	4 (44)	9 (75)	
	fiancé	4 (44)	2 (17)	2 (40)
	single	1 (11)	1 (8)	3 (60)
Education (%)	< primary	3 (33)	1 (8)	1 (20)
	completed			
	primary	3 (33)	6 (50)	4 (80)
	secondary	2 (22)	2 (17)	
Job (%)	unknown	1 (12)	3 (25)	1 (20)
	housewife	3 (33)	1 (8)	
	selling	1 (11)	4 (33)	2 (40)
	farmer	1 (11)		2 (40)
	different	1 (11)	2 (17)	
	unknown	3 (33)		1 (20)
Religion (%)	apostolic	4 (44)	4 (33)	4 (80)
	catholic	3 (33)	3 (25)	
	presbyterian		4 (33)	1 (20)
	other	2 (22)	1 (8)	
Tribe (%)	north west	5 (55)	9 (75)	2 (40)
	south west	4 (44)	3 (25)	3 (60)

Values are in means ± SD or %

Table 1 describes women in different categories of age, educational level, practicing different jobs and religions, and coming from different tribes with different traditions. This sample represents different groups of the Cameroonian population and is therefore relevant for this research. In the next sections I would like to discuss the results of the questionnaire concerning “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure of HIV status” and “HIV stigma”.

Several questions and their answers concerning topics about HIV will be discussed in the following sections. I will discuss the results per topic. Every topic contains three or four questions. Every question will be the heading of a paragraph. In these paragraphs the summary of typical quotes will be mentioned.

4.1 Knowledge of HIV

Question: Can you tell me what you know about HIV?

Rural participants

All the participants living in the rural area (9/9) stated that HIV and AIDS are very dangerous things. Rural Participant 01 answered: *"I know that it has no cure, but it has treatment."* 44% (4/9) of the participants in the rural area mention that HIV kills. Women in the rural area do not really know what to say about HIV. Rural Participant 02 explained: *"HIV is a sickness. Each time I don't know what to say about HIV. Each time I want to talk about it I feel like crying. When people have the sickness they die before their time."*

City participants

42% (5/12) of the city participants mentioned that HIV kills. They are able to explain why it kills, as City Participant 02 mentioned: *"Later on we heard HIV is already in Cameroon. People are dying of HIV in it. They say, when you get this HIV AIDS, there is no cure. Nothing, you can only die. Then out of the sudden they told us again that there is medicines, so expensive. But it doesn't cure, just control it."* City Participant 09 said: *"When there is HIV, the blood cells are still strong. And when it gets to AIDS, that's when you're already sick."* Participant 11 said: *"You can transfer to AIDS, that is when it can easily kill somebody."* The first reaction of City Participant 03 was shocked; she thought she was already finished. But the hospital staff made her to see that she should regard HIV like any other disease. She said: *"I have HIV. What am I going to do? Soon I will die. Yeah, they've been talking to us about HIV, that it is just like any other disease. That it's just like any other sickness. So the only thing we're supposed to do is that our treatment on time. And we should not put, that we have HIV, we should not put in our memory. Because that sickness is not going to kill us but that thinking."* 42% (5/12) of the women in the city reviewed HIV as a disease just like any other. City Participant 11 said: *"I know about HIV that HIV is a bad disease, but even my daughter made me to understand that HIV is bad"*

when you're not taking your drugs. But when you have it and you're following your drugs and you eat well, HIV will not do anything. You can stay long. And you can get children with it. And give birth. And teach you how to control the HIV when you have it. Then you can be with HIV and there's no problem."

Bottle-feeders

All bottle-feeders (5/5) mentioned that HIV is a disease. They did not go into detail except for Bottle-feeder 02: *"I had a theory. I was hearing that they were talking on the tv. And they were saying that it kills. But when I went to the hospital, they told me that as I have only the virus. I never had the illness. so I can still live if I control. So what I was hearing, I did not hear without feeling inside. It sounds a type, it makes you uneasy. When you some way even talk about it, it makes you feel uncomfortable. I didn't know anything. I only know that it kills."*

Conclusion

A comparison of the answers between the three groups shows that 42% to 44% in the rural- and city groups mention that HIV kills. This seems similar, but the rural participants were using significantly less sentences to talk about HIV/AIDS than participants in the city. It was as if women in rural areas were afraid to talk about HIV/AIDS. 89% (8/9) of the participants in the rural area answered in one to three sentences, while only 25% (3/12) of the participants in the city answer in four sentences or less, so three-fourth was talking extensively about HIV/AIDS. Although the general content of the answers between both groups is somehow the same, the participants in the city mention more details about HIV, like that it has symptoms like cough and rashes. 42% (5/12) of the city participants regard HIV as any other illness. Nobody in the rural area mentioned this. Women in the rural area were more focused on the feeling of fear and anxiety to death, which comes along with HIV. Women in the city were more focussing on facts than feelings. The bottle feeders did not mention a lot about HIV, except for the fact that it is a disease. All other participants in the rural and city group answered this too.

Question: Do you know the difference between HIV and AIDS?

Rural participants

67% (6/9) of the participants in the rural area answered that there is no difference between HIV and AIDS. Rural Participant 09: *"HIV is a very bad illness, a very bad disease but I don't know any detail about it. HIV and AIDS, it's all the same."* 22% (2/9) in the rural area answered that HIV leads to AIDS, but still they could not say why. Rural Area Participant 04: *"They say HIV is a virus which leads to AIDS. I don't know the difference."* A typical quote came from Rural Participant 05: *"HIV leads to AIDS. When somebody has a cough, it's HIV. When somebody has a bad cough, it's AIDS."*

City participants

In the city, 58% (7/12) did not mention anything about differences between HIV and AIDS. 25% (3/12) could name the differences between the virus and the sickness. City Participant 09: *"I know that when they say HIV, they mean the virus. That there's no illness, the blood cells are still strong. And when it gets to AIDS, that's when you're already sick. Tomorrow you'll have stomach ache, the next time another illness will come then."* City Participant 11 said: *"They told me two things. HIV and AIDS. That HIV can be not really cured but you can take your drugs very well and cope. But you can transfer to AIDS, that is when it can easily kill somebody."* 17% did not know the differences. City Participant 05 said: *"I always hear about that one but I don't know anything. I always hear about HIV AIDS. That it is a dangerous disease. There is no treatment. If you have it you cannot cure it. They always say that."*

Bottle-feeders

The group of the bottle-feeders did not say anything about the difference of HIV and AIDS.

Conclusion

A remarkable difference between the rural area and the city is that most participants in the villages do not know the difference between HIV and AIDS. They see it as the very same thing, which implies that they do not know much about HIV/AIDS. Only 17% of the city participant could not name any difference, which I recognize as a basic general knowledge about HIV/AIDS. Answers of women in the city were more diverse and ex-

tensive than the answers of women living in the rural areas. They were able to give more specific details about the differences between HIV and AIDS and they could summarize facts. Women from the rural areas thought that AIDS is a worsened form of HIV. In all the three groups there were persons who did not answer the question. All of the bottle feeders did not answer the question. I cannot tell why exactly the bottle-feeding group not answered this question.

Question: Where did you learn about HIV and AIDS?

Rural participants

78% (7/9) of the rural participants answered this question. Surprisingly, only 2 could specify where they got their information about HIV. In both cases it was from the hospital. As Rural Participant 08 said: *"The doctor there advised me I should breastfeed the baby for 3 months."* All the other rural participants were more vague about where they learned about HIV and AIDS. In some cases the expectation is that they meant the hospital, like the case of Rural Participant 04: *"They say HIV is a virus which leads to AIDS. I've been told that after three months there's no harm. So but, during the period of three months, there's no harm but after three months the child can be infected. So that's the reason I'll stop it. Yes, I'll continue with the artificial milk."* And Rural Participant 02: *"When they told me about the milk, I couldn't say otherwise."* Sometimes the expectation is that the participant aims for friends or media like radio or television, as Rural Participant 06 said: *"They say HIV it kills."* These women explained quotes by using 'they' instead of names.

City participants

Women living in the city also described their source of information by 'they'. In most cases the expectation was that the women were pointing at hospital staff. 92% (11/12) of the women mentioned that they were told by others about HIV or breastfeeding. In 73% of the cases it was clear that they meant the hospital staff by 'others'. Like City Participant 12 said: *"They told me to eat fruits, vitamins. Stop alcohol. Take my medicine on time. It should not be finished before I come to the hospital."* City Participant 05 might have heard her information at the hospital, as well as through media: *HIV is a dangerous disease. There is no treatment. If you have it you cannot cure it. They always say that."* And City Participant 06: *"They say it is a virus that runs through you."* These women did not specify where they learned it.

Bottle-feeders

The women who chose to bottle feed right after delivery were all (5/5) attending the apostolic hospital where the Give Milk Stop Aids program runs for a longer while. They were informed about their feeding options by the hospital staff and chose to give artificial bottle feeding before they delivered. The hospital staff told them about HIV and AIDS as well. There are no quotations that I can use for this question.

Conclusion

In the bottle-feeding group, everyone was told about HIV and AIDS by the hospital staff, because they were attending antenatal care with one of the Give Milk Stop Aids health workers. In both the rural and the city groups, almost everyone was told about HIV or AIDS by other health workers. In most cases an hospital provided information.

Question: Do you think AIDS can be cured?

Rural participants

55% (5/9) of the women living in the rural area answered this question. Among them, 80% said that it is possible to cure AIDS. Rural Participant 05 explained: *"Yes, God can cure AIDS, he will punish the weaker of faith and he will punish them by diseases like AIDS."* Rural Participant 07 said: *"I think God can take AIDS away."*

City participants

Of the 42% (5/12) of the women living in the city who answered the question, 40% thought it is able to cure AIDS. City Participant 04 said: *"I know God can cure AIDS. He can make you stay long with the HIV."* 60% said that curing AIDS is not possible. City Participant 05 said: *"HIV AIDS is a dangerous disease. There is no treatment. If you have it you cannot cure it."* City Participant 10 looked at it in a different way. She said that through strong believe in God a medicine could be developed. *"To have faith in God. Because maybe one day, we can have the medicines. That will cure it."*

Bottle-feeders

2 out of 5 participants (40%) regarded HIV/AIDS as a disease that can be cured. Bottle-feeder 01 said: *"The thing only, I only had this feelings to me that... as it is a sickness, you can get healed. I believe that God almighty made me to be that way. I know he has giv-*

en that to me, because... he does not give that thing to someone who cannot carry. He gives you loads according to your size. So along, God prepared me to go to somewhere. To take me to another level." These participants regarded having HIV as something that would eventually improve them as a person.

Conclusion

A slightly greater percentage at the rural areas than the city thought that HIV is possible to cure. More rural women are convinced that God can cure AIDS. This is understandable, because knowledge about HIV and AIDS is smaller in rural areas than in the city. Women who were bottle-feeding thought that HIV was a way of improving as a person. I see this as a way of coping with the disease, and for that reason it is not strange that the bottle-feeders saw HIV like a way to make you stronger. The expectation is that the bottle-feeders are better able to cope with HIV than women who want to breastfeed. In all the categories, 40% to 55% answered the question. Everyone who answered the question was sure that HIV can be healed in one way or another.

4.2: Knowledge of HIV transmission

Question: What do you know about the transmission of HIV?

Rural participants

89% (8/9) of the participants in the rural villages were able to summarize two or more ways to transmit HIV to another person. Only one participant could not think of any way of transmission. The best knows ways to transmit the virus were: through sexual intercourse and through breast milk. 67% mentioned these two ways. 33% mentioned cracked nipples, needles, blades and delivery as ways to spread the virus. Only one participant mentioned blood contact and transfusion as a way to spread the virus. Rural Participant 05 knew remarkable ways to contaminate another person with the virus: *"HIV can be transmitted through sexual intercourse, wearing each others clothes and urinate on the same toilet."* Rural Participant 09 talked of mosquito bites: *"Mosquito can transmit HIV from me to the baby. I am afraid that the baby can be infected."*

City participants

In the group of the women living in the city, 83% (10/12) were able to summarize ways to transmit the virus. Through sexual intercourse and through needles and blades were the most common ways. Some women mentioned delivery, blood transfusion and cracked nipples as ways to contaminate others. One woman mentioned that transmission occurs via urinating. City Participant 07: *"When you go and ease yourself somewhere, maybe that person had HIV and I might have carried it from there."* Participant 12 stated: *"I can contaminate another person by using one razorblade, by knife, when by using needles. By using teeth brush together."* City Participant 03 wanted to stress on her conviction that besides sexual intercourse, transmission through sharp objects is a relevant source of contamination. *"In order to avoid that you have to avoid to use any sharp objects with other persons. Most people they have put in their memory that most contact with HIV is through sexual intercourse. They forgot about the sharp objects that you can use. For example when there are women out there. They put on nails, nails, when you want to come and put make-up now, you come and go out there. They would use just sharp objects. Then through this or this object you can still contact it. But all their minds just focus on sexual intercourse. Because they should know that there are many ways to contact it, not just through sexual intercourse. There are many ways. Even little children, they should know if I use this needle, if I use this blade I could contact HIV."*

Bottle-feeders

3 out of 5 participants (60%) answered with some examples of HIV transmission. They mentioned blood, needles, breast milk and sexual intercourse. Bottle-feeder 03 could tell more about sexual intercourse: *"I knew my status when I met the father of my child. I asked if he did a test. Then I asked myself. If I not get married, I will not bare a child. I can still have a child, even if the fact that the child will be single is no problem. God will help me know that I did one thing that I was purposed for. That is what pushed me to keep this baby. And I'm very proud."* This woman knew her status but chose to become a mother. Having children is important in Cameroon because they will take care of the parents once they have grown old. This purposively hid her status from the father of the baby, in order to become a mother.

Conclusion

Although all groups mention sexual intercourse most frequently as a way to contact HIV, I have the feeling that the women don't see it as the most obvious way to contact the virus. At least not how the participants contacted the virus. They summarize ways of transmission that others have taught them. In all groups are sexual intercourse, blood transfusion and use of blades and needles mentioned equal. Women in the rural areas mention breast milk more often as a way to contact HIV than women in the city, especially among the bottle-feeders. Whenever breast milk was mentioned as a way of transmission, the participants were talking about cracked nipples. The non-bottle-feeders thought that transmission from mother to child occurs via blood that comes out cracked nipples. The non-bottle-feeders did not think that HIV was inside breast milk. In the rural and city groups there were one or two persons who believed in myths to transmit the virus. These myths were through toilets, wearing each other's clothes, mosquitos and tooth brushes.

Question: Do you know how to prevent others from getting infected?

Rural participants

4 out of 9 participants in the rural areas (44%) answered this question. They all mentioned that condoms are useful to prevent others from getting infected. Two persons added that use one's own blade or needle is also a way to prevent others from contacting HIV. Rural Participant 04 said: *"You can prevent yourself by not using blades, you want to use needles that are sterilized, use condom."*

City participants

6 out of 12 participants in the city (50%) answered this question. Five of them said that you should sterilize blades and needles to protect others from HIV. Three of them mentioned that the use of condoms is necessary to protect others. City Participant 10 said: *"You can take HIV through needle. Now it depends. It's through sexual intercourse. Let me say, two people cannot use the same blade. As for the sexual intercourse, you use condoms. So you cannot use the same blade with another person or the same needle. If you can use it and still have a wound then you can infect it."* Two women added the risk of breastfeeding with cracked nipples and told me that they should always apply Vaseline on their nipples to protect their child. City Participant 03 explained: *"I have to prepare*

my breasts before I put to birth. So they advised me to apply Vaseline. Each day on my nipple. To prepare the breast for the child. So I was doing that. Because if you don't do that your breast is going to have some cracks, you have wounds. And when you have wounds, that is when you can affect the baby. So I did that. All day. All this while I was pregnant."

One woman told me to avoid mixed feeding; the combination of breastfeeding with other food like water, cereal and rice or cassava. *"And this breastfeeding also, it is when you have given breast milk, and introducing another food at the same time to the child, now, it can affect the child. But that can only happen with breastfeeding. For the length of time, six months, without water, without any food. The child cannot have it."* The remaining 6 participants did not say anything about the ways to prevent others from getting HIV.

Bottle-feeders

Two participants (2/5, 40%) answered this question. They mentioned ways to prevent the baby from getting the virus through the mother. As bottle-feeder 03 explained: *"They tell us and then they give us the drugs that make to separate the way that it would not affect the baby, would not get to the baby. They gave us the drugs. So even the drugs that they were giving, they give a drug that if you are pregnant, they'll be giving you to stop the other ones."* She tried to explain that she received medication to protect her child from HIV during pregnancy and delivery.

Conclusion

In all groups, between 40%-50% answered the question through what ways you can prevent another person from getting HIV. This means that over half of the participants did not answer this question, which is remarkable because there are many anti-AIDS programs in Cameroon that specifically teach in ways to prevent HIV. These programs are broadcasted or taught in schools and hospital. This could mean that my participants were unlucky not to hear anything about HIV on the radio, or my participants purposively do not pay attention when HIV is mentioned, as a way of coping with HIV. Of those who answered the question, the participants in the rural area mentioned condoms most often, while participants in the city were keen on the disinfection and single use of blades and needles. As previous questions were answered, I think this is remarkable. The rural participants seemed to be more timid than the participants in the city. My expectation was that the rural participants would not want to mention condoms as a way of prevention, but results show that the city participants did not mention con-

doms as often as rural participants. None of the participants in the rural areas said anything about prevention of mother to child. In the city group, three participants talked about prevention of mother to child transmission through mixed feeding and preparing nipples against wounds. In the bottle-feeding group all participants who answered the question mentioned prevention of mother to child transmission as well, like the use of drugs. Bottle-feeders did not mention other ways of prevention, like condoms or needles. The bottle-feeders were very focused on mother to child transmission.

Question: Is there a risk of transmission through breast milk?

Rural participants

78% (7/9) of the participants in the rural area answered this question. Among them, 6 (67%) said that HIV is inside the breast milk. As Rural Participant 07 said: *"A mother can contaminate the child through blood and when you breastfeed the child."* Rural Participant 08 said: *"HIV can go through breastfeeding and when the mother is still pregnant."* 3 of them added the special importance of cracked nipples; through the wounds their child should be contaminated faster. 22% (2/9) did not mention anything about transmission through breast milk and one participant (11%) did not know whether the virus was inside breast milk.

City participants

67% of the women did not say anything about breast milk in relation to HIV. Only 33% (4/12) of the participants in the city answered this question. 3 of them said that contamination through breast milk occurs when there are cracked nipples. Only one participant (City Participant 02) explicitly pointed on the virus inside the milk. She said: *"As you are pregnant, HIV can easily go through the child. (...) Through birth placenta. And this breastfeeding also."*

Bottle-feeders

All bottle-feeders were aware of the risk of transmission through breast milk. For 80% (4/5) this was the reason to give artificial milk instead of breast milk.

Conclusion

All bottle-feeders knew about HIV inside the breast milk. Non-bottle-feeders in the rural areas knew more often about milk as a way of transmission, than non-bottle-feeders living in the city. Cracked nipples were mentioned a lot by the city group. This myth is very alive among the women I interviewed. Contamination through blood is better understandable to them than contamination through breast milk, which they regard as something valuable and nutritious to the baby. Non-bottle-feeders do not believe that the HIV is inside the milk.

4.3: Choosing between bottle-feeding and breastfeeding

Question: What is your association with breast milk and artificial milk?

Rural participants

67% of the rural area participants answered this question. 4 of them stresses on the value of breast milk, because the artificial alternative was not healthy. Rural Participant 06 said: *"I choose to breastfeed the baby for six months because if I don't give breast milk to the child, the child is weak and slack. The child doesn't grow well. I have this experience from my late sister's child. The thing is that my sister died and left the child. My sister died and left the child and we gave the child artificial feeding. And the child didn't grow well."* Rural Participant 08 experienced this with her own child: *"With the second child that I gave artificial milk, the baby would no longer physically grow well. The child looked pale, would be weak. Artificial milk is not healthy."* Participant 09 agreed that breast milk is preferable over bottle feeding. She delivered many children but only one survived. This child was having bottle feeding, but she did not like it. Now she wants to compare if her new born set of twins will grow more healthy than the previous child that survived. *"Breast milk is more preferable. That if you don't care about the feeding bottles the child will have too much of diarrhea. Then when I delivered the other one, I gave artificial milk, the one survived. Now I have delivered another set of twins and have decided to give them breast milk to see whether it was because of the breast milk that causing the death of those children or not. Previously I was having children and they would just die. This is even the third time that I'm delivering twins. But previously they were dying, they were dying, they were dying. (...) If you give the artificial feeding, the milk, they will just conclude you're an HIV patient. Here, that's what they believe in this environment, yeah."* Rural Participant 04

was told that breastfeeding is necessary and harmless in the first three months of the child's life: *"I've been told that after three months there is no harm. So but, eh, during the period of three months there's no harm but after three months the child can be infected. So that's the reason I'll stop it. Yes, I'll continue with the artificial milk."* Nobody said that artificial milk is strong or healthy.

City Participants

83% (10/12) of the participants in the city answered this question. 50% (6/12) said that breast milk is good. City Participant 02 claimed: *"I told you that breast milk is more than artificial. Because it carries antibodies. Yes, breast milk is more healthier than this. Breast milk is nutritious, more than artificial feeding. (...) Three months is not enough. I know it is six months. But at least the child should take breast milk. even for one day. It is good."* Another reason to choose breast milk above artificial milk is that 33% (4/12) said that artificial milk is expensive and they do not have the means to afford it. City Participant 01: *"I breastfed for three months. Because I was afraid that the child would be affected. Because I didn't have the source to go and start to give her milk because there was no money in the beginning. They advised that we breastfeed for six months. So to me I was saying I would breastfeed for four months. I stopped and I was struggling to do something so I can buy the child milk. They say breast milk is good for the children. But I was still afraid."* Another 33% choose to breastfeed because they regard preparing artificial milk as difficult. It is not easy to clean the bottles and some children have diarrhea. City participant 05 said: *"Artificial milk is not like breast milk. it is difficult to make. Even if the artificial milk was free I would still choose breast milk."* One woman associated bottle feeding with both rich people and people with HIV. This woman (City Participant 09) said: *"At first I knew those who give artificial milk are those who are rich. They have their money, they can buy. And feed the baby with that one. But now we have seen it all over, even with feeding the baby with milk. people may feel that you are HIV positive. They may feel that it is proud, that you do not want to breastfeed your young child with the breast milk."* Two participants (17%) did not say anything about their opinion about bottle milk or breast milk. One of them is City Participant 08. She said: *"They said in the hospital that I should not do mixed feeding. If I decided on giving artificial feeding, concentrate on that. If I decided on giving breastfeeding, concentrate on that. No mix it because the child might get sick."*

Bottle-feeders

4 out of 5 participants (80%) chose to bottle-feed because they thought breast milk was dangerous to the child and they did not want to take the risk to infect the baby with HIV. Bottle-feeder 01 said: *"I not want the child to be infected."* Bottle-feeder 04 said to me: *"I knew my baby would get sick from the milk he got from me."* One participant, Bottle-feeder 03 preferred to breastfeed but her breast was not flowing *"After delivery, when they come back to check my breast, it was not running. And up to today, there's no milk coming out. You see, when you breastfeed your baby you feel this contact more than else. When you don't breastfeed it's as if I can go and leave the baby without having a problem. The think with breastfeeding, it always makes you to come back to the baby. That's the thing. I don't feel the baby as the mother of the baby has to feed the baby. Breast milk is the best. Breast milk is good for the baby."*

Conclusion

In the rural non-bottle-feeding groups, almost everyone who answered thought that breast milk was better than artificial milk. The non-bottle-feeders thought that breast milk is valuable and contains nutritious components. The bottle-feeders did not agree with the non-bottle-feeders. The bottle-feeders thought that it was dangerous to feed their child with breast milk, because the child could get infected with HIV. Only one participant said that she would rather breast feed if she had the choice. This is an important factor in determining why women choose a certain feeding option. Value of breast milk and artificial milk is important for feeding decisions. The rural non-bottle-feeding group did not tell a lot at all about their associations with bottle-feeding and breastfeeding, just that 'they preferred breast milk'. This is in contradiction with the city non-bottle-feeding group. Among them, participants said that artificial milk was expensive; some women could not afford it. Others complained about the difficulties in preparing the artificial milk. They could think of many reasons why not to give artificial bottle milk. Almost every bottle-feeder thought that giving breast milk was dangerous. One participant said that she would rather breast feed if she had the choice.

Question: Did anyone give you advice about feeding your baby?

All participants in the rural-, the city- and the bottle-feeders groups did not answer this question except for one participant (Rural Participant 01). Her mother in law forced her to breastfeed her child. *“My mother in law is very attached to breast milk. She regards it as something valuable. She insists so much on breast milk. (...) Tradition tells me to stay for three months at my mother in law before I return to my own house. I don’t know how to use artificial feeding there.”*

Question: Would you consider starting bottle-feeding from the birth of the child, and not give breastfeeding?

Rural participants

8 out of 9 participants (89%) in the rural area answered this question. Every participant said that she did not want to start the bottle-feeding right after birth. They wanted to breastfeed for at least three months, sometimes up to six months. 5 of the participants (62%) were worried about what people would think when they would notice the artificial milk, whether they were (in-law) family or people in general. Rural Participant 06 expressed herself very clear: *“I don’t want to give bottle to the baby now because I’m afraid what people say about me. And that’s what I’ve been saying from the first day. That’s the main problem, what the people will talk about me. They’ll say that I’m an HIV patient. It’s very bad to be an HIV patient.”* Rural Participants 01 and 07 worried especially about the opinion of their parents and in-laws. Rural Participant 01: *“I have to stay with my in-laws for three months. I just want to breastfeed while being with them. My husband lives not in Cameroon. He lives for a least two or three years outside. By then, the baby must have grown up.”* Participant 07: *“I am afraid only about my parents. That they will ask my why I’m not breastfeeding. I fear tell them. I’ll feel bad. (...) That they’ll ask. We want to give artificial feeding but now is that the parents are the intruders, that we are like this. If we had the means to afford it we could inform my parents, convince my parents. We could go on with the artificial milk.”* 3 participants were afraid that they would not be able to explain the bottle feeding to others, like participant 04 said: *“If I say I want to start the artificial milk now, my husband has some questions to ask, and really I will not be able to really know what to tell him. After three months I can start the artificial milk. Because I know from then I know what to tell my husband. Yes. For him to understand.”* Participant

08 did not have a reason to choose either breast milk or bottle milk. I asked her several times but she told me she just preferred breast milk.

City participants

75% of the city participants answered this question. Among them, every single woman would not start artificial feeding from the birth of the baby, because they anticipated on questions from the environment or they experienced difficulties with previous children. 67% of the women who answered (6/9) told me that their family would trouble them with difficult questions when they would start the bottle feeding. City Participant 08: *"I decided to breastfeed not to call my in-law's attention. Some people say that if you don't breastfeed you don't like your child. They will say that. Especially the in-laws from my husbands' side."* City Participant 12: *"People would ask me why I stopped to breastfeed my previous child. People were asking that. Then I said my breast is paining. I don't feel fine when I'm discussing with a person. Yes, I heard somebody talk about me, someone. And I'm not fine. Since I not breastfeed the other baby, all that they are asking me is you're not breastfeeding the child, why you're not breastfeeding the child?"* City Participant 02 explains why not breastfeeding is strange: *"In the rural area you can find out when somebody is giving artificial milk. you know because in the rural area a woman will always breastfeed her baby. Yes, some will breastfeed one year six months, some will breastfeed two years. When you begin to give this to the child, they begin to ask many questions. But in town, people in the town they go to work, they do many activities. They don't have time to hear about such things. But in the rural area it's difficult."* One of my participants would prefer to start the artificial milk right after delivery, but her husband refused. City Participant 04: *"My husband would refuse to start the artificial milk from the start. He said that I should breastfeed for at least six months. (...) Me, I would like the idea to give it from the beginning but it was my husband. Yes. You know, I cannot refuse and take the power alone. So I headed home."* One woman would not consider to switch to bottle feeding because she believed that God would protect her breast milk. She said that as God watched nothing would happen to the child while breastfeeding.

Bottle-feeders

I did not ask the bottle-feeders this question, because it is not relevant.

Conclusion

None of the non-bottle-feeders in both groups would prefer to give bottle-feeding right after delivery. The most common reason for this decision was that they anticipated or experienced troubles with people in their environment, who asked questions about why they did not breastfeed. Two participants from the rural area explicitly mentioned that they would not know how to explain others why they were giving bottle-feeding.

4.4: Disclosure of HIV status

Question: How did you react when you heard you were HIV positive?

Rural participant

In the rural areas, 8 out of 9 participants answered. One participant, Rural Participant 06 was very shy and was crying when she was thinking about this question. She did not answer. 5 women (55%) were really shocked and not feeling fine when they received the news. Rural Participant 07: *"When I heard about my status I felt bad. I know that by this time I must have died. That is why I felt bad when I heard of it. It is my only main focus that I would die. That's why I was afraid."* 22% believed that it was a mistake that they got an HIV positive result. They denied the HIV status. Rural Participant 03: *"I believe that I don't have AIDS. It's because I don't have any of those symptoms. Then I'm not like scattered girls that... I'm just a spot, I am no scatter. I just... I don't have it."* One participant (04) was doubting. *"From the initial stage I was like doubting. I did not accept because I was really doubting the likeliness where the period came from. So I did not accept at initial stage. But I could not keep on denying the status. So I accepted. (...) I did not accept at initial stage because I don't know how I got it."* The women mostly felt bad because, like participant 03 stated, people associate HIV with people who live a promiscuous life. So when the women received the positive status, they either reacted shocked or rejected the status.

City Participants

Women in the city all answered this question. 50% of them (6/12) were expecting an HIV positive status or took it normal like any other disease. City Participant 03 said: *"I got married to a man. He was sick off and on, off and on. Just like that. In Bamenda they told us he was poisoned. (...) It's from the hospital that they discover HIV AIDS. It's from*

there they said I should make my own test. (...) From there I knew I am HIV positive. I said I cannot be HIV positive and I just ignore everything. (...) It disturbed me for a while but afterwards I got up. Then I was like let me take my treatment. Just give me my treatment, I'll be fine. Thanks be to God." City Participant 04 experienced a somewhat similar situation: *"My husband was the one starting treatment before me."* 5 of the city participants (42%) were shocked by the news. They felt like killing themselves after receiving the positive status. City Participant 11: *"When they tell me, it was paining me so much. It worried me. I felt like killing myself and something like that. I feel so much pain. But when I met the pastor and the wife, and the sister that was working here. Because it was here that they discovered it. So they give me advise and talk to me. Tell me that and how somebody can live with it. And then I removed it as a Christian also. I have to remove it and put everything down to God."* One participant was doubting and said: *"They told me I have HIV. I could not believe, because I was such a person who, I am not scattered. I have no cum. So I gathered my courage and go back to the house. (...) I was very worried at first but now I'm fine."* 50% of the participants were talking about God. That through God they would not have been able to manage. Like City Participant 10 explained: *"I believe. If not of God, I cannot be here. To talk about my health, because now my health is really... but at first, I was not really fine. But now I'm healthy. I was not sick but it bothers me a lot. I was crying and all those sorts of things, but now that God is, I just put it out of my heart and no more thinking of anything or things. I just believe that God has overtaken. I feel like dying really, I cried. But after my husband also said I should take it easy, and there is nothing that we can do so just take it easy and... I went to see the pastor because I was feeling (not understandable). So when I discovered I was HIV positive, he said that I should not let anything in my mind that, that one is affecting more than the disease. When I see them we talk. I used to encourage them, to take it normal. To have faith in God."*

Bottle-feeders

For all the bottle-feeders (5/5) the HIV positive diagnosis came as a shock as well. Bottle-feeder 01 said: *"I was sick, I went to the hospital. We did all the tests, they said I have the HIV virus. The doctor encouraged me that I should not be afraid. (...) I am afraid I will die. And that this child should live she will not have anybody to take care for her and will suffer for her life."* Three of the women were expecting to receive the status so they were a little prepared. Like Participant 05: *"I went to do a test myself. Because I was feeling this, I was having fever on and off. On and off. I asked myself, what is happening? I went to the hospital, see the doctor. Tell the doctor I wanted to do an HIV test. He asked mee why, I said*

I just want to do the test. It's good that you should know. Not staying unto the end without knowing you are sick. They sent me to the lab and after they told me I have the sick. (...) Sometimes I feel really bad. But I asked myself this: Am I the only one? I'm not the first and I will not be the last."

Conclusion

Receiving the HIV positive diagnosis was a shocking event for all women in all groups, whether they wanted to breastfeed or bottle-feed. Non-bottle-feeding women in the rural area seemed to receive the HIV positive status more as a shock (55%) than non-bottle-feeding women in the city (42%), because they associate it with death. They thought they were doomed after they got their seropositive status. 50% of the non-bottle-feeding women in the city took the HIV positive status just like any other disease, while none of the women in the rural area reacted this way. 5 of the women in the city talked about God to cope with their positive status. The non-bottle-feeding women from the city said that God would have a purpose with them by giving them this sickness. None of the rural women talked about God. 3 out of 5 women who chose to bottle-feed expected to have the virus and were a little 'prepared'. They told me they had some difficulties but accepted their status eventually. This conclusion shows different coping strategies. The rural non-bottle-feeders mainly received their status in silence but imagined themselves dead already. Non bottle-feeders from the city could distance themselves more obviously from the HIV status. The city women told themselves there was a purpose for them, that they had HIV, or that HIV was just like other diseases like high blood pressure or diabetes. Bottle-feeders coped calm and to the point with HIV, more than half of them were expecting the diagnose already.

Question: Did you tell anyone about your status? Who? How did they react?

Rural participants

In the rural area, 8 out of 9 women (89%) chose not to disclose *their* status to anyone. Only one participant told her husband. Rural Participant 02: *"I told my husband that the doctor has said he should come and do the test but he keeps on refusing."* Three participants explicitly mentioned that they did not want their husband to know their status. Rural Participant 01: *"I don't want my husband to know. I don't have any problem with what people say, but I just want to save my marriage. I don't want to be free. I want to remain under my husband. He will abandon me because of the virus."* Rural Participant 08:

"I don't know how I can explain it to my husband. His reaction would be bas. I don't have anybody who is trusted, that I trust. That I can actually disclose my status to that person. That's why I decided to keep it to myself. People will run away, people will abandon me when I disclose my status."

City participants

11 out of 12 women in the city disclosed their status to another person, mostly to their husband (75%, 9/12). City Participant 01 told me: *"I told my husband about my status before but he was not accepting that it is true. I just didn't know that I come to do, they send me for, go and make a test. So the result was not good. So when I was speaking to him, he was crying so and he felt for me and asked me to go and do it again. He was unhappy, unhappy. Angry. (...) After the counseling he took it normal."* City Participant 07 said: *"Nobody knows about my status except for my husband. Because it's not good to tell. It's good to keep it as a secret."* 2 participants told their pastors in church so they could pray for them. One person told her mother, another told her junior sister. City Participant 03: *"My husband took it normal. I told my junior sister. It's only my junior sister and my husband. In case of any incident. Let her be aware.(...) She said I should not go outside (cheat) with such a condition. You should not kill yourself. That is what encouraged me."* One participant told nobody about her status. Three others were purposively hiding their status to their parents (participant 03), their brothers and sisters (participant 04) and their grandparents (participant 05). City Participant 03: *"My father is off late. My mother is there. I just keep it as a secret to her. She'll have a distortion. I mean, she'll worry. Worry."*

Bottle-feeders

80% (4/5) of the bottle-feeders chose to disclose their status to someone. Some told it to their husband, others to their sister. Bottle-feeder 05 was left by her husband after disclosing her status to him. *"My husband was giving me much troubles. He went away and I didn't know when he would come back."* The other remaining women who disclosed their status got support from their family after disclosure. Bottle-feeder 03 got support from her sister. *"She took it normal, really normal. And said I should not worry."*

Conclusion

It is remarkable that non-bottle-feeders in rural areas in almost every case (89%) liked to keep the HIV positive status to themselves (non-disclosure), while 75% of the

non-bottle-feeders in the city disclosed their status to at least one person. Approximately the same percentage of the bottle-feeders disclosed their status. This complies with the previous findings that non-bottle-feeders from rural areas find more troubles with coping with HIV than non-bottle-feeders in the city and bottle-feeders. Women in the rural area were afraid to be abandoned by husband or friends and family. Women in the city who chose to keep the status to their selves, did this to avoid to trouble the mind of their relatives.

Question: Do you know how you got the virus?

Rural participants

Only two women (22%) in the rural area mentioned anything about how they thought where their virus came from. Rural Participant 02 did not know how she got it. Rural Participant 01 suspected a spiritual attack. She said: *"My mother took me to a traditional doctor and they did some scarification on me. They did it because of this pregnancy. They used sharp objects on me."*

City participants

75% (9 out of 12) of the women living in the city did not know how they got the virus. One woman was very surprised by the news because she associated an HIV positive status with people who live a promiscuous life. City Participant 01: *"I don't know how to manage. Because I was not working anyhow as some girls, some girls behave. I don't know."* The remaining 3 women I interviewed knew their HIV positive status through their husband who was already positive.

Bottle-feeders

Two women answered this question (40%). They both suspected their husband, that he was the carrier of the virus. Bottle-feeder 04: *"I had problems with the family of my husband's family. I don't talk to them, because I am very annoyed with them. They knew my husband was positive and they hid it for me."*

Conclusion

In all groups (bottle-feeders and non-bottle-feeders from city and rural areas) it was unclear for most participants how they got the virus, so they didn't answer the ques-

tion. The difference between these groups is that one participant in the rural area was talking about a spiritual attack from an indigenous belief. The women in the city and the bottle-feeders who knew where their sickness came from, blamed their husband.

4.5: HIV Stigma

Question: Do you know anyone who is HIV-positive? Is it a friend of yours, or family? How did you react on the disclosure?

Rural participants

The women in the rural area did not answer this question. They know women of the support group meetings organized by Give Milk Stop Aids. It is possible that these women did not want to talk about other HIV patients because of the strict social control in the rural areas.

City participants

There was one participant in the city who told me she knew another HIV positive person. This was her neighbour. *"I also have a colleague, we met at the hospital. Who is also selling besides me. She knows that I'm HIV positive, and I know she's HIV positive. If she says that I'm positive I tell them that she's also positive. That is not my problem."* All the other 11 participants did not know anyone who was HIV positive, except for their partners.

Bottle-feeders

60% (3/5) of the bottle-feeders knew other persons who were HIV positive. Two talked about the women they met during the support group meeting organized by Give Milk Stop Aids. The other person said she saw her neighbour using the same antiretroviral medicine as she used. That is how she found out about her neighbour, but they did not discuss it with each other.

Conclusion

In both rural- and city non-bottle-feeding groups, the women barely knew HIV positive persons. This implies that it is not common to discuss about an HIV positive status to others. The bottle-feeders knew many HIV positive persons. The bottle-feeders

mentioned friends from the support group meeting, organized by Give Milk Stop Aids. In these meetings, they knew about each other that they were HIV positive. One bottle-feeder knew that her neighbour was an HIV patient also, but the neighbour did not know the status of the bottle-feeders. All participants liked to keep their status to themselves and generally did not know statuses of others. It appears to be a shameful thing to disclose an HIV positive status to one another. The support group meeting encourage women to be open, to give them a feeling that they are not the only one, having this sickness. This complies with the earlier finding that bottle-feeders cope better with HIV than non-bottle-feeders.

Question: Are you afraid that people treat you different when you disclose your status?

Rural participants

4 out of 9 participants (44%) answered these questions with among them 3 (33%) who were afraid that after their disclosure the husband and family would treat them differently. Rural Participant 01 said: *"The family of my husband can not know because the marriage will get scattered. I'm going to lose my marriage. My own mother is like a difficult person because she might get angry about my status. If I'm explaining that even while I'm faithful, my mother will get angry."* Rural Participant 02 as afraid that people on the streets would treat her differently: *"I am afraid that it's going to spread out. I want to keep it to myself. When it's going to spread out, each time I want to go around the people, the people know I have HIV. They will talk behind and say I have HIV. When the people know they won't come to me. They won't feed me, they won't even eat with me."* The other 5 participants (55%) did not say anything about their expectancy that others would treat them differently.

City participants

7 of the 12 city participants (58%) answered the question. 3 of them (25%) pointed on the fear that their family would treat them different. City Participant 08 anticipated on what might happen: *"The way my family members do with me in a conversation, what they say about someone who is positive, is as if I tell them they will drift me away. The way due to their conversation. I'm not able to tell them that I am positive. Because of the family meeting. They usually say people who are having it are those who are going out with men."*

So whenever they are seeing them and they know I'm having it. They'll say I'm the one who brought the sickness into the family, so I don't want them to know." City Participant 11 already experienced that her husband got fired because of the HIV: *"My husband also, they removed him from the jobside. He did his own test, but after that, he did the test for where he was working, in the hospital. When he go and make the test, that is where the problem of the work now, comes from. So we just think that they might have seen it."* Two of the participants (17%) were afraid of the reactions of people in general. City Participant 01: *"When they see you are HIV sick and you even touch something, they don't like the food you eat, don't like to share it with a cup."* Participant 03 (8%) was more optimistic and believes that the attitude of people towards HIV improves. *"Before they were thinking that as HIV patient, they will look at you as the worst person. And then, it's now that they put a small understanding to us. The people out there, to understand that HIV is not a very dangerous sickness as you people think. Because the stigma here is worse. And we cannot contact it without this kind of thing and this kind of thing, it's not a born disease where you can spread it with eating. HIV patients cannot contaminate it like that. (...) They even said on the radio, they should not deprive all the HIV patients from their social life or their job sides. They should not deprive them from anything."* Participant 04 (8%) was not afraid of any negative reaction from other people. She was confident and reassured that others could not identify her as an HIV patient, and for that reason others would not treat her differently.

Bottle-feeders

I did not ask this question to the bottle-feeders, so I will leave them out of the analysis.

Conclusion

Both non-bottle-feeders from the rural area and non-bottle-feeders from the city mentioned that they were afraid that people in general would treat them different; that they would not want to share food anymore or would not have physical contact anymore. The non-bottle-feeders also anticipated on being treated differently by people they knew. But there was a difference between the rural- and city non-bottle-feeding group at who they feared that would treat them otherwise. A remarkable difference between the women in the rural areas and the city who feared to be treated differently by others was that the women in the rural area mostly feared their direct family, and mostly their husband. They thought they might be abandoned or sent away by the family. The wom-

en in city mostly disclosed their status to heir husband but did not want to tell their status to family member, because they would get upset. There were two women in the city (17%) that stated that the stigma was lowering down compared to a decade ago. Women in the rural area did not say anything about this. The anticipated stigma of being treated differently after disclosing an HIV status had more consequences for the rural non-bottle-feeders than for the city non-bottle-feeders. This might explain why rural non-bottle-feeders did not disclose their HIV positive status to anyone, while most city non-bottle-feeders disclosed their status to at least one person.

Question: What is the general opinion of Cameroonians about HIV and AIDS?

Rural participants

I asked this question to find out more about anticipated stigma of the participants. 67% (6/9) of the rural participants mentioned something about the general opinion of Cameroonians about HIV and AIDS. Rural Participant 07 said: *"Why I kept my status to myself? Because it's a secret. A secret. Weah, it's a bad secret. If they know, the people will talk about us. They gossip of the past of the sickness, that I'm an HIV patient. I will feel bad. In this area people put you in a negative way."* And why is it that people put HIV patients in a negative way? Rural Participant 05 stated: *"God will punish the weaker of faith and he will punish them by diseases like AIDS."* Rural Participant 06 said: *"it's a shameful thing. It is an illness that is very bad. When people hear it, they don't like it."*

City participants

Women in the city told several things about what they thought the general opinion of Cameroonians was about HIV. 83% (10/12) of the participants answered and half of these women said that others hate this sickness, that others regard it as if it is a death sentence. City Participant 03 said: *"As we Cameroonians are, it's more that we go behind. If you see a woman like that you say, that's how she is, that's how she is. Meanwhile she has AIDS and she does not want you to know. They think very, very bad about HIV. Wow! Yeah if you're in Cameroon and HIV positive, you're the one that... I remember when I was in the village. In the village when you are sick, they just know you are HIV. You know, oh that one is already finished (dead)."* City Participant 10 said: *"They think that when you have the sick, you just die like that. And even when they know you have it they will run away from you. They think that when you have it and we just touch our body they have it. But that's*

not how you get it. When they know you have HIV they're afraid because... I don't know." Participant 02 said that HIV is a virus that is associated with cheating; going outside. Participant 08 was afraid to disclose her status because she was afraid that her son would be indoctrinated with 'strange ideas' by others once they knew his mother was HIV positive. Participant 11 was talking about the general opinion about HIV when she became sentimental and poured out her feelings: *"So I want to say if anybody has it that they should open their heart. (...) I really want that Cameroon people know that it is not a disease that people go and die. They can still be with HIV. There are many people who have HIV. When they're sick, they begin to go to the hospital. In the hospital they tell them they have HIV. And then they leave and tell the others they are poisoned. While HIV is the one that kills. That's why when I see a person, I have to tell. So he can understand. HIV. They're afraid. Only the name only, it's too big! So when you hear that name, you have to have that fear. Because somebody when they're eating that virus in that body, the virus will be growing but small small. Small small. What people will say is that they put slow poison in you. That it is eating you. They say that HIV is eating your white cells of the blood. It is eating and as it's eating you're growing small small. Black men will say that it is this slow poison that you have it. It's poison they say, in your food, in your drinks. But it's HIV!"*

Bottle-feeders

Although most bottle-feeders did not specifically answer this question, they did tell me that whenever people ask why they are giving bottle milk instead of breast milk, they never tell that they are HIV positive. They make up excuses like bottle-feeder 03: *"Sometimes I give them the answer and tell them that the breast milk is not running. When you want to start talking it would be a very long discussion."* Bottle-feeder 05 explained the view of Cameroonians about HIV according to her view: *"People see cancer different than HIV. Because cancer, HIV is an illness that people are ashamed of. Because it is a thing that you can only take it when you have sexual intercourse. Yes. They are ashamed. Yes. They see HIV so bad over cancer, which is very dangerous. More than HIV. HIV even is better than that cancer. Or I'm talking like this because I'm inside, I don't know."*

Conclusion

During the analysis of this question, I noticed that women in the city were freer of speech than those living in the rural areas. 67% in the rural area answered the question, mostly in short sentences. The bottle-feeders were short of speech as well. I think it is difficult

for these women to name the stigmatization around HIV, because they have to admit that they are outcast. Women in the city told me about anticipated stigmatization of HIV than the ones living in the rural areas. 83% in the city answered and these women were talking very much about what others think. I was very moved by the answer of City Participant 11, where she explained that she tried to make the HIV topic more discussable. My overall impression was that women in the city were more open to discuss about HIV than women in the rural areas.

Chapter 5

Results study 2

RESULTS STUDY 2

Research among health workers at Give Milk Stop

Since study 2 is an additional research to this paper, I will present the results succinctly, according to the following six topics: “Statistics of HIV-positive pregnant women attending antenatal care in the participating hospitals”, “Counselling”, “Realities of artificial feeding according to the health workers”, “Protection of mother to child transmission”, “Disclosure of status and perceived stigma” and “Influence of health workers”. I will compare the answers of the health worker in the rural areas and the health worker in the city. The answers of the two health workers are based on statistical recorded information and their personal experiences.

5.1: Statistics of HIV-positive pregnant women attending antenatal care in the participating hospitals

Rural area

In the rural area, approximately 75% of the HIV-positive pregnant women choose to breastfeed, 25% to give artificial bottle milk. Women are between 16 and 32 years of age. The majority is single and live alone. 80% knew their seropositive status before they got pregnant. 5% of the women participating in the program drop out, because they move to other places or do not see the need to come again because their children are able to eat solid foods. 98% of the children complete the program and are HIV-negative. There are 26 women participating in the program at the moment of writing.

City

Approximately 70% of the women living in the city choose to breastfeed, against 30% who choose to give artificial bottle milk. Their ages range from 20 to 32 years. The majority of the women is married or has a fiancé. Approximately 25% is single. Living in the city is expensive, so many women live with relatives. 50% knew their status before they got pregnant, against 50% who did not know. There are no drop outs in the program, 100% completes it. 99,5% of the babies are HIV-negative after completion of the program. One baby out of 150 children was found HIV-positive after completion. There are 56 women participating in the program at the moment of writing.

5.2: Counselling

The following results count for both the hospitals in the rural area, as the hospital in the city

Pregnant women have to compulsory antenatal tests, and they include an HIV test. Women get pre-counselled before they undergo the tests. During this counselling, they learn about HIV and other diseases. After the results are in, they get post-counselled. They are being prepared for positive outcomes and the health workers give present ways of coping with diseases beforehand. After that, the results of the tests are presented. If a pregnant woman is HIV-positive, she gets treatment immediately. The health workers present the feeding options and try to let women decide through a dialogue, where they discuss advantages and disadvantages of all the feeding options. The WHO recommends artificial milk when it is AFASS, or exclusive breastfeeding. Give Milk Stop Aids chooses to promote artificial milk because: *“Children who are exclusively given formula feeding right after birth until one year 6 months they can come out negative. Just to reduce the risk of mother to child transmission. Most women who practice exclusive breastfeeding they break for the time of recommendation in the hospital. Because of problems in the breast or they need to go to work. To give exclusive breastfeeding without good precounsel or postcounsel in the hospital, most babies will come out HIV positive. But because along the line, there were one or two who complained about the breast and they had to switch to formula feeding. To protect HIV is to breastfeed exclusively for 6 months without switching to formula feeding. With all the complications along the line we have, the child will surely come out HIV positive.”* The health workers use different techniques to help women cope with their HIV-positive status. Some accept difficult, others are easy. In general, women who accept their status easily, are more open to the artificial feeding option instead of breastfeeding, than those who have difficulties with accepting.

5.3: Realities of artificial feeding according to the health workers

Rural area

There is always enough stock of tins of artificial milk. Women who give artificial milk mostly experience difficulties with preparing the milk with the lack of clean water. They cannot afford clean water. It happened in a few cases that women ran out of their own stock and were not able to come to the hospital to collect new tins. In that case they decided to borrow tins of milk at the shop, which they later returned. They do not have

problems with hygiene. There are a few cases, two or three until now, where women had problems with cleaning the feeding bottle. These babies had diarrhoea. Other babies are admitted in the hospital for other diseases, like malaria. Give Milk Stop Aids pays 50% of the hospital bill.

City

The health worker in the city has never run out of stock with the milk tins. The women in the city also complain about clean water, and find it difficult to prepare the milk well with no access to clean water. The health worker had never heard of women running out of stock with the tins of milk. There are no babies who are unhealthy because of bad preparation of the milk, there are no babies with diarrhoea.

5.4: Protection of mother to child transmission

Rural area

The most common reason why women choose to give artificial bottle-feeding in rural areas is that they want to protect their child from HIV. Besides that, the milk is free. Women who choose to practice exclusive breastfeeding do this because of recommendations of other hospitals (different schools of thought about protection of mother to child). Others do not want their family and husband to know, and they want to practice breastfeeding because that is normal in rural areas. It's stigmatization.

City

90% of the women who choose to give artificial bottle-feeding say that they do not want their child to become positive. Women who choose to breastfeed say that they do not want their friends to know that they are positive. For some people artificial milk is associated with HIV.

5.5: Perceived stigma

Rural area

The general perception of HIV in rural areas is that it is a dangerous disease that kills and is easy to transmit. When you have HIV you are doomed for life. People gossip a lot in the rural areas, so that makes the HIV-positive persons to be silent about their status,

in order to protect their social life. Breastfeeding is the norm in the rural areas. Some will say that breastfeeding has more content than artificial feeding, the child will be stronger and more intelligent. They think that the child will grow closer to the mother. 80% of the women keep their status to themselves. They do not disclose it to anyone, not even their partners. When women choose to give artificial bottle milk, they tell others that they have a little infection at the breast. Sometimes the health worker explains this to family members, to help the woman to keep the status as a secret.

City

The general view of HIV is changing in the city. They do not see it as they saw it before. They used to refuse to share cups or food, but now they know more about it and accept those with HIV more easily because they know it can only be contacted through body fluids. Through the Give Milk Stop Aids support group meetings, women are encouraged to take the disease normal. Stigma reduces in the city. The norm is to breastfeed for six months and above. Most women have disclosed their positive status to one or two persons, mostly to their partner. When women want to give artificial milk without disclosing their status, they say that the doctor told them to stop breastfeeding. The health worker helps them by telling their family that they are obliged to give artificial milk by the recommendations of the hospital.

5.6: Influence of health worker

The following results count for both the hospitals in the rural area, as the hospital in the city

The health workers try to create a friendship relation with the HIV-positive women. They want them to see them as their sister. They give advice about breastfeeding and artificial milk, taking care of the baby. They organize support group meetings with seminars about all kinds of topics; how to start a small business, how to take proper care of the baby, how to deal with stigmatization. The women in the program call the health workers for all kinds of problems; problems with the health of the baby, but also personal issues.

Additional note: The health worker in the city wanted me to include the following in my research: *"in African culture, we don't talk about sex. Even in schools, we don't talk about*

it. So what they do is, they self discover it. There is no sex education. They are shy in the house. That is why most young girls go out for adventure. In the cause of that adventure the women can get the virus, because of their background. How they bring up their children, in some cultures there is polygamy. In some households the mother has no attention. What do you expect them to do? Jump out! Once the African mentality is changed, there will be less HIV. Because 70% and above, HIV is caused through sexual intercourse.”

5.7 Conclusion study 2

Study 2 is carried out for two reasons. The first reason is to test whether the health workers of Give Milk Stop Aids practice influence on HIV-positive pregnant women in choosing an feeding option. The second reason is to compare results of answers of the health workers with results of answers of HIV-positive women.

It can be concluded that the health workers of Give Milk Stop Aids try to create a relation with HIV-positive patients on a friendly base. They do this to help their patients cope with HIV. For HIV-positive pregnant women, the health workers have a special treatment. They introduce different feeding options for the children, right after they disclosed the HIV-positive status to the pregnant women. Whatever the pregnant women choose, breastfeeding or bottle-milk and participation in the Give Milk Stop Aids program, the health workers stress on the pregnant women that they support their feeding choice. The health workers act this way to prevent women to practice mixed feeding. When a woman is forced to practice bottle-feeding but would rather give breastfeeding, she might mix the two feeding options.

The other aim of this research was to see if the health workers experience the same findings in the program as HIV-positive women. In short, the results of study 1 resemble the results of study 2. In study 1, participants talk about perception of breastfeeding, knowledge about HIV and stigma that influence their feeding decisions. The health workers recognized these factors and mentioned stigma and lack of knowledge about HIV as factors that influence feeding decisions.

Chapter 6

Conclusion and discussion

CONCLUSION AND DISCUSSION

This research aims to answer the question “What are the motives of HIV-positive pregnant women with regard to choose a certain feeding option?” In chapter 2, five core determinants were introduced that might influence feeding decisions. These determinants are: “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure” and “HIV stigma” and I designed a questionnaire based on these topics. With this questionnaire, I interviewed 26 women.

Because literature showed that influence of hospital staff might force women into choosing a feeding decision, study 2 was designed to investigate the influence of the staff of Give Milk Stop Aids onto HIV positive pregnant women. The next sections in this chapter will present conclusions of study 1 and 2 in order to answer three sub-questions that will provide the answer to the main research question: “What are the motives of HIV-positive pregnant women with regard to choose a certain feeding option?” The first sub-questions is: “What determinants influence HIV positive women in choosing a feeding option to feed their child?” The second sub-question of this study is: “Why does the Give Milk Stop Aids program run better in the city than the rural areas?” The third sub-question is: “What influence practice hospital staff on HIV positive women with regard to choosing a feeding option?”

6.1 General conclusion Study 1

Comparison of similarities and differences per topic between groups in study 1

In this section, the general overview of the results of study 1 will be presented. I will discuss the conclusion of my research according to the structure of topics that I used in the questionnaire that might influence women in their feeding decisions: “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure” and “HIV stigma”. To answer the research question, I will focus on differences in answers between the groups, to find out if these differences might explain the difference in choosing a feeding option. Similarities between groups do not explain the research objective and will therefore be excluded from the final conclusion in paragraph 6.2, but they are mentioned in the following sections in this paragraph.

Knowledge of HIV

All interviewed women (rural participants, city participants and bottle-feeders) associate HIV with death. Most participants were taught about HIV and AIDS in the hospital. Some knew about HIV/AIDS through media like television and radio. HIV-positive women do not know the difference between HIV and AIDS. There were no remarkable differences in intelligence between the three groups I interviewed (rural area, city and bottle-feeders). Women living in the city were slightly better able to summarize facts and details about HIV, such like associated symptoms. Women in the rural areas stuck to general knowledge, for example that HIV kills. All three groups thought that AIDS can be cured, but women in the rural areas especially mentioned this.

Knowledge of HIV transmission

All groups were able some ways of transmission like sexual intercourse, blades and needles and blood transfusion. In both the rural area as the city there were one or two participants who mentioned myths about transmitting the virus, like sharing clothes or tooth brushes. A larger amount of women said that transmission from mother to child occurs via cracked, bleeding nipples. Only a few women in the rural area and city names breastfeeding as a way to transmit the virus, but always in combination with cracked nipples (blood). Women who chose for artificial bottle-feeding after delivery knew that HIV is also inside the breast milk. A small amount of participants in all the groups was able to summarize ways to prevent others from getting HIV.

Choosing between bottle feeding and breastfeeding

Almost all participants in both the rural and the city group told me that breast milk is healthy, good for children, nutritious and, according to two women, even indispensable because of antibodies that would protect the child. The women that chose to breast-feed preferred breast milk over bottle milk, because of the nutritious components that breast milk contains. None of the women would change their mind and give bottle feeding right after delivery. Women who were bottle-feeding from the beginning, explicitly pointed on the danger of giving breast milk to children, because it contains HIV. Some had experienced it with their previous children. They got HIV through breastfeeding.

Disclosure of HIV status

Receiving an HIV positive diagnosis was shocking for all groups of women. I noticed a small trend in the answers per group. Women from the rural area acted helpless. They associated HIV strongly with death, as if they were already dead. They did not cope well. Women from the city seemed to be more light-minded and tried to see HIV as any other disease. They depended on their faith in God to cope with the positive diagnosis. Women who chose to bottle-feed were the most optimistic about their status. One participant even regarded her positive status as something that would change her for the better. Almost every participant in the rural area did not disclose her status to anyone, but preferred it to keep it to herself. In both the city and the bottle-feed group, 75% of the women had told at least one person about their positive status.

HIV stigma

All participants anticipated on being treated differently by people in general after disclosing their status. Examples of different treatment are: no physical contact or avoid sharing food. Rural women expected that they would be abandoned by family or husband after disclosing the status “because they were the bringers of the sickness into the family”. In most of the cases, the women living in the city had disclosed their status to their partner/husband. They chose to keep their positive status to themselves to avoid to upset family members, like parents. All the groups did not know many others who were HIV positive, except for the bottle-feeders. They knew many, because they attended the Give Milk Stop Aids support group meetings, organised for HIV positive women. All the groups explain that others think very bad of HIV, like you are a dead person living. It is a shameful disease, because it has to do with your sexuality. A typical Cameroonian would think that HIV is worse than cancer or diabetes. Especially in the rural area the women were quiet on explaining the general Cameroonian opinion about HIV. I think this has to do with the heavy amount of stigma they experience. Women from rural areas were less nuanced about HIV, as I noticed when I spoke with them about what they knew about HIV. They saw HIV as a death sentence. Maybe this is one of the reasons why the women feared to talk about HIV stigma in general.

6.2 Schematic overview findings study 1: differences in interviews that might explain differences in feeding decisions

Figure 1 Schematic overview of the most important findings of study 1

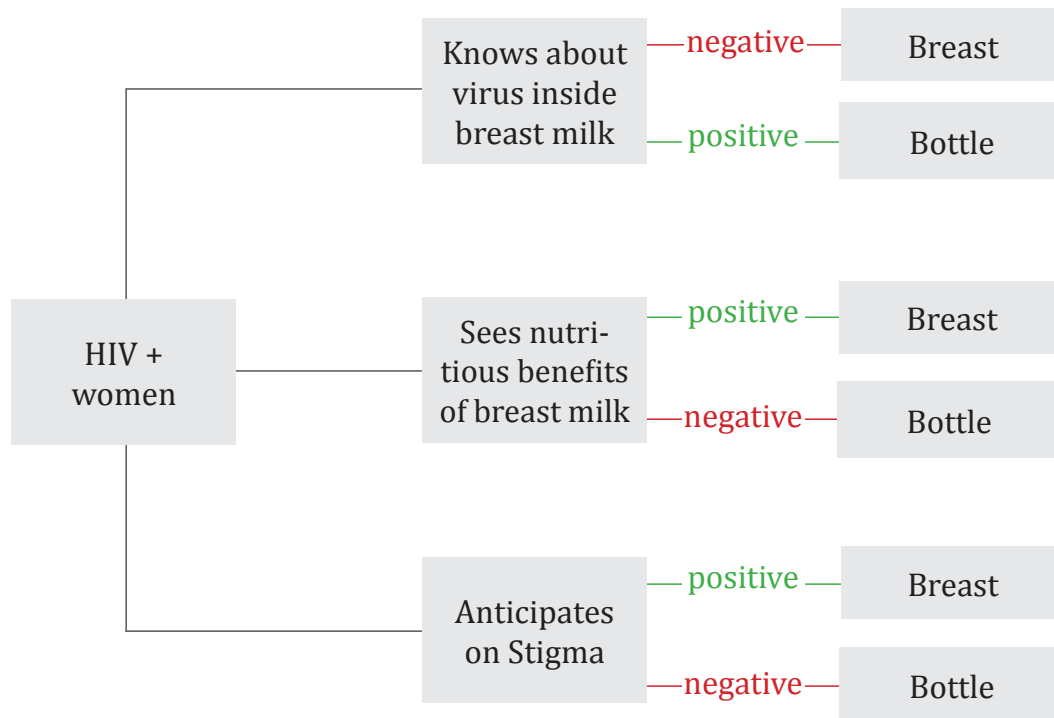


Figure 1 presents the results of Study 1 in a simplified schema. In chapter 6.1, the results of the five topics of the questionnaire were discussed. These topics were “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breast-feeding”, “Disclosure” and “HIV stigma”. It was concluded that there were remarkable differences in three categories: “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, and “HIV stigma”.

In “Knowledge of HIV transmission” there was a division between bottle-feeders and non-bottle-feeders in the knowledge of HIV inside breast milk. Women who knew that HIV was inside breast milk and was a way to contaminate children, chose to bottle-feed their child. Women who did not know this, preferred to breastfeed. This is represented in the schema under the sub-head: ‘Knows about virus inside breast milk’.

In “Choosing between bottle-feeding and breastfeeding”, women who chose to breast-feed unanimously mentioned the nutritious value of breast milk, that cannot be found in bottle milk. In the schema this is displayed through ‘sees nutritious value of breast milk’. Whenever a woman saw this, she chose to breastfeed. When this was not important to women, because of a same conviction that bottle milk is as nutritious as breast milk, women chose to give bottle milk.

In “HIV Stigma”, women living in rural areas said that they anticipated on being abandoned by their family and relatives once they revealed their HIV positive status, as being the bringer of the sickness into the family. In the city, almost all women told at least one or two persons about their sickness. According to the women who anticipated on stigmatization, it is necessary to reveal an HIV positive status as a mother by avoiding bottle-feeding. Therefore, women chose to breastfeed to avoid stigmatization. This happened especially in rural areas, where the risk of being abandoned was felt deeply by the mothers.

6.3 General conclusion chapter 2

Study 2 was designed for the two employed health workers of Give Milk Stop Aids. They were answering a questionnaire based on the following topics: “Statistics of HIV-positive pregnant women attending antenatal care in the participating hospitals”, “Counselling”, “Realities of artificial feeding according to the health workers”, “Protection of mother to child transmission”, “Disclosure of status and perceived stigma” and “Influence of health workers”. This research showed that, although literature mentioned that hospital staff might force women into a feeding decision, the staff of Give Milk Stop Aids tries to diminish their influence on feeding decisions as much as possible by creating a relationship based on mutual trust. In this way, a dialogue between health worker and mother is possible.

The health workers mentioned lack of knowledge and anticipated stigma as factors that make women choose to breastfeed instead of giving bottle-feeding. This corresponds with the findings of the analyse of study 1.

6.4 Research questions

Sub-question 1: What determinants influence HIV positive women in choosing a feeding option to feed their child?

According to the literature, several factors can be of influence on women to choose a feeding option when they are found HIV positive. These factors can be: *Costs of artificial feeding, Influence from health workers, Knowledge, Disclosure of HIV status* and *Avoiding HIV and AIDS-related stigma* and are mapped in previous research done by Cherry and Smith (1993); Chisenga, Siame, Baisley, Kasonka and Filteau (2011); Doherty, Chopra, Nkonki, Jackson and Greiner (2005); Kinsler, Wong, Sayles, Davis and Cunningham (2007); Miller and Belak (1993); Rodkjaer, Sodemann, Ostergaard and Lomborg (2011); Turan, Bukusi, Onono, Holzemer, Miller and Cohen (2011) and Vyavaharkar, Moneyham, Murdaugh and Tavakoli (2011). Because the “Give Milk Stop Aids” program provides tins of artificial milk free, costs of formula was eliminated from the research. Results from study 1 showed that knowledge and anticipated stigma are of influence on HIV positive mothers in Cameroon. A general archetype of women that choose to breastfeed/bottle-feed can be sketched from study 1:

Women choose to breastfeed when they

1. Do not know that breast milk carries HIV
2. Stress on nutritious value of breast milk in order for the child to grow healthy
3. Anticipate on being stigmatized when practicing exclusive bottle-feeding

Women choose to practice bottle-feeding when they

1. Are aware that breast milk is a way to transmit HIV to their children
2. Regard bottle-feeding as nutritious as breast feeding
3. Expect that others will not abandon them after disclosing their HIV positive status

Sub-question 2: Why does the Give Milk Stop Aids program run better in the city than the rural areas?

According to the results of the studies that were carried out in Cameroon, women in rural areas anticipated on being abandoned by family and relatives after disclosing an HIV positive status. HIV is a stigmatized disease in rural areas. It is regarded as witchcraft, a dangerous disease that equals your death sentence. Knowledge about HIV and AIDS is

missing; people get scared because it is unfamiliar. People avoid carriers of HIV to protect themselves. Since mixed feeding (combination of breastfeeding and other foods) is the cultural norm in Cameroon, people will notice when women choose to either practice exclusive breastfeeding or exclusive bottle-feeding. People associate it with HIV. Of these two options, exclusive bottle-feeding is associated highest with HIV. To practice exclusive bottle-feeding on your child, brings the risk that people start to ask questions and you will have to disclose your HIV positive status. This may lead into abandonment by family. Since many women in rural areas are unemployed or working in their husband's farm, abandonment brings risks of financial problems. The women depend on their husbands and are not able to take care of themselves.

Women in the city appeared to worry less about abandonment. Most of them disclosed their status to one or two persons. Women in the city know that HIV is a bad disease, but that they can live a long, relatively healthy life when they take treatment. Carriers of HIV in the city are not the social outcast as carriers of HIV in rural areas. Women in city are more frequent employed, so they do not depend as heavily on their family for support as women in rural areas.

Differences in stigmatization of HIV due to knowledge and need for support by family might explain the success of the "Give Milk Stop Aids" program in city, while the program in rural areas does not attract many women.

Sub-question 3: What influence practice hospital staff on HIV positive women with regard to choosing a feeding option?

The literature study done in chapter 2 revealed that influence of health workers could force HIV positive women into making a feeding decision for their child. Hospitals preach a certain 'school of thought' that promotes a feeding pattern, like breastfeeding for six months and a rapid weaning after that. At the moment that women receive an HIV positive status, they are vulnerable and need time to process having HIV. At this point HIV positive women are easy to influence. Hospital staff may tell them about advantages of one feeding option, while they keep the advantages of other feeding options. This may result in women choosing for the recommended feeding option by the hospital staff, while they would prefer a different feeding option. This can result in mixed feeding, a combination of breastfeeding with other foods. Mixed feeding enlarges the risk of HIV transmission from mother to child.

One of the goals of the “Give Milk Stop Aids” program is to support HIV positive women in their feeding decisions, whether it is to breastfeed or to bottle-feed the child. The health workers of Give Milk Stop Aids encourage women to choose one feeding option and stick to that option, to avoid risks of transmission via mixed feeding. The health workers exchange telephone numbers and addresses, so that the HIV positive women are able to visit the office for more information. They do this to help the women to make the right feeding decision that is suitable for their situation, which brings the least risk for mother to child transmission.

Main research question: What are the motives of HIV-positive pregnant women with regard to feeding decisions?

Taken the three sub-questions together; it can be concluded that HIV positive women in Cameroon base their feeding decisions on three factors: knowledge about breastfeeding and HIV transmission, attitude towards breastfeeding/bottle-feeding and anticipated stigma in relation with bottle-feeding. The most important factor in choosing a feeding option is how women regard breastfeeding and bottle-feeding. Costs of milk and influence of health workers do not interfere with feeding decisions of HIV positive women. There is a distinction in anticipated stigma between women living in rural areas and the city. This distinction can be explained by differences in knowledge and dependence of support by family. Women in rural areas generally do not know much about HIV and are therefore afraid of the disease, and they are generally unemployed and therefore count on support by family.

6.5 Literature review compared to findings research

The questionnaire used to collect the data for this qualitative research, was based on the literature review in chapter 2. Factors that could influence women in their feeding decisions were: “Knowledge of HIV”, “Knowledge of HIV transmission”, “Choosing between bottle-feeding and breastfeeding”, “Disclosure”, “HIV stigma” and “Influence from health worker”.

Confirmations

This research confirmed that the choice between breastfeeding and bottle-feeding is influenced through level of knowledge about transmission of HIV (Becquet, Castebon,

Viho, Ekouevi, Bequet, & Ehouo, 2005); (Doherty, Chopra, Nkonki, Jackson, & Greiner, 2005). If women are aware that breastfeeding is a way of mother to child transmission, they will prefer to bottle-feed. The cultural relevance of breastfeeding in African settings was also confirmed (Desclaux & Alfieri, 2009). Women who believe in nutritious value of milk that cannot be competed with bottle milk, will choose to breastfeed. Disclosing an HIV positive status and anticipating on stigma correlated in the results of this study. When women disclosed their status to others, they were not very afraid of stigmatization and gossiping, while women who kept their HIV positive status secret anticipated on stigmatization and different treatment by others than before. Giving bottle milk to children is associated with having HIV (Chisenga, Siame, Baisley, Kasonka, & Filteau, 2011); (Give Milk Stop Aids, 2010).

New findings

Before the research was carried out, it was expected that women in the city would be higher educated in HIV and AIDS than women in rural areas. This assumption was not proven through this research. In general, women do not know much at all about HIV and AIDS. The health workers of Give Milk Stop use tactics to diminish influence in feeding decisions. This was different from the expectation, because before hand it was not clear at what level the health workers would communicate with patients. Literature showed that almost every health worker/patient relationship is based on hierarchy (Doherty, Chopra, Nkonki, Jackson, & Greiner, 2005). Health workers of Give Milk Stop Aids base their relationship with patients on friendship and mutual trust.

6.6 Discussion

Limitations

The data of this research is collected in three places in Cameroon from November 2011 to April 2012. My colleagues, the health workers in Banga Bakundu and Douala, helped me a lot to start the collection of my data. They were the ones to locate and invite participants for this research, so I did not have influence in choosing the participants. This has an advantage because the health workers know exactly which women I needed to interview to collect a diverse group of participants, because they knew them all personally. This had the disadvantage that my participants were not randomly chosen.

The sample of participants that I worked with was rather small. For study 1 I interviewed 26 participants. For study 2 I interviewed 2 participants. This is a rather small sample to generalize findings on that count for the whole population of Cameroon, since the country knows many different cultures. To prove the findings of this results, the research should be performed among a larger sample.

Cameroon knows an entirely different culture than the Netherlands. Because of cultural differences I might have interpreted answers of the interviews different than how they were originally meant. Likewise, women might have interpreted my questions differently than I meant them. Cameroon knows a certain level of hierarchy among people. White coloured people are usually higher in status than black coloured people. Therefore I sometimes got the idea that the women I asked to participate in the interview only participated because of politeness. They did not dare to refuse, because of my colour. The questionnaire of this research emphasizes the participants to express their opinion about topics like HIV, coping strategies and stigma. Their answers were often not based on experiences, but on anticipated expectations. The research focused on anticipated problems, not actual problems. Through this research it is not possible to predict actual behaviour of the population towards HIV-positive persons.

I scored, labelled and analysed the data of this research entirely by myself. This has the advantage that I know the Cameroonian culture better than an average person, so I am able to interpret linguistic styles more correctly than others. I am aware of cultural bounded expressions. I was the one that performed the interviews, so I can recall the manners of expression that the women used. When they were sarcastic or tremendously serious. The fact that only one person worked with this data means that the analysis and conclusion of this research are harder to check on reliability and validity. In order to improve this research, another person should score and label the data as well. When the scores and labels match between two researchers, this research is proved to be reliable and valid.

Recommendations

This research is qualitative and descriptive. It investigated the far-reaching consequences of anticipated stigmatization among HIV positive pregnant women that need to choose between feeding options. Further research on this topic should be performed

among a larger sample of participants and could be focused anticipated stigma, coping strategies and attitude towards breast milk and bottle milk.

In order to diminish the factors that influence women in their feeding options, I suggest that the Give Milk Stop Aids health workers continue with the organization of the support group meetings for HIV positive women, to encourage them and help them, so the HIV-positive women will not feel like they are the only ones having HIV. The attitude of women that bottle milk is inferior to breast milk could be diminished through increase of knowledge. The hospitals could design a flyer to give to HIV-positive women with feeding options and their advantages and disadvantages. In this way, the HIV-positive pregnant women are able to overthink their preferable feeding option for a long time, without forgetting important information about the feeding options. The Give Milk Stop Aids health workers should continue to counsel HIV-positive patients in the way that they do it already.

The previous recommendations are rather small solutions to encourage women to choose their preferred feeding option. In my opinion, the real problem lies within the mentality of Cameroonians. The attitude of the population towards people with HIV has to change positively. Although the government organizes campaigns to increase discussions about HIV, HIV stigma remains. Now it is the challenge for the health workers to comfort their patients in a way to help the patient to cope with stigma in their best personal way. It would also help to promote bottle milk among the population as a feeding option that is related with healthy food. Bottle milk needs to be associated with nutritious food that is a healthy replacement for breast milk. Bottle milk should not be associated with HIV. This is important because the use of bottle milk will be less sensitive to stigma when it is not longer associated with HIV.

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APPENDIX A

QUESTIONNAIRE GIVE MILK STOP AIDS (RURAL PARTICIPANTS, CITY PARTICIPANTS AND BOTTLE-FEEDERS)

Introduction

I would like to discuss some topics with you about Give Milk Stop Aids. You have been here before to have a council from Lorraine/Hanna and at that time you did not want to join the program of the artificial milk. I am here to do research for my school in the Netherlands. This is why I will be asking you a few questions about why, at that time, you didn't want to join the program. Please try to tell everything you know or think of when I ask you the question. This will help me a lot.

Demographic questions

1. What is your age?
2. What is your living situation? (still living with parents/husband/own..)
3. Are the father of your child and you still together? How did you two meet?
4. Did you go to secondary school?
 - a. Did you finish it?
 - b. Did you go to high school after that?
5. Do you earn money of your own? What do you do?
6. Does your baby has a name already? What's its name?
7. Have you been pregnant before? How many times?
8. To what church do you go?
9. From which tribe are you?

Perception about having HIV/AIDS

1. Can you tell me what you know about HIV/AIDS?
2. Do you think aids can be cured? Through medicine?
3. How did you react when you heard you were HIV positive? Why?
4. Did you tell anyone yet about your status? Who? How did they react?
5. IF MARRIED/RELATIONSHIP: Did you tell your husband about your seropositive status?
6. IF DISCLOSED: How did he react? Did he reacted in the way you expected before telling?
7. IF UNDISCLOSED: Why not? What do you think will happen if you tell him?

Knowledge about HIV and transmission

8. Can you tell me what you know about transmission of HIV? How do you know it?
9. Do you know how to prevent transmission of HIV?
10. What do you know about mother to child transmission?
11. How do you think you can protect your baby from getting infected?
12. Is there a risk of transmission through breastfeeding? Do you know the consequences?
13. How do you know the information about HIV? And breastfeeding?
14. Did you take prophylaxis (terminology pills) during labour and/or another time during pregnancy or after that? Why?
15. Did you get any advice about feeding during your pregnancy? From whom?
16. What is your association with artificial milk? Positive/negative

Knowledge about artificial feedings and mixed feeding

1. Do you remember what Lorraine/Hanna told you about the artificial feedings? What do you remember?
2. What do you think is the effect of artificial feeding on your baby?
3. Have you ever heard of mixed feeding? If not, no more questions. If yes, ask what they know

Social Environment and stigma

1. Do you know anyone who is HIV-positive? Is it a friend of yours, or family? How did you react on the disclosure?
2. Are you afraid of losing your job/not getting a job when you disclose your status?
3. Do you know anyone who gives artificial milk instead of breastmilk to her baby? What do you think about it? What do you think about her behavior? What is her reason for artificial milk?
4. Imagine that you did start the artificial feeding; how do you think your mother would have reacted? And your friends and family? (angry, sad etc.)
5. Do you think their opinions are important? Why?
6. Would you give artificial milk if you could use an excuse?
7. What are the negative sides about artificial milk in your opinion?
8. Do you think that maintaining hygiene in the preparation is difficult? Why (not?)
9. Have you heard of Give Milk Stop Aids before? If yes, from whom?
10. Can you tell me why you didn't want to join the GMSA program?
11. Do you have any questions for me?

APPENDIX B

QUESTIONNAIRE HEALTH WORKERS BANGA BAKUNDU & DOUALA

Statistics

1. How many women on formula feeding/ how many on breastfeeding?
2. Average age of women?
3. Marital status?
4. Living situation?
5. How many women knew their status before this pregnancy?
6. How many women complete the program?
7. How many babies are HIV negative after completion of the program?

Counseling

1. Can you explain how the ANC in TAHBB is provided?
2. Nowadays, the WHO recommends breastfeeding together with medicine above the use of formula feeding. Can you explain why GMSA chooses to recommend HIV positive women the formula feeding?
3. When does the counsel take place? (immediate after test results, few days later, before/after labor)
4. Is there a difference of approach depending on which time the counsel is given? (counseling just after hearing about HIV status/ counseling after few weeks/ years knowing the status)
5. What kind of women do you meet? Are there “prototypes” of reactions on which you can anticipate?
6. Can you describe these reactions?
7. How do you approach women who are negative about GMSA? What kind of “techniques” do you use on them?
8. How do you keep in touch with the women? What do you do when there is no telephone number available?

Realities of formula feeding.

1. Is there enough stock? (Banga/Munyenge). How do you keep track on the stock?
2. What are the common complaints about preparation of formula feeding?
3. How is the health of the babies? What kind of diseases do they face? Do these diseases correlate with bad preparation of formula feeding?

4. Did you ever hear that women ran out of stock and therefore started mixed feeding?
5. Do the women complain about difficulties with hygiene?

Protection of the child

1. What are the most common reasons women give when they choose to give artificial milk?
2. What are the most common reasons women give when they choose to give breastfeeding?
3. Are there any women who refuse to give artificial milk but are willing to give breastfeed and remain under the GMSA program? (taking drugs, baby tested after 18 months etc.) aka control group.
4. What are the costs for an HIV test?
5. What are the costs for a CD4count?
6. Can you explain to me how the health care system in Cameroon is working? What kind of medicine are spread by the government, CD4 count?

Disclosure and perceived stigma

1. What is the general view on HIV/aids here in this area? How do you notice this?
2. What's the normal feeding option among mothers in Cameroon, breastfeeding or formula feeding? Why?
3. Do the women in your program disclose their status? To whom? If not, why not?
4. What kind of excuse do women give their relatives when there is no disclosure but there is formula feeding?
5. Do you help them with making up excuses or do you support them on telling the truth?

Influence of health worker

1. How would you describe the relationship between you and the mother? Equal/not equal
2. Hierarchy?
3. Additional notes?