

Dear Peter,

Every day I hear something about problems in Zimbabwe. Only yesterday the US State Dept advised Americans not to travel there and those there to consider leaving. It is an incredible tragedy given all that Zimbabwe has to offer. You have been so much further along than most of Africa, I only hope that things will settle and there will be some light at the end of the tunnel.

We have struggled with many of the issues that you bring up about infant feeding for our HIV infected women. There are so many guidelines and lots of advice being given, but very little information about whether the advice is helpful or in fact actually harmful. It has certainly caused lots of confusion among the healthcare workers, so you can only imagine the confusion it has caused for the women.

Our initial PMTCT program supported by the Pediatric AIDS Foundation did not include formula as part of the package. We felt that it would be very difficult for our population of extremely poor women. However when the UNICEF/UNAIDS/MOH pilot program decided to include Mulago hospital as one of their sites, the free formula was provided as part of the UNICEF contribution. Free formula for six months was provided from about April 2000 until Sept 2002 when UNICEF decided to stop providing the formula. So currently we do not offer infant formula. As with most of the "pilot" implementation programs, there was not funding or provisions made for any active followup to evaluate the effect of this formula program. Hence we also have very little real data to support any claims about the effectiveness of the program. Most of it is anecdotal or "gut feeling" based on the experiences reported by staff. Because there was no active follow-up, our loss to follow up rate was considerable. Only about half of the women who joined the PMTCT program were ever seen again, including both women who chose formula and those who breastfed. So we know that many women who left the hospital with formula after delivery never came back to get more--thereby assuming that they reverted to breast feeding or mixed feeding. We don't know why this was, what the mothers experienced after going home with formula etc.

When we started the program, there were many more women who said that they wanted formula, we think because the offer of free milk was too good to turn down. There were many problems including lack of health care worker/counselor knowledge about teaching a women to formula feed safely. They knew to tell them about using clean water, utensils etc, but nothing about how often to feed the baby, how much a baby should drink in a day, what formula fed infant stools are like compared to a breast fed infant etc. We had women diluting formula because of "constipation" though the infant was having normal formula fed type stools, we had a woman giving 50-60 ounces of formula a day to her several week old infant and was wondering why she was urinating all day long, a baby being admitted with severe diarrhea and the staff throwing away the formula and yelling at the mother for feeding her baby poison because the mother was afraid to tell her why she was giving formula. There were mothers who couldn't afford a flask to keep the boiled water in etc The usual horror stories.

Our staff started a checklist of questions to ask the mother to help her decide. Things like, what will you do when the baby wakes up in the

middle of night for food? How will you prepare the formula and feed the baby when you have no electricity and the crying baby is waking up the family? What will you do on a matatu (bus) when the baby cries and everyone tells you to put the baby to the breast? What are you going to tell your husband who you haven't told your HIV results to? How will you feed your baby when you have to go to the village for a burial? Just to give the women an idea of the type of commitment it takes to feed an infant with formula. Before then, most women had no idea of the reality of it all. I think that it helped somewhat in selecting women who might be able to manage, but not very well given our huge loss to follow-up.

I personally think that we significantly increased the mixed feeding by offering formula. We had a higher transmission rate among our formula feeders than breast feeders, which is intriguing but given the poor follow-up, incredible selection bias etc this is completely unreliable as any proof of harm. We certainly didn't see evidence of benefit though.

On the other hand, some women were very motivated and did a great job, their babies were healthy, grew well and they didn't have problems. These tended to be the women who were more educated, had family support, and seemed to understand the issues more than just looking at it as free milk. The women who did the best by far were those mothers who went home breastfeeding, came back at six weeks for infant testing, found out their child was negative and then switched to formula. They were the most likely to come back for each of their formula refill visits. We found that it was easier for women to come up with a reason to stop breastfeeding early than to never breastfeed at all. This also probably selected for a more motivated group of women because they were in the half who returned for followup, wanted to know their infant results, and seemed to be much more committed to the program.

I believe that these programs cannot be successful without some sort of active followup and support, especially since the experience with formula feeding is so limited and women don't want to reveal their status. Therefore, once they go home, they have no one to help them, to answer questions that arise, so they may give up or make a wrong decision about what to do. It is all about resources however. In the early Uganda days, there used to be domiciliary services that would follow up women at home after delivery. So it can be done, but no longer because of lack of resources.

As for the logistics, they were a problem even with UNICEF support. Several times the program ran out of formula and had to run around to the sites to see who had a few cases left that might be able to use by other sites who had run out. There was a problem with a large amount of formula expiring before use because of an over estimate of the number of women who would choose formula. At least once, the formula was found to be contaminated with black specks of something (sent for analysis, but I never found out what it was) that necessitated the ministry of health people running to Shoprite to buy large quantities of local formula to replace the free formula. This caused all kinds of problems since the boxes were replaced with tins, the scoops and ratios of formula to water were completely different etc. I think local alternatives to imported infant formula would be much more reasonable and feasible.

In the last six months or so of the program we started to follow up a small group of formula feeders to try to sort out some of the issues that they were facing. I have not seen the results of this yet, but Joyce might be able to give you an idea of what kind of information she has found. I also have not looked at what has happened since we stopped offering formula at the end of Sept.

I don't think that we say any spillover though again I can't really show you any data to support that.

Joyce is really the one who has been tackling the infant issue at our site. She has done the most in terms of training if Infant feeding for HIV infected women. She trains most of the staff etc so could give you a much better perspective. Since I am now back in the US, I have not been able to keep up with all the latest on site, so her information will be very valuable.

In many ways, I think that the infant formula issue is much like the ARV issue. It is not as simple as just sending formula or sending ARV to the sites. The issues are incredibly complex. I also don't want to sound like I am saying that it can't be done so we should just forget about it. I think that there are significant numbers of women and infants who could benefit from access to free formula and drugs pretty quickly and easily, without alot of support. And that by providing them we can increase the number of people who have access. However I do not think that the majority of current health care systems or families are ready for such programs in the absence of significant investment in resources, training, manpower, etc to handle them without causing harm.

Several programs seem to believe it is just about access and that by sending the supplies, the problem will be solved. This shows an incredible lack of understanding of the context of the problem. I think that building on the infrastructure and health care capacity in some way is a must for these programs to be successful.

I don't have Joyce's presentation at Barcelona on my computer so I can't send it to you, but will ask Joyce to. I have attached a copy of her slides from the talk she gave at the EGPAF Call to Action meeting in Zambia in August.

Hope this helps. I am sorry that we don't have much real data to give you.

Paul Bakaki, one of our pediatricians did a small study for UNICEF looking at women who chose to wean early and what problems they faced. He may be able to give you some idea of some of those data. He can be reached at pbakaki@mujhu.org

Good luck with sorting all of this out!
We all can use the advice.

I will continue to keep you and all those in Zimbabwe in my thoughts and prayers!

Sincerely,

Laura

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