

Q&A Session After Linda's Presentation: Feeding in the Context of HIV

Q: Do the Mentor Mothers get paid for the work that they do?

Linda: Yes, they do and the community health workers have some mechanism for remuneration that is all done through the government so they get paid a minimum wage and it is part of the review at the national level. There was a best practice review and a critical look at how this keeps the staff within the health system. They make the equivalent of a minimum wage and are required to be at the facility for 8 hours 5 days per week. They rotate through different service areas and they are trained. It is a livelihood strategy to provide employment and build the competencies of mothers who are HIV positive. This has been endorsed through the government.

Q: How do the Mentor Mothers differ from community health workers?

Linda: The community health workers in Kenya have a defined package of support which is largely primary care interventions for all of the population. Some focus on mothers and children. They provide the support at the community level so they will often visit households, connect mothers with care, and screen children to identify their needs. They do some promotion of key messages like family planning or exclusive breastfeeding. Mentor Mothers have a much more focused role and are based at the health facility. They were from the maternal and child health services and they follow mothers who are HIV positive individually with counselling and support. They provide much more of an individual follow up. The point where they connect is where there is follow up. The Mentor Mothers will follow an agreed route with a mother they have connected with and it is negotiated as part of what is appropriate. If the mother defaults or cannot be reached for her care, the maternal and child health nurse in charge works with the community health extension worker, who oversees the community health workers. They have a mechanism for identifying mothers who need to come back to the facility. The community health workers will then go and follow up with the mothers and guide her to come back. One of the important things is that the community health workers not know the HIV status of the mother. That is part of the separation of support.

Q: Regarding the Mentor Mothers, how many have now been employed? And do they report any resistance from community members since they work with both people living with HIV and those without?

Linda: Fifty percent of the country is now accelerating to the Mentor Mothers program. USAID, in its support to Kenya, funds a substantial amount for strengthening HIV care and services. This has been endorsed as their model of support and will be accelerated nationally. Mentor Mothers don't usually go to the community level. They give the support to mothers but they are not following the mothers along to the support they receive in the community. A lot of their support is facility-based groups that meet and that's where the differentiation of roles also comes into play. The community health workers will follow any mother at the community level regardless of her status.

Q: One slide showed an increase in infection of babies from around 4% at 8 weeks to 7% at 18 months. Is exclusive breastfeeding effective?

Linda: We still have challenges with exclusive breastfeeding so it's just been in the last 6-9 months where we've seen a lot more clarity. Mentor Mothers provide clear messages about exclusive breastfeeding but it's sometimes health workers who still give the confusion. We have seen improvements in this area. That's where you will still see impact with increased rates beyond that first EID. Those rates show some promise in reduction of MTCT of HIV. As I compared, they are half of what is estimated at the national level. It is showing promise.

Q: Were the mothers of any of the babies who were infected on prophylaxis on ART?

Linda: We don't know at a facility level. We have not tracked those specifically. We are doing monitoring and getting anecdotal reports.

Q&A After Nigel's Presentation: Breastfeeding, HIV & ARVs

Q: Do we have documented experiences on stopping breastfeeding around 12 months? How successful has that been and what are the challenges?

Nigel: The simple answer to that question, and probably to most that will come in, is no. We have very little documented experience on most of the issues around post-natal transmission and the programmatic issues around implementation of the guidelines. The evidence that was available for the recommendations in 2010 were almost entirely based on research studies. The area where we have gaps is programmatic experience and best practices. Also, the real challenge to health systems is about how to collect data about post-natal practices and ARV coverage. This is a major gap in our knowledge base at the moment. I'm sure it will come. Obviously, after a recommendation is issued, there is time for companies to adapt their own decisions and then there is a lag period before women and children actually get to 12 months to be able to document their experience. I personally am not aware about any documented experience about stopping at 12 months. In saying that, there's certainly a lot of experience saying that physiologically we can provide diets for children at 12 months that don't require breast milk. Children can take full family foods. Children can take undiluted cow's milk and that was one of the main considerations in the 2010 guideline.

Jessica: Just to comment on data on breastfeeding at the health facility level – there was an interesting report released recently by the MOH in Mozambique about early infant diagnosis and it showed transmission rates increasing with age and perhaps some of that was due to breastfeeding transmission and then it showed the link to need for improvement of collection on breastfeeding data at the health facility level. I just wanted to add that as well.

Q: Regarding the study you shared on the low level of knowledge about breastfeeding from 2008, do you think there has been improvement since then?

Nigel: Again, I think the answer is, I just don't know. This is where we really want implementation-type research. But there is no reason to expect any change unless there has been good communication to health workers. One of the things I'm fearful of is that it's very easy for a ministry to send out guidelines and in a very quick way, say "this is how we're changing" without addressing some of the areas of misbelief or misunderstanding. If those misunderstandings don't come out as part of the reorientation or if the question of, "what do you really think is best?" is not answered, then evidence and simply stating the new recommendation does not necessarily change the behaviour of the health worker in what they communicate. This is exactly the reason why the communication to health workers, to give them confidence, is recognized as a key important issue. That's the reason why I wonder whether it is really an issue of confusion of lack of confidence.

Q: In Latin America and the Caribbean region, PAHO guidance recommends that HIV positive mothers avoid all breastfeeding. In this region, many countries are middle income countries and their governments are opting for following the example of high income countries that are discouraging HIV positive mothers from breastfeeding. Some go even further by criminalising breastfeeding by HIV positive mothers. PAHO should revise their guidelines to allow informed choices and reduce the current stigmatisation and discrimination.

Nigel: I think it's very difficult. It all depends on the quality of the health system of the reliability of the health system to get drugs to mothers and support them at the time and to keep women in care. If you have very high confidence in that, then it is a reasonable thing to suggest that HIV positive mothers avoid all breastfeeding, especially if you have relatively low infant mortality due to diarrhoea or malnutrition. One of the difficulties is national data on mortality are averages and do not reflect the diversity of individual situations that a woman is faced with. Within a country, you could imagine that in South Africa or Brazil, there are some places where women have access to clean water, electricity at all times of the day and are very well educated. At the same time, in the same country or even the same city, there will be other women who don't have those same opportunities. To make a blanket policy in some of those situations can be difficult. The question about allowing informed choice is not an unreasonable one to examine. It is one that some countries, maybe Kenya, can comment on from a point of having more informed choice.

Linda: We have struggled with that and we have a bit of variation within the country. One of the areas of the country that has achieved their MDG targets really wanted to support a formula-based approach. We would really like to see stringent research around that that shows evidence of improvement and not a detrimental effect on neonatal and infant mortality. Some of the struggles that you're talking about are real struggles. The issue of stigma and disclosure is still a real struggle. We've had programs promoting formula use among mothers and the issues of stigma were not addressed within those programs so child and neonatal survival are huge issues but stigma and disclosure are equal issues that need to be addressed. Yes, the government has taken the adaptation of exclusive breastfeeding with their ARVs to mothers with the adoption of the WHO 2009 guidance but there is some variation of what is going on in the country. We will have to wait and see if the interventions are improving the situation or causing detriment.

Karan: Is there any update on mother to child transmission risk from exclusive breastfeeding versus mixed feeding? In your paper from November there was no evidence of a difference. Is there any update?

Nigel: With respect, in some ways, I think this may be the wrong question. In the data that has been presented on all the ARV interventions, the research teams, including the study I was involved with, we said that women were supported to exclusively breastfeed but I think in the studies, there was a lot of mixed feeding in those research studies and in those studies, the drugs still worked. Although I don't have the data to share with you, it's my belief that ARVs are very effective at reducing transmission even when there is mixed feeding. I think there's a different question – when you have ARVs provided to women, is there still value in promoting and supporting exclusive breastfeeding? We have just finished analysis, which we are sending to publication, that shows that in both infected mothers and their infants, as well as HIV uninfected mothers and their infants, in situations like South Africa, promoting exclusive breastfeeding reduces the risk of diarrhoea and mortality in all groups. The justification and the importance of promoting exclusive breastfeeding is maybe not so much to reduce transmission but to protect these children, who are maybe not going to be infected because of the ARVs, but to prevent them from dying from diarrhoea, pneumonia and malnutrition. Hence, there is still a major value and importance for promoting exclusive breastfeeding, because it saves lives. That's why HIV survival is the parameter we should be focusing on. I think that this is possibly the more important area to focus on. How do we promote health workers to promote exclusive breastfeeding with ARVs to reduce transmission but also to reduce the deaths from diarrhoea, pneumonia and malnutrition?

KK: UNAIDS shows that as MTCT during pregnancy and delivery decreases, the amount of MTCT during breastfeeding is increasing. There is urgent need to ensure protected breastfeeding with ARVs. Following your comments on the importance of educating health care providers and increasing their confidence of promoting exclusive breastfeeding, how will the upcoming WHO consolidated guidelines address this problem?

Nigel: The first point is that, we need to be careful in saying that the amount of transmission in breastfeeding is increasing, it's not. It's not increasing. The *proportion* of transmission that occurs during breastfeeding is increasing. If over a two year period, there were no drugs and you had 20 children becoming infected through transmission and delivery and that 20 now reduces to 3, then in the same time, there were 15 children becoming infected during breastfeeding. When you have ARVs available to decrease the transmission during pregnancy and delivery down to 3, it's not that the number of children becoming infected through breastfeeding changes from 15 to 20, 25 or 30, that doesn't happen. Relatively, before it was 20 to 15 and now it is 3 to 15. So the number of children becoming infected during breastfeeding is the same but proportionally, it is a lot larger and therefore people become much more concerned about it. Exactly as KK is saying, we need now to design and deliver on the health systems so the way in which ARVs are being delivered to prevent transmission during pregnancy and delivery, are delivered to women in exactly the same way with the same regularity, the same consistency, the same commitment as before. That is where our experiences are not adequate.

The second question, how will the upcoming guidelines address this – I don't think the guidelines will address the issue of importance, they will highlight that it is important to educate health care providers, but I don't think they will give anymore "how to do this" guidance. This is something that WHO and UNICEF have been talking about – how is it best to communicate to healthcare providers the best communication strategy at national level, community level, specifically among health workers, to really convey the evidence and to give people confidence? I don't think the upcoming guidelines will specifically address the how-to in that sense.

Tin Tin: As Nigel mentioned, we had a meeting at the end of last year where we discussed some of these issues, especially how to boost healthcare workers' capacity, knowledge and confidence about giving the appropriate messages to the affected and infected women. One of the things that UNICEF will be taking the lead on this year is to develop a communication strategy that is aiming at different levels of populations but also at policy makers and program managers on the program components are different and things that need to be taken into account so the capacity of health services and health care workers are increased in the area of infant feeding and infant feeding practices. We are going to be working with partners and key stakeholders on that area and hopefully, maybe not by the time the WHO guidelines come out, but maybe by the end of the year, we will have a communication strategy around HIV and infant feeding within the context of the revised 2013 WHO guidelines.

Tin Tin (written): Stefano – in countries in Latin America, do you do multiple HIV testing (PCR) in exposed infants after birth? For example, at 6 weeks, 6 months, 12 months, 18 months. That will definitely show if there is any post-partum HIV infection.

Stefano (written): Apparently, 10% of infections attributed to breastfeeding (approximately 200 cases in 2011)...only 50% of po. have access to antibody testing and only 20% of infants have access to viral testing...even if it was proposed as an option, very few women are likely to adopt breastfeeding while being HIV positive, although, this seems like an instance where global guidelines are better than the regional ones in particular to reduce stigmatization.