Two HIV positive breastfeeding mothers in the UK - their story

The Leeds Teaching Hospitals NHS
NHS Trust

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INTRODUCTION

- In resource limited settings, breastfeeding when the mother is HIV positive, is fully endorsed by the World Health Organisation, because of increased infant morbidity and mortality associated with replacement feeding (1).
- Randomised controlled trials conducted in Africa (2,3,4) where antiretroviral drugs (ARVs) were given to mother and/or baby during the breastfeeding period showed reduced rates of HIV transmission. From these studies, the rate of transmission is 1-4% compared with 7-8.7% when no ARVs were given.
- The BHIVA/CHIVA Position Statement 2010 (5) recommends that, in the UK, mothers known to be HIV infected, regardless of maternal viral load and antiretroviral therapy, refrain from breastfeeding from birth.
- However, many pregnant mothers in the UK are of African descent and it is therefore not surprising that some are starting to enquire about breastfeeding, as they become aware of the differing advice given in their home countries.
- We present the cases of two women from our clinic who, after detailed documented discussions with senior doctors and midwifery team, decided to breastfeed. Both cases were discussed at the departmental Pregnancy MDT meeting.

APPENDIX

Breastfeeding in an HIV positive mother
Points for discussion

1. Bottle feeding = no risk of HIV transmission; Breastfeeding = 1-3/100
2. Discuss BHIVA position statement including:

   a. Breastfeed for the shortest time possible
   b. No mixed feeding
3. There may be HIV present in breastmilk even if the plasma HIV viral load is suppressed. More research is needed in this area.
4. Benefits and risks - need to weigh up the short term gains of breastfeeding in the UK (decreased respiratory and diarrhoeal illness/?improved psychological factors in mum) vs the long term situation of a child/adult living with HIV
5. Have they considered how they would feel if the child was positive (guilt, regret)?
6. Being HIV infected from childhood is different from being infected as an adult. Issues to consider include:

   a. Possibility of developing drug resistance earlier in life
   b. Poorer life expectancy
   c. Possible difficulty in dealing with HIV diagnosis during teenage years
7. The very long term drug toxicities of taking ART as a baby (incl via breastmilk) and as a child remain unknown.
8. Cultural issues:

   a. Stigma associated with not breastfeeding, will this disclose diagnosis?
   b. If planning not to breastfeed, should we be counselling women away from attending very pro-breastfeeding support groups?
9. If the woman has any doubts about breastfeeding the default position should be that she does not breastfeed.

CASE 1

30y Nigerian female
Diagnosed HIV positive in 2008

BACKGROUND

- Two children born via vaginal delivery in the UK - both HIV Ab negative at 18/12
- Not breastfed previously
- Undetectable HIV viral load throughout pregnancy on Nevirapine and Combivir

OUTCOME

- Breastfed for 6 weeks
- Developed mastitis at 6 weeks prompting switch to formula feed
- Mum's HIV PCR remained undetectable throughout
- Baby's HIV PCR negative at 6/52 and 3/12 after cessation of breast feeding

IN HER OWN WORDS

Why did you consider breastfeeding this time?
"I had heard that my friends back home in Nigeria were doing it and their babies were ok. I wanted to feel like a "real mum"."

Where did you get your information from?
"Mainly from the clinic. I didn't get much information from the internet."

How did you feel beforehand?
"Confident that everything would be ok"

How did you get on?
"Overall ok but struggled as the baby was very hungry and it was difficult to satisfy him. I developed an infection (mastitis) and contacted the GP about this. They advised to continue feeding on that side and I worried when I was advised by the HIV team not to feed on that side. The baby had fed a little on that breast before I got that advice."

How do you feel now?
"I enjoyed breastfeeding - it was a good experience. I feel happy and like a "real mum". I did have some ongoing worries re the infection and feeding on that breast until the blood test at 3 months after stopping breast feeding."

Would you do it again?
"Yes, but if I had a hungry baby, I would be quick to switch to bottle feeding!"

CASE 2

24y Ugandan female
Diagnosed HIV positive at term with her first child in 2008

BACKGROUND

- First pregnancy was a result of rape. She had been held hostage during this time
- Felt issues surrounding pregnancy and caesarean section affected her ability to bond with her first child. Concerned about bonding with new baby
- HIV viral load undetectable since starting treatment (Atripla)

OUTCOME

- Breastfed for 5 weeks
- Advised to stop when her HIV viral load was 51 copies per ml and health visitor reported baby had developed significant gynaecomastia
- Baby's results are awaited

IN HER OWN WORDS

Why did you consider breastfeeding this time?
"I thought it would help with bonding with the baby, and to have the experience of breastfeeding. I remember playing with dolls as a child and thinking of it."

Where did you get your information from?
"The midwife at my GP's" (re the idea to BrF)

How did you feel beforehand?
"Excited. But I did have some worries about passing (HIV) to the baby and thought "Am I doing the right thing?""

How did you get on?
"Ok. I felt as though I didn't have enough milk at the beginning but by the time things were easier I was told to stop"

How do you feel now?
"As long as baby is ok I am glad I did it. There is a difference between the first and second child."

Would you do it again?
"I would love to do it again if my viral load is undetectable."

CONCLUSION

- It is likely that more women will enquire about breastfeeding as they become aware of current research and recommendations in resource limited settings.
- The information they get online may be variable and/or misleading (see Poster 72).
- As healthcare providers, we need to give accurate detailed information to guide their decision. We have formulated a clinic checklist upon which to base any future discussions around breastfeeding (see Appendix 1).
- If choosing to BrF women and their partners need professional support before, during and after BrF. Both our mums found that stopping BrF was a more emotional event than we anticipated. We suggest that discussion of this should also form part of the counselling process.
- Data regarding mode of feeding is collected as part of the UK National Study of HIV in pregnancy & childhood and should be reported by paediatricians involved in the care of babies exposed to HIV.

OTHER COMMENTS

"I have some worries about sharing my story as I wouldn't want another woman's baby to become infected because of reading my story. I might be lucky and another person may not be lucky."

References

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