

Technologies of hope?
Motherhood, HIV and infant feeding in Eastern Africa
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The documentation that HIV can pass from mother to child through pregnancy, birth and breastfeeding was received with apprehension and shock worldwide. As much as half a million children become infected with HIV through their mothers every year and nearly 90% of them live in sub-Saharan Africa (UNAIDS, 2008). How to fruitfully approach the challenge of mother to child transmission of HIV in low income contexts is one of the ethically most taxing global health issues of our time (De Cock et al. 2000; Kuhn et al. 2004; Thairu et al. 2005).

Resources invested in the development of knowledge and technology related to mother to child transmission of HIV has reduced transmission rates to less than 2% in high income contexts (Dorenbaum et al. 2002; WHO 2008). In low income contexts, by contrast, the transmission rate remains high varying between 20-45% (De Cock et al. 2000) and prevention of mother to child transmission of HIV (PMTCT) programmes continue to struggle with slow roll out, low up-take and low adherence (UNAIDS 2006). The reasons behind these problems are complex. This article inspects the so-called ‘adherence problem’ and discusses how the PMTCT programme with its particular knowledge and technology impacts on HIV positive mothers’ lives, identity and infant feeding experiences.

The HIV positive diagnosis is a focal part of the issue at hand. We are reminded time and again that a diagnosis does far more than passively register facts. Gibbon and Novas (2008) explore how novel biological or medical knowledge and technologies have the potential to shape identity and forms of identification and Mol (2000) importantly points out how ‘diagnostic devices intervene in the situations in which they are put to use.’ In this article we are concerned not only with a diagnostic device, but with the broader global PMTCT package which in turn is part of a hybrid (Latour 2005) where globalised health messages, medical institutions and experts, industry, science and rights activists emerge in a particular alignment and with particular effects. Our main concern here will not be the many and entangled elements of this hybrid but rather its complex impact on individual HIV positive mothers enrolled in the programme.

In the recent social science literature there have been many attempts to study how emerging biological truths create new scenarios and alignments. Rabinow’s (1996) concept of *biosociality* has proven to be useful in capturing how the social and biological link up and become ‘more or less temporarily and productively aligned’ (Gibbon and Novas 2008, 9). Rabinow’s concept was developed to enhance our understanding of the manner in which new genetic truths shape knowledge and identity and form group activism, but the concept has also fruitfully been drawn upon in attempts to grasp how people relate to and identify themselves with a particular illness, as well as how they relate to others suffering from the same illness (Gibbon and Novas 2008). The concept of biosociality is particularly interesting in the analysis of the processes at work in AIDS activism. Nguyen and colleagues (2007) have shown that participation in various forms of groups, training and workshops anchored in Western notions of ‘self help through disclosure,’ can produce radically altered domains of possibility for people living with HIV (PLWH). They argue that through such self help groups

individuals gain a range of interpersonal skills that are not only self transformative but also transform social relationships. These ‘social laboratories’ have through discourses of empowerment been able to train large numbers of effective HIV advocates and have created mass movements of AIDS activists. Robins (2006) comments on the remarkable social and ritual processes that have generated the conditions for PLWH to turn HIV/AIDS stigma, shame and isolation into a ‘badge of pride’. Recent writings have also revealed how such groups have opened new opportunities and avenues for marginalized individuals and their families to access resources. In their studies from West Africa, Nguyen and colleagues use the concept *therapeutic citizenship* to describe the ways in which PLWH engage in HIV activism, and how they appropriate ART as an encompassing set of ‘rights and responsibilities’. ‘Therapeutic citizenship’ implies a simultaneous personal engagement that requires self-transformation and a political claim to belong to a global community that offers access to anti-retroviral treatment (ART). The concept reveals how being on ART embodies the historical process by which local ideas and practices relating to health and the body articulate with the global political economy of AIDS relief (Nguyen et al. 2007,34).

In this article we will make an attempt to position our discussion of the PMTCT programme in relation to the concepts *biosociality* and *therapeutic citizenship*. In HIV and AIDS related work, these concepts have been particularly fruitful in the conceptualisation of the South African context (see e.g. Robins 2006) where the HIV epidemic has a history of an exceptionally high prevalence (18.5% in 2007) and where strong HIV activism has developed. In the settings where the present studies took place, the prevalence is much lower - at 6.5% in Tanzania and 0.9-3.5% in Ethiopia - (UNAIDS 2006, 2008) and AIDS activism is poorly developed. However, the policies on PMTCT are very similar in the three countries, not least because the programmes are guided by the same international guidelines. We aim to demonstrate that although biosociality and therapeutic citizenship are powerful concepts in an analysis of AIDS activism broadly speaking, they do not contribute to our understanding of the PMTCT programme and HIV positive pregnant women’s experiences as participants in the programme. We shall argue that the PMTCT programme and the structural conditions surrounding pregnancy and breastfeeding do not constitute a basis that is suited for HIV related activism.

We will investigate how the PMTCT programme impacts on women’s agency and power in relation to childbearing and infant care, and will show how ideals of motherhood and maternal nurture on the one hand, and biomedical knowledge and technology on the other, produce outcomes that sustain ingrained inequalities and deprivations. We shall argue with Bernays and colleagues (2007) that *hope* is a pivotal but commonly missing piece in the understanding of success or failure in HIV prevention and treatment programmes. The ways in which the programme generates differing degrees of hope of success of producing an HIV negative child, and beyond that a hope for the future of mother and child, becomes a key in the attempt to increase our understanding of the challenges that continue to haunt the PMTCT initiative.

The two authors have carried out extensive community and ethnographic fieldwork in Tanzania and Ethiopia since the 1980s. The specific material drawn upon in this paper was collected during several more structured study periods between 2002 and 2007, including 7 months in Addis Ababa and shorter periods in Arba Minch and Yirga Alem in Ethiopia and

Hadyom/Mbulu and Moshi in Tanzania. HIV positive mothers and PMTCT counsellors make up the main categories of informants. The talks took place at hospitals and health centres as well as in the informants' homes. The study findings are presented through case material and quotes from the interviews. We also refer to findings from PMTCT related work published by our Masters and PhD students (Koricho 2008; S. Leshabari et al. 2007a; S.C. Leshabari et al. 2007b; S. C. Leshabari et al. 2006).

The PMTCT regime: knowledge, experts and technology

If no precautions are taken, about one third of the children born to HIV positive mothers will be infected by HIV (De Cock et al. 2000), but with the current knowledge and technology most infections are preventable through ART and avoidance of all breastfeeding. In sub-Saharan Africa however, where breastfeeding is normative and essential to child survival, the latter is highly problematic. Unfortunately the customary prolonged breastfeeding pattern with early supplementation of fluids and solids, so-called mixed feeding, has been documented to strongly increase the risk of HIV transmission to the baby (De Cock et al. 2000). Research that has aimed at making breastfeeding safer has shown that exclusive breastfeeding, i.e. giving only breast milk and no other liquids or solids, brings down the transmission rate to less than one fourth compared to mixed breastfeeding (Coovadia et al. 2007; Coutoudis et al. 1999; Iliff et al. 2005).

During the last decade a global concerted action to save the child from HIV infection has been launched through so-called PMTCT programmes targeting pregnant women. The programme has quickly grown in scale, and has generated a whole range of interests and activities both inside and outside the health system on local as well as global levels. PMTCT offices have been established in antenatal clinics all over sub-Saharan Africa, thousands of PMTCT counsellors and lab technicians have been trained, and the development of counselling material and testing equipment has become an industry. Infant formula producing and pharmaceutical companies, governments, international-, faith based-, and non-governmental organisations, and human rights groups have all become parts of the complex global PMTCT network. PMTCT services are nonetheless accessible to less than 10% of the target group worldwide (UNAIDS 2008).

The initial standard PMTCT package was exclusively preventive of HIV transmission to the baby, and did not address the survival chances of the mother. The services included counselling and testing, different regimens of antiretroviral (ARV) prophylaxis to mother and child around the time of birth, and infant feeding counselling based on international guidelines promoted through WHO. These guidelines have been shifting with developments in knowledge and technology (WHO 2001, 2006a, 2006b, 2008), but the 2001 version promoting replacement feeding as the first choice of infant feeding method for HIV positive mothers has informed training and infant feeding counselling in PMTCT programmes across sub-Saharan Africa. After solid evidence of the risks of childhood infections and malnutrition associated with replacement feeding, and with the path-breaking documentation of a higher HIV free survival rate among exclusively breastfed than among replacement fed infants (Coovadia et al. 2007), the guidelines were revised in 2006 and the wording modified. It presently reads: 'Exclusive breastfeeding is recommended for HIV-infected women for the

first 6 months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe (AFASS) for them and their infants before that time' (WHO 2006b, 4).

The feeding options for HIV positive mothers suggested in local PMTCT programmes to date commonly include exclusive breastfeeding with early cessation (4-6 months) and exclusive replacement feeding with commercial infant formula or modified cow's milk. The guidelines grant the counsellor a key position as the expert possessing the knowledge and authority to enable mothers to make an 'informed choice' of infant feeding method (WHO 2001). The AFASS principles are fundamental to infant feeding counselling, but have proven to be hard to assess for counsellors. Furthermore both replacement feeding and exclusive breastfeeding have been found extremely challenging to adhere to for the large majority of the HIV positive mothers (S.C. Leshabari et al. 2007b; Rollins 2007).

In the following we explore how the PMTCT regime with its particular knowledge, experts and technology, is experienced by HIV positive women carrying and feeding their babies, and what this experience does to their sense of self and to their lives as social persons. We ask what the status as HIV positive does to the identity as mother and to the sense of hope and meaning in an environment constrained by poverty and structural inequalities.

Carrying and nurturing the child

After the introduction of routine HIV testing (WHO 2006b), the great majority of pregnant women attending antenatal clinics where PMTCT is offered are tested for HIV. They commonly get to know their HIV status during the first antenatal visit which usually takes place in the second or third trimester. This is a time when their bodies are visibly pregnant, when the mother feels and sees the movements of the baby in the womb, and when the bond between mother and child is getting stronger. It is a time when women are carefully watched by relatives, neighbours and friends. In times of HIV, pregnancy has in large parts of sub-Saharan Africa come to be considered an HIV test in itself. If mother and child survive and the child thrives it is taken as a sign that the mother is HIV negative. Pregnancy, as a transitional phase, is culturally elaborated with the aim to provide safety and protection of the mother so that she in turn can protect the child growing in her womb. It is at this vulnerable peak in the procreative cycle that the mother gets to know that she is HIV positive and that she is in danger of infecting her baby.

Despite the many social and relational dimensions of an HIV diagnosis received during a pregnancy, it is basically only the concern that the baby should be free of HIV that underlies the PMTCT programme. The messages that come across in PMTCT counselling; safe sex, ART regimes to prevent HIV infection at birth, birth in hospital and safe infant feeding are all precautions that a mother will have to take to prevent her from infecting her child. But even if the woman carefully follows the instructions of the counsellor there is no guarantee that she will get an HIV negative child. The uncertainty of the health of the baby is a great burden to carry, and for many of the mothers the thought of the foetus feeding through their infected body while still in the womb is very difficult to bear. The period after birth was however for most of the women we talked to, experienced as even more challenging. In a PMTCT context it is at this time that the mother can most actively affect the risk of transmission through her daily routine infant feeding practices.

Infant feeding counselling is framed in a discourse of choice. Based on information from the counsellor and on judgement of what would be appropriate, the HIV positive mother should choose to replacement feed or to breastfeed exclusively.

Struggling to exclusively breastfeed

In this study, the majority of the HIV positive mothers ended up breastfeeding, and tried to adhere to the infant feeding prescriptions of the counsellor to breastfeed exclusively.

Eli is 28 years and the mother of four children. She learnt that she was HIV positive when she was 7 months pregnant. The counsellor told her about infant feeding and said that the safest would be to formula feed, because 'the virus is in the milk'. But since she was poor and probably could not afford to buy formula she was recommended to breastfeed and only breastfeed for 6 months. Eli was upset and frightened, but felt that she had no choice but to breastfeed. After two months she felt extremely tired. She did not have enough food to eat and worried that her milk was not sufficient for the baby. Sometimes she could not stop the baby from crying, and she believed he was hungry. Her mother who visited said Eli had to introduce complementary food - otherwise the child would not grow. Eli recalls the argument with her mother: 'She said I would kill her grandchild'. But Eli was determined to stick to the instructions of the counselor, and was hoping that her persistence could save her baby from getting the virus: 'I do not want to harm my child so I have to breastfeed and give nothing else up to six months. When the baby is crying and I feel so tired, I sometimes want to give up. I think maybe I should give him some porridge to settle his hunger and get some rest. But then I remember my problem and I say to myself: "Instead of the baby having a problem, I better have the problem. I was the one who brought the problem."'

Adhering to the exclusive breastfeeding regime for six months was experienced as extremely challenging for the mother. A major worry, as we saw in the case above, is that the child will not get enough food. In areas where it is customary to introduce water and complementary foods in the first weeks after birth, or in some cases even before breastfeeding is established, and where close kin, like mother or mother-in-law commonly provide assistance and care to mother and child after delivery, exclusive breastfeeding is perceived as virtually impossible. A key concern is the risk that an uncustomary infant feeding practice, insisting on feeding the baby only breast-milk, may raise suspicion of HIV positive status on the part of the mother. In order to avoid being pressurised to give supplements including water or to involuntarily disclose HIV status, Mäsret, like many other women, tried to keep to herself during breastfeeding: *'My mother-in-law wants to assist me during confinement, but I have not disclosed to her and I do not like people close to me. I get nervous when they come. I used to like it, to chat and to discuss, but now I want to be left alone and feed my baby.'*

The responsibility for the HIV status of the child rested heavily on the mother's shoulders, and the fear of failing could at times lead mothers to take extreme precautions: *'I breastfed my baby for six months. I never gave her anything else. When I went out I even breastfed on the road. When I washed her body I was so afraid that water could enter her mouth. I never gave even a drop. I wanted a child free of my virus.'*

For most HIV positive mothers breastfeeding exclusively is experienced as unmanageable. This experience is also related to confused counselling messages:

'I chose exclusive breastfeeding because I had nothing else to give, but when I went for follow up in the clinic I met a nurse who reminded me that there is virus in the milk. She said it was better to stop breastfeeding. I was worried about feeding my child bad milk, so I decided to stop. I started feeding formula, but did not have money to buy enough, so I gave a little bit of each. Next time at the clinic I met a different nurse. She said: 'Are you bottle feeding? You should breastfeed'! So I went home and tried to breastfeed only, but I was so tired. I was exhausted. I was very skinny and could not eat. I could not feed my child. I hated myself, and fed him whatever milk I had.'

The fear of mother's milk

Although counsellors aimed to build their infant feeding guidance to the HIV positive women on knowledge and judgement, the infant feeding issue commonly was a highly emotional one also to them. A strong fear of transmission through breast-milk tended to undermine the promotion of exclusive breastfeeding as an appropriate and safe option. Many counsellors were terrified by the thought of HIV positive mothers breastfeeding: *'If I was HIV positive I would never breastfeed my baby. I would use my money, my intelligence and my time to make sure that the baby would get formula to feed.'*

A strong tendency among counsellors to ignore other aspects of the infant feeding choice than safety and affordability produced a notion that was expressed in two conflicting counselling messages: *'there is virus in the milk, you should not breastfeed'* and *'you are poor – you should breastfeed.'* The combination of the two was experienced as extremely disturbing: *'When the nurse told me that I have HIV in my breasts, I became so frightened of breastfeeding. I didn't have savings to buy tin milk, but I just couldn't feed my child my breast milk which is filled with the virus'* (Koricho 2008).

To many of the mothers the thought of breastfeeding was repugnant. A mother who had managed to secure support to replacement feed explained: *'During pregnancy the counsellor told me to breastfeed because I am poor. But I do not want to breastfeed. I will never give my baby my breast. I know the milk is coming from my body. I do not want him to grow by my body.'* The abhorrence against breastfeeding could take on physical manifestations. Another woman said: *'Every time the baby was sucking my breasts I felt like throwing up'* (Koricho 2008). Many women recalled the breastfeeding period as an extremely trying time when they felt that their bodies were a constant threat to their babies. *'I was so envious when I saw other women bottle feed their babies while I was feeding my child with my milk which has the virus.'*

In retrospect many of the women blamed themselves for not doing more to avoid exposing their babies to their milk and to HIV. Some perceived breastfeeding their infant as a sin that was punishable by God or in court: *'If God gives me a second chance to live the last two months over again, I would rather stop eating and buy tin milk for my child. I cannot believe I was breastfeeding my child knowing that I have the virus in my breast-milk. If you were a judge, you might have sent me to jail. I almost killed him.'* (Koricho 2008). As was

summed up in a discussion with counsellors: *'If women had a choice no one would breastfeed. Many feel guilty breastfeeding. But really, there is no choice.'*

In the context of HIV the symbolism surrounding breastfeeding and mother's milk seems to be changing. From a substance that is celebrated as necessary to sustain life, mother's milk is increasingly associated with contagion and a substance that threatens life. Its unquestionable superiority in preventing infections and malnutrition in infants is often ignored. Among our informants the social pressure to breastfeed is however experienced as tremendous. Julia who replacement fed her baby recalled a dramatic incident:

It was my daughter's baptism. I was not breastfeeding. She started crying and I gave her a bottle. People around asked me why I was not giving her my breasts. I told them I was bottle-feeding because I did not have enough milk. My elder sister immediately collected warm water and started massaging my breasts. She tried to express my breast milk. She told me to put my nipple in to my baby's mouth. I had nothing to say, and had to do what she told me to do. Since my breast was new for the baby, she did not take it. Instead, she started playing with it. I told them she does not like my breasts. I was praying to God that she would not be able to suck. (Koricho 2008)

Struggling to escape breastfeeding

Given the counsellors' messages of the risk of mother to child transmission of HIV through breast-milk, large numbers of women will try to avoid breastfeeding altogether. Hannah is 26 years old and single. Her boyfriend left when she got pregnant. She recalls:

When the counsellor informed me about infant feeding she said I should breastfeed because I am poor. I did not want to breastfeed, I wanted to formula feed, but I had no money. I breastfed the child for two months because I had nothing else to give, but I was nervous all the time and I was crying a lot when the baby was feeding my milk. I was all alone in a rented room and could think of nothing but death. My daughter forced me to go on. If I died, the child would die. Then I saw other women getting powder milk from a programme in the hospital where I went for check-ups and I got very upset. Why was I not offered that opportunity to give my baby safe milk? If I had known about the programme I would never have started breastfeeding. I stopped abruptly at two months and managed to get into the programme. I got monthly supply of free NAN, but only half of what I needed to feed my baby, and I did not have money to buy the other half. I started selling the NAN to the local kiosk and bought cows milk for the money. Eight tins of NAN was worth 116 birr. I spent 100 birr on cows milk, one litre a day and had 16 birr to spend on other foods. The baby took the bottle without problems. I should never have given my baby breast-milk. What if she becomes HIV positive?

To women who did not experience a great social pressure to breastfeed in their daily lives, replacement feeding appeared as the only option that they could live with, often irrespective of their actual ability to afford buying infant formula or cows milk. Very few of the mothers who replacement fed their babies had a permanent income. Many relied on the income of their partners, relatives, friends, or passers-by, and tried to get by from day to day. Some of the mothers begged in the street in order to buy infant formula or cows' milk. The mothers revealed that the appeal of the suffering innocent child is very strong:

Mulu, who was homeless and lived in the streets was very proud that she had not given her baby any breast-milk at all. At the time of the interview she had been to the health centre to pick up medicine for the baby who had diarrhoea. Mulu got to know her HIV status during her previous pregnancy, but breastfed then because she could see no other option: 'People said I could kill my baby'. She did not want to experience the tension and guilt again and was determined not to breastfeed this time: 'Every day I go to the big traffic lights in town, where the cars stop and I beg. I carry my daughter on my back and when people see her, they give me a few coins so that I can buy cows milk to feed her.'

The commitment to breastfeed

But despite the fear of breast-milk, there is a fundamental ambivalence attached to mother's milk which complicates the choice also for HIV positive mothers who have access to infant formula. A common statement among our informants is that a real mother is a mother who breastfeeds her child (S.C. Leshabari et al. 2007b; Moland and Blystad 2008). In a part of the world where breastfeeding is by and large seen as a condition for infant survival, the commitment to breastfeed is very strong and the motive of a mother who does not breastfeed may be questioned. If there is no good reason, like sickness or inability, a non breastfeeding mother may find herself condemned as a mother who puts her own needs before those of the child and the family or kinship group: *'If a woman does not breastfeed her newborn, people will ask why, especially the husband's relatives. They will ask: "What is the problem? Is it HIV? Or is she trying to maintain her body?" So everybody wants to feed breast-milk after birth.'* Some women who replacement-fed their babies felt that they deprived their child of the attachment and love otherwise accompanying breastfeeding. They struggled with guilt and with their identity as mothers: *'I wanted to breastfeed, but since it was not good for the baby, I decided not to. Also now I would like to breastfeed. I wonder when he grows up whether he will see me as his real mother.'* The experience of confusion over breast-feeding in the context of HIV was summed up by a counsellor: *'Women fear breastfeeding and they fear not breastfeeding.'*

Struggling for respect and survival

The notion that *'the poor have to breastfeed and let their children die'* was strongly communicated among our informants. The risk of transmission had a tendency of being exaggerated. Hence, according to nurse counsellors it was difficult to convince the mothers who had breastfed to test their children at 18 months out of fear of the result. If the baby should test positive it was experienced as a crime. One of the nurse counsellors explained how the moment of testing the child is perceived as intense and fatal: *'The mothers will not sleep until they have the results. When I tell them they are shaking. When the child is negative they kiss me, kneel down and praise the lord. They will not worry about themselves. It is very painful to reveal positive results. One mother fainted. They will cry and complain to God. "What did I do my Lord? The sin is mine. The child is clean."'*

The social status and respect of the mother vis-a-vis the community is closely linked to how she succeeds in feeding and raising her child. Elisabeth made a highly unusual act and disclosed her HIV status on TV, but regretted doing so as the assets that she had been

promised never materialised. Instead her family and neighbours treated her with disdain and kept her child at a distance. However, through the negative HIV test of her child, she felt that she eventually regained her status as a useful and proper mother: *‘Getting a child that was negative was like winning in a lottery. It changed my life and my status in the neighbourhood. Now he can play outside with the other children and the parents don’t care. I have gained respect as a mother. People see me as useful. There will be somebody to replace me.’*

But this case was an exception, and the road to this empowered status was commonly long and highly insecure both in medical, social and economic terms. For the large majority of the women we talked to, life was a battle to avoid sickness and disclosure, to maintain respectability and to secure their daily food and shelter. With the persisting stigma, disclosure often leads to homelessness. In a group discussion with five women, all had been thrown out of their houses at least once during the last year due to involuntary disclosure.

Eli had moved three times since she got her last-born. The son was now two years old and Eli was so thankful that he had tested negative for HIV. Her husband had moved out, but she still depended on him for economic support: ‘My husband buys things for the children, pays house rent for us, but I do not want to have sex with him so he does not come regularly. Now I worry. He has started losing his strength. He is becoming weak. I am afraid that he will soon die and leave us without support. If I die there is no father either. Without him, what will we do?’

Shattered identity, strained sociality

We began this article by referring to the transformative discourses leading to empowered identification with the HIV diagnosis, and the utility of the concepts biosociality and therapeutic citizenship to grasp the transformations at work. It has become evident in the pages above that we find few signs of similar ‘empowering’ transformative processes among women enrolled in PMTCT programmes. Indeed, rather than processes of positive identity making or positive modes of identification, we have found processes producing utterly negative identification with the HIV positive status and related problematic perceptions of body and self. Negative self image and identification obviously do not make news in an HIV context, but the particular force it gains and the particular ways in which this identity surfaces among young HIV positive mothers are particularly disturbing.

As we have seen, women enrolled in PMTCT programmes commonly receive their HIV diagnosis at a peak procreative moment, at a point in life where their focus is on the life in their womb. The embodied knowledge of having and being a body that through blood and milk can infect the offspring with a deadly virus gives the woman an intense sense of posing a physical threat to other living beings, whether inside or outside her. In PMTCT programmes women often develop an aversion towards their bodies as exemplified by the mother who recalled that she felt like throwing up when she breastfed her infant. Deep-rooted ideals about the female body, nurturance and care contrast with knowledge of her body as a risk to her offspring and produce a tendency among HIV positive women to constitute themselves as failed bodies. Biomedical knowledge of mother to child transmission of HIV, ideals of gendered identity, ideals related to the ‘right to know your status’ and ‘rights to individual informed choice’ appear in PMTCT programmes to be caught up in mutually detrimental ways and work to dissolve or ‘unmake’ rather than to ‘make’ the person.



Biomedical truths that are being produced about humans in diverse fields do not only shape our identities, but, as we have been reminded by Gibbon and Novas (2008) assist us in thinking through what kinds of sociality can emerge from disease and illness. Robins (2006) has, as we pointed out in the introduction to this paper, written about the extraordinary biosocial power of ART and HIV activism in a context of hyper stigma and HIV/AIDS traumas. In and around PMTCT programmes there has been no similar growth of activism and advocacy organisations. The PMTCT programme remains individualising in scope and approach and seems to restrain rather than facilitate the development of existing and new social bonds. As we have seen in the accounts above, the women commonly make great effort to stick to themselves, and often experience people in their social surroundings as barriers to their infant feeding regimes, whether opting for exclusive breastfeeding or for replacement feeding.

The recent HIV activism has revealed the links between avenues to new individual and social identities and access to drugs and other resources. Nguyen and colleagues (2007,34) highlight this point: 'Bluntly speaking skill at telling the right stories got activists drugs and kept them alive.' Among HIV positive mothers who desperately try to hide their HIV positive status, AIDS activism is highly irrelevant. Hence, potential avenues for external material support, except for scattered NGO initiatives linked to PMTCT, remain out of reach. The text above has shed light on the ways in which conditions of poverty and marginalisation create conditions of uncertainty and adversity for women in PMTCT programmes who desperately struggle to secure their own and their infant's survival.

The scenarios presented by our informants emerge in stark contrast to the overarching narratives of hope generated by knowledge production and ART scale up. Hope emerges as a key ingredient in the global PMTCT model, but also in our informants' accounts where hope is centred around ensuring the life and HIV negative status of the infant. Bernays, Rhodes, and Barnett (2007) bring attention to the close link between hope and the characteristics of the wider risk environment. The scrutiny of health inequalities demonstrates links between the environments people occupy and perceptions of possibility, autonomy and agency. A vital point, write Bernays and colleagues (2007, 6) is an understanding of the embodiment of social conditions—a process whereby wider social forces of health opportunity and inequality are internalized over time by individuals. High risk environments simply do not engender hope or encourage long-term planning or decision making (Bernays et al. 2007, 8).

In a PMTCT context we see that the influence of the social environment mediates behaviour in a manner which often privileges the accommodation of immediate risk over investing in health considerations for the future. Albeit the latest PMTCT guidelines state that mothers' health should be ensured and ART provided, the vast majority of HIV positive mothers to date receive no treatment. This implies that a mother lives with the knowledge that she may soon die and leave her child orphaned. In her daily struggle, the HIV positive mother will moreover be more immediately concerned about giving her infant food to secure his/her life than to search for the PMTCT identified optimal foods. Other PMTCT related scenarios have revealed that a mother will be so concerned with the HIV preventive advice given by the counsellor that she refuses to breastfeed even if her infant is malnourished and on the verge of starvation. Both approaches have been revealed in the accounts above and demonstrate how the HIV positive mothers' strategies are fundamentally situated within impoverished

environments that hardly engender hope and that cannot afford a consideration of long term health.

Concluding remarks

Let us close by raising the question of what it is that so fundamentally seems to prevent new mothers from becoming empowered HIV activists and advocates with the gains in self esteem, social ties, and life conditions that that may imply. An important part of the answer lies in the unacceptable fact that most of the women in PMTCT programmes are still not on ART, the number one trigger for empowered AIDS activism. The answer moreover has to be understood in light of the procreative peak these women find themselves in, a moment in a woman’s life which generates a fundamental experience of dependence and vulnerability. We do however believe that we have to bring the argument one step further in order to more fully grasp the problematic dynamics at work in PMTCT programmes. We will argue that the challenge is linked to the conceptual incongruity between notions of fertility and life on the one hand and notions of death and dying on the other hand, or more concretely between motherly love, nourishment and care on the one hand and threats of immoral sexuality leading to a deadly infection on the other. These incompatible notions are visibly manifested in the bodies of these young HIV positive women; through growing wombs and infants placed at their mothers’ breast the babies are an extended part of their mothers’ bodies, and hence their (HIV infected) blood and milk. It is the young vulnerable mother who has to carry the burden of these incompatible notions. This burden generates coping strategies characterized by non-disclosure and social caution rather than disclosure and social exposure which is demanded when the HIV positive status is to be drawn upon in quests for respect and resources. The knowledge and technology that make up the PMTCT programme unfortunately never came to consider such embedded scenarios. Policy makers were blinded by the potentials emerging from newly gained biomedical knowledge cast within an attractive ‘rights to know’ and ‘rights to choose’ discourse. The result has been a global programme that has added a daunting burden to a most vulnerable category of HIV positive women.



References

- Bernays, S., Rhodes, T., and Barnett, T. 2007. Hope: a new way to look at the HIV epidemic. *AIDS*, 21: S5-S11.
- Coovadia, H. M., Rollins, N. C., Bland, R. M., Little, K., Coutsooudis, A., Bennish, M. L., et al. 2007. Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first 6 months of life: an intervention cohort study. *Lancet*, 369 (9567): 1107-1116.
- Coutsooudis, A., Pillay, K., Spooner, E., Kuhn, L., and Coovadia, H. M. 1999. Influence of infant-feeding patterns on early mother-to-child transmission of HIV-1 in Durban, South Africa: a prospective cohort study. South African Vitamin A Study Group. *Lancet*, 354 (9177): 471-476.
- De Cock, K. M., Fowler, M. G., Mercier, E., de Vincenzi, I., Saba, J., Hoff, E., et al. 2000. Prevention of mother-to-child HIV transmission in resource-poor countries: translating research into policy and practice. *JAMA* 283 (9): 1175-1182.
- Dorenbaum, A., Cunningham, C. K., Gelber, R. D., Culnane, M., Mofenson, L., Britto, P. et al. 2002. Two-dose intrapartum/newborn nevirapine and standard antiretroviral therapy to reduce perinatal HIV transmission - A randomized trial. *Jama-Journal of the American Medical Association*, 288 (2): 189-198.
- Gibbon, S., and Novas, C. 2008. *Genetics, biosociality, and the social sciences : making biologies and identities*. London: Routledge.
- Iliff, P. J., Piwoz, E. G., Tavengwa, N. V., Zunguza, C. D., Marinda, E. T., Nathoo, K. J., et al. 2005. Early exclusive breastfeeding reduces the risk of postnatal HIV-1 transmission and increases HIV-free survival. *AIDS* 197: 699-708.
- Koricho, A. T. 2008. The fear of mother's milk in the era of HIV: A qualitative study among HIV positive mothers and health professionals, Addis Ababa, Ethiopia Centre for International Health. Bergen: University of Bergen.
- Kuhn, L., Stein, Z., and Susser, M. 2004. Preventing mother-to-child HIV transmission in the new millennium: the challenge of breast feeding. *Paediatr Perinat Epidemiol* 181: 10-16.
- Latour, B. 2005. *Reassembling the social: an introduction to actor-network-theory*. Oxford: Oxford University Press.
- Leshabari, S. C, Blystad, A., de Paoli, M., and Moland, K. M. 2007a. HIV and infant feeding counselling: Challenges faced by nurse-counsellors in northern Tanzania. *Human Resources for Health* 5: 18.
- Leshabari, S. C., Blystad, A., and Moland, K. M. 2007b. Difficult choices: Infant feeding experiences of HIV-positive mothers in northern Tanzania. *Journal of Social Aspects of HIV/AIDS* 41: 544-555.
- Leshabari, S. C., Koniz-Booher, P., Astrom, A. N., de Paoli, M. M., and Moland, K. M. 2006. Translating global recommendations on HIV and infant feeding to the local context: the development of culturally sensitive counselling tools in the Kilimanjaro Region, Tanzania. *Implementation Science* 1: 22.
- Mol, A. 2000. What diagnostic devices do: The case of blood sugar measurement. *Theoretical Medicine and Bioethics* 211: 9-22.

- Moland, K. M. and Blystad, A. 2008. Counting on mother's love: The global Politics of prevention of mother-to-child transmission of HIV in Eastern Africa. In *Anthropology and public health: bridging differences in culture and society*, ed. R. A. Hahn and M. C. Inhorn. New York: Oxford University Press.
- Nguyen, V. K., Ako, C. Y., Niamba, P., Sylla, A., and Tiendrebeogo, I. 2007. Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS* 21: S31-S35.
- Rabinow, P. 1996. Artificiality and enlightenment: from sociology to biosociality. In *Essays on the anthropology of reason*, ed. P. Rabinow, 91-112. Princeton: Princeton University Press.
- Robins, S. 2006. From "rights" to "ritual": AIDS activism in South Africa. *American Anthropologist*, 108(2): 312-323.
- Rollins, N. C. 2007. Infant feeding and HIV. *BMJ*, 334 (7592): 487-488.
- Thairu, L. N., Pelto, G. H., Rollins, N. C., Bland, R. M., and Ntshangase, N. 2005. Sociocultural influences on infant feeding decisions among HIV-infected women in rural Kwa-Zulu Natal, South Africa. *Matern Child Nutr*, 11: 2-10.
- UNAIDS. 2006. Report on the global AIDS epidemic 2006:133.health/New_Publicationa/NUTRITION/consensus_statement.pdf.
- UNAIDS. 2008. 2008 Report on the global AIDS epidemic. pp. 1-358.
- WHO. 2001. New data on the prevention of mother-to-child transmission of HIV and their policy implications: conclusions and recommendations. WHO technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS inter-agency task team on mother-to-child transmission of HIV. Geneva: WHO.
- WHO. 2006a. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: Towards universal access. Recommendations for a public health approach.
- WHO. 2006b. WHO. Consensus statement. WHO HIV and infant feeding technical consultation held on behalf of the inter-agency task team IATT on prevention of HIV infections in pregnant women, mothers and their Infants. Geneva: WHO.
- WHO 2008. Towards universal access, Scaling up priority HIV/AIDS interventions in the health sector. Geneva:WHO.