## The Right to Bottle Feed versus the Right to Life: Lessons Learned from the Prevention of Mother-to-Child Pilot Programme in South Africa

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South Africa serves as a quintessential example of how debates surrounding HIV/AIDS policies unfold on the ground. The prevention of mother-to-child transmission (PMTCT) pilot programme in South Africa was rolled out in 2001 using vertical policy, that is to say, implanting untailored policies from other countries into the South African context. South Africa's population spans a host of different socio-economic conditions making a one-size-fitsall PMTCT programme ineffective or even detrimental, especially in the case of infant feeding patterns. This paper will argue that the feeding pattern portion of the PMTCT pilot programme was unsuccessful because it failed to give the necessary attention to the contextual nuances of the HIV endemic in South Africa. In order to build the argument I will first, discuss what the PMTCT pilot programme entailed and the cultural barriers that hindered women from exclusively or effectively bottle-feeding. Second, I will explain why the government and weak health care infrastructure were also barriers of proper formula use. Finally I will use recent studies of exclusive breast feeding, flash heating breast milk, and the Kesho Bora Report to illustrate why innovative and more culturally sensitive responses would produce more successful PMTCT than vertically implementing policies based on the West's best practices.

Each year 700,000 children across the world, 90% of them being from Sub-Saharan Africa, are infected with HIV through mother-to-child transmission (MTCT), either in-utero, during delivery or as a result of breastfeeding.<sup>2</sup> Methods to reduce MTCT have been formed for all stages of possible transfer. Taking antiretroviral therapy as well as extra medical intervention, such as Nevirapine prophylaxsis, while the infant is in-utero has decreased the chances of MTCT enormously.<sup>3</sup> Equally, it has been decided that choosing a caesarean section over natural birth is the best practice for HIV positive mothers. The largest success for PMTCT is the practice of strict bottle feeding. Bottle feeding has guaranteed that a HIV negative child will remain that way throughout infant feeding. Breast feeding results in a 5 to 20% risk of vertical transmission.<sup>4</sup> Furthermore, 40% of MTCT of HIV happens during breast feeding.<sup>5</sup> Proper formula use acts as a 100% protection from MTCT; therefore, it is considered the best practice in the West. However, infant feeding choice has not proven to be so obvious in the developing world.

Historically nations respond to widespread disease outbreaks using draconian measures. Mandatory vaccinations for small pox, for example, were often administered forcefully by local authorities. HIV/AIDS is unique in that most nations agree that it is unacceptable to form responses that are not entrenched in the standards of human rights law. The Universal Declaration of Human Rights states that all humans have a right to the highest attainable standard of health. It is because of this right that the Office of High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS and Human Rights in 1998. Based on universal human rights,

every mother in South Africa has the right to the best method to prevent MTCT of HIV. Exclusive bottle feeding provides mothers with the option to feed their infants with zero risk of transmitting HIV. For this reason the South Africa PMTCT pilot programme was based on this method. Unfortunately, the socio-economic and political conditions under which these mothers live have caused considerable pitfalls for the use of instant formula and bottle feeding.

As stated by the World Health Organization (WHO), exclusive formula feeding is the best practice for preventing vertical transmission. <sup>7</sup> The organization however, does recognize barriers to formula feeding. As laid out by the WHO, to prepare formula one requires enough water to wash, rinse and sterilize one's hands, cleaning tools and the bottle pieces. As formula should not be used two hours after preparation, fuel to heat water and sanitize the working area are required. 8 This is problematic for families living in resource poor conditions because the lack of clean water or hygienic areas causes contamination of bottles and formula, thus bottle feeding causes more harm than good for the infant. Furthermore, formula costs can act as a barrier to effectively bottle feed. The price of formula can act as an incentive for mothers to add too much water in order to make the supply last longer which results in the infant's malnutrition. 10 In addition, breast milk supply during formula feeding becomes an issue. Breast milk production is controlled by a positive feedback loop; that is, a mechanism which is activated and perpetuated by an external input. In the case of breastfeeding, only as long as the infant suckles and consumes milk regularly will the mother continue to produce breast milk. Thus if the mother loses her access to formula because she cannot afford it, or there is an interruption to the delivery to the clinic, the mother may

not be able to produce enough sustenance or nourishment for the infant <sup>11</sup>

Due to these issues the WHO advices formula feeding only when it is acceptable, feasible, affordable, sustainable and safe (AFASS) otherwise exclusive breast feeding should be practiced with rapid cessation at six months. 12 Early cessation is done to allow children to obtain some antibodies from their parents while simultaneously limiting the amount of time they are at risk of MTCT. 13 However, there is little proof that early cessation helps to avoid MTCT as well as boost infants' immune systems. Rather, many others argue that early cessation may increase the rates of morbidity and mortality in developing countries. 14 These debates question what the 'best practice' for developing countries is. Because of these conflicting opinions, healthcare workers of the PMTC pilot programme in South Africa received inconsistent information and training, and often reported to be confused as to who falls into the right ASAFF conditions. This confusion translated into poor counselling when advising individuals on ideal feeding patterns.<sup>15</sup>

The WHO advocates exclusive feeding of one method or the other to avoid the dangers of mixed feeding. Mixed feeding is the feeding of breast milk as well as non-human milk, other liquids or solids. <sup>16</sup> The mixed feeding method is the most detrimental as it subjects the child to the risks of artificial feeding, vulnerability to infectious diseases as well as HIV. <sup>17</sup> Breast milk contains antibodies, which formula does not, and thus builds infant immune systems more quickly than bottle feeding. <sup>18</sup> This is extremely important for populations that live in unsanitary areas or that have unclean water supplies. Bahl et al. found that infants in developing countries that had not been

breastfed had a ten times higher risk of dying of any cause and a three times higher risk of being hospitalized for any cause when compared to those who had been predominantly breastfed. This could be attributed to formula prepared with contaminated water or diluted and kept too long in order to stretch the supply. One study found that, as opposed to exclusively breastfed infants, infants of HIV positive mothers that were fed both breast milk and other liquids were twice as likely to contract HIV. Furthermore, those that were mixed fed with solids were nearly eleven times as likely to acquire HIV. The bottle versus breast question, along with others, and the high incidence of MTCT in South Africa prompted the government to begin the development of the PMTCT pilot programme in 2000. The supplies the development of the PMTCT pilot programme in 2000.

The PMTCT pilot programme in South Africa was modelled on west's best practices. There were eighteen pilot sites, two in each of the nine provinces in order to equally represent urban and rural sites. It was developed to: provide voluntary HIV testing and counselling services to all pregnant women; provide micro nutrient supplements; screen for and treat STIs during the antenatal period; administer a single dose of Nevirapine to mother and infant pairs; adhere to proper obstetric practice during labour and delivery; and give 6 months of free formula, counselling and monitoring of infant feeding practices. <sup>23</sup> In theory this appears to be a well put together criterion for the PMTCT. Unfortunately traditional feeding practices and stigma surrounding HIV/AIDS in South Africa intensely hindered mothers from following the counselling and suggestions of the pilot PMTCT programme.<sup>24</sup> Even with the knowledge of mixed versus exclusive feeding and these guidelines, fear of stigmatization, socio economic conditions of mothers and poor counselling adversely affected the

intentions of the PMTCT programme and the allocation of free formula <sup>25</sup>

The programme covered a host of policy issues that still surround PMTCT today. Since not one indicator could encompass the full range of nuances that accompanied each site the initial government report on the programme used interviews to assess, more qualitatively, what had happened in the first year of the programme. 26 A multifarious and diverse body of analysis has developed since the pilot programme began to expand. The focus of the studies discussed here ranged from bio-medical to social, economic, cultural and so on. The indicators and methods of success or failure are just as varied. Consequently, for the interest of this paper, as with the initial government study, a holistic and qualitative vantage will be preferred for the analysis of the pilot programme. The quantitative analysis and methods used for any topics touched upon will not be discussed in detail and would be better served if explored in their original studies. One of the most highly questioned areas of the PMTCT pilot programme evaluation was around the benefits of free formula allocation and its impact on exclusive feeding patterns.

Ineke Busken's work concluded that traditionally, South African mothers mix feed their children from a very early age for three main reasons. First, they do not feel that breast milk sufficiently hydrates infants and as a result, they regularly feed them water. Secondly, mothers use herbal medicines to treat diarrhoea, colic or other common illnesses. Finally, solids, such as porridge, are given to infants almost immediately after birth because breast milk is thought of as a liquid not as food and thus, is not considered to be enough sustenance. Additionally, South African mothers feel that an insufficient diet and negative

feelings result in poor and too little nutrition in breast milk causing them to feel obliged to mix feed their children.<sup>27</sup> Education campaigns could potentially change these notions of breast milk but other socio-cultural factors contribute to mixed feeding practices.

HIV positive mothers often understand the rational of formula feeding and the dangers of mixed feeding but given that exclusively formula feeding is very unusual it can been seen as a signal of HIV positive status.<sup>28</sup> In South Africa, HIV is highly stigmatized and often disclosure of positive status results in domestic violence, outing and ousting.<sup>29</sup> This creates a fear of stigmatization so great that HIV positive mothers may continue life as normal because they feel that the consequences of disclosing their status outweigh the possibilities of transmitting HIV to their children.<sup>30</sup>

In addition to cultural norms and stigma, the financial and living conditions of mothers have made safe formula use very difficult. Despite the WHO guidelines for formula feeding, the PMTCT pilot programme promoted formula use in rural areas even though 67% of families there did not meet bottle feeding conditions.<sup>31</sup> Moreover, 60% of rural women took advantage of the free formula that was provided.<sup>32</sup> This high percentage illustrates serious operational problems of the PMTCT pilot programme. One conclusion that can be drawn by these findings is that feeding counselling was not taking the WHO's AFASS guidelines into consideration before distributing formula.<sup>33</sup> Another suggestion that can be made is that within the context of extreme poverty, free formula acted as an incentive to choose a feeding method that was not appropriate for those who are most at risk of the potentially lethal effects of bottle feeding.<sup>34</sup> Worries that mothers are

malnourished or cannot produce enough milk to sustain the infant's needs both encourage mothers to buy formula even if they only plan to use it to supplement mixed feeding. Also, the safety criteria of the WHO guidelines was not well-defined and thus both counsellors and, in turn, women are mislead as to what constitutes appropriate formula use in resource deficient conditions. These studies illustrate that vertical implementation of western feeding policies was unsuccessful in the rural South African context.

Poverty was not the only barrier to effective bottlefeeding in South Africa. The government funded evaluation, led by David McCoy, acknowledged that weak human management and physical infrastructure constrained the success of the PMTCT programme. <sup>36</sup> A substandard healthcare system left the PMTCT pilot programme with insufficient human and financial resources to properly train nurses how to counsel mothers on appropriate feeding practice choice.<sup>37</sup> Furthermore, clinics across South Africa were reported to have run out of formula.<sup>38</sup> This is particularly dangerous because of the way breast milk production acts on a positive feedback loop, as described earlier. A cross site study of the PMTCT pilot programme concluded that regardless of the socio-economic conditions of the sites, counselling of formula feeding was dismal, leaving mothers with insufficient knowledge of how to properly prepare formula or how to collect more formula if needed. 39 This poor counselling resulted in one third of women who met the WHO AFASS formula use conditions to choose to breastfeed. Conversely, it led to two thirds of mothers that did not live in AFASS conditions to prepare formula and bottle-feed anyway.<sup>40</sup>

Compounded with poor water and sanitation, unequal access to healthcare yielded even poorer results of

the PMTCT pilot programme. South Africa's healthcare annual district health expenditure ranges from R50 (US\$8) per capita to R389 (US\$55) per capita with those needing the most getting the least. 41 Underfunding of the PMTCT pilot programme caused a host of barriers to effectively lowering the rate of MTCT. Lack of human resources often left only one physician appointed to each site causing low staff moral and little on-site mentorship of lower-level employees. In addition, logistical difficulties arose given that any further training of the physician was usually in a larger city, therefore disrupting the service of the clinic. 42 In 2008, 36% of South African women still believed that vertical transmission was certain if the mother was HIV positive and furthermore, 50% of HIV positive mothers practiced mixed feeding even though exclusive feeding had been promoted since 2001. 43 Jeanne Raisler & Jonathan Cohn reported that after four years of PMTCT programmes few health workers had received training on HIV/AIDS, and it is argued that many still shared the general prejudices that stigmatize people with HIV/AIDS. For these reasons the PMTCT programmes have been largely ineffective and not until they become more widely available will these attitudes change.<sup>44</sup>

The inadequacies of South Africa's healthcare system are not easily remedied due to their historical entrenchment in the International Monetary Fund (IMF). After the oil crisis in the early 1980s the IMF began to grant loans to developing countries; however, these were not without strings attached. South Africa received one of these structural adjustment loans in 1984. This type of loan was called a structural adjustment loan because the conditions attached ensured that the countries would shift their governance in order to favour market based economies. Characteristic conditions of structural

adjustment loans include: cutbacks in government funding and spending, privatization of government programmes, reduced protection of domestic industry, currency devaluation, increased interest rates and elimination of food subsidies. All of these conditions are geared towards minimizing government intervention in the economy. 47 The encouragement of liberalization, privatization and the outsourcing of health services damaged the capacity of central governments, resulting in disorganized and fragmented health systems. 48 Africa, as a whole, still needs investment in health and infrastructure before it can be competitive in the global economy. However, for over two decades structural adjustment loans have been forcing countries, including South Africa, to skip these steps and, in turn, weakening healthcare systems and governments' abilities to respond to the HIV/AIDS pandemic.<sup>49</sup>

In the South African case we can see the legacy of these loans by the under-staffing of the PMTCT programme and the inability of many rural people to access clinics due to poor infrastructure, such as poor road systems.<sup>50</sup> Although South Africa is now a middle income country showing response to the HIV/AIDS epidemic, Peltzer et al found that in some areas of South Africa road systems are still so rudimentary that they hindered mothers from accessing health care facilities.<sup>51</sup> Trying to implement sweeping programmes, such as a national PMTCT programme, within weak health and physical infrastructure highlights the vulnerability of the poor and marginalized to unregulated markets. As the programme funding is stretched, rationing of treatment becomes inevitable and those who are easier to reach (read: higher income, typically urban) target groups receive preference. 52 Without investment into infrastructure, responses to health and access to clinics become inequitable based along social and geographic disparities.

The PMTCT pilot programme was a package of western developed best practices that did not take South African context into account. Given that HIV/AIDS responses have been built around an individual human rights movement, this is not surprising. Binagwaho argued that the reason that PMTCT programmes fail is because. from the beginning, the Westerners developing the programmes, feel that formula use is too costly and complicated for women in developing countries to use.<sup>53</sup> Farmer et al. argue the same notion pertaining to highly active antiretroviral therapy (HAART).<sup>54</sup> Both authors state that even though prevention programmes are rolled-out their managerial aspects are too weak to be effective. This is because they focus on condom use and education instead of going the tougher route and trying to effectively implement HAART or formula feeding.<sup>55</sup>

Both realize that poor health infrastructure makes it very costly and difficult to implement programmes that require sanitation, proper staff training and electricity. However, they do not feel that this is reason enough to set the bar for prevention and treatment programmes at a lower standard for developing countries. To emphasize this view they both cite studies of successful prevention and treatment programmes that used the countries' current healthcare infrastructures. 56 The success that Farmer and Binagwaho found in Haiti and Rwanda respectively, are valid and uplifting stories of responses to HIV/AIDS. To the authors' credit, they do not use these examples as crutches to avoid questioning the affects that poor governance and poverty have on effectively battling the disease. Rather they argue that while pushing to implement the West's best practices we must also fund programmes that will end 'structural violence'. 57 Structural violence

being conditions brought forth by economic, political, legal, religious and cultural forces that hinder humans individually or en masse from reaching their basic human needs or their potential. <sup>58</sup>

Fighting to end corruption, poverty, sexual violence, gender inequality, poor water supply, sub-standard infrastructure, diarrhoea, pneumonia, malaria, and the like is an enormous, time consuming endeavour. Unfortunately, today there are over thirty-three million people around the world living with HIV and 2.7 million acquiring new infections every year.<sup>59</sup> The funding that we have now is not preventing HIV through vaccines, education or MTCT. Binagwaho insinuated that those against bottle feeding feel so because they consider poor, uneducated and illiterate women in developing nations incapable of following instructions for medicines and treatment regimens. 60 The reason that the programme did not work outside of the western world is not because local citizens are not smart enough or willing enough to implement the programme, but rather, the programme fundamentally did not fit the context of a developing South Africa. In the face of so many structural problems bottle feeding is not now, nor will it soon be the best option for the nation's HIV positive mothers. Claudio Shuftan put it well saying, "...arguing for the right to bottle-feed is at best like arguing for access to a band-aid when faced with a haemorrhage. Poverty is the haemorrhage and it is the dominant human rights violation endured by these women and children,".61

Funding and research should not be going to free formula campaigns which are often detrimental to infant health.<sup>62</sup> It is true that 40% of child infections due to HIV are from prolonged breastfeeding but the fact that death due to other diseases is 6 fold higher for bottle fed infants ages

zero to two months make the inappropriateness of bottle-feeding in developing nations apparent.<sup>63</sup> If more research were to go into finding contextually sensitive methods of preventing and treating HIV/AIDS surely more people would get the help that they need sooner. There have been some very responsive and hopeful works done in South Africa responding innovatively to the HIV endemic, mainly exclusive breast feeding and flash heating breast milk.

The work that Hoosen Cooyadia has done on exclusive breast feeding and HIV transmission is an excellent example of innovative funding use. A study done by Coovadia et al. in South Africa found that MTCT was much lower for those infants that were exclusively breastfed. 64 Transmission was found to be 4.0% if the mother practiced exclusive breast feeding, lower than the most conservative WHO estimate, 5%. 65 Children who were fed both breast milk and formula were twice as likely to contract HIV and those who were mixed fed were eleven times more likely. 66 The study hypothesized that these types of results are due to complex proteins found in solid foods acted as an irritant on the infant's stomach lining. Once the integrity of the mucus lining is compromised there is less of a barrier between the HIV infected breast milk and the intestine therefore increasing the likelihood of HIV transmission 67

This type of research found a much more practical way of reducing MTCT for South African women while concurrently cutting the risk of infant morbidity and mortality due to other illnesses. Although exclusive breast feeding is unusual it would not act as a flag of HIV status. Coovadia's study found that with intensive counselling, mothers complied and successfully breast fed exclusively and, for a longer period of time than they would have

outside of the study. 68 With proper training of health staff, infants could remain healthier longer, thus taking strain off of clinics. Furthermore this type of training could be given to rural women such as respected elders or midwives; therefore, all local mothers could be educated on how to address their children's feeding needs without having to disclose their status or take long trips to the nearest health facilities. 69 All of these findings could have a greater impact on PMTCT programmes than does unilaterally giving free formula, as the PMTCT pilot programme in South Africa did. Had health workers implemented a programme in South Africa which paid more attention to what conditions the HIV positive mothers lived in, the programme may have been more successful.

Another body of research that is currently being formed in South Africa is flash heating breast milk. Although there still needs to be field work done on the feasibility of the method, flash heating breast milk is fast becoming a new hope for effectively nullifying the transmission of HIV through breast milk. Kirsten Israel Ballard et al. concluded that flash pasteurization of breast milk inactivates HIV-1cells that cause MTCT. 70 The sentiment is that this method is easy and effective therefore acting as a better method for PMTCT. 71 A glass jar of breast milk is placed into a pot of water which is then boiled. The boiling water heats the milk, deactivating the HIV-1 virus while still maintaining its antibodies and nutritional properties.<sup>72</sup> Although this method may fall to the same fate as formula due to lack of fuel for heating. signal of HIV status and such, it may not. Using funding to push formula use, a prevention method that has already proven ineffective in the South African context, is a waste of resources. New research may fail at first but may lead to

far more effective methods to battling MTCT in South African conditions

The Kesho Bora Report is a very recent example of such research. This report was released at the International Aid Society Conference on Pathogens, Treatment and Prevention, in Cape Town, South Africa in July, 2009. The report found that if women were part of antiretroviral therapy for the last trimester of their pregnancies and through the duration of breast feeding, it would reduce the risk of MTCT transmission by 42 %. Although the study was conducted in three areas of Africa, one being South Africa, the feasibility of implementing policy based on this research still needs to be studied. However, as professionals find solutions like these to cut MTCT risks, they give us hope that developing countries are coming closer to obtaining their own zero risk MTCT interventions.

South Africa's PMTCT pilot programme was supposed to train health staff to counsel HIV positive mothers to choose the best feeding option given their individual living conditions.<sup>74</sup> The number of women that chose inappropriate feeding methods based on the WHO's AFASS criteria speaks to three things. First, the healthcare system's lack of proper resources to spearhead such a project. Dismal training and staffing, unequal access to health clinics and poor infrastructure all contribute to misinformation or inability of mothers to understand the costs and benefits of different feeding choices. The second apparent hindrance of the PMTCT pilot programme is the socio-economic status of many rural or impoverished mothers. Those without access to clean water, sanitation or electricity or heating fuel were left without the means to properly prepare fuel even though free formula was being promoted throughout South Africa. Furthermore, free

formula paired with poverty gave incentive for mothers to take the formula for nourishment rather than PMTCT. This is considered extremely dangerous because given South Africa's traditional feeding patterns and stigma against HIV positive status it promoted mixed feeding rather than exclusive breast feeding. This alludes to a third all encompassing factor in the failure of the programme: inattention to the South African context.

The strong following to implement health policies based on universal human rights to health caused the vertical implementation of West's best practice for feeding in the PMTCT pilot programme. The adverse results that were found prove that these practices do not work in the developing context of poor or rural South Africa. Although this makes responding to HIV/AIDS much more difficult, there is a silver lining. From the poor outcome of the programme came innovative and more case sensitive responses that may prove to become best practices for developing world. In addition these methods may yield results equal to those found in western countries. The lessons learned from the pilot programme have the potential to increase health care outcomes to all women and mothers in South Africa, increase the communication and coalescence of different healthcare units' goals and decrease stigma by bringing HIV out into the open.<sup>75</sup> Undoubtedly, the goal of HIV/AIDS research and programme development is to find effective responses to the epidemic. This falls true even if those involved must go against the doctrine of universal human rights by finding alternate routes to attaining the same target, in this case finding a zero risk way to feed infants. Attention to context was missing from the South African PMTCT pilot project but hopefully the results will yield a more contextually

vibrant and thus more effective method for HIV positive mothers to safely feed their newborns in the future.

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## **Notes**

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<sup>9</sup>Rajiv Bahl, Chris Frost, Betty Kirkwood, Daren Edmond, Jose Martines, Nita Bhandari & Arthur Paul "Infant feeding patterns and risks of death and hospitalization in the first half of infancy: multicentre cohort study" *Bulletin of the World Health Organization* 83 (2005): 423

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<sup>&</sup>lt;sup>19</sup>Bahl, Frost, Kirkwood, Edmond, Martines, Bhandari & Paul "Infant feeding patterns and risks of death and hospitalization in the first half of infancy: multicentre cohort study" 421

<sup>&</sup>lt;sup>23</sup>Ibid. 4

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