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## Breastfeeding in the HIV Epidemic:

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## ABSTRACT

### **Breastfeeding in the HIV Epidemic: A Midwife's Dilemma in International Work**

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A nurse-midwife working with HIV positive women during the childbearing cycle in the United States is expected to implement protocols to prevent transmission of the HIV virus to the newborn. These include administration of antiretroviral medications to the women during the pregnancy and labor, as well as the policy of no breastfeeding, since breast milk contains the HIV virus and can be a source of passing the infection to the baby.

Ethical dilemmas develop when the nurse-midwife is an international worker in a country which is in the midst of the HIV epidemic such as South Africa. Current South African policy regarding mother-to-child transmission recommends either exclusive breastfeeding with rapid weaning at six months, or exclusive bottle feeding. Cultural practice favors breastfeeding with the addition of cereals, in effect, mixed feeding. These practices lead to a high risk of transmission and infection in the newborn.

What are issues an American trained healthcare provider might face in these circumstances? How does one uphold the right to self-determination, which assumes that the policies of the South African government represent the best interests of its people, and also discuss the potential risks of transmission with the current policy on breastfeeding? How does one uphold the principles of beneficence and non-maleficence if it has been established that breastfeeding carries a high risk of transmission, yet you work side-by-side with midwives promoting breastfeeding? What are the cultural competency issues that will demonstrate respect and integrity for this culture and society?

Guidelines which are culturally derived for resolution of these dilemmas must be researched and developed. This paper attempts to explore the ethical dilemmas faced by both international and indigenous nurse midwives in response to the mushrooming HIV virus epidemic in South Africa. Included are four guidelines intended to inform the ethical debate from the perspective of one who has been immersed in the culture.

**Key Words:** Nurse Midwives, HIV Virus, South Africa, Breastfeeding, Autonomy

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### **INTRODUCTION**

Imagine these scenarios. In a New York City healthcare center, a woman who is HIV positive has just birthed her child; she has received antiretroviral treatment during her pregnancy and labor. The midwife giving care reviews with her the need to bottle-feed her baby to minimize transmission of the HIV virus to her infant through her breast milk. She leaves the facility with plans for care of her breast, as well as a supply of infant formula. She can receive more formula as the baby needs it.

In the second scenario, the same midwife sits with her South African counterpart in a maternity clinic in Durban, the epicenter of the current HIV epidemic. The South African midwife explains to a woman, who is HIV positive and just birthed her child, that she will need to either exclusively breastfeed for the first six months or exclusively bottle-feed. The mother received one dose of an antiretroviral medication in labor, and her baby received one dose before discharge. The midwife tells the woman that she can receive infant formula if she attends a clinic for HIV- positive women. The woman opts to breastfeed, saying that she will be identified as HIV- positive by her family and community if she gives formula to her baby. The South African midwife wishes the woman luck and later informs the American midwife that the woman will probably not only breastfeed, but also, as is customary, give maize to the child within the first few weeks. If the woman had taken the infant formula, she would most likely breastfeed in front of her in-laws, as is also customary.

As an international health care provider, the American midwife faces an enormous challenge ethically to clarify roles regarding standards for breastfeeding in daily work with South African midwives, who work in the midst of this epidemic. Does one support the South African policy, which is contraindicated in the standards one follows at home? In respecting cultural practices and protocols developed in a resource-limited environment, is one to implement a policy that is potentially hazardous to the newborn's well-being?

### **BACKGROUND**

A major form of transmission of the HIV virus is perinatally from mother to child. Of the estimated 5.1 million children worldwide who have been infected with HIV, transmission from the mother to the child accounts for more than 90 percent of these infections, with two-thirds occurring during pregnancy and birthing, and one-third through breastfeeding (Joint UNAIDS/WHO, 2003). The rate of transmission is estimated to range from 15-30 percent, if the woman receives no antiretroviral intervention. With the addition of breastfeeding, another 15 percent is added to the transmission rate to the newborn (WHO). These figures apply globally to all women who are HIV positive.

Different standards for the diagnosis and treatment of HIV during the perinatal period exist between the United States, and other countries. Because of the disparity in the healthcare systems for black and white South Africans, South Africa is classified as a

developing country. In the United States, the Centers for Disease Control have specific recommendations for treatment of an HIV- positive woman during pregnancy. They include highly active antiretroviral treatment (HAART) during the pregnancy, which is initiated in the second trimester for all newly diagnosed HIV positive women; zidovudine treatment in labor for the mother, with the availability of cesarian section if the viral load remains high; zidovudine syrup by mouth to the newborn for six weeks; and exclusive bottle-feeding (Anderson, 2003). Implementation of this protocol has had a dramatic effect on transmission rates, reducing rates from 25 percent to 1 to 2 percent. (Coovadia, 2004).

In sharp contrast to resources in the United States in South Africa there is minimal access to antiretroviral therapy for the majority of women. South Africa has the fastest growing number of HIV cases in the world. Over five million people diagnosed with HIV and women account for over half of this number. The reasons for the explosion of this epidemic are complex, involving the unfulfilled promises of the current United States administration to give urgently needed aid; the pharmaceutical empire's slow response to making antiretroviral medications available at affordable rates; and the present South African government's delayed policies of addressing this rapid transmission of the HIV virus within the context of a two tiered health care system resultant from past apartheid policies. The South African Ministry of Health's standards for pregnant women have included voluntary counseling and testing (VCT) during the pregnancy and oral administration of one dose of the antiretroviral (Nevirapine) to women during labor and one dose to babies before discharge within 72 hours of delivery (Summary MTCT Protocol, 2002), reducing the risk of HIV transmission to 13 percent (WHO, 2003). With the initiation of the antiretroviral roll-out in April 2004, the government authorized provision of HAART to women whose viral load is less than 200. Implementation of this policy change is in its beginning stages. The policy regarding breastfeeding is a complicated one.

Given that the norm in South African society is for all women to breastfeed, that in rural areas access to safe water is often limited, and that infant formula is expensive for the majority of the population, the current policy recommends exclusive breastfeeding for six months with rapid weaning, or exclusive bottle-feeding. Policy supports the traditional understanding of the nutritive values to the baby from breast milk, now questionable with the impact of HIV. Worldwide, it is estimated that of the 700,000 children who were infected with HIV in 2003, approximately 315,000 were infected from breast milk (Coovadia, 2004). In reality, across South African society, the common practices are to breastfeed and add grains and water; it is rare that a woman, even with instructions, will exclusively breastfeed. A study being promoted in South Africa suggested that non-exclusive breastfeeding may increase the risk of transmission, arguing that the integrity of the intestinal mucosal barrier is not compromised with the exclusive use of breast milk, lowering the risk for the transmission of the virus. This research concluded that babies who were exclusively breastfed for three months had a lower risk for transmission than babies who received breast milk with other foods and fluids (Coutsoudis, 1999). An update to that study acknowledged the "breastfeeding-induced loss of efficacy of these regimens, (with) the overall risk of transmission at 18 to 24 months remain(ing) as high as 15 to 25 percent." (Coovadia, 2004). While policy is being debated on these issues, cultural practices continue to be a force. By South African

cultural standards, a woman who bottle-feeds is at risk to identify herself to her family and community as HIV positive, with the potential sequelae of social and economic isolation and even abandonment.

WHO standards recommend “when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV- positive infected mothers” (WHO, 2000). Given that urban areas in South African have access to safe water, it is clear that cultural considerations play a noticeable role in policy-making to give more credence to the safety of exclusive breastfeeding.

As a U.S. midwife working alongside South Africa midwives on training issues for giving care to HIV positive women, the question of support and implementation of current South Africa standards for breastfeeding is a challenging one. In Durban, where the majority of households have access to safe water and infant formula from special programs for HIV positive women, and where the current leadership supports exclusive breastfeeding more than exclusive bottle-feeding, what are the ethical issues and how can they be resolved?

### **ETHICAL ISSUES**

Autonomy is one issue to consider in a country with limited resources. This is especially true for foreign workers who provide health care in these countries. A country has the right, as a competent entity, to make decisions regarding the well-being of its citizens. This right to self-determination should be a driving force for ethical decisions, according to modern bioethics (Mappes, 2001). Applied to this situation, the South African Ministry of Health, assuming it represents the best interests of the health of its citizens, should be respected in the policies it develops to promote health. As South Africa develops its protocols regarding breastfeeding and HIV positive women, international workers need to respect the autonomy of this country’s justifications for choice and decisions to work within their standards.

A second principle of modern bioethics, the principle of beneficence, upholds the standard of doing good to others (Pellegrino, 2001). Its complementary principle is that of non-maleficence, or not harming others. These principles are more difficult to apply to the current situation in South Africa. Beneficence, in regards to breastfeeding, assumes that exclusive breastfeeding is in fact doing the greatest good for women and children; on the other hand, non-maleficence assumes that this policy is not harming children. If it is established that breastfeeding carries enough of a risk of transmission of the HIV virus to be prohibited in U.S. standards, and if there is enough access to safe water and infant formula in most urban settings in South Africa, are these principles being applied or confused? Dialogue to distinguish right from wrong and to determine the effects of acts on well-being are ethical mandates of a professional, be it in an international context or within one’s own society. (Thompson, 2004).

If a society determines how beneficence applies to the well-being of its citizens, then an international healthcare worker must be sensitive and open to the concept that cultural competence and respect also helps in negotiating another society’s ethical behavior. People from different cultures may have different perspectives, and therefore, disagree on ethical matters. Critics of western bioethics argue that many cultures value family and society as more important than individual autonomy. The principles of morality might be defined with different emphasis, depending on the culture (Macklin, 2001). South

African culture cherishes the role of breastfeeding in its definition of nurturance between mother and child. This cultural practice, with the onslaught of the HIV epidemic, now has the awful reality of producing its opposite effect, that of sentencing a child to infection and death. If an international worker respects the cultural practices of its host country, then that respect must also guide one in being open to different ethical outlooks in developing appropriate actions in this contradictory situation.

Certainly, guidelines for appropriate actions must include a fourth principle of ethics-justice. Conditions in the United States are not equitable with conditions in South Africa. Antiretrovirals are not accessible in a broad way in South Africa; the diagnosis of HIV in the United States has the potential for being a chronic condition, rather than the lethal sentence of AIDS and death as it is in South Africa. So, can standards that are considered safe in the United States, such as exclusive bottle-feeding, be applied to a country where the possibilities for their implementation do not currently exist? The principles of inequity and injustice need to be rigorously acknowledged before any conclusions about ethical behavior can be decided. Ethics and human rights are inextricably linked. If human rights provide a framework for defining human relations, then Thompson (2004) argues for a professional code of ethics based on “universal ethical principles of justice (equity) and respect for human dignity.” With implementation of standards and, in reality, the standards themselves differ between rich nations and nations with reduced resources; the potential for a vacuum of unclarity for application of ethics is created. Decision-making needs to reside within the hands of those who, ‘own the problem/decision,’ and each party needs to clarify its role.

When the question of developing standards regarding HIV transmission and breastfeeding is considered from a feminist ethics perspective, the issue of the role of women in South African society and their voice, or lack-of-voice in decision-making, demands attention. What are the views, needs, considerations and opinions of the midwives themselves, who have a strong ethic of care to the women they serve? Does this issue affect the status of women, promote their individual needs and rights? A feminist ethics perspective “urges careful examination of the interests of women as decision makers in maternal-fetal conflicts” (Mappes, 2001). An ethical approach, from an international perspective, requires an openness to the issues women face and their power, or lack of power, to impact on them.

## **GUIDELINES**

The development of guidelines is an appropriate way to frame the ethical questions raised by the issue of breastfeeding in HIV positive women and give direction for international work with South African midwives. Suggestions for these should include:

- 1) Encouragement of open dialogue with South African health care providers, particularly midwives, rather than passive acceptance of their standards. This should be done with respect for their autonomy, their cultural values, and great appreciation for the complexity of their situation. In the main hospital in Durban, King Edward Hospital, over 45 percent of laboring women are HIV positive ( J. Moodley, personal communication, 2004). With over 10,000 births a year, it is a

daunting challenge to expect midwives to counsel women to be tested for HIV, to take their antiretroviral medication in labor, to tell their partners of their status, and then to not breastfeed. A more appropriate approach is sharing knowledge, appreciating the dilemmas that arise, and supporting South African midwives as they test out current policy and strengthen, or struggle to change it.

Maintenance of open communication is a critical means of changing knowledge and attitudes towards breastfeeding. Communication is vital in respecting norms that exist in a culture and the possibility of changing them. Workers in Uganda found that “infant feeding for babies of HIV positive mothers remains a major communication challenge” (New Vision, 2004). They recommend that exposing local cultures to new ideas, such as bottle-feeding, is dependent on excellent communication channels.

- 2) Encourage research. More studies of the risks versus benefits of exclusive breastfeeding with rapid weaning or exclusive bottle-feeding need to be conducted. Facilitating and encouraging South African midwives to engage in research on modes of infant feeding are much needed, as well as urgent contributions from an international worker. Safe practices can only be developed when adequate information on outcomes has been obtained. This will also maximize the input of women on policies that affect them.
- 3) Encourage the establishment of committees and commissions to review policies for safety, efficacy and fair, deliberative process within the South African context. A group of researchers at Harvard University has debated the ethics of WHO’s goal of treating 3 million people with antiretrovirals by the year 2005, questioning the morality of this proposal when there are 6 million who need treatment. What will happen to the remaining 3 million infected people who will not receive treatment, and how will those treated be chosen? Their recommendation is an appeal to procedural justice, with the “need to rely on fair procedures (that include) publicity..., stakeholder involvement in agreeing to relevant reasons,... revisability,... and enforcement to assure that fair process is involved” (Daniels, 2004). Why not include the critical issue of breastfeeding in these policy forums? This would promote a fair and open debate over the controversies of values and encourage decision-makers to be accountable for solutions that maximize mother and child safety in an ethical manner.
- 4) Encourage dialogue among healthcare providers and the communities they serve. Honest discussions with women and families - in the churches, schools, healthcare centers, about the issues of HIV, its transmission, its prevention and its treatment are needed, if this epidemic is to be challenged. The issues of sexual practices and breastfeeding - the two major forms of HIV transmission in South African, can best be addressed by indigenous South African healthcare providers, who understand the cultural taboos and expectations. An international worker can support this dialogue as its urgency is accepted. South Africa, in its mobilization to defeat apartheid, has been exemplary of how a country can organize to defeat an unjust system. The country’s track record for mass organizing can be reignited to take on the issue of HIV. From the community level, new ideas will develop that will guide midwives in new policies. Ideas will emerge to contain this epidemic if the wall of silence can be broken. That is, if an environment where it

is permissible to be openly HIV positive and receive support can be established, if women understand how they can protect themselves from becoming infected and, if infected, prevent their babies from transmission. For example, why not have HIV- negative women give breast milk to babies of HIV positive women, thus preserving a cherished cultural practice?

These guidelines can only work within the larger global framework of recognizing the injustice of the HIV epidemic in Africa and organizing to provide resources. To mobilize one's community, one needs hope that life can replace death. In the epidemic of HIV, this means access to antiretrovirals. As treatment access becomes a reality, South Africans will, in their own unique and creative way, organize their communities. New policies will develop to improve health for mothers and babies. An ethical responsibility for an international worker is to raise these issues within the larger global community for discussion. It is only by developing and applying guidelines for action that an international worker can operate within a moral and ethical realm that makes health care truly caring for another society's health.

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