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Burden on my Breast: HIV and Infant Feeding in Zimbabwe

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Burden on my Breast: HIV and Infant Feeding in Zimbabwe

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Burden on My Breast: HIV and Infant Feeding in Zimbabwe

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**Introduction**

In 1999, the Joint United Nations Program on HIV/AIDS estimated that a total of 23.3 million people were HIV-infected in southern Africa [1]. As a result of the high prevalence of HIV, life expectancy in many southern African countries has decreased by as much as ten years, and adult death rates have doubled in many countries, reversing the gains of past decades of public health efforts. The highest incidence of HIV infections is among women aged 15-19; estimates of prevalence in antenatal clinics range from 30-40% across southern Africa [2]. Consequently, each year, an estimated 570,000 babies become HIV-infected by perinatal transmission, resulting in stagnant or rising under-five child mortality in Africa [3]. The global epidemiologic features of HIV infection among children reflect the pattern of HIV among women. Perinatal transmission occurs during pregnancy, delivery, and breastfeeding. Mother-to-child HIV transmission rates range from 14-32% among non-breastfeeding populations in industrialized nations and from 25-48% among breastfeeding women in developing countries [4]. Current technology for detection of HIV infection cannot distinguish between intrapartum and early postpartum transmission, however, meta-analysis data suggest that in breastfeeding populations, 20-25% of all transmission occurs during pregnancy, 35-50% during delivery, and 20-25% during breastfeeding [5].

**Figure 1.** Relative proportion of perinatal HIV transmission

![Perinatal HIV Transmission](image)
Although the rate of breast milk transmission has been difficult to quantify, 29% of acutely infected and 14% of chronically HIV-infected women are thought to transmit the virus to their infants through breastfeeding [6]. Risk factors for transmission via breast milk include high maternal viral load, increased duration of breastfeeding, non-exclusive breastfeeding and clinical mastitis or breast lacerations [7],[8]. Although breastfeeding is not the predominant route of perinatal transmission, infant feeding is a potentially modifiable behavior which, with effective intervention, could reduce or eliminate postpartum HIV transmission.

Even in the midst of a large-scale epidemic, treatment for HIV disease is still predominantly unavailable to Africans due to cost. In 1999, researchers working in Uganda found that giving a single dose of nevirapine to mother and to baby reduced transmission by 47% compared to an “ultrashort” course of AZT [9]. These findings have suggested the opportunity of an affordable intervention for reducing mother-to-child transmission in African countries and have led to a discussion of the most cost-effective and ethical approach in such settings.

Without available treatment for HIV or pharmaceutical interventions to prevent post-partum transmission, the benefit of offering voluntary counseling and testing (VCT) to pregnant and post-partum women has been questioned [10]. The purpose of this thesis is to address this question, is knowledge of HIV status beneficial for pregnant and post-partum women in southern Africa? The first paper reports the finding that in a small sample of women in Zimbabwe, HIV+ women who were unaware of their status held different attitudes about infant feeding and employed distinct infant feeding practices from HIV+ women who knew their status and from HIV-negative women. Specific infant feeding recommendations are offered as part of post-test counseling protocols; consequently,
women who do not return for their VCT results do not have access to the same information as women who return to learn their HIV status. Without access to this information, women may make infant feeding decisions that jeopardize the health of their infants.

The second paper is a discussion of human rights issues as they relate to VCT and infant feeding decisions. Lack of available information and pharmaceuticals continue to be important barriers to control of the HIV epidemic in southern Africa. However, although current discussions in the scientific community broach the subjects of investigators' responsibilities for and impact in communities with high HIV prevalence, researchers' ability to affect significant behavior change is dependent upon participants in the local settings where interventions are taking place. For many women in Africa, decisions to participate in a study, in HIV testing, or in interventions to reduce transmission from mother to child are constrained by power relationships with their health care providers, husbands and families. Even with adequate information, women may not be able to make behavioral changes that will benefit themselves and their infants because of fear of poor health care, family violence and community stigma.
Acknowledgements

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Paper 1:  
HIV and Infant Feeding in Zimbabwe: Knowledge, Attitudes and Practices

Introduction

The global human immunodeficiency virus (HIV) pandemic continues to advance and current estimates suggest that in resource-poor sub-Saharan Africa, more than 1600 children become infected with HIV each day [1]. The vast majority of children acquire HIV from their mothers. Mother-to-child transmission (MTCT) of HIV can occur in utero, intrapartum, and postnatally through breastfeeding, although the relative contribution of each of these routes needs to be further clarified [2]. Without preventive therapy, 25-35% of breastfed infants will be infected either peri- or postnatally [3]. Prevention of postnatal HIV transmission through breastfeeding is one of the most pressing research issues facing health care professionals in resource-poor settings where HIV infection is common and breastfeeding is almost universally practiced. Breastfeeding has been considered critical for optimal child nutrition in developing countries and its revival in such countries has been a major public health gain. However, meta-analysis data indicate that breastfeeding by HIV-positive women carries an additional risk of transmission between 14% (95% confidence interval [CI], 7%-22%) for established maternal infections and 29% (95% CI, 16%-42%) during acute maternal infections [4]. In two recent studies, early breastfeeding (1-5 months and <6 weeks) has conferred the highest risk of transmission [5],[6]. Risk factors for transmission via breastfeeding include mastitis during breastfeeding, long duration of feeding and mixing of breastfeeding with other infant foods ("mixed feeds") [7],[8],[9]. Postulated explanations for this high early transmission rate include immature infant immunity, disrupted gastrointestinal mucosa, and the large number of HIV-infected cells present in early milk [10],[11]. In 1998, a revised statement by the Joint United Nations Program on
HIV/AIDS recommended offering voluntary counseling and testing to all pregnant women, informing HIV-infected women about the risks of breast milk transmission, encouraging women to make a decision that incorporates their individual and family situations, and supporting each woman's decision [12]. However, most African women are unaware of their serostatus, and breastfeeding for at least two years continues to be recommended to all women of unknown status by WHO and other United Nations agencies because of high infant morbidity and mortality for diarrhea, malnutrition and acute respiratory infections among formula-fed infants in developing countries [13]. Identification of short, inexpensive antiretroviral regimens for reduction of postpartum HIV transmission is an urgent public health priority in sub-Saharan Africa [14]. Recently, the HIVNET 012 randomized trial in Uganda demonstrated that perinatal transmission could be reduced by nearly 50% in a breastfeeding population during the first 14 weeks of life, using a single oral dose of nevirapine (NVP) administered at the onset of labor to HIV-infected women and to their babies within 72 hours after birth compared with oral zidovudine (ZDV) given in labor and to the infant during the first week of life [15].

Due to the incomplete understanding of early transmission risk, the complexity of designing universal infant feeding recommendations, and the possibility for therapeutic intervention, there is an immediate need to elucidate current knowledge, attitudes and practices related to infant feeding in African countries. Published data describing infant feeding practices in Africa are scant but demonstrate that breastfeeding is virtually universal in Africa and that infant feeding practices (introduction of weaning foods, frequency of feeding, methods of increasing milk supply) vary considerably by country [16]. Pregnancy is a time notable for parents' unusual willingness to change behavior in many settings, and not surprisingly, some women in Africa have expressed a willingness to modify infant feeding
behavior in accordance with recommendations if such changes reduce the risk of infant infection and death from HIV [17]. However, because breastfeeding is socially valued in many communities, failure to breastfeed carries substantial stigma and may be perceived in itself as an indicator of HIV infection [18].

Knowledge of HIV status has been previously documented as a method of risk reduction for heterosexual transmission, but in the antenatal care setting, post-test counseling involves a discussion of specific recommendations for infant feeding. Therefore, women who do not return for their HIV test results receive less specific information about the risk and timing of HIV transmission through breast milk. Consequently, women who do not return to learn their status may have different beliefs and behavior related to infant feeding from women who have knowledge of their status. This aim of this report is to describe the knowledge, attitudes and practices of women in a peri-urban area of Zimbabwe related to infant feeding, and to determine whether knowledge of HIV seropositivity influences infant feeding behavior.

**Materials and Methods**

Zimbabwe is a southern African country of approximately 10.4 million inhabitants whose capital city, Harare, has a population of 1.5 million. The prevalence of HIV infection in Zimbabwe is one of the highest in the world. HIV seroprevalence among women presenting for care in peri-urban antenatal clinics has been estimated to be between 28 and 40% [19]. The study was conducted in Seke North antenatal clinic situated in Chitungwiza, a satellite community 25km south of Harare, where approximately 2400 deliveries occur annually.

This study was conducted in parallel with a clinic-based prospective cohort of women recruited for a clinical trial of short-course ZDV to prevent MTCT of HIV. Women
who booked for antenatal care at Seke North Clinic but were ineligible for the intervention trial due to late gestational age (>34 weeks by fundal height) were offered inclusion in this study. Informed consent was obtained for blood and breast milk collection at delivery, one day, four weeks and six weeks post-partum and for completion of standardized questionnaires at one day and four weeks post-partum. Figure 1 shows the number of study participants, those who were excluded from the study, and those who returned for test results. At enrollment, documentation of the presence of vaginal lesions and discharge was collected from the obstetric examination record. At subsequent visits, a history of specific symptoms and diagnoses, breastfeeding practices and breast problems (swelling, other signs of infection, cracked nipples) was obtained by interview. Each participant agreed to have any blood sample tested for HIV, regardless of whether she participated in voluntary testing and counseling (VCT). VCT was offered to all interested women and willing husbands free of charge and follow-up counseling was offered to participants and their husbands. Women who tested HIV-positive were provided with additional written and verbal information about risk and prevention of HIV transmission and about risks and benefits of infant feeding methods in accordance with the WHO Guidelines for Infant Feeding [20]. In accordance with these guidelines, HIV-infected women who were told their HIV-infection status were not discouraged from breastfeeding. The study was approved by human subjects committees at the University of California, Berkeley and at the Medical Research Council of Zimbabwe.

Focus groups with lay volunteer community counselors were held during questionnaire development in order to formulate the questions to be asked. The questionnaire was translated into Shona by a social work student and was piloted by the study research assistant. Revisions were made and the questionnaire was translated from
Shona back to English by another social work student to check for accuracy and clarity. Questionnaires were administered to each woman at two different time points. During the piloting phase, categories were chosen for many variables from the most common responses. During data collection, participants were asked to respond to open-ended questions and a research assistant coded the response into a response category or “other.” 97% (184/190) of questionnaires were administered by one research assistant. The other six questionnaires were administered by other trained research nurses or counselors.

The questionnaire administered on post-partum day one included demographic information, medical/health history and breastfeeding practices. Participants were asked if they practice a religion (yes/no) and the specific name of the religion was recorded. Source of income was recorded as salaried, informal (e.g. street vendor, dressmaker) or none for both the participant and her husband. Educational status was collected as the last year of school attended by category (any college or university/A-level/O-level/form 1-4/grade 1-7/none). Prior number of child deaths, stillbirths and miscarriages was recorded. The age of each child’s death was collected.

The questionnaire administered at four weeks post-partum included questions related to symptoms of mastitis, current feeding practices, future feeding and weaning plans, and hypothetical questions about the best way to feed or best choice of foods in a particular scenario (e.g. ‘If a mother is working, should she breastfeed? If a mother is pregnant with another baby, should she breastfeed?’). Number of feedings per day currently being given was collected as a categorical variable in increments of five feedings. Duration of breastfeeding was collected as a categorical variable in increments of ten minutes. Mixed feeding was defined as the addition of any food or fluid other than breast milk to the infant’s diet. Specific food choices were recorded. Questions related to future feeding plans (e.g.
planned time of weaning, planned time of supplementary food addition) were open-ended and were recorded as a number of weeks, months or years of infant age. Women were also asked to select several acceptable supplementary foods and one best food from a list of common infant weaning foods.

Maternal health was addressed by asking a series of questions (yes/no) related to symptoms of HIV or previous HIV-related diagnoses or hospital admissions previously associated with HIV seropositivity in Africa [21]. Additionally, participants were asked to compare their own health to a theoretical group of women of their age (more/less/equally healthy).

After enrolling in the study, a women was given two free HIV test vouchers which could be brought to the clinic by the participant or her husband during the hours of clinic operation. All VCT participants gave a blood sample prior to delivery. Women choosing not to participate in VCT were asked for a blood sample within one day of delivery. Two rapid HIV tests were performed on each sample. A Western Blot was performed if the two rapid test results differed (n=2). A Western Blot was considered positive if at least one band reactive to a core protein and one band reactive to an envelope protein of HIV-1 were present.

Questionnaires were entered using EpiInfo version 6.0 and after range checks and double entry of all questionnaires, the data were analyzed using SPSS. The X² test was used for analysis of proportions and ANOVA was used for comparison of means.

**Results**

Of the 116 women enrolled into the study; 17 (15%) were willing to have only a blind HIV test and 99 (85%) received VCT. Of the women receiving VCT, 52 (53%) returned for results. The number of women returning for results is consistent with reports
from Zimbabwe and elsewhere in Africa [22]. Thirty-six of 116 women (31%) tested HIV-positive. This seroprevalence is consistent with other antenatal clinic population point prevalences that have been reported in Zimbabwe and elsewhere in southern Africa [23]. 97 women completed questionnaires at one day and four weeks post-partum. Fifteen women were lost to follow-up (moved, returned to their rural home, or never returned for scheduled appointments), five women were excluded due to infant demise, and ten women dropped out. Three babies were stillborn (one mother HIV-positive, one HIV-negative, one unknown status) and two babies died during the study period (both mothers HIV-positive). Women who were HIV+ were more likely to have had a previous infant death (p=0.003), and women who knew and did not know their HIV status had similar past histories of infant death (p=0.759). The distribution of sociodemographic characteristics of the 97 women completing questionnaires is given in Table 1. The mean age of women participating in the study was 23.4 years (range, 16-35). The majority of women (90%) had more than a seventh grade education. 92% of women were married and 70% of women were dependent upon their male partner for all income. HIV-positive and -negative women differed only by education, HIV-positive women having less education (p=0.023). All children were breastfed at least once.

Mastitis has been identified as a potential risk factor for transmission of HIV through breast milk [24]. At four weeks post-partum, 14% of the total study population reported experiencing a breast symptom: breast pain (7%), breast “heat” (1%) or nipple cracks or lacerations (6%) within the first four post-partum weeks. Only one woman reported more than one symptom. HIV-infected women who did not know their HIV-status reported breast pain more frequently (18%) when compared with HIV+ women of known status (14%) and with HIV- women who knew and did not know their status (4%,
\( \chi^2 = 3.7, p = 0.053 \). Women were asked about symptoms, diagnoses and events associated with HIV disease (Table 2). HIV+ women were more likely to report three or more health problems \( (p = 0.038) \), and the subset of HIV+ women who did not know their HIV status were more likely to report health problems than HIV+ women who were aware of their HIV status \( (p = 0.047) \). 11.7% of study participants had vaginal lesions, discharge or both during the current pregnancy. HIV-infected women had a higher prevalence of vaginal symptoms than did HIV-negative women \( (44.4% \text{ vs. } 7.1\%, \chi^2 = 5.6, p = 0.018) \), and the largest proportion of women with vaginal symptoms was HIV+ women who did not know their status.

Participants were asked to compare their own health to a theoretical group of women of their age \( (\text{more/less/equally healthy}) \). HIV-infected women considered themselves less healthy than did HIV-uninfected women \( (p = 0.029) \), regardless of knowledge of status. Overall, HIV-infected women reported more health problems. The subset of HIV-infected women who did not know their status was equally symptomatic by self-report when compared to HIV+ who knew their status.

A majority of women reported feeding their babies within 60 minutes of delivery \( (70\%) \) and half of the sample \( (50\%) \) interpreted crying as the main sign of the baby’s hunger. 79% of women reported planning to continue breastfeeding until 1.5 years \( (25\%) \) or 2 years \( (54\%) \) of age. Three variables differentiated HIV+ women who did and did not know their status: average amount of feeding per day at four weeks post-partum, mixed feeding at one day and at four weeks post-partum, and planned age of weaning.

To describe the amount of feeding per day, women were asked to report their average daily number of total feedings and duration of each breastfeeding. A group of minimal feeders was identified \( (<10 \text{ feedings/day}, <20 \text{ minutes/feeding}) \) based on the
distribution of frequency and duration of feeding. HIV+ women of unknown status were significantly more likely to feed their infants minimally when compared to HIV+ women of known status and HIV- women (p=0.005).

Mixed feeding increased predictably with infant age. On the first day post-partum, 6% of women had given a food or fluid other than breast milk to their infants. The small group of mixed feeders gave mostly water due to perceived thirst or insufficient breast milk. HIV+ women of unknown status were significantly more likely to have initiated mixed feeding at day one than were HIV+ women of known status or HIV- women ($\chi^2=3.73$, p=0.05). At four weeks post-partum, 100% of study participants continued to breastfeed and 22% of women were mixing breastfeeding with supplementary foods and fluids. Of women who had introduced supplementary foods, the majority added either cereal packets (45%) or water (40%) to the infant's diet. HIV-positive women who did not know their status tended to mix feed sooner (16.7% at day 1, 33.3% at four weeks) than HIV+ women of known status (7.1% at day 1, 7.7% at 4 weeks) and HIV- women (2.9% at day 1, 22.7% at four weeks, p=NS). Consistent with counseling recommendations, HIV+ women who knew their status reported a younger age of planned weaning (15.8 months) than HIV-women. HIV+ women of unknown status reported an intermediate mean age of planned weaning (19.8 months), younger than the age of planned weaning of HIV-negative women (21.3 months, F=4.37, p=0.02). These data are presented in Figure 2.

When asked to choose the best food for supplementing an infant's diet, women chose powdered milk (48%) and porridge from maize meal, the staple food (33%). Formula was infrequently chosen as the best supplemental food (10%) and wet nurse was almost never identified (1%).
Women were read specific situations and asked if the woman in the situation should or should not breastfeed. The majority of women felt that women should still breastfeed if the mother is working (97%) or if the infant is ill (95%). Conversely, participants felt that a mother should not breastfeed if she is pregnant with another child (82%), if she is ill (83%), or if she is HIV+ (96%). 70% of women stated that never breastfeeding would imply to her husband that she is HIV-positive. Results are given in Figure 3. HIV-positive women were more likely than HIV-negative women to indicate that a woman should not breastfeed if the baby is ill (p=0.003). HIV+ women who knew their status responded similarly to HIV+ women who did not know their status (p=0.93). Because women in this study knew that HIV could be transmitted by breastfeeding, this finding may indicate that symptomatic HIV+ women may avoid breastfeeding when they believe it is the cause of their baby’s illness.

Discussion

The recognition that HIV is transmitted through breast milk raises the critical question of whether strategies that promote breastfeeding in areas of high HIV prevalence should be changed [25]. Formulating infant feeding recommendations is particularly difficult, given the maternal and child health benefits of breastfeeding, including the protective effect against infections diseases, which account for over two-thirds of the 12 million annual deaths in children under 5 in developing countries [26]. If formula were reintroduced into African populations, the phenomenon of cultural diffusion could result in a loss of confidence in breastfeeding and widespread use of formula and breast milk substitutes [27]. The WHO has expressed concern for a “spillover effect” of formula feeding by HIV-negative women if formula became affordable and available in developing countries [28]. Breastfeeding is virtually universal in sub-Saharan Africa, and without currently instituted
treatment for HIV or therapeutic interventions to prevent post-partum transmission, the
benefit of offering voluntary counseling and testing to pregnant and post-partum women has
been questioned. The finding that knowledge of HIV seropositivity may influence infant
feeding behavior provides a new perspective on infant feeding decisions in areas of high
HIV prevalence. In this study, HIV-positive women’s knowledge of their serostatus resulted
in infant feeding knowledge, attitudes and practices consistent with WHO
recommendations. In addition, lack of knowledge of HIV seropositivity may negatively
infant feeding behavior. Without post-test counseling including information about the risks
and benefits of breastfeeding, symptomatic HIV+ women in this sample who did not know
their HIV status may have made infant feeding decisions based only on the knowledge that
HIV can be transmitted by breastfeeding. Women may be detrimentally modifying their
infant feeding practices in the absence of HIV testing and specific counseling
recommendations. This spontaneous adaptation to available information emphasizes the
need for offering clear information about post-partum HIV transmission to all women
seeking antenatal care. Infant feeding is a potentially modifiable behavior which, with
effective intervention, could reduce or eliminate post-partum HIV transmission.
Unfortunately, however, in an effort to prevent HIV transmission to their infants,
symptomatic women may be inadvertently endangering their infants’ health.

Knowledge

In this study, women consistently reported knowing that HIV can be transmitted
through breast milk. Despite this knowledge, the majority of participants planned to
breastfeed for 1.5 to 2 years.

Attitudes
Participants distinguished between situations in which breastfeeding would and would not be optimal. Formula was not frequently chosen as the “best” supplementary food. Although this response may have been cost-based, women were discriminating about infant feeding situations, and formula feeding might not “spill over” to HIV-negative women in this Zimbabwean population if it were recommended only to HIV+ women. Finally, 70% of women interpreted never breastfeeding as a signal of HIV+ serostatus to their husbands. In this population, stigma may serve as an additional important deterrent to inappropriate formula feeding.

Practices

Most women in the sample fed their babies within 60 minutes of delivery. This finding may have relevance for the timing of a first dose of a pharmaceutical administered to prevent transmission of HIV-1 through breastfeeding. As in previously reported findings on infant feeding in Zimbabwe, many women perceived crying as a sign of their infant’s hunger and breastfed in response to the infant’s cry [29]. If a woman were planning not to breastfeed, substitute food would need to be prepared between feedings, so when the infant cries, the mother has food prepared and will not be tempted to breastfeed.

In Zimbabwe, the prevalence of mixed feeding is significant by four weeks post-partum. This finding is worrisome in light of a recent report demonstrating that mixed feeding may be associated with a higher risk of MTCT of HIV than either exclusively breastfeeding or exclusively formula feeding in the first three months of life [30]. If mixed feeding was confirmed as a risk factor for HIV transmission, it could be associated in this population with an early risk of transmission. Studies measuring prevalence of mixed feeding have largely excluded water, which was introduced early and frequently in this population. Future
studies should include water in questions related to mixed feeding to further consider its potential significance as a risk factor for post-partum HIV transmission.

HIV-infected women who did not know their status emerged as a distinct subset of women in this study. They reported more health problems than did HIV-uninfected women and more had more commonly experienced a prior infant death. In this study, symptomatic HIV+ women without knowledge of their status employed sub-optimal feeding practices: a tendency to introduce mixed feeding early and more frequently, to feed infants less food and to plan earlier weaning than HIV-negative women. In contrast to HIV-negative women, HIV-infected women of unknown status felt that a woman should cease breastfeeding if the infant is ill. Together, these findings suggest that women may treat their infants differently if they suspect themselves to be HIV+ but do not know their HIV status. In this population, women know that HIV can be transmitted through breast milk, and women who did not return to learn their HIV test results did not receive specific information about risks of post-partum HIV transmission. Therefore, their perception of their own poor health may influence their feeding practices, resulting in a tendency to feed less breast milk, introduce supplementary foods, and to plan relatively early weaning. While feeding less breast milk may decrease the infant’s exposure to HIV, decreased intake overall may increase the infant’s risk for malnutrition.

These feeding practices could result from fear of HIV transmission, but may also be an attempt to conserve limited maternal resources due to illness. In contrast to the concern for “spillover,” there may exist an additional “underfeeding” risk in this population resulting from mothers’ lack of knowledge of their HIV status. The majority of HIV-positive women in sub-Saharan Africa do not know their HIV status; if the attitudes and practices observed in this study are widespread, early supplementary feeding by HIV+ women who do not
know their status could lead to diarrhea, and decreased caloric intake could lead to malnutrition in infants of HIV-infected mothers.

This study was limited by the small sample size and by the potential for misclassification due to self-reported and unconfirmed data relating to infant feeding practices. Additionally, the study participants and the women lost to follow-up differed significantly, so the potential exists for selection bias. An “underfeeding” phenomenon was observed in this small Zimbabwean population, indicating that lack of knowledge of HIV status may be detrimental to infant health. Reproduction of these results in a larger cohort would be of serious concern. Due to the high HIV seroprevalence of women of childbearing age in Zimbabwe, these findings suggest an urgent need to improve HIV education and testing efforts, focusing on detailed infant feeding information for women seeking antenatal care.
Figure 1. Study Profile

Recruited
n=146

Dropped or excluded
n=30

Enrolled >34 weeks gestation
n=116

Women receiving VCT and returning for results
n=52
- HIV-positive: n=21
- HIV-negative: n=31

Women not receiving VCT or not returning for results
n=64 (17 no VCT, 47 VCT but never received results)
- HIV-positive: n=15
- HIV-negative: n=48
- Never HIV tested: n=1

Followed with questionnaires
n=97
Table 1. Demographic characteristics of antenatal women in Chitungwiza, Zimbabwe completing questionnaires (n=97).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV seroprevalence</td>
<td>31%</td>
</tr>
<tr>
<td>Mean age (years)</td>
<td>23.4</td>
</tr>
<tr>
<td>Currently practicing a religion</td>
<td>89%</td>
</tr>
<tr>
<td>Educational status greater than or equal to grade seven</td>
<td>90%</td>
</tr>
<tr>
<td>Married</td>
<td>92%</td>
</tr>
<tr>
<td>Husband has an income</td>
<td>96%</td>
</tr>
<tr>
<td>Dependent upon male partner for all income</td>
<td>70%</td>
</tr>
<tr>
<td>Percent primiparous</td>
<td>50%</td>
</tr>
<tr>
<td>Percent multiparous</td>
<td>50%</td>
</tr>
<tr>
<td>Previous child death</td>
<td>7%</td>
</tr>
<tr>
<td>Ever breastfed this infant</td>
<td>100%</td>
</tr>
</tbody>
</table>
Table 2. Percentage of study participants reporting health problems (n=97).

<table>
<thead>
<tr>
<th>Health Problem</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three or more loose, watery stools in the past two weeks</td>
<td>16.5%</td>
</tr>
<tr>
<td>Fever (hot to the touch) lasting longer than two days</td>
<td>4.1%</td>
</tr>
<tr>
<td>Swollen glands for more than one month in the past three months</td>
<td>18.6%</td>
</tr>
<tr>
<td>Coughing all day for more than two weeks in the past three months</td>
<td>12.4%</td>
</tr>
<tr>
<td>Tuberculosis diagnosis/treatment</td>
<td>2.1%</td>
</tr>
<tr>
<td>Genital sore ever</td>
<td>14.4%</td>
</tr>
<tr>
<td>Syphilis diagnosis ever</td>
<td>20.6%</td>
</tr>
<tr>
<td>Skin blisters in a linear pattern which are painful (herpes zoster)</td>
<td>0%</td>
</tr>
<tr>
<td>Admitted to hospital for reason other than delivery in past one year</td>
<td>13.4%</td>
</tr>
</tbody>
</table>
Figure 2. Percent mixed feeding and mean age of planned weaning
Figure 3. Situational attitudes about breastfeeding.
Nearly two decades into the HIV epidemic in Africa, there is a compelling need to ensure that effective and appropriate strategies to reduce HIV transmission are established. Expensive regimens that prolong life for people with HIV in developed countries are unlikely to become available to HIV-infected people in Africa; even short-course antiretroviral drugs to prevent perinatal HIV transmission continue to be prohibitively expensive. Substantial debate has surrounded the potential for access to antiretroviral therapy in Africa, and this vehement debate has forced a discussion of worldwide disparities in wealth and in health care [1],[2]. Although investigators from the United States are carefully considering the impact of their actions and the breadth of their responsibilities in developing countries, what is missing from the debate is attention to the factors limiting women's self-determination and active participation as subjects of research.

23.3 million people were living with HIV in southern Africa at the end of 1998, and the highest incidence of HIV is among women aged 15-19 [3],[4]. Estimates of prevalence in antenatal clinics range from 30-40% across southern Africa, resulting in an estimated 570,000 infected babies each year [5],[6]. Because of AIDS, adult life expectancy is expected to drop to 45 years, its lowest level in half a century, and under-five child mortality is stagnant or rising [7].

Up to this time, clinical trials reducing perinatal transmission have involved Voluntary Counseling and Testing (VCT), a process by which participants are informed about modes and risks of HIV transmission, are tested for HIV, and are given the result of their test. VCT is a technique that was established and utilized in developed countries to control the HIV epidemic in those countries and has been brought to Africa in the hope that
it would yield similar results. VCT has been available in Uganda and Rwanda for more than ten years, and in some studies, has demonstrated efficacy in slowing HIV transmission in the populations receiving testing and counseling services [8]. Recently, VCT centers have been established in Zambia, Malawi, Mozambique and Zimbabwe in antenatal clinic settings. Although it is too soon to have observed a reduction in sexual transmission of HIV in the new testing centers, measures of acceptance for VCT are generally high [9]. However, one could argue that unless VCT promotes desired behavior changes, it might not be a helpful intervention, so it is not the proportion of women who find testing “acceptable,” but the proportion returning for their test results that measures the effectiveness of VCT.

Unfortunately, high acceptability in antenatal populations has not been predictive of the numbers of women receiving HIV testing or spontaneously returning for test results [10]. In order to increase return rates in research studies, women are often scheduled for return appointments to collect test results, or the center provides same-day test results [11]. Return rates have varied between 30% and 82% in one meta-analysis [12].

But even when women are willing to participate and return for results, their consent may not have been truly voluntary. The requirement for participation in VCT is informed consent. Some have argued that the power differential between patients and health care providers prohibits true informed consent [13]. Women may perceive the health care worker’s desire for them to be tested and may succumb to this perceived pressure. They may feel compelled to participate, or they may believe that not participating will adversely affect their health care [14]. In addition to pressures in the health care system, participation in VCT may not be truly voluntary because of pressures within the family and community with regard to decision making.
In general, African women do not exert individual reproductive health decision making power. Historically, reproductive decisions in Africa are seen as a male right of marriage, and fulfilling the responsibilities of those decisions is the corresponding female duty. In addition to the historic male dominance of reproductive decisions, women in urban Africa are largely economically reliant on men and may fear the abandonment or violence resulting from making an independent decision. As one Zimbabwean man said, “If a wife comes to me with an idea, it is downsizing me [15].” Reproductive rights are an extension of human rights in marriage, education and employment. In societies where women are valued by the number of their offspring, have limited access to education, few rights in marriage and in property ownership, making reproductive health decisions; specifically, choosing to have an HIV test, might not be their first priority.

Others have argued that it is not the unacceptability of a woman making a decision but her fear of disclosing a positive HIV test result to her husband that obstructs her freedom to be tested. Sexual coercion and physical violence have both been associated with disclosure of HIV seropositivity in the home [16],[17]. However, the relationship between violence and HIV status is complicated and needs further elucidation. Women who experience violence may have an increased risk of HIV acquisition, and women who have HIV may have an increased risk of violence. In any case, the threat of violence or the existence of a power differential within marriage that is expressed as acts of violence may deter a woman from seeking HIV testing where it is available.

And even when a woman is tested and able to learn her test results, she may not be able to transform her knowledge into a behavior change. Studies have shown that although women may consistently report a desire to cease childbearing after learning that they are HIV+, the expected outcome of decreased subsequent fertility has not been shown to occur
[18],[19]. Evidently, there is a disjuncture between intention and action for African women concerning reproductive health.

Researchers have documented reports of violence against HIV-infected women whose consent for testing may have been a result of inadvertent coercion by health care workers [20],[21]. After observing that women seeking antenatal care may not be prepared for the decisions and consequences involved in HIV-testing, researchers have asserted that a woman should have the "right" not to know her HIV test results [22],[23].

Unfortunately, while not knowing one's HIV status is always a possibility, it is not a right that when exercised, will benefit a woman. Not receiving her test results may avoid coercive consent and may avert the potential harm of disclosing a positive test result. However, a woman who is HIV+ and ignorant of her status is still HIV+, and may unknowingly put others at risk. In addition, even with very high HIV prevalence among women seeking antenatal care, most women (70%) remain HIV-negative, and never returning for their test result precludes the health discussion about condoms and STD prevention that is part of post-test counseling. So, yes, it should be possible for a woman never to learn her HIV test results, but more importantly, it should also be possible for her to learn them without coercion or fear.

What public health officials fail to recognize in Africa is the interplay of social and cultural values in women's health needs and wants. In order to give true consent, a woman must have the ability, in the clinic and in her marriage, to make that decision. Furthermore, what has been consistently overlooked is that the same principles will operate to deter women from participating in interventions. If most women cannot freely and effectively participate in the process, interventions risk failure.
Women have the right to participate in any ethical intervention without violence, stigma or shame. They should be free to comply with the best available information that could improve their own health or that of their children. Strategies to prevent perinatal transmission should therefore not only consider what people deserve in a theoretical way, but what they identify as useful. Central to building useful interventions is a careful consideration of the situation and status of women living in communities of high HIV prevalence. One analysis of family planning programs found that the biggest determinant of reproductive rights implementation success was gender equality [24]. Not all prevention approaches need to be pharmacological, and women could benefit greatly from strategies that respond to, rather than blame or ignore, the social and cultural forces contributing to their vulnerability.
Conclusion

Voluntary counseling and testing for pregnant and post-partum women in Africa functions as more than a means to an end. Knowledge of HIV status may influence a woman's sexual risk taking behavior, but also may effect the beliefs and behaviors she employs in feeding her infant. Women who do not know their status may risk becoming infected, infecting others, and may inadvertently jeopardize the health of their infants. The findings reported in Paper 1 emphasize the urgent need to improve HIV education and testing efforts, focusing on detailed infant feeding information for women seeking antenatal care.

However, even with adequate information, women in southern Africa may not be able to make behavioral changes that will benefit themselves and their children because of fear of poor health care, family violence and community stigma. Because the HIV epidemic has persisted in sub-Saharan Africa, disseminating information and encouraging participation in voluntary testing and counseling should be considered as important as the introduction of pharmaceutical interventions. Future research and prevention efforts should address both the immediate risk factors for HIV transmission and the underlying social asymmetries in power, which facilitate its continued devastation.
Endnotes

Introduction


Paper 1


Paper 2


