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# "They Have Already Thrown Away Their Chicken": Barriers Affecting Participation by HIV-infected Women in Care and Treatment Programs for Their Infants in Blantyre, Malawi

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### Abstract

HIV-infected infants and young children are at high risk of serious illness and death. Morbidity and mortality can be greatly reduced through early infant diagnosis (EID) of HIV and timely initiation of antiretroviral therapy (ART). Despite global efforts to scale-up of EID and infant ART, uptake of these services in resource poor, high HIV burden countries remains low. We conducted a qualitative study of 59 HIV-infected women to identify and explore barriers women face in accessing HIV testing and care for their infants. To capture different perspectives, we included mothers whose infants were known positive (n=9) or known negative (n=14), mothers of infants with unknown HIV status (n=13), and pregnant HIV-infected women (n=20). Five important themes emerged: lack of knowledge regarding EID and infant ART, the perception of health care workers as authority figures, fear of disclosure of own and/or child's HIV status, lack of psychosocial support, and intent to shorten the life of the child. A complex array of cultural, economic and psychosocial factors creates barriers for HIV-infected women to participate in early infant HIV testing and care programs. For optimal impact of EID and infant ART, reasons for poor uptake should be better understood and addressed in a culturally sensitive manner.

# Keywords

HIV; HIV testing; barriers; infants; children; early infant diagnosis

# **BACKGROUND**

Until recently, the prospect for HIV-exposed infants was bleak, with 52% of perinatally infected children dying by two years of age, and a significantly higher morbidity and mortality even among those uninfected (Newell et al., 2004; Obimbo et al., 2004). The availability to diagnosis HIV at age six weeks by PCR (Sherman et al., 2005), and the demonstration that antiretroviral treatment (ART) reduces infant mortality by 76% (Violari, Cotton, & Gibb, 2007), resulted in the development of the early infant diagnosis (EID) and infant ART strategy (WHO, 2007). Unfortunately, factors such as lack of integrated services, poor quality of counseling, fear of disclosure, and fear of stigma have been cited as

important barriers to achieving high EID and infant ART coverage rates (Braitstein et al.; Ciampa et al.; Cook et al.; Nuwagaba-Biribonwoha et al.). Few qualitative studies have addressed barriers experienced by HIV- infected women in accessing care and treatment for their infants. A small study in South Africa (n=38) observed that mothers found EID highly stressful, and suggested that health care providers should understand how their messages are influenced by community views that may undermine the effectiveness of health programs (Lazarus, Struthers, & Violari, 2009).

Malawi is greatly affected by HIV, with 13.3% of pregnant women (ORC Macro) and 90,000 children estimated to be HIV-positive (UNAIDS/WHO). Mother-to-child transmission (MTCT) accounts for over 90% of all pediatric HIV-infections. We aimed to identify and explore in depth the barriers that HIV-infected Malawian women experience in participating in EID and infant ART programs.

### **METHODS**

# Setting and study participants

Study participants were HIV-infected women attending antenatal care programs from three clinics in Blantyre, Malawi. Prevention of mother to child transmission (PMTCT) services were present in all three clinics and included provision of single dose nevirapine to mother and infant and cotrimoxazole prophylaxis for all HIV-exposed infants until after cessation of breastfeeding. Infant HIV testing between 4–6 weeks of age was provided at the two clinics where children of participating women were enrolled in a study of the effects of HIV on infant neurodevelopment. To increase the likelihood of capturing a variety of experiences, women were purposively sampled during routine clinical care visits from four groups: (1) HIV-positive mothers of infants who tested positive for HIV; (2) HIV-positive mothers of infants who tested negative for HIV; (3) HIV-positive mothers who presented in the first month after delivery, prior to the six week EID visit, and (4) HIV-positive pregnant women.

The Institutional Review Boards of the Blantyre College of Medicine and the University of North Carolina approved the study. Written informed consent for participation was obtained.

### **Data Collection and Analysis**

Qualitative data sources employed included semi-structured, in-depth interviews of participating women. In addition, observation of clinical sites and informal investigator discussions with clinic staff were used to help interpret and contextualize the findings of the interviews. The interview guide included themes developed from the literature and clinical experiences, and was refined by the interviewers (three women and two men) prior to data collection (Table 1). All interviews were conducted in Chichewa, the native language of participants, and lasted approximately one hour. The interviews were audio-recorded, transcribed and translated into English soon after the interview was conducted. Transcribed interviews were coded using Atlas.ti, to identify themes and patterns that emerged from the data.

### **RESULTS**

# **Demographic Characteristics**

Of the 59 HIV-infected women, only 56 transcripts were analyzed due to technical difficulties with the audio-recording equipment. The women's ages ranged from 21 to 36 years, most were married and had other children. Only 15 (27%) of women were on ART for their own health (Table 2). Most children (92%) had received a single dose of nevirapine shortly after birth.

# Knowledge of mother to child transmission of HIV, EID and Infant ART

Most women had a good understanding of how and when MTCT occurs and were aware that interventions to prevent such transmission were available. Nearly all women knew that breastfeeding was a risk factor, but expressed serious concern about the financial feasibility of early weaning at six months. Two nurses believed this deterred women from seeking care for their infants. None of the women expressed the understanding that breastfeeding was beneficial in preventing respiratory and diarrheal illnesses during infancy. Many women believed that the purpose of cotrimoxazole was to further prevent MTCT.

Most of the women were aware that infant testing is available and could describe how it was performed but only had a vague awareness about the availability of infant ART and did not understand that early testing was the pathway to early treatment. This was especially true for women not receiving ART for their own health. In addition, women suggested that many other women in the community lack knowledge about infant testing and suggested that cultural beliefs were also important.

A wise mother should have her baby tested because this disease is happening every day. Some women, when a baby is sick, they do not go to the hospital, rather they go to the witch doctor thinking their child has been bewitched. Then the baby dies because of lack of knowledge. [Z20]

There are a few people who know the difference between the importance of testing themselves and the importance of testing their babies. They are just staying in the community because they do not know... [N05]

### **Disclosure and Stigma**

Most women (80%) had disclosed their HIV status to their partners soon after receiving their HIV diagnosis. Those who did not disclose to their partners spoke about how men were not deemed worthy of disclosure, rather than reporting fear of abandonment or violence.

My husband takes alcohol. When I try to share my problems with him, he doesn't care. [M12] I did not tell him but he knew because he saw me taking Bactrim.

I don't think he deserves to know because he is always away. [M16]

One study participant reported her husband's initial supportive attitude changed with time.

I thought he should be the first person to tell and he is a part of my body, we live together and do everything together. ...In the first days, he showed support saying that "it is not an issue, it has happened and there is no problem." After a month he started changing, at times he would not welcome me at all, he would tell me that I should go to my home. He acted as though he doesn't want me. [N05]

Nearly all women had disclosed to at one or more family members, most often their mothers or sisters because they will "keep secrets".

She [my mother] can keep my secrets unlike a friend. You might have a friend who think loves you and you might tell them your secrets but you wouldn't know what they really think of you and who they will tell your secrets to. [M12]

Despite the fact the most women had disclosed their HIV status to family members, very few women disclosed their status to friends or others outside their families, unless others disclosed their HIV-positive status to them first.

I told my neighbor because she opened up to me. She told me "I am HIV positive." ... Since she was the first one to tell me, it was also an opportunity to tell her. I am afraid if I tell other people, they might segregate me or speak badly about me.

Instead of it being something good, it may end up causing problems and keep me sad. [N04]

Women also expressed fear that attending HIV treatment or support services in their communities and weaning their infants from breastfeeding might result in involuntary disclosure.

They are scared of joining groups because they think people will know their status. [Z18] The problem is now that everybody knows that if one stops breastfeeding at 6 months, it means you are HIV-positive - so I fear a lot. I fear people will know about my status at that time. [N17]

Although participants acknowledged that attitudes about HIV changed as treatment became more widely available, HIV stigma persists. When asked how HIV-infected women were perceived by others in the community, several women used the phrase "she is already a corpse." The meaning of this in the cultural context of Malawi is unclear, but based on conversations with Malawian clinical staff and the context of the comment, it appeared the phrase meant a fate to which one is resigned.

It hurt me so much because I was faithful and clean before the eyes of God. So it is very painful and it is a huge burden for me. [M08]

[My sisters] were avoiding me. When I started taking ARV's I got sick, I had mouth sores, I had to eat alone. I had my own eating utensils. [Z20]

## **Autonomy**

Most women said their husband or other male family member made major decisions in their families, even when the husbands had moved away from home for employment or had left the family; however, women did not feel that their husband would refuse to allow them to seek care for themselves or their children. Very few women had financial autonomy, as they were unable to obtain a source of independent income.

Another theme that emerged was the lack of autonomy women exhibit in discussing issues with health care providers. Many women stated that disease progression and HIV transmission to their babies could be avoided if they simply "followed instructions". Women did not question their recommendations and deferred completely to the health care providers as authority figures.

If health personnel give you instructions and you do not follow them, you will face problems. On the other hand, if you follow the instructions given, you will not have any problems. [N05]

### **Psychosocial support**

Most women reported receiving very few psychosocial supports, resulting in isolation and sadness. Many women articulated their beliefs that stress from illness and lack of social support directly contributes to poor health outcomes for themselves and their infants.

I shouldn't lie. There's no one. Someone cannot just come from nowhere to encourage me maybe because they do not know my status. So, there is no one who encourages me. [N06]

At first I was worried, that is why maybe my immunity dipped so drastically within a short period. But when I came to this organization/group, they encouraged me and assisted me to be strong....When people encouraged me that I should not be stressed that I may die early, I managed to overcome the stress so that I can take

care of my child because if I am too stressed, I may die and leave the child suffering. [N09]

Even though all women reported a religious affiliation (mostly Christian), very few received church-related social support. It is not clear if this occurs because women do not disclose their status to church members or because some community religious leaders openly preach that HIV-infection results from sinful behavior.

# "They Have Already Thrown Away Their Chicken"/M(Other) Love

Nancy Scheper-Hughes uses the term *(M)Other Love* to capture the philosophy that the love a mother feels for her child is not a natural or universal phenomenon, but represents "a matrix of images, meaning, sentiments and practices that are socially and culturally produced (Scheper-Hughes, 1992)." This conceptualization is appropriate when considering responses that that several women gave when asked "What would keep mothers from getting their infants tested?" They stated that some mothers might decide not to seek care for a very sick infant or even hasten the death of their infants. None of the women referred directly to themselves but rather describe what "some women" in their community might do. Given the sensitive nature, little probing or further exploration of these remarks was done.

What prevents mothers from having their babies tested is that they are scared that once they know that their baby is HIV positive then ("nkhukhu yawo ayitaiyalatu") they have already thrown away their chicken. And they might shorten the life of that baby because they are worried most of the time. [M08]

Some people think that they would just throw them [HIV-infected infants] away and others would give them termik [a phosphate-based poison]...people tell her that "why not get rid of him, he is a child, he will keep you busy." [M17]

I will answer you like this that most women don't see the importance of going to hospital when their child is found positive because they feel in that in any case their child is going to die so they better leave him alone rather than troubling him by giving him drugs. [N09]

For a person who gets fed up (giving the infant medicines) you can stop giving the medicines with the aim that the child should die. [N05]

### DISCUSSION

In this study of HIV-infected Malawian women, we obtained in-depth information on the barriers to participation in EID and infant ART programs. We confirmed that fear of stigma place an important role in the low coverage of infant HIV diagnosis and care (Braitstein, et al.). We identified four other important themes: lack of psychosocial support, lack of community knowledge of EID and infant ART, lack of autonomy, and "M(other) Love". We also concur with previous research that adherence to care and treatment depends on interacting cultural and environmental determinants (Vreeman et al.).

Disclosure and stigma are barriers that are closely intertwined and operate bidirectionally in affecting the experiences of HIV-infected women. High levels of stigma in a community can affect the willingness to disclose and the lack of disclosure can perpetuate internal and externalized forms of stigma. Fear of disclosure of HIV status and stigma have been frequently cited barriers to testing and seeking care (Berendes & Rimal, ; Ostermann et al.). Fears of abandonment or violence have also been reported as reasons for a woman's reluctance to be tested or disclose her status (Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001). Despite the ominous presence of stigma in the community, most participating women had disclosed to partners and/or immediate family members but few had disclosed to friends

or other members of the community. This lack of disclosure appeared to result in social isolation and lack of social support. In contrast to the South African women who were "embedded in a social network that provided support in caring for their babies and coping with stress", the Malawian women highlighted the negative effects of the lack of social support on their health and the health of their infants. We also noted male partners could initially be accepting and supportive but later could become more distant and rejecting. Disclosure is thus best seen as a process influenced by context and cultural norms, with both benefits and consequences changing over time (Varga, Sherman, & Jones, 2006).

Gender inequality resulting in lack of autonomy has been observed to limit participation in PMTCT programs (Maman, et al., 2001). Malawian girls are socialized from birth to be "submissive, polite, and put herself last (White, Kachika, & Banda, 2005)." Participating women reported limited financial and decision-making autonomy, but did not suggest this poses barriers to seeking health care for themselves or their infant. As a lack of gender autonomy may limit the likelihood that women would identify it as a barrier, interviews specifically tailored to address gender autonomy may be necessary to better elucidate its role. The lack of autonomy Malawian women feel may have led to the view of health care workers as authority figures who are not questioned, resulting in women's perception that they cannot ask explanations or voice concerns. "Following instructions" may have led women to keep silent about the feasibility of operationalizing the instructions in their own lives. The misunderstanding of the role of cotrimoxazole and the difficulties posed by the breastfeeding recommendations are examples. These findings suggest shortcomings in health worker communication, similar to that observed in South Africa, and indicate that more effective communication between health care workers and HIV-infected patients should be more closely attuned to the changing needs and experiences of HIV-positive mothers, and take account of normative community views (Lazarus, et al., 2009).

Unquestionably, the most surprising, complicated and highly charged theme that emerged was the suggestion that "some women" may prefer to let their children die rather than bring them for testing treatment. Although these quotations are compelling, a comprehensive grasp their meaning is not possible without a deep understanding of the social, cultural, and political contexts of the women in the Blantyre community. The work of two anthropologists is relevant. In her ethnography of women in a shantytown in Brazil, Nancy Scheper-Hughes illustrates in rich detail the meanings of deprivation, loss, and social abandonment, as well as their effects on the ability of women to love, nurture, and trust (Scheper-Hughes, 1992). She shows that the high expectancy of child death is a powerful shaper of maternal thinking and practices. She posits that day-to-day moral thinking is guided by a variation of "lifeboat" ethics, i.e. who should be saved when it may be dangerous to try and save all (Scheper-Hughes, 1992)? Sarah Hrdy describes infant abandonment and infanticide as a continuum that has existed throughout history. Hrdy argues that mothers do not set out to do harm to their children and that maternal behavior cannot be evaluated in isolation from the mothers' circumstances. Moreover, she argues that those societies where infant neglect or infanticide is unthinkable tend to be those where women have some degree of reproductive autonomy, access to birth control, or societies where mothers are economically and culturally able to delegate care of their children to others (Hrdy, 1999). The circumstances of extreme poverty and high child mortality rates are a reality for HIV-infected women in Malawi who are faced with making similar decisions that set the survival of themselves and/or other children against the needs of an ill child.

While this study is one of the first to present in-depth information on barriers to EID and infant ART, there were important limitations. First, because we did not have permission for home visits of women who do not present to the clinic, which could lead to involuntary

disclosure of HIV status, we included only women who engaged in care and not women who had defaulted EID. However, we believe that the women we did include are likely to have encountered and overcome some of the barriers, and can therefore provide valuable insight into the barriers that women in the community must negotiate in order to present for the EID services. Second, two of the three sites were involved in research, which may limit the generalizability of the findings to more typical settings characterized by crowding and long waiting times. Finally, while the data is presented in discrete categories, it is essential to understand that the factors are interrelated, dynamic and likely to interact in a myriad of ways that must be contextualized for each mother's circumstances.

In all areas of HIV testing and treatment, a variety of cultural, economic and psychosocial factors must be considered when determining the best approach to maximize access to potentially lifesaving services. It is clear from our research that there are multiple barriers to the rollout of EID services, including a lack of awareness of the availability and benefits of these services. The specific reasons for poor uptake need to be better understood and subsequently addressed in order to facilitate expansion of the testing and treatment services necessary to protect the youngest population affected by the HIV epidemic.

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#### Table 1

### **Interview Guide Topics**

#### Disclosure

- · When were you first tested for HIV?
- Describe what it was like when you found out you were pregnant.
- Describe how you felt to be HIV-infected and pregnant.
- Describe the reaction of the baby's father, other family members, friends.
- Whom did you disclose your status to? Why that person?
- Describe the reaction of those you disclosed to.

### **Psychosocial Supports**

- Describe the social supports you receive.
- Describe the support you receive from the baby's father (financial, emotional, care of the baby)
- Talk about the people who encourage you to take care of yourself.
- · Talk about the people who encourage you to take your medicines.
- Talk about the people you can talk to when you feel sad.
- Talk about the people who can help you take care of your children.
- · Talk about any community organizations, including religious organizations that provide you with community support.

### **Community Stigma**

- What do people in your community think about HIV-infected women?
- What do people in your community think about HIV-infected men?
- What do people in your community think about HIV-infected children?

### Autonomy

- How do you make decisions regarding health-related issues for yourself and your baby?
- · Who is involved in the decision-making process?
- What happens if there is a disagreement about what should be done? Who makes the final decisions?

### Knowledge

- Talk about what you know about how babies become infected.
- Do you know anyone with an HIV-infected child?
- Are there ways to prevent transmission of HIV to babies? Discuss them.
- How well do these methods work?
- Describe what you know about HIV-testing for babies
- If a baby has a negative HIV test at 6 weeks, can they still get infected? How?
- Talk about what you know about treatment for HIV for babies and children.

### **Challenges Mothers Face**

- What makes it difficult for mothers to bring their babies in for testing?
- What would help mothers bring their babies in for testing and/or treatment?
- Why might some mothers not want their babies to be tested?

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**Table 2** Demographic Characteristics of Participants (n=56)

	Number (Percentage)
Infant HIV status	
HIV-infected infants	9 (16)
HIV uninfected infants	14 (25)
Infants of unknown status (age < 6 weeks)	13 (23)
Infant not yet born (HIV + pregnant women)	20 (36)
Marital Status	
Married	50 (89)
Divorced	3 (5)
Separated	3 (5)
Number of Children < 18 years of age, living at hom	ne (answer missing in 3 participants)
0	5 (9)
1	22 (39)
2	17 (30)
3 or more	9 (16)
Received PMTC (single dose NVP during labor and	single dose to infant)
Yes	31 (55)
No	3 (5)
Not eligible	20 (36)
Did not know	2 (4)
Maternal ART	
Yes	15 (27)
No	41 (73)