

Barriers Affecting Participation by HIV-infected Mothers in Care and Treatment Programs for Their Infants

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Background: Mother-to-child transmission accounts for over 90% of all pediatric HIV-infections with transmission occurring during pregnancy, labor and delivery, and throughout the breastfeeding period. The youngest children are at greatest risk of rapid disease progression and death. By one year of age, 35% of perinatally infected children have died and by 2 years of age 52% of them have died. Mortality in these children could be greatly diminished through early diagnostic testing and timely initiation of antiretroviral therapy. Despite the recent scale-up of infant care and treatment programs, uptake of services in the developing world has been low for reasons that are as yet unclear.

Methods: This descriptive, cross-sectional, qualitative study was designed to identify and explore barriers to infant care experienced by HIV-infected pregnant women and mothers. Semi-structured, in-depth interviews were conducted with 60 women attending three clinics in Blantyre, Malawi. Participants included: HIV-infected pregnant women and HIV-infected women with infants less than 6 months of age. Inductive and deductive codes were developed during several reviews of verbatim transcriptions; ATLAS ti was utilized in this coding process. Recurrent themes and patterns will be identified during the analysis process.

Preliminary Results: Partner disclosure has been cited in previous studies as a barrier to care for HIV-infected pregnant women. However, this was not found to be a barrier in this sample as nearly all women had disclosed their HIV status to their husbands. But several other barriers have been identified in the analysis thus far. These barriers will be illustrated using brief passages from the interviews:

HIV-related Stigma

“It hurt me so much (my HIV diagnosis) because I was faithful and clean before the eyes of God. So it is very painful and is a huge burden for me.”

“My sisters were avoiding me. When I started taking ARV’s, I got sick, I had mouth sores, I had to eat alone using my own utensils.”

Issues Related to Infant Feeding Practices

“The doctors tell you not to breastfeed your baby, but people notice and will know you are HIV-positive.”

“If I do not breastfeed my baby, where will I get the money to buy milk?”

Fatalism When HIV Diagnosis Is Made

“Mothers are afraid of being disappointed (if their infant tests HIV-positive). You are HIV-positive and so is your baby. You just think you are both already dead.”

“What prevents women from having their babies tested is that they are scared that once they know that their baby is HIV-positive then ‘they have already thrown away their chicken.’ “

Implications: Interventions to increase the uptake of pediatric HIV care and treatment programs must address infant feeding challenges mothers face as well as psychosocial issues such as HIV-related stigma and the sense of fatalism associated with HIV diagnosis.