

How to increase uptake of HIV tests for HIV-exposed babies

in Uganda



This study is part of the Access, Service and Knowledge (ASK) Programme which aims at improving the sexual and reproductive health and rights of young people, aged 10-24 years. It has been coordinated by STOP AIDS NOW! in partnership with Mama's Club.

Aim of the study

This study has been conducted to understand why young mothers living with HIV don't return their babies to health facilities after the first HIV test.

Background of the study

During the first 18 months of their lives, babies with mothers who are living with HIV remain at risk of being infected with HIV. Early Infant Diagnosis (EID) services are available to make sure babies are tested for HIV after birth, again once their mothers have stopped breast feeding and at 18 months. In Uganda, 60% of the HIV exposed babies do not return to a health facility to undergo a second HIV test. Without proper care and treatment undiagnosed HIV positive babies are at higher risk of dying.

Brief methodology

The study has been conducted in January 2015 within 12 health centres in three districts in Northern Uganda: Gulu, Amuru and Kitgum. It involved interviews with 61 pregnant women and mothers who are living with HIV, interviews with 27 key service providers (mentor fathers/mothers, midwives, nursing assistants and lab technicians), 12 focus group discussions with 8-10 parents (1 male and 11 female groups) and document and literature review.

Demographic characteristics respondents

The majority (98%) of the respondents is aged 20-24 years. Their education level is relatively low: 82% of respondents didn't go to school at all or attended primary school only. The poverty level is high: 95% of the women is unemployed. The majority (72%) has a partner. Almost all women (93%) have received Elimination of Mother-To-Child Transmission (EMTCT) services. These services include EID.



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Findings

Lack of Knowledge

Knowledge about the HIV transmission risks of breastfeeding is one of the main factors why the uptake of EID services remains low. Two out of 5 women don't know that HIV negative babies at the age of 6 weeks can become infected later on. Especially less educated mothers express little knowledge. Uncertainty about the advised timeframes is prevalent as well. Some mothers are not aware of the advice to stop breast feeding after one year. All mothers are uncertain about the right timeframes to have their babies tested.

Practical barriers

Several practical constraints are hampering mothers to return to health centres:

- The long distance to a health centre. The means of public transportation are lacking and/or unaffordable for many mothers.
- During planting and harvesting periods mothers are temporarily migrating to work in plantations. Mainly in Amuru this affects the adherence to appointments of mothers and babies.
- It can be hard to stop breastfeeding after one year due to lack of proper nutrition supplements and high poverty levels.
- Illiterate mothers find it difficult to read appointment cards.

The following health centre based challenges make it difficult to offer continuous HIV care and treatment:

- Irregularities in the availability of HIV test kits and lack of laboratory equipment.
- Delays in Dry Blood Spot test results. Mothers reported they gave up coming back after one attempt to get results.
- Long waiting hours at the health facility.
- Inadequately trained health workers or unprofessional behaviour.
- Missing data like contact addresses, allowance forms.

Lack of HIV related psychosocial support

Although psychosocial support in general is high, still a proportion of the community experiences stigmatisation. Lacking support is a critical barrier in seeking care.

Couples: lack of male involvement

At health facilities, more than 75% of the visitors are women and their children. According to the men the services are dedicated to women. More than 90% of the men don't know when babies should be tested. Although most women feel free to seek care, they are sometimes

missing practical support from their husbands, like transportation to the facility. Men are often the decision makers at home.

Singles: drop out more easily

Single mothers tend to drop out more easily from services because of financial constraints, migration or fear to disclose their HIV status to a new partner.

Non-disclosure

Almost all (90%) of the women disclosed to family members. Far less women share their status with friends or others outside the family. Some women don't go to health centres because they are fearing to be identified as HIV positive by the community.

Implications of these outcomes for programmes and policies

Increasing knowledge

Health centres and local organizations should organize educational sessions about specific topics, like breast feeding. Mothers living with HIV who have HIV negative babies can be powerful advocates in the community, convincing others to use EID services. Health workers need to reach out to clients in remote areas to make sure they will receive the right information and use the available services. EID services could be scaled up or health workers could use bicycles to visit clients at home.

Overcoming practical barriers

Follow up is more likely to occur when pregnant women and mothers who are living with HIV are economically empowered and supported with income generating activities. The government should offer incentives to pregnant women living with HIV to stimulate them to deliver in health centres. Health centres need to improve capacity building of health workers, data collection, and logistics & supplies management systems to avoid stock outs.

Increasing psychosocial support

Men should be more involved. It's best to start involving men during antenatal care, where they will feel encouraged to support their wives. Community leaders, as role models, can address stigmatisation issues.

For more information

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