Challenges faced by health workers in implementing the prevention of mother-to-child HIV transmission (PMTCT) programme in Uganda

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ABSTRACT

Background To report the experience of health workers who had played key roles in the early stages of implementing the prevention of mother-to-child HIV transmission services (PMTCT) in Uganda.

Methods Interviews were conducted with 15 key informants including counsellors, obstetricians and PMTCT coordinators at the five PMTCT test sites in Uganda to investigate the benefits, challenges and sustainability of the PMTCT programme. Audio-taped interviews were held with each informant between January and June 2003. These were transcribed verbatim and manually analysed using the framework approach.

Results The perceived benefits reported by informants were improvement of general obstetric care, provision of antiretroviral prophylaxis for HIV-positive mothers, staff training and community awareness. The main challenges lay in the reluctance of women to be tested for HIV, incomplete follow-up of participants, non-disclosure of HIV status and difficulties with infant feeding for HIV-positive mothers. Key informants thought that the programme’s sustainability depended on maintaining staff morale and numbers, on improving services and providing more resources, particularly antiretroviral therapy for the HIV-positive women and their families.

Conclusion Uganda’s experience in piloting the PMTCT programme reflected the many challenges faced by health workers. Potentially resource-sparing strategies such as the ‘opt-out’ approach to HIV testing required further evaluation.

Keywords health impact assessment, health services

Introduction

In 1999, the HIVNET 012 study in Uganda demonstrated the effectiveness of nevirapine in preventing mother-to-child HIV transmission, offering an intervention that was affordable in less-developed countries.1 In January 2000, the Ugandan Ministry of Health started a programme of prevention of mother-to-child HIV transmission (PMTCT), with five pilot sites in three districts. The antenatal clinic HIV prevalence in these districts at that time ranged from 5 to 12%.2 By the end of 2004, there was at least one PMTCT site in all 56 districts of Uganda.3 We thought that it was important to evaluate such a rapidly expanding programme from the perspectives of the health workers responsible for implementing it.

By the time of our study, the Ugandan PMTCT programme offered HIV tests to women at antenatal care clinics after counselling (an ‘opt-in’ service).4 The majority of HIV-positive women were given a single dose of nevirapine at the onset of labour, but a minority received zidovudine monotherapy from the 36th weeks of gestation, 6 hourly through the delivery till 1 week postpartum. Very few HIV-positive women received Highly Active Antiretroviral Therapy (HAART). The programme recommended modified intrapartum obstetric care: vaginal cleansing, delaying rupture of membranes in labour, limiting the number of episiotomies and delivery by caesarean section in exceptional circumstances.4 Neonates born to HIV-positive mothers were given nevirapine or zidovudine for a week after delivery, according to the mother’s PMTCT regimen. HIV testing of babies born to infected mothers...
was by rapid tests at 3 and 6 months after breast-feeding cessation or when the baby was 18 months old (if sooner).

In order to go beyond the statistics of numbers of women tested and numbers found to be positive, we conducted a qualitative evaluation of the PMTCT programme to explore the issues that might limit its success.

Methods

Five PMTCT sites were chosen for this study: St. Francis Hospital Nsambya, Mulago and Mengo hospitals in Kampala, and Arua and Hoima hospitals which are 504 km north-west and 200 km west of Kampala, respectively. One of the first five pilot phase sites (Lacor hospital in Gulu district) was excluded because of the difficulty in arranging interviews. Key informants were purposely selected from the health workers at each of the five PMTCT sites. At each site, the key informants were: the lead PMTCT counsellor, the site obstetrician and the coordinator of PMTCT activities, i.e. a total of 15 key informants. The interviews were conducted by the first author between January and June 2003.

An interview guide with standardized open-ended questions was used to collect views about the running of the PMTCT programme, changes in obstetric care since the introduction of the programme, the benefits and challenges of implementing the programme, what could improve the running of the programme, the sustainability of the programme and the advice for sites starting to implement the programme.

With the key informant’s permission, interviews were audio-taped and the audio tapes transcribed verbatim. Two key informants declined to be audio-taped, one preferred to write her responses whereas the other allowed the interviewer to take notes during the interview. Although information obtained during the latter interview was used in the development of themes, it was not used in the illustrations.

The ‘framework approach’ to qualitative analysis developed by the Social and Community Planning Research of London was adopted for data analysis. Data analysis was done in the following stages: familiarization with the scripts, identifying a thematic framework, charting and mapping of the data and interpretation of the results. Validation of the data was done through triangulation with data from the Ugandan Ministry of Health reports, and from observations made by the first author at site visits.

For each of the predetermined aspects of this evaluation, a thematic framework was identified by content analysis. Using methods described by Marvasti and Silverman, data were coded by working forwards and backwards through the scripts to identify frequently recurring themes. Data were charted onto the thematic frame work and the charts used to define and illustrate concepts, views and experiences of the key informants.

Results

The informants and their opening statements

Of the 15 key informants, 11 were female and 13 were Ugandan. Fourteen of the key informants had worked at their respective sites for at least 3 years, and one for 1 year. All but two key informants made positive opening statements about the running of the programme, and expressed relative satisfaction at its performance. They regarded the PMTCT programme as ‘necessary’ and ‘successful’ and they were proud to provide the services. They described the PMTCT programme as having ‘been grafted onto existing antenatal services’ and had aroused positive interest in the recipient communities. They thought that the PMTCT programme demonstrated how research leads to feasible interventions. The two key informants who did not make positive opening remarks about the programme were from two Kampala sites with a relatively high volume of clients, and they started the interview by immediately describing the challenges they were facing in its implementation.

The benefits of the PMTCT programme

The benefits of the PMTCT programme had occurred at four levels: to the community, to the implementing hospital, to all women coming to the hospital and to women who were HIV-positive. PMTCT programme staff had been involved in community awareness and education, using the radio, newspapers and meetings held with community leaders. They noted that this had improved health-seeking behaviour especially among women.

All five hospitals had new or refurbished buildings to accommodate the PMTCT staff and had new equipment ranging from delivery beds to computers. The staff benefited from training and these first PMTCT sites became resource centres for training other health workers, sharing expertise and giving technical advice. There was increased interaction between staff at each site, the Ministry of Health and non-governmental organizations. At some sites, the Ministry of Health had seconded more staff to help with the programme.

All five hospitals had improved obstetric care and laboratory services. The provision of PMTCT services had attracted research studies to the hospitals. Pregnant women had been prioritized in healthcare and benefited from the HIV pre-test counselling. Many key informants felt that there was an increase in the number of women delivered in
hospital. They considered HIV-positive women to have benefited from the interventions to reduce the chances of transmitting HIV to their babies. After childbirth, the PMTCT clinic had given access to HIV treatment clinics, family planning clinics and socioeconomic support.

**Challenges facing the PMTCT programme: the clients**

Challenges in implementing PMTCT were the most widely discussed issues by the key informants. These included challenges in four areas: with the clients, the staff, the infrastructure and current healthcare.

Challenges with clients were reported by informants to start with the women who chose not to have an HIV test (Text box 1). At some sites, the number of women refusing a test had been high at the beginning of the programme, but had then declined. One key informant reported a rise in acceptance from 40% of women in 2001 to 75% in 2003. At other sites, however, the percentage of non-consenters for HIV testing was reported to have risen (from 7 to 50% at one site). Moreover, it was reported that some women avoided the counsellors at the clinics. At one of the sites, this was thought to be because group HIV pre-test counselling made confidentiality difficult. In general, private patients were reported to be less willing to be tested than the general patients.

Women who accepted HIV testing sometimes did not wait for their results, although these were normally available later in the same day. Some of the women who were identified as HIV-positive refused antiretroviral prophylaxis. This problem appeared to particularly be when women were tested late in the pregnancy, without time to cope with their HIV status.

The follow-up of HIV-positive women was a major challenge. Some women attended the antenatal clinic once and then vanished without a trace. Others did not deliver in the PMTCT hospitals and so missed antiviral prophylaxis and modified intrapartum obstetric care. This difficulty was more common in rural areas and when women depended on spouses for transport to hospital. The follow-up of women and their babies after delivery was even more difficult. Those who had normal vaginal deliveries sometimes did not see the need to return to the PMTCT hospitals for postnatal services.

Key informants considered women disclosing their HIV status to their partners as being particularly difficult. They saw this as compounded by a lack of male partner involvement in PMTCT activities at all sites. They also reported non-disclosure of the HIV status to the partner as creating serious problems in family planning. Some women, for example, had returned with second and third pregnancies after initial diagnosis of HIV. Some key informants spoke of a few instances where one partner had started antiretroviral therapy without informing the other. They were concerned that women who had not disclosed their HIV status to their partners would be more likely to get lost to follow-up, as they preferred not to be traced into their community.

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**Text Box 1: Challenges with the PMTCT programme’s clients**

“So we introduced group counselling … That one increased the number of people counselled, ‘covering’ as they call it, but it reduced the acceptance…because you know when these women are in a group, you may find that you are there with your co-wife, or with your sister, so in front of those, accepting is difficult.’ Obstetrician/PMTCT Co-ordinator

‘The general clients are very willing to have the counselling and the HIV testing. But when it comes to private patients some of them are a bit difficult…. we tend to have more of the people from the general clinic than from the private ward.’ Obstetrician

‘Some of the educated group, including staff… they demand for the tablet (of nevirapine) but they don’t want to be tested for HIV.’ Obstetrician/ PMTCT Co-ordinator

‘At the PMTCT coordination meetings which the Ministry of Health conducts every 6 months, you will find poor husband or spouse involvement verbalized by every site coordinator at every meeting.’ PMTCT Co-ordinator

‘When time for monitoring starts, the women feel isolated to be pulled from the general pool. They are questioned by their friends: why are you treated in a special way?’ Counsellor

‘If the woman goes with an HIV positive result and tells the man, he will say ‘where have you got it from?’ He will not take the responsibility that it could be him who brought the HIV. He will straight away start blaming the woman.’ Obstetrician

‘Africans usually do stay with their in-laws. If a mother opts not to breast feed, the mother-in-law asks “why are you not breast feeding”? . . . If you tell the mother to boil breast milk, they would call her a witch!’ PMTCT Co-ordinator

‘…in terms of child bearing practices, it is usually the mother-in-law who dictates what the mother will do; where she will deliver the baby and if she will breast feed for 2 months or 2 years.’ PMTCT Co-ordinator

‘…our women are very poor women that they even do not have the money to come here to get the infant formula.’ PMTCT Co-ordinator

‘We give the women the option (of replacement feeding), but the truth is it isn’t much of an option. We actually try to insist on breast feeding, because there’s no (infant) formula. And even if there was free (infant) formula sometimes they would not be able to mix it because they do not have the water, the utensils, or the hygienic preparation facilities to use.’ PMTCT Co-ordinator
A further major challenge in dealing with the women was reported to be advice on breast-feeding. Public health messages in Uganda continued to advocate breast-feeding, and replacement feeding (‘infant formula’) was not normal practice. The key informants pointed out that infant feeding was not a matter for the mother alone in Uganda and other family members had a say in how infants were fed. Because of poor disclosure of HIV status, women also tended to breast-feed for long periods, thereby increasing the risk of mixed feeding. In addition, they noted poverty as further undermining the programme of replacement feeding: often women could not afford the hygienic preparation of infant formula feeds.

**Challenges with staff, infrastructure and current practice**

Concerns about staffing were raised by the key informants early in the interviews (Text box 2). Shortages of PMTCT staff (counsellors, midwives and laboratory personnel) were reported at all five hospitals. The staff needed motivation to deal with the increased workload, but some managers thought the health workers’ wish for additional motivation was unreasonable. The need for motivation stemmed from false expectations of the rewards for working on the PMTCT programme. Therefore maintaining morale among staff had been a challenge. Rotating staff between departments also posed a regular staff re-training challenge. In addition, the key informants thought that doctors needed more skills and training in working with antiretroviral drugs in pregnancy, particularly HAART.

Shortages and interrupted supplies of materials (laboratory re-agents, disinfectants, sterile equipment and dressings) were reported to have occurred at all five sites. Antiretroviral drugs for PMTCT appeared generally readily available, although one key informant reported an incident when the drugs expired. There was a shortage of space for counselling, and privacy and confidentiality were sometimes compromised. The constraints led to long waiting periods for post-test counselling, and some women left without getting their HIV test results.

Key informants described the difficulty in estimating the gestational age of clients. As a result, some women went into labour before receiving PMTCT prophylaxis, whereas in other instances, prophylaxis had been given to women too early in the pregnancy. They suspected that the policy of avoiding artificial rupture of membranes had resulted in longer labours, and one key informant thought the rate of emergency caesarean section deliveries had been increased by attempts to avoid likely instrumental deliveries.

**Text Box 2: Challenges concerning staff, infrastructure and current practice**

‘The point is, we should be motivated. Like today, we are doing immunization, then the mothers have come back for follow up, we work, we work, . . . and yet we are very few.’ **Counsellor**

‘Definitely this is tiring. We are trying to see whether we can . . . support our staff with incentives because the work takes a lot of time.’ **PMTCT Co-ordinator**

‘They don’t see being able to provide additional care as simply being able to provide quality care. That is one of the biggest challenges. Sometimes staff misunderstand, each time you introduce a new thing they want more money, or they think it is a research and they want to be paid for it.’ **Obstetrician**

‘People should realize that this is a new service that should be integrated in the old service. It is not something to be paid for; it is not going to stop after 2 years. It is like when we introduced family planning . . . people said ‘family planning sister’. Now it is routine, the staff know people are offered family planning.’ **PMTCT Co-ordinator**

‘The very high rate of staff turnover makes it very difficult to have staff who are committed and have learnt what to do with HIV positive mothers. There are constantly new staff coming in . . . you are constantly training and as soon as they have learnt the skills and they are keen enough or interested – they are gone! And you start over again.’ **Obstetrician**

‘Sometimes mothers are willing to be counselled but we have a problem of counselling rooms, we don’t have any privacy . . . and mothers at times do not wait for the results. They may find the laboratory very busy, so they have to wait for a long time to get their results. At times some give up and, when they reach home they may change their mind and do not come back for results.’ **Counsellor**

‘. . . 36 weeks is not measured, it is a subjective thing. Who measures 36 weeks? And who will really confirm? The women give wrong dates . . . and how will the woman know that she is in labour? Sometimes, labour-like things can start, and the woman takes the tablet and then doesn’t progress in labour. Sometimes, labour-like things can start, and the woman takes the tablet and then doesn’t progress in labour’ **Obstetrician/ PMTCT Co-ordinator**

‘Materials and supplies should be in place so that once the work starts, you do not run short of things. Patients get problems when on some days you do not give the service.’ **Counsellor**

‘The aim is not to prevent the babies being infected this year; the aim is to make it for the future and for the next 10 years, the next 20 years or so. If you start off on a rough footing, then it will not be a sustainable programme.’ **PMTCT Co-ordinator**
It was noted that because women had to wait for up to 18 months before their babies’ HIV status was determined, mothers were consequently very anxious whenever their babies fell ill. A lot of babies were lost to follow-up by 18 months with an unknown number of deaths, so infant HIV status and the effectiveness of the programme in reducing MTCT were largely unknown.

Sustainability of the PMTCT programme and advice to other sites
The general view of the key informants was that the PMTCT programme depended on support from the Ministry of Health. Most key informants felt that without the additional funding from partner organizations, the programme would not be sustainable. A condition emphasized for the sustainability of the programme was the continued provision of antiretroviral therapy to the women and their families, which was essential in drawing people to the PMTCT programme.

The key informants who were optimistic about the PMTCT programme’s sustainability based their opinion on the feedback from women, the administration’s commitment and the integration of PMTCT into the teaching of Ugandan doctors and nurses. Strong local leadership in obstetrics and paediatrics was essential.

The advice to other centres was to have the materials and personnel requirements in place before starting PMTCT services. Particular attention should be paid to having enough counsellors and laboratory staff, and to ensure that staff training was all inclusive. The plan should be to integrate PMTCT into the existing service and encourage self-reliance rather than dependence on external donors. New sites should start slowly, being aware that they will not reach all women at first. The pace of the work can increase as staff gain the experience to manage more women. During the first days, it could be useful to borrow expertise from more experienced sites for faster learning. Although the key informants considered that PMTCT was a matter of urgency, it was important to set up the service with plans to maintain it for a long time.

Discussion
Main findings
This qualitative study showed the positive attitudes to staff implementing PMTCT in the hospitals as assessed shortly after the programme started in Uganda. The program had led to changes in obstetric care that had benefited the clients, the implementing hospitals and the wider community. There were many challenges facing the PMTCT program including non-consent for HIV testing, non-disclosure of HIV status, management of infant feeding, lack of definitive early infant diagnosis and shortages in staff, space and resources for more effective implementation. This study highlighted the need to strengthen follow-up services of HIV-positive women especially with regard to support for HIV-positive women’s choice of infant feeding and family planning services. The success of the programme depended on local leadership and continued funding.

What is known already
Previous PMTCT program evaluations in Africa had mostly relied on quantitative data from the PMTCT ‘cascade’: e.g. number attended ANC, number counselled, number tested and number positive.9–11 By the time of our qualitative study, a cumulative total of 224 410 women had attended for antenatal care at 75 PMTCT clinics nationwide, 160 478 (72%) of whom were counselled, 104 643 (65%) accepted to be tested for HIV and 11 536 (11%) HIV-positive women were identified for PMTCT services.12 Rwanda and Burundi had also observed such high rates of counselling in the first year of their PMTCT program.13

The challenges observed with the Ugandan program like staff and space shortages were also observed in other sub-Saharan Africa PMTCT programs.13 Although a significant proportion of women did not accept to be tested for HIV, there was a slight overall downward trend for non-consent from 37% in 2000 to 35% in 2003.12,14 The issue of motivating counselling staff with a reasonable workload for reasonable pay had been identified in Kenya, where the main reason women gave for not returning for PMTCT services was staff with limited time and sympathy.15

What this study adds
This study was a useful qualitative evaluation of the PMTCT program from the viewpoint of implementing health workers at sites. It highlighted the numerous challenges faced by these health workers. A particular strength of this study was that the informants were all experienced people who had the enthusiasm of working in a pilot PMTCT site.

Limitations of this study
Because of the overall enthusiasm of staff at the pilot sites, their views may be more positive and optimistic than staff working in later entrants to the programme. Their advice to new centres on what is needed to sustain the programme in the long run could therefore be understated.
Conflict of interest

None declared.

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