

A study using knowledge, attitude and practices on the prevention of HIV-1 vertical transmission with outcomes in early infant HIV-1 diagnosis in Eastern Uganda

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Abstract

Objective: The objective of this study was to assess trends over time using knowledge, attitude and practices (KAP) among mothers living with HIV and rates of early infant diagnosis (EID) of human immunodeficiency virus type 1 (HIV-1) in a hospital in Eastern Uganda, which is included in the National HIV Prevention Strategy (NHPS) in Uganda.

Methods: A thematic qualitative assessment was conducted using focus group discussions (FGDs) with pregnant women, breastfeeding mothers and women attending the antiretroviral therapy (ART) clinic, all living with HIV. In addition, we have performed key informant interviews (KIIs) in October 2011 (baseline) and November 2016 (follow-up) at Mbale Regional Referral Hospital. Data were captured through customised source documents, written narratives and voice recordings. Social scientists decoded, analysed and interpreted the qualitative data with quality control. Retrospective data were obtained from EID registers for 2010 before and 2015 at the end of the NHPS, respectively. Supplementary quantitative data from the same hospital regarding trends of HIV-1 vertical transmission rates were collected from EID registers at baseline and at follow-up. Comparisons were made between HIV-1 transmission rates and KAP levels at baseline and at follow-up.

Results: Three paired sets of FGD sessions, consisting of 8–10 participants for each of the groups of pregnant women, breastfeeding mothers and women attending ART clinic, all living with HIV, were conducted at baseline and at follow-up. Age ranged from 17 to 40 years. Two sets of paired KII interviews corresponding to the periods before and after the NHPS were also held. All study FGDs and KIIs showed improvement in KAP on HIV-1 vertical transmission and lower EID rates when comparing baseline to the follow-up period [9/69 (13.0%) and 14/336 (4.2%)], respectively ($P=0.004$).

Conclusion: Improvement was noted in KAP on HIV-1 vertical transmission in pregnant women, breastfeeding mothers and women attending ART clinic, all HIV positive, in a regional referral hospital in Eastern Uganda over a 5-year period and was associated with a reduction in vertical transmission rates. Our data suggest that KAP is an effective type of intervention with regard to the prevention of HIV-1 vertical transmission in this population in resource-limited settings.

Keywords: KAP, HIV-1 vertical transmission, early infant diagnosis, Uganda

Introduction

HIV type 1 (HIV-1) remains an important public health issue in sub-Saharan Africa (SSA) [1]. The global estimate of children living with HIV-1 in 2009 was at 2.5 million [2], with an incidence at 390,000 cases [3,4], as compared with the figure in 2015 at 1.8 million [3,4], with a decreased incidence at 150,000 cases [3,4]. These trends seem to indicate progress in reduction of the pandemic in this population. However, there remains a substantial lack of data on the contribution of knowledge, attitude and practices (KAP) surveys in preventing vertical transmission and achieving early infant diagnosis (EID) in resource-limited settings. Current evidence suggests that universal access to antiretroviral drugs (ARVs) included in the elimination of HIV-1 vertical transmission programmes plays a significant role in the declining incidence of newborn infections [5], when considering a transmission rate of about 35.2% in the absence of intervention [6]. These data support epidemiological trends on HIV-1 vertical transmission in

the ARV era, even though SSA remains burdened with high rates as 66% of children living with HIV-1 globally were either born or are living in the region [7]. As the subcontinent strengthens preventative measures in terms of vertical transmission and promotes testing using the EID strategy based on an HIV-1 DNA-polymerase chain reaction (DNA-PCR) hub system, a more reliable estimate of the disease burden is emerging [8].

At a country level, Uganda, an East African nation, has been a model for innovation and implementation of strategies, guidelines and policies for HIV-1 prevention and control [7]. The country's significant achievements include stopping and starting to reverse the burden of new infections as per the Millennium Development Goal (MDG) target 6 in 2015 [9]. Despite these gains, Uganda is still classified as an HIV-1 high-burden country [10]. Overall estimates indicate that 7.3% of the total population is HIV-1 positive, an increase from 6.5% in 2010 [11]. Additionally, a cumulative total of 150,000 children below the age of 14 years are living with HIV-1 [12]. The EID targets those aged 18 months or less, a group where HIV-1 DNA-PCR remains the most accurate diagnostic method. Estimated rates of exposure to HIV-1 vertical transmission in Uganda have used projections from antenatal HIV-1 testing records. It is thought that 1.3 million women deliver each year, and at the current 12% HIV-1 prevalence rate among

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mothers attending antenatal care, approximately 94,900 newborn babies are exposed to HIV-1 annually. The strengthening of programmes on the elimination of vertical transmission includes the encouragement of pregnant women living with HIV-1 to deliver in hospitals, though many still do not [13], thus representing a missed opportunity. With effective strategies, HIV-1 vertical transmission could potentially be reduced to less than 0.5%, similar to developed countries [14,15]. However, it has remained at about 5%–8% in Uganda, similarly to many other resource-limited settings [16,17]. This figure suggests that an assessment of the current preventative strategies in this type of settings is needed. EID has been proven to be beneficial [17] as it allows prompt ARV initiation, which prevents death in over 50% of those infected by their fifth birthday [18]. Therefore, programme scaling-up with a dual approach of EID and prompt treatment initiation is essential for infected children's survival.

In this study, we have used a KAP survey in terms of the prevention of HIV-1 vertical transmission and assessed outcomes in EID HIV-1 diagnosis in Eastern Uganda.

Methods

This study was performed at Mbale Regional Referral Hospital (Mbale RRH), which is located at the heart of Mbale Municipal Council, 214 km to the east of the capital city of Kampala. It is the main referral hospital in the Elgon zone in Eastern Uganda, a geographic area that borders the western part of Kenya. The hospital is situated at an altitude of 1140 m with a catchment area at 980–1800 m above sea level. Over 70% of inhabitants in this area are of Bantu ethnicity, and the great majority are part of rural agrarian communities. The Mbale RRH is a government-run, not-for-profit and charge-free 470-bed hospital including four major medical specialties, namely, surgery, internal medicine, obstetrics, gynaecology and paediatrics. It serves a catchment population of approximately 4.5 million from 16 administrative districts with about 650 antenatal attendees, 600 maternal deliveries and 1300 paediatric cases seen monthly (Mbale RRH, Records 2017).

Two studies were conducted on KAP among pregnant women, breastfeeding mothers living and women attending the antiretroviral therapy (ART) clinic, all living with HIV at baseline and 5 years later (follow-up). In addition, in order to assess the potential relationship between KAP among mothers and HIV-1 vertical transmission, we retrospectively collected rates of HIV-1 infant infections 1 year prior to the KAP baseline and at follow-up.

Qualitative studies applying focus group discussions (FGDs) to gather views on KAP among target study participants were conducted. In addition, key informant interviews (KIIs) took place in order to gain an in-depth understanding on appropriate KAP among mothers as quality control. Both FGD and KII were conducted in November 2011 (baseline) and October 2016 (follow-up) using a standardised interview. Participants in the FGD included individuals attending medical care at the HIV maternal healthcare delivery entry points at Mbale RRH where clients received information, counselling, and/or ARVs. These included antenatal, perinatal, postnatal and HIV care clinics. The perinatal and postnatal care points were also an EID care point.

Three paired sets of FGD sessions, consisting of 8–10 participants (antenatal, postnatal and HIV clinics) were held at baseline and at follow-up. Participants were recruited on the basis of similarity, convenience, willingness, and consent to participate in the study. All FGDs were held conveniently in order to accommodate participants' availability. All were recruited after they had been

approached and briefed on the study. Groups initially verbally consented and gave individual written consent thereafter. All discussions used the most appropriate local language spoken by study participants, which was understood by a research team of three individuals, including a moderator, a notetaker and an interpreter.

Two sets of paired KII interviews were also held. The first one targeted a category of individuals responsible for the oversight on resource-limited setting implementation of the National HIV Prevention Strategy (NHPS) and included one physician at the district health office, two paediatricians and community leaders (two males and two females). The second one involved health-care workers attached to the HIV care entry points at Mbale RRH, such as nurses, HIV counsellors, midwives, clinical officers and doctors.

Data were captured in writing and recorded with tape recorders, manually coded with spontaneously emerging themes and interpreted with quality control by a team of social scientists. We summarised our findings and presented them in a tabular format as pairwise comparisons of baseline and follow-up data for each category.

Ethical approval to conduct the study was obtained from the Mbale Regional Referral Hospital Research and Ethics Committee (MRRH-REC).

Results

Results of our thematic qualitative assessment using FGD with antenatal, postnatal and ART clinics and KIIs in 2011 (baseline) and 2016 (follow-up) at Mbale RRH, Eastern Uganda, are shown in Tables 1–3. Six FGDs, (three baseline–follow-up pairs) and two sets of KIIs were performed, each one at baseline and at follow-up during the same periods. The age range of the study participants was 17–40 years. Table 1 shows the summary results of the FDG discussion at baseline and at follow-up and the researchers' inference when comparing data between the two time-points from antenatal, postnatal and ART clinics. Initial FDG sessions in 2011 show that only half of the women knew about HIV-1 vertical transmission with improvement overtime to reach a majority of women in 2016 in the antenatal clinic. There was initially little EID knowledge. This is most likely linked to the fact that rural communities often did not have access to information. The importance of the knowledge acquisition through the regional referral hospital and radio programmes was established.

All study FGDs and KIIs showed marked improvement in KAP on HIV-1 vertical transmission and EID when comparing baseline with the 5-year follow-up period. Two sets of paired KII interviews were also held, one with key informants and healthcare workers and the other one with key informants and policy implementers. Results of these interviews are shown in Tables 2 and 3. The KII suggests that health worker work overload, low levels of staffing and poor referral organisation, compromised maximal NHPS implementation at the regional referral hospital (Table 2). Conversely, the support of policy makers from initiation through to the completion of the set NHPS was noted as an important aspect of the prevention of HIV-1 vertical transmission (Table 3).

All study FGDs and KIIs showed marked improvement in KAP on HIV-1 vertical transmission and rates of EID when comparing baseline data with the 5-year follow-up period. The proportion of infants testing HIV-1 positive at baseline was 9/69 (13.0%), whereas that at 5 years of follow-up was 14/336 (4.5%) ($P=0.004$).

Table 1. Summary results of FGDs at baseline and at follow-up

FDG	Opinions at FGDs		Researchers' inference
	Baseline (November 2011)	Follow-up (October 2016)	
I. Pregnant women living with HIV attending antenatal clinics	<p>Over half of pregnant women attending the clinic knew about HIV-1 vertical transmission, but only 2/8 knew about EID. None had been informed about EID in any clinic in the hospital or in their villages. Two mothers had heard about EID on television. All respondents thought that the distance they came from and lack of awareness in most rural areas might be factors associated with little knowledge about prevention of HIV-1 vertical transmission and EID. A majority noted that the available options for pregnancy for HIV women included spiritual healing, herbal remedies and abortions. Those taking part in the prevention of HIV-1 vertical transmission services reported that they were adherent to their medication. All respondents thought that there was a need to improve awareness on HIV-1 vertical transmission and EID in rural areas. <i>'Many radio health programs are aired during the time when we are busy either in the garden or cooking. Our husbands are the ones who always listen to the radio'</i> – Focus group participant</p>	<p>A majority (7/8) of mothers attending the clinic knew about HIV-1, prevention of vertical transmission and EID. They reported to have obtained the information mostly from the hospital, healthcare centres and some radio stations. <i>'What I know is that when a mother gets an accident when she is pregnant and the blood mixes with that of the baby, the baby will get HIV.'</i> – Focus group participant Some mothers said that their babies need to be tested three times from the time of their birth until one and half year of age. Those who test positive are to be given medicine. <i>'We are encouraged to deliver in the hospital so that the babies can also receive medicines.'</i> – Focus group participant They also said that they are informed on how best to feed their babies. <i>'We were told that if you breastfeed, the baby can get the virus. So if you are positive you only breastfeed for a short time.'</i> – Focus group participant</p>	<p>There was improvement in the awareness of HIV-1 vertical transmission and EID among pregnant women living with HIV attending antenatal clinics during the study period. While the efforts of the Ministry of Health to provide information through radio talk shows were noted, the timing of programmes was not appropriate for the target audience in rural places. There remain gaps in specific knowledge and practices for better outcomes of prevention of vertical transmission of HIV-1.</p>
II. Postnatal clinic: breastfeeding mothers living with HIV-1	<p>All mothers at the clinic knew about preventing HIV-1 vertical transmission, but only 3/8 were informed about EID. The three mothers had learned of EID about 1 year previously. They had obtained information from antenatal clinics both at the nearby rural health centres they attended and at Mbale RRH where they had delivered. Many thought that the lack of knowledge about vertical transmission of HIV-1 and EID was due to limited healthcare manpower and work overload among nurses (midwives). <i>'Services do not reach the grassroots (lack of sensitization of the community by health workers), there is also stigma, delays from medical people and poor timing of medical talk shows.'</i> – Focus group participant</p>	<p>All (8/8) breastfeeding mothers living with HIV-1 attending the clinic knew of vertical transmission, and 7/8 knew of EID. Those who knew of both (7/8) reported that they had obtained this information at healthcare clinics, from medical radio talk shows and Mbale RRH. <i>'We were told that medicine can be given to us to prevent the baby from getting AIDS. That is why I accepted to have my blood tested when I was pregnant and to have my newborn baby also tested.'</i> – Focus group participant The mother who did not know about EID was young (16 years old) and had attended antenatal clinics in a rural health centre. She also reported that she did not have secondary school education.</p>	<p>There was marked improvement in knowledge on prevention of vertical transmission of HIV-1 and EID among women attending postnatal clinic over the 5-year period. Whereas only one mother said she had not heard of EID, low levels of education and mother's young age may be barriers for the successful use of EID. A larger study may be important in establishing these facts.</p>
III. Women living with HIV-1 attending the ART clinic	<p>All (10/10) women in this clinic were already on ART when they became pregnant. They were informed that their treatment was also for the prevention of HIV-1 vertical transmission. Some (4/10) had heard about EID during their last postnatal clinic. However, they mentioned stigma, lack of healthcare outreach to the community, negative attitudes by women living with HIV-1 towards the EID policy and limited information flow as some of the factors preventing them from bringing their babies for EID. They all agreed that, to a large extent, healthcare services had a role to play in bringing EID awareness to women living with HIV-1. They emphasised that if information was available for the communities, then EID awareness would be achieved. Most women living with HIV-1 at the ART clinic thought that the critical factors to promote knowledge about EID were carrying out community sensitisation, fighting stigma, ensuring regular medical talk shows in the media, building health centres closer to the people in rural places and employing a sufficient number of healthcare workers.</p>	<p>All (10/10) women attending the clinic were aware of EID. They had learned about it from the hospital, radios talk shows and television programmes. However, they stated that the majority of women living with HIV in rural areas did not know about EID. Those at the clinic had received information from the infectious diseases clinic and were later asked to go to the EID clinic (across the street) for more information and services. At the ART clinic, mothers said the following: <i>'We and our babies take our medicines on a daily basis. When you [19] have wounds on your breasts, don't breastfeed. When the child is one year, you [19] stop breastfeeding; avoid sharing sharp objects.'</i> – Focus group participant Whereas all the women at the ART clinic knew that they should stop breastfeeding when their baby was 1 year of age, only 3/10 knew why, and these had secondary school level of education. <i>'If you breastfeed for more than one year, the child will get HIV.'</i> – Focus group participant</p>	<p>It is likely that more women attending the ART clinic had received health education and information about EID as compared with those at other points of care. If this information was to be evenly provided across all HIV care points, more cases of vertical transmission would possibly be prevented.</p>

ART, antiretroviral therapy; EID, early infant diagnosis; FGD, focus group discussion; HIV-1, HIV type 1; Mbale RRH, Mbale Regional Referral Hospital.

Table 2. KIIs with healthcare workers

KII	Opinions at KIIs with healthcare workers		Researcher's inference
	Baseline (November 2011)	Follow-up (October 2016)	
Healthcare workers	<p>Most healthcare workers reported that some mothers did not know about prevention of vertical transmission and HIV-1 and EID due to minimal sensitisation on this matter.</p> <p><i>'Few HIV positive mothers understand prevention of vertical transmission and EID. Most of them fear to disclose their status to their spouses.'</i> – KII – Healthcare worker</p> <p>They noted that more efforts were needed to create awareness of EID among mothers living with HIV.</p> <p><i>'There is a big challenge in terms of referral forms in the antenatal unit. This hinders the follow-up of pregnant mothers. Stigma is also a big challenge. The Ministry of Health should employ extra staff to help the existing few staff to handle the EID policies for HIV positive mothers. Unavailability of referral forms for HIV positive mothers has curtailed knowledge of EID.'</i> – KII – Healthcare worker</p> <p>The strategy needed for a successful EID programme is to offer all services as integrated and under one roof. This is currently lacking in our settings.</p> <p><i>'The EID clinic is far away from the obstetrics and gynaecology wards and antenatal clinic, making the mother referral for services difficult. For example, mothers must walkover 300 meters, crossing the road through a busy street and market to the outpatient department where the EID care point is located.'</i> – KII – Healthcare worker</p>	<p>'The EID program started well and then stagnated. However, it later resumed and now is running quite well. Knowledge has improved and we have rolled out testing at all departments to maximize opportunities for all mothers and their babies.' – KII Healthcare worker</p> <p><i>'The entry point to EID is the identification of HIV positive mothers and following them up. Uptake of HIV testing among mothers is still slow. We talk about it to all mothers and the majority of them know about it, but many do not attend antenatal clinics, what happens to these women?'</i> – KII – Healthcare worker</p> <p>Fear and stigma remain a major hindrance to the success of prevention of vertical transmission and EID.</p> <p><i>'There is still a lot of stigma among mothers. Some are initiated on treatment during the antenatal period and when they present in labour and during the postnatal period, they don't disclose their status.'</i> In addition, most rural mothers prefer continuing care at their local health units</p> <p><i>'About the program: the EID program started well then stagnated midway. However, it later resumed and now is running quite well. The knowledge has improved and we have rolled out testing at all departments to maximize opportunities for HIV testing to all mothers and their babies.'</i> – KII Healthcare worker</p> <p><i>'The entry point to EID is the identification of HIV positive mothers and following them up. Uptake of HIV testing among mothers is still slow. We talk about it to all mothers and the majority of the mothers know about it, but many do not attend antenatal clinic, what happens to these women?'</i> – KII – Healthcare worker</p> <p>Fear and stigma remain major hindrances to the success of prevention of vertical transmission and EID.</p> <p><i>'There is still a lot of stigma among mothers. Some are initiated on treatment during antenatal period and when they present in labor and postnatal period, they don't disclose their status.'</i> In addition, most rural mothers prefer continuing care at the local health units but we don't know whether they attend care there. – KII – Healthcare worker</p> <p>For a successful maternal programme, male involvement is important, especially for HIV since both partners may be infected.</p> <p><i>'There is still a problem of disclosure. Women don't disclose to their spouses, yet they depend on them for support in terms of transport facilitation to attend clinics. This affects clinic attendance and adherence to treatment. Ironically, most of these husbands are s infected as well and obtaining treatment secretly without their wives knowing.'</i> – KII – Healthcare worker</p> <p><i>'Some mothers are involving their husbands and this is improving adherence to appointments and medications.'</i> – KII – Healthcare worker</p> <p><i>'Some mothers from the antenatal clinic and other health centers having continuously tested negative throughout pregnancy, turn positive at immunization and young child clinics. Some of them are in denial yet the infant is at risk of HIV infection.'</i> – KII – Healthcare worker</p> <p>A lot of changes have been made since we adopted the National HIV Prevention Strategy 5 years ago.</p> <p><i>'We now test infants at 6 weeks, 9 months, 13.5 months and 18 months so that we do not leave chance for a late initiation of treatment in children who test positive.'</i> – KII – Healthcare worker</p> <p><i>'Mothers whose babies test negative at 18 months are used as peer mothers to encourage others to increase the uptake of EID services.'</i> – KII – Healthcare worker</p> <p><i>'Mothers who are on ART and become pregnant are escorted by a health worker to the HIV care point to avoid lost opportunities and diversion.'</i> – KII – Healthcare worker</p>	<p>Supporting environment and adequate staffing are important requirements for the programme implementation.</p> <p>The innovative community-based participatory approach of involving mothers living with HIV as peer support (success stories) will reduce stigma among HIV-positive clients and potentially promote prevention of vertical transmission and high uptake of EID in rural and resource-limited settings.</p>

ART, antiretroviral therapy; EID, early infant diagnosis; KII, key informant interview.

Table 3. KIIs with policy implementers

KIIs	Opinions at KIIs with policy implementers		Researcher's inference
	Baseline (November 2011)	Follow-up (October 2016)	
Policy implementers	<p><i>'There is a lack of health centers or clinics in some communities and still little awareness as a result of limited resources from the Health Ministry. There is stigma, especially from husbands. We have just received the National HIV Prevention strategy, a new policy; there is less need for manpower to implement it. If information materials were available, district health services would help HIV positive mothers understand about prevention of vertical transmission and EID, but other factors to consider are a lack of funds for outreach, a need for more health units and more manpower.'</i> – KII – Policy implementer</p> <p>On the needs for mothers to obtain a better understanding of EID, most key informant interviewees suggested the following changes: <i>'Massive mobilization and sensitization, increase funding from the Ministry of Health, drama group outreach in communities for awareness and partnerships between the Ministry and private health development organizations such as World Vision, STAR-E, SUSTAIN, AIC and TASO.'</i> – KII – Policy implementer</p>	<p>All policy implementers thought that the current level of uptake of both prevention of vertical transmission of HIV services and EID was lower than expected. The lack of knowledge about vertical transmission and EID was common among HIV-positive mothers.</p> <p><i>'People's attitudes, though difficult to measure, are still a critical factor contributing to the low EID uptake. Culture, education and exposure are key issues. Some people still have different perceptions about the transmission of HIV.'</i> – KII – Policy implementer</p> <p>The Ministry of Health has made some good efforts to reach the communities with EID messages.</p> <p><i>'Awareness has been targeted through radio announcements and talk shows, television advertisements and community meetings. Radio talk shows, however, are scheduled at the wrong time. Most women are outside during the day and most men are away from home most evenings. Radio programs need to be better scheduled to reach the targeted audience.'</i> – KII – Policy implementer</p>	<p>There is a probable gap in understanding on how much mothers know about vertical transmission and EID among policy implementers. An objective assessment on how much of the targets have been achieved is needed. This will help inform policy implementers on the level of success of the prevention of vertical transmission of HIV and EID programmes.</p>

EID, early infant diagnosis; KII, key informant interview.

Infant HIV-1 transmission trends

Rates of HIV-1 vertical transmission for the period from November 2010 until October 2011 (baseline data) were 9/69 (13.0%). However, MTCT rates for the period from October 2015 to September 2016 representing the follow-up period were decreased at 14/336 (4.5%). This was a significant reduction over 5 years ($P=0.004$). These data were obtained for the women who tested HIV positive and brought their babies for EID at Mbale RRH.

Discussion

Few data exist on KAP [20] and prevention of HIV-1 vertical transmission and EID among mothers attending various maternal HIV care entry points. Furthermore, there are hardly any reports correlating the trends on KAP among HIV-positive mothers with HIV DNA-PCR results for their exposed babies/infants. Several strategies to increase the uptake of prevention of HIV vertical transmission and EID services have been implemented. Prior to this study, there was little understanding on how KAP levels on vertical transmission and EID among mothers related to trends in MTCT.

Our findings show that it is not a single approach as mentioned by HIV-positive mothers, health workers and policy implementers that would dramatically increase the uptake of prevention of vertical transmission of HIV services and EID in Eastern Uganda. Study participants reported interventions that have already been implemented. This suggests a need to engage in new strategies for the prevention of vertical transmission and the EID programme to fully succeed in these settings.

This qualitative study, however, has demonstrated an improvement in awareness about prevention of vertical transmission and EID among mothers attending antenatal clinics during the study

period. Additionally, it was noted that this period corresponded to the introduction of the new NHPS in Uganda. Its impact has not been formally assessed and policy implementers knew of its intentions but not its targets. The remaining gaps in knowledge and practices that can help mothers attending antenatal clinics to accept HIV testing, those found HIV positive to be enrolled into prevention of vertical transmission of HIV services and to have their babies tested via the EID strategy need to be identified and bridged. It was noted that knowledge about the indications for EID was lacking in HIV-positive young mothers with low levels of education. If widespread, then young age with low levels of formal education potentially impedes uptake of HIV care services, including EID [21]. Whereas formal education may contribute to literacy levels and empowerment for mothers to seek information on their own, there are community and socially acceptable means of creating awareness that could be used in rural settings. These have not been identified or used to help younger mothers with low levels of formal education. This is largely due to the lack of creativity in the type of messages intended to raise awareness and to disseminate health messages at the community level. The content of the information given by health workers speaks more about 'what must be done' and very little or not about 'why it must be done' [22]. This affects the comprehension and retention of information for knowledge development [23]. This could be improved by approaches that apply community-based participatory research [24].

As pointed out by most respondents at baseline in both KIIs and FGDs, very little has been done to promote uptake of health interventions at community level [25], including prevention of HIV vertical transmission and EID. Traditionally, interventions are facility-based, yet low level of staffing and other deficiencies remain common in most of such settings in rural Uganda, generally like in SSA [26]. In Eastern Uganda, concentrating all activities

at hospitals with low levels of staffing makes it difficult for health workers to offer comprehensive sensitisation to clients alongside other specialised healthcare services [27]. Rather than only decentralising service delivery, it would be good practice to decentralise the flow of information at community level as well.

An observed obstacle to the provision of prevention of HIV vertical transmission and EID services at Mbale RRH was the difficulty in linking postnatal mothers to the EID care point. This care point was located over 300m away, and its access involved manoeuvring across a busy street and through a market place (the Mbale central market was under construction and the market vendors were provided with temporary space for a couple of months at Pallisa road near Mbale RRH). Furthermore, there was no evidence of service integration at antenatal and postnatal clinics. Therefore, we envisaged a potential loss to follow-up of mothers and their exposed infants. Client referral was further hindered by a lack of referral forms. Mothers–infant pairs could not be appropriately linked to care, especially at peripheral service points, and this reduced the chances for early ART initiation in these infants; which is a key bottleneck for resource limited settings [28]. A supportive environment and adequate staffing are important prerequisites for the programme implementation.

We have observed the impact of stigma among HIV-positive mothers, a factor in their reluctance to test for HIV, and which represents a major impediment in terms of prevention of vertical transmission and EID for their babies. Some HIV-positive mothers only knew about EID after delivery. This further reduces the effectiveness of prevention of vertical transmission, thus increasing the chances of HIV acquisition by infants, and subsequent high mortality and morbidity before their fifth birthday [19]. For effective policy implementation, information and service delivery for EID need to be available along the continuum of care at community level from conception through antenatal care, delivery and postnatal care [29].

While policy implementers cited EID as an important strategy to monitor effectiveness of the current strategies for prevention of HIV vertical transmission and as an entry point to care for infected infants, they noted that the low utilisation of EID services was a result of complex logistical, human resources and infrastructural challenges. Little was being done to strategically increase the NHPS gains in light of the remaining challenges. This study strongly recommends simple and cost-effective interventions, such as family-centred care and community involvement [30]. These will strengthen policy roll-out to increase the gains of the current eMTCT guidelines by the World Health Organization as customised in the NHPS in Uganda.

Policies and strategies, once developed, are disseminated at NHPS at the national level during stakeholder forums and at the subnational level through the districts. Dissemination among nonstate actors does not occur at service level. The key challenge for the NHPS, however, remains implementation arising from complex issues, including human resources, logistics and processes, as noted by both health workers and policy implementers in this study. Under Uganda's decentralised healthcare provision system, effective governance of the implementation arrangements is in the domain of the local authorities, such as districts, urban authorities and subcounty administrations. Under the decentralisation programme, district authorities are responsible for overseeing implementation of policies and strategies and for developing by-laws to support service delivery. Regional referral hospitals under central government administration in the districts where they exist may not be able to implement policies and strategies without liaison with the district teams, which

unfortunately operate under limited resources [31]. In terms of planning, a major shortcoming has been that health sector targets and activities are set without robust evidence-based approaches. This makes the implementation of well-intended strategies like NHPS difficult.

Our study has provided ways for understanding the role of KAP in the implementation of health programmes. However, it has limitations in so far as it is an institution-based study. It is likely that there are different ways in the community through which the level of KAP affects the HIV vertical transmission. Nonetheless, we have shown that an effective programme for the elimination of HIV-1 vertical transmission requires corresponding efforts aimed at improving KAP among mothers and their communities.

Conclusion

The marked improvement in KAP in the prevention of vertical transmission and EID among pregnant and breastfeeding mothers living with HIV over the 5-year period corresponded with the marked reduction in HIV vertical transmission in Eastern Uganda. This suggests that to achieve elimination of vertical transmission in resource-limited settings, targeting KAP on effective interventions in pregnant women and breastfeeding mothers living with HIV is paramount.

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Conflicts of interest

All authors have no conflicts of interest to declare.

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