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Impact of the Elimination of Mother-to-Child Transmission of HIV Program at St. Francis Health Care Services in Uganda: Factors Affecting the Program and Avenues for Improvement

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ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
MCH (MNCH)	Maternal and Child Health
CBPR	Community-Based Participatory Research
EMTCT	Elimination of Mother-to-Child Transmission of HIV
MTCT	Mother-to-Child Transmission
FGD	Focus Group Discussion
ANC	Antenatal Care
PNC	Postnatal Care
KI	Key Informant
RA	Research Assistant
VHT	Village Health Team
WHO	World Health Organization
OPD	Outpatient Department

ORIGINAL ABSTRACT

The initial proposal prepared for this research had two components: (1) the personal statement, consisting of three separate sections that look into the country and culture, research tract, and personal growth and development, and (2) the literature review which consisted of four sections, namely, an introduction into the theme of Maternal Newborn and Child Health (MNCH) in Uganda, approaches and tools of Community-Based Development, the history of foreign aid in the country, and finally the importance of a Community-Based Participatory Research (CBPR). Based on the way community-based research track works, this initial proposal

is meant to be broad and cover a range of topics in order to get the researcher acquainted with the background and different aspects of the research. The following is an abstract of the original literature review:

Maternal and Child Health in Uganda: Interventions supported by community-based research and continually assessed through program evaluations provide the most impactful tool we can use to promote maternal and newborn survival and improve equity. Bhutta et al. broadly classifies interventions as family and community interventions (mainly at household level) and interventions through outreach services including community health workers operating from village health posts or first-level facilities. Their study analyzed implemented interventions to conclude that inclusion of evidence-based interventions in MNCH programs in primary health care in Uganda and Tanzania could prevent 20–30% of all maternal deaths (up to 32% with capability for caesarean section at first-level facilities), 20–21% of newborn deaths, and 29–40% of all post neonatal deaths in children aged less than 5 years. Their research also revealed that there was variation of the mortality ratios between districts. This information allows the country to use tailored interventions to target districts with higher relative risk of under-5 mortality.

Approaches and Tools of Community-Based Development: Understanding the socio-economic and socio-cultural factors that affect mothers is an important aspect to overcome the obstacles hindering maternal, newborn, and child health care. Various studies done in both developing and developed countries show that interventions that address specific vulnerabilities of mothers and children prove highly beneficial to maternal and child health.

History of Aid in the country: Uganda is one of the most aid dependent countries in Africa, where (1) there is a need for improvement in terms of accountable spending of aid, which calls for improvements in transparency and accountability (2) government allocation to the health

sector is low. According to research by Agba E (2009) health spending in Uganda covers about 1/3 of what the country needs to meet its minimum health care package. This gap therefore needs to be supplemented by the government in order to achieve sustainable development goals in health care.

Community-based participatory research: Methods of community based participatory are commonly employed to provide a holistic analysis of the interventions. This is based on the logic that, when tailored to the community they cater, promotive and preventive interventions as well as curative services that can be provided by well-trained midwives and other health care providers in first level facilities have the potential to save countless lives of mothers and children. And in the struggle to end all avertable maternal, newborn, and child death, community based research is fundamental to gain the understanding of the barriers in the delivery of MNCH interventions necessary to develop strategies that overcome them.

INTRODUCTION

Background

Mother-to-child transmission (MTCT) of HIV remains a global challenge with 150,000 new infections in children in 2015 (UNAIDS, 2016) . Globally, about 1.4 million women living with HIV become pregnant every year. Without treatment, they have a 15-45% chance of transmitting the virus to their children during pregnancy, labor, delivery or breastfeeding (WHO, 2018). Acquired immune deficiency syndrome (AIDS) has now become the leading cause of under five deaths in sub Saharan Africa (Mboup, Musonda, Mhalu, & Essex, 2011). In Uganda and other sub-Saharan African countries, women and girls constitute the bigger proportion of people living with HIV/AIDS and are 4-5 times more at risk of contracting HIV than men (Avert, 2017), making EMTCT a major priority for such countries.

EMTCT programs

EMTCT programs provide an opportunity for eliminating transmission of HIV from mother to child and enrolment of infected pregnant women into antiretroviral treatment (ART) together with their families. UNAIDS targets for the virtual elimination of MTCT include reducing the rate to 5% or less among breastfeeding populations, and 2% or less among non-breastfeeding populations.

In August 2012 the Uganda MoH decided to adopt option B+ as the national policy based on the understanding that B+ provides significant benefits and propels the country further towards EMTCT targets. The main advantage of option B+ is having a simplified but highly effective approach throughout the entire period of potential transmission (pregnancy, labor, delivery or breastfeeding). The risk of MTCT drops to just over 1% if ARV medicines are given to both mothers and children throughout the stages when infection can occur (CDC, 2018). The WHO also emphasizes that Option B+ in particular could have significant advantages beyond EMTCT; like providing better protection for maternal health and, compared to other options, enables the highest reduction in the sexual transmission of HIV (WHO, 2012).

This research on the EMTCT program– which is the most developed program within Maternal and Child Health Care Services at St. Francis Healthcare Services–was done in order to enable St. Francis to (1) get valuable community input (2) to determine whether the program is living up to its objectives, and (3) to enable opportunity for continuous development and strengthening of the program.

RESEARCH METHOD

This prospective study conducted utilized a qualitative approach. The goal of this study was to do a community based participatory research that plans to assess the value and impact of

the Elimination of Mother-to-Child transmission of HIV (EMTCT) program at St. Francis Healthcare Services with the aim of strengthening and improving it through direct feedback from the community of women, health care workers, and others taking part in the program.

A total of 36 HIV positive mothers, which corresponds to 25% of all active EMTCT participants in St. Francis's EMTCT program, participated in the study. 14 of those participants were interviewed one-on-one for 30-45 minutes. The remaining mothers had taken part in one of the there focus group discussions that were conducted, which took from 1-2 hours.

Participants were chosen (1) based on their adherence, with priority being given to active mothers that have missed at least one EMTCT appointment day (2) randomly from the appointment book (3) on a voluntary basis during EMTCT appointment day.

The Questionnaire

Strengthening the integration of Elimination of Mother-to-Child Transmission of HIV (EMTCT) services within maternal, newborn and child health (MNCH), sexual and reproductive health, antenatal care (ANC), as well as delivering antiretroviral treatment(ARV) services in health facilities is one of the priorities outlined by WHO for reaching the EMTCT targets (World Health Organization, 2007). Based on past literature review the major issues arise in accessing services like ante and postnatal care, adherence to ART treatment, and retention of patients within the program. Therefore the questionnaire takes into consideration these factors paired with the objectives of the PMTCT program listed in the St. Francis 5 year strategic plan book.

Data Collection

Prior to the interview or FGDs, the mothers were asked to fill out a survey of close-ended questions. Demographic characteristics of participants were collected before the interviews or focus groups from the initial survey. The data collected from the interviews was reviewed

repeatedly with the intent to extract similar themes from the transcribed interviews. Key informant interviews were also conducted consisting of three of the five midwives, the two peer mothers that work with the midwives in EMTCT, the members of the Village Health Team assigned to St. Francis by the Ministry of Health (MoH), and the M&E representative at St. Francis.

Table 1 . List of Interviewees

Participants and KIs	**Number interviewed**	**Total participation in EMTCT**
Mothers taking part in EMTCT	35	137
Peer mothers	2	2
Midwives	3	5
Husbands	2	-
VHT(village health team)	4	4
M&E	1	-

Research Assistants

Two Research assistants (RA) were used though the course of both the interviews and focus groups. One of the research assistants was an interpreter. The interpreter would help facilitate discussions or interviews that were conducted in Lugandan as well as continually translating responses from the participants. The second RA would help by reading the participants the consent forms as well, upon request by participants, the RA would also read and help fill out the survey.

Ethical Considerations

Informed consent was obtained from participants before the start of every interview and FGD. Informed consent forms were available for participants in both English and Lugandan, with a research assistant prepared to read the form if necessary or requested by the participants.

Focus groups participants were given numbers as a way to ensure their confidentiality and make them feel comfortable to share their perspectives.

Both the survey and the interview questionnaires were initially translated to Lugandan. Each interview question was read to the participants in both English and Lugandan.

Research assistants were given a brief training consisting of what the position requires of them, ethical expectations regarding anonymity of participants, obtaining informed consent, handling of sensitive issues, and an overview of the project conveying the goal of the research, its justification, and objectives.

Table 2. Participant Number and Characteristics

Participant	District	Primary Language	Languages Spoken	Age	Sex	Educational Attainment	Occupation	Martial Status	Religion	Number of Children
1	Jinja	Musoga	1	22	F	Primary 6	Farmer	Married	Protestant	3
2	Buikwe	Musoga	2	40	F	Primary 4	House wife	Married	Muslim	7
3	Iganga	Musoga	1	40	F	Primary 7	Farmer	Married	Christian	9
4	Buikwe	Musoga	1	39	F	Primary 7	Farmer	Married	-	4
5	Jinja	Lusoga	1	29	F	Primary 6	Business woman	Married	Protestant	4
6	Buikwe	Luganda	1	30	F	Primary 7	House wife	Married	Muslim	5
7	Iganga	Lusoga	1	30	F	Primary 4	-	Single	Protestant	1
8	Jinja	Lusoga	3	30	F	Primary 7	Tailor	Married	Muslim	3
9	Buikwe	Luganda	2	24	F	Primary 3	House wife	Single	Christian	1

10	Buikwe	Luganda	2	31	F	Primary 7	Trader	Single	Muslim	3
11	Buikwe	Luganda	1	16	F	Primary 6	n/a	Single	Christian	1
12	Buikwe	Luganda	2	27	F	Primary 1	House wife	Married	Protestant	2
13	Buikwe	Luganda	1	30	F	Primary 7	House wife	Married	Muslim	2
14	Jinja	Lusoga	3	30	F	Secondary 3	House wife	Married	Protestant	3
15	Jinja	Lusoga	3	22	F	Secondary 4	House wife	Married	Protestant	1
16	Buikwe (Mukono)	Lusoga	2	32	F	Primary.5	Market vendor	Married	Protestant	3
17	Buikwe	-	-	32	F	Primary 7	-	-	-	4
18	Buikwe	Luganda	2	44	F	Primary 4	Farmer	married	Muslim	8
19	Buikwe	Luganda	2	36	F	Primary 7	Hairdresser	Married	Christian	5
20	Buvuma	Luganda	2	20	F	Secondary 2	Tailor	Married	Protestant	1
21	Buikwe	Luganda	2	40	F	never attended	Farmer	Married	Christian	6
22	Kayunga	Luganda	2	38	F	Secondary 6	Grocery attendant	Married	Christian	2
23	Buikwe	Lusoga	3	34	F	Tertiary	Fisheries	Married	Christian	2
24	Jinja	Lusoga	3	27	F	Secondary 3	House wife	Married	Muslim	3
25	Buikwe	Lusoga	4	27	F	Secondary 2	Trader	Married	Christian	2

26	Buikwe	Luganda	3	31	F	Primary 7	Business woman	Cohabiting	Muslim	3
27	Buikwe	Luganda	1	25	F	Primary 6	House wife	Married	Catholic	2
28	Buikwe	Luganda	1	44	F	Primary 4	Farmer	Married	Christian	6
29	Mukono	Luganda	2	45	F	Primary 5	Farmer	divorced	Muslim	4
30	Kayunga	Luganda	1	31	F	Primary 7	House wife	Married	Christian	3
31	Buikwe	Lunyalwanda	4	24	F	Primary 6	Self employed	Married	Christian	1
32	Buikwe	Luganda		26	F	Secondary 2	Farmer	Divorced	Christian	2
33	Jinja	Lusoga	2	33	F	Primary 5	Fish far	Cohabiting	catholic	6
34	Buikwe	Luganda	3	18	F	Secondary 1	House wife	Married	Christian	1
35	Kiyunga	Lusoga	3	30	F	Senior Six	Tailor	Separated	Catholic	3

RESULTS

The study identified institutional, patient level, as well as social level factors and challenges that affect the provision of EMTCT services at St. Francis.

Patient level factors

Most of the patient level challenges that were identified by participants related to socioeconomic factors like money for transportation and being hungry and delayed at appointments (since most of the mothers would be coming with their small child/children but would not have anything to feed them when they get delayed at appointments).

Of two similar natured questions that were asked, namely “What challenges did you have getting here?” and “What obstacles, if any, have kept you from attending EMTCT appointments?” most frequently stated challenges faced with the frequency of answers is shown below.

Table 3. Frequently mentioned challenges and how frequently they were mentioned

Reason Stated	Money for transport	Being hungry and delayed at appointments	Being Sick	Home or work priorities	Seeing people they know when they receive treatment
Frequency of response	21	2	4	8	3
Percentage	55. 2	5.2	10.5	21.1	8

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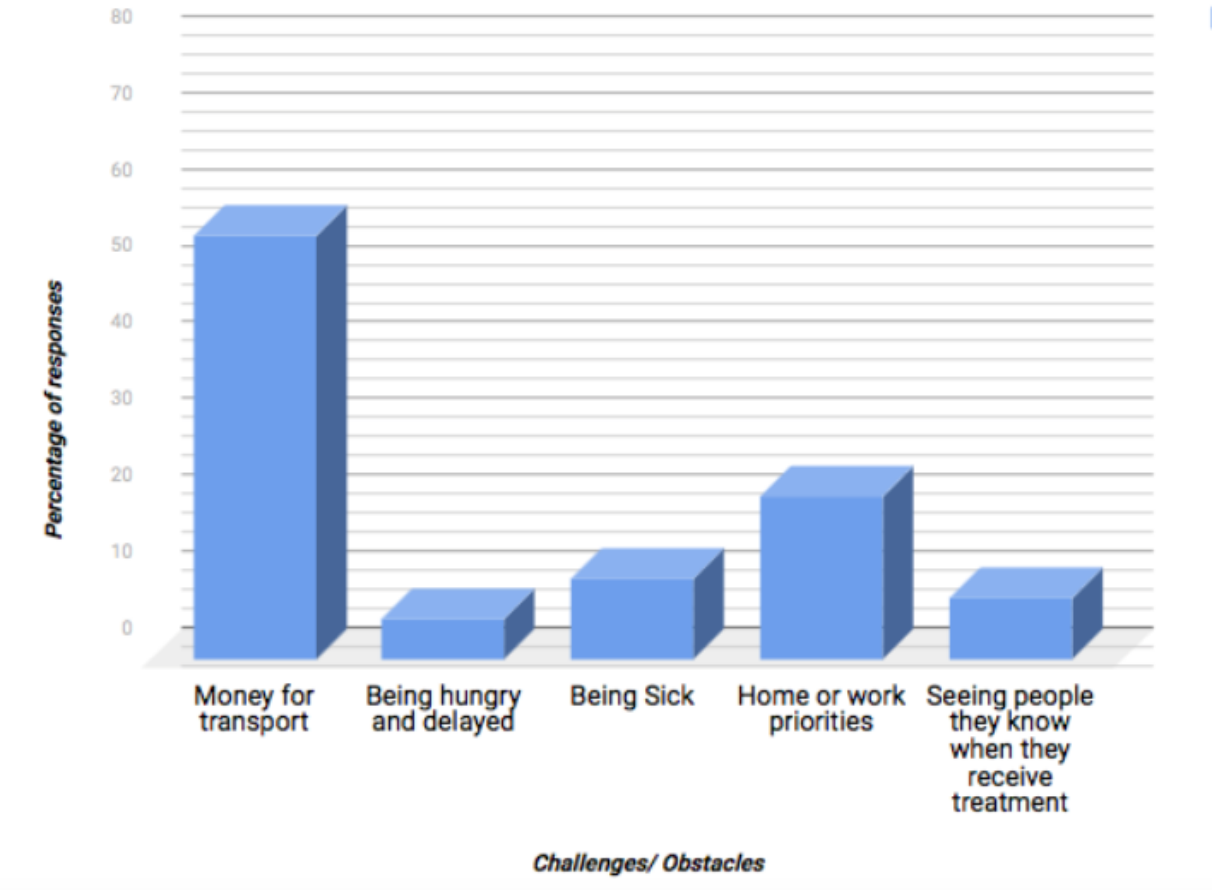
Figure 1. Relative frequency distribution of frequently mentioned challenges



Institutional Level Factors

All of the respondents except two out of 35 respondents stated that they were satisfied with the services received from MCH staff. An optimal level of care and treatment was most frequently stated as the reason for their satisfaction.

Although survey respondents reported an overall satisfaction with the care provided by St. Francis, some of the aspects they found dissatisfying or needing improvement included the following: (1) Needed a separate space for EMTCT where they would feel comfortable and free from the risk of encountering anyone they know. They referred to the fact that women coming for ANC or immunizations for their children would sometimes be accomodated in the same space as them, was a cause of distress for them. (2) availability of some drugs. Several women mentioned that there was a lack of some drugs when they came for refills, particularly the drug Septrin.

Social Factors

Some social factors that were mentioned either directly or indirectly included stigma, social networks, and gender roles. The majority of participants reported that the attitude towards HIV positive people was discriminative. Several participants stated that HIV positive people in there communities were perceived as “walking dead people” which, they said, also makes it hard to find employment. One mother said, “they [employers] think how can I employ someone that is going to die tomorrow?”

Women who reported presence of discrimination and lack of social networks in their community also had less positive interactions with their community. They also reported that it caused them to feel constant anxiety. One mother, having encountered some people from her community at one of her appointments, said that her encounter made her feel very nervous and

scared. She added, “this would be the reason that could lead me to stop coming for treatment.” After that experience she said she had to look around the whole compound checking to see if there was anyone she knew. Another mother told us that there was a time (before she was enrolled in EMTCT) when she had saw some of her neighbors after arriving at St. Francis to receive her ART medication. She said she quickly left without even getting refills, for fear that they would see her and “spread rumors about her in the community.” Overall, 36 % of the mothers started that they would be more willing to receive treatment if they knew they would not encounter someone they know.

Gender Roles

A surprising aspect of the survey results was that more than half of the respondents (51%) did not disclose their status to their male partners. Some attributed their non-disclosure to fear of how their husbands would react and/or fear of their husbands leaving them. During the survey seven respondents (20%) stated that they missed medication within the last month because they did not want somebody to find out. And some of those women mentioned during the interview, that they missed due to their partners being around.

Male partner involvement is also very low. During the of EMTCT husband key informant interviews, husbands were asked “What are the challenges faced when male partners get involved in PMTCT?” One husband stated that most other men might feel like they would have nothing to do if they came to their wives’ appointments, and that the MCH space is perceived as a female space. Transportation was also mentioned as a challenge. Both men suggested that the message of the importance of male partner involvement would get the most uptake if the information was being taught or dispersed by other men in the same situation, and that more should be done on awareness creation and sensitization.

Gender roles also affect the women's access to services in regard to being dependent on male partners for transport money. One mother said, "Many ladies depend on their husbands for transport money, which makes it hard for them to come if they don't have money or if they don't have anything(food) to give their children. That is a major challenge that I always have and that others also struggle with."

Limitations

One limitation of the study was that the mothers were recruited in a clinical setting, which could bias enrollment toward individuals, which are more likely to have good adherence in the EMTCT program. Therefore effort was made to specifically target women that had problems in retention.

Another limitation was the fact that some of the women on the appointment sheet did not have phone numbers listed (mostly due to participants lacking a phone, oversight, or incorrect numbers consisting of a missing or extra digit). Some of the mothers listed with issues of retention that were called to take part in the research sometimes denied their identity and other times had incorrect numbers listed. Although this was a limitation to our research in terms of its aim of getting more input from mothers with problems of retention/adherence, this issue also poses a significant barrier that hinders the capacity of St. Francis staff to provide follow-up to these patients with such issues.

FGD participants were also selected from a single clinic, so their ideas may not be generalizable to all health care centers. However, their responses are valuable starting points for further intervention and empiric evaluation, which are urgently needed to ensure that opportunities for improvement of EMTCT programs are not missed.

DISCUSSION AND CONCLUSION

To achieve elimination of MTCT, interventions must work within communities to address barriers that have been identified and increase service use. Our results show that there are some significant barriers to optimal uptake of EMTCT services that occur at community level (i.e., outside the healthcare setting) that present priority focus areas for St. Francis:

Gender roles need to be addressed to ensure equitable HIV/AIDS health service expansion, particularly in EMTCT programs. Inequality in Gender roles with respect to barriers in EMTCT, also relate to (1) challenges of disclosure of status to partners (2) male partner involvement (3) access to services(with regard to being dependent on male partners for transport money), and (4) adherence to prescribed medication.

The results reveal that male partner involvement is an important priority area to work on for the EMTCT program in St. Francis. Male partner involvement is also difficult to achieve since there is a significant gap in the amount of mothers that disclose their status to their husbands. This poses a significant barrier in effectiveness of the program, since failure of an HIV positive woman to disclose her status to her partner and lack of male partner involvement in EMTCT interventions have been identified as two social factors that hinder the success of programs aimed at achieving EMTCT(Nyandat & van Rensburg, 2017; Thomson et al., 2018).

Disclosure of HIV status as well as male partner involvement are affected by social perceptions. Participants who reported having good social networks through a supportive and understanding community, had also disclosed their status to their partners.

Several studies confirm the importance of stigma and social perceptions on adherence (Li, Murray, Suwanteerangkul, & Wiwatanadate, 2014; Ware et al., 2009). Although stigma manifests differently depending on the cultural context, stigma in Uganda has been linked to decreased adherence and emotional distress (Chan et al., 2015)). Where as presence of social

networks and access to social support promotes adherence (Li et al., 2014; Ware et al., 2009). Qualitative researchers studying adherence in Botswana and Tanzania found that clients lacking strong social networks in the community have reduced motivation to remain in treatment (Busza et al., 2012).

To achieve elimination of MTCT, interventions must work within communities to address barriers that have been identified in order to increase service use. Therefore efforts to improve the EMTCT program at St. Francis can be guided by the community input exacted through the process of this study.

SUGGESTIONS AND RECOMMENDATIONS

1. Clients coming for EMTCT should be received and accommodated in a space that is separate from other services like ANC.

   EMTCT clients all value their privacy and do not feel comfortable when they are receiving treatment while in mixed company with people coming for ANC or immunizations. A lot of the women expressed that they feel anxious about the possibility of running into a neighbor or community member.

2. Finding ways to try to address the problem of transportation costs.

   Transport money has been identified as the most recurring challenge for both the mothers and fathers for coming to the facility. And studies have shown that distance to facilities and cost of transportation affect testing, collection of results and health-seeking behaviours (Posse, Meheus, van Asten, van der Ven, & Baltussen, 2008).

   To address this one mother suggested that they [mothers] receive training on income generating activities. And since some other mothers and both of the husbands interviewed identified finding employment as another challenge, it would be one

approach to try to address two important challenges that were identified by the community taking part in EMTCT.

3. Addressing the problem of HIV status disclosure and male partner involvement

   _____ Since ANC was the most stated reason for how mothers first encountered St. Francis and later learned their status. There needs to be more outreach and more initiative given to support male partner involvement in ANC. One suggestion given by an EMTCT husband, is to facilitate ways to continually engage male partners in the space, since he claims most husbands think "what will I do if I go."

4. Refresher trainings for staff involved in EMTCT.

   One of the objectives outlined for the EMTCT program in St. Francis' five year plan includes refresher trainings for the midwives, which has not yet been started. Ethics and other relevant training and also receive encouragement would be beneficial.

   And in relation to Addressing the problem of HIV disclosure, one of the WHO outlined strategies to improve disclosure is to cross train HIV and domestic violence staff. According to the WHO: *This cross-training could involve providing staff information on the dynamics of domestic violence that may ultimately help them to identify and refer women who are living in violent relationships, thereby diminishing the risk of negative out- comes of HIV status disclosure* (WHO, 2004).

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