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Innovative Approaches for Eliminating Mother-to-Child Transmission of HIV

Empowering Clients Through Peer Support: Experiences from Community Mentor Mothers in Malawi and Uganda

Optimizing HIV Treatment Access for Pregnant and Breastfeeding Women (OHTA), a UNICEF-supported initiative with funding from the Governments of Norway and Sweden, aimed to accelerate access to Option B+ for the elimination of mother-to-child transmission in Côte d'Ivoire, the Democratic Republic of the Congo, Malawi, and Uganda. Option B+ is an approach recommended by the World Health Organization in which all pregnant and breastfeeding women living with HIV are offered treatment with antiretrovirals for life regardless of their CD4 count.[1]

The OHTA Initiative's primary focus was to strengthen the capacity of the primary health care system to deliver lifelong HIV treatment to pregnant and breastfeeding women; create demand for programmes aimed at preventing mother-to-child transmission (PMTCT), increasing uptake and timely utilization of PMTCT programmes by women, and retaining women in care; and strengthen monitoring and evaluation for decision making to improve service delivery.[2] The OHTA Initiative was implemented between 2012 and 2017 through in-country implementing partners.

> ***"Women think about the education and support we provide. Seeing we are HIV positive gives them support so when they go back they continue with their drugs [ART]."***
>
> — Mentor Mother, Malawi

Better service delivery and improved uptake, adherence, and retention in care are essential to the achievement of universal access to lifelong antiretroviral therapy (ART) for people living with HIV, and innovative approaches are often required. Individual client support, such as peer support and counselling from a Mentor Mother who has been through PMTCT programmes herself, has been identified as a promising practice to support lifelong ART in Malawi and Uganda.[6] The Mentor Mother approach, which has been implemented in countries all over the world, has been found to improve ART retention, early infant diagnosis, infant ART initiation, the number of antenatal care (ANC) visits, and disclosure of HIV status.[7,8,9]

Description

The Mentor Mother approach has been implemented by the Africa-based non- governmental organization mothers2mothers (m2m) in 10 countries in sub-Saharan Africa and aims to provide education, psychosocial support, tracking, and follow-up to women living with HIV who discontinue their care, in order to decrease mother-to-child transmission and support women's right to health. Mentor Mothers traditionally work at the health-facility level. In order to strengthen community-facility linkages to prevent loss to follow-up, the OHTA Initiative, in partnership with m2m and the Governments of Malawi and Uganda, supported and funded the implementation, testing, and documentation of a Community Mentor Mother (CMM) programme – the first of its kind in both Malawi and Uganda. Lessons learned from the implementation of CMMs under the OHTA Initiative can be used to inform future PMTCT programming and global efforts to achieve universal access to lifelong ART.

Globally, AIDS-related deaths have declined over the last 11 years by 48 per cent, due largely to the scale-up of ART.[3] While there has been a sharp decline in the number of children dying of AIDS-related deaths, from 210,000 in 2010 to 120,000 in 2016,[3] 2.1 million children under the age of 15 are living with HIV.[3]

In both Malawi and Uganda, important strides have been made to address the HIV epidemic, including the provision and scale-up of PMTCT services. For example, both countries have achieved an unprecedented decline in the number of children acquiring HIV – from 17,000 new HIV infections among children in Malawi in 2010 to 4,300 in 2016, and from 26,000 in Uganda in 2010 to 4,600 in 2016.[3] Despite these accomplishments, in 2016, there were an estimated 36,000 new HIV infections among the total population in Malawi and 52,000 in Uganda, and 4,100 AIDS-related deaths among children 0 to 14 years old in Malawi and 5,800 in Uganda.[4] Additionally, although 84 per cent of pregnant women living with HIV in Malawi were receiving ART, more than 4,000 children were newly infected with HIV in 2016, and less than half (49 per cent) of children living with HIV were on treatment.[3] In Uganda, more than 95 per cent of pregnant women living with HIV were receiving ART, but 4,600 children were newly infected with HIV in 2016 and only 47 per cent of children living with HIV were on treatment.[3]

Locations

The CMM programme was implemented in three districts of Malawi – Blantyre, Mangochi and Thyolo – at six sites. In Uganda, the CMM programme was implemented in six districts – Kamuli, Bugiri, Namayingo, Iganga, Mayuge, and Kaliro – serving 12 communities and 20 health facilities.

Implementing Organizations

m2m implements the Community Mentor Mother programme in Malawi and Uganda with support from the OHTA Initiative, Ministries of Health (MOH), and district health offices.

Implementing Organization	Role
District Health Office	In both countries, MOH district health offices provided supportive supervision to all CMM sites and supported resource allocation, monitoring, evaluation, and service provision.
OHTA	The OHTA Initiative provided critical financial resources and support in the research, implementation and documentation of the CMM programme in both countries, including training and logistics support, strengthening of community-facility linkages and, in Malawi, supporting assessment of the programme's impact among adolescents.
MOH	The MOH in Malawi and Uganda supported all OHTA Initiative activities by working with m2m to create strategic plans, ensure uniform messaging and adherence to training standards, participate in supervisory meetings with m2m, set targets for the programme, identify locations for interventions, monitor activities, and report on progress.
m2m	m2m oversaw and implemented the CMM programme in Malawi and Uganda. m2m trained and employed CMMs to provide essential health education and support to women to prevent maternal-to-child transmission and provide care and support to those living with HIV.

> *"...If I get a client, I really put myself in their shoes because I know what it means [to live with HIV]. ... it is hard, but I will tell her I'm ready to support you through all this, I'll support you even if it means you need me to come to your home to help you disclose because I know how hard it is. It took me two years. How can I tell a young mother of 16 years who has tested positive that you can tell your partner the next day. I just have to assure her, I'm there to support you. I'll support you through all this."*
>
> *– Former Mentor Mother, m2m staff member, Uganda*

What Are Community Mentor Mothers?

Services Provided

Mentor Mothers are local women and mothers living with HIV who work to ensure that newly diagnosed pregnant women are supported through initiation of HIV testing, counselling and treatment, and that they are retained in care. Most Mentor Mothers work at the health-facility level to identify pregnant women living with HIV and prevent mother-to-child transmission. Facility Mentor Mothers facilitate health education sessions during ANC visits and lead peer support groups. Although CMMs worked alongside facility Mentor Mothers, they primarily worked in the communities in which they lived to prevent loss to follow-up and identify and support newly pregnant mothers for PMTCT services.

In Malawi and Uganda, CMMs provided individualized education, psychosocial support, appointment reminders, referral services, and follow-up services to women and their families through home visits. Home visits are provided for general reproductive, maternal, and newborn child health in order to protect the HIV status of the mother and minimize

stigma. CMMs visited newly pregnant mothers, regardless of their HIV status, as well as women who have discontinued their care. Home visits often focused on the importance of early and repeat ANC and HIV testing and counselling, and provided encouragement to women to access health services at the facility. In Uganda, CMMs also discussed tuberculosis screening, nutrition, and immunization with families during home visits, and if a woman and/or her child tested positive for HIV, a CMM followed up with them two weeks later to support treatment adherence and provide psychosocial support.

In Malawi, CMMs hosted community support groups for both women and their male partners living with HIV. They also worked with community leaders to host community meetings with key stakeholders – including village chiefs, community-based organizations, religious leaders, health surveillance assistants, and local teachers – on the importance of early infant HIV testing and diagnosis. CMMs in both countries also provided community health education talks during community events focused on maternal, newborn and child health, and PMTCT.

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To support their ability to conduct home visits and provide community support, all CMMs received a bicycle, provided and maintained by m2m. In Uganda, CMMs also received mobile phone credits to provide reminder phone calls.

The CMM programme also strengthened community-facility linkages through routine community-facility meetings between CMMs, facility Mentor Mothers and site coordinators to review monitoring data, discuss client service uptake, and address issues raised at the community level with facility staff.

Identification of Clients

In Malawi, newly pregnant women were identified by CMMs through home visits. Additionally, facility Mentor Mothers informed CMMs of women who discontinued their care and required follow-up services in the community. In Uganda, CMMs worked closely with existing village health teams (VHTs) and facility Mentor Mothers to identify pregnant women and women who required follow-up services.

Recruitment and Motivation of CMMs

The CMM recruitment and hiring process was the same in both countries. m2m and the MOH worked together to assess which facilities and communities qualified for a CMM, according to the prevalence of HIV among women seeking ANC at the facility. If the community qualified for a CMM, an advertisement for the position was posted in the facility and around the community. Applicants were interviewed and needed to meet the requirements for the position, which included being a woman living with HIV, having disclosed her status to others, and being willing to discuss with others her experience living with HIV. They also needed to be able to read, write, and speak in the local language. Once in the programme, CMMs served for one to two years, allowing other women living with HIV the opportunity to be mentors. Most mothers who applied were motivated by an interest in helping other women living with HIV in their community, having a job, earning a modest salary, and having the opportunity to gain additional skills and training.

Training of CMMs

In both countries, all new CMMs participated in a two-week pre-service training facilitated by m2m. The training covered topics such as HIV and AIDS, counselling, family planning, nutrition and tuberculosis, and on how to facilitate health education sessions. The training also included interpersonal skills development, communication, confidentiality, and community engagement, as well as the steps to conduct a home visit. In Uganda, new CMMs were also required to work at the health facility for a two-week period to learn from the health workers and facility Mentor Mothers before beginning their work in the community. In both countries, all CMMs also received in-service trainings on an annual basis, with additional in-service trainings offered when necessary, for example, when new HIV developments occured or updated guidance was available.

Supervision of CMMs

Some CMMs also served as CMM Coordinators. CMM Coordinators received an additional week of pre-service training and were responsible for overseeing other CMMs, conducting monthly data review meetings, reporting, and programme oversight. CMM Coordinators also occasionally provided on-the-job supervision to CMMs in the community

as they observed education sessions. Project managers also supervised CMMs to ensure CMMs addressed concerns and provided accurate information during health sessions and that they knew how to accurately complete forms, thus ensuring the delivery of quality services and reporting.

Malawi Spotlight: Since 2016, CMMs in Malawi have reached more than 26,000 community members through education sessions focused on the importance of HIV testing and treatment.[10] Additionally, CMMs interacted with more than 40,000 households, including more than 2,000 men, providing individualized education, reminder services, and care and support in the communities they served.[10]

Uganda Spotlight: : Since 2016, CMMs have provided education to more than 19,000 couples through home visits.[11]

Promising Outcomes of the Community Mentor Mother Programme

Throughout the course of the programme in Malawi and Uganda, CMMs:

- Provided education on disclosure of HIV status and reduction of HIV-related stigma through community support groups, household education, and the involvement of male partners and community leaders
- Created and strengthened collaborations with community stakeholders to enhance facility-community linkages
- Improved women's comfort with seeking care by providing education and escort services
- Provided mothers with individualized peer support
- Nurtured supportive family and community environments to support women to disclose their HIV status
- Stimulated demand and interest for increased HIV education, counselling, and testing among communities with and without CMMs
- Empowered CMMs through trainings in health education and communication strategies
- Strengthened male engagement through home visits and education

Essential Components and Factors for Success

Several factors were identified as essential to the success of the Mentor Mother programme including:

Individual:

- CMMs were motivated by earning a modest salary, gaining additional skills, receiving recognition from the community, and supporting other women living with HIV
- CMMs were from the communities in which they worked and were seen as relatable peers
- CMM expectations, roles, and responsibilities were clearly defined and understood

Interpersonal:

- Peers provided individualized client support to mothers living with HIV
- One-on-one psychosocial support provided women a private setting to ask questions
- CMMs' disclosure of HIV status to mothers supported the mothers to disclose their own status to partners, family, and the community
- Confidentiality and trust between the CMMs and client

Community:

- Identification of mothers, early linkages to care, and proactive home visits encouraged women to attend early ANC and adhere to treatment schedules
- CMMs strengthened family support networks and male partner involvement
- Participation of village leaders and community stakeholders improved community involvement
- Existing structures and networks, such as VHTs, helped CMMs identify women for services in Uganda

Facility:

- Community-facility meetings and feedback sessions strengthened linkages between the community and facility
- Supportive supervision of CMMs ensured quality messages during education sessions and accurate reporting
- Standardized reporting tools ensured client tracing and identification
- Clear supervision structures ensured CMMs received support
- Strong monitoring and evaluation mechanisms assessed progress and track clients

Structural:

- Provision of bicycles to CMMs ensured transportation mechanism to conduct home visits
- Quality and consistent training throughout the programme prepared CMMs for their roles
- Provision of modest salaries helped motivate CMMs

> *"Mothers describe the support groups as their other families. It's a safe place to offload. The other women are in the same situation as you and come from the same community so they understand."*
>
> *— m2m staff, Malawi*

Considerations for Scale-Up and Sustainability

Through the OHTA Initiative, CMMs in Malawi and Uganda strengthened community-facility linkages and played a critical role in identifying women for early ANC and HIV testing and preventing loss to follow-up by providing peer and psychosocial support to women living with HIV in their communities. Several factors should be considered when considering replicating or scaling up this practice nationally or in other settings.

- **Financing:** Consistent funding needs to be available to support a modest salary for CMMs. Funding is also required for the extensive pre-service and in-service training, one of the key factors for the quality and success of CMMs, as well as for robust programme performance management and quality improvement. Additionally, funding is needed to provide and maintain a bicycle for each CMM.
- **Health Workforce:** Job responsibilities of CMMs and facility-based staff should be clearly defined and understood in order to limit task-shifting to CMMs that could negatively affect their workload and limit their ability to provide personalized support and care to clients.
- **Supply Chain:** Consistent stock of critical ART medications and testing kits are needed to ensure clients return to care and receive the services they need when they are referred to a facility by a CMM.
- **Distance:** Distance to the health facility and family relocation can cause challenges to adherence and follow-up.
- **Existing Resources:** Working through existing community structures and networks, such as pre-formed VHTs, can increase credibility and sustainability of the approach.

Contextual Considerations

- **Location:** Geographical differences between urban and rural areas should be considered in every context. Conducting client tracing in urban areas, where people move frequently and do not know one another, may pose a challenge. Finally, the sense of community and accountability may be stronger in smaller, rural communities.
- **Capacity:** Education and literacy levels of potential Mentor Mothers should be considered in every context while ensuring reporting tools are easy to fill out and understand for all CMMs.

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> *"Families and communities that have been reached by [CMMs] reported there is an impact for the Mentor Mothers to allow them to come out of their closet and communicate their status to both their families but also to their communities, and be able to live with it [HIV] in a positive and dignified manner."*
>
> *— m2m staff member, Uganda*

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Methodology for Documenting Mentor Mothers as a Promising Practice

The Johns Hopkins Center for Communication Programs (CCP) supported the documentation of this promising practice. Information and data were collected through a desk review of existing OHTA Initiative documents, including annual reports, partner reports, and presentations. Site visits by CCP and project staff were also conducted, including interviews and focus group discussions among implementing organizations, Ministries of Health, and programme implementers.

For more information about the OHTA Initiative, visit http://childrenandaids.org/optimizing%20HIV%20treatment%20access.

For more information about UNICEF's HIV and AIDS programme, visit childrenandaids.org.

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