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Improving Uptake, Retention, and Quality of PMTCT Services along the Entire Continuum of Care:

Evaluation Findings, Tested Changes, and Guidance from Tanzania

SEPTEMBER 2014

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DISCLAIMER

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Acronyms

AIMGAPS	Assuring infants and mothers get all PMTCT services
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
ASSIST	USAID Applying Science to Strengthen and Improve Systems Project
CD4	Cluster of differentiation 4
CHMT	Council health management team
CHSS	Community health systems strengthening model
CTC	Care and treatment centers
DBS	Dried blood spot
DRCHCO	District Reproductive and Child Health Coordinator
EBF	Exclusive breastfeeding
EID	Early infant diagnosis
FGD	Focus group discussion
HCI	Healthcare Improvement Project
HEI	HIV exposed infant
IP	Implementing partner
L&D	Labor and delivery
MOHSW	Tanzania Ministry of Health and Social Welfare
PDSA	Plan-Do-Study-Act
PLHIV	Person living with HIV
PMTCT	Prevention of mother-to-child transmission
QI	Quality improvement
RCHS	Reproductive and child health services
RHMT	Regional health management team
SES	Standard evaluation system
URC	University Research Co., LLC
USAID	US Agency for International Development
WHO	World Health Organization

I. INTRODUCTION

An estimated 260,000 children are newly infected with HIV every year with the vast majority of those infections occurring in sub-Saharan Africa (UNAIDS 2013). Globally, 49% of women who are HIV-positive are on anti-retroviral therapy (ART) while breastfeeding compared to 62% during pregnancy and delivery, presenting an opportunity for infants to become infected while breastfeeding.

To prevent mother-to-child transmission of HIV (PMTCT), women and their infants must be enrolled and retained into care throughout the PMTCT continuum of care from antenatal care (ANC) through delivery and 18 to 24 months post-partum. However, many women fail to enroll in care despite several opportunities and many others drop out or are lost to follow-up. Barriers to enrollment and retention may be associated with the individual woman (e.g., maternal education and age, knowledge and beliefs, maternal depression, pregnancy history, and health status and disease self-management); her partner and community (e.g., disclosure, stigma, community support, and socio-cultural norms); and/or the health system with which she interacts (e.g., shortage of trained health care providers, patient-provider relations, facility resources and infrastructure, and physical access to services) (Chinkonde, Sundby et al. 2009, Arreskov, Minja et al. 2010, Falnes, Tylleskär et al. 2010, Busza, Walker et al. 2012, Watson-Jones, Balira et al. 2012, Gourlay, Birdthistle et al. 2013). Keeping HIV-exposed infants (HEIs) in treatment through the first 18 months of life is also a challenge. One review found that during the first three months of life 33.9% of HEIs in sub-Saharan Africa were lost to follow-up and 45% of HEIs were lost after being tested for HIV (Sibanda, Weller et al. 2013). In Tanzania, 31% of HEIs did not follow through on referrals to the Care and Treatment Centers (CTC) and 61% of HEIs enrolled in treatment were lost to follow-up (Chiduo, Mmbando et al. 2013).

Another review noted that many PMTCT interventions focus on the facility despite growing evidence of the benefit of multiple and varying community approaches (Marcos, Phelps et al. 2012). Of the nine studies included in that review, all the community-based interventions focused on individuals (e.g., peer mothers, educators, counselors, or lay providers) offering supportive services to women in their communities. Yet another paper reviewed interventions to strengthen linkages between community and facility; all reviewed interventions utilized systems within the facilities (e.g., mobile phone messages to remind patients of appointments) or created new systems such as establishing a cadre of volunteers or hiring staff to guide patients through the facility (Busza, Walker et al. 2012). While these approaches have achieved results, the focus on lay workers, often based out of the facility, may not be sustainable due to attrition (Nkonki, Cliff et al. 2011).

The HIV epidemic in Tanzania is generalized with a national prevalence rate of 5.1% among adults ages 15-49 (UNAIDS 2013). Vertical transmission is estimated at 6.3% (Buchanan, Dow et al. 2014). In 2013, the Tanzanian Ministry of Health and Social Welfare (MOHSW) has set the goal of virtual elimination of mother-to-child transmission by 2015.

Involving male partners in ANC has been hypothesized to result in improved effectiveness of PMTCT programs and increased HIV-free survival among exposed infants. In Kenya, there was a lower incidence of HIV infection among infants born to women whose male partner attended ANC appointments compared to infants of women whose male partner did not attend (16 per 100 person-years versus 31 per 100 person-years, respectively) (Aluisio, Richardson et al. 2011). Data from Tanzania that indicate that encouraging men to be tested for HIV may lead to improved adherence to treatment for their pregnant or breastfeeding partners (Msuya, Mbizvo et al. 2008).

II. AIMGAPS Intervention

Tanzania's Iringa Region, located in the southern highlands, has one of the country's highest HIV prevalence rates at 9.1% among adults age 15-49. Among women who utilize ANC services in the Iringa region, 81% receive HIV testing and counseling and receive the results of their HIV test.

Starting in 2011, the USAID Health Care Improvement Project (HCI), funded by the United States Agency for International Development (USAID) and the US President's Emergency Plan for AIDS Relief (PEPFAR), began working with the Tanzania MOHSW, EngenderHealth, TUNAJALI-Deloitte, and Regional and Council Health Management Teams (RHMTs and CHMTs) to support 11 facilities in the Iringa Region to improve PMTCT services. Iringa was chosen because its high HIV prevalence meant high-volume PMTCT services which would allow the project to learn a lot in short amount of time about improving PMTCT services. In 2012, this work transitioned to the USAID Applying Science to Strengthen and Improve Systems project (ASSIST), the follow-on to HCI.

Assuring Infants and Mothers Get All PMTCT Services (AIMGAPS) aimed to improve the uptake, retention, and the quality of care along the entire continuum of care; from the antenatal period, throughout the entire breastfeeding period, and until the HIV status of the exposed infant is definitively determined. PEPFAR knew there was high attrition in PMTCT services among mothers and babies after receiving HIV tests. PEPFAR wanted to find out what could be done through AIMGAPS to retain mothers and babies in care.

The objectives of this activity were to assist frontline health care providers in Iringa to:

- Determine the baseline uptake, retention, and attrition rates for PMTCT services;
- Determine factors contributing to poor quality PMTCT services;
- Apply the collaborative quality improvement (QI) approach to improve PMTCT service uptake through identification of attrition points and test changes to reduce the problem; and
- Use results to develop a package for regional and national scale-up.

A. Facility-based improvement

Eleven high volume health facilities representing all levels of the health system were included in the intervention. HCI and MOHSW established indicators to measure gaps and track progress in improving PMTCT service uptake at ANC, child welfare sections of Reproductive and Child Health Services (RCHS), labor and delivery (L&D), and CTCs.

Prior to the start of AIMGAPS activities, HCI had presence in Iringa through a short-term infant feeding QI activity. HCI staff met with RHMT and CHMT before the baseline assessment. Baseline data were collected through focus group discussions with providers and patients and facility registers from January through April 2011 at six of the 11 facilities. Results revealed 96% of pregnant women who came for ANC services received HIV testing and counseling. However, the baseline assessment identified many gaps along the PMTCT cascade. Women started on ARV prophylaxis or ART, timely enrollment of infants, retention in PMTCT follow-up, and enrollment of mothers at CTC after delivery were all below 50%. Partner HIV testing, women receiving their CD4 test, and infants receiving definitive tests were all below 20%. The client record system at the time of baseline data collection was not designed to capture mother-baby pair data during the postnatal period, making it impossible to determine service uptake for mothers and their babies during the postnatal period. Therefore, a separate infant cohort was obtained for tracking service uptake for HEIs during the postnatal period. During the baseline, it was also found that a mother may look lost to follow up based on the registers, but she had either moved to another facility or received a referral that had not been noted. Similarly, women often delivered at higher level facilities, not their regular point of care, so providers did not always know when she had delivered, making it harder to provide timely post-natal care (PNC). A lack of a network between facilities and generally poor documentation also hindered efforts to follow mothers and their babies through the PMTCT continuum. Factors hindering providers' ability to provide quality services were found to be late initiation of ANC, meaning women were not being identified and entered into the PMTCT cascade by 14 weeks' gestational age as recommended. Poor and inconsistent documentation, mixed infant feeding, and frequent stock-outs of test reagents and critical medicines were also noted. In April 2011, HCI staff presented the findings to RHMT and CHMT members and to each of the facilities and held initial conversations with facilities about QI.

To begin the AIMGAPS intervention, HCI staff met with RHMT/CHMT prior to conducting the baseline assessment. They were already conducting infant feeding activities at the sites in partnership with the TFNC and PMTCT from the national level.

Facility QI teams were composed of staff from ANC, RCHS, L&D, and CTC, along with laboratory technicians and pharmacy/dispensing staff. Collectively, these staff members represented all steps in the PMTCT care cascade and coordinated with each other to improve care, linkages, and service uptake. Following the establishment of QI teams at all facilities, activities were launched in May 2011. The QI teams were to focus on improving ANC attendance (namely that pregnant women were coming for all four ANC visits), partner testing, cotrimoxazole uptake, breastfeeding initiation, CD4 testing, early infant diagnosis (EID) at four weeks, monthly child follow-up, testing after cessation of breastfeeding, and enrollment into care for babies. Every facility was assigned a day of the week to send CD4 specimens for testing to improve CD4 testing and lessen the burden to clients.

The teams identified gaps, conducted problem analysis, tested suggested changes through repeated Plan-Do-Study-Act (PDSA) cycles, collected data and conducted monthly improvement meetings at their respective facilities to discuss performance and plan for future improvement activities. Using the collaborative improvement approach, teams from different facilities met periodically to share experiences and learn from each other. Teams were supported through coaching and mentoring by HCI and later ASSIST staff in collaboration with government and implementing partners (IPs).

In the first month of activities, providers from the 11 sites participated in the first learning session where they were oriented on the AIMGAPS objectives, introduced to the principles of QI, discussed current gaps in PMTCT care, presented with the monitoring system (indicators and data collection tools), and had an opportunity to develop work plans for the first action period with assistance from HCI staff. This first learning session was five days while all following learning sessions were three to four days.

At the end of June 2011, the first coaching visits were conducted by a team of HCI staff, IP representatives (EngenderHealth) and regional and district health officials. At the end of each visit, the coaches and QI team members discussed challenges with current data systems and methods for improvement, reviewed past work plans and activities to date, and developed a plan for the upcoming weeks before the second learning session.

Following this coaching visit, indicators and tools used were revised based on the existing data systems to facilitate routine data collection. The number of indicators was reduced to a total of 18: seven for the ANC clinic, five for the maternity ward, and six for the PMTCT HEI child follow-up.

The second learning session was held in August 2011, with representatives from each of the 11 sites participating in the improvement collaborative, along with representatives from EngenderHealth, RHMTs, and CHMTs. At the learning session, QI team members had an opportunity to present data on one or two indicators as well as changes currently being tested to improve PMTCT services.

After the second learning session, HCI advisors and partners conducted additional coaching visits in September with a focus on assisting the teams to improve documentation, data collection, and analysis so facilities would have the information necessary to see if the changes they were testing yielded improvements. Some of the improvements in documentation showed larger gaps in services than previously recorded. For example, a provider may have marked that a woman was enrolled at CTC, but oftentimes only a referral had been provided if a provider told an HIV-positive woman she should go to CTC. The definition was thus revised to state that enrolled to CTC meant a provider had to write the patient's CTC number in the register once they had received it. Additionally, in August 2011, changes in MOHSW guidelines that reduced treatment initiation from CD4 counts under 250 to 350 made more people eligible for ARVs, reducing the enrolment to ARV initiation gap.

During October through December 2011, HCI continued to provide support to PMTCT IP, RHMT and CHMTs to implement PMTCT QI activities. Two coaching sessions were conducted where 4 RHMTs, 21

CHMTs and 51 QI team members were supported to test and implement changes to increase PMTCT service uptake, follow up and retention. QI teams received support from HCI to document and collect data from registers and redesign processes of care to improve CD4 testing and enrolment of HIV positive pregnant women to CTC. HCI provided on the job training on collection of CD4 samples and QI teams moved sample collection to RCH. Teams also began enrolling HIV-positive pregnant women to CTC on the same day as diagnosis to increase enrollment. Sites were also continuing to implement changes to improve IF practices according to WHO 2010 guidelines through peer to peer learning.

In early 2012, HCI held the third learning session. This learning session focused on sharing experiences on collection of CD4 samples at RCH.

HCI staff mentored RHMT and CHMT so that by the fourth learning session in June 2012, CHMTs and RHMTs took the lead. They conducted sessions on logistics and supply chain management to reduce stockouts; increasing HIV testing; QI team roles; and the improvement model. The District Pharmacist attended and talked about supply management.

As found in the baseline assessment, HIV testing for pregnant women was already high at 96%. Follow-up testing, recommended three months after a negative test or during labor if no follow-up test has been given in six months, was low. Timely testing for babies four to six weeks after birth was also quite low. To address this, teams began giving mothers PNC appointment dates at discharge from L&D. They discussed the date with the mothers to ensure they could come at the date and time given. To improve four-week follow-up testing for HEI, providers began screening infant health cards to identify if they were HEI. Additionally, at this final PNC appointment, providers began escorting mothers and their babies to PMTCT services for the next phase of care.

B. Community linkages

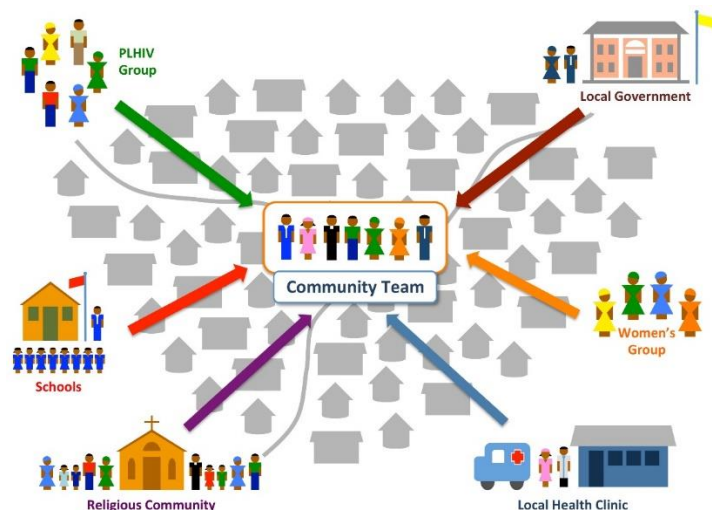
Working purely at the facility level, it was observed that male partner testing at RCHS remained low. Common practice was to send a letter to male partners to invite them for testing but this did not bring male partners in. On the other hand, despite increasing trend for exclusive breastfeeding (EBF) there was tendency to mixed feeding in the first 6 months among many women, which may predispose to increased mother to child transmission. It was also observed that the majority of pregnant women booked around and after 20 weeks of pregnancy thus delaying initiation of ARVs to those testing HIV positive. Responding to these gaps, at the third learning session in January 2012, a community component was initiated with the following objectives:

1. Increase early booking at ANC (pregnant women presenting at ANC by 14 weeks' gestational age);
2. Increase male partner involvement in ANC (including HIV testing);
3. Increase EBF among women 0-6 months postpartum; and
4. Improve follow-up of HEIs and under-five children.

The community component focused on getting all pregnant women in for early ANC and attempted to enhance PMTCT efforts primarily by using community leaders to sensitize people in the catchment area around the facilities via community meetings. Facility-community workplans were developed, and health challenges were made a permanent agenda in village meetings. However, after eight months there was little to no improvement on any of the objectives.

HCI introduced the Community Health System Strengthening Model (CHSS) (Figure 1) in which active and established community groups use their existing networks to strengthen the linkage between the community and health facilities.

Figure 1: Community Health System Strengthening model



One to two representatives from each existing and active community group (e.g., village local government office, agricultural, religious, sports, education, credit and savings groups) were selected to serve on community QI teams in each village. Facility outreach nurses were trained to serve as community QI coaches helping to identify and mobilize existing community groups in their catchment areas to encourage women to access ANC services early in their pregnancies. Community groups were oriented on how to identify and refer pregnant women, their male partners, and HEIs in their community. Home-based care volunteers were part of the community team and conducted follow-up with HIV-positive patients per Ministry of Health guidelines.

Community groups actively identified and referred pregnant women, their partners, and HEIs from their households, neighborhood, relatives, and anonymously through announcements on ANC services in prayer houses and village meetings. The groups tracked data of their referrals on a monthly basis. At monthly community QI team meetings, members reported the number of clients he/she had referred. Concurrently, facility providers identified clients referred for ANC booking through community groups by asking first-time clients whether they were referred by a community QI team member, or if they were informed at meetings or prayer houses. During meetings with facility nurses, community QI team referral data was compared to the number who visited the facility. Gaps were identified and possible reasons for clients not reaching the facility were discussed. Potential changes to fill the gaps were suggested and tested by community QI teams. Community QI teams organized their meetings to overlap with facility nurses' outreach activities to facilitate their participation. Where possible, the meetings also coincided with monthly village health committee meetings to allow members of the village health committee to participate.

Community QI team members shared that before they could educate others they needed to first educate themselves. Once they became aware of the importance of PMTCT services, they felt it was their responsibility to share the information and mobilize their fellow community members to access care. The act of educating one's self and others was viewed as continual:

"There is one saying which says that education has no end. This is because there is the next generation they need to get that education so they can live normal lives."

Thus, much of the work carried out at the community level was disseminating health education messages and mobilizing community members to utilize services.

A spillover effect of community engagement was observed by service providers from a nearby facility due to increased number of clients booking early for ANC and reported to be sent by community groups from their village.

C. Harvest meeting

In May 2014, the 11 sites came together for a two and a half day meeting to harvest tested changes for AIMGAPS and develop a how-to guide for improving PMTCT services. Nine domains (listed below) of PMTCT service cascade were set on four tables, with each table allocated participants from three sites as a group to contribute their performance to the theme in response to questions on the theme. Participants made four rounds of documenting and ranking the changes across the domains using the tested changes templates. The changes were ranked based on four parameters: evidence, simplicity, scalability, and relative importance using a scale of 1-5, with 1 being the least and 5 being the highest (see Appendix: Pre-workshop facility tested template). The nine domains were as follows:

- Access to care
 - male partner testing for HIV at RCH
 - pregnant women enrolled to CTC
 - HIV Exposed children enrolled into follow-up care
- Provision of medicines: ARVs and CTX
- Early Infant Diagnosis
- Infant Feeding
- Retention in care
- QI
- Data use
- Supply Chain Management
- Community linkages

The teams ranked and averaged each change across the 11 sites and provided a summary of how the change was implemented. ASSIST staff used a combination of the top ranked changes, experience, and number of sites that tested each change to develop the how to guide (see Annex) for others for application of QI elsewhere. The teams participating in the harvest meeting also reflected on their high-level advice to other teams who wanted to improve PMTCT services and recommended the following:

- 1) Identifying committed service providers from all PMTCT service sections (RCHS, L&D, and CTC if the facility also provide CTC services) to form the facility QI team;
- 2) QI teams should be formed at district and regional levels (RHMT/CHMT) related to PMTCT service supervision to support the facility QI teams;
- 3) QI training to QI team members to build their knowledge and skills for implementation;
- 4) QI team leadership should be elected and members assigned roles that include: note taker, time keeper, and data focal persons at each PMTCT service delivery station and overall program QI leadership and roles. The roles should be rotated among members to capacity across members and simplify transition in situations when a leader leave the facility as transfer or to pursue further studies to avoid weakening of team performance;
- 5) QI teams should conduct baseline assessment using national indicators to identify baseline performance and existing gaps;
- 6) QI teams at all levels should set up work plans to be implemented, monitored on monthly basis and results should be shared during QI team monthly meetings and with other members of the facility as an integral component with existing fora of the facility such as morning clinical meetings;

- 7) Day-to-day work should ensure timely and appropriate documentation. QI teams were used to the slogan "Do and Document Diligently";
- 8) PMTCT trained providers must support others through peer-to-peer learning so that all providers acquire basic skills for PMTCT implementation; and
- 9) QI teams should use existing technical forums at all levels to discuss the QI agenda at their level or share across facilities (e.g, the DRCHCO can organize a short sharing meeting on the day the facilities submit their reports, this may be more lively and could motivate teams to improve on their performance). Facilities are expected to support transport and meal allowance for their staff.

III. Results

Generally, there was improvement across key indicators from baseline in February 2011 to the final data collection in May 2014, however some indicators showed more improvement than others. Across the sites engaged in AIMGAPS, the percentage of HIV-positive pregnant women attending PMTCT care who received ART/ARV prophylaxis increased from 43 to 99%. In the 3 sites that added the CHSS component, the percentage of women from ANC whose male partner receive HIV testing last month increased from 30 to 70%. Changes in all key indicators are in Table 1.

Table 1: Changes in key indicators from baseline to endline

Indicator	Baseline February 2011	Midline July 2012	Endline May 2014
% women from ANC whose male partner receive HIV testing in the previous month (male partners testing for HIV at RCHS)	17	28	26
% women from ANC whose male partner receive HIV testing last month (in 3 sites with community participation through community groups)	30	41	70
% HIV+ pregnant women attending PMTCT care who received ART/ARV prophylaxis	43	95	99
% HEIs enrolled in PMTCT follow-up care by 4-6 weeks each month	43	40	52
% HEIs starting on cotrimoxazole at 4-6 weeks	60	48	66
% HEIs receiving confirmatory HIV test at 18 months	8	53	52
% HEIs retained in monthly infant follow-up care up to 18 months	76	80	88

A. Qualitative Findings

Following the conclusion of AIMGAPS, we collected qualitative data with PMTCT patients and health care workers to understand their experiences in strengthening the linkages between community and facility-based PMTCT services. A total of 53 patients and 17 healthcare workers were interviewed from the 11 AIMGAPS facilities. The following criteria were applied for the selection of patient respondents: pregnant or had delivered no more than six months prior to data collection and were at least 18 years of age. Healthcare workers were included if they provide PMTCT services and had worked at the facility for at least six months. A non-random selection process was used to identify patients and healthcare workers

who met the criteria. Patient interview guides included: PMTCT education, PMTCT enrollment decision-making process, experience with PMTCT services, knowledge and perceptions of Option B+, and exposure to the community component of the project. Healthcare worker interviews covered similar topics: perceptions of the quality of PMTCT services, perceived barriers to women accessing ANC and PMTCT services, and knowledge and perceptions of Option B+. We also conducted three focus group discussions with community improvement team members. Topics covered in the discussions included orientation to and experience being on a community improvement team, perceptions of the impact of the community improvement team within their communities, and the relationship between the community improvement team and the facility. Discussions had between 10 and 12 participants for a total of 33 participants (13 female, 20 male; age range 30 to 59). Participants were drawn from local government, churches, mosques, savings and credit groups, agriculture, poultry, and people living with HIV (PLHIV) groups. Eight respondents also identified themselves as village health workers and one identified as a home-based care worker.

The following results are combined qualitative and quantitative results by the broad categories of: testing and uptake; retention; infant care; supply chain management; documentation and data use; perceived impact of the community improvement work; community-facility relationship; male partner involvement; and client perceptions of quality.

1. Testing and Uptake

Most patient respondents indicated that they did not learn of their HIV status until they came for ANC services, signifying a gap in broader HIV awareness programs that encourage testing prior to conception. Three patients indicated that had they known of their status, they would have used condoms and avoided pregnancy altogether:

“If I had known this problem [HIV status] before I would not allow conception because becoming pregnant also reduces body immunity”. For those who were tested once they came for ANC services, several reported that they did not know about PMTCT services and had they known they would have come for testing earlier. However, one respondent, who knew her HIV status prior to conceiving, elected to become pregnant because she knew, with treatment, the baby could be born HIV-free: “A person who is HIV positive can deliver a child safely...I knew about this when we were given a seminar at the centers where we were picking up our drugs. That is why I decided to get pregnant.”

Providers viewed counseling and education as essential when encouraging a pregnant woman to test for HIV. Respondents attributed women coming for PMTCT services earlier in their pregnancies to the improvement work:

“The improvement teams have increased the percentage of women attending and joining the service. For example, formerly the mothers used to start attending the clinic after six months which was risking the baby to have infections, but nowadays after being mobilized they come to the clinic timely, when they have 14 weeks of pregnancy.”

In nine of 11 facilities, health workers also identified and escorted patients to CTC for enrollment. Health worker respondents indicated that additional work was needed in educating and encouraging mothers to bring their babies for definitive testing at 18 months:

“Many of them like to have the first test but when you give them the results that her child is fine, they relax knowing that the child is ok and do not make follow-up on anything else. That is a bit problematic.”

The opportunity to take medicine to prevent the transmission of HIV from the mother to her unborn child was viewed by patients as “normal”. In the words of one patient:

“I thought it could be better to enroll because it is normal to be enrolled to these services to prevent this child from being infected”.

This normalization of HIV and its treatment provided some comfort to patients in that they were able to see that others who were also infected were living productive lives and were delivering babies free from infection. Patients indicated that health workers also drew on this as a means of reassuring patients:

“The health workers...tell us we should not worry, that we are not the first and only people who have this problem. Many people are affected and most of them gain confidence through seeing others who are affected.”

Uptake and retention of PMTCT services as well as perceived efficacy were informed by previous experience and the experience of others. When asked whether the services had brought success to her health, one patient commented:

“Because I have used the dose for a long time and I have not yet experienced any side effects, but before I used it I was very weak during pregnancy and this led to the death of my baby. This pushed me to go for HIV testing and I was found positive. I started attending the clinic whereby I was initiated to medication which I am still using to date.”

Similarly, uptake and retention in Option B+ was related to side effects; most respondents reported having no side effects which, in their view, helped them adhere to their treatment. Patient respondents interpreted quality services as those which made them feel physically better and which resulted in an HIV-negative infant. Some could quantify their improvements, citing their CD4 counts for example, but most respondents drew on their lived experience, indicating they had fewer fevers and were stronger or that they had no negative side effects from the medication. This improved health status, from the perspective of the women interviewed, played a role not only in their decision to enroll in PMTCT services, but also to be retained in care. This was especially true for those who, prior to diagnosis, had felt the physical effects of the infection. Quality services were also perceived as those where the providers acted kindly and demonstrated compassion and medicines were available.

However, other factors were also listed by respondents as keeping women from seeking ANC or counseling and testing services, including male partner involvement, or distance. Patient and health workers offered the terms ‘negligence’ and ‘ignorance’ as another explanation for why women did not seek or adhere to services. This vocabulary could indicate that some women willfully failed to attend services while others did so unwittingly. One health worker explained:

“Some women don’t attend the clinic because they fear to come with their husbands and some don’t attend because of laziness and negligence as well as little knowledge on the importance of HIV testing, some still seem to be shy in front of the people because of being pregnant.” A patient was more pointed in her remarks: “Now even if it is a hard lifestyle she is living, but you have tested and found you are HIV positive, is that enough reason to prevent you from going to protect your child? The medication is free. You don’t pay. Does it mean that just using your legs to come here bothers you? That is negligence.”

2. Retention

Service providers conducted group health talks and individual health education session with mothers emphasizing the importance of keeping their monthly appointment. Since the registers for WHO 2010 PMTCT guidelines did not provide for mother baby pair follow up, providers insisted mothers to bring their CTC 1 cards at each visit. Service providers will confirm mother’s retention to care from this card as it provide all client’s information on attendance, CD4 testing and ARV uptake. Looking at this card the

provider will know whether the mother is retained to care, lost to follow up or not enrolled if she cannot produce the card. The provider will then either facilitate enrollment to CTC if the client is not enrolled, link back to CTC if the client has missed appointment or is lost to follow-up.

Some facilities were able to reorganize services to integrate HIV services for mothers into the RCHS and thus better coordinate care. In the view of health workers this process improvement removed the stigmatizing obstacle of the public knowing that a patient was seeking HIV services while making it a “one stop center”. This impacted retention into care as one provider noted:

“They [clients] do not disappear because the area where they are getting services has been isolated. Previously they were disappearing because they were self-stigmatizing themselves as they were having [CTC] services near our area...It is as if they feared that the other person will go to publicize...’ahh, so now I see so-and-so going to CTC’. So that situation many did not like at all. The services have been transferred here [RHCS]”.

Following-up with patients as a means to improve retention was done regularly with mothers; however, as one respondent noted, there was little proactive follow-up of exposed infants done prior to the improvement activities. One mechanism for improving follow up of children was to attach the exposed infant’s card to the mother’s card. While this has become a best practice with the national roll-out of Option B+, during the intervention period facilities were operating under the WHO 2010 guidelines (World Health Organization 2010) which stipulated that follow-up of mothers ended between four and six weeks post-partum. As a result, medical information of mothers and their infants was not linked, inhibiting follow-up and continuity of care. By attaching the two cards, health workers were able to take the opportunity during an infant visit to check on the wellbeing and retention of the mother and vice versa.

3. Infant Care

HIV testing for HEIs faced challenges, notably stockouts of reagents hindered Dried Blood Spot (DBS) sample collection at the time of enrolment. DBS sample collection increased when reagents were available. In Tanzania, there were only three sites to analyze DBS. To address these challenges, DRCHCOs provided on-the-job peer training in which providers from EID sites demonstrated DBS sample collection to non-EID sites. During supervision visits, DRCHCOs also supported providers on supplies stock management to reduce stockouts and facilitated the redistribution of DBS kits between facilities with overstocking to facilities that were running low. Providers used visits to the regional hospital as opportunities to learn how to collect DBS samples.

Babies are delivered in L&D wards while follow-up (growth monitoring, immunizations, etc.) was done at the child welfare clinic. A change that was made was to link babies at their 4-week immunization appointment to HIV follow-up. Providers called mothers when the child was eligible for testing and then providers would pick up results in town and make phone calls to those with positive test results.

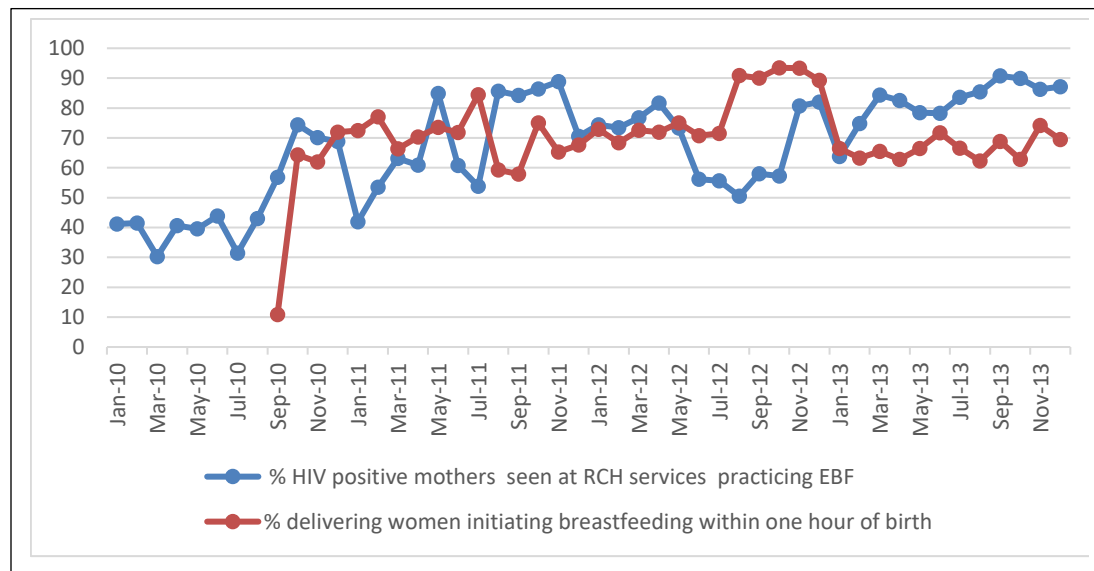
Some mothers wanted to stop breastfeeding when their babies tested negative, but nurses encouraged them to continue breastfeeding and conducted health education on the importance of exclusive breastfeeding.

Another change was creating a register for capturing HEI who were due for 18-month definitive testing. Providers made a list of the number of HEI expected to be 18 months for each month.

To increase ARV within 72 hours of birth, QI teams moved nevirapine to L&D, where previously it was in CTC or the PMTCT follow-up clinic. Previously when mothers delivered, they were given their first dose during their stay and then told to go to CTC for remaining doses. By moving all doses to L&D and providing them at discharge reduced risk of mothers missing their treatment.

Per Ministry guidelines, nurses were expected to support all mothers to put the baby to the breast within the first hour post-birth, however there was no way to track this in the register, so QI teams added a line to track it and found it was being done widely. In cases where nurses were too busy, the task would be shifted to medical attendants (see Figure 2).

Figure 2: Increasing trends for infant feeding practices in 11 facilities of Iringa Region



4. Supply Chain Management

Before testing changes ARVs were kept at only at CTCs; RCHS clients had to go to the CTC to get their medicines which was cumbersome for PMTCT clients and providers. The first change tested by QI teams was keeping supplies of ARVs at RCHS to shorten the process of dispensing. However, this change did not address the frequent stockouts. This was partly due to providers not knowing how to forecast, request, and reorder supplies.

Stockouts were observed by and a concern for mothers in care, especially in the context of EBF:

“Say the child has been breast feeding for up to seven months and on the eighth month you go for service only to find that there are no drugs and the child is still breast feeding. What will happen? Do I suddenly stop the child from breast feeding as I will not be having my normal dose or what do I do? That is what is worrying me.”

DRCHCOs worked with pharmacists to support sites through on the job training on logistics management, specifically forecasting, requisition, and reordering supplies using appropriate forms. A session on logistic management was delivered by a pharmacist during the fourth learning session as a knowledge and skill building activity. CRCHCOs and IPs also redistributed supplies during supervision visits from facilities which had excess stock to those with shortages.

5. Documentation and Data Use

During learning sessions, providers were trained on basic principles of QI including the importance of measurement and how to use data to monitor performance and plan for changes to be tested for improving care. PMTCT and QI trained providers mentored their colleagues on proper documentation in PMTCT registers, indicators tracked, and data to be collected on monthly basis. A data focal person was identified for each QI team for each service area (L&D, ANC, PNC, CTC). In hospitals or high volume facilities, each department had a focal person who facilitated data collection and presented data to the

team during QI meetings. Data was submitted to the DRHCOS and HCI QI Associate, who submit the data to URC country office. Teams were encouraged to review their data on the same day they had to submit it to the district.

By December 2013, the sites had made notable strides in the delivery of PMTCT services, gained skills in use of the Standard Evaluation System (SES) tool introduced at the first learning session on testing changes, compiling data, and drawing and annotating run charts. Providers reported that documenting and measuring changes had a positive impact on how facility staff worked together and communicated:

“Communication among us has become good; our working has become simple because every improvement is reported so as to progress with the services as a working team with a common goal”.

While improvements in documentation practices were observed it continued to present a challenge given the number of registers that had to be completed and the volume of clients and other tasks that providers had to carry out. As Option B+ was rolled out across Tanzania, a new register was also disseminated; facility staff had to transfer patient information from the old registers to the new Option B+ registers, creating additional registers to be maintained. In the words of one health worker:

“The real situation and the reporting system is that in some instances you are required to put the information and data in a certain place and the same data and information have again to be recorded somewhere else. In actual fact, some time it is duplication. It is hard to say but in implementation it is very difficult and sometimes you feel the weight of the task. The situation has made many other things to have some gaps”.

The volume of work and complexity of the registers impacted accurate enrollment documentation as providers forgot or were too busy to document the enrollment of a new client, even if she had been given test results and medication.

Language was also a barrier to complete documentation. One health worker shared that registers and other documentation were to be completed in English. Primary school is conducted in Swahili with English not introduced into the education system until secondary school. As many RCHS staff exited school in grade 7 they did not have strong English language skills; thus the requirement to complete documentation in English presented a language barrier for some facility staff. An additional challenge mentioned by several providers was that the register for HEIs only ran through the first 18 months of life when the recommendation was to follow them for 24 months. Eventually, the MOH was persuaded to translate registers to Swahili to improve completeness.

6. Perceived impact of the community improvement work

Community QI team members commented that over time, and with the help of the community education they provided, testing for HIV and enrolling in care and PMTCT had become more “normal” within the community.

“As a community, we have gained in that when the HIV pandemic was heard for the first time people were saying once you are infected you will die and if you don't have a child you will never get one. However after getting education, the concept that when you want to marry you must go for testing and if one of you is positive the marriage arrangement is put off. This is not the case currently. Couples now marry and have children provided you follow instructions so it becomes a sustainable generation. This is so for even us who are leaders or some who are decision makers in the community. This is what we have gained.”

Focus group participants shared that there were challenges at the start with getting people to listen to them and take their advice, with some commenting that community members were verbally abusive and disrespectful. In their perception, community QI team members were not viewed as being in a position to share health messages as this was the role of identified community health workers and health facility staff. Over time, those feelings dissipated and community QI team members began to feel appreciated and valued for the information and support they could provide. From their perspective, this appreciation and valuation was demonstrated by those who acted on the advice given, such as pregnant women attending ANC services, male partners accompanying pregnant women to the facility, couples developing a birthing plan and saving money to prepare for the costs associated with delivery, and lactating women demonstrating good breastfeeding practices. In one focus group discussion, participants shared that they took more aggressive action in the event that a community member did not heed their advice:

“We have agreed that a pregnant mother should go to a health center, dispensary or hospital for delivery. But deliberately and without any concrete reason a mother delivers at home. We “punish” the couple by sending health committee members telling them that what they did was unacceptable and endangering the woman’s life so as next time she will not do so again. We do this because we are trying to discourage this behavior which can result in their using untrained traditional midwives. The traditional midwife can help the mother to deliver but she can be infected with HIV and this can result in infecting the newly born infant or the mother who was not originally infected.”

The act of being visited by the community team brought shame to the family.

Among patients there was a clear preference to be educated by health care workers rather than community QI team members, both because of the nature of the relationship and the perceived authoritative knowledge the providers possessed. One patient respondent had mixed views on whether involving community organizations would impact uptake of PMTCT services, stating

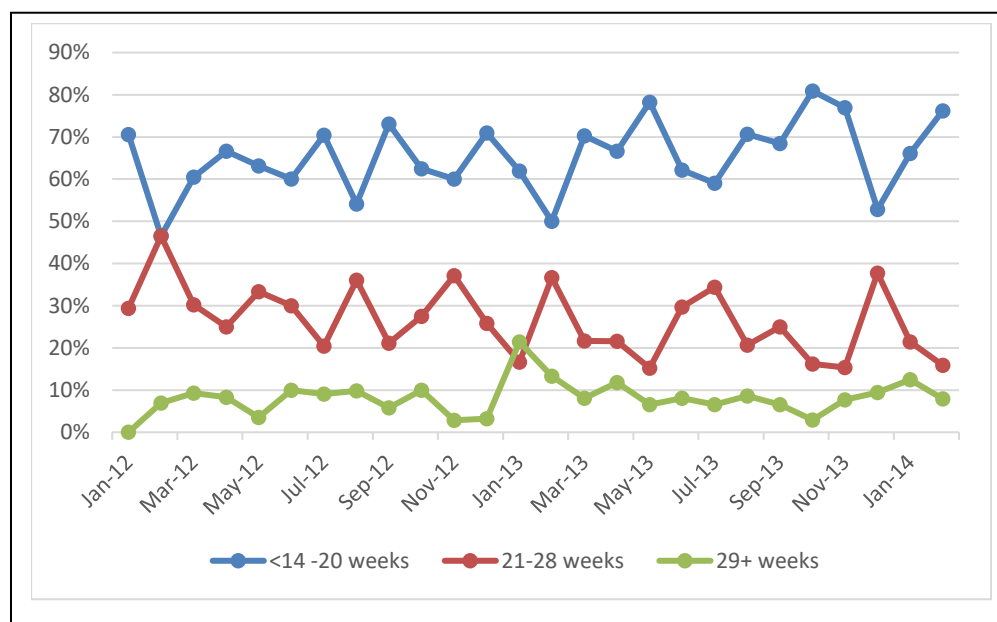
“I think they [community groups] fear how to start asking a person about that issue while she/he have never talked to her”.

Another patient responded that she did not believe that community groups would be effective in encouraging attendance at the facility because these representatives did not have sufficient knowledge to educate the community. However, patients also shared that community educators, as they were referred, could help in raising awareness about ANC and PMTCT services and could “encourage” attendance to these services.

Beyond the impact community team members felt the team had on their own communities, there was also the sense that the CHSS model could easily be spread across Tanzania and expanded to other health areas because it is “simple”. One respondent also expressed that people move around the country and all should be able to have access to the types of services they, as a community improvement team, provide:

“This program should be national because people in Tanzania intermarry. If a woman comes from Mwanza and is married here she will be surprised at what she sees, but if this program is also implemented there, there will be nothing new. For example, the Maasai tribe who are shifting (nomads) societies, with this program everywhere they go they get services”.

Figure 3: Trends of ANC Booking: Improvement observed among sites community linkage sites



7. Community-facility relationship

Facility-based staff, predominantly nurses, provided guidance and supervision to the community QI teams through educating team members and participating in regular community QI team meetings. Providers recognized the value in engaging community improvement teams because the nature of the relationship between these team members and the community at large was different that the relationship providers could have with the community. As one provider noted:

“My experience about these improvement teams through their duties is that most clients tend to trust these team members as regards the education they provide, thus enabling them to attend the clinic on time...The clients also use these team members to know how she [a pregnant woman] will be attended if the card gets lost.”

Another provider:

“We started forming groups in every village. To the service providers it is not possible for them to go everywhere because other villages are far. We have formed small groups of about five or six people which we visit once a month. Had we had the resources we would have done it more frequently. When we are there we sit with them and select group members, one representing the churches, one from the mosques, one from the farmers, teachers and so forth...We educate them on the importance of joining CTC, the importance of testing and starting clinic early and the importance of bringing your child to clinic...Those group members now go to their respective areas and mobilize their respective groups...As service providers we wait for the client to come but these community team members are at the level where our clients are and so they are closer to them than we are. Sometimes they even divulge their concerns to them about the activities at the center like if a client does not want to be served by a particular service provider, they tell these and they discuss in detail and in most cases the community team member finds a solution around such problems. This helps us a lot.”

This was reinforced during focus group discussions with the community QI team members who expressed that their access to the community facilitated the dissemination of information and awareness-raising. One community QI team member explained:

“Two community health workers serve 650-plus households. It was difficult for these two health workers to serve all these households to ensure that this education reaches every household. So we saw that this arrangement is good in that a religious leader gets a lot of people of the congregation and so if the knowledge is disseminated here it will reach a big population. Also, the person from the local saving and credit society will put this as an extra agenda after the normal proceedings. So this education will spread quickly. For example I am a village executive, and I am at a funeral I can have an opportunity to give this education to people who have gathered there and this will be an opportunity for those at the funeral to learn and have this knowledge. I have a public meeting. I can introduce this topic and a lot of people present will have this knowledge. So we saw that in this way a lot of people will access this knowledge rather than leaving the task to the primary health workers alone.”

During the regular meetings between facility staff and community QI teams, members discussed anonymously who in the community had not enrolled or been retained into care and identified possible mechanisms for identifying and locating those in need of services and supporting them to attend care. This approach was viewed as contributing to improved uptake and retention as well as strengthening the relationship between the community and facility.

8. Male partner involvement

Involving men in ANC care may, as one health worker noted, help women be retained into care after delivery because *“when they both participate it becomes easy to remind each other.”* However, health workers expressed the view that women tended not to inform their male partners that they accessed services because of a lack of trust within the relationship. As one health worker noted:

“When you counsel her and find her to be positive after testing, you initiate her to the medication process but she doesn’t ever tell her husband about it...the reason behind is that everybody tends to blame his/her partner that he/she is the source of the disease. Therefore this may lead to serious conflicts between the couple. Everybody tends to blame the other.”

Through the efforts of QI teams, some facilities elected to provide no cost services to men accompanying their partners, such as weight or blood pressure measurement or HIV testing, as a means of incentivizing involvement; however, there was no mechanism for documenting these services on the mother’s card or in the register.

Male involvement was, from the perspective of the providers, also thought to negatively impact cessation of breastfeeding at one year. For women who had not disclosed their HIV status to their partners it was difficult to stop breastfeeding in light of the common practice to breastfeed for two years. As one provider explained:

“In this area you find that, say, you have 10 children who are supposed to stop breastfeeding, but they haven’t. It is the male-oriented system. When you ask many women about this they say that their fathers have refused, that I should not stop the child from breastfeeding. There comes a time you ask the contact of the father so as you can try to convince him. Some agree but some also refuse.”

At the community level, men were encouraged to escort women to ANC, particularly for the first visit.

Community improvement team members recognized that there were cultural challenges with engaging males in care as a mechanism for encouraging their female partners to enroll and be retained into PMTCT services. As pregnancy and child rearing was viewed as a female domain, male involvement was perceived as a threat to their masculinity. However, community improvement team respondents perceived these norms as having changed over time:

“Something that brings happiness is that men do understand and have discovered the importance of testing HIV. Also they escort their wives to go for monthly clinic test. So they are aware of the existing condition comparing to the past, they used to dispute, For example a man could refuse to go to clinic for testing saying that ‘am I the one pregnant?’. We are thankful because they are aware and continuing to play their roles although some are still a little bit disputes but I am sure they will change.”

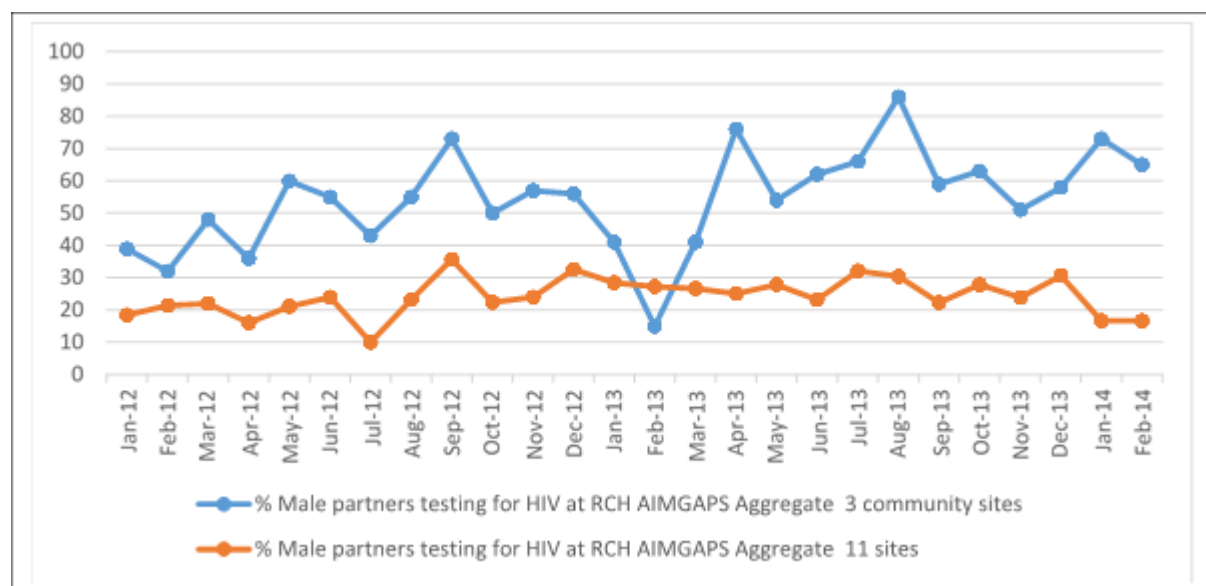
Another respondent:

“The first benefit is more knowledge also another benefit is that in the past men could not escort their wives to clinic. They could not accept that to the extent of saying that it is not their responsibility, but now they are...they are also being involved in mother’s preparation before delivery. It’s true I see this as benefits.”

Another respondent indicated that the men only accompany their wives during the first ANC visit and are not continuing their engagement through the course of pregnancy and in the post-partum period. Respondents also indicated two actions to motivate men to accompany their wives. The first was a *“regulation [community bylaws] which says that a man is obliged to escort his wife to clinic throughout the pregnancy till birth”*. These community bylaws were established and ratified by the local governing body. The other, implemented by the community QI team itself, was to *“call the man and his wife and advise them to continue clinic services for the born child”*. Both actions were perceived by community team members to be effective. This was corroborated by a provider who noted *“They [community QI team members] are also able to reach the father and convince him to escort his wife to the clinic. This has also increased fathers’ response.”*

As illustrated in Figure 4, the three facilities providing services to the communities with the CHSS model had more male partners attending the RCHS for HIV testing than all facilities combined.

Figure 4: Percentage of male partners getting tested for HIV at RCHS in 11 AIMGAPS facilities, Iringa, January 2011-February 2014



9. Client perceptions of quality

When asked about the information and treatment they received from health workers, most patient respondents were positive, indicating that the information was clear, health workers answered questions and were kind. There was confusion and inconsistency in the information regarding breastfeeding. For some the confusion was around duration:

“I mean, formerly the breastfeeding duration was six months but now it has been extended to one year, so I was worried what would happen when the baby sucks for one year instead of six months.”

Maintaining a client’s confidentiality as a component of quality care was listed by health workers as both an area of successful improvement and an area in need of further improvement. Challenges focused on the layout of the facility which had limited private space for consultation and treatment. Providers did feel they were able to maintain the “secrecy” of their clients’ medical information, but the inability to hold private consultations was viewed as negatively impacting their relationships with the clients:

“Most of the clients want their secrets to be kept accordingly; once there is lack of keeping clients secrets, then it becomes difficult in working.”

Coordination of care proved to be a challenge as one facility would provide RCHS and another would provide CTC. One respondent noted that mothers were attending both facilities and receiving and taking medications from both:

“There are people who do not know that the clients attending the CTC are also given medication and so they give them Option B+ on top of the other drugs given to her previously. You see how it can become difficult. This can be an overdose and dangerous. So as a client, she comes, you ask her to show the drugs she is taking. She shows you Option B+ the one tablet dose and she shows you other drugs and you are surprise. My God, didn’t they give this client directive on these drugs?”

The respondent clarified that clients will come to the facility where she worked to get more clarification on the drugs they should be taking and that the problem was not created in her facility.

However, several patients highlighted unintended consequences both of PMTCT as an option and of the way facilities chose to deliver such services. Availability of ARVs, according to one respondent, “*seems to mobilize people to have unsafe sex because it [the government] provides the medicine to the people*”. Taking precautions to protect oneself were no longer a priority given that medicine was readily available to prolong one’s life and prevent vertical transmission. Additionally, some facilities elected to prioritize women who came for services with their male partners as a means of increasing male testing and counseling. Both patient and health worker respondents had the opinion that the requirement for women to be accompanied by their male partner was a barrier to accessing services. One health worker noted:

“Some women don’t attend the clinic for expectant mothers due to their negligence, however a mother is forced to come with her husband so that she can access the service otherwise she cannot be attended. This also leads to some mothers to ignore the service.”

IV. CONCLUSION AND RECOMMENDATIONS

This report shares the implementation and results of the AIMGAPS activity that sought to improve uptake, retention, and quality of PMTCT services in Iringa, Tanzania.

Patient respondents reported not learning of their HIV status until they were already pregnant and PMTCT awareness among patients was low, which may indicate that targeted awareness raising is needed. However, the view expressed by many patient respondents that having HIV and being on treatment had become “normal”.

Providers felt that pregnant women were accessing services earlier in their pregnancies, but still faced challenges having women bring their 18 month old babies to the facility for definitive testing. Service reorganization and integration was also viewed as positively impacting retention. Respondents suggested that counseling was necessary to improve retention.

The AIMGAPS experience with the CHSS model suggests that establishing teams within the community using existing community structures can increase the reach of the formal health system. Members of community groups who participate on community QI teams expressed their awareness of HIV and how to prevent transmission from mother to child had increased. Members felt an obligation to share this information with their community members and peers whom they could access more regularly and in different settings compared to facility-based providers. Community QI teams served to disseminate information to their networks and, together with facility staff, identified patients in need of services. QI team members also represented diverse sectors of the community (e.g., local government, representatives from religious organizations or agricultural groups) that had varying roles, reach, and authoritative voice within the community. That patients could not always recognize or articulate the role of community QI team members is not unexpected as this has been found elsewhere.

Some of the approaches the community QI teams elected to implement included a punitive response to mothers who did not deliver in the facility or were viewed as leaving their children malnourished. These approaches were not endorsed by the project; ASSIST staff conducted quarterly visits to the community QI teams during which they clarified any controversial issues such as taking punitive actions and advised community improvement teams to employ more productive ways to change practices. The CHSS model encourages communities to identify their own potential solutions to challenges or service gaps they observe. In the communities that participated in this study, one solution was enforcing bylaws that stipulated facility-based delivery and appropriate nutrition of children. These shaming measures that were discussed in the focus groups were a last resort after more moderate approaches, including educating the mother and family, were unsuccessful.

In the AIMGAPS activity, providers shared that women were reluctant to disclose their status to their male partners for fear of abuse, limiting the impact of strategies involving male partners. Our experience indicates that social factors, including stigma and gender-based violence, have a notable role in disclosure and are outside the direct influence of the providers. Additionally, some facilities elected to prioritize women who attended services with their male partner which, as noted by some respondents, may have had the unintended consequence of deterring women who were no longer with their male partner or had not disclosed.

Our findings also indicate a shift in the socio-cultural norms regarding male partner involvement in initial ANC visits, while subsequent ANC visits and post-natal care, including early infant diagnosis, remained the responsibility of the female.

The process of working with colleagues to use data to improve quality of care was felt to positively impact health worker engagement. A study from Dar es Salaam, Tanzania, found that health workers felt that teamwork and communication among colleagues did facilitate improved quality of care (Garcia, Li et al. 2011).

Engaging with and working through existing community groups presents an opportunity to link HIV-positive women, their male partners, and their exposed infants to essential services to prevent mother-to-child transmission of HIV and can easily be translated into other health or social services. Future research on the cost-effectiveness of the CHSS model compared to other community-based approaches is needed.

By January 2014, AIMGAPS sites had transitioned to Option B+. CHMTs supported sites on documentation, data collection from new tools and ensuring availability of ARVs. Providers welcomed the introduction of Option B+ as it was viewed as potentially reducing loss to follow-up. However, providers also noted that with Option B+ came an additional register that needed to be completed, adding to their workload. The rollout of Option B+ across Tanzania since the completion of AIMGAPS resulted in a very different landscape for eliminating vertical transmission of HIV however, the following recommendations based on the AIMGAPS experience should be considered:

- **Counseling of HIV-positive pregnant women should be improved.** Counseling needs to emphasize infant feeding in general due its long duration (12 months), and six-month exclusive breastfeeding in particular. Teams found that mothers expressed concerns that their milk was insufficient to satisfy their infants. It is recommended that providers begin counseling about supplementary feeding when the infant is five months old and weaning when the infant is 10-11 months old. Counseling should also cover the importance of strict adherence to treatment and cover planning for the next pregnancy, emphasizing that treatment is lifelong and reduces risk of transmission to both the baby and their partner and improves the health of the mother. Counseling needs to encourage partner testing if their status is unknown and regular testing and prevention methods if the couple is discordant. Lastly, counseling must address facility delivery and its importance in initiating treatment for babies immediately upon delivery, further reducing risk of transmission. In-service training on up-to-date messaging should be provided, along with mentorship and supportive supervision.
- **Mechanisms to involve male partners should be reviewed** and evaluated for socio-cultural appropriateness and gender sensitivity, including unintended impacts on women who are not accompanied by male partners. Balancing measures such as retention of women who do not attend services with a male partner should be evaluated.
- **Documentation systems should be streamlined to reduce burden on health workers and facilitate continuity of care.** This should include ensuring adequate copies of the HIV Exposed Child Care and the CTC1 Card.

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