Champion Stories:
Integrating Family Planning with HIV Services in Uganda
August 2008

Introduction

In Uganda, where the total fertility rate is 6.7 lifetime births per woman, having children is a social expectation, and becoming a parent is considered an honor and a blessing. However, communities often condemn people living with HIV and AIDS (PLHIV) if they become pregnant. It is assumed that a pregnancy will kill the mother and could result in another HIV-positive orphan who will become a burden to the community. The community also perceives that PLHIV who become pregnant are spreading the virus to sexual partners. Yet, people living with HIV and AIDS often want to have children and are fearful of the stigma of the community.

With wider access to antiretroviral therapy (ART) and to medical techniques for the prevention of mother-to-child transmission of HIV (PMTCT), there is new hope for PLHIV to have children. Family planning (FP) can be used to help a woman avoid an unintended pregnancy and to help her plan for the time when she is strong enough to have a child. A mother's dreams to have HIV-negative children and watch them grow into adulthood can be realized with careful planning and follow-up care.

However, mother-to-child transmission continues to account for 22% of new HIV infections in Uganda (Mugisa, 2008). A U.S. Centers for Disease Control and Prevention (CDC) study conducted at Ugandan ART sites found that 97% of pregnancies among ART clients were unintended (Homsy et al., 2008). The Uganda AIDS Commission believes that Uganda's rapid population growth makes it hard to fight the spread of HIV and AIDS effectively (Mugisa, 2008). More public awareness about PMTCT and FP as means of ensuring healthy mothers and babies is critical if mother-to-child transmission is to be reduced.

Integrating FP into ART Services: ACQUIRE and The AIDS Support Organization (TASO) Project

The TASO flag (with mission statement) flies in front of the TASO/Mbale clinic.

One strategy for meeting the FP needs of PLHIV is to integrate such services with HIV prevention and treatment programs. FP-integrated HIV services are acutely needed in Uganda, where many of the approximately 500,000 women living with HIV (UNAIDS & WHO, 2008) may have an unmet need for FP resulting in unintended pregnancies and new HIV infections. In particular, ART centers can be a key service point for PLHIV to obtain FP information, methods, and services.

In 2006, the ACQUIRE Project partnered with The AIDS Support Organization (TASO) on a U.S. Agency for International Development (USAID) Global Leadership Priority–funded project for FP-ART integration. TASO, founded in 1987, was one of the first centers in Africa for the prevention, care, and support of HIV and AIDS. There are now 11 TASO centers in the North, Central, East, and West regions of Uganda. Each center offers facility-based care and treatment, as well as community-based services. TASO/Mbale, situated in the Eastern Region of Uganda, was chosen as the site for comprehensively

integrating FP into ART services in Uganda. Approaches and tools developed for service integration and community outreach were developed and tested throughout the process. A previous publication (ACQUIRE Project, 2007) noted the following client needs and desires:

- PLHIV want guidance on how to achieve desired pregnancies, as well as accurate information on how to avoid unintended pregnancy.
- Women living with HIV want options for preventing pregnancies when their partners refuse to use condoms.
- Men living with HIV feel pressured to reproduce and strengthen the clan; this becomes a challenge if they have not disclosed their HIV status to their family and/or they want no more children.
- PLHIV who used an ART center wanted a dedicated area where they could receive FP without having to go through clinic processes, particularly for refills.
- Clients indicated that they preferred receiving all services (including FP) at one place.

To address the above concerns, TASO/Mbale managers and staff worked together to identify champions of all sorts (managers, providers, clients, and members of the community) to help clients with their range of FP questions, concerns, and needs. The stories presented here highlight personal as well as programmatic accomplishments with integrating FP with HIV in Uganda that came out of the project overall. The stories were collected in July 2008 as a way of documenting the lasting results of the initial project and to show other organizations interested in integrating FP into HIV and AIDS services some of Uganda's lessons learned.

TASO/Mbale Institutionalizes Integrated FP and HIV Programming

Dr. Charles Ngobi, medical coordinator for TASO/Mbale

Leadership is a critical component to ensuring the launch and sustainability of program initiatives. Dr. Charles Ngobi, the Medical Coordinator of the TASO/Mbale Center, said that previous attempts to initiate FP services within the HIV and AIDS program were hampered by provider biases and misperceptions. He noted that the prevailing attitude of providers was that HIV-positive people should not get pregnant. Consequently, clients were not free to talk about their desires, and if they were pregnant, they hid their status from providers as much as possible. Providers and the community also perceived that people who were HIV-positive would not live long. Dr. Ngobi saw that these perceptions were roadblocks to integrating FP and HIV. After recognizing this situation, he decided to make a positive change so that PLHIV could discuss their fertility desires and obtain FP services. With assistance from the ACQUIRE Project, Dr. Ngobi led the way to creating a supportive environment at TASO/Mbale for integrating FP with HIV programs.

Offering FP became a priority for Ngobi and his colleagues at the Mbale center. They integrated it into their strategic plan, developed TASO FP guidelines, and ensured that FP was included in the center's budget. In particular, TASO directly budgeted for commodities to counter the frequent stock-outs that occurred within the government's distribution and logistics system. They then communicated the guidelines to PMTCT staff and trained them to understand that improved services for pregnant HIV-positive clients would include FP counseling early in their pregnancies.

The efforts of Dr. Ngobi and his staff were impressive. The project's postintervention evaluation, conducted in November 2007, revealed that 78% of PLHIV were counseled on FP methods; of the sexually active women (n=105), 15%, 44%, and 10%, were using oral contraceptives, injectables, and condoms, respectively. Of those not using FP, 38% intended to do so in the future. More than 70% (n=37) of TASO providers were trained in FP, and in a major shift, all now believe that FP methods are suitable for PLHIV. Providers noted clients' rights to a healthy sexual life and and to childbearing, for those who want to have children. One hundred percent of providers now reach out to men with FP messages. Despite systemic stock-outs of FP supplies, the evaluation shows strengthened integration of FP in community activities, use of job aids, record keeping, and linkages to the Ugandan Ministry of Health's (MOH's) logistics system.

Gerald Ochieng, the original manager of the FP Desk, TASO

As noted above, Dr. Ngobi was a champion and an early leader in the introduction of FP into HIV and AIDS services in TASO/Mbale. His staff followed his lead and become champions themselves. One example is Gerald Oching (seated at left), who oversaw the Tuberculosis Desk at TASO/Mbale. For him, offering FP to HIV-positive clients was a new concept. Gerald was impressed by the evidence-based information generated during the performance needs assessment, as well as the practical application of the training events that followed to introduce FP skills to staff and to troubleshoot service-delivery issues.

Gerald was immediately motivated to establish an area for FP services within TASO/Mbale and established the TASO/Mbale Family Planning Desk. The FP Desk is manned by a trained volunteer who helps people understand what services are available to them. Once potential clients decide that they want more information and services beyond the introduction given at the FP Desk, they can enter the adjacent FP counseling room, which is staffed with medical personnel. Gerald says, "Family planning is about people's lives. People do not stop having sex, even when they know they are HIV-infected. I don't want them to have unintended pregnancies." Gerald continues his support of FP for HIV-positive clients in his new job as a counselor/trainer for the Positive Prevention Project, a project funded by CDC and the President's Emergency Plan for AIDS Relief (PEPFAR) to strengthen HIV counselor training in Uganda.

Agnes Nambuya, who is HIV-positive and is open about her status, is a volunteer at TASO/Mbale who works at the Family Planning Desk eight hours a day, five days a week. After her initial FP training, Agnes was able to do basic FP counseling, referral, and record keeping. A widow with five children, Agnes often invites young mothers to sit with her at the desk to begin conversations about FP. When asked why she gives so much of her personal time to the FP, she says, "I console myself by talking to other people." Agnes's role is crucial for identifying clients in need of FP methods, getting them interested in FP services, and then following up with them if they have questions or concerns.

Agnes Nambuya, a volunteer at the TASO Mbale clinic

Integrating FP and HIV and AIDS Services at the Community Level

Community outreach and support is a critical component of all TASO's activities, and FP became part of community work as well. After FP became part of TASO's strategic plan and budget, the next logical step was to train and support community-based services for PLHIV. Training was conducted

for community-based staff, including community volunteers and peer educators who work side by side with health personnel, to support PLHIV in communities and in their homes.

Eunice Mukwanais, a community nurse with TASO/Mbale

Eunice Mukwana (at left) is a community health nurse for TASO/Mbale in Bubobi Community, a collection of many villages in TASO's catchment area. She has served as the community nurse there since 1996, keeping the clinic open six days a week and making selected home visits every day. Eunice attended the TASO/ACQUIRE training and now provides counseling and contraceptives such as oral contraceptives, injectables, and condoms to her HIV-positive clients, at their request. Eunice said that the communication skills she learned in the TASO/ACQUIRE training were especially helpful, as she can now talk with people about FP with confidence and address the many myths the community has concerning FP and HIV and AIDS. In addition to providing FP and HIV support, Eunice and her team discuss maternal health and delivery services for all women, including HIV-positive women in the Bubobi community. The community members now recognize the signs of early labor and support each other to go to the hospital to deliver. With the encouragement of Eunice, the community members started a revolving fund to pay for transport costs. PLHIV now recognize that a delivery with skilled providers is especially important, because it ensures that they will have a safe delivery and an HIV-negative baby.

Building on the Mbale Experience: The SCOT/Positive Prevention Project

The successes and lessons learned from the TASO/Mbale project generated interest in scaling up the experience within the TASO network throughout Uganda and in spreading lessons learned to other organizations. Since April 2006, the ACQUIRE Project has partnered with Strengthening HIV Counselor Training (SCOT) on the Positive Prevention Project to provide FP technical support to a group of HIV organizations. The Positive Prevention Project focuses on informing PLHIV how to avoid infecting others and how to avoid sexually transmitted infections and other blood-borne infections. Under the SCOT project, staff and volunteers in facility and community settings are trained to include FP information when counseling PLHIV on how to live healthily. Together, SCOT and ACQUIRE developed training curricula and then trained providers, community workers, and volunteers to strengthen skills related to positive prevention, including FP. As of today, the Positive Prevention Project has trained 213 community-based peer educators from nine PLHIV peer groups.

Faridah Nakimera and Grace Nantege, peer educators in Lugo

Faridah Nakimera and Grace Nantege (at left) from Lugo, Uganda, are SCOT peer educators affected by HIV and AIDS. Both women despaired when HIV first entered their lives. Grace says, "I was embarrassed for having the virus," and she did not seek care. After Grace was hospitalized due to an AIDS-related illness, a friend reached out to her and linked her to peer services. Inspired by her friend's leadership in an HIV and AIDS support group, Grace became the leader of her own group. She now leads peer educators who discuss all aspects of HIV and AIDS, including the importance of FP for PLHIV. Grace's training from the Positive Prevention/ACQUIRE project gave her the skills and confidence to provide FP counseling to her community, to dispel rumors and myths and to prevent others from experiencing the pain that she and Faridah have suffered.

Many peer educators like Fridah and Grace are important change agents in their communities. Local community members learn about FP methods from peers who have confidence in speaking in front of crowds and who can provide correct information and refer clients for services. Peers hold group meetings twice a month, reaching approximately 600 people monthly. The peer educators are from the communities they serve, and all are affected by HIV and AIDS in some way. Consequently, all of the peer educators understand the suffering, pain, and humiliation that can come from the stigma of HIV and AIDS. Yet having the new knowledge that PLHIV can have healthy families gives them courage and joy. The training from Positive Prevention/ACQUIRE has given them this confidence. They want others to understand the facts like they do. As one peer educator said, "We learn to change our minds and have also learned to change other minds."

Peer educators at work in Lugo

Partnership with Uganda MOH for Scale-Up of Integrated Services

Dr. Godfrey Esiru, PMTCT Director for Monitoring and Evaluation with the Uganda MOH

In addition to working with SCOT's Positive Prevention Project and the TASO network, the ACQUIRE Project worked closely with the Ugandan MOH to plan and monitor FP as it is integrated into other health services. Dr. Godfrey Esiru, the PMTCT Director for Monitoring and Evaluation for the MOH, says that he appreciated the support from ACQUIRE in the integration of FP into HIV and AIDS programs. He noted that before the government integrated FP into HIV and AIDS policy guidelines, HIV-positive women would return frequently to PMTCT clinics with new pregnancies. Dr. Esiru heard women say that "if they had access to family planning they would use it. There was an unmet need."

During this time period, the Uganda's PMTCT Guidelines were revised and strengthened. The guidelines noted that "…the guiding principle [of programs] should be to respect the sexual and reproductive health rights of women and men regardless of their HIV status" (MOH, 2006). The prevention of unintended pregnancies among women living with HIV is now the second of a four-pronged approach (MOH, 2006):

1. Prevention of HIV among women of reproductive age and among parents to be
2. Prevention of unintended pregnancies among women living with HIV
3. Prevention of HIV transmission from pregnant women living with HIV to their babies
4. Comprehensive HIV care for the mother and her family

Dr. Esiru believes that the key barrier to the integration of FP with HIV and AIDS services in MOH facilities is a shortage of staff, since there is often only one midwife at a facility handling all maternal health services. He points out that only 41% of women deliver in facilities, making it difficult to reach women at delivery time; in contrast, 93% of pregnant women attend antenatal care. Consequently, addressing FP and PMTCT during antenatal care visits could be a good avenue to pursue. However, to make this a reality, more work needs to be done to decrease stigma at the community level. Dr. Esiru remarks that once people notice that HIV-positive women are pregnant, these expectant mothers often go into hiding. His goal is get all mothers the care they need to minimize mother-to-child transmission, because "all people have a right to have healthy families."

Dr. Ramathan Lukoda, the MOH's Technical Officer for the Integration of HIV and AIDS into Maternal Health

The MOH is planning to scale up the delivery of FP services in HIV and AIDS programming and has adopted a positive prevention manual developed with input from the ACQUIRE Project. Their work is just beginning, but the foundation is in place to continue scaling up these important initiatives.

For Dr. Ramathan Lukoda, the MOH's Technical Officer for the Integration of HIV and AIDS into Maternal Health, his "biggest task is to coordinate reproductive health, FP, and HIV and AIDS." ACQUIRE's partnership and contribution "boosts the government initiatives" and "needs to be scaled up to improve the quality of life in the whole country." He adds, "People now have hope."

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