

MOTHERS' SUPPORT GROUPS IN ETHIOPIA

A PEER SUPPORT MODEL TO ADDRESS THE NEEDS OF WOMEN LIVING WITH HIV



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Background

Ethiopia has the third largest number of HIV-infected people in the world. In 2007, over 8% of pregnant women in Ethiopia were estimated to be living with HIV.¹ Without preventive interventions, more than a third of the infants born to HIV-positive mothers will go on to contract the HIV virus.

Through USAID-funded projects, IntraHealth International has collaborated with the government and with community-based entities since September 2003 to provide prevention of mother-to-child transmission (PMTCT) of HIV services in 248 public health centers in the nine regions of Ethiopia. Uptake of PMTCT services is often low, however, in part because Ethiopians tend to have limited contact with the health care system. In addition, there are many other barriers to the use of PMTCT services. Barriers include HIV-related stigma and discrimination, limited use of antenatal and postpartum services, uneven quality of care in antenatal and obstetric settings, and insufficient male and community involvement. As a result, many women end up grappling with their HIV status unaided and alone. Creative strategies are therefore needed to ensure that HIV-positive mothers receive psychosocial and emotional support and are able to navigate the health care system to access antenatal care (ANC) and PMTCT services.

Developing a network for HIV-positive mothers

IntraHealth established the Ethiopian Mothers' Support Group (MSG) program to address the special needs of pregnant and postpartum women who are living with HIV and caring for new babies. The MSG program is the product of a successful knowledge-sharing partnership between IntraHealth and the groundbreaking **mothers2mothers (m2m)** program in South Africa.² This partnership has included site visits by IntraHealth country office staff to South Africa, and travel by **m2m** staff to Ethiopia to provide in-person training on the **m2m** model.

Like **m2m**, the overall goal of the MSG program is to reduce mother-to-child transmission by empowering HIV-positive mothers and mothers-to-be to make informed decisions about their reproductive health and the health of their babies. Both the **m2m** and MSG programs are based on the concept that peer support is an optimal model for effective education and social empowerment, and that mothers are particularly well-suited to provide support to other mothers.

Achieving successful PMTCT outcomes

The MSG program has seven broad objectives:

1. To **enhance access** to and use of PMTCT services by building strong linkages between health care providers and peer support networks
2. To **ensure adherence** to antiretroviral therapy among pregnant and postpartum women

3. To **lessen** HIV-related **stigma** and discrimination
4. To **increase** HIV-positive mothers' **understanding** of infant feeding options
5. To **reduce** the **incidence** of new sexually transmitted infections and HIV among girls and women
6. To **increase acceptance** and use of family planning among postpartum women
7. To **build linkages** with other programs and services that strengthen women's health and decision making (e.g., nutritional support, income-generating activities and skills training).

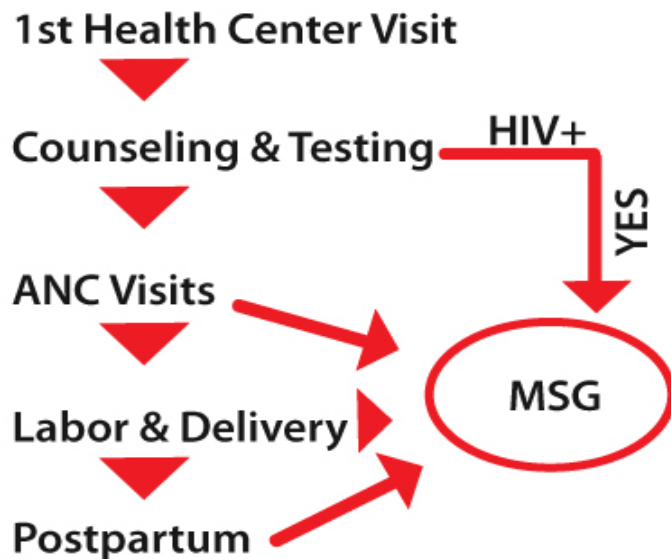
To achieve these objectives, the MSG program fosters several mutually reinforcing strategies for peer-to-peer contact (see Table I). Health center-based peer support groups for mothers-to-be and mothers living with HIV are the core of the MSG program. In the groups, trained “mentor mothers” help their HIV-positive peers address their unmet psychological, social, medical and even economic needs. In addition, both the mentor mothers and mothers who graduate from the support groups are encouraged to reach out to their communities to provide prevention education, decrease stigma and refer pregnant women for ANC and PMTCT services.

Table I. MSG intervention strategies

Relationship	Who Is Involved	Purpose
1. Mothers to mothers-to-be	Mentor mothers Mothers-to-be	Counseling, peer support
2. Mothers to mothers	Mentor mothers Postpartum mothers	Counseling, peer support
3. Mothers to community	Mentor mothers MSG graduates Community members	Education, referrals

The MSG program is designed to reach women from the beginning of pregnancy through the first year of motherhood. Mothers-to-be and mothers may join a mothers' support group following their first HIV counseling and testing visit at a health center, after any repeat ANC visit, following labor and delivery, or postpartum (see Figure I).

Figure 1. Points of entry into the MSG program

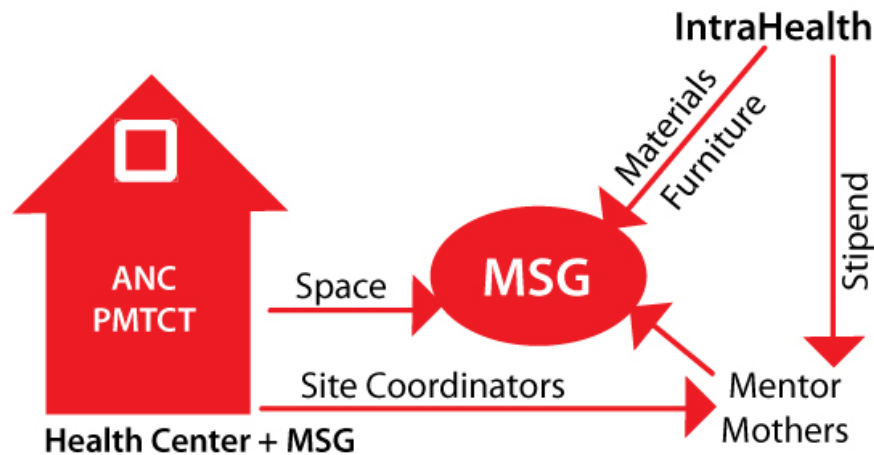


Integrating MSG program elements

The MSG program is health center-based and closely integrated with the clinic-based PMTCT programs (see Figure 2). There are a number of advantages to locating a peer support intervention within clinic walls. These include the fact that the MSG program draws women into the formal health care system who otherwise might not seek services. Because women tend to feel safe with and respected by their mentor mother peers, the peer model also lessens the distance and discomfort that women sometimes undergo when interacting with clinicians. Finally, the MSG program helps alleviate some of the counseling burden experienced by health centers, shifting basic counseling tasks from nurses and other providers to the mentor mothers.

Sites: Health centers are selected to become MSG sites based on ANC and PMTCT flow, HIV prevalence, and availability of space for support group meetings and mentor trainings. Health center staff (including HIV counselors) must be willing to work with the MSG program's site coordinators and mentor mothers. IntraHealth provides some modest material assistance to the health centers for the support groups and pays a monthly stipend to the mentor mothers and site coordinators to cover their time and transportation.

Figure 2. MSG program structure



Site Coordinators: Each health center participating in the MSG program has one to two site coordinators who supervise the mentor mothers; identify, recruit, and enroll mothers-to-be and mothers to participate in the support groups; and ensure that the support groups are taking place smoothly. The site coordinators also serve as the PMTCT counselors for their health center. IntraHealth provides three days of training to the site coordinators and a regular monthly stipend of approximately \$22 (200 birr), which covers travel for home visits and mobile phone costs to track participants who do not return to the groups.

Mentor Mothers: The mentor mothers are the linchpin of the MSG program. The mentors are recruited by the site coordinators. Themselves HIV-positive, the mentor mothers are selected according to the following criteria:

- Willingness to be a mentor
- Willingness to disclose HIV status with peers
- Firsthand experience with PMTCT services
- Ability to read and write (8th grade completed).

There are four mentor mothers per site, and two mentor mothers work on any given day. Mentor mothers must be willing to spend at least three full days per week supporting HIV-positive mothers at the health center. The three-day-a-week schedule allows the four mentors to cover an entire month of working days with two mentors per shift.

“I approach pregnant women in the ANC/PMTCT room or waiting area and discuss with them the testing advantages for themselves and their baby by setting myself as an example of an HIV-positive woman raising an HIV-negative baby. After testing, if a woman is diagnosed with HIV the counselor refers her to the mothers’ support group, where I and the site coordinator will be there to provide her support... This way the woman will be comfortable in confiding with someone she already met.”
 —Mentor mother, MSG program

Training of Mentor Mothers: The South Africa **m2m** project developed the curriculum used to train the mentor mothers. The MSG program translated the materials into Amharic and adapted them to the Ethiopian context. The basic content of the five-day training covers HIV transmission and infection, HIV and pregnancy, psychosocial issues, self-care, antiretroviral therapy, ANC, labor and delivery and infant care. The trained site coordinators also attend the mentor training and present some topics.

Support groups: Once trained, the mentor mothers facilitate separate support group meetings for mothers-to-be and mothers. On occasion, a postpartum mother may be invited to attend a group meeting of mothers-to-be to discuss topics such as partner disclosure. The support group meetings provide a safe and open space for discussion of a variety of topics (see Table 2). The mentor mothers also refer support group members for care such as PMTCT and family planning services.

Table 2. Discussion topics at MSG meetings

Category and Topic
<p>Psychosocial</p> <ul style="list-style-type: none"> -How to disclose HIV status to partners and others -Confronting stigma and discrimination -Living positively -Gender violence
<p>HIV Care: Mother</p> <ul style="list-style-type: none"> -The PMTCT process -Antiretroviral therapy for mothers
<p>HIV Care: Infant</p> <ul style="list-style-type: none"> -Infant feeding options and family nutrition -Antiretroviral therapy for infants
<p>Reproductive Health</p> <ul style="list-style-type: none"> -Family planning and prevention of unintended pregnancies -Safer sexual practices

Graduates: To graduate from the MSG program, a mother must attend all 48 group sessions. Because women are not always able to consistently participate, program duration can vary; some women may complete the 48 sessions in six months while others may remain for up to a year. In addition, each mother must participate in home-based care training before graduating. Women who graduate from the program become community educators, joining forces with the mentor mothers to lessen stigma and refer pregnant women and mothers for needed services.

“It is so important to focus on women and their families. Through the MSG program there has been a remarkable increase in access to HIV prevention, care and treatment services—through the advice and counsel of other mothers in their communities.”

—U.S. Deputy Chief of Mission in Ethiopia

Expanding the MSG program

The MSG program began in 2005 in three sites and scaled up to 31 additional sites in 2006-2007 for a total of 34 sites. As of September 2007, IntraHealth had trained 135 mentor mothers and 60 site coordinators in these sites, enrolled 1,566 mothers in the program and graduated 234 women from the support groups.³

As of June 2008, the MSG program has scaled up to an additional 50 sites. Because the groups tend to quickly outgrow the space allocated for their meetings, part of the focus of the expansion plans included working with health centers to devote adequate space for the support groups. In addition, due to the success of IntraHealth’s experience, USAID has asked JHPIEGO to implement mothers’ support groups as well. IntraHealth is collaborating with JHPIEGO to maximize opportunities for MSG expansion through appropriate site selection, coordinated and standardized training and other support.

At the policy level, the program’s appeal to providers and participants has led the Ethiopian HIV/AIDS Prevention and Control Office (HAPCO) to include MSG in its national HIV/AIDS response strategy (or Road Map). HAPCO has also included MSG in its recently revised national PMTCT guidelines.

Building on the program’s successes

The MSG program appears to be making an impact in terms of both health indicators and psychosocial benefits. At the psychosocial level, women have found support group membership to be so rewarding that they are sometimes reluctant to graduate and leave the supportive environment of the group. Moving graduates to follow-on groups at the health-post level is a strategy that is showing some promise.

The MSG program appears to have generated a deep commitment among mentor mothers and site coordinators to the program and its goals. In some sites, mentor mothers or site coordinators contribute 10 birr/month to support the most disadvantaged participants and encourage retention of women in the program. Moreover, mentor mothers in three sites have been so active locally that they are working to be recognized officially as an association of persons living with HIV/AIDS.

Because the site coordinators and mentor mothers serve as *de facto* counselors for key health center services such as PMTCT, support group members and the health centers receive maximum impact for a relatively small investment. In some instances, however, the support groups have been so popular that the designated room or space in the health centers has proved insufficient, either because it is not available as often as is needed or because it is not large enough. IntraHealth has provided some support to those health centers to convert additional space or install new tables or benches. As more and more mentor mothers take on counseling responsibilities, it will be important to assess the quality of the counseling provided by the mentor mothers as compared with health center counselors. This will help determine whether the greater comfort that community women experience with their peers is accompanied by effective communication of key prevention and treatment messages.

The Capacity Project is currently analyzing the MSG data to date, but it is clear that the MSG program shows promise in both its popularity among women and its increasing effectiveness at linking participants with other programs and services. Effort is under way to link the MSG program with the broader support to orphans and vulnerable children, whereby children exposed to HIV will access ongoing care, treatment and support.

In addition to connecting mothers and mothers-to-be with critical services and emotional support, the MSG program has learned that it is important to take stock of the broader context of women's lives. Income-generating activities are likely to become an increasingly important spinoff of the program, and the support groups for male partners are sure to enhance the effectiveness of the MSG program in lessening the social isolation and stigma that HIV-positive women and mothers experience.

¹ The United States President's Emergency Plan for HIV/AIDS Relief, Ethiopia Country Operational Plan 2007, April, 2007.

² For more information about the **mothers2mothers** program, visit www.m2m.org.

³ The data included in this report cover October 2005-September 2007, during which time the MSG program was funded through USAID's bilateral prevention of mother-to-child transmission of HIV project in Ethiopia (the Hareg Project). IntraHealth is continuing the MSG program in Ethiopia through USAID's global Capacity Project.