Mailman School of Public Health Researchers Guide Program for African Families with AIDS

BY MATTHEW DOUGHERTY

At a conference in Uganda in September 2001, a group of local women living with HIV performed a drama skit in an ante-natal clinic. The focus was on the remarkable ability of a simple intervention to prevent HIV transmission to the women’s babies. The women were joyful as they reported on the miracle of having healthy babies after taking one dose of the drug nevirapine during labor and giving another dose to the babies after birth. Yet, the drama had an anguished ending as one of the HIV-infected women cried out: “But what about me?”

“It made the audience stop and reflect on what this epidemic is doing to these women and their families,” says Wafaa El-Sadr, professor of epidemiology at the Mailman School of Public Health and professor of clinical medicine at the College of Physicians and Surgeons (P&S).

While programs to prevent mother-to-child transmission (MTCT programs) are critical, most have little to offer the women themselves or their HIV-infected partners and children. In sub-Saharan Africa, the region of the world hardest hit by HIV/AIDS, more than 30 million people are living with HIV, of whom more than 10 million are women. It is estimated that already 11 million or more children have been orphaned because of AIDS, according to UNAIDS, a United Nations program on HIV and AIDS.

“Dr. Allan Rosenfield, dean of Mailman, and I became determined to develop a program to provide care for these women and their families,” says El-Sadr. They had been thinking about what they could do ever since Dr. Rosenfield presented a paper at the 2000 International AIDS Conference in Durban, South Africa, entitled “Where is the M in MTCT Programs?”

Through funding from several foundations, Rosenfield and El-Sadr established the MTCT-Plus Initiative, a unique program to build comprehensive care and treatment for HIV-infected women, their children, and their partners with HIV. The program, launched in July 2002 at the Barcelona International AIDS Conference, has already begun to enroll in several countries, including Ivory Coast, Kenya, Mozambique, Rwanda, South Africa, Thailand, Uganda, and Zambia.

The program is built on four principles: the need for comprehensive HIV care rather than only providing antiretroviral therapy; the importance of family-focused services; the necessity for multi-disciplinary teams of providers; and the value of community linkages. Its goal is to provide care to 10,000 individuals with its current funding. The Mailman-led program builds on existing pMTCT programs.

“The key issue is not just to enroll patients but to retain them in care so they can reap the program’s benefits,” says El-Sadr, MTCT-Plus director. “We are working with the sites to build responsive programs and to establish clinics that will be safe havens for the patients where they feel secure, comfortable and free of the terrible stigma associated with having HIV in many of these settings.”

El-Sadr has been providing HIV care for 15 years at Harlem Hospital, where she is chief of the Division of Infectious Diseases. With its initial grants, MTCT-Plus secretariat members have worked on developing procedures, clinical manuals, training programs, data collection plans and evaluation parameters. A team of specialists visited each site and trained clinical providers, community workers, peer workers, and others in HIV and AIDS care. Supporting the sites, as well as ongoing training, is now of paramount importance to the team.

The program directors are keenly aware of the importance of building local support for MTCT-Plus and of the remarkable challenges that people with HIV face day in and day out. In February, the MTCT-Plus Initiative hosted the first meeting of the African Women’s Leadership Group in Johannesburg, South Africa. This group, co-chaired by Graca Machel, former minister of education in Mozambique, included 21 women leaders from government and non-governmental organizations throughout sub-Saharan Africa. They discussed the problems of HIV/AIDS for women and families in Africa, the mechanisms for overcoming these difficulties, and concrete ways of supporting the MTCT-Plus programs in their communities.

“We are working with sites in settings where there are few resources and little prior experience in treating HIV and AIDS,” says Rosenfield, principal investigator, MTCT-Plus. "In addition, some speculate that the stigma associated with HIV may hinder patients from participating in the program for fear of being identified as HIV-infected. However, others have reported that availability of HIV treatment has had a surprisingly positive effect on stigma.”

Rosenfield is confident that these issues can be managed and that the program will thrive and serve as a model for others. “We hope the experience gained in MTCT-Plus will be useful to organizations, such as the Global Fund, the World Bank, the Centers for Disease Control and Prevention, the World Health Organization, and others that are planning major AIDS care and treatment programs,” Rosenfield says.