Creating Hope

The Origins of ICAP: The Story of the MTCT-Plus Initiative

ICAP
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Columbia University
Mailman School of Public Health

MTCT-Plus Initiative Sites

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Beginnings

The MTCT–Plus Initiative, the world's first multi-country HIV treatment program, was announced at the 14th International AIDS Conference in Barcelona in July 2002. Its aim was to demonstrate to a disbelieving world that it was possible to provide care and antiretroviral (ARV) treatment in resource-limited settings, using programs to prevent mother-to-child transmission of HIV (PMTCT) as an entry point.

"We were trying to bridge the gap," says MTCT–Plus founding director Wafaa El-Sadr. "The world had divided into people who said you've got to do prevention, treatment is not an option, and you are going to have raging resistance in Africa; and the few people who were advocating for treatment, saying it was completely unethical not to treat people."

Four years later, the MTCT–Plus Initiative of Columbia University's Mailman School of Public Health was providing HIV care and treatment for nearly 17,000 people at 14 sites in nine countries. By 2010, ICAP, the successor of the MTCT–Plus Initiative, had provided HIV care and treatment to more than one million people.

This is how it all began…

Pills Cost Pennies

By the late 1990s, it was clear that the triple cocktail of antiretroviral drugs was a lifesaving regimen. In the industrialized countries HIV had been transformed from a death sentence into a manageable chronic disease. Yet in the high burden countries of sub-Saharan Africa treatment was not available and all major HIV initiatives remained focused on prevention.

Not only was treatment deemed unaffordable in poor countries, few people outside of a small group of AIDS activists believed it was even feasible. Not one of the major donors or multilateral agencies was promoting or funding large-scale ARV treatment programs for people living with HIV.

By the year 2000, an estimated 2.4 million people were dying each year from HIV and treatable AIDS-related diseases in sub-Saharan Africa. Activists across the world were marching in the streets. With the slogan 'Pills cost pennies, greed costs lives,' the focus of their anger was the pricing and intellectual property policies of the pharmaceutical research and development industry.

Although treatment was a distant dream, programs using a short-course ARV regimen to prevent mother-to-child transmission of HIV were proliferating in resource-limited countries. While this was welcome, there was growing concern that these PMTCT programs were neglectful of women, treating them as mere vehicles to deliver drugs to their infants.

"For me personally I think it was like a dream come true. There's something that really bothers me about dismissing people's human needs, their need to live a life without pain and suffering and to keep their kids alive — and to assume that somehow for 'people out there' it's not as painful for them to lose their partners, to lose their child or to suffer. In a small way MTCT–Plus was saying, 'we care and we are going to make it happen. It must happen.' It was not a question of it being doable. It had to be done."

— Wafaa El-Sadr, first director of MTCT–Plus. She is currently director of ICAP.

"Since treatment has become the norm, we have forgotten what trailblazers Wafaa and Allan Rosenfield were at the time, and how we really would not be where we are now without their vision. Allan Rosenfield brought international heft to the project. Wafaa brought the human heart and experience with treating patients and providing care and support to people. This was not a research endeavor; this was a public health effort."

— Andrew Fullem led the quality assurance team for MTCT–Plus. He is director for John Snow, Inc.'s Center for HIV and AIDS.

The 'M' in PMTCT

The Rockefeller Foundation was one of many institutions in the process of examining this complex terrain. In 1999, the leader of the Foundation's AIDS strategy in Africa, Ariel Pablos-Mendez, invited colleagues from Columbia's Mailman School of Public Health to join a consultation on the prospects for

a multinational treatment program. He also engaged with Mailman's charismatic dean, the late Allan Rosenfield, who was renowned for his advocacy on women's health.

In July 2000, Rosenfield gave an influential address to the 13th International AIDS Conference in Durban in which he argued for a greater focus on the 'M' in PMTCT. "Do we expand treatment to decrease MTCT without treating women, only to increase the number of orphans?" he asked. "It is difficult to believe that this question even needs to be asked."

In the fall of 2000, HIV experts from across the world endorsed the idea of a treatment program. Soon after, the emergence of cut-price generic drugs removed another major obstacle to treatment scale-up. Rockefeller president Gordon Conway and Rosenfield began raising funds from several foundations for the new venture.

Rosenfield and Pablos-Mendez worked together on developing the program, concluding that PMTCT was a practical and compelling entry point for treating mothers and their families.

Rosenfield put together a team at Mailman, which included El-Sadr at its helm along with other leading HIV clinicians. Five multi-partner working groups were constituted to define the scope and structure of the project. The proposal finally agreed was for a demonstration project at carefully selected sites in affected countries. The intention was for lifelong treatment and care.

The MTCT–Plus Initiative was launched at the 14th International AIDS Society (IAS) conference in Barcelona. By then the funds were assured and sites had been selected from among a number of applicants who were already delivering PMTCT services.

In a special session on July 11, 2002, Rosenfield described the MTCT–Plus Initiative to an international

audience. "We are hoping through this program to treat the women, their HIV-positive children, and their HIV-positive partners," he said. "This is indeed a family program, which will provide prevention and treatment for opportunistic infections."

UNAIDS chief Peter Piot gave personal and heartfelt thanks to Rosenfield and the MTCT–Plus team, saying, "This for me is really one of the defining moments in my own life and how I look at AIDS."

"The lesson of MTCT–Plus was that the simplest idea turns out to be extremely complicated to make happen. We began to realize how many things fall apart.... There are so many little demons in the woodwork."

— Joe Mamlin, site coordinator at the AMPATH, Eldoret site, Kenya.

"I have to work harder but I feel happier than when I was doing routine nursing because I can contribute to the health and the benefit of the patients and their families, so that they can be productive members of their society."

— Pornpen Methajittiphun, head nurse of OPD Sriracha Hospital, Thailand.

"The start of treatment was like a gift to the patient. It was a great opportunity because there was no way of doing treatment at that time."

— Didier Ekouevi, coordinator of the MTCT–Plus program in Côte d'Ivoire.

A Certain Lease on Life

The model for the MTCT–Plus program was strongly influenced by the experience of two members of the Secretariat, Wafaa El-Sadr and Elaine Abrams, who had been treating adults and children living with HIV in New York's Harlem Hospital since the 1980s. The lessons they learned in Harlem helped shape the MTCT–Plus Initiative into a family-focused program in which a comprehensive package of care was delivered by a multidisciplinary team comprising outreach workers, peer educators, and case workers, in addition to physicians, nurses, and other health professionals. The treatment model employed an algorithm approach, with simplified regimens that were easy to implement.

PMTCT would serve as the entry point for care of women and their families. The full package was to include medical care for HIV-infected adults, infants and children, prevention of opportunistic diseases, early infant diagnosis, and antiretroviral therapy for eligible adults, including pregnant women, infants, and children. Treatment and care was also to be offered to 25 health workers at each site. In addition, core services included patient education, counseling, adherence support, and primary prevention. The aim was to retain participants in long-term care and lifelong treatment.

Initially there were to be 12 demonstration sites in eight countries — Thailand and seven in sub-Saharan African. This was later expanded to 14 sites in nine countries. The chosen sites were extremely diverse, ranging from primary care clinics to teaching hospitals; from research institutions to non-governmental organizations; from mission hospitals to public sector facilities. Most were urban or peri-urban, but a few were in rural areas. Partners were also diverse in nature and experience, ranging from global experts in PMTCT research to public sector clinicians with little experience in HIV.

Groundwork

There were a mere six months between the official launch of the program at the Barcelona conference and the opening of the first site in January 2003. In that time extensive groundwork had to be done to ensure that the program could be fully operational at the sites.

The team in New York, now officially the MTCT–Plus Secretariat, was effectively starting from scratch. There were few experienced clinicians at the sites, and little in the way of infrastructure to deliver this new service. There were also no tried-and-tested models of HIV care. In the few pilots that already existed, ARV treatment was seen as acute care — an emergency response — rather than an entry point for long-term care. Indeed there were few models of chronic care for any disease in the public sector of these countries.

The paucity of skilled medical staff at country-level meant that training was paramount. The MTCT–Plus team created a competency-based framework and an extensive set of modules, slides, and training materials. Multidisciplinary training teams including doctors, nurses, and counselors with psychosocial expertise were assembled to mirror the desired team at the sites.

Determining how to get the drugs to the sites was another logistical hurdle. David Hoos, a physician working with Wafaa El-Sadr, discussed the proposal with several organizations. He ultimately selected the UNICEF Supply Division, which had been involved with PMTCT drug procurement for some time.

A mechanism for ensuring quality was created in the form of ongoing site visits by a quality assurance team

"The medicine part was the easy part. You are dealing with disenfranchised populations, you are dealing with a stigmatized disease, you are dealing with these complex psychosocial issues and there's no way to effectively do treatment if you don't take them on. And that was the major part of the work. You couldn't just dispense a pill. HIV is a disease of body and soul... and of families."

— Elaine Abrams, second director of the MTCT–Plus Initiative. She is currently research director for ICAP.

"MTCT–Plus gave us an opportunity to improve capacity for health workers and sensitize the community, to prime them. Things happened at a most hospitable time, when resources started flowing in. And it just gave the health workers the confidence. It was a celebration for them to say well we can do something for people who are testing positive.

— Moses Sinkala, director for the Lusaka District Health Management Team in Zambia.

from the public health research and consulting firm John Snow, Inc. (JSI). JSI was also contracted to develop a monitoring and evaluation plan that could keep track of data for every patient enrolled in the program.

Planning, facilitating, and implementing MTCT–Plus was an exciting time charged with energy and hope; though with that excitement can come the angst of roads untraveled. "There was the burden of experimentation — really ultimately believing in and endorsing what we had decided to do; that it was the best way to use this money. It was a huge responsibility," said Abrams.

To the Sites

Getting the program going at site-level was a monumental challenge — from starting a system from scratch to ensuring retention of patients through all stages of the PMTCT cascade. This was a huge undertaking both for the Secretariat and for partner agencies.

Challenges regarding patient management were common, but a system was put in place to resolve these through ongoing mentoring by email and telephone. The system worked well, catering to sophisticated sites with expert physicians in addition to less experienced sites that needed more help.

Managers also had to find ways of dealing with the deep structural issues that can act as barriers to many care and treatment programs — poverty, gender inequity, and HIV-related stigma. A complex mix of stigma and gender norms presented an obstacle to engage male partners at all the African sites. Men were reluctant to visit a maternal and child health unit believing it was a place for women only.

With time most sites experienced a gradual decline in stigma. Moses Sinkala, Director of the Lusaka, Zambia, District Health team noted, "We had to do a lot of community education, sensitization through the support groups, dramas and talks on the benefits of treatment until we saw a rise in the numbers of people

getting enrolled." More and more, men began engaging with the program. Former Kenya CDC Director Kevin De Cock observed: "I saw something in South Africa which I have never seen anywhere else. In those days they were providing milk formula, and in the waiting room you had men sitting waiting to be given formula to take home. It was very touching."

Holistic Care

The MTCT–Plus Secretariat and site staff managed constructively with the many challenges facing the new program. Within a short span of time they had fully enrolled HIV-positive women and their families and were providing them with comprehensive care.

After the pregnant woman, the first family member to benefit was the child. The improved drug regimen and continuity of care offered at MTCT–Plus sites significantly increased an infant's prospects of being born HIV-free, and remaining so.

When it came to treating HIV-positive children, MTCT–Plus broke new ground. Pediatrician Abrams advocated very strongly for treating children and developed the first tools for this. One such tool included algorithmic charts based on weight, which helped staff at the sites to easily calculate the correct dosage of antiretroviral medications without having to make complex calculations for each drug.

Lessons from Harlem showed that the complex psychosocial and medical challenges presented by HIV could best be met by the concerted effort of a multi-disciplinary team. In the MTCT–Plus model, nurses, caseworkers, psychologists, and trained community health workers all had valuable roles to play. Counselors and peer educators were close to the communities and were often better able to understand the complexities of the lives of the patients enrolled in the program. In addition to health education, they performed a valuable role in tracking patients and reducing loss to follow-up.

The Greatest Joy

By 2007, the MTCT–Plus program had enrolled nearly 17,000 people across 14 sites in nine countries. This included more than 14,000 women and children and 300 health workers.

Results were outstanding: of the patients that began anti-retroviral therapy (ART) 86% were alive and still enrolled after 30 months and there was marked improvement to their health and CD4+ cell count response.

For people working at the sites, the experience was enriching and rewarding. Pediatrician Philippa Musoke explains, "For a long time in Uganda we didn't have a lot of adolescents because our children were dying young. But now we have adolescents who have grown up in our program and have done very well. This program gave pregnant women and their families a certain lease on life. For me it's been the greatest joy to help women and families to see that there is hope and there is life beyond HIV."

Beyond MTCT–Plus

By the end of 2004, the treatment landscape had changed significantly and large numbers of ARV treatment programs were being established across sub-Saharan Africa and other resource-limited regions.

The MTCT–Plus Initiative was influential through the successful demonstration of treatment to families, but it was also swept aside by the tide of rapid scale-up. It was no longer necessary to demonstrate that treatment could be done in Africa — it was being accomplished on a previously unimaginable scale, and mostly under the aegis of national governments.

The MTCT–Plus Secretariat in New York was well placed to participate in this scale-up, and in December 2003, they received their first grant from the new President's Emergency Program For AIDS Relief program. Before long, the MTCT–Plus team had created a new agency, ICAP, under the leadership of Wafaa El-Sadr. Elaine Abrams took over the leadership of MTCT–Plus in 2004, which now became one of ICAP's HIV care and treatment programs.

Global Influence

The MTCT–Plus Initiative influenced and shaped ICAP and the other mass treatment programs that followed.

Throughout the life of the program, the MTCT–Plus experience influenced the treatment discourse at national and global levels, as staff shared their learning in many ways — stressing the importance of chronic comprehensive care and the role of a multidisciplinary team. Innovative aspects of the MTCT–Plus model, such as pediatric treatment and the algorithm approach, spread to other programs. MTCT–Plus also shaped the global landscape for ARV drug procurement and

"I remember seeing a patient in Soweto with one of the nurses and when we were bringing the visit to a close she sort of stopped me and said 'I need to say something,' and we said 'OK great' and she said 'I want you to know how you've brought us hope.' It was a very touching moment."

— Bill Burman, one of the first trainers for the MTCT–Plus Initiative. He is currently medical director of the Infectious Diseases Clinic at Denver Health.

"I was the first client to start ARVs on MTCT–Plus and I'm the first peer educator here. From the beginning my doctor was Dr. Deo. On the first day he gave me ARVs he was certain that I was going to die because the ARVs are very strong and at that time I had no energy. And when he saw me coming back after one week to collect the ARVs, he said, 'Oh! Are you Margaret?' I said, 'I'm the one.' He said, 'You girl, you have life! You really have life. I think he had confidence in me!

"Since AIDS didn't take me, and PCP didn't take me, and this TB — three times — didn't take me, I know I'm going to live long."

— Margaret, a Peer Educator in the MU-JHU MTCT–Plus program at Mulago Hospital.

supply, catalyzing the development of the World Health Organization prequalification mechanism.

In many of the nine countries where MTCT–Plus was located the program had a lasting influence on both the nature and speed of the treatment scale-up. Not only were country staff able to use their experience to assist in the creation of national policy and strategy, but MTCT–Plus also strengthened the health services to deliver HIV treatment beyond its 14 sites. For ICAP programs and others that came after, the MTCT–Plus experience had laid the groundwork and strengthened the health system to cope with treatment scale-up.

Another significant legacy of the MTCT–Plus Initiative was its thorough training program. At most sites, health workers from other programs were welcomed into the training and this extended the reach of benefits far beyond the MTCT–Plus sites. The MTCT–Plus commitment to the training and deployment of a multidisciplinary team also provided models that influenced the global dialogue around task shifting.

A Potent Legacy

The MTCT–Plus (also referred to as M+) experience was fundamental to the formation of ICAP, now one of the largest providers of HIV care and treatment in Sub-Saharan Africa. Abrams notes, "The core values, principles, and priorities of M+ continued to drive ICAP programs."

El-Sadr agrees. She maintains, "Lessons learned from M+ certainly influenced how we bring excellence and attention to detail that is needed day in and day out. You don't just hand over money and hope that it will be done. You work in partnerships so that it can be done well."

It is now three years since the last patient was enrolled. Although the MTCT–Plus Initiative has faded from the public gaze, it has left a potent legacy.

AIDS activist and former UN AIDS Ambassador, Stephen Lewis, credits the MTCT–Plus Initiative with keeping PMTCT on the global agenda in the early years of the century. "They understood, they kept it alive, while everybody else fooled around," he said.

The Initiative has certainly touched the lives of all who participated in it — from a generation of babies born HIV-free, to mothers who have lived to see their children grow; from international physicians to a new cohort of indigenous health workers who are now global leaders in HIV care.

"I am proud to see patients in good health. I know that the People with Aids volunteers are happy and have good self-esteem. Before joining M+ they thought having HIV infection was the end of their lives, but now they know they can contribute to other patients and to the health of other PWA so they feel valuable and that they are very fortunate to have joined this program."

— Samsong Teeratakulpisarn, nurse coordinator in Bangkok Red Cross Hospital MTCT–Plus program, Thailand.

"Make the patient trust you so that they can tell you everything they are thinking and feeling. From my heart the most important thing I have learnt is to love the patient.... It wasn't just helping other patients, it was also helping myself."

— "Thandeka," peer counselor at the MTCT–Plus site, Cato Manor, South Africa.

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