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THE RIGHT OF CHILDREN IN DEVELOPING COUNTRIES TO BE BORN AND LIVE HIV-FREE

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Ten years ago, in international public health circles, it was common to suppose that people with HIV in developing countries had no right to life — although health experts avoided stating the point quite so bluntly. The problem was that survival for those in advanced stages of AIDS depended on their receiving triple therapy with antiretroviral medicines (ARVs) — a treatment judged too costly for poor people in low-income countries and too complex for them to manage. As a clinician, I remember clearly that, at the time, ARVs were in effect considered so mysterious and sophisticated that it was assumed one had to be an extraordinary specialist to prescribe the drugs and care for the patients taking them. To understand the multiple permutations and interactions of the different classes of ARVs, along with their possible side effects, seemed to constitute a distinct science reserved for initiates. The patients, too, were thought to need unusual discipline — and an arsenal of timers, watches, and other tools — to adhere to the complex ARV regimens, which required ingesting a battery of different pills at precisely regulated time intervals. For the therapy to succeed, patients had to be knowledgeable and determined enough to apply their wise doctors' instructions unfailingly — a condition that many people imagined most poor Africans would be unable to fulfill.

Attitudes about AIDS therapy in developing countries have changed dramatically in the decade since, as have the realities of AIDS treatment provision in these regions. Between 2001 and 2006, the number of people on antiretroviral therapy (ART) in low- and middle-income countries increased almost sevenfold — from 240,000 to about 2 million. In 2003, only 100,000 Africans — a mere 2% of those in need of life-saving antiretroviral treatment — were receiving it. By 2007, this figure had been multiplied a dozen times. Sub-Saharan Africa was estimated to have more than 1.3 million people on ART, approximately 28% of those in need.[1]

These gains have come, above all, thanks to the activists who struggled resolutely to expand access to ARVs. Activists and their allies have battled on all fronts: from drug prices and intellectual property rights regimes; to the design and financing of ART programs; to the training of health workers; to treatment education among people living with HIV; to action for overall health systems strengthening.[2] The struggle is not over. Much still remains to be achieved on the way to truly universal access to HIV/AIDS prevention, treatment, care, and support. But, thanks to the efforts of activists, especially people living with HIV, we are no longer arguing about *whether* poor African patients should have access to life-saving antiretrovirals, but about *how* best to implement AIDS treatment in African settings, building on the successful programs already firmly established in many countries.

Antiretroviral treatment programs in sub-Saharan Africa and other low-income regions have been difficult and time-consuming to build.

However, their progress has proven to the world the profound error in thinking committed by those who, a decade ago, assumed that poor people living with HIV in the global south would have to be sacrificed in order to protect people in the north. Their argument was based on the fear that drug-resistant HIV strains would proliferate if ARVs were widely distributed in developing countries, where neither providers nor patients could be trusted to handle these precious drugs properly.

However, five years of large-scale treatment programs in both urban and rural settings in the developing world have demonstrated unequivocally that to explain to poor, illiterate people how to follow an antiretroviral triple therapy regimen is not an impossible challenge for African, Asian, or Latin American health care providers. At the same time, these programs have confirmed that poor, HIV-positive people who lack education by northern standards are able to understand and follow instructions on how to use these medicines.

The people living with HIV, social workers, nurses, physicians, and patients who, together, have led these ARV treatment programs are true pioneers. They have advanced the struggle for the right to health as a fundamental right for all people, of all social conditions, in all regions, and concerning all forms of illness for which effective treatments exist. They give us an example to follow in resisting the fatalism of those who insinuate that poverty and illiteracy make it impossible, in practice, to realize people's right to life and health.

Today, this example must strengthen our resolve on the question of breastfeeding versus replacement feeding for the children of HIV-positive mothers.[3] The history of expanding access to ART encourages us to challenge those who now argue that safe replacement feeding is beyond the capacity of poor, illiterate, HIV-positive mothers. This is an area of great controversy, and experts deeply committed to children's well-being find themselves on different sides of the question. Some construe the existing evidence as showing that, in low-income African settings, replacement feeding will inevitably cause greater harm to children than other available alternatives (e.g., exclusive breastfeeding to six months, with maternal ART), because of the excessive demands that replacement feeding imposes on mothers.[4] For replacement feeding to work, mothers must, day after day, secure uncontaminated water to mix infant formula and ensure the cleanliness of feeding implements — a challenge some critics maintain is insuperable. However, the historical lessons learned from the treatment access movement caution us against portraying as an inherent and unchangeable incapacity of poor African people or beleaguered African health systems what is in reality an implementation failure that can be remedied through effective delivery strategies.

In Rwanda, a recent study conducted in the rural areas of Kayonza and Kirehe shows a reduced mortality rate for children born to HIV-positive mothers and fed with breastmilk replacements, compared with the mortality rate for the rest of the population in the same age range.[5] This outcome provides evidence that, when properly conducted, the fight against AIDS can be an opportunity to improve general survival rates for children under 12 months. For 198 children enrolled at birth in this study, the mortality rate was 26 per 1000 live births, compared to 125 per 1000 live births for the general population.[6] This finding contrasts sharply with the negative outcomes reported in other studies in which HIV-positive mothers used replacement feeding.[7] These results ought to make us consider carefully before decreeing that such mothers are not capable of preparing a baby bottle correctly.

Universality is the very essence of human rights. It is therefore unacceptable to promote a two-tiered approach to AIDS treatment or to replacement feeding, because doing so implies that some people enjoy more human rights than others. It suggests that wealthy women's rights include being able to feed their children safely, while poor women's do not. This contradicts the most basic principles of human rights theory. Moreover, on the level not of rights theory but of practical implementation, health care providers and people living with HIV in developing regions have shown that effective training combined with the appropriate technical and financial resources can ensure excellent delivery and follow-up of ARV treatment. Why then, should this not also be the case for infant feeding with breastmilk substitutes? The study conducted in Kayonza and Kirehe proves that it is possible. The preliminary results of the study show a rate of vertical transmission of HIV reduced to about 2%. Meanwhile, the rates of diarrhea and acute malnutrition among children fed with breastmilk substitutes in the program are not higher than

those in the general population, as reflected in a baseline study conducted by UNICEF in Kayonza and Kirehe districts in 2006.[8]

The right to choose is a fundamental human right. It should be up to a mother and her family to choose the way they want to feed their child, among a range of different means available to them. In the Kayonza and Kirehe study, fewer than 1% of women who received information and were given the option of providing replacement feeding chose to nurse their babies.[9] This result challenges the notion that women will refuse to bottle-feed in a culture where breastfeeding is the norm, out of fear of the stigma that might come with being seen to bottle-feed their children.

All this is not to minimize the obstacles that confront efforts to expand replacement feeding in low-income communities: lack of infrastructure, unreliable access to water, lack of information, and many other factors. These problems are real and serious. But that should not prevent us from setting for our people in the global south the same objectives that exist in the north. When the means are available, what is criminal is to mismanage those means, to fail to use them judiciously for the good of the community, by failing to provide people with the knowledge and tools they need to care for their children and themselves properly.

The low mortality rates for infants of HIV-positive mothers in the Kayonza and Kirehe program show that the fight against HIV and AIDS, including replacement feeding programs linked to the prevention of mother-to-child transmission, can be opportunities for public health — even though we know too well that these programs, when mismanaged, can be dangerous. Let us not once again mistake a contingent and correctable implementation shortfall for an eternal verdict on the capacities of Africans, decreeing that this type of service can never be delivered effectively by African health care providers to African patients. That some programs have failed to meet appropriate performance standards is undeniable and bitterly disappointing. But let us place the responsibility for this bad management where it belongs — with the bad managers. Let us not ascribe the failure to the incorrigible ignorance of African communities and poor African women — and then make them pay for their supposed failure with the health and lives of their children.

We must not repeat now with replacement feeding the same tragic error that was made ten years ago with antiretroviral medicines. Mothers living with HIV have the will to survive and to raise healthy children. Let us offer them the choice and provide them with the means to carry it through. Let us stop deciding who has the right to life and who does not. Let us respect human rights and seek together the way to realize them in practice.

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