

# Gender, AIDS, & Togo

At what point do we focus this discussion on health as a human right?

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AIDS is the most globalized epidemic in history, and we are witnessing its growing 'feminization'.

-Peter Piot, UNAIDS Executive Director

Human rights violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm.

-Paul Farmer, Co-Founder Partners in Health

## AIDS as a human rights issue

When I first arrived at post (Kara, Togo) in February 2004, I facilitated—actually I really just observed—an AIDS sensibilisation concerning ways individuals should change behavior to prevent HIV infection, the type that is supposed to be effective (you know the small, intimate group settings that make behavioral theorists giddy). Of course, someone gave away a few condoms, but not too many, for we do not want to start a cycle of dependency, and plus we needed these people to buy them eventually. At the end of the day I wondered who was the most affected by our CHAP-sponsored, Washington-endorsed activity. I mean, was it the formateur or *moi-même*? We both went home that night feeling productive, like we had *done* something in the 'lutte contre le VIH/SIDA'. But I wondered then and wonder now: How much do such activities really affect our AIDS pandemic? Would this approach have prevented the deaths of any of the estimated 10,000 Togolese adults and children that died from this disease in 2003? More personally, would such activities have prevented any of the 32 deaths that we have observed in the 11 months I have been working with Kara's only association of people living with HIV/AIDS?

This individual behavior change focused/social marketing paradigm can be likened to putting Barney & Friends decorated Band-Aids on freshly amputated limbs. The paradigm of 'prevention only', with a focus on individual behavior change, was enthusiastically launched in late 80s and is still fully endorsed with few revisions by most major AIDS NGOs in Togo. It contends that education, especially at the individual level, is fundamental to behavioral change. Great. Lets get out there and educate these uneducated folks. Sensibilize the stupid. You tell them they need to knock it off with all the sex and multiple partners, and just to be safe, I will get them to buy themselves a *Protector* condom and the kiddies can buy themselves *Rebel* brand. (As a somewhat aside question, why are we so against giving away effective preventative products; i.e. condoms, malaria prophylaxis, bed nets, etc? Is there really not enough aid money in the whole damn world so that it becomes necessary to sell condoms to sexually active, poor kids? On a personal note, I get nauseous like the synergistic effect of too much Bonita brand boxed wine and Mefloquine when I hear the terms 'social marketing' and 'life-saving preventive, health measures' used together. Commodified health approaches, or the

commodification of health promotion, especially in Africa, unjustly leverages culpability on individuals and ignores the larger social forces at play)

If prevention-only paradigms are still being subscribed to and ardently defended, then there must be a mountain of evidence that such approaches are effective in containing our epidemic. What does the public health and medical literature suggest? Mayaud, in a fairly comprehensive review article, concludes:

Somewhat surprisingly, towards the end of the second decade of the AIDS pandemic, we still have no good evidence that primary prevention works.

What? Primary prevention is effective with most communicable diseases, not to mention cheap, which usually satisfies donor and governing agencies in Washington and Geneva. And so I get to the point I have not been able to make in the previous 500 words. The causes, that is, the *social factors* that propagate this virus are rooted in economic and gender inequality. Until health interventions are designed with these inequalities in mind then this pandemic will continue to grow. Being poor and/or female are the most significant predispositions for HIV infection in Africa, and in most cases it is inconsequential whether that poor girl knows the modes of transmission or ways to protect herself, or whether she can buy a femidom for 500, 300, or even 50 CFA. From a better source and with more authority, Stephen Lewis, UN Special Envoy for HIV/AIDS in Africa:

In so many parts of the world, gender inequality and AIDS is a preordained equation of death. There's nothing new in that. It's irrefutably documented in encyclopedic profusion. The culture, the violence, the power, the patriarchy, the male sexual behavior—it's as though Darwin himself had stirred this Hecate's brew into a potion of death for women.

There is a social power dynamic involved that most 'individual centered' prevention strategies fail to address. The assumption is that the individual has the ability to make a choice, and unfortunately, economic and gender inequalities trump personal will or choice. AIDS is a human rights catastrophe, indeed the most revealing health and human rights issue of our time. It is one of the clearest social divisions between our societies' *haves*

and *have-nots*, for it overwhelmingly tends to infect and kill the *have-nots*. It is futile to talk about AIDS without addressing the larger social context and its reliance on poverty, and it is ineffectual to discuss poverty without acknowledging its insidious interdependency with gender, especially in Togo.

This is an editorial that calls for solidarity, in the pursuit of health as a human right, with those that are either at risk of HIV

## **Relating AIDS & Gender Inequality: Statistics and Anecdotes**

### *Statistics: Lie or Limits?*

Human Immunodeficiency Virus (HIV) was identified in 1981 and later proven to cause Acquired Immunodeficiency Syndrome (AIDS), which contributed to approximately 3,000,000 deaths—adults and children—in 2003. Sub-Saharan Africa—host to 10% of the earth's human inhabitants—is home to 60% of all of the world's individuals living with HIV/AIDS. In a world without AIDS the average life expectancy in Sub-Saharan Africa would be 62. The current average is 47. Without treatment—that is, anti-retroviral therapies in combination with good nutrition and management of opportunistic infections—90% of people with HIV infection die within 3-5 years as a result of a deteriorating immune system, or AIDS. And without treatment, nearly 100% of people living with AIDS will die. The type of treatment that I am referring to—sometimes called ARV, ART, or HAART—has been made available to only 7% of the millions in need. Our failure can be and is attributed to a lot of factors, but is mostly the result of a majority of policy-makers' and international health/development experts' failure to find the will and the way to deliver treatment. Or like McNeil stated in a New York Times article:

There are at least 34 million HIV-infected people in the world, at least 30 million of them poor. Poor not just by American standards: living on less than \$2 a day. AIDS specialists rarely say this bluntly, but the majority of those 30 million people have simply been written off, because the first priority for the first few billion dollars is prevention, not treatment.

Another number to think about, if we continue our ineffective 'prevention only' approach in the midst of rising infection rates, 60% of Africa's 15 year olds will not live to see their 60<sup>th</sup> birthday. Welcome to the catastrophe that is our current AIDS pandemic.

But what about females and all this brouhaha about gender inequality and human rights? Females living in sub-Saharan Africa account for 57% of people living with HIV/AIDS, and for younger women (15-35) that number rises to 75%. Want a 'quick and dirty' (did not make that up, statisticians have a sense of humor too) see-for-yourself analysis? Search the World Bank website ([www.worldbank.org](http://www.worldbank.org)) and look at a country's *Gender Inequality Index* and compare it to HIV incidence and prevalence. Your results will not be surprising. Also not

infection or living with AIDS, especially women. It is founded on the following beliefs: one, that our inability to effectively address gender inequalities contributes to steadily increasing HIV infection rates in sub-Saharan Africa, and two, that the 'individual behavior change /prevention only' paradigm is a questionable response to AIDS in Togo.

surprising is the fact that more inequity usually translates into disproportionately more female cases. If you want something more 'professional', check out a book called *Women, Poverty, and AIDS* (1996).

As a caveat, I should say that although they are sometimes powerful and illuminating, epidemiology and statistics are definitely limited in utility. Epidemiological interpretations are complicated by mantras like 'correlation does not equal causation' and 'absence of proof is not proof of absence'. Although the aim is always *truth*, it is sometimes impossible for health experts to ever *prove* causation using epidemiology. Some health problems simply never lend themselves to the type of analysis needed to appease the masses of critics, and most epidemiological models are too basic to account for the multitude of variables. But we still take these statistics and interpret—sometimes even with common sense—and this is the tricky part (and why people claim that statistics can lie), because not all the data is always top notch and humans are plagued by the ability to see the same thing and interpret it differently. So these numbers end up having different meanings and are used to make different arguments for different policy makers for different reasons and agendas.

Let us just use the UNAIDS interpretation, the source of all aforementioned statistics, in the 2004 Global Report of the AIDS Epidemic:

In most societies, the rules governing sexual relationships differ for women and men, with men holding most of the power. That means that for many women, including married women, their male partners' sexual behavior is the most important HIV-risk factor.

In 2000, the World Health Organization published a three-page fact sheet (N°242) that outlines their interpretation of available data on women and HIV/AIDS. Here is in its original format:

Why are women more vulnerable to HIV infection?

Biologically,

- Larger mucosal surface; microlesions which can occur during intercourse may be entry points for the virus; very young women even more vulnerable in this respect.
- More virus in sperm than in vaginal secretions
- As with STIs, women are at least four times more vulnerable to infection; the presence of untreated STIs is a risk factor for HIV.
- Coerced sex increases risk of microlesions.

Economically

- Financial or material dependence on men means that women cannot control when, with whom and in what circumstances they have sex
- Many women have to exchange sex for material favours, for daily survival. There is formal sex work but there is also this exchange which in many poor settings, is many women's only way of providing for themselves and their children.

Socially and culturally

- Women are not expected to discuss or make decisions about sexuality
- They cannot request, let alone insist on using a condom or any form of protection
- If they refuse sex or request condom use, they often risk abuse, as there is a suspicion of infidelity
- The many forms of violence against women mean that sex is often coerced which is itself a risk factor for HIV infection
- For married and unmarried men, multiple partners (including sex workers) are culturally accepted
- Women are expected to have relations with or marry older men, who are more experienced, and more likely to be infected. Men are seeking younger and younger partners in order to avoid infection and in the belief that sex with a virgin cures AIDS and other diseases.

And there are theories and interpretations from other sources as well. Many studies suggest that women are disproportionately subjected to sexual exploitation via prostitution and trafficking and that these groups notoriously have the highest rates of infection on the continent. Even considering that females are biologically more susceptible to HIV via sexual transmission, the body of data and coinciding analyses overwhelmingly support

the notion that gender inequality is the major contributing factor to higher female infection rates in Sub-Saharan Africa. Alas, women are disproportionately infected and infection rates continue to rise for females despite prevention efforts.

Studies. Statistics. Supporting evidence. How about a Story...

*A Story of Grace*

For the past 11 months I have been working with Association Espoir pour Demain (AED-Kara), Kara's only association of people living with HIV/AIDS. It turns out that AED-Kara members are overwhelmingly female (like 90% to be exact). I have been fortunate to know people that give new meaning to words like strength, compassion, and humility. And my first story is about one of these individuals, whom I will call Grace.

Grace married in her late teens without completing the equivalent of a junior high school education, which was irrelevant to her at the time because she was in love and expecting. It is important to hear the next part of this story in her words (and with her permission):

*I became pregnant. From time to time he [the husband] would tell me that he was going back to his village, in a canton called [omitted]. Always on the weekends he would go to his village. I began to ask myself why he went to his village so often, and I began to suspect that he had another woman. It turned out she was in Benin and they would meet on the weekends. I was pregnant at the time and I gave birth. One day I learned that my husband's girlfriend was sick...soon after the child was sick, always to the hospital and always with the child. At eight months his body was covered with sores. He got better and started walking. But then he got worse and he died...just a few days later I began to see boils on my husband's body. I asked him what it was and said that we should go to the hospital, but he refused. And then one day things got bad. He had diarrhea, everything. We took him to the hospital two or three times. His family abandoned us. It was only my parents who would help us. I asked him again and again to take an HIV test but he refused. And then one day I decided that even if he wouldn't that I couldn't stay like this. I lied to my husband, telling him I was going to visit my family, and I went to the hospital. I explained the problem to the doctor and after many questions he accepted to give me the test...The test was positive.*

Grace's husband died in following months, after which *his* family kicks her out of *her* house on account of *her* alleged infidelity. She now lives with her parents and is co-coordinator of AED-Kara's HIV counseling and testing program. Grace's husband fathered a child with his Benin village girlfriend—who has since passed away as well. Just recently, Grace found the means to have this child participate in a Global Fund sponsored, AED-Kara organized assistance program for AIDS orphans.

Such statements and experiences of both social injustice and benevolence are common in the AED-Kara family of women, and are usually expressed in a perfunctory, matter-of-fact tone, as though this is just the way things are chez nous. As previously stated, 90% of AED-Kara members that are living with AIDS are female. With this number, I am only suggesting that Kara women are more likely to be tested (mostly a result of prenatal counseling, better health practices, and child-rearing responsibilities) and are more willing than males to join and participate in an association like AED-Kara, despite overwhelming stigma and discrimination concerns. Despite an absence of clear statistics, I do believe that Kara's epidemic mirrors that of its sub-Saharan neighbors, with proportionately more women being infected and in a similar pattern. Gender inequality affects women here from birth, and creates a complicated web of risk factors—ranging from economic disadvantage to gender discrimination—which individual-based prevention methods fail to address and rectify. The stories coupled with the statistics present an informed perspective regarding the social dimensions of the epidemic and provide a base from which to mount a response.

### **Our Response: More Excuses & (Evidently) Ineptitude**

In the late 90's, Uganda was heralded as the miraculous breakthrough in the global AIDS pandemic, often overshadowing the more telling and encouraging success story that is the Brazilian experience. Many policy makers and international health experts attributed the first instance of a reduction in HIV prevalence and infection rate in sub-Saharan Africa to a social marketing approach with a cute acronym, **ABC**. **A**bstinence, **B**e Faithful, **C**ondom Use (conveniently translates into French & Spanish as well). The exuberance proved to be shortsighted and supported by unsubstantiated assertions rather than public health evidence. As the World Health Report 2003 notes:

The "ABC Campaign" is a social marketing effort to promote abstinence, monogamy and condom use. However, declining HIV prevalence in Uganda involves far more than high-level political will and forceful condom promotion, important as these factors are. Developments in Uganda reflect a complex biosocial pattern that includes war, death, migration and many other events and processes, including, in Kampala and beyond, increased access to ARVs, not necessarily included under the rubric "ABC Campaign".

Of course, the advantages of hindsight should not count for much in the case of the United Nation Agencies, who previously embraced Uganda and the ABC approach just years earlier in similar reports. Major international agencies and governing bodies—not to mention the majority of Sub-Saharan governments—continue to support this social marketing technique, despite the absence of evidence that supports its effectiveness to contain infection rates.

Think back to Grace and the many married women of AED-Kara of whom have similar stories. What part of the ABC/social marketing campaign might have changed the outcome?

**Abstinence.** It is impractical and irrelevant in a marriage, even ones sanctioned by religion and society. In Grace's case, she claims to have abstained from sexual relations until she was married.

**Be faithful.** Grace was being faithful; it was her husband who wasn't. 'B' only partially applies, unless one believes that Grace had power to control her husband's infidelity. As Grace explained to me, her husband felt that he had a right to a girlfriend or two and that her leaving him was not an alternative. In fact, the problem did not rest with her behavioral choices. The problem was her husband and the dynamics of the relationship. The problem was Grace's dependency on her husband, not in the emotional sense that Americans like to romanticize about, but in the economical and social sense.

**Condom use.** Using a condom, male model or femidom, for a married couple is also quite absurd and introduces more problems than solutions for the female spouse. If you don't believe me, just ask one of your Togolaise friends what would happen if she told her husband that he had to wear a condom. Is there a technique for negotiating power disparities with a male spouse? At this point, one is also making the assumption that the women/negotiator is informed or aware of her partner's infidelity. In Grace's case, she was not aware for several months after the affair began.

ABC as a social marketing approach fails miserably because it assumes, often arrogantly, that the problem lies with personal decisions made by the individual—in this case woman. It does not address the social forces and inequality that more often determine what one *can* do. Currently in Togo, the most effective interventions to fight and prevent AIDS are programs like the Karen Waid Scholarships (and in my opinion the entire Girls Education and Empowerment philosophy). Unlike the ABC/social marketing approach, these programs attempt to address a fundamental inequity in gender, thereby providing remedy to a social factor fueling our pandemic.

A social marketing/prevention only agenda ignores all those women that have just been infected, because these types of prevention strategies rarely include or coordinate treatment efforts. As a representative of a major AIDS ONG in Togo told me, "we don't do *prise en charge*". Thus, these folks have simply written off twenty six million Africans—mostly women—known to be infected and living with HIV/AIDS. Let me repeat that for the sake of clarity: 26,000,000 human beings.

Obviously, my allegiance is with AED-Kara and those living with and dying of AIDS. And the arguments will come that social marketing/ABC campaigns raise awareness and sometimes even reduce stigma. In fact, without strong public leadership and without legislation to protect rights of people living with AIDS or women in general, such self-proclaimed accomplishments usually do little for my friends in Kara. The social marketing/ABC approach has tried to improve its doctrine in the

past few years to include notions of empowerment and with this a real push to get people tested. The idea—which has been supported in many studies—is that people walking out of testing centers with a negative results tend to avoid future high risks behaviors, i.e. retain negative status. Unfortunately, these campaigns have no such encouraging news for those with positive results and the approach does not address how to get people into testing centers in the first place. What is our response to those who come out positive? Ironically, the same people preaching ‘prevention only’ are simultaneously arguing against treatment in resource poor settings, because it is officially too expensive and not sustainable. They simply don’t do *prise en charge*. But is there really not enough wealth on the whole damn earth for treating the 26,000,000 people living with a death sentence? Or are we simply trying to hide our ineptitude with excuses of convenience?

A favorite conversational topic in international development and health worker circles is discussing why an intervention ‘is not sustainable’ in a world of limited resources (how limited is a question for another day, but ever consider how much money we spend to see teams of grown men running around, knocking the life out of opposing players with the goal of advancing a oval-shaped ball 100 yards?). Instead of focusing the discussion on *how* to deliver treatment, AIDS experts waste time arguing about *whether* treatment should be the goal, and use all sorts of fancy analyses to do so—analyses that create jobs for development workers and keep them employed. There are reasons to have hope though. Some experts don’t sit around blaming the victims and assuming that it was a series of personal choices that created our pandemic. There are groups that address the larger social context, the inequality that is linked to HIV infection and AIDS deaths. Partners in Health, Médecins Sans Frontiers, and the Brazilian government—just to name a few laudable examples—have found the will and the way to introduce effective AIDS prevention and treatment interventions in resource-poor settings, and they have done this in the midst of the critics’ *unsustainable* anthem and *not cost-effective* chorus. Dr. Paul Farmer notes:

What, then, is not sustainable? It is not the cost of HIV treatment that is not sustainable; it’s rather the opposition to treatment in high-burden areas that is not sustainable. It’s not morally sustainable, it’s not intellectually sustainable, it’s not epidemiologically sustainable or socially sustainable

And so it follows, what the hell are we really trying to accomplish? Are we planning our interventions with the individual’s human rights and the larger social context in mind? Usually not, because that would require more than doing simple KAP surveys—a favorite in Togo—which assume that HIV infection is predicated on individual decision-making gaps instead of focusing on the underlying gender and economic inequalities that propagate the virus. Women are bearing the majority of the burden arising from our custom of blaming the individual. Our failure to cut new infection rates is a reflection of

an unwillingness to reach beyond a weak, simplistic prevention-only framework that focuses too much attention on what individuals are not doing right, instead of addressing the social dynamics directly influencing behavior.

### **Mounting a Comprehensive, Human Rights-Based Response**

I should have prefaced the piece by stating that its tone and theme were inspired by two recent events: The first, to the negative and discouraging reception AED-Kara receives from individuals working with better-funded and more developed organizations in Togo. Second, to the response an American development worker gave me at dinner one night in Kara. After a couple (actually maybe it was three or four) of much-needed Flags, she asked me, ‘so you work with an AIDS organization. How many people do you have that are positive?’ I replied, ‘We currently have 113 people living with the virus, 300-plus AIDS orphans, some of whom are positive.’ Her reply: ‘That’s not a lot. Only 100.’

I admit she made me think about something that had never crossed my mind since I started working with AED-Kara. What constitutes ‘a lot’? I mean, what is a respectable number, an ambitious goal? At what point do we have enough members (or members dying each month) to officially warrant the distinction, ‘a lot’? Does West Africa have to turn into its southern neighbor countries before we describe the morbidity and mortality as ‘a lot’?

Maybe I am merely inflating a relatively innocent remark made by a thoughtless person on account of my personal attachment to AED-Kara. I don’t know for sure nor do I care. At some point, the discussion needs to focus on the basics of what development and international health work ought to—and so often fails to—mean: ensuring health as a human right and promoting social justice. And the Universal Declaration of Human Rights, which was ratified by most of the world in 1948, supports this definition:

Article 25: Everyone has the right to a standard of living adequate for the health and the well-being of himself and of his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

The failure to provide this essential right to the masses results in people suffering and dying in holocaustic numbers. AIDS is a stark reminder of our failure. In the United States, clinicians refer to AIDS as a treatable chronic condition, yet no such description exists in the world of the poor. Today, AIDS remains the leading contributor to premature death from infectious disease (and infectious diseases as a group account for the

most deaths world-wide), for women and men living in resource poor settings.

So how do we mount a significant response to this pandemic?

Maybe our response should start with a mandate for prevention *plus* treatment. Treatment activities have been shown in both South and Central America and Africa to augment prevention efforts by increasing demands on testing, lowering viral load (and thus lowering the rate of transmission), decreasing associated stigma and discrimination, boosting health personnel morale and time for prevention activities, and decreasing the prevalence of related opportunistic disease. As Dr. Lisa Hirschhorn, a Boston-based advisor to our work at AED-Kara, told me, 'Treatment is prevention.' Comprehensive approaches to the epidemic must be the norm, and anything less ought to be deemed unacceptable. The narrow-mindedness that breed comments like 'we don't do prise en charge médicale/psychosociale' need to be replaced by 'we coordinate those services in collaboration with a partnering agency or the following public clinics'.

Maybe our response involves more 'out-of-box' thinking coming from people in the field, people working at the community level. In an article titled 'AIDS Treatment is Learnt by Doing It', and in accounts by similar-minded authors, Ariel Pablo-Mendez and cohort call for more creative and ambitious prevention plus treatment responses from local, national, and global level AIDS actors. Clearly there is no one authoritative manual or procedure to follow for preventing and treating the complex pandemic that is AIDS. However, there are some good models and guidelines-not to mention leadership-from those with first hand experience in implementing complex health intervention in resource-poor settings. We can use these examples to form the foundation, and entrust the rest of the building components to the discretion of local experts and communities.

Maybe our response requires a stronger emphasis on listening to what these communities think and want (i.e. if they want a hospital so they can receive decent health care, then that should be the goal). It is likely that such an approach will require a multi-disciplinary frame of action. The notion of 'health' will need to include a comprehensive prevention and treatment initiative that includes gender rights activism, girls empowerment and education, job creation or income generation, and new and better agricultural techniques.

Maybe our Peace Corps-specific response necessitates better coordination of the four programs, 'the cluster model'. From a more progressive stance, maybe we ought to strip off the program labels Washington assigns and start working in as many domains necessary to get a community initiative moving—even if this involves training ourselves outside our respective program and the four existing PC project areas.

Maybe it starts by acting in the name of social justice, seeing wrongs and finding ways to right them. Stand in solidarity with

the many that suffer and die. Reject the opinions of experts focused on delineating the reasons why treatment for poor people is not sustainable but suffering and death is.

Maybe our response simply starts with personal belief, belief that the inequality that defines the state of world health is unacceptable, and belief that we must pursue that conviction with a sense of duty. And with enough people fulfilling this duty, from community health workers to policy makers, the *fates* may change for the many women, men, and children living with AIDS.

-Kevin Fiori, Jr.  
November 21, 2004  
Kara, Togo

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