



# A virus, democracy, and sustainable society: the experience of community-based HIV/AIDS programs among the Gurage, southern Ethiopia

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Makoto Nishi\*

**Introduction: whose sustainability matters?**

Since the establishment of antiretroviral treatment (ART) in the mid-1990s, the average lifetime of people with HIV/AIDS (PHA) has increased dramatically. According to a study in Denmark, the average remaining lifespan of PHA at age 25 was just 7.6 years in 1995–1996. By 2000–2005, this figure had more than quadrupled to 32.5 years (Lohse et al., 2007). Life expectancy is an important indicator of capability and quality of life (Sen, 1981; UNDP, 1990). By increasing life expectancy, ART has made immense contributions to the potential and wellbeing of PHA. However, this achievement has not only changed the lives of individuals with the virus. By changing the prospects for the future lives of PHA, it also brings into question conventional understandings of the conditions of a sustainable society.

Under what sorts of conditions is a society considered sustainable both for the infected and the uninfected? We tend to consider as a sustainable society one that can effectively eliminate external factors that affect the survival of its own entities. One such external factor would be HIV, as it affects the survival of individuals and the continuity of existing social institutions. In this sense, to be sustainable, a society should eliminate the virus. However, this statement is true only in regard to those people who are not living with the virus. For PHA, we need to think of sustainable life in a different way. A sustainable society should not be narrowly defined as one that eliminates the virus promptly, but rather a society that can cope with the existence of virus.

It is useful to consider how medical and other technologies have impacted the relationship between viruses and human society. In some cases, medical advances have enabled us to eliminate a germ or virus from our society, as is the case for smallpox. In other cases, such as HIV/AIDS, treatments do not remove a virus from the human body, but instead allow the infected person to live with that virus. In the latter case, we should understand the relevant medical technology not as a tool that will allow us to live without a virus, but as something that will prompt us to “co-exist” with the virus.

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The idea of co-existing with viruses, chief enemies of human beings, may sound obsolete. However, such experience is not new to our history. A number of infectious diseases, including smallpox, measles, dysentery, and cholera, were not known to human society until the beginning of agriculture and domestication. As humans developed sedentary lifestyles and denser population concentrations, they created favorable conditions for viruses and germs. Constant sharing of parasites and germs with domestic animals such as dogs, cattle, and pigs also facilitated the transmission of diseases to human populations (Crosby, 2008). This process was further encouraged by urbanization, which has surged on a global scale since the industrial revolution. The relatively recent introduction of HIV into global society was expedited by increased human mobility, but it is merely another addition to our long history of coping with viruses.

The experience of living with the virus is by no means easy. The fact that HIV is often a sexually transmitted disease often leads to complicated debates over the methods of prevention and the possible relationships between those living with and those without the virus. Although humans have long experience of coping with infectious diseases, the experience of those living with the virus is still unclear to the majority of the uninfected population.

Community-based HIV/AIDS programs are expected to address issues concerning sustainability and democracy by providing preventive education to ensure the community's sustainability and also by caring for democracy through combating bias against PHA and helping support their lives. However, by addressing the ideas of prevention and support simultaneously, a community-based HIV/AIDS program gives contradictory messages to community members. On the one hand, it tells a community to eliminate the virus to be sustainable. On the other hand, such a program says that those living with the virus should be included in the community to make it democratic. But how can a community strive to eliminate a virus and at the same time work to include people who are living with that virus?

In this report, I describe problems with community-based HIV/AIDS programs promoted by different stakeholders in the Gurage Zone, southern Ethiopia. Chapter 1 explains the problem in terms of ideas of democracy and sustainability that are incorporated in contemporary community-based HIV/AIDS programs. Chapter 2 provides a brief overview of HIV/AIDS in Ethiopia. Chapter 3 explains local initiatives among the Gurage to prevent transmission of HIV and to support people with HIV/AIDS. Chapter 4 outlines some of the ongoing debates among the Gurage over issues concerning HIV prevention and necessary care for AIDS patients. Finally, in Chapter 5, I discuss

possible ways in which stakeholders in the Gurage Zone might construct democratic and sustainable relationships between those who live with and those without the virus.

## **1. Democracy and sustainability in community-based HIV/AIDS programs**

Under what conditions can we consider a society sustainable for those infected and those uninfected with HIV/AIDS? This question involves groups of people with different positions. In other words, it is a “political” question. According to some political philosophers<sup>1</sup>, politics is a form of practice through which we change rules, usually through negotiations among peoples with different social, cultural, or economic positions. In democratic political practice, a core value is inclusion; if rules are changed to include a group that used to be marginalized, this political practice can be considered democratic.

However, there seems to be a major contradiction between the ideas of democracy and sustainability. A sustainable society needs a sustaining set of rules and institutions, whereas in a democratic society, rules and institutions are changing constantly. Such a contradiction is particularly apparent in HIV/AIDS programs.

Prevention, treatment, and mitigation are principal measures for controlling the negative effects of HIV/AIDS on communities in Africa and elsewhere in the world (UNAIDS, 2006a; World Bank, 2008). Preventive programs, such as educational programs promoting changes in sexual behavior, may help people decrease their risk of becoming infected by HIV. For those who are already infected, programs providing ART and other treatments try to reduce the risk of aggravation of AIDS symptoms and early death. In addition, income-generation projects for PHA and support for AIDS orphans can help mitigate the impact of HIV on households. These components may be provided as a package by state bureaus and/or international organizations (UNAIDS, 2007) or may be among the many initiatives offered by various stakeholders (as is the case in the Gurage Zone, discussed below).

For policymakers, these components may seem mutually harmonious, because they promote the welfare of every member of the community by responding to risks that affect their lives. However, the introduction of such programs can create problems as well as solutions for a community. Preventive programs call on community members to identify the risk of infection and differentiate the infected from the uninfected. This process may help ensure continuity of social institutions and practices, particularly those

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<sup>1</sup> I am referring to Mouffe’s argument on radical democracy (Mouffe, 1993; 2000) and Fraser’s discussion on counterpublics (Fraser, 1997).

related to labor, marriage, and reproduction. However, the same process inevitably terminates or alters existing social relationships in the community, often leading to the isolation of people who are infected. Those infected with the virus are more likely to be seen as a risk to the community than as a part of that community.

The empowerment of PHA is, of course, one important remedy for such a problem. Governments, international organizations, and nongovernmental organizations (NGOs) in Africa have promoted the establishment of PHA associations and have supported their income-generation efforts. Promotion of self-reliance and mutual help among PHA is important to avoid the immediate dangers of poverty and deterioration of health. However, little is known about how to renegotiate broken or altered relationships within the community.

This is the situation faced by the Gurage, one of many peoples in southern Ethiopia. Traditional leaders of the Gurage have actively engaged in HIV/AIDS prevention activities by promoting pre- and post-marital voluntary testing, and Gurage women living with the virus have formed an association to renegotiate their current situation of isolation. Currently, local debates over infection risk and support for AIDS patients are ongoing between men and women, married and unmarried, and *positiboch* (HIV-positive people) and *negatiboch* (HIV-negative people). Before examining local initiatives and debates over HIV/AIDS among the Gurage, I will provide a brief overview of the HIV/AIDS problem in Ethiopia in the next chapter.

## **2. HIV/AIDS in Ethiopia: an overview**

Ethiopia, with a population of more than 73 million in 2005, is the third most populous country in Africa after Nigeria and Egypt. According to estimates by the Ethiopian government, Ethiopia had 1.1 million PHA in 2005 (MOH and HAPCO, 2006). HIV prevalence among the adult (15–49 years old) population of Ethiopia was 3.5% in the same year (MOH and HAPCO, 2006), and UNAIDS provided low and high estimates of 0.9% and 3.5% infection of the total population. This figure is much lower than those for southern African societies, where HIV prevalence is well over 10%<sup>2</sup>, but probably higher than percentages for Asian and Pacific countries, including Papua New Guinea (1.8%), Cambodia (1.6%), and Thailand (1.4%) (UNAIDS, 2006b).

HIV prevalence in Ethiopia rose from 0.0% in 1985 to 4.5% in 1999 and then started to

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<sup>2</sup> HIV prevalence in southern African countries is estimated to range from 14.1% in Malawi to 33.4% in Swaziland (UNAIDS 2006b).

decline steadily. One of the reasons for the reverse trend has been the decline in the number of new infections following a peak in 1995 (when there were more than 157,000 new infections), probably due to prevention campaigns by the government, local and international NGOs, and international organizations.

The other reason for the decline, however, is deaths, the number of which continued to increase until 2005, when more than 101,000 PHA died from the disease. Antiretroviral treatment was too expensive for most Ethiopians with HIV/AIDS until 2005, when the government started to provide antiretroviral drugs free of charge<sup>3</sup>. Provision of antiretroviral medicine to PHA in developing countries was delayed mainly because international pharmaceutical companies, which held patents for antiretroviral drugs, strongly objected to the idea of providing cheap, “copy” drugs to the poor. The situation changed drastically in 2001, when the World Trade Organization (WTO) encouraged the production and use of copy drugs to address a public health crisis, such as the crisis of HIV/AIDS<sup>4</sup>.

In the following year, the Global Fund to Fight AIDS, Tuberculosis, and Malaria was established. In Ethiopia, the Ministry of Health and the HIV/AIDS Prevention and Control Office (HAPCO) have been providing ART with financial and technical assistance from The Global Fund. In 2008, approximately 240,000 people with HIV/AIDS were estimated to need ART in Ethiopia (MOH & HAPCO, 2006). However, the government reported that only 97,158 people were taking ART as of March 2008<sup>5</sup>. Failure to achieve universal access to ART in Ethiopia will lead to a higher death rate of PHA, resulting in a relatively fast decrease in HIV prevalence among the general population. It is estimated that adult HIV prevalence will stay at 3.1% by 2010 if universal access to ART is achieved, but will decrease to 2.8% if many PHA remain without access to ART.

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<sup>3</sup> “Ethiopia’s free ART eligibility criteria revised,” Press release, HIV/AIDS Prevention and Control Office of Ethiopia, 3 October 2005.

<sup>4</sup> See “Declaration on the TRIPS agreement and public health” (WT/MIN(01)/DEC/2), adopted on 14 November 2001 at the World Trade Organization Ministerial Conference, Doha, Qatar. In the face of global protests against international pharmaceutical companies, the WTO was forced to accept the idea that the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS Agreement) “should not prevent its members from taking measures to protect public health”, as stated in the above-mentioned declaration.

<sup>5</sup> “Monthly HIV care and ART update: Update as of March 10, 2008,” Federal Ministry of Health and the HIV/AIDS Prevention and Control Office of Ethiopia.



### **3. Local initiatives within the Gurage community**

#### **HIV/AIDS and livelihood of the Gurage**

The Gurage Zone is situated in the northernmost part of the Southern Region<sup>6</sup>, one of the nine regions of Ethiopia. As part of the Central Ethiopian Plateau, the Gurage Zone consists mostly of mountainous terrain at elevations above 2,000 m. Approximately 2.2 million people live in the Gurage Zone, most of whom practice agriculture. The main crop is ensete (*Ensete ventricosum*), a perennial plant commonly cultivated in the highlands of southwestern Ethiopia. Ensete supports relatively high population densities compared to cereal crops (Brandt et al., 1997). However, it is not easy for households to survive on agriculture alone, as farmland is highly fragmented. Coffee is a major source of income for some Ethiopian farmers, but among the Gurage, coffee production does not exceed the level of consumption.

It is common for young Gurage, particularly males, to migrate from rural areas to towns and cities in search of job opportunities. Currently, half a million Gurage live in Addis Abeba, the capital of Ethiopia. Fellow Ethiopians recognize the Gurage as major players in the domain of national commerce (Bahru, 2002). A typical life course for a young man born in the Gurage Zone is to migrate to an urban area such as Addis Abeba in his teens and engage in a trade business run by immediate family members or other relatives. When he and his family feel that his life is well established, he will return to his home village to marry a rural woman. Such mobility of young Gurage males is firmly built into their life course, grounded on practices of agriculture and national commerce.

However, in recent years, the Gurage have recognized that such mobility presents not only opportunities but also serious risks to productive and reproductive activities in their community. The prevalence of HIV in urban Ethiopia was 14.1% in 1998 and 10.5% in 2005, much higher than the values of 2.3% in 1998 and 1.9% in 2005 found in rural Ethiopia. Faced with increasing numbers of deaths among young couples in rural villages, the Gurage realized that young male members of their community had been exposed to HIV while living in urban areas.

There are no reliable data that show adult HIV prevalence in the Gurage Zone. According to the zonal health bureau, 2,646 or 3.8% of 69,904 people who underwent voluntary HIV testing in the zone were HIV positive. (Note that HIV prevalence would be higher among those who visited voluntary test centers than for the whole population.)

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<sup>6</sup> The region is officially referred to as the Southern Nations, Nationalities, and Peoples' Regional State.

ART was provided at four medical institutions in the zone as of September 2007, with plans to add four more. In an interview, a staff member at the zonal health bureau told me that the ART supply was sufficient to treat anyone needing the drug at any of the four health institutions. In addition, the bureau employed several health outreach workers to facilitate care for PHA who had difficulty accessing health institutions. The outreach workers were expected to visit PHA regularly and collect their blood, which would then be taken to a laboratory for CD4 tests, which are used to assess the immune system of PHA. Between July 2006 and June 2007, 430 PHA started ART in the zone.

On the other hand, a member of the association of PHA in Gurage Zone reported that there were individuals who knew that they had the virus but had never visited a health institution. Some of them were afraid of what their neighbors would think, whereas others refused to take ART because of distrust or misunderstanding about the antiretroviral. Some PHA in remote villages also wished to take ART but could not afford to travel to health institutions regularly.

### **The pre-marriage testing campaign**

As noted above, labor mobility, in the form of work outside the village followed by a return to agriculture at home, is a livelihood foundation among young Gurage males. However, such mobility has provided a pathway for HIV infection from urban centers to rural Gurage villages. More Gurage people have become aware that migration is a major factor in the increased number of HIV cases in their villages. Anxiety about the future of their communities has driven the Gurage to launch pre-marriage testing campaigns.

A unique aspect of the prevention campaign in Gurage Zone is the important role played by traditional leaders. In Gurage villages, elders (*shimagle*) have critical roles in maintaining the traditional social order and enhancing communal discipline. If a Gurage couple wishes to have formal marriage that is recognized by their community, the preferred way is to ask certain elders to endorse their marriage. The revised family code of Ethiopia provides that marriage may be concluded either by a government official or in accordance with the “religion” or “custom” of the future spouses<sup>7</sup>. However, marriage according to custom is by far the more recognized form of marriage among the Gurage.

The Gurage customary law (*qicha*) is maintained by elders who confirm, revise, and apply regulations by consensus. A qualified elder not only has seasoned knowledge of customary law, but also has experience in solving various conflicts among community

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<sup>7</sup> See Article 1 of the “Revised family code,” *Federal negarit gazetta*, Proclamation 213/2000, Federal Democratic Republic of Ethiopia.

members. An elder is not necessarily a very elderly person; rather, competency can determine whether a person (usually a male) is considered an elder. Meetings of the elders are usually held at the village level. A larger council of elders (*yejoka*) is held once every several years, bringing together all the chiefs and important elders of the Gurage. The council discusses important issues, such as solutions to disputes between clans and revisions of important customary laws.

Gurage customary law is generally unwritten and is held in the collective memories of Gurage elders. However, important provisions were compiled and published by an association of Gurage migrants in Addis Abeba in 1998 (GPSDO 1991EC). This association, the Gurage People's Self-help Development Organization (GPSDO), is led by urban Gurage elites, including lawyers educated in modern law. The association's interests show that not only rural Gurage, but also urban Gurage are committed to observing their customary law<sup>8</sup>.

It is within this social setting that the Gurage's pre-marriage testing campaign has been deployed. Since 2003, elders have increasingly asked young couples to undergo HIV testing as a precondition for recognizing their marriage<sup>9</sup>. A young couple is asked to be tested twice before their marriage. The first test is required immediately before the rite of engagement, which takes place several months before marriage. The second is required before the marriage ceremony. The second test is considered necessary because the HIV tests cannot determine infection in the first three months after infection. The largest numbers of pre-marriage tests take place at the end of the rainy season, when many Gurage urban workers return to their home villages to spend the Mesqal Festival with their families. Mesqal (meaning "finding of the true cross") is celebrated throughout Ethiopia by followers of the Orthodox Church, but for the Gurage, its cultural implications are most profound. For the Gurage, the Mesqal Festival is a time when family members scattered throughout Ethiopia return home for an annual reunion. Young males who have been working in towns for several years come home to marry village women. Elders await them at home to bless their hard work and their new marriage. Young couples line up at the gates of the voluntary testing centers in the days prior to Mesqal in the Gurage villages. Many of them will get married, but for some, marriage will not be allowed.

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<sup>8</sup> However, the GPSDO leaders had great difficulty compiling the customary law, as there are significant variations in its provisions. Although some essential features seem to be held in common, each clan and village may have its own provisions. As a result, many Gurage have some reservations about the "orthodoxy" of the published law.

<sup>9</sup> At this time, I do not know exactly how the campaign started, but some elders told me that it started around 2003 and became common practice by 2006.

### **Support for PHA**

Side by side with these preventive efforts are initiatives to support PHA and orphans who lost their parents to AIDS. For example, in Welqite, the capital city of Gurage Zone with a population of approximately 30,000, an association of some former classmates of a local high school started to help orphans attend school.

A number of HIV/AIDS-related projects are also run by the Gurage People's Self-Help Development Organization (GPSDO), which was originally established as the Gurage Road Construction Organization in 1962 by Gurage migrants in Addis Abeba to promote construction of roads and schools in their home villages (Nishi, 2008). Current GPSDO leaders consider HIV/AIDS to be one of the most important issues in the Gurage community. The headquarters of GPSDO is located in Addis Abeba, where members solicit donations from Gurage migrants and international donors. The association also owns a small center in Welqite that provides training for local health workers who care for AIDS patients in the zone.

An association of PHA was also established in 2004 with the assistance of the zonal health bureau. The bureau provided the association with an office, including furniture, a photocopy machine, and a telephone line. The association, called the Fana Association of People Living with HIV/AIDS, was first led by a retired teacher, who was later replaced by a young woman named Meseret. In 2003, the association had 120 members, 71 of whom were women. According to Meseret, participation by women has been greater in part because men tend to leave home for urban centers outside the zone when they realize that they are infected. They choose to detach themselves from their families and neighbors. However, women do not have the choice to leave because they do not have social networks outside their home villages. As a result, women are more likely to admit that they are infected and join Meseret's association.

To generate income for fellow PHA, the association runs a small shop and a grain mill in Welqite. Meseret and other staff also provide counseling to other PHA. In an interview, Meseret described the desperation of some PHA. She said that she tries to convince them that life with the virus is still manageable, but sometimes she too becomes quite depressed after the conversations. The Fana Association and GPSDO jointly organize an annual campaign during September to call for HIV testing and an end to discrimination against PHA.

#### 4. Local debates over HIV/AIDS

##### **Debates over pre-marriage testing**

As discussed in the previous chapter, various stakeholders in the Gurage Zone are involved in efforts to prevent HIV and support PHA. Currently, debates are underway locally regarding the relevance of such initiatives; these debates are between men and women, married and unmarried, and *positiboch* and *negatiboch*.

The efficacy of pre-marriage testing is a key point of argument. Although most elders believe that the two-test scheme works well, married women have argued that they are still at risk. Because married men continue to travel between their urban bases and home villages to support their families, infection after marriage remains a risk. As the result, many married women worry about becoming infected from their husbands.

Gurage elders have not discounted women's fears. They have discussed the possibility of compulsory post-marriage testing, and in September 2007, the majority of elders seemed to agree on this measure. The GPSDO published a revised version of Gurage customary law that includes the new provisions concerning pre- and post-marital HIV testing (GPSDO, 2000EC). Article 4.3 of the revised customary law provides that a young couple should be tested twice before marriage and that a married couple should be tested again after they have lived apart for some time (GPSDO, 2000EC: 12-13).

However, I was told by some Gurage males that they are skeptical about the "effectiveness" of post-marital testing. They expressed doubt that married men could be convinced to get tested. On the other hand, Meseret considers post-marriage testing to be essential. She told me about some tactics a woman can use to convince, or even force, her husband to get tested. For the Gurage, pre-marital testing is easier to enforce, because elders have the authority to recognize marriage. If a young couple refuses to be tested, they cannot get married. Elders do have the authority to order a divorce, but a woman wanting her husband to be tested might not want a divorce. Therefore, Meseret considers it better for a woman to try tactics to get her husband tested before consulting the elders.

##### **"Cultivate the backyard of your neighbor"**

The debate over the effectiveness of pre- and post-marriage tests has engaged both rural and urban Gurage. Concern has also been raised about the livelihoods of PHA in rural Gurage villages. HIV/AIDS results in household poverty in many ways, as the disease deprives households of the most productive members, who are also the sexually active members. Debility or death of household workers makes it difficult to maintain ensete

cultivation. Intensive labor is needed during the ensete transplanting period in December and January, when households require several men to transplant dozens of ensete that have grown to heights of several meters. The household may also lose the cash income men earn working in urban businesses. Without cash income, obtaining regular treatment is difficult for rural Gurage with HIV. Although ART is provided free of cost at health institutions, some PHA cannot afford the transportation to get to the clinics. In addition, the number of orphans who have lost parents to AIDS is rising in the Gurage Zone.

Bekkele Gebremichael is a national parliament member from the Ezha district of the Gurage Zone. He was one of the leaders of the GPSDO and became a candidate for an opposition party in the national election in 2005. He is now serving his first term, which lasts until 2010. He visits his constituency regularly, meets with local elders, and exchanges ideas on various issues, including HIV/AIDS. One of his and the elders' concerns is how to support local households affected by HIV/AIDS. They have agreed that the key to supporting affected households is to provide them with agricultural labor, particularly to transplant ensete. Elders are now asking the villagers to "cultivate the backyards of their neighbors" who are affected by HIV/AIDS. Labor exchange is a common agricultural practice among the Gurage. Several neighboring households may form a "gyez," the local term for labor-exchange associations. Adult male members of the households work together until they finish transplanting ensete in the backyards of all member households.

However, a Gurage woman with HIV/AIDS told me that her neighbor might be willing to cultivate her backyard several times, but not forever. *Gyez* is basically a system for exchange of labor, not for endowment of labor. Every household in a *gyez* is expected to provide the same amount of labor. Otherwise, a household would have to buy labor, that is, hire people to cultivate the backyard for cash payment. Although some elders are working hard to convince villagers to support their neighbors with HIV/AIDS, it is too early to judge at this time whether or not the *gyez* system works as a sustainable local safety net for PHA.

Despite efforts by various agents, limited local and international resources have been mobilized to support PHA in the Gurage Zone. According to Meseret, the PHA association she leads has a very weak financial base. Most of her staff devote their time and labor without payment. However, local residents tend to believe that her association receives vast amounts of financial and material aid from international donors. Such misunderstanding is partly understandable, as ordinary Ethiopians hear on the radio that international donors make multi-million-dollar donations to fight HIV/AIDS in their

country.

Meseret knows that members of local government and international NGOs expect that she will work to empower her fellow patients by helping to create and find job opportunities. She has been trying hard to play her role. However, in my conversation with her, I had an impression that she was more interested in something else. She seemed more interested in telling the other women (infected or uninfected) how to negotiate the situation with their husbands and with the elders. Providing them with tactics to convince their husbands get tested is an example. Of course the real challenge comes when a woman finds out that her husband is actually infected. Meseret told me a story of a woman living in a rural village who noticed that her husband had started to use condoms after his return from Addis Abeba. She asked him to get tested and he agreed. When he was found to be HIV positive, local elders recommended that she divorce him. However, she told the elders she would not. She said that she had recognized that her husband was infected because he was using a condom, and that he was doing so because he cared about her life. Thus she made the choice to stay with her husband on the condition that he was concerned about her life. Meseret raised this case not to tell me that a Gurage woman is always expected to take care of her infected husband, but to show the choices that women have and the conditions under which such choices are made.

## **5. Discussion: infected and uninfected Gurage people**

The pre- and post-marital testing campaign promoted by traditional Gurage leaders is an interesting example of a community-based HIV/AIDS initiative. Some have wondered about the effectiveness of post-marriage testing and whether married men will undergo testing. Others may question the initiative's political relevance, particularly in relation to democratic ideas. This is certainly a case in which democracy and sustainability seem to conflict with each other.

However, prevention of infection is of primary importance in rural Ethiopia, where resources for HIV treatment are limited. Although the situation has improved dramatically since 2005, when the Ethiopian government began providing ART free of charge, not every infected person is receiving proper treatment for various reasons, including lack of cash to travel to treatment centers. Effective programs for prevention are, therefore, of primary importance in rural Ethiopian society.

Some may argue that the prevention initiative will be more democratic if it promotes

voluntary testing based on the decisions of individuals, rather than compulsory pre-marriage testing enforced by the elders. However, the idea of voluntary testing is somewhat tricky. Infectious diseases do not only affect the lives of individuals who are infected, but also the sustainability of the affected community. This is particularly true for HIV, which is often transmitted through reproductive activities. If a community fails to convince its members to be tested, it might suffer grave consequences. In addition, even under a voluntary program, it would be difficult to judge whether a person took the test voluntarily, because there are ways to force others to get tested while pretending that one did so voluntarily.

What really matters in this issue is under what condition people are asked to get tested rather than whether they do so voluntarily or not. One such condition seems to be whether they will have access to resources to support their livelihoods if they are HIV positive. In this regard, ensuring access to proper treatment is one of the most important conditions. Ensuring income for households affected by HIV/AIDS is also an important condition, although popular income-generation schemes promoted by various aid agencies seem to have limited potential. The “cultivate the backyards of your neighbors” initiative promoted by some Gurage elders is interesting, as it is aimed at meeting the most compelling need of rural Gurage households affected by HIV/AIDS, namely agricultural labor. To work, this program requires active community involvement, and more effort may be required to establish this practice as a sustainable local safety net for PHA.

Whereas some elders have focused on agricultural labor, Meseret focuses on another aspect of community involvement. Through her own experience and through her conversations with other women (infected or uninfected), she has been thinking about the conditions under which the infected and the uninfected may (or may not) live together. Sharing experiences of negotiating such conditions seems to be an essential element in seeking democracy and sustainability for communities affected by HIV/AIDS.



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