

***A Rapid Assessment of Nutritional Status and Food Security
for Victims of Gender-Based Violence Living with HIV/AIDS***

When gender-based violence is compounded by HIV/AIDS and poverty, the impact on the lives of women, their families, communities and on the nation at large, is devastating. In this report, African Rights looks at the inter-connections between women's human rights, violence against women and women's health in the context of Rwanda. The findings highlight the extent to which food security is an essential weapon in fighting this assault upon the health and human rights of women. It makes a strong argument for greater attention to nutrition and food security as the most basic tools in helping those HIV positive women, who have endured violence, in regaining their health, dignity and autonomy. This research paper was supported by UNIFEM as an integral part of its 2005 campaign to End Violence Against Women. The 2005 theme, "For the Health of Women, for the Health of the World" is a timely reminder of the grievous toll that violence against women inflicts on society as a whole. The findings were discussed at a meeting in Kigali on 2 March organized jointly by UNIFEM and the Ministry of Health. It was attended by government officials working in the health sector, international agencies and NGOs and women's organizations. The recommendations which emerged from the meeting have been incorporated in the paper.

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ACRONYMS

ARV	Anti Retroviral
ATDTP	Agricultural Technology Development Transfer Project
BMI	Body Mass Index
CIAT	International Centre for Tropical Agriculture
CNLS	National Commission to Fight AIDS
GBV	Gender Based Violence
GFL	Gift for Life
ICAP	International Centre for AIDS Care and Treatment Programmes
MOH	Ministry of Health
PLWHA	People Living with HIV/AIDS
VCT	Voluntary Counselling and Testing
UNIFEM	United Nations Development Fund for Women
TRAC	Treatment and Research AIDS Centre
WFP	World Food Programme
WLWHA	Women Living with HIV/AIDS

OVERVIEW

Gender-Based Violence (GBV) against women, who are the focus of this report, is traumatic to the body, the mind and the spirit. It can prevent a woman from being a fully active participant in her family, community and in the process of national development. Gender-Based Violence has also been a critical factor in elevating the prevalence of HIV/AIDS in women. For large numbers of women living with HIV/AIDS in Rwanda, the burden of the disease is made much worse by the lack of adequate nutrition and healthcare.

In December 2005, UNAIDS estimated that 250,000 people are living with HIV/AIDS (PLWHA) across the country, 130,000 of them women.¹ In the same month, a Demographic and Health Survey, published by the Ministry of Finance and Economic Planning, in collaboration with the Ministry of Health, USAID, CNLS/MAP, UNICEF, UNFPA and other partners indicated that “in Rwanda, 3% of the people, are people living with HIV/AIDS. The survey also indicates that women are more infected than men, 3.6% of women are infected with the HIV/AIDS virus, and 2.3 % of men are infected with the HIV/AIDS virus.” A recent UNAIDS press release suggests that the prevalence rates among women aged between 15-24 may be as much as five times higher than those for men in the same age range.

One of the major consequences of GBV is that it has resulted in many women contracting HIV. This compromises women’s health and becomes an obstacle to food production or procurement and hence to good nutrition and food security. HIV/AIDS increases vulnerability and negatively impacts on food security for the entire household, particularly in Rwanda where households depend primarily on women’s labour for food production and preparation, animal tending, crop planting and harvesting. The infections that can accompany HIV infection leave those who suffer from the disease weak and unable to care for themselves and their families.

The impediments to accessing good nutrition and food security for PLWHA and their families are numerous. For women, in addition to the trauma of GBV, poverty, ill health, lack of skills, stigma, neglect and abandonment, are among the impediments to women’s ability to become full, productive members of their communities and to procure food for themselves and their families. Anxiety about the future of their children is a constant preoccupation.

Sr. Spéciose, a psychosocial counsellor for “women living with HIV/AIDS”, PLWHA, and victims of GBV at Butare Teaching Hospital, is in daily contact with women victims of violence who have contracted HIV. She has counselled numerous traumatized women, many living in abject poverty, including underage girls who have eventually agreed to voluntary HIV testing and later to ARV treatment. In addition, she provides information on nutrition and how to join associations in order to take advantage of income generating opportunities available in the province.

¹ UNAIDS, AIDS Epidemic Update, December 2005.

In her daily encounter with victims of GBV, Sr. Spéciose has further observed the following

- In the majority of cases, GBV victims do not report rape or other domestic violence related cases to the police unless they are seriously injured. The culture of silence regarding sexual matters and/or domestic violence is deeply rooted in Rwandese society. By the time the survivors make up their minds to come to the clinic, it is too late to take advantage of early drug intervention, which may prevent HIV transmission.
- An increase in cases of defilement of children. At the time, she was helping a young girl who had been gang-raped and who had refused to communicate with anyone, including her family. Sr. Spéciose believes that many young girls are abused by their immediate families, but remain too scared to report them. Many jeopardize their future by dropping out of school. This abuse has led to a tendency for these girls to marry young, after which they may well find themselves again in abusive relationships.
- The manifestations of GBV have long-term consequences. Many GBV victims become prostitutes and of these many have contracted HIV. Yet many more fall pregnant and have no means to care for themselves and their children.

Confronted with the onslaught of HIV/AIDS, women and their families struggle to meet their most basic caloric and nutritional needs. Balanced nutrition is a fundamental component in the fight against HIV/AIDS, in strengthening the body's immune system and warding off the diseases to which WLWHA are susceptible. The Rwandan government has made Anti Retroviral (ARV) treatment available free of charge, however, in an environment where gender inequalities, poverty and stigma are challenges women living with AIDS face on a daily basis, it is extremely tough to adhere to the strict regimen associated with ARV treatment, even when the drugs are free. In particular, significant obstacles remain in ensuring adequate food security, which is necessary to complement the treatment.

It is especially difficult for people living in grinding poverty to maximize the benefits of ARV treatment. Without proper nutrition, the adverse side effects of these drugs can reverse the gains otherwise achieved. According to community health workers, many women decide that the side effects such as physical weakness and an increased appetite when the drugs are taken on an empty stomach, are too much to bear. As a result, they stop taking the drugs even where they are freely available. Poor nutrition further offsets the benefits of ARV treatment by leaving the body vulnerable to opportunistic diseases. Hungry and ill, women are left unable to farm and perform other economic activities critical for their wellbeing and that of their families. The inability of women to fend for themselves has serious implications for household food security, which in Rwanda depends primarily on women's labour.

Interviews with women on ARVs, like Laetitia² in Kigoma, Gitarama, revealed the difference that food makes in their ability to withstand the effects of the drugs.

ARVs have boosted my CD4 count. However, I have developed a big appetite and I feel like eating all the time. The problem I face now is that my eyes have turned red and I can't see properly during the day. My legs swell from time to time. I also experience a tingling feeling in my feet. These symptoms are alleviated whenever I have something substantial to eat.

Nathalie in Butare was started on ARVs in April 2005 when her CD4 count was 95. (She had not had her CD4 count checked again). She is, she said, careful to take her ARVs "as directed by the health worker."

But we feel very hungry. If you don't eat something as soon as you begin to feel hungry, the only choice is to sleep off the hunger. Like a child, I feel completely helpless when I'm hungry.

Lucie in Kigoma also tries to stave off hunger through sleep.

ARVs have helped, but they have also aggravated our health. We are always hungry. All you can do is to try and sleep it off.

For women like Esther in Butare, who have become wholly dependent on a relative, the combination of constant hunger and helplessness is debilitating.

I started ARVs when my CD count was 200. It went up to 340 after I started taking the drugs. Sometimes we have porridge in the morning and then nothing the rest of the day. These drugs make you feel weak if you don't eat, but it's difficult to get what you need. When I eat, I feel better and strong and contribute to household chores.

Rose in Kigali is confused about ARVs.

ARVs seem to make me feel worse, although my CD4 count is high. My eyes are always red and I can't see when there is a lot of light. I pray that I don't become blind. My legs are swollen and I feel like there are pins underneath my feet. If I had enough food to eat I would stop taking ARVs, but we are told that once you start you must continue otherwise you die. Is this true?

Governments, health practitioners, development specialists and development agencies have acknowledged the importance of good nutrition and food security in the fight against HIV/AIDS. The donor community has provided technical assistance in research on nutrition and food security. Almost every ministry of health in Africa, including that of Rwanda, boasts a copy of guidelines for nutritional care and support for PLWHA. Information sheets illustrating the types of foods required for the body to function properly have also been developed for health practitioners, programme managers and home-based care givers and are used to educate PLWHA, particularly those engaging with the ARV treatment.

² Pseudonyms have been used for all the women who were interviewed for this report.

However, it is becoming increasingly clear that the issue is not ignorance about the benefits of a well-rounded diet. The women interviewed for this assessment were well aware of the importance of good nutrition. The problem, which was reiterated again and again, was the lack of access to the necessary food. Like so many others, Christine in Kigoma questioned the value of being given information about nutrition when she could not afford the food itself.

They show us pictures of all the food we would love to eat, but we cannot eat pictures. We have to have the means to purchase or produce the food. Visit us in our homes and see how we live. Then you will understand.

Lucie in Kigoma used to work as a casual labourer but had to stop when she no longer had the strength.

I eat one meal a day. When I do get some food, I use it very sparingly. I know about good nutrition, but in my situation the knowledge is not helpful. If you manage to eat a banana today, tomorrow you will not get it. Even if you get it, you have to think of your child first.

Nathalie, a 35-year old widow in Butare whose husband died of AIDS, agrees.

We were taught about good nutrition, but we don't have the money to buy all the right food. We have to survive on whatever is available.

What turned Laetitia's life around is not the lessons she was taught about nutrition at her local health centre, but the new farming techniques she learned which have enabled her to grow new and more nutritious food.

The health centre teaches those of us on ARVs about nutrition, but we are can't actually get all the nutritious foods we need to eat. People from ISAR taught me farming skills and provided me with a variety of new seeds: potatoes, soya beans, dodo, cassava, sweet potatoes, *isogi* and kale. These are indigenous vegetables and are pest resistant. They also require less input and thrive on organic fertilizers. I have planted some of the vegetable seeds distributed by ISAR. Some are doing well.

Women's testimonies reveal that many families cannot afford two meals a day, and sometimes go for a day or more without food.

African Rights does not underestimate the practical challenges involved in providing adequate food to the large numbers of WLWHA, especially against a backdrop of widespread poverty. Aware that many of the women they look after have migrated to Kigali from the provinces, Dr Mpfizi of the Kicukiro health centre in Kigali spoke of the economic reality that poor women in Kigali face.

The majority of the women who come to our clinic are very poor. Many have lost the support system they used to enjoy in their homes in the districts. Kigali is very harsh for these women.

Immaculée, aged 26, found herself a single parent when her husband, a policeman, walked out when their young daughter was diagnosed as positive. She lives in Kigali and said she "doesn't receive any food support."

Another concern is the risk of creating dependency on the part of recipients, thus making such aid unsustainable. Nevertheless, a number of organizations currently run programmes around the country, which provide food support and skills development to PLWHA, the majority of whom are women. In Rwanda these include the Agricultural Technology Development Transfer Project, the World Food Programme, CARE International and African Rights itself, through its newly-established project, *Gift for Life*. Despite the valuable contribution which these groups are making, much more needs to be done. Given the resources, energy and dedication which are being channelled towards the fight against HIV/AIDS, ensuring that WLWHA receive adequate food to slow the progression of the disease and to achieve a sustainable means of producing and or procuring food, is an essential investment without which the gains against HIV/AIDS will be short-lived.

Secondly, the argument in favour of food is an integral part of a broader strategy, rather than about the provision of food as an isolated gesture that is an end in itself. The women we spoke with see food as a necessary first step on the road to recovery. Their goals are the means to attain a degree of self-sufficiency, either by learning new skills or engaging in productive work.

Immaculée's priority is gaining a measure of economic independence. Buying the cheapest food she can find at the market, she has not started ARVs and gets by on one meal a day in order to make sure that her young daughter can supplement her ARVs with three meals a day. Determined and feeling strong, she nevertheless is anxious about the time when she "will no longer have the energy to look after my children."

Food support would be good, but more than that we have to learn some skills that will give us a monthly income.

A number of HIV positive women who have experienced some form of GBV were randomly selected in various provinces of Rwanda. Through semi-structured interviews, they provided information about their overall health and well-being. Professionals working in the sectors of HIV/AIDS, nutrition and food security, and GBV, were also interviewed. It is our hope that a more detailed study, based on clinical nutritional status indicators, can be initiated in the near future.

Obstacles To Good Nutrition And Food Security For PLWHA

Lessons learnt in the course of HIV/AIDS treatment indicate that with correct nutrition, which includes a balanced diet and affordable vitamin supplements, it is possible to maintain health almost indefinitely if one starts early enough and adheres consistently to the regime.³ Caught at an early stage, nutrition, together with treatment of opportunistic infections, can keep a person in reasonable health and allow them to remain in employment. In addition, good nutrition supports the immune system when undergoing pharmaceutical treatment and serves to minimize its side effects.

When the women who were interviewed first visited clinics for ARV treatment, they received information regarding nutrition and what they should eat to remain healthy. Many organizations, which offer assistance to victims of GBV, also teach the women about nutrition. The women we met were able to cite the nutritional requirements for PLWHA: energy-giving foods (carbohydrates): sweet potatoes, Irish potatoes, rice, yams sorghum, wheat, maize and cassava (*ugali*); body-building (proteins): beans, peas, groundnuts, meat, chicken, milk, yoghurt, fish and eggs; protective foods: papayas, pineapples, dodo, cabbage, carrots, cassava leaves. Therefore, it seems that the problem is not lack of knowledge, but a lack of access to these foods.

The Impact of Gender-Based Violence

Violence against women is a pervasive human rights violation, public health crisis, and an obstacle to development. In times of war, women bear the brunt of the conflict when they become targets of violence, particularly rape. In times of peace, they continue to endure domestic and other forms of violence associated with their powerlessness within family structures, lack of education and poverty.

Sr. Spéciose is a psychosocial counsellor at Butare Teaching Hospital. She deals with the consequences of GBV on a daily basis which, as she underlined, are not always evident, but are nonetheless very real and undermine a victim's capacity to survive their ordeal, and to face the reality of HIV/AIDS. She identified the following characteristics as recurring experiences of GBV faced by women of all ages.

- Lack of confidence and self-esteem;
- A tendency to take the blame for the rape;
- A bleak outlook on life and a sense of hopelessness about the future;
- Young victims feel that they are neither single women nor married because their bodies have been violated;
- They feel ostracised from society and would have preferred to remain silent about their predicament had it not been for the need to test for HIV/AIDS;
- A fear of men, and often a hatred of men;
- Resort to prostitution;
- Susceptibility to suicide attempts due to stigma and social isolation, including rejection by spouses, family and friends etc.

³Nutrition and HIV Infection: Experience in Zimbabwe – Interview with Lynde Francis, available from www.thebody.com/atn/355/interview.html, accessed: 10/11/2005.

Sr. Spéciose commented that the risk of violence and sexual abuse is high among girls orphaned by AIDS, many of whom face a heightened sense of hopelessness along with a lack of emotional and financial support. According to the Rwandan Government's 2002 Census, "Rwanda has one of the highest proportion of orphans in Sub-Saharan Africa, where 30% or more of all children under 18 were orphaned. Out of 1.3million orphans from all causes, 160,000 were orphaned because their parents died of AIDS-related causes."⁴ Sister Spéciose added that many of the orphaned young girls resort to prostitution, which further erodes their self-esteem and prevents them from continuing with their education.

Depression, suffered by many GBV victims, can be debilitating. It can weaken the already compromised immune system if they are living with HIV/AIDS, further undermining the ability of women to become productive. However, depression as an illness is not yet fully comprehended and/or acknowledged in Rwanda, as is true in many African countries.

By draining women of energy and a positive outlook, the psychological impact of GBV and HIV/AIDS makes it harder for women to find economic solutions to their plight. For example, many of them are not in a position to take advantage of poverty reduction initiatives such as the recent proliferation of micro-financing schemes in the provinces, which would greatly improve their health and general well-being.

Many WLWHA possess limited formal education and the majority are unemployed. Some of the women interviewed do not own property and have to rent their accommodation. Often, as a consequence of the debilitating effects of HIV/AIDS, they are unable to pay rent and remain perpetually in arrears. Many of the women, particularly those living in Kigali city, require access to cash to survive as they do not have land to subsist on. Everything they need must be purchased, including water. African Rights found that many of those who have some semblance of property were forced to sell it in order to obtain a supply of cash. This is an unsustainable solution, which only serves to impoverish them further. The daily realities of WLWHA include a real lack of food and adequate nutrition, a lack of clean water, and the absence of transportation to the clinic or hospital. They also include the lack of a means to keep themselves and their families clothed, and find themselves unable to keep their children in school. In addition, many women are also caring for HIV/AIDS orphans, adding an extra burden to already untenable living situations.

⁴ As cited in UNAIDS Press Release: http://data.unaids.org/pub/PressRelease/2006/PR-Rwanda-20060214_en.pdf, accessed 02/02/2006.

Women Within the Family: A Sense of Powerlessness

Gender-based violence has broad implications for domestic relations. Some of the women interviewed became HIV positive as a result of rape. Other women did not experience physical violence upon them, but were rather intimidated into sexual relations with infected partners. Women, particularly those married, are aware of the possibility of being infected as a consequence of sexual but have little or no control over abstinence or condom use at home or the activity of their husbands or partners outside the home.

Ancille is 35-year old widow living in Gitarama. She has five children. She had become uneasy about her husband's health and avoided having sex with him for some time. As a result, her husband started accusing her of extra-marital relations, became very abusive and started coercing her into sex. She succumbed when she found the threats unbearable, but took the precaution of testing for HIV when her husband became seriously ill. He died of an AIDS-related illness in 2003.

As women we have no power, we cannot refuse our men or insist on using a condom. Our men continue to spread HIV to unsuspecting young women.

When Espérance's husband, a soldier, learned that he was positive, he became a heavy drinker, adding to her fears and her woes.

Whenever he started to drink a lot, he would assault me and my three children. We were terrified of him because he had a gun. One night, I ran away with my children.

Alphonsine in Kigali had little choice but to succumb to the pressure from a male relative. Orphaned at 15, she moved from one household to another.

I became HIV+ when one of the male relatives forced himself on me. It went on for a long time until I became pregnant. I had a miscarriage. The man who infected me has refused to go for a test, and now has another girlfriend.

Lucie discovered that her HIV status after her youngest child died.

I had three miscarriages before my child passed away. I was co-habiting with the father of my children who used to travel to Kigali a lot and he would threaten me with violence every time I had a miscarriage. One day he packed his things and left for Kigali. I never saw him again. I hear that he is married to another woman.

When Rose's husband found out that he was positive, he turned his rage on his wife.

He started harassing me and would also become violent.

The marks which are still evident on her back and legs are a reminder of what she endured. She eventually decided to leave him, and he died in 2001.

Marie in Kigali lost her husband to AIDS over a decade ago. Though positive herself, she is just grateful that her five children tested negative. But she worries about their future.

I fear for my children, especially the girls. Men are spreading this disease, and there is nothing we can do to stop them.

Berthilde in Kigoma, Gitarama, wants the government “to imprison all those men who are spreading AIDS to their wives.”

They bring this deadly disease to our children and to us.

Her bitterness is easy to understand.

My husband died 3 years ago of AIDS. He knew about his HIV status, but would not disclose it and refused to test. He became abusive and would disappear from the house for days. It was really too late for me to do anything. I was confirmed as positive when my child died at the age of two. I wanted to commit suicide, but kept hoping that the child might get better.

Berthilde now lives with her elderly parents. Her thoughts are focused on what will happen to her remaining child.

The child is negative. I am looking for my late husband’s sister so that she can take care of my child when I am gone.

For most Africans, the extended family is their only form of social security. Problematically, women often find themselves especially exposed and isolated after the death of their husbands, and sometimes are left not only waging a struggle to survive, but facing outright hostility from in-laws. Athanasie’s husband died of an AIDS-related illness in 2002 and left her with three children. In addition, she looks after two AIDS orphans. She believes that the husband was aware of his HIV status and infected her deliberately. He used to fall sick, she said, but whenever he felt better he would become very violent and beat her. She lives in a dilapidated house. Thieves have broken into her house on a number of occasions and she feels defenceless. She owns a smallholding but does not have the energy to put it to productive use. If she had money, she would employ a labourer. The family eats two meals a day, porridge (*igikoma*) for breakfast and dinner of sweet potatoes or cassava and beans. CARE International distributes food rations, which help the family when the situation becomes desperate. Instead of finding protection and a safety net from her in-laws, Athanasie said she found abuse, especially from her mother-in-law who is determined to evict her from her house. She worries about the lack of security for herself and her children and what will happen to the children after she dies. She would be happier if she built her own house and had something to leave to her children.

It is not helpful to always speak to us women about violence when the men who commit it feel free to abuse us with impunity. A lot more needs to be done to bring the men to their senses. They are killing us!

When Alexia’s husband died of AIDS in 2002, she was left with five children—three of her own and two orphans—as well as a dilapidated house.

The state of the house makes me and the children feel very much on edge. People sometimes threaten me so that I can leave my house and return to my village but I will not go.

Her most determined opponent is her brother-in-law.

I own a small piece of land, which I don't have the energy to dig anymore. My brother-in-law comes here to abuse me and threatens to kill me. He wants to take the plot of land. He accuses me of killing his brother with AIDS. I keep quiet because I'm in such a weak position.

Since her husband died, Espérance and her children have lived with a relative, for which they pay a heavy price.

I don't have a job at the moment and this is my biggest problem. I sell an assortment of goods, but they don't fetch enough money for our needs. Besides, we have to contribute to our upkeep every month. Our host demands an unreasonable amount of money from us. This makes me very unhappy. Sometimes I spend two weeks without uttering a word and my children become very anxious. My daughter wants to leave school to stay with me, but I can't allow that. What about her future?

I'm taking ARVs but they don't help much because my body is perpetually weak. I don't eat enough. I keep some of the food I get for my children. I sleep away the hunger.

No, I didn't receive any food support. But even if I did, the family I live with would take it away. I get severe headaches whenever I feel hungry and my back itches all the time. The doctors can't help me. They always encourage us to continue with ARVS, whether we are sick or not.

One of the few male interviewees was quite forthright about his decision to hide his HIV positive status from his wife.

Frédéric is partially paralysed and appears frail. He lives with his two children and his wife who is also HIV positive. He showed little remorse about the fact that he had knowingly infected his wife with the disease. She is a casual labourer and also sells an assortment of goods for extra cash and works the land. In all practicalities, she is the breadwinner. Most of the money goes to school fees, which leaves very little for food consumption at home.

I knew I was HIV positive in 1995 but I couldn't tell my wife. At that time you couldn't really, could you? People would have ostracized us. If I had used a condom it would have been obvious that I was involved with other women. I started taking ARVs in September 2004 and my CD4 count has gone up. However, grinding poverty is aggravating our health.

Unemployment

Many of the women we spoke with are unable to maintain their jobs once they become ill. They had been able to buy food, keep abreast of the school fees for their children, pay medical expenses and provide other needs. However, without a regular income, many are no longer able to afford basic needs despite having access to free ARV treatment.

Without sustenance and energy, these women's lives are virtually paralysed. They cannot engage in meaningful income generating activities to sustain themselves and their families, nor can they grow their own food to subsist on. This creates a perpetual cycle of food insecurity and poverty.

Odette used to work for the National University of Rwanda in Butare but lost her job due to constant ill health and absence from work. While working she managed to purchase some land and started building a house with the help of a local leader who provided some materials.

I have to live in an unfinished house because I have no means to complete it. I also can no longer grow my own food because I have no strength to work the land. If it weren't for my sister who works as a casual labourer on a neighbouring farm, I would starve.

Esther in Butare, who has a 13-year-old child, was forced by ill-health to move in with her sister when she could no longer cope on her own.

I'm not working. How can I work when I am sick like this? My sister has been my strength. If she wasn't there I would be gone by now.

Overcome by emotion, Esther was unable to continue talking and stopped for a while. Trembling and scratching herself all over, she was evidently in very poor health physically, and was also very depressed.

My sister works on the neighbouring farm to support me and my child. I used to work before this illness. I was very strong. But now here I am ...

All Charlotte says she wants, is a job. She told *African Rights* that she had, "a good job with the government" but that changed after she fell ill.

They took a blood and I tested HIV positive. I became very depressed and stayed in the house a lot. My boyfriend stopped visiting me and it made me more depressed. I contemplated suicide, but a friend of mine persuaded me to take ARVs. My CD4 count has improved, but I can't afford a decent meal. I can't get my job back and I'm afraid of meeting my former colleagues. I no longer look as good as I used to. I wish I could go to a place far away and find a job. Without work I can't sustain myself. My relatives no longer visit me because I don't have money. What is there left for me now?

No, I have never received food support. It's better to get a job and to have money to buy your own food. I used to eat the best food, but now I can't even afford a proper meal. This makes me feel worthless.

My boyfriend found another girl friend. She is the next one to die.

All I'm asking you to do is to help me find me a job, but not in government please because everyone knows me.

Poor Diet, Hunger and Ill-Health

All of the women interviewed by African Rights are on ARV treatment provided free of charge at Government clinics. Those on the drugs, without exception, complained of perpetual hunger and lack of energy. Consequently, these women lose the capacity to earn a living and to grow food for themselves and their families. Admittedly, the ARV treatment has increased their CD4 count since commencing the regime, but the pervasiveness of hunger is reversing this trend.

The majority of the women interviewed are able to have a meal in the morning, generally porridge (*igikoma*). Depending on the availability of food, they have lunch or dinner, but rarely both, preferring to eat the evening meal to ensure they can at least fall asleep. They mostly eat sweet potatoes or *ugali* (cassava bread). When there is a little extra money, they may purchase rice, dried fish, or dry beans, but this is rare. Those women who own smallholdings grow their own food during the planting season. As a result of illness they have increasingly resorted to growing certain foods, predominantly carbohydrates, which are less labour-intensive and tend to stave off hunger. However, they are low in protein and thus nutritionally inadequate. Those protective foods such as fruits and vegetables, which are rich in vitamins and minerals and critical in strengthening the immune system, are rarely grown because they are labour-intensive, involving constant weeding and pest control. These foods are normally purchased from the market but remain unaffordable to impoverished families.

Angélique, a fairly young woman, was visibly hungry with red eyes and dry lips, and appeared faint. Her skin has dark patches. She could not afford 300 francs for transport and normally walks to the clinic to fetch her drugs and does not always have lunch or dinner on those days. This is the case for many of the women who can rarely afford the 200-300 francs for transport to the health centre for their dose of anti-retroviral drugs.

I had to walk two and half hours to come here hoping that I will get some help. I don't think I will have anything to eat tonight either

Alexia, who no longer has the strength to dig her land, finds her situation impossible to comprehend.

I eat once a day. My children go hungry sometimes, but they are getting used to it. This kills me because I used to be energetic. I used to grow potatoes and the harvest was always good. I would sell some and keep some for the family. My family used to be in good health. And then the ARVs drain us. I get headaches and feel very hungry, but where can I find food?

Rose said she used to own land, but was forced to relinquish it.

I had no energy to work it. I used to grow beans, vegetables, potatoes, but now vegetables have become difficult to grow. They require pesticide and they are expensive. I'm not employed as such, but sometimes I get casual work, peeling cassava for sale. The man who employs me sometimes gives me cassava free of charge.

Life becomes meaningless when you depend on casual work. Sometimes I don't eat properly for two days. I get tired of cassava. I would love to have porridge everyday, but I don't have the money. My energy is really low. It takes me two hours to get to the clinic every Tuesday. By the time I get back, I'm too hungry to do anything, so I just go to bed. Hunger sends me to sleep but the following day I feel worse and I just continue sleeping.

For Eugénie in Butare, HIV/AIDS has reduced her to a state where she must either beg for food, or try to forget her hunger by seeking solace in sleep. What matters most to her is the fate of her two sons, and having a place to call her own.

I have no place to call my own; I have no relatives and I have AIDS instead of a life. I have two sons. I rent the house I live in. I have not paid rent in the last four months. I feel embarrassed when I see the landlord. I can't even afford the 300 francs to come here to the University clinic. I started walking at 6:30 a.m. so that I can be here at 3:00 p.m.

I eat one meal a day, in the evening. I give my children porridge in the morning and take whatever is left over. ARVs make me hungry. If I had food I would eat even five times a day.

I used to grow potatoes and vegetables near the house, but I can't continue. I have been very sick lately. The land is fallow and it has been for a long time. I was hospitalized from September 2004 to April 2005 which made my situation worse. I'm poorer than I was before. What is degrading is not having food for my children and for myself. A person who begs for food loses her dignity. Sometimes I sleep off hunger rather than ask for help. But sometimes I can't fall asleep when I go to bed hungry and I stay awake until the morning. I try to sell cassava flour to get some cash for other essentials, but when we are hungry we consume it. It's also degrading to borrow clothes when you want to go somewhere. My clothes are in tatters. Our lives have completely changed. We are totally messed up. But I worry about my children.

What I would ask for is a house of my own. Even if I starve, I will do so in my house with my children.

Supporting HIV/AIDS Initiatives The Government's Input

The Rwandan government is currently scaling up its HIV/AIDS efforts, through a multi-sectoral approach that includes bodies such as the National Commission to Fight AIDS and several ministries, in conjunction to working with UN agencies such as WHO, UNICEF, UNFP, UNAIDS and WFP and a broad spectrum of local and international NGOs⁵. Unfortunately, most efforts fail to prioritize a significant nutritional component in their treatment and support for PLWHA.

Rwanda has a national policy on nutrition as part the health sector policy framework. This is in line with the Government's policy on global development as defined in Vision 2020 and in the Strategy Paper on Poverty Reduction.⁶ Malnutrition is a serious issue in Rwanda⁷ and has been aggravated by the AIDS pandemic.

In an interview with *African Rights*, Dr Ben Karenzi, the Secretary General of the Ministry of Health (MOH), emphasized the government's understanding of the importance of nutrition in the fight against HIV/AIDS, pointing out that it had developed a nutrition guide for PLWHA, through the Treatment and Research AIDS Centre (TRAC) established in 2002. He understands that the adverse side effects of the ARV treatment further weaken those whose immune systems are already compromised and therefore he is supportive of initiatives that provide food support to those in need. However, the test for the government is to boost its nutrition programmes and to ensure proper coordination and long-term sustainability of its current food support programmes, which should ultimately empower WLWHA. To this end, the government's AIDS coordinating agency, the National Commission to Fight AIDS (CNLS), which was established in 2001, is tasked with assisting PLWHA to access funds for viable income generating activities.

The Nutrition Unit within the Ministry of Health was set up to coordinate the implementation of policy and strategies on nutrition at the national level. The unit has several components, one of which is Nutrition and HIV/AIDS that deals with the execution of nutrition rehabilitation and nutritional support for PLWHA. If fully implemented in practice, the recently developed National Guidelines for Nutritional Care and Support for PLWHA would go a long way to meet these goals. Alphonsine Nyirahabineza, a nutritionist working in the Nutrition Unit, echoed the Secretary General's views that it is necessary to provide food to PLWHA from poor households, with the eventual aim of empowering people through sustainable activities. She also reiterated the Unit's support for NGO and AIDS service programme initiatives in this endeavour. However, the Unit is also aware that these initiatives are limited in scope and coverage and that a great deal more could be done.

The Nutrition Unit works very closely with WFP, one of the government's partners in mitigating the impact of HIV/AIDS on needy families. WFP has been providing

⁵ WHO "Summary CP for HIV/AIDS Treatment Scale-up 2005"
http://www.who.int/3by5/support/june2005_rwa.pdf, accessed: 17.02.06.

⁶ www.worldbank.org.

⁷ Republic of Rwanda Ministry of Health. *National Guidelines for Nutritional Care and Support of People Living with HIV/AIDS in Rwanda*. 2005, Kigali

monthly food support to PLWHA in order to enhance their participation in life-skills vocational training, income generating activities, voluntary counselling and testing (VCT), peer support and home based care. The MOH supports this kind of assistance as it encourages self-reliance and empowers individuals.

In 2002, the CNLS assumed responsibility for implementing the National HIV/AIDS strategy and developed a national strategic framework to combat HIV/AIDS for 2002-2006, which addresses all aspects of HIV/AIDS. It is the responsibility of CNLS to coordinate the operations of its provincial and district committees. The decentralized Commission has the mandate to integrate all sectors in the national response to HIV/AIDS. J.P Ayingoma, who is in charge of community outreach programmes, spoke of some of their efforts to address the HIV/AIDS pandemic. PLWHA have been assisted in creating associations (*amashyirahamwe*) in order to access funds for income-generating activities. This initiative is intended to enable PLWHA to become productive enough to fend for themselves and their families. CNLS, through recognized agencies, such as CARE International, has disbursed funds to over 500 associations for income generating activities. To ensure the efficient and effective use of funds, an association must prove that it has the capacity to run and sustain a project in order to access the funding. For most WLWHA, particularly for those in the rural areas, their only possible point of contact for assistance and information may be through such associations, since the remote location of their homes makes access to other support difficult.

Discouragingly, the majority of the women interviewed for this assessment do not belong to any associations for a number of reasons, including ill-health, lack of self-confidence and the fact that many of the associations in the countryside are not robust enough to offer them hope for the future. One group, interviewed at Butare University Hospital, made it clear they did not want to hear about associations. One woman expressed their collective view in these terms:

We receive no assistance from any organization despite the fact that we are members of one association or another. We feel cheated because we contributed money to these associations but we get nothing in return. No money, no food, nothing. And as you can see, we people here are very poor.

Nathalie, amongst the group, has not joined any group and places her priorities elsewhere.

I don't receive any food support. I hear about it but the hospital here has not said anything about food. We have only been told about becoming part of an association in order to get assistance. But where am I going to get the 5000 francs to join one? There is not even any assurance that the association will assist you once you have paid that money. Many people have lost their money in associations. They have never received any food, no money to start a business, as they always tell us, nothing!

I would appreciate it if you could find me a place to stay. Come and see where I live with my children. Food support would also be welcome, particularly for the children. And help us to get work.

Unless the issue of under-nourishment is addressed, the chances that these women will have the capacity to run a project successfully are distant. They need to be

assisted and encouraged to join associations or to form their own. An important issue that the CNLS must tackle is how to include those women who cannot join associations due to ill health, or who are fearful of doing so because of stigma, and therefore fall through the net for government support.

While the government has created the tools and shows the willingness to work with partners on this issue, it needs to intensify and broaden its complimentary activities to accompany the ARV treatment, in order to have a significant impact on the lives of WLWHA across Rwanda.

Making a Critical Difference

The Provision of Food and the Development of Skills

The research by *African Rights* demonstrates that when WLWHA are given food support to relieve their immediate hunger and to regain their energy, they request assistance for income generating activities, and/or skills development for alternative livelihood strategies. Programmes such as the Agricultural Technology Development Transfer, Gift for Life and World Food Programme have proved beyond doubt that nutrition and food security is central to the battle against HIV/AIDS. A combination of food availability and anti-retroviral therapy can ensure that WLWHA lead a productive life, become less of a burden on their families and communities, and place less strain on the health system.

Agricultural Technology Development Transfer Project (ATDTP)

This project, sponsored by USAID, operates in the following health centres: Ruhengeri (one); Gitarama (two); Rwamagana (one); Bugesera (one) and in Gikondo and Kinyinya in Kigali. It distributes fortified sosoma to PLWHA to help them regain energy, after which they are encouraged to participate in the project. Supported by the agricultural institute, ISAR, ATDTP has reintroduced indigenous vegetable and tuberous seeds, which are well adapted to Rwanda's climate and soils and thrive on organic manure prepared by the recipients themselves. WLWHA households participate in programmes, which include training in improved soil fertility, crop diversification and the use of the improved seeds. They also receive seeds from the programme. A rural development worker responsible for ATDTP in Gitarama, Hodari Gatsimbanyi, has observed that WLWHA households have, as a result, had access to a continuous source of nutritious foods. He is optimistic about the future and added that community members who are not on the programme have shown interest and would like to access the vegetable seeds as well.

Hodari has planted some of the vegetables at the Gitarama Health Centre as a demonstration. The WLWHA are free to harvest the produce for consumption when they visit the centre. A nutritionist from the International Centre of Tropical Agriculture (CIAT) visits the health centre to demonstrate the methods of preparing the vegetables without destroying their nutritional value. In addition, Hodari distributes the seeds to the women for them to plant in their home gardens and imparts knowledge regarding nutrition while monitoring progress.

From our interviews with women in Kigoma, the impact on those who have been targeted was evident. Berthilde looks forward to the day when she can rely on her garden produce and forego food aid.

The new seeds distributed by the ISAR community worker have greatly improved our diet. These vegetables are easy to grow. Also a woman from CIAT comes around to show us how to prepare the vegetables. We used to cook vegetables for a long time, but now it takes a short time to prepare them and they taste better.

CARE International provides food support of 45 kilos of maize meal, 5 kilos of sosoma, 12 kilos of peas and 3 litres of cooking oil per month. Food from my garden is better than food aid, but I cannot refuse it.

The project started with fifty women in Gitarama and now has 90 members, all of them on anti-retroviral treatment. Before they joined the programme, many of them said they had suffered the adverse side effects of the drugs, such as extreme hunger. They were given fortified sosoma to regain their energy, after which they were encouraged to participate in the project and form associations. There has been a marked improvement in the health of the majority of participants. Women have gained weight and they are less afflicted by infections. Some of them, Hodari added, look and seem to feel healthier than the women who are not positive. In turn, the women are urged to impart the knowledge and skills to non-participants in their villages.

There have been new developments subsequent to the interview with Hodari. Donors discontinued the supply of fortified sosoma and Hodari managed to secure a long-awaited piece of land for the women to jointly grow food, including a variety of vegetables. The women have, however, received these developments with mixed feelings. Although they are happy about the additional space for cultivation, they felt that the supply of sosoma should have continued until there was sufficient food from the land to offset the period before the rains are due.

The World Food Programme (WFP)

The World Food Programme of the United Nations (WFP) provides food support to WLWHA, through well-established organizations. It enables them to participate in life-skills training, vocational training, income generating activities, voluntary counselling and testing and peer support and home-based care.

Gift for Life (GFL)

GFL is a new programme run by *African Rights* (AR) in Rwanda, which supports women who suffered various forms of sexual violence and are now living with HIV/AIDS. It was launched in 2005 in Butare and Cyangugu as a follow-up to our report, *Broken Bodies, Torn Spirits: Living with Genocide, Rape and HIV/AIDS*. The women who are assisted by AR at present were at an advanced stage of the disease when AR intervened. They had no means of livelihood for either themselves or their families. GFL began the project by purchasing food from local markets. This includes dry rations such as rice, cooking oil, sosoma, sugar, tubers, potatoes and fresh milk, fruits and vegetables. The women receive financial support for rent, transport to the health clinic when necessary, and other non-food items such as school fees for their children. The impulse behind the policy of direct service is to ensure that the women have the kind of support necessary to move them out of despair.

Several of the women have all regained their energy and are currently engaged in various income generating activities. When Triphonie was identified for the programme, she lived in a corner of a warehouse at a military base with her four children. Noisy and crowded, it was a home she shared with several other families. She had to walk some distance from there to her stall in the market, and then frequently leave the stall to go and check on her children, the youngest aged three. Since then, she has been helped to find a decent house a minute's walk from the market. Her stall is now busier because food for other *Gift for Life* participants is

purchased there and she manages it more effectively, having hired a young helper to look after her children.

Catherine used to feel “crippled” by her worries, so much so that she suffered from insomnia. The struggle to support two adopted children, and two younger siblings on a tiny salary left her with little energy and hope. She is now a much more cheerful person and describes stress as “a thing of the past”. She has recently opened a bank account.

Grâce has made improvements to the house she owns and is renting a part of it out for extra income. “Sometime I pinch myself to see if I’m really alive and sitting in my own house”, she commented.

Tatienne, who established the programme in Butare, has seen the changes in the women’s lives first-hand.

There has been a sharp drop in the frequency with which the women used to seek treatment for opportunistic infections. And for some, it has ceased altogether. Because their health has improved, the women are now occupied with plans for the future to support themselves and their children. Catherine used to cry all the time, but now she is a healthy, working woman.

Like Catherine, some of the other women in Butare have opened bank accounts and have a more optimistic outlook on life.

AR is in the process of expanding its programme to reach a greater number of WLWHA through both nutrition support and by facilitating skills training for income-generating activities, particularly in the field of agriculture.

CARE International

CARE International distributes food rations to WLWHA over a period of six months after which the women are expected to fend for themselves. A number of women interviewed have received from CARE food rations of 44 kilos of maize flour, 13 kilos of dry peas, three litres of cooking oil and five kilos of sosoma. During the six months of food support, the women observed a marked improved in their health and energy levels. The rations supplement the little food they are able to harvest from their fields. Some of the women find the temporary nature of the food rations difficult to cope with. Nonetheless, Laetitia, combining this assistance with the new vegetables she grows thanks to ATDTP, considers herself lucky

I receive food support from CARE International which is helpful and supplements my produce from the garden and whatever else I can afford to buy. To be honest, the vegetables have assisted me greatly. I don’t visit the health centre as frequently as I used to. “Look, don’t I look like a normal person?”

The Basic Lifeline: Individual and Family Support Structures

WLWHA are often viewed simply as victims of the disease, when in reality they must, and do, play a key role in ensuring their survival, and that of their families. They must rely on their own capacities, and when these are diminished, they turn, first and foremost, to their families and friends for help, whenever and wherever this is possible. Organizations need to recognize and work with these existing support structures and take heed of the needs they voice, such as skills training, rather than imposing outside solutions, which can create dependency.

Béata, a 26-year old woman living in Butare, appeared relatively strong. She shares a rented house with friends and a young brother who goes to school. She works at a pharmacy and earns 5000 francs per month. She braids hair at weekends to earn extra income. With the limited amount of money she earns, she is able to purchase maize flour, cooking oil, beans, dry fish and occasionally, Irish potatoes. Her friends sometimes contribute towards buying essentials such as milk, sugar and affordable fruits like bananas, whenever they have casual jobs. They are able to eat three meals at least four days a week. This demonstrates that a regular income, however limited, can make a difference. Nevertheless, Béata worries about the years ahead since she does not possess skills that would enable her to get more secure and better paid employment.

It would be great if I was able to develop my hairdressing skills. Maybe one day I will own my own hair salon and have a stable income.

Costasie, 30, has two children and lives with her mother and six other people in Kigoma. She appeared strong and was breastfeeding her four-month-old baby and will continue breastfeeding for another two months as directed by the health worker. She was not aware of her HIV status until she became pregnant with her second baby when, infected by a range of ailments, she was advised to take an HIV test. As soon as the father of her children learned of her HIV status he disappeared, leaving her to fend for herself.

The men are not concerned with the fate of their children when they are orphaned.

Costasie's brother works as a labourer to supplement what they produce on their smallholding. They grow a variety of food including cabbage, amaranth (dodo) and cassava. To grow these vegetables, she is dependent on her family. Fortunately, the family finds it possible to eat three meals a day. She is on ARV treatment and spoke of increased appetite and extreme hunger. Although she complains of their poverty, the support system she enjoys keeps her in relatively good health. Since she started on the ARV treatment, she rarely suffers from infections and her baby is also in good health. Costasie feels that she would greatly benefit from any training, which would enable her to start a small business.

Esther in Butare believes that she would have died if it was not for her sister, and spoke movingly of her devotion. Esther and her 13-year-old daughter now live with her sister after she became too ill to cope on her own.

The women repeatedly called on NGOs to prioritize food and nutrition for WLWHA.

Recommendations from African Rights

Food Security, Nutrition and Skills Development for Income Generation

- In order to halt the cycle of vulnerability, HIV contraction, poverty and AIDS, which blights the lives of so many Rwandese women and their children, programmes providing food assistance need to be reinforced. The Government of Rwanda, in partnership with UN agencies and other international and local NGOs, should explore the most efficient and effective strategies to help women in need, in conjunction with skills development. The need for food should diminish as the income generation activities increase, thus allowing the women to become self-sufficient.
- For those women who are able to grow their own food, there is a need for technical assistance and agricultural inputs in diversifying crops to include protective foods such as vegetables and fruits. This is essential for boosting the immune systems of the sick.
- Both the government and donors should give greater priority to enhancing skills. In the long term, this will reduce the burden on the health sector as women become more independent and less susceptible to opportunistic diseases.

Household Support

- Housing is a problem for the majority of the women interviewed. Those renting houses cannot afford to pay rent due to the lack of a regular income. The government, together with partner organizations, could assist them with building materials so that the women can build their own homes. Once individual women, or an association, owns property, it can even become a source of income. This is particularly useful for WLWHA at a later stage of the disease as it will provide an income while requiring little physical labour.
- The majority of the women interviewed have taken on responsibility for orphans in addition to their own children. Assistance with the education of these dependents, from Government institutions and partner agencies such as UNICEF and UNESCO (?) is vital for the future of these children.

GBV and HIV Prevention

- Preventive, not just curative methods, need to take a prominent role in tackling the issues of GBV and HIV/AIDS. There needs to be an emphasis by the Ministry of Education and other advocacy groups on intensifying HIV prevention in schools;
- Government and NGO sensitisation campaigns need to raise greater awareness among men of the consequences of gender-based violence and the spread of HIV.
- The government should speed up the process of passing the Domestic Violence Bill and enacting it into law.

- Government and NGOs must intensify HIV prevention campaigns, including advocacy on the importance of testing in order to catch the disease early, particularly focussing on young people who may not yet be infected.

Collaboration and Funding

- The Government, in conjunction with its partners and international institutions, must make funding WLWHA related projects a priority; in particular it should oblige medical schools and nursing schools to teach good nutrition to medical professionals, and particularly to junior staff who are in contact with ordinary people on a daily basis. It needs to go beyond advocacy materials and become more actively and widely involved at the grass roots level.

Recommendations from the Meeting of 2 March

The government has put in place sufficient policies and procedures; the imperative now is to consolidate activities at the practical level. In particular, there should be an emphasis on working at the grassroots, at the level of sector, through partners and associations on the ground.

There must be a holistic agenda, which includes an emphasis on trauma therapy and counselling.

Food Security, Nutrition and Skills Development and Income Generation

- The group agreed that associations form an important component in enhancing food security and skills development as an effective and sustainable strategy for reintegrating vulnerable women back into society. It therefore urges the government and civil society to prioritise this in their efforts to address GBV and WLWHA. It is strongly recommended that associations promote mixed membership of both HIV-positive and negative women in order to de-stigmatise involvement and to offer wider community support;
- The importance of skills training is key once the women are strong enough to take part in such activities, and turning raw materials into finished products, such as banana and potato chips, can boost income generation significantly.

Household Support

- The creation of support centres for peer support and specialised services is necessary in the rehabilitation of victims of GBV, particularly for those living with HIV/AIDS;
- As an immediate response, making available, at police stations, lists of organizations that victims of GBV can contact for assistance should be explored. This would also entail giving greater support to the police to deal with GBV victims;

- There needs to be greater promotion regarding the importance of family planning for the future health and security of the household. Access to family planning services should be readily available and actively encouraged by all health institutions, with a particular focus on WLWHA;
- Much more attention must be focused on men when tackling issues of GBV and the transmission of HIV/AIDS, so that men can become active partners in discouraging and stigmatising GBV and the transmission of HIV/AIDS.

Prevention of GBV and HIV

There needs to be a concerted effort at lobbying justice institutions to ensure that the following measures are in place:

- Legal sanctions if a person knowingly infects another with HIV/AIDS;
- Laws that make GBV, and not only domestic violence, a criminal offence;
- A legal framework or institution which would make it possible to trace the past partners of an HIV positive individual. This calls forth many sensitive issues which would need to be looked at carefully, but the matter should be considered.

Collaboration and Funding

- The group identified key collaboration networks such as CNLS and the HIV/AIDS cluster, which are integral in the implementation stage of the recommendations highlighted in this report. It is urged that these networks actively take on board the findings of this report and add them to an integrated policy framework;
- Advocacy is an essential tool in working towards better standards of living for WLWHA. In order to utilise this effectively, there needs to be one united message from all levels of civil society and government regarding the fight against GBV and HIV/AIDS for the women of Rwanda.