

Living with AIDS in Rwanda:

*A Study
in
Three
Provinces*



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Living with AIDS in Rwanda: A Study in Three Provinces

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The Illustrations in this report are part of the Rwanda AIDS Quilt—a group of more than 300 cloth panels hand-painted to remember loved ones who have died of AIDS. More than 1 out of every 10 people in Rwanda is HIV positive, yet it is difficult for Rwandans to talk about AIDS. The Quilt breaks the silence around those who have died of AIDS, and it honors their memory in a positive way. The quilt paintings were first shown to the public on World AIDS Day 2000 at Amahoro Stadium in Kigali.

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Acknowledgments

With a national HIV infection rate of about 11 percent, Rwanda is one of the countries in sub-Saharan Africa most affected by this disease. The high level of poverty and low access to modern medical care make the situation of people living with HIV/AIDS (PLWHA) in this tiny East African country particularly difficult. The study described in this document was conducted to provide a better understanding of the conditions of PLWHA in Rwanda and to serve as an empirical basis for developing appropriate strategies and interventions for addressing the needs of these people. The Johns Hopkins University Center for Communication Programs (JHU/CCP) provided technical assistance in the design and implementation of the study, which took place in three Provinces: Byumba, Gitarama and Kigali Ville. The study was conducted in collaboration with the Rwandan Association of PLWHA (ANSP+) with funding from the United States Agency for International Development (USAID).

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Executive Summary

This study was conducted to provide information on people living with HIV/AIDS (PLWHA) in Rwanda to design appropriate interventions that will address their current problems. The major research questions focused on determining what a community education program should include to improve conditions for PLWHA who are trying to survive, upon whom the program should focus and through what channels, and how PLWHA are able to seek and receive such information.

To gather this information, focus group discussions (FGDs) and in-depth interviews with male and female PLWHA, home-based caregivers, leaders of PLWHA associations and key informants along with field observations of households of PLWHA were conducted in May 2001 in three provinces in Rwanda: Kigali, Gitarama and Byumba. Information was collected about knowledge and attitudes of PLWHA and home-based caregivers concerning HIV/AIDS transmission and adopting a positive life style, factors that affect HIV screening, sexual practices of PLWHA, how PLWHA are treated and their coping mechanisms, the content and quality of home-based care, and sources of support for PLWHA.

Results show that PLWHA live in poor conditions and that upon confirming their positive serostatus, a cycle is triggered in which their initial impoverishment becomes worse. Physical deterioration and inadequate medical care make PLWHA less able to work and therefore more prone to poor nutrition, living conditions and hygiene, which further the declining cycle.

PLWHA who belong to active support associations appear to have a more accurate knowledge of issues concerning HIV/AIDS than those who do not. In general, PLWHA, home-based caregivers and association leaders understand that HIV/AIDS is mainly sexually transmitted and can be prevented by using condoms or abstaining from sex. They are aware of activities that weaken them physically, such as drinking alcoholic beverages, but men especially continue to do so because of the important social role it plays in their lives. They are also aware of the necessity of a healthy diet, but because of lack of money many are unable to buy food. They have a basic understanding of opportunistic infections, but are frequently unable to avoid them because of the poor quality of their living conditions.

Data show that many PLWHA wait a long time to get tested for HIV, many suspecting their seropositive status for years. Factors deterring the respondents from being tested are fear, neglect of their own health while caring for a sick spouse or belief that their persistent illnesses are caused either by poisoning or bewitchment (*ifumbi*). Emotional responses to a seropositive status vary. Those suffering from persistent illness for a long time or who have had a spouse die of AIDS are more emotionally prepared for the positive results and accept it with resignation. For others, responses range from wanting to commit suicide, to not talking to anyone for a few days, feeling despair, sadness, fear and worry about the future of their children.

PLWHA hesitate to talk about their seropositive status for fear of being abandoned and scorned by family, friend and neighbors. Unfortunately this fear is often justified. A major reason for abandonment appears to be fear of becoming contaminated by sheer close proximity with an HIV-infected person.

Study participants tended to continue having sexual intercourse even if they suspected being seropositive. Married PLWHA continued to have sexual relations with their spouses if they had enough strength.

The PLWHA interviewed did not have a support network other than a few individuals who helped sporadically upon request. When asked to rank their sources of support from strongest to weakest, women ranked family and prayer as strongest while men ranked friends as strongest. The home-based care that PLWHA receive is limited since caregivers live in the same poor conditions as PLWHA and have no special resources for the assistance they provide.

The primary role expected of PLWHA associations by PLWHA is the provision of charity or money through income-generating activities in which PLWHA can participate. The provision of HIV/AIDS information, moral support and problem-solving activities is perceived as secondary. However, in reality associations have been able only to provide moral support and comfort. Membership is mainly composed of women since men are less willing to reveal their seropositive status because of pride and fear of abandonment.

The study findings have important policy and programmatic implications. To improve the conditions of PLWHA, a community education program should promote compassion for PLWHA and HIV screening, increase awareness that PLWHA can live and be productive for a long time, encourage local employers to hire PLWHA, motivate PLWHA to protect themselves and their sexual partners, and involve authorities in working in community prevention activities. The program should be channeled through and focused on PLWHA associations, churches, voluntary counseling and testing (VCT) centers, parent-teacher associations in schools and local authorities. Finally, the findings from this study suggest that PLWHA are willing to do as much as they can, physically and emotionally, to help themselves, but they do not always know where to get what they need. Thus, pertinent information should be made accessible to PLWHA in ways that minimize fatigue, transportation and cost.

Context of the Study



Background

An estimated 11 percent of Rwandans (9 percent of men and almost 14 percent of women) are infected with HIV (UNAIDS, 2000¹). It is especially striking that the seroprevalence rate is almost the same in rural as urban areas (11 percent) in Rwanda. There is a high level of stigma around HIV/AIDS and a low level of support for those infected with the virus. People who are seropositive occupy most hospital beds. Unfortunately, medical services are inadequate and many people cannot afford to pay for them. As a result, emphasis is on home-based care and creating associations for people living with HIV/AIDS (PLWHA) with the objective of improving their conditions through the provision of material resources, moral support, education and income-generating activities. Many of these associations, however, are new and experiencing problems that prevent them from being effective.

The present study was carried out in May 2001 on PLWHA in three provinces of Rwanda: Kigali, Gitarama and Byumba. The information will be used to design appropriate interventions that will address current problems of Rwandans who are living with HIV/AIDS². The Johns Hopkins University Center for Communication Programs (JHU/CCP) provided technical assistance in the design and implementation of the study; funding came from the United States Agency for International Development (USAID).

Methods

Questions—The study was conducted to answer three major questions:

1. What should a community education program include to improve the conditions of PLWHA who are trying to survive?
2. Through what avenues should a community education program and activities be channeled and upon whom should the initiative be focused?
3. To what degree are PLWHA able to seek and receive information to address their needs?

¹ Report on the global HIV/AIDS epidemic. Available from: http://www.unaids.org/epidemic_update/report/Epi_report.pdf [Accessed October 2001].

²In this report the acronym PLWHA will be used for the people who participated in this study who reported to have been screened for HIV and were seropositive. They all had already reached the point of having frequent ailments and many could be said to have full-blown AIDS. However, none were consistently bedridden and while their physical strength varied, all but one were healthy enough to do some work and carry on a somewhat normal daily life in between their bouts of illnesses.

Objectives—To answer the above questions, the following objectives were set:

1. Ascertain knowledge and attitudes of PLWHA and home-based caregivers concerning HIV/AIDS transmission;
2. Elucidate knowledge and attitudes of PLWHA and home-based caregivers concerning a positive life style and determine the possibilities of PLWHA to adopt such a life style;
3. Clarify factors that affect HIV screening;
4. Describe sexual practices among PLWHA;
5. Explore the attitudes of family and community members, how they treat PLWHA, and how PLWHA cope with those;
6. Elucidate the types and sources of support PLWHA receive;
7. Analyze the quality and scope of home-based care received by PLWHA; and,
8. Examine the strengths and weaknesses of PLWHA associations.

The data was collected through focus group discussions (FGDs), in-depth interviews and unstructured field observations. With a total of 52 participants, 5 FGDs (3 with women, 2 with men) were held. In addition, six male and eight female PLWHA, six home caregivers and six association leaders were interviewed in-depth using a carefully designed guide. As an additional source of data, field observations were made in households of PLWHA and home caregivers to ascertain living conditions. Field observations were also conducted of the meeting places of associations to ascertain their resources. Finally, information was gathered from several key informants including the Director and a counselor of the volunteer counseling and testing (VCT) center in Byumba, the Regional Medical Officer of Byumba, and the Director of the HIV/AIDS counseling center of Rwamagana.

Profiles of PLWHA

A total of 66 PLWHA (22 male, 44 female) participated in the study. The PLWHA participants ranged in age between 23 and 69 years. All except five had ever been married and more than half were widowed. Almost all the widows' spouses were believed to have died of AIDS. Educational levels included 11 who had no schooling and 42 who had some primary education. Most of the study participants engaged in petty trading (24) or subsistence farming (20) while some (10) were not economically active. Of the participants, four had no children under their care while the majority cared for three or more children.

Findings of the Study



1 Living Conditions of PLWHA

Poverty is widespread in Rwanda. For many PLWHA, the problem precedes the HIV diagnosis but has been made worse by their serostatus. Impoverishment for many widows began when their husbands died of AIDS and has been exacerbated by their own incapacity to work consistently because of frequent illness and physical debilitation.

The cycle of poverty faced by PLWHA is a vicious one: inadequate resources prevent PLWHA from obtaining proper nutrition, hygiene and required medical health, which further weakens them, makes them more susceptible to opportunistic illness and limits their ability to work. Also many PLWHA have been abandoned by family and friends. Those relations and family who are willing to help are themselves poverty stricken or believe that they will become infected with the virus by being near PLWHA. Many also believe it is wasteful to use already limited resources on an individual who will soon die rather than on a healthy person who will be able to contribute something in return.

Housing is a worry for urban-dwelling PLWHA who do not own their home—they often cannot meet their rent and get evicted. Those who own their home are not always able to maintain them because of poor health and lack of funds. Thus during the rainy and colder seasons, PLWHA are unable to protect themselves sufficiently from dampness and chill, further contributing to the deterioration of their health.

Obtaining wood or charcoal for cooking fuel is difficult because it is scarce and expensive. PLWHA in rural areas fortunate enough to own a grove of eucalyptus trees have a constant supply of wood. But most PLWHA living in rural areas send children to find wood, sticks, brush, leaves, or anything that can be used as fuel. In urban areas, PLWHA buy wood or charcoal if they can afford it; when they cannot they too have children find whatever will burn including paper or trash. A few PLWHA reported that when they could not obtain fuel, they skipped meals.

Getting water poses a problem as well. Because it is important for PLWHA to maintain proper hygiene, especially if they have skin problems, having water is vital. Some PLWHA in Kigali have running water (included in their rent) on their house lot. Urban dwellers buy water in 20-liter gerry cans for 20frw to 30frw (5 to 7 cents U.S.). Often PLWHA do not have enough money to buy water in sufficient quantities. Those living in rural areas have access to water from rivers, natural springs or wells, though it may be located several hours away. While piped-in water is treated in Rwanda, it is still

necessary to boil it to assure its safety for drinking. This again is expensive due to fuel costs. Thus most PLWHA drink unsafe water and are exposed to intestinal infections.

Obtaining enough food for daily meals is frequently a challenge. Some women in the FGDs ask for money, borrow money, or were hoping that members of the research team would give them some money for food.

2

Knowledge and Attitudes Concerning HIV/AIDS



A. TRANSMISSION AND PREVENTION

Results of interviews with PLWHA and home-based caregivers show that they understand that HIV/AIDS is mainly transmitted sexually or through HIV-infected blood. Those PLWHA belonging to PLWHA associations appear to have a more accurate understanding of transmission than those who do not belong.

While everyone interviewed said that transmission is mainly through sexual intercourse, there remain some erroneous notions. For instance, some respondents believe that sexual intercourse itself (especially sexual promiscuity) is the cause of transmission, rather than understanding that one partner has to be infected with HIV. Also, some PLWHA believe that HIV can be transmitted by sharing the same eating utensils or clothes with an infected person. Most of them are aware of transmission from mother to infant but do not understand how or when it happens.

The main methods of prevention cited were abstinence, condom use, and avoiding patronizing traditional healers (*majendu*).

B. RE-INFECTION VERSUS EXACERBATION OF ILLNESS

There appears to be confusion between an exacerbation of the symptoms of HIV and a notion of re-infection, which may stem from the Kinyarwandan phrase, *kiyongerera ubukana by'yo ndwara*, that refers to both ideas. The notion of re-infection is understood as increasing the amount of the virus in the body. Some PLWHA believe that sexual intercourse exacerbates the symptoms of HIV illness because it requires a lot of energy resulting in a weakening of the body and sickness. Others, however, understand sexual intercourse as “re-infecting” the person because it can “increase the amount of the HIV virus or *agakoko* in the body” through an exchange of blood during ejaculation or through genital secretions. Other causes of “re-infection,” indicating the misunderstanding of this notion, include anything that weakens the body, such as giving birth, lack of adequate food or water, drinking alcohol or smoking tobacco.



3

Positive Life Style: Knowledge, Attitudes & Practices

A. DIET

Despite the fact that most PLWHA lack the means to obtain the necessary nutrition, the data show that they have a fair knowledge about an appropriate diet for an HIV-positive person. It was evident that some had learned about the components of an appropriate diet through their PLWHA association or possibly during community health education talks. An appropriate diet is understood to include three categories of food:

- *Ibitera imbaraga* - foods that give energy such as sweet potatoes
- *Ibyubaka umubiri* – body-building foods such as beans, manioc leaves and other leafy vegetables, and meat
- *Ibirinda indwara* - foods that prevent illnesses such as green vegetables, cabbage, and manioc leaves cooked with a cow's foot.

Generally, PLWHA report a decline in the quality of their diet since they were infected with HIV. PLWHA who live in rural areas and have some land and children to work on it tend to have a better diet than those in the city who sometimes have no money with which to buy food.

B. ALCOHOLIC BEVERAGES

The negative effects of alcohol on physical and sexual health are generally well recognized among the study participants. Many were able to articulate the relationship between alcohol and unprotected sex, and some told about how alcohol had impaired their judgment and led them to indulge in unsafe sex.

“I stopped drinking alcohol because when I’m drunk, I can have sex without even realizing it.”

- Female PLWHA, Gikondo

“Before, I drank beer a lot ... drinking makes people stupid. It was because I drank that I became infected because I used to have sex with prostitutes.”

- Male PLWHA, Gikondo

Nonetheless, many still continue to drink. One reason is the social significance of alcohol consumption. For men, drinking in the company of friends is important as it provides a forum for the expression of friendship, relaxation, amusement and a sense of belonging. One of the male participants expressed his dilemma about his need for

social contact despite his health needs saying “...*drinking makes you more tired, but you can't just stay by yourself and fall into despair.*” A great concern of those interviewed is solitude because neighbors, friends and relations tend to abandon PLWHA when their seropositive status becomes known. For this reason, PLWHA avoid telling their friends that they are infected and also avoid changing any behavior that could inadvertently reveal their seropositive status.

Another reason why some PLWHA continue to drink in spite of the negative consequences of alcohol is that it helps them to relax, sleep better and temporarily forget their problems. Some also believe that alcohol has therapeutic attributes and provides relief from some of their symptoms.

“...one takes alcohol to erase some thoughts from your head.” - Male PLWHA, Kigali

“I have some unusual intestinal worms, when I take alcohol, they calm down but if I take too much I become really sick.” - Male PLWHA, Byumba

By and large, declining incomes was an important reason for reducing alcohol intake. Other PLWHA have stopped drinking alcoholic beverages altogether since they became aware of their seropositive status.

C. TOBACCO

Tobacco, like alcohol, is an important social activity and usually accompanies drinking. PLWHA who participated in the study generally knew that tobacco affects the lungs, causes coughing and aggravates tuberculosis. For some, knowledge about the negative effects of tobacco on the lungs came from personal experience as their cough worsened when they smoked. Others read about the negative effects in a brochure, heard it on a radio program concerning HIV/AIDS or were told by a health caregiver.

Almost all the females in the study either never smoked or stopped smoking for health reasons. Many of the men who smoked quit because it irritated their cough. Some men, however, continue smoking because of the emotional benefit they derive from tobacco.

D. OPPORTUNISTIC ILLNESSES

Malaria

Although most PLWHA generally know that malaria results from mosquito bites, there is a lot of misinformation about how the infection is transmitted from person to person. Those who gave an explanation believe that malaria is transmitted by the blood that the mosquito takes from one person and transfers to another person.

Most of the respondents know ways to prevent malaria, such as eliminating stagnant water around their houses and using mosquito nets, but do not take those precautions. Some are too weak to rid their surroundings of stagnant water, while others report that they either cannot afford mosquito nets or do not have a suitable ceiling from which to hang the nets.

Intestinal parasites

Many of the study participants understand the cause of intestinal parasites, citing lack of proper hygiene, drinking contaminated water, using dirty cooking utensils, not washing hands after defecating, parasites entering the feet when walking barefooted, eating raw food, and handling objects after flies have settled on them.

However, not everyone cited all of these causes and there are still some misconceptions about the cause of intestinal parasites. The following example described by a woman explains why some people may choose not to use modern health services to treat malaria: "...intestinal parasites are things that come from our parents and are transmitted from mother to child. To protect yourself against this, we used to use the seeds from a squash, and then perform a special ritual and the 'inzoko' would die. You see these plants..." And she went on to name plants she collects for her home remedies. Some participants, confused about indigestion versus abdominal discomfort that may be caused by intestinal parasites, said that if you eat something that "doesn't agree with your organism" you will have intestinal parasites (*inzoko zo munda*, literally, "worms or snakes in the stomach"). Another said that if you eat rice instead of potatoes, eat vegetables cooked in water without rice, or eat food that has become cold after being prepared, you will get intestinal parasites.

The respondents indicated that it is difficult to protect themselves or their children from getting intestinal parasites due to their living conditions. For example, while they recognize the need to boil water, they do not have money to buy fuel to do so. In some households, small livestock such as pigs, chickens and rabbits sleep inside the house with people at night and during the day wander in and out of the area where food is being prepared and children are crawling around, thus contributing to poor hygienic conditions. Latrines are often dirty and sewage water drainage systems are frequently in poor condition.

Respiratory illnesses

Most of the study participants have had tuberculosis and/or pneumonia and many are currently suffering from a chronic cough. Most know about modes of transmission of respiratory illnesses citing: through the air, from dust in the air, breathing air from a person infected with tuberculosis, and through saliva by eating after a person infected with tuberculosis. Some misconceptions reported include a belief that tuberculosis is transmitted through fresh milk drunk straight from the cow, that a cough is caused by rain and tuberculosis by intestinal parasites, and that tobacco and factory emissions cause tuberculosis.

Sexually transmitted infections (STIs)

Many study participants named AIDS, gonorrhea, syphilis and chancroid as STIs and most believe that STIs are transmitted via promiscuity rather than unprotected sex. Some PLWHA believe that STIs are contracted by sharing undergarments with or using the same toilet as an infected person.

4

Discovery and Acceptance of Seropositive Status



A. THE DECISION TO BE TESTED

An analysis of 45 cases identified from individual interviews and FGDs indicates that the following factors play a part in the respondent's decision to obtain an HIV test:

- a long history of repeated opportunistic illnesses;
- a spouse and/or child who died of AIDS;
- miscarriages or infertility;
- a promiscuous life style or that of their spouse.

The data indicate that the people in this study tended to wait for years from when they first suspected they were infected before being tested. Evidence suggests that many respondents continued to have sexual relations (while not yet confirming their seropositive status) for 4 to 7 years and in one extreme case, 18 years. The earliest reported date of a husband being sick was in 1982 when he died of "mysterious causes." In 1983 his wife began having repeated illnesses, abscesses, a miscarriage, and loss of hair. A man interviewed in Kigali reported that his child was born seropositive in 1989 and his wife died in 1992. A woman from Byumba who was tested in 2000 reported suffering from opportunistic illnesses since 1996. Another woman stated that she was raped during the war in 1994, began frequent illnesses in 1996 and had a positive test in 1998.

Several factors contribute to the delay in getting tested. One is the burden of caring for a sick spouse or child that makes the caregiver neglect her/his own health even in the presence of symptoms of opportunistic illnesses. Another compelling reason is fear of confirming a seropositive status and the perceived results: suffering, rejection by significant others, and ultimately premature death.

"I was afraid to go for the test because out of 100 people who go for the test, 80 are positive. If your friends are sick, then you should suspect that you are too. I already had a cough for a long time and some of my friends were already positive. Since there is no treatment, nothing to do about it, why go?"

- Male PLWHA, Byumba

Other factors that deter people from getting tested are related to prevalent beliefs among the Rwandan population about the cause of HIV. It is common in Rwanda to attribute unexplained illnesses to *ifumbi*, poisoning or bewitchment. *Ifumbi* is an ill-defined medical condition that is believed to be innate and affects mainly the genital areas although it may also manifest itself in other parts of the body (Niang, 1999³). In men, the symptoms of *ifumbi* include sterility, lower abdominal pain, lack of appetite,

³Niang CI. (1999). *Representations, Itinéraires, Thérapeutiques et Communication concernant les Maladies Sexuellement Transmissibles au Rwanda (Cas de la Région Sanitaire de Kigali)*. Final report submitted to IMPACT-RWANDA.

redness of the eyes and swelling of the testicles. For women, *ifumbi* is suspected when symptoms such as vaginal secretions, pain during sexual intercourse and during menstruation, lower abdominal pain and swelling and itchiness of sexual organs are experienced. Some of these symptoms may indicate an STI. If *ifumbi* is considered to be the cause of a person's symptoms, treatment is sought from a traditional healer rather than from a medical practitioner in a health center or hospital. The same applies if bewitchment or poisoning is perceived to be the cause of the person's symptoms. It is only when the symptoms persist after a period of treatment by traditional healers that the person resorts to a health center to seek advice and eventually goes for HIV screening.

“When I first became sick, I thought it was poisoning, so I went to the healer. My husband and I stayed at the healer's for 7 months in 2000. When I saw that I was not getting better, I decided to go get tested to see if we had AIDS...”

- Male PLWHA, Gitarama.

Thus, for a variety of reasons including misconceptions about the cause of their health condition, fear about having their suspicions confirmed, and lack of time to dwell on their own symptoms, most of the study participants waited a long time to be tested. Astérie's story in the box below reflects the typical health-seeking process that culminates in getting tested for HIV.

Astérie's Story

In 1994, Astérie began to experience frequent bouts of illnesses that included coughing, headaches, nausea, vomiting and diarrhea while she lost a considerable amount of weight. At that time, she thought she had been poisoned or bewitched. So she went to a traditional healer, but the treatment did not help. Astérie continued to be ill frequently and eventually suspected that something serious was wrong with her health. She was advised by friends to get an HIV test but she did not go immediately for fear of finding out that she was seropositive. Her fear was reinforced by the knowledge that some of her friends with similar symptoms had already tested positive for HIV. One day in July 2000, Astérie had a severe bout of coughing and was rushed to the hospital where she was diagnosed with tuberculosis. While there, she was tested for HIV and her results were positive.

B. INITIAL EMOTIONAL RESPONSE TO TEST RESULTS

The data suggest that the type and intensity of emotional response to test results depend on the person's suspicion of being infected, their own or their spouse's past or current sexual behavior, and their experience with the death of a spouse due to AIDS. While some might initially refuse to believe the test results, most had little problem with denial.

“I was not afraid because I knew that my wife had died of it (HIV). I knew I was seropositive because I used to be a blood donor and they refused to take my blood, so when I went for the test I was getting information that I already knew.”

- Male PLWHA, Gitarama

“...they had said it [the husband’s illness] was from poisoning. He was treated as though for poisoning but others knew that he had AIDS and after his death I went to be tested, so I wasn’t at all surprised.”

- Female PLWHA, Kigali

One type of emotion frequently reported upon hearing the test results is that of despair, especially for those PLWHA who have children to support and no source of financial help. For them, learning about their serostatus engenders emotions of intense sadness and anxiety about the future of their children.

“I...was very scared, and thought I would die right away after I heard I was infected. I was very worried about the future of my children, if I die and their father is still in prison...”

- Female PLWHA, Gitarama

Some reported an initial emotional response characterized by suicidal thoughts and acute depression, refusing to eat and isolating themselves from others for days.

“...I lost my head and I wanted to commit suicide. I wanted to throw myself in the river. Then I wanted to put rat poison in my porridge and drink it. Then I remembered that I was Christian, that I was baptized, that God can help me and can punish me and I put myself in the hands of God.”

- Female PLWHA, Gitarama

Anger, directed toward a variety of people including the perceived source of their infection, was also frequently reported. One woman reported being intensely angry at her husband although he was already dead.

Underlying the reported initial response to the test results are uncertainties about the future and fear of imminent death. Upon discovering their serostatus, most PLWHA expected to die within a short time. When they continue to live, however, the initial reaction gives way to quiet resignation, which provides the strength for them to cope with their situation. They continue to deal with emotions consisting of fear of ensuing death, sadness and despair combined with the courage and desire to survive.

C. REACTION OF SIGNIFICANT OTHERS

Most PLWHA went alone to get their test results and eventually shared their seropositive status with their entourage (family, friends and neighbors). They initially told people who they thought would not reject them or who could possibly help them. The data suggest that while the reactions of the entourage varied, in general their attitudes are quite negative. During the in-depth interviews and FGDs, the topic of reactions and subsequent treatment by the entourage made some respondents so emotional they could not talk about it. Most respondents tried to conceal their seropositive status from their family, friends and neighbors. But the entourage usually suspected that the respondents were seropositive because they were frequently ill.

One man interviewed in Gitarama said that his family no longer visits him because they are afraid that he will invite them to drink beer from the same straw. One woman

described a neighbor bringing her a bowl of food carrying it in between two sticks so she would not have to touch it. Another narrated how a nun was nice enough to give her a house to live in, but the neighbors complain that the nun gave it to someone dying instead of one of them. In Kigali, one woman reported that when neighbors found out about her seropositive status, they stopped greeting her and would not let her children play with theirs.

The reaction of the entourage has marked effects on the capability of PLWHA to deal with their status. Some of the study participants are particularly bitter because they are having a hard enough time accepting their own status and dealing with their many problems without having to deal with the poor treatment they are receiving from others. Since this study found that many PLWHA in Rwanda have been diagnosed for more than 6 years and have experienced symptoms of HIV infection for much longer, the treatment from their family and friends is a meaningful aspect in their lives.

D. MORBIDITY SINCE SEROPOSITIVE STATUS

The study participants reported a variety of ailments since learning of their seropositive status, including diarrhea, tuberculosis, malaria, asthma, chronic weakness, intestinal worms, abscesses, herpes, rashes, pneumonia, loss and thinning of hair, and miscarriages. When symptoms of illness are experienced, PLWHA either go to the health center or simply stay home and hope to get better. Lack of money for transportation and medication, and general discouragement are major deterrents to going to the health center.



5 Sexual Behaviors of PLWHA

Most study participants continued to have sexual intercourse prior to being tested even when they suspected being seropositive. After being tested, most continued having sexual relations until they became too sick or weak to do so. Married PLWHA continued to have sex with their spouse if they were able. Some single or widowed women trying to survive reported occasionally having sex for money though they knew they might be infecting their partners.

Even with the knowledge that they could infect their partners, PLWHA generally engage in sexual intercourse without using a condom. The only participants that reported occasional condom use were those who received free condoms from the health facility where they were tested for HIV.

Since their illness, some women and men reported being disgusted by sex and no longer had any desire for it. A few men had become sexually impotent as a result of their illness while others deliberately stopped sexual relations so as not to infect their partners.

There is some level of awareness about masturbation and other ways of achieving sexual satisfaction without penetration and a few study participants reported practicing those methods.

6 Support Network and Home Care

A. SUPPORT NETWORK

When describing their situation, most of the study participants repeatedly spoke about their fear of being alone. For some, this fear made them postpone going for a test. Once the serostatus of PLWHA becomes known or once they start to manifest visible symptoms of AIDS, people with whom they usually associate — family, friends or neighbors — tend to avoid them. As a result, PLWHA lose the support of those who ordinarily would help them in difficult situations.

In describing their support network, study participants talked about individuals who sometimes helped them. Those individuals are most often a distant friend, child, or someone not in their entourage, whose help is typically not consistent and rarely, if ever, adequate to fulfill their needs. There are family members who, though poor, do what they can, but most others refuse to share their resources with PLWHA. Families with limited resources face the dilemma of choosing between feeding a healthy child who is expected to live and contribute to the welfare of the family or helping a seropositive person who will soon die.

To obtain assistance, PLWHA often have to beg for it or at least ask several times. Those who do receive help are extremely grateful. The only organized support seemed to be the PLWHA associations that have a system to care for sick members. Those PLWHA interviewed were asked to rank their sources of assistance from those who helped the most to the least. Some differences between support networks were expressed by men and women. For women, family, spiritual leaders, and prayer fell in the strongest category whereas men rely on friends. Both men and women put family, PLWHA associations and friends in the middle category, but women added health center practitioners. Both men and women put neighbors and family in the least category, though men also included friends.



The data also suggests that the main support persons vary between urban and rural areas. In rural areas it is more likely that PLWHA will be cared for by a family member. In the city, it is more likely that PLWHA will receive assistance from a PLWHA association member, a friend or neighbor. Generally, city dwellers are separated from members of their extended family and are not willing to return to the rural hillsides for fear of being rejected.

The support PLWHA receive is limited. An individual may receive 1500frw (less than \$4 U.S.) per month from a sibling or 2000frw (about \$5 U.S.) if they are more fortunate. Others are given money occasionally from a family member voluntarily or when asked for it. Some are able to borrow money from friends regularly, others only periodically or rarely. They may receive some food or help from the PLWHA association or a priest or nun in their neighborhood, but not on a regular basis. Some PLWHA rely on neighbors, their children or younger siblings for care. A common way that Rwandan shop keepers help those in need is to give PLWHA retail items on credit. PLWHA sell the items, pay back their value and keep the profit.

The types of assistance PLWHA would like to receive include: money for medical care and drugs, food, housing, credit for goods to sell, and financial assistance for meeting their children's current and future needs. The strongest wish expressed by PLWHA was the assurance that their children be well cared for after their demise.

B. HOME-BASED CARE

The information in this section is based on case studies of six home-based caregivers, two in each province. All the home-based caregivers were women of similar ages and economic status as the PLWHA in their care. Four of them assist female PLWHA while two assist men.

Socio-economic status of home-based caregivers

Five of the caregivers were poor, living in the same conditions as PLWHA. A noticeable exception was a woman caring for her seropositive affluent husband. She lives in a large well-furnished house, owns an automobile, eats well, and has necessary medications.

The fact that most home-based caregivers are just as poor as PLWHA in their care means that they have no more to offer than what PLWHA already have. Yet their willingness to help nonetheless demonstrates compassion and selflessness.

Two of the caregivers are family members of the PLWHA while four are not. In one case, the PLWHA was the husband of the home-based caregiver while in the other he was a paternal uncle. In two cases, the home-based caregiver was a friend of the PLWHA and agreed to care for them in exchange for a place to live. In the other two cases the home-based caregivers did not live with the PLWHA. One had cared for her older sister until she died and then decided to care for another PLWHA whom she had met at a Red Cross meeting. The other belongs to a PLWHA association in which the members are organized to care for one another when they become bedridden or need special help.

Rose's story in the box below provides useful insights into the living conditions of home-based caregivers. While the situation described may be specific, the conditions are typical.

Rose's Story

Rose is a home-based caregiver who also sells avocados and eggs in the market. She is a single mother whose soldier husband has yet to return home from the Congo after the war, which claimed the lives of her parents and siblings. Rose has an 11-year-old mentally handicapped child from her first marriage and a two-week-old baby from a man she currently dates. While she has not been tested, Rose shows signs of HIV infection including bouts of opportunistic illnesses. A few years ago when Rose was unable to find adequate housing, she met the PLWHA she is currently assisting. The PLWHA, a widow with two small children, offered Rose living accommodations in her two-bedroom house in exchange for a small amount (\$4 U.S.) of monthly rent and having Rose care for her. It is an arrangement that benefits both parties. The two women live isolated from other people in their neighborhood for fear of negative reactions should their seropositive status become known.

Knowledge of the home-based caregiver

Home-based caregivers have the same general knowledge and misconceptions concerning HIV/AIDS transmission, opportunistic illnesses and a positive life style as those PLWHA interviewed. The home-based caregivers are generally aware that it is important for PLWHA to have a regular, nutritious diet, but often struggle to get them anything to eat. Some caregivers expressed despair knowing the person in their care is not able to have enough nourishment.

The home-based caregivers understand that tobacco and alcohol are not good for a seropositive person. Some report learning this from brochures or clinic-based health talks concerning HIV/AIDS. Since some of the home-based caregivers are also HIV positive, they may have experienced the same consequences of drinking alcohol and smoking tobacco as the PLWHA in this study, and therefore try to convince PLWHA in their care to stop drinking and smoking.

Their knowledge of caring for a person with HIV/AIDS comes from what they hear on the radio or what the PLWHA association teaches its members. They are quite aware there is much to know and are interested in learning more.

Attitudes of others toward home-based caregivers

Attitudes toward the home-based caregivers vary from admiration to outright hostility. For example, one home-based caregiver interviewed in Kigali who is also seropositive and a member of the PLWHA association reports that the majority of her friends and neighbors appreciate that she takes care of PLWHA and admire her for it. Some neighbors invite her to their houses to ask advice on caring for PLWHA. However, there are other neighbors who ridicule her and say that the only reason she takes care of PLWHA is because she is paid to do so. With time those neighbors have become more tolerant although not completely supportive.

Other home-based caregivers report negative attitudes from people who know they are caring for PLWHA. The following quote from one of the home-based caregivers describes the attitudes of others toward her.

“It is a very serious problem for me and it’s very difficult. When I’m with my neighbors, they say, ‘You, you live by the side of a person with AIDS. You aren’t afraid or ashamed. You will become infected also. You better not share the same bed with her and you should get your own plates and goblets to eat and drink from. Or you are also seropositive.’ The family of the PLWHA I’m taking care of is mean to me. This is shocking. And they send their big boy to my house to beat me in order to threaten us. He cries out, ‘when you die, who will wash your corpse?’ One day the conseiller of our cell passed by and cried, ‘Colette, how are you doing with your Sideen’ (person who has AIDS). The neighborhood children throw stones at our windows. No one will lend us a pot, a ladle because they are afraid of getting infected. No neighbors will enter into our house. When there are festivities in the neighborhood, (like marriages or baptisms) they invite the others, not us.” - Caregiver, Gitarama

A home-base caregiver in Byumba reported that her mother has rejected her and believed that she also must be infected. Her friends and neighbors have stopped visiting her also. Other caregivers are derided for caring for someone who will soon die. In spite of such difficulties, these home-based caregivers are proud of taking care of PLWHA, and that helps to counter the negative attitudes and problems they face.

Nature of care provided

The care provided is limited since the caregivers have inadequate resources and little specialized knowledge. Caregivers who do not live with PLWHA in their care make frequent visits to bring them cooked food or help prepare food in their household. In most cases, PLWHA and caregivers find it difficult to obtain food on a daily basis. Caregivers will help PLWHA take their medication if they have any.

Although caregivers are aware of the importance of good hygiene, it is hard for them to help their clients maintain it because water is frequently limited due to its cost and/or the distance to a source. Also they do not always have soap, washcloths or towels. When water and soap are available, caregivers help bathe their clients if they are too weak, and do their laundry.

When their client is hospitalized, the caregiver stays with them and brings them food if no one else can do so. Some PLWHA receive free medical care from hospitals

or, as anyone else, receive services and medications only if they are able to pay for them. Home-based caregivers express discouragement when they cannot provide any financial aid for the hospitalization or medical treatment for their clients.

The home-based caregiver may also take care of the client's children. If there is no one else to do so, the caregiver helps with household chores, including cultivating their gardens. PLWHA tend to do as much as they can for themselves, but as they become weaker the caregivers do more.

The home-based caregiver also provides moral support and companionship to PLWHA. The caregivers report that by simply being and talking with them, PLWHA often improve physically even without medications or a proper diet.

7

PLWHA Associations



The information on PLWHA associations was obtained through interviews with leaders of six associations in the study provinces, including communal and clergy-based organizations.

A. COMPOSITION OF MEMBERSHIP

Because of limited resources, the only criterion for membership in the associations is documented seropositive status. Were the association membership open to anyone, there would be so many poor people asking for food or free medical care that it would be impossible to address the needs of PLWHA.

Members feel more comfortable discussing their problems with others who are seropositive thus providing each other with moral support. The leaders expressed belief that it would be difficult for a seronegative person to understand or empathize with an infected person. Some members would resent opening the association to persons who are seronegative.

Although both men and women are welcome to join the associations, women overwhelmingly dominate the membership. One association has 200 women and 6 men while another has 40 female and 2 male members. The reason for the skewed sex ratio of the membership has to do with the culture of Rwandan men. Men prefer not to make public their serostatus because their social relationships, which revolve around drinking and smoking with friends, are an important aspect of their lives. They want to preserve these relationships for as long as possible. Divulging their positive serostatus

would destroy these relationships since few people are willing to associate with a seropositive person.

Another reason is that activities of PLWHA associations (e.g. sewing, taking care of a sick person, raising chickens, etc.) are perceived as essentially female-oriented and do not reflect the socially prescribed roles for Rwandan men. Moreover, the need for assistance through the associations is probably greater for women than for men. Many men still have their wives to take care of them when they are bedridden, whereas seropositive women rely on other women for care. The associations may be the only social support for women whereas men have their social relationships. Additionally, prevailing norms in Rwanda dictate that social activities be carried out among people of the same sex.

Almost no member of the associations studied has a significant level of education or can be considered to be well off economically. This is because Rwanda is a socially stratified society where the various socio-economic strata hardly mix. The associations studied were those of the indigent. The membership therefore consisted of people with little financial resources and education. Most of the members are in semi-skilled occupations, petty commerce or subsistence farming. Better-educated PLWHA with adequate resources can afford better medical care, drugs, and food. Thus, those who are well-off share little with the poor in illness or in health. Since HIV/AIDS in Rwanda is still generally perceived to be a shameful condition, it is reasonable to expect that few higher-status people will admit they are seropositive.

B. ACTIVITIES OF ASSOCIATIONS

The activities of the associations were limited. They included provision of charity, meetings for HIV/AIDS education and the sharing of problems, income-generating activities, and provision of home-based care for members by other members.

Some of the income-generating activities appear to be successful and sustainable. In Gitarama, one association started a bakery using credit received from an external source and according to members, the demand is greater than their production. In Kigali, members of an association run a hair salon for which there is also demand. However, members of another association in Gitarama made woven crafts, which had low demand, and members were left with many unsold items.

Some associations with leaders knowledgeable about HIV/AIDS organize educational sessions for their members. However, some leaders are as misinformed about HIV/AIDS as their members.

Members' satisfaction with the activities of the association depends on what they perceive the association should be doing. Two male members of the same association held almost opposite views. One, who was not pleased with the association, said that the objectives of the association were the cultivation of mushrooms to provide money for small commercial activities, but to date the members had received nothing. The other said that the members provide morale support and comfort. "...we listen to God's words and at this moment we feel encouraged." Others expressed concern that monies earmarked for the membership are taken by leaders of the associations and never given to them.

C. MAJOR PROBLEMS OF ASSOCIATIONS

Six major problems in PLWHA associations were identified:

- weak mission and objectives of the association,
- limited material and financial resources,
- lack of member participation in activities due to frequent illness,
- lack of management and technical skills by leaders,
- limited knowledge of HIV/AIDS and related subjects, and
- lack of skills in organizing and developing useful activities.

Most associations do not have a clearly defined mission or set of objectives. One objective frequently stated is “...to aid people living with AIDS.” Leaders could not articulate, however, how the association was going to help PLWHA nor the role of members in the process.

Most associations have little or no financial backing. Some associations that are clergy-based receive money from the sponsoring church but not enough to run the association or provide services to members. Some associations based within the local government structures or institutions of civil society look for external funding but are not always successful in obtaining it because of lack of skills in grant writing and financial management. And income-generating activities are not always successful partly for lack of proper management. Inconsistent participation of members, especially in the income-generating activities, contributes to the lack of success of some activities. Members may have good intentions to do the work required but are unable to continue because of illness.

Many associations lack the skills needed for organizing and developing useful activities. Leaders, who are responsible for providing information on HIV/AIDS and related subjects, generally have limited or erroneous knowledge on these issues and so are not able to provide accurate information. Frequently, those who are elected as presidents of the associations do not understand their role and expect the organizer of the association to tell them what to do. In some cases the organizers are also new at their task.

Conclusions and Recommendations



The findings of this study provide some answers to the three questions posed below.

I. What should a community education program include to improve the conditions of PLWHA who are trying to survive?

A. PROMOTE SOCIAL SUPPORT FOR PLWA.

The main problems expressed by PLWHA are abandonment and loneliness. The data suggest that a major reason for this is fear by community members that they could become infected through physical contact with PLWHA. This indicates a need to clarify how HIV is transmitted and to inform the population about how to avoid getting infected. Reducing this unjustified fear of infection may help to lessen the stigma surrounding HIV/AIDS.

Because fear of solitude is felt by both PLWHA and Rwandans in general, the program can play on this shared emotion and emphasize the value of visiting and showing compassion to PLWHA. PLWHA interviewed expressed their need for social contact and reported how helpful it is to have people visit with them.

B. INCREASE AWARENESS THAT PLWA LIVE AND ARE PRODUCTIVE FOR A LONG TIME.

Another reason for abandonment reported by PLWHA is that their family or friends are convinced that they will soon die and thus are reluctant to come to their aid. However, the PLWHA interviewed have been living with AIDS for several years and still are working and contributing to their household, although on a reduced level. Messages should emphasize that PLWHA can continue to work and be productive for a long time. Messages may identify types of chores and activities PLWHA can do when they are too weak to work in a field or walk to the market.

C. ENCOURAGE LOCAL EMPLOYERS TO HIRE PLWA.

Local enterprises can be encouraged to hire PLWHA on a job-sharing basis in which several PLWHA share one job so that if one is sick, then another can work.

Job sharing can be arranged through PLWHA associations. Day or seasonal employment of PLWHA has been implemented successfully in a few Rwandan establishments, including a Kigali coffee company and a hospital in Byumba. Merchants can also be encouraged to give credit to PLWHA to sell their merchandise.

D. INVOLVE AUTHORITIES AND HIGH-STATUS PLWA TO WORK IN COMMUNITY PREVENTION ACTIVITIES.

It is important to encourage respected and successful individuals who are seropositive to share their testimony at public meetings. This would contribute to reducing some of the stigma associated with HIV/AIDS. It should also help to involve both high- and low-status people in planning and implementing community activities for PLWHA.

E. ENCOURAGE EARLY HIV TESTING.

To promote early testing, the campaign should address factors identified in this study as barriers to testing including fear of socio-economic and health consequences of AIDS and erroneous beliefs about the cause of AIDS-associated symptoms (i.e. poisoning, bewitchment or *ifumbi*).

F. ENCOURAGE PEOPLE WHO SUSPECT OR KNOW THEY ARE SEROPOSITIVE TO TAKE PRECAUTIONS AGAINST INFECTING OTHERS.

A campaign should address how to continue sexual activity while protecting your partner and not revealing your serostatus, the issues surrounding using sexual relations for pecuniary gain, and ways of experiencing sexual satisfaction without penetration.

2. Through what avenues should a community education program and activities be channeled and upon whom should it be focused?

A. PLWA ASSOCIATIONS

PLWHA associations have the potential to improve the quality of life for PLWHA through association activities and to play a larger role in community awareness programs to de-stigmatize HIV/AIDS. Evidence from the study suggests that PLWHA who are members of an association generally have a more positive outlook on their life and are better able to talk to people in the community.

Because they are advantageous for both PLWHA and the caregiver, home-based care programs in which association members take care of each other should be promoted.

Association-based interventions should inform family members of PLWHA

about HIV transmission and home care, and should address ways of encouraging family members to provide needed care to PLWHA.

Income-generating activities and management training should be developed.

Donor agencies can partner with food distribution programs to help PLWHA through associations. Possibilities of assistance specifically for PLWHA from the World Food Program should be investigated.

The associations' leadership and membership need strengthening in capacity building through such skills as community mobilization, grant writing, project development, resource management, and technical knowledge. Some of this can be achieved through visits to successful associations.

B. CHURCHES

Clergy are an influential group in Rwandan communities and should be more heavily involved in HIV/AIDS activities. While they can reduce the stigma surrounding HIV/AIDS, they sometimes increase it by blaming PLWHA for their sinful sexual behavior. However, by establishing PLWHA associations, churches are currently playing a large role in helping PLWHA.

Interventions should inform clergy about HIV/AIDS transmission, needs of PLWHA, and train clergy to coordinate PLWHA associations effectively.

Churches should be encouraged to establish PLWHA associations along with informal groups among their church members. Group members can help PLWHA by arranging visits, planning home-based care, taking up collections, providing credit to PLWHA, and conducting community sensitization meetings.

C. VOLUNTARY COUNSELING AND TESTING CENTERS (VCT)

VCT centers often do not have the capacity to provide community education or follow-up for the people they test. However, VCT centers should partner with PLWHA associations to share ideas and resources.

D. PARENTS-TEACHERS ASSOCIATIONS (PTA) IN SCHOOLS

Many schools have active PTAs that meet periodically. Community campaign issues, such as treatment of seropositive children and community attitudes toward PLWHA, can be raised at meetings.

E. LOCAL AUTHORITIES

Local authorities need to be sensitized and encouraged to take a lead role in providing community activities and support for PLWHA.

3. To what degree are PLWHA able to seek and receive information to address their needs?

The PLWHA interviewed demonstrated evidence of strong enthusiasm to do as much as their physical and emotional condition allows them to address their needs. However, they do not always know where or how nor have the resources to get what they need. Nonetheless, they want and are willing to use information. Thus, information must be disseminated in close proximity to their homes and should be practical and realistic in reflecting their actual resources.