



Seconde Nsabimana at the RBP+ office

Taking action against HIV and AIDS in Burundi

The experience of Seconde Nsabimana of RBP+

Article produced as part of the KIC project

In Burundi, HIV and AIDS, as in many African countries, bears a feminine face. According to a 2002 national investigation, the seroprevalence rate among women was 13% in urban areas compared to 5.5% among men. In rural areas, 2.9% of the women were infected with HIV whereas only 2.1% of men were living with the virus. By the end of 2005, the number of people living with HIV (PLWHA) in Burundi was estimated to be 150,000, of which 60% were women.

The first organization to rise to the challenge of HIV and AIDS was the Society for Women and AIDS in Africa (SWAA-Burundi), which was established in 1992. It was followed by the National Association of Support for Seropositives (ANSS) in 1994. Some years later, RBP+ was founded, the Burundian Network of People Living with HIV and AIDS. SWAA, ANSS and RBP+ were the principal organizations that realized the need to engage PLWHA in their structures, especially women living with HIV, who joined these organizations and took up leadership positions. HIV-positive women occupy key positions in RBP+. For instance, the board is composed of five members, three of whom are women.

For me, a new experience began in 1988, a period in which being infected with HIV almost meant death. I went to a family doctor who presented me with what I thought was a false HIV test result. My determination to learn the truth took me to an expatriate doctor who confirmed my seropositivity. It was too hard for me, I was just married, and with this development I thought life had nothing to offer anymore. I resigned from my marital obligations –

having intimate relations disgusted me instead of giving me pleasure. The only concern I had were my two children. I breastfed my three-months-old baby at the time. My doctor had assured me that there was no risk of infecting my baby with HIV through breast milk. Six months later, I

From that moment a force was born inside me that now drives me into taking actions to enable me to live positively

learned from the radio that it was strictly forbidden to breastfeed when one is seropositive. The picture that will never leave my memory is that of my baby girl. One morning as she anxiously waited to be breastfed as usual, she was instead given cow milk in a bottle. She reacted badly by screaming and throwing away the milk bottle. This greatly alarmed me.

I endured my initial years of seropositivity in loneliness because my husband was in denial about my HIV status. In the hospital where I worked, emaciated faces, particularly of women confined to their

bed, desperate, rejected by their loved ones who nicknamed them 'candidates for death', scared me. Wherever I went, the shadow of death seemed to follow me. I devoted myself from that time to bringing hope and happiness to the hospitalized women, who, like me, lived with HIV.

Starting to live positively

From that moment a force was born inside me that now drives me into taking actions to enable me to live positively. This is what motivated me to join SWAA-Burundi in 1992 to support positive women. It was the start of my living positively. Now, almost 15 years later, I am the Vice-President of RBP+ and a member of the Centre GIPA, an association that initiates HIV and AIDS-related activities at workplaces.

It is not easy for HIV-positive people to become involved in the fight against AIDS. If one is seropositive, the principal barrier to him or her becoming more active in this fight is that the people in charge of NGOs treat one as a beneficiary of their services and tend to avoid involving PLWHA in management. They expect you to wait and receive the services they offer. This is a form of stigmatization and discrimination. Further, because of the remarkably active involvement of HIV-infected persons in NGOs, staff considers the PLWHA as competitors when paid jobs are available.

Resources

on women living with HIV

Sexual and reproductive health of women living with HIV/AIDS

Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings
UNFPA/WHO, 2006 (83 p.)



This publication addresses the specific sexual and reproductive health needs of women living with HIV/AIDS and contains recommendations for counselling, antiretroviral therapy, care and other interventions. The document argues that sexual and reproductive health services are uniquely positioned to improve women's sexual and reproductive health, treat HIV infections and prevent new ones.

www.unfpa.org/upload/lib_pub_file/616_filename_srh_hiv-aids.pdf

ICW/GCWA Fact sheets (2006)

With support from the UNAIDS-led Global Coalition on Women and AIDS (GCWA), ICW has produced three fact sheets. These frame key advocacy messages based on the findings of ICW project work on:

- Violence against women:
[www.icw.org/files/VAW-ICW fact sheet-06.doc](http://www.icw.org/files/VAW-ICW%20fact%20sheet-06.doc)
- Sexual and reproductive health rights:
[www.icw.org/files/SRHR-ICW fact sheet-06.doc](http://www.icw.org/files/SRHR-ICW%20fact%20sheet-06.doc)
- Access to care, treatment and support: [www.icw.org/files/ACTS-ICW fact sheet-06.doc](http://www.icw.org/files/ACTS-ICW%20fact%20sheet-06.doc)

I do not let anyone point a finger at me. Instead, I prefer to say what I want to say in a vocal manner. The most important thing is that I have informed my family and friends of my status. My spouse only allowed me to speak openly about my seropositivity later in 2000, when he was a volunteer with the United Nations. He at last understood the necessity to break the silence and crack the shell bothering us all – stigmatization. Support can be the motor of change for PLWHA. Earlier, my husband prohibited me from my seropositivity to doctors when I went for consultation. He advised me, to leave them to do their own diagnosis and to guess what was wrong with me. Can you imagine? He even was not comfortable with me disclosing my HIV status to my brothers and sisters.

It was very difficult to disclose our status to our children. The day that I decided to do that, the children said: *“we knew this for a long time mom, the other children nastily told us that we are infected with AIDS like our parents. What's more, dad takes medicines, doesn't he?”* This was the ideal moment to sensitize them on HIV and AIDS and also explain to them the importance of having joined support organizations and to prepare them for voluntary testing.

Becoming more active

In 1992, one of the founding members of SWAA whom I had disclosed my HIV status to asked me if I was interested in joining the new association. I joined them without hesitation because I was motivated by my experiences and my knowledge of the needs of infected women. At SWAA, I learned to talk about my status during the pre- and post test counselling I gave. From 1998 to 2000, I participated in the prevention activities of ANSS because I wanted to make a contribution through exchanging experiences with other PLWHA. In 2001, I joined a pilot project on GIPA initiated by the United Nations Development Programme (UNDP). Today, I am a member of the Centre GIPA. At the end of 2001, we put in place the structures of RBP+, of which I soon became the Vice-President.

Involvement of PLWHA like me in organizations such as SWAA and the Centre GIPA was a lesson and a model for not only public services but also NGOs in the fight against HIV and AIDS. At SWAA, we proved that it was easier for infected women to disclose their status and that psychosocial care could be satisfactory due to the exchange of life experiences. What is more, the people who came for voluntary counselling and testing (VCT) were more confident, more open, reassured and more inclined to behaviour change.

The testimonies given with open minds were an added value for the members of SWAA. At the Centre GIPA, PLWHA's expertise contributed in a remarkable manner to the workplace programmes. It led to more disclosures by PLWHA and to responses such as the setting up of special company-level solidarity funds for purchasing medicines and the development of workplace policies to sensitize management on the need to mainstream HIV and AIDS in programmes.

Finally, I regard RBP+ as my *oeuvre*, a result of my long-time involvement in the fight against HIV and AIDS. Its initiation facilitated the mobilization of PLWHA of all walks of life to become actively involved in advocacy in defence of their basic rights. When we established RBP+ in 2001, people still made fun of us. Stigmatization was rampant and the responses to the epidemic were limited. United we stand! Nowadays, I can confirm without hesitation that in Burundi, despite the fact that access to care is not satisfactory, HIV-positive people and especially women, have an ideal structure through which to express their worries – a network of peers. ■

Seconde Nsabimana

Vice-President RBP+ (Réseau Burundais des Personnes vivant avec le VIH/SIDA)

Correspondence:
E-mail: sekundansa@yahoo.fr