Associations of Seropositive Individuals and Management of the Risk of Stigmatization in Bobo-Dioulasso (Burkina Faso)

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Introduction

In 1997, Burkina Faso had a seroprevalence rate of 7.17%. [1] More recently, in 2000, WHO/UNAIDS data indicated that 500,000 people were living with HIV/AIDS out of a total population of 10.9 million.[2] The epidemic is growing and it is estimated that 122 individuals are infected every day: these figures mean that Burkina Faso ranks second only to the Côte d'Ivoire (12.7%)[3] among West African countries in terms of HIV prevalence. These figures are, moreover, lower than the actual numbers owing to the biases and limitations of epidemiological studies.

However, aside from the epidemiological constraints of sentinel studies, one of the major obstacles to the visibility of AIDS would seem to be difficulties of a social order: seropositivity continues to be experienced as a disaster, a taboo and a shameful secret in many societies (Le Palec, 1994). The interdependence between the social and the public health aspects of HIV/AIDS has led us to focus, from a socio-anthropological perspective, on the mechanisms of stigmatization as they relate to seropositivity in certain social contexts (Desclaux, 1996, p. 267). In Burkino Faso, as in other countries with high infection rates, the spread of the epidemic has been accompanied by the designation of certain groups, such as women, sex workers and truck drivers, as being "at risk" and has led to these groups and individuals being stigmatized and discriminated against.

To study these phenomena, we shall attempt to describe and analyze the way HIV-positive individuals are integrated in a number of PLWHA associations in the city of Bobo-Dioulasso,[4] where in the year 2000 HIV seroprevalence was estimated at 5.22% in a population of 2,450 persons ranging in age from 13 to 49 years.[5] While it might, in principle, be assumed that associations would be shielded from ostracism, observation of their functioning and analysis of the attitudes expressed within them reveal an entirely different picture. For example, PLWHA in Bobo-Dioulasso usually have recourse to associations for material assistance, and it is often not until they have taken care of their material needs that seropositive individuals discover the benefits of psychological help. Relations between PLWHA association members are not straightforward either. Like any social universe, PLWHA associations are marked by the coexistence of a whole range of viewpoints concerning HIV/AIDS – a tendency often reinforced by the lack of clarity surrounding the definition and role of these associations, whose members are divided on various issues. For example, the desire of young women members to have children is often a subject of dispute among PLWHA association members.

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[1] Source: WHO/UNAIDS.

[2] For 1997, the number of HIV orphans in Burkina Faso was estimated at 200,000.

[3] Source: United States Census Bureau, HIV/AIDS Surveillance Database, 6/6000. Note that these figures date from 1997.

[4] Bobo-Dioulasso, located in the southwest of the country, is the second largest city in Burkina Faso. Twenty-six percent of its population, estimated at more than 600,000 in 1999, is employed and 46% is under 15 years of age. Bobo-Dioulasso is a crossroads town. It is characterized by a significant mix of urban and rural populations owing to its location on the main highway (Mali, Ghana, Niger) and railway axes (Côte d'Ivoire). Bobo-Dioulasso is also the largest industrial area in Burkina Faso.

[5] Survey conducted by the Muraz Center, Bobo-Dioulasso.

The field data cited here were collected as part of a research project supported by the Agence Nationale de Recherche sur le SIDA (National Agency for AIDS Research). The research is being conducted jointly by social science researchers belonging to a research unit at the Institut de Recherches sur le Développement (IRD, UR 002) in Marseilles and a SHADEI[6] research unit at the Muraz Center in Bobo-Dioulasso.

Establishment of PLWHA associations

The Espoir-Vie (EV) association: "While there's life, there's hope!" From assistance to mutual support

The history of the EV association is closely linked to that of the SAS Center. Initially, it seems, the Center was to be called "SIDA Actions Sociales" (AIDS Social Action). However, to shield users of the center from stigma, it was decided to call the center "Solidarité Actions Sociales" (Solidarity Social Action). SAS centers are located in several African countries; their mission is to provide support for children and families affected by HIV/AIDS with a view to enabling them to be reintegrated and/or remain integrated in their community of origin. The support can take various forms: advice, socio-economic help, legal aid, economic development assistance in the form of support for income-generating activities, and the linking of this initiative with local association and community networks.

From its first year of operation, the Bobo-Dioulasso SAS center was confronted with a growing demand for services. Faced with this "enormous need for someone to talk to" and an overworked staff, it was decided to reorganize the center's clients into an association with a view to promoting mutual support among individuals with common identity markers, thereby lessening their feelings of isolation. That was how the Espoir et Vie association came into being in 1997.

Espoir et Vie, a non-political, non-denominational and non-profit-making humanitarian association, has the following aims:

- to provide moral and psychological support to any person affected by and infected with HIV/AIDS;
- to defend the rights of persons affected by and infected with HIV/AIDS;
- to collect drugs and donations for redistribution, ensuring that they will be used for those who need them the most;
- to work closely with African and other associations pursuing similar goals with a view to undertaking coordinated action, and to support any initiative to improve the psychosocial, medical or legal situation of PLWHA in Burkina Faso.

Between June 2000 and May 2001, the association provided services to 171 previously enrolled clients and 114 new ones, or a total of 285 individuals (197 women, 35 men and 34 children). Of the clients, 167 were known to be seropositive and 88 were asymptomatic.

Many of the sick arrive in a "fatigued" state even when they are unaware of their serological status. Most are experiencing social and economic difficulties and have come to seek help. Membership in the association is based on a positive test result or simply on suspicion of infection by the virus. Members of the association (numbering 62 at the end of 2002, out of which 22 were women) are no longer over-concerned about serostatus; they are looking for people who can contribute something to the fight against HIV/AIDS: "What have you got to give to the Association that makes you want to become a member?"

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[6] Sciences Humaines Appliquées à l'Evaluation des Interventions.

Since April 2001, the EV association has decided to "adopt a higher profile" and to make some of its activities more visible. A charity run ("*cross de l'espoir*") was organized in April 2001, with the aim of informing the public of the existence of the associations and their activities in support of individuals infected with and affected by HIV/AIDS. The event provided an opportunity for some members of the association to make personal testimonies – a topic to which we shall return later. Similarly, since August 2002 the statutes of the association have been modified, so that it is no longer a body providing support to PLWHA but rather a PLWHA mutual-support association.

From the outset, the SAS center has been the parent structure of Espoir et Vie: SAS counselors are also EV counselors and EV Headquarters is located on SAS premises. However, EV officials have the impression that the relationship with SAS is infantilizing and stands in the way of EV developing and maturing. They are also critical of the fact that EV is left out of SAS center activities:

> "EV considers itself to be an SAS-center association. We would like to participate, if only in SAS meetings, so as to keep ourselves in the picture. We would also like to have access to the offices and equipment, which we are equally concerned to look after. We look to you also for information on project development, fund-raising and advocacy initiatives." (EV executive committee member, March 2001)

The SAS center, for its part, has accused the Association of making improper use of SAS property at a time when SAS is having difficulties in mustering funds. In addition, certain members of the association have been criticized for having told partners that SAS no longer exists.

The Yèrêlon Association: "Know thyself!"

The creation of the Yèrêlon Association ("Know thyself") was linked to a public-health research project of the same name. This project was launched in response to a growing awareness of the difficulty of combating STIs (sexually transmissible infections) and HIV/AIDS among women categorized as "prostitutes".

A study on prostitution carried out from December 1997 to May 1998 by researchers at the Muraz Center[7] helped to deconstruct this category by demonstrating the wide variety of practices engaged in by women classified as "prostitutes". This anthropological investigation identified six categories of women classified as most vulnerable: "stools" (prostitutes who work in small studios), "street-walkers" (women who solicit on the street), waitresses (women in bars), sellers (of fruits and vegetables), students and "cabarets" (sorghum-beer sellers). Nevertheless, the use of such categories can in the long run lead yet again to stigmatization of the individuals so classified. Careful distinctions must therefore be made by researchers wishing to employ these categories or to refer to certain social practices to explain the propagation of an illness in general and of HIV infection in particular (Taverne, 1996; Vidal, 2000). For public health purposes, the project is conducting a clinical follow-up on a cohort of 300 women representing these six categories.

The *Yèrêlon Association* was set up at the suggestion of those in charge of the Yèrêlon *public action project*, in response to the large number of requests to participate in the cohort study. The association, which was founded on 28 September 1999 and now has over 800 members, is a community-based

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[7] See P. Huygens et al. 2001. *L'initiative Yèrêlon. Comprendre et atteindre les prostituées clandestines à Bobo-Dioulasso dans le contexte de l'épidémie de VIH: vers une approche étiologique et compréhensive de la prévention auprès des femmes vulnérables*. [*The Yèrêlon Initiative. Understanding and Reaching Clandestine Prostitutes in Bobo-Dioulasso in the ¨Context of the HIV Epidemic: Towards a Comprehensive Aetiological Prevention Approach for Vulnerable Women*]. Report, UNAIDS/SHADEI (Muraz Center).

organization bringing together vulnerable women in Bobo-Dioulasso involved in prostitution.[8] The membership of the association, reflecting the circumstances in which it was set up, is not limited exclusively to HIV-positive women. It is not, therefore, a PLWHA association technically speaking.

The aims of the *Yèrêlon Association* are to improve the physical, social and economic well-being of the women involved; to prevent the emergence of new cases of STI and HIV in women through awareness-raising and education; to promote the use of condoms and establishment of a support fund for the creation of income-generating activities for the women to ensure their economic self-realization.[9] Since its inception, the association has been organizing HIV/AIDS prevention activities, followed by "talks/debates" at prostitution sites. The purpose of these activities is to promote the association and to make a profit.

The difficulties encountered by the association, which was a spontaneous "spin-off" from the cohort study, arise from the fact that it tends to distinguish between two types of members: participants in the cohort study, who receive free health care, and others who must pay. As a result of this two-track system, the association has to cope with the disappointment of some of its members (not included in the cohort) who feel left out. In addition, the linguistic and cultural diversity of the association members leads to distinctions being made between English-speaking and French-speaking women.

Unlike other associations working to combat HIV, which target their efforts on an outside group, the Yèrêlon Association sets out to provide counseling services for its own members, functioning as both a service provider and a mutual-help group. Because of the risk of indiscretion, owing no doubt to the close link between counselors and patients, the Yèrêlon Association is a care provider without "patients". Concerned about leaks in confidentiality about their serostatus, some association members voice the fear during the consultation process (notably when receiving psychological support) that other members of the association will find out about their seropositivity. Concealment of seropositivity within the association itself explains why it has proved difficult to organize discussion groups among seropositive members.
More recently, the association's PLWHA members have timidly begun meeting in mutual-support groups, fearful that their serostatus will become known.

The fact that they engage in clandestine prostitution makes it difficult for certain women to join the association or be active members. Some of these women do not attend the monthly meetings because they do not want to be regarded as prostitutes. Furthermore, the association's executive committee is eager to demonstrate that the association is not composed solely of sex workers.

Like Espoir et Vie, the Yèrêlon Association retains close links with the context in which it developed: its headquarters are located on the health service premises, adjoining the Yèrêlon project, making the association dependent on the latter: "The project is on vacation; so where can we meet? We are not free. We would like to be independent so as to pursue our goals all the way"[10] (a member of the executive committee).

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[8] All the women concerned do not define themselves explicitly as sex workers and this can have implications for the life of the association. For example, English-speaking woman calling themselves sex workers tend to be excluded from the association's activities by the French-speaking sex workers. In addition, women who are "clandestine" prostitutes are afraid to be seen in the association and to be openly associated with other prostitutes.

[9] Declaration of the Yèrêlon Association.

[10] Following recommendations made by a socio-anthropological study, the coordinators of the project had begun to look for premises outside of the project site to enable the association to become independent. However, if the project itself decides to move the association to another location, that would hardly be a token of independence!

Responsabilité-Espoir-Vie-Solidarité (REVS+): "Always remember that our efforts are meaningless unless they contribute to the well-being of people and their community"

REVS+ defines itself as an association of persons infected with and affected by HIV/AIDS. Aware of the difficulties of informing individuals of their seropositive status and the consequences of such a disclosure, health professionals took the initiative of establishing an association to assist HIV-infected and -affected individuals. Study groups were set up with a view to improving the organization of disclosure and ensuring the follow-up of individuals testing positive. Against that background, and with the support of a French physician, a group of individuals infected by HIV/AIDS established REVS+ on 10 June 1997. By the end of November 2002, the association had 412 members – 329 women and 83 men – and was taking care of 220 orphans.

REVS+, which was officially recognized on 17 February 1998 and whose headquarters are located in the precinct of the Bobo-Dioulasso Regional Health Department, is sponsored by the regional director of health. Apart from the executive committee, the association's staff includes the chiefs of the: home and hospital visit unit; the information, education and communication unit; the advocacy unit; the training and documentation unit; the unit for the follow-up of orphans and vulnerable children; and the medication unit.

The overall aim of the association is to combat the stigmatization of PLWHA. Faced with the abandonment and stigmatization of PLWHA, the REVS+ association hopes to improve the lives of people living with HIV/AIDS, orphans and their families in Bobo-Dioulasso. The specific objectives are as follows:

- to combat AIDS-related stigmatization, discrimination and rejection;
- to assert and defend the rights of seropositive individuals, AIDS sufferers and orphans;
- to facilitate exchanges between PLWHA by furthering mutual support among its members;
- to develop the skills of its members through training, information and counseling.

Once again, advocacy and personal testimonies are regarded by the association as a means of publicizing its work. Indeed, one of the members of REVS+ was the first PLWHA to speak about his HIV infection in public. According to the president of the association, individuals should prepare their testimonies in advance to cushion the impact on themselves and their families. At the same time, testimonies should not be made in the sole interest of the individual and to the detriment of the association: "Individuals must not see themselves as separate; we are part of a group". Another REVS+ official believes that the "appropriation" of HIV is essential to dealing with the fear following upon the disclosure of seropositive status: "we must 'own' HIV, master our fear of it and continue to be committed at the international level. AIDS is not something that only happens to other people!"

Protecting associations against stigmatization

Having described the background to the creation of these associations, and outlined their aims, we may now focus on their common characteristics, with particular reference to stigmatization.

PLWHA associations in Bobo-Dioulasso are all recent creations. Although AIDS was officially recognized in 1986, it took 10 years for "self-help" associations to emerge.[11] The creation of such associations and the expansion of their activities undoubtedly owe something to the first testimony by a seropositive individual (November 1997). The creation of these bodies was also a consequence

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[11] Self-help associations bring together individuals sharing the same social circumstances (vulnerability for example) or victims of the same stigma; these individuals meet to defend their common interests.

of the official recognition of AIDS as a social disease in 1995. The official declaration of AIDS cases and the establishment of plans and programs to combat HIV/AIDS dates from 1986; but it was not until the long-term government plan for 1996-2000 that the psycho-social and social care of individuals infected with and affected by AIDS was identified explicitly as a main line of action[12] by the national authorities.

Moreover, because of the risk of stigmatization, the associations avoid all reference to "AIDS" in their acronyms. The same is true of their slogans: "As long as I am alive, I have hope!" (EV); "Know thyself" (Yèrêlon); and "Always remember that our efforts are meaningless unless they contribute to the well-being of the people and their community" (REVS+).

The significant problems of visibility experienced by all these bodies is linked to the fact that they are all located in and/or affiliated to public health structures. This can help to protect them by not raising suspicions about the seropositive status of their clients, who can justify their visit to a health center on grounds other than those of being a member of a community of seropositive individuals.

> "We have a big family. We have the same mother, but different fathers. I don't have my father anymore – he died. We don't all live together but we get together in the family compound. I don't want to tell them about my problem. They have money, but they can't help me. Worse, they're going to tell other people that I'm infected. My sister also goes to the health service. She took a test and got the results. Each time she asks me why I don't go back to pick up the results. I told her I didn't have the courage. I was really worried that she would find out that I am infected; but she didn't discover anything; I sounded her out and realized that she didn't know anything. She doesn't even talk about it anymore. That encouraged me; that's why I keep going to the health service." (a female member of the association).

The associations described here are far from uniform, at least as regards the criteria used to define members. On close examination, one finds that these are based on "constructed" categories: members, active members, group leaders, volunteers, beneficiaries, PLWHA, infected persons, affected persons. Classified in that way, members are not necessarily beneficiaries and vice versa. Nor is account taken of the fact that a PLWHA might be infected with and affected by HIV at the same time.

We are faced with a variety of concepts whose content is still far from being firmly established. This constellation of concepts necessarily gives rise to ambiguity, an uncertainty with regard to whether members of the same "self-help" association can openly share their serostatus. Within a PLWHA association comprising infected and affected individuals, it is often a delicate matter for a seropositive person to speak openly about their serostatus to other members. The distinction between "affected" and "infected" persons leads to feelings of suspicion among members, which hardly makes life any easier for some individuals, who end up seeking strategies to hide their seropositive status.

We found that in the Yèrêlon Association, which brings together vulnerable – including seropositive – women, very strong emphasis is placed on discretion about members' seropositivity. Secretiveness leads seropositive women to avoid going to meetings with donors involved in the combat against HIV. Paradoxically, even within the Yèrêlon executive committee, it is impossible for officials to designate individuals to attend donor meetings since that would be tantamount to a public revelation of their seropositivity. As an administrative official put it: "it's like a masked ball since no one knows who is infected and who is not!" It was these "community facts of life" that led the

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[12] Decree N98-467/PRES/PM/MS of 2 December 1998 provides for the establishment of a solidarity fund for AIDS patients and AIDS orphans.

psychologist/counselor for the Yèrêlon Association to orient the women towards another self-help association in which seropositive women can speak more freely about their seropositivity with their fellow members.

Individual management of seropositivity within the associations

The membership of PLWHA associations is in the main female. This finding poses certain questions: are women more affected by the epidemic than men? Or why, given equal infection rates, do women turn to associations more than men? To what extent are women faced with social difficulties outside of these associations? How do women cope with questions about their seropositivity within the associations?

Generally speaking, knowledge and disclosure of seropositivity leads to a drop in self-esteem and a fear of rejection. Social attitudes with regard to AIDS make it difficult to share the information about being HIV-positive with other people. Knowing that one is HIV-positive therefore means devising strategies for hiding this serological status.

The decision to go for HIV testing generally follows the illness or death of a loved one. Often it is a decision prompted by the appearance of physical signs resembling those associated with AIDS. Nonetheless many women go for HIV testing under pressure from their husbands. When the results are negative, some husbands show the test results to their friends to prove that they are not HIV-positive.

In countries practicing the levirate, when a husband falls ill, a brother-in-law may urge HIV testing to be sure that the woman who will become his wife is not infected. If the test turns out positive, "social camouflage" strategies may be deployed: the brother-in-law will take the precaution of publicizing the marriage to the entire community, but the two partners will abstain from any sexual relations.

Reasons for resorting to associations

People generally contact an association after visiting an anonymous screening center, hospital clinic or health center. In an environment where seropositivity will most likely entail stigmatization, recourse to an association becomes necessary to lighten the burden of silence. Still, the frequently advanced explanation for contacting an association is the material and therapeutic help it can offer. The importance of psychological support only emerges after a person becomes a member of an association. That being said, PLWHA are confronted with the difficulty of communicating their serostatus after as well as prior to membership.

Strategies for communicating seropositivity

Who should you tell? How should you say it? When should you say it? These are the questions haunting the PLWHA whom we met in the associations. PLWHA are worried first of all about how their family will view them, and then about their reputation among friends or neighbors. A difficult family situation, often linked to family size and its socio-economic status, can discourage talking about HIV/AIDS infection:

> "In polygamous families, the wives are afraid of each other; people don't trust each other. If they find out, they will tell on me; I don't want one day to be pointed at in

> public like an AIDS victim. I can't tell anyone at home; we have a very large family." (30 year old woman, mother of two children, living in the family compound)

For an adult female, the fact of living in the parental compound is already problematic. Disclosing her seropositivity would accentuate the disrespectful behaviour towards her.

> "It made me sick, I was depressed for two days. I was sick all the time, my parents had spent too much; since I didn't get any better, I decided to have the test done; when I found out, it was sad, I felt sorry for myself, I said to myself 'How can a person who is not respected when they haven't got AIDS be respected when they have it.'" (27 year old woman, mother of three children, single)

Anita's situation says a great deal about how family circumstances can lead individuals to hide their serological status from their parents. Anita is the mother of a two-year-old boy. Two other children died very young. Following repeated hospitalizations during a pregnancy, she decided to take a screening test. Even though her results were positive, her son is not HIV-positive. The father of her child is a civil servant, but it is Anita's father who pays for the medical expenses. Anita's boyfriend decided to "pull out" (leave her) when his mother told him (on the telephone) that Anita was seropositive: "He says that he cannot take care of me, that he is sorry, he doesn't know why he did it, but he doesn't want to squander his life. And to think I had two children with him (the second one died)." Anita and her son live in her parents' compound. At the time we met, she had still not told her parents about her serological status. Even though she says she is ready to tell them, the constraints of family life make her hold back:

> "No one in my family knows. As for me, well, I am ready to tell them, but we have a large family, in our family there are 60 people because there are the wives of my older brothers, my sisters have male children who have wives. I have sisters, my mother has co-wives, and there are the children of my older brother who are there, so we are a big family. So my father is not going to be understanding, he is going to say – you went out and picked up a filthy disease, he's going to say that in public. He won't kick me out but he will say it in public and you will feel ashamed in front of the others. Then your life will be difficult. He is not going to keep it to himself, he will say it out loud, he doesn't think that's going too far, he will say it and then according to him it will be all over with, but he doesn't know that the others are going to take note. Then in the neighborhood your name will be dirt and you will have problems living with your own family. So that is why even the father of my child does not... know."

Anita urged one of her younger sisters to take an HIV screening test, and this younger sister found out that she was HIV positive. Even though she gives her cotrimoxazole everyday, Anita does not feel ready to share her serostatus with her sister who, she believes, would not be able to keep the secret if a conflict arose.

Let us take the example of another woman:

> "I didn't tell my parents anything. If my father finds out he is going to tell everyone; when someone comes to our house my father starts to tell him what the father of my children did to me. I already complained to him about his behaviour one day and asked him whether I was not his daughter? Especially because there are already problems in the family: I have twin sisters who are complicated, you can't sit around the fire with them (chat); one day they told me that they have money and that I could become like them. Yesterday, my father hit my mother. We all slept outside, he told

> us to leave with our mother. We told our uncle what happened, he wanted the old lady to leave and go to Niangoloko, she refused; the old man isn't speaking to us anymore; today when you haven't got any money! When I had money, I would give it to everyone and I was appreciated! But today, this same family buys their wood elsewhere while I sell wood." (37 years old, mother of four children)

The case of another HIV-positive woman, forced to leave the home she shared with her husband to go and live with her parents even though she was ill, is instructive. This woman is from a large polygamous family (three wives and more than 20 children). She left her husband two years ago:

> "My husband says that he has spent too much and that he couldn't spend anymore. After my two stays in hospital, his behaviour towards me completely changed. He could go for two or three days without speaking to me. When I was feeling a little better, with the agreement of his family he asked me to go back to my parents, saying that he had no more money to take care of me. 'I sold goats, sheep, everything, to pay for your medical care; all I have left is my bicycle. I am not going to sell it to pay for your treatment', he told me. I don't know if he was thinking of AIDS. He never mentioned it to me; anyway, I was very ill, to the point where I couldn't even get up. Aside from my health problems, we got along fine; I have always shown him respect. I keep asking myself where I could have gotten infected. My husband is still alive; he has never fallen ill; in fact he is in very good shape. With this illness, I am afraid to go back to my husband; he has not remarried; but if I get sick he might throw me out again. I am afraid of that happening. My father would curse me! He says it's because of another man but not my ex-husband. He is very frustrated, my father, especially since my husband is a relative; he comes from a neighboring village. I prefer to be by myself. If I leave, I will find the family door shut in my face; I choose to be by myself." (30 years old, mother of two children).

As for sex workers, their relatives are far from the city and it is difficult for them to tell their partners about their seropositivity owing to the instability of the relationships. While they speak of their "regular" partners as significant figures for them, they confess that they still fear being abandoned by them if their seropositivity is discovered. They evince a general mistrust of men ("you can never understand men"), but also fear economic vulnerability ("at the cabaret if they learn that you have AIDS, the clients disappear one by one"). English-speaking sex workers fear that social networks will reveal the secret of their seropositivity. In one of the associations, the issue of fellow members failing to respect confidentiality has been raised. Sharing information is not any easier for women who are "clandestine" sex workers. The couples are unstable. Naturally the decision to disclose one's seropositivity is made only after assessing the discretion of the person who will be told. Making one's serostatus known may lead to belittlement in the eyes of others.

For widows, revealing their serostatus to the members of their former husband's family is a strategy to preserve their dignity, in anticipation of illness: "so, in case I fall ill my parents-in-law cannot accuse me of having become infected after my husband died".

When is the right time to tell one's family about being seropositive? The seropositive individuals we met tended to adopt a strategy which consisted of frequently bringing up the topic of AIDS with their family. Such frequent discussions can even lead in the long term to the decision of another family member to have a screening test. What we observed is that while tensions and conflicts in large families can discourage the disclosure of an individual's serostatus, conflict in a small family can provide an opportunity for PLWHA to announce their seropositive status. The disclosure serves to underline the vulnerability of the infected person and the need for their relatives to be more indulgent with them. The family then becomes more compassionate.

Regardless of whether they are members of an association, PLWHA have strategies for keeping their seropositive status secret, from hiding symptoms associated with the illness (diarrhea, weight loss, dermatosis, hair loss) or any medical bills which might arouse the suspicions of the family to denial of the illness in cases where family members suspect HIV infection. Because of the risk of being found out during social interaction, the daily life of seropositive individuals is characterized by behaviours based on pretence.

Social camouflage

For some women social camouflage means finding a stable partner and/or having a child. A seropositive woman, age 27, describes it this way:

> "I have a boyfriend – you really have no choice. He is married, he's a policeman, he doesn't know my serostatus, from time to time if he wants to have sex with me, he uses protection ... When you are alone at home all the time, you think too much, you imagine yourself being rejected, that's the reason, you want to have fun and then, if you tell a man that you are seropositive, it's all over. He's going to reject you and tell everyone. So you will be rejected, that is why we control ourselves, we're here, the family insults us, that we don't want to get married, that we want to be prostitutes, and on and on; it really hurts, often if you think about it, it keeps you from sleeping, it really worries you!" (young woman, member of an association).

Within the associations, women are often very preoccupied with the source of their infection: widows wonder if they were infected by their dead husband. It seems as if being a widow is proof of the absence of guilt. However, in reality, the situation is often more complicated.

We met Aline, a young woman, widowed and mother of a two-year-old child, at one of the associations. Aline says that she was at her husband's bedside until his death. Her husband had had a screening test while he was ill but had not informed anyone in the family, not even Aline, his wife.

> "When he came in, I asked him if he had got the results, and he said that they had not given him anything. I said: "they didn't say anything, not even what illness it was?" He said that they suspected it was that, but that it wasn't. And until he died he never showed me the results. It was when we were doing the paperwork after his death that we found the results in one of his garments, it was positive. I don't know how he managed to hide it there since he could not even get up by himself."

While her son was in the hospital, Aline's mother-in-law learned through a relative who was a public health worker that her son had HIV/AIDS. She decided to take him out of the hospital on the pretext that she had no more money: "They said that he wasn't going to live, that it wasn't worth wasting any more money." She then accused Aline of infecting her son: "Because before she tells me to go take the test, they are already accusing me of bringing the illness into the family".

After the death, the mother-in-law continues to accuse Aline: "They discussed it with my older sister, that since the time I married their son, I didn't get any better, that her son also didn't get better, that our child didn't get better, so that it was me who brought the illness into the family". But Aline's parents defended her: "She is not someone who runs around, she would probably have become a nun if your son hadn't proposed to her!" "So", Aline continues, "since my parents spoke out, they have stopped; but then they started up again, saying that he was living with a girl before he got married, that he had a child with her and that she died." After taking a screening test, which turned

out positive, Aline decided to tell her mother-in-law, who replied "May God help us!" After her disclosure, Aline decided, on the advice of her parents, to remain in the compound of her parents-in-law. While she has not been banned from the family household, she has been dispossessed of most of the household goods.
As we have already seen, in associations with members who are both infected and affected, PLWHA have to keep their serostatus secret, which leads them to employ concealment strategies.

A 32-year-old woman, the mother of four children and belonging to an association, expresses her doubts about the discretion of another member of her association:

> "Aside from E., no one else in the association knows me personally. How did I discover my HIV-status? My husband was sick, I learned that his first wife had died of AIDS. He also had diarrhea: after he died, I wanted to be tested. I discussed it with one of my friends, she is very attached to me, we do everything together, and she was worried. Why do you want to take the test? She asked me. Your son is nice and chubby (*it was after giving birth that she decided to test her serostatus*), what are you afraid of? I insisted and she spoke to her brother who is a counselor at an anonymous screening and information center (CADI). I went to see him. I didn't even have enough to pay for the test, I only had 250 francs and the test cost 500 francs. He agreed to do a blood test on me after asking a lot of questions. I said that I wasn't afraid. He told me to come back for the results in 15 days; but it took me 30 because I got scared after the test.
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> "When I heard the results, I was shocked; I couldn't say a word. I didn't want to talk about it with anyone; not even with his sister (*the counselor's*), who is my close friend; he told me it wasn't good to hide it from his sister; so I told her.
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> "A few days later I went to an association meeting. At the meeting, the president of the association said that the association had signed an agreement with the screening center so that members of the association could find out their serostatus, that any woman who was interested should give her name.
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> "E., who had asked me to take the test after the death of my husband, signaled me to put my name on the list for the test. I gave my name, my stomach in a knot; I didn't want to tell her that I had already taken the test and that it was positive. That day, they said that there was a counselor for individuals who were infected or who needed to talk to someone confidentially; so I went to meet with the counselor. I told him that I had already taken the test and that I didn't want to go back there; but I didn't want to disappoint E. either by telling her I didn't want to do it. I didn't want to give her my results either because E. can't keep her mouth shut; she told on a woman who lived in the neighborhood (*she disclosed her results*). So I said to the counselor that I didn't want E. to know; since I wanted to see him again without arousing E.'s suspicions, he gave me an appointment elsewhere. These meetings helped me to understand certain things."

One day when the counselor was seeing people in his office on the association's premises, while she was waiting her turn, a group leader who knew her went into the office and told the counselor: "she's a member of the association; she lost her husband to a disease which looked like AIDS. X, who is her neighbor, tried to get her to come and take the test. Her husband died of AIDS. She herself had severe health problems especially during pregnancy. Today she is sick, persuade her to take the test, it is important that she learns how to take care of herself." Later, during the consultation, a dialogue takes place between the patient and the counselor:[13]:

> "- So, you're here to take the test?
> - She (*the group leader*) came by to check on my health and then she asked me again to take the test. Can I tell her that I know my results?
> - I don't know.
> - Her sister was sick; she sent her to the village to get medical care. She had her take the test. When she learned her sister's results, she let it be known. I would like to tell her, but how can you trust her in those circumstances? I still think she wants what's best for me. When I think of that, I say to myself that I shouldn't hide anything from her. It's thanks to her that I am being treated: before, I took whatever medication I could get my hands on; that gave me diarrhea; so she helped me live longer. I think that she has been honest with me; she supports me.
> (After a moment of silence, she asks me to call in the group leader. I asked her some questions about her social environment; after some hesitation, she maintained that the decision to tell the investigator about her status was a good one; as soon as the investigator came into my office, I noticed that the consultee was a little embarrassed; she lowered her head; she asked me to explain the situation. I explained to the group leader that the consultee had already taken the test at CADI a while ago; only she had not had the courage to share her serostatus with anyone, not even the members of her family). 'It's a bad neighborhood; I don't want anyone to know that I am sick', she said, wiping away her tears."

Managing disclosure to fellow association members and the outside world

Disclosure of status is not systematic within associations attached to health facilities (anonymous screening and testing centers, maternal and infant health clinics, hospitals). It is easier to reveal the information in the context of a personal relationship – having first assessed the risk of stigmatization. However, other criteria justify the use of strategies for retaining information on a person's seropositive status.

Corinne, 35 years old, is single and mother of a small boy. She is an active member of an association. At a charity run held in Bobo-Dioulasso on 7 April 2001, she appeared in public and made a tearful speech. While the words left no doubt about her precise seropositivity, her tears raised some questions about her precise serological status.

> "So everyone was left in doubt; people said that I had gone public, others said I hadn't and that I cried out of pity, each one had their opinion, and ... I believe that two weeks after the charity run, B.D. (television presenter), who invited me to Ouaga, during a broadcast on AIDS with Doctor P.T.S. and S.M. (*the first person to reveal AIDS publicly in Burkina Faso*) and other members who are involved in the struggle were there. And during the questions, she showed the charity event and asked me whether or not there had been criticisms, what impact that had on me, afterwards she wanted to know my serostatus and I couldn't, I told her no! I wasn't going to answer that."

When she is questioned about her reluctance to make an explicit public disclosure, she explains:

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[13] As reported by the counsellor.

> "A public disclosure. Well! I often ask myself the question. Most often what stops me, the thing that stops me from going public is the fact that I come from a rather poor family, I have a child who is not recognized by his father, so the child is my responsibility, then I had a boyfriend who helped me a little, just a little, well I tried to persuade him, to convince him to take the test, but he didn't want to. He didn't want to and, well, he left. He always used to come and hassle me, he wanted to know why I am in the AIDS movement, why I didn't look for other work. Myself, I don't work, I have to live, if it happens that ... I have had two or three boyfriends in Bobo here, and sexual relations at least with a few who didn't use any protection. So I tell myself that if I went public just now, then I might make an enemy. Really, I don't know; what I have in mind are all those constraints."

The spheres in which individuals are willing to go public are therefore limited. A charity run is a restricted social venue whereas a television program is broadcast to a wide audience. For another woman, belonging to the association and being involved in the combat against HIV/AIDS also means worrying about protecting the reputation of her seropositive husband, who has a profession of some social standing. Membership in a PLWHA association does not rule out strategies for controlling information in the various social spheres.

The cooperation between PLWHA associations and health workers pursued in Bobo-Dioulasso since 1995 has led to a significant improvement in medical and psychosocial care for PLWHA.[14] The almost daily presence of members of PLWHA associations within some clinics – in this case, the medicine and pneumonology unit of the national hospital center of Bobo-Dioulasso – helps to lighten the heavy burden shouldered by health workers dealing with HIV patients.

Given the difficulty of disclosing seropositive status, the presence of associations within the hospitals is a means of overcoming the problem of "unregulated screening", in which the results are not divulged to the patient. The involvement of associations has helped forge a chain of confidentiality between patients, caregivers and association members, enabling an effective screening, disclosure and treatment strategy to be put in place. Yet family members are hardly ever involved in the chain. How is it possible to combat HIV/AIDS and its social consequences effectively if the patient's family is excluded?

Conclusion

AIDS is rife in contexts beset with economic difficulties. Access to antiretroviral drugs remains problematic for most sufferers. The way HIV/AIDS patients are looked after from the standpoint of the social environment reveals a growing trend of individualism in African societies, a consequence of the economic crisis affecting many African countries: "People are searching for themselves; families do not want to invest in a sick person who, as they see it, is going to die". The stigmatization of seropositive individuals can thus be seen as a mark that disqualifies them with respect to social solidarity. As regards family relations, the seropositivity crystallizes family tensions pre-dating the disclosure of serostatus (due to the behaviour of the seropositive individual in anticipation of rejection). For women who remain in the family household, relations with their brothers often become strained.

Associations are not without their social constraints either and must cope with the problem of stigmatization. Their members are daily confronted with the spectre of shame and develop reflexes that anticipate stigmatization. Widows, whose property has often been looted by the families of their

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[14] In an article (1999), N. Meda emphasizes that of a total of 400 physicians in Burkina Faso, less than 10% are involved in counselling or the disclosure of serology results.

deceased spouse, join associations but do not bring charges for fear of the consequences. The future of children is a permanent concern in a time of AIDS. Dealing with the serological status of children is still problematic, even for members of associations. It is difficult to get a screening test done on a child, and this is hardly foremost among the concerns of PLWHA. On the contrary, an almost total silence continues to reign, almost certainly reflecting a reluctance to know the serological status of the children of PLWHA.

> "I don't really want to know the serological status of my children. I have AIDS, that's already an enormous burden, I don't want to think about the idea that my children might be infected, I prefer not to know" (35 years old and father of two children).

Interactions do not take place between, on the one hand, individuals "shameful" of their HIV infection and, on the other, those who are "without shame". Stigma is a social construction, shaped in a context of social relations:

> "... the notion of stigma does not so much imply the existence of a set of particular individuals who can be separated into two columns, the stigmatized and the normal; but rather the effect of an omnipresent social process that causes everyone to have two roles, at least in some respects and at some phases of life. The normal and the stigmatized are not persons but points of view. These points of view are socially generated interactions in contacts between mixed groups, as a result of unsatisfied norms that influence the encounter." (Goffman, 1968, p. 163)

In short, the internalization of fragility (in relation to sexuality, power, and gender) is present within associations. It is important here to stress that the social consequences of discovering seropositivity vary depending on whether the infected individual is well or ill. It seems that shame of the family is greater when it learns of the seropositivity of one of its members if that person is already ill. In this case, it is as if they were confronted by a failure: "people lose hope"; some people come to visit out of curiosity, just to see the physiological effects of AIDS. Out of shame for their appearance, some AIDS patients do not want to be seen by other people: "Others will laugh at me!".

The shame arising from the discovery of seropositivity is governed by a process of communication (direct and indirect[15]) that is instrumental in the social degradation of the individual. Associations are scarcely exempt from this phenomenon.

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[15] Rumours play an important role in the communication process. As a female patient belonging to an association put it: "people are looking at me, they are whispering ... people have been criticizing me ...".

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