The ambivalence of stigma and the double-edged sword of HIV/AIDS intervention in Burkina Faso

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A B S T R A C T

This article analyses the causes of HIV stigmatisation in Burkina Faso as perceived by people living with HIV/AIDS (PLHIV) and people working in AIDS-related Community Based Organisations (CBOs). Stigmatisation continues to be a pressing issue when dealing with HIV/AIDS in Sub-Saharan Africa. The article is based on direct observation of HIV-related practices within 20 CBOs in Burkina Faso, as well as semi-structured interviews or focus group discussions with 72 PLHIV and 90 professionals and volunteers working in CBOs. PLHIV were chosen by convenience sampling among the persons who accessed CBO services and were interviewed about their life quality and experience relating to HIV. Professionals and volunteers were interviewed about their strategies, their achievements, and the problems they encountered. The research was conducted in the course of three months fieldwork between September and November 2009.

Our principal findings show, firstly, that moral or social stigmatisation does not in any simple way derive from fear, ignorance or inaccurate beliefs but that it is also established and continually reinforced by official campaigns addressing HIV/AIDS. Secondly, we show that stigmatisation is a socially complex and ambiguous process. Based on these empirical findings we conclude that HIV/AIDS need no longer be approached in AIDS intervention as a sexually acquired and fatal disease. When reliable access to antiretroviral drugs is in place, AIDS becomes a chronic condition with which one can live for many years, and this makes it easier to address HIV and moral or social stigmatisation by downplaying the current focus upon sexuality and morality.

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Introduction

The dramatic consequences of stigmatisation for People Living with HIV (PLHIV) and for attempts to address the HIV/AIDS pandemic have often been highlighted. “Zero discrimination” has therefore become one of the three UNAIDS goals, along with “zero new HIV infections” and “zero AIDS-related deaths” (UNAIDS, 2010). In Burkina Faso the response to HIV/AIDS depends heavily on the work of Community-Based Organisations (CBOs), many of which have been created specifically by and for PLHIV with the support of foreign donors (Nguyen, 2010). These organisations have been at the forefront of the fight to make antiretroviral (ARV) drugs accessible to the general population through public health care facilities (Nguyen, Grennan, Peschard, Tan & Tiendrébéogo, 2003). The CBOs stand for more than 90% of all HIV blood tests as well as almost all socio-psychological care provided (Ky-Zerbo, Somé, Simaga, Kéré, Conombo & Obermeyer, 2008). The response to AIDS in Burkina Faso seems to have had an impact since the estimated adult prevalence rate was 1.2% in 2009, down from 2.1% in 2001 (UNAIDS, 2010). Yet, despite many years of interventions, stigmatisation is still reported as being widespread.

According to Goffman (1986), the term stigma refers to an attribute that is “abnormal” (when compared to a specific norm) and deeply discrediting, leading to individuals being denied full social acceptance. The stigma can be physical, as in the case of handicap or medical symptoms, or it can be moral and derive from the disapproval of sexual, criminal or “abnormal” behaviour, or else the stigma can be social and attached to a certain identity or profession. People bearing a stigma are ascribed a specific social identity and are expected to be different (or behave differently)
from the rest of the population. They are then treated differently and thereby stigmatised (treated as discreditable or less worthy).

HIV stigmatisation in Africa is referred to as building on a combination of physical, moral and social stigma (Bond, Chase & Aggleton, 2002; Holzemer et al., 2007; Nyblade et al., 2003; UNAIDS, 2000). First, the physical stigma derives from the fear of infection by the HIV virus and leads to physical rejection (refusing to eat with PLHIV, shake their hand, use the same toilet or bathroom, etc.) The first prevention campaigns reinforced this fear of a physical contagion by using images inspiring disgust and repulsion (Ogden & Nyblade, 2005; Pezeril, 2011). Today, prevention messages use less dramatic images; people are often well informed about contagion and AIDS symptoms are less frequent due to the increasing availability of ARV (see Sanou et al., 2008). Nevertheless, many people continue to have ambiguous feelings about physical contact with PLHIV.

Second, HIV brings a moral stigma because it is closely associated with types of sexual behaviour regarded as “immoral” (multiple sexual partners, adultery, promiscuity, sex work, anal sex) that were already stigmatised prior to the emergence of AIDS (see also Herek & Glunt, 1988; Nyblade et al., 2003). PLHIV are thus stigmatised not so much because they are HIV-positive, but more specifically because they are seen as unfaithful or promiscuous. They are consequently blamed for their misery, HIV being presented as a just punishment for their perceived “immorality”, even though it can be acquired non-sexually or within marital relationships.

Third, HIV and sexual behaviour considered as “immoral” have been closely associated with specific professions or social groups (truck drivers, hairdressers, street or itinerant vendors, sex workers, college students, local beer brewers) perceived to be less faithful or more promiscuous than others, which has led to their social stigmatisation (see also Gruénais & Ouattara, 2008). The risk group approach has in recent years been invigorated through the UNAIDS campaign labelled “Know your epidemic, know your response” that recommends targeting resources to “key groups” (such as sex workers, truck drivers, men who have sex with men). Although this can be legitimated by the need to provide specific types of prevention or care to those who are most at risk and have special needs, it also reinforces their stigmatisation and the development of an imagined immunity or denial among those who do not belong to these groups, and it fails to take account of the political dimension of HIV prevention (Buse, Dickinson & Sidibé, 2008).

Thus, HIV stigmatisation derives not only from the fear of physical contagion, but also from the fear of social and moral contagion and, as Egrot (2007) argues, the fear of social death is in Burkina Faso (and other parts of West Africa) much stronger than the fear of the disease itself. Yet, when reading the literature on stigma, physical stigma is given much more attention than social or moral stigma. HIV stigmatisation is often presented as closely linked to the fear of contracting HIV via everyday interactions with PLHIV and based on ignorance or inaccurate beliefs about HIV transmission (see for example Boer & Emons, 2003; Bond et al., 2002; Brown, Machtyre & Trujillo, 2003; Genberg et al., 2009; Kalichman & Simbayi, 2004; Kohi et al., 2006; UNAIDS, 2000). Such studies usually recommend better education campaigns to disseminate accurate knowledge about how HIV spreads, together with measures improving confidentiality in blood tests and treatment and the improvement of legal protection. They often measure stigmatisation through questionnaire surveys that objectively stigma as a kind of “thing” which individuals impose on others and that can be “measured”, rather than as a constantly changing (and often resisted) social process reproducing structural inequalities of class, race, gender and sexuality (cf. Parker & Aggleton, 2003).

Some studies do take the wider structural context of HIV stigmatisation into consideration and link social rejection to the high cost of HIV treatment or the low coverage of ARV (Abadia-Barrero & Castro, 2006; Castro & Farmer, 2005; Genberg et al., 2009; Hardon et al., 2006, 2007; Maman et al., 2009; Rankin, Brennan, Schell, Laviwa & Rankin, 2005; Warwick, 2006). Such studies advocate a scaling up of treatment and care in order to reduce the fear of infection and the financial drain that PLHIV represent for their family, and thereby the stigmatisation of PLHIV. Yet, in Botswana, where there is universal and free access to ARV, stigmatisation remains very high and does not seem to disappear with the availability of ARV, despite the fact that a significant reduction in stigmatisation has been reported (Wolfe et al., 2008). The great majority of PLHIV who receive ARV continue to keep their status secret from their community or family (Wolfe et al., 2006) and stigma remains a key constraining factor in addressing HIV in many countries even after the introduction of ARV (Hardon et al., 2006, 2007). Some studies even report increasing stigmatisation following the introduction of ARV roll-out (Maughan-Brown, 2010; Roura, Uassa, Busza, Mbata, Wringe & Zaba, 2009). Improved access to ARV might increase the HIV testing rate (Warwick, 2006), but “where anticipated stigma prevails, provision of antiretroviral drugs alone is unlikely to have sufficient impact on VCT uptake” (Voluntary Counselling and Testing) (Roura et al., 2009: 308).

The above studies indicate that more knowledge and more ARV will not, by themselves, remove all stigmatisation. In this paper, we argue that stigmatisation cannot be addressed satisfactorily unless the perception of HIV/AIDS changes, and that this perception cannot change unless official campaigns and health care practices are revised. We will develop our argument in two stages.

Firstly, we argue that moral and social stigmatisation do not simply derive from fear, ignorance or inaccurate beliefs but are also reinforced by official campaigns addressing HIV/AIDS, an argument that runs parallel to other studies criticising current health care practices (see for example Allen & Heald, 2004; Buse et al., 2008; De Cock, Mbori-Ngacha & Marum, 2002; Heald, 2002; Roura et al., 2009). We further argue that AIDS needs no longer be exclusively approached as a sexually acquired and fatal disease. With reliable access to ARV, AIDS is now becoming a chronic disease with which one can live a satisfactory life for many years (a point that has also been made by Fee & Fox, 1992; Maughan-Brown, 2010; Nyblade et al., 2003; Ogden & Nyblade, 2005). Focussing on this aspect rather than on AIDS as a sexually transmitted and fatal disease can help to address HIV-related stigmatisation. Nevertheless, in many countries (e.g. Burkina Faso) the increased availability of ARV has not had a significant effect on the way in which intervention and information campaigns are defined. Our hope is that people working in AIDS organisations, activists and policy makers will seize these new opportunities and rethink interventions in ways that help PLHIV to live positively — for a long time — with their HIV-positivity.

Secondly, we argue that stigmatisation is a socially complex and ambiguous process. Social life is full of conflicts as well as solidarity, and identifying what belongs to the realm of stigma and to the realm of social support can sometimes be difficult (similar arguments are discussed in Allen, 2007; Nyblade et al., 2003; Ogden & Nyblade, 2005; among others). Many actions perceived as stigmatising by PLHIV can be made with the intention to save lives, without any link to the fear of HIV infection.

**Methodology**

The data for this study were collected in September, October and November 2009 by a team of 10 researchers from the Research Institute in Health Science (IRSS), the Centre Muraz, and the University of Copenhagen, in collaboration with 7 research assistants coming from AIDS-related CBOs. The research took place in 20 CBOs chosen for their different size, activities, and locations (6 in...
Results

The double-edged sword of HIV/AIDS interventions

In Burkina Faso, as elsewhere in Africa, HIV is mainly acquired through sexual relations and prevention campaigns continue to insist explicitly on the message that multiple sexual partners and unfaithfulness contribute to spreading the virus. Although this statement is not false, and in spite of the fact that most official actors in the response to AIDS try to avoid blaming PLHIV, the campaigns continue to reinforce the perception of PLHIV as persons having had multiple sexual partners or having been unfaithful and as being thereby responsible for their own misery (see also Duffy, 2005; Ouattara, Crünénais, Huygens, & Traoré, 2004). This is, according to many of our informants (both among heads of CBOs, people in charge of programmes, employees and volunteers, as well as among PLHIV themselves), a major source of stigmatisation, and they have repeatedly expressed the view that “the official prevention campaigns have spoilt the reputation of AIDS from the start” by associating HIV with “immorality”. For example, the “ABC” campaigns, ever-present in Burkina Faso as well as in many African countries, advise people to Abrstain, Bee faithful, or else use Condoms if neither of the first two options is feasible. This campaign thus tend to associate condom use with unfaithful sex and, as a consequence, become accused of “encouraging immorality” and thereby contributing to “spreading the disease” (see also Allen & Heald, 2004; Heald, 2002). Proposing to use a condom engenders the suspicion of infidelity and undermines the trust of the sexual partner (Gausset, 2001; Guiella & Madise, 2007; Samuelsen, 2006). Refusing to use condoms when a partner proposes it then becomes a way to present oneself as a respectable and trustable person, especially for women who must remain faithful to one partner and are generally not supposed to experience pleasure in sexual relations (female circumcision is still widely practised) while men are expected to take pleasure in sex and may have several wives (Ouattara et al., 2004). ABC campaigns thus fuel the stigmatisation of those who use condoms at the same time as they “promote” condoms.

Very few PLHIV in our study explained their serological status by admitting to having had multiple partners and the few who did were exclusively males (polygyny is socially acceptable). Most PLHIV claim either to have been infected by their regular or legal sexual partner, to whom they were faithful, or through their professional practice (medical staff, for example), or else by having taken care of a close relative who died of AIDS – washing this person, treating his/her sores, washing his/her dirty clothes, etc. Even though prevention campaigns downplay the possibility of becoming infected through taking care of sick or dying persons, it nevertheless remains a convenient means for PLHIV to avoid moral stigmatisation. Since women are generally the ones taking care of sick persons, and since their reputation is more vulnerable than that of men, they are more likely than men to use this explanation.

The counselling done before and after a blood test also contributes to reinforcing the link between HIV and unfaithfulness, and thus the stigmatisation of PLHIV. People who wish to test their blood must first talk to a counsellor who assesses their risk by following a list of questions about their sexual practices that focus on unfaithfulness. People are, for example, asked whether they doubt the fidelity of their partner, whether they currently have several sexual partners and how many partners they have had in their life. The risk assessment has a moral undertone that, according to several counsellors we interviewed, can become counterproductive. Some people become irritated by such personal questions and refuse to answer them; others lie during the risk assessment. The words of a counsellor working in a CBO (Female, 56 years old, Ouagadougou):

I have met several people who refused to answer the questions about their sexual life. They would tell me: “I came here just to get my blood tested. I don’t want to answer all these questions” (…). Some will tell you that they have never had sex or have never been unfaithful, but they are so relieved when their result
is negative and thank God so much that you realise they lied and were actually at risk.

The practices intended to ensure anonymity and confidentiality of HIV/AIDS health services do help shield PLHIV from stigmatisation. But in a broader perspective, it is but one more factor that contributes to defining AIDS as a shameful and stigmatising disease. When going for a blood test, people are guaranteed anonymity, as fewer people would be willing to test their serological status if this were not the case. As soon as someone has tested positive, anonymity disappears (PLHIV are asked to give names and contacts in order to be integrated into the health care system) and confidentiality takes over. However, confidentiality is, for various practical reasons, difficult to ensure, especially in small towns. It is easy to guess that someone visiting an AIDS organisation regularly is likely to be HIV-positive (see also Batino & Bila-Ouedraogo, 2007). As a result, those who have the means to do so prefer to go to a private clinic or to another town in order to receive their ARV drugs which has the unfortunate consequences that at times treatment is interrupted due to difficulties in finding means of transport. The register of a guesthouse for PLHIV in Ouagadougou indicates that people come from all over the country (including from places in which they could receive appropriate treatment) to receive their ARV drugs in the capital. The register also shows that men are overrepresented in the guesthouse, although they are underrepresented in AIDS-related CBO (70% of PLHIV members of AIDS-related CBOs are women and, in terms of everyday attendance, this percentage is even higher, see Obermeyer, Sankara, Bastien, & Parsons, 2009). Men are traditionally responsible for the well-being and health of their household. They must earn an income in order to cover household expenses and they usually have more means than women to access ARV far from home. Men feel ashamed and diminished if people come to know that they are suffering from sickness or are losing control over their fate, and they are thus more reluctant than women to test for HIV, to seek health care, psychologically support and embark upon ARV treatment (Batino & Bila-Ouedraogo, 2007; Bila & Egrot, 2008 and 2009). Thus, anonymity and confidentiality do at times shield PLHIV from stigmatisation, but since it cannot be guaranteed by the current system, people (especially men) attempt to remain anonymous by avoiding CBOs or seeking treatment in places where they are not known, which can delay their search for treatment. Moreover, by creating health care structures exclusively designed for PLHIV the system contributes to defining AIDS as “abnormal”. Emphasising anonymity and confidentiality within these structures maintains the notion that HIV is something that is worth hiding and thereby worth stigmatising. It is a double-edged sword, paradoxically protecting PLHIV from stigmatisation and keeping stigmatisation alive. We thus agree with De Cock et al. (2002: 69) that “the quest for secrecy promotes rather than breaks the destructive silence around HIV/AIDS”.

As we can see, the association of HIV with “immorality”, secrets and shame does not come from supposedly irrational beliefs and incorrect knowledge, but derives logically and meaningfully from (or, at the very least, is reinforced by) the messages spread by prevention campaigns and from the current practices surrounding blood testing and HIV-related health care. Addressing stigmatisation thus requires a revision of current official practices.

The fear of stigmatisation

The fear of stigmatisation has dramatic consequences. As many PLHIV told us: “it is not AIDS but stigmatisation that kills” or “people do not die from the virus, but they die from being stigmatised and rejected by others”. Destitution is an acute problem in Burkina Faso and without social support and solidarity, poor PLHIV are in dire straits. Those who are socially rejected suffer tremendously from the lack of economic support to access medicine, food or shelter, and from losing the respect of others. Women are especially vulnerable due to their limited access to ownership, inheritance and salaried jobs. Women are closely controlled by men and are largely confined to their parents’ or husband’s home (Samuelsen, 2006). The patrilineal and patrilocal kinship systems found among most ethnic groups in Burkina Faso entail that a woman leaves her father’s home when marrying and moves into her husband’s home. A woman’s status is associated mainly with reproduction but even after she has become a mother, she continues to be looked upon as a kind of “stranger” in her husband’s family. She remains a threat and she will often be accused of being the one introducing HIV infection in her new family (Bila & Egrot, 2009). It is almost impossible for a woman to divorce on her own initiative, but a man has the right to divorce a woman and deny her access to his land, property, or even children. Women are thus vulnerable in many ways and they are reported to be more frequently and more seriously exposed to exclusion and discrimination than men (Bila & Egrot, 2009).

Second, the fear of stigmatisation delays the search for and weakens adherence to treatment. On the one hand, the association of HIV with certain groups or sexual practices engenders a false feeling of immunity or even denial, among those who do not identify themselves as belonging to such groups or as engaging in such behaviour. As shown by Samuelsen (2006) young people do consider AIDS a dangerous disease, but they do not see themselves as being particularly at risk of HIV even though they experience a general anxiety about their future. Several PLHIV described to us how seeing themselves as virtuous people made it difficult for them to acknowledge their HIV-positivity and delayed their HIV test until they had come close to death (see also Obermeyer et al., 2009). For the same reasons, doctors might also be afraid to suggest a blood test, unless as a last recourse after everything else has been tried, out of fear of their patients’ reactions (see also Grünais & Ouattara, 2008; Kalichman & Simbayi, 2003; Obermeyer et al., 2009; Ouattara et al., 2004). On the other hand, the search for anonymity creates adherence problems, as people travel long distances to get medicine in a locality in which they are unknown and may refrain from following their treatment if they fail to find the money they need to enable them to travel. Fear of taking medicine in public and thereby being identified as PLHIV is a recurrent theme in group talks. Such a fear leads to several strategies (putting medicine in a box of vitamin pills, putting a pill in the mouth and drinking water 2 min later, taking pills while in a toilet or taking a shower), but can also hamper the correct following of treatment.

Third, the association of HIV with sex described as morally unacceptable has severe consequences for the disclosure of status to sexual partners, and therefore for the control of the epidemics. Disclosing status inevitably leads to the question of infidelity or blame and it might destroy the relationship if the partner runs away from it. As a result, less than 60% of PLHIV share their status with their regular sexual partner (Yameogo, Bila, & Kouanda, 2008). The figure is lower for women (55%) than for men (70%) presumably because women are more vulnerable and have more to lose if the relationship comes to an end. We met many PLHIV who had not told their wife or husband about their status, or who had discovered the positive status of their wife/husband through other means than being told directly:

During a group talk in an AIDS organisation for women in Bobo-Dioulasso, one female PLHIV (in her thirties) explained how she suspected that her husband was hiding something and urged him to tell her what he was suffering from. But he did not tell her anything, claiming that everything was fine. Several months later,
Once their status is disclosed. But it is just as true to say that PLHIV appear as ARV drugs become increasingly available. Rather, we are physical stigma and it cannot be expected to automatically disappear (see also Maughan-Brown, 2010; Ogden & Nyblade, 2005; of the most important obstacles to improving HIV prevention and close people whose support is most needed.

The fear of being stigmatised hampers the disclosure of the status, even to close people whose support is most needed.

Thus, in Burkina Faso the fear of HIV stigmatisation remains one of the most important obstacles to improving HIV prevention and care (see also Maughan-Brown, 2010; Ogden & Nyblade, 2005; Rankin et al., 2005; Wolfe et al., 2006). Such fear, and the related search for anonymity, cannot be explained simply by reference to physical stigma and it cannot be expected to automatically disappear as ARV drugs become increasingly available. Rather, we are dealing with a moral stigma that is inadvertently reinforced by current campaigns and health care practices.

The ambiguity of stigmatisation

It is clear that many PLHIV are socially rejected or discriminated once their status is disclosed. But it is just as true to say that PLHIV often receive life-saving support from their relatives and friends. Identifying what belongs to the realm of stigma or to the realm of help can sometimes be difficult, as one can see in the following example:

In an interview, a 39 years old male informant living in Ouagadougou explained that when he became sick, his family brought him to the hospital and asked for an HIV test to be made. Learning that the result was positive, the family collected money to buy the ARV drugs, and this financial support continues to this day. Our informant would probably be dead by now, if it were not for his family. Yet, he bitterly complains that his family has stigmatised him with subtle behaviour changes — cleaning the toilet or shower after he used it, etc. He feels diminished in his position of first born of the family.

People’s reactions to PLHIV cannot be easily classified as either stigmatising or supportive. As in the above case, families may save the life of an HIV-positive relative and at the same time develop forms of behaviour that are perceived as stigmatising.

To be HIV-positive is costly as money is needed for transport, for the regular blood tests that determine the level of CD4, and sometimes for accessing ARV drugs or other medicines (Bila, Kounda, Desclaux, 2008; Kounda, 2008). PLHIV we interviewed often complained that the financial support they received from relatives had been dwindling (something they perceived as HIV-related stigmatisation) and that they had had to rely increasingly on themselves or on the solidarity of an organisation to survive. Lack of resources is a real problem in Burkina Faso, one of the poorest countries in the world, where people are at times literally dying from hunger while being kept alive on ARV. In addition, due to the shame surrounding HIV, a blood test is often delayed until all other options (including traditional healers) have been tried and have failed. Thus, AIDS is often diagnosed after a long and costly period of alternative treatments, and when the test is finally taken and the result is positive, relatives fear the lifelong reliance on medicine and medical tests, even if the drugs themselves can be accessed for free or for minimal cost. One could perceive this as a stigmatisation of PLHIV, but one could also acknowledge the sacrifice that many families have made and recognise the paramount importance of early HIV testing, both for the health of PLHIV and for the quality of familial support. ARV drugs have saved lives but they have also redefined AIDS as a chronic disease, with all the challenges that chronic conditions pose to family support.

The disclosure of one’s status may trigger social rejection, even though there are studies showing that this happens less frequently than might be expected (see e.g. Brou et al., 2007). But we should be careful not to assume that the social rejection of PLHIV is due only to the disclosure of their HIV status. Rather it is usually woven into already existing conflicts and tensions. We heard of several cases in which young female PLHIV were having serious conflicts with their families who felt that they misbehaved and wanted them to stay at home during evenings instead of going out with friends or boyfriends. In other cases, the situation was very tense due to a relationship with partners belonging to another religion (Christianity or Islam), relationships that were strongly disapproved of by the parents who were on the verge of rejecting their daughters. In such cases, the disclosure of the HIV status triggered a rejection that seemed to have been on the way for some time, regardless of the presence of HIV. Once a person’s HIV status is disclosed, any problem that a new PLHIV encounters tends to be perceived as a consequence of his/her new status.

Another point to be made is that social rejection, marginalisation and isolation do not always come from those who are not infected or who do not know their serological status. Many PLHIV anticipate the judgement and fears of others and indulge in self-isolation, internalizing stigma and refraining from helping in a kitchen, or conscientiously washing a shower after using it (Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007). Some are also terrified by the idea that they could infect their closest and most loved relatives and refrain from sharing a glass or plate with them, despite knowing that the virus is not transmitted through these means. At times PLHIV also feel stigmatised by other PLHIV:

In an interview, a 45 years old female informant living in Ouagadougou with HIV told us that she lost four siblings due to AIDS, and that she knows about 3 other HIV-positive half-sisters. She learnt about their status by seeing the first in an AIDS organisation, being told about a second one by a doctor, and being confided in directly by the third one. But none of them know about her own condition and she is determined not to share it with them out of fear that they would use such knowledge to harm her. One of her infected half-sisters revealed the status of a PLHIV hairdresser in public in order to jeopardise her business, and our informant is afraid that this could also happen to her.

Revealing the HIV status of someone can be used as a weapon in social conflicts, both by people who are themselves infected and by those who are not. Denouncing someone else’s status, as stigmatising as it might be for the victim, can sometimes be seen as a strategy to reduce the stigmatisation faced by the person who denounces.
A final point to be made is that treating a PLHIV differently on the ground of his/her HIV status can be based on good intentions, even though it is often perceived as stigmatising by PLHIV, as can be seen in the following quote:

My family wanted me to be tested, but I did not want to. For me, AIDS was for people having sex outside marriage, and this was not my case, so I did not feel concerned. When I got sick, my family brought me to the hospital. I fainted and was tested while I was unconscious. My family got the result but did not tell me. I took my pills without knowing what I was suffering from, until several months later, when I read what was on the box and understood that I was HIV-positive. I thank my family for having done this, as I was not prepared to accept my status at the time (Female informant in her late thirties, Ouagadougou).

In the quote above a blood test was made without the consent of the person, which was justified by the fact that the person was not ready to face reality although her life was at stake. We heard many stories in which family members tried to know the status of a relative and to help this person, sometimes against his/her will. A positive HIV test inevitably changes relations between people, at times negatively, but often also positively. A positive test can result from care and concern, e.g. monitoring that a PLHIV takes medicine at the right time or telling a PLHIV that s/he must change his/her sexual behaviour, now that s/he is HIV-positive. Some PLHIV feel patronised and perceive such acts as stigmatising while their relatives perceive these acts as supportive and carried out in the interest of the PLHIV. Self-perceived stigma (the shame felt by PLHIV) differs from enacted stigma (the actual discrimination on their basis) (Scrambler, 1998; Ramakrishna & Somma, 2006), and the same action can be perceived as either supportive or as stigmatising depending on the point of view, the point in time and the larger social situation in which it takes place.

Thus, in the cases discussed above, incidents of stigmatisation of PLHIV are rarely clear-cut. It is never solely due to physical stigma, inaccurate beliefs or harmful behaviour from non-infected people. It derives from a drying up of finances, conflicts that existed prior to the blood test, or from the fear of harming someone. It can come from self-isolation or from fellow PLHIV and it can be carried with the intentions of providing support to the patient.

Discussion and conclusion

In this article, we have developed two main arguments. Firstly, HIV/AIDS interventions are, at times, doubled-edged swords indirectly reinforcing self-perceived stigmatisation through attempts to fight stigmatisation. Addressing HIV-related stigmatisation requires a de-coupling of HIV from sexual practices considered to be “immoral”. This, in turn, requires a revision of the official practices relating to blood tests, care and prevention. We need to acknowledge that focussing our messages exclusively on the sexual transmission of the virus can be counterproductive as it fuels stigmatisation, even though sex is the primary mode of HIV transmission in Africa (see also Ogden & Nyblade, 2005).

Some might disagree, taking for example the Ugandan case to argue that, as unpleasant and discriminating as they might be for PLHIV who become associated with unfaithfulness, promiscuity or sex work, strong moralistic and stigmatising campaigns focussing on faithfulness or abstinence rather than condom use seem to work in deterring so-called “risky behaviour” and reducing HIV prevalence (Allen, 2006; Allen & Heald, 2004). But we believe that there is much more to win than to lose by abandoning stigmatising discourses and practices.

One of the main problems today in Burkina Faso is that people do not know their status and are not taking any specific preventive measures or following any appropriate treatment. And the main reason why they are not doing so is, we have argued, due to the fear of moral stigmatisation of HIV (reinforced by official campaigns and practices), which deters people from having a blood test or adhering to treatment.

It is possible to promote condoms without stigmatising them. The first step is to stop presenting condoms as the alternative to fidelity and abstinence. A second step could be to shift the focus from the prevention of HIV to contraception (both aspects can be fruitfully combined, but the second is less stigmatising than the first one). Likewise, it is possible to promote safe sex without talking of abstinence, fidelity and condoms and without mentioning any particular social group or sexual behaviour, for example by encouraging the taking of a blood test and the sharing of status before engaging in a new sexual relationship, regardless of its type (Gausset, 2001).

Finally, acknowledging the impact that ARV has on redefining AIDS as a chronic condition makes it easier to change the focus of current campaigns and practices. Due to the increasing accessibility of ARV drugs in Burkina Faso, one now finds people living a healthy life even though they are infected with HIV. PLHIV may have healthy children (as is the case of several of our informants), and children born with HIV may become adults. Presenting AIDS as a chronic disease, like high blood pressure or diabetes, would help to shift the focus of information campaigns from negative, frightening and stigmatising messages centred on death and sex to positive and hopeful messages focussing on the possibility, if treated, of having a satisfactory life, including having a family and children. In other words, it would shift the focus of HIV prevention from controlling sexual behaviour and avoiding infection to generalising blood tests, improving treatment coverage, and promoting health and well-being. Presenting AIDS as one disease among others (and enabling CBOs to test blood for more than just HIV or opening CBOs to help people who do not live with HIV, for example) would contribute to downplaying the current focus on anonymity and encourage PLHIV to visit organisations more often without running the risk of being recognised and stigmatised. We could expect, as a result, less stigmatisation, a lower fear of being stigmatised if infected, and consequently more people willing to have their blood tested, to share their serological status, as well as fewer problems with treatment adherence.

The second part of our argument is that it is problematic to measure enacted stigmatisation as something that is either present or absent. Stigma and stigmatisation are ambiguous terms that often fail to properly grasp multifaceted social situations. Social life is permeated with ambivalence, with tensions between relatives as well as care and concern for relatives. What may be referred to as stigma and stigmatisation are often ambiguous social situations, where there is no easy answer as to who does what to whom.

One of our male informants (49 years old, living in Ouagadougou) used to hide his status and to isolate himself from others, but he is now open about his HIV status. He has gained self-esteem by developing a business and becoming financially independent. But most importantly, he has come to realise that stigmatisation also originated in his head and that it could not reach him if he lived his own independent life in peace with himself and with others. His words provide us with an important lesson:

I think that, in order to minimise stigmatisation, everyone must refrain from paying attention to what others are saying. Inequalities have always existed between men and HIV is just another form of inequality. Even a father cannot give the same
attention to all his children. There will always be differences between people and we must learn to live with them.

Acknowledgements

We would like to thank DANIDA and the Royal Danish Embassy in Ouagadougou for funding this action-research project. The research was conducted by the Research Institute in Health Sciences in Ouagadougou (IRSS), which is a department of the National Centre for Scientific and Technical Research (CNRST), as well as by the Centre MURAZ in Bobo-Dioulasso, in collaboration with the Department of Anthropology of the University of Copenhagen, Denmark, and we would like to thank Seni Kouanda and Helle Samuelsen for their support as well as Lise Rosendal Östergaard و Ouagadougou: SP/CNLS-IST.

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