



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

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ABSTRACT

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 anti-retroviral 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)

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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, MacIntyre & 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 objectify 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, Urassa, 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

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