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Constitution, diversification and normalization of a health problem: organizing the fight against AIDS in Switzerland (1984-2005)

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Constitution, diversification and normalization of a health problem: organizing the fight against AIDS in Switzerland (1984–2005)

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The article traces the formation, diversification and normalization of the AIDS cause in Switzerland. Particular emphasis is placed on interactions between the medical field, public authorities and associative space, the latter being understood as the place where individual and collective actors compete to define the cause. The authors argue that the major phases in the structuring of the struggle, the pace of state intervention and the creation of a multi-organizational field, can only be understood if one adopts a 'configurational perspective' attentive to the manner in which, in a given context and under the effect of particular constraints, key actors strategically interact and contribute to transforming their environment and their chances of reaching their goals. This approach takes into account the changing socio-biological characteristics of those who have committed themselves to the cause. In turn, internal movement divisions about how to respond to the epidemic as well as the changing perceptions of the disease have modified the opportunities for commitment, encouraging certain individual kinds of people and excluding others.

Keywords: AIDS; activism; social movements; volunteers; Switzerland

Introduction

It is often challenging to ascertain the construction and transformation of causes. In the fight against AIDS in Switzerland the construction of responses to the epidemic and their successive transformations since 1984, particularly during the period known as 'normalization', may only be understood through correlating the organization of the struggle with the social characteristics of activists (both volunteers and professionals). These successive waves of activist involvement have served to shape the responses to the epidemic. Battles amongst activists during the transformation of the epidemic's public image affected the possibilities for involvement, thus permitting us to explain the participation, persistence and withdrawal of various activists.

We reject the perspective of a heterogeneity of causes (much earlier determinants, and initial states) and their effects (the various forms of mobilization and their results). Instead, we suggest an examination of causal chains, the processes by which individual acts and the structures of action are set in place and are modified as a result of strategic interactions. Thus we adopt a processual perspective, attentive to the manner in which, in a given context and under the effect of particular constraints, the actors, strategically interact, and contribute to transforming their environment and their objective chances of reaching their goals. In such a model, activism is

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conceived as a long-lasting social activity articulated by phases of joining, commitment, and defection (Whittier 1997, Fillieule 2001, 2010). Our theoretical approach is in line with the concept of 'configuration', denoting a dynamic pattern in articulating different scales of analysis, that was coined by Elias (1939, 1970) when describing certain patterns of relations between human beings (figuration in German).[1]

This paper considers the interactions between the medical field, public authorities and associative space in the fight against AIDS, the latter being understood as the place where individual and collective actors compete to define the cause. Indeed, integrating these three spaces allows us to show how the public image of HIV/AIDS has been transformed (Pinell *et al*. 2002) and how this impacts on the possibilities for participation. This demonstrates the evolution of the AIDS problem from the beginnings of 'exceptionalism' (Kirp and Bayer 1992) to the phase of 'normalization' (Kübler *et al*. 2002, Rosenbrock *et al*. 2000) on the basis of the transformation of the public problem. In fact, as Setbon (2000, p. 63) emphasizes:

> It is not the problem which changes as an effect of the responses, but its perception and social acceptability that are modified by the exceptional responses, by the advances, however limited, in AIDS therapies, and, more broadly, by the uncertainty which characterized the mobilization phase. Together this creates a new depiction of the problem, provides the public with preventive measures and makes the risk more acceptable.

These notions of 'normalization' and 'exceptionalism' are 'scientific categories', as well as 'practical categories', used both by scientists, to describe all the developments in the fight against the epidemic, and actors who invest time and energy in the anti-AIDS fight. The definition of normalization is itself one of the issues at stake in the struggle. As a scientific category, normalization refers to the process of institutionalization of the social movement of the fight against AIDS, the transformation of the AIDS problem from a major danger to a controllable problem and the corresponding retreat of public authorities, with AIDS losing its central character on the public health agenda.

The article is based on research focusing on participation in the fight against AIDS in Switzerland (at the federal level and in seven federated states – cantons).[2] We begin by showing the basis of the initial response to the epidemic and the form it assumed. Then, we focus on the aspects contributing to modifying the cause at the end of the 1980s. Finally, we discuss the impact of the introduction of HAART on the redefinition of the fight against AIDS in Switzerland.

The formation of an initial response

As in most countries (Altman 1994), when AIDS arrived in Switzerland, the initial framing associated the illness with male homosexuality. The debate that subsequently occurred in homosexual organizations was to determine whether they prioritize the issue, thereby running the risk of redoubling the stigma attached to the gay community. This issue was rapidly resolved in favour of active participation. While the 1970s had seen tensions between homophile groups (the main one being the Organization suisse des homophiles – SOH (the Swiss Organization of Homophiles)) and homosexual working groups, brought together within the Coordination homosexuelle suisse (CHOSE – Swiss Homosexual Coordination), the start of the 1980s was marked by greater collaboration. The costs and the risks (Wiltfang and McAdam 1991) of involvement in homosexual liberation groups, particularly the high visibility that they demanded of their members, prevented wider recruitment. Gradually, in a similar fashion to what Armstrong (2002), in particular, revealed in the case of the USA, mobilization became less radical and more sectorial, giving rise to new groups or a transformation of activist philosophy within existing associations towards more of an identity model (Gay Identity).

These associations also remain the only ones to publish a specialized gay press and be connected to the most visible social gathering spots. The gay commercial scene was, by comparison, small. There is not unlike in France, for example (Pinell *et al*. 2002), a specialized press or a commercial centre large enough to compete with Swiss associations, that remain dominant in determining the orientation of the fight that the 'homosexual community' must lead. In other words, while it is true, as Duyvendak (1995) claims, that at the time when the AIDS epidemic emerged, there was a solid foundation of homosexual movements at the local level, it is incorrect to claim that these movements were fragmented, with little national presence. The movements are mostly represented in one of two umbrella organizations, CHOSE or SOH, and often collaborate. This point is important, because when the epidemic appeared, the people involved in the associations were capable of providing a rapid response to this new threat.

The creation of the Swiss Aids Federation

Homosexual activists received substantial support from the recently named director of the epidemiological section of the FOPH, Bertino Somaini. Somaini proved to be one of the principal architects of rapprochement of public authorities and homosexual groups. Before being named to the FOPH, he was engaged in post-graduate study at the University of California, Berkeley. It was at Berkeley that Somaini first heard of AIDS. He also witnessed the initial organizing of the American homosexual movement. He combined what he learned from this experience with the Swiss administrative approach to social problems:

> The homosexuals in San Francisco were very well organized, and therefore it was a hundred times better to let a private organization act rather than have the authorities intervene. [. . .]. So we, the state, we said: 'we will finance you, but only if you get together' [. . .]. There was no direct pressure from the state; there was the experience of what happens when the state wants an organization like the FOPH to intervene. [. . .] The state supports an umbrella organization and, after that, it works, parliament comes up with the money. This is the administrative approach. So, I followed it. (Somaini interview)

To avoid dispersal of resources, Somaini suggested that AIDS delegates create a unified organization as quickly as possible, stressing that the FOPH could only associate with preventative actions in the field of AIDS if the structure that it might support was sufficiently generalist. This would allow for the widespread dissemination of HIV prevention messages to the entire population and unite people active in other groups who were also strongly affected by HIV/AIDS notably sex workers and social workers dealing with drug users.

AIDS delegates of homosexual working groups first attempted to coordinate their actions and then present a united front before the FOPH. From this dual perspective, they chose to establish the first organization, named AIDS-Hilfe Schweiz (Swiss Help Against AIDS). Three people played a pivotal role in its conception: Marcel Ulmann, president of SOH, Herbert Riedener, president of the Zurich 'leather association', Loge 70, and Roger Staub, member of the Zurich gay liberation group (HAZ). Given the urgency of the situation, and putting aside the dissensions amongst the gay associations concerning AIDS, all three volunteers defended an approach favouring rapid intervention in the field of prevention.

On 2 June 1985, the Swiss Aids Federation (Aide Suisse contre le sida/AIDS-Hilfe Schweiz – SAF) was officially founded in Zurich at an assembly bringing together fourteen homosexual associations. The FOPH also became a member, which was unprecedented: this was the first time that a state organization belonged to a private association, not to mention a organization founded by homosexuals. The first president of SAF was the television journalist André Ratti. At the opening of SAF's first press conference on 2 July 1985, he declared: 'My name is

André Ratti. I am homosexual myself, I am 50 years old, and since April I have known that I have AIDS'. The conference served to remind the public that gays were not the only ones affected, and neither were drug users or sex workers. The entire population was ultimately at risk of contracting the disease. Nonetheless, there was no minimization of the heavy toll on homosexuals, and the fight has remained closely linked to homosexuality.

It is important to highlight that the situation in Switzerland was different to most other places in Europe, and particularly France and the UK, concerning the way in which the anti-AIDS campaign was organized. Switzerland is closer to that of the USA or Australia (Kippax *et al*. 1993, Altman 1994). In France, the association AIDES was a unifying force, with the sick individual firmly at the centre of their concerns: 'from this [comes] a movement that, in putting sick people at the heart of their concerns, does not organizationally link the fight against AIDS to the gay community, but rather establishes itself as a space to unite those who are sick and all those who are concerned about the epidemic' (Pinell *et al*. 2002, pp. 47–48). In Germany, the perspective adopted during the founding of Deutsche Aids-Hilfe was also one of offering support to those who were ill (Schilling 2000). Putting the illness at the centre of the mobilization effort, in France for example, meant that, very rapidly, there was both dehomosexualization (the distinction between AIDS and homosexuality) and heterosexualization (an influx of heterosexual activists into the associations). As Staub underscored concerning the different approaches:

> One has to observe that Deutsche Aids Hilfe was created in 83 already, but to help and provide support to the sick. For us, this was not the case at all. [...] So, SAF has taken a different path [...]. We were a prevention agency based on the groups affected. This made for a strong concept. (Staub interview)

Activists agreed on the question of *prevention*, and this was the basis for the initial actions of SAF's local offices, showing that the way a cause is built contributes to how subsequent initiatives unfold. The division of responsibilities within the Swiss federal state means that it is largely up to the cantons to lead the fight against health problems within their territory. The creation of cantonal associations (local offices) was only to obtain financing to fight against AIDS and to work closely with the affected groups. In all the cantons where homosexual groups were active, they supported the creation of SAF local offices. SAF placed their infrastructure at the disposal of cantons with active homosexual groups, and members participated on a volunteer basis to ensure the prevention work continued. Thus, where homosexual groups existed, organizational and individual networks allowed for the rapid creation of local associations to fight against AIDS.

It is not possible to describe all the actions organized by SAF and various local groups in the field of prevention, as well as their support for affected individuals. It is sufficient to mention some of the most prominent, including promotion of condom use amongst the gay community, battles for anonymous HIV testing, for the maintenance of health insurance coverage for those whom insurers excluded due to their HIV-positive status, for access to new treatments and rapid listing as 'special treatments' (allowing for a reimbursement from the health insurance board), and for decent hospital conditions for the sick.

All these actions were, at the outset, undertaken on a volunteer basis, mostly by homosexual men who were involved because of their closeness to the illness, either because they were themselves affected (direct proximity), because they knew people who were ill (affective proximity) or because they identified with people with AIDS (cognitive proximity). Gradually, these activists were joined by others with a distinct vision of the nature of the fight against AIDS. This situation gave rise to numerous tensions culminating in the departure of the first wave of activists.

Changes at the heart of associations in the fight against AIDS and the tendency for homosexuals to withdraw

Three elements contributed to transforming the face of the fight in Switzerland and to the withdrawal of a first wave of homosexual activists from the associations. First, the initial results of the ELISA test in 1985 showed that homosexual men were not the only ones affected by the epidemic. The involvement of public authorities, at the federal level and in the cantons, also became more apparent. In particular, financing the fight against the spread of HIV increased very significantly starting from 1987 (900,000 Swiss francs, i.e. double the amount of the previous year). Finally, the campaign STOP AIDS was launched in February 1987, and it also encouraged the transformation of the epidemic's public image, by showing that it hit the entire population.

Archives and interviews, as well as responses to our quantitative survey, clearly showed that those first involved in the fight, mostly homosexual men, were joined first by heterosexual women, and then heterosexual men often because of their involvement in social services. This coexistence was not without its problems, because newcomers and long-time activists disagreed, particularly regarding the objectives and priorities of the fight against AIDS. Thus, crises erupted in the new umbrella organization and in many local offices as the following article, published at the end of 1987, demonstrates:

> The determining factor in current dissension is that AIDS has become a political matter. Suddenly, federal money for prevention is in the millions, and, with the FOPH, a major federal office was looking for an alliance with SAF. In the wake of this development, it became increasingly difficult for the Swiss Aids Federation to reconcile homosexuals', doctors,' politicians' and administrative officials' divergent interests and demands. To these, groups previously little or badly represented (drug specialists, and women) were added to the structures of the organization. The first line of combatants, coming from the homosexual scene, suddenly saw themselves involved in internal fights for power and prestige. (Tages Anzeiger, 14 November 1987)

These developments led to an initial professionalization within the associations due to the arrival of health and social workers. They also again resulted in a questioning of the authority of those first gay participants. Many homosexual activists left the SAF and its local offices, some returning to homosexual working groups. This tendency could be clearly seen in interviews with activists and ex-activists, as well as in the archives of gay associations. Our quantitative investigation offers a graphic illustration of this trend (Figure 1).

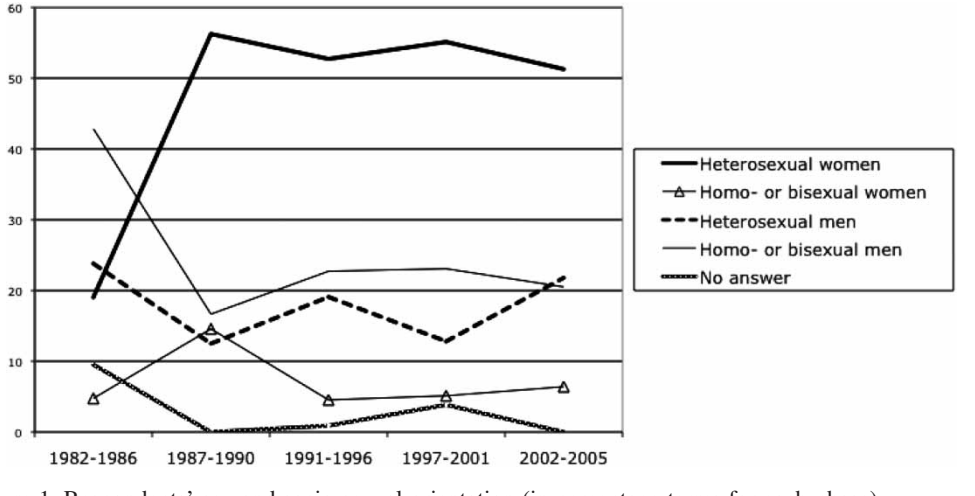

Figure 1. Respondents' sex and socio-sexual orientation (in percentage terms for each phase).

These quantitative data also confirms our conclusions gained from other sources about the fight against AIDS, namely, that homosexual men, a majority up until 1986, were joined in the movement by heterosexual women. Often as part of their training in the social or health sectors, these women participated in developing recreational activities suitable for different stages of the illness. Thus, prevention was no longer the central focus. At the organizational level, the separation between homosexual associations and local offices of SAF became increasingly apparent. There was also a distinct separation of activities between anti-AIDS organizations and homosexual associations, with subtle variations, in practically all the cantons.

It is clear that male homosexuals increasingly did volunteer work in the fight against the epidemic, but the process of dehomosexualization of AIDS and heterosexualization of populations active within the associations continued in subsequent years, culminating in the middle of 1996.

Changes in the fight against the epidemic: the 'normalization' of HIV/AIDS

From the summer of 1996, and with the widespread availability in Switzerland of HAART, the fight against AIDS changed considerably. Above all, there was a significant drop in mortality and morbidity. There was also a further tendency towards the professionalization that began at the end of the 1980s, placing the fight against AIDS fully in the 'normalization' phase. In other words, as Rosenbrock *et al*. (2000, p. 1608) noted, the period was characterized by a change in status of AIDS: 'In Europe – and with differences in all the wealthy countries – an impending catastrophe has turned into a problem that can be managed by public health and medical care'.

The trend described by Rosenbrock *et al*. dramatically changed the anti-AIDS cause and ways of being involved in it. The links between public authorities and actors in the associative spaces were considerably transformed. This period was characterized by a decline in public authorities' attention to AIDS. The most symptomatic dimension of the normalization process was the FOPH's intention to dissolve SAF, transferring responsibilities and structures and eventually reintegrating the HIV/AIDS into more mainstream public health organizations. The evolution of the number of people affected by the epidemic certainly had an effect on the diminution of public financing allocated to the fight against AIDS. Indeed, in Figure 2, we observe that the Confederation expenditures oscillated for the first part of the 1990s between approximately 13 million francs in 1990 and 15 million francs in 1996, peaking at almost 16 million in 1994. Over the course of the following years, the credits allocated to the fight consistently decreased, down to slightly more than 9.5 million francs in 2001, a third less than five years earlier.

Nonetheless, the epidemiological data must also be situated in the political context of the reduction in expenditures starting from the 1980s, which affected the policies of the Confederation from the mid 1990s on. This orientation is evident in the new Law on the organization of government and administration, of 1997. The law 'introduces the notion of term benefits that the Federal Council could transfer to certain administrative units, which will function according to the principles of new public management' (FF 1996, p. 17). Conceived on the basis of New Public Management (NPM) principles (Giauque 2003) it must allow, according to its promoters, the Confederation to limit its operational costs, to propose more efficient management and to decrease federal expenses.

Policies to fight AIDS were not spared from administrative reorganization and decreased public financing. Nevertheless, the introduction of NPM alone does not entirely explain the decline in resources. Indeed, while AIDS financing dropped between 1996 and 2001, money relating to general HIV prevention remained stable, even increasing at the end of the period. We could suppose that the decrease was due to new perceptions of the epidemic, and to the rise of other major public health problems that emerged during this period ('the mad cow

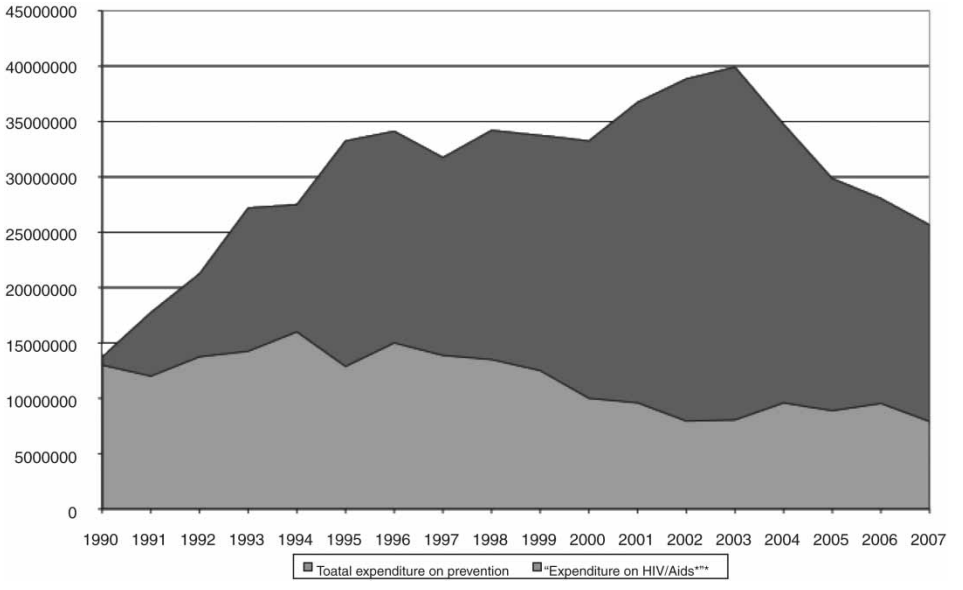

Figure 2. Evolution of the Confederation financing of the fight against AIDS.

crisis', and the fight against alcoholism and smoking). The evolution of public authorities' attention to the epidemic is, thus, directly linked to the transformation of the 'AIDS problem'.

Here, we reach an important point allowing us to focus on the mechanisms that change causes. It is not so much the characteristics of the phenomenon as how it is depicted that changes, and contributes to the perception of, the public problem. In the Swiss case, it is certainly this transformation of the problem that made public authorities consider that AIDS had become an 'acceptable risk', and which saw a decrease in public financing (from 16 millions francs in 1994 to 9.5 in 2001), in a context of limiting the cost of public finances. The new perception of the epidemic led to a series of transformations within the space of the fight against AIDS.

The effects of the transformation of the epidemic on the associative space of the fight against AIDS

The effects of this transformation are evident on a number of levels. First, the type of collaboration between the FOPH and SAF, allowing activists a considerable freedom in their actions, was questioned. This situation gradually evolved over the 1990s, and the widespread use of subsidies linked to term benefits produced an increased role for the FOPH in the implementation of strategies in the fight against the epidemic.

Then, to partially counter the tendency to make SAF a formally part of federal administrative policy, SAF sought to increase its own financing. After a period up to 1992 when the proportion of its own funds declined, to settle at less than 10% of its total income, it then tended to rise. Indeed, this indicated a new direction in the association's financial strategy, to allow greater freedom in its actions. Between 1996 and 2001, the proportion of the SAF funds which were its own went from slightly more than 27% to 38.7%.

This tendency towards normalization, closely associated with the emergence of HAART, led to further professionalization of members at the coordinating level of SAF. This increased for three reasons. On one hand, HAART prompted certain activists to rethink their commitment to the fight, and some withdrew after being involved for many years. On the other hand, the

SAF leadership modified the selection criteria for members. In other words, affective or effective proximity to the epidemic was no longer conceived as sufficient for involvement. The association adopted recruitment principles based on the possession of officially recognized skills, usually through training in health and social services, as a member of the SAF committee at the time stressed:

> In 1997 we decided to change. We told ourselves that it is not necessarily those who feel called upon to do something and who are close to AIDS who are the best ones to work in this field. We said that certain qualifications and skills are also required if one wants to work in this sector. Being affected was a meaningful qualification too, because those concerned have experience with the illness and often knowledge that professionals lacked. But today, nobody thinks that this is sufficient anymore. So, other qualifications are needed. In addition, knowledge of the associations and the management process are required. Also, specialists' knowledge of HIV. (Interview with the SAF committee)

The third element resulting from the process of normalization and leading to professionalization was the development of fundraising activities, influencing in turn the search for professionals who could do this. Those equipped to fundraise or manage programmes and teams were favoured, as a member of the SAF leadership of the time said:

> I no longer know how many people were there at the start, but approximately twenty people worked together at the secretariat, along with external experts. Such an organization could only be run in a professional manner. And it was with professionals that one could organize fundraising. And this is fairly independent of the theme. This could be AIDS or HIV, cancer, or I don't know what. This has to be done by professionals. (Interview with the SAF leadership)

Here we see that the link to the people affected was considerably weakened between the 'exceptionalism' phase and the present phase of 'normalization'. This very gradual evolution at the end of the 1980s was due to the growth in budgets allocated to the association, the concentration of volunteer work on the ground in cantonal offices and the type of collaboration established with public authorities.

These transformations served to further reinforce the institutionalization of the social movement against AIDS at the highest level, in that SAF is now seen more as an organization implementing public health programmes largely determined within the FOPH. This trend can also be observed in the cantons.

Changing patterns at the cantonal level

The normalization phase within the cantonal structure was also characterized by a number of reorientations within associations, although the upheavals affected them differently. Here, we consider three dimensions. First, we see how therapeutic advances transformed social connections within associations. Secondly, we examine the evolution of local associations' financing to measure the decline in public financing. Thirdly, we attempt to grasp the impact of the transformation of the AIDS problem on the eventual withdrawal of volunteers. Less a massive wave of volunteer disengagement, the period beginning in 1997 until today has been characterized more by a restructuring of the rationale for participation in the struggle.

Impact of treatments on the people affected and restructuring social links within associations

As Broqua (2005, p. 296) stressed in his analysis of Act Up Paris, the impact of therapeutic advances includes 'two levels of apprehending the problem: the individual level of managing the illness (one's own or that of those close to you) and the collective level'. On an individual basis, for most of those affected, therapeutic advances resulted in significant physical improvements. Generally, for those who are HIV-positive, the new treatments combined to bring about a reexamination of their lives, causing them to reinvest in areas that they had up until this point

neglected (notably the professional domain), either because of their state of health, or because their imminent death meant that, they had to be involved in what was considered most urgent, notably the fight against the epidemic.

Enhanced life expectancy and improvement in the state of health led to greater visibility of new concerns. Joining or rejoining the professional world raised the question of possible discrimination in hiring once again. More broadly, the decision of whether to reveal or conceal HIV-positive status resurfaced. This became still more complicated given the potentially greater number of those to whom one may reveal their status (both because the person has a greater life expectancy and because an improved state of health allows for involvement in an increased number of social subsets: professional, familial, affective, social, etc.). This become more complicated because, as Mellini *et al*. (2004, p. 156) stressed,

> the theory of the progression of the illness turns out to be no longer relevant in explaining the disclosure of one's HIV/AIDS. The asymptomatic phase now being of more or less of indefinite duration, the thesis according to which revealing the illness would take place when it became visible or when the person needed material or emotional support is null and void.

At the collective level, this development also posed a series of problems. In one association of HIV-positive individuals, a member observed that therapeutic advances had the effect of breaking the group's internal solidarity:

> I also felt that, while before, everyone was in the same situation, since 1996, there have been those for whom HAART worked, whom we offered instead lifelong assistance, they had plans, they had recreational activities, and, depending on their state of health, even a job. While, at the same time, others were experiencing very serious side-effects from the therapies, even dying because the therapy had no effect on them. And this led to a considerable diversification of the association's activities. Also, for the first time, within the association, among HIV-positive individuals who had always had a great sense of solidarity, for example, we felt tensions, uneasiness/suffering [. . .]. While undergoing the same treatment, some were doing well and some were not doing well at all; some were doing badly. We started to feel that things were less united. (Interview Sid'action)

This extract shows that the links within the movement were transformed due to the impact of treatments. Thus, solidarity within the group was dissolving because expectations of the association were no longer the same for everyone. While it is difficult to obtain accurate data on this phenomenon from individuals who are part of such groups, we may hypothesize that this 'inequality' regarding the illness could have led, in some cases, to a withdrawal of certain activists. In any case, it influenced the perception of solidarity within the associative movement and on the community dimension of the group. While earlier the consolidation of an '*entre-soi*' had a bearing, primarily on identification with a 'community of destiny' (Pollak 1988) where the support for another was encouraged by the imminence of death, therapeutic advances individualized the experience of the illness and limited the development of an 'esprit de corps' (Blumer 1951. On this dimension of the fight against AIDS, cf. Herzlich 2002). To this was added the difficulty of identifying someone or something responsible for the new situation: while it was possible to blame the 'wait-and-see' attitude of public authorities, given the diversity of individual reactions to treatments, any generalization proved impossible. More widely, all the actions of associations in the associative space of the fight against AIDS changed and, consequently, so too did the definition of the cause.

Decrease in cantonal public financing?

The process of 'normalization' led to a drop in federal financing. It is worth determining whether such a tendency can be observed in the cantons. For most of the local offices, financing has not diminished significantly since 1996. However, according to the cantons, it is the type of complementary financing of local offices that has changed, and they are still more reliant on

fundraising activities. Conversely, we see that after a period of growth in financing up until 1992, financing stagnated in subsequent years. This is shown in the case of local SAF offices in the cantons of Berne (AHBe) and Bâle (AHbB) (Figure 3).

Up until 1992, public financing increased each year. For example, in the case of AHBe, cantonal financing between 1990 and 1991 more than doubled. In other words, the stabilization of public finances preceded the introduction of HAART, indicating that 'normalization' took place earlier.

Therefore, rather than a drop in cantonal financing, it seems that two trends affected the evolution of the local offices' work. These are the drop in donations, on one hand, that diminished the freedom of members in managing independent projects. On the other hand was the transfer of responsibilities of the Confederation to the cantons and the development of term benefits, which also limited the possibility of launching specific projects. This latter created greater uncertainty about the long-term status of financing – which might be reduced – meaning that a project would have to be abandoned. The transfer of Confederation responsibilities to the cantons led to a decrease in public financing available for the fight against the epidemic, contributing to financial instability at the level of cantonal offices, which became more dependent on private financing. Overall, the maintenance of cantonal subsidies could not completely compensate for the drop in federal credits. Consequently, it became more difficult for local offices to plan for the long term usage of funds and to innovate in responding to changes in the epidemic.

A withdrawal of volunteers in local associations?

The effect of normalization on the withdrawal of volunteers at the canton level is important. It is difficult to systematically evaluate the evolution of the number of volunteers in local offices, since the data are often incomplete. However, on the basis of the figures available we note a slight decrease in volunteer participation, observable in most SAF local offices. It also seems that participation has declined and activist turnover is considerable.

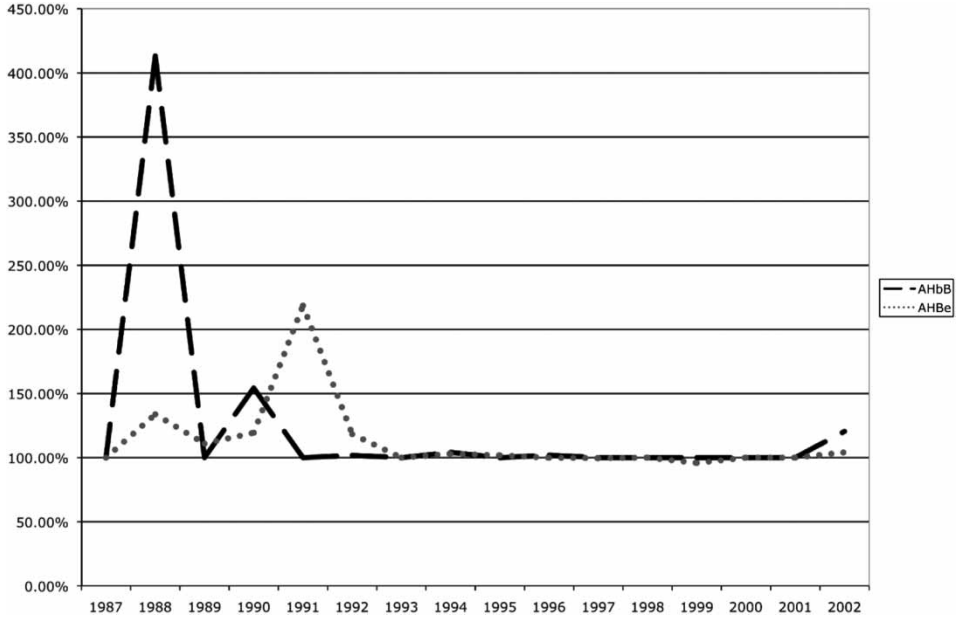

Figure 3. Evolution of public financing (in percentage terms) in comparison to the previous year (1987–2002).

From this perspective, participation would be both more limited over time and would involve individuals with a weaker link to the illness than in the earlier phase. This hypothesis could be supported by the indication that, for all those studied, there is a noticeable decline in affective proximity to the epidemic. Those who claimed that they had no acquaintances with HIV/AIDS rose from 32% between 1991 and 1996 to 40% between 1997 and 2001. This hypothesis is also supported by the fact that the withdrawal of the original activists in this phase marked the end of a long-standing involvement at a time when the fight against AIDS was being redefined and the motives for joining were changing (for an analysis of motives, cf. Fillieule 2001), making continuous involvement now more difficult.

Of the 27 respondents leaving anti-AIDS associations in the period 1996–2001, half did so in 2000. Heterosexual women represented most of those leaving (21 cases); eleven of them left the associative environment in 2000. Amongst those, seven left one of the cantonal associations that year. This defection was due to different motives. On one hand, for some the disengagement was related to the changing nature of participation within the collective, with a series of working groups disappearing during this period. On the other hand, and this is the reason for most of the withdrawals, those disengaging referred to motives related to the transformation of 'biographical availability' (Fillieule and Broqua 2005), in other words involvement and investment in competing social subsets. We find two illustrations of this below, the first reason for disengagement being offered by a woman involved since 1995, the second by a volunteer active since 1993. In the latter case, the reasons for withdrawal also relate to the difficulty of persisting in one's involvement following the upheaval provoked by the death of a person they were caring for:

> I have rebuilt my family life. I am happy to still have two children, so I am short of time.

> Return to studies and less time available. Last person cared for died.

Finally, a third type of motive is similar to that of biographical availability, but relates this issue to a feeling of exhaustion and of weariness in the area of HIV/AIDS. This is the case in the two following responses, the former involved since 1996 and the latter since 1991:

> When my husband and I had our son, we decided to take a breather. Fed up with HIV 100% of the time.

> I got involved in politics, and I felt a certain weariness, a need for a change.

Thus, for all of these people, the reasons for the defection do not make direct reference to the new therapeutic breakthrough but rather to the effects it has. Here, one may draw a parallel with the study of the defection within the Act Up and AIDES associations. The authors stressed (Fillieule and Broqua 2005, p. 200) that

> the most massive observable departures from 1996 on were only minimally due to the lethal effects of the illness, but instead resulted from the questioning born of the new configuration of the epidemic which seemed to encourage a withdrawal justified by a lack of availability or, even more often, by more conflictive situations than in the past.

The reasons linked to the emergence of conflictive situations did not appear to include the motives mentioned above in the case of the association. Instead, this evolution of the discourse is based on the lack of availability, a dimension which largely takes account of a new register of motives for withdrawal which were not often mentioned earlier because they were things that could not be said.

Conclusion: mobilization process and the transformation of social problems

In retracing several stages of the fight against AIDS in Switzerland, we wanted to emphasize the fact that, as Sawicki and Siméant (2009, p. 115) mentioned, 'activist organizations, *as organizations* and regardless of their degree of institutionalization, transform the individuals and are

transformed by them'. It is important to remain attentive to factors contributing to shaping the mobilization starting first with the structuring of the homosexual associative space, then linking the resulting mobilization to the formation of the fight against AIDS, and finally detailing the various aspects of the transformation of the cause and the progressive institutionalization of the movement against the epidemic. Such an analysis remains attentive to the transformation of AIDS; examining the context of mobilization; and, finally, of linking the development and transformation of the AIDS cause to the evolution of the social characteristics of the actors who become involved, as well as to their reasons for engaging in the fight against the epidemic.

Examination of the development of the AIDS cause over a long period allows us to better understand how both a public policy, and social movement organizations, could become institutionalized at the same time, which decompartmentalizes questions too often examined separately (see Meyer 2005, Fillieule and Blanchard 2012 on this point). We argued here for an analysis of the development and transformation of causes as situated and contextualized, an analysis of the process of mobilization, careful to accurately depict those social actors who were the protagonists at the time and those who now are.

Over the course of this story, between the beginnings of the mobilization against the epidemic, when the urgency of taking action was paramount, and in its most recent developments, the AIDS cause has changed considerably. The current phase is characterized by attempts to diversify the fight. Nonetheless, there remains a profound indecisiveness following the 'normalization' of the cause, which led tangentially to treating AIDS as a social-health problem 'like any other'. In a context of budget cuts and trivialization of the epidemic, the cause is certainly at a turning point. Will we be witnessing the failure of a great cause to diversify, which Pollak (1990) described in another context or a success, at least temporarily, in repositioning the fight against AIDS consistent with the diversification of the issues and the objectives of mobilization?

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Notes

1. The concept of configuration is key to Elias' sociology of civilization. He defines these configurations as the changing pattern, which players form with each other, relations of suspense, interdependence of players *and* the fluctuating balance of suspense, the to-and-fro of a balance of power (Elias 1939).
2. The study combined archival analysis (reports and minutes produced by the voluntary groups, documents published by the Parliament as well as by the Federal Office of Public Health (FOPH) over the period), semi-structured interviews with activists of the Swiss Aids Federation, local AIDS groups, and members of the FOPH ($n = 41$), in depth interviews with activists ($n = 60$) and a quantitative analysis via a self-administered questionnaire sent to volunteers and ex-volunteers of eight associations during the Summer of 2005 ($n = 363$, answer rate 20.2%.) The study (dir., O. Fillieule, with M. Voegtli, S. Horat and P. Blanchard) was funded by the Swiss Scientific Funds 'Changes in AIDS epidemic, associational dynamics and commitment. Case Studies on seven swiss cantons' (3346C0-104177/1). See Voegtli (2009) for a detailed presentation of data and methods used.

References

Altman, D., 1994. *Power and community. Organizational and cultural responses to AIDS*. London: Taylor & Francis.

Armstrong, E.A., 2002. *Forging gay identities*. Chicago: University of Chicago Press.

Blumer, H., 1951 (1939. Collective behavior. *In*: A. McClung Lee, ed. *Principles of sociology*. New York: Barnes & Noble, 165–222.

Broqua, C., 2005. *Agir pour ne pas mourir. Act Up, les homosexuels et le sida*. Paris: Presses de Sciences Po.

Duyvendak, J.W., 1995. Gay subcultures between movement and market. *In*: H. Kriesi, ed. *New social movements in Western Europe. A comparative analysis*. London: University College London Press, 165–180.

Elias, N., 1939. *Über den Prozess der Zivilisation. Soziogenetische und psychogenetische Untersuchungen*. Frankfurt: Suhrkamp.

Elias, N., 1970. *Was ist Soziologie?* München: Juventa.

FF, 1996, 19th November. Message concernant une nouvelle loi sur l'organisation du gouvernement et de l'administration (LOGA) du 16 octobre 1996. *Feuille fédérale*, 5 (46) 1–23.

Fillieule, O., 2001. Propositions pour une analyse processuelle de l'engagement individuel. *Revue française de science politique*, 51 (1–2), 199–215.

Fillieule, O., 2010. Some elements of an interactionist approach to political disengagement. *Social Movement Studies*, 9 (1), 1–15.

Fillieule, O. and Blanchard, P., 2012. Fighting together. Assessing continuity and change in social movement organizations through the study of constituencies' heterogeneity. *In*: N. Kauppi, ed. *The new European political sociology*. Oxford: Routledge, 112–135.

Fillieule, O. and Broqua, C., 2005. La défection dans deux associations de lutte contre le sida: Act Up et AIDES. *In*: O. Fillieule, ed. *Le désengagement militant*. Paris: Belin, 189–228.

Giauque, D., 2003. New public management and organizational regulation: the liberal bureaucracy. *International Review of Administrative Sciences*, 69 (4), 567–592.

Herzlich, C., 2002. Vingt ans après … l'évolution d'une épidémie. *Etudes*, 396 (2), 185–196.

Kippax, S., *et al.*, 1993. *Sustaining safe sex. Gay communities respond to AIDS*. London: Falmer Press.

Kirp, D.L. and Bayer, R., 1992. The second decade of AIDS: the end of exceptionalism? *In*: D.L. Kirp and R. Bayer, eds. *AIDS in industrialized democracies. Passions, politics and policies*. Montréal: McGill–Queen's University Press, 361–384.

Kübler, D., *et al.*, 2002. *Aidspolitik in der Schweiz: welche Normalisierung? Normalisierungsszenarien und Neue Partnerschaften in der HIV/Aidsprävention auf Bundesebene und in fuenf Kantonen*. Lausanne: Institut universitaire de médecine sociale et préventive.

Mellini, L., *et al*., 2004. *Le sida ne se dit pas. Analyse des formes de secret autour du VIH/sida*. Paris: L'Harmattan.

Meyer, D., 2005. Introduction. Social movements and public policy: eggs, chicken, and theory. *In*: D. Meyer *et al.*, eds. *Routing the opposition. Social movements, public policy, and democracy*. Minneapolis: University of Minnesota Press, 1–26.

Pinell, P., *et al.*, 2002. *Une épidémie politique. La lutte contre le sida en France 1981–1996*. Paris: PUF.

Pollak, M., 1988. *Les homosexuels et le sida: sociologie d'une épidémie*. Paris: Métailié.

Pollak, M., 1990. Constitution, diversification et échec de la généralisation d'une grande cause: le cas de la lutte contre le sida. *Politix*, 4 (16), 80–90.

Rosenbrock, R., *et al.*, 2000. The normalization of AIDS in Western European countries. *Social Science and Medicine*, 50 (11), 1607–1629.

Sawicki, F. and Siméant, J., 2009. Décloisonner la sociologie de l'engagement militant. Note critique sur quelques tendances récentes des travaux français. *Sociologie du travail*, 51 (1), 97–125.

Schilling, R., 2000. The German AIDS self-help movement: the history and ongoing role of AIDS-Hilfe. *In*: R. Rosenbrock *et al*. eds. *Partnership and pragmatism. Germany's response to AIDS prevention and care*. London: Routledge, 82–90.

Setbon, M., 2000. La normalisation paradoxale du sida. *Revue française de sociologie*, 41 (1), 61–78.

Voegtli, M., 2009. *Emergence, constitution et diversification d'une cause. Processus de mobilisation, identités collectives et socialisations militantes dans l'espace associatif homosexuel et de lutte contre le sida en Suisse (1980–2005)*. Dissertation Thesis. Lausanne University and EHESS-Paris.

Whittier, N., 1997. Political generations, micro-cohorts, and the transformation of social movements. *American Sociological Review*, 62 (5), 760–778.

Wiltfang, G.L. and McAdam, D., 1991. The costs and risks of social activism: a study of sanctuary movement activism. *Social Forces*, 69 (4), 987–1010.