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Managing Risks through Solidarity? HIV/AIDS and the Organization of Support in South Africa

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Abstract:

Within the sociological literature on risk and uncertainty as central features of a 'second modernity', the formation of new relationships of solidarity as responses to ever-growing uncertainties is mostly addressed in terms of 'collateral benefits' enjoyed by members of social movements, activists, or other people who partake in processes of 'lay expertification'. While the AIDS epidemic is often mentioned in sociological accounts on globalization, risk, and uncertainty, there is rather scant knowledge on how the creation of such relationships affects the *politics and management of everyday life* of HIV-positive people and the lives of those at sexual, medical and symbolic risks.

In this paper I will argue that the organization of relationships of solidarity through *support groups* among HIV-positive South Africans is an ambivalent reflection of their capacities to 'empowerment from below' in the face of massive uncertainties, which strongly resonates with the assumptions of communitarian political theory. I will describe and explain the processes, conditions, and manifold functions of support groups as acts of community-making on the basis of a socially momentous biological condition that is shaped by a global networks of *bio-politics and bio-solidarity*. The paper is based on empirical research in Cape Town/South Africa.

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1. **Introduction**

In present day South Africa, with roughly 6 million people living with HIV and AIDS and an infection rate of 22% of the adult population, AIDS is arguably the greatest health risk not only for "risk groups" as defined in the laboratories of public health discourse but for the population at large. With heterosexual intercourse, followed by mother-to-child transmission at distance, being the dominant mode of transmission, AIDS has rendered intimate and sexual relationships problematic in novel ways in that it attaches medical meanings to the sexual act that crosscut the objectives of pleasure, romanticism, procreation, and marital union, inscribed into sexual practices in modern culture (Giddens 1992). Disease and death emerge as possible consequences of sexual intercourse, as threats to be avoided and as concrete medical articulations of the contingencies of an everyday life practice. In this sense, AIDS prevention discourse invites people to undertake the organization of one's sexual life as a practical engagement with the risk of HIV infection, in which every health-driven sexual choice is an investment into a healthy future, an element in an infinite series of responsible practices.

However, the contingencies AIDS infuses into sexual and intimate relationships are only one type of risks among others. After HIV-infection has taken place and is established by diagnostic testing, for people living with HIV or AIDS (henceforth: PLWHA), risks and uncertainties multiply: For how long will they be able to survive? Should they enrol on an ARV treatment regime? What kind of health-related practices in everyday life should they adopt in order to stay healthy? Will they be able sustain themselves economically and to continue acting as breadwinners for their families? Will they receive care when actually falling sick? Will they be able to mobilize support from their partners, families and communities after disclosing their diagnosis or will be stigmatized and discriminated against?

It has been argued that the secular rise of the concept of risk has helped to place health at the centre of the production of late modern 'normalized' subjectivity (Lupton 1995). Populations, groups, and individuals are increasingly enmeshed in a web of institutions and apparatuses, which seek to enhance their health by means of monitoring, control and surveillance, by generating knowledge about the health-related habits and routines of people and by suggesting ethical models for the rational management of everyday life to be embraced as strategies of individual risk

management, which are based such knowledge. The objective of this paper is to analyse how *support groups* mediate the experiences, views and practices of HIV-positive people, and thereby to shape their capacities to engage in strategies of such kind. More precisely, it aims at understanding how support groups shape the ways, in which PLWHA perceive, communicate, and practically act upon the risks and uncertainties attached to their biological condition and corresponding social positions. I will argue that the formation of new relationships of solidarity, upon which these groups are sociologically founded, is one of the most important forms of organized civic responses to uncertainty in two major regards: As an *end in itself*, solidarity among PLWHA is a practical re-enactment of social life and social ties, from which many of them have been cut off the day they disclosed their test result, and as such, a symbolic achievement in the struggle for *recognition* in a hostile social environment from which the uncertainties regarding life chances and the risks of symbolic exclusion arise. On the other hand, solidarity is a *means* on the basis of which PLWHA mobilize the resources that capacitate them to *practically act* on economic insecurities and medical uncertainties, and to 'expertify' themselves within domains of knowledge and practice, which are pivotal for their physical and social survival.

I begin by analysing the ways in which the experience of HIV/AIDS in South Africa is related to the sociological themes of risk and uncertainty. After that, I trace the of the emergence of support groups and its societal and political conditions as an organized response within the South African struggle against AIDS, highlighting its significance in mediating between individual experience and public and popular AIDS discourse, its character as a social movement, and its ambivalent relationships to state apparatuses as an expression of nascent post-Apartheid civil society activism. Finally, I will provide an ethnographic account on forms and functions of support groups as we find them in the South African city of Cape Town. The paper is situated within the broader confines of the *cultural sociology of public interventions and social technologies* that seeks to identify the mechanisms by means of which human subjectivities and conduct are moulded and managed in relation to governmental techniques of power and their pedagogical objectives.

2. Living amidst and with a Virus – HIV/AIDS, Risk and Uncertainty in South Africa

Back in 2002, Alex de Waal critically remarked that on any account the South African struggle against HIV/AIDS so far had failed (de Waal 2003: 238). It goes without saying that there is a multiplicity of reasons for this failure, some of which apply to other African countries in a similar fashion whereas others are related to the very specific historical trajectory of South Africa and the related intricacies of its public AIDS discourse. Many scholars have lamented the lack of political attention to the problem, the delay of the setting up of comprehensive HIV/AIDS programmes and policies, the general lack of funding for education and communication infrastructure, public health institutions and for public sector treatment schemes. What was most puzzling to researchers and public health officials alike, however, was that even where institutions were in place, where health information was available and where the levels of knowledge on ways of transmission, prevention techniques and the basic medical facts were rising, rates of infection did not appear to decrease. Despite many public efforts to normalize the disease, AIDS continued to be stigma and a sign of shame. And despite the lamentably slow but increasing enrolment of AIDS patients on ARV treatment regimes, mortality rates continued to rise because of lacking patient competence, deficient treatment adherence, or what medical sociology used to call "patient compliance". Again, the sociological explanations for these phenomena are complex but there appears to be common and fundamental insight that is remarkably simple: That the dissemination of information about medical facts and their behavioural implications through educative programmes alone is insufficient to change the HIV/AIDS-related patterns of social and individual practice, which are more deeply embedded in cultural traditions, socio-economic conditions, and the mute routines of everyday life decision-making than many health development experts believed.

What almost disappeared from view within the assessment of governmental efforts to manage the numerous HIV-related risks and their myriad failures, was one model of civil society response, which for its very cultural newness alone has to be seen as a remarkable success: the emergence of HIV/AIDS support groups. Support groups appear as cultural modes of tackling and acting upon HIV-related risks in ways that reveal how and why welfare

state interventions have failed. By virtue of their very number and prominence, support groups represent a social movement that not only has the capacity to substantially re-shape the nature of the South African AIDS industry; in addition to that they extend the limits of civil society mobilization, activism and volunteerism in South African society at large.

With regard to the theme of HIV/AIDS and risk in South Africa, two observations stand out quite paradoxically: The centrality of the concept in policy and public health discourse and its overall absence in social science literature. Within public health and policy debates, the notion of risk has come to dominate how the AIDS epidemic is interpreted as a public health crisis in three important ways: as a hazard for individual lives, as a force with potentially negative or even disastrous repercussions for the national political economy and the management of the population in its demographic properties, and as a threat to institutions and organizations.

In terms of individual risks, policy discourses are attempting to seek out interventionist mechanisms to capacitate individuals to make choices that effectively minimize the risks of infection, as a means to safeguard life. From the perspective of risk management, one of the primary objectives of preventing infections is, of course, to keep the budgetary burden of the epidemic and the allocation of resources for medical care and treatment as low as possible and – in the long run – under control. Public health research is therefore busy calculating, predicting and documenting the overall impact of the epidemic on national and provincial economic performance and its interaction with AIDS-induced demographic developments (see i.e. Natrass 2003). One of the most frequently made observations in this context is that the epidemic threatens to take the lives of the young and economically most productive generation. The economic loss is calculated according to age-related productivity coefficients and such calculations promoted as the basis for the further allocation of funds. In the field of institutions and organizations, public health research concerns itself with how infection and mortality rates effect the working of national and provincial bureaucracies, the security forces such as army and police, as well as economic units. Companies and corporations are encouraged to engage in "AIDS at the workplace"-programmes with the aim of controlling and hopefully minimizing the epidemic's impact on their workforce and the loss of human capital and skills through death- and illness-related employee turnover. All of these

discourses combine to make governmental HIV/AIDS programming the single most important project of *bio-political regulation* in present day South Africa.

Precisely because the tremendously increasing salience of the concept of risk as a generator of bio-political techniques and strategies, and as a lens through which to look at the social and political implications of HIV/AIDS thoroughly conforms to the propositions of both, 'risk society' theorists and 'risk and governmentality' researchers alike, the virtual absence of it in social science research on HIV/AIDS comes as a surprise (for exceptions see Douglas 1990, Bujra 2000). In the following part of this section I will address the particularities of HIV/AIDS as a health risk, which explain this reluctance, and argue that aspects of the social infrastructure and corresponding social processes that emerged in response to AIDS nonetheless closely resemble that of other types of risks and risk management practices.

Borne from the concern with questions as to the probability, calculability, and predictability of threatening future developments, the risks and uncertainties that are at the heart of the risk society approach are those related to late modern developments in science, industrialism, and high technology (Beck 1992). Whereas to the general population such risks are often intangible and invisible, difficult to perceive, estimate, and act upon, a whole new infrastructure of expert systems emerged in response and is being held responsible for their management. From the perspective of the individual, HIV infection instead appears as avoidable by resorting to relatively simple means of protection. It is a health risk that everyone can in principle act upon individually. That is, the exposure to risk and its possible repercussions can effectively be reduced by individual strategies of action and are not to the same degree depending on the actions of distant and unknown others as in the cases of nuclear energy, air contamination, or even technologically induced epidemics such BSE or SARS.

Sociological research into current sexual economies and the norms and values guiding sexual decision-making processes has plainly shown how gendered imbalances of power, poverty, social inequality, and other social and cultural conditions work to render this theoretical possibility for many South Africans, especially women, unattainable (Varga 1997, 1999; Schoepf 2002; Preston-Whyte 2000, Hunter 2002). These forces have been found to continuously determine sexual decision-making, and often the lack of considerations for AIDS prevention, even when the subjective

perception of risk was high. These puzzling findings reveal the highly contingent relationships between knowledge, subjective risk perception, practice, and alternative rationalities.

Just as the risks and uncertainties that arise from advances in high technology, AIDS is not limitable socially, temporally, and spatially. In principle, it may affect people regardless of their age, gender, class, religion, education and cultural background. It impacts upon people's life chances, present and future ones, and moves across regions and continents as the global movement of people accelerates. But while the chances for individuals to take preventive and protective measures against geographically distant, large-scale industrial accidents are very limited in scope, the uncertainties regarding AIDS are always interpreted and acted upon in localized contexts by means of the symbolic resources pertaining to specific cultures. This means that the democratizing effect, which Beck sees at work in relation to the exposure to technological risks, may be rendered ineffective by local economic and cultural conditions. With regard to HIV/AIDS in South Africa, the effects of these conditions are in fact quite well explored (Gilbert/Walker 2002). AIDS has been found to progressively hit the lowest levels within the hierarchies of social inequality. Low levels of formal education are often the result of economic pressure on young people to contribute to the household income. As a result, learners prematurely drop out of school and are thus less confronted with pivotal health information than their more affluent peers. Besides, poverty negatively effects people's broader perception of their own capacities to exert control and influence over their affairs, and thereby to master the contingencies associated with them. The most important dimension, however, impacting upon the differential exposure to risk of infection as well to the risks of progressive marginalisation is gender (Bujra 2000). The infection rates of young women have proven to be three to four times higher than those of young men of the same age group. By virtue of extreme generalized gender hierarchies and their subordinated position, women's power in sexual decision-making, and thus in negotiating condom use and the general terms of sexual engagement, is limited (Wood/Jewkes 2005). Moreover, their economic dependence on husbands or male partners also limits their possibilities to choose exit options and multiplies their burden on sustaining household economies in the case of their partners falling ill. If women disclose their status to their husbands or partners, being abandoned is a typical experience with all its economic corollaries.

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Theorists of both, the 'risk society' approach as well as of the 'risk and governmentality' concept have argued that the rising salience of risk and uncertainty has been accompanied by a massive proliferation of expert systems and expert cultures (Beck/Giddens/Lash 1994; Lupton 1995). In fact, our very knowledge and perception of as well as sensibilities and responses to risk are shaped by public discourses within which experts play a key role in relation to identifying, defining and assessing them. Expert cultures are social arenas for the generation new knowledge as solutions to problems; they make claims to the legitimate ownership of social problems (Gusfield 1996), and many of our everyday social practices as well as processes of social change at large are increasingly being mediated by the bodies of expertise they produce as injunctions for action.

HIV/AIDS in South Africa is a supreme example for studying the mutually constitutive relationship between risk and experts. AIDS experts are now filling the ranks of public health agencies, medical and human science research institutions, community-based organizations, religious charity organizations, provincial health service provision departments, advocacy groups, human rights councils, national prevention campaigning agencies and multi- and international development organizations where "experthood" is organized in and through the social roles of "AIDS outreach" project managers, peer educators, counsellors, activists, and social workers, to name just a few. Some of these organizations have expanded, others have sprung up in response to AIDS. Risks as social problems generate the perceived need for solutions through intervention, and are thus bound to trigger the emergence of a new cultural infrastructure of expert knowledge, expert discourses and expert practices, which attempts to reflexively re-fashion patterns of risk-related practices in the name of people's *best interest* as well as the very ethical subjectivities, which underpin them. In doing so, however, AIDS experts are in competition with alternative social forces informing people's actual engagement with risks against which they have to defend their interpretation of disease in public and popular discourse. To that end, AIDS expertise becomes canonized, standardized and passed on through processes of professionalisation. As a profession, AIDS expertise makes claims to legitimate competence, which it 'borrows' from the discursive hegemony of biomedical and social sciences. On the flipside, traditional everyday life rationalities and alternative ways of perceiving, evaluating and acting upon AIDS-related uncertainties than

emerge as what in AIDS expert discourse is commonly being referred to as 'AIDS mythologies'.

If AIDS has somehow created this expert culture, it is equally clear that in and through the day-to-day professional practices of these groups particular socio-cultural constructions of the disease and its practical, moral and political implications are established and disseminated. The bulk of the operations within this vast sector are based on data on certain habits, practices and routines of the population, gathered with the objective of detecting the locus of the problem. In this context, Caceres (2000) has highlighted that the problematization of sexuality as a key field of AIDS intervention has resulted in hitherto unknown extents to which the intimate practices of people are being recorded, categorized and aggregated into statistical variables within the archives of the medical and social sciences as a knowledge base upon which interventions are premised. Through such processes, new categories and analytical distinctions of behaviour such as "protected sex" and "unsafe sex" are created. By virtue of its risk-reducing benefits, the category of "protected sex" is established as the normal practice and becoming naturalized, while seen through the prism of everyday cultures of intimacy it appears as highly artificial. Likewise, hostile actions against PLWHA are registered through the notions of stigma and discrimination. By way of academic discourse, but more importantly, through the practices of AIDS experts in the pedagogical apparatuses these notions are channelled back to the general population and *vernacularized*. In this sense, AIDS expert cultures play pivotal roles not only in shaping what people do, but also in mediating their ways of thinking, and by extension their desires, needs and preferences. The vernacularization of the terminologies and rhetoric of risk thus provides the analytical means for people to turn to themselves, to understand and to act upon themselves.

These processes epitomize the *reflexive turn* the modes of knowledge formation and social life in general have taken in late modernity. According to Giddens, what is characteristic of the late modern kind of reflexivity is that "(…) social practices are constantly examined and reformed in the light of incoming information about those very practices, thus constitutively altering their character" (Giddens 1990: 38). The circular relationship between knowledge production and social practices in relation to risk within the struggle against AIDS in South Africa is visible on the level of both, the practices of people in everyday life and policy

formulation and intervention processes. On the level of everyday practices, public AIDS prevention discourse has come to provide the inescapable 'knowledge context' within which people are engaging in health-related practices. Being fully unknown for centuries, in the course of the past two decades the notions of "protected" and "unprotected sex" have now come to pervade the way South African think about and look upon sex, regardless of whether they actually opt for the use of condoms or marital fidelity or not. Rather than merely providing people with information on how to act and inviting them to follow the behavioural suggestions of prevention discourse, AIDS campaigning makes practices visible as *choices* to begin with.

On the level of political debate and practice, the reflexive nature of risks lies in its capacity to generate anxieties and pose questions about current practices (Beck 1992: 21; Lupton 1995: 66). The AIDS epidemic is highly indicative of the ways in which risks are seen as posing new challenges *and* opportunities to the government and management of populations at the aggregate level. As a hazard to the health-related properties of populations qua workforce etc., the social construction of the AIDS epidemic has contributed to a vast expansion of bio-political technologies of government and the political concern with the enhancement of physical life as such.

To summarize, the social construction of the AIDS epidemic in South Africa as well as the social and political responses to it whose organizational expression is now widely referred as the 'AIDS industry' have much in common with the way risk and uncertainty have been theorized within the most prominent approaches in sociological theory. What has remained largely unexplored, however, are the ways in which the creation of bottom-up relationships of solidarity and care through support groups has come to mediate the modes of perceiving, negotiating and acting upon uncertainties among PLWHA. The following section addresses these issues in greater detail.

3. Managing Risks and Uncertainties through Solidarity: The Emergence of Support Groups

The first HIV/AIDS support groups came into existence in the early years of the epidemic in the United States. In their initial stage, they were little more than informal gatherings of sick people, their friends and relatives, whose only concern was to break the silence. As Cindy Patton powerfully reminds us, they were about crafting a

language of suffering and pain, for which there was no explanation at hand, and about giving expression to the experience of a disease about which there was only scant if any knowledge (Patton 2002). For the formation of these groups, two kinds of cultural resource were of paramount significance: firstly, the solidarity networks within the gay community that emerged as a result of the gay struggle for public recognition; and secondly, an elaborated culture of grassroots therapeutic relationships that was part of a flourishing civil society movement.

When the epidemic started to become a major social problem in South Africa in the beginning of the nineties, neither of these resources were at hand or relevant to Black South Africans, the hardest-hit group. But although the social, political and cultural context and the state of medical knowledge were totally different now, we could witness the emergence of a support group movement, which displays some remarkable resemblances to its Western precursor. Therefore, Patton, de Waal and others have argued that as an organizational expression of bottom-up self-help relationships, support groups must be seen as one of the most successful examples of the global dissemination of civil society responses to disease (Patton 2002, de Waal 2003).

Now, while by the middle of the nineties the body of medical knowledge on HIV/AIDS had considerably grown and South African prevention campaigning efforts slowly intensified, HIV/AIDS was overwhelmingly framed within discourses of danger, sin, and blame. South Africans' attitudes towards the disease and their interactions with AIDS patients were informed and continue to be informed by those discourses. Although practices of discrimination and stigmatization are now frequently scandalized through mass media, stigma keeps on pervading the social environment within which the subjective experience of HIV/AIDS is located. The emergence of support groups in South Africa has to be understood against this backdrop as a pivotal step in the struggle against AIDS as a whole. Support groups provided a pivotal cultural resource for they appeared as protected social spaces of unconditional solidarity, as spaces for the articulation of experiences and personal problems.

While essentially being borne from the experiences of familial, economic and symbolic exclusion on the part of AIDS sufferers, support groups at the same time emerged in the context of a nascent post-Apartheid civil society activism. Seen from the perspective of the relationships between civil society on the on

hand, and the state and its governmental apparatuses on the other, two sharply distinct modes of engagement have to be distinguished. First of all, many support groups were and continue to be founded within the broader social context of AIDS activism as a *political movement*. The most important objectives of this globally organized and grassroots-initiated struggle are the improvement of access to anti-retroviral treatment therapies (ARVs) and the acceptance of PLWHA as citizens with equal rights, duties, and entitlements. Robins notes that South African AIDS activists

"(…) share similar concerns with Northern illness-based movements that have emerged as a result of citizen perception of inadequate scientific and government responses to a range of health and environmental hazards, for example, BSE, foot and mouth, biotechnology and GMOs, pesticides, AIDS, global warming and so on. (…) While the linking of biology and health to identity and social movements is certainly not new, what is new are the ways in which biological identities and the interest groups formed in their name are emerging in different parts of the world (Petryna 2002: 14). These movements have important implications in terms of extending liberal democratic notions of citizenship" (Robins 2005: 6).

For years now, the social movement organization Treatment Action Campaign (TAC), established in December 1998 in Cape Town, and Medicine sans Frontiere (MSF) have been at forefront in the political struggles around treatment and biological citizenship (Nguyen 2005), while TAC has meanwhile become the single most important AIDS advocacy organization in the world (on TAC compare Friedman/Mottiar 2006). Many support groups receive information and training materials from TAC. Besides, for a number of them TAC serves as kind of an umbrella organization to which they are linked through numerous personal, organizational, and ideological ties. One expression of this is that support group leaders often encourage group members to disclose their HIV status on public functions or rallies through disclosure rituals, which can be traced back to the cultural repertoires of TAC. But also in terms of the broader politicization of health service provision, the critical spirit of TAC activism has made inroads into the organizational culture of the support group movement. By means of their connections to this movement, support groups take a critical stance towards the state and its apparatuses, which are seen as paternalistic, unhelpful, and even partially discriminating. Taking the perspective of social movement theory therefore points

to support groups as highlighting the self-organizing and self-help potentials of civil society *beyond* the state, and the forces of pharmaceutical markets.

However, as de Waal (2003) has pointed out, the South African welfare state has not only failed in creating a supportive public discourse through its health campaigning efforts. It also failed in providing PLWHA with the intellectual resources, competences and practical skills, which are necessary to master the numerous challenges and contingencies of living with HIV and AIDS in an environment of biosocial risks. Support groups emerge in response to and account for these failures in ways that have to be seen as intensifying the pedagogical efforts of governmental health agencies. In a similar vein, Oyen has noted that "(…) there are self-help groups which are extensions of the activities of the professions. (…) The individuals assist each other in following the prescribed treatment or way of life, and they function as controlling agencies if someone falls behind. Mutual information about the disease and about day-to-day life therefore becomes part of the treatment and a presupposition for the functioning of the group" (Oyen 1982: 33).

In such cases then, support groups may themselves become extensions of pedagogical apparatuses, working very much in concert and coordination with governmental interests in that they assume welfare functions free of cost. Seen from the perspective of the state, support groups appear as and are meanwhile proactively promoted as 'social capital' filling the gaps that the insufficient allocation of public funds for health training and education infrastructures have left (on social capital promotion policies in the Western Cape province see Swart 2006; on the political implications of responsibility transfer from the state to citizens see Robins 2005: 7). The bottom-up formation of solidarity is thereby becoming a strategic asset for governmental health programming. Similarly, the promotion and support of the formation of support groups has become a standard strategic component within the policy framework of internationally operating development and humanitarian NGOs and bilateral development agencies. Thus, the flipside of such processes of empowerment from below is that they work in compliance and complicity with governmental efforts towards the privatization and NGO-isation of risks, and welfare and social service provision in the broader context of what Loic Wacquant has called the "Neo-liberal Revolution". Support groups are being enmeshed in the webs of

the very institutions whose work they vicariously do by proxy, and whose functioning Foucault depicted in the notion of 'governmentality' as the contact between technologies of domination and technologies of the self (Foucault 1988: 19). In pursuit of the 'imperative of health', Lupton notes, "(…) the techniques and strategies of governmentality emerge not simply from the state. While the state is important as part of the power relations, so too are the myriad of institutions, sites, social groups and interconnections at the local level, whose concerns and activities may support, but often conflict with, the imperatives of the state" (Lupton 1995: 9).

In this section I have revealed some of the interconnections support groups entertain with other actors within the field of AIDS interventions, as well as their ambivalent positions as expressions of civil society activism vis-à-vis the state. In the remaining part of this paper I provide an ethnographic account on support group processes in the South African city of Cape Town. Methodologically, the research design follows the principles of grounded theory in combination with a triangulating data gathering approach. The description synthesizes the analysis of participant observations, support group meeting protocols, individual interviews with group members as well as expert interviews with group facilitators, which I gathered over a period of nine months in 2006.

5. Mobilizing Support, Transforming the Self: Elements for an Ethnography of Support Group Processes

For many South Africans, the experience of HIV/AIDS combines at least four types of risks that Lupton found to be dominant in the concerns of individuals and institution in contemporary societies: lifestyles risks, medical risks, interpersonal risks, and economic risks (Lupton 1995: 13f). In the following section I will argue that the formation of solidarity through support groups provides creative avenues for PLWHA to practically act upon all of these risks in novel ways.

Given that one among the many fears PLWHA are facing is being exposed to public stigma if their HIV status is being revealed, confidentiality is a pivotal concern. The decision itself to join a support group implies the risk of revealing one's status in an involuntary act of disclosure if the location of the group meeting is such, that group members can be identified by bystanders on their

way to the sessions. Some people therefore choose to visit groups outside of their residential neighbourhood. Most groups hold their meetings in township community halls or at the premises of local NGOs, churches or other faith-based or community development organizations to which they are affiliated. The group meetings are usually facilitated by employees or volunteers of the organizations. The facilitators have some level of formal training, which affords them the status of 'AIDS experts'. With regard to the structure of the group processes, they distinguish between two types. So-called "open groups" are open to anybody who wants to join. Here the members exert full authority over the issues of group debate and other common activities. "Closed groups" are limited to individuals who find themselves at a similar (usually: initial) stage of their disease and identity trajectory. These groups are facilitated in a more structured way: Whether organized along the lines of psychological or pedagogical manuals or not, the group process follows a defined trajectory of stages aiming at assisting people with transforming their selves. This structure exhibits some remarkable resemblance to the ritualized 'Twelve Steps' Norman Denzin identified as central to the organization of the recovery processes among the Alcoholics Anonymous (Denzin 1987; see also Robins 2005: 5).

With regard to the anticipated or perceived benefits of membership as motivational forces to join a support group, two dimensions can be distinguished: First, people differ in relation to which kind of risk or uncertainty rising from their HIV infection is most virulent for them (see above). Some might join in a personal situation of advanced economic marginalisation, having been abandoned by their families with almost no material and social resources at hand to organize their day-to-day survival. Others might still live under economically more or less stable circumstances, but fearing they are not prepared to deal with the medical contingencies, i.e. how to react upon side effects, whether to enrol on a treatment regime etc. Still others might primarily be looking for a space in which to create new personal relationships. The problem with this classification is that in the case of AIDS the various types of risks are typically entangled and overlap to form *chains of progressive exclusion*: Infection leads to the breakdown of personal ties, which in turn reduces the levels of economic security or the chances for a regular income within the largely informal township economies. Unemployment and lack of economic resources is usually accompanied by bad nutrition, depression, alcoholism or substance abuse, all of which – as

lifestyle risks in Lupton's sense of the term (1995: 13f.) – combine to increase the individual's exposure to medical risks, and thus the probability to proceed to the medical stage of so-called "full-blown AIDS".

A better way to distinguish is therefore the degree to which people are already exposed to the various kinds of risks when joining the group. People who live in a situation of advanced social exclusion will join group in the search for solidarity as a means to solve the practical issues of organizing their day-to-day life in rational ways. I often found that particularly women use support groups to create and strengthen personal social ties with other women and assist each other with issues of childcare and household organization for instance. Besides, people come to mobilize mutual support and assistance to skill themselves for their interaction with medical institutions. Many group sessions' debates revolve around issues of 'medicalized lifestyles' and treatment. The purpose of these sessions is to make patients aware of the specific requirements of the treatment process, to give them the skills that are necessary for successfully living on treatment, and to teach them about their disease: about symptoms, their meaning and how to react to them, about bodily processes, about the properties of their medicine, about acceptable and non-acceptable side-effects, how to treat or cure side-effects, opportunistic diseases, proper nutrition and so on and so forth. These sessions we could call the production sites of 'medicalized identities' in that they are sites in which the medical meaning and practical requirements of living on HIV-treatment are systematically organized into the life-perspective and daily routines and practices of chronically ill persons. In effect, people move from HIV-positive individuals to patients to eventually become 'doctors of themselves' in the way Foucault has argued (Foucault 1988: 31).

The more people are in control of their individual life circumstance (and the more they increase this control in and through group membership), the more we can expect identity issues to move centre-stage in their concerns. While mobilizing practical support in coping with the problems of everyday life is in essence a collateral benefit of group membership, the processes of identity transformation and personal 'conversion' are at heart of the groups' *raison d'etre* and the primary foundations upon which the formation of solidarity rests. In terms of individual trajectory, this process can be construed in an ideal-typical fashion as being

organized in *three steps*: disclosure, acceptance of one's status, acting upon one's status.

Whereas for virtually all PLWHA, support groups are exclusive and privileged social spaces in which they feel free to articulate their subjective experiences of HIV/AIDS, for some it is here that they disclose their HIV-status for the first time to others than their closest relatives or partners, or even for the first time at all. Disclosure within the group takes place by way of storytelling. These stories comprise accounts on how individuals came to go for a diagnostic test, how they experienced the test-result emotionally and psychologically, how they subjectively interpret their life course and the events leading to infection, and what kind of experiences they subsequently made in dealing with their new life situation within their interpersonal life-worlds. This type of disclosure ritual within the small and protected public sphere of the support group thus elicits very personal and private information about people's intimate lives. However, support groups are not only places that enable people to articulate collectively shared experiences; in its reciprocal nature, the willingness to share is also generally constructed as an implicit cultural expectation. Disclosure is central to this expectation and is construed in a way that transforms the act of disclosure itself into the first step of acquiring a new self-image and a new positive identity as an HIV-positive person. At later stages of the group process, if the group decides to partake in outreach and awareness raising activities to influence the attitudes of the broader population in their residential areas by way of public rallies, the internally trained act of disclosure then assumes the form of "illness testimonials" that are a central ritual component of the cultural repertoire of the South African AIDS movement.

Accepting one's status is the next step in building a positive identity, which unfolds as a process in time and implies the rejection or reversal of what AIDS activists typically refer to as "living in denial". Living in denial can either mean that persons observe symptoms indicating HIV-infection without having the courage to go for a test, or that persons have made a test but deny the existence of the virus in their blood and do not take any subsequent action. The way the concept of acceptance is construed by support groups exhibits the entanglement of the subjective and inter-subjective processes of negotiating identities and modes of practices and conduct. Groups establish criteria for the degrees to which members have 'accepted' their status such

as the willingness to talk freely about AIDS as a personal experience not only to group members but to outsiders as well. At the same time, for virtually all groups protecting the confidentiality of member's information is central to their code of conduct. Disclosure "by proxy", that is, talking about others' AIDS experiences outside of the group is highly repudiated and in some cases penalized by sacking.

'Accepting one's status' is a precondition for 'acting upon one's status' in the course of which people re-organize their everyday life activities intent on the specific requirements of their biological conditions but with full subjective recognition of, and respect for, their autonomous self-hood. It is important to note that this is in principle an open-ended process. To successfully live with an HIV-infection in the long term requires the perennial subjection of oneself to strict regimes of monitoring body, health, and conduct of life. This involves a healthy diet, abstaining from alcohol and smoking, exercising to enhance overall physical fitness, the tight surveillance of medial treatment regimes, the empowered 'circulation' of the individual within the webs of health institutions, as well as abstaining from unprotected sex for the sake of avoiding so-called super-infection. Within the group, mutual monitoring is fundamental to this end, and comes down to a 'regime of truth' within which members are required to incessantly interrogate themselves as well as others in relation to the degrees to which the ethical imperatives and techniques are being observed. The following passage is taken from an interview with a support group leader and highlights the interaction between identity process, solidarity, and individual practices of acting upon HIV-related uncertainties:

Because what is the biggest problem we encounter with PLWHAs, if somebody's having anger because of this, they will tell you, I will spread it. I will not go to die alone. I will go outside and spread it. Most of the people are coming to the support group with that attitude. And then, the coordinator once called me saying, mom, there is this other man there, so can you please come, Because this man was saying, there is nothing wrong because you are already infected, so why should you worry because you die, of course you will die. So I come and I ask him a question. It was a bold man saying, no no no, I am telling you I will spread it. I am already infected and I haven't been born with HIV and aids. Some of these girls gave it to me so I will give it to others. Then I said, listen, yes, it is alright, but tell me, when you think you give it to

somebody, what do you think about your body? Because your immune system is low. So the more you give it somebody the more you reduce your CD4 count. So how would you think your CD4 count, your immune system could fight this virus? Then he says, it doesn't matter because I am already dying. Then I say, in how many days do you think you will die? He says, it can be today, it can be tomorrow, it can be that day. Then I said, when did you last hear that you are HIV positive? When did the doctor tell you? And he said, 2003. Then I asked, how much time you were alive after? Then he said, many years. Then I said, so why do you want to kill yourself now? Why didn't you kill yourself the day the doctor told you that you are HIV positive? (…) And then two days after he came to my office and says, Sisi, thank you very much. I love my partner. I won't spread this thing. From now on I tell my partner that we must use this condom.

The passage clearly demonstrates the ways in which support group membership moderates processes of identity transformation and changing everyday practice. The initial identity of the client is very much that of an innocent victim whose life has been destroyed and put into brackets by HIV infection. The objective of the facilitator's intervention is then precisely to remove these brackets by equipping him with the medical expertise that to some extent allows for monitoring and stabilizing his biological condition. The client's reference to the issue of condom use and the love for his partner at the end of the excerpt signals the shift towards a self-image of ethically and medically 'responsibilized' subjectivity, the move to the positive acceptance of HIV-positivity and to the re-enactment of precarious personal relationships.

In the course of my field research it became clear that through support group processes some PLHWA had managed to 'normalize' their everyday life in divergent ways. Some had transformed themselves to become committed members of the local AIDS activist scene or had become professionalized AIDS experts of some kind themselves. Others instead had re-stabilized their former social life and social networks of kinship, family, and friends with the help of support group solidarity such that prolonged membership was rendered unnecessary. Group membership turned out to be a transitional stage in crafting a new form of personal life but the more routinized life with HIV became the more the illness-related aspect of personal identity could recede to the background of daily experience. Both trajectories

exhibits the capacities support group provide to HIV-positive people in successfully dealing with risks and uncertainties.

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Abbreviations:

AIDS – Acquired Immunodeficiency Syndrom

ARV – Anti-retrovirals

HIV – Human Immunodeficiency Virus

MSF – Medicines sans Frontieres

NGO – Non-Governmental Organization

PLWHA – Persons Living with HIV or AIDS

TAC – Treatment Action Campaign