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Struggling with AIDS in South Africa

The Space of the Everyday as a Field of Recognition

The space of volunteering is often seen as a place for rebuilding a world for individuals for whom life has been destroyed by the discovery of AIDS infection. People living with AIDS get involved in HIV support groups, become volunteers, and take care for each other. Without denying the reality of these processes leading to a “positive life” this article questions narratives of the transformation of the self implied in the “caring for other” logic and argues that other spheres of life, less discernable because inscribed in the ordinary and in the intimacy of domestic life are at least as important as the involvement in biomedical care. The limits of voluntary work is highlighted and contrasted with a presentation of how life, love and affection is reconfigured within everyday life, leading to a consideration of people’s struggles to build spaces of recognition. The argument of this article is built on a three year ethnography (2001–04) carried out in Soweto and Alexandra townships (South Africa). [HIV/AIDS, South Africa, recognition, everyday]

Since Paul Rabinow introduced the notion of biosociality to describe the space of mobilization based on a common somatic experience, much has been written on the nexus of science, medicine and the self (Lock 2002; Rabinow 1996, 2000). Adriana Petryna proposed the notion of biological citizenship to describe how Chernobyl survivors negotiated and mediated state recognition and medical science (2002). Nikolas Rose and Carlos Novas developed this concept further , “to encompass all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as men and women, as families and lineages, as communities, as populations and races, and as species” (Rose 2007 :132). Developed countries have been the site of extended research on biological citizenship in relation to the medicalization of life, with considerable focus on issues such as prenatal diagnosis or gene therapy. In developing countries, however, biological citizenship acquires significance through a relatively different set of concerns. Life and death are still matters of accessing basic resources: food, essential medicines, and primary care. The AIDS pandemic has sometimes been described in accord with the paradigm of biological citizenship, as demonstrated in development of care for People Living with AIDS (PLWA). It has evolved into a variety of institutions and instruments premised on treating of and living with a biological condition: support groups, the delivery of ARVs, new technologies and ways of relating one’s body in terms of CD4 count and viral load, mobilization around access to drugs, and fighting related stigma and discrimination. Vinh Kim Nguyen has shown in Burkina Faso how the integration of HIV-positive people into a network of care creates what he calls a “therapeutic citizenship” whereby they receive recognition inside their own countries and in international networks of care (Nguyen 2005). South Africa offers a comparable example with the ongoing Treatment Action Campaign (TAC; see Robins 2008). Yet the concrete realities in which people

continue to be inscribed, the “local ecology within which illness experiences take shape” (Das 2007b:67) receive less scholarly attention. Indeed, as Veena Das reminds us “technologies of the self intersect with objective points of power and constraints as the poor deal with illness: they engage their illnesses neither as heroic fighters nor as pure actors of cultural scripts. Such is the texture of the ordinary” (Das 2007b:92).

In a similar vein, this article suggests situating the life of AIDS sufferers in South Africa in the local ecology in which their life is inscribed. If one looks at the experience of PLWA in terms of the everyday, TAC gatherings and support group meetings represent only a small aspect of their life, sometimes only a few hours per week. Moreover the engagement of PLWAs in voluntary work sometime presented as a new life (Robins 2006) is often an experience mired in denial and frustration. The transformative experience of AIDS would thus be better understood not only as experiences of individual and collective mobilization but also through an exploration of the everyday, of new relations of the self and to the other implied in intimate relations of care. The latter participate in the “remaking of the world” after the experience of loss, disconnection with communities or families and despair associated with the discovery of HIV infection. Thus, the rupture in life brought by HIV (Robins 2008) is not just addressed through the politics of public confessions and testimonies associated with participation in support group activities. It relies as well on the rebuilding of spaces of recognition in domestic life, in intersubjective relations, part of what Axel Honneth calls “ethicity”: “all the intersubjective conditions which we can prove are a necessary prerequisite for the realization of the self” (Honneth 2008:207).¹

Drawing on works of Mead and Hegel, Axel Honneth aims at “explaining social transformation processes according to normative standards within the relation of mutual recognition” (Honneth 2008:113). “It is through struggles,” he continues, “that social groups are engaged in with regard to moral motives, and it is by their collective attempts to promote extended forms of mutual recognition at the institutional and cultural level, that the normative transformation of societies occurs in practice” (Honneth 2008:114). Furthermore:

We can understand ourselves as bearers of rights only if we have noted at the same time the normative obligations we must respect toward others. It is necessary that we incorporate the normative perspective of a “generalized other,” which teaches us to recognize other community members as bearers of rights, in order to understand ourselves as legal persons, inasmuch as we are sure to see some of our demands met in the social context. [Honneth 2008:115]

Trying to identify the unifying grammar hiding behind the apparent diversity of the motive of human action, he proposed examining the “struggle for recognition.” As Andy Blunden reminds us, Honneth distinguishes three underlying kinds of recognition in this grammar:

(i) the demand for *love*, confirming the reliability of one’s basic senses and needs and creating the basis for *self-confidence*, (ii) the demand for *rights*, through which one learns to recognise others as independent human beings with rights like oneself, creating the basis for *self-respect*, and (iii) the demand for recognition as a unique person, the basis for *self-esteem* and a complex and tolerant social life (social solidarity). [Blunden 2003:1]

These three dimensions of recognition are complementary to one another and necessary to the self-realization of the individual. The biopolitical analysis of AIDS experience in Africa tends to focus on the second and third dimensions. In this article I would like to highlight the importance of the ethical inscribed in the first dimension. For people with AIDS, remaking a world often implies rediscovering what is to be taken care of and what is to care for (Paperman and Laugier 2005). More broadly it implies the rediscovery of the meaning of solicitude. Through the shared experience of solicitude, subjects are recognized through their needs, which can be shared and fulfilled. Thus, recognition appears beyond its inscription in language: it is embodied in acts of care.

In describing these experiences, my aim is not to question the pertinence of the biopolitical subject in Africa but to call for a greater attention to the way persons, on an everyday basis, develop new ways of being and new spaces of recognition, building on the resources available.

Fieldwork

This article is based on a three year ethnographic study in two townships (Soweto and Alexandra) with People Living With AIDS (PLWA). Antiretroviral therapy was not available in the public health system at the time of my fieldwork. PLWA were dependent on NGOs providing home based care and on clinics delivering antibiotics, vitamins, immune boosters, and treatment for opportunistic infections. Fieldwork started initially within support groups of two organizations. The first was located in Soweto, the “South Western Township,” approximately 15 kilometers away from downtown Johannesburg. The second was in the Alexandra Township less than one kilometer away from Sandton, one of Johannesburg’s wealthiest neighborhoods. I introduced myself to both groups as an ethnographer, a kind of sociologist interested by the experience of life with AIDS of the group’s participants and willing to describe their conditions of life. Our first encounter was organized around a light meal I did provide to both groups during which I did explain my project. After two collective discussions, members of both groups granted me access to their meetings, which I did attend with a collaborator able to translate in English isiXhosa and isiZulu sentences. From there trust relationships were built with members and apart from the support group meetings, we have been meeting individuals at their home, at Church, during burials or parties during the three years that lasted the fieldwork. Thus, if the entry point of my ethnography was located within support groups, my aim has been to cross their borders to grasp with the life constructed by its members outside of them.

At the time of the fieldwork, around 15 members of the first group met on the Thursday of each week in a clinic. The group was part of a support group network widespread in South Africa, originally founded by a North American Christian NGO. Although the Christian origin of the NGO was not stated upfront within the support groups, its members (as often in South Africa) would pray together, share meals and food parcels, along with receiving advice about treating opportunistic diseases and (to a lesser extent) social welfare access. The group’s connections within the clinic (with an HIV-positive nurse) afforded members relatively easy access to consultations and drugs. Indeed getting access to them requires usually hours of queuing from early morning (which is not the case for support group members thanks to their acquaintance with a nurse).

The second group in Alexandra township offered the same kinds of services but had a stronger organization. It grew from a South African NGO formerly run by white South Africans,

but was now controlled by residents of Alexandra. As such this organization embodied the “new South Africa.” This NGO organized home based care, trained counselors for the local clinics, and provided care for orphans in the Township. In 2000, the organization had only one office in Alexandra but has since acquired branches in Kwazulu Natal and Eastern Cape. Over the past ten years the organization has dramatically expanded bureaucratically and professionally. Volunteers now receive a stipend for their work and although not directly housed in a health facility, its members have good connection with local clinics. Some of its members are employed as counselors and others as volunteer caregivers. Many of the staff are also clients (i.e., as members of the support group) and volunteers (as a caregiver or counselor).

This second group was much more active in helping its members to become recipient of social grants. At the time of the research, people with CD4 count below 200 could receive a monthly disability grant of ZAR750. Nevertheless, the NGO support in this process was accompanied by a regular moral evaluation of the legitimacy of the recipient. Recipients found to, for instance, spend their grants indiscriminately on alcohol instead of fruits and vegetables could lead to the withdrawal of support and public recriminations from the head of the NGO. Moreover, the fact that HIV-positive volunteers were sometimes receiving both a disability grant and stipend created considerable tension within the organization. HIV negative volunteers complained of the uneven compensation. Envy of the resources the HIV positive received was not uncommon. At the same time, as we will see, it created among some HIV-positive members a mixed experience of empowerment and bitterness.

Both support groups, as collectives, showed no strong political commitment to the fight for access to ART. Some of their members were affiliated with the Treatment Access Campaign (TAC). But the TAC’s strong positioning against President Thabo Mbeki was a point of contention expressed by some members that resisted taking a side against the ANC government. As an example, when TAC launched a civil disobedience campaign in March 2003 to get the South African government to implement an ARV delivery plan in communication with business, labor, and local communities at a national level, the director removed TAC posters on the walls of the Alexandra NGO. She blamed the youth of the NGO who she said “did not know” because they were “too young.” She could not accept seeing political tactics mobilized during the struggle against apartheid used against the ANC government. (In Soweto the support group had never openly discussed the TAC campaign or publicized its message.)

Apart from support groups, churches, diviners, healers were also accessible to PLWA and turned to in attempts to make sense of their illnesses. Some PLWA (at least in major urban areas such as Johannesburg) established a living through “thinking positively” about themselves, their lives in venues provided by voluntary work within HIV/AIDS NGOs.² TAC was one of those. Steven Robins has shown how “this globally connected social movement was able to mediate ideas about biomedicine and rights as well as catalyze and mobilize a powerful sense of community belonging and identity amongst its members” (Robins 2008:116). He describes how: “These modes of mobilization created the political space for the articulation of new forms of health/biological citizenship linked to attempts to democratise science in post-apartheid South Africa” (Robins 2008:117). Building on Nguyen’s concept of “therapeutic citizenship” and Rose’s idea of “responsibilized citizenship” he adds:

Through grassroots mobilization and treatment literacy campaigns TAC is able to articulate new forms of health/biological citizenship and political subjectivities that resonate amongst young, educated black youth in South African townships. Many of the

testimonies demonstrated a sophisticated understanding of rights talk as well as intimate biomedical knowledge relating to AIDS treatment. They also expressed a quasi-religious sense of collective purpose, solidarity and belonging. [Robins 2008:117]

Despite the “new life” claimed in public testimonies or talked about in interviews, most PLWA—even TAC members—are still stuck in severe poverty, political disempowerment, and social marginalization. Although TAC mobilization has had tremendous impact on political subjectivation, and agency of PLWA (not to mention access to drugs),³ this conversion process remains nevertheless partial (Robins 2008:123).

Mundane Transformations

Exploration of the everyday, the mundane side of life, present occasions to understand how life and selves are being transformed and take us beyond interviews or observations in very specific spaces of the HIV support group. João Biehl expresses the relevance of ethnography in his work with the urban poor living with AIDS in Brazil: “In this work I am not concerned with finding psychological origins for the will to live that AIDS Survivor voice and enact. Their sense of interiority is rather ethnological, that is, the variable whole of their desires and actions in relation to the outside world of AIDS” (Biehl 2007:361). Extending the ethnography of AIDS to the ethnography of life with AIDS, to the ways people concerned by the pandemic inscribe themselves in new networks, not only of cure but also of care, and not only political but also domestic, broadens our ethnographic reach. It allows for a deeper understanding of what people—when they are inaccessible to activist groups such as TAC (still the majority of PLWA in South Africa), or have difficulty accessing scientific discourse and medical techniques—do on an everyday basis, how they struggle with the illness, its consequences and rebuild a world. In doing so, one highlights the constraints of the process of living with AIDS. The understanding of the logics and conditions of recognition implies focus on the uniqueness of individuals and therefore on their voice, as expression of distinctiveness and means for the recognition (Le Blanc 2007). As such, voice is not limited to words but refers to the face and to the expression of singularity. I describe two situations to sustain my argument.

One is about a young woman I call Thembisa. She was a member of a Sowetan support group but she devoted her mind, time, and energy to her sick baby. She found relief, not in the transfiguration of her own self into a biopolitical subject, but only when her boyfriend eventually took care of her and her child, helping her to create a place she could call home. There she was inscribed again into a reciprocal, mutual process of recognition, a condition for the development of her self-confidence and agency.

The second situation I want to describe is the experience of Mantwa. HIV positive, a volunteer in an Alexandra NGO and mother of a young boy, her life was a mix of experiences of biological citizenship, denial, and discrimination. Her story is an example of the multiple identities people carry.

Conditions of Recognition

This exploration of the possibilities and constraints of recognition at the heart of family relationships, friendships, or business is situated in a unique social configuration: that of South Africa after the apartheid. Considerable migration at national (Bozzoli 1991) and regional

(Coplan 2001) levels have had significant impact on the spread of the pandemic (Lurie 2000). South Africa is often noted for its endemic violence, present in different kind of interactions and social spaces (Le Marcis 2004), namely between publics and health institutions (Jewkes et al. 1998) and widespread violence against women. Research has indeed shown the prevalence of domestic violence and their gender based inscription (Jewkes et al. 2005; Kotze and van der Waal 1995; Wojcicki 2002; Wood et al. 2007). Gendered vulnerability to violence, infection, and unemployment has been exacerbated by strong inequalities along racial groups stemming from apartheid policies.⁴

In this context, Honneth's normative model provides a framework to reflect on PLWA in post-apartheid South Africa. This reflection could start with three observations. Firstly, the mechanisms of political mobilization described by Robins are innovative but they remain limited. Secondly, discrimination and contempt are still prevalent in the sphere of social solidarity (Robins 2006:126). Finally, the development of patient agencies—a condition for further mobilization—is linked to how they think of themselves and build their lives after discovering the disease. They negotiate this in their everyday lives, with or without their families and spouses, relations that often break down with knowledge about having AIDS. Thus, in the context of social displacement in which many PLWA find themselves in South Africa,⁵ the recognition emerging from the intimacy of a new relationship or domestic grouping has sometimes appeared to be a prerequisite for a renewed sense of agency. To look at these spaces of recognition is to make visible one of the places where PLWA find resources for living.

Thembisa: The Absence of the Expression of the Self

When I first met Thembisa (26 years old) in a Sowetan squatter camp, she was living in a shack with her boyfriend. Next to the camp was the clinic where she attended an HIV support group. Every Thursday she came with her baby wrapped into a blanket. She did not feel at ease in the group and was quiet most of the time. Not long after our encounter, the camp where she was living was destroyed by the Johannesburg city council and she had to find another place to stay.⁶ Other members of the camp went to an alternative site proposed by the city council (an old mining site on the outskirts of Soweto where people were invited to rebuild their shacks), but Thembisa could not go as she needed to live next to Baragwanath Hospital because of the ill health of her baby. Thembisa's silences and her lack of a place to stay spoke strongly to her struggle for life.

She was born in Ezibeleni, a city created in the former Transkei homeland in the 1960s to host the black population expelled from Queenstown. Her mother worked in Johannesburg (about 1,000 km away from home) and her father, a miner, died in an accident while she was still young. Thembisa was raised by her maternal grandmother and attended school up to the high school level. In 2001, she discovered she was HIV positive. Without disclosing it, she went to Johannesburg to live with her mother, only to find she had gone back to Transkei, unable to work anymore because of back pains. Thembisa then moved in with a maternal aunt in Diepkloof (Soweto). There, she met a young man who became her boyfriend. They later moved in together in a shack in the squatter camp. Thembisa fell pregnant twice, with a miscarriage in the first pregnancy and birth to a son in the second. He was often sick and at the age of three months was diagnosed HIV positive. At around this time, Thembisa and her boyfriend separated. Shortly after, the squatter camp where she lived was destroyed by the municipality of Johannesburg. Thembisa could not leave the area as she spent nearly three days a week taking her child to the

Baragwanath hospital nearby. Having nowhere to go, Thembisa went back to her aunt, who grew suspicious when she heard about the ill health of her child. Unhappy, Thembisa left and found a place in backyard shacks. She paid her rent with money earned from washing clothes for people working at the hospital and coming from Transkei. Her daily worry was finding paraffin to warm milk for her child and to heat her shack. Much to the annoyance of her landlord, she did frequent washing as the baby had constant diarrhea. Afraid of complaints, and of being disclosed as HIV positive, Thembisa moved again. During all this time she came to the support group every week where we met. Each week she received a food parcel, some milk and had a warm meal. She had no friends in the group. She kept quiet and held her baby, wrapped in a blanket to protect him against the wind and possible prying eyes. Her child was eight months old but he looked like a new born.

Despite the regular visits to the hospital, her child's condition worsened. My field assistant and I took Thembisa to a clinic situated in the hospital and where a U.S. medical team ran trials looking at the cost of ARV delivery and Prevention of Mother to Child Transmission (PMTCT). In this clinic, Thembisa sat in a warm and welcoming waiting room, a stark contrast with the public health facilities. After the consultation, her child received attention for pneumonia and an appointment was given to Thembisa for both of them to start ARVs. She was also sent to the social welfare services and to the chemist to get drugs. We accompanied her, walking through the maze of the hospital that was familiar ground to her, as she took shortcuts between blocks and walking along the walls. After receiving syrup bottles and syringes for dosage, she went to the social workers. In her situation (a mother without support) and her health, she was eligible for a child grant and a disability grant (given to HIV-positive persons with CD4 counts below 200). But Thembisa and her child did not have any identification and could not apply for the grant. To apply for ID papers for her child, Thembisa was required to present a birth certificate but she could not obtain one without proof of her own ID. Getting her own identity document entailed going personally to Queenstown in the Eastern Cape where she was born and filing a claim, a trial in itself given her lack of resources and the baby's ill health. Thembisa was confined to the margins of society: unable to get the administrative status of, and claim "rights" as, a "single mother" or "disabled," for which she could receive substantial aid from the South African State. She eventually disappeared completely from the support group.

I met her again a few months later; she was staying in a new shack. The father of her child had come back to her and decided to take care of them. He worked at night as a driver. He did not give money to Thembisa but provided food and clothes and paid the bills. He also financed the journey for Thembisa to Queenstown, where she applied for her ID papers. Her child was still very sick but Thembisa was now thinking ahead. She explained that she had been too depressed to benefit from being in the group. At that time she could not bear the fact that the father of her child was giving her no support.

She explained that after obtaining her ID papers, she hoped to find a job and visit her brothers and sisters in Khayelitsha, near Cape Town. After this last meeting, I did not meet Thembisa again. She had my cell number but never called and I respected her desire to disappear. Thembisa was not available to come to the support group: both practically, because she was devoting her time and energy to caring for her child, and because the "free speech," normally ensured by the liminal space of the support group, had little meaning for her.

Reflecting on the conditions of possibility of ethnography with women who witnessed violence that led to the looting of their homes and the murder of their husbands, Das has shown through a "descent into the ordinary" and an ethnography of language and the everyday, how

these women rebuild a world. Faced with the silence of some women raped during the riots who she found prostrated in front of their destroyed homes, she concludes:

The intuition that some violations cannot be verbalized in everyday life is to recognize that work cannot be performed on these within the burned and numbed everyday. [Das 2007a:90]

Thembisa's experience, the biological reality of her child's illness occupied her mind and kept her busy. The loneliness in which she was confined, the comments heard, the discrimination felt, the temporary abandonment of her boyfriend and the impossibility of accessing state resources theoretically available to all citizens, limited how, and how much, she could be available to herself as herself, and to others. Her "voice," its form and purchase, what it is capable of articulating, is tied to the trials of relations and responsibilities she has experienced. Michael Jackson wonders:

If stories, lives and journeys are so entwined, what happens to our capacity to tell stories when our lives are torn apart? ... and when suddenly we have no settled place from which to venture forth each day, nor haven at the end where we can recover our lives in the stories we share, what becomes of our stories and our lives? [2006:33]

He argues that storytelling is about:

Providing strategies and generating experiences that help people redress imbalances and correct perceived injustices in the distribution of Being, so that in telling a story with others one reclaims some sense of agency, recovers some sense of purpose, and comes to feel that the events that overwhelmed one from without may be brought within one's grasp. [Jackson 2006:36]

But stories are sometimes incommunicable. The task of the ethnographer in this case could not be premised on finding the hidden truth of facts, but to venture elucidating the meanings of silences, to express the embodied history of people (Fassin 2002, 2007). Michael Jackson writes: "Though most experience—but especially extreme experience—often seems to us singularly our own, storytelling discloses that which is held in common" (2006:62). When experience reduces people to silence, the task of the ethnographer could be—not to speak on behalf of the other—but to analyze the condition of the nonenunciation, as another example of what is singular and held in common. Thembisa's transformation happened not through a new life as a biological citizen, but as a woman and mother, who loved and cared.

When a new member joins a support group, he is invited to a private interview with the coordinator of the group, what can be likened to a form of a confession as Christian ethos is highly pregnant in South African Society. Some members will tell their story to the group later, others never will. The production of testimonies within support groups is based on a shared agreement: what people hear within the group should not be disclosed outside of it. Yet on several occasions, members of support groups reported to me that they had discovered that their stories were being disseminated in their vicinity by comembers. This set a limit on the sharing of experience within support groups. But understanding the silence kept by some members should not be limited to the question of a threatened confidentiality. Silence, such as the absence of Thembisa to herself

and her inability to share her story with others in the group also reflects the reality of situations that cannot be uttered through words. To acknowledge them would eventually confirm a position outside life, as the violence received also delineates what makes us human or not.

Themبisa does not speak about herself, but the words she utters sparingly, her confidences and retractions, temporary presence and long disappearances, reflect a life inscribed in an emergency and exposed to a biological reality that she faces alone. Themبisa is afraid of sharing her HIV status with her aunt in Soweto, who regularly expressed contempt toward AIDS sufferers. Moreover, her remaining kin staying in Eastern Cape are not aware of her condition. She resisted disclosure and her constant movements were a camouflage, an “art of the weak.” The unspoken is filled with meaning. Themبisa stayed quiet in front of the “positive life” professed in the support group: her life outside too harsh to share, her mind too preoccupied to “think positively.” Within the support group, she was just getting food. The return of her boyfriend, aware of her condition, created a sense of belonging and experience of recognition. Her new expressions of life were not subject to the need of the *zoe*, but projected into the *bios*,⁷ the social and political life, a life of dignity despite the threat of death.

Sandra Roberts described in South Africa the various forms of support obtained from support groups: “emotional *support, as in comforting*, informational *support, practical information about ailment* and instrumental support, *practical assistance with daily living*” (Roberts 2008:84). She proposes to add another dimension: the normative support. “Normative support teaches PLHAs options for transforming stigmatising representations of HIV to enable a positive identity ... through drawing on informational, emotional and instrumental support, whilst encouraging health-promoting behaviours” (Roberts 2008:84–96). Her description fits with Honneth’s social theory as the experience of recognition within the support group: the ability of members to speak as a “we” builds on the reversion of stigma, in part the foundation of political mobilization. Support groups create a space of recognition. But all the benefits of support groups are not accessible to everybody (Nguyen 2010) and although couples are sometimes formed within them, these spaces often remain highly disconnected from the everyday where individuals are searching for love and for support. Being an HIV support group member does not turn you into a political activist. This is coherent with Andreas Kalofonos observations carried out in Mozambique. Writing about support groups in this country, he states: “While these biosocial spaces did engender a group identity, the scarcity of opportunities and benefits paradoxically led to an atmosphere of competition and mistrust” (Kalofonos 2010:367).

Thus, long-term ethnography carried out within and outside support groups—with members at home, at the hospital, and in between—contributes to a less idealistic description and a more complex and contextualized understanding of their impact. Support groups may be a place of political subjectivation and recognition but they are also a place of ‘sheer survival’ or even ‘bare life’. Other demands are fulfilled in other settings, in domestic life, in the intimacy of couples, which equally need to be documented.

What an anthropological study of the spaces of recognition can add to the biopolitical analysis is, through the attention to the everyday, a focus on the discordant voices and the multiple layers of the self. I demonstrate further with a description of Mantwa’s experience.

Contextualized Selves

Mantwa is 30 years old and the mother of a young child. She and her son lived in Alexandra in her parent’s home. Both she and her son are HIV positive. Mantwa often complained to her

friends about the difficult relationship she had with her family. She felt ostracized by her parents for being HIV positive and a single mother. In her neighborhood, she had been involved in two NGOs working on AIDS. In each of them she attended the support group and acted as a care giver at the same time. From both experiences, Mantwa was bitter. She witnessed a clear distinction between those who are HIV positive (clients and volunteers) and the mainly HIV negative NGO staff. Mantwa felt stigmatized for being an HIV-positive single mother. Among the comments and criticisms expressed by caregivers about PLWA were: alcohol consumption, smoking, living alone as a woman, being known as a “womanizer” for a man, or as a woman “panding.”⁸ These factors were often mentioned by the care givers to explain the ill health of their clients. Later when ARVs started to be available, the fact for an HIV-positive woman living alone, and worse, to sometimes drink alcohol, defined her as a low priority for the access to the drugs. Moral categories were applied to clients living in a situation often shared by the caregivers themselves, and that they were themselves often reproducing. Thus, the criteria shaping eligibility for ARVs were also shaped by moral evaluation.

The moral enterprise inherent in care of PLWA is also discernable in the Christian rhetoric used to describe HIV prevention that has become influential in South Africa. Prevention has become reframed as and through a form of gospel, such as by explaining the ABC of prevention (“Abstain, Be faithful, Condomize”), promoting the HIV test as one preaches the word of God. But Mantwa’s experience in the AIDS NGOs cannot be limited to bitterness. She complained of the relationship between HIV-positive and HIV-negative people in the organization she worked with, but she could also access medical resources and had relative financial independence. She was also an active TAC member. Listening to her sentences, paying attention to her voice, offer an entry into the mixed experience of subjectivation and subjecthood, of recognition of her work and negation of her feelings, as is showing this extract of comments she made concerning her experience in the HIV/AIDS ONG she worked with as a care giver:

You know, we are not free, we are not really free to work with people we do not know, especially the leaders, they do not even know their status, you understand, it is sad, really. So, most of the time, you will hear them say I talk too much around that. Let’s say, in our office at, ... we are a team of four caregivers. So, only two of us know our status and they know us too. This two, they do not know their status, and they are preaching the word to an extent that they do not do this thing [i.e., to test]. When we ask them why they do not go for a blood test, they tell us what will their men say? It is sad, you know. Sometimes, they become very loose when talking, and I sometimes say: “Could you please mind your words because you are talking to people who are positive.” You understand something like that, things like this bore [i.e., it’s annoying]. ... The way they sometimes harass us. I sometimes tell them: “You do not even know yourselves [i.e., their HIV status]; it is better just to keep quiet. At least, we do. We know ourselves what is happening.” They keep telling people to eat fresh vegetables, no salt or oil, and all that, though we do not know where they stand [i.e., where they are talking from, if they are themselves HIV positive or not]. [taped interview, Alexandra Township, December 2003]

Thus, HIV-positive volunteers suffer from an unequal recognition within this organization. The need of their body is acknowledged: they get food, basic drugs, money, but the recognition of the basic needs goes along with a denial of their singularity. Moreover the intrusion felt on one side (HIV-positive volunteers have disclosed their status and received

exhortation to live a “positive life,” while staff are exempt from disclosure and occupy more authoritative positions), appears to be the price to pay for accessing resources. Mantwa explained:

The treatment we get from our organizations is not right, by God! It is nice, we are just exercising our patience, we want to know, we want to have more information, you understand, and help people because with them, the way they help people, it is for the money; they are using us, really. But, we are holding on. [taped interview, Alexandra Township, December 2003]

“Being patient” and “holding on,” are ways to deal with this situation. Individuals take in these organizations what support can be taken, get knowledge and skills, and wait for better days. The inscription in parallel networks offering knowledge and sustaining political mobilization constitutes another path. But if the presentation of the self emerging within these networks is happening under brighter lights, the focus on these spaces of recognition is made to the detriment of spaces where Selves are emerging in an everyday reality made of bitterness, discrimination, and subjection.

This distinction is nevertheless dualistic and does not speak to the ethnography. Individuals navigate in between these networks and distinguish spaces where a kind of “minimalist biopolitics” would be at stake (where the basic needs for survival would only be recognized, even at the cost of denying what makes us human) and spaces where new political agency and subjectivities are emerging (Robins 2009). But the frontiers between these spaces are blurred and these two spaces, of minimal survival and of nascent activism and experience, are not the only places of production of the self. The everyday and the sphere of the primary relations are another locus. In terms of ethnography, the challenge is then to articulate the three spaces defined by Honneth (demand for love, for rights, and for social solidarity) and to describe and analyze how individuals navigate between them and end up developing a self both contextualized and articulated. As I have been trying to show, this implies to give time to ethnography to grasp the mundane part of life, to accept to see life not only through the lens of AIDS but also life per se through wandering with informants (Le Marcis 2010). Short ethnographies do not allow such explorations.

Eventually, death won over Mantwa’s hope. Her friends in Alexandra said that after the hospitalization and death of her son for pneumonia, she passed away too. They commented that she had no reason to fight anymore. Her burial was the occasion of a huge TAC mobilization for the right of the HIV Positives. Only her HIV-positive friends from Alexandra who knew her well emphasized her suffering. Other comments were about her condition at home, the worries for her son’s future in case of her disappearance and the condescendence of the HIV negative Staff of the NGO where she volunteered. These everyday worries related to me by Mantwa’s friends during her funeral starkly contrasted with how she was presented by TAC. A picture of her had been print on T-shirts and were worn by TAC members from all across Johannesburg that attended her funeral. The difficulties she faced were not mentioned by her political friends nor acknowledged by the NGOs she volunteered with.

When listening to Mantwa’s words, being an HIV patient and a volunteer caregiver appears an ambiguous experience of subjection and subjectivation, an experience that has to be understood together with the situation she faced at home. Support groups and NGOs providing training on counseling or organizing income generating activities offer the sick a welcoming

place, providing help and answers to the newly infected. Mantwa explained: “Especially when you become diagnosed and you find that you are positive and all that. You do not know where to start, you understand? And you do not know what to do, who to trust, things like that.” Although she gained knowledge, skills (on counseling), financial support (she was involved in a program of red ribbon production made out of beads), the subsequent notion of the self developed through this process was nevertheless affected by the discrimination she felt at home and in the NGO. Nor can we exclude the denial of hopes, fears, feelings and frustrations, and her despair for her child’s condition. If Mantwa had some experience that could be linked to the resources afforded by having “therapeutic citizenship,” even so, her day to day life was shaped by far greater trials. It is generally agreed that “involvement of young people is seen as a precondition of successful HIV/AIDS management and has become a central pillar of international AIDS policy” (Campbell et al. 2009:94). Little is said however about lay caregivers need for support (Webb-Robins and Wilson 2008), and even less about the tension such as the one expressed by Mantwa.

People living at the margins of the South African society, especially those that are HIV positive, experience everyday situations that are inscribed in multiple dimensions of recognition, which do not necessarily overlap. For example, the issue of legal recognition of patients as having a right to drugs is not indicative of the recognition of the individual in the domain of primary relationships and vice versa. Similarly, antiretroviral therapy delivery (rights granted by the South African constitution) is not necessarily associated with the legitimacy of the HIV patient in the sphere of the social solidarity. The act of caring for the body may also be accompanied by contempt from caregivers, creating a complex situation for HIV-positive caregivers. Knowing that patients and caregivers are often the same in areas with high HIV rates (primarily of young women), projects relying on volunteers in this context suggest, from its conception the possibilities for contradiction and bitterness.

Discussion and Conclusion

Scholarly accounts of how people deal with AIDS in South Africa have tended to emphasize the importance of recognition in the political or legal domain. Or they tend to only assess the impact for individuals who struggle for the legal recognition of the sick and for their health care without considering the particularities of everyday life. The empirical data supporting these analyses is mainly composed of narratives collected from public testimony or formal interviews. In analyzing these narratives, researchers forget that they are typically highly formalized, shaped by the culture of confession strongly inscribed in South African society and the ethos of NGOs. One exception is found in Erik Bähre’s work. He shows how the care or support received or rendered is inscribed in the concrete reality of township life. Solidarity here can only be understood in relation to the concrete realities in which it is thought and enacted (Bähre 2007). As the sociologists Jean-Paul Payet and Alain Battégay write:

Instead of considering society as a context already given and shaping the distribution of recognition, the attention has been given to recognition as a modality of “making society,” calling for the analysis of social facts as moral facts and for the taking into account of this contemporary event: the rebuilding of alterities. Struggle for recognition have been approached in their complexity, liability and ambivalence, requiring from research work greater reflexivity. [Payet and Battégay 2008:24]

This recognition, a complex and situated reality, is not limited to the actions of the state or institutionalized forms. It may have more subtle and less visible expressions: within selves or in the intimacy of a couple. In a time of unavailability or scarcity of treatment, what is left is to observe in the intimacy, and perhaps in the heart of the everyday of the AIDS pandemic, the spaces of recognition or denial inscribed in intersubjective relations.

As Paul Ricoeur has noted, recognition speaks in two voices: active (I recognize) and passive (I am recognized). Recognition is a reciprocal act: “In mutual recognition ends the recognition of oneself” (Ricoeur 2004:294; see also Paperman and Laugier 2005). To be recognized sometimes requires individuals match their conduct to the moral exhortation of the organization they work with, and to endorse the stereotypes produced about the sick. And to refuse is to imply denial and contempt.

The anthropology of recognition is not an anthropology by which the researcher simply bears witness on behalf of the other, but an anthropology that is concerned about the humanity of the other, and tries to express the diverse ways to be in the world, and to account for what Hannah Arendt (1983) calls the condition of plurality. This is an anthropology interested in the conditions of possibilities, both constraints and opportunities for the recognition of the self in a world where disease, legal or social status often undermines the sense of belonging. In doing so, it adds to the philosophical reflection on voice from a practical dimension. The French philosopher Guillaume Le Blanc noted: “If having a voice is one of the most important tasks of the self, this possession is still suspended to a social necessity which either acknowledges it or not” (2007:233). Beyond intersubjective borders, voice must have a social relevance, a materiality that ultimately acknowledges recognition. Thus, to philosophical reflection, anthropology adds empirical description and analysis of the context of recognition. It highlights the complex interaction between different spheres of recognition and their contradictory experiences. Ethnography reminds us that the production of the self cannot be summed up in a linear story. Experiences of subjectivation and agency appear together with situation of subjecthood, of denial of autonomy or singularity. To give an account of them demands spending time with people, not only to listen but also to share mundane aspect of life as well as its extraordinary moments. It demands taking risks in the encounter, of being transformed by it: allowing the other the power to inform me as much as being informed by me. Is this not one step toward mutual recognition at the heart of ethnography?

Notes

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1. The English translations of quotations from books published in French are mine.
2. In Alexandra, in three years' time the stipend received by the caregivers went from ZAR800 a

month in 2001 to ZAR1,500 a month in 2004.

3. The fight for treatment in South Africa is no more about getting the government to recognize the necessity of ARV delivery (and the link between HIV infection and AIDS) but to get everyone to be tested and to get the health system to be able to deliver to all the patients eligible for antiretroviral therapy.

4. The overall unemployment rate for the first quarter of 2010 was 25.2 percent. A look at the rate of unemployment by population group for the same period shows significant differences. The rate of unemployment for Black/African is 29.7, 21.8 for the Coloured, 9.2 for the Indian/Asian, and 6.1 for the White (these categories used for statistical purpose reflect the inequalities inherited from Apartheid policies; see Statistics South Africa 2010).

5. I am well aware that “PLWA” is an acronym highly connoted. It refers to the register of activism and NGOs. I use it here literally, in a descriptive sense: someone who lives with the illness.

6. For a description of the removal of this camp and its consequences in terms of care, life and death see Le Marcis 2010, chapter 1.

7. Giorgio Agamben reminds us that the Ancient Greeks had two words to express what we call life. The word *Zoe* relates to the simple fact of living, a biological reality, and *Bios* relate to the ways individuals or groups organize their own life. *Bios* implies a political dimension absent in the notion of *Zoe* (1997:9).

8. “Panding” is a neologism built on the verb in isizulu “uku phanda,” meaning for a chicken to scratch the soil looking for food but referring to the fact for the women to get involved with men to find financial support.

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