

A Feminist Struggle? South African HIV Activism as Feminist Politics

By Katarina Jungar¹ and Elina Oinas²

Abstract

This paper is a feminist reading of HIV activism in South Africa, of a social movement that does not describe itself as a women's movement: it advocates both women's and men's, trans, hetero- and homosexual peoples' rights for adequate health care and antiretroviral medication. Like many others, Chandra Talpade Mohanty suggests that today's powerful feminism is found in anti-globalization movements that do not necessarily call themselves feminist. These critiques maintain that the theory, critique and activism of grass-root women across the globe, for example around anti-globalization, should also inform academic feminist discussions. This article studies discourses on HIV in Africa by contrasting the politics of the *Treatment Action Campaign*, a South African activist movement, with social science research literature on HIV in Africa. The contextual and political dimension of the illness is a central feature in activist discourses, a feature that can be described as inherently feminist. The representations of HIV/AIDS in Africa and the policies these imply are strikingly different in the activist and academic discourses. We argue that activists' political orientation and the consequent anti-individualism are key dividing features that lead the activist and research discourses down divergent paths. In contrast, HIV research inhabits a de-politicized and individualizing tendency.

Key words: HIV, activism, feminism, ethnography

Introduction

We are not going to change peoples' perceptions, we are not going to change behavior because the value of life is not significant in South Africa, because people continue to die while we know full well what we can do to save peoples lives. (Sipho Mthathi at SA Commission on Gender Equity on 01.04.2003)

Our bodies are the evidence of global inequality and injustice. They are not mere metaphors for the relationship between inequality and disease. But our bodies are also the sites of resistance. We do not die quietly. We challenge global inequality. Our resistance gives us dignity. In the Treatment Action Campaign (TAC), the voices of our comrades, friends and children echo around the world to resist

¹ Researcher at the Department of Women's Studies at Åbo Akademi University, Finland. She is interested in issues around health and Women's Movements. Her PhD (forthcoming 2010) is an ethnographical study of the Treatment Action Campaign. She has been involved in (Women's) Activism in Finland and South Africa. E-mail: kjungar@abo.fi.

² Senior Lecturer in Sociology, University of Turku, Finland, and Affiliated Professor in Women's Studies, Åbo Akademi University, Finland. Her research interests are embodiment and health among girls in Northern Europe and Southern Africa, and re-thinking controversial concepts like "medicalisation" and "empowerment". She has worked in projects funded by the Academy of Finland and at the Nordic Africa Institute in Uppsala, Sweden. 2007-2009 she has acted as one of the editors for *NORA – Nordic Journal of Feminist & Gender Research*. E-mail elina.oinas@utu.fi.

injustice. Our voices demand life even as our bodies resist death. (Zackie Achmat, John Foster Lecture 10.11.04.)

Women's movements and feminist activism have been the source of inspiration, energy and ideas for Women's Studies ever since its beginning (e.g. Bernstein & Ndinda 2008). In this article we will study the politics of one contemporary activist group, and ask in which ways such activism could enrich the academic discussions on power and social change. The movement studied here is the South African HIV activist organization Treatment Action Campaign (TAC). We will do a feminist reading of the TAC's agenda even though the TAC does not describe itself as a women's movement; it advocates both women's and men's, trans, hetero- and homosexual peoples' rights for adequate health care, including access to antiretroviral medication (see also Msimang 2003, Mbali 2003). Like many others, Chandra Talpade Mohanty (2003) suggests that today's powerful feminism is found in anti-globalization movements that do not necessarily call themselves feminist (see also Conway 2007; Braun 2008). These critiques maintain that the theory, critique and activism of grass-root women across the globe, for example around anti-globalization, should also inform academic feminist discussions. In this article we wish to investigate some of these, especially in terms of feminist theory of embodiment, and feminist approaches to HIV/AIDS in Africa (cf. Kakaru 2008).

The Treatment Action Campaign takes active part in shaping HIV/AIDS discourses and policies both globally and in South Africa (Friedman & Mottiar 2006). The personal, individual experience of the illness is maintained as a starting point not to be bypassed, but the campaign does not remain on the individualizing level, like a lot of AIDS narratives and interventions. The TAC agenda moves the focus from the personal to the political dimension of the local, state and global contexts (Robins 2004; Fassin 2007). The common denominator for this contextualizing practice is to politicize, much in the same way the 1970s' feminist movements did in their claim that the private is political.

The main conclusion of this article is that a turn away from individualizing perspectives, towards a contextualizing, collective and political definition of sexuality and the body, is already a move towards feminist practices that makes a difference in HIV policies and the public interrogation of African sexualities. Such a claim is not new in feminist scholarship, but even more so needed, especially in the context of HIV/AIDS epidemic and the absent voices of activism and women's everyday resistance in a lot of research literature (cf. Kakaru 2008).

Gender, Sexualities and Africa: Politics of Knowledge

The HIV/AIDS epidemic in Africa can be viewed as a discursive construction, an "epidemic of signification" (Treichler 1999) *and* an embodied epidemic – a double existence that creates dilemmas for the study on gender and sexualities. It is important to address these tensions and take them seriously. "Politics" refer to feminist politics of writing and knowing as well as politics of sexual lives, including structural politics of states, economies and global social injustice. This article is an exercise in detecting effects of "difference" (Archer 2004; Mohanty 2003) – what are the viable subjects that emerge in the politics around an epidemic (cf. Butler 1993)?

When looking at research literature on HIV in Africa, it is clear that HIV has legitimized the scholarly interest in detailed documentation of sexual lives in Africa in a way that one could say goes beyond any past colonial imagination of biopower. What are the effects of numbers and statistics? The urgency to implement any prevention measures that could curb the spread of the epidemic has placed sexuality firmly in the public domain to such an extent that the private element of intimacy is seriously questioned in African contexts. The private is made public. Prevention efforts work through constructions of sexuality and explicitly invest in breaking silences – but what does this mean in terms of policing and surveillance of every day lives and emotions? Or in terms of sexual integrity and dignity? The ads and campaigns in the public space indeed paint a very Foucauldian picture of governmentality (Zenebe 2006; Jassey & Nyanzia 2007). The need to address asymmetries of gendered and global power poses a challenge to feminism: how are sexualities depicted in accounts of powerlessness? What are the configurations of gender, power and subjectivity that emerge on the battlefield of war metaphors in the fight against AIDS?

And yet, concrete feminist strategies are needed; merely criticizing discursive power does not suffice. Analyses of potentially helpful interventions into the epidemic as a discursive-material reality become crucial. As Ettorre (2005, 543) has suggested, a critical reading of discourses of care and health management can be done even when holding on to a pursuit, desire or even passion for health and technologies of the self. How to theorize the ways in which gendered individuals employ ethics and forms of self-constitution in their health seeking? Against our background of post-colonial feminist critique, and interest in alternative health policies, the Treatment Action Campaign seemed to us to offer a novel perspective. The focus here is on the TAC's messages on how to create a *positive* self through collective mobilization and politicization of HIV/AIDS, in contrast to mainstream AIDS discourses¹.

Methodology

The data of this study includes both social science research literature on HIV/AIDS in Africa 2000-2009 and an ethnographic study with the TAC. Most of the ethnographic research was conducted in Cape Town, South Africa, and included participant observation in rallies, at national and international conferences, official meetings, workshops, public funerals, church services and marches. About 40 events during 2000-2009 have been taped and transcribed. The events were either organized or co-organized by the TAC. 33 interviews have been conducted with key informants, mainly women activists and volunteers, but also with volunteers at clinics, health care workers, researchers, clinic administrators and policy makers. Public TAC documents, the newsletter, their web page and media coverage of their activities also constitute part of the empirical material (see www.tac.org.za). The method of analysis here is discourse analysis.

In this kind of feminist ethnography it is crucial to reflect on what it means that knowledge is situated and partial, and to try to articulate the positionality of both the researchers and the researched. The methodology demands us to situate our knowledge and to reflect upon the practices of our knowledge. This does not simply mean to acknowledge that we are Finnish, white, middle class researchers doing research on activities of working class or unemployed poor African women, many of them living with

HIV/AIDS; nor the obvious fact that this constellation creates specific ethical considerations. Reflexivity here means that we as subjects, and the accounts we generate, are thoroughly, and inevitably, embedded in these power relationships. We are not merely implicated in them, we materialize through them (cf. Butler 1993). Postcolonial theory focuses on power and violence in knowledge production and shows how power in a very fundamental way is about what is said about oneself in relation to others (Lewis 2004). We describe the HIV activists as being “authentic” and part of a “reality”, but at the same time we are aware of the fact that our analyses, politics and method also construct a particular, and limited, narrative about the TAC.

This means that when we do research about the TAC we are also negotiating the tension in feminist theory between our feminist methodological (political) imperative to make women’s lives visible, and the poststructuralist critique of representations of women’s experiences (see Lather 2001). For our fieldwork these are questions of how we ethically and politically negotiate our “will to knowledge” that we believe is located in certain positions held by others (Lather 2001). One key choice for us was to focus on public agendas of a movement rather than private experiences or the movement’s internal dynamics: we document and analyze public statements and activities of women who have chosen to be activists. Many of them have talked about their lives and their HIV status openly not only to their families but also in TAC events and in the media. They are part of a social movement, and they have often critically reflected upon their experiences. Their activism means on the one hand that they do not present themselves only for research purposes, and on the other, that it hopefully gives them a way to relate critically towards how our research constructs their lives.

From Pills to Political Subjects

The TAC was founded in 1998 when a small group protested in Cape Town for access to antiretroviral drugs for pregnant women to reduce the risk of transmitting HIV to newborn babies. The number of TAC activists has grown radically during the last few years and now there are up to 20 000 registered members, to a large extent unemployed, black working-class women even though the membership is heterogeneous (Peacock, Budaza & Greig 2009, 86; Robins 2004).

The movement draws on forms of activism from the anti-apartheid struggle in their mass mobilization, such as street marches and civil disobedience campaigns. Protesters often sing rewritten struggle songs at marches, rallies and funerals. They also use formal channels such as the courts, the media, and national and international networks to advance their goals. The main objective of the movement is to guarantee access to biomedical treatment of HIV, especially the antiretroviral medication, for all citizens through the public health care, but this call for medical health care also raises a wide variety of other questions, including prevention of new infections (cf. Robins 2004).

Year 2003 can be seen as a turning point and a victory in the TAC history as the national Treatment Plan concerning HIV/AIDS in the public health care sector in South Africa was achieved. Today the TAC is working for the actual implementation of this plan, since most people still do not have access to the medicines. The TAC is also campaigning locally and globally for new, more efficient drugs to be available in the public health care sector. The current challenge is the acute global funding crisis of antiretroviral treatment programmes. Gendered power relations are part of its agenda, and

even though there has been a lot of criticism about male dominated leadership of the movement, it is not hard to find testimonies like the following:

Indeed, the TAC's readiness and capacity to mobilize its membership in the struggle for gender justice gives us all hope that patriarchal notions of sex and women's subordination can be ended and that gender relations between women and men can be truly transformed. (Peacock, Budaza & Greig 2009, 100)

HIV in Research Discourses: Numbers and Prevention

How do the TAC messages relate to the HIV discourses that circulate? Despite a wide variety of social scientific texts on HIV/AIDS in Africa there are some common trends in how HIV/AIDS in Africa is represented in research documents, and what kinds of subject positions these representations allow. Two features appear regularly: shocking statistics and an emphasis on prevention. Many articles include statistics; almost habitually texts open with a presentation of numbers, as in the following examples:

South Africa has one of the highest HIV prevalence rates in the world (UNAIDS, 2004). In 2002, 26.5% of pregnant women attending ante-natal clinics nationally were HIV positive (Department of Health, 2003), and a national survey revealed an HIV prevalence rate of 11.4% for the South African population (Shisana and Simbayi, 2002). (Morojele et al. 2006, 217)

In sub-Saharan Africa (SSA), the effect of HIV/AIDS is overwhelming. Of the 42 million people worldwide estimated to be infected with HIV from the beginning of the epidemic until December 2003, SSA accounted for 70% of all cases (UNAIDS, 2003). (Luginaah et al. 2005, 1219)

The objective of such openings is to emphasize the importance of this research by underlining the urgency of the matter. But the numbers are often contradictory, even within the same publication, which is not surprising as statistics in this field are a complicated matter (Treichler 1999). Numbers on death and illness are powerful rhetorical tools, and their effect is clear: a moral obligation to pay attention to the issue is established. Such display of numbers, however, has also its dangers; through this catastrophic imagery, a "lost", or "dark", African continent is invoked. Large numbers on a scale of a large continent produces a mass, where subjects drown. Cindy Patton analyzes the discourse of an African catastrophe; its promise is the difference, a difference that offers a relative safety and stability of other, wealthier parts of the world (Patton 1997; see, also, Gilman 1988; Watney 1994).

One of the outcomes of this discourse is a paralyzing effect, here elaborated on by Zackie Achmat, the spokesperson at the time and one of the founding members of the TAC:

What is the meaning of 1000 new infections and 900 deaths a day? [...] What is the meaning of statistics? Why do they numb us? How can we mobilize and

marshal our facts without loosing our humanity? (Zackie Achmat, TAC march, University of Cape Town, 06.09.06)

Foregrounding the massive scale of the disaster undermines attempts to manage the epidemic, as efforts to save a few lives may seem insignificant when millions are continuously lost. In texts that focus on prevention the result often is that people living with HIV are used to attract attention, then abandoned, and the real “marshaling” targets the assumed “HIV-free” women and men.

Numbers could, however, also be used to challenge the “lost continent” discourse. Statistics can show how these numbers change, and the phenomenon becomes contextualized when catastrophic numbers are connected to policies. When activists point out that “600³ lives could be saved daily” they use statistics to show that something not only must but also *can* be done. These numbers are contextualized as actual people, with faces, in communities where health policies could be implemented:

Comrades, you be aware that in South Africa 600 people die as the result of HIV/AIDS every day. And those are not statistics, these are real lives of people that have been lost. These are parents of children who are being lost, and their children are being left, especially those children are being made vulnerable. Most of them are women, the majority of them black women, and the vast majority of them poor black women. Kebareng Moeketsi is the face of that statistics. (Sipho Mthathi, activist, currently the TAC’s General Secretary; here speaking during the Civil Disobedience Campaign at the South African Commission for Gender Equality, 01.04.03.)

Here the activist messages resemble those from feminist post-colonial theory on how to “encounter a stranger” (Ahmed 2000), or “speak to the subaltern” (Spivak 1999) in ethical ways that avoid “stranger fetishism” (Ahmed 2000). These theories help to see which numbers are troubling. From a feminist postcolonial perspective it can be possible to address the figures of African women living with HIV/AIDS without producing “a universe of strangers”. When discussing the scale of the epidemic, urgency should not be created in a way that fetishizes the ill and evokes an image of a mass of suffering that seems impenetrable. Rather, numbers can be used to point at possibilities, and the faces behind the numbers should be granted a status of subjects with real lives affected by global power relations.

Similarly, there are different approaches to prevention of new infections in the activist and scholarly discourses. The prevention of new HIV infections is obviously crucial. While it is possible to argue that all interventions, including abstinence campaigns, should be welcome in the face of a global catastrophe, the concern for us is how prevention discourses argue their case and what meanings these discourses cite and reproduce. Often, after having mentioned numbers of HIV infected, the prevention literature does not address the needs of the growing numbers of HIV positive people. People living with HIV become invisible or uninteresting. This lack of concern for HIV positive people was brought up by one of the activists we interviewed, challenging the idea that the HIV epidemic is all about simply using condoms, or “condomizing”, like the

³ The most recent number of daily AIDS related deaths is 900, 600 was for year 2003.

prevention jargon puts it: "When they are just saying you must condomize, you must protect yourself, what about the infected ones, where do they go?" (Interview with TAC-activist, female 30.5.03). An omission of people living with HIV in prevention messages may actually increase stigmatization. Zenebe (2006) argues that in Ethiopia HIV prevention campaigns fail because the messages are othering and stigmatizing. When HIV is depicted as a consequence of sinful behavior, programs implicitly produce an image of the infected "Other".

TAC activists who are open about their status, in contrast, challenge the boundary between the "normal" and the "diseased". The well-known t-shirts displaying a large text HIV POSITIVE are encouraged to be worn by all activists, showing, among other messages, that anyone can be HIV positive, and everyone is in one way or another, affected. Here a TAC activist explains how she addressed a friend:

I told her you don't know your status so you can't laugh at me. You haven't tested. You haven't tested. (Interview with Nomfundo Dubula, 13.05.03)

Another activist explains the reaction in her school when she disclosed her status and thus countered the usual distancing and stigmatizing effect of HIV education:

I think I started in my school, disclosing in my school. I did it in front of people. Yes, I started in my school when I was educating them. They didn't believe that there could be someone who is HIV positive like me, who looks like me, who is so beautiful. (Interview with a female high-school student, 08.06.03)

HIV activism worldwide is an example of an alternative knowledge generation processes. At the *International HIV Treatment Preparedness Summit* in Cape Town in March 2003, one crucial point raised frequently was the importance of employing people living openly with HIV in the "HIV sector" —meaning in prevention, policy making and planning, in treatment and in care. This was also seen as one important step in fighting the stigma and creating plausible prevention campaigns. A TAC activist explains the connection between stigma and the importance of affected communities' involvement in HIV work in the following way:

It is so nice if you are counseled by someone who has experience, you know. Because I know what happen when you first heard the news that you are HIV positive. (Interview with Judith Dzulani, 13.05.03)

Embodiment and illness also involve emotions and grief. "Mobilize and Mourn!", a slogan in one of the TAC campaigns, is a re-writing of the slogan "Don't Mourn! Mobilize!" from the anti-apartheid struggle. We read this citation as a way of paying tribute to the historical struggle, showing continuity in the fight for a better society, but also pointing to the personal and emotional side of this illness: in the face of this epidemic, there must be room for mourning. The TAC has turned funerals and deathbeds into political sites where participants wear the HIV POSITIVE t-shirts and sing TAC songs alongside religious hymns. TAC funerals can address stigma not only because they openly proclaim a community of people living with HIV but also because the political focus translates death from a fetishizing theme to a mobilizing message.

It is easy to detect a continuity here despite a historical and geographical difference. The strategy of fighting shame and silence by political mobilization has a

striking resemblance with the 1970s women's movements and later, the 1980s gay rights and HIV movements (cf. Davis 2007; Epstein 1996). Such continuities are, of course, not accidental, but ideas and strategies of social movements are connected and travel.

Behavior change versus situated agency: The example of ABC prevention

The so-called ABC approach ("abstain, be faithful, condomize") to prevention, common in many African countries, serves here to illustrate the difference between an individualizing, behavior oriented HIV prevention strategy and the politically oriented activist approach to HIV. The TAC criticizes ABC as remote from people's realities:

ABC is too simple. It's simplistic [...] to say abstain. Many young women, the only way they can get schoolbooks is to have sex. And other people choose to have sex. Many of our parents are forced to have sex. It is the only way they can survive. So simply to say abstain, is not good enough. (Zackie Achmat, 01.12.03, Workers' Rally on World AIDS Day)

In South Africa the ABC has influenced prevention strategies, including the national one (Morrell et al. 2002, 16; Epstein et al. 2004). Many researchers have pointed to the problems with ABC. Mitchell and Smith (2001) argue that the ABC approach fails to take into account the lack of negotiating power of many girls and women. In addition, the "A-Abstinence" injunction does not consider the dimension of pleasure and emotions in sexual decisions. Likewise, the "B-Be faithful" message constructs couplehood as safe, even if women often are infected in what they believe to be exclusive sexual relationships with a steady partner or husband (UNDPI & UNAIDS 2001). The "C-Condomize" rule is presented as the last resort of prevention. The message is: "First and foremost, **A**bstain from sex until marriage; if not abstaining, **B**e faithful to one, uninfected partner; if this is not possible, use a **C**ondom" (Gallant & Maticka-Tyndal 2003, 3).

The ABC logic implies that condoms are the last resort and signify problems in the relationship (Mitchell & Smith 2001; see also Holland et al. 1998). A study of South African township youth shows that girls who wish to be real girlfriends in heterosexual relationships need to insist on *not* using condoms to underline the steady and proper status of their relationships (Selikow et al. 2002, 28; see, also, Campbell & MacPhail 2002). Raising the issue of condoms in a relationship suggests lack of trust and is frequently interpreted as an insult. Paradoxically it is the ABC approach that feeds this line of thinking. According to ABC condoms are needed only in bad, unhappy, violent or hopeless relationships. In the light of the above, the quote from one TAC activist is not exaggerated: "ABC kills people" (interview with Taghmeda Achmat, 18.06. 03).

The activists' prevention messages address the question of prevention from a different angle; that of personal experience of living with the illness in the community (Robins 2006). The point of view is from the inside, from within realities that make it hard to issue instructions about how other people should live their sexual lives.

The difference between the activists' prevention messages and the mainstream prevention campaigns can bluntly be analyzed as the individual versus society dichotomy familiar from social sciences. Many prevention texts include an acknowledgement that social and economic circumstances for women in Africa are indeed harsh, but this statement does not change the overall picture of individuals made responsible for the spread of the epidemic by emphasizing behavior *choices* (Bujra 2000; Gilbert & Walker 2002). Whereas in a lot of HIV prevention the focus is on the individual and his/her

behavior, the activists focus on societal circumstances where infections occur.

Feminist theory has during its last 30 years suggested that subjectivity needs to be analyzed as contextual and situated (e.g. Braidotti 1991; Butler 1993). Individual, heroic agency has become a troubled perspective, replaced by a view on social circumstances and situated agency as simultaneous, constitutive processes of subjectification (Butler 1993). The activist approach could be described as “situated agency” where post-structural feminist perspectives are combined with a strong emphasis on subjectivity situated in the context of a collective. The TAC documents include a wide variety of statements that point at agency, but often in form of a collective agency. *We* “are not going to sit down and die”, as one of the informants phrased it (interview with TAC-activist, female 30.05.03). They describe activism as a transformative force that turns stigmatized and marginalized people into global human rights’ advocates, and mobilizes communities into active citizenship. This includes encouragement to responsible sexual behavior, but the emphasis is not there, but in politics that contextualize sexuality and health care.

Treatment or politics; pills as body/politics?

At first sight the TAC breaks away from its approach that foregrounds social contextualizing when they advocate for a biomedical intervention, the antiretroviral treatment. Instead of focusing only on clearly social issues, like gender or poverty, they argue for an intervention that sociologists have for decades criticized as medicalization; a transfer of power from people to experts; a technical solution to social problems (Oinas 1998; Lupton 1997). But, the TAC maintains that those policy makers who argue for poverty reduction or gender equality as more pressing issues than antiretroviral treatment, are putting people’s lives in danger. This can also be read as an argument against another dichotomy: biomedical versus social interventions.

In the activists’ discourse treatment and prevention are two sides of the same coin that have to go together in order to people to survive and have hope. In literature the relationship between treatment and prevention is often seen as antagonistic. For example Campbell (2003, 6) argues that “it’s sometimes alarming to see how the issue of drugs often has the potential to draw energy and attention away from debates about prevention”. The TAC argues that treatment is a crucial part of a successful prevention strategy. Nomfundo Dubula explains one relationship between treatment and prevention:

When treatment was available, people were much more likely to go for HIV tests [...] Once people knew their status they were more likely to practice safe sex and, if they needed it, to seek treatment. (Nomfundo Dubula quoted in *The Cape Times*, 2003)

The underlying message of the TAC agenda is that biomedical interventions are inherently social and political. Feminist scholarship on health has had different takes on medicalization and the dichotomy biomedicine-social but recent post-structural feminism and Science and Technology Studies scholars have argued in the same line with the TAC approach: the materialization of bodies and the technologies that shape them are social, constitutive processes (Haraway 1991). Feminist theories around “matter” maintain that health is not just a question of bodies of individuals, rather, health is a result of

technological, materializing and meaning making practices (Barad 2007). A dichotomy between interventions on material bodies versus social processes is an approach that denies the complexity and intra-agency of materialization (Barad 2003).

The TAC attempts to demonstrate that education programs that are combined with access to health care, including ARVs, have had a major impact in stigma reduction. The argument is that different aspects of health and embodiment need to be addressed simultaneously:

TAC is very strong in Khayelitsha so I can speak openly about my status. There is Nomfundo, there is Judith, who is going to support you. So for those two reasons [you can be open]. The other reason is that there are HIV dedicated clinics for opportunistic infections. There is antiretrovirals so people have hope that they are going to live longer. So all those are giving strength to people and hope to people. That is why Khayelitsha is the big place, known worldwide for its people that are living openly with HIV. (Interview with Nomfundo Dubula, 13.05.03)

Activism, biomedicine and support groups are seen as important components in HIV work, a combination that can offer a community against stigma. To encourage people to go for voluntary counseling and testing is done only provided that counseling involves information on what can be done after a positive test result, including information about treatment.

Education is especially crucial with respect to the high risks involved in developing drug resistance:

...as much as HIV treatment or antiretrovirals are good or effective they can be dangerous if you are not monitored. If [...] nobody is making sure that you are taking them in a right way. They can be very much dangerous. So we need trained doctors. (Interview with Nomfundo Dubula, 13.05.03)

She could also have said “we need to train doctors”, as this is a part of the TAC agenda. Treatment programs depend on lay and professional people educating themselves and each other about the disease and how to live with it, and activism plays a crucial role in education. Similarly, American gay HIV activism has shifted the knowledge/power relationship between medical doctors and patients, contributing towards co-operation between the two interdependent communities (Epstein 1996). The TAC shows that informed agency in treatment advocacy is not limited to the (Western) educated middle-class, but can be an empowering resource for marginalized people provided there is an active patient movement.

Robins (2004, 666) explains the strength of the TAC with reference to the legacy of the anti-apartheid movement, a history that provides the movement with an “organizational memory” of how to mobilize people to work towards a progressive and democratic civil society, including “health citizenship”. The TAC’s major focus is in the *state* providing services for anyone in need. This is as much a statement about the social and political nature of biomedicine, as a statement about what *kind* of health care politics this activist group advocates. It is noteworthy that they do not address the private sector or NGOs as possible providers of treatment in the same manner as they target the South

African government. This implies that the objective is not strengthening health care provision through the private sector, like in the US model, but a strong state that provides basic services (see Oinas & Jungar 2008). They lobby for the classic welfare model of many European states in contrast to other models like the more privatized one in the USA. This choice is about national party politics and ideological questions crucial for the state of South Africa taking shape, and about the ANC politics. In this sense the TAC is a lobby group: its aim is to advocate a specific policy.

National health care can take different shapes, and the one advocated by the TAC is a social democratic one, which undoubtedly fits well together with a view on embodiment as both personal, community and material “matter”. A social democratic view on public health and social politics includes liberal sexual ethics combined with information campaigns and surveillance of populations, and emphasis on state provided social and medical services (see Mkandawire 2005). The agenda of the TAC emphasizes that treatment, prevention, political struggle, and affected people’s local knowledge generation are simultaneous processes (c.f. Robins 2006; Poku 2005), thus creating a view on embodiment and health that insists on multiple complexities (Barad 2007). The argument here is that even though well grounded, it is, however, important not to be blind to certain political aspirations in activist agenda. The campaign is a call for political direction in South Africa. It is about the state and its future – antiretrovirals through public clinics actualize the question of government accountability for its people regarding basic services (de Waal 2006; Oinas & Jungar 2008). In most general terms, antiretrovirals invoke questions of nationhood, history and future, race and democracy (Fassin 2007).

The quote of Sipho Mthathi that opens this article is from a discussion where Mthathi is trying to explain the intertwined relationship between education, hope, politics and treatment, to gender bureaucrats. The discussion is symptomatic for how these dimensions of HIV are seen as separate. The virus, however, evokes not only South African political debates on the future of the welfare state and democracy, but also political questions on globalization, development and poor people’s rights. TAC activism takes a clear stand for a certain political direction, albeit not always in explicit terms, often using a de-politicizing human rights rhetoric.

Conclusion

The activist approach to the HIV epidemic, embodiment and the social order challenge existing discourses in at least three ways. Firstly, the activists challenge the dominant “Dark Continent” discourse of HIV in Africa as an incomprehensible catastrophe of a massive scale with passive recipients of interventions. They claim to be important actors on local, national and global levels demanding policies that have proved to be successful elsewhere. Their perspectives should be taken seriously in policy making and research. Secondly, they maintain that biomedical antiretroviral treatment is an effective HIV policy that is used in industrialized societies, and should be there too in the 3rd World, instead of only a narrow focus on sexual behavior. For example during the court case where the TAC was supporting the South African governments’ case against the multi-national pharmaceutical companies in 2001, the message that African lives, too, could be saved if there is political will, was broadcast worldwide. Third, activism is said to turn stigmatized and marginalized people into global human rights’ advocates, and

mobilize communities into active citizenship (Robins 2004). In contrast, stigmatizing and fetishizing discourses can be fuelled and reproduced by campaigns that target communities from the outside, and that insist on individualistic behavioral changes in a moralizing way. This discursive shift is important in all writing about HIV, including social science, and feminist accounts on for example sexual violence against women in Africa.

We argue in this article that politically oriented, community based treatment activism has a potentially de-stigmatizing element that may contribute to concrete change even when no treatment is available exactly because it questions the solely individual responsibility discourse typical for health promotion. This view on sexualities and embodiment is familiar from feminist literature. Sexual behavior does not need to be reduced to individual choices only, but sexuality can be seen as a socially negotiated phenomenon, strongly influenced by group-based social identities, and socio-economic factors, like material inequalities. People living openly with HIV generate local and contextualized knowledge about HIV/AIDS, and thus make a contribution to HIV education and policy. Treatment activism is an education movement in communities, work places, schools and churches, offering information about HIV, prevention, and care. The individualizing trend in HIV work that values the personal story to motivate individuals to behave in certain ways, is channeled to a political agenda for a community of actors.

Secondly, the TAC contests the presumed distinction between prevention and treatment, and thereby the dichotomy between the material and the social, also well known in feminist discussions. The link between prevention and treatment that the activists consider to be two parts of the same coin is often left out in research, especially in studies focusing on prevention. Challenging the dichotomy between the biomedical and the social, typical for mainstream social sciences, however finds allies in recent feminist theories on posthumanist performativity (Barad 2007).

The agenda of the TAC on the global scale is that they fight for the right to treatment for poor people; they have campaigned, for example, against international trade deals that are claimed to reproduce poverty and benefit multinational pharmaceutical companies. At the same time the TAC maintains another level, the centrality of people's own knowledge about their lives and health care practices. Both of these, we argue, are central in the work against stigmatization of people living with HIV, but also more generally for feminism. Following Mohanty (2003) and Braun (2008) we argue that whether activists name their politics "feminist" is not crucial, but the content is clear: the private is still political. The grassroots mobilization of marginalized people can create new political subject positions and new relationships in combination with new knowledges about HIV, prevention and health. Beyond the focus on HIV, the activist message is about the materiality of bodies, tightly connected to private and public politics – questions of dignity, rights and inequalities.

References

- Ahmed, Sara (2000). *Strange Encounters. Embodied Others in Post-Coloniality*. London: Routledge.

- Archer, Louise (2004) Re/theorizing “difference” in feminist research, *Women’s Studies International Forum*, 27(5-6), 459-473.
- Barad, Karen (2003). Posthumanist performativity: Toward an understanding of how matter comes to matter, *Signs*, 28(3), 801-831.
- Barad, Karen (2007). *Meeting the Universe Halfway. Quantum Physics and the Entanglement of Matter and Meaning*. Durham: Duke University Press.
- Bernstein, Lisa & Ndinda, Catherine (2008). Women’s activism for Gender Equity in Africa and the Diaspora, *Journal of International Women’s Studies*, 10(1), 1-4.
- Braun, Yvonne A. (2008). “How can I stay silent?” One woman’s struggles for environmental justice in Lesotho, *Journal of International Women’s Studies*, 10(1), 5-20.
- Bujra, Janet (2000). Targeting men for change: AIDS discourse and activism in Africa. *Agenda*, 44, 6-18.
- Butler, Judith (1993). *Bodies that Matter: on the Discursive Limits of "Sex"*. New York: Routledge.
- Campbell, Catherine (2003). *‘Letting them Die’. How HIV/AIDS Prevention Programmes often Fail*. Indiana: Indiana University Press.
- Campbell, Catherine & MacPhail, Catherine (2002). Peer education and the development of critical consciousness: participatory HIV prevention by South African youth, *Social Science & Medicine*, 55(2), 331-345.
- Conway, Janet (2007). Transnational Feminisms and the World Social Forum: Encounters and Transformations in Anti-globalization Spaces, *Journal of International Women’s Studies*, 8(3), 49-70.
- Davis, Kathy (2007). *The making of OurBodies, Ourselves. How feminism Travels across Borders*. Durham: Duke University Press.
- Epstein, Deborah; Morrell, Robert; Moletsane, R; Unterhalter, Elaine (2004) Gender and HIV/AIDS in Africa south of the Sahara: interventions, activism, identities, *Transformation* 54, 1-15.
- Epstein, Steven (1996) *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Ettorre, Elizabeth (2005). Gender, older female bodies and autoethnography: Finding my feminist voice by telling my illness story, *Women’s Studies International Forum*, 28(6), 535-546.
- Fassin, Didier (2007). *When Bodies remember. Experiences and Politics of AIDS in South Africa*. Berkeley: University of California Press.
- Friedman, Stephen & Mottiar, Shauna (2006) Seeking the High Ground: The Treatment Action Campaign and the Politics of Morality, in: Ballard, Richard, Habib, Adam & Valoodia, Imraan (Eds) *Voices of Protest. Social Movements in Post-Apartheid South Africa*. | Scottsville: University of KwaZulu-Natal Press.
- Gallant, M., Maticka-Tyndale, E. (2004) School-based HIV prevention programmes for African Youth, *Social Science & Medicine*, 58(7), 1337-1351.
- Gilbert, L., Walker, L. (2002). Treading the path of least resistance: HIV/AIDS and social inequalities – a South African case study, *Social Science & Medicine*, 54(7), 1397-1411.
- Gilman, Sander (1988). *Disease and Representation: Images of Illness from Madness to AIDS*. Ithaca: Cornell University Press.
- Haraway, Donna (1991). *Simians, Cyborgs and Women. The Reinvention of Nature*. New York: Routledge.

- Holland, Janet; Ramazanoglu, Caroline; Sharpe, Sue; Thomson, Rachel (1998). *The Male in the Head. Young People, Heterosexuality and Power*. London, Tufnell Press.
- Jassey, Katja & Nyanzia, Stella (2007). How to be a 'proper' woman in the time of AIDS. *Current African Issues* No. 35. Uppsala: Nordic Africa Institute.
- Kakaru, Doris M. (2008). Rural livelihoods, HIV/AIDS and women's activism: the struggle for gender equality in primary education in Uganda, *Journal of International Women's Studies*, 10(1), 36-47.
- Lather, Patti (2001). Postbook: Working the Ruins of Feminist Ethnography. *Signs*, 27(1), 199-227.
- Lewis, Desiree (2004). Postcolonial Feminisms; The Politics of Freedoms. Retrieved November 15, 2005 from <http://www.library.wisc.edu/libraries/WomensStudies/mags.htm>
- Luginaah, I.; Elkins, D.; Maticka-Tyndale, E.; Landry, T.; Mathui, M. (2005). Challenges of a pandemic: HIV/AIDS-related problems affecting Kenyan widows, *Social Science & Medicine*, 60(6), 1219-1228.
- Lupton, Deborah (1997). Foucault and the Medicalisation Critique, In Petersen, Alan & Buntun, Robin (Eds) *Foucault. Health and Medicine* (pp. 94-112). London: Routledge.
- Mbali, Madisa (2003). A Postcard from Bangkok: reflections of gender and sexuality in contemporary, global AIDS activism, *Agenda*, 62, 107 – 113.
- Mitchell, Claudia & Smith, Ann (2001). Changing the Picture: Youth, Gender and HIV/AIDS Prevention Campaigns in South Africa, *Canadian Women's Studies*, 21(2), 56-61.
- Mkandawire, Thandika (2005). *Social Policy in Development Context*. London: Palgrave/UNRISD.
- Mohanty, Chandra Talpade (2003). *Feminism without Borders. Decolonizing Theory, Practicing Solidarity*. Durham: Duke University Press.
- Morojele N. K.; Kachieng'a M. A.; Mokoko E; Nkoko M. A.; Charles D.H.; Parry, C. D. H.; Nkowane A. M.; Moshia K. M.; Saxena, S. (2006). Alcohol use and sexual behaviour among risky drinkers and bar and shebeen patrons in Gauteng province, South Africa, *Social Science & Medicine*, 62(1), 217-227.
- Morrell, Robert; Moletsane, R; Abdool Karim Q.; Epstein, D. & Unterhalter, E. (2002). The school setting: opportunities for integrating gender equality and HIV risk reduction interventions, *Agenda*, 53, 61-68.
- Msimang, S. (2003). HIV/AIDS, globalization and the international women's movement, *Gender & Development*, 11(1), 109-113.
- Oinas Elina (1998). Medicalization by whom? Accounts of menstruation conveyed by young women and medical experts in medical advisory columns, *Sociology of Health and Illness*, 20(1), 52-70.
- Oinas, Elina & Jungar, Katarina (2008). A luta continua! South African HIV activism, embodiment and state politics, *Development Dialogue*, 50, December 2008, 239-258. Available at http://www.dhf.uu.se/pdffiler/DD2008_50_mass_violence/Development_dialogue_50_art12.pdf
- Patton, Cindy (1997). Inventing 'African AIDS', in: Lancaster, R. N., di Leonardo, M. (Eds.) *The Gender/Sexuality Reader: Culture, History, Political Economy* (pp.387- 404). New York: Routledge.

- Peacock, Dean; Budaza, Thokozile & Greig, Alan (2009). The Treatment Action Campaign's Activism, in: Ndinga-Muvumba, Angela & Pharoah, Robyn (eds) *HIV/AIDS and Society in South Africa*. Scottsville: University of Kwa-Zulu-Natal Press.
- Poku, Nana K. (2005) *AIDS in Africa. How the Poor are Dying*. Cambridge: Polity Press.
- Robins, Steven (2004). 'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid, *Journal of Southern African Studies*, 30, 651-672.
- Robins, Steven (2006). From 'rights' to 'ritual': AIDS activism in South Africa, *American Anthropologist*, 108(2), 312-323.
- Selikow, T-A.; Zulu, B. & Cedras, E. (2002). The ingagra, the regte and the cherry: HIV/AIDS | and youth culture in contemporary urban townships, *Agenda*, 53, 22-32.
- Spivak, G. C. (1999). *A Critique of Postcolonial Reason: Toward a History of the Vanishing Present*. Cambridge: Harvard University Press.
- Treichler, Paula (1999). *How to Have a Theory in an Epidemic. Cultural Chronicles of AIDS*. Durham: Duke University Press.
- UNDPI & UNAIDS (2001). *Fact Sheets: Global Crisis ... Global Action*. New York: UNDP & UNAIDS.
- De Waal, Alex (2006). *AIDS and Power. Why There is No Political Crisis – Yet*. London: African Arguments/Zed Books.
- Watney, Simon. (1994). *Practices of Freedom. Selected Writing on HIV/AIDS*. Durham: Duke University Press.
- Zenebe, Mulumebet (2006). *Negotiating Gender and Sexuality in the HIV/AIDS Discourse in Addis Ababa, Ethiopia: Contradictions and Paradoxes*. Tromsø: Tromsø University Press.

¹ The notion mainstream is of course problematic on field so full of controversies, for example around AIDS denialism. Fassin (2007) and Robins (2004) have analyzed differences between the AIDS dissident views and dissident policy discourses in contrast to the TAC politics. Robins reading of the differences in these two different political approaches to HIV/AIDS in Southern Africa shows an alarming resemblance to our findings on a clearly less controversial body of literature; that is, social science literature on HIV/AIDS in Africa. Whereas it is obvious to most readers that AIDS dissidents who deny the connection between HIV and AIDS can have a paralyzing and harmful impact on implementation of effective HIV policies, we are concerned about the central finding of our study: a near silence on antiretroviral therapy as an option when social scientists discussed HIV in Africa during the early 2000s. At the same time, during the 2000s, there has been a major political shift and a new commitment to treatment issues in HIV policies among the key players across the political spectrum -- the World Health Organization, the Global Fund, and the Gates Foundation. This turn was however not yet reflected in the social science literature. We anticipate a growing interest in realities of treatment among scholars too. It is however important to note the recent, and partly continuing disparity between academic perspectives, still focusing on prevention and often silent or hesitant about treatment, and the call for urgent action among activists, media and global health agencies.