



# LONG LIVE!

South African HIV-activism,  
Knowledge and Power

Katarina Jungar

**LONG LIVE!**



# Long Live!

South African HIV-activism,  
Knowledge and Power

**Katarina Jungar**

Åbo 2011

Sociological Discussions. Occasional Papers from the Unit of Sociology at Åbo Akademi University  
Sociologisk diskussion. Rapporter från ämnet sociologi vid Åbo Akademi  
<http://www.abo.fi/student/sociologiskdiskussion>

Series editor: Ralf Kauranen  
Contact: [sociologi@abo.fi](mailto:sociologi@abo.fi)

Cover design and lay-out: Graeme Arendse  
Photographs: Katarina Jungar

ISSN 1799-7410 (print)  
ISSN 1799-7429 (online)  
ISBN 978-952-12-2639-7 (print)  
ISBN 978-952-12-2640-3 (online)

Painosalama Oy

Åbo 2011

# Contents

<b>1. Introduction</b> .....	7
Description of articles .....	10
Structure of the summary .....	12
<b>2. An Epidemic That Matters</b> .....	15
'Denialism' questioned by TAC .....	16
Activist discourses and the return of materiality .....	21
Rethinking medicalisation .....	30
<b>3. Method and Material</b> .....	35
An ethnographic study of the TAC .....	36
Material .....	38
The interviews .....	38
The ethnography .....	40
'I have a house in Africa' – research, power and transnational relations .....	43
The ethics of self-reflexivity as non-mastery .....	46
Reading from the local .....	48
<b>4. 'A Luta Continua'</b> .....	51
'We have to use the same tools of [the] struggle' .....	52
The 'HIV-POSITIVE' T-shirt: Challenging the division between 'us' and 'them' .....	55
Celebrity appropriation of social movements .....	58
'TAC, the Swedish government and ACT-UP Paris' .....	61

# Contents (contd.)

<b>5. Health and HIV Research Revisited .....</b>	<b>65</b>
'AIDS is everything'.....	66
Collaborative medicine.....	67
Behavioural change – a heteronormative colonial HIV prevention project.....	70
Case study: Male circumcision.....	75
Treatment versus prevention.....	77
Obstacles to promoting treatment.....	82
'Treatment goes hand in hand with prevention'.....	84
<b>6. Conclusions.....</b>	<b>87</b>
<b>References.....</b>	<b>91</b>
<b>Svensk sammanfattning .....</b>	<b>105</b>
<b>Dissertation Articles.....</b>	<b>109</b>
Article 1.....	112
Article 2.....	134
Article 3.....	150
Article 4.....	166
Article 5.....	178
<b>Acknowledgements.....</b>	<b>195</b>

---

# 1. Introduction

The picture on the cover of this book shows a group of women toyi-toying<sup>1</sup> in 'HIV-POSITIVE' T-shirts. The woman in front is holding a jar of pills in her hand. This image encapsulates my view of the activist movement, the Treatment Action Campaign (TAC), which is the focus of this study. TAC can be expressed by four key words that have been central in this research: activism, community, knowledge and treatment.

In the photograph, the women activists are at a rally outside the Department of Trade and Industry in Cape Town in April 2003. The demonstration is part of the TAC's civil disobedience campaign to increase pressure on the South African government to take action against the HIV<sup>2</sup> epidemic (TAC Annual Report: 2003/2004). Activism, the first key word, has led the TAC to groundbreaking victories on a national and global scale to make health care and medications more accessible for poor people.<sup>3</sup> Furthermore, the legacy of the anti-apartheid activism is evident in the fact that the women at this demonstration are singing old, anti-apartheid-era struggle songs with new lyrics.

The Treatment Action Campaign was launched in 1998 with the main objective of campaigning for greater access to HIV treatment for all South Africans (*Fighting for our lives*, 2010). Today, the TAC is an organisation with about 20 000 registered members. This study is based on ethnographical material about the TAC collected in South Africa from 2000 to 2006. Most of the ethnography was done in Cape Town and included participant observation at rallies, at national and international conferences, official meetings, workshops, public funerals, church services, marches and interviews. Public TAC documents and popular texts are part of the empirical material. Even though parts of the study were done in collaboration with Elina Oinas (Jungar & Oinas, 2004, 2007, 2010, 2011), most of the ethnographic fieldwork that the analysis is based on, was conducted by myself alone (for a more detailed description see page 38). One article was written together with Elaine Salo (Jungar & Salo, 2008).

---

1 A Southern African dance that became famous for its use in political protest in apartheid-era South Africa.

2 Human Immunodeficiency Virus.

3 The year 2003 can be seen as a turning point and a victory in TAC's history because the national treatment plan concerning HIV/AIDS in the public health care sector in South Africa was achieved.

Activists often refer to the TAC as ‘a home’, implying a sense of community, which is the second key word. The organisation has created a community for mostly unemployed working class black women in South African townships (Peacock, Budaza & Greig 2009; Robins, 2004). The photograph represents this community. TAC activists were among the first to talk about their HIV status and to live openly with HIV in their communities, thus helping to de-stigmatise the disease and giving hope to others affected by it. This was possible mainly because of the support from activists and the TAC ‘community’, even though HIV-positive activists may be discriminated against in other areas of their lives.<sup>4</sup>

To educate and create awareness is an important part of the TAC, therefore knowledge is the third key word. Spreading medical knowledge about the virus, about antiretroviral treatment (ARVs), and bodily biological processes are all part of the TAC’s agenda. Furthermore, the rights of citizens in the new South Africa, and knowledge of trade and patent laws on a global scale, are important parts of the activist education. The TAC organises treatment *literacy workshops* for activists, some with very little formal schooling. In the TAC, increasing knowledge implies awareness of societal power structures and how these impact on public health and personal health. This in turn enables activism and change.

The jar of pills in the picture’s foreground is the fourth key concern in TAC activism, namely treatment. The jar is a reminder of the global fight against unfair trade laws. The tiny jar, representing what could be seen as a very narrow cause – access to medicine – highlights a wide area of local, national and global concerns. The jar in the woman’s hand symbolises a fight for democracy globally, since the TAC argues that everyone, even poor people, should have access to health care and life-saving drugs. The TAC adopted the slogan ‘Long Live!’ from the anti-apartheid movement. The slogan has been used by the oppressed classes, for example in proletarian struggles<sup>5</sup>. It means a long lasting struggle. The TAC associates the slogan with a personal struggle, while at the same time the slogan highlights a

---

4 Being a TAC activist, especially as a young woman, can be very dangerous at times. There are reports of violence and sexual assault against TAC activists (see Orford, 2010).

5 The slogan has roots as far back as wishes for the king; ‘Long Live the King!’ However, it is also a propagandist slogan increasingly used by the oppressed sectors in society.

global struggle. In this new context the slogan is especially apt, as it foregrounds the fact that this is a struggle for survival.

One of the central features of this study is that it shows how activism, more specifically HIV activism, can enrich academic discussions on health globally. By focusing on the politics of one contemporary activist group in South Africa, and by investigating how the TAC formulates its demands for health care and access to medicines for people who are living with HIV, this study is able to highlight new ways of thinking about medicalisation and social movements. By contrasting TAC discourses to academic and popular discourses on HIV/AIDS<sup>6</sup> and health, the study shows one example of how to think beyond binaries such as treatment/prevention, social/medical, and agent/victim. The study also considers the ways in which social science research produces and reproduces representations of HIV/AIDS, Africa, and people living with HIV.

## Description of articles

The first article ‘Hiv-aktivism som postkolonialt motstånd’<sup>7</sup> examines the TAC as a form of resistance that challenges mainstream discussions on HIV health research.<sup>8</sup> The article argues that TAC’s struggle questions the use of statistics, and the tension between prevention and treatment that often is created by research on prevention. The article concludes that mobilising people at the grassroots level has a double effect: people’s own knowledge about their own lives becomes important and, their demand for health care and medication makes the political dimensions of health and sickness visible. The second article, ‘A Feminist struggle? South African HIV activism as feminist politics’ maintains that community-based treatment activism includes de-stigmatising elements that may contribute to change because it questions the individual responsibility discourse typical of many HIV prevention discourses. The individualising trend leads to the blaming of individuals for their ‘risky behaviour’, instead of analysing structures that make people sick. TAC’s view on sexuality

---

6 Acquired Immune Deficiency Syndrome.

7 HIV-activism as ‘post-colonial’ resistance.

8 I am presenting the articles in an order that works thematically, and not in a chronological order according to the publishing year.

and embodiment as dependent on power-relations and context is therefore similar to feminist politics, where the personal is seen as political.

The third article, 'Beyond Agency and Victimization: Re-reading Women's Embodied Experiences', argues that the work of African feminist and post-colonial critics, who show how feminist research may exclude African women's voices and subjective experiences, and who also expose uncritical assumptions by researchers that African women are 'victims', have influenced recent feminist research in significant ways. Despite these important critiques, the emphasis on 'victimhood' still largely persists in applied research on gender and HIV/AIDS in Africa. This emphasis has been challenged further by 'agency' approaches that are aware of the important critique of representations of African women as mere victims of disease, violence, and patriarchy. In this article, Oinas and I explore this equally problematic re-invention of 'victims' as 'agents' in research on gender and HIV/AIDS in Africa. The article suggests that researchers could learn from how the TAC blurs the victim/agent divide. Furthermore, the article concludes that the desperate search for the active agent leads to research that does not take victimhood seriously, whereas the TAC struggles against these simplistic representations. "They [the TAC] point to the circumstances that created their victim status, not to themselves as tragic figures." (Article three, 259)

The fourth article, 'Shop and Do Good?' compares the TAC's discourses on HIV/AIDS to those of the commercial campaign 'Product Red'. Product Red is a brand initiative by U2's frontman, Bono (Paul David Hewson). The brand is designed to 'eliminate AIDS in Africa' and is based on the idea that you can 'shop and do good at the same time' (<http://www.joinred.com>). An unspecified portion of the profits from the so-called 'Red' products, is donated to the Global Fund to Fight AIDS, tuberculosis and malaria. The article shows that the brand 'Product Red', via its advertisement and products, constructs Western consumers as global saviours and Africans as local victims, a position that TAC activism continuously questions.

The fifth article, 'Preventing HIV? – Medical discourses and invisible women' is an analysis of a debate in medical journals on

male circumcision as an HIV prevention strategy in Africa. The article investigates discourses on 'African AIDS' and gender in a medical debate and concludes that some male circumcision research displays an inability to reflect on the politics involved in representations of sexualities and race, and a belief in their enterprise as being an objective and neutral science.

The articles, upon which this study is based, were written in collaboration with Elina Oinas. One article was written in collaboration with Elaine Salo. The process usually involved writing an outline of the planned article together. The actual writing was done sometimes so that the authors sat together at the computer. More often the writing was done individually, and the draft text was emailed back and forth between the authors.

### **Structure of the summary**

The summary discusses core themes of the whole study. Furthermore, it highlights and explores questions that are not to any large degree discussed in the articles, although they emanate from the discussions in the articles. The second chapter offers a reading of the TAC and the discourses and experiences put forward by the activists, especially in connection with so-called South African 'denialist discourses', but it also contrasts TAC discourses to discourses around medicalisation. This chapter shows how feminist theories of materiality could add to the social science discussions on HIV/AIDS, and it explores more closely how feminist theories of materiality could benefit the discussion on HIV/AIDS. Taking one scientific article as an example, I demonstrate how material realities, in this case the fact that people die because they do not have access to ARVs, can paradoxically be forgotten in analyses that focus on the workings of culture, discourse and language in relation to disease. The last part of this chapter suggests that, in the light of the TAC's activism, we need to rethink the term 'medicalisation', a term that has been central to, and widely discussed in health research. The demand for treatment by activists in the global South casts a different light on the medicalisation debate, since mainstream theories on medicalisation do not discuss access to health care and medications on a global scale.

The third chapter discusses methodology. Returning to the cover picture of the thesis, a white woman can be seen in the background.

She could be me, looking a bit curious and lost, and not dancing with the crowd. Emma Goldman is often quoted as having said: “If I can’t dance, I don’t want to be part of your revolution.”<sup>9</sup> This phrase has come to my mind several times when I have stood stiff among dancing or toyi-toying TAC activists. In my case, my stiffness might be taken to mean that if I do not know how to dance, I cannot be part of the TAC revolution. In this summary, much space is given to methodological and self-reflexive questions, since the format of the articles did not allow extensive discussions around methodology. One core question in contemporary feminist methodology is how to take into account the difficulties or even impossibilities of representation in research which aims to make certain experiences visible. Another important related question would be: How does one write about the TAC activists in an ethical way? The picture on the cover, photographed by me, reminds me of feeling lost and trying to hide behind the camera at TAC events. The anxiety and the problematisation of participation and power relations involved in doing ethnographic research are central in feminist methodology.

Chapter four shows how the TAC’s struggle draws from the legacy of the anti-apartheid movement. This chapter furthermore presents the TAC activists as political navigators among global donors and activists. It also shows how the politics of the TAC produces completely different representations of HIV/AIDS from the AIDS celebrity discourse. Chapter five discusses health and HIV research, and compares them with TAC activism. This chapter examines how feminist post-colonial theories, together with TAC activist approaches, challenge theories on women’s health that have been put forward within social science research. Furthermore, TAC works with a form of collaborative medicine that challenges the clear-cut expertise/lay knowledge divide. This chapter additionally examines what I call the ‘behavioural change approach’ in prevention discourse, and it shows how TAC challenges this approach. One focus in this chapter is the debate around voluntary male medical circumcision, which functions as an example of the need to take

---

9 There are many versions of this phrase in circulation, and in fact Emma Goldman never wrote any of the circulating sentences. The most common version “If I can’t dance, I don’t want to be part of your revolution” was first printed on a T-shirt for a festival in New York in 1973 to celebrate the end of the Vietnam War, supposedly quoting Goldman. The sentence can be described as trying to catch the sentiment of one story in her autobiography (Shulman, 1991).

gender-power relations into account in one's work. Lastly, this chapter problematises TAC's messaging around voluntary male medical circumcision. To me this reads as an example of how post-colonial feminist theory could serve to develop the gender analysis and feminist politics in South African HIV activism.

The main argument in Chapter five is that research on activism (in this case HIV activism) can effectively avoid some of the shortcomings often present in HIV research which lack any connection to activist communities or social movements. One such shortcoming was the absence of discussions on treatment in African contexts. Furthermore, the chapter questions the dichotomy between treatment and prevention, a dichotomy repeated in much HIV research, and argues that TAC manages to move beyond this dichotomy. Additionally the chapter investigates the representation in social science of ARVs as allegedly 'too technical and too complicated' for an African context and contrasts these discourses to TAC discourses. When ARVs are represented as too complicated for Africans, it reveals a certain discourse on Africa that the activists continuously challenge when they, argue that "you can take ARVs even though you live in a shack" (TAC/COSATU National Treatment Congress, 27–29.06.02, Durban).

The central argument that runs through the articles and the summary is how research on HIV activism in South Africa can enrich academic discussions on health, disease, gender and sexualities.<sup>10</sup> Many questions raised by activist discourses directly address core debates in feminist theory, such as questions around sexuality, materiality, and representation. The following chapters will show this in greater detail. I would recommend that the reader begin with the articles and then read the summary.

---

10 The study shows how gendered power relations are very much part of TACs agenda, even though there has been criticism about male dominated leadership of the movement. This study however focuses on the public politics of the movement and not on the internal politics of the TAC.



March to Parliament February 2001

---

## 2. An Epidemic That Matters

## 'Denialism' questioned by TAC

We don't want the beetroot!  
 We don't want the garlic!  
 The only thing we want is the ARVs!  
 – Song outside parliament at Night Vigil, 07.09.06

During the International Aids Conference in Toronto 2006, the then South African Minister of Health, Mantombazana<sup>1</sup> Tshabalala-Msimang, caused a national and international debate because the South African official exhibition stand focused mostly on displaying vegetables as a central solution in the country's HIV/AIDS policy. The reactions should be read against the background of the South African government's extraordinary HIV/AIDS policy which drew on so-called 'dissident' views in the United States and AIDS 'denialist' views in South Africa. The vegetable stand at the AIDS conference was in line with governmental policy adopted at the time, where nutrition was emphasised at the cost of antiretroviral (ARV) treatment. The Minister of Health promoted garlic, olive oil, beetroot and the African potato as important HIV cures, not only in Toronto, but on several other occasions. The former minister's HIV policy can be read as a reactionary response to the medical discourse and the brand of medicine that she considered to be colonial. One could say that she picked an anti-medicalisation discourse, and 'Africanised' the critical stance on medicalisation by adding the African potato. The reactions and the debate are a good example of the conflicting views that can be found in relation to HIV/AIDS in a post-apartheid context. The lines cited at the beginning of the chapter and below complain about the minister's lack of connection with reality:

You Manto.  
 Can't you see that this country is falling apart?  
 And you keep saying bla, bla, bla.  
 – Song outside parliament at Night Vigil, 07.09.06

---

1 The late Minister of Health was commonly referred to as Manto by the general public and TAC activists.

The debate has been heated. Activists have been loud and the voices raised against the government's policy have been many. Denialism is explained on the TAC website as follows: "It is the promotion of one or more of the following pseudo-scientific views: (1) HIV does not cause AIDS, (2) the risks of antiretrovirals outweigh their benefits, and (3) there is not a large AIDS epidemic in sub-Saharan Africa." (<http://www.tac.org.za/community/debunking>). I am uneasy about the term 'denialism' as it implies an objective body of 'true' knowledge, which is repudiated or 'denied' by a particular group of people. Thus, rather than understanding 'denialism' as lies or errors spread by politicians (see Oinas & Jungar, 2008), I prefer to define it as a denial of "facts that others generally accept as proven on the basis of massive and overwhelming evidence" (Cameron, 2005:132). According to Fassin (2007), the debate in South Africa has been so polarised between adherents of scientific orthodoxy and supporters of the government thesis that there has been no room for social scientists to carry on with their work of "presenting and analysing discourses, positions and facts" (Fassin, 2007:12). I am aware of conceptual difficulties in using the term 'denialism' which may serve to foreclose rather than to develop a discussion of the medical and socio-political contexts relevant to the epidemic.

'Denialist' views combined with a lack of accountability, which together have led to delayed implementation of antiretroviral treatment by the South African government, have outraged activists. According to the TAC, this has caused many deaths in South Africa under the leadership of the former President Thabo Mbeki and the former Minister of Health, Mantombazana Tshabalala-Msimang. A TAC employee criticised the minister after the Toronto conference as follows:

We are saying that the health system in South Africa is in a shambles. We are losing many health care workers. We are losing teachers. We are losing young people in our country. Where is the comprehensive treatment plan that really responds to the realities of our country? We are also demanding that there should be a national team that looks to a plan that is going to talk to our realities, talk to our needs, but also respond to the science.

- Linda Mafu, 19.09.06, speech at TAC rally outside parliament

In this speech Mafu demanded that the government should acknowledge that people are dying of AIDS. She asked for a plan that would respond to people's needs, but also to the different views on science. The activists argued, often from their own experiences of seeing people being sceptical towards ARVs, that the health minister's policy was deceiving people:

Some of you might have seen our health minister on TV yesterday. When Manto was misleading our sick people! I even sent a child to buy airtime because I wanted to intervene [make a call to the TV channel]. Manto must come to the TAC and take lessons about HIV/AIDS.

- Mama Dalina from the New Women's Movement, speech at Interfaith Service organised by TAC, 28.08.06

Steven Robins (2004) has shown how HIV activists in South Africa, in contrast to denialist or dissident views on science, have been instrumental in the democratisation of science in post-apartheid South Africa. Didier Fassin (2007:33) writes that the AIDS epidemic represents a war of meanings that has torn South African society apart virtually since the democratic elections in 1994. This semantic war is, according to him, much more than a war between explanatory models. "It is a confrontation between worldviews, ways of relating to history and memory, definitions of morals and politics" (Fassin, 2007:33).

Several authors have analysed and discussed President Thabo Mbeki's position on HIV science and policy (Fassin, 2007; Furlong & Ball, 2005; Geffen, 2006; Gray, 2005; Heywood, 2002, 2005; Mbali, 2004, 2008; Nattrass, 2007; Posel, 2005; Robins, 2004). According to Mandisa Mbali (2004), government denialism grapples with the ghost of colonial medicine and old traditions in Western culture that project 'negative' sexual practices onto the African other. Both Mbali and Robins see denialism as an African nationalist response to Western AIDS discourses. The nationalist rhetoric is also an ingredient in the argumentation of activists. When the activists invited parliamentarians to listen to them outside parliament and only one ANC MP arrived, a TAC employee stated:

They [ANC MPs] are not talking to us. Again they have done it. Again they are going to say TAC is not patriotic, they are going to say

TAC does not respect MPs, [...] they are going to say we hate ANC. When we were in Toronto they said that we sold out, we sold out our country. But we were angry especially because of this. Exactly because they are disrespecting the people of this country. We cannot have members [of parliament] that are saying that we should eat garlic and we should eat beetroot and call that a comprehensive plan to respond to HIV in our country. We cannot have members that we invite to talk to us and they don't come because they have caucus and lunch. We are here, we are hungry, we are waiting for them. They are busy having lunch.

– Linda Mafu, 19.09.06, speech at TAC march to parliament

The problem of nationalism and patriotism is cited as something that both parties share. Both sides employ similar terms to legitimise their own priorities. This quote also highlights the TAC as citing patriotic discourse. When Mafu asserts that the TAC will be accused of not being patriotic, she simultaneously defends them as being patriotic. The TAC's position is not easy. In the midst of this 'war of meanings' there are no neutral positions. Being simultaneously patriotic and critical of the ANC is a position that can seem contradictory.

During this study of the TAC, the campaign, the methods and the targets have changed. The year 2003 can be seen as a turning point and a victory in the history of the TAC, as the national treatment plan concerning HIV/AIDS in the public health care sector in South Africa was achieved. Today, the emphasis is on state accountability for the well-being of citizens. There are still many people in South Africa who do not have access to ARV medicines and proper health care. TAC's struggle has been a struggle on local, national and global levels. The failure of the South African leadership was the target in the above quotes, but earlier the multinational pharmaceutical companies and international trade laws were targeted because TAC argued that pharmaceutical companies were profiteering at the expense of poor people's health (*Fighting for our lives*, 2010).

Finally, I will return to the debate between the South African government and the TAC, because the debate is descriptive of discourses that, as the study will later show, also flourish in social science health research. I argue that one can distinguish between a treatment discourse and a prevention discourse in the debates. To emphasise the point, one could argue that a prevention discourse draws on the colonial fantasy of

civilising African men through HIV training and workshops, whereas a treatment discourse argues for treatment for everyone.

While the former president withdrew from publicly expressing ‘denialist’ views, the Minister of Health continued to promote them. Interestingly, President Mbeki’s ‘denialist’ views seemed to be a reaction against ideas circulated in the prevention discourse (see also Arnfred, 2004). In one of his often quoted speech, he argued

Convinced that we are but natural-born, promiscuous carriers of germs, unique in the world, they proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust.

– Address by President Thabo Mbeki at the Inaugural ZK Matthews Memorial Lecture, University of Fort Hare, 12.10.01

This comment<sup>2</sup> reflects Mbeki’s reaction to the prevailing ‘prevention’ discourse, which focussed on controlling African sexual behaviour, as will be discussed in Chapter five. Mbali (2004) argues that government AIDS denialists are opposed to a discourse that, according to her, has been surpassed in the ‘AIDS world’ by rights-based, anti-discrimination discourse and a shift to a medical, technical, non-‘moralistic’ or stigmatising approach. I would add to this analysis the fact that the prevention discourse is still, to a large extent, fuelled by racism (see Chapter five and article five). There is a difference in this sense between the prevention discourse and the treatment discourse. The much less stigmatising treatment discourse draws largely on activist arguments about the right to health care for all in the new South Africa. It is obvious that patriotism and nationalism thrive more easily in the prevention discourse.

The distinction between treatment and prevention discourse is helpful in analysing the discourse on ‘denialism’ as it places the argument in a context. Gayatri Spivak argues that a central colonial narrative is that of “white men saving brown women from brown men” (1993:92). President Mbeki’s response to HIV/AIDS could be seen as a

---

2 The words are directed at “others who consider themselves to be our leaders [and who] take to the streets carrying their placards” (Address by President Thabo Mbeki at the Inaugural ZK Matthews Memorial Lecture, University of Fort Hare, 12.10.01). “Leaders [...] carrying their placards” could be seen as referring to TAC leaders. Mbeki’s views on ARVs and HIV are obviously a reaction against treatment. My point is, however, that his responses are a reaction to a prevention discourse.

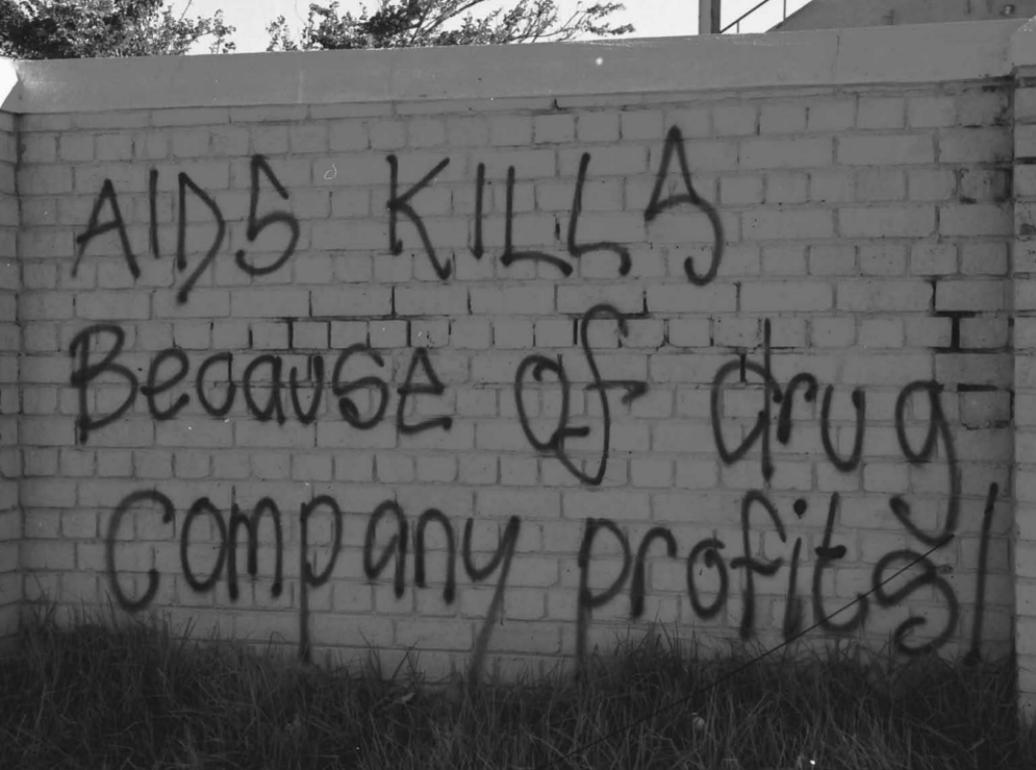
nationalistic response to a prevention discourse in which the ‘Western’ model of family and gender relations is seen as a way of ‘saving’ African women from promiscuous African men.

Ironically, it is the statements of President Mbeki and Mantombazana Tshabalala-Msimang that received global attention and reproduced the very same racist ideas that they were intended to counteract. Ideas such as the ‘irrational African’ spread with the ‘denialist’ debate and allowed the stereotype of the dying African to flourish (see also Younde, 2007). Against this background it becomes clear why it is even more important to analyse the discourse of denialism. According to Fassin, AIDS is also “a test for the social sciences, since they too participate in the semantics through which the meanings of the epidemic is construed” (Fassin, 2007:33). Neville Hoad (2005) reminds us that it is important in analyses, for example of President Mbeki’s statements, to remember the homophobic, racist and irrational responses to the epidemic put forward by Western governments.

### **Activist discourses and the return of materiality**

Denialism is not only found in the rhetoric and politics of the South African government on HIV/AIDS, but is also evident in the social science discourses on HIV that, until recently, have not emphasised treatment in an African context (see article one and article two). In my reading of what I call the ‘denialist debate’ and social science research on HIV, I want to show how material effects – in this case the fact that people die – are easily overlooked in popular debates. I argue furthermore that the materiality of people’s lives is also ignored in some research debates. By studying and reading activist accounts, this study attempts to bring materiality back to research debates. Materiality in this instance refers to both the virus and the medicine, and how they interact in the body.

The discourse analyses in this section focus on three actors: firstly, the former South African government and its rhetoric on HIV/AIDS; secondly, a social science study (Marshall 2005) on HIV/AIDS in which material conditions are surprisingly absent; and thirdly, activists’ practices and accounts concerning materiality. Each of these actors relies on one of three different arguments: arguments in favour of medication, ‘denialist’ arguments which either reject the role of medication or stress the toxicity of ARVs, and arguments about medications that are based



Cape Town 2001

on South African nationalism. The study describes this discursive field with its major players, and considers the discursive context of the arguments of each player. ARV treatment has successfully altered HIV/AIDS from a lethal infection to a chronic disease. In the words of an activist slogan: 'HIV is not a death sentence anymore' (TAC/COSATU National Treatment Congress, 27–29.06.03, Durban). Although HIV/AIDS is now seen by many as a chronic disease, the fact is that globally, millions of people do not have access to medication. Politically, discourses on HIV/AIDS still concern questions of life or death. Although we can now say that it is not a lethal infection due to ARV drugs, the meaning of this argument must be seen in relation to the context. For some HIV/AIDS still is a lethal infection. Today, TAC activists and AIDS activists globally are worried about the international decline in political will to prevent and treat HIV/AIDS. Long time AIDS activist Gregg Gonsalves says:

[...]for many people AIDS is like diabetes or hypertension – take some medicine and you’ll generally be fine and you’ll have a long and relatively healthy life. For others it’s still a death sentence, but death by public policy this time.

– <http://sciencespeaksblog.org/2011/05/20/aids-at-30-an-interview-with-activist-gregg-gonsalves/>

The denialist discourse that the former South African government used rests upon dualisms between Africa and the west, poverty and medicalisation, and treatment and prevention; dualisms which the activists continuously challenge. Using one example from social science research, I want to show how these dichotomies operate. Karen Barad’s theories on matter and language are used in order to advance the argument that materiality is quite obviously lost in the denialist discourse, but also to some extent in social science, and that it is the TAC activist discourse that eventually brings material conditions into the debate. The AIDS activist discourses are read as an example of a discursive resistance that exposes dualist thinking and forms new radical relationships to science, medicalisation, nationalism and global power structures.

I will present you with an example of a study in social science research on HIV/AIDS where material conditions are surprisingly absent. The study referred to is Wende Marshall’s (2005) article ‘Aids, race and the limits of science’. I argue that this article can be seen as symptomatic of a wider discursive unwillingness during the last fifteen years to consider antiretroviral drugs for Africans in social science research, although this has changed radically today. Marshall’s article is interesting, firstly because it was published in the journal *Social Science and Medicine*, and one may conclude that this journal regarded its arguments as fitting, or at least in line with its ethical research standards; and secondly because it bears a remarkable resemblance to Mbeki’s and the South African government’s so-called HIV/AIDS ‘denialism’ discourse. In my reading here, the similarity between the South African government’s denialist discourse and social science discourse is apparent.

Marshall’s argumentation is influenced by three main themes: firstly, the debate around medicalisation; secondly, the legacy of colonial racism; and thirdly, the so-called ‘denialist’ views on HIV/AIDS. The journal *Social Science and Medicine* publishes extensively on HIV in Africa, although until 2005 relatively few articles had dealt with

ARVs in an African context. This makes it even more curious that the only article which actually deals with these issues in this context clearly has features that could be defined as ‘denialist’ or as borrowing arguments from denialist discourses. The article begins by quoting James Baldwin (1951), Franz Fanon (1967), W. E. B. Du Bois (1903), and Toni Morrison (1992), and makes many important points about racism and science, but, as the article turns to medical issues the argument becomes problematic.

Marshall (2005) maintains that the ‘overmedicalisation’ of treatment and prevention efforts obscures socio-cultural and political-economic realities. The word ‘overmedicalisation’ as used here can be questioned, keeping in mind firstly the large population in Sub-Saharan Africa who needs the drugs, and secondly the strong popular movements who are working to give people access to treatment. Furthermore, this argument works against the TAC’s struggle for access to antiretrovirals – a struggle which highlights global inequalities. Both Marshall and the TAC highlight the importance of economics, but in diverse ways, and with an emphasis on different realities.

A critique of medicalisation that does not take into account the struggles of local activists in a specific post-colonial context will lose sight of the fact that people are dying because they do not have access to medication. Marshall’s (2005) research is an interesting example. She makes a brilliant analysis of racism in science; in doing so, however, she critiques science as Western form of knowledge and thus obscures the crucial campaigns of ‘third world’ health movements which are working to make medical solutions more widely available.

The problem with Marshall’s article is consequently that it overlooks the materiality of HIV. She argues that we should value other ways of interpreting the world and not just Western scientific logic:

What I am contesting is not the tragedy [of AIDS], but how the tragedy is *interpreted* and how the discourse on HIV/AIDS valorises Western scientific logic at the expense of other ways of interpreting the world.

– Marshall, 2005:2515

What are these ‘other ways’, and how would they lead to alternative forms of treatment in this setting? This sentence shows a romanticising of ‘the other’, implying there is some traditional ‘other’ way of interpreting ‘the tragedy’. In the quote below, Marshall indirectly comments on one of Mbeki’s so-called denialist positions, in which he questions that HIV causes AIDS. She writes:

It is simple common sense in the United States that HIV is *the* virus that causes AIDS, and to suggest otherwise is to incur the wrath and ridicule of institutional medical and scientific orthodoxy. [...] It is precisely the taken-for-granted nature of AIDS, and the generally unquestioned hegemony of scientific knowledge production, that occludes the possibility of other interpretations of life and death, health and disease.

– Marshall, 2005<sup>3</sup>:2515

Marshall does not give examples of other interpretations of death or disease. While death, for example, may have different meanings in different contexts, a mere shift in interpretation will hardly affect the material workings of the virus. It seems self-indulgent and callous to emphasise the importance of ‘other interpretations’ of death in a context where millions of people are actually dying. Overlooking this fact constitutes a refusal to acknowledge material realities. Karen Barad’s argument is fitting here: “Language matters. Discourse matters. Culture matters. There is an important sense in which the only thing that does not seem to matter anymore is matter” (Barad, 2003:801). This point is especially important when one is analysing a discourse that is about dying, or about a potentially lethal disease. I have found Barad’s discussions on the relationship between matter and culture especially helpful in my attempt to understand the denialist position in the debate

---

3 In Marshall’s article in *Social Science and Medicine* she does not mention President Mbeki, but her website reads: “I am also committed to research on health disparities and on developing an analysis of the role of structure and culture in the production on health and disease. Along these lines I have been conducting textual analysis of the discourses on AIDS in Sub-Saharan Africa that originate in the West. I continue to be fascinated by Thabo Mbeki’s critical stance toward western medical knowledge, and to the firestorm of controversy this stance has engendered in the West.” (<http://www.virginia.edu/anthropology/wende.html>). I then found that Wende Marshall had signed the petition on the *virusmyth* homepage (<http://www.virusmyth.net/aids/>). The petition reads “In science, no theory should be immune from challenge, and debate over an issue affecting millions of lives should never be declared over. I support South African President Thabo Mbeki’s intention to investigate the definition, causation, treatment and prevention of AIDS”.

about access to ARVs. When Marshall engages in the otherwise necessary critique of the cultural meanings embedded in science and medicine, she allows no room for the material realities of diseased (African) bodies.

Seen from a material perspective, it might be useful to start from what works on the body. To ignore the material questions is to incur the wrath and ridicule of people who are living with HIV/AIDS on ARV treatment. It also constitutes a failure to attend to the activists who state that HIV causes AIDS, and to understand what they mean by their claim that “denialism is killing our communities” (<http://www.tac.org.za/community>). Instead the denialist argument emphasises that good food, nutrition and vitamins will keep you healthy. This is an argument circulated in the ‘HIV does not cause AIDS discourse’.

Marshall’s position excludes the knowledge of South African AIDS activists and AIDS sufferers, and especially the knowledge of those activists who fight against denialism and who are in favour of mainstream science. She also assumes that the unquestioned hegemony of Western medicine that she refers to is equally powerful in all contexts. On the contrary, the TAC has, over the years, put much time and energy into defending science from the critique of it by government: “Defend science, Defend government’s antiretroviral programme” ([http://www.tac.org.za/newsletter/2005/ns19\\_04\\_2005.htm](http://www.tac.org.za/newsletter/2005/ns19_04_2005.htm)).<sup>4</sup> When Marshall writes about “the generally unquestioned hegemony of scientific knowledge production” (2005:2515), or “how the discourse on HIV/AIDS valorises Western scientific logic” (2005:2516), she renders the different struggles of treatment activists (especially in a post-colonial context) invisible. Activist knowledge enables us to have a broader perspective on the whole discursive field. When Marshall questions the hegemony of Western science she simultaneously constructs science as Western. As I have argued, activist discourse seems to be particularly good at questioning such harmful oppositions:

---

4 TAC has, for many years, fought against Matthias Rath, the German “alternative medicine seller” (Geffen & Gonsalves, 2008) or “pharmaceutical proprietor” (Geffen 2006) who aggressively advertises his multivitamins while arguing that ARVs are ineffective and harmful (Geffen 2006). The Rath Foundation has placed large advertisements in several national South African newspapers and has advertised its multivitamins in South African townships via so-called ‘Astroturf’ lobbying groups. Astroturf lobbying groups are apparently grassroots organisations that are actually created by corporations (Youde, 2006). One such group is called the Treatment Information Group (TIG). The name, graphics, and layout of their pamphlets are similar to the TAC’s style. Someone who is familiar with TAC could mistake a TIG pamphlet for a TAC pamphlet. Furthermore, Nathan Geffen (2006), a TAC activist and researcher, has shown how Rath’s ‘pseudo-science’ has been state sponsored in South Africa.

Africa, Asia (particularly China, India, Iran, Egypt), Europe, North and South America, as well as the Pacific have contributed to science and medical science. The best of all our knowledge in the sciences such as medicine, chemistry, mathematics and engineering comes from all these traditions.

– Zackie Achmat, Speech at TAC march, University of Cape Town, 06.09.06

Furthermore, activists highlight the fact that medical knowledge about HIV/AIDS is a collaborative project, which is developed through the exchange between activist knowledge and medical expertise, as will be discussed in Chapter five. As I argued earlier, activist discourses also question the binary between the health effects of social structures and the use of medicine. Of course, poverty and global economic structures are crucial in analysing the epidemic. But if an analysis of these structures excludes a discussion of the role of medicine in relation to a disease, it also excludes the material realities that people live in: it overlooks the central point that disease affects peoples' bodies. The activist discourse, with its emphasis on treatment, has made this point clear. One activist stated:

On the 25<sup>th</sup> of April 2001 I got sick. Not because of poverty, but because of my viral load [audience laughing and clapping].

– Thirty-something woman, TAC/COSATU National Treatment Congress, 27-29.06.02, Durban

She continued to explain that, because of financial problems caused by her husband “who just ran away with the money and the medical aid”, she could not afford treatment for a while. In this example, we can see how poverty, access to treatment, and gendered structures all play a role in her life and how all of these influenced her health. The importance of medication is especially clear on an individual level. Without access to treatment, a person infected with HIV has a greatly reduced chance of survival. Mandisa Mbali makes a similar point:

At a microbiological level, Western biomedicine provides a powerful model for understanding the direct physical causes of disease and developing effective treatments, preventative methods and cures

for them. Such rights based and Western biomedical models will have to be used to devise rational government policy to alleviate the very real human suffering that the epidemic is causing.

– Mbali, 2004: 117

I conceptualise both ARVs and the HIV-virus as material phenomena that interact with their environment. Karen Barad describes the relationship between culture and materiality in useful ways. She argues that “Language has been granted too much power” (2003:801) in social science research. Sari Irni (2010) takes up this point and suggests that this is a result of the post-structuralist focus on language and discourse. Matter is regarded solely as a form of cultural representation or a question of language (Barad, 2003). “What compels the belief that we have a direct access to cultural representations and their content that we lack toward the things represented? How did language come to be more trustworthy than matter?” (Barad 2003: 801). She writes “matters of ‘fact’ (so to speak) have been replaced with matters of signification” (Barad 2003:801). The importance of Karen Barad’s work is that it helps to conceptualise and analyse the ways in which the materiality of the virus is linked to the various meanings attached to HIV.

One of the most quoted phrases that I have encountered during my study on HIV is Paula Treichlers’ (1999:1) explanation of AIDS as “an epidemic of signification”. Stacy Alaimo and Susan Hekman (2008) claim that even though in the last years there has been much scholarship on ‘the body’, nearly all the work has been confined to analyses of discourses *about* the body. Discursive critique is important, but these bodies have diseases that are subject to medical interventions that may or may not cure them (Alaimo & Hekman, 2008). Alaimo and Hekman (2008) further insist that we need a way to talk about bodies in order to engage with medicine or science in innovative, productive and affirmative ways. Otherwise, the engagement will just lead to the well-worn path of negative critique (see also Peltonen, 2009). In the following quote, Marshall, who is one actor in this debate, criticises medical science, but disregards the importance of the pharmaceuticals for the suffering patient:

My point here is that this peculiar scientific emphasis on pharmaceuticals as the single means of disease eradication places

scientists in the implausible position of supporting one magic cure after another, which have never (at least not yet) materialized.

– Marshall, 2005:2520

However, both those who have begun ARV treatment, as well as health care workers, do indeed describe ARVs as a ‘miracle’ or even a ‘magic’ cure. Where HIV was initially considered to be a death sentence, ARVs have altered its status to that of a chronic disease. The activists strongly argue for ARVs and medicine using expert medical language. The following extract from a radio debate, where Nathan Geffen from TAC explains the efficacy of ARVs, illuminates this point:

When your CD4 count drops below 200, there’s a 35% chance that you will survive three years, without treatment. If you go on to anti-retroviral treatment that chance of survival goes up to 80%, and I think that statistic, which is based on a large sample of people and has been confirmed in other studies and other anti-retroviral centres throughout the country and around the world, demonstrates unequivocally that anti-retroviral treatment is very important once people get Aids.

– [http://www.tac.org.za/Documents/Court\\_Cases/Rath/Defamation/modise.html](http://www.tac.org.za/Documents/Court_Cases/Rath/Defamation/modise.html)

TAC activists have adopted a medical and statistical language in order to show that medicine makes a difference. Zackie Achmat writes: “Our work as treatment activists must be based on evidence and data – we cannot advocate for AIDS treatment unless we understand and operate on rigorous principles of analysis based on hard facts” (Email to TAC activist list, Zackie Achmat, 06.12.06). The importance of ARVs is also underlined by the repeated testimonies of TAC activists who have been sick, suffering or almost dying, but now, because they are on ARVs, live a ‘normal life’. People living openly with their HIV-positive status are essentially living examples of the fact that HIV exists and that ARVs work. Emphasising ‘hard scientific facts’ however could undermine a valuable aspect of the campaign: the message that the HIV/AIDS epidemic is also political (Oinas & Jungar, 2008). Oinas and I (2008) argue that the argument for a biomedical intervention need not resort to the argument that medical knowledge is the only and highest authority. When science is

represented as the ‘truth’, it becomes vulnerable to denialist views which quite rightly challenge this claim. For an example of this vulnerability, consider a document that reflects Mbeki’s denialist discourse:<sup>5</sup>

[...] there are many unanswered scientific questions about the HIV/AIDS thesis and many hypotheses about this matter that are falsely presented as facts.

– Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and Statistics: HIV/Aids and the Struggle for the Humanisation of the African, <http://www.virusmyth.com/aids/hiv/ancdoc.htm>

It is clear that the emphasis on hard facts is a rhetoric that TAC uses when countering denialist arguments. In other contexts, when the TAC is addressing HIV on personal, national and global levels, the focus is shifted to a wide range of political issues: “Our bodies are the evidence of global inequality and injustice” (Zackie Achmat, 2004). If Barad’s theory is applied to illness, it would show that illness is not only a question of the bodies of individuals, but that individual health is a result of technological, materialising and ‘meaning making’ practices (Irni, 2010). Although HIV can and should be read as “an epidemic of signification”, I argue that Barad can be helpful in emphasising that HIV is also about matter, not just about “culture”.

## Rethinking medicalisation

The South African government’s position on HIV responds to a particular discursive context. The politics and activism of the TAC is an effort to alter these discourses. The feminist and post-colonial critique of ‘medicalisation’ is another example of a politics that sets out to alter these discourses. The term ‘medicalisation’ is used to refer to a complex process through which a phenomenon is defined in medical terms, usually as an illness or a disorder, and is then often treated by means of a medical intervention (Oinas, 2001; Riska, 2003; Ahlbeck-Rehn, 2006). Medicalisation has been widely debated among sociologists, health researchers, feminists, and others. The term became popular in the 1970s and was used to describe the fact that several health problems that were understood in medical terms were actually socially based

---

5 This is a “long, rambling and vitriolic document” (Posel, 2005:143) with disputed authorship, but which is alleged to be closely associated with Mbeki (Posel, 2005). In a biography Mbeki did not directly claim authorship of the document, but said it reflected his views (Gevisser, 2007).

(Zola, 1972). Feminist health researchers participated in this debate from the beginning and they highlighted the fact that women in particular, especially concerning their reproductive capacity, were vulnerable to the expansion of the practice of medicalisation (Ehrenreich & English, 1978). Feminist health researchers understood the medical establishment as an extension of patriarchal society, making medicalisation a form of patriarchal control over women (Ehrenreich & English, 1973; Oakley, 1980). Feminists especially criticised the fact that it was easier to medicalise a problem than to tackle the social circumstances around it, or indeed to create social change (Ettorre & Riska, 1995; Oinas & Ahlbeck-Rehn, 2007).

At first, medical professionals were seen as the prime agents of medicalisation (Conrad & Schneider, 1980). More recently, researchers have shown how doctors have become subordinate to the pharmaceutical industry, which, together with consumer interests, has been largely responsible for promoting medicalisation (Conrad, 2005; Rose, 2007). For example, Peter Conrad (2005) argues that medicalisation is today more driven by commercial and market interests than by medical professionals. "Marketing diseases, and then selling drugs to treat those diseases, is now common in the 'post-Prozac' era" (2005:6). Another important turn in the analysis of medicalisation took place in the early 1990s, when the perception that health care was driven by a powerful medical profession which dominated the lay society of passive and helpless patients, was questioned (Lupton, 1997; Oinas, 2001; Ahlbeck-Rehn, 2006).

The fact that women were seen as a homogeneous group by feminist health researchers was pointed out by black feminist scholars (Davies, 1982). Early medicalisation theories often built on the assumption of a unitary category of 'women' as heterosexual, white, middle class and European or North American. Stereotypical assumptions about 'women' in the discourse on medicalisation meant that women who did not fit into this category were not recognised (Beverly Smith, 1982). For example, black feminists in the US argued that enforced sterilisation was as much of a pressing question for black women as the right to abortion.<sup>6</sup> Charis

---

6 "During the 1960s and 1970s, thousands of poor black women were coercively sterilized under federally funded programs. Women were threatened with termination of welfare benefits or denial of medical care if they didn't 'consent' to the procedure. Southern blacks claimed that black women were routinely sterilized without their consent and for no valid medical reason" (Roberts, 2000, <http://www.gutmacher.org/pubs/journals/3209200.html>)

Thompson (2005:59) has pointed out that when feminist writings (between 1984 and 1991) on reproduction “had any global dimension, they tended to deal with contraceptive technologies for the fertile Other and conceptive techniques for infertile Westerners.” However, there are still very few critical accounts which question the focus on whiteness or heterosexuality in the debate on medicalisation. Accounts based on diversity are even rarer.

Today, women’s own participation in the medicalisation process is being addressed (Lupton, 1997; Oinas, 2001; Thompson, 2005). Feminist health researchers no longer regard medicalisation merely in negative terms. Yet, the important critique of medicalisation offered by feminist health researchers continues to be relevant. This ethnography of the TAC is a contribution to the medicalisation debate. In article two, ‘A Feminist Struggle’, Oinas and I write:

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 medicalisation; a transfer of power from people to experts; a technical solution to social problems (Lupton, 1997; Oinas, 1998). 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.

– Jungar and Oinas, 2010:185

The TAC stance here can be read as an argument against a dichotomy between biomedical versus social interventions. As discussed earlier in this chapter, a discursive critique of ‘the body’ might sometimes miss the material dimensions of sickness and disease. It is important to note that a non-contextualised critique of medicalisation can easily evolve into a ‘denialist’ discourse. Frank (1990) argues that all criticism of medical praxis should take the crucial importance of institutional medicines for suffering patients as its founding premise.

The TAC’s struggle also questions another assumption about medicalisation. When poor women in the global South rally for access to medical treatment, they fundamentally challenge an

understanding of medicalisation which is seen to be about controlling women's bodies. On the contrary, the call for access to medicines is a critical demand for change in an unequal world order.

Discourses on medicalisation influence debates and discussions around access to HIV medicines in South Africa. One such example is the debate between TAC activists and the former South African government. In particular, South Africa's former president and minister of health could be seen as citing or mobilising a critical stance on medicalisation, in that they argued that poverty and non-nutritious food are the reasons why people fall sick with AIDS. In the denialist view, poverty rather than the lack of access to medication causes illness. In this sense, there is a resemblance between the former president's and health minister's arguments and early feminist critiques of medicalisation; in both cases, the arguments focussed on the relevance of social circumstances for health, but failed to acknowledge the importance of medicines to prevent suffering or dying.

Academic accounts of medicalisation are surprisingly silent on issues concerning access to medicines for poor people. For example, Peter Conrad, who is often cited in discussions on medicalisation, does not discuss access to drugs on a global scale. When global inequality is not discussed in the medicalisation debate many issues such as availability and affordability of drugs, which would actually lead to a deeper understanding of medicalisation, become invisible. This critique also applies to the feminist medicalisation debate. Feminist health research has put forward an important critique of the way in which the medical profession may control women's bodies, but it seems that this approach has made it difficult to discuss both local and global inequalities in access to health care. Thus an analysis that restricts itself to the politics of race and gender may serve to obscure the equally powerful forces of global economics.

The figures of the often poor and unemployed HIV activists in the South African townships who protest against unfair patent laws and demand access to medicines do not feature in feminist writing on medicalisation. From a global post-colonial perspective, the questions raised by these activists about unequal access to medicines and health care, highlight global power structures. In this way, the socio-political aspects of medicalisation become manifest through

activist campaigns, in contrast to the claim that medicalisation makes social structures invisible. Feminist researchers in health and illness have not discussed the privilege of health care, or showed consequences for those who do not have access to health care (Jungar & Oinas, 2003). Feminist health scholarship needs to continue to be critical of the tendency of the medical establishment to biologise social problems and to control women's bodies. At the same time, in the global South, the AIDS activists call for an urgent rethinking of inequalities in access to health care. Economic aspects cannot be avoided when confronted with multinational pharmaceutical companies' patent rights. I argue therefore that an analysis of the South African HIV activist discourses foregrounds the potentially positive role of medicalisation, as well as the need for a politics around access to medicine; points which raise urgent questions not only in the field of responding to HIV/AIDS, but also for the debates and theories of feminist health research (see Jungar & Oinas, 2003).

In this chapter, I have set out the positions taken by the South African government and TAC activists in relation to HIV/AIDS and antiretroviral treatment. The chapter then showed how activist discourses not only challenge the 'denialism' of government politics, but also challenge what could be called social science 'denialist' views, in which the material impact of medication on the virus is given less significance than an analysis of social conditions, culture and discourse. To conclude, the chapter argued that TAC activism forces one to rethink the important, but sometimes problematic medicalisation critique in health research. In different ways and in relation to different actors and discourses, this chapter has shown how TAC activism brings questions of matter to the agenda, not only in connection to HIV and global politics, but also in connection to HIV and social theory.



Cape Town 2003

---

### 3. Method and Material

## An ethnographic study of the TAC

Most of the ethnography on TAC was conducted in Cape Town and included participant observation at rallies, at national and international conferences, official meetings, workshops, public funerals, church services, and marches. The speeches, testimonies, discussions and songs at different events, about forty in all, from 2000 until 2006, were recorded and transcribed.<sup>1</sup> All the events were either organised or co-organised by the TAC. My material also consists of interviews conducted with six key informants, all women activists and volunteers, one of whom was an employee in the organisation at the time. Public TAC documents, newsletters, the web page, the internal e-mail list, Facebook profiles, You Tube clips and media coverage of TAC activities also constitute part of the empirical material. The empirical material for one article in the thesis is a collection of popular texts from and about the commercial AIDS campaign 'Product Red' (for a description of the campaign see page 11)

My interest in social movements grew from my activist involvement in a women's helpline in Finland, and from an interest in research on women's health. While studying Women's Studies in 1999–2000 at the University of the Western Cape, in Cape Town, I came into contact with the TAC, and was, although very briefly, involved as an activist in the organisation.<sup>2</sup> From August 2002 until September 2004, I was employed as a PhD Student in the research project 'HIV, Knowledge and Power' financed by the Academy of Finland (79687) and led by Elina Oinas (PhD). When I first learned about the TAC in 1999, the organisation (founded in 1998) only had a few members. Today, there are over 20,000 registered members. To write about an organisation that grows and changes from day to day has been challenging. I have been frustrated at times at the slow progress of my own writing compared to the movement which has not only grown, but has also achieved major victories and goals during these years. In June 2011, TAC, Doctors Without Borders/Médecins Sans Frontières (MSF) and the Western Cape Provincial Government Department of Health

---

1 I am indebted to Nina Nyman and Hanna Lindberg for doing some transcriptions. Most of the transcriptions were done by me.

2 On several occasions, much later during my fieldwork, I considered getting involved as an activist in the TAC, but always decided not to do so. This decision was not an attempt to stay outside the organisation, and therefore to be supposedly neutral. The decision was rather based on personal time restrictions and constraints.

celebrated the tenth anniversary of the first public sector antiretroviral treatment programme in South Africa. TAC explains its agenda today in the following way:

Just like 10 years ago, TAC and MSF's work in Khayelitsha still provide a useful model for rolling out ARV treatment in high HIV prevalence communities. TAC's Khayelitsha office provides treatment and prevention literacy education, runs TB workshops, and helps run various support groups for the community. At the same time, the organization works to monitor public healthcare service provision to ensure that people with HIV/AIDS have access to appropriate services.

[...]

Through the implementation of peer educator programs, gender based violence advocacy and condom distribution, TAC Community Health Advocates with the help of Community Health Workers are working towards a better community understanding of HIV prevention and treatment.

– <http://www.tac.org.za/community/node/3079>

My analysis is informed by post-colonial and feminist theory as well as health research.<sup>3</sup> This chapter will describe the methodology of the study, and explore some of the questions that emerged from the ethnographic approach, such as the power and position of the researcher. Many of these questions have been at the core of feminist methodology debates for over two decades, and these have had a significant influence on my methodology here (Davies, 1982; Harding, 1986, 1993; Haraway, 1991, 1992, 1997; Spivak, 1993; Lather, 2001). Feminist theorists have shown that knowledge is always partial and situated in a particular context, and in this chapter I will reflect on the relevance of this understanding to the study of an activist movement in the global South. Situating and contextualising knowledge means that I articulate and map out different positions taken both by the researcher and the researched. I argue that the questions explored here are not only about HIV, or Africa, or activists, but also about interrogating my own position as a European, or Finnish, researcher. This process has helped me to develop a more complex and nuanced sense of the politics of social science research, and thus also enhanced my understanding of feminist practice.

---

3 I use discourse analysis to analyse the context as well as the power structures evident in the material. However, this is not strictly the only method of analysis that I use.

## Material

### *The interviews*

After conducting participant observation studies of the TAC during the first two years of the ethnography, I decided to include interviews in the empirical material. Many of the interviews went well and were the sources of valuable information. However I had a sense that information accessed via the internet, which contains numerous testimonies from TAC activists living with HIV, would have been equally fruitful. The analysis of the discourses around HIV/AIDS could have been conducted in Finland, simply by studying the TAC's web page, its newsletters, documents, documentaries, YouTube footage, media coverage, speeches, email lists, and so on. In that sense there was no real necessity to travel to South Africa for interviews, or for the participant observations for that matter.

Feminist ethnographic research has been the subject of some far-reaching critiques in recent years. Judith Stacey (1988), for example, argues that feminist ethnography risks even greater violation of the researched than the more distanced objectivity of conventional research methods. Doris Sommer (1994) describes the interview as a voyeuristic invitation to intimacy where the feminist researcher develops a relationship, even friendship with her informants and then departs. One of the interviews that I conducted could be described in a similar way. I felt that the activist whom I interviewed would have liked to have been my friend and I found myself responding accordingly. Jane Bennett (2009:54) writes that: "One of the most persistent anxieties in writing on feminist research involves the possibility of violation through the process of research, the likelihood of 'doing harm'". At times, the complicated and complex ethics concerning interviewing made a study based on material from the internet seem more attractive. At the same time, distance is no guarantee against violation. My analyses of someone's statements found on the internet might also 'do harm' if the person quoted reads the analyses and feels misunderstood, misinterpreted or even violated.

A striking aspect of my research has been that, even though my material consists mostly of participant observation, with six interviews being a very small part of the ethnography, the interviews seem to attract more interest from other researchers. They somehow stand out

in the material. It might be that interviews are seen as closer to 'reality', and as a more reliable reflection of 'the truth' or 'experience'. Another explanation is that interviewing as a method has a dominant position in social science research, and especially in feminist social science research. The interviews might be regarded as more 'scientific' than participant observation with field notes, and to have a 'personalised' connection to the researcher him/herself. Interviews may be regarded as the most authentic form of encounter with the subaltern subject.

When my co-writer and I submitted one of the articles on the TAC to an academic journal, the editor contacted me to ask if I thought that it would be a good idea to include an interview with the TAC's chairperson Zackie Achmat in the journal. The editor was hesitant because she thought that the TAC might not share the arguments and perspectives put forward in the article. The purpose and goal of such an interview was not clear to me. While it is clearly desirable that TAC activists and employees are interviewed and published, in this instance the voice of the activist would be there merely to ratify the arguments of the researchers. This appeared to undermine the strength of the TAC's independent arguments. I found it interesting that the article provoked such a response from the editor. It resembled the interest that researchers show in the ethnographic interviews in that, here again the presence of the activist is required to verify 'how things really are'.

The interviews, which were conducted in 2003, were unstructured, open-ended and thematic. Most of the interviewees are named in the study, by their request. One interview was conducted at my home, two at one informant's home, two at another informant's home, and one in a park in Cape Town's city centre. The interviewees were asked about themselves, and then I asked them to tell me what the TAC meant for them personally. Some interviewees were asked if they felt that there was space to disagree and change things in the TAC, and in some interviews I asked why they thought that there are so many women active in the TAC. Five of the activists interviewed were HIV-positive and were living openly with HIV in their communities. One activist was open about her status in her church and in her neighbourhood, one at her workplace, and two learners in their high schools; one had also spoken about her experiences on national television. These interviewees were asked about their experiences of living openly with HIV.

### *The ethnography*

In this study, I use a broad range of empirical material. Despite my reservations about ethnography, I must acknowledge that being present at TAC rallies, conferences and civil disobedience campaigns was central to developing an awareness of the issues, debates and the style of campaigning that characterise the movement. The initial contact with TAC was mainly via two key informants, Colwyn Poole and Taghmeda (Midi) Achmat. I met Poole at a TAC conference and Achmat at the University of the Western Cape where she was a student in gender studies. Both were TAC activists; Achmat was one of the founding members, and Poole was an employee of Doctors Without Borders/Médecins Sans Frontières (MSF) in Khayelitsha (a township outside Cape Town) at the time. Achmat was also one of the interviewees. Both Poole and Achmat were invaluable to my research. For example, at the beginning of the TAC campaign, not all the events were announced via email, but rather via the TAC branches. This meant that it would have been very difficult or even impossible for me to find out about these events without the information received via Poole and Achmat. They also suggested the interviewees. Most importantly, they both generously offered responses and opinions to my research questions.

The TAC conferences were often co-organised with trade unions, health care workers and religious congregations, which gave me especially valuable information. The conferences showed how the TAC educated its activists about everything from how the virus works in the body to how international trade law works globally. Additionally the conferences functioned as a way to recruit nurses, doctors, home-based care workers, congregational leaders, traditional leaders, unionists, and politicians into the TAC community. The conferences often included long plenary sessions, combined with workshops in smaller groups where themes such as ‘Why are prevention and treatment two sides of the same coin?’ (TAC/COSATU National Treatment Congress, 27–29.06.02, Durban) could be discussed in a small group and then presented in the plenary. Often, themes and questions were first discussed at conferences on a provincial level, to be brought for discussion at the national conference. An important role of the national conferences was to bring the often very strong and established HIV activism from the Western Cape TAC branches together with the less-established TAC branches from other parts of the country.

The TAC and Doctors Without Borders/Médecins Sans Frontières (MSF) started a pilot project in Khayelitsha to demonstrate that ARVs could be rolled out in Africa. TAC activism was very closely connected to MSF and their offices were located in the same building. MSF decided to establish an office in Khayelitsha, even though South Africa has a much better economic situation than the other countries which could have been considered. This was done because MSF realised the potential in South Africa for a strong health movement that could ultimately influence questions around access to treatment globally (Private conversation with MSF employee at TAC/COSATU National Treatment Congress, 27–29.06.02, Durban). Khayelitsha functioned as an important successful example in the Western Cape – or worldwide for that matter – as one activist phrased it (Interview with Nomfundo Dubula, 13.05.03).

The rallies and demonstrations were often very vibrant, loud events with slogans, songs and toyi-toying, but they also meant much time waiting around. The civil disobedience campaign meant hours standing or sitting in the streets outside police stations, hotels, churches, health departments and parliament. Sometimes there were sit-ins at a department where a few TAC activists were inside, but most of the activists stayed outside with very little information about what was happening inside. The TAC usually provided food, but sometimes the food arrived late and some people were hungry and tired because they might have been up since six o'clock in the morning to be in time for the transport from the townships that TAC had organised. Almost all these meetings closed with some kind of conclusion about the events of the day and the singing of the South African national anthem, *Nkosi Sikelel' iAfrika*.

The written ethnographical material has been used to enrich the analyses. I have both fortuitously found and sometimes searched for texts and video clips that relate to the ethnographic material from the participant observations and interviews. Although this is not always the case, sometimes the material found on the internet does not directly relate to the interviews or events observed, but rather to the questions posed in the study. Zackie Achmat is often quoted in this study. For most of the duration of the study, he was the chairperson of the campaign. For many years, even though he was sick and in need of ARVs, he refused to take ARVs until they were available in the public health care

sector. This obviously made him very visible in the media. Furthermore, he is articulate and expressive, and therefore easy to quote.

Even though I had key informants, it took me a long time to build up a relationship with the TAC. The TAC employees and activists were very busy and I was also careful –perhaps to an extreme – not to take up the time and space of the activists. One colleague who wanted to do fieldwork around mother-to-child HIV prevention in Khayelitsha said, when in Cape Town, that, “I have never been on the field where it has been so difficult to get to the field.” I thought it was a very accurate description and felt comforted that someone else had similar experiences. She asked me whom she could call at the TAC offices. I felt very uncomfortable and did not know what to answer. It was difficult after having built up a relationship with the organisation for years to give another researcher a telephone number and a name. My relationship with some TAC activists and employees was fairly established at the time, and if I had told her whom to contact and she had mentioned my name it would probably have meant that this person would have given time and space to try to accommodate her. This was exactly what I tried to avoid, because my ethics was not to interfere and take up the time and space of activists who were working ‘24/7 trying to save lives’ (TAC activist 18.06.03), not to mention dealing with journalists, donors and, during the years, more and more researchers. To explain this feeling to my colleague was uncomfortable, so I just avoided answering her. Today I agree that I was a little paranoid.

Most of the ethnography was done by me alone. In 2002, Elina Oinas joined the empirical study in South Africa for a period of three months, and again in 2003 for a period of six months. At one time, a research colleague from Finland visited Oinas and me in Cape Town, and she came along to a TAC hearing at parliament, although she was not involved in the research project. This was a very awkward moment for me, as I tried to be as invisible as possible in the field, and suddenly, because the hearing was small, it was overcrowded with Finnish sociologists. Once again, my reaction was perhaps paranoid, but it shows how fragile my relationship to the TAC often felt to me, and how self-conscious I was.

The feminist methodology class at Åbo Akademi University taught me that one ethical approach to research involved giving feedback about the findings of a study to the informants. My co-writers and I have, at times, sent article manuscripts back to TAC activists. This was done

randomly to people whom we thought might wish to comment before the article was published. This could have been done more systematically and with more follow-up. On several occasions, people have asked how the research findings are made available to the organisation. Over the course of time, the question has become almost amusing for me, since the TAC is a strong organisation that has no particular 'need' for my research findings. This is not to say that the TAC would not be interested in some of the findings, but I see myself first and foremost as writing for other academics. On one occasion, the bibliographic reference for the already-published article around male circumcision (article five) was sent to a TAC employee, accompanied by a letter explaining the main arguments in the article. This was because I thought that TAC's stance on male circumcision was problematic and that our article might raise some discussion in the organisation. I did not receive any feedback on the article, but I also did not follow up if the employee actually received the email.

### **'I have a house in Africa' – research, power and transnational relations**

The following quote is from a paper that I presented in 2007 in Sweden among feminist scholars:

I have a house in Africa, at the foot of Table Mountain. I was able to buy this house because of the steady income that I received from development aid research funding from the Academy of Finland. I therefore qualified for a loan in Finland. The first sentence above is a paraphrase of Isak Dinesen's (the pseudonym of Karen von Blixen-Finecke) memoir *Out Of Africa*, which starts with the sentence "I had a farm in Africa, at the foot of the Ngong Hills" (Dinesen 1937/1989:3). The position of the Finnish researcher in the 21<sup>st</sup> century is obviously very different from the position of the Danish Baroness in the 19<sup>th</sup> century, but at the same time there are similarities – both positions are related to a colonising continent. The colonial situatedness of contemporary researchers from the North is often discussed in research literature. The guilt feelings of anthropologists and sociologists are not new, but addressing our own complicity with neo-colonial practices is more rare, especially for researchers in a Nordic context (for two exceptions see Mikela Lundahl, 2009; Ulla Vuorela, 2009).<sup>4</sup>

---

4 Parenthesis added later.

For me, development money has also meant access to a big city like Cape Town, with good jazz concerts, theatres, restaurants, and shopping which are not available in my university town, Turku. My standard of living is, in many ways, higher in South Africa than it is in Finland. This of course means that the social gap between me and many of the people whom I am studying, who often live in shacks in the townships far outside of Cape Town's city centre, is wide. My house is located two kilometres from the city centre, in a former white working-class area. The houses in this area were built at the beginning of the 20<sup>th</sup> century and they have colonial features like Oregon pine floors, fireplaces, and sash windows.

The text above is the intentionally provocative opening of the paper on the problems of situatedness, difference, and power in feminist methodology. The paper fuelled a heated discussion and was referred to throughout the day, even when we were discussing something completely different. The comments and questions were very varied; some expressed irritation, some were curious and some were unenthusiastic. Questions arose such as: "Should you feel guilty if you have research as your main occupation, or should you only study certain themes?" "What if you study homeless women in Helsinki, do you need to write about owning a house?" "Did you spend enough time in the township, if you didn't live there?" "What about all South Africans, Nigerians and Indians living in the USA and travelling around the world nonstop as representatives of the 'Third world'? They have houses not only in Cape Town, but also in New York, Delhi and Lagos." "All TAC activists don't live in shacks, do they?" These reactions became interesting and important for me in various ways.

Some of my responses to these questions were: "No, I do not spend much time in the townships". "Yes, there are TAC activists who live in nice, even fancy, houses". "Yes, it may be relevant to write about your own home, if you write about homeless women in Helsinki". Although it is critical to be aware of power imbalances at work in the research process, I also argued at the seminar that guilt about the relative privilege of the researcher is not a reason to give up research. These comments revealed that the way in which I present my research topic establishes a dichotomous world, of the North and the South. To just talk about a hegemonic North is not fruitful, rather, we also have to look at differences within locations in the North. It is important to recognise differences, for example, between my position as a researcher at an anonymous small

university in Finland, and that of a researcher at Berkeley in the United States.<sup>5</sup> Relative power and privilege are always complex and need to be explored in the context of each specific situation. In the context of my research, for example, it is easy to construct an inaccurate stereotype in which only women from the North travel – within the North, to the South, or within the South.<sup>6</sup> Furthermore, in looking at the representation of Europe and Africa it is easy to construct Europe as a homogenously white and middle class society, which it obviously is not. African societies also include middle class and white communities.

Some Nordic feminist scholars who had been living and working in Africa for long periods, and who have strong networks and collaborations with African feminist scholars, found the argument in my paper offensive and provocative. They thought it was a pompous attempt at pointless self-reflection, and one of them remarked on its resonance with old colonial tropes of the lonely white woman in Africa, asking me, “Don’t you have friends in Cape Town?”

How does the call to be self-reflexive relate to the old guilt discourses? Is self-reflexivity connected to economics, and if so, how? Does the reader of my research project need to know that I own a house in Cape Town? Akosua Adomako Ampofo (2009:29) points out that self-reflection has an image of not being a “particularly intellectual exercise”, which according to her in part explains why many academics shy away from self-analyses. One might simply end up stating the fact about one’s situatedness. Does self-reflexivity then mean ‘acknowledging’ that I am a Finnish white middle-class researcher conducting research on mostly working-class poor African women, many of them living with HIV/AIDS, and that this might create some ethical considerations? Is it enough to state that there are power relations involved in research, or do I also have to acknowledge that I am implicit in these power relations? Is it not also the case that my position as a researcher to an extent establishes my relative privilege and authority? (Butler, 1993) Does this mean that I am more than just ‘implicated’ in them? The question is then: How do I go about this process of ‘acknowledging’ power relations and what are the consequences of this for the ethics of the project?

---

5 For an interesting discussion on being a Finnish researcher at a US university see Vuorela (2009).

6 Anu Hirsiaho (2005), who has written about Pakistani women’s biographies, points out that one of the most important lessons of the study was that South Asian women’s history is full of travels.

## The ethics of self-reflexivity as non-mastery

This study assumes that post-colonial feminism inevitably asks us to reflect on ourselves as researchers (Spivak, 1993). Feminist post-colonial theory calls for situated knowledge and urges us to reflect upon the practices of knowledge production (Salo, 2009). One of the most important lessons from post-colonial theory is that we continuously create ‘the other’ in our texts (Lewis, 2004). Gayatri Spivak (1993) asks how ‘the European’ re-invents herself or himself in the project of studying the African. We construct the ‘other’ through our analyses and debates about ourselves. Everything we say about ourselves also reflects on our view of ‘the other’. Achille Mbembe (2001:3) writes that “[...] Africa is the mediation that enables the West to accede to its own subconscious and give a public account of its subjectivity.” Spivak’s and Mbembe’s critiques suggest that (feminist) theorists in general should ask questions about the ‘others’ they construct in their texts. What are the implications of this lesson for health researchers? What are the implications when you carry out research about HIV/AIDS in an African context? And what does self-reflexivity mean in practice? The article ‘Beyond Agency and Victimization’ (article three) argues for example that research which focuses on the passive African victims of HIV/AIDS can be seen to construct Western selves, by contrast, as active and energised agents of their own destinies.

One of my colleagues was a bit annoyed after reading a first draft of this text and said “We want to hear about what you did and not about where you lived”. It is true that although my wish is to be self-reflexive, the danger is that this might lead to “egocentrism emerging from constant self-appraisal and self-reflexivity” (Miraftab, 2004:595), or it might provoke other researchers in “its insistence on the centrality of the (privileged) representing voice to the significance of the text” (Bennett, 2009:56). Situated knowledge implies challenging the truth claims of detached, disembodied observation in favour of located, partial and embodied understanding (Haraway, 1991). Everything that one writes has to be situated in a particular context, and one constantly needs to articulate the relative positions of both the researcher and the subjects of research (Haraway, 1997). Accordingly, my research attempts to foreground global power structures and economic relations, as in the case of my house, as well as the funding practices that enabled it.

While research funders might indeed have a sincere concern about

women becoming infected with, or living with, HIV in Sub-Saharan Africa, I argue that images and representations of Africa also play a role in generating funding. Here, the lessons of post-colonial feminist theory are relevant. In the US context, critics have shown how discourses on 'African AIDS' (Patton, 1997) are important in constructing the African 'other' as potential victim of the disease, while implying that North Americans are safe from infection. Discourses on Africa, which tend to represent it as a site of catastrophe, offer to their readers the promise of being part of a different world, one which offers the relative safety and stability of wealthier parts of the world (Patton, 1997; see also Gilman, 1988; Watney, 1994; Treichler, 1999). Furthermore, discourses on 'third world women' as oppressed and as victims serve as a way to construct Western women as equal or less oppressed (Mohanty, 1988).

These discourses might work in my favour in the case of research funding. To put it very crudely, the figure of the African female victim helps to support the image of the gender-equal, liberated Finnish woman (for a discussion on constructions of Finnishness through equality discourses see Honkanen, 2008; Tuori, 2009). How does one take this into account in the methodology and ethics of the research project? What effect might this have on my study? In this project, my aim is to deconstruct these discourses while being aware of the fact that they enable my practice. My research is unavoidably part of the very power structures that it aims to resist.

Patti Lather (2002) draws on Spivak (1993, 1999) when she writes about non-mastery as an ethical move. She is interested in the limits of reflexivity and the possibilities of non-mastery as a practice of constantly trying to take into account one's limitations, while simultaneously being aware of the fact that a full account of one's limitations is not possible. Non-mastery as an ethical move in this study means to constantly try to take into account limitations to the ethics of the research, but also to be aware that such an account is not possible. Taking into account the limitations of one's position means that one questions one's intervention, in this case the account of the TAC that I have created. I would argue that it is precisely the process of interrogating the conditions that enable and motivate my research project which constitutes its politics. (cf. Lather, 2002: 221).

However, in posing questions about my own intervention, about the ethnography, and about the process of analysis does not mean that

I consider my research results invalid or without value. Spivak (1993) argues that to be silent is not a solution. Anu Hirsiaho (2005) maintains that one cannot take the tropes of modesty and vulnerability too far. “A feminist needs her utopias and her subversive fairy tales, but then she must get back to work and make the best of the existing worlds on her laptop” (Hirsiaho, 2005:129). I argue that the results of the study become more valuable because of the attempt to question ethics and power; at the same time it is essential to record and publish the findings of the research. The value of my research does not lie in a belief in objective results, but rather in that it participates in a discussion around ethics and power in relation to the study (Irni, 2010).

In this study, at times the HIV activists are described as somehow ‘authentic’ and part of a ‘reality’ but at the same time, I am aware of the fact that my analyses, politics and methods simultaneously construct a particular narrative about the TAC (and myself). However, the TAC discourse should not be read as ‘the truth’ or as ‘the right’ testimony that comes from outside of the general discourse on HIV. This means that I need to discuss and problematise how these ‘authentic’ and ‘real’ activists are represented and used in the material. Spivak (1993) sees the deconstructive position as a way of saying an impossible ‘no’ to a structure that one intimately lives in. The power structures are present in the material research and in my own practices. My research shows that, to constantly question structures is essential in understanding HIV activism, social sciences and medical practices, as together they create ways of understanding HIV in a specific context.

### **Reading from the local**

In a study of TAC, one is also negotiating the tension in feminist theory between a feminist methodological (political) imperative to make women’s lives visible, and the post-structuralist critique of representations of women’s experiences (see Lather, 2002). How can one ethically and politically negotiate one’s wish for knowledge that one believes is located in certain positions held by others, without romanticising these positions? Ida Susser (2009) argues that while we need to take full stock of the agency and ingenuity of TAC, we must not romanticise it either. In the article ‘Beyond Agency and Victimization’ (article three), the co-writer and I discuss what could be called the ‘desperately seeking agency’ approach in social science HIV research.

The challenge is, in a way, to romanticise neither victimhood nor agency, for that matter. The article argues that TAC offers a radical way out of this often dichotomous thinking around victimhood and agency.

In the following section, I present an example of how TAC challenges the victim/agent dichotomy. I do this in order to make a methodological point concerning the relationship between situated knowledge and activism. During the anti-apartheid struggle, funerals were used as political sites and rallies. In the same way, TAC has made the funerals of TAC activists into rallies where activists wear their 'HIV-POSITIVE' T-shirts and thus make the cause of death open to the community. This is a way of de-stigmatising the disease.

The TAC has turned funerals and death beds 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 fetisizing theme to a mobilizing message.

– Jungar & Oinas, 2010: 183

The first TAC funeral that I attended was that of Queenie Qiza in 2000. She was one of the first women in a South African township who lived openly with HIV. She joined the TAC just some weeks after its formation in 1998, and later started a TAC branch in Gugulethu, a township outside Cape Town. The branch is today called the Queenie Qiza branch.

On many occasions Queenie and I marched together for HIV treatment. On 28<sup>th</sup> of November 2000 [actually while] dying in a shack Queenie wrote 29 postcards to President Mbeki. She appealed to him to implement a program to prevent mother to child transmission of HIV".

– Zackie Achmat, documentary, 'It's a Nice Country'

Qiza's life (and death), and her struggle for health and access to life-saving drugs for all poor people living with HIV in the global South sheds light on the effects of local, national and global power structures. Zillah Eisenstein (2004) writes that AIDS makes black bodies parade as victims in the world, but at the same time it is from here that democratic struggles and social justice can be written. Chandra Mohanty (2003)

argues that it is especially on the bodies and lives of ‘third world’ women that global capitalism writes its scripts. Accordingly, I read Qiza’s life as an example of how, by theorising her experiences, we can see how capitalism works through sexism and racism, but it also allows us to envision anti-capitalist resistance.

In 2003, 20 000 people demonstrated for greater access to antiretroviral treatment in Cape Town (‘Stand Up for Our Lives’ march to Parliament, 14.02.03). At the time, questions around ARVs were seldom discussed in studies on HIV/AIDS in an African context. Lindisfarne’s (2002:420) analysis of academic writing shows that “contrary to what many academics imagine, it would seem that academics *follow*, rather than lead, popular interests and concerns”. In the case of access to ARVs in Africa, researchers have definitely moved more slowly towards discussing and analysing the availability of treatment, than the activists have. In line with Lindisfarne (2002), Mohanty (2003) and Eisenstein (2004), I argue that the work of political and social movements of people living with HIV should be included in health research because of the particular situated knowledge that they possess. They are subjects in a double sense, subjected to knowledge and producers of knowledge (Foucault, 1978).

The fact that I am writing about people who have chosen to be activists, many of whom have publicly disclosed their HIV status to their families, to TAC meetings and in the media, gives direction to the ethical considerations of this study. The activists are part of a social movement and they are already engaged in analysing their own lives. That is, they constantly and critically reflect upon how their experiences have been constructed for them, and thus they are in a position to engage critically with the way in which my research constructs their lives too. People living with HIV articulate general interest and concerns, but they also have an ability to challenge and deconstruct normative representations of illnesses, health, gender and (hetero)sexualities. When Qiza writes to the president a few days before she dies, she challenges the view of ‘African AIDS victims’ and turns her struggle and death into a mobilising message.



Cape Town High Court, May 2005

---

## 4. A Luta Continua

## 'We have to use the same tools of [the] struggle'

On National Youth Day, 16<sup>th</sup> of June 2006, exactly thirty years after the Soweto uprising of 1976, I attended a rally in Khayelitsha, a township outside of Cape Town. For many South Africans, this is one of the most important national holidays. The rally was a march against violence against women organised by TAC, the Simelela Post Rape Care Centre, and Médecins Sans Frontières/Doctors without Borders in Khayelitsha. I arrived at the Site C taxi rank in Khayelitsha at ten o'clock in the morning. What immediately struck me was that there were many more very young people present than I had seen since I started to follow the TAC in 2000. The rally consisted mostly of young women, demanding improved health care services and a violence-free society. One of their slogans said: 'Break the silence, Rape is a community problem'. They were toyi-toying and singing old struggle songs with new lyrics.

In this chapter, I will show some parallels between the contemporary HIV activist movements and the anti-apartheid struggle. The slogan 'A Luta Continua', (The struggle continues) was the rallying cry of the FRELIMO movement during Mozambique's war of independence. As the title of a song, written by her daughter and popularised by South African singer Miriam Makeba, the slogan and the song were adopted by the anti-apartheid movement in South Africa. More recently, the song has been sung by TAC activists during conferences, rallies and demonstrations, as it was on that day in *Khayelitsha*.

The day before the rally a cartoon appeared in a local newspaper by South Africa's renowned political cartoonist Zapiro.<sup>1</sup> The image replicated the famous photograph of the dying youth, Hector Pieterse, being carried by a fellow student. Pieterse, at the age of thirteen, was gunned down in the Soweto uprising of 1976. Zapiro's cartoon depicts the same image, but with the words 'HIV/AIDS' written on the boy's T-shirt. The cartoon thus offers a pithy depiction of the new problems of the new South Africa. On one of the TAC's and the Congress of South African Trade Union's posters, the image of Pieterse was juxtaposed with the young South African boy, Nkosi Johnson (Fassin, 2007). The poster showed the two photographs, bearing the captions '16 June 1976. Hector Pieterse. Age 13' and

---

1 Jonathan Shapiro is known as Zapiro.

'1 June 2001. Nkosi Johnson. Age 12'. When Nkosi Johnson died of AIDS in 2001, he was well-known in South Africa after speaking at the Thirteenth International AIDS Conference in Durban 2000, where he asked President Mbeki to make ARVs available to all. As Fassin comments: "Both images represent symbols of the past and present struggles. Apartheid not long ago and AIDS from now on" (2007:3).

In the same way that the youth in Soweto 1976 were mobilising against Bantu education<sup>2</sup> the youth in Khayelitsha thirty years later are mobilising for change. Many of these young people have been affected by HIV/AIDS and violence against women, in one sense or another. They might have lost parents or family members due to HIV/AIDS, they might have a family member who is HIV-positive, and some of them are themselves HIV-positive, in some cases because they have been subjected to sexual abuse. Some of them are living openly with HIV in their communities and schools. The struggle is for issues that affect their daily lives. HIV/AIDS and violence against women are a regular aspect of daily life in their communities, in the same way that the apartheid-era school system had been.

The TAC draws from the legacy of the anti-apartheid movement, a history that according to Steven Robins (2004), provides the movement with an 'organisational memory' of how to mobilise people to work towards a progressive and democratic civil society. TAC activists often draw parallels with the anti-apartheid struggle. One activist explains:

When I was young, I was an activist. The late Matthew Goniwe taught us the politics of the struggle. I feel disappointed by the ANC government's response to AIDS. We have to use the same tools of struggle that Matthew taught me to use to fight for the rights of people with HIV. Nelson Mandela spent 27 years in prison so that each and every South African can have equal opportunities. This is why I joined the Treatment Action Campaign to force the ANC to live up to his promise.

– Lwazi P. Nontyi, [www.tac.org.za/Documents/](http://www.tac.org.za/Documents/)

NationalCongressDocumentation2005.doc

---

2 Black students in Soweto protested against the Afrikaans Medium Decree of 1974 which forced all black schools to use Afrikaans and English in a 50-50 mix as languages of instruction. On the morning of 16 June 1976, thousands of black students walked from their schools to Orlando Stadium for a rally to protest against compulsory Afrikaans-medium instruction in schools.



Cape Town 2001

The activist quoted here sees the TAC's struggle as a continuation of Nelson Mandela's and Matthew Goniwe's struggle for equal opportunities. He is also pointing to his own struggle history and his disappointment with the ANC today. The TAC's position in relation to the previous South African government under president Thabo Mbeki has posed a challenge to TAC politics. The TAC's leading figure, Zackie Achmat, has remained an ANC member, a stance which he declares in public. During their civil disobedience campaign<sup>3</sup> in which the activists accused government ministers of murder, the TAC simultaneously supported the ANC as the leading party. This dual position, in which the TAC both criticises *and* supports the ANC, requires sophisticated negotiation in order to be convincing. At an international conference, a former ACT UP<sup>4</sup> activist from New York said that they had never needed to be as sophisticated as TAC because they could simply oppose U.S. president George Bush

---

3 As the start of TAC's civil disobedience campaign in 2003, it demanded that a police docket should be opened to charge the Minister of Health, Mantombazana Tshabalala-Msimang, and the Minister of Trade and Industry, Alexander Erwin, guilty of homicide for failing to issue compulsory licenses. For a discussion of the politics of embodiment that informs the activist views, see Oinas and Jungar (2008).

4 AIDS Coalition to Unleash Power.

(Private discussion at the International Treatment Preparedness Summit, Cape Town, 2003)

The slogan, ‘Don’t Mourn! Mobilise!’ from the anti-apartheid struggle has been re-written in TAC’s struggle as ‘Mobilise and Mourn!’. In article two we write:

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.

– Jungar & Oinas, 2010: 183

### **The ‘HIV-POSITIVE’ T-shirt: Challenging the division between ‘us’ and ‘them’**

The TAC’s struggle has been directed against the government’s inadequate HIV/AIDS policies, but it has also, to a great extent, been a struggle against the stigma of HIV/AIDS. This has often meant an individual struggle for activists facing stigma and discrimination from partners, family, friends and the community:

A challenge that millions of South Africans faced throughout the late 1990s and early 2000s was that testing and disclosing one’s HIV status was taboo. We encouraged openness and debate on HIV in communities through our HIV-positive T-shirts.

– Vuyiseka Dubula, 10.12.09, TAC activist email list

The TAC maintains that, on an individual level, HIV/AIDS policies and discrimination are connected:

A Treatment Plan will help remove the stigma of HIV/AIDS. Making treatment available will encourage people with HIV to be open about their status, because the fear of death associated with HIV/AIDS will be reduced. If more people become open about their status, it will be more difficult to discriminate against people with HIV. Ignoring treatment will exclude and marginalize people with HIV.

– Forward to a people’s HIV/AIDS treatment plan! A Treatment Action Campaign Briefing Pamphlet, <http://www.tac.org.za/Documents/TreatmentPlan/tpbriefingsheet.pdf>

One TAC activist was distressed after having been in Berlin on International AIDS Day, 2002. According to him, the events were exclusively focussed on African AIDS victims, as if nobody in Europe had HIV or AIDS. In South Africa today many TAC activists are open about being HIV-positive and many testify that this has helped them to come to terms with their disease (*Fighting for our lives*, 2010). Moreover, it is easier for those who have declared their status publicly to gain support when receiving treatment:

I know how hard it is to reveal your status, but I also know how important it was for me. If I had not disclosed, I don't think I would have lived this long. I would have carried the burden alone. Disclosure is important so that people around you can offer treatment support. They can remind you to take your tablets and to go for regular check-ups at your nearest health facility.

– Nokhwezi Hoboyi, *Equal Treatment* - Magazine of the Treatment Action Campaign, <http://www.tac.org.za/community/>

The 'HIV-POSITIVE' T-shirts that are worn by infected and non-infected AIDS activists alike, and by other TAC supporters around the world, challenge the clear boundaries drawn between those who are infected and those who are not. This implies challenging commonly held stereotypes about who is likely to be infected, both within South Africa and in the global AIDS community, such as those that the TAC activist in Berlin encountered on AIDS day. TAC uses the T-shirt in order to politically demonstrate that anyone could be infected, or become infected, hence blurring the boundaries between the supposedly non-infected and the infected.

The TAC not only challenges the divide between the assumed non-infected and infected, but also the divide between the infected and the (medical) experts. This argument is developed further in Chapter five. HIV-positive activists who take part in the TAC's treatment literacy workshops learn about the HIV virus and CD4 counts, as well as the global structures which impact on health. In the following quotation, the knowledge of TAC activists is compared to that of some sociologists:

I went to a conference in Bloemfontein a few days ago. The discussion amongst sociologists was so terrible. They didn't even

understand HIV and they didn't understand medicines. Even in the poorest areas of TAC there are comrades in our branches who speak of HIV better than the professors can.

– Zackie Achmat, speech at opening of People's Health Summit,  
02.07.04

For the TAC an understanding of HIV/AIDS not only involves knowledge of the relevant political and social context (Robins, 2004; Jungar & Oinas, 2007), but also questions around discrimination like xenophobia, homophobia, violence against women, homo- and transsexuals, sexism, and racism. The TAC was one of the first organisations to mobilise in 2008 when African foreigners in South Africa were being harassed and attacked. In one march organised by the TAC fairly soon after the first xenophobic attacks, TAC activists were wearing T-shirts with the slogan 'FOREIGNER'. Here the TAC used the same tactic as they did with the 'HIV- POSITIVE' T-shirts in which activists assumed an identity in order to unsettle the boundaries between perceived 'categories' of people. In this case, the boundaries between those presumed to be South Africans and those presumed foreign were questioned.

In the article 'Shop and Do Good' the TAC is compared to the commercial campaign 'Product Red'. The brand's founding premise is that 'Good business is more sustainable than philanthropy' (Vanity Fair, 2007:222). According to Sarna-Wojcicki (2008), Product Red allows the consumer to connect their purchase to saving the lives of others. Salo and I argue furthermore that the consumers are told that they can change lives, as well as history:

First world consumers are told that what we choose to buy can change 'life and history on this planet.'

– Jungar & Salo, 2008:96

One Red campaign T-shirt, sold by the clothing company Gap, bears the slogan '2 weeks' in brackets, indicating that, if purchased, it will provide someone with a two-week supply of antiretroviral medication. By indicating that the consumer has bought two weeks of life, the campaign constructs a very clear line between the infected sufferer and the consumer who 'saves'. As we argue, "Western consumers are given an almost god-like power over the lives of



Cape Town High Court, May 2005

HIV-infected Africans” (Jungar & Salo, 2008:98). The Red campaign markets social difference. The Red T-shirt conjures up an image of Africa as a place of death and victimhood, and a corollary vision of the West as a vibrant, animated world which has the power to save. By contrast, the ‘HIV-POSITIVE’ TAC T-shirt makes it impossible to distinguish between ‘them’, the infected, and ‘us’, the presumed uninfected, and therefore also to distinguish between victims and saviors.

### **Celebrity appropriation of social movements**

In articles three and four, we analyse representations of African women in two very different contexts. In the article ‘Shop and do Good’ the context is – as mentioned – the commercial campaign Product Red, and in the article ‘Beyond Agency and Victimization’ the context is applied

research on gender and HIV/AIDS in Africa. In both contexts we argue that these discourses about African women emerge out of, and further sustain, discourses in the global imaginary about the bodies of African women, which are conceived of as being strong and resilient, but also constantly subjected to structural forces. Lately, much research has been done on so-called brand aid (Richey & Ponte, 2011), celebrity humanitarianism (Yrjölä, 2009) and celebrity philanthropic culture (Magubane, 2008) (see also Himmelman & Mupotsa, 2008). Riina Yrjölä (2009) argues that Celebrity Humanitarianism elaborates on a colonial imaginary by (re)producing Africa as a specifically Western project. Magubane (2008: 102) argues that the “‘White Man’s Burden’ [responsibility for the well-being of the world] ideology is making a comeback, thanks to the efforts of musicians, movie stars and models.”

In the field of HIV/AIDS activism, there are two significant examples of this phenomenon. Both the Product Red Campaign, and Annie Lennox’s campaign, SING, can be described as ‘Celebrity Humanitarianism’ which appropriates the work of social movements into the service of celebrity culture. As I will show later, Lennox’s campaign is especially relevant as it uses explicit images and footage of TAC activists. The TAC is also one of the beneficiaries of her campaign.

The Product Red brand is marketed in the image of a social movement (Sarna-Wojcicki, 2008). Consumers are told that by buying Red products they join a movement for change. This ‘consumerism’ is portrayed as voicing radicalism and dissent, yet the ‘activism’ is limited to the shopping mall (Sarna-Wojcicki, 2008). Often this is accompanied by images and language which display the flair of contemporary sub-culture. For example, one advertisement features the rapper Common:

This is the weapon to change. Converse weapon to change. It’s a movement. Red movement. You dig? We go do it. Do the music. And do Activism. Allright. Red is for the people.

- [http://www.converse.com/index.aspx?mode=c1#home\\_red\\_2007](http://www.converse.com/index.aspx?mode=c1#home_red_2007)

Paradoxically, in the quote above, Red consumers are constructed as joining a movement for change, although the workers who produced the products and want change in their working relations are not allowed to mobilise, as the clothing company Gap itself admits

<sup>5</sup>(see Engler, 2004). Stefano Ponte, Lisa Ann Richey and Mike Baab (2008) argue that Red can improve a corporation's brand without challenging its practices. To focus on 'distant' beneficiaries enables the Red companies to profit in a way that appears socially conscious, instead of extending this social consciousness to addressing the "problematic aspects of their own operations" (Ponte, Richey & Baab, 2008:4). Richey and Ponte (2011: 177) argue that this "is aid to brands", because the companies can boost their sales by building brand value.

Annie Lennox's SING campaign was launched in 2007, with the intention to give "a voice for HIV/AIDS, women and children"<sup>6</sup> (<http://www.annielennoxsing.com>). The money from SING goes to TAC and two other projects. The SING Campaign's second anniversary film includes footage of several TAC activists with their 'HIV-POSITIVE' T-shirts, but the TAC is never mentioned in this film (<http://www.youtube.com/officialSINGcampaign#p/a/f/0/v6N30ywPwt8>). Most prominent in the film is an image of Lennox with her arms around two TAC activists, all three wearing 'HIV-POSITIVE' T-shirts, accompanied by a voice-over in which she says: "The SING campaign is inspiring people all over the world". This representation of HIV/AIDS activism eclipses the specific campaigns of the TAC movement; instead the activists are shown to be participating in Annie Lennox's personal philanthropic campaign. In the third anniversary film, Lennox has manufactured her own 'HIV-POSITIVE' T-shirt with the SING logo on the sleeve (<http://www.youtube.com/officialSINGcampaign#p/a/u/0/GxKMLeZqsoE>). Thus Lennox appropriates the TAC movement, their characteristic

---

5 Gap states in their own report that they have not been able to track retaliation against workers trying to organise (Engler 2004).

6 The urge to 'save Africa' is clearly gendered, but also works together with the 'save the African children' discourse. The SING campaign talks about giving a voice to 'women and children', and Product Red generally invokes 'women and children', rather than men, as the ones who need to be saved. The Global Fund money goes to men, women and children. The money from the SING campaign goes at least partly to TAC, which means that it goes to men, women and children. Lee Edelman (2004:3) has pointed out that the appeal for the child "remains the perpetual horizon of every acknowledged politics, the fantasmatic beneficiary of every political intervention." According to Edelman, even proponents of abortion rights in the USA frame their political struggle, mirroring the anti-abortion, as a "fight for our children – for our daughters and our sons". The TAC also started a campaign for access to antiretroviral drugs for pregnant women to reduce the risk of transmitting HIV to newborn babies. One of the founding members explains: "It's a soft target, because [it's] mothers. If you [are] campaigning around mothers and saving babies obviously you are going to get the attention of each and every citizen." (Interview with Midi Achmat, 18.06.03)

T-shirt and images, and transforms these into the Annie Lennox brand. African agency becomes invisible as Lennox philanthropy becomes visible.

Among the many You-Tube clips about the campaign, there is a film called ‘The Treatment Action Campaign – The SING Campaign’ (<http://www.youtube.com/watch?v=tMgmaKhH038>). This film offers more information about the township of Khayelitsha than about the TAC. It also offers sweeping, often incomplete, statistics which show the suffering of black Africans living with HIV/AIDS<sup>7</sup>, but does not offer statistics, for example, about the high numbers of people on ARVs in Khayelitsha. It does not show the TAC as a powerful movement, or represent the work of its activists. Instead the narrative follows Lennox and a TAC employee visiting a woman who appears not to be open about her status and fears her partner. This focus on a ‘woman as victim’ in a narrative about Khayelitsha in 2010, with no alternative information about the work of TAC activists, constitutes an extraordinary refusal to acknowledge Africans as global agents of change. TAC testimonies reveal a different picture of life with HIV/AIDS in Khayelitsha:

On Friday, the 3<sup>rd</sup> of June [2011], TAC Khayelitsha will hold a 10 year anniversary celebration of the first roll-out of Antiretroviral Treatment program in the public sector of South Africa. Today there are 20,000 HIV positive individuals on ARV treatment in Khayelitsha alone and this anniversary celebrates those who have stayed with the HIV struggle from the beginning of treatment.

– <http://www.tac.org.za/district/?p=712>

Khayelitsha is the big place, known worldwide for its people that are living openly with HIV.

– Interview with Nomfundo Dubula, 13.05.03

### **‘TAC, the Swedish government and ACT-UP Paris’**

As discussed earlier, the TAC is constantly negotiating its relationship with the South African government, and, to some extent, with celebrities and rock stars. Furthermore the TAC also negotiates its relationships with other activists and donors worldwide. At one annual

---

7 This includes, for example, incomplete statistics about numbers of people who have access to clean water.

general meeting of the TAC, the discussions concerned international donors. The TAC was aware that at the time they were quite popular among international donors, but that this could change very quickly. Being dependent on international donors made the organisation quite vulnerable (see also Friedman & Mottiar, 2006), as explained in the following quote:

And although the Swedish government likes us now, if our government starts saying “we will not buy airplanes from you” or something, then TAC will be thrown away in five seconds.

– Mark Heywood, TAC Annual General Meeting, 04.03.05

Another important relationship for TAC is the connection with other activists globally. These relationships have been crucial, and many of TAC’s methods are a combination of especially ACT-UP’s New York demonstrations and ways of demonstrating that come from the anti-apartheid struggle. However, as an organisation, TAC is also vulnerable in this community to the ‘othering’ discourse that characterises discussions of African experience and African politics.

An exchange between TAC and ACT-UP Paris illustrates how the organisation itself can be constructed as an ‘African other’, even by its potential allies within the global community of HIV/AIDS activism.<sup>8</sup> The background to this rather confrontational exchange is a drug trial in Uganda and Zimbabwe that ACT-UP Paris campaigned against, raising concerns about ethics in the ways that the trial was conducted. ACT-UP Paris claimed, for example, that not enough information to potential participants in the trial was provided, there was no biological monitoring in clinics where such monitoring is available, and this situation therefore deprived clients of optimal care, with potentially harmful treatment interruptions for specific clients. The TAC wrote a detailed letter to ACT-UP Paris asking it to provide proof of its allegations against the trial (see also Geffen & Gonsalves, 2008). The TAC argued that ACT-UP Paris’s campaign against the trial was irresponsible and unethical, and provided a meticulous account of why the accusations against the trial were either untrue or without

---

8 Nathan Geffen and Gregg Gonsalves (2008) have written about other actions and campaigns by ACT-Up Paris which they argue are counter-productive, and even dangerous.

evidence.<sup>9</sup> The TAC further asked ACT-UP Paris to provide evidence for its accusations or issue a public apology to the researchers involved:

If Act Up-Paris chooses neither of these options, or continues to present confused arguments as evidence, the TAC regrettably will have no reasonable choice but to end any future partnership with Act Up-Paris.

– Letter to ACT-UP Paris from Zackie Achmat, TAC National Chairperson, and Siphon Mthathi, TAC General Secretary, 29.09.06

The TAC received a letter, but no response to its questions from ACT-UP Paris and consequently felt that it had “no choice now but to make our letter to Act-Up Paris public” (Letter from Zackie Achmat, TAC National Chairperson, and Siphon Mthathi, TAC General Secretary, 06.12.06). The reply from ACT-UP Paris to the TAC is revealing:

Act Up-Paris will never need TAC for AIDS activism in France (just as TAC is unlikely to ever need Act Up-Paris for AIDS activism in South Africa). Therefore, the prospect that there might never be any “partnership” between our two groups is not really distressing. Yet we are taking your letter EXTREMELY seriously. The reason is very simple: there are few AIDS activists in the world whom we admire as much as the two of you (and also because you have addressed us about this with the basic civility appropriate for communication between fellow activists, which other parties worth admiring didn’t bother to do).

– This email was received by TAC on 10.10.06 and attached to the email that TAC sent out on 06.12.06.

ACT-UP Paris claims that there are few activists that it admires as much as Achmat and Mthathi. It also says that it takes the critique extremely seriously. Yet ACT-UP Paris did not alter its position, or provide evidence for the allegations that it made against the trial. This contradictory discourse could be read as an example of an engagement with ‘the other’. The ‘others’ – in this case represented by Achmat, Mthathi and other black HIV/AIDS activists - are admired, but not listened to. Furthermore the TAC is dismissed as a potential partner with common interests, as ACT-UP Paris is convinced that it

---

<sup>9</sup> The trial is a key study of antiretroviral therapy in Africa called the DART trial, which has been conducted in Uganda and in Zimbabwe.

“will never need TAC” for its work in France. When describing the relationship from the perspective of the TAC, however, the phrasing is not as strong. The organisation claims that it is “unlikely that TAC will need Act Up-Paris”, without categorically stating that this will “never” be the case.

The TAC campaigns for access to medical treatment in an African post-colonial context. Globally, discussions of HIV/AIDS are characterised by conflicting discourses about medicalisation, which has been forcefully critiqued both by feminists and by post-colonial theorists. Global approaches to African HIV/AIDS are characterised by the perpetuation of the image of Africa as a continent of poverty and helplessness. The TAC argues that in this context, access to medication is a key starting point in addressing HIV/AIDS in Africa. The TAC needs to take a subtle and sophisticated position in relation to medical trials in Africa, which have a history of being imposed by colonial administrations, without regard to ethics. However, the TAC cannot allow an awareness of this history to force it into an anti-medicalisation position. The “irrational activism” (Geffen & Gonsalves 2008) of ACT-UP Paris shows how the conflicting discourses concerning ‘African AIDS’, anti-medicalisation and North-South relations can produce paradoxical outcomes which do not support the cause of HIV/AIDS activists in Africa. This chapter has highlighted some of the paradoxes for the HIV activists in a post-colonial context. It should be noted however that the TAC works closely with AIDS activists globally, and international networks have been crucial for mobilising and campaigning. The exchange with ACT-UP Paris is therefore not representative of relations to other activists.



March to Parliament, September 2006

---

## 5. Health and HIV Research Revisited

## 'AIDS is everything'

Post-colonial theory expands the boundaries of mainstream feminist thought on women's health by calling for critical 'intersectional' analyses of women's health, which take into account class, race, gender, sexualities, and colonial history. Such analyses of women's health enable us to see the way colonial and neo-colonial practices continue to construct non-European women in essentialising terms, often as inferior, subordinate others (Anderson, 2000). An intersectional analysis is not only aware of differences related to various social categories (such as gender, race, class, religion, disabilities, age), but also involves reflecting on the situatedness and personal investment of the researcher in creating these categories. Thus, post-colonial theory teaches us to be aware of how we understand ourselves in connection to, and through others (Lewis, 2004).

Edward Said's (1978) account of Western 'Orientalism', Chandra Mohanty's (1988) work on Western feminist research on 'third world women' and Gayatri Spivak's (1993) notion of 'the subaltern' all describe how writers, researchers and critics in the West construct themselves through a process of 'othering'. Post-colonial thought has dramatically shifted the ways in which we think about power and knowledge production. A feminist post-colonial perspective on women's health not only offers an understanding of health and social inequalities, but it will also fundamentally alter the ways in which health is defined and theorised in so-called mainstream feminist theories.

The discursive field of HIV/AIDS research in a post-colonial context is complex. The intertwined sites of death, illness, sexuality, medicine, poverty, globalisation, gender, femininities, masculinities, and nationalism, construct an almost explosive field of competing investments. Silence, negligence and political apathy are also features of the discursive landscape (de Waal, 2006). Post-colonial theory is helpful in deconstructing and understanding the discourses that shape what we have come to understand as HIV/AIDS. Post-colonial theory reveals the ways in which these discourses construct 'us', those who write and speak about the disease, as distinct from the 'infected others'. This is what Paula Treichler means when she argues that "The AIDS epidemic is cultural and linguistic as well as biological and biomedical" (Treichler, 1999:1).

Sipho Mthathi, TAC's general secretary during 2005, has argued that: "AIDS is everything. It is political. It is social. It is economic. It is

not only a health crisis” (Sipho Mthathi, TAC general secretary, TAC Annual Report 2005/06). A similar idea can be found in social science when Didier Fassin (2007:35) argues that “Health care policies are not only about health”. The TAC’s chairperson Zackie Achmat has also argued that our bodies are the evidence of global inequality and injustice and serve to represent the relationship between inequality and disease. Moreover, infected bodies can become the sites of political resistance (Zackie Achmat, John Foster Lecture 10.11.04).

These statements can be aligned with a post-colonial as well as a post-structuralist critical perspective. This not only involves an analysis of AIDS as a disease, or a health issue, but also of the construction of power and meaning through an intersectional approach. The TAC itself describes its politics as inspired by post-structuralism, stating that: “Foucault’s ideas about the principles of truth and power continue to inform TAC’s approach to politics” (Treatment Action Campaign, *Diary* 2008). In addition to the fact that the TAC’s analysis of power could be described as post-structuralist, one could argue that the TAC’s politics are also in line with what Gayatri Spivak calls ‘strategic essentialism’ – this involves a strategic adoption of an identity or a position, which enables effective campaigning for political change (see Oinas & Jungar, 2008).

In this chapter the work of the TAC is contrasted with some general discourses in social science health research on HIV/AIDS in Africa. Firstly, the chapter introduces the concept of collaborative medicine which, I argue, is a core part of the TAC approach. Then it discusses the dichotomy between prevention and treatment on the one hand, and the individualising behavioural change approach on the other hand. The chapter argues that these two discourses in social science begin to flourish when HIV/AIDS is not contextualised, problematised, and analysed in connection to power structures.

## **Collaborative medicine**

Activist discourses often introduce new, unfamiliar concepts, which appear to arise from within the activist work itself. This suggests that the situated and materially-anchored nature of activist engagements drives the production of new knowledge and insights that move beyond the strictly ‘textual’ field. The work of the TAC, for example, has introduced me to, and developed my understanding

of, the concept of *collaborative medicine* (Jungar & Oinas, 2003). This refers to a practice in which medicine is not seen as the domain of experts alone, but also as constituted by lay knowledge and understandings. For example, activist work at times creates a social space in which a meaningful dialogue between expert knowledge and lay knowledge becomes possible. I read this as a radical new form of relationship that dislocates hegemonic ideas of the knower, the patient, and the expertise (see Jungar & Oinas, 2003). New ways of negotiating knowledge and health practices can be found in the everyday lives of the activists, such as when a TAC activist says that she or he needs to discuss her/his treatment regimes with the doctor, but also campaigns globally to ensure that she or he has access to the treatment.

The TAC is a movement that both campaigns for access to drugs, and in that sense strives for medicalisation, but at the same time critiques aspects of medicalisation. The TAC defies the prevailing free-market ideology around medicalisation when it campaigns on a global scale against unfair patent laws that profit pharmaceutical companies. At the same time, it campaigns for the manufacturing, licensing, and parallel importing of affordable generic drugs, especially for distribution to people in the global South.

In their campaign for medical treatment, TAC activists question the assumed dichotomy between nutrition and treatment as stated by the former president and former minister of health:

No-one denies the importance of nutrition, both for people with and without HIV. But nutrition is not an alternative to medicines; for people with HIV, both are needed. Nutrition cannot be simplified to a few products, such as the vegetables promoted by the Minister. For most people in South Africa faced with food insecurity, the key challenge is not whether to eat chicken or beef, lemons or beetroot. The challenge is for poor people to have enough money to buy sufficient healthy food to eat.

– TAC’s million dollar petition, September 2006

Here the TAC challenges the ‘false’ dichotomy between nutrition (read as related to poverty and thus as a social issue) and access to medicines. The TAC also challenges the division between lay and expert knowledge in that the movement defines an ‘own’

knowledge of HIV (focusing on collaboration), which, at least partly, is different from the medical, 'expert' knowledge about the illness. Health researchers have, especially in more recent writings on medicalisation, focused on the fact that patients are not simply passive victims, receivers of 'health' from others, but rather actively involved in their own medicalisation (Oinas, 2001; Ahlbeck-Rehn, 2006). The TAC emphasises medicine as a collaborative movement between researchers, health care workers, communities, and people living with HIV. This emphasis is crucial in that it enables the shift in perspective that overcomes the established dichotomy between medical experts and patients in research by contextualising medicalisation (see Oinas & Jungar, 2008). Here, one activist living with HIV explains the importance of collaboration to fellow activists and patients on ARVs:

It is very important to notice everything that is going on in your life when you are taking the drugs so that you can go immediately to report it to the nurse or doctor. *Then you and your nurse and your doctor can decide what to do to stop that particular side effect.*

– Matthew Damane, *ARVs in our life – a handbook for people living with HIV and treatment advocates in support groups, clinics and communities*, <http://www.tac.org.za/community/>, my emphasis

Patients are empowered to negotiate their treatment based on the knowledge that they have about HIV. Studying activism enables us to see how a social movement can alter the customary 'expert-patient' power relationship; furthermore it shows in what kinds of situations knowledge becomes empowering and therefore contributes to improved health. The social movement empowers activists/patients to become experts on their own health:

Even I demanded acyclovir from the clinic in Bisho in June. I was caught by high fever. I developed herpes around my mouth. They took me to Bisho hospital and they gave me anti-fungal tablets. I said it's a viral infection, not a fungal one. She said because you are HIV+, the only thing you must be given is Bactrim. I said that's only for people on stage 3. I went to the village clinic, we argued about the dosage but in the end they gave me what I needed!"

– Nocawe Jijimba, TAC Treatment Literacy Trainer, Oliver Tambo District, Eastern Cape, TAC Annual Report 2005/2006

Jijimba finally received the right medication and dose, but he had to go to another clinic and argue for what he needed. This example is from a rural area with deprived health care services, but the patient is not ‘passive’ or ‘helpless’ in the face of medical incompetence. This example may even suggest that under-trained health care workers may be educated by such encounters with knowledgeable patients. In this instance an activist, who is also a TAC employee, teaches the health professionals about medications for opportunistic infections. The initial confrontation between them leads to a dialogue, which might promote changes within the health care system. At the very least, the quotation shows how the collaborative approach to medical knowledge within the activist community challenges existing ideas about “expertise”.

### **Behavioural change – a heteronormative colonial HIV prevention project**

This section examines some discourses in social science prevention research. I will contrast these discourses to TAC arguments on effective prevention. I first examine the recent trend in prevention research which focuses on men and masculinities. The argument is that the focus on (male) sexual behaviour enhances the notion of individual responsibility; furthermore it also suggests a possible connection to a ‘civilising mission’ with connotations of a colonial project. Lastly, the argument is that in much prevention research, infected people and gay people are excluded.

The vulnerability of young women and girls is a key concern in HIV prevention work. Economic circumstances, cultural scripts around passive female sexuality, along with dominant ideas about heterosexual masculinity, rape and sexual violence, colonial history, and apartheid history, are some of the factors relevant to the work on HIV prevention. In spite of the stated importance of the focus on young women in particular, much prevention research incorporates a general well-meaning ‘gender-sensitivity’, and thus argues for a need to focus on men and masculinities. It is argued that the failure of HIV education programmes is caused by the silence on issues of masculinity (see for example Thorpe, 2002; Pinkowsky Tersbøl & Silberschmidt, 2003). Rather than critically examining the effects of male dominance, what I call prevention research argues that a change

is needed in the way that men practise their domineering role. This point of view posits an ‘enlightened ruler’ logic according to which men should learn to exercise their power responsibly, and argues further that HIV prevention interventions have an opportunity to foster new forms of behaviour for men (see Morrell et al, 2002).

The focus on men in research literature can be explained by the history of prevention work. Involving men was an attempt to move away from the tendency to place the responsibility solely on women and girls and to make boys and men responsible for their sexual practices (Epstein et al, 2004). It is important to keep this background in mind when analysing accounts which focus on men, in order to show that empowering the already-powerful is not the intended effect of the research.

This focus on masculinities can also be traced to a mission to ‘civilise the African man’. According to Ronald Frankenberg (1996), HIV research opened a field that again made it legitimate for researchers to study African sexual behaviour and African sexual cultures. It is quite obvious that this field of study runs the risk of becoming what one could call a ‘colonial enterprise’ and the focus on prevention could be seen as redeploying the colonial project of ‘civilising the native man’. Moreover colonial medicine often used Africans as subjects in medical experiments and trials (Gilman, 1988). Colonial medical discourses on black bodies often also sexualised these bodies, and discourses on HIV/AIDS in Africa in medical research repeat this tendency to construct Africans, and particularly African men, as sexually deviant.

Furthermore, the focus on male sexual practice shifts the focus onto individual behaviour, thus moving the discussion away from solutions based on social policy. In much of the work on prevention, there is an acknowledgement that social and economic circumstances for women and men in Africa are indeed harsh. However, this statement does not alter an analysis in which individuals are held to be responsible for the spread of the epidemic through their behaviour *choices* (Bujra, 2000; Gilbert & Walker, 2002). Cultural differences or lifestyle practices are often analysed in order to show high infections rates.

Analyses of material realities, such as access to condoms and medicines, or the level of free choice available to young women (see Adomako Ampofo, 1998) concerning sexual encounters, might be discussed within the research, but the real emphasis falls repeatedly

on individual behavioural change. By contrast, the TAC constantly points to the complex power relations in sexual encounters: “Many young women, the only way they can get schoolbooks is to have sex” (Zackie Achmat, 01.12.03, Workers’ Rally on World AIDS Day). A focus on behaviour carries with it colonial undertones about controlling social behaviour and militates against a politics that addresses unequal economic and power structures. The following quote, for example, suggests that behaviour causes poverty<sup>1</sup>:

They also need to acquire tools that will enable them to change behaviors and actions that lead to vicious circles of abuse, neglect, and poverty in their relationships and in their families.

– Pinkowsky Tersbøl & Silberschmidt, 2003: 203

How poverty can influence behaviours, such as abuse and neglect, and how certain behaviours can lead to poverty in Africa is not adequately explained here. This means that poverty is individualised and not placed within a social context. I argue that the concept ‘behavioral change’ fits the logic of neo-liberal individualism in the way that it ‘blames’ individuals of their behaviour, rather than questioning the power structures that can cause certain behaviours to emerge in the first place. The article ‘Beyond Agency and Victimization’ (article three) makes a similar point and offer as an example a study of sex-workers in Johannesburg. The sex-workers are represented as negotiating with their clients in a way that recasts them as self-determining despite harmful practices such as agreeing to sex without a condom for a higher rate. This leads to a situation where:

[...]claims about agency hide and even normalise violence and oppression. A repetitive evocation of agency overshadows the oppressive circumstances that inhibit individuals’ scope for action.

– Jungar & Oinas, 2011: 253

While, on the one hand, activist discourses has tried to move away from the individualising tendency and the individual guilt and blame pertaining to HIV, on the other hand, some prevention

---

1 This quote is from the proceedings of a seminar on “Gender, Sexuality and HIV/AIDS- Research and Intervention in Africa”.

researchers restore the notion of individual responsibility (see also Pereira, 2010).

Another constructed stereotype found in prevention discourse is what I call 'the responsible intimate individual'. The responsible intimate individual is a central 'discursive agent', within the prevention discourse. Connell et al. (1989) have raised a critical voice here and argue:

We need to move beyond the individualistic approach of much official health education and academic AIDS research, towards collective, social strategies for change. The aim of such work is not so much to change individual 'attitudes' or 'health behaviours' as to move whole networks of people towards safer practices and encourage the social process among them which can sustain the prevention.

– R. W. Connell et al., 1989: 21

I agree with Connell et al. and argue that what is needed is a focus on activist agendas and a collective consciousness that encourages change and empowers collectives. Furthermore, if HIV is represented as the consequence of sinful behaviour, programmes responding to it will implicitly produce an image of the infected 'other'. Additionally, I suggest that the focus on the responsible intimate individual in prevention research is furthermore often a heteronormative project, which has a normalising effect and which can actually increase male power and the negative effects that follow. Based on a study in West Africa, Adomako Ampofo (1998) has also pointed out that there is a need to examine to what extent prevention messages reinforce traditional sex-stereotypes and gender roles.

The article 'A Feminist Struggle?' (article two) shows how the ABC (Abstain from sex, Be faithful, use a Condom) prevention campaign in fact creates harm rather than promoting prevention. Mitchell and Smith (2001) mean that the ABC approach fails to acknowledge the lack of negotiating power of many girls and women. The message in these campaigns is: "First and foremost, Abstain from sex until marriage; if not abstaining, Be faithful to one, uninfected partner; if this is not possible, use a Condom" (Gallant & Maticka-Tyndal, 2004:3). The ABC logic therefore implies that condoms are the last solution 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). Insisting on condoms in a relationship suggests lack of trust and is therefore easily interpreted as an insult. Paradoxically, it is the ABC approach that feeds this line of thinking. According to the ABC logic, condoms are needed only in bad, unhappy, violent, or hopeless relationships.<sup>2</sup> 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) (for an extended discussion see article two).

Kylie Thomas (2003) has shown how the South African ‘loveLife’ campaign, “rather than contesting the inequity that fuels the spread of HIV, [...] presents a particular form of heterosexist normativity as the most desirable for young South Africans” (Thomas, 2003:34). Similarly, I argue that some prevention research and campaigns seek to create alternative representations of sexuality and masculinities, while at the same time reproducing hegemonic norms and stereotypical images. Prevention research that does not focus on same sex desire, or homo- lesbo- or transphobia, runs the risk of imposing heterosexual identities as unquestioned and natural (Thomas, 2003, see also Ratele et al.)

Additionally if heterosexuality is seen as the norm, research easily overlooks the role that homophobia plays in the construction of heterosexuality and specifically in a post-colonial context (Gunkel, 2010). TAC is a home for HBTL (lesbian, gay, bisexual, and transgender) people and has been a visible advocate against hate-crimes on lesbians.

The erasure of same sex desire in prevention campaigns leaves them fundamentally compromised (see Phillips, 2004). Similarly, one can argue that the exclusion of HIV-positive people, and of the question of treatment, in some prevention research further alienates

---

2 There is a TAC song which could be seen as a reaction to the ABC approach. The song is sung in Xhosa. “They are in love, they need a condom. They are together, they need a condom. They are married, they need a condom.” (PWA summit, Strandfontein 2005). The song highlights that you need to use a condom every time you have sex, it does not attach stigma or hierarchy to condom use since it insists on condom use in all relationships. It even indicates that you might just be in love, but not in a relationship, and you might have sex and need to use a condom. The song therefore does not tell people just to abstain, rather, it allows for the fact that people might have sex even though they are not in a relationship.

HIV-positive youth. This position is made clear in one activist's statement: "When they are just saying you must condomise, you must protect yourself, what about the infected ones, where do they go?" (Interview with TAC activist, female, 30.05.03)

A debate on male circumcision as a form of prevention strategy for HIV illustrates the way in which women can paradoxically become invisible in prevention discourse.

### **Case study: Male circumcision**

Male circumcision as a prevention strategy in Africa has attracted much attention in international media. Studies today show that male circumcision is a prevention measure against HIV for heterosexual men (Bailey et al., 2007; Gray et al., 2007). TAC writes in its newsletter:

The evidence that circumcised heterosexual males have less risk of contracting HIV is compelling. Three randomised controlled clinical trials conducted in high-prevalence areas in sub-Saharan Africa, whose results have been published in reputable medical journals, have found that the risk of HIV-negative males contracting HIV is reduced by 50 to 60% when they are circumcised.

– <http://www.tac.org.za/community/node/2782>

Voluntary male medical circumcision, seems to be one of the many important prevention measures. Here I wish to question the messages associated with the promotion of this practice, which in my view does not take sufficient account of the issues facing women around sexually transmitted diseases. My view is that the arguments in our article on the debate on male circumcision as HIV prevention (article five), even though it was published several years ago, still apply. We argue that this debate sometimes makes women invisible and therefore does not take account of the need to protect women from infection (see also Susser, 2009). The debate around male circumcision as a form of HIV prevention focuses obviously on heterosexual men (article five). The fact that male circumcision is directly a prevention measure only for heterosexual men is not always highlighted or interrogated in the messages surrounding the promotion of male circumcision.

The ongoing debate about voluntary male medical circumcision deserves a thorough analysis; here I will only briefly examine some

of the arguments put forward by one prominent male circumcision researcher<sup>3</sup> which were forwarded on the TAC activist list in 2009. At issue was the question of whether male circumcision could be seen, to protect women from infection. The quote below discusses the assumptions about the impact on infection rates of condoms versus male circumcision:

Of course, we must continue to distribute condoms, and make them widely available, etc., but here's the question: what is more likely to prevent more infections -- at the population level over time -- an infection which is on the order of 80-90% effective when always used, or one which is 'only' in the range of 60-75%, but is a PERMANENT, one-time procedure?

- Forwarded from an electronic forum by Victor Lakay on the TAC activist email list, 12.10.09

The researcher asks if male circumcision is not more effective because it is a permanent, one-time procedure, compared to condoms that need to be put on properly every time. In citing the measure of protection in each case, he is not referring to the protection given to women. He neglects to point out that the protection percentage that is given for condoms applies to both women and men, whereas the given percentage for male circumcision reflects the protection of men only. According to some studies, male circumcision protects men in 60-75% of cases, and condoms protect both women and men in 80-90% of cases. Clearly these two statistical numbers are not really comparable. What happens to the protection of women in the male circumcision debate? This discussion of percentages that are not comparable excludes the impact on women from the discussion altogether. The fact that women are more vulnerable to HIV infections in general is also relevant to any discussion on the efficacy of prevention measures.

The tendency to exclude the impact on women in the debates about male circumcision is evident in an article in a TAC newsletter:

It is important that counseling at VMMC [voluntary male medical circumcision] sites and public messaging on VMMC emphasises

---

3 The researcher quoted here has published widely on the issue of male circumcision. I choose to leave the researcher anonymous here since the quote is from an electronic forum and not from a published article.

that VMMC is not completely protective against HIV transmission and using condoms for sex remains necessary to reduce the risk of contracting HIV.

- TAC web page, <http://www.tac.org.za/community/node/2782>

What is omitted in this call for public messaging is that it is solely directed towards men. Here, the TAC has neglected to state that male circumcision is not completely protective for men, whereas male circumcision offers no direct protection for women. These unclear messages are harmful if they are misread as referring to both genders. This misunderstanding may lead to a mistaken belief among women that it is safe to have unprotected sex with a circumcised man.

As a social science researcher, I am not in a position to argue for or against, male circumcision as an HIV prevention strategy in medical terms. I am able to analyse the terms and effects of the debate. The potential for dangerous misunderstandings emerging from this discussion is even more alarming now that voluntary male medical circumcision is being promoted by the WHO<sup>4</sup> as an HIV prevention measure.

## Treatment versus prevention

Often, research on HIV/AIDS in Africa refers to statistics. Articles often begin with statistics about infected and dying Africans (article two). However, statistics can be used in other, less sensationalist, ways, as research on activism shows. By contrast to research

---

4 The article 'Preventing HIV? Medical Discourses and Invisible Women' elaborates on why male circumcision is promoted in Africa and not in the West, and that sometimes it is even seen as a more viable option than condoms for Africans. The article demonstrates, drawing on Patton's work (1997), that male circumcision resonates with Western fantasies about tribal Africa. "In Western eyes, Africa's problems can only be solved through civilizing forces - or in the romantic version, through a withdrawal from civilisation and a return to pristine 'tribal ways'" (Patton 1997, 391). In several of the texts that the article analyses, it is suggested that male circumcision is, anyway, already a part of African culture, at least in many areas. In 2009 the Zulu king started to promote voluntary male medical circumcision for all Zulu men in Kwa-Zulu Natal. Zackie Achmat's Facebook status read: "Cultural revolution as King Goodwill Zwelithini announces that Zulu males will be circumcised to prevent HIV. This step is progressive and based on the best scientific evidence." (<https://www.facebook.com/zackie.achmat/posts/193719273235>). Many Facebook friends cheered this decision, with the same sentiment as the researchers in the article. For example one Facebook friend writes that this is "an African solution for an African problem" and that the "half-hearted awareness campaigns and expensive condoms are probably enough to control the spread of the disease in most of the populace. But here, where we're dying at an alarming rate, we can't afford to be as civilised as the West who are nowhere near as affected by this as we are" (<https://www.facebook.com/zackie.achmat/posts/193719273235>).

discourses, TAC activists question the way in which statistics are used and, demonstrate a different application of statistics to highlight how many people can be saved, rather than how many will die. “What is the meaning of 1 000 new infections and 900 deaths every day?” (Zackie Achmat, TAC Chairperson, speech at University of Cape Town, 06.09.06). TAC argues that 900 people could be saved daily with access to treatment and many more with effective prevention. They deconstruct the ‘lost continent’ discourse (Jungar & Oinas, 2008), which presents the epidemic in Africa as too extreme for meaningful solutions, and deploy statistics to argue for both prevention and treatment. TAC additionally shows how statistics can be altered by changes in policy. Death from HIV/AIDS is thus contextualised, and the anonymous victims recorded in statistics are recast as actual people in the TAC discourse:

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 statistic.

– Siphso Mthathi, speaking during the Civil Disobedience Campaign at the South African Commission for Gender Equality, 01.04.03

The activist message resembles that of feminist post-colonial theorists who reflect on how to “encounter a stranger” (Ahmed, 2000), or to “speak to the subaltern” (Spivak, 1999) in ethical ways that avoid “stranger fetishism” (Ahmed, 2000). From a feminist post-colonial perspective it is possible to address the figures of African women living with HIV/AIDS without producing “a universe of strangers” (Ahmed, 2000). When discussing the scale of the epidemic, the language of urgency, supported by the overwhelming but faceless record of statistics, can construct an analysis that serves to fetishise the ill and to evoke an image of a mass of suffering that seems impenetrable. The statistical record can be used differently to foreground the possibility of intervening in meaningful ways. Moreover, the faces behind these numbers should be granted the

status of subjects with real lives, who are affected by global power relations. It may then become possible for researchers in the field to “encounter” these strangers in collaborative and meaningful ways.

When prevention policy efforts on the African continent use statistics to contextualise the importance of their research (see article one ‘Hiv-aktivism som postkolonialt motstånd’), the ones infected are used to argue for the importance of the research project. However, these infected people are often later excluded from the discussion as the focus within the text shifts from those infection rates to the effort to prevent new infections. The quotation below illustrates this often repeated discursive strategy:

With over 80% of those currently living with AIDS aged between 15 and 24 and three quarters of these youth living in sub-Saharan Africa, it is not an exaggeration to say that youth in sub-Saharan Africa must become a focus for prevention efforts if the problem is to be controlled.

– Gallant & Maticka-Tyndale, 2004: 1337

The quote opens with statistics about youth who live with AIDS<sup>5</sup> in Sub-Saharan Africa and then swiftly proceeds to a discussion of prevention efforts. For the problem ‘to be controlled’, only preventative measures are mentioned as a solution. This implies that the already infected youth are forgotten. The word ‘control’ further indicates that the focus is not on the ethical responsibility towards the youth living with HIV, but rather on controlling the ‘sick’ in order to protect the ‘healthy’(see also article one). When antiretroviral treatment is not even mentioned in a text which grounds its argument in the vast number of infections, then, in terms of the argument, those infected are abandoned to their inevitable deaths (see article one, ‘HIV-aktivism som postkolonialt motstånd’). Together with Zackie Achmat, I would want to ask “What is the meaning of statistics? Why do they numb us?” (Zackie Achmat, TAC march, University of Cape Town, 09.09.06). It is also worth asking how they can be made to serve an agenda for meaningful policy change.

---

5 The correct formulation here is probably living with HIV and not with AIDS.

The struggle for access to drugs for people living with HIV has a long history, first within the queer activist movements in the United States and Europe (Duggan & Hunter, 2006), and later in a global context. African AIDS activists have been instrumental in mobilising for access to ARVs. The activists in Africa had to convince both national and international communities that Africans too need antiretroviral treatment (*Fighting for our lives*, 2010). While antiretroviral medication has been on the market for over ten years, prolonging lives in the United States and Europe<sup>6</sup>, treatment was not seen as a realistic option in Africa. Different stakeholders, such as Western donors (Jones, 2004) and health researchers, promoted prevention rather than treatment for Africans (article one).

The choice of either treatment or prevention concerns “the lives of individuals and the future of populations”, argues Fassin (2007:33). Promoting only prevention in a context where many are already infected has significant consequences. Achille Mbembe suggests in an interview that the ultimate expression of imperial sovereignty “seems to reside, to a large extent, in the power to dictate who may live and who must die” (Christian Hoeller, 2002, <http://www2.h.net.msu.edu/africa>). Taking up this point, Jones (2004) demonstrates that we can liken the struggles over treatment to broader Western intrigues in the ‘Third world’ and therefore these struggles directly address post-colonial issues. One argument used against ARVs is that the focus on treatment is not only detrimental to prevention, but also to other health care services (Jones, 2004) in situations where resources are limited, such as in South Africa, because it may take away resources from other lethal diseases. A dichotomy is created between money spent on HIV treatment on the one hand, and on other diseases and health care in general on the other hand. The following quote from the popular media shows an argument of this kind:

Experts want African aid funds channelled away from HIV. Focus on Aids, they say, has led to neglect of other fatal conditions killing young children. Top scientists are demanding a controversial

---

6 One should also remember that there are groups of people with very limited access to treatment in the rich North, for example people without health insurance, immigrants without papers, or people in economically precarious positions.

overhaul of health spending in Africa, arguing that the billions of pounds targeted at HIV during the past 20 years have led to a neglect of other killer diseases and basic health problems such as diarrhoea.”

– *Observer*, 25.10.09, accessed from TAC’s email list

This article from the *Observer* prompted a debate on the TAC activists’ email list. According to TAC employee Nathan Geffen, the argument referred to Roger England’s (2007) earlier article in the *British Medical Journal*. The email from the TAC activist list was forwarded to England and he replied to the list:

I have made my case that HIV has taken more than its fair share of available health resources, and that the ways in which HIV aid is delivered have been detrimental to the countries’ development.

– Email to TAC activist list from Roger England, 27.10.09

In response to England, Gregg Gonsalves, who is a former ACT-UP activist and the former co-ordinator of the Regional Treatment and Prevention Literacy and Advocacy programme with the AIDS and Rights Alliance for Southern Africa, as well as a TAC activist, writes:

Roger; we have always supported the strengthening of health systems--please get your history right at least. From the early calls for national health care in the USA by AIDS activists in the 1980s to the calls for a people’s health service in the 90s/2000s in South Africa by TAC, to the push for health care workers by HealthGAP and others---we have been some of the most noisy advocates for primary health care for 30 years.

– Email to Roger England via TAC activist list from Gregg Gonsalves, 28.10.09

The debate shows how HIV activists are accused of having a narrow focus on a single cause – access to drugs – overlooking all other problems that require the attention of the already strained health care system. This is not the case. On the contrary, as Gonsalves argues, AIDS activists in both the North and the South have been instrumental in advocating for better health care in general. One could argue that HIV/AIDS has functioned as a catalyst to promote

health care to a higher position on the political agenda. Furthermore, one could argue that the focus on treatment has served to motivate an interest in developing meaningful prevention strategies. Ultimately these are questions regarding the politics of life and death. Who and what subjects are granted the status of a livable life, and on what terms?

### ***Obstacles to promoting treatment***

With the right medication, HIV is today a manageable chronic disease. The lack of focus on treatment in social science research on HIV can be traced to a powerful discourse which defines Africa as different and catastrophic. Peris Jones (2004) argues that Africa is seen as too underdeveloped to cope with the complexities of treatment. A further logic used in promoting prevention alone in the South is that so many people are already dying that treating everyone who is infected and sick is not possible. For this reason, the focus should rather be on the non-infected. This logic is effective in discourses in which Africa is constructed as a place of darkness, disaster, ignorance, and death. Jean Comaroff (2007:201) talks about the part of the world where “from the vantage of the privileged, misery is endemic, life is cheap, and people are disposable”.

Several problems specific to Africans are listed as obstacles to the treatment paradigm. For example, in some early health writings Africans were regarded as not capable of taking medicines on a regular basis. This is not the case in Africa any more than anywhere else. A study that took place in Khayelitsha, for example, shows that adherence to ARVs after two years was 85.4% (<http://www.tac.org.za/community/node/2130>). In developed countries, adherence to medication for chronic diseases in general averages at only 50%. (Rosen et al., 2007). TAC activists also relate to that drugs are seen as too ‘complicated’ or ‘scientific’ for Africans.

It is not simple to use these medications because you have to take them for the rest of your life. But if a person like me who does not have two degrees in science or any other subject can take them, anyone who wants to live can learn about them and take them well.”

– Thobani Ncapayi, *ARVs in our life – a handbook for people living with HIV and treatment advocates in support groups, clinics and communities*, <http://www.tac.org.za/community/>

Furthermore, TAC testimonies show that economic realities and a lack of availability of drugs, tend to be the more serious problems in the administration of treatment. One TAC member explains:

I worry more about money for transport to get to my hospital than I struggle with taking the drugs. I worry that maybe I will get there and they will say, sorry, we run out of drugs you must come back tomorrow. Then I think I will have to default and fear because I know if I miss my drugs I will develop resistance.

– Nompumelelo Kweza, 2006, *ARVs in our life – a handbook for people living with HIV and treatment advocates in support groups, clinics and communities*, <http://www.tac.org.za/community/>

Another frequently cited obstacle to providing treatment is that African health care systems are often inadequate. The argument is that therefore prevention is a more effective solution to the epidemic in Africa:

A major question is if lifelong anti-retroviral treatment chemotherapy in fact is a realistic option. Especially for the millions of HIV/AIDS patients living in Sub-Saharan Africa and other poor continents of the world that suffer from the lack of adequate health infrastructures.

– Pinkowsky Tersbøl & Silberschmidt, 2003: 194

What is a ‘realistic’ option available then to those who are infected? Death? To argue that inadequate health infrastructure is the reason why treatment is not a realistic option is a circular argument. The logic is comparable to saying that we cannot give people water because there are no wells. This kind of argument often passes as common sense. With no access to ARVs more people would become ill faster, and it is highly likely that there would be a greater need for an extended health care system.

It is a common approach to regard prevention as the only realistic option for the global South. In the quotation below, this argument is supported by comparing the poor with the more affluent parts of the world:

Safe sex remains the only practical means by which people in the developing world can protect themselves from AIDS-related

mortality. Whilst drug regimes and healthy lifestyles have emerged as treatment models in Europe and North America, safe sex remains the only option for the vast majority of the world's population.

– Liddell, Barrett & Bydawell, 2005:691

Here medication and a healthy lifestyle are considered appropriate for people living with HIV/AIDS in the global North, whereas prevention is the 'solution' that must serve the rest of the world, even in cases where people are already sick. Arguments like these which are based on the purported ill-fatedness of poor black Africans, or the alleged incompetence of African individuals or governments to manage the administering of medication, mask a lack of political will to intervene effectively in addressing the needs of those currently living with HIV in poor communities, whether in South Africa or elsewhere in the world.

### ***'Treatment goes hand in hand with prevention'***

As has become clear, treatment and prevention are often seen as being in opposition to each other in social science research on HIV/AIDS. This opposition is constructed through arguments which claim, for example, that providing treatment might lead to decreased awareness of prevention. This risk is noted even in research discourses that emphasise treatment as vitally important. For example, Catherine Campbell, a meticulous researcher who has made important contributions in the HIV field, can argue:

However, debate and activism regarding treatment must not be allowed to create a false complacency about the continued dangers of infection, or to divert attention away from the importance of ongoing prevention efforts.

– Campbell, 2003:6

Treatment and prevention are frequently regarded as being in opposition to one another, premised on the notion that if treatment is available, people will take less care to protect themselves from infection. This assumption once again constructs Africans as naïve and ignorant.

Both activist discourses and academic discourses show that the discursive opposition between treatment and prevention is central

to the debate about HIV and ARVs. Activist discourses, however, frequently challenge this dichotomy, in their use of slogans such as: “Treatment and prevention are two sides of the same coin” (TAC/COSATU National Treatment Congress, 27-29.06.02, Durban) or “Treatment as prevention” (<http://www.tac.org.za/community/search>). One TAC activist comments that:

[...] what lots of people don't understand is that there won't be prevention until there is treatment, as treatment goes hand in hand with prevention.

– Interview, Taghmeda Achmat, 18.06.03

This activist hints that people will be less concerned about HIV prevention if treatment is not available. At the same time the comment draws attention to the fact that the less that HIV is associated with inevitable death, the less the illness will be stigmatised, making it easier for people to live openly with HIV. This in turn makes it easier to negotiate safe sex. This applies not only to people who know their status, but also to those who do not. My analysis of the prevention discourse demonstrates the striking difference between the activist and the academic discourses. I have shown how some academic discourses construct prevention and treatment as opposites. The activist discourses relate to the constructed binary, arguing for the simultaneity of both strategies. Activists fight for treatment and prevention, by contrast to accounts where prevention and treatment are seen as mutually exclusive. In recent years, however, there is a positive development in that researchers have increasingly placed treatment high on the agenda (Mbali, 2003, 2005; Jones, 2004; Robins, 2004, 2006; Thomas, 2003; Poku, 2006; Posel, 2007).

One clear example of how treatment becomes a form of prevention is the case of ARV treatment for pregnant women to prevent their babies from becoming infected. Another important instance is the fact that people who take ARV drugs are much less likely to transmit the virus to a partner ([http://www.tac.org.za/community/node/3101#\\_ftnref8](http://www.tac.org.za/community/node/3101#_ftnref8)). One activist argues, contesting the constructed dichotomy between treatment and prevention, that:

And until people are beginning to understand that [HIV can be treated] by seeing other people waking up from their death

bed because of treatment, we are not going to change people's perceptions, we are not going to change behaviour.

– Sipho Mathati, TAC Civil Disobedience Campaign at  
Commission for Gender Equality, 01.04.03

Here access to health care, rather than education, is seen as the key to behavioural change. Access to ARVs is shown to help in destigmatising the disease, and removing the blame from the individual, as illness and death are no longer seen to be caused by the individual's behaviour, but rather by the fact that she or he has no access to treatment.



'Stand Up for Our Lives' march to Parliament, February 2003

---

## 6. Conclusions

This ethnographic study of the South African HIV activist movement called the Treatment Action Campaign (TAC) has convinced me that research on activism enables a radical re-thinking of approaches to social science research. The work of TAC activism calls for broader and more nuanced reflections on the intersecting questions of illness, medicalisation, health promotion, race, gender, sexuality and global politics, than much of the social science research in the field offer.

Following the TAC has been fruitful for me as a feminist researcher since the study has opened up many important contemporary feminist debates. In its work the TAC highlights the continued relevance of the old feminist slogan 'the personal is political'. The everyday struggle of the activist reads as a powerful critique of globalisation and neoliberalism. My study has confirmed Mohanty's (2003) point about contemporary feminism. According to Mohanty, some 'Third world' globalisation critical movements can be defined as feminist even though they do not necessarily call themselves feminist, since their critique of global capitalism provides the most powerful analyses of how girls and women, especially in the Global South, bear the brunt of globalisation.<sup>1</sup> When the TAC insists on the materiality of bodies by challenging the dichotomy between the biomedical and the social, it goes hand-in-hand with emerging new models of materiality in feminist theory. Activist women living with HIV are global agents of change, and their critiques clearly demonstrate that theories of health and illness that lack an intersectional perspective will fail to explain the complex connection between race, class, gender and global power structures.

The struggle of the TAC activists is also about representation and meaning. In its approach to HIV/AIDS, the TAC refutes Western representations of Africa as a place of inevitable death and catastrophe; an image which, as post-colonial theories show, is still prevalent in discourses about Africa. When the TAC activists rally against multinational pharmaceutical companies in their 'HIV-POSITIVE' T-shirts, which explicitly represent them as a community of 'victims', they reclaim and own the stereotypes of victim, race, and gender in subversive ways. When a teenage activist speaks to a crowd of 20 000 demonstrators in Cape Town about being raped

---

1 See also Sisonke Msimang (2003:109) talking about the "deafening silence on AIDS in the global women's movement".

and contracting HIV, she is able to transform her 'victimhood' into a form of agency and protest, through her activism ('Stand Up for Our Lives' march to Parliament, 14.02.03). By studying activism, it is possible to address the agent-victim dualism that has had such a strong hold in feminist research.

The construction of a specifically 'African AIDS' (Patton, 1997) led social scientists to center their discussions on prevention for Africans (article two). Treatment, when mentioned, was seen as an unrealistic option. TAC activists insist on giving HIV/AIDS a social context by questioning the discourse of individual and heteronormative responsibility typical in health promotion. The central question that informs the TAC activism would be: In what circumstances does HIV/AIDS flourish? By contrast, many social scientists working in the field asked: What are the behaviours that spread HIV? (see also Fassin, 2007). In some health promotion campaigns, girls are blamed for not saying 'no' to sex. However this individualised critique takes no account of the surrounding gender-power context in which it may be difficult, risky or impossible for a young woman to make sexual choices. Focusing on the context makes the link between global economics, gender, sexuality and illness clearer and therefore lifts the burden of responsibility for the disease from the individual.

Testimonies by activists living with HIV/AIDS, at seminars, meetings, conferences, rallies and demonstrations, are important in this process of transferring the responsibility for illness (and death) from the individual to the social and political context. The TAC treatment literacy workshops teach activists about the virus, the drugs, but also about the relationship between capitalism's exploitative practices and disease. The pedagogy of the TAC is unique and to some extent it is discussed in this study, although there is scope for further analysis of the TAC's programme to educate activists, who often have very little formal schooling. In such a study, the focus should be especially on what politicised embodiment means for the pedagogy of HIV/AIDS.

Contrary to the language of medicalisation that traditionally tends to de-politicise sickness, as feminist critiques have shown, the TAC's struggle for access to medication is highly political. Feminist criticism of medicalisation has been important, but it has also

caused a certain unease about 'the medical' in social sciences. The feminist critique of medicalisation has not incorporated a discussion of the privilege of health care, or of the position of individuals without access to medication on a global scale. For the discussion of medicalisation to evolve, it is, however, clear that economic disparities must be taken into consideration, especially in the light of confrontations over multinational pharmaceutical companies' patent rights. These questions need to be included in the core theory of (feminist) health research.

One important lesson from this study has been how to think beyond binaries with reference to TAC politics: a simple but effective tool, such as the 'HIV-POSITIVE' T-shirts worn by infected and non-infected activists alike, dismantles the perceived division between 'agents' and 'victims', as does the role of TAC activists as both global advocates and HIV/AIDS sufferers. Similarly, the TAC refuses the familiar opposition between treatment and prevention through its slogans and campaigns, which shows that 'treatment is prevention'. Moreover, the opposition between medical expertise and lay knowledge is deconstructed when activists on ARVs insist that medicine is a collaborative effort between 'you and your nurse and your doctor'. The TAC campaign concerns access to medicines, control over representations of Africa, and an engagement with body politics, but it is also a struggle about democracy in that it makes visible the global political dimensions of health and disease. TAC activism challenges a series of accepted binaries that inhibit the development of a meaningful politics, and urges us to think beyond dualism. This, in turn enables us to better understand, treat, prevent, and live with HIV/AIDS in local and global communities.

---

## References

- Achmat, Zackie. 2004. HIV and Human Rights: A New South African Struggle. *John Foster Lecture*, 10 November 2004. <http://www.tac.org.za/Documents/JohnGalwayFosterLecture-finalVersion-20041116.pdf> (accessed 06.10.06).
- Adomako Ampofo, Akosua. 1998. Nice guys, Condoms and Other forms of STD Protection; Sex Workers and AIDS protection in West Africa. In: Becker, Charles; Dozon, Jean-Pierre; Obbo, Christine & Touré, Moriba (eds.). *Vivre et Penser le Sida en Afrique / Experiencing and Understanding AIDS in Africa*. Paris: Codesria. pp. 559-588.
- Adomako Ampofo, Akosua. 2009. One Who has Truth – She has Strength: The Feminist Activist Inside and Outside the Academy in Ghana. In: Arnfred, Signe & Adomako Ampofo, Akosua (eds.). *African Feminist Politics of Knowledge-Tensions, Challenges, Possibilities*. Uppsala: Nordiska Afrikainstitutet. pp. 28-51.
- Ahlbeck-Rehn, Jutta. 2006. *Diagnostisering och disciplinering. Medicinsk diskurs och kvinnligt vainsinne på Själo hospital 1889-1944*. Åbo: Åbo Akademi University Press.
- Ahmed, Sara. 2000. *Strange Encounters. Embodied Others in Post-Coloniality*. London: Routledge.
- Alaimo, Stacy & Hekman, Susan. 2008. Introduction: Emerging Models of Materiality in Feminist Theory. In: Alaimo, Stacy & Hekman, Susan (eds.). *Material Feminisms*. Bloomington & Indianapolis: Indiana University Press. pp. 1-19.
- Anderson, Joan M. 2000. Gender, 'race', poverty, health and discourses of health reform in the context of globalization: a post-colonial feminist perspective in policy research. *Nursing Inquiry*, 7:220-229.
- Arnfred, Signe. 2004. Re-thinking Sexualities in Africa: Introduction. In: Arnfred, Signe (ed.). *Re-thinking Sexualities in Africa*, Uppsala: Nordic Africa Institute. pp. 7-29.
- Baldwin, James. 1951. *Many thousands gone. Notes of a native son*. Boston: Beacon Press.
- Barad, Karen. 2003. Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter. *Signs*, 28 (3), 801-831.

- Bailey et al. 2007. Male circumcision for HIV prevention in young men in Kisumu, Kenya: a randomised controlled trial. *Lancet*, 369(9562), 643-56. <http://www.ncbi.nlm.nih.gov/pubmed/17321310> (accessed 08.08.11)
- Bennett, Jane. 2009. Connections to Research: The Southern African Network of Higher Education Institutions Challenging Sexual Harassment/Sexual Violence, 1996-2001. In: Arnfred, Signe & Adomako Ampofo, Akosua (eds.). *African Feminist Politics of Knowledge- Tensions, Challenges, Possibilities*. Uppsala: Nordiska Afrikainstitutet. pp. 52-82.
- 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.
- Cameron, Edwin. 2005. *Witness to AIDS*. London: Taurus.
- 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.
- Comaroff, Jean. 2007. Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order. *Public Culture*, 19(1), 197-219.
- Connell, R. W. et al. 1989. *Unsafe Anal Sexual Practice Among Homosexual and Bisexual Men, Social Aspects of the Prevention of AIDS*. Study A, Report 7, Macquarie University, School of Behavioural Sciences, pp 19-20.
- Conrad, Peter. 2005. The Shifting Engines of Medicalization. *Journal of Health and Social Behavior*, 46(1), 3-14.
- Conrad, Peter & Schneider, Joseph. W. 1980. *Deviance and Medicalization. From Badness to Sickness*. St. Louis: C.V. Mosby.
- Davies, Angela. 1982. *Women, Race and Class*. London: Women's Press.
- de Waal, Alex. 2006. *AIDS and Power: Why There is No Political Crisis – Yet*. London: African Arguments/Zed Books.

- Dinesen, Isak. 1937. *Out of Africa*. London: Putnam.
- Du Bois, W.E.B. 1903. *The Souls of Black Folk*. Chicago: A.C. McClurg & Company.
- Duggan, Lisa & Hunter, Nan D. 2006. *Sex Wars: Sexual Dissent and Political Culture*. New York: Routledge.
- Edelman, Lee. 2004. *No Future: Queer Theory and the Death Drive*. Durham & London: Duke University Press.
- Ehrenreich, Barbara & English, Deirdre. 1978. *For Her Own Good: 150 Years of the Experts' Advice to Women*. New York: Anchor Doubleday.
- Ehrenreich, Barbara & Deirdre, English. 1973. *Complaints and Disorders. The Sexual Politics of Sickness*. New York: The Feminist Press.
- Engler, Mark. 2004. The End of Gap Sweatshops? Victories and challenges for the anti-sweatshop movement. <http://www.democracyuprising.com/articles/2004/gap.php> (accessed 02.07.09)
- England, Roger. 2007. Head to head: Are we spending too much on HIV? *British Medical Journal*, 334 (7589), 344.
- Eisenstein, Zillah. 2004. *Against Empire*. London: ZED press.
- Epstein, Debbie; Morrell, Robert; Moletsane, Relebohile & Unterhalter, Elaine. 2004. Interventions, Activism, Identities: Gender and HIV/AIDS in Africa. *Transformation*, 54, 1-16.
- Ettorre, Elisabeth & Riska, Elianne. 1995. *Gendered Moods: Psychotropics and Society*. London: Routledge & Kegan.
- Fanon, Franz. 1967. *Black skin, white masks: the experiences of a black man in a white world*. New York: Grove Press.
- Fassin, Didier. 2007. *When Bodies Remember: Experience and Politics of AIDS in South Africa*. Berkeley: University of California Press.
- Fighting for our lives. The History of the Treatment Action Campaign 1998 - 2010*. 2010. Cape Town: Treatment Action Campaign.
- Foucault, Michel. 1978. *The History of Sexuality*. Volume I, New York: Vintage.
- Frank, Arthur. 1990. Bringing Bodies back: A Decade Review. *Theory, Culture and Society*, 7(1), 131-162.
- Frankenberg, Ronald. 1996. Learning from AIDS: The future of Anthropology. In Cabrera, C; Pitt, D & Staugård, F (eds.). *Aids and the Grassroots*. Ipelegeng Publishers. pp. 125-144.

- 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. pp. 23-44.
- Furlong, Patrick & Ball, Karen. 2005. The more things change: AIDS and the State in South Africa, 1987-2003. In: Patterson, Amy S. (ed.). *The African State and the AIDS Crisis*. Aldershot: Ashgate.
- Gallant, Melanie & Maticka-Tyndale, Eleanor. 2004. School-based HIV prevention programmes for African Youth. *Social Science & Medicine*, 58(7), 1337-1351.
- Geffen, Nathan. 2006. *Echos of Lysenko: State-Sponsored Pseudo-Science in South Africa*. CSSR Working Paper No. 149. Published by the Centre for Social Science Research University of Cape Town. <http://www.tac.org.za/community/files/wp149.pdf> (accessed 09.06.10).
- Geffen, Nathan & Gonsalves, Gregg. 2008. In defence of rational aids activism: how the irrationality of Act Up-Paris and others is risking the health of people with HIV or at risk of HIV infection. *Southern African Journal of HIV Medicine*, 22nd of September.
- Gevisser, Mark. 2007. *Thabo Mbeki: The Dream Deferred*. Cape Town: Jonathan Ball Publishers SA.
- Gilbert, Leah & Walker, Liz. 2002. Treading the path of least resistance: HIV/AIDS and social inequalities – a South African case study. *Social Science & Medicine*, 54(7),1093-1110.
- Gilman, Sander. 1988. *Disease and Representation: Images of Illness from Madness to AIDS*. Ithaca: Cornell University Press.
- Gray, Andrew. 2005. The challenges of implementing antiretroviral treatment in South Africa. In: S Karim, Abdool & Karim, Q, Abdool (eds.). *HIV/AIDS in South Africa*, Cambridge: Cambridge University Press. pp 524-537.
- Gray et al. 2007. Male circumcision for HIV prevention in men in Rakai, Uganda: a randomised trial. *Lancet*, 369(9562), 657-66. <http://www.ncbi.nlm.nih.gov/pubmed/17321311> (accessed 08.08.11)

- Gunkel, Henriette. 2010. *The cultural politics of female sexuality in South Africa*. New York: Routledge.
- Haraway, Donna. 1991. *Simians, Cyborgs, and Women. The Reinvention of Nature*. London: Free Association Books.
- Haraway, Donna. 1992. *Primate Visions. Gender, Race, and Nature in the World of Modern Science*. London: Verso.
- Haraway, Donna. 1997. *Modest\_Witness@Second\_Millennium. FemaleMan\_Meets\_OncoMouse*. New York: Routledge.
- Harding, Sandra. 1986. *The Science Question in Feminism*. Ithaca: Cornell University Press.
- Harding, Sandra. 1993. Rethinking Standpoint Epistemology. 'What Is Strong Objectivity'? In: Alcoff, Linda & Potter, Elizabeth (eds.). *Feminist Epistemologies*. New York: Routledge. pp. 49-82.
- Heywood, Mark. 2004. Price of Denial. *Development Update* 5(3). Interfund. <http://www.tac.org.za/community/debunking> (accessed 06.06.09).
- Heywood, Mark. 2005. The Achilles heel? The impact of HIV/AIDS on democracy in South Africa. In: Karim, S. Abdool & Karim, Q. Abdool (eds.). *HIV/AIDS in South Africa*, Cambridge: Cambridge University Press. pp. 371-383.
- Himmelman, Natasha & Mupotsa, Danai. 2008. (Product)Red: (re)Branding Africa? *Journal of Pan African Studies*, 2(6). <http://www.jpnafrican.com/archive.htm> (accessed 01.02.10).
- Hirsiäho, Anu. 2005. *Shadow Dynasties. Politics of Memory and Emotions in Pakistani Women's Life-Writing*. Tampereen Yliopisto: Tampere University Press.
- Hoad, Neville. 2005. Thabo Mbeki's AIDS blues: The intellectual, the archive, and the pandemic. *Public Culture*, 17:101-27.
- Holland, Janet; Ramazanoglu, Caroline; Sharpe, Sue & Thomson, Rachel. 1998. *The Male in the Head. Young People, Heterosexuality and Power*. London: Tufnell Press.
- Honkanen, Kattis. 2008. Equality Politics out of the Subaltern. In: Magnusson, Eva; Rönnblom, Malin & Silius, Harriet (eds.). *Critical Studies of Gender Equalities. Nordic Dislocations, Dilemmas and Contradictions*. Göteborg: Makadam. pp. 205-219.

- <http://sciencespeaksblog.org/2011/05/20/aids-at-30-an-interview-with-activist-gregg-gonsalves/> (accessed 03.09.2011)
- <http://www.annielnoxsing.com> (accessed 12.03.11).
- [http://www.converse.com/index.aspx?mode=c1#home\\_red\\_2007](http://www.converse.com/index.aspx?mode=c1#home_red_2007) (accessed 05.06.08)
- <https://www.facebook.com/zackie.achmat/posts/193719273235> (accessed 17.05.11)
- <http://www.guttmacher.org/pubs/journals/3209200.html> (accessed 28.07.11)
- <http://www.joinred.com>. (accessed 01.03.08).
- <http://www.tac.org.za/community/> (accessed 03.07.11)
- <http://www.tac.org.za/community/debunking> (accessed 08.02.10).
- <http://www.tac.org.za/community/node/2130> (accessed 14.01.10).
- <http://www.tac.org.za/community/node/2782> (accessed 26.07.11).
- <http://www.tac.org.za/community/node/3079> (accessed 27.07.11).
- [http://www.tac.org.za/community/node/3101#\\_ftnref8](http://www.tac.org.za/community/node/3101#_ftnref8) (accessed 08.08.11)
- <http://www.tac.org.za/community/search> (accessed 26.07.11).
- <http://www.tac.org.za/district/?p=712> (accessed 10.06.11).
- [http://www.tac.org.za/Documents/Court\\_Cases/Rath/Defamation/modise.html](http://www.tac.org.za/Documents/Court_Cases/Rath/Defamation/modise.html) (accessed 08.01.10).
- <http://www.tac.org.za/Documents/NationalCongressDocumentation2005.doc> (accessed 28.07.11).
- <http://www.tac.org.za/Documents/TreatmentPlan/tpbriefingsheet.pdf> (accessed 27.08.11).
- [http://www.tac.org.za/newsletter/2005/ns19\\_04\\_2005.htm](http://www.tac.org.za/newsletter/2005/ns19_04_2005.htm) (accessed 01.06.11).
- <http://www.virginia.edu/anthropology/wende.html> (accessed 20.02.06).
- <http://www.virusmyth.net/aids/> (accessed 20.02.06).
- <http://www.virusmyth.com/aids/hiv/ancdoc.htm> (accessed 31.08.11)

- <http://www.youtube.com/officialSINGcampaign#p/a/f/0/v6N30ywPwt8> (accessed 12.03.11).
- <http://www.youtube.com/officialSINGcampaign#p/a/u/0/GxKMLeZqsoE> (accessed 12.03.11).
- <http://www.youtube.com/watch?v=tMgmaKhH038> (accessed 12.03.11)
- <http://www2.h.net.msu.edu/africa> (accessed 15.01.10)
- Irni, Sari. 2010. *Ageing Apparatuses at Work – Transdisciplinary negotiation of sex, age and materiality*. Åbo: Åbo Akademi University Press.
- Jones, Peris, S. 2004. When ‘development’ devastates: donor discourses, access to HIV/AIDS treatment in Africa and rethinking the landscape of development. *Third World Quarterly*, 25(2), 385-404.
- Jungar, Katarina & Oinas, Elina. 2003. Treatment Action Campaign – HIV-activism transforming the notion of medicalization, Paper presentation at *Vital politics – Health, medicine and Bio-economics into the twenty-first century*, 5-7 September 2003, London, under the auspices of the London *History of the Present* network.
- Jungar, Katarina & Oinas, Elina. 2004. HIV prevention? Medical Discourses and Invisible Women. In: Arnfred, Signe (ed.). *Rethinking Sexualities in Africa*. Uppsala: Nordic Africa Institute. pp. 97-111.
- Jungar, Katarina & Oinas, Elina. 2007. HIV- aktivism som postkolonialt motstånd. In: Oinas, Elina & Ahlbeck-Rehn, Jutta (eds.). *Kvinnor, kropp och hälsa*. Lund: Studentlitteratur. pp. 11-43.
- Jungar, Katarina & Oinas, Elina. 2008. “Mobilize and Mourn!” South African HIV activism as feminist politics. In Lassenius, Marina; Charpentier, Sari; Honkanen, Kattis; Jungar, Katarina; Kinnari, Eva-Mikaela; Mattson, Kristin & Tuori, Salla (eds.). *Feminist Dialogues – motstånd, möten och möjligheter*. Åbo: Meddelanden från Ekonomisk-Statsvetenskapliga fakulteten vid Åbo Akademi. pp. 178-194.
- Jungar, Katarina & Oinas, Elina. 2010. A Feminist struggle? South African HIV activism as feminist politics. *Journal of International Women’s Studies*, 11(4),177-191. <http://www.bridgew.edu/soas/jiws/May10/index.htm> (accessed 03.01. 2010).

- Jungar, Katarina & Oinas, Elina. 2011. Beyond Agency and Victimization: Re-reading Women's Embodied Experiences. *Social Dynamics*, 37 (2), 248–262.
- Jungar, Katarina & Salo, Elaine. 2008. 'Shop and Do Good' *Journal of Pan African Studies* 2(6), 92-102. <http://www.jpanafrican.com/archive.htm> (accessed 01.02.10).
- Lather, Patti. 2001. Postbook: Working the Ruins of Feminist Ethnography. *Signs*, 27(1),199-227.
- Lewis, Desiree. 2004. *Post-colonial Feminisms; The Politics of Freedoms*. <http://www.library.wisc.edu/libraries/WomensStudies/mags.htm> (accessed 20.01.09).
- Lindisfarne, Nancy. 2002. Starting from Below – Fieldwork, Gender and Imperialism Now. *Critique of Anthropology*, 22(4), 403-423.
- Lundahl, Mikela. 2006. Nordic Complicity? Some Aspects on Nordic Identity as 'Non-Colonial' and Non-Participatory in the European Colonial Event. In: *Rethinking Nordic Colonialism*. Act 1: Iceland, March 24-April 16, 2006. <http://www.rethinking-nordic-colonialism.org/files/pdf/ACT1/ESSAYS/Lundahl.pdf> (accessed 06.04.10).
- Lupton, Deborah. 1997. Foucault and the Medicalisation Critique, In: Petersen, Alan & Bunton, Robin (eds.). *Foucault. Health and Medicine*, London: Routledge. pp. 94-112.
- Magubane, Zine. 2008. The (Product) Red Man's Burden: Charity, Celebrity, and the Contradictions of Coevalness. *Journal of Pan African Studies* 2(6). <http://www.jpanafrican.com/archive.htm> (accessed 01.02.10).
- Marshall, Wende E. 2005. Aids, race and the limits of science. *Social Science & Medicine*, 60(11), 2515-2525.
- Mbali, Mandisa. 2003. A Postcard from Bangkok: reflections of gender and sexuality in contemporary, global AIDS activism. *Agenda* (62),107-113.
- Mbali, Mandisa. 2004. AIDS Discourses and the South African State: Government denialism and post-apartheid AIDS policy-making. *Transformation*, (54), 104-122.

- Mbali, Mandisa. 2005. The Treatment Action Campaign and the History of Rights-based, Patient-driven HIV/AIDS Activism in South Africa. Research Report No. 29, pp. 63-85. In: *From Local Processes to Global Forces*. Research Reports 2005 Volume 1. Durban: Centre for Civil Society, University of KwaZulu-Natal.
- Mbali, Mandisa. 2008. Gender, Sexuality and Global Linkages in the History of South African AIDS Activism, 1982-1994, In: Follér, Maj-Lis & Thörn, Håkan (eds.). *The Politics of AIDS: Globalization, the State and Civil Society*. London: Palgrave. pp.177-198.
- Mbembe, Achille. 2001. *On the postcolony*. Berkeley: University of California Press.
- Miraftab, Faranak. 2004. Can you Belly Dance? Methodological Questions in the Era of Transnational Feminist Research. *Gender, Place and Culture: Journal of Feminist Geography*, 11(4), 595-604.
- 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.
- Mohanty, Chandra Talpade. 1988. Under Western Eyes: Feminist Scholarship and Colonial Discourses. *Feminist Review*, Number 30, Autumn 1988.
- Mohanty, Chandra Talpade. 2003. 'Under Western Eyes' Revisited: Feminist Solidarity through Anticapitalist Struggles. *Signs*, 28(2), 499-535.
- Morrison, Toni. 1992. *Playing in the dark: whiteness and the literary imagination*. Boston: Harvard University Press.
- Msimang, Sisonke. 2003. HIV/AIDS, Globalization and the International Women's Movement. *Gender and Development*, 11(1), 109-113.
- Nattrass, Nicoli. 2007. *Mortal Combat: AIDS denialism and the struggle for antiretrovirals in South Africa*. University of KwaZulu-Natal Press
- Oakley, Ann. 1980. *Women Confined: Towards a Sociology of Childbirth*. Oxford: Martin Robertson.
- Oinas, Elina. 2001. *Making Sense of the Teenage Body. Sociological Perspectives on Girls, Changing Bodies, and Knowledge*. Åbo: Åbo Akademi University Press.

- Oinas, Elina & Ahlbeck-Rehn, Jutta. 2007. Blod, fläsk och performativitet. Kropp och hälsa i feministisk forskning. In Oinas, Elina and Ahlbeck-Rehn, Jutta (eds.). *Kvinnor, kropp och hälsa* Lund: Studentlitteratur. pp 11-43.
- Oinas, Elina & Jungar, Katarina. 2008. A Luta Continua! South African HIV activism, embodiment and state politics. *Development Dialogue* (50), 239-258. [http://www.dhf.uu.se/pdf/iler/DD2008\\_50\\_mass\\_violence/Development\\_dialogue\\_50\\_art12.pdf](http://www.dhf.uu.se/pdf/iler/DD2008_50_mass_violence/Development_dialogue_50_art12.pdf) (accessed 02.01.10).
- Patton, Cindy. 1997. Inventing 'African AIDS'. In: Lancaster, Roger N. & di Leornado, Micaela (eds.). *The Gender/Sexuality Reader: Culture, History, Political Economy*. New York: Routledge. pp. 387-405.
- Peacock, Dean; Budaza, Thokozile & Greig, Alan. 2009. The Treatment Action Campaign's Activism. In: Ndinga-Muvumba, Angela & Robyn, Pharoah (eds.). *HIV/AIDS and Society in South Africa*. Scottsville: University of Kwa-Zulu-Natal Press. pp. 85-102.
- Peltonen, Salla. 2009. *Debatter om betydelser. Kön och språk i feministisk teori*. Åbo: Meddelanden från Ekonomisk- statsvetenskapliga fakulteten vid Åbo Akademi, Kvinnovetenskap, Ser. A:563.
- Pereira, Charmaine. 2002. 'Where Angels Fear to Tread?' Some Thoughts on Patricia McFadden's 'Sexual Pleasure as Feminist Choice'. *Feminist Africa*, 2. <http://www.feministafrica.org/fa%202/2level.html> (accessed 20.01.09).
- Pinkowsky Tersbøl, Britt & Silberschmidt, Margarethe. 2003. Epilogue 2003. HIV/AIDS Treatment and Prevention: Which way now? A Glance at the Current Situation. In: Pinkowsky Tersbøl, Britt (ed.). *Gender, Sexuality and HIV/AIDS. Research and Interventions in Africa. Proceedings from a seminar*, pp. 194- 204.
- Poku, Nana K. 2006. *AIDS in Africa. How the Poor are Dying*, Cambridge: Polity Press.
- Ponte, Stefano; Richey, Lisa Ann & Baab, Mike. 2008. *Bono's Product (RED) Initiative: Wedding Hard Commerce and Corporate Responsibility*. Working Paper Number 2008/13. Danish Institute for International Studies.

- Posel, Deborah. 2005. Sex, Death and the Fate of the Nation: Reflections on the Politicization of Sexuality in Post-Apartheid South Africa. *Africa*, 75(2), 125-153.
- Posel, Deborah. 2007. A Matter of life and death. In: McGregor, Liz & Nuttall, Sarah (eds.). *At Risk*. Johannesburg & Cape Town: Jonathan Bull Publishers. pp. 48-76.
- Ratele, Kopano; Fouten, Elron; Shefer, Tamara; Strebel, Anna; Shabalala, Nokuthula & Buikema, Rosemarie. 2007. "Moffies, jock and cool guys": boys' accounts of masculinity and their resistance in context. In: Shefer, Tamara; Ratele, Kopano; Strebel, Anna; Nokuthula, Shabalala & Buikema, Rosemarie (eds.). *From Boys to Men*. Cape Town: UCT Press. pp. 112-127.
- Richey, Lisa Ann & Ponte, Stefano. 2011. *Brand Aid: Shopping Well to Save the World*. Minnesota: University of Minnesota Press.
- Riska, Elianne. 2003. Gendering the medicalization thesis. In: Segal, Marcia & Demos, Vasilikie & Kronenfeld, Jennie Jacobs (eds.). *Gender Perspectives on Health and Medicine (Advances in Gender Research, Volume 7)*. Amsterdam: Elsevier. pp. 59-87
- Roberts, Dorothy. 2000. Black Women and the Pill. *Family Planning Perspectives*. 32(2).
- Robins, Steven. 2004. 'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid. *Journal of Southern African Studies*, 30(3), 651-672(22).
- Robins, Steven. 2006. From "rights" to "ritual": AIDS activism in South Africa. *American Anthropologist*, 108(2), 312-323.
- Rose, Nikolas. 2007. Beyond Medicalisation. *The Lancet*. 369 (9562), 700-702.
- Rosen, Sydney; Fox, Matthew P. & Gill, Christopher J. 2007. Patient Retention in Antiretroviral Therapy Programs in Sub-Saharan Africa: A Systematic Review. *PLoS Medicine*, 4(10), 1691-1701.
- Sarna-Wojcicki, Margaret. 2008. Refigu(red): Talking Africa and Aids in "Causumer" Culture. *Journal of Pan African Studies*, 2(6), 14-31. <http://www.jpnafrican.com/archive.htm> (accessed 01.02.10).

- Said, Edward. 1978. *Orientalism*. New York: Pantheon Books.
- Salo, Elaine. 2009. Coconuts do not live in Townships: Cosmopolitanism and its Failures in the Urban Peripheries of Cape Town. *Feminist Africa*, 13. <http://www.feministafrica.org/fa%202/2level.html> (accessed 17.07.11).
- 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.
- Shulman, Alix Kates. 1991. Dances with Feminists, *Women's Review of Books*. [http://sunsite.berkeley.edu/goldman/Features/dances\\_shulman.html](http://sunsite.berkeley.edu/goldman/Features/dances_shulman.html) (accessed 09.06.10).
- Smith, Beverly. 1982. Black Women's Health: Notes for a Course. In: Hull, Gloria T.; Bell Scott, Patricia & Smith, Barbara (eds.). *But Some of Us are Brave: Black Women's Studies*. New York: The Feminist Press. pp. 103-114.
- Sommer, Doris. 1994. Resistant text and Incompetent readers. *Politics Today*, 15(4), 523-51.
- Spivak, Gayatri Chakravorty. 1993. Can the Subaltern Speak? In: Williams, Patrick & Christman, Laura (eds.). *Colonial Discourse and Post-Colonial Theory. A Reader*. London: Harvester Wheatsheaf. pp. 66-111.
- Spivak, Gayatri Chakravorty. 1999. *A Critique of Postcolonial Reason: Toward a History of the Vanishing Present*. Cambridge: Harvard University Press.
- Stacey, Judith. 1988. Can there be a feminist ethnography? *Women's Studies International Forum*, 11(1), 21-27.
- Susser, Ida. 2009. *AIDS, sex, and culture, Global Politics and Survival in Southern Africa*. West Sussex: Wiley-Blackwell.
- TACs Annual Report. 2003/2004. <http://www.tac.org.za/Documents/AnnualReport2003.pdf> (accessed 05.05.10).
- Thomas, Kylie. 2003. A Better Life for Some: The loveLife Campaign and HIV/AIDS in South Africa. *Agenda*, 62:29-35.
- Thompson, Charis. 2005. *Making Parents: The Ontological Choreography of Reproductive Technologies*. Cambridge: The MIT Press.
- Treichler, Paula. 1999. *How to Have Theory in an Epidemic. Cultural Chronicles of AIDS*. Durham: Duke University Press.

- Tuori, Salla. 2009. *Politics of Multicultural Encounters. Feminist Postcolonial Perspectives*. Åbo: Åbo Akademi University Press.
- Vanity Fair*. 2007. Condé Nast Publications.
- Vuorela, Ulla. 2009. *Colonial Complicity: The "Postcolonial" in a Nordic Context*. In: Keskinen, Suvi; Tuori, Salla; Irni, Sari & Mulinari, Diana (eds.). *Complying With Colonialism Gender, Race and Ethnicity in the Nordic Region*. Farnham: Ashgate. pp. 19-33.
- Watney, Simon. 1994. *Practices of Freedom. Selected Writing on HIV/AIDS*. Durham: Duke University Press.
- Yrjölä, Riina. 2009. The Invisible Violence of Celebrity Humanitarianism: Soft Images and Hard Words in the Making and Unmaking of Africa. *World Political Science Review*, 5(1), 1-23.
- Younde, Jeremy R. 2007. *AIDS, South Africa, and the Politics of Knowledge*. Hampshire: Ashgate.
- Zola, Irving. 1972. Medicine as an Institution of Social Control. *Sociological Review*, 20 (4), 487-504.

---

**Svensk  
sammanfattning**

## **LONG LIVE! Sydafrikansk hiv-aktivism, kunskap och makt**

På vilket sätt kan en studie av hiv-aktivism berika akademiska diskussioner om sjukdom och hälsa? Denna breda fråga behandlas i den etnografiska studien av organisationen Treatment Action Campaign (härefter TAC). Organisationen TAC är en hälsorörelse som fokuserar på hiv på såväl ett personligt, nationellt som globalt plan. TAC förskjuter därmed frågor om hiv från att handla om en individuell sjukdom till att handla om ett brett spektrum av politiska frågor. Under den tid som denna studie utfördes, med början år 2000, har TAC vuxit från att vara en organisation med få medlemmar till att innesluta närmare 20 000 medlemmar. Utgångspunkten i studien är en diskussion om hur aktivister i södra Afrika formulerar sina krav på hälsovård och tillgång till bromsmediciner. Studien hävdar att en analys av aktivism och mobilisering av kvinnor som lever med hiv och kämpar för tillgång till bromsmediciner utmanar hälso- och hivforskningen och kastar vidare ljus på globaliseringens effekter på hälsa och sjukdom.

TAC, som grundades 1998 i Kapstaden, har blivit känd internationellt för sin mobilisering av människor som lever med hiv. TAC insisterar på att människors hälsa måste gå före de multinationella läkemedelsbolagens vinster och internationella handelsavtal, men TAC har även drivit rättsprocesser mot den tidigare presidenten Thabo Mbekis regering som motsatte sig bromsmediciner inom den allmänna hälsovården. Sydafrika har idag det största bromsmedicinprogrammet i världen genom den allmänna hälsovården, vilket många skulle hävda att är TACs förtjänst. Idag kämpar TAC för att detta program på allvar implementeras överallt i Sydafrika, men mobiliserar även globalt för tillgång till bromsmediciner och hälsovård.

Det empiriska materialet för studien av TAC insamlades mellan åren 2000 och 2006 genom en etnografisk studie främst i Kapstaden, men också i andra delar av Sydafrika. Studien har inneburit deltagande i demonstrationer, civila olydnadskampanjer, rättegångar, nationella och internationella konferenser samt workshops, offentliga begrävningar av TAC-aktivister och intervjuer med TAC-aktivister. Att följa TACs arbete har varit berikande för mig som

feministisk forskare eftersom studien har lett mig till många nutida feministiska diskussioner. TAC håller fast vid att det personliga är politiskt, en välkänd feministisk slogan, som fortfarande visar sig vara dagsaktuell.

När hiv-positiva kvinnor i sydafrikanska kåkstäder yrkar på att deras hälsa måste gå före de multinationella läkemedelsbolagens vinster utmanar de den dominerande synen på medicinsk behandling som ett snävt mål. Istället visar deras protester på att medicinska ingripanden är en del av en social intervention. Deras kamp för mediciner synliggör därmed globala orättvisor, detta i bjärt kontrast till de teorier som visat hur medikalisering effektivt ofta döljer maktstrukturer. Medan över 15 000 aktivister demonstrerade för tillgång till bromsmediciner på gatorna i Kapstaden 2003, diskuterade samhällsvetenskapliga hälsoforskare främst prevention som bekämpning av epidemin i Afrika, eftersom medicinska interventioner ansågs som för komplicerade eller dyra.

Förutom att åskådliggöra att bromsmediciner är ett realistiskt, självklart och nödvändigt alternativ även för afrikaner har TAC-aktivisterna även visat på vilket sätt bromsmediciner är en viktig del av preventiva åtgärder. "Behandling är prevention" hävdar aktivisterna och visar hur tillgång till mediciner gör att hiv/aids destigmatiseras, då människor med hiv lever längre och en hiv-diagnos därmed inte lika omedelbart kopplas till sjukdom och död. Att förhandla om säkert sex blir då lättare. Dessutom har studier visat att människor som tar bromsmediciner löper betydligt mindre risk (rentav 90% mindre risk) att föra smittan vidare i sexuella relationer.

Studien visar även att samhällsvetenskapliga hälsoforskare gynnas av att fokusera på aktivism i sin forskning och hävdar att radikalare frågeställningar som till exempel utmanar diskurser om en speciell "afrikansk aids" aktualiseras. Hiv/aids är laddat både i västvärlden och den globala södern eftersom sjukdomen är kopplad till en mängd maktstrukturer som hetero- och homosexualitet, sjukdom, död, mediciner, kön, våld och Afrika. Avhandlingen situerar och läser aktivisternas kamp i dessa kontexter som består av en rad paradoxala diskurser. Studien för en diskussion främst med hälsoforskning, men grundar sig på postkolonial och feministisk teoribildning.

Förutom den konkreta kampen om bromsmediciner handlar TACs aktivism också om en kamp om representationer. Afrikanska aktivister utmanar representationerna av anonyma aids-offer, som saknar aktörsskap. När TAC-aktivister demonstrerar för tillgång till bromsmediciner också för den fattiga delen av världen, klädda i T-skjortor med texten "HIV-POSITIV", är de offer på samma gång som de är globala aktörer för en rättvisare värld. Detta utmanar i sin tur det dikotoma tänkandet kring aktörs- och offerskap, som länge dominerat diskursen om hiv i Afrika. I TACs arbete dekonstrueras också de ofta skarpa kontrasterna mellan expert- och lekmannakunskap, eftersom TAC belyser på vilket sätt läkare, patienter och aktivister samarbetar för en fungerande hälsovård. "Då kan du och din sköterska och din doktor bestämma" vad som skall ändras i medicineringen, säger en TAC-aktivist när han yrkar på vikten av att direkt rapportera eventuella biverkningar av bromsmedicinerna till hälsovårdspersonal.

I denna studie är metodologiska frågor centrala. En viktig fråga inom feministisk metodologi är hur man tar i beaktande svårigheterna eller det omöjliga i att synliggöra vissa erfarenheter. En annan relaterad frågeställning är: Hur skriver man om TAC-aktivisterna på ett etiskt sätt? Frågor kring ansvar och makt är centrala i en etnografisk studie. Detta betyder att frågor i denna studie också ställs om forskarens position och praktik. Studien hävdar att en analys av forskningens brister är central, på samma gång som forskaren måste vara medveten om att en fullständig sådan redogörelse inte är möjlig.

Även om TACs kampanj handlar om tillgång till läkemedel och kontroll över representationer om Afrika, handlar deras kamp i lika hög grad om demokrati eftersom den synliggör den globala dimensionen av hälsa och sjukdom. Genom att kontrastera aktivistdiskurser mot akademiska diskurser visas hur aktivisterna utmanar ett ofta dikotomt tänkande kring kategorier som socialt/medicinskt, prevention/behandling och aktör/offer. Detta möjliggör i sin tur att bättre förstå, behandla, förebygga och leva med hiv i lokala och globala samhällen.

---

---

## Dissertation Articles



### Article 1

Jungar, Katarina & Oinas, Elina. 2007. Hiv-aktivism som postkolonialt motstånd. In: Oinas, Elina & Ahlbeck-Rehn, Jutta (eds.). *Kvinnor, kropp och hälsa*. Stockholm: Studentlitteratur. pp. 215-235.

### Article 2

Jungar, Katarina & Oinas, Elina. 2010. A Feminist struggle? South African HIV activism as feminist politics. *Journal of International Women's Studies*, 11(4),177-191. [Available online: <http://www.bridgew.edu/soas/jiws/May10/index.htm>]

### Article 3

Jungar, Katarina & Oinas, Elina. 2011. Beyond Agency and Victimization: Re-reading Women's Embodied Experiences. *Social Dynamics*, 37 (2), 248-262.

### Article 4

Jungar, Katarina & Salo, Elaine. 2008. "Shop and Do Good". *Journal of Pan African Studies*, 2(6), 92-102. [available online: <http://www.jpanafrican.com/archive.htm>]

### Article 5

Jungar, Katarina & Oinas, Elina. 2004. HIV prevention? – Medical Discourses and Invisible Women. In: Arnfred, Signe (ed.). *Re-thinking Sexualities in Africa*. Uppsala: Nordic Africa Institute. pp. 97-111.

---

---

## Acknowledgements

First of all, I want to thank my supervisor Professor Harriet Silius for granting me intellectual freedom and for being critical as well as encouraging throughout the process of writing this thesis. My other supervisor, Dr Kattis Honkanen, has generously shared her wisdom, time and insights. To avoid the risk of becoming sentimental when thanking Kattis, I quote one of my colleagues: “Kattis’ comments and ideas are at once creative, challenging and supportive – and usually unique” (Tuori 2009). Professor Elianne Riska was briefly my supervisor at a very early stage of the study, and I want to thank her for introducing me to significant bodies of work. Thanks are also due to Professor Mikko Lagerspetz who provided me with key support and supervision in the final stages of the study.

The Department of Women’s Studies at Åbo Akademi University, and the seminars at this department, were my most important intellectual collective throughout the study. I feel very fortunate to have had such a working environment. Thank you Jutta Ahlbeck-Rehn, Eve Hed-Kattelus, Kattis Honkanen, Pauline Hortelano, Sari Irni, Katarina Leppänen, Xin Liu, Suvi Keskinen, Marika Kivinen, Mickan Kinnari, Kristin Mattsson, Elina Oinas, Lotta Palmgren, Salla Peltonen, Malin Siimes, Harriet Silius, Salla Tuori, Mia Österlund, Ann-Catrin Östman, Faith Manyonga, Mia Franck, Janis Barry, Albina Gakuru-Hipp and Jenny Wikström. Docent Elina Oinas, with whose cooperation much of this study was done, needs to be thanked for opening the field of women’s health to me, and also, for her wise, insightful and challenging comments and co-writing style. I also want to thank Dr. Elaine Salo for her sharpness and inspiration, while co-writing one article with me.

Furthermore, I wish to thank the following people who read through various versions of this manuscript: Jutta Ahlbeck-Rehn, Katarina Leppänen, Ralf Kauranen and Professor Maria Olausson. Salla Peltonen and Sari Irni helped me with parts that I found especially difficult. With great patience, Jutta read sections of the thesis in various stages and contributed with invaluable wise and creative comments. The pre-reviewers Dr Lindsay Clowes and Dr Anu Hirsiaho worked hard and gave insightful and valuable comments.

In addition, I wish to thank Ann-Louise Grönholm for being the best librarian ever, Graeme Arendse for the layout and cover of the book

and Lannie Birch for all the editing over the years. Lannie did much more than editing. She clarified arguments and pointed out problems in text and thoughts Lannie-style i.e. with utter carefulness and rough enough humor. Thank you to Janice Barrett and Lannie for being so professional in the editing of the summary. I also wish to thank Monica Nylund and Mia Österlund for helping me with the editing. Also, Mia's never-failing encouragement and support has been invaluable.

At the Department of Sociology at Åbo Akademi University, I wish to thank Professor Mikko Lagerspetz, Professor Susan Sundback, Thomas Heikell, Jan Wickman, Andreas Häger, Lise Kanckos, Catharina Lojander-Visapää, Kirsti Suolinna and Solveig Bystedt.

The Women and Gender Studies Programme at the University of the Western Cape, especially Professor Tammy Shefer and Dr Desiree Lewis, were very generous in accepting me as a visiting scholar and in making me part of an inspiring collective. Thank you to Chris Stander who was my supervisor while writing one of the articles in Cape Town.

I wish to thank Signe Arnfred and Mai Palmberg for organising important networks in Gender and Cultural Studies at the Nordic Africa Institute. These networks gave me the opportunity to take part in many inspiring seminars and workshops. I am grateful to book editors, journal editors and referees, who read and commented on the article manuscripts. I especially want to thank Desiree Lewis for her careful, generous and wise reading of the third article.

I want to thank the following agencies and foundations for the financial support that gave me the freedom to conduct my research both in Finland and South Africa, and especially my empirical study in Cape Town: Academy of Finland (79687), Ella and Georg Ehrnrooth Foundation, Otto A. Malms Donationsfond, Oskar Öflund Foundation, Waldemar von Frenckell Foundation, Research Institute of the Åbo Akademi Foundation for several travel grants to conferences, Nordic Africa Institute for travel grants and research visits, and the Rector of Åbo Akademi University.

I have mentioned people who helped me cope with the text, but there are also people who need to be thanked for helping me cope

with life. Some of these people helped me with both: Lannie Birch and Peter Kohler, Anki Hellberg-Sågfors, Alexandra Jacobs, Leena Keisala, Marilyn De Klerk, Malin (for daily conversations and Sunday lunch!) and Esa Siimes, Nathalie Siimes, Marika Uggeldahl, Shirene Rosenberg, Koresh Wessels, Mia Österlund, Amina and Mustafa Maluka, the aunties Uta, Thandi and Esther Wessels, Mortimar De Boer, my brother Måns Jungar and my sister-in-law Tina Jungar, Ouma Nabawaya (Nabs) Wessels and Oupa Chris Wessels (who both know what struggle, activism and organising mean in practice), and especially my mother, Birgitta Jungar, for providing me with feminist thoughts from girlhood onwards and my father Håkan Jungar for the insight he has given me from first being a health professional, to later being a health activist while living with a chronic illness. My partner Christopher Wessels and our children Amílcar and Leila, I want to thank for being such cool company. Thanks also to Christopher for many illuminating discussions about activism and life in South Africa and Finland.

Åbo Kvinnojour/Turku Women's Helpline has been another important collective, where I have learnt, together with activists like Kattis, Salla P. and Marika, what (shelter movement) activism means in practice.

The most important thanks are due to the Treatment Action Campaign. TAC activists who I especially want to thank are Midi Achmat, Fredalene Boyseen, Nomfundo Dubula, Thembeka Majali, Colwyn Poole and Theresa Raizenberg.

I dedicate this study to the TAC activists.







The Treatment Action Campaign is a South African health movement that addresses issues around access to health care locally, nationally and globally. Activism for access to antiretroviral treatment for poor people living with HIV reveals the global politics of health and disease. This study, based on extensive ethnographic work, shows how activists challenge dichotomies between the “social” and the “medical”, “treatment” and “prevention”, or between “agents” and “victims”. Their struggle is equally about representation, which is perhaps best illustrated by their ‘HIV POSITIVE’ T-shirts, which are worn by all activists, and thus blur the boundaries between the infected and the assumed non-infected. TAC activist living with HIV are global agents of change, and their critiques clearly demonstrate that theories of health and illness that lack an intersectional perspective will fail to explain the complex connection between race, class, gender and global power structures.