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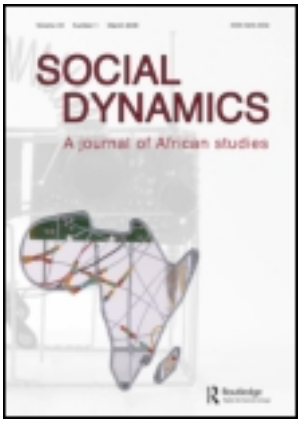

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Beyond agency and victimisation: re-reading HIV and AIDS in African contexts

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Beyond agency and victimisation: re-reading HIV and AIDS in African contexts

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We explore a range of projections that, we argue, are increasingly characterising much applied research on and popular representations of HIV/AIDS, gender and embodiment in Africa. Showing how the image of the victim is being challenged by a growing emphasis on agency, we identify continuities between these approaches. It is argued that both the insistence on victimisation and the celebration of agency naturalise neo-liberal ideas about the autonomous individual. Our paper reflects on our work on the South African Treatment Action Campaign (TAC), focusing on how we have confronted issues such as research design, reflexivity, methodology and ethics. We also show how TAC activists have redefined entrenched ideas about agency and victimisation. In developing a language and politics of activism that radically unsettles conventional understandings of embodied acts in the context of the HIV epidemic, TAC raises challenges for research, writing and media representations of embodiment and social marginalisation in African contexts.

Keywords: agency; HIV/AIDS-activism; reflexivity; stranger fetishism; Treatment Action Campaign; victimization; *Yesterday* (film)

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Introduction

Yesterday (Roodt 2004), the award-winning South African film, presents as main character a young mother living with HIV who heroically struggles in an environment in which she receives little support. Living in a village in KwaZulu-Natal, a province with one of the highest HIV infection rates in South Africa, the eponymous woman seeks treatment for a persistent cough. Following a number of failed attempts to see the doctor at a regional clinic, Yesterday is finally diagnosed. When she discovers that she has contracted HIV from her husband, a migrant labourer who works in mines, she tries to inform him of his own status. He aggressively refuses to accept the truth, but, after becoming progressively sicker, he returns to her. Yesterday ends up caring for her sick husband, their young daughter and herself. Determined not to give in to the disease until her daughter starts going to school, she resolves to give her daughter opportunities that she never had.

The character's portrayal – as a strong, resourceful actor whose determination and resilience cannot change the inevitability of the epidemic – captures the dilemma we wish to discuss in this article: the troubling dualism of victimisation and agency in many representations of contemporary embodied experiences of disease and social marginalisation in Africa. *Yesterday* is a film that provokes

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intense emotional effects. The simultaneous defeat and courage of the central character's struggle leaves the viewer with a troubling combination of responses: admiration for her strength in the face of formidable challenges, coupled with pity for her entrapment in circumstances that she cannot change.

Although activists have pointed out that the film neglects important factual attention to the context of Yesterday's story, for example the anti-retroviral medication as a life saving option, it *does* tantalisingly identify the different social circumstances that influence her experience of living with AIDS: her poverty, and the way in which this affects her diagnosis and access to health care; her distinctively gendered vulnerability to infection; the role of long-established migrant labour systems in influencing high HIV infection rates in southern Africa; the multiple pressures on women living with AIDS to care for the sick in the absence of adequate healthcare resources and facilities; and, the fear that has driven violent denialism and stigma. While these patterns shape the broader context the film refers to, it is noteworthy that the story's action and agency revolve entirely around a single character's courage in dealing with the personal challenges that directly confront her. The broader context, one which ultimately shapes her unique suffering, goes unchallenged. Thus, the image with which the film begins and ends, of Yesterday walking along a road, conveys the simultaneous hope and hopelessness of its message. We wish to discuss a set of questions that are related to the contradictoriness of the film's message and that, we believe, continue to haunt many interpretations and images of women's embodied experiences in African contexts. In the context of the HIV epidemic and its politics, these questions concern how to depict voices and subjective experiences, while confronting suffering in a meaningful way.

The image of 'the victimised woman', and the debate about how to deal with it, is a recurrent theme in feminist scholarship, especially in applied research on gender-based violence and HIV/AIDS in Africa. One response, which has become especially prominent in current donor-driven research and project work, is the simple denial of victim status: women should *not* be viewed as victims; they are *agents* of their lives. For us, researchers based in the global North, anxieties about replicating stereotypical images of suffering in the South, the imperative of politically-responsible research on areas affecting subjects' lives and discourses of aid are the unavoidable and often contradictory frames influencing our perspectives. In negotiating these frames, we have sought to contribute to critical feminist work on gender and embodiment in the context of the HIV epidemic in Africa. Some of our earlier work interrogated racist and gendered representations in arguing that their constructs of Africa, African sexualities and African women perpetuate stereotypes of devastated, passive, pathological and lost bodies (see Jungar and Oinas 2004). Yet we have also been prompted to ask a number of questions that complicate any straightforward adoption of analytical perspectives now deemed non-exploitative, politically-correct and relevant: Are there ways of exploring social subjects and contexts by drawing on theories of subjectivity, agency and social structure often associated only with esoteric theorising? Are we pushed to either-or dualisms by the logic of culturally entrenched thinking about the self, as well as the political and intellectual efforts to correct this? If the attempt to regard the individual as situated has long been central to social science research, why is it still so easy to fall into the logic of bifurcating agency and victimisation in popularised discourses on and responses to embodied experiences of disease in Africa?

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In this article we wish to discuss the victim emphasis as well as its challenger, the 'agency approach', as two sides of the same coin: a problematic focus on the socially dislocated individual. The emphasis on celebrating individual agency was a needed critique of representations of African women merely as victims of disease, violence and/or poverty (see Raimondo and Patton 2002). The increase in writing and policy that questions assumptions about women's victimisation has also been influenced by the expansion of strategies and discourses for driving 'women's empowerment' and 'gender transformation', especially in developing countries (Gouws 2004; Rai 2003; Adomako Ampofo and Arnfred 2009; Lewis 2009). It is also an expression of the increased visibility of grass-root activism in research. The celebration of agency therefore appears to be a definitive response to the need for non-exploitative and ethically accountable ways of knowing. Responding to the messages of victimisation, catastrophe and loss in traditions that have been critiqued by scholars such as Cindy Patton (1997), these ways of knowing about Africa and HIV/AIDS are creating a new constellation of images and messages in popular media, as evidenced in *Yesterday* as well as applied and policy research often associated with NGOs and developmentalist work.

However, we want to argue that, despite its apparent policy relevance and rhetorical attractiveness, the agency–victim dualism is a counterproductive one which leads to a political cul-de-sac. Furthermore, while there appears to be a marked difference between presenting women as victims on one hand, and celebrating their agency on the other, the two currents reveal very similar assumptions. Through reflections on our own research project, we confront the limitations and politics of a dualistic approach in relation to methodological and conceptual issues raised in our research with activist women. This article therefore proceeds by first reflecting on a form of reflexivity that encourages both acknowledging *and* questioning the power relationship that leads us to project images of ourselves in our research about others. It goes on to explore how deeply and obliquely power relations can be embedded in work describing others' embodied experiences. Finally, in the last section, we review some conclusions based on our work on the political agendas' of activist women, the Treatment Action Campaign (TAC) and HIV/AIDS in South Africa.

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Learning to learn about ourselves

The TAC was founded in 1998 when a small group protested in Cape Town for access to antiretroviral drugs for pregnant women to reduce the risk of transmitting HIV to their babies. Of the 20,000 members of the campaign the majority are black women from marginalised communities (Robins 2004). The campaign draws from the legacy of the anti-apartheid movement, a history that, according to Steven Robins (2004, p. 666), provides the movement with an 'organizational memory' of how to mobilise people to work towards a progressive and democratic civil society, including 'health citizenship'. Our fieldwork led us to the streets of Cape Town doing ethnography with the HIV activist women involved in the movement. Our empirical data includs participant observation in rallies, at national and international conferences, official meetings, workshops, public funerals, church services and marches. These events, about 40 in all from 2000 to 2006, were taped and transcribed. Interviews were conducted with informants including women activists, volunteers, health workers and researchers. Public TAC documents, the Campaign's

newsletter, web page and media coverage of their activities also constituted part of the empirical material.

At the outset, in 2002, our research aim was not to study women's activism or lives with HIV, but the macro-level politics of HIV that for us seemed to counter many of the assumptions of medicalisation literature within the sociology of health and illness (see Jungar and Oinas 2010). The challenge we confronted was how to tell 'stories that belong to others' (Lather 2002, p. 203) in non-exploitative ways. Attempts to foreground others' voices and their counter-practices of knowing were, however, only partially responding to the politics of our research design and writing. We have constantly struggled to research the 'stubborn materiality of others' (Lather 2002, p. 202) without falling back compulsively on stereotypical ways of identifying and interpreting them.

Members of the TAC use the familiar rhetoric about claiming agency; indeed the indictment of 'victim' recurs: 'We must not be seen as victims, we must be seen as the people who are living. That is why we say we are living with HIV/AIDS. Not people with HIV/AIDS. We are people living with HIV/AIDS'.[1] The sense of energy and determination in TAC gatherings was palpable, and easily supported the romantic feminist image of triumphant and wholly independent women. Many activist women are deeply committed to HIV literacy, to seeking and generating knowledge on HIV and its treatment. They educate communities, debate in the media and are involved in legal battles with different sources of authority and opposition: the South African government, AIDS dissidents and multi-national pharmaceutical companies (see Mbali 2005). Their determination was also inspiring in the context of the panic generated by national and global anxieties about the epidemic; participating in rallies and witnessing the TAC women encouraged our sense of optimism in people's capacity to confront the HIV epidemic.

Yet, during our ethnographical fieldwork, it became increasingly clear to us that to describe an activist in terms of her personal ability to, for example, make choices in her private life was simply reductive and presumptuous. Inherent in the appreciative applause of her agency is a troubling power dynamic which belies the impression that her subjectivity is being acknowledged. The celebration of 'her' individual agency that 'we' can detect is created within a hierarchy of power: we claim the authority to define her as an autonomous individual while also making assumptions about the sameness of the actions, codes and values that constitute agency. Whether this is based on a confirmation of our codes, or whether this derives from our desire to recognise these codes in others, research and writing that judges others' individual agency inevitably objectifies others as projections of our struggles and goals. Our need for clearer research ethics informed by scrutinising the politics of representation led us to consider dilemmas beyond the mere acknowledgement that we should neither speak for nor to others. Literature that we have found useful ranges from philosophical critiques of Enlightenment modernity to postcolonial theory and feminist epistemology. This has provided routes for us to re-read others' embodied experiences in terms which we believe to be practical and highly relevant to applied research.

Patti Lather's (2002) work on Ohio women in HIV support groups, has provided an especially useful starting point. Lather writes about non-mastery as an ethical move, and the possibilities of non-mastery as a practice of constantly trying to take into account one's limitations. She draws attention to the need to be aware of the fact that a full account of one's limitations is not possible; it is crucial to reflect on

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what it means that knowledge is situated and partial. The methodology associated with this requires us to situate our knowledge and to reflect upon the practices of our knowledge. This does not simply mean an acknowledgement that we are Finnish, white, middle-class scholars doing research on the activities of working-class or unemployed poor African women, many of them living with HIV/AIDS; nor does it refer to the obvious fact that this configuration creates specific ethical considerations. Reflexivity here means that we as subjects, and the accounts we generate, are thoroughly and inevitably embedded in power relationships. We are not merely implicated in them; we materialise through them (Butler 1993). We describe the HIV activists as being part of a 'reality', but at the same time register awareness of the fact that our analyses, politics and methods also construct a particular, and limited, narrative about the TAC and about ourselves. Before going on to deal with the implications of this reflexivity in our work, in the following section we analyse the prominence and implications of the dualism of agency and victimisation in examples of recent work on women, gender and HIV/AIDS in Africa.

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Desperate agency and circumstances of vulnerability

In the context of HIV and Africa, the turn to celebrating women's agency began from a critique of damaging representations of third-world women as silent and abject figures (Patton 1997). The argument goes that women are active in different, often difficult situations, and research should emphasise what women do in response to hardship; it should, for example, foreground women's different coping strategies. In the move where individual agency is foregrounded, however, the rhetoric of agency is merely superimposed on the structural analysis. In many ways, this amounts to the use of a triumphant formula of individual determination that is rooted in Enlightenment ideas (McNay 2000) alongside evidence which actually testifies to profound deep victimisation.

This tendency is exemplified in an article by Janet Wojcicki and Josephine Matalala (2001) on sex workers and the risk of HIV in Johannesburg. It should be stressed that this article is not particularly problematic or special, but it is a typical, respected piece of work within an influential tradition on gender-related health issues in African contexts. The following excerpts show how victimhood needs to be constantly defended against, and how the non-passivity of the actor is insistently created. The argument about agency is sustained by the rhetoric of repetition: here, literally, truth effects are produced through 'reiterative repetition' (Butler 1990, p. 140). The extracts are quoted at length to highlight the extent to which women's 'agency' is painstakingly constructed through language:

> This project *does not simply conceptualize the sex-worker as victim* of her circumstances and powerless in her interactions with clients, managers and other sex-workers … Rather, we emphasize the bargaining that commonly occurs in negotiating condom *usage so as to move beyond the prostitute (and woman) as 'victim' imagery* … By emphasizing the victimhood of sex-workers and women in general, past studies have failed to *recognize women as decision-makers and as actors* and contribute to an overall negative discourse. (Wojcicki and Matalala 2001, pp. 101–102; emphases added)

Shifting from the image of the triumphant actor to the resourcefulness of her action, Wojcicki and Matalala emphatically ascribe choices, rational motivation and free will to their subjects.

> In short, many of these women who *choose to have unsafe sex* engage in these practices as a sort of irrational, depressed response to life's predicaments. As we have mentioned, they often do not have strong educational or employment backgrounds. However, *to argue that these women are only victims of sexism, racism and poverty dismisses the notion that these women are making decisions*, albeit at the micro level. *. . . Some women are manipulative and deceptive* in their attempts to get more money from clients. These behaviours clearly indicate that these women *are making decisions to advance their own interests*. . . These examples demonstrate that sex-workers are *not passive victims but rather actively participate in the power struggle* that often exists between sex-workers and their clients. (Wojcicki and Matalala 2001, p. 112; emphases added)

Similar strategies are at work for example in an article by Margarethe Silberschimidt and Vibeke Rasch (2001), on Tanzanian girls who have had illegal abortions. The word victim is not mentioned, but agency and victimhood are explicitly defined in diametrical opposition to each other. This article, a qualitative study of 51 adolescent girls in Dar es Salaam, reveals that these girls are not simply acted upon by circumstances, but often willingly make particular choices and are 'active social agents engaging in high-risk social behavior.' (Silberschmidt and Rasch 2001, p. 1815).

In both the above works, the conclusion is that agency is the quality of the individual person. The rich interview data the researchers have managed to collect does therefore not lead to conclusions beyond a repetitive assertion that however much women are suffering and in despair, these women *are* agents of their decisions. The data reveals the great complexity of subjects' lives, and the extent to which numerous circumstances constrain and determine their actions. Paradoxically, the continuous emphasis on 'agency' alongside, and often in direct contradiction to, the women's own accounts of their despair and hopelessness, makes these women seem more tragic. Despite the assumptions about sameness and shared goals, their lives, actions and choices may therefore appear to many readers to be quite unintelligible. For example, within the framework of the universalistic understanding of rational motivation constructed in the text, taking risks with unsafe sex for small sums of money is not 'obviously' rational. Consequently, the categorical identification of 'agency' can leave many readers feeling alienated, unable to recognise the (implicitly) universal non-victimhood of all women which the texts assume and advocate.

It is important to ask what happens when the victim-woman is first established and then negated within one sentence. Does victimhood disappear the moment the text decides to disclaim it? Or is the statement an obvious gesture that the writer needs in order to attest to political correctness? What is clear is that 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. When focusing on individual agency, the analysis operates by conflating it with choice-making, while juxtaposing this with extensive evidence of subordination. Even if the sex workers discussed by Wojcicki and Matatala (2001, p. 110) do indeed 'take advantage of clients', this does not explain the selective attention to their 'bargaining' abilities and choices, rather than to the other circumstances of their lives. In the attempts to revive the individual agent, the social is both downplayed and sedimented as a separate, even more powerful entity (Butler 1997). The consequence is that individuals are made responsible for the spread of the epidemic

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by an emphasis on behaviour choices (Bujra 2000; Gilbert and Walker 2002; Jungar and Oinas 2010).

There is of course also a wealth of social science research on women and HIV that does not insist on the centrality of individuals' agency. Leah Gilbert and Liz Walker (2002) use the concept of 'vulnerability' to avoid the figure of the helpless victim-woman. They employ the familiar rhetoric contesting victimisation to state the problem, but find a different route out of it. By highlighting how decisions are formed in a context, within the environment that restricts and influences subjects' choices and actions, it is possible to understand the ways in which women's lives are shaped – how inequality operates in and through the bodies of women. They write:

> [T]here are forces beyond the control of the individual women which influence their capacity to alter or change individual behaviors (their own or their sexual partners'). Freedom of choice of lifestyles is thus restricted by the environment, reiterating. . .that the explanations for the development and outcomes of the epidemic should be based on an integration of cultural/behavioral and materialistic approaches. (Gilbert and Walker 2002, p. 1106)

Gilbert and Walker's insights highlight the starting point of feminist research and writing. Politically-oriented feminist research has explicitly set as its goal an analysis of the difficulties and constraints that limit women's lives, because these can and must be changed. That women still make decisions and choices is not questioned, and this does not have to be presented as a research 'finding'. The reasons for the determined ways in which certain writers have foregrounded constructions of women's agency therefore requires more attention. This is particularly important when, as the film *Yesterday* makes clear, confounding images of courageous women, whose actions are severed from their deeply oppressive circumstances, are often popularised in widely-disseminated media. The next section explores the origins and political effects of this image, and explains how we have drawn on Sara Ahmed's (2000) postcolonial feminist work in seeking to transcend it.

Whose agency?

Albeit accountability is a theme fraught with tensions, we read Judith Butler's (1997, pp. 46–50) work as an invitation to ask what our scholarly discursive practices produce. The performative act of a research design and our descriptions of informants accomplishes specific projections and trajectories. In research that celebrates the agency of women and erases their constraining circumstances, the subject of the research is greeted with a warm welcome as she successfully 'passes' as a similar agent (or so we believe) to 'us', the researchers and their potential audience. What is constructed, then, is the idea of both researcher and research subject as the dynamic modern sexual negotiators who are not powerless. Yet, to which cultures do such descriptions of sexual agency really ever apply? Can sexuality, anywhere, be framed in those terms? Are there such heroic women? Can we recognise ourselves in such a depiction? Not really, but we recognise a political utopia that is dear to us.

Ahmed (2000) warns that such performative acts, often unintentionally, create the fiction of triumphant neo-liberal selfhood. The welcome is an act of self-creation of 'us' as strong women. The heroic agents, for example, Wojcicki and Matalala's

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sex workers in Johannesburg, are recast as self-determining despite their desperate decisions. Consequently, the fiction of agency comfortingly endorses neo-liberal individualism; it takes neither the researcher nor the reader into the dangerous territory of 'not knowing', a territory which Lather (2002) urges us to inhabit. Paradoxically, too, the protagonist in the narrative which ostensibly deals with 'her' agency is us. It is 'we' who have the power to welcome her to join 'us'.

According to Ahmed, the figure of the agent-woman is a fetishised stranger. She is a product of a discursive regime; one that does not defy the discursive production of either the tragic, less competent agents (often of the South) or that of powerful women (implicitly of the North). This construction is hardly motivated by the researcher's conscious assumption of power. In fact, advocates of this approach attempt to change, radically, existing power relations. The problem is that existing and historical power relations, as well as the fictions that mystify and sustain these, are denied and obscured in the declaration that 'we are all agents'.

With stranger fetishism Ahmed refers to the practices whereby the 'non-strangers' produce the strange in order to state something about themselves. Often the stranger appears to be appreciated as an autonomous subject, but Ahmed argues that dilemmas of representing others' embodied experiences revolve precisely around the act of 'welcome'. It is exactly this welcoming act that also produces the strangeness, the fetish. When loving the stranger, one actually loves oneself loving the stranger (see hooks 2000). A problematic way of neutralising the encounter is through the assumption that 'we are all strangers'. But neutralisation succeeds only in helping to avoid dealing with the political processes whereby some others are designated as stranger than others (Ahmed 2000, p. 6).

Ahmed (2000, p. 8) suggests that we 'reopen the prior histories of encounter that violate and fix others in regimes of difference'. By this she means that the social relationships and circumstances that create differences must be put under scrutiny. With stranger fetishism, these processes are concealed, but it is possible to 'consider how the stranger is an effect of processes of inclusion and exclusion, or incorporation and expulsion, that constitute the boundaries of bodies and communities, including communities of the living … as well as epistemic communities' (Ahmed 2000, p. 6). Interrogating and exposing the researchers' encounter with strangers should therefore disrupt the safety of 'home', the way the vantage point of the researcher provides a safe epistemic home (see also Mohanty and Martin 1986).

A belief that we can make sense of another person's self-expression, that we can 'simply hear what she has to say' (Ahmed 2000, p. 144), is therefore seen as disrespectful. We continue to assert our power and agency when fantasising about listening carefully to her across the inevitable distance. Rather, we should acknowledge Ahmed's ethics of recognition – that is, for example, the recognition of weakness and lack of power. For example, HIV positive women in impoverished circumstances are not understood in an ethical and respectful way when it is insisted that they, too (like we writers, researchers and policy-makers), are agents, while at the same time their 'choices' appear limited to us. If oppression and lack of power to make choices is a part of the context of her life, it should not be erased by glorifying her assumed agency. Rather, an acknowledgement of lack of power to make choices, and sometimes lack of agency, becomes an ethical way of reading her *situation*. Her person, in contrast, is left at a distance. Powerlessness is therefore not attached to her as an individual, as a personal shortcoming, but as an outcome

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of a historical context. Urging the necessity to identify and speak out strongly against the conditions that lead to others' 'subalternity' at the same time that one avoids speaking for them, Gayatri Spivak says in an interview:

> Who the hell wants to museumize or protect subalternity? Only extremely reactionary, dubious anthropologistic museumizers. No activist wants to keep the subaltern in the space of difference ... You don't give the subaltern voice. You work for the bloody subaltern, you work against subalternity'. (de Kock 1992, p. 46)

Our commitment to studying the processes of power that shape the contexts in which women act is not a call for a return to structuralist determinism, where all experiences are rendered to their structural backdrop. When leaving a description of who the woman research subject 'really is' to the domain of uncertainty, the researcher can attempt to sketch out the context behind a certain encounter. What can be done is an examination of the socio-economical-cultural context in which the description of her response or action took place. According to Ahmed, relevant 'prior encounters', such as prior racism and poverty, must be acknowledged. An ethical analysis of, for example, interview accounts takes the broader social processes as its starting point, and goes beyond the particularity of this meeting. The encounter is located in space and time. Thus, Ahmed (2000, p. 145) urges us to inquire: 'What are the conditions of possibility for us meeting here and now'. Ethical research encounters do not attempt to 'grasp' and present the woman whose life is being described. They aim at describing and deconstructing asymmetrical relations that mediate the encounters. The interview account is therefore not presented as a static description of an individual as though she were in a museum showcase, or as the subject's complete 'reality'. In what follows, we deal with the ways in which TAC activism challenges influential interpretations of women's embodied experiences in relation to the HIV epidemic, and how it has guided our encounters with 'the strange'.

Strange encounters: working on the TAC

Ahmed's elaboration of the work of Spivak has offered us a theoretical and methodological vocabulary with which to untangle our responses, at times driven by emotion, to TAC activism. In short, Ahmed looks for 'encounters with a stranger' that avoid 'stranger fetishism'. Neither investigating an abstract woman's possible agency, nor trying to represent her as carefully and closely as possible, can be satisfactory, ethical research objectives if one is to take questions about the power embedded in performative acts seriously. The HIV treatment activists whose work we followed can be interpreted in a frame that focuses on individual agency. But during our fieldwork we began to see that other ways of framing agency may be more sensitive to the political agenda they try to put forward. During the rallies and speeches, activists celebrate their ability to transform their citizenship from marginalised people to political actors. What is also significant, however, is that agency is collectively defined in TAC politics, even when it clearly has individual implications. The TAC argues that HIV is a virus that affects all South Africans; it affects the society as well as individuals. The epidemic demands urgent action, including general knowledge about and access to anti-retroviral treatment, which has changed the face of AIDS in wealthier parts of the world. Moreover, the TAC is a mass movement and a community of people, a community that influences individual

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lives. One march can engage 15,000 supporters, like the Treatment Access Rally in Cape Town in February 2003.

The individual activist's agency is therefore embedded in a rich web of relations in which this agency takes shape. The TAC acknowledges this in the way its songs have displayed a sense of community, a 'we', that includes the non-infected. The t-shirts stating HIV POSITIVE, that became symbols of solidarity in South Africa, are worn by all, without distinction of who carries the virus and who does not. When worn by celebrities, doctors and patients, they indicate a move away from identity politics. The TAC could have chosen a strategy typical for patient movements (see, for example, Crossley 2006) where only people living with HIV are members and where a sense of community defined through a life as HIV positive is transformed into a collective force for identification. They *do* occasionally also stress such identity politics, as in Sipho Mthathi's statement that 'as long as people with HIV are not in the front of the struggle [against HIV], this struggle is not going to be won'.[2] In general, however, the TAC affirms a politics of establishing communal connections, irrespective of individual experiences in relation to HIV (Oinas and Jungar 2008).

The individualist framing of 'responsibility' in the context of the HIV epidemic is also contested by shifting the focus away from prevention to treatment. The movement has challenged many influential discourses about HIV in public policy, media reports and research literature, many of which focus on prevention, and carry messages of individual behavior change (Jungar and Oinas 2004). The TAC raises HIV from being a matter of individual behaviour to the level of the political (Oinas and Jungar 2008; Jungar and Oinas 2010), with demands for health care and medication unsettling the automatic assigning of blame to those with the disease and giving responsibility to the healthy to protect themselves from 'the sick'. Campaigning for access to medication therefore aspires to strengthening civil society and revitalising the political landscape of democracy.

TAC has unsettled entrenched neo-liberal understandings of 'agency' not only by locating it in the collective; it has done so also by re-shaping the meanings of victimisation. The TAC activists argue that prevention and treatment of HIV/AIDS are two sides of the same coin; similarly, they show that the victim and agent positions are also interconnected. For example, Zackie Achmat, as former chairperson of the TAC, has articulated experiences of vulnerability and subjection not in the disempowering ways in which 'agency feminism' is concerned about. As he shows, identifying victimhood enables resistance; it does not pre-empt agency:

> Our bodies are the evidence of global inequality and injustice. They are not mere metaphors for the relationship between inequality and disease. But our bodies are also the sites of resistance. We do not die quietly. We challenge global inequality. Our resistance gives us dignity. In the Treatment Action Campaign (TAC), the voices of our comrades, friends and children echo around the world to resist injustice. Our voices demand life even as our bodies resist death. (Achmat 2004)

Related to this is a redefinition of the active-passive binary. The definition of social movements often assumes obvious activity and dynamic processes. For example, the TAC activists challenge dominant discourses of the 'lost continent' (Patton 1997) by saying that they 'are not going to sit down and die', as one of the informants phrased it in an interview in 2003. At the same time, TAC's activism around

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the stigmatising and erasure of bodies that are *not* active and *not* healthy overturns conventional ways in which the passive body is seen in social movements. Marja-Liisa Honkasalo, dealing with the implications of her work among elderly women in Finland, alerts us to the fact that: 'Agency is [frequently] considered intentional, individual, rational, and normative, aiming at social change in some measurable sense. An actor – to be a proper actor – needs a goal-oriented mind and the appropriate tools to achieve a rational goal, mostly considered as a form of social transformation' (2009, p. 62). TAC has not always defined agency in the sense of noteworthy public acts and dynamism. It has worked with grass-root activists in poverty stricken contexts, where silent suffering is not seen as being diametrically opposed to agency.

'Mobilise and Mourn!', a slogan in one of the TAC campaigns, is a re-writing of the slogan 'Don't Mourn! Mobilise!' from the anti-apartheid struggle. We read this inversion as a way of paying tribute to the historical struggle, showing continuity in the fight for a better society, but also forging an activist space for grief, social withdrawal and states of physical passivity: in the face of the epidemic, there must be room for mourning. The TAC has turned funerals and deathbeds into political sites where participants wear the HIV POSITIVE t-shirts and sing TAC songs alongside religious hymns. TAC funerals can address stigma not only because they openly proclaim a community of people living with HIV, but also because the political focus translates death from a fetishising theme to a mobilising message. The disease, suffering and death that affect certain bodies are therefore connected to the determination to take action in a way that refuses to privilege the robust active body (evident in the earlier anti-apartheid struggle slogan, 'Don't mourn! Mobilise!') and that creates an equivalent significance of active and passive bodies. Providing an interpretation of this, Honkasalo (2009, p. 64) highlights the repetitive, practical quotidian forms of 'action' that has no visible aim to change anything, but remains an important social force because it is part of the broader process of communal action: 'From a community perspective, action is like breathing, a process of intermittent phases, where the acts of inhaling and exhaling are equally necessary. The passive, receptive phase of action is extremely important in this sense, but in social sciences it is rarely thematized'.

What is targeted in acts of agency is as important as the form of agency in considering actions that transcend neo-liberal triumphalism, and the idea that it is simply through demonstrating individual courage in the face of personal setbacks that agency is performed. This is evident in the connections between the local, national and global challenges to which TAC activism has responded. The activist women in the TAC are not only victims of global economics and colonial history; they are also global human rights advocates. The major impact of the TAC on the global scale is that they fight for the right to medical treatment for poor people, by, for example, tackling the pharmaceutical companies and unfair patent laws. Chandra Mohanty (2003, p. 510) argues that 'while globalization has always been a part of capitalism, and capitalism is not a new phenomenon, at this time I believe that the theory, critique, and activism around anti-globalization has to be a key focus for feminists'. The connections made among local and global relationships and institutions of power therefore highlight the dangers of naming agencies in relation to the personal, immediate or highly localised contexts in which even the most constrained responses can be read in terms of choice and free will.

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Conclusion

TAC activism reveals its struggle not only for justice, resources and rights in material terms, but also its struggle around the meanings of embodied experiences. The activist women are not silenced subaltern victims. When they rally they 'do' victimhood, race and gender in subversive ways by practicing slightly different, less melancholic, reiterative repetitions of the ideas about bodies associated with these social labels (Butler 1990). They point to the circumstances that created their victim status, not to themselves as tragic figures. The activists fight hierarchies between the rich and the poor, experts and lay people, politicians and citizens, powerful companies and consumers, and people infected and affected by HIV (see Fassin 2007; Richey and Ponte 2011). At the same time, they challenge existing power relations by going beyond dichotomous thinking and therefore draw attention to a continuum of connected stereotypes, economic injustices and political hierarchies.

The Campaign encourages us to view the epidemic in Africa as a discursive construction, an 'epidemic of signification' (Treichler 1999) *and* an embodied epidemic – a double existence that creates challenges for representing embodiment, gender and sexualities in ethical ways. In the evolution of our research project, we have been prompted to think carefully about whom we ask to become our informants. Typically, researchers have often chosen to study those most marginalised: youth in need of prevention, village women with HIV or those caring for the ill. Yet if research design is an ethical and political choice, and this choice can either de-stabilise old myths and images, or hold them intact, a focus on the most marginalised can easily lead to fetishism. When trying to avoid fetishism, it has been more useful to approach women who are already directly involved in a social movement, rather than the 'silent' ones. We do not suggest that it is only the extraordinary that requires the attention of feminist social science. On the contrary, we have learned that 'passivity', silence and ordinariness are central subjects for research, along with the 'small agency' within broader social processes and struggles. However, activist women embedded in social movements direct us to the contextual (local, national and global) and collective parameters for making sense of individuals' embodied experiences. The major lesson for us is that research should focus on power as a constitutive process in very concrete ways. Thus, by placing change at the centre of our analysis, even the 'ordinary women' become less static and dislocated from broader social processes.

We eventually chose to study the *politics* of women who publicly act and represent themselves as women living with HIV. During the research process we shifted the focus away from the lives of activists to the public acts of women who are engaged in a political struggle, who are trying to transform the conditions of their lives and deaths. We therefore directed our attention away from fixating on and judging the individual acts of self-possessed persons. The story of the central character in the film *Yesterday* presumes to uncover and evaluate the actions of an individual who is seen to have complex motivations, beliefs and choices. Simplifying the circumstances under which she acts, the story echoes the assumptions of certain researchers who insist on the free will of their subjects. By identifying and applauding the actions of the rational and autonomous subject, they reduce the strange to the familiar, and therefore compromise an ethical and political challenge of acknowledging and respecting both difference and the boundaries of the person who can never be fully known.

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A look at literature and representations of HIV in Africa reveals that HIV legitimises media and research attention to sexuality, gender and embodiment in a way that mirrors the colonial imagination of biopower. Emerging constructions of sexuality and embodiment reinforce past images, break silences and/or challenge entrenched ideas. But what are the effects of the apparent diversity of images and messages in terms of policing and surveillance, or the entrenchment of familiar power relations? In the public domain, many of the advertisements and campaigns that claim to break silences and counteract stigma paint a very Foucauldian picture of governmentality (Zenebe 2006; Jassey and Nyanzia 2007). TAC activism has emphasised that treatment, prevention, political struggle and affected people's local knowledge generation are simultaneous processes (Poku 2005; Robins 2006; Jungar and Oinas 2010), thus creating a view on embodiment and health that insists on multiple complexities (Barad 2007). At the same time, activism has both explicitly and implicitly destabilised the cherished images and formulae we use to identify agency, power and resistance. Despite the 'best intentions' of their producers, these images and formulae easily reinforce the dualisms, silences and hierarchies that have historically elevated certain bodies' normalcy and power, and entrenched the silence, invisibility or inferiority of others. The activist approach to the HIV epidemic, embodiment and the social order challenges existing discourses in ways that oblige us to revisit some of our most fundamental assumptions about embodied experiences.

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Notes

1. Statement during TAC/COSATU National Treatment Congress, Durban, 27–29 June 2002.
2. Statement during TAC/COSATU National Treatment Congress, Durban, 27–29 June 2002.

Notes on Contributors

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