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HIV Politics and Structural Violence : Access to Treatment and Knowledge

Oinas, Elina

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Gender, Global Health, and Violence

Feminist Perspectives on Peace and Disease

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Catia C. Confortini

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About the Editors

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Chapter 5

HIV Politics and Structural Violence: Access to Treatment and Knowledge¹

Elina Oinas

'Amandla!', echoed the activist women's forceful outcry in one of the massive rallies against President Thabo Mbeki's HIV politics in South Africa on the streets of Cape Town in 2003, evoking the spirit of the anti-apartheid struggle. By shouting the well-known *'Amandla-awethu'* slogan, with their fists raised high in the air, the women connected their fight for medication to a long line of struggles about power: 'power', *amandla* in the Xhosa language, to *awethu*, 'the people', 'us'. The women marching on the streets made a case for HIV being political. Their message, underlining the connection between health, death, and politics, was radical at the time, when AIDS was seen as a result of personal sin or stupidity – reckless sex without condoms. A month later, the image of one of the women, Kebareng Moeketsi, was on one of the flyers used by the activists. Moeketsi died at the age of thirty-three, only a year before the medicines were made available through the public sector healthcare system in South Africa.

In the rallies and meetings of the early 2000s, the energy of the Treatment Action Campaign (TAC) movement was palpable and inspiring, yet the people were also seriously sick and dying, sometimes only weeks after attending a rally. Remarkably, despite the hundreds of deaths, there was a sense of victory around the movement. 'Mobilise and mourn!' was another important slogan derived from the anti-apartheid 'Don't Mourn! Mobilise!'. This reformulation was a way of paying tribute to the historical political struggle, not only showing continuity in the fight against political violence but also pointing to the personal and emotional side of the illness: in the face of this epidemic, there must be room for mourning (Jungar and Oinas 2010, 183).

While it might be fair to state that the field of peace and violence research is seldom concerned with health, in the field of global HIV policies, the themes of violence and even genocide have been central (Oinas

and Jungar 2008). This is largely due to the tight links between activism and HIV science, as shown by the South African TAC and also evident in the earlier phases of HIV research (Epstein 1996). In the 1990s US, gay men's health movements and medical science joined forces in unique ways, blurring the boundaries between scientist insiders and lay outsiders in a way that had never been seen before in medical history, claims Epstein (1996). Thus, from the moment AIDS became a matter of public attention, questions of state violence through negligence and inattention were raised.

Regarding the axis of geopolitical structural violence of the North-South divide, HIV was an exception there too. In 2001, HIV became the first health issue brought before the UN Security Council. Currently, in the *UNAIDS 2016–2021 Strategy* (UNAIDS 2015), peace is one of the items mentioned in its eight key result areas. In general, research on the origins, historical and social contexts, as well as the concrete forms of genocide and related acts of mass violence in the global South has often focused on the economy, poverty, colonisation, and colonial rule, not health as a matter of violence. Yet, already a decade ago, Henning Melber (2008, 10) underscored the 'need to include forms of gender-based violence, consequences of ecologically changing environments as a result of human interventions and the effects of climate change for the survival of people (and the threat to it), as well as other effects of structurally induced violence – such as HIV/AIDS and its non-treatment' – in the issues crucial for genocide research.

That existing life-saving medications were not made available for the poor in Africa was defined by activists as genocide in the early 2000s. This was before academics turned their attention to the link between access to medicine and social justice and the so-called new materialist turn (Oinas and Jungar 2008). The TAC, against all odds, was victorious, leading to a re-negotiation of international patent laws and the introduction of antiretroviral treatment (ART) through public health care in South Africa in 2004 (Fassin 2007). The global shift in the HIV policy landscape during the 2000s was the result of an assemblage of a wide array of concurring phenomena, yet one of the important ones was the global struggle of activist women living with HIV in South Africa (Jungar 2011).

This chapter discusses the landscape of HIV activism and politics since the 2000s (see also Biehl 2007; Campbell 2003; Comaroff 2007; Fassin 2007; Nattrass 2004; Robins 2004, 2006). It argues that global health politics is a field of tremendous political contestation and tension, one that, in the case of HIV, uses the discourse of violence and political power. HIV challenges the vast literature on medicalisation that views medicine and public health interventions as technical and depoliticising (Conrad 2007). Reflecting upon the themes of the book, this case demonstrates why it is important to articulate

global injustices as forms of violence, and how such articulations may result in positive changes for global health politics.

Recent threats to the goal of universal access to ART underline the key difficulty in global health care: it is a process with no end or permanent victory. It demands a constant discussion on the value and nature of life, on whose life matters, and a constant negotiation regarding political accountability for the costs. In this process, people living with HIV play a crucial role not only in any successful policy or treatment intervention but also in formulating what constitutes global justice and peace in the context of health care.

The case of HIV in South Africa shows that within structural violence of inequality, there are (at least) three different aspects of violence: the *material*, the *symbolic*, and the *epistemic*, and that all of them have embodied consequences. The theoretical stance I present in this chapter employs a poststructuralist conceptualisation of power and violence, drawing loosely on Gayatri Chakravorty Spivak's (1988) broad notion of epistemic violence, where she critically deconstructs the Foucauldian framework to consider the discursive construction of the subaltern 'other'. This chapter does not dwell on existing debates on theories of violence; instead, I will use Spivak's notion as a tool to read the different types of violence I detected during the empirical analysis.

For the sake of analytical clarity, I choose to make some grave simplifications, apparent for everyone with knowledge of Spivak's complex framework. While Spivak's epistemic violence is a broad term, it is here compartmentalised into three different aspects of structural violence. Structural *material* violence, drawing rather bluntly from the Marxist tradition, refers to the systematic denial of material resources to certain groups of people, with consequences to their embodiment. With *symbolic* violence, I refer to the way structural material violence is rendered natural, often by a systematic denial of rights, subjectivity, and citizenship for certain groups of people while others continue enjoying them (cf. Reuterswård's discussion of cultural violence, this volume). While Pierre Bourdieu (1984) is regarded as the master of the analysis of how class distinction draws on symbolic violence (cf. Lukić and Lotherington this volume), the one who explicitly underlines the discursively denied subjectivity as epistemic violence is Spivak (1988), the main source of inspiration here (but see also, for example, Cornell and Panfilio 2010).

For the sake of analytical precision, the violence of being denied full humanity is here named symbolic, and the last component, the *epistemic*, refers explicitly to knowledge systems that exclude people from legitimate, hegemonic knowing and understanding, and denies them the possibility to engage in authoritative knowledge production. Science is one such system which is analogous to Spivak's example, the colonial legal system. The distinction between the material, the symbolic, and the epistemic is an attempt to be clear in my analytical work, yet I acknowledge that any one of these

elements always already comprises the others too, so the difference lies in the foregrounding by the analyst. Dissecting these endless entanglements, however, may well be at the very core of feminist research on gendered violence in global health. As this entire volume suggests, feminist scholarship and activism in both peace and global health have the capacity to seek such dis-entanglements. It is only by disentangling the different forms of violence that we make them fully visible and, as a consequence, make lessening or eliminating violence possible (see Confortini and Vaittinen this volume).

Empirically, this chapter has its beginning on the streets of Cape Town where TAC marched against government negligence in 2002, and it ends in a gentrified downtown office complex in Johannesburg in late 2017, where an hour-long, catch-up interview with high-level leaders of the movement took place. The first round of fieldwork with the TAC activists in 2002–2003 included eight months of ethnographic observation of the public appearances of the movement in South Africa with Katarina Jungar, whose PhD study expands our shared project (Jungar 2011). The second set of data, interviews with volunteer treatment counsellors and HIV patients, I collected in a township in the Western Cape near Cape Town in 2009 and 2012. Here I enquired about the influence of activists' discourse and movement politics on the daily work and lives of the people living with HIV and attempting to support an ART programme in their community.²

In their rallies, TAC highlighted that, when the actual *material goods, the pills*, are denied to poor people, that is, when they cannot access existing life-saving medicines, such abandonment also signals *denied subjectivity* (Biehl 2007; Comaroff 2007). In my reading, this constitutes the interlinkage between material and symbolic violence. Their marches for the constitutional right to health care demanded a symbolic recognition of the poor and the marginalised as viable subjects, citizens with rights. Feminist scholarship further adds the elements of the everyday and epistemic violence to the study of structural violence. First, it demands attention to the more mundane acts against violence that are overshadowed by the vocal protests and marches. While political movements are crucial, everyday resistances should be highlighted too, based on the motto 'the private is political', argued the early women's health movement (Boston 1972). In my analysis, the grass-root work of voluntary HIV counsellors consists of subtle, everyday acts against structural violence and as explicit articulations against both material and symbolic violence, in contexts where the material violence of poverty takes the shape of everyday danger and aggression within communities. Anti-violence work on a daily basis also involves the refusal to accept the label of what Spivak (1988) calls *the subaltern*, and hence it can be read as action against symbolic violence. Second, while the voluntary HIV counsellors' work involves both of the aforementioned levels of work with violence,

additionally, it highlights the third aspect of violence in the context of health: the potential epistemic violence of biomedicine if it is not translated to be attuned to the circumstances and the prevailing structural violence of the everyday in the community.

STRUCTURAL VIOLENCE OF A VIRUS? THE GLOBAL AIDS EPIDEMIC AS CONTEXT

Since the early 1980s, the HIV epidemic has been a remarkable case with an unusually mediatised global health policy interest. Yet, it is also an epidemic where global inattention and structural abandonment of the ill in the global south can be witnessed in the statistics of millions of (unnecessary) deaths (UNAIDS 2015). To date, there still is no vaccine or cure for HIV, but since the late 1990s, ART, a complex medication that needs to be taken daily for the rest of one's life, enables living with HIV in a manner that resembles life with many other chronic illnesses, such as diabetes (Cameron 2005). Shortly after the introduction of the first lines of ART, access to medication became a highly political issue, gaining momentum in the global south in the early 2000s.

Media and science alike operated within a risk-group framework, thus launching a series of symbolic exclusions from early on. In the early 1980s, media attention focused on depicting a shocking, unknown, gay men's disease. HIV quickly became a universal concern with overly liberal sexual behaviours, and then an epidemic that changed sex education for young people globally, often engaging different religious authorities to take a firm stand alongside health and medical experts. Towards the mid-1990s, pharmaceutical innovations and the availability of treatment weakened northern alarmism. Media attention disappeared and shifted to Africa only, while discursively HIV was depicted as less of a threat in the global north (Patton 1997). By isolating the actual and potential HIV risk to clusters and risk groups, new boundaries of risk were constantly drawn (for the violent impacts of this on marginalised groups, see Nuño, this volume). While the virus can be transmitted to anyone, risk-group-thinking focused on gay men, sex workers, drug users, and Africans. Africa as a continent (or a country, one could ironically add) became one massive risk group (Patton 1997).

South Africa has a special place in the history of the epidemic because of its uniquely rapid growth rate, from a minimal HIV+ population at the end of the apartheid era in the early 1990s to the largest HIV+ population in the world by the early 2000s. In the hardest-hit region, KwaZulu Natal, the statistics in the early 2000s estimated every third pregnant woman to be HIV+ and life expectancy to fall by twenty years within a few decades (Fassin and

Schneider 2003). That this catastrophic turn took place right after the end of apartheid that had inspired so much hope across the globe, during the first years of democracy, was stunning and led to a passive, inadequate political response to the epidemic (Fassin 2007). The political delay in implementing effective HIV policy was a deliberate choice by President Thabo Mbeki, despite massive protests. It led to a catastrophic death toll – according to one study (Chigwedere et al. 2008), more than 330,000 unnecessary deaths occurred in 2000–2005, putting a precise number to the mass suffering due to inaction. While public health policy is seldom a topic attractive to the media, Mbeki, who came to power after Nelson Mandela, was soon in the global limelight as the president who failed the poor because of his explicit ‘AIDS denialism’.

President Mbeki was notoriously suspicious of ‘western medicine’ and allied himself with dissident scientists who doubted both the existence of the virus and ART as a safe intervention (Nattrass 2011). During the 1990s and early 2000s, ART programmes were introduced only with private funding or by international actors, leaving most poor people with no medication. While activists and researchers were outraged by the government’s lack of initiative, the history of racist violations in the name of public health may help to understand Mbeki’s reluctance to resort to expensive drugs (Fassin 2007). In one of his widely quoted speeches, the frustrated Mbeki stated: ‘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’ (Mbeki 2001).

In many ways, the arguments President Mbeki used highlight juxtapositions which are familiar to the medicalisation literature in sociology: either AIDS has to do with poverty, being a social illness, or with sexuality, being a behavioural problem or a racist stereotype, or it is a biomedical condition and is then relegated only to experts. Mbeki operated on the level of suspicion: perhaps the epidemic is just a racist social construct and the political leadership can continue remedying the true ills of the nation, such as inequality, poverty, and an economy that needed restructuring (Hoad 2005). The activists, in contrast, attempted to introduce a line of thinking that was radical and challenging, and resembled a more complex feminist politicising epistemology of embodiment (Thompson 2005): medicine is far from a technical practice, it is a socio-political intervention and can both enhance and undermine democracy (Jungar and Oinas 2010). If poor people are not seen as worthy of medication, they are denied their citizenship, argued activists, referring to the new constitution (Achmat 2004). Both the Mbeki administration and the activists shared the view that HIV was not a single apolitical biological entity but a construct that carried with it the history of racism.

The first clinics around Cape Town offering treatment for poor people were initiated as political responses to government reluctance, using alternative funding sources. For example, Doctors without Borders (MSF) introduced the famous Khayelitsha ART programme to show the government and the entire world, including doubtful scientists and funders, that ART could work in resource-poor settings (Interview with MSF in 2009; cf. Coetzee 2004). Some clinics were founded based on scholarly – biomedical or public health – interests, often with developmental aspirations (cf. Sariola and Simpson 2019). The focus on ART was radical, as most HIV interventions in the global south at the time focused on prevention and sexual behaviour. Shifting the focus to care and treatment demanded a shift in discourse, and there were no guarantees that it would work.

After four years of protests, the South African government introduced ART in its national HIV/AIDS policy in late 2003. Since 2004, the rapid change has been remarkable, even if activists have continued to campaign for better implementation of the new policy. From less than 50,000 people on ART in 2004, South Africa quickly became the largest ART provider in the world, with 1.79 million people on ART in 2012 (Johnson 2012, 22–23). A major shift in the epidemic took place, both in the country and globally, although HIV by no means was defeated. The number of people living with HIV in South Africa was hoped to have stopped growing around 2006 and remained first rather stable, at less than five million (Johnson 2012, 25). In 2018, however, the total number of people living with HIV in South Africa is estimated at approximately 7.52 million. For adults aged fifteen to forty-nine years, an estimated 19 per cent of the population is HIV positive (Statistics SA 2018). This recent increase in cases is all the more worrisome considering that globally the number of new infections has dropped. Especially the number of children becoming infected has dramatically declined by 30 per cent worldwide, a shift that has mostly to do with health care improvements, the availability of treatment for mothers and pregnant women, and increased awareness among pregnant women, according to UNAIDS (UNAIDS 2010). UNAIDS, however, warns about the lack of adequate funding and decreasing interest on the global scale, putting the successful trajectory at risk (UNAIDS 2015).

Overall, it is fair to say that the 2000s were a remarkable era in the history of epidemiology: although catastrophic outcries of unmanageable emergency and hopelessness characterised the mid-1990s (Epstein 2006, 15), today there is clear evidence that many of the 2000s massive interventions have worked. The HIV epidemic deemed too difficult to deal with – due to issues of sexuality, stigma, and weak infrastructure in places where the problem was most urgent – was by the end of the 2000s no longer viewed as a looming global disaster. It still created personal tragedies and national challenges, but it was

shown to be manageable too, as long as there was political will and funding. Politics, science, and individual health go hand in hand, the statistics of the 2000s show. Rather straightforward public health measures such as treatment and care were enabled by the sense of urgency created among local, national, and international activism but also among the media, international actors, national politicians, and funders – and the statistics did change. Behind public health programmes lies an enormous effort by activists, patient movements, experts, politicians, and funders – and individuals affected by HIV. The framing of the HIV epidemic as explicit violence was crucial in the shift.

CIVIL DISOBEDIENCE, GENOCIDE, AND A POLITICISED JAR OF PILLS

To get an understanding of how a single health issue became successfully framed as a key question for democracy, peace, and justice, it is worthwhile to pause in February 2003. TAC made a daring decision to charge individual politicians with homicide – 600 homicides a day, to be precise. Two ministers, Manto Tshabalala-Msimang, the minister of health, and Alec Erwin, the minister of finance, were personally sued. Their alleged crime was the failure to respond to the HIV/AIDS epidemic in South Africa, leading to preventable deaths. In addition, TAC started a ‘civil disobedience campaign’, a political campaign that has a very strong symbolical meaning in South Africa. The decision to use civil disobedience, a tool that was used in the anti-apartheid struggle, was a bold step in the new democracy, with the still-very-popular ANC in government (cf. Friedman and Mottiar 2006).

The activists’ message was that these two individuals were personally responsible for the lives lost every day. The campaign also pointed at the political machinery, addressing the government as a whole, as an institution, accountable for deaths in the country. In 2003, the focus was on the South African leadership, but activists addressed the international community too. Linking health, suffering, and death to larger social structures was novel. The TAC speeches depict the ‘embodiment of violence’ that I analyse as a multi-level approach to violence: connections were drawn between cells and viruses, community violence, and national and global politics. Multiple intersecting layers of violence (cf. Tanyag this volume) were highlighted at all TAC events: global intellectual property rights and a neoliberal, bio-economic order were discussed in the same meetings where community stigma was addressed; viral cells and capitalism were seen as interlinked; treatment literacy and biomedical basics were woven with political jingles. Women dancing with a jar of pills and singing anti-apartheid melodies brought the history of racism to the question of medication.

Accusations of criminal acts aimed at politicians who did not show commitment to leadership in the face of the AIDS epidemic – that is, a political standpoint being interpreted as a crime – had previously not been taken to court. D’Adesky (2004, 7) documents a case where the Malawian activist Chatinka Nwoma, during a rally at the Durban AIDS conference in 2000,

grabbed the microphone, pointed to a building behind her where World Bank officials and drug company experts were discussing the cost-effectiveness of global AIDS treatment, and shouted to a sea of African faces like hers: ‘There is a crime being committed here! You cannot have 42 million people dying and have the issue be about money!’

Similarly, the Wola Nani activist Gary Lamont used the following language in a speech on the South African government’s lack of policy regarding ART provision to pregnant women: ‘Every month that the government withholds these drugs is a cumulative act of genocide for thousands’ (Fassin 2007, 52), also indicating a crime committed by a government. Eventually, TAC dropped the threat to pursue the legal case when the political campaign was successful.

The civil disobedience campaign highlighted the two components of the activists’ view on state violence: structural violence consists of the material elements of denied health care, poverty, and other material social injustices, as well as the symbolic element of exclusion from the realm of worthy citizens. In a lecture given by Zackie Achmat (2004, 10), a founding member of TAC and its spokesperson at the time, a long list of interlinked issues was present, including discourses on sexuality and gender inequality:

We die because of excessive drug company profiteering. We die because our governments are in denial of the seriousness of the HIV epidemic by governments and bureaucratic procrastination and equivocation. We also die because men have greater access to resources and power than women; because rich countries invest substantially more in war than in public goods, and because many global corporations live outside the law of global human rights. We die because religious dogma and reactionary traditionalism suppress sexual freedom and because some African leaders label homosexuality unAfrican. And we die because we cannot buy life-saving medicines. Unlike some of our neighbours in the north, we cannot afford to buy life.

The quote is an illustration on how structural violence has a multitude of interlinked actors and acts that enforce it and enable it to continue. Achmat asserted that embodiment is shaped by global biopolitics, that power/knowledge networks enable certain subjectivities, and that the implications are local and personal (cf. Nuño, this volume). In the following, material, symbolic,

and epistemic elements of violence come together in individual bodies, death, and suffering:

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, 13)

The TAC language often brought up oppositions between the rich and poor, politicians and patients, pharmaceuticals and poor people, and government ministers and citizens. But TAC both utilised and challenged dichotomous models of thinking typical for political struggles. A polarising set-up between the power of the government versus lay civil society thus appeared in some statements but was also constantly revoked. Sometimes a juxtaposition of ‘us’ and ‘them’ was there, sometimes everyone was part of the ‘nation’ or ‘us’. A similar contradiction (or, rather, a double strategy) was applied regarding who was ‘affected’ by AIDS: sometimes there was a clear ‘us’ who were dying, sometimes ‘everyone’ was included. For example, the famous T-shirts stating ‘HIV POSITIVE’ that participants in TAC rallies wore indicated an erasure of difference between HIV positive people and the others. The message was that everyone was affected by the epidemic. The T-shirt did not mark the identity of an HIV-positive person but a commitment to resistance. ‘We all need treatment to be made available’ (Cameron 2005, 130).

With the message that AIDS affected everyone, victims ceased to be a clearly defined group of subaltern ‘others’. Rather, the epidemic compelled everyone to take responsibility – including government ministers. The government was implicated in a different way because of different access to resources and the possibility to make policy and budget decisions, but often the campaign pointed to the possibility for everyone to act and be part of a change.

The civil disobedience campaign’s message against the symbolic violence of subalternity – that is, the outrage in the face of the denial of materialised citizenship rights in the form of existing medication – had an interesting outcome in terms of health promotion. There clearly was a link between effective HIV prevention and the move to challenge state violence against the poor when the state neglected health services. The fight against structural violence included de-stigmatising elements that contributed to HIV prevention because activism went beyond the individual-responsibility discourse that was typical of many HIV prevention discourses (Jungar and Oinas 2010). HIV prevention with an individualising agenda – ‘you must stop *your* risky behaviour’ – blames individuals for their infection. When the message is only

that 'risky behaviour' causes the infection, it must have been the individual's own fault, leading to shame, silence, and secrets. In contrast, the politicising of structural violence by activists focused on structural issues that contributed to the risk factors underlying the potential for the epidemic to spread, including violent, gendered structures (cf. Ratele 2006; also Ikhile, Gibson and Wahidin, this volume in regard to breast cancer). In the individualising discourse, being open about one's status becomes very difficult, whereas in the politicised movement, being openly HIV positive was possible and brave. While in the former case, HIV-positive people were regarded as a risk towards innocent victims, in the latter case, the HIV positive themselves were framed as victims of structural violence. The victimhood itself was turned into political fuel: these were active, vocal, and rebelling victims, not silent, silenced subalterns (Jungar and Oinas 2011).

The success of TAC in challenging the Mbeki HIV policy in 2003 lay in its ability to define ART anew, moving away from medicine as a costly, technical, western intervention to focus on the denial of the pill as material violence and the simultaneous symbolic violence of the denial of worthy citizenship. It may also be that in the activist campaign for ART, the progressive white middle class found a way to legitimately criticise the ANC and President Mbeki, something that otherwise was difficult during the first decade of democracy. The leadership of TAC tapped into the sentiments of the white healthcare professionals and rights activists. I argue that this may be connected to the subjective sense of loss and disorientation among the liberal white middle class that was hard to articulate. This segment of society supported the shift to democracy but found little means to be politically active in a complex, new political landscape. They agreed with the discourse that demanded space for the marginalised yet were feeling strangely alienated and voiceless themselves. This is a speculative argument, but if it has any value, it suggests that TAC was insightful in envisioning that the symbolic and material forms of violence experienced by the poor could be connected to the experience of symbolic violence of a formerly dominant but newly silenced voice in society – the educated middle class – when forming a mass movement. The different experiences of Mbeki's South Africa treating its citizens violently could be united behind a single legitimate cause, HIV. The deliberate choice of the first campaign, to focus on new-born babies, created a sense of unnecessary mass violence and a shared political goal in a divided nation.

GRASSROOTS INTERVENTIONS WITHIN MEDICAL PRACTICE

Having focused on HIV activism as a strong public voice against structural violence in South Africa in the first half of the 2000s, it became increasingly

important for me to learn how people living with HIV but not actively involved in movements perceived the politicised HIV field. Thus, in my 2009–2012 study, I enquired how the political situation and ‘treatment fury’ affected the lives of people living with HIV who were also active in health care. To get some data on women dealing with HIV outside the movements, I conducted interviews with a group of patients who were acting as volunteer counsellors for other patients. I did not conduct the study ethnographically inside a clinic; rather, I interviewed the individuals about their views and daily life. These data, too, dealt with resistance to the material and symbolic aspects of structural violence but in more every day, practical ways, as feminist scholars have often claimed to be the case in women’s mundane resistance (Honkasalo 2009). Furthermore, the data brought the element of epistemic violence to the fore. In contrast to the activist agendas, these interviewees had a more subtle and pragmatic approach to structural violence, yet the embodied consequences of violence were equally dramatic and palpable in the ways the volunteers spoke.

In a smaller scale compared to the activists, these women too formed a vocal support and advocacy group within the clinic where they volunteered as well as in the larger community. They described their lives, care, and survival as an entangled net of different relations that sustained them, and this entanglement included both human and non-human actors, for example, food, laboratory results, transport to the clinic and, last but not least, the pills. These entanglements of relations that produced healthier embodiments required a lot of work but not in an individualistic, heroic manner. The entanglements these women ‘held together’, as they put it, required a lot of knowledge, but such knowledge was not bookish or abstract. It was a matter of solidarity, of feeling, living, and doing together (Honkasalo 2009). Linda, one of the counsellors, described her motivation as follows: ‘I was helped, so I wanted to help. I wanted to show to people that there is life after HIV, it is not so that once you get HIV you are going to die. As long as you are taking your medicines properly.’ When I asked if it was easy for the patients to talk to her, she replied: ‘Yes, because I disclose to them too. That’s when I give them hope. If you are HIV positive, it is not so that you are going to die. So they take me as a sister’ (Linda, interviewed 2009).

The way the interviewees described their engagement with HIV medicine, I suggest, is resistance against an understanding of them as passive subaltern victims with little resources and knowledge. This, I argue, is a strong stand against symbolic violence that ‘others’ poor women in the global south (Ahmed 2000; Spivak 1988). The interviewees spoke about their work in an apolitical manner, and the violence they mentioned was the material one on the streets and in the homes, but I argue that this precisely challenged two

assumptions that every now and then emerge in social science discussions on health care: the dichotomy of medicine versus lay agency in medicalisation (Riska 2010) and the dichotomy of north versus south as the two poles in the axis of modernity (Ahmed 2000). Both assumptions are symbolically violent in their negation of viable subjects with capabilities and rights. Feminist literature and activism often criticise such dichotomies, but that repetitive act ends up reproducing the dichotomies. The voluntary counsellors' pride in their work with the doctors deconstructs dichotomising boundaries. The interviewees countered the symbolically violent representations of subaltern victims with disinterest; rather than debating this, they stubbornly insisted simply going on with their work. Their bypassing of the insulting, othering symbolic violence is in stark contrast with the vocal campaigns of the activists. The counsellors said, however, that they valued the movements and learned from them, sometimes attending workshops, so these stances were not oppositional to each other, just different in mode of operation.

The dichotomy of medical experts versus lay patients was simply set aside in the volunteers' way of speaking confidently of the importance of their work and their way of collaborating with the professional medical staff. Instead of maintaining dichotomies, lay counsellors created and maintained links between medical care, treatment knowledge, patients, and the wider community with a great effort, but, in their way of talking about their activities, with surprising ease. Fiona, one of the lay counsellors, asserted in an interview that 'doctors and counsellors here work together, as a team, as equal partners. They need us, we need them. Not like in the other clinics, where they [doctors] know. Here, it is sharing' (Fiona, interviewed 2009). They viewed their role in the HIV treatment as essential in successful care relations, thereby strongly resisting the kind of epistemic violence that devalorises or marginalises lay knowledge of medicine.

Thus, these uneducated women who could be defined as subaltern can also be seen as key nodes in the networks that, against all odds, curbed the spread of the pandemic during the 2000s (UNAIDS 2010, 7–8). Their voluntary work illustrates an implicit practice against symbolic and epistemic violence through the simultaneous presence of different levels of human and non-human relationality that enables sustainable care, knowledge, and survival. In the early years of the AIDS, epidemic, patient activism, gay movements, and medicine collaborated in path-breaking ways (Epstein 1996); similarly, in the context of the South African slum, where uneducated patients and high-tech medicine interacted, important aspects of lay medicine collaborations were present. The non-human elements are important to underscore here, as seen in the previous chapter: without the actual pills and laboratories, people with HIV die.

TRAJECTORIES OF COUNSELLING PRACTICE: THE CLIENT, THE CLINIC, AND THE COMMUNITY

While all the interviews, not very surprisingly, emphasised the importance of volunteer counselling in a successful treatment programme, they recounted remarkably many elements as aspects of their work. All these I read as ways of countering structural violence. The activities addressed three different recipients of care: the client, the clinic, and the community. First, the most obvious and easily anticipated was support to the client. Second, the interviewees portrayed the counsellor as someone who engaged in knowledge generation about living with HIV and ART, thus informing doctors and cooperating with the medical staff in successful ART. The third direction of the activities was the contact with the community at large. This mainly involved the local community where the counsellors and clients lived and practiced. Only some of the interviewees touched upon global politics and their work against an unjust world order. The politicised context of the South African HIV epidemic (Fassin 2007; Nattrass 2004, 2007) was both present and absent in the interviews. The South African and global context of HIV and ART politics was often implicitly mentioned in the interviews, assuming I as a researcher in the field would know what inevitably framed the entire setting.

‘I am a sister, priest, and a doctor’, said Fiona about her work in her first interview with me in 2009. Peer support, meaning the interviewee’s work with an individual client, was portrayed as the main focus of counselling, but this too intertwined with the other layers and involved several elements. I analysed peer support to deal with three separate areas of work: understanding and support for the *social realities* of living with HIV, that is, dealing with a rather demanding drug regimen in a certain community; dealing with the *psycho-social* issues related to diagnosis, survival, and treatment in everyday lives; and, lastly, *disclosure*, an issue that was discussed at length in each interview and seemed to be the key aspect in ART. Anyone on ART was expected to eventually ‘disclose’, that is, tell about his/her HIV+ status and the drugs to at least one person, but only when one was ready, as was said over and over again in the interviews. Discussions around disclosure involved a lot of practical advice about stigma, secrecy, integrity, and rights, knowledge that was highly contextual. The three elements guiding the counsellors’ work were all connected to violence, also to the often-individualised psycho-social aspect due to the violence of stigma and the structural, material violence of poverty. Only when the material violence was mentioned as a central theme and not as something to downplay could the language of hope be brought up and effectively challenge the symbolic violence.

Both the counsellors and the medical professionals I talked to stressed the importance of peer support, grasping the everyday realities of the clients in

their communities. Fiona also began with mentioning hope: ‘It is so much about hope. Counsellors are examples. They are patients too, and they are open about it. They have lived through all that, they know.’ For Fiona, knowing about the social realities on the ground was the crucial difference between the doctors and the peer counsellors: ‘They know the circumstances where people live; they understand what they talk about. You don’t even need to say yourself, a counsellor can anticipate things. You are not scary. You share the language, community’ (Fiona, interviewed 2009).

The counsellors said that their knowledge of the larger issues, like how poverty works in the shacks, allowed them to give accurate advice and support and even to anticipate the questions that the clients would ask or might not dare to ask. For example, the way South African welfare grants – which may be the only income for an extended family – are conditional may mean that, when the ART starts working and one recovers, one may lose the grant. This dilemma, if not addressed well in counselling, may risk the entire programme, cost lives, and create resistant strands of the virus due to juggling with the pills when facing desperate circumstances. The counsellors acknowledged the material, structural violence in the everyday life of a township with their own situated knowledge and the epistemic translation of ART. This is also an example of how the human and non-human entanglements resist the coming together of multiple forms of violence: material violence needs to be taken seriously for the symbolic violence not to happen – and for the treatment to work in the body.

The interviews indicated that the questions clients asked were of medical nature, but the volunteer counsellors felt fully equipped to answer. A lot of the questions dealt with side effects, infections, and worries about the possibility of getting pregnant again (Richey 2011). They were universal yet also highly contextual, situated questions. The counsellors’ point of view on the side effects of medication seemed different and complementary to the answers the doctors gave, as most doctors did not live through those physical sensations and did not know the context of the concern, or lacked the language. ‘We can even help the doctors’, said Fundiswa. She also reminded me of the importance of knowing the many rumours to be able to counter them: there were ‘too many stories that antiretrovirals are dangerous, change their bodies’ (Fundiswa, interviewed 2009). As some people did not respond well, and some died despite ART, or some simply had too-high expectations regarding the medicine, there tended to be rumours that this or that was caused by the medicine. A local peer voice was able to tell ‘that the doctor is not Jesus’ (Fundiswa, interviewed 2009) and strengthen the motivation to stay on ART.

When asked about the major difficulties in achieving good ART, the answers mainly touched upon socio-economic issues, varying from poverty, unemployment, alcoholism, and crime to lack of transport between homes

and the clinics and airtime for mobile phones – a rich variety of levels of structural, material violence manifesting in the everyday. Here, it would be easy to overemphasise the enormous difficulty of the allegedly ‘white’ medicine, as it sometimes was named, to even start to grasp the realities of the black township dwellers, a gap that still, and increasingly, is the reality in post-apartheid South Africa. Eve, the research assistant, repeated daily to me: ‘You know, there is still apartheid in South Africa’ (Field Notes 2009). In these violent circumstances, the medical staff alone was not best-equipped to do the work around coping with and understanding the illness, diagnosis and care in everyday context, but in collaboration with activists and peer counsellors, epistemic violence was held at bay. Indeed, it was emphasised often that biomedical knowledge did not feel alien or difficult for the counsellors. Thus, I argue that biomedicine should not be considered ‘western’, or foreign, in itself, even if it needs to be attuned to the realities on the ground – anywhere. A feminist critique of biomedical knowledge and its potential for epistemic violence should always account for the intersections of violence that go beyond monolithic identifications of the ‘west’.

THE POTENTIAL EPISTEMIC VIOLENCE OF BIOMEDICINE

For Fiona, the counsellor had a double role: on the one hand, the counsellors represented the clinic in the homes of people; on the other, they represented the people at the clinic. When I interviewed the leading ART programme director in a university hospital, Dr. O., she also mentioned that in her clinic, the real key to their success as an HIV clinic was the counselling programme. However, she also noted that this aspect had not been studied in the otherwise well-researched and documented ART practice. ‘What is this ingredient that makes this difference that makes it work? We have decided that it is friendship’ (Dr O., interviewed 2009). It is revealing that the richness of the counsellors’ work and the complexity of social relations they deal with were reduced to vague ‘friendship’. There clearly was appreciation in Dr O.’s way of viewing the counsellors’ capacities; Dr. O. told me she was personally involved in initiating the programme and called it crucial.

That such a key element was never properly studied, documented, let alone published in a medical journal by her research group, however, testifies to the limits of the scope of biomedical science. This leading medical researcher did not comprehend the social aspect of the treatment to be a medical issue; the social matters were mentioned with appreciation but relegated to the non-medical domain, to the socio-technical administration side separate from the actual research. This separation of domains that some researchers analyse

as gendered-masculine hard science versus gendered-feminine care of the patient, regardless of the gender of the scientist (Riska 2010), in my view, caters to epistemic violence, as it, in the long run of ART research, renders the knowledge and context of the patients irrelevant.

In the South African case, the usage of the notion ‘friendship’ can be read as a possibly well-meaning acknowledgement of not really comprehending social lives across the racialised divide, a polite recognition of difference typical for post-apartheid South Africa. While this may be a sign of respect and distance that indicates non-intrusion and appreciative non-sameness (cf. Ahmed 2000), it is also a gesture that confirms academic biomedicine’s inability to engage with the social context. The interviews show that the intricate web of community relations taking place in ART management had a pattern and meaning that should not be reduced to ‘friendship’, however much ‘friendship’ was a positive attribution. The cosy term belittles and feminises the highly needed expertise of the volunteers. Yet, while the leadership delegated ‘the social’ to volunteer counsellors’ domain only, the medical staff on the ground were said to be fully co-operative. The interviews indicate that the medical staff embraced the counsellors’ knowledge of the community, patient’s needs, and language. Thus, while the research-side of the programme dismissed and denied the medical importance of the context by not studying it, therefore signalling the epistemic violence of half-hearted half-engagement, in the concrete daily life of ART such epistemic violence was countered and renegotiated.

The statement by this director was ambivalent but descriptive of the realities in HIV medicine. The counsellors were in the first place granted a central role in the programme due to the recognition that township conditions have medical relevance, but the programme was not documented, and only a while later the counsellor programmes were cancelled in the majority of sites. By being a volunteer programme, it exploited the cheap labour of the patients, not offering them proper employment. Yet, such voluntary workers’ presence might have been the only way of communicating between communities and clinics due to lack of diversity and numbers among educated healthcare staff – indicating the deeper roots of structural violence in the entire education system, when so few of the educated healthcare workers in general at the time came from the communities most impacted by HIV. Something crucial in the social embeddedness of the programme was lost when everyone involved in the clinic was required to be on an employment contract only, and professional skills and qualifications became the primary recruitment criteria. The loss of counselling programmes, I argue, is an unfortunate resignation in the face of structural, material, and epistemic violence that underpins social life and medical practice in South Africa.

Peer counselling and support groups are necessary in order to counteract the epistemic violence of academic biomedicine, when there is an enormous

gulf in living conditions between clients and doctors. It is not a question of a one-way translation but of a thorough engagement with local knowledge systems that also inform medicine. Biomedical science's lack of engagement with the everyday life on the ground and the health consequences of the political conditions people live in can be seen in recent statistics: in Africa, the number of people on ART has grown in exemplary ways, but the statistics on a major biomedical indicator of success, the suppressed viral load, are still lower than expected. The pills are there, but they work less well than they scientifically should (UNAIDS 2015). This indicates that, in spite of access to ART, something is still missing. Research on material, symbolic, and epistemic violence in ART can explain the missing link.

I argue that the potential epistemic violence inherent in biomedicalisation can be challenged by practices of engagement, like in the voluntary counselling programme, where a socially embedded negotiation of ART took place. Instead of imposing medical authority on people living with HIV, something that mainstream sociology of health and illness criticises (Conrad 2007), the peer counsellors were an access point that generated new modes of situated knowledge about living with ART and HIV. They contextualised the medical knowledge and transformed it into local realities (e.g. Das and Das 2007) in collaboration with the trained clinic staff.

In the classic view of medicalisation research, the ART programme and the counsellors visiting homes could be seen as biomedicalising and pharmacologising intrusions in the community (Conrad 2007; Riska 2010; Williams, Martin and Gabe 2011). Yet the activists and counsellors alike argued that with the HIV epidemic, biomedicine is already unavoidably present (cf. Whyte et al. 2002). Despite a wide range of modes of structural violence, the township dwellers are already 'cyborgs', socio-technological hybrids (Haraway 1985), and any claim that western biomedicine is alien to them was treated as foolish by the peer counsellors. While their bodies 'bear witness to global injustices' (Achmat 2004), they are also evidence of the uselessness of the developed world versus third-world distinction in terms of patients' 'will to life' (Biehl 2007).

The counsellors' peaceful response to epistemic and symbolic aspects of structural violence comes together in the claim that HIV treatment can be managed also by uneducated poor people in a township in the global south (Jungar and Oinas 2010). For the participants living with HIV, ART was an enabling force, an extremely sought-after asset, not a threatening colonisation of the life-world (Zola 1972). They did not want to resort to African traditional medicine only; the pills represented hope, dignity, and justice. Having said this, it is important to bring the issue of epistemic violence to the fore. Without local activists and counsellors, the treatment programme would have probably been much more alien and inaccessible for the community.

The contextualising and politicising component of counselling and activism translated ART to local needs and practices, and reduced stigma. Following Charis Thompson (2005), it is clear that the issue here is not *if* a social process is biomedicalising or not, but what the political *effects* of biomedical practices are – for example, ART as social justice, as in staying alive just like the richer neighbours.

Simi, one of the women I interviewed in 2009, talked more about the girls' football team she coached than about the ART I actually asked her to tell me about. Her life did not revolve around her HIV status. However, the framework of our conversation was all the time clear for both of us. Without the treatment she would die. Had she needed the drugs five years earlier, when the health minister still recommended garlic and beetroot instead of costly western medicines, she would not have been there telling me how she collects shoes for her team, or avoiding the topic of ART she was already used to and found nothing remarkable about. The simple view that medicine is an enterprise that enables life, as advocated by activists who remind us that they would die if deprived of medicines (Fassin 2007; Jungar and Oinas 2010; Natrass 2007; Robins 2004, 2006), is, I claim, in fact a radical claim about structural violence. It is sometimes made through an insistence to speak about football rather than grief.

The TAC activists and the counsellors did not themselves use the concept of potential epistemic violence of biomedicine. The activist discourse needed to defend its agenda against accusations of ART being too difficult, complicated, or 'scientific' for Africans. Due to racist stereotypes, they had to downplay the need to translate and contextualise medicine. TAC presented a rather straightforward, respectful 'pure science' account (Oinas and Jungar 2008) to also counter the political agenda of dissident science. For example, the following quote, discussed by Jungar (2011, 82), was typical for the time: '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' (Ncapayi, TAC activist).

STRATEGICALLY SUBALTERN CYBORG EMBODIMENT AND THE STRUCTURAL MATERIAL VIOLENCE IN DENIED HIV TREATMENT

In this chapter, I suggested a three-dimensional view on structural violence: first, that the absence of pills signifies *material* violence; second, that the absence of pills for some citizens but not for others signifies *symbolic* violence of denied rights and humanity; and third, that the absence of engagement

with local realities and knowledge practices, that is, a denied translation of biomedical knowledge, signifies *epistemic* violence. The 2000s showed a remarkable shift towards the better in all these aspects. Now, approaching a new decade, with a shift towards colder winds in global solidarity, a focus on violence is more important than ever.

A situation where only a part of the global population has access to life-saving medication indicates material violence against the less-fortunate ones, argued the vocal cries of HIV activists in South Africa in the early 2000s. Such an optimist approach to medicine as a right may seem naïve to the most critical, but I argue that it does not require abandoning the critical approach to medicine as biopower (Agamben 1998; Comaroff 2007; Foucault 1980; Rabinow 2011), nor the critique of neoliberal capitalism in new development practices that render political problems technical or consumerist (Richey and Ponte 2010). The HIV activists who advocated a more explicit attention to questions of *access* to biomedical treatment suggest that these are questions of not only material but symbolic violence because, when denied the material reality of the antiretroviral medication, one's rights, citizenship, entire subjectivity, and humanity are also put in question. My research suggests, furthermore, that alongside material and symbolic violence, healthcare systems should also be concerned about the potential *epistemic* violence inherent in biomedicine, if it does not seriously engage with the everyday lives and politics on the ground.

The politics and practices of ART of HIV are a network of relations that involves a variety of actors and layers. Activists and volunteers are key figures in global politics of health and social justice through both symbolic and epistemic – and practical – work against structural violence. The volunteer HIV counsellors I interviewed for my research explained their care work and their own treatment management in terms that constantly drew links between the knowledge and ability to utilise a high-tech biomedical, anti-retroviral HIV treatment regimen with more traditionally sociological components, such as social support for negotiating poverty and crime. In their accounts, different elements of care and survival smoothly intertwined in this setting, with little need to create hierarchies in expertise or authority, in western or southern patients. For them – the hybrid subaltern cyborgs of a township – biomedicine is not alien, foreign, or 'western' in itself as it was claimed by President Mbeki to be. It is a set of knowledges, tools, and practices that can be learned, understood, translated, and elaborated on by people living with HIV. In their activism, the focus of action was not an individual subject in a neoliberal, modernist sense (Butler 1990, 1993; Martin 2006; Richey 2011); nor authority over medical expertise. Rather, their anti-violence work was geared towards solidarity, life, and hope, a hope that required a multitude of relational, collective agencies to be sustained (Campbell 2003; Das and Das

2007; Honkasalo 2009; Whyte et al. 2002), a hope that effectively rejected subalternity. While the activists were more vocal and strategic about subalternity, and the counsellors more pragmatic than explicitly political, in both cases, the different elements of violence were central.

ART and peer counselling are not magic bullets that erase the epidemic of HIV. Yet, currently, while still waiting for better means of intervention, they are crucial politico-epidemiological tools in the fight against a massive catastrophe both on personal and global levels. ART captures the crux of health care: there is no cure nor quick fix for the vulnerability of the physical body; survival and dignified life are thoroughly political questions that are never resolved once and for all. Currently, the success of the 2000s global HIV management is possibly heading towards a downward spiral again (UNAIDS 2015), making the urgency to connect it to violence even more crucial.

Social science scholarship on medicine is traditionally more likely to approach medicine critically than to address issues of material and epistemic access to biomedicine. If academic approaches remain limited to a mere critique, academics are also complicit in culpable homicide, the activists might argue. If social science does not address the vital dimensions of health care – and the lack thereof as violence – the way activist agendas do, social and political sciences will continue the problematic tradition of not taking the materiality of life seriously.

NOTES

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2. While the first data, with the movement, were observational, the second data set with the volunteers was composed of interviews. I visited the clinics for a few weeks at a time, conducting semi-structured interviews of thirty to sixty minutes with twenty volunteers.

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