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Biopolitical precarity in the permeable body: the social lives of people, viruses and their medicines

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The lives of HIV and its Medicines: Post-humanist Performativity in the Permeable Body

This article is based on multi-sited ethnography that aimed to trace a dynamic network of actors (activists, policy makers, health care systems, pharmaceutical companies) and actants (viruses and medicines) that shaped South African women's access to, and embodiment of, antiretroviral therapies (ARVs). Using actor network theory and post-humanist performativity as conceptual tools, the article explores how bodies become the meeting place for HIV and ARVs, or nonhuman actants. The findings centre around two linked sets of narratives that draw the focus out from the body to situate the body in relation to South Africa's shifting biopolitical landscape. The first set of narratives articulate how people perceive the intra-action of HIV and ARVs in their sustained vitality. The second set of narratives articulate the complex embodiment of vitality alongside precarity. These narratives flow into each other and do not represent a totalising view of the effects of HIV and ARVs in the lives of the people with whom I worked. The positive effects of ARVs (as unequivocally essential for sustaining life) were implicit and the precarious vitality of the people in this ethnography was fundamental. However a related and emergent set of struggles become salient during the study that complicate a view of ARVs as a 'technofix'. These emergent struggles were biopolitical, and they related first to the intra-action of HIV and ARVs 'within' the body; and second, to the 'outside' socio-economic context in which people's bodies were situated.

Keywords: post-humanist performativity; actor networks; embodiment; HIV; antiretroviral therapy

Introduction: The aftermath of ARV struggle in South Africa

President Zuma's face smiled down from a large billboard, impressing his vision for South Africa onto throngs of jetlagged people as we navigated our bodies and luggage trolleys out of Cape Town's International Airport. The billboard emphasised the government's commitment to creating decent jobs, education, health, fighting crime, and rural development. I maneuvered my luggage under the billboard and into the car.

With Khayelitsha behind me and Table Mountain in front of me, I drove past the green mosque that marked the turn-off to Nyanga - Khayelitsha's neighboring township and my fieldsite in 2003. In the course of my ethnography with Luvuyolwethu, an HIV homebased care organization, I came to know Nyanga's streets as I walked from one home to another with the carers during their 'rounds'. This is how I met Peggy. She lived with her 22-year-old son, Zithulele, and her 25-year-old daughter, Patricia. When I started my fieldwork, Patricia was still able to sit up in the bed that Luvuyolwethu had set up in the sitting area of Peggy's home. Without ARVs, HIV had become AIDS and Patricia had become immobile. We did not realise – or perhaps articulate – that when we moved Patricia from her bed to lie down in the back seat of my car, eventually to lie down in Groote Schuur hospital, that she would not come back home. We went to visit Patricia a few days later: on the cusp of death, she had been heavily sedated with morphine. After driving in silence most of the way back home, Peggy pulled her jersey more tightly around her body and said, "I fought in the streets for this government. Now the holes in my roof are just bigger and they are not giving me medicine for my daughter." Patricia died three days later, just a month before the government was forced by cabinet to initiate the ARV roll-out.

At that time, in 2003, the presence of the post-apartheid state in people's lives was felt through its absence, embodied in death, evident in the blossoming of wooden crosses on graves carefully dug to run as closely as possible alongside each other. In the course of my fieldwork that year, the graves had pushed out and against the feeble fence that lined NI – the main road that ran like Nyanga's spine between this space of death and homes of Luvuyolwethu's clients as they navigated their precarious lives. On a bitterly cold winter's day in July 2003, Peggy's family and I clustered around the parcel of earth that had been designated for Patricia's grave as her minister led the funeral. When we returned to Peggy's home after the ceremony we all washed our hands in one of the three buckets that had been placed on the street outside her front yard. Peggy explained to me that by washing our hands after Patricia's burial we signified to the ancestors that we had distanced ourselves from death and looked, instead, towards life.

In this pre-ARV era, HIV became AIDS became death so rapidly that the forward slash between HIV/AIDS made sense. In 2016, it no longer does. ARVs have pried open the space between HIV and AIDS. Now, this opening out of life brings to light a set of complex challenges around the biopolitics of HIV therapies and the socioeconomic conditions in which life on ARVs is lived. These new generation struggles call into focus an assemblage of actants and actors that, together, are networked into women's embodied precarity. While a longer life with HIV is possible through 'technologies of life' like ARVs, for the women I worked with over a decade I met Peggy and Patricia, it is still a precarious life that, everyday, pushes out and against the possibility of death.

This article draws on ethnographic research conducted in South Africa between 2010 and 2011. Through this research, I explored two interlinked themes: first, women's embodied experience of HIV and ARVs and, second, women's perception of and engagement with the state based on their embodied experience of illness and biomedicine. Drawing on post-humanist performativity as a conceptual tool (Barad 2003, 2007), the article traces the 'intra-action' of HIV and ARVs as nonhuman actants (Latour 2005) inside the body, and it locates the body in a broader context where emergent biomedical and socio-economic challenges confound a straightforward reading of ARVs as the solution to the problem of HIV.

2. Ethno-theoretical Connections

[E]thnographic engagement can help us chart some of the complex and often contradictory ways in which neoliberalizing health structures, moral economy, and biology are forged in local worlds where biotechnology and structural violence now exist side-by-side (Biehl, 2004: 125).

In researching the embodied ramifications of illness and medicine on people's perception of the state, the men and women I met during my fieldwork took the feminist adage that the personal is political and mixed it up, thoroughly. The ethnography called for theoretical agility as people's accounts of the pathways that brought HIV and later ARVs as actants into their bodies implicated a network of actors, including scientists capable of reverse engineering essential HIV medicines in India's laboratories, South Africa's capacity to negotiate international trade law to access these medicines, health systems and its professionals who dispense medicines through small 'ARV-only' pharmaceutical counters in Khayelitsha's clinics, and transnational activist coalitions with international organisations like Médecins Sans Frontières (MSF). As I discuss in this article, my ethnographic research highlighted the importance of understanding the

body as permeable, as neither material nor semiotic, but as a material-semiotic assemblage of networks.

My own thinking about HIV and ARVs as non-human actants follows the trajectory of thought around the social lives of things (Appadurai 1988) and Whyte, Whyte, van der Geest and Hardon's (2002) exploration of biomedicine as material medica. More recently, Michael and Rosengarten (2012) have looked at HIV prevention technologies, or pre-exposure prophylaxis (PrEP) as actants enmeshed in a web of relations. They consider two case studies (of the AIDS clock and accounts of randomised control trials) and explore how their "global reach weaves into various local contingencies, particularly localizing critiques that emphasize the conditions of infection and death, and local political protest against the clinical trials" (Ibid: 95).

Globalisation and technological developments have certainly prompted a rethinking of governance in which we recognize that the contemporary 'body of the state' is far less 'sovereign' and far more porous than it was – ontologically and epistemologically – at the time of Weber (1984), Arendt (1958) and Foucault's (1998) theorising. Not only are the state and citizen porously implicated in each other's vitality but their own lives form part of a much larger assemblage. The term 'global assemblage' was coined by Ong and Collier (2005) to capture this dynamic, and has been used to reflect on the conflicts and controversies of globalisation, as changes in technologies, bodies and governments precipitated and were precipitated by global-local transformations.¹

At the same time that Ong and Collier (2005) coined 'global assemblage' for a collection of articles on the anthropology of ethics and technologies, George Marcus and Erkan Sarka were also, but more cynically, writing about the usefulness of this concept.

While not one of the prime or key terms of recent and past discourses of theory in the social sciences ... assemblage in its uses here and there is actually keenly symptomatic of one of the major, if not the major, thrust of critical social and cultural theory toward the emphasis on the modernist focusing of attention on the always-emergent conditions of the present (2006: 101 - 102).

I follow Marcus and Sarka's (2006) caution against an 'unthinking' application of assemblage by engaging with the tools offered through ANT to look at how assemblages take shape in people's lives. In line with Latour's (2005) assertion that we cannot simply look at the form that networks take, but need also to look at the associations that bring these elements together, Collier (2009) similarly argues – specifically in relation to the evolution of governmentality in Foucault's lectures – that we cannot only identify a form of the assemblage but that we need to extend our analysis to understand how this formation comes to take shape. This connects to the way I work with ANT as a tool to look at, and possibly interfere in, relations between actors and actants that generated the politics of life I observed through my fieldwork.

ed by Deleuze and Guattari (1986) to convey, as Callon explains,

[T]he idea of a combination of heterogeneous elements that have been carefully adjusted to one another... Agencement has the same root as agency: agencements are arrangements

endowed with the capacity of acting in different ways depending on their configuration (2006: 13).

¹ As a concept, 'assemblage' can be traced further back to its French origins: *agencement*. It was developed by Deleuze and Guattari (1986) to convey, as Callon explains,

I suggest that assemblages and actor networks are not only conceptually useful, but they are also politically important: in using them together, they work against isolating politics from the body, and offer a set of tools to think usefully about the ways that actants and actors across scale, from the global to the molecular, are networked into an assemblage around the biopolitics of life. Specifically, I use ANT to think about the actors (people and institutions) and non-human actants (HIV and ARVs) and how they interacted with each other through an assemblage that moved from under the skin right into the global arena of pharmaceutical developments, emerging trade policies and contested intellectual property rights. In doing so, I speak to porous interconnection and against representationalism and the discursive construction of distance that relies on reified entities held separate through their pairing in dichotomies.

Drawing on feminist, queer, Marxist and science studies, and building on insights from Butler (1989, 2004), Foucault (1978, 1986, 1998), Hacking (1990) and others, Barad (2007) issues a challenge to the metaphysical foundations of representationalism by offering a post-humanist performative account of the relationship between material and discursive practices.

When discussing the limits of representationalism, which often relies of the reification of binaries, Butler too asserts the danger of separating out materiality (the body) and discourse (power).

Butler (2009), Gregson and Rose (2000) and Haraway (1997) have similarly proposed a series of conceptual approaches that incorporate performativity in order to move away from representational accounts with regard to gender, space and science respectively. Performativity is defined as, "the citational practices which reproduce and/or subvert discourse and which enable and discipline subjects and their performances" (Gregson and Rose 2000: 434). I draw on the notion of performativity to explore how individuals embody, reproduce and subvert discourse through particular sets of strategies and tactics, with reference, too, to de Certeau (1984).

In particular, I use Barad's concept of post-humanist performativity as, [O]ne that incorporates important material and discursive, social and scientific, human and nonhuman, and natural and cultural factors. A posthumanist account calls into question the givenness of the differential categories of 'human' and 'nonhuman,' examining the practices through which these differential boundaries are stabilized and destabilized (2003: 808).

This article integrates the conceptual approach of actor networks with performativity, and post-humanist performativity in particular, through the concept of intra-action (Barad 2008: 174). Through this concept, I explore how bodies become the meeting place for HIV and AIDS therapies, or nonhuman actants in Latour's terms (2005); the AIDS therapies, for example, disrupt distinctions or causal connections between the body they animate and the life they take on through this animation. As such, "[d]iscursive practices and material phenomena do not stand in a relationship of externality to one another; rather the material and the discursive are mutually implicated in the dynamics of intra-activity" (Barad 2008: 174). I use 'intra-action' in place of 'interaction' as the latter reflects the Newtonian legacy in which 'things', or actants, are constructed as determinant, stable, prior-existing and bounded (Barad 2003). Intra-

action, instead, reflects Haraway's call for a material-semiotics that transcends (by connecting) the materiality of things – like medicines, bodies, viruses – and the discourses that shape them – like beliefs around health or practices of self–care, for example (1997, 1991).

I found that HIV-positive women's lives are woven into a biopolitical assemblage that makes it more or less possible for them to be able to secure their own vitality. The dynamics of this assemblage generate particular sources of vulnerability for women that are embodied and experienced, for example, through side effects from old generation medicines or through the limits placed on life by limiting treatment possibilities in the public sector to second and not third line medicines. Therefore, in this article I use the term 'biopolitical precarity' with reference to Butler's 'precarious life' to denote the intra-action of actants that shape and are shaped by women's embodied experience of precarity in a biopolitical network that is threaded into the permeable body. If we think about bodies, governments and technologies as related and porous, then it is harder to not face each other and hold actors accountable for actions that ricochet across this assemblage and permeate people's bodies and lives.

3. Methodology (525)

This article is based on multi-sited ethnographic research and encompasses a range of visual and participatory methods. By conducting multi-sited ethnography, I sought to trace a dynamic network of actors (activists, policy makers, health care systems, pharmaceutical companies) and actants (viruses and medicines) that shaped South African women's access to, and embodiment of, ARVs. The findings discussed in this article relate specifically to fieldwork that was conducted in Khayelitsha, a semi-formal housing area in the Cape Town Metropole, in 2010 and 2011.

While it may be located on the periphery of the Western Cape's economic centre – Cape Town's Central Business District – Khayelitsha has played a pivotal role in South Africa's political history. It was the first place where governmental and non-governmental actors worked together to provide ARVs through the public health sector. The space of Khayelitsha, therefore, holds a history that reflects the South Africa's shifting biomedical and political landscapes: as people resumed their health, their testimonies about the lazarus effect of ARVs further bolstered activists' calls for the government to roll out ARVs across the country (Robins 2010). This particular confluence of history and space underpinned the rationale for conducting fieldwork in Khayelitsha.

The findings draw on ethnographic research with a core group of women on ARVs (aged 30 – 50); they all lived in Khayelitsha and had worked with Treatment Action Campaign (TAC) in the course of the decade long struggle for this treatment. In addition to participant observation, informal conversations and life history interviews, I used a set of visual research methods including participatory photography and film, and actor network mapping (Dennis Jr et al. 2009). The findings also reflect close engagement with a group of seven people (one man and six women) with whom I have worked in various capacities since 2004. In this article, I reflect on the narrative life history interviews (Hurwitz, Greenhalgh, and Skultans 2004) I conducted with this group in parallel with a series of body-maps that they created in 2003 and 2011 (see: MacGregor 2009b). I was invited by the group to participate in the series of workshops in which the 2011 set of body-maps were developed by the artists with the support of Jane Solomon, who had developed this particular method and worked with this group in 2003. The 2011 workshops included a set of 'visual enquiries' that I proposed to the group (including creating an 'ARV timeline' and showing where they 'felt' medicine in

the body) which I then explored in greater detail through subsequent discussions with the artists.

The findings in this article corroborate the overall findings of the study that, in addition to participant observation, included: 20 key informant interviews with policy actors; 40 narrative life history interviews with men and women on ARVs; participant photography and film; and body and journey mapping.

Ethics permission for this study was formally obtained through the University of Sussex, through consent forms with each of the study participants, and through ongoing dialogue throughout the course of my research – beyond fieldwork – with the participants to discuss how they would like to be represented, which stories should be shared most boldly, and which stories should not be shared at all.

4. Findings

The findings centre around two linked sets of narratives that draw the focus out from the body to situate the body in relation to South Africa's shifting biopolitical landscape. The first set of narratives articulate how people perceive the intra-action of HIV and ARVs in their sustained vitality. The second set of narratives articulate the complex embodiment of vitality alongside precarity. These narratives flow into each other and do not represent a totalising view of the effects of HIV and ARVs in the lives of the people with whom I worked.

The positive effects of ARVs (as unequivocally essential for sustaining life) were implicit and the precarious vitality of the people with whom I worked was fundamental. However, I discuss this set of narratives here because I found, in the course my fieldwork, that a related and emergent set of struggles was becoming salient; they complicate the view that ARVs are a 'technofix' and present a challenge to the idea that only 'local biologies' like HIV and ARVs are embodied. As I go on to discuss, these emergent struggles were biopolitical, and they related first to the intra-action of HIV and ARVs 'within' the body; and second, to the 'outside' socio-economic context in which people's bodies were situated.

4.1. The Struggle for ARVs and Embodied Vitality

In May, a week after the Municipal Elections, Mamello and I were walking down Queen Victoria street in central Cape Town. Not only did the name of the street speak to the colonial legacy of South Africa, but the Memorialised 'Slegs Blankes/Whites Only' bench that we passed outside the High Court was a reminder of South Africa's more recent history – one that Mamello had actively shaped through her affidavit and testimony in the court case that TAC brought against the government to compel them to provide PMTCT. We walked in silence past the bench; our conversations often had more silences than words.

Over months of walking and sometimes talking, I learnt that Mamello's activism was born from her anger with the government for failing to provide treatment to stop HIV from moving into her daughter's body. On this particular day, Mamello held up her thumb to me with its indelible stain, showing me that she had voted. I asked her why, and she pointed to Parliament, its white buildings barely visible over the green trees of the Company Gardens on Queen Victoria street. She said, 'I voted for my treatment'. She went on to say,

I was here [gesturing to parliament] pressuring the government. I told them, 'You must give us the treatment because the people are dying'. The government – [former Health Minister] Manto Tshabalala-Msimang – was telling us that if we had HIV, we must take the veg... They ignored the virus (Mamello, 2011).

I asked, "When did they start taking things seriously?" "As I give them pressure!" she replied. We turned right onto Wale Street and walked to the bottom of the stairs of the St George's Anglican Cathedral.

The Cathedral is situated next to the Parliament Buildings, in the Company Gardens, and has been used historically by apartheid and post-apartheid activists alike as a site of resistance and a place of mourning. It was, in fact, the same place where TAC had first assembled, almost thirteen years previously. The Gardens, which move out from the Cathedral, mark an important politico-juridical intersection with the High Court on the right and Parliament on the left. It was through these two spaces of the state spanning policy development and juridical implementation that Mamello worked with TAC to challenge the pharmaceutical companies, and later the government, to provide ARVs to stop HIV from travelling along vertical pathways through breastmilk and blood from a parent to their child, and along horizontal pathways through sex and into people's bodies.

Zukile had worked alongside Mamello, Yandisa and the other women in my ethnography through TAC, as they called on the government to scale up the ARV rollout. When Zukile started ARVs through the MSF trial in June 2001 he weighed 30 kilograms and his CD4 count was 174. He reflected the skeleton of his story in a body map that he created but did not complete in 2003. In 2011, he participated in an initiative with the Departments of Public Works and Health to create a new body map. The 2011 body maps track the journey of each artist's life since starting ARVs and were placed in the waiting areas of Khayelitsha's hospital as mosaics; like the activists described above, the artists' mosaics bear witness to the legacy of the struggle for to bring AIDS medicines into the country's public health system, and into their own and their comrade's bodies.

In his 2011 body map, and in his speech at the MSF 10 Year Celebration, Zukile notes the change in his health over the last decade: in 2011, his CD4 count is 622 and his viral load is undetectable. These biomedical indicators connect to the life cycles of HIV and ARVs as actants, with ARVs having successfully prevented HIV from coopting CD4 cells and replicating, thus supporting the CD4 cells in sustaining his immune system. In the contours of his body, he has drawn his source of strength: a spear, represented by a red sheath and a white handle. This spear, he said when describing the symbols in his map, represented his isiXhosa heritage and the way that he was encouraged (particularly through traditional male circumcision) to be strong. This is reflected in the message that he wrote for other people living with HIV: Life is a challenge – face it. He attributes his emotional strength to his heritage and his physical strength to ARVs. The white markings in his body symbolise his ARV tablets. He said, when discussing his body map, that he had been on ARVs for so long that they had become part of who he is; that they were not simply pills that he put into his body, but that they were his body.

ARVs had intra-acted so intimately with his body that he no longer distinguished between the boundaries of the medicine and the boundaries of his body – they had become each other. As an activist, Zukile had called on the state to intervene in the space of his body by providing medicines; with these medicines, he had not only resumed full health but had also come to embody ARVs so fully that he no longer separated the boundaries of the pill from the state of his body.

His account draws into focus the biopolitical dynamic that linked the state of his body with the body of the state. Lambert and McDonald (2009) consider, similarly, the shifts in attitudes towards the body that have followed technological developments, particularly those that have the capacity to 'remake life and death' (Franklin and Lock,

2003). Like Butler(2011) and Barad (2007), they challenge historical 'representationalist' approaches to embodiment in which the body is separated from the social and understood to be a 'slate for inscription' (see Douglas, 1966). By foregrounding the entangled intra-action of HIV and ARVs with each other, illustrated in Zukile's body map and his account of ARVs, it becomes more possible to view the body as porous. His vitality is intimately entwined with a global assemblage that moved out his embodied experience of the intra-action of ARVs with the virus, to include a network of organisations (like MSF, TAC and Indian pharmaceutical companies) that spanned local, national and global levels.

Further, Zukile draws his cultural heritage, that of strength represented by a spear, within his body and alongside the ARVs that gave his body strength, disrupting dichotomies that separate the social from the science, discourse from materiality, human from non-human. Drawing on the definition of post-humanist performativity as "one that incorporates important material and discursive, social and scientific, human and nonhuman, and natural and cultural factors" (Barad 2003: 808), Zukile's account illustrates how - as non-human actant - ARVs moved into and become a part of his materiality, his body. The visual depiction of his body filled with ARVs illustrates the post-humanist dimension described by Barad (2003) as iterative intra-activity. Nowotny (2001), too, reflects on the extent to which scientific knowledge becomes integrated into everyday life because, as Latour (2005) writes, science is 'internal' to rather than separate from society. Here, Zukile's body map similarly illustrates the extent to which scientific knowledge moves beyond an abstract set of concepts into the very space of his body and outwards, too, through his activism and leadership within TAC, and a speech he gave at the MSF ten year celebrations for example.

Andiswa, too, spoke of the impact of ARVs on her body and in her life through two body maps, one in 2003 and the second in 2011. I asked her about the white marks she had drawn in her 2011 body map. She said, "These are the ARVs." Tracing her hand over the red contour of her body, moving in and out of the white circles representing the ARVs, she echoed Zukile, saying, "They're all over the body". Andiswa's description suggests that the ARVs had, as with Zukile, become her body; by intra-acting with HIV, her ARVs were embodied in the fuller fleshier body she contrasts with her frail 'pre-ARV' self. As a way to describe how ARVs 'cooled' the fire of HIV, Andiswa echoed the other body map artists by referring to a set of biomedical indicators of relative illness and health that had changed between 2003 and 2011: "My CD4 count was 18 at the time, and I was weighing 48 kg. This is me now, 2010, my CD4 count is 1045, my viral load is undetectable and I weigh 76 kilograms". Andiswa's account, like Zukile's, suggests that the self-care practices entailed in adhering to ARVs were embodied by resumed health, indicated through these biomedical markers.

These markers suggest an 'internalisation' of scientific knowledge generated through TAC's treatment literacy programme: as ARVs prevent HIV from changing its genetic material and entering the CD4 cell, they enable healthy cells to support the body's immune response and quell the effect of HIV as a 'fire' that burns. MacGregor (2009a) reflects on TAC's treatment literacy initiatives in light of this group of women's body mapping and suggests that TAC's education activities reflect a 'context-sensitive' science. In the initial body maps, and now with this later set of maps, the narratives held in the women's body maps continue to reflect a sensitivity to the context in which people take ARVs; many of the women, for example, drew fruit and other foods on their maps and spoke about the importance of employment in supporting them to adhere to their treatment.

Across the body maps, ARVs were depicted as powerful non-human actants that had challenged the power of HIV within the arena of the body. Nokukhanya, for example, spoke about her sense of ARVs 'calming' the storm of HIV within her body through her body map in 2011:

HIV is like nothing to me now. I'm not worried about it. Because I just see that it is calm. I show in this [2011] map that I'm walking up on - on top of - it. It's like the sand, you know, when you walk on the sand there is that mark... [With] wet sand it leaves a mark and then when the water comes it just wipes that mark. It's like the treatment that I already am taking has wiped the HIV. So now I don't feel like I have HIV. (Nokukhanya, 2011).

Nokukhanya's description of ARVs as radically transformative, an actant able to 'wipe HIV away', is a theme in many studies conducted just as ARVs became internationally available (Biehl, 2005, 2009, Rasmusen and Richey, 2012). Robins (2006), for example, refers to the 'treatment testimonies' of activists who give accounts of the 'lazarus effect' of HIV as they transitioned from bare life to full health. Their bare life was, as Robins argues, a result of the state refusing to provide ARVs and therefore withholding their citizens' ability to secure long-term vitality; he links the 'lazarus effect', however, to both medicines and the responsibilities entailed in taking them. Similarly, although activists like Zukile, Andiswa and Nokukhanya accorded agency to ARVs, as actants, in their embodied health I found, too, that their resumed health was linked to a set of complex disciplining techniques in which the activity of ARVs with HIV within the body is played out, or performed.

These 'regimes of care' speak to Foucault's conception of 'technologies of the self' (1998). He describes the 'techniques of self' prescribed by ancient Greek pagan morality in order to condition sexual ethics. His work has been taken up by anthropologists researching biomedical regimes of care to show a contradiction in the practices required of those receiving ARVs (Kalofonos 2008). For people on ARVs are told to follow a set of practices, a regime, that entail strict adherence to their medicines and healthy eating. Unlike the Ancient Greeks, Marsland (2012) describes the contradiction she observed in Tanzania as those people with whom she worked were not moving from a place of decadence and plenty into one of ascetic restrictions; instead, they were required by biomedical regimes of care to – almost impossibly – secure scarce food and other material resources as techniques of 'positive living' on ARVs.

The people with whom I worked may have reflected Robins' (2006) description of compliant and 'responsibilised' citizen activists who, when starting ARVs a decade ago, committed to following a set of practices entailed in joining the MSF pilot trial. However, a decade later, we see that these practices of self-care are fraught and not simply a matter of 'compliance' or 'resistance' to biomedical regimes of care among the people with whom I worked. Through her research in Uganda, also with people receiving ARVs, Whyte (2004) similarly calls us to pay attention to the different contexts in which social, economic and biomedical subjectivities unfold.

Returning to my own ethnography, context mattered. But I take context to matter both within and beyond the body, as I read the body itself as permeable. This deviates, slightly, from these emerging ethnographies (Marsland 2012, Marsland and Prince 2012, Kalofonos 2008) that present a challenge to the politics of life literature. Below, I turn to look into the body to see how, as actants, HIV and ARVs intra-act in complex ways with each other to generate risk and also opportunity. As we see in the following section, a new set of struggles have surfaced that problematise both the context in which ARVs intra-act with HIV 'within' the body, and the context in which people live that, too, is precariously embodied.

4.2. New Generation Struggles and Embodied Precarity

During my fieldwork, it became apparent that TAC's branch members were raising concerns around adherence, side effects and viral resistance. In an effort to address these concerns, and to call on the government to introduce new biomedical technologies (for TB and HIV), TAC developed an Equal Treatment issue on these 'new generation struggles'. Nathan Geffen wrote the editorial for this issue. Writing about the life cycle of HIV, he described how both ARVs and viruses are constantly changing inside the body. These changes, wrought through the intra-action of older ARVs with an agile shape-shifting virus, underlined the political imperative to bring new generations of ARVs to South Africa in order to reduce the risk of side effects, to increase the likelihood of adherence and to provide third line treatment to people who have developed resistance to second line treatment. His article reflects a conception of HIV as an actant, as particular kinds of germs' that change, evolve, mutate. He describes this process of intra-action in the excerpt below:

Medicines are developed to attack particular kinds of germs. But over time germs change; they evolve; they mutate. Sometimes they change sufficiently so that the medicines that are supposed to be effective against them stop working. This is natural; it's the way the germs work (Geffen 2011: 1).

The fear of developing resistance to second line treatment permeated my fieldwork with people who were on second line treatment, or who had children on second line treatment. A number of the activists I engaged with through the course of my fieldwork referred to a prominent activist who had also become tired and who had 'given up' taking his medication; it was a shock to them because he was well informed, worked to raise awareness around the efficacy of AIDS medicine, and yet had reached a point where he was too 'tired' to continue taking his treatment. His treatment fatigue was also compounded by depression and alcoholism: he became very seriously ill with meningitis and asked to be placed back on ARVs, but by this stage his body had developed resistance to both lines of treatment and he died.

Treatment fatigue and viral resistance are two inter-linked 'new generation struggles' that emerged in my fieldwork. Participants frequently used the term 'tired' to describe their frustration with taking medicine every day at a particular time. Brenda, for example, decided to 'take a break' because she was tired of taking ARVs. During a conversation about the current government and changes in the politics of health, she said,

If [President] Zuma could try to get third line I think it's good for us, or an injection. Because tablets are not easy to take. It's not easy to take ARV tablets every morning. That's why they have a lot of defaulters. So I think Zuma must try again or try harder to get something to help us. Because ARVs, wow! They're good, but if you take tablets... Yoh! You feel tired! But if I'm getting injection for a month to protect my virus, I think it's good for me (Brenda, 2011).

As a result of interrupting her treatment, the virus had mutated sufficiently to outwit her first line ARVs and she was therefore placed on second line treatment.

The artists of each of the body maps represented HIV in different ways inside their bodies. Andiswa, for example, drew HIV as the embers of a former conflagration, saying that ARVs had 'cooled' the fire down. Nokukhanya described HIV as the soft indentations of footprints on the wet sand, saying that ARVs had 'calmed' the storm of HIV down. In contrast with all of the body maps developed in both 2003 and 2011, Nceba drew HIV outside her body.

She said that now HIV was not what defined her and that, instead, it was a source of opportunity for her. HIV was symbolised by white ribbons around her body.

Inside the ribbons she had drawn maple leaves; the leaves referred to the artistic collaborations that she had entered into with colleagues in Canada through her HIV activism and art. Her body map extends Zukile's description of ARVs as his body. Nceba, in an interview about her body map, said that ARVs had been so powerful that they had moved HIV outside her body. She pointed to the marks on her body, shown in the map as light brown markings along her legs and arms, saying, "Yes, the effect of HIV is still on my skin, but HIV is not who I am."

This marks a key shift in socialities as Nceba both claimed HIV through the kinds of opportunities she was able to access, while also asserting that she did not want to be fundamentally labelled as 'HIV-positive'. She said, instead, when telling the rest of the group of artists about her map, that she wanted to be thought as, "Just someone living with X. X is my child, or my art. I'm not my HIV." This further reflects Whyte's (2009) call to understand how subjectivities shift as people's embodied experience of illness changes. In Nceba's case, her experience of illness changed markedly after she accessed ARVs in 2002. Ten years later, I visited Nceba, Andiswa and Zukile at an exhibition in London. They had worked with the British Council, in conjunction with the Paralympics, to develop a body of work with a British artist. I watched a performance, as part of this exhibition, where HIV took the form a dancer's body as she flew around the stage, wild and dangerous, before ARVs – another dancer – came to tame her.

As we see above in Andiswa and Zukile's accounts, it is through the intra-action of ARVs with HIV that Nceba was able see HIV as 'beyond' her body. It is also, as I discuss above, through her discipline and self-care practices, particularly around adherence, that she was able to manage HIV to the extent that she could 'see' it outside herself in the opportunities she was able to access. This presents another layer to the discussion above around Zukile's body map and post-humanist performativity as ARVs intra-act with HIV: it is through taking ARVs, every day, that Nceba 'saw' the presence of HIV in the form of her ARVs even as it was felt to be absent from her body. A tension therefore surfaced for Nceba between wanting to move away from being defined by HIV, and the struggle for ARVs, and recognising that ARVs also enabled her to move 'beyond HIV'. She spoke of this tension at length in the course of our work together, and spoke too, of her frustration with her sense that people also patronised her and overlooked her skills because she was HIV-positive and a woman.

This tension was a strong finding in my ethnographic research with the women in the core group. In contrast with the notion of 'bare life' described by Robins (2005) and generated through the state's historical failure to provide essential ARVs, the way in which precarity was strategically performed by the research participants points to a different narrative. In connection with findings presented elsewhere on pathways of precarity where I suggest that instead of being either reduced to bare life or 'acted on' by national and international development programmes, women 'acted up' by strategically placing themselves within the 'development subjectivities' that had been discursively narrated through development interventions and policies that framed women as economically, socially and biologically 'vulnerable' to and as a result of HIV-infection (Mills 2016).

5. Conclusion

The ten year celebration of MSF's first ARV trial in Khayelitsha was a poignant and powerful marker of transitions in South Africa's biopolitical landscape: at the time of my fieldwork, ARVs were no longer the scarce resource they were when people like Lilian, Zukile, Andiswa and Nceba first started taking these medicines a decade ago. It is for this reason, I propose, that we start to see a shift in the embodied accounts of the

intra-action of HIV and ARVs in people's lives. I refer to embodied 'accounts' here as it was through hanging out, and in verbal and visual narratives (in the body maps) that the people I worked with communicated how they embodied these actants in their lives, over this last decade. This article traced these fluid accounts across time, and in relation to the people with whom I worked most closely during my fieldwork. It is therefore with the understanding that I worked with a particular group of people who were on ARVs and had engaged as activists in the historic context of the struggle for ARVs in South Africa, that I situate the following observations.

I suggest that if we really are going to move beyond the 'nature/culture' dichotomy that separates biology from sociality, we need to explore how the world 'outside' the body permeates and shapes life 'inside' the body. This requires a shift away from privileging 'biology' as that which exists inside the body to recognising, through the lens of biopolitical precarity, how the body is porously networked into an assemblage that brings the 'outside' 'inside'. To this end, this article juxtaposed interiority with ethnology: drawing on ANT and the concept of post-humanist performativity, it looked between the world 'inside' and the world 'outside' the body. The article outlined how HIV and ARVs, as actants, were felt to within the body, and it illustrated how these actants are brought into the body through socialities that take place between multiple actors outside the body: in relationships between the people I worked with, TAC, MSF and the government. The socialities that were formed among the people with whom I worked around their HIV status was a strong feature of my fieldwork as I observed and took part in the networks of connection that brought friends and colleagues together.

Anthropologists like Marsland (2012), Prince (2012), Meinart (2003) and Le Marcis (2012), who have also researched ARV programmes in Eastern and Southern Africa in the decade following the initial struggle for ARVs, have suggested a reframing of the historical approach to governmentality, biosociality and biopolitics (see Nguyen 2010, Robins 2006). In a special issue on medical anthropology and biomedicine, these anthropologists reflect on their research and probe the limits of biopolitics as a 'one size fits all' conceptual approach. In response to the assertion that "biosociality does not look inward to the body, but outward to human relationships" (Marsland 2012: 473), this article suggests that perhaps there is a way of thinking about biosociality that does not ask us to look either into the body, or outward to socialities, but across them.

In conceptualising HIV and ARVs as actants, this article draws the social dimension of these actants lives into relief; further, 'new generation' struggles linked to adherence viral resistance, side-effects and socio-economic inequality bring the biological dimension of social, political and economic relationships into focus. For HIV not only enters women's lives through human relationships, but as an actant, HIV itself becomes alive and has, in Appadurai's (1988) terms, a 'social life' in the body. Once in the body, the virus learns to intra-act with the body's immune system – its CD4 cells – and, over time, manages to con these cells into mimicking the body's basic biological identity – its DNA. ARVs, like HIV, also call attention to the social, economic and political relationships that women navigated as activists in order to mobilise the government to bring these medicines into South Africa's public health system. However, once in the body, ARVs also take on a social life. They each interact with each other as they are technologically honed – as a triple therapy – to block HIV in its attempts to con the CD4 cells.

Where my research perhaps connects to, but also moves from, earlier accounts of HIV and biosociality is that, as actants, the posthumanist performativity of ARVs is not solely embodied in positive terms (described by Nguyen (2005, 2010) and Robins

(2006); nor do these accounts highlight the limitations of biomedical programmes in places where people can sometimes simply not afford to take medicines that make them even more hungry and even less able to work (described by Marsland and Prince (2012), for example). Thinking about ARVs as actants, things with a social life, highlights another form of sociality as they become felt by the people I worked with, and visible to other people, through their manifestation in side effects, like lipodystrophy. What is held in the body becomes social.

These actants intra-act and move into the social space of people's relationships with each other as they become visible as facets of sociality: through activist networks that mobilise around ARVs; around ARVs as they become embodied in people's physiological health and parallel side-effects; through the kind of sexual relationships that women can and cannot negotiate with their partners; through the economic resources they are able to secure by foregrounding one particular subjectivity – HIV – over the multitude of others; and through the emerging citizen claims that draw these women back into a biopolitical relationship with the state to access newer medical technologies that will have fewer negative effects on their bodies and that will be better able to combat HIV as it learns to outwit the older generation medicines. Therefore, I use the term 'diffracted biosocialities' to describe a dynamic connection across these facets and to denote the complex ways in which the social is not only forged through biology, but where biology, itself, is social and forged through sociality.

In addition to the embodied precarity linked to side-effects, viral resistance and adherence, the new generation struggles discussed in this article also relate to the socio-economic contours of these women's everyday lives. We see, in this strand of the new generation struggles, how HIV can and has been used performatively to secure, albeit precariously, resources through which women have been able to navigate the tightly stretched economic landscape in which they live.

Therefore, using ANT and post-humanist performativity as tools to explore the embodiment of biopolitical precarity, the paper reveals two overarching findings that, together, point to the value of moving away from the 'problem/solution' framing of HIV and ARVs (Lock 2012, Lock and Nguyen 2010). First, the findings suggest that although HIV can be a form of embodied precarity, it can also be a resource. Second, HIV – as an actant within the body – can also be performatively mobilised 'outside' through socio-economic relationships to manage precarity. In this regard, the women I worked with were able to strategically secure critical economic resources in a development milieu that perpetuates the 'gender/HIV' dyad. The article's findings suggest, then, that as 'local biologies' (Gilbert 2013, Bharadwaj 2013) both HIV and ARVs have not only influenced the kind of social relationships that people form, but they too intra-act and perform social lives that are differentially embodied in people's lives.

References

- Appadurai, Arjun. 1988. *The Social Life of Things: Commodities in Cultural Perspective*. Edited by Arjun Appadurai. Cambridge: Cambridge University Press.
- Barad, Karen. 2003. "Posthumanist Performativity: Toward an Understanding of How Matter Comes to Matter." *Signs* 28 (3):801-831.
- Barad, Karen. 2007. Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning Duke University Press Books.
- Barad, Karen. 2008. "Living in a Posthumanist Material World Lessons from Schrodinger's Cat." In *Bits of life : feminism at the intersections of media,*

- bioscience, and technology, edited by Anneke Smelik and Nina Lykke. Seattle: University of Washington Press.
- Bharadwaj, Aditya. 2013. "Subaltern Biology? Local Biologies, Indian Odysseys, and the Pursuit of Human Embryonic Stem Cell Therapies." *Medical Anthropology* 32 (4):359-373. doi: 10.1080/01459740.2013.787533.
- Butler, Judith. 1989. "Foucault and the Paradox of Bodily Inscriptions." *The Journal of Philosophy* 86 (11):601-607.
- Butler, Judith. 2004. Undoing gender. New York; London: Routledge.
- Butler, Judith. 2009. Performativity, Precarity and Sexual Politics. Antropólogos Iberoamericanos en Red (AIBR).
- Butler, P.J. 2011. *Bodies That Matter*: Taylor & Francis Group.
- Callon, Michel. 2006. "What does it mean to say that economics is performative?".
- Collier, Stephen J. 2009. "Topologies of Power: Foucault's Analysis of Political Government beyond 'Governmentality'." *Theory, Culture & Society* 26 (6):78-108. doi: 10.1177/0263276409347694.
- De Certeau, M. 1984. The Practice of Everyday Life: University of California Press.
- Deleuze, G., and F. Guattari. 1986. *Kafka: Toward a Minor Literature*: University of Minnesota Press.
- Dennis Jr, Samuel F., Suzanne Gaulocher, Richard M. Carpiano, and David Brown. 2009. "Participatory photo mapping (PPM): Exploring an integrated method for health and place research with young people." *Health & Damp; Place* 15 (2):466-473. doi: 10.1016/j.healthplace.2008.08.004.
- Foucault, Michel. 1978. The History of Sexuality, Vol. 1. Vol. 1. New York: Pantheon.
- Foucault, Michel. 1986. "The Use of Pleasure." In *The History of Sexuality, Vol. 2* New York: Pantheon.
- Foucault, Michel. 1998. "Technologies of the Self." In *Technologies of teh Self*, edited by Luther Martin, 16 49. Amherst: University of Massachusetts Press.
- Geffen, Nathan. 2011. "Drug Resistance." Equal Treatment.
- Gilbert, Hannah. 2013. "Re-visioning Local Biologies: HIV-2 and the Pattern of Differential Valuation in Biomedical Research." *Medical Anthropology* 32 (4):343-358. doi: 10.1080/01459740.2013.773328.
- Gregson, N., and G. Rose. 2000. "Taking Butler elsewhere: performativities, spatialities and subjectivities." *Environment and Planning D* 18 (4):433-452.
- Hacking, Ian. 1990. *The Taming of Chance Ideas in Context*. Cambridge: Cambridge University Press.
- Haraway, D.J. 1991. Simians, Cyborgs and Women: The Reinvention of Nature: Free Association.
- Haraway, Donna. 1997. Modest_Witness@Second_Millennium:

 FemaleMan_Meets_Oncomouse: Feminism and Technoscience. New York:

 Routledge.
- Hurwitz, Brian, Trisha Greenhalgh, and Vieda Skultans. 2004. *Narrative Research in Health and Illness*. Malden: Blackwell.
- Kalofonos, Ippolytos Andreas. 2008. " All I Eat is ARVs": Living with HIV/AIDS at the Dawn of the Treatment Era in Central Mozambique: ProQuest.
- Latour, Bruno. 2005. *Reassembling the Social: An Introduction to Actor-Network-Theory*. Oxford: Oxford University Press.

- Le Marcis, Frédéric. 2012. "Struggling with AIDS in South Africa: The Space of the Everyday as a Field of Recognition." *Medical Anthropology Quarterly* 26 (4):486-502. doi: 10.1111/maq.12003.
- Lock, Margaret. 2012. "The Epigenome and Nature/Nurture Reunification: A Challenge for Anthropology." *Medical Anthropology* 32 (4):291-308. doi: 10.1080/01459740.2012.746973.
- Lock, Margaret, and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine*. Oxford: Wiley-Blackwell.
- MacGregor, Hayley. 2009a. "Mapping the body: tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa " *Anthropology and Medicine* 16 (1):85 95.
- MacGregor, Hayley N. 2009b. "Mapping the body: tracing the personal and the political dimensions of HIV/AIDS in Khayelitsha, South Africa." *Anthropology and Medicine* 16 (1):85-95.
- Marcus, George E, and Erkan Saka. 2006. "Assemblage." *Theory, culture & society* 23 (2-3):101-106.
- Marsland, Rebecca. 2012. "(Bio)Sociality and HIV in Tanzania: Finding a Living to Support a Life." *Medical Anthropology Quarterly* 26 (4):470-485. doi: 10.1111/maq.12002.
- Marsland, Rebecca, and Ruth Prince. 2012. "What Is Life Worth? Exploring Biomedical Interventions, Survival, and the Politics of Life." *Medical Anthropology Quarterly* 26 (4):453-469. doi: 10.1111/maq.12001.
- Meinert, Lotte, Michael WHYTE, Susan Reynolds Whyte, and Betty Kyaddondo. 2003. "Disease, risk and globalisation: Introduction to a global medical anthropology: Faces of globalisation AIDS and ARV medicine in Uganda." *Folk* 45:105-123.
- Michael, Mike, and Marsha Rosengarten. 2012. "HIV, globalization and topology: Of prepositions and propositions." *Theory, Culture & Society* 29 (4-5):93-115.
- Mills, Elizabeth. 2016. "When the skies fight: HIV, violence and pathways of precarity in South Africa." *Reproductive Health Matters*.
- Nguyen, Vinh-Kim. 2010. *The republic of therapy: Triage and sovereignty in West Africa,Äôs time of AIDS*: Duke University Press.
- Nowotny, Helga, Scott, Peter and Gibbons, Michael. 2001. *Re-thinking Science:*Knowledge and the Public in an Age of Uncertainty. Cambridge: Polity Press.
- Prince, Ruth. 2012. "HIV and the Moral Economy of Survival in an East African City." Medical Anthropology Quarterly 26 (4):534-556. doi: 10.1111/maq.12006.
- Robins, S.L. 2010. From Revolution to Rights in South Africa: Social Movements, NGOs & Popular Politics After Apartheid: Boydell & Brewer, Limited.
- Robins, Steven. 2005. "AIDS, science and citizenship after apartheid." In *Science and Citizens. Globalisation and the challenge of engagements*, edited by M Leach, Scoones, I, and Wynne, B. London: Zed Books.
- Robins, Steven. 2006. "From 'Rights' to 'Ritual': AIDS Activism in South Africa." American Anthropologist 108 (2):312 - 323.
- Weber, Max. 1984. *Legitimacy, Politics and the State*. New York: New York University Press.
- Whyte, Susan Reynolds, Michael A Whyte, Lotte Meinert, and Betty Kyaddondo. 2004. "Treating AIDS: Dilemmas of unequal access in Uganda." *SAHARA J (Journal of Social Aspects of HIV/AIDS Research Alliance)* 1 (1):14-26.