

**IDS Working Paper 251**

**Rights passages from “near death” to “new life”:  
AIDS activism and treatment testimonies in South Africa**

**Steven Robins**

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INSTITUTE OF DEVELOPMENT STUDIES  
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Steven Robins is Professor of Social Anthropology, University of Stellenbosch, South Africa. These two papers (also 'From "medical miracles" to normal(ised) medicine: AIDS treatment, activism and citizenship in the UK and South Africa', *IDS Working Paper 252*) were written as inputs to the IDS, DRC programme on Citizenship, Participation and Accountability. The papers benefited from discussions held amongst participants in the Science and Citizenship cluster of the DRC. This cluster was convened by Ian Scoones and Melissa Leach, both Fellows at IDS. Melissa Leach and Linda Waldman provided written comments which helped revising earlier drafts. Further comments are welcome and can be sent to [robins@netactive.co.za](mailto:robins@netactive.co.za).

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## **Summary**

The paper investigates how the moral politics of AIDS activism in South Africa are contributing towards new forms of biological/health citizenship (Petryna 2002) that are concerned with both rights-based struggles and creating collectively shared meanings of the extreme experiences of illness and stigmatisation of individual AIDS sufferers. The paper argues that it is precisely the extremity of “near death” experiences of full-blown AIDS, and the profound stigma and “social death” associated with the later stages of the disease, that produce the conditions for AIDS survivors’ commitment to “new life” and social activism. It is the activist mediation and re-telling of these traumatic experiences that facilitates AIDS activist commitment and grassroots mobilisation. It is the profound negativity of stigma and social death that animates the activist’s construction of a new positive HIV-positive identity and understanding of what it means to be a citizen-activist and member of a social movement.

Keywords: Citizenship, AIDS, politics, subjectivity, identity.



## Contents

	Summary	iii
	Acknowledgements	vi
	Preface: DRC working paper series on citizens, science and mobilisation	vii
<b>1</b>	<b>Introduction</b>	<b>1</b>
<b>2</b>	<b>From “bare life” to “new life”</b>	<b>2</b>
	2.1 Revisiting “the ritual process”: treatment activism and “responsibilised citizens”	4
<b>3</b>	<b>Identity transformations and transitions: from the AA to the TAC</b>	<b>5</b>
<b>4</b>	<b>AIDS activism and biological citizenship</b>	<b>6</b>
<b>5</b>	<b>Treatment Action Campaign</b>	<b>7</b>
<b>6</b>	<b>‘AIDS is in my blood’: illness narratives and treatment testimonies</b>	<b>8</b>
	6.1 ‘AIDS has been a “blessing in disguise”	8
	6.2 ‘I am like a born again, ARVs are now my life . . .’	9
<b>7</b>	<b>Discussion of the treatment testimonies: the ritual process revisited</b>	<b>12</b>
<b>8</b>	<b>The limits of social movement theories</b>	<b>14</b>
<b>9</b>	<b>Some concluding thoughts on “biological citizens” and “responsibilised subjects”</b>	<b>15</b>
	<b>References</b>	<b>17</b>

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## **Preface: DRC working paper series on citizens, science and mobilisation**

Rapid advances in science and technology are accompanied by changing forms of public engagement, with implications for citizenship. There is evidence both of apparent crises of public confidence in science, linked to the emergence of new risks, uncertainties and threats thrown up by science, technology and its application. At the same time, certain local knowledge is being re-worked as citizen science, in which the public conducts research and engages critically with expert perspectives on scientific and technological issues.

The Citizens and Science Programme of the Citizenship DRC has been exploring emergent engagements between citizens and public issues involving science, and the processes of rights-claiming and participation involved. This inquiry has moved beyond institutionally-orchestrated attempts at public participation in science to look at more spontaneous forms of citizen mobilisation and activism around scientific and technological issues. Across a diversity of issues and contexts and drawing together perspectives from social movement theory and science studies, the Programme has asked:

- Who mobilises and who does not, and why?
- What are the patterns of experience, profiles and identities of activists?
- Within what spaces do debates about science and policy take place, and what processes of inclusion and exclusion exist?
- What forms of knowledge – including values, perceptions and experiences - frame these public engagements and movements?
- How are activist networks constituted, and what diverse forms do they take?
- How do science and scientists become enrolled in these networks?

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'From "medical miracles" to normal(ised) medicine: aids treatment, activism and citizenship in the UK and South Africa', by Steven Robins.



## 1 Introduction

The award winning South African film *Yesterday*<sup>1</sup> tells the story of a black woman with HIV/AIDS whose migrant miner husband returns from Gauteng to his home village in rural KwaZulu-Natal to prepare to die from HIV. Both the dying man and his wife are stigmatised and isolated by most of the villagers.<sup>2</sup> The wife builds her dying husband a corrugated iron room on the border of the village so that he can live his last days away from the inquisitive and accusatory gazes of unsupportive villagers. Anti-retroviral (ARV) therapy and the possibility of treatment appears nowhere in Roodt's moving portrait of this couple caught in whirlwind of this tragic pandemic. *Yesterday* reflects the grim realities of AIDS as the harbinger of social and biological death for millions on a continent where most countries do not have ARV treatment programmes. South Africa now has an Anti-retroviral programme, as well as a national AIDS social movement, that offers the prospect of a more optimistic script, one in which HIV-positive people are able to access life-enhancing drugs that can return the patient to health and the possibility of reintegration into the social world.

This paper explores how the combination of illness experiences and enrolment in the Treatment Action Campaign (TAC) and *Medecins sans Frontieres* (MSF) treatment programmes has, under certain circumstances, dramatically altered the lives, subjectivities, identities, life-narratives and futures of people living with HIV/AIDS (PWAs). It investigates these issues in the context of AIDS activist struggles for free treatment in South Africa's public health sector. While these activist organisations are generally understood as rights-based social movements (Friedman and Mottiar 2004), the illness narratives and treatment testimonies that are analysed in this paper suggest that experiences of illness, treatment and participation in TAC and MSF can produce radical transformations in subjectivity and identity that go well beyond conventional liberal democratic conceptions of "rights" and "citizenship". At the same time, these changes in subjectivity can, in certain cases, produce the kinds of "responsibilised citizens" that public health professionals believe are required for safe and effective AIDS treatment to take place.

There has been considerable public debate in the South African media about the need to balance individual rights and responsibilities when it comes to HIV/AIDS. This is not surprising given the widespread fear that poor treatment adherence could produce multi-drug resistant HIV. Some public health professionals have sought to justify compulsory testing and status notification and the over-riding of individual rights to treatment for those who show signs that they may not be able to adhere to treatment' (Cape Times April 15 2005). For example, Professor Solly Benatar, the director of the Bioethics Centre at the University of Cape Town, recently called for a balance between the rights of individuals and

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<sup>1</sup> *Yesterday* is set in the AIDS-ravaged rural areas of KwaZulu-Natal, one of the regions of South Africa that has been most devastated by the pandemic. Infection rates for young black women are in the vicinity of 30 per cent. A Human Science Research Council (HSRC) study estimated the overall HIV prevalence in the South African population at 11.4 per cent, or about 4.5 million people (*Mail and Guardian*, 6 December 2002). Other estimates put the figure of HIV-positive South Africans at between five to seven million.

<sup>2</sup> In a moving cinematic depiction of AIDS stigma, isolation and death, the film shows the ex-miner breaking down as he tells his HIV-positive wife about how his fellow workers avoided him because there were no toilets underground and his diarrhoea was out of control. He cries uncontrollably as he tells his wife how his pants were regularly caked in excrement.

the public health needs of society. To maximise adherence to ARV treatment, he argued, required that patients take some responsibility for their own health (*Cape Times*, 15 April 2005). There have also been calls from progressive public health circles for a “new contract” between provider and client that would replace the paternalistic surveillance model of direct observation therapy (DOT) Tuberculosis (TB) treatment. The latter, it is argued, cannot work with life-long ARV treatment and what is needed are “responsibilised citizens” and knowledgeable and empowered HIV-positive clients. But how can these new rights and responsibilities approaches take hold in contexts characterised by extreme forms of AIDS stigma, shame, denial and fear? What role should the State, public health practitioners and civil society organisations play in fighting the AIDS pandemic in such contexts? What kinds of subjectivities, and social, economic and cultural conditions, are necessary for safe and effective treatment of HIV/AIDS? These are some of the questions that this study seeks to address.

Drawing on illness narratives and treatment testimonies, it will be argued that these rights and responsibilities approaches do not adequately acknowledge the profoundly traumatic and transformative nature of illness and treatment experiences.<sup>3</sup> Neither do they recognise the complex mix of religious, communal, biomedical and activist mediations and narrations of illness and treatment experiences, and how these can contribute towards creating the kinds of “responsibilised citizens” that public health practitioners desire. Liberal individualist “rights talk”, I argue, cannot grasp the radically transformative character of the new biosocial subjectivities and HIV-positive identities that I discuss in this paper. The latter are not simply the product of liberal modernist discourses on the rights bearing citizen. Instead, they are forged in course of the traumatic journeys from “near death”/ “bare life” to “new life” that I refer to as rights passages.

## **2 From “bare life” to “new life”**

Hannah Arendt (1958) noted that the modern state had become increasingly concerned with biological existence and the management of “life processes”. Similarly, Giorgio Agamben (1998) claims that both modern and archaic political orders have been preoccupied with the capacity to control life by excluding it from meaningful social and political existence. Drawing on the ideas of both Arendt and Agamben, Jean Comaroff argues that in the modern world the management and politics of “bare life” has shifted centre-stage: it is both the object of state enforcement and the subject of projects of democratic emancipation and citizenship (Comaroff 2005: 14). According to Comaroff, the political history of the West leads us to a situation whereby there is ‘an unprecedented capacity and concern to enhance life [which] is rivalled only by the power to destroy it’ (ibid). Comaroff reminds us that Agamben draws on *homo sacer* – the archaic Roman law figure who ‘could be killed but not sacrificed’ – to illustrate that modern life is ‘simultaneously sacred, and utterly dispensable’ (Comaroff 2005: 15). Whereas Agamben is specifically concerned with the relation between *homo sacer* and sovereign power, Comaroff notes that scholars such as Joao Biehl (2001) and Ulrike Kistner (n.d.) are beginning to make the connection between this Roman law figure and ‘the

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<sup>3</sup> This study is based on 15 interviews done in 2002 and 2004.

Third World HIV/AIDS sufferer: a being condemned to callous exclusion, to death without meaning or sacrificial value, in an age of widespread humanitarian empathy; a being left untreated in an era of pharmacological salvation' (Comaroff 2005: 15). Comaroff draws our attention to a moral politics of AIDS in places like Brazil and South Africa that insists on 'making death sacrificial [and meaningful] once more.'

This paper shows how this new moral politics is constructed by AIDS activists and people living with AIDS through the deployment of religious, communal, biomedical and social activist discursive framings. People living with AIDS often draw on these framings to make sense of their illness and social suffering. These framings, I argue, can contribute to the production of "positive" HIV-positive identities and new forms of sociality for AIDS sufferers in Third World settings where stigma and social isolation are pervasive and access to treatment continues to be a life and death struggle.

Pain, illness and suffering are often represented as inherently private and physical phenomena that have little to do with the social world. Yet, numerous scholars have pointed out that the experience of pain and suffering is fundamentally social (ibid). For anthropologists this observation is neither new nor surprising. Writing in the 1960s, Victor Turner (1961, 1969) showed how Ndembu interpreted the sick individual body as a sign of disease and disorder in the wider social body; here, healing involved the realignment of the social. Biomedicine, by contrast, tends to depoliticise and individualise illness. Paul Farmer is amongst a number of scholars who have challenged these depoliticising and individualising discourses by drawing attention to broader social, political and economic structures that determine the epidemiological distribution and subjective experience of disease and suffering in the Third World. Farmer (2004) draws on the concept of "structural violence" to show how conditions of chronic poverty, gender inequality and everyday violence limit the life choices of the HIV-positive poor women he encounters at his HIV/AIDS clinic in rural Haiti. These patients are the literal embodiment of global structures of inequality and structural violence.

Farmer's linking of the individual AIDS body to structural processes resembles anthropological accounts of how small-scale societies interpret the sick individual body as a sign of disease within a broader social body. South African AIDS activists belonging to the TAC and MSF make similar connections between individual people living with HIV/AIDS (PWAs) and the body politic. Here the wider social world is characterised by conditions of unequal and inadequate health care reproduced by the greed and profiteering of global pharmaceutical companies. These health inequalities are also understood by activists to be the product of a legacy of apartheid racism, as well as more recent forms of state indifference and inaction in relation to the provision of AIDS treatment in the public sector (Robins 2004). With the South African Government's decision in October 2003 to establish a national ARV programme, activist attention has increasingly shifted towards monitoring this programme and drawing attention to the regional inequalities and "blockages" within the national public health system.

South Africa now has one of the largest AIDS treatment programmes in the world. Yet, only approximately 40,000 of the estimated 500,000 people needing treatment are receiving ARVs through the public health sector, while another 45,000 are accessing treatment in the private sector (*Cape Times*,

15 April 2005). This limited access to treatment is particularly worrying given current estimates that there are between four to five million HIV-positive South Africans. Notwithstanding the introduction of a massive national ARV programme, AIDS activists find themselves having to continue to challenge the global pharmaceutical industry's patents policies and pricing structures, the national leadership's perceived lack of political will when it comes to treatment, as well as AIDS dissidents who persist in questioning the link between HIV and AIDS, the scale of the AIDS pandemic and the efficacy and safety of anti-retroviral therapy (Robins 2004). This paper, however, is concerned with another dimension of TAC activism, namely its capacity to create the conditions for the production of new subjectivities and identities out of the traumatic experiences of illness and stigmatisation of individual AIDS sufferers. The study focuses on the ways in which experiences of illness, treatment and activism can together contribute towards profound changes in the lives of people with HIV/AIDS. The following section will discuss how I use Victor Turner's pioneering work on the ritual process to interpret these illness and treatment experiences (Turner 1969).<sup>4</sup>

### *2.1 Revisiting "the ritual process": treatment activism and "responsibilised citizens"*

Turner's analysis of the ritual process provides a rich heuristic device and analytical lens through which to interpret how the extremity of "near death" experiences of full-blown AIDS, followed by "miraculous" recovery through ARV treatment, can produce the conditions for AIDS survivors' commitment to "new life" and social activism. It is the activist mediation and re-telling of these traumatic experiences, I will argue, that facilitate TAC's highly successful grassroots mobilisations. It will also be argued that it is precisely these processes of illness, stigma and treatment that provide activists with the "raw materials" with which to construct new HIV-positive identities and social solidarities.

These activist mediations of illness and treatment experiences can be distinguished from AIDS treatment in the public sector, which is shaped by the conventional doctor-patient dyad and highly technician and depoliticised modes of biomedical intervention in the private spaces of doctors' consultancy rooms. By contrast, TAC activism creates the conditions for more collectivist responses to HIV and treatment. Whereas public health practitioners report that most of their HIV/AIDS patients wish to retain anonymity and invisibility at all costs, TAC successfully advocates the transformation of the stigma of AIDS into a "badge of pride" that is publicly displayed on T-shirts at township funerals, demonstrations, workshops and other public spaces. It is through these activist mediations that it becomes possible for the social reintegration and revitalisation of large numbers of isolated and stigmatised AIDS sufferers into a social movement and a caring community. This AIDS activist culture has been very present at the two MSF-Department of Health ARV programmes in Khayelitsha, Cape Town, and Lusikisiki, Eastern Cape

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<sup>4</sup> The study resonates with Melissa Leach's observations, based on her ethnographic work on MMR vaccination controversies in the UK, that it is often simply the strength of shared experiences – of having children who they believe have become ill because of exposure to the vaccination – that produces the motivation and commitment to participate in these social movements (Leach's personal correspondence). These anthropological studies draw attention to the relationship between participation in illness-based movements and transformations in subjectivities, identities and social commitments.

Province. However, by far the majority of the public sector ARV programmes in South Africa are characterised by hierarchical and authoritarian doctor-nurse-patient interactions. Doctors and nursing staff working in these settings also believed that most of their HIV-positive patients would probably want to avoid involvement in AIDS activism precisely because of its emphasis on public visibility and disclosure (Dr Ruth Cornick's personal correspondence). So what kinds of social and ritual processes can create the conditions for people living with AIDS to turn AIDS stigma, isolation and shame into a "badge of pride"?

### **3 Identity transformations and transitions: from the AA to the TAC**

In *The Recovering Alcoholic*, Norman Denzin (1987: 12) draws attention to the role of Alcoholics Anonymous (AA) treatment rituals in 'the transformations in experience that produce situational and long-term commitments to the identity of the "recovering alcoholic."' Denzin describes these AA rituals as processes of "adult socialisation" and "identity transformation or conversion", terms that 'refer to the process by which the self of the person actively enters into the acquisition of new self-images, new languages of self, new relations with others and new bonds or ties to the social order' (Denzin 1987: 19). In his account of "the social worlds" of the recovering alcoholic, Denzin identifies the central role of AA rituals – the 'Twelve Steps' and 'Twelve Traditions' and rituals of storytelling – in the treatment and recovery process (ibid 118: 121). While ritual may not appear at first glance to be a useful and appropriate concept for describing AIDS activism and social mobilisation, this paper will draw on Turner's (1969) analysis of the ritual process to understand the extraordinary biosocial power of ARV treatment and AIDS activism in a context of "hyper-stigma" and AIDS traumas of social and biological death. This will be done by analysing the treatment narratives of two AIDS activists on life-long ARV treatment. Discussion of these case studies will rely on Turner's use of Arnold Van Gennep's (1960) identification of the three stages of rites of passage: separation; liminality/communitas and reintegration. Ritual analysis offers analytical insights into the radical transformational power of these death-to-life transitions that PWAs personally experience, or witness. Turner's work can also throw light on the social status shifts that take place when the stigmatised and isolated sick recover and become reintegrated into TAC as healthy and socially active members of society.

While it is problematic to generalise beyond these individual cases, I suggest that the two illness and treatment testimonies analysed below do indeed resonate with narratives of AIDS experience that are widely shared and circulated within TAC. These narratives have become part of the collective cultural repertoire of TAC even though not all members have personally been through these illness and treatment experiences. Although AIDS activists may not frame illness and treatment experiences through ritual analysis, it would seem that the transformations and transitions from "near death" to "new life" can be illuminated through the analytical heuristic of rights of passage. But what is the nature of these transformations and how do we relate these to questions of citizenship and subjectivity?

#### **4 AIDS activism and biological citizenship**

Elsewhere I have written about the extraordinary activism that has accompanied the struggles for access to anti-retroviral Therapy (ART) in South Africa (Robins 2004). TAC and MSF have been at the forefront of this global and grassroots struggle for treatment. AIDS activists have used the courts, mass action, the mass media, the internet and grassroots mobilisation to challenge drug patent policies and pricing structures of the global pharmaceutical industry, as well as contesting AIDS dissident science and pressuring the South African government to provide ARVs.

AIDS activism in South Africa shares similarities with identity-based illness movements elsewhere in the world (Epstein 1996; Petryna 2002). Concepts such as “biological citizenship” (Petryna 2002) speak to a range of illness-based movements that have mobilised around nuclear radiation, breast cancer, psychiatric illnesses and HIV/AIDS. As was mentioned earlier, “lay expertification” (Epstein 1996) and “citizen science” (Irwin 1995) are increasingly used to describe citizen responses to unpredictable and poorly managed health and environmental hazards. These developments, which often result in citizen scepticism and distrust of mainstream science and expertise, are linked to what Ulrich Beck (1992) and Anthony Giddens (1991) refer to as contemporary conditions of reflexive modernity and “world risk society”. For Beck and Giddens, both of whom are writing specifically about the advanced capitalist countries of the West, citizens have become increasingly distrustful of scientists and the scientific findings produced by governments and business. It is within this context that “citizen science” (Irwin 1995), “expertification from below” and the making of biological citizens is taking place. These processes intersect with the popular fascination – at least in the US and Europe - with “risk factor” epidemiology, a technician discourse that involves ever finer calibration and endless attempts to control risk in every aspect of our lives (Chris Colvin, personal correspondence).

TAC and MSF activists argue that they are not only interested in medical treatment, but that they are also concerned with creating “empowered citizens” who understand the connections between biomedicine and the wider social world and political economy of health. This is evident in their legal challenge to the drug patents and pricing structures of the global pharmaceutical companies (Robins 2004). TAC activists also share similar concerns with the Northern illness-based movements that have emerged as a result of citizen perceptions of inadequate scientific and government responses to a range of health and environmental hazards, for example, BSE, foot and mouth, biotechnology and GMOs, pesticides, AIDS, global warming and so on. TAC also has its roots in distrust of governments’ response to the pandemic, especially President Mbeki’s flirtation with AIDS dissident science and his government’s initial reluctance to provide ART to AIDS sufferers. It is this broad range of health and environmental concerns that are driving the growth of these illness-based social movements.

While the linking of biology and health to identity and social movements is certainly not new, what is new are the ways in which biological identities and the interest groups formed in their name, are emerging in different parts of the world (Petryna 2002: 14). These movements have important implications in terms of extending liberal democratic notions of citizenship. In South Africa, for example, there has been a

recent call from public health experts for a “new contract” between provider and client (Coetzee and Schneider 2004). The advocates of this contract suggest that the passive and paternalistic surveillance model of direct observation therapy (DOT) TB treatment is not a viable solution for life-long ARV treatment. Instead what is needed, they argue, are highly motivated, “responsibilised” and knowledgeable HIV-positive clients. But they do not seem to be able to provide clear indications as to how the public health system will be able to make this seismic shift from DOT paternalism to a more client-centred approach to HIV/AIDS.

It is perhaps not entirely coincidental that “responsibilisation” also appears in the recent work of political theorists writing about contemporary liberal rationalities of government (see Barry, Osborne and Rose 1996). Here the term refers to the ways in which, under liberalism and neoliberalism, ‘the governed are encouraged, freely and rationally, to conduct themselves’ (ibid: 29). For example, neoliberal rationalities of government encourage the governed to “govern themselves”. This relationship involves citizens becoming responsible for issues previously held to be the responsibility of government authorities’ (cited in Barry, Osborne and Rose 1996: 29). These ideas about “responsibilised citizens” are clearly by-products of this post-socialist and (neo) liberal age. But how do people living with AIDS engage with these calls for a “new contract” between health providers and empowered and responsibilised clients? Before investigating how activist treatment testimonies reflect upon and reconfigure these “new” public health ideas and practices, the paper will provide a sketch of the TAC and the social backgrounds of its activists. It will also briefly discuss TAC’s mobilisation strategies and the discursive framing of its interventions.

## **5 Treatment Action Campaign<sup>5</sup>**

TAC was established on 10 December 1998, International Human Rights Day, when a group of about 15 people protested on the steps of St George’s Cathedral in Cape Town to demand medical treatment for people living with the virus that causes AIDS. By the end of the day, the protestors had collected over 1,000 signatures calling on the government to develop a treatment plan for all people living with HIV.

TAC’s membership has grown dramatically over the past few years. The rank-and-file comprises mainly young urban working class African women with secondary schooling. Most of these volunteer members are either HIV-positive or they have family members and friends who have died of AIDS or are living with HIV. However, the organisation has also managed to attract health professionals and university students. The international face of the organisation is Zackie Achmat, a 40-something Muslim former anti-apartheid and gay activist. Until very recently Achmat had made it known publicly that he refused to take ARVs until they were available in the public health sector. Other TAC leaders include African men and women who joined TAC as volunteers and moved into leadership positions over time.

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<sup>5</sup> For a detailed history of TAC see Robins (2004), Friedman and Mottiar (2004) and *Treatment Action: An Overview, 1998–2001*, [www.tac.org.za](http://www.tac.org.za).

When TAC was founded, it was generally assumed that anti-AIDS drugs were beyond the reach of developing countries, condemning 90 per cent of the world's HIV-positive population to a painful and inevitable death. While TAC's main objective has been to lobby and pressurise the South African government to provide AIDS treatment, it has been forced to address a much wider range of issues. These included tackling the global pharmaceutical industry in the media, the courts and the streets; fighting discrimination against HIV-positive people in schools, hospitals and at the workplace; challenging AIDS dissident science; and taking the government to court for refusing to provide anti-retroviral treatment, including prevention of mother-to-child-transmission (PMTCT) programmes in public health facilities (Robins 2004; Cameron 2005). TAC's highly effective mobilisation at the global scale and within working-class black communities enabled it to challenge both "Big Pharma" drug pricing and patents policies and the South African government's initial refusal to provide ARVs to the poor in public health facilities (Robins 2004). It has also worked in partnership with MSF at two highly successful ARV treatment programmes in Khayelitsha, Cape Town, and Lusikisiki, Eastern Cape Province. Elsewhere I have discussed in some depth the nature and extent of TAC and MSF activism and the politicisation of AIDS science, treatment and statistics in South Africa (Robins 2004). Rather than revisiting these issues, the following section turns to an analysis of the illness narratives and treatment testimonies of two TAC and MSF AIDS activists.

## **6 "AIDS is in my blood": illness narratives and treatment testimonies**

### **6.1 'AIDS has been a "blessing in disguise" '**

Thembeke is a 30-something HIV-positive Treatment Action Campaign (TAC) activist in Lusikisiki, a small rural town in the former Transkei homeland in the Eastern Cape. She told me that discovering her HIV status and joining TAC and the *Medecins sans Frontieres* (MSF) anti-retroviral (ARV) treatment programme had dramatically improved her life: "Thanks to TAC and MSF I'm flying. I've got wings to fly." I recall being shocked when Thembeke first described her experience of HIV as a "blessing in disguise", yet as I got to know her, it became clear that being tested for HIV, joining TAC and the MSF ARV programme in Lusikisiki had indeed ushered in for her a new and better life. She recalled the trauma of sexual abuse by an uncle as a young girl, being sent away to stay with her mother's friends as a teenager while her younger sister stayed at home and attended a good 'Model C' school. She also tearfully recollected a violent gang rape by four youths and being unable to tell her parents about it because she feared that they would not believe her. Her rape led to pregnancy and her decision to have an abortion, while her later discovery of her HIV-status led to her decision to have a sterilisation operation.

After I had my VCT [Voluntary Counselling and Testing] the Counsellor told me that I'm HIV positive and that all my dreams are finished and I'm going to just die. And then they told me that all



my kids would be HIV-positive. It's either I'll condomise, or if my husband sometimes doesn't want to use condoms then I should just use sterilisation. That's the way that can help me. Because the more babies I have the more quickly I will die.

Thembeke's life story included accounts of child sexual abuse, rape, abortion, sterilisation and the onset of serious debilitating illness, culminating in her discovery in 2001 that both she and her baby were HIV-positive: 'I was very sick but then I found TAC and MSF and my life changed . . . *TAC is my mother, MSF is my father*'. While her mother, who was a nurse, subscribed to the Minister of Health's controversial nutritional diet of garlic, lemons, olive oil and the "African potato" for HIV-positive people, Thembeke's involvement with MSF and TAC led to her rejection of these "alternative" and "traditional" remedies and her participation in anti-retroviral therapy (ART) at the MSF programme in Lusikisiki. The Health Minister's promotion of this "nutritional advice" was interpreted by AIDS activists such as Thembeke as tacit support for the dissidents' claims that ARVs were dangerously toxic (Robins 2004). Yet, during an earlier spell of illness arising from opportunistic infections and at the same time that her mother was giving her "traditional" medicines, Thembeke was receiving allopathic medicines from an uncle, who happened to be a senior official in the national Department of Health. As her health improved under ARV treatment, Thembeke became integrated into the closely-knit and supportive network of TAC activists and MSF doctors and nurses. She learnt AIDS awareness training skills and acquired basic scientific knowledge about HIV/AIDS, prevention and treatment. She was also personally handed her ARVs by former President Nelson Mandela when he officially launched the ARV programme in Lusikisiki in 2003. When I met her in 2004 she was being "headhunted" by NGOs in the Eastern Cape but had decided to stay on as an MSF treatment literacy practitioner (TLP) and youth organiser in Lusikisiki. She spoke about her work as "preaching the gospel".

Busi's story is quite similar to Thembeke's. Busi, a young black female TAC volunteer in Khayelitsha, was raped by an uncle who later committed suicide. She was later diagnosed with AIDS, rejected by family members, hospitalised and told that she 'must wait for my day of death'. She joined TAC and received ART at the MSF programme in Khayelitsha. For Busi, like Thembeke, ARVs literally saved her life, and TAC became the family that she had lost when she was diagnosed HIV-positive: 'Mandla and Zackie are like my brother and father'. The trauma and profound negativity of Busi's experiences of rape, social isolation and her dramatic recovery from imminent death from AIDS contributed towards her embrace of TAC's "positive" framing of HIV-positive identity. The following account of illness and treatment shares some of these aspects.

## **6.2 'I am like a born again, ARVs are now my life . . . '**

Sipho, another activist with HIV/AIDS in his early forties, told me a similar story. In 2001 Sipho became desperately ill. He had headaches, dizziness, he suffered from a range of other opportunistic infections, he had lost almost 30 kilograms, his CD4 count was down to 110, his viral load was 710,000, he could not walk, he was barely conscious at times and he secluded himself in a room in his sister's house waiting for

death. On 12 November 2001 he became one of the first 50 clients to participate in MSF's ARV treatment programme in Khayelitsha. His recovery was dramatic: after six months his viral load had dropped to 215,000, his CD4 went up and he was feeling much stronger. When I met Siphio in 2004, his viral load was undetectable and his CD4 count was 584.<sup>6</sup> He had also become something of an AIDS celebrity and was also regularly interviewed by journalists, filmmakers and academics about his experiences – for instance, he had represented South Africa at a Southern African Development Community (SADC) meeting in Lesotho on AIDS and he was in demand from medical and social science researchers involved in HIV/AIDS research projects.

At the time of writing this paper, Siphio was working at a private health insurance company where he tele-counselled HIV-positive clients who were referred to the call centre by general practitioners who detected treatment adherence and related problems. As a result of requests from some clients for face-to-face meetings, Siphio sometimes visited them at their homes. Even though the call centre was established to create the conditions of anonymity and confidentiality, Siphio's own seropositive status and his highly personal style of tele-counselling elicited requests for more personal forms of interaction. As a result he spent many weekends visiting people living with AIDS in Cape Town and elsewhere in the country. As he put it: 'I am committed to my AIDS work. "AIDS is in my blood."' Tele-counselling could not adequately meet his own needs for more personal face-to-face interactions.

Clinical indicators such as "normal" CD4 counts and "undetectable viral loads" do not adequately convey the sense of social, psychological and spiritual recovery that Siphio and others have experienced on their journeys from "near death" to "new life". Neither do these indicators account for why Siphio, like Thembeke, viewed HIV as "a blessing in disguise". For Siphio, getting his life back through ARV treatment was a gift from God that he could not afford to squander:

I'm not a church-goer. My faith comes from the time I got sick . . . In the bible there is the story of a sick beggar on the road. Jesus comes by and tells the beggar to stand up. And he stands up. The miracle of Jesus revived him from death so that he could heal other people through the belief that Jesus is on earth. Faith is in yourself. If you don't believe in yourself who do you believe in? God brought me back to life for a purpose. He wants me to go out there and talk to people. He's giving me another chance. A day could cost me a lot if I don't speak about HIV . . . At Groote Schuur [Hospital] I prayed a lot. I was thinking of my children growing up without their father's love, support and guidance . . . *I am like a born again. ARVs – that's where my commitment comes from. It's like committing yourself to life because the drugs are a lifetime thing. ARVs are now my life.*

At the 2003 TAC national conference in Durban, I witnessed a particularly powerful session in which members gave impromptu testimony of their treatment experiences. Each highly charged testimony was followed by outbursts of song, dance and struggle chants: 'Long live, Zackie, long live. Long live, TAC, long live!'

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<sup>6</sup> Patients usually go onto ARV treatment when their CD4 count is below 200.

I'm a person living with HIV. I received counselling before and after I tested. The counsellors at the hospital where I work as an admin clerk gave me nothing. I just found out I was HIV-positive and that was that. Three times I tried to commit suicide. *Now I'm more positive than HIV-positive, thanks to TAC.*

*(Thirty-something black man)*

When I go to my doctor I tell him exactly what medicines I need. He asks me if I've trained in medicine at the university. No, I say to him. It was TAC that taught me.

*(Thirty-something black woman)*

Thank you to MSF. My CD4 count was 28 now it is 543. Thank you to TAC.

*(Twenty-something black man)*

I'm Dudu. I was tested in 1986. In 1999 my CD4 count was below 200. I have lost many things in my life. But now with ARVs my CD4 count is 725 and the virus is undetected. I'm a person living with HIV. *Today I have a life. I can have a family. But it's painful when I take my medicine [ARVs] because I know someone is dying because he can't get treatment.*

These treatment testimonies – with their references to CD4 counts, viral loads and the role of TAC in giving “new life” – seem to blur the lines between science and religion, medicine and spirituality, technology and magic. The quasi-religious quality of these testimonies is particularly evident in the excerpt from Siphos testimony that was cited earlier. The testimonies seem to implode efforts to erect an artificial “Great Divide” between “the modern” and “the traditional” (Latour 1993). They also express the sense of personal empowerment that comes from having survived the passage from “near death” to recovery. This was evident during Siphos testimony at the Durban meeting in 2003:

I'm Siphos from Cape Town in the Western Cape. I was diagnosed in 2001, three days after my birthday. I was very sick. When you get sick you just ignore it. You say, ‘Oh, it's just the flu’. You're in the denial stage. You say your neighbour is a witch . . . We thought this disease belonged to other people elsewhere in Africa. From my point of view HIV is real, it's here. *I never thought I would be here today. I couldn't stand, I was sick. My CD4 count was 110 and my viral load was 710,000. Then I started ARVs with MSF in Khayelitsha. Now I'm strong.*

Siphos statement ‘AIDS is in my blood,’ which was cited earlier, serves as a double entendre in relation to the scientific statement of infection as well as a metaphorical statement about “who I am and what my purpose is”. This symbolically charged language captures the extraordinary agency and sense of purpose that Siphos and many other activists living with AIDS seem to share.

The following section analyses these treatment testimonies and narratives by drawing on Turners method of ritual analysis. Ritual analysis of illness and treatment experiences, I argue, is able to transcend the limits of social movement theory with its focus on “rational” and instrumental behaviour and political

processes of mobilisation. An analysis of ritual processes can enrich this theoretical approach by drawing attention to the salience of processes of personal transformation and how these articulate with collective beliefs and mobilisation practices. Conventional social movement theory tends to assume an already existing, stable and coherent activist subjectivity, and that members simply need to be “invited” to participate in an already existing organisational structure built upon shared interests.

## **7 Discussion of the treatment testimonies: the ritual process revisited**

Turner’s *The Ritual Process* (1969) identifies three stages of *rites de passage* – separation, liminality/communitas and reintegration. It would seem possible, based on the treatment narratives discussed earlier, that the extremity of the forms of stigma, ostracisation and isolation that PWAs experience are analogous to the stage of ritualised *separation* identified by Turner. During this first stage the individual becomes sick, is afflicted with opportunistic infections and may already be in an advanced stage of AIDS. The illness may be understood by sick persons, family members and neighbours to be the work of *abathakathi* (witchcraft), a sign of having been chosen by the ancestors to be a *sangoma* (traditional healer or diviner), or simply an “ordinary” illness such as “flu” or Tuberculosis. Alternatively, the onset of these illnesses may lead to testing and the confirmation of an HIV-positive status. This extreme state of illness often results in the withdrawal of the sick person from everyday social spaces (see Siphos illness narrative). The “smell of death” may also heighten stigmatisation, ritualised avoidance and social and physical isolation by neighbours and family members. For example, ‘Nomsa,’ a 20-year-old HIV-positive woman I met in Lusikisiki in the Eastern Cape Province, spoke of how, upon disclosing her HIV-positive status to her family, she was given her own plates and utensils to eat with. Thereafter her stepfather chased her from his home and she moved to her mother’s home. Isolation is also produced by the illness itself. An HIV clinician who works at an ARV rollout site in Cape Town tried to explain to me the obstacles to communicating with patients with fully blown AIDS. “They are so sick that it is often very difficult to have a conversation with them. They are sometimes like walking skeletons.” This exceptionally dedicated and committed HIV/AIDS clinician talks of being unable to socially interact with these skeletal-like patients; at this advanced stage of AIDS they were like the “walking dead”, almost completely cut off from sociality. These descriptions are strikingly similar to the *musselmans* of the concentration camps that Primo Levi (1979) wrote about in *The Drowned and the Saved*.

In the second phase the sick person may seek biomedical treatment of opportunistic infections, join a TAC support group and enrol, depending on clinical indicators, for ARV treatment with MSF. The patient-activist learns basic scientific and biomedical knowledge about HIV/AIDS, including its symptoms and ARV treatment. During this stage patients are in a state of liminality as their future health status remains precarious and uncertain. They are “betwixt and between” in that it is not clear whether they are dying or on the path to recovery and health. They may have to wait to find out whether the drugs

will work and whether there will be serious side-effects. Meanwhile, recruitment into TAC allows them access to a supportive community and non-hierarchical social space that is analogous to the experience of *communitas* that Turner describes as characterising states of liminality.

Finally, the recovery of the patient-activist with HIV/AIDS can be likened to Turner's third phase of *reincorporation*. In this third stage, the individual starts getting physically and psychologically well, the CD4 count increases, the viral load drops and the person begins putting on weight and rediscovers his or her appetite for food, sex and sociality. This phase usually involves social incorporation into the TAC and possibly also the wider community and society. It can transform the stigmatised and dying AIDS sufferer into an activist-citizen empowered with knowledge about HIV/AIDS and an ability to speak out in public spaces. Of course there is no inexorable linear treatment trajectory and rejection and expulsion from community cannot be excluded as a possible treatment outcome. For Siphso and Thembeke, however, this phase culminated in personal empowerment and spiritual awakening that convinced them 'HIV is a blessing in disguise'. TAC members with HIV/AIDS are hereby reinstated into the social world as human beings with dignity; they have a new positive HIV-positive status. In the case of Siphso and Thembeke it was clear this process of social reintegration also involved a commitment to a "new life" and social activism. This is what I mean by the biosocial passage from "near death" to "new life".

While there are clearly dangers in seeking too tight a fit between Turner's model of the ritual process and the actual experiences and subjectivities of patient-activists with HIV/AIDS, this approach can account for why ARV treatment and TAC mobilisation appears to have been so successful at reconfiguring the stigma, isolation and suffering of AIDS into a positive and life-affirming HIV-positive identity and quasi-religious commitment to "new life" and social activism.

Revisiting Turner's *The Ritual Process* can provide other important insights that have been ignored by theorists of both "old" and "new" social movements. For example, Turner finds common themes and structural features in millenarian religious movements, hippies and Franciscans; all these movements comprise marginal, or self-marginalised, people who are committed to the eradication of distinctions based on inequality and property. They are dedicated to the levelling of status and a communitarian ethos of unselfish commitment to collectively shared ideals. According to Turner, these movements strive to instantiate a permanent state of liminality and *communitas* – a status-less egalitarianism – that is not that different to the middle passage of "traditional" rites of passage.

Like the social groups identified by Turner – millenarians, hippies and Franciscans – TAC consists largely of "social marginals" – i.e. the sick and stigmatised poor, especially young unemployed black women. It is not surprising that this social category of "marginals" would be drawn to a social movement that strives to eradicate distinctions based on status and hierarchy. These women are either HIV positive themselves or they have family members who have been deeply affected by the epidemic. They are also in many instances members of a generation that the liberation struggle has left behind. Unlike the high profile anti-apartheid activists of the 1980s, the majority of whom are now in government or business, TAC's rank-and-file members are generally without jobs and career prospects. This post-revolutionary generation of young people are caught in liminal space – "betwixt and between" structural marginalisation

and the dream of post-apartheid liberation. Many of them do not have the material means, education or cultural capital to move beyond this structural location of marginality and liminality. In addition, they face the very real threat of social and biological death from AIDS, making it unlikely that they will be able to move through the life cycle rituals and trajectories of personhood of their parents' generation. In other words, this social category is caught in the zone of liminality and the shadow of death. What happens when the transition from youth, to adulthood and elder status is blocked by structural unemployment and the lethal equation: sex = death? How is it possible to participate in social and biological reproduction and life cycle rituals given such life-threatening circumstances? It is here, in the shadow of social and biological death, that the combination of ARVs and TAC offers such a compelling possibility for "new life".

## **8 The limits of social movement theories**

Conventional social movement theory cannot adequately account for how these structural conditions of marginality and biosocial liminality shape the political culture and life-blood of organisations such as TAC. Neither can these theories adequately account for how the illness experiences and "spoiled identities" associated with AIDS stigma, denial and discrimination are reconfigured and transformed by TAC activists into a "badge of pride", a new HIV-positive identity and form of social belonging. This new identity, I suggest, cannot be understood simply in terms of the instrumentalist logic of political and economic struggles for access to health resources. Neither is this struggle for recognition and human dignity in the face of threats of stigma and social and biological death confined to marginalised members of society. This perhaps explains why, although the majority of its members are working class or unemployed, TAC also appeals to HIV-positive middle class professionals. The organisation's appeal has also spread to (HIV-negative) human rights activists, professionals and ordinary citizens who see in TAC's leadership and mobilisation strategies a heroic and progressive vision of "moral truth" and social justice. Clearly TAC is able to articulate commonalities across a range of differences in ways that resemble the multi-class, multi-ethnic and non-racial composition of the United Democratic Front (UDF), an anti-apartheid umbrella organisation that emerged in South Africa in the mid-1980s. Notwithstanding the extraordinary successes of TAC, it appears that the majority of HIV-positive South Africans prefer to avoid joining an organisation that encourages, if not obliges, its HIV-positive members to publicly disclose their status. This may also explain why relatively few HIV-positive people who use private health care are willing to wear the HIV-positive T-shirt and "out" themselves.

TAC and MSF activists claim that they provide much more than AIDS drugs, condoms and the promise of a more equitable access to health care. They also provide the possibility of meaning and human dignity for people facing a profoundly stigmatising and lethal pandemic. To reduce TAC and MSF to a rights-based movement solely concerned with access to health resources underestimates the movement's work at the level of the body, subjectivity and identity. Neither can mainstream social movement theory account for the powerful ways in which activists with HIV/AIDS make meaning of their terrifying and traumatising journeys from the shadow of death to "new life". It is in this passage

from the space of social and biological death that Turner's analysis of the ritual process can illuminate how new HIV-statuses, subjectivities and convictions are rooted and routinised.

## **9 Some concluding thoughts on “biological citizens” and “responsibilised subjects”**

Drawing on the successes of MSF treatment programmes and TAC treatment literacy campaigns in Khayelitsha and Lusikisiki, public health professionals have called for the creation of an empowered citizenry with high levels of understanding of AIDS issues reinforced by community advocacy and mobilisation processes that promote the rights of people living with HIV/AIDS. According to the David Coetzee and Helen Schneider (2004: 1), a “public health revolution” is necessary if ART is to succeed.

Alternative approaches to the traditional management of chronic diseases, such as “directly observed therapy”, are needed if the stringent adherence requirements of ART are to be achieved. The evidence from pilot projects is that high levels of adherence stem from ‘a new kind of contract between providers and clients’. The contract is premised on very high levels of understanding, treatment literacy and preparation on the part of users, the establishment of explicit support systems around users, and community advocacy processes that promote the rights of people living with HIV/AIDS. The responsibility for adherence is given to the client within a clear framework of empowerment and support. This is very different to the traditional paternalistic and passive relationship between health care workers and patients – changing this represents the key innovation challenge of an ART programme.

(Coetzee and Schneider 2004: 72–3)

The idea of a “contract” – written or unwritten – between providers and clients is not new in the public health field. However, the nature and scale of the AIDS pandemic, along with the requirement of life-long treatment, reinvigorated calls for a change in the paternalistic culture associated with conventional public health interventions. These calls took place in a context in which the national Health Minister had conceded that DOT programmes were failing, largely because of ‘insufficient human resources to supervise and monitor implementation,’ culminating in a declining cure rate for TB of only 53 per cent. (*Cape Times*, 12 October 2004). In terms of this call for a paradigm shift, clients would be entitled to free government health care, including anti-retroviral drugs, but they would also need to show that they were “responsibilised clients”, i.e. through demonstrating treatment adherence, disclosing their HIV status, using condoms, abstaining from alcohol abuse and smoking and so on.

These calls from South African public health professionals for a “new contract” between clients and providers also resonate with MSF's own ideas about the “responsibilised” citizen-patient. Both draw on the importance of creating empowered HIV-positive identities and non-hierarchical relations between providers and clients, experts and patients. However, neither of these models of health promotion and

rights-based mobilisation adequately acknowledges the profoundly traumatic character of illness experiences; nor do they recognise the complex mix of religious, communal and activist discourses, interpretations and mediations of these illness experiences. Yet, it is precisely the discursive power of these interpretive frames of illness that facilitate the making of new HIV-positive identities and “responsibilised” subjects. Rationalist and liberal individualist conceptions of the “modern subject” and the rights-bearing citizen are inadequate for understanding the transformative character of these new biosocial identities.

Sipho’s treatment testimony reveals that AIDS illness experiences can be narrated in ways that reveal hybrid subjectivities and multiple interpretative frames, including religious, communal, biomedical and liberal modernist rights-based discourses. In other words, the “responsibilised” citizen-patient that MSF and progressive public health professionals desire may not be simply a product of modern, liberal individualist conceptions of the rights bearing citizen. It is for this reason that Turner’s analysis of the ritual process can serve as a useful heuristic device for producing a more complex and nuanced understanding of illness and treatment experiences. Treatment testimonies, this paper has argued, can provide a view into the social consequences and emancipatory possibilities of this potent triple combination therapy: ARVs, AIDS activism and the individual experiences of the passage from “near death” to “new life”.

Finally, Sipho’s testimony reveals how a creative combination of religious, communal and activist mediations and interpretations of these traumatic transitions can, under certain conditions, contribute towards the “conversion” of HIV-positive people into committed activists and “responsibilised” client-citizens. It also shows how activists are able to shift discursive and narrative “frames” strategically according to the specific context and audience. For instance, the illness experience/personal transformation frame may appear in testimonies in a particular form when used to rally others collectively, while shifting again into the “responsibilised citizen” mode in interactions with patients at clinics, treatment literacy audiences, MSF staff, public health professionals and policy-makers and so on. Social movement theories, I conclude, are generally incapable of appreciating the fluid and situational character of these multiple framing strategies and the complex ways in which these may be strategically deployed in social movements. Clearly, the moral politics of AIDS has produced collectively shared meanings and forms of political subjectivity that question wholesale representations of the Third World AIDS sufferer as *homo sacer*, the person who could be killed but not sacrificed.



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