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Mobilising and Mediating Global
Medicine and Health Citizenship:
The Politics of AIDS Knowledge Production
in Rural South Africa

Steven Robins
April 2009



Citizenship DRC



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Mobilising and Mediating Global Medicine and Health Citizenship: The Politics of AIDS Knowledge Production in Rural South Africa

Steven Robins

Summary

The paper investigates the ways in which global health messages and forms of health citizenship are mediated by AIDS activists in rural South Africa. It focuses on how international health agencies and NGOs engage with local communities through AIDS prevention and treatment programmes. Some critics regard such global health programmes as conduits for the medicalisation of social life and social problems. From this perspective global medicine is an all-encompassing process that results in systematic normalisation, depoliticisation and dis-empowerment of patients and citizens. However, this case study draws attention to the agency of the 'targets' of biomedicine. It also highlights the observation that AIDS activists and treatment literacy practitioners are not only concerned with biomedical matters, but are also committed to recruiting new members into their biopolitical projects and epistemic communities. These mobilisation processes involve translating and mediating biomedical ideas and practices into vernacular forms that can be easily understood and acted upon by the 'targets' of these recruitment strategies. However, these processes of 'vernacularisation' or localisation of biomedical knowledge often occur in settings where even the most basic scientific understandings and framings of medicine can not be taken for granted. This ethnographic case study shows that global health programmes, and their local NGO and social movement mediators, often encounter considerable 'friction' not only from powerful national state actors, who may view such programmes as challenges to national sovereignty, but also from the most marginalised village-level actors.

Keywords: HIV/AIDS; mediation; global health; citizenship; knowledge production; South Africa.

Steven Robins is a Professor in the Department of Sociology and Social Anthropology at the University of Stellenbosch. He has published on a wide range of topics including the politics of land, 'development' and identity in Zimbabwe and South Africa; the Truth & Reconciliation Commission (TRC); urban studies, and most recently on citizenship and governance. His recent book entitled *From Revolution to Rights in South Africa: Social Movements and Popular Politics* (James Currey and University of KwaZulu-Natal Press, 2008) focuses on globally connected social movements, NGOs and CBOs that are involved in democratic struggles over access to AIDS treatment, land and housing. He has edited a book entitled *Limits to Liberation After Apartheid: Citizenship, Governance and Culture* (James Currey and Ohio University Press, 2005), and his edited volume (with Nick Shepherd) is entitled *New South African Keywords* (Jacana Publishers and University of Ohio Press, 2008).

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Local Global Working Group preface

Working paper series on Citizen Engagements in a Globalising World

Around the world, globalisation, changes in governance and emerging transnational social movements are creating new spaces and opportunities for citizen engagement. Indeed, some would argue that citizenship itself is being de-linked from territorial boundaries, as power is becoming more multi-layered and multi-scaled, and governance increasingly involves both state and non-state actors, which often are transnational.

One of the research programmes of the Development Research Centre on Citizenship, Participation and Accountability, the Working Group on Citizen Engagements in a Globalising World explores the significance of these changes to poor and disenfranchised citizens. In particular, the group's work explores how the diffusion of power and governance resulting from globalisation gives rise to new meanings and identities of citizenship and new forms and formations of citizen action. The research programme is asking questions across local-national-regional scales related to

- The dynamics of mobilisation, paying particular attention to new forms and tensions of alliance-building and claim-making;
- The politics of intermediation around representation, legitimacy, accountability;
- The politics of knowledge around framing issues, the power to frame, dynamics of contestation across forms of expertise and ways of knowing; and
- The dynamics and processes of inclusion and exclusion to examine who gains and who loses.

The group's work is a unique contribution to a vast literature on transnational citizen action in the way in which each project examines the vertical links from the local to the global from a citizen's perspective, looking up and out from the site of everyday struggles. And while much normative and conceptual literature examines the concept of global citizenship, few studies of the theme are actually grounded in empirical study of concrete cases that illustrate how global reconfigurations of power affect citizens' own perceptions of their rights and how to claim them.

The group is made up of 15 researchers carrying out field projects in India, South Africa, Nigeria, Philippines, Kenya, The Gambia, Brazil and South Africa, as well as other cross-national projects in Latin America and Africa. The projects examine new forms of citizen engagement across a number of sectors, including the environment, trade, education, livelihoods, health and HIV/AIDS work and occupational disease, agriculture and land – and across different types of engagement, ranging from transnational campaigns and social movements, to participation of citizens in new institutionally designed fora.

The working papers in this series on Citizen Engagements in a Globalising World will be available on the Citizenship DRC website www.drc-citizenship.org, as they are completed. The Citizenship DRC is funded by the UK's Department for International Development.

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Acronyms

ALP	AIDS Law Project
ANC	African National Congress
ART	antiretroviral therapy
ARV	antiretroviral
CCM	Countr Coordinating Mechanism
DoH	Department of Health
DOT	directly observed therapy
GFATM/ Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
ICRC	International Committee of the Red Cross
LCs	Lay Counsellors
LRC	Legal Resources Centre
MCC	Medical Controls Council
MRC	Medical Research Council
MSF	Médecins San Frontieres/Doctors Without Borders
NGO	non-governmental organisation
OIs	opportunistic infections
PEPFAR	United States president's Emergency Plan for AIDS Relief
PMTCT	prevention of Mother-to-Children Transmission
PWAs	people living with AIDS
SANAC	South African National AIDS Council
TAC	Treatment Action Campaign

TLPs	Treatment Literacy Practitioners
TRC	Truth and Reconciliation Commission
TRIPS	Agreement on Trade-Related Aspects of Intellectual Property Rights
UDF	United Democratic Front
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

Introduction

In recent years a number of observers have written about the dramatic expansion of antiretroviral therapy (ART) in Africa and elsewhere in the Global South. Vihn-Kim Nguyen (2005), for example, describes 'antiretroviral globalisation' in Africa as an intervention on a scale similar to that of colonialism. Similarly, I have written elsewhere about how AIDS activists in South Africa have become part of a global health movement that has introduced new ideas about rights to health care as well as new forms of health citizenship (Robins 2004). This paper is concerned with how these global biomedical interventions are mediated by a group of AIDS activists in the rural villages of Lusikisiki District in the Eastern Cape Province, South Africa. It focuses on how AIDS activists, as 'true believers' of AIDS science and medicine, seek to 'convert' rural villagers into acceptance of the fundamentals of AIDS science through recourse to rhetorical strategies that are not that dissimilar to those deployed by Christian missionaries (see Niezen 1997). Similar to the missionaries before them, AIDS activists, and health professionals, have had to resort to persuasive arguments, rhetorics, and translations that resonate with local idioms and discourses on illness and healing.

Although the global expansion of biomedicine in the developing South has been taking place for decades, the 'antiretroviral revolution' and HIV/AIDS prevention programmes have dramatically extended biomedicine's reach. This has been facilitated through the massive injections of resources from international agencies such as the Global Fund, PEPFAR, the Gates and Clinton Foundations, WHO, the World Bank, UNAIDS and many others. In addition to the infusion of these global health resources, there has been a dramatic expansion of NGOs, community-based organisations and globally connected health social movements such as South Africa's Treatment Action Campaign (TAC). These social movements, together with NGO allies such as Medecins San Frontieres (MSF or Doctors Without Borders), mediate these new biomedical technologies of health citizenship in ways that can, under certain conditions, contribute towards the promotion of innovative forms of agency, citizenship and solidarity (Robins 2004). But this is clearly not a seamless narrative of scientific and biomedical progress and citizen empowerment. The case study discussed in this paper suggests that activist mediators of AIDS knowledge regularly encounter 'small acts of resistance' in their daily attempts to disseminate 'scientific facts' and 'medical solutions.' The study highlights the forms of 'friction' encountered when global processes 'land' in local spaces.

There is a longstanding critical intellectual tradition within the social sciences that makes the argument that the medicalisation of social life and social problems is an all-encompassing process that results in systematic normalisation, depoliticisation, disempowerment and the production of 'docile bodies' (Freidson 1970; Ehrenreich and Ehrenreich 1971; Zola 1972; Illich 1975; Armstrong 1983; Butchart 1998).¹ However, there have also been cogent critiques of the seamless application of medicalisation and Foucauldian critiques of biomedicine. For example, Megan Vaughan (1991) suggests that the individualising and normalising ideas and practices of Christian missionary medicine in Africa had limited reach and impact in terms of shaping African subjectivities. Scholars, drawing on Foucauldian conceptions of biopower, have in turn argued that the

medical interventions of colonial states were more concerned with the control and surveillance of colonised populations rather than the production of subjectivities through modernist forms of biopower (Kistner n.d.). This recognition of the limited reach of the state seems to have even more salience in many contemporary, post-colonial settings where public health systems are either chronically dysfunctional or extremely thin on the ground. In other words, it would seem that such post-colonial state interventions are seldom as hegemonic and totalising as biomedicine's critics imply. Although these observations converge quite closely with broader critiques of claims about the homogenizing effects of globalisation, this paper is specifically concerned with the confluence of globalisation and medicalisation processes and how these impact upon the agency and political subjectivities of citizens and members of social movements.

While recognising the salience of aspects of the medicalisation critique, including its emphasis on individualisation and normalisation, this paper focuses on how public health interventions and grassroots health activism in South Africa (and elsewhere) can, under certain conditions, produce new forms of political agency and active health citizenship.² These forms of agency may include rejections or reinterpretations of biomedical discourses as well as the embrace of its scientific explanations and medical technologies. In other words, the expansion of the global reach of biomedical discourses and products in the South has generated both rejections and suspicion of 'Western' medicine as well as the promotion of new desires and expectations amongst the Third World poor who are increasingly demanding that they too deserve access to life-prolonging medicines. Similarly, the 'conversion' of people living with AIDS into activists and 'true believers' of modern science and medicine can be understood as evidence of the potentially empowering and 'redemptive' consequences of access to biomedical resources. Alongside this heroic and emancipatory narrative of the progress of biomedicine and science in Africa, there is of course considerable evidence of colonial legacies of distrust and scepticism of scientific expertise (Robins 2004; Steinberg 2008a; Cassidy and Leach 2007). There is also the phenomenon of contemporary forms of globalised technocratisation and medicalisation that are generating their own resistances as part of emergent regional modernities and nationalist politics (Melissa Leach, pers. comm). These responses include nationalist assertions of

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- 1 For comprehensive reviews of critiques of the (bio)medicalisation literature see Clarke *et al.* (2003) and Lupton (1997). Both scholars draw attention to the agency of the subjects and patients of biomedicine. For instance, Clarke *et al.* conclude that 'We refuse interpretations that cast biomedicalisation as a technoscientific tsunami that will obliterate prior practices and cultures. Instead we see new forms of agency, empowerment, confusion, resistance, responsibility, docility, subjugation, citizenship, subjectivity, and morality' (Clarke *et al.* 2003: 184–5). Lupton provides an equally compelling critical analysis of Foucauldian critiques of medicalisation.
 - 2 In her account of the politicisation of patienthood in the US, Lisa Diedrich (2007: 38–9) draws attention to the vibrant challenges to medicalisation that were spearheaded by the women's health movement of the 1970s. For instance, feminist health activists challenged the transformation of childbirth into an increasingly technological experience (Diedrich 2007: 37). They also challenged what they referred to as Cancer Inc. and the Cancer Industrial Complex (Ehrenreich and English 1974). Some of these forms of health activism were later re-appropriated and recast by gay men in mobilisations against the AIDS pandemic in the US in the 1980s and 1990s (Epstein 1996).

postcolonial sovereignty in the face of the expanding reach of transnational health programmes, donors and NGOs. Such a response was evident in South Africa where former President Mbeki³ and his health minister sought to contest AIDS science orthodoxy and promote 'African solutions' to HIV. This diversity of reactions to modern medicine has been very evident in responses to HIV programmes throughout the Global South. This paper is particularly concerned with the responses of AIDS activists, citizens and 'targets' of these global health programmes.

The paper is divided into two sections. Section I focuses on the global and national dimensions of HIV/AIDS programmes in South Africa. Section II of the paper provides an ethnographic perspective on the everyday experiences, interactions and rhetorical strategies of community-based AIDS activists involved in treatment literacy and HIV prevention programmes in rural villages in the Eastern Cape Province. This ethnographic case study suggests that global health programmes, and their local NGO and activist mediators, often encounter considerable 'friction' and contestation from national state actors, who may view such donor driven programmes as challenges to national sovereignty, as well as from village-level actors who may subscribe to alternative conceptions of illness and healing. The paper's conclusion draws attention to both the limits and possibilities of these grassroots activist mediations and translations of global health messages, practices and technologies.

Section 1

1.1 Global health and AIDS activism in South Africa

In 2002, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM or Global Fund) was launched as a private-public partnership that aimed at financing treatment programmes to fight these three killer diseases. A year later, in October 2003, following almost five years of concerted AIDS activism, the South African government finally agreed to provide free antiretroviral therapy (ART) to the 5–6 million people living with HIV who could require treatment within the public health system. By then there had been drastic reductions in ARV prices, again largely due to activist pressure. Responding to this shift in the government's AIDS treatment policy, the GFATM agreed to provide R430 million rand over five years to support the Western Cape Province's Department of Health in its ARV rollout programme. The highly successful MSF-Western Cape Department of Health ART programme established in Khayelitsha in Cape Town in 2001 was one of the first recipients of this donor funding. By June 2006, over 20,000 people were receiving ART treatment in the Western Cape Province, and by 2008 over 350,000 people were on ARVs in South Africa's public health system.⁴

3 In September 2008, former President Mbeki was recalled by his party and replaced by President Kgalema Motlanthe. President Motlanthe appointed a strong supporter of the TAC, Barbara Hogan, as the new Minister of Health.

While donors such as the Global Fund contributed significantly towards funding the South African national ART programme, which is now one of the largest in the world, the Department of Health has never been reliant on this donor funding. Unlike the situation in many other African countries, there have been no signs of financial dependency in terms of the relationship between international donors and the South African state. If anything, donors have operated in South Africa under conditions determined largely by the South African government. The South African National AIDS Council (SANAC) under the former Vice-President Jacob Zuma was meant to regulate relationships between donors, civil society and the state. Due to the ongoing tensions resulting from the former President Mbeki's AIDS dissident position, SANAC remained ineffectual and paralysed until quite recently.

While SANAC, as the Country Coordinating Mechanism (CCM), was meant to facilitate a culture of participatory governance, it found itself caught in the crossfire of a highly conflictual AIDS politics. Notwithstanding these ongoing tensions, the South African Government's HIV policies have been influenced by the strong emphasis of both activists and global health agencies such as UNAIDS, WHO and the Global Fund on human rights and the non-discrimination of people living with AIDS (PWAs). For instance, the South African government did not seriously consider compulsory notification, and confidentiality and Voluntary Counseling and Testing (VCT) were prioritized in HIV policies, protocols and programmes. In other words, human rights concerns were at the centre of these public health interventions from the onset. However, rather than focusing on the role of SANAC, the Global Fund and other actors in mediating human rights discourses and relationships between the state, international health agencies and civil society organisations, this paper is specifically concerned with the role of community-based AIDS activists as grassroots mediators of global forms of health citizenship and scientific knowledge about HIV and treatment.

In South Africa, the political landscape after apartheid created new opportunities for citizens and social movement activists who were capable of activating the country's 'cutting edge' democratic Constitution. Nowhere was this more visible than in the assertions of health citizenship made by AIDS activists fighting for access to antiretroviral drugs and better health care. Yet, these political demands and rights claims were somewhat clouded by former President Mbeki's AIDS dissident views and his persistent denial of the scale of the pandemic. It became increasingly clear from the former President's speeches that he believed that AIDS discourses, including those of health professionals and AIDS activists, reproduced racist and colonial assumptions about disorderly and undisciplined African bodies and sexualities (Robins, 2004; Fassin 2007; Steinberg 2008a). The former President's dissident position, and his reluctance to respond to calls for the provision of antiretroviral therapy in the public health sector, also resonated with those black South Africans who had learnt to distrust colonial and 'Western' science and medicine (Robins 2004). For the latter, AIDS, and the biomedical

4 The estimated number of people needing treatment (children and adults at Stage 4 with CD4 counts below 200) in South Africa was 764,000 by the middle of 2006 of which a total of 353,945 (46 per cent) were enrolled in the ART programme (www.tac.org.za/community/keystatistics).

responses to it, were associated with the excesses of colonial domination and white minority rule. So, on the one side there were newly acquired rights to health care that Treatment Action Campaign (TAC) and MSF activists, health professionals and NGOs had won through tenacious global, national and community-based mobilisation in the courts, on the streets and through the media. On the other side, there was a political response 'from above' that undermined the activists' campaigns for access to AIDS treatment.

What emerged in the course of this David and Goliath battle for AIDS treatment was a creative reinvention of anti-apartheid political traditions and strategies of mobilisation. These included strategies of litigation, spearheaded by NGOs such as the Legal Resources Centre (LRC) and the AIDS Law Project (ALP), alongside grassroots mobilisation in churches, township streets, shebeens (taverns), universities, schools, trade unions, at funerals and so on. The TAC was also responsible for global mobilisation in their struggles against the international pharmaceutical industry as well as the state's initial reluctance to provide treatment. Mobilisation also involved international health and human rights agencies and NGOs and social movements that were sympathetic to the AIDS activists' cause. This transnational AIDS alliance, along with grassroots campaigns, contributed to the successes of the TAC, MSF and their allies.

TAC contributed towards politicising health care in South Africa in ways that were unprecedented and these democratic gains have diffused into the public health sector and influenced NGOs and community-based organisations involved in health matters. In the past few years, I have become increasingly interested in community-based off-shoots from TAC. These include the community and nurse-driven MSF treatment programme in rural Lusikisiki in the Eastern Cape Province, as well as Khululeka, a support group for men living with HIV in Cape Town (Robins 2008; Colvin and Robins 2008a and b). Both of these initiatives draw attention to the shifting terrain of AIDS activism and health citizenship in South Africa. They also draw attention to the immense difficulties of translating and mediating global health messages in local spaces. They foreground the contentious politics of knowledge and competing ways in which health, illness and disease are framed by differentially situated actors. This paper focuses on the Lusikisiki case study which highlights how a global health programme was translated and mediated by MSF and TAC activists and health professionals in rural villages in which health resources and scientific knowledge about AIDS were very thin on the ground. The case study locates this translation process within the context of South Africa's national antiretroviral therapy programme.

The Lusikisiki case study discussed below investigates the ways in which global health messages and forms of health citizenship were mediated by AIDS activists who were not only concerned with changing the lives of people living with AIDS so they could better manage biological conditions associated with their seropositive status. Instead, they were also committed to recruiting new members into their biopolitical projects and epistemic communities. These mobilisation processes involved translating biomedical ideas and practices into vernacular forms that could be easily understood and acted upon by the 'targets' of these recruitment strategies. However, these processes of translation and 'vernacularization' of biomedical knowledge often occurred in settings where even the most basic

understandings and framings of medical science could not be taken for granted. The Lusikisiki case study shows that global health programmes and their grass-roots mediators often encounter stiff opposition from the most powerful political actors as well as the most marginalised.

1.2 Global medicine in local places: the contentious politics of AIDS knowledge

HIV/AIDS has become a window and a mirror onto global inequalities between the North and the South (Benatar 2001, 2002; Farmer 2004; Schoepf 2001). Whereas since the late 1990s, HIV/AIDS increasingly became a manageable chronic illness in the North, it remains a harbinger of death and devastation in the South where 90 per cent of those living with HIV and AIDS live. At the start of the new millennium an estimated 19 million people had died of AIDS, and more than 36 million were infected. Some 70 per cent of those infected, an estimated 27 million people, were Africans (Schoepf 2001: 335). With limited and uneven access to anti-retroviral therapies in Africa, notwithstanding recent international efforts to make ARVs available, it was estimated that the vast majority of people living with AIDS (PWAs) in 2000 would have died by 2006. In other words, in the North people can live with AIDS, while those in the South die. These were the stark realities of global health inequalities at the beginning of the twentyfirst century (see Benatar 2001; Bastos 1999; Schoepf 2001; Iliffe 2006). It was within this context that international health and development agencies became involved in AIDS interventions in the South.

Like most forms of globalisation, the processes of embedding and translating biomedical discourses in particular places are anything but straightforward or stable. Former President Mbeki's dissident science position on AIDS,⁵ as well as the President of The Gambia's claims to use 'seven herbs named in the Koran' to cure AIDS (Cassidy and Leach 2007), suggests that the global hegemony of Western medicine and science is often vulnerable to challenges from political and religious leaders (see Natrass 2007; Fassin 2007; Epstein 2007). Similarly, it should not be surprising that the increasing involvement of international health agencies in health programmes in the South has periodically unleashed backlashes from governments claiming that these humanitarian interventions represent 'foreign interests' and constitute 'Western' threats to national sovereignty.

Mbeki's persistent questioning of the authority of mainstream biomedicine and scientific orthodoxy is a particularly striking example of such challenges to scientific expertise and global medical hegemony (Robins 2004; Fassin 2007; Natrass 2007). This has tended to take the form of a *knowledge politics* in which senior officials, primarily the former President and his Health Minister, contested the findings of the scientific establishment for instance by challenging statistics on

5 For accounts of the politics surrounding President Mbeki's position on HIV see Fassin (2007), Natrass (2007) and Robins (2004). It is important to bear in mind that most ANC leaders, including the ANC's trade union and Communist Party alliance partners, did not appear to share the President's controversial dissident views on AIDS.

AIDS mortality and morbidity, and questioning the efficacy and safety of ARVs. It has also taken the form of the government support for scientific trials and the promotion of 'African solutions' for AIDS such as Virodine (an industrial solvent), 'traditional medicines' such as *Ubejane*, and an 'alternative diet' of garlic, lemons, African potatoes and olive oil advocated by the Health Minister, Manto Tshabala-Msimang. These challenges to scientific orthodoxy have at times taken on the form of anti-imperialist and anti-racist rhetoric and arguments about the imposition of Western hegemony and the undermining of 'African culture' and the national sovereignty of African countries (Fassin 2007).⁶

These national level challenges to global biomedicine also often connected in complex ways with local expressions of distrust, scepticism and opposition to 'Western' medical interventions (Steinberg 2008a). Such responses are often based on alternative indigenous understandings about the causes of illness, for instance African beliefs in witchcraft (Ashforth, 2000, 2005; Rodlach 2006, Epstein 2007). They may also involve consumer preferences for alternative and complementary treatment such as traditional African medicine, New Age treatment or homeopathy. The fear and shame associated with HIV may also trigger a refusal to test or even accept the existence of the disease. This rejection of the scientific authority and claims of global biomedicine were also evident in the South African Minister of Health's support for Matthias Rath, an AIDS dissident and wealthy multivitamin manufacturer who claimed that ARVs were dangerously toxic and who promoted his own vitamin products as effective treatment for HIV-related illnesses.⁷

In South Africa there are many examples of government officials *and* ordinary citizens expressing deep suspicion of the motivations of practitioners and advocates of Western science and biomedicine (Robins 2004). South Africa is of course not unique in this regard. Similar responses elsewhere in Africa include conspiracy theories and popular myths about the dangers of modern medicine ranging from resistance by Islamic clerics in West Africa to 'Western' immunisation programmes to the promotion of 'alternative cures' for HIV by political leaders and healers in The Gambia (Cassidy and Leach 2007). In South Africa, official challenges to the findings of the mainstream scientific establishment have also involved direct government interference in the institutional arrangements of key medical bodies. This has included government attempts to influence the composition and positions of the South African National AIDS Council (SANAC),

6 Elizabeth Mills also suggests that this distrust of scientific expertise could have emerged from historical uses by the colonial and apartheid state of science and biomedicine to control and reduce the black population through the use of depo-provera and distribution of condoms among black South Africans (personal communication November, 2007). The revelations that emerged at the Truth and Reconciliation Commission (TRC) of the apartheid state's biological warfare programmes under the notorious Dr Wouter Basson have no doubt also contributed towards this distrust.

7 The controversial Rath Foundation sought to establish 'trials' in Cape Town's African townships to show that whereas ARVs produced toxic side-effects, Rath multivitamins were a safe and effective way to treat AIDS. The TAC took the Rath Foundation to court on a number of occasions, claiming that the government was not monitoring Rath's 'trials' adequately, and that his unverified claims to contain and reverse the trajectory of HIV infection constituted a violation existing medical regulations.

the Medical Research Council (MRC) and the Medical Controls Council (MCC). Some of the most visible clashes between government officials and AIDS activists have been in international forums such as AIDS conferences. These public conflicts have generally been between government officials, especially the Health Minister, and TAC and MSF activists. They have also involved UNAIDS' outspoken representative Stephen Lewis and, to a lesser degree, officials from the Global Fund and other international funding organisations. While much of the attention of the media and scholarly analysis has focused on AIDS politics at the national and global levels, less is understood about the local dimensions of global AIDS interventions in South Africa.

There seems to be a strong link between national level AIDS politics and the obstacles encountered by activists and health workers at the clinic level (Dr Herman Reuter, personal communication). There is, for instance, considerable evidence that confusion about the safety of ARVs and the causality of HIV have contributed towards difficulties in convincing South Africans to participate in Voluntary Counseling & Testing (VCT) and ART programmes. The relatively low uptake of HIV services, especially amongst men, in certain provinces reflects these ongoing difficulties that health workers, NGOs and activists encounter on a daily basis. Whereas the ANC local government and provisional leadership in the Western Cape actively supported MSF and TAC campaigns for the provision of ARVs in the public health sector, the political leadership in most of the other provinces were far more 'loyal' to what they perceived to be former President Mbeki's position on HIV/AIDS. For example, prior to 2003, Eastern Cape and Mpumalanga provincial political leadership vehemently opposed TAC and MSF activists and health professionals who advocated for ARV programmes. These national and provincial political battles were played out at the local clinic level in these provinces and elsewhere in the country.

AIDS activists and health professionals operating at the clinic level also routinely encounter social and cultural obstacles that raise questions about the taken-for-granted assumptions about female bodily autonomy, individual rights and freedom of choice that animate rights-based public health approaches and HIV prevention and treatment programmes.⁸ For example, as a result of the entrenchment of patriarchal cultures, especially in the rural areas of the former homelands, women often do not have autonomy to decide for themselves whether to test for HIV or whether go onto antiretroviral therapy (ART) should they require treatment. Whereas my earlier research focused on the individual agency and rights-based politics of AIDS activists (Robins, 2004), the case study discussed below highlights some of the social and cultural limits on individual agency and health messages predicated on an individualist rational choice model. These constraints and obstacles are discussed in relation to attempts by MSF and TAC activists to broker and translate global biomedical messages in settings where there are deeply entrenched alternative conceptions of health, illness and agency that are grounded in local social and gender relations.

8 I observed similar obstacles to treatment access during visits to rural clinics in Mpumalanga, Eastern Cape and Limpopo Provinces.

Section 2

2.1 MSF's biomedical foot-soldiers in Lusikisiki

In 1971 a small group of French doctors and journalists established MSF in response to the perceived inadequacies of humanitarian responses to the Biafran war in Nigeria. This new humanitarian organisation, unlike the International Committee of the Red Cross (the ICRC), strove to be fully independent and not limit itself through the conventions of state boundaries. By 2006, MSF had grown into a massive humanitarian organisation that had field missions and advocacy positions in 83 countries and over 1,500 expatriate and 13,000 national staff.⁹

Typically MSF intervenes in contexts defined by the breakdown in state health and welfare services, often precipitated by war, famine, population displacement, disease, drought and natural disasters. Generally these interventions involve providing emergency health and welfare services to meet physical survival rather than providing more long-term needs. This form of medical intervention is characterised by the 'humanitarian kit' – a mobile repository of medical logistics designed for rapid action in the field (see Redfield 2007). Redfield also describes MSF's *modus operandi* as an evolving tradition of *temoignage* (witnessing) in which NGOs 'now play a central role in defining secular moral truth for an international audience' (Redfield 2006: 3). This form of collective advocacy and 'motivated truth' aims to leverage resources and shame states and international agencies into action in settings demanding immediate humanitarian aid. Redfield argues that by integrating medical expertise and public advocacy, MSF participates in producing and mediating scientific and technical knowledge that can be used for ethical ends.

MSF's response to AIDS in South Africa fits in with the overall ideology of the organisation. It aimed to ensure, through activist strategies of state blaming and shaming, that the public health system benefited from the fruits of the 'antiretroviral revolution.' This involved not only ensuring that state clinics were stocked with ARVs, but also promoting community-based treatment literacy programmes and scientific understandings about HIV amongst the general population. From the start, MSF's aim was to catalyse, and perhaps shame, the South African state into action by showing that it was indeed possible to provide ARVs to people living with AIDS in Africa. MSF's Lusikisiki project, like its partner project in Khayelitsha in Cape Town, was integrated into the country's public health system at the primary health care clinic level. It was specifically designed as a short-term intervention that would be handed over to the Department of Health after three years. However, by establishing ARV programmes in South Africa, MSF ended up committing itself to more long-term involvement than its more typical short-term modes of humanitarian intervention.

In October 2003 the National Department of Health gave the green light for MSF

9 See Redfield (2005, 2006) for excellent accounts of the emergence of MSF and its evolving ideas and practices.

to provide ARVs in Lusikisiki and on 10 December 2003 the programme was officially launched by ex-president Nelson Mandela. By mid-2006, less than three years later, approximately 2,500 people had been started on ARVs, and 46,039 had been tested (MSF 2006: 4). The programme's treatment success rates were recorded in medical journals and celebrated at international AIDS conferences, and Lusikisiki received considerable positive attention in the national and international media. This extraordinarily successful community and nurse-driven AIDS programme involved voluntary counseling and testing (VCT), condom distribution, prevention of Mother-to-Children Transmission (PMTCT) of HIV, HIV/TB integration, and Antiretroviral Therapy (ART). It included doctors, pharmacists, nurses, adherence counsellors, pharmacy assistants, community care givers, support groups, community clinic committees, activists, and people living with HIV/AIDS. The October 2006 MSF Report on Lusikisiki describes the workings of this innovative decentralised ART programme and the various roles of the health staff:

The traditional model of community care givers is to do community-based health promotion. In Lusikisiki they work in the clinics, taking on some of the nurses' workload (including VCT, opening of HIV folders with social history, transferring lab results into folders, conducting support groups). Given the nature and magnitude of the HIV epidemic, it is critical to educate service users to empower them to take responsibility for their own treatment, rather than relying on the community health worker going to the community to enforce directly observed therapy (DOT). Defaulter tracing is done by support group members who come from the same rural village as the person who missed their appointment. These support group members are appointed by the adherence counselors and are given training on approaches to ARV adherence.

(MSF 2006: 11)

The Lusikisiki programme was involved in a close partnership with a social movement (TAC) and the state's public health system. This partnership represented a significant departure from typical humanitarian interventions, which tend to be defined by sudden population displacements or disease outbreaks in which the immediate goal is to arrive on site as rapidly as possible with sufficient equipment to be effective (Redfield 2007: 4). By working closely with both a social movement and the state, MSF was able to redefine its usual mode of operation, and it became increasingly involved in more long-term processes of policy engagement as well as programme implementation. MSF and the TAC were also able to leverage access to state health resources by legally challenging the pricing and patent protocols of the global pharmaceutical industry,¹⁰ as well as by deploying the South African Constitution to legally challenge the state for its initial refusal to provide ARVs in the public health sector. These forms of legal activism and social mobilisation, which resonated with the 1980s political traditions of anti-apartheid activism of the United Democratic Front (UDF) (see Robins 2004),

10 This particular legal challenge to the global pharmaceutical industry was launched together with the South African government.

contributed towards the emergence of new forms of health citizenship that have migrated beyond AIDS activism to include health mobilisations around cancer, mental health, and disability. In addition, the culture of health activism promoted by TAC and MSF has also diffused into the broader South African society and the public health system.

2.1.1 From Brussels to Khayelitsha to Lusikisiki

In an interview a few years ago, Dr Eric Goemaere from MSF-Belgium told me about his first attempt in 1999 to persuade South African Department of Health (DoH) officials to establish a national antiretroviral (ARV) treatment programme. His meetings with DoH officials in Pretoria went nowhere. It became clear quite early on that there was no political commitment for establishing such a programme. Government's arguments against treatment included the high cost of antiretroviral drugs as well as assertions by some senior members of the political leadership that these drugs were toxic and ineffective. Given the lack of government interest in such an initiative, Dr Goemaere decided to visit Cape Town for a few days before returning to Belgium. It seemed to be a clear-cut case of 'mission unaccomplished.' However, in Cape Town he met Zackie Achmat, a Cape Town-based AIDS activist from the newly emerging social movement, Treatment Action Campaign (TAC). Many TAC media campaigns, demonstrations and court cases later, the global pharmaceutical industry was eventually convinced that defending TRIPS and brand drugs was not only morally flawed but also detrimental to profit margins. Later, as a result of concerted AIDS activist campaigns, the South African government was ordered by the courts to provide antiretroviral drugs to pregnant mothers to prevent the vertical transmission of HIV from mothers-to-children. In October 2003, with the anti-AIDS drugs prices dramatically reduced as a result of successful campaigns spearheaded by MSF and TAC, the South African Government finally agreed to establish a national ARV programme. The rest is history (see Natrass 2007).

The success story of South African AIDS activism provides insights into the workings of global health citizenship in the twentyfirst century. However, focusing on this extraordinarily heroic account of a David and Goliath struggle against the might of 'Big Pharma' and the South African Government, can also obscure the more mundane aspects of the fight against the pandemic. The following account describes the story of how ARVs arrived in Pondoland.

2.1.2 Bringing ARVs and hope to Pondoland

ARVs were seen as a key aspect of HIV care as it is an extremely effective intervention that can be targeted in a relatively small group of the community, thus creating a sense of optimism in an otherwise depressive atmosphere of the worsening HIV epidemic. ARVs are also medically speaking the best intervention as treatment for OIs [opportunistic infections] improves the quality of life; however it is only ARVs that really extend life.

(MSF 2004: 3)

Before I was very weak and sick. I was a skeleton. I weighed only 43kgs. I didn't know what was wrong with me. I went to the [Lusikisiki] clinic and they told me I have HIV. Then, my CD4 count was 24. Today, I am 66kg and my CD4 is 375.

(Nozibele Mditshwa, one of the MSF programme's first ARV patients, upon receiving her certificate for treatment adherence; Health-e News Service, 31 October 2005)

When MSF doctors and nurses and TAC activists began their ARV treatment 'trial' in 2000 in the Xhosa-speaking working class township of Khayelitsha in Cape Town, they were fully aware that they had their work cut out for them. Government and public health sceptics seemed to have concluded that the public health system would not be able to implement what was portrayed as an unaffordable, complicated and inappropriate 'First World' AIDS treatment regimen. By implementing an ARV programme in an urban African context, MSF doctors and nurses hoped to challenge this claim. As the findings of the studies of the efficacy of the Khayelitsha programme began to be released it became clear that ARVs could work in Africa (Coetzee *et al.* 2004). Sceptics were still not satisfied. The next problem they posed was whether it would be possible to replicate an urban-based ARV programme in a rural site. Influential public health professionals and academics argued that a dysfunctional and under-resourced public health system, along with rural poverty and inadequate sanitation and poor nutrition and poor transport infrastructure in most rural areas, meant that the Khayelitsha ART programme could not be reproduced in most parts of the country. Whereas the Health Minister's prescriptions of garlic, African potatoes and olive oil as alternatives to ARVs could be dismissed on strictly scientific grounds, the dire conditions in underdeveloped rural areas had to be taken seriously. It was with this in mind that MSF and TAC identified the Eastern Cape Province health district of Lusikisiki in Pondoland as their first rural ARV site.

MSF's first line of attack at Lusikisiki was opportunistic infections. Prior to the arrival of MSF, nurses knew extremely little about HIV/AIDS, and had no training on treating people with HIV with the drugs already in their clinics. Patients who presented typical HIV symptoms at the clinics were routinely sent back to their home villages and told to prepare themselves for death. With the arrival of MSF, clinic nurses were empowered with knowledge and drugs to treat thrush and a range of other opportunistic infections. Treatment of opportunistic infections dramatically altered popular perceptions about this dread disease. This created a new sense of confidence amongst nurses, volunteers, counsellors and ordinary villagers. Suddenly HIV/AIDS was no longer a death sentence. Even though ARVs were not yet available in the local hospitals and clinics, there was a palpable sense of hope amongst AIDS activists and health professionals. I was told that once nurses learnt that it was possible to treat HIV/AIDS, those diagnosed with HIV were no longer seen as the 'walking dead.' By the time national government announced its national ARV treatment programme in October 2003, Lusikisiki health workers were trained and ready.

Fast-forward to February 2004 and a group of Lusikisiki HIV counsellors discussing their experiences working in the area. Many of these HIV-positive counsellors spoke of the initial disbelief amongst villagers when they began to

publicly disclose their status. Villagers claimed that the MSF counsellors were paid to say they were HIV-positive. How could they be HIV-positive when they looked so healthy? The treatment of opportunistic infections had created a dilemma for these counsellors. As one counsellor recalled of her early counselling sessions: 'Some of the villagers would say to me, 'You look so fat and beautiful, and your skin looks so smooth, how can we believe that you have this thing?'. Another counsellor based at St Elizabeth Hospital spoke of how a taxi-load of HIV-positive Umtata residents who had heard about MSF's treatment programme arrived at Lusikisiki demanding to be treated: 'Dr Themba [Reuter] examined them, gave an appropriate prescription for their problems but told them that they should go back to Umtata and demand ARV treatment from Umtata clinics which are designated ARV sites.' For MSF the problem was no longer that of challenging government over AIDS policies, but rather applying pressure on the state's public health services to ensure that treatment policy was implemented properly.

The accounts from the counsellors revealed that the treatment of opportunistic infections had contributed significantly towards breaking the silence and stigma surrounding HIV/AIDS. Dr Reuter, the nurses and the counsellors all spoke of the dramatically increased demand for treatment from Lusikisiki residents. The demand for AIDS testing too was up, as was the treatment of opportunistic infections. TAC Treatment Support Groups were flourishing and HIV-positive T-shirts were visible in the streets of Lusikisiki town. This relative openness was largely the result of MSF's policy of encouraging, if not insisting upon, disclosure in their counseling approach. Before someone was tested they were asked who they would disclose their status to.

Another catalyst for this open attitude towards HIV/AIDS in Pondoland was the Cape Town 'Stand Up For Our Lives' march on Parliament in 2003. A large contingent from the newly formed TAC branches in Lusikisiki came back from the Cape Town march highly motivated and aware that they were part of a national social movement. Many of the key HIV-positive TAC activists realised that their personal experiences were similar to thousands of other South Africans. They were no longer alone. In just over a year, Lusikisiki had been transformed from a place where HIV/AIDS was a taboo topic, to a place where hundreds of HIV-positive people were open about their status and flocking to the clinics. Rather than promoting the protection of privacy and confidentiality about HIV, MSF and TAC chose to push the disclosure line. All of this took place in a rural setting portrayed by government officials as characterised by conditions of chronic poverty, illiteracy and ignorance. Government and public health sceptics had assumed that these were insurmountable obstacles to the implementation of ARV programmes.

Post-apartheid South Africa provided MSF with an ideal opportunity to challenge mainstream biomedical and public health approaches to HIV/AIDS in the Third World. The emergence of TAC as a grassroots-based social movement created the conditions for MSF's empowering vision of health citizenship. TAC's massive support base provided MSF with the necessary political legitimacy and credibility to intervene in South Africa. This NGO-social movement partnership was extremely effective in rural Eastern Cape and elsewhere in the country. Whereas MSF has often had to appear neutral and non-partisan, the conditions in South

Africa, and its partnership with a relatively militant social movement, obliged the NGO to take on a more overtly political stance. Given TAC's civil disobedience campaigns, court cases and street demonstrations, MSF could not afford to treat its South African mission as 'business as usual'. These developments draw attention to how global governance processes, including the role of transnational NGOs such as MSF, are mediated by the particular national and local political conditions and trajectories. It remains to be seen to what degree the experiences gained from this MSF-TAC alliance in South Africa will translate in MSF strategies and practices elsewhere in the world. What is clear, however, is that individual MSF activists developed extraordinarily sophisticated ways of mediating global health technologies and messages in these local settings.

During a visit to Lusikisiki I attended a MSF and TAC sex education workshop. At the workshop an openly gay AIDS activist from East London shocked the moral sensibilities of the young, mostly female and heterosexual, group of Xhosa-speaking AIDS activists by regaling to them accounts of homosexual practices that most of them never knew existed – as a woman told me afterwards, 'I am completely traumatised;' a lesbian activist attending the workshop told me that if she were to be open about her lesbianism in Lusikisiki's rural villages she would probably be killed for being *umthakati*, a witch. The East London visitor departed leaving many of the activists dazed and bewildered. There is probably a significant difference between doing AIDS activist work and sex education in rural Lusikisiki and the more cosmopolitan urban townships of Cape Town, Durban and Johannesburg. Yet, even in 'liberal' and cosmopolitan Cape Town, lesbian and gay couples are attacked for being open about their sexual orientation, and a young TAC AIDS activist was killed in 2005 by her rapist after she revealed her HIV-positive status. AIDS activists, it would seem, are mediators of potentially dangerous and empowering knowledge about sexuality and sexual rights.

These accounts of the daily practices and experiences of South African AIDS activists in rural Pondoland draw attention to the difficulties of translating the 'HIV scientific truths.' i.e., ideas associated with global health programmes about HIV transmission, prevention and treatment. These epistemological and cultural challenges are of course not unique to Pondoland or South Africa. A number of anthropologists have written about the tensions between biomedical and 'lay' or indigenous interpretations of illness and healing. However, few have investigated the rhetorical strategies of activists as brokers of biomedicine.

2.1.3 Brokers of biomedicine and medical evangelists

There are of course a number of studies that have focused on the role of missionaries as mediators and translators of modern medicine. For example, writing about the Cree of the James Bay region in northern Quebec, Ronald Niezen (1997) compares biomedical interventions amongst indigenous peoples in Canada with religious conversion and the imposition of Christian beliefs amongst these colonised peoples. He describes the various ways in which 'medical evangelism' undermined indigenous Cree ideas and practices relating to illness and healing. Whereas Christian missionaries and medical evangelists depended on some degree of indigenisation in their mediations of modern medicine

(Comaroff 1985), the independent medical administrations that followed on their heels resorted to prohibition and more coercive methods of persuasion ‘to attempt to transform native behavior into a more consistent reflection of biomedical belief’ (Niezen 1997: 464). In some respects, AIDS activists in South Africa can also be seen as medical evangelists. In rural Pondoland, AIDS activists drew on rhetorics of persuasion that were in certain respects similar to those deployed by medical evangelists in Canada and other former colonies.

The AIDS dissident debate and the persistent questioning of the efficacy and safety of ARVs by former President Mbeki, as well as a plethora of ‘AIDS myths,’ obliged TAC and MSF activists to acknowledge and respond to lay interpretations of illness. These locally embedded lay explanations included the blaming of AIDS on witchcraft, and AIDS conspiracies and beliefs, for instance, that AIDS was invented by ‘whites’ who want to limit black population growth; doctors and nurses inject patients with AIDS when they go for tests; free government condoms are laced with HIV-infected ‘maggots’; pharmaceutical companies seek to create markets for their drugs in Africa; Africans are used as guinea pigs for scientific experiments with AIDS drugs; sex with virgins, including infants, can cure AIDS; and anti-retrovirals are dangerously toxic (Robins 2004). This plethora of popularly held ‘AIDS myths,’ as well as the stigma, shame and silence associated with AIDS, has contributed towards widespread AIDS denial. It is within this generalised context of AIDS myths, folk epistemologies and denialism that MSF and TAC activists attempt to deploy scientific authority and rhetorics of persuasion to promote the objectives of HIV/AIDS programmes.

The discussion below is based on fieldwork done during visits to the MSF programme in Lusikisiki. It focuses on the role of MSF and TAC lay counsellors (LCs) and treatment literacy practitioners (TLPs) who sought to mediate scientific discourses on HIV in the rural villages of Pondoland. These pedagogical and epistemological interventions hoped to produce ‘scientific’ ways of understanding the body, disease, sexuality and treatment. These forms of medical activism and knowledge politics, it will be argued, are revealing in terms of what they can tell us about the *globalisation and localisation of these discourses on science, medicine, and citizenship*.

2.2 Mediators of global medicine and contested ‘facts’

At a TAC Congress in Cape Town a couple of years ago, a veteran AIDS activist told me that the fundamental goal of TAC was to convert members to ‘a scientific world view.’ This would, he believed, shift people away from attributing illness and misfortune to witchcraft and the ancestors. The Treatment Literacy Practitioners (TLPs) and Lay Counsellors (LCs) that I met in Lusikisiki appeared to share this absolute faith in science and modern medicine. They seemed unquestioning and unwavering in their belief in the importance of disseminating the ‘scientific facts’ about AIDS to ‘the masses’. They themselves had acquired these ‘facts’ during the course of numerous TAC and MSF workshops on AIDS awareness, sex education and treatment literacy. In addition, a significant number of them had acquired their scientific and biomedical literacy as a result of being HIV-positive and being on anti-retroviral therapy.

Notwithstanding their deep commitment to the ‘scientific facts’ about HIV and AIDS, activists encountered numerous obstacles and challenges during their daily attempts to implant these ‘facts’ in the hearts and minds of residents in the small towns and rural villages in which they worked. These obstacles included age and gender hierarchies and sexual taboos. For example, local teachers questioned the scientific knowledge and authority of these youthful AIDS activists, especially young women who spoke about sex, condoms, AIDS science and biology. Older people were particularly offended by ‘sex talk’ from young people. For instance, activist educators found it difficult to identify culturally appropriate words for genitalia and sexual intercourse. Other challenges came from members of the community who questioned the actual existence of HIV and AIDS, and who attributed illness and death to sorcery and witchcraft (*umthakati*). Some claimed that what activists and health workers referred to as HIV/AIDS’ opportunistic infections were simply pneumonia, diabetes or TB, and that these were therefore ‘not new diseases’. Similarly, certain OIs and HIV-related illnesses were identified as *twasa*, which was widely understood as being a sign that the ill person had been chosen by the ancestors to become a *sangoma* (diviner). The following section examines the experiences and rhetorics of conversion deployed by two TAC activists, Anna and Siphon.¹¹ Although global health programmes can be seen as standardised global assemblages, the responses of the mediators and targets of these programmes can contest the truth claims of these biomedical discourses. Like the Christian missionaries before them, in the face of scepticism and alternative conceptions of illness and healing, activist mediators of these biomedical discourses strive to develop convincing scientifically based rhetorics of persuasion.

2.2.1 Latter day Livingstones and the gospel of global medicine

These accounts of village workshops, discussions and arguments about science, medicine, ancestors and witchcraft, resonate with the well-known narrations of Dr Livingstone’s attempts to convince African chiefs and rainmakers that it was God, rather than the ancestors, that delivered rain, wellbeing and health. In the cases below, AIDS activists deployed the authority of science and medicine, rather than God, to fight a pandemic widely attributed to ancestors, witchcraft and other ‘non-scientific’ causes. Activists such as Anna fought these epistemic battles by drawing on the authority of science and medicine as well as their personal experiences and testimonies of illness, treatment and the harrowing passage from ‘near death’ to ‘new life’ (see Robins 2006). As Anna told me, ‘In my work as a treatment literacy practitioner I preach the gospel of AIDS prevention and treatment based on my own experiences.’

Contrary to the universalistic and decontextualised scientific language of mainstream public health discourses (e.g., family planning, and AIDS education manuals, curricula and guidelines), the specificities of *gender, age and education* influenced the encounters between AIDS activists and community members in

11 These are not their real names.

Lusikisiki. For example, Anna, a 20-something year old HIV-positive Xhosa-speaking woman, spoke of how, during the AIDS awareness workshops at schools, some teachers challenged her about her knowledge of science and biology: 'Sometimes they're kind of confusing you ... They're happy when you don't understand more biology than them. They only want to prove the point that they know more about biology than you.' These age, gender and educational barriers were especially visible when it came to 'sex talk':

Anna: Ja, we do have that challenge more especially when you go to the rural areas where you cannot teach old men how to use condoms because they will tell you 'You're not going to teach me how to have sex with my husband or my wife. How can you teach me about sex because you're so young, it's really unacceptable? ... When I use penis in Xhosa I say ipipi. Then elders say 'No, you're not supposed to say that.'

My discussions with activists such as Anna revealed that they experienced concerted challenges 'from below' in the course of their treatment literacy and AIDS awareness workshops and discussions with villagers. There appeared to be myriad ways in which the power of science and medicine was contested in places like Pondoland. For instance, Anna spoke of how she attempts to convey the 'scientific facts,' which include references to HIV transmission, viral loads, CD4 counts, the immune system, drug regimes and resistance. These 'facts' were mediated through accounts of her own experiences as an HIV-positive woman who uses ARVs. She conceded, however, that not everyone was persuaded by these 'facts.' Alternative explanations of illness included claims that opportunistic infections such as shingles were simply due to stress or *twasa*, a condition believed to be a sign that the ancestors wanted the ill person to become a *sangoma* or diviner:

Anna: Ja, ja, there are people who don't believe in HIV and AIDS. They will tell you that you that if you've got shingles it's because you've got stress, and that people who always get shingles are the same people who always have stress and that its not AIDS ... If you're losing weight, you've got shingles and you've got peripheral neuropathy and you don't want to wear shoes because your feet are always paining, people will always tend to think that you are twasa. We tell them if you've got these opportunistic infections then you can go and become a sangoma [diviner] but at least go to the clinic and do HIV tests and see what the results are. Then if your results are positive it means you've got HIV, you're not a sangoma [laughter].

It was also quite common for people to refuse to believe that TAC and MSF activists and treatment literacy practitioners (TLPs) such as Anna were themselves HIV-positive. It was often said that they looked too healthy to have AIDS and that they were being paid by NGOs to make false claims about their status. In addition, many discussions between these TLPs and villagers focused on claims that symptoms of 'opportunistic infections' such as diarrhoea and physical wasting were in fact a result of witchcraft and the actions of jealous neighbours. Anna claimed, however, that with the increasing availability of AIDS treatment it was becoming easier to persuade ill people to go to the clinics for testing. Yet, if clinics were overcrowded, understaffed and at some distance from peoples' homes, villagers would tend to seek help from *sangomas* instead.

... People [in Lusikisiki] were denying that there is this virus because they wanted to believe that they have been bewitched and they were saying it was from ukudlisa, which is like being poisoned. And they wanted to believe that because when you're being bewitched or poisoned, you're getting thin and you have got a running stomach and then it's really similar to the opportunistic infections of HIV. But now people are starting to go to the clinic to do VCT.

Sipho, a 20-something Xhosa-speaking TAC activist in Lusikisiki, attributed this rejection of the 'scientific facts' to elders' beliefs in ancestors, witchcraft and the efficacy of traditional medicines (*muti*). According to Sipho, they were also extremely suspicious of doctors and modern medicines, and claimed that 'whites are the people trying to kill us coming here with their pills.'¹² By contrast, the younger generation, according to Sipho, subscribed to modern science and medicine. Sipho recalled how he grew up with his grandparents' and neighbours' suspicion of modern medicine and 'modern diets'. The elders, he claimed, blamed these modern drugs and foods for making the younger generation weak and susceptible to illness.

The grandmothers and grandfathers don't want any person to take the ARVs or any tablets from the hospital. When I was young I wasn't fed eggs and drinking milk, I was eating maize only. The old people told us that eggs and eating the nice food of the whites every day is why we're getting sick ... They tell us that the HIV is coming here because we're eating eggs, eating cheese and everything, that's why we're getting sick. 'If you're getting sick, umtwanam [my child], I can't take you into hospital. The only thing I can do is go into the forest and dig for roots and make muti. This can make you strong, rather than using the tablets.

Both Anna and Sipho concluded that rural villagers in Lusikisiki resorted to traditional healers and *sangomas* because they did not have easy access to clinics and medicines, or because the nurses were rude and disrespectful towards patients. This, they argued, increased the numbers of those who turn to traditional healers for help. Anna thought that better resourced and more accessible clinic services would bring more patients to the clinics, and ultimately win them over to 'scientific medicine.' In other words, from Anna's perspective, it was not necessarily belief in treatment efficacy alone that determined whether someone went to a clinic or a traditional healer. Accessibility, she argued, was the key factor.

Sipho and Anna spoke also extensively about 'AIDS myths' that circulated in Lusikisiki. These included the belief that sex with a virgin could provide a cure for AIDS by allowing the infected person to expel the virus through sex. This belief also mitigated against the use of condoms, which would 'block' the expulsion of

12 It is possible that this scepticism of science and modern medicine is connected to forms of neo-traditionalism associated with 'Red' and 'School' orientations amongst Xhosa-speakers (see Mayer 1961). It is also likely that this scepticism and suspicion is being fuelled by the President and his Health Minister's questioning of mainstream AIDS science and their claims that anti-retroviral drugs are toxic. The turn to 'traditional medicine' and 'alternative therapies' by the Health Minister, and her tacit support of Dr Matthias Raths' vitamin 'solution' is probably also fuelling these local responses.

the virus. Siphon tried to convince people in Lusikisiki that the virus was not confined to the penis. He did this by pointing out that HIV tests were done by taking blood from the finger or some other part of the body.

Siphon: There are other bad stories about youth who think if you have sex with a virgin, if you're HIV positive, the HIV is going out ... Some believe it but we tried to tell them that the virus is in the whole body, it's not in the penis. Because they think the HIV and aids is staying in the penis [and] not going anywhere else. Because they think that's why, if you have sex without a condom, you take the virus is not staying in the vagina and the penis. It can go out. But we convince them, no man, if this thing is living in the penis, why if you're going to test your blood, maybe the drop of blood is taken from your finger, then you test positive. If ever this thing was staying in your penis or in the vagina I think the blood test should be done in the vagina or the penis.

Steven Robins (SR): So they have a very different understanding of the disease, where it is located and how it works ... How do you explain what the virus is?

Siphon: We try to tell the people, the virus is like a germ. Then we're living with a germ in the body ...

Siphon was convinced that the major obstacle to scientific understanding in Lusikisiki was the 'backwardness' of the traditionalist elders, a theme that he repeated throughout our discussions. It is also quite plausible that Siphon's positing of a generational divide – between modern, scientifically literate youth and traditionalist elders – is also reflective of a sharp rural-urban divide in terms of access to health resources. Rural areas tend to be at a significant disadvantage when it comes to the availability of trained staff and access to medicines and equipment.¹³ This may account for the widespread use of traditional healing in rural areas. Although TAC activists such as Anna and Siphon appear to subscribe to a totalising scientific worldview that has no place to 'things traditional,' it is not inconceivable that, were they to experience difficulties in accessing to modern medicines, they too could be driven to seek the services of traditional healers. However, given TAC's stridently scientific worldview, which could perhaps be described as a form of 'techno-fundamentalism', TAC activists may be reluctant to acknowledge in interviews or at TAC branch meetings, that their beliefs and behaviours, like those of 'the elders', may not always conform to a strictly scientific rationality. These activists' mastery of the basics of AIDS science and treatment literacy allowed them to imagine themselves as modern subjects rather than docile objects or 'targets' of biomedicine. Yet, this access to scientific and biomedical literacy and modern subjectivity did not necessarily preclude them from appropriating the same 'traditionalist' beliefs and practices that they attributed to 'the elders.' Yet, in the face of government lethargy in relation to supporting AIDS treatment, as well as AIDS dissident thinking within government and unsubstantiated claims by traditional healers that they could 'cure AIDS,'

13 Similar disparities in access to health resources exist between provinces, with the Western Cape Province being considerably better resourced than the Eastern Cape (Chris Colvin, personal correspondence).

many TAC and MSF activists seemed to be driven towards an intransigent techno-fundamentalist position in relation to AIDS science.

The political fallout surrounding HIV/AIDS was a serious obstacle to the spread of the 'scientific facts' in Pondoland, as it was in other parts of South Africa. Anna and Siphos blamed former President Mbeki and his Health Minister Manto Tshabalala-Msimang for 'confusing people'. Anna mentioned that some people in Lusikisiki interpreted the Health Minister's 'anti-AIDS' nutritional diet of African potatoes, garlic, lemon and olive oil, as an alternative to 'dangerous ARVS.' Anna's mother, who was a nurse in Lusikisiki, was sympathetic to the Health Minister's 'African solutions.' As a result Anna was given this '*muti*' when she became seriously ill as a result of HIV. She was also sent conventional allopathic medicines by her uncle, who at the time was a senior official in the Department of Health. Anna eventually confronted her mother, and subsequently joined TAC and was selected for the MSF ART programme in Lusikisiki. Her own life experiences as a person living with AIDS infused her approach to AIDS awareness and treatment literacy programmes. The excerpt below draws attention to the highly personalised, and at times quite improvised, rhetorics of persuasion and evidence that are deployed by activists in their responses to scepticism towards medical science, ARV treatment and AIDS messages:

A: Yes, some people are saying that they don't believe in HIV and AIDS because it's the [former] President who's saying that [it doesn't exist]. What we always do is to educate them about HIV ... But when they ask about the African potato and stuff, obviously I won't have good answers for that because I'm not sure. But the only thing I always say is, 'I'm sure what anti-retrovirals are doing because I'm using anti-retrovirals. So that's the only thing I can tell you about' ... I cannot just say, 'Go and use garlic because it's good'. It is not approved [so] I cannot promote that ...

SR: ... How do you deal with people who say nutrition is more important than ARVs?

A: Ja, I tell them that I agree that nutrition is important, but nutrition doesn't lower the viral load in the body. Nutrition can boost your immune system, but when we deal with the virus, then we deal with the viral load as well as the CD4 count. And that's when you need nutrition and you need treatment. And then, let's say you've got oesophageal thrush, it's not easy to eat because you are in pain. Then that's where you need treatment to treat oesophageal thrush so that you can be able to eat. That is why I strongly believe that they work hand in hand, they work together, you need nutrition and you need treatment, you see.

Siphos also spoke about the widespread scepticism, questioning, suspicion, rumours and open opposition that he encountered in response to his treatment literacy and 'safe sex' messages. He also spoke of popular beliefs that government condoms were contaminated with 'maggots'¹⁴ and HIV, a topic that was widely discussed amongst clients at *shebeens* or taverns.¹⁵

S: ... In my location there's a tavern where young girls are drinking beer and brandy and they get into love with older people who are maybe HIV positive

... They often say that if you have sex with a condom you're wasting your time. Both the men and the women say they don't want condoms. They will say, 'No, I want flesh to flesh.' The other one's telling you 'You can't eat a sweet with the paper wrapping. I want flesh to flesh.' They will tell you it's nice to have sex without a condom. But I tell them the condom is protecting you not from the virus only, but even from pregnancy, because some of the girls are teenagers but they already have two children ... People are also saying the free condoms from government have maggots ... They say it's better to not use condoms because they are scared of these [government] condoms. My brother was telling me, it's better to use a plastic bag than to use a condom from the government ... If you're HIV positive, you have the virus but you may not have AIDS. You are living with the virus. But most people think that if you are HIV positive you already have AIDS and you're going to die immediately ...

Sipho's reflections on sexuality, including the widespread antipathy to the use of condoms, are supported by Jonny Steinberg's (2008a) observations in Lusikisiki. Steinberg found that young men avoided testing because they felt that if they tested positive no women would want to marry them and risk having children with them, and they would thus lose their reproductive and sexual capacity. In other words, the virus and an HIV-positive status was perceived to be a direct assault on a man's virility and 'his capacity to have children who would bear his name and thus on his permanence beyond the grave' (Steinberg 2008b). It was this combination of social and cultural factors, which included profound fear and shame associated with a potentially fatal disease, that threatened to stymie AIDS interventions in Lusikisiki.

Sipho also identified the churches in Lusikisiki as a serious obstacle to AIDS activists' attempts to make people more aware of HIV and AIDS and treatment. He claimed that Christian religious ideas presented major barriers to HIV/AIDS and sex education efforts in Lusikisiki. Far from being part of a biomedical juggernaut, the attempts of activists such as Sipho to mediate these AIDS messages encountered constant questioning, evasion and resistance from villagers they encountered in Pondoland; religious beliefs, beliefs in witchcraft, *itwasa*, AIDS dissident science, conspiracy theories and myths all contributed towards this friction to the dissemination of biomedical truth. As Sipho put it:

S: The churches here also don't understand [HIV and AIDS] easily ... I was trying to educate the church elders about HIV and they told me, 'This is a church, don't talk like a sinner because here we are praying for each other each and every day. If you're getting sick come in front and pray, God can

14 During a visit with MSF and TAC activists to a Lusikisiki tavern to demonstrate the femi-condom, a number of inebriated clients told us that if you poured hot water into the condom you could see these 'maggots'. It appears that they were referring to the lubricant in condoms.

15 In September 2007, 20 million government condoms had to be recalled as a result of the nationwide distribution of 'reject condoms.' The government's decision followed allegations that quality control officials were bribed to pass these flawed contraceptives. This has no doubt heightened fears and suspicions about government condoms.

help you no matter what happens.’ Last month the reverend died of AIDS. No one from the church wanted to attend the funeral because he died badly, from AIDS. AIDS is a big disgrace in this place ... A big reverend [in Lusikisiki] told me ‘If I attend this funeral God can punish me.’ ... So we need to destroy this discrimination in the churches ...

Those who are not ‘true believers’ of medical science may be profoundly ambivalent, uncertain and sceptical, if not outright hostile, towards scientific explanations of HIV and ARV treatment. Even those who claim to have been ‘converted,’ and who appear to accept the truth of biomedicine may waiver in the face of evidence of its failures and vulnerabilities. For instance, given that not all those who undergo ARV treatment survive, people in places such as rural Lusikisiki watch closely for signs of treatment success or failure.¹⁶ There appears to be an agnostic and experimental attitude towards both modern medicine’s ‘magical drugs’ and the claims of traditional healers and diviners. In other words, people in places like Lusikisiki do not necessarily fully buy into either, and instead may demand concrete, observable evidence of their efficacy. For instance, whereas nurses in Lusikisiki diagnose shingles as an HIV-related opportunistic infection, it is widely believed that shingles is the result of the malevolent actions of someone using witchcraft (Steinberg, personal communication). If the nurses are seen to be able to effectively treat shingles, and another person with shingles goes to an *inyanga* and is not cured or dies, then the popular interpretation could be that nurses and doctors have more powerful *muthi* than the traditional healers and diviners. People living in areas of high HIV prevalence often closely observe and follow the progress or regression of those who go onto ARVs. For example, when an HIV-positive person who is asymptomatic becomes visibly ill because of ARV side-effects, this often leads to lay interpretations that that the drugs brought there by ‘the whites’ are dangerous and toxic. Deaths and side-effects that are seen to be associated with ARVs can of course seriously setback treatment programmes. Yet, if a seriously ill person is seen to go through a Lazarus-like recovery as a result of ARVs, this can dramatically shift the balance of power in favour of modern medicine at the expense of traditional healing. Given the precarious and risky nature of AIDS treatment, the rhetorics of persuasion deployed by activists and health workers require the production of sound arguments and hard evidence. These mediators of global health are called upon to embed the ‘scientific facts’ within local conceptions of truth, power and evidence.

3 Conclusion

This case study from Lusikisiki has drawn attention to the agency of the ‘targets’ of biomedicine. It also showed how AIDS activists and treatment literacy

16 Jonny Steinberg’s recent (2008) book *Sizwe’s Test* tells the story of a young man in Lusikisiki who refuses to test even though he has extensive knowledge about HIV and ARVs, and he himself expends great energy persuading his neighbours to take an HIV test. Steinberg shows how Sizwe’s avoidance of testing is the result of the extraordinary fear and shame associated with HIV.

practitioners engaged with both biological and biomedical concerns and the recruitment of new members into their epistemic communities. These social mobilisation processes involved translating and mediating biomedical ideas and practices into vernacular forms that could be easily understood and acted upon by the ‘targets’ of these recruitment strategies. However, these processes of ‘vernacularisation’ or localisation of biomedical knowledge occurred in contexts where even the most basic scientific understandings and framings of medicine could not be taken for granted. It was therefore not surprising that these brokers of biomedicine encountered ‘friction’ and contestation in their interactions with the ‘targets’ of these biomedical interventions.

The paper has argued that AIDS activists from MSF and TAC can be seen as part of a modernist vanguard of foot soldiers responsible for mediating global discourses on biomedicine, science, rights and responsibilities. They can also be seen as cultural translators and catalysts for the creation of globally connected epistemic communities and new forms of solidarity and social belonging amongst people living with AIDS (see Robins 2004, 2006). Although the long-term outcomes of these activist interventions are far from predictable, this paper has questioned assumptions by critics who bemoan the disempowering effects of an all-powerful and depoliticising biomedical industry. Instead, the Lusikisiki case study suggests that the scientific authority of the activist ‘foot soldiers’ of modern medicine and public health is often fragile and routinely contested. This contestation, it would seem, is particularly visible in places like Pondoland, situated as they are in the heartland of the rural periphery of southern Africa.

These TAC and MSF AIDS activists are of course not the first wave of modernist reformers to embark upon sexual education in Pondoland. In *Reaction to Conquest*, a path breaking ethnography of Pondoland published in 1936, Monica Hunter (1936: 180–6) described the partial successes of attempts by Christian missionaries to outlaw premarital sexual practices of Mpondo youth such as *ukumetsha*, *izitshotsho* or *amagubura*.¹⁷ Family planning, AIDS prevention and sex education materials and interventions have become remarkably globalised and standardised since the colonial era interventions of the Christian missionaries that Monica Hunter writes about. Yet, like the first wave of Christian reformers, today’s reproductive health, sex education HIV practitioners also have to take cognisance of the small acts of resistance to these conversion processes. Not surprisingly, the biomedical ideas and practices associated with the forms of health citizenship promoted by MSF and TAC continue to encounter ‘friction’ in the rural hinterlands of South Africa and beyond.

17 Hunter (1936: 180–6) writes, ‘Girls between the ages of 8 and 12, and boys between 9 and 14 begin to go to *izitshotsho* or *amagubura*, gatherings of unmarried girls, boys, and young men, for dancing and sweetheartening (*ukumetsha*). The young people of one small local district ... gather in the evening and sing, then pair off to sleep together. The couple lie in each other’s arms, but the hymen of the girl must not be ruptured. If it is, the boy responsible is liable to a heavy fine ... Alongside the Pondo law and custom governing the relations of unmarried persons are another set of ideas introduced by Christian missionaries. The churches have condemned *ukumetsha*, and forbid their members to allow their children to attend young people’s dances. Children of church members do not normally attend dances, but *ukumetsha* is commonly practiced among them ...’

The case study is a helpful antidote to studies that treat globalisation as a juggernaut that simply sweeps aside all forms of local agency and cultural autonomy that it finds in its path. Instead, this study suggests that there is no necessary and inevitable linear trajectory or teleology in relation to the outcomes of interventions by global health agencies such as the Global Fund, UNAIDS, PEPFAR etc. Neither can there be any predictability concerning the relationship between these globalising/biomedicalising governance initiatives and local citizen engagement. In other words, the scientific knowledge regimes, practices and technologies of global biomedicine can be contested, circumvented, accommodated or embraced depending on specific social and cultural settings and national and local political histories. So, in conclusion, global health initiatives, like other globalising processes, seldom result in the seamless imposition of global epistemologies, assemblages and forms of therapeutic citizenship. Instead, these global health interventions, in which local health workers and activists routinely act as foot soldiers and mediators, often result in complex citizen responses and contested forms of knowledge politics.

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