

What only heaven hears:  
Citizens and the state in the wake of HIV scale-up in Lesotho

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## ABSTRACT

What only heaven hears: Citizens and the state in the wake of HIV scale-up in Lesotho

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This dissertation poses a set of questions about the political impacts of the rapid and large-scale deployment of HIV programs (HIV “scale-up”) in Lesotho. As HIV and global health initiatives have expanded over the past decade, they have had sociopolitical, as well as epidemiological, impacts. In particular, HIV scale-up elicited and demanded new political processes that continue to change how policy is crafted, how citizens are represented, and which values drive new health initiatives. More fundamentally, HIV initiatives have altered the ways that citizens, patients, and communities perceive themselves, the state, and their political worlds. Utilizing multi-sited ethnographic methods, this project observes how citizens in Lesotho are coping with these dramatic changes in their political worlds. The research reveals HIV scale-up’s considerable and far-reaching impacts on citizen faith in democracy, perceptions of rights, access to key social protections, and feelings of belonging.

In contrast to work on the impacts of social movements, activism, and political will on HIV policies, this dissertation inverts the causal direction of inquiry regarding health and politics. In doing so, it recognizes new global health movements as drivers of political change, mobilizing actors and resources in deploying programs in ways that are altering political worlds and subjectivities. A rich recent literature on biological and therapeutic citizenship in the time of AIDS has begun recognizing these trends and their impacts on patient subjectivity. This research expands the frame of inquiry to examine how public health interventions can also alter citizen subjectivity, expectations of democracy, and the

structures of associational life. The dissertation also contributes data towards better understandings of recipient populations' perspectives on accountability, good governance, public-private partnerships, transparency, and participation—approaches currently touted as solutions to poor project outcomes. For citizens in Lesotho, these initiatives still look very much like anti-democratic enterprises.

Field research was undertaken in two sites surrounding different clinical care models: the first was a government-run primary care clinic, and the second was a factory-based clinic in the country's garment industry, where a public-private partnership provided HIV services to workers. In both sites, research extended far beyond the clinic. In the former site, this meant working with: peri-urban communities served by the clinic; two support groups struggling to build partnerships with NGOs; local government institutions tasked with managing the HIV response; and traditional healers, community health workers, and patients giving and seeking care outside the clinic. In the second site, this meant exploring dynamics of discipline, productivity and "ethical" production in a transnationally-linked industry, as well as the social lives of workers outside their work.

Though largely unforeseen by most global health actors, HIV policy has become an extremely effective delivery mechanism for specific political ideologies and ways of practicing politics in poor countries. Research conducted in these sites demonstrates that the expansive, far-reaching scale-up of HIV programs has fundamentally changed ideas about *what* citizens deserve, *who* is deserving, *how* decisions will be made about services, and *who* takes responsibility for services, and ultimately, the survival of citizens. The predominant experience of politics for most citizens in post-scale-up Lesotho is a feeling of abandonment, of not being heard. The research thus raises significant normative as well as pragmatic questions about the role and responsibility of global health projects in already

fragile political systems, and the potential impacts of the political changes described here on patterns of health seeking and ill health in countries like Lesotho.

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## **Abbreviations**

- ABC – All-Basotho Convention (party)
- AGOA – African Growth and Opportunities Act
- AIDS – Acquired Immune Deficiency Syndrome
- ALAFA – Apparel Lesotho Alliance to Fight AIDS
- ANC – African National Congress
- API – AIDS Programme Effort Index
- ARVs - Antiretrovirals
- ART – Antiretroviral Therapy
- BCC – Behavior Change Communication
- BCP – Basutoland Congress Party
- BNP – Basotho National Party
- CBO – Community-Based Organization
- CCM – Country Coordinating Mechanism (of the Global Fund)
- CHAL – Christian Health Association of Lesotho
- CHW – Community Health Worker
- CSO – Civil Society Organization
- CRS – Catholic Relief Services
- CSR – Corporate Social Responsibility
- DC – Democratic Congress (party)
- DHS – Demographic and Health Survey
- EGPAF – Elizabeth Glaser Pediatric AIDS Foundation
- ESP – Essential HIV and AIDS Services Package
- FAO – Food and Agriculture Organization



GFATM – Global Fund for AIDS, Tuberculosis and Malaria

GDP – Gross Domestic Product

GIPA – Greater Involvement of People with AIDS

GPA – Global Programme on AIDS

GIZ - Deutsche Gesellschaft für Internationale Zusammenarbeit

HAART – Highly Active Antiretroviral Treatment

HBC – Home-Based Care

HCT – HIV Counseling and Testing

HEARD – Health Economics and AIDS Research Division

HIV – Human Immunodeficiency Virus

ICAP – International Center for AIDS Care and Treatment Programs, Columbia University

IEC – Independent Electoral Commission

IFC – International Finance Corporation

ILO – International Labour Organization

IRB – Institutional Review Board

KYS – Know Your Status (campaign)

LCD – Lesotho Congress for Democracy

LECONGO – Lesotho Council of NGOs

LENPWHA – Lesotho Network of People Living With HIV/AIDS

LTEA – Lesotho Textile Exporters’ Association

MAP – Multi-country HIV/AIDS Program (World Bank)

MCA – (US) Millennium Challenge Account

MFA – Multi-Fiber Agreement

MMC – Medical Male Circumcision

MOH – Ministry of Health

MOHSW – Ministry of Health and Social Welfare, Lesotho

MOLGC – Ministry of Local Government and Chieftainship

MOTICM – Ministry of Trade and Industry, Cooperatives and Marketing

MP – Member of Parliament

M&E – Monitoring and Evaluation

NAC – National AIDS Commission

NGO – Non-Governmental Organization

NSP – National Strategic Plan

OVCs – Orphans and Vulnerable Children

PEPFAR – President’s Emergency Plan for AIDS Relief

PLWHA – Person (or Persons) Living With HIV/AIDS

PMTCT – Prevention of Mother-to-Child Transmission (of HIV)

POSWA – People Openly Surviving With AIDS, one of two support groups in Ha Mamello

PPP – Public-Private Partnership

SADC – Southern African Development Community

STI – Sexually-Transmitted Infection

SWAp – Sector-Wide Approach to Health

TB - Tuberculosis

UN – United Nations

UNAIDS – Joint United Nations Program on AIDS

UNDP – United Nations Development Program

UNGASS – United Nations General Assembly

UNICEF – United Nations Children’s Fund

USAID – United States Agency for International Development

VCT – Voluntary Counseling and Testing

WHO – World Health Organization

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For my parents

## **A note on language and spelling**

The official languages of Lesotho (pronounced less-oo-too) are Sesotho and English. Those who reside in Lesotho, as well as those who claim heritage from Lesotho or speak Sesotho in South Africa, refer to themselves as Basotho; an individual is called a Mosotho. The multiple meanings of Basotho can cause confusion, particularly in a study of politics. It is further complicated by the considerable migration patterns between Lesotho and South Africa for work, as well as cross-border familial connections. Here, because I am interested in the experiences of those citizens currently living in Lesotho, I use the term Basotho to typically refer to political, rather than cultural, linguistic, or familial connections, but this is not intended to discount these other aspects of Basotho identity.

As in other parts of Southern Africa, titles and terms of respect are extremely important in Lesotho, and denote symbolic relations according to age, stature, and familiarity. Adult men are typically referred to as Ntate, or father; adult or married women as Mme, or mother (an abbreviated spelling is 'Mè). Older adults or those garnering particular respect are referred to as Ntate-moholo (grandfather) or Nkhono (grandmother). Teens and unmarried girls and boys are referred to as abuti (brother) and ausi (sister). Here, for the sake of simplicity and to assist readers, I typically only use the appellations Ntate and Mme. I use them as I would in everyday conversation in Lesotho (which is to say, very frequently), though occasionally in the text I will drop them and simply use someone's first name after introducing them in a short section of text. I do this as a way of showing respect for my informants, and for calling them as they would wish to be called, though many could also be referred to as Ntate-moholo or nkhono in person.

A few brief notes on pronunciation and spelling may assist readers. Th (as in Lesotho) is pronounced as an aspirated /t/, as in Thailand (though more aspirated), not

there. An l preceding the vowels i or u is pronounced as a hard /d/, so lumela, meaning “hello,” is pronounced doo-may-lah. Readers may note that some words are spelled differently in Lesotho and South Africa. In Lesotho, an aspirated /ts/ sound is written as ts`-; in South Africa it would be spelled tsh-. A q is pronounced as a sharp click, as it is in Zulu and Xhosa.

## 1.

### Introduction

*“Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds a dual citizenship, in the kingdom of the well and in the kingdom of the sick.”*  
-Susan Sontag (1990, p. 3)

At the first meeting I attend of the POSWA (People Openly Surviving With AIDS) Support Group in the village of Ha Mamello, its 15 or so members attend to the business of being a support group in the time of HIV scale-up in Lesotho. They collect monthly dues from each member—10 Maloti (M), or about \$1.15<sup>1</sup>—to go into a savings account from which they assist members who are sick, without food, or dying. They recently received training from a national non-governmental organization (NGO) in household gardening schemes, and so members earnestly report back to the group the number of trenches and round gardens they have built. Though they receive little material assistance from the NGO and no financial support, the members spend the bulk of their meeting discussing the mundane details of acquiring rocks, tools, and seeds for building and planting their gardens. The group does not mention HIV, illness, treatment, prevention, or anything related to psychosocial support.

And then someone asks the support group’s “president,” an emaciated older man whose baseball cap and glasses give him a casual but professorial air, whether he has found someone to “type up” their proposal. Over the course of the next half hour, I learn that they are attempting to write up a lengthy grant proposal in response to a funding announcement from the Global Fund’s in-country coordinating body, which is responsible

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<sup>1</sup> Calculated at an exchange rate of \$1 = M8.58, on January 18, 2012.

for disbursing the multi-million dollar grants the country receives for HIV and tuberculosis (TB) programs.<sup>2</sup> The recent funding call is intended to support community-based groups in developing grassroots HIV prevention activities. The president has a printout of the online application form, which includes a number of prompts for one- to two-paragraph answers about intended activities, and measures of impact. But his concern at the moment is how they will find someone to type up the form. “It needs to be typed on a computer,” he explains, “it needs a flash drive so it can be typed on a computer.” He is confused about prompts that ask for paragraphs of information but are followed by small boxes that “can’t hold two paragraphs, even if they are typed on a typewriter,” and mentions some prompts that even require a specific number of words. As he continues talking it becomes apparent that the group has little idea about the content of the answers they are supposed to provide. “We would need guidance on how to fill this thing [proposal] up, since I really don’t know everything that should be written in there.” He pauses. “It’s a lot of work to write up a proposal.” He is priming them for the request that follows: He wants to hire a consultant to write the proposal for them, who will charge M20,000 (approx. \$2,300). This is a staggering amount of money. Given the 10 Maloti these 15 members contribute each month, it would take them two and half years to raise such a sum, and that’s assuming none of it was spent on funerals, food or transport to the clinic—expenses that continually deplete their savings.

In the strange economy of Lesotho’s HIV programming, this situation is hardly outside the bounds of reason. In fact, these sorts of discussions may be familiar to many researchers who have worked with community associations and support groups in resource-poor contexts, where citizens struggle to gain a meaningful foothold within the

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<sup>2</sup> As Lesotho is not a Malaria-endemic zone, grants are not awarded for Malaria-related activities.

vast conglomerations of money and expertise involved in HIV scale-up. Most citizens in places like Lesotho have no way to bridge the vast divide between themselves and the monolith of HIV programming. They lack the language, the tools, and the wherewithal to be heard as citizens, patients, or even “recipients” of aid—as well as the resources with which to hire someone to speak for them.

As the group continues talking, there is a great deal of confusion over whether the consultant would be crafting a full conceptual project for them and writing it up, or simply transcribing their own ideas. One group member argues, “what is more important... is that the proposal should be based on the opinions of the *people* [i.e., not the consultant]—it’s a *person* who is supposed to answer the questions on this form... not a computer (emphasis original).” Another woman looks worried: “Whatever the consultant would be writing on the proposal, it would be our ideas and opinions, right?” But when the group finally gets around to talking about their ideas, they have little to do with prevention activities. They are poorly equipped to develop or deploy the kinds of interventions that are of interest to the Global Fund and its partners. What they want to do is raise pigs, which would provide income, as well as some measure of insurance against the poverty and hunger that constantly haunt them.<sup>3</sup> The consultant will serve as a translator, taking the group’s desires for certain forms of survival that have little to do with HIV (beyond the special vulnerability which the disease confers upon already poor families), and turning these into a proposal for community-based prevention activities—wrought in the peculiar, technical language of

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<sup>3</sup> Pigs can provide for forms of survival that are meaningful to these group members, as I discuss in more detail in Chapter 5. Because pigs are a long-term investment and cannot easily be divided or turned into cash, they represent an attractive form of savings for support groups in Lesotho, who can easily go into debt paying for hospital, transport, or funeral expenses for sick and dying members. When capital is bound up in livestock, it is more likely to provide some long-term savings for members—or at least those who survive to see the livestock sold. For a much more extended discussion of cattle, wealth, and property in Lesotho, see Ferguson (1985, 1994)



HIV experts. This is a bizarre form of translation, however, as it masks rather than reveals the desires and intentions of the group. Exasperated by members' desires to be reassured that their own ideas will be in the proposal, the president finally snaps: "Don't you people understand what an expert is?!"

What this short-tempered but savvy support group leader means is that they will hire a consultant "so that the proposal will be successful," not in order to faithfully document their ideas. The desires of this group, the forms of life and survival that matter to them, have no place in the grant-making procedures of HIV scale-up. And though they continue to challenge the leader about whether their views will be represented in the proposal, they eventually concede, and three months later re-elect him as president of the group, though he continues to be dismissive of their concerns. Later, after the first time she attended one of the group's meetings, my research assistant commented to me, "If you are rich or educated here people will always elect you. You 'win' their trust.... they think you know things, even if you don't." Indeed, it was likely worth the group tolerating his derision to benefit from his connections, knowledge, and education, limited though they were. But in the coming months, his skills prove insufficient to help them: After the global institutions have set their priorities, and the international experts have weighed in on strategies, and the state has ensured that its favored partners and bureaucrats will sit on the boards that apply for and disburse the grants, and after the civil society partners that purport to represent support groups such as this one have advocated for the strategies they want—after all of that and more, this small support group enjoys the paradoxical privilege of trying to apply for funding. It will be no surprise when they can't raise the money for the consultant, and don't finish the grant application; it raises the question of whether the funding was ever really intended for them.

But by other measures, the members of this group are considered lucky. Their neighbors whisper that they get special treatment because they have HIV, and accuse them behind their backs of hoarding and stealing the money for HIV programs. In contrast to the members of POSWA, citizens who have less direct contact with HIV programming look at the money pouring into Lesotho; look at the ways in which their lives have not been visibly improved; observe that their friends and relatives are still sick, dying, poor, or unemployed; and reasonably conclude that the government must be keeping HIV funding all to itself.<sup>4</sup>

Such perceptions are reinforced by the obvious wealth and power of government ministers, NGO employees, and expert consultants involved in HIV programming, by the plethora of new white Toyota Hilux pick-up trucks emblazoned with ministerial seals and NGO logos that transport them, and by the fact that their local clinics remain poorly staffed, under-resourced, and over-crowded. “All you see is people misusing money,” one patient tells me when she is unable to get her medicine from the clinic:

It seems like the government doesn't care about the nation that elected it, we who elected them so that we could get better services.... It's God's honest truth, there's nothing that the government cares about! –Nothing, in terms of the *life* and *health* of this nation. It only cares about itself... You hear them [government representatives] on the radio, and the words that come from their mouths—you'd think they still have hearts, but they don't (emphasis original).

Blame of the government for poor services breeds not protests (though of course there is anger), but a striking distrust of democracy itself. Between 2005 and 2008, the years of the most acute funding surge for HIV programs in Lesotho, the proportion of citizens who thought another form of government was necessary rose by nearly 40%, with a third of

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<sup>4</sup> The importance of the *visibility* of HIV program outcomes is essential to understanding how citizens assess success, defeat, and corruption. This is echoed in other countries, and even among program leadership. As one community leader in Kenya described the efforts of international funders to Edström and MacGregor (2010), “no, you can't be working for seven years and involved with all of the communities [like they have] and not notice anything!” (p. 5).

those surveyed preferring a non-democratic form of government (see chapter 2; Hall & Leduka, 2008). It is abundantly clear that Lesotho's citizens are not just unhappy with their leaders; they are unhappy with the entire system of governance that makes decisions on their behalf.

In places like Lesotho, citizens' most fundamental experience with HIV programming is one of not being heard. From the foreign doctors and nurses hired to staff HIV clinics, to the absence of meaningful national dialogues about how HIV grants should be spent, citizens are finding that they have no way to speak about matters that shape the boundaries of their own survival. Their silence is not just a matter of lacking the skills to participate, but of not having a voice; it is the difference between not speaking a language and finding yourself to be deaf, blind, and mute. This dissertation asks about the impacts of these experiences on how citizens perceive the state, its partners, the democratic process, and most importantly, themselves. Interactions like the one above begin to paint a picture of how HIV programs—for all of their good intentions, and their considerable strides in assessing, treating, and (sometimes) curtailing the epidemic—are altering political worlds, citizen subjectivities, and democratic futures.

### **Democracy in the Time of AIDS**

The AIDS activist movements that began in the late 1980s indelibly shaped the way we view HIV, pushing the world to acknowledge and act on the rights of people to access HIV treatment, care, and prevention in countries across the world. Well-documented activist movements bravely appropriated and challenged scientific process (Epstein, 1996), built dynamic and flexible transnational movements for treatment access (Petchesky, 2003), and forcefully demanded that governments address HIV by breaking through

societies' most trenchant prejudices and mitigating racial, sexual, gender, and global inequalities (Berkman, Garcia, Munoz Laboy, Paiva, & Parker, 2005; Parker, 2009, 2011). In particular, these remarkable forms of collective action challenged the powers of governments, international agencies, corporations, and experts to determine who might live, who would die, and how the disease would be prevented and treated. The story of how these movements evolved—and the global changes that challenged their very identities over time—is a powerful one, and its detailed history is expertly recounted by a number of scholars (Berkman et al., 2005; De Souza, 1994; Epstein, 1996; Heywood & Altman, 2000; Parker, 2011; Petchesky, 2003; Robins & von Lieres, 2004; Treichler, 1999). By delving into a short history of the evolution of social activism surrounding the HIV epidemic, we can begin to understand the markedly different global politics that produced the conditions of a more technocratic HIV scale-up in places like Lesotho—conditions that were nearly inconceivable even a decade ago.

Richard Parker (2011, 2012) identifies four major periods in the “social history” of politics and mobilizations in the HIV epidemic, and these are useful for outlining the major political dynamics shaping HIV policy over the past three decades. The decade following the identification of HIV in 1981 was marked by a crisis, primarily within gay communities, that provoked radical mobilizations to raise awareness, to secure access to scientific knowledge and products, and to challenge the prejudices inherent in much of the discourse and the silence surrounding the epidemic at the time. The second decade of the epidemic saw a blossoming of new global institutional actors (The Joint United Nations Programme on AIDS [UNAIDS], the World Bank Global HIV/AIDS Program of Action [GAP], and umbrella organizations for AIDS activist and service organizations within countries). As HIV treatments became available, emerging global activism for treatment

access also blossomed, rooted in human rights language and ideas. It was in the third period of the epidemic—largely throughout the 2000s—that HIV organizations, movements, institutions, and global actors multiplied to address the global impact of HIV/AIDS. This period saw a race to treat, contain, address, and prevent HIV. Yet this vast expansion of organizations, resources, initiatives, and funds also created fragmentation, duplication, competition among agencies, and an absorption of activists and social movements into large—and very powerful—transnational institutions and projects. Finally, the fourth period is the one in which we find ourselves now: A global financial crisis has challenged notions of “treatment for all” and reinvigorated the emphasis on cost-effectiveness and short-term gain in developing many new approaches to addressing the epidemic. At the same time, HIV initiatives are being folded into broader global health initiatives, and global health itself is increasingly professionalized, technocratic, and expert-driven.

As the global institutional architecture responding to HIV expanded rapidly in the late 1990s and early 2000s—and began to acknowledge and incorporate activist movements—HIV programming settled, paradoxically, into focusing on “administering the epidemic”—a technocratic shuttling of drugs into bodies (Parker, 2000, p. 51).<sup>5</sup> This tended to divert attention from the social drivers of disease acquisition, suffering and early death (Lewis, 2007; Parker, 2000), to neglect the social and economic survival of already sick patients (Biehl, 2007; Kalofonos, 2008), and to hoist responsibility for care, disease

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<sup>5</sup> The question of *why* this occurred is not a simple one. Parker (2000) asserts that AIDS activist movements never coalesced into a truly *global* movement that could adequately challenge global institutions and participate in agenda setting. Equally important, perhaps, is the fact that global institutions addressing HIV grew with an extraordinary pace, marshaling vast amounts of funding over a short period of time. This contributed to the phenomena of what might have been quite oppositional activist organizations becoming absorbed into the broader AIDS architecture, serving as service providers and experts *within* these institutions, rather than maintaining a solidly independent activist stance.

management, and prevention onto the shoulders of patients and communities (Le Marcis, 2003; Makoae, 2009). Amidst all of this, discourses about a global right to treatment access became hollowed out, distilling the very authentic participation of social movements in a broad array of initiatives into a notion that accessing and taking pills was somehow itself a radically participatory form of health politics. This is not to deny the terribly grave consequences of lacking treatment access for the world's poor, or the importance of activists' achievements in treatment access. But at the very moment that global treatment access became a realizable possibility in countries like Lesotho, the social movement politics of accessing treatment transformed into the "anti-politics" (discussed below; Ferguson, 1994) of a professionalized, hierarchical administration of the epidemic. As Parker (1994) had warned, "without a political and conceptual base, technocratic solutions to the epidemic have failed in every sense...While technocrats may successfully administer the epidemic, they offer no hope of defeating it. Even science offers nothing unless based upon critical reflection and political commitment" (in De Souza, 1994).

With a few notable exceptions, however, political science was late to engage with HIV. A few early works focused on the conditions under which HIV policies emerged, and the compelling ethical and advocacy issues driving policy agendas in developed countries (Baldwin, 2005; Bayer, 1992; Nathanson, 2007). It was only in about the mid-2000s that a small group of works emerged, examining the political factors driving HIV policy choices across or within African countries (Bor, 2007; Parkhurst, 2001; Patterson, 2005; Poku & Whiteside, 2004). Most analyses tended to compare country responses to the epidemic, probing what caused countries like Brazil, Uganda, and Botswana to develop active responses while AIDS denialism grew in South Africa, and other countries remained mired in inaction (Berkman et al., 2005; Nattrass, 2004; Parkhurst, 2001; Poku & Whiteside,

2004; Swidler, 2009a). Researchers and international organizations tended to hone in on the idea of “political commitment” as a possible explanatory variable, but successfully operationalizing such a vague phenomenon—let alone extracting policy lessons from it—proved difficult. Other research attempted to standardize measures of political response to the epidemic and analyze these against various variables of HIV spread and impact across a larger sample of (usually African) countries (Bor, 2007; Patterson, 2005; USAID, UNAIDS, WHO, & The POLICY Project, 2003). Researchers at the US Agency for International Development (USAID), UNAIDS and other international institutions even went so far as to develop a standardized measure of national policy responses to HIV and AIDS, called the AIDS Program Effort Index, or API (USAID et al., 2003). This second strand of research tended to face difficulties in linking policy outcomes to political process. That is, it was hard to tell a compelling story that held true across national political contexts about what factors drove countries to develop forward-thinking HIV policies: Was it the felt impact of the virus? Levels of stigma and discrimination? International pressure? In many cases, the story of how HIV policy emerged as it did was a complex tale, influenced by such large-scale factors as religion, history, economics, and political party divisions. Finally, a notable but slim literature, primarily originating from African countries, posed important but under-recognized questions hypothesizing that the impacts of the HIV epidemic (through illness, death, and their impacts on economies and societies) might destabilize already fragile states or political systems (Alexander De Waal, 2006; Manning, 2002; Owusu-Ampomah, Naysmith, & Rubincam, 2009; Poku & Whiteside, 2004).

Evan Lieberman’s *Boundaries of Contagion* (2009) is perhaps the most significant offering from a political scientist to the scholarship on HIV policy to date. Recognizing the methodological weaknesses of earlier approaches, Lieberman painstakingly constructed an

elegant multi-method analysis, developing his own measures of political responses to HIV. He proposes that deeply-rooted, institutionalized boundaries between ethnic groups can impede political initiative in implementing robust HIV policies—and that these effects hold regardless of politicians' own ethnic affiliations or the patterns of HIV prevalence across ethnic groups in the nation. The book draws attention to the pervasive and considerable effects of stigma—what Lieberman calls “shaming and blaming”—and the tendency of social groups affected by HIV to place blame on vulnerable, poor, minority groups. This echoes anthropological accounts that highlight how ethnic politics impact HIV policy, especially Hyde's (2007) considerable contribution on ethnicity and HIV in China. One of the most important lessons from Lieberman's book is that strong HIV policy does not necessarily make for smart political decisions: Enacting the sort of HIV policies so aggressively promoted by international organizations (what Lieberman [2009] calls the “Geneva Consensus”) may actually involve considerable political costs for politicians (see also Strand, 2010). Even today, we can observe how galvanizing political issues among conservative, or overtly discriminatory, interest groups reshape HIV politics—as in the striking shift towards criminalizing homosexuality in Uganda, where HIV policies were once considered so progressive. Steven Robins (2008, ch. 7) discusses these tensions at some length in reference to South African President Jacob Zuma's rape trial, during which his political supporters drew on neo-traditionalist discourses and public displays of masculine privilege to defend his actions, which included strikingly erroneous and sexist ideas about HIV risk and sexual practice—views that nonetheless served to galvanize his political power base (ch. 7).

The research I present here inverts these key questions, asking not how politics impacts HIV policymaking, but how the dynamic outcomes of HIV policies (in terms of



institutional changes, policy shifts, and influxes of organizations, money, and people) impact political functioning. The research chooses to look at variables associated with HIV policy and institutions, rather than the direct impacts of the HIV epidemic; it takes stock of HIV as a phenomenon of international politics, diplomacy, and governance in addition to its epidemiologic trends and effects. It emerges from a realization that the period during which national politics in recipient countries or the whims of African political leaders were the primary drivers of HIV policy response has rapidly come to a close. As national responses are increasingly “streamlined,” and particular policy choices are mandated by international institutions or incentivized by funding structures, HIV policies show far less variability than they did in the past, and adhere to a fairly rigorous set of “best practices” regardless of epidemiologic, social, or political variation (Biesma et al., 2009; Cassidy & Leach, 2009; Edström & MacGregor, 2010; Lieberman, 2009; Strand, 2010).

The emergence of HIV, and later, of strategies to prevent and treat it, presented numerous ethical quandaries that challenged some of the most fundamental political values in societies. Crafting HIV policy has consistently meant confronting tensions regarding: individual and collective well-being; private and public domains; how and when experimental science could be accessed by the public; how to create non-discriminatory policies for epidemics concentrated in stigmatized groups; and where to draw the line between policies that restrict individual rights in the service of public safety, and preserving privacy by allowing individuals to take matters of prevention, treatment, and partner notification into their own hands. Of course, the ways in which societies dealt with these questions reflected core national values as well as the peculiarities of each national epidemic (Baldwin, 2005; Bayer, 1992; Nathanson, 2007). But everywhere, as Bayer (1991) noted, policy seemed to be coalescing upon the notion that HIV was

somehow exceptional—something to be dealt with differently than, say, syphilis or tuberculosis (TB). As HIV programs expanded transnationally, exceptionalism also blossomed. Entire agencies were developed to address HIV as an issue somehow separate from other health issues (for example, UNAIDS sits outside of the World Health Organization [WHO]). Even as the UN called for “multisectoralism” in HIV programs—so that HIV would be seen as an issue requiring attention from the health, education, trade, labor, social welfare, and other government sectors—strategies reinforced the notion that both the disease and its policy responses operated according to a different set of rules.<sup>6</sup> (Exceptionalism also generated a rich and extended debate as to whether or not it was justifiable that AIDS be treated as exceptional by global institutions, donors, and states [see Piot, 2003, 2008; J. H. Smith & Whiteside, 2010].)

In resource-poor contexts, this exceptionalism can be especially striking. Duana Fullwiley’s (2004, 2011) research on sickle cell anemia in Senegal demonstrates how a vast public health emphasis on HIV (despite Senegal having the single lowest prevalence rate of HIV on the continent) *created* the “socio-political invisibility” of other diseases and conditions like sickle cell anemia (2004, p. 159). Even in Lesotho, where HIV’s impacts were so acute, the combined effects of rampant HIV stigma, entrenched and generalized poverty, a crippled national health system, and considerable primary health problems made the singular and resource-intensive scale-up of HIV programs seem like a misguided, or simply externally-imposed, prioritization of public goods. Such unfairnesses are not lost on citizens: “taking care of your health *beyond* HIV/AIDS” (emphasis added) a private

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<sup>6</sup> In some respects, this was, of course, true. The scope of the HIV epidemic and its toll on life expectancies and population structures across many sub-Saharan African countries is simply shocking. But this sense of exceptionalism is also due to the ways in which HIV came to embody a new category of global humanitarian emergency, and it was in part the dynamics of HIV *as* emergency that warranted this kind of exceptionalism in response.

clinic sign calls out to passerby on one Lesotho's main roads.

In resource-poor contexts, the prioritization of HIV initiatives tends to appear in conjunction with projects that fail to address or acknowledge the many social, political, and economic conditions which drive HIV infections, make accessing treatment more difficult, and speed along death due to AIDS (Altman, 1999; Barnett & Whiteside, 2002; Farmer, 2001; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008; Parker & Aggleton, 2003; Pfeiffer, 2004). Though many global HIV initiatives use language which identifies poverty, vulnerability, or gender as important considerations of HIV prevention and response, a number of scholars argue that initiatives in practice often ignore the “structural determinants” driving HIV risk, stigma, illness, and treatment experiences (Auerbach, Parkhurst, & Cáceres, 2011; Gupta, Ogden, & Warner, 2011; Gupta et al., 2008; Ogden, Gupta, Fisherc, & Warner, 2011; Parker, Easton, & Klein, 2000; Parker, 2000; Pfeiffer, 2004). In Lesotho, as will be evident throughout these chapters, “administering the epidemic” (Parker, 2000) without addressing other social ills provokes acute citizen confusion and ire. HIV programming has been so totalizing in places like Lesotho that citizens often resort to articulating claims to *other* social and political rights in the language and rationale of HIV programming. Thus, members of the youth wings of Lesotho's opposition parties in May 2011 angrily protested the release of the government's new behavior change communication (BCC) strategy for HIV prevention by citing the economic drivers of the epidemic:

It is useless to fund strategies like these because they don't directly help uplift the lives of youths. We are all aware of what is largely contributing to new HIV infections among young people, which is idleness [lack of jobs]. Therefore, promoting behavior-change without economic empowerment is like trying to move a mountain from Thaba-Tseka [a remote mountainous district] to plant it here in Maseru [the capital city]! (Matope, 2011)

In response, the youths were lambasted for “politicizing” an HIV intervention (Matope,

2011), making it not about prevention, but about political issues of the economy and of public participation in HIV policymaking.

Of course, any and all HIV policies are in some way political, and failing to acknowledge the social drivers of the epidemic represents a form of “anti-politics” (Ferguson, 1994) that separates out political causes of suffering and sickness from behavioral, individualist attempts to address infections. HIV programs, particularly in contexts where they address large, generalized epidemics, have now become a prominent force that shapes the ways we see and understand social life, and collective vulnerabilities. In this they are a representation of what Foucault (1980a, 2008) referred to as forms of governmentality: By shaping *discourses* about what drives HIV infections, *ideas* about legitimate and illegitimate responses HIV, and the range of possible *actions* for intervention, global institutions, experts, and NGOs have produced new social realities through the practice and provision of HIV policy. The anger of those youths in Lesotho indicates that the failure to include broader political participation in the crafting of HIV policies has also silenced important citizen voices that are attempting to re-link social ills with patterns of biological illness, in order to resist the prevailing governmentality of HIV approaches.

Finally, for countries like Lesotho, HIV treatment programs were late to arrive and broadly executed by a global conglomeration of organizations, funders, and experts, matched with the willing and flexible participation of the national government. Early networks of persons living with HIV and AIDS were absorbed into HIV scale-up as implementing agencies and routes for program delivery (c.f. Biehl, 2007; Birdsall & Kelly, 2007; Cassidy & Leach, 2009; Rau, 2006; Swidler, 2009b). As new government “partners” in HIV program scale-up—and now entitled to receive large grants and contracts—these

groups had little intention of biting the hands that were feeding them resources. Coming on the heels of these civil society movements, and seeming to promise a new means of securing survival, efforts to expand HIV treatment and services in places like Lesotho created lofty expectations among would-be recipients. The proliferation of HIV treatment “success stories”—aided in no small part by the “confessional technologies” encouraging narratives of transformative survival among patients (Nguyen, 2010)—fostered the belief that HIV programs would change lives. While patients in Lesotho can now access HIV treatment with relative ease, few would say their lives are good. The most important effect of HIV programming for many is the rare opportunity HIV status provides to receive short-term food aid, a stipend for attending an HIV workshop, or access to small grant resources through a support group (on this, see also Swidler, 2009b; Smith, 2003). The predominant changes brought about by HIV scale-up for citizens in Lesotho have been *pharmaceutical* (the effect of a “drugs into bodies” approach), and *political*. In this dissertation, I will argue that the political changes of HIV scale-up are extremely important, but grossly overlooked. HIV programs have changed the way governments do business, concentrating power in the hands of non-elected bureaucrats, removing many decisions from the public purview, allowing the provision of crucial services to be overseen by an array of NGOs with competing values and interests, and setting priorities without the broad input of citizens.

Thus, the expansive, far-reaching scale-up of HIV programs has fundamentally changed ideas about *what* citizens deserve (pills, rather than social well-being), *who* is deserving (patients, rather than citizens), *how* decisions will be made about services (by technocrats, not elected representatives, and regarding eligibility, rather than rights), and *who* takes responsibility for services and the survival of citizens (patient-consumers themselves, rather than the state). *As a result, HIV policy has become an extremely effective*

*delivery mechanism for specific political ideologies and ways of practicing politics in poor countries.* I argue that this has had an indelible impact on political life and democratic functioning in Lesotho, and that HIV and global health programs—however well-meaning their efforts—have ignored, failed to notice, or under-recognized these political impacts. Before turning to a more comprehensive assessment of some of the driving themes of this study, I will first provide a more in-depth analysis of HIV “scale-up” as a social process and its trajectory in Lesotho, a discussion that will be expanded considerably in chapter 3. I then discuss how the research draws on, and speaks to, literature across the fields of African studies, development studies, medical anthropology, political science, and public health. In doing so, I highlight a set of recurrent, crucial leitmotifs that repeatedly arise from the data in the following chapters.

### **Confronting Scale-Up: Localizing a Global Campaign to Treat HIV and AIDS**

Between 2004 and 2010, the small, Southern African country of Lesotho experienced a dramatic rewriting of its health systems in the name of HIV treatment. Though the first case of HIV was identified in 1986 (Owusu-Ampomah et al., 2009), and the country declared its HIV epidemic a national emergency in 2000 (UNGASS, 2008), producing the funding and initiative necessary for building a systematic response to HIV required the confluence of a number of domestic and international efforts. In a setting like Lesotho, mobilizing effective HIV programming requires harnessing and disbursing an enormous array of material and human resources. In a number of countries across Africa, the scale-up of HIV services happened in roughly the same manner, and with the same overarching goals and objectives: large emphases on treatment and behavioral interventions with minimal attention to care, primary health, or structural interventions; a

broadly externally- and expert-led process, with governments being asked to “align” policies with international standards; and, especially in the early years, intense competition among donors, NGOs, and research enterprises to claim patient populations, areas of expertise, and responsibility for positive outcomes. “The global AIDS funding industry,” Cassidy and Leach (2009) write, “is helping put into play an epistemological standardization – a standard set of solutions, responding to a standardized set of framings of the problem that link biomedical notions to what have become globalised received wisdoms about HIV and AIDS” (p. 15). But these were not the only ways in which HIV scale-up was a social process. As I will describe in the section that follows, HIV scale-up involved dramatic shifts in institutional arrangements, political processes, and the relations between citizens, states and transnational actors.

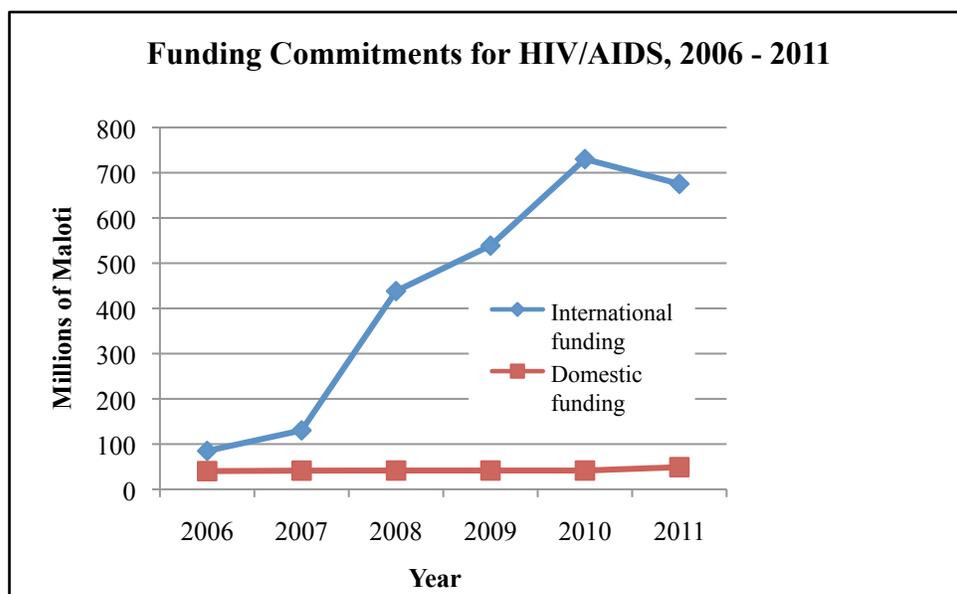
In 2003, Lesotho had only 7 doctors and 33 nurses per 100,000 persons (compared with 25 physicians and 140 nurses in neighboring South Africa) (Liese & Dussault, 2004); fewer still worked in the public sector, which could claim only 89 doctors and 1123 nurses and midwives across the entire country (Mwase et al., 2010). Nursing staff was poorly equipped to manage the secondary infections and symptoms of HIV, let alone distribute and manage more advanced treatment to patients. Those who arrived at clinics sick and with signs of AIDS were mostly sent home to die, and family members were given brief instructions and few supplies with which to care for them. Though the epidemic went relatively unnoticed in Lesotho for the better part of a decade, by 1995 a 31.3% HIV prevalence rate was reported among ante-natal clinic attendees at the national referral hospital. The absence of effective treatment in the country for another decade created an acute, generalized epidemic whose death toll was terrifying; even today Lesotho claims the world’s third highest HIV prevalence (about 23.3%), outpaced only by Swaziland and

Botswana (UNAIDS, 2012). Between 1990 and 2009, the life expectancy among women dropped from an already low 65 to 50; in men, from 55 to 46 (World Health Organization [WHO], 2012). The health system's already weak capacities had been further damaged by years of structural adjustment policies that mandated de-investment in public sector services and fee-for-service policies at clinics (Pfeiffer & Chapman, 2010). Lesotho's rugged, rural terrain made providing even the most basic care at far-flung clinics a major infrastructural challenge, and few health workers wanted to work in such isolated areas. Even today, many clinics remain inaccessible by car or motorcycle, and can only be reached on foot, by donkey, or through an aerial transport service maintained by a network of NGOs. Even in 2009, HIV clinicians reported to me that the country lacked its own viral load machine, which is essential for monitoring the efficacy of drugs in patients, the progress of the disease, and signs of drug resistance. (Lesotho paid to send tests to a machine in South Africa, but reportedly lost its contract with South Africa after failing to keep up on its bill payments. As a result, viral load testing was no longer publicly available.)

Despite these challenges, by 2010, 93% of clinics were offering Highly-Active Antiretroviral Treatment (HAART) across all 10 districts (Mwase et al., 2010; National AIDS Commission [NAC], 2011). In order to facilitate treatment provision, nurses were intensively trained in the management of HIV therapy, and counselors and community health workers were recruited to serve as foot soldiers in HIV treatment and testing campaigns. Antiretroviral therapy (ART) centers were carved out of already tight clinic spaces, sometimes even occupying temporary shelters. Antiretrovirals (ARVs) and blood samples—transported on motorcycle and even horseback—began moving to and from remote areas, as did patients seeking and maintaining access to life-saving therapies.

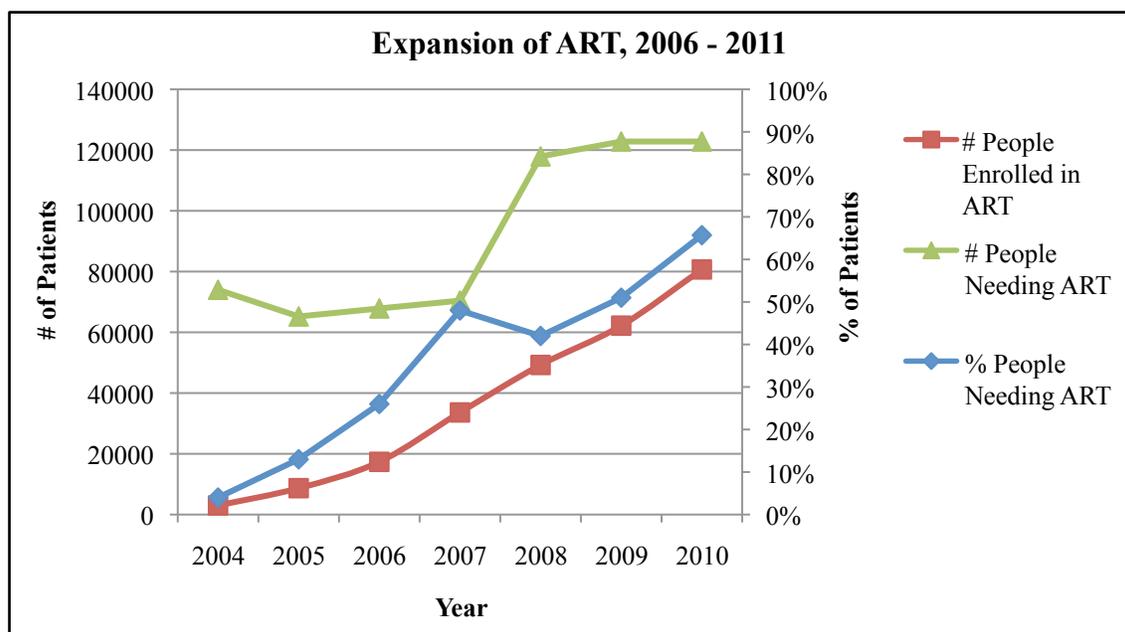


Patients testing HIV-positive were now shuttled from the testing room to multi-day trainings on HIV treatment and prevention. Total HIV/AIDS funding (from domestic and international sources) increased more than six-fold between 2006 and 2010, and international funding alone increased almost nine-fold over the same five-year period (NAC, 2011). Funding from the President’s Emergency Plan for AIDS Relief (PEPFAR) in 2011 was 85 times what it was in 2006 (*ibid*). In 2011, I counted no less than 216 domestic and international organizations on a national registry that listed HIV/AIDS services or interventions as part of their activities; less than a quarter listed dates of establishment in Lesotho prior to 2000.<sup>7</sup>



**Table 1.1: Total funding commitments for HIV/AIDS, 2006-2011** from international and domestic sources, in millions of Maloti. Source: NAC, 2011.

<sup>7</sup> Even this figure most likely grossly overestimates the number actually *involved* in HIV activities prior to 2000. Many organizations established in Lesotho prior to 2000 were general service NGOs, church organizations, or other NGOs whose efforts have shifted towards HIV as funding has become available. This pattern of task-shifting among civil society organizations is extremely common as a result of the increase in HIV funding (Swidler, 2009b; Biesma et al., 2009). A survey of civil society organizations in Lesotho found that 69% of those organizations surveyed reported a change in their emphasis and activities over the course of HIV scale-up (Birdsall & Kelly, 2007, p. 60).



**Table 1.2: Expansion of ART to patient populations in need in Lesotho, 2006 – 2011.** Lines reflect the total number of patients enrolled in ART, the total number of people in need of ART (according to clinical criteria), and the percentage of people who qualify for ART but have not yet been enrolled. The significant increase in the number of patients in need of receiving ART in 2007 – 2008 reflects the efforts of a national testing campaign and changes in the ART eligibility criteria, see chapter 3. Sources: NAC, 2010a, 2011; UNAIDS & WHO, 2008; UNGASS, 2008.

Scale-up had a vast impact on the biological futures of many patients, and drastically improved the biomedical efficacy with which we can manage the HIV epidemic across contexts whose resource-scarcity presents very significant hurdles. Nevertheless, it is naïve to envision scale-up as simply a medical intervention, or a revision of health systems. Scale-up in Lesotho required a vast deployment of policies delineating everything from behavior to rights to institutional responsibilities; programs for managing not just treatment, but patients, activities, money, and resources; grant-making processes and agencies to receive and spend those grants; and institutions like the National AIDS Commission (NAC) and the Global Fund’s Country Coordinating Mechanism (CCM) to manage HIV priorities and grant disbursement. It is these latter aspects of scale-up with which I am most concerned. My aim is to highlight some of the frequently overlooked dynamics of this global movement, and to situate them in concrete field data. In order to begin examining

these dynamics in more detail, and to understand why they are so powerful, it is essential to examine the dimensions of scale-up as a global, political process in further detail.

If we could point to a single moment when the idea of a global scale-up of HIV treatment began to gather broad social recognition, it would likely be the International AIDS Conference hosted in Durban, South Africa, in 2000.<sup>8</sup> This conference brought global attention to a number of coinciding trends. These included: the now well established efficacy of ARVs in combating the disease, and the success of developing countries like Brazil in managing large-scale treatment programs; the efficacy of activist groups in challenging drug pricing and patents; the acute inequities of treatment—and the particular injustice of political barriers to accessing the inexpensive regimens for prevention of mother-to-child transmission (PMTCT)—in places like South Africa; the emergent discourses about access to treatment as a fundamental human right; and finally, the acute failure of South Africa’s leadership to mobilize resources to make ARVs available to its own population, and to recognize HIV as the virus that causes AIDS. The flurry of activity and activism in Durban seemed to elicit a paradigm shift, allowing the idea of universal access to treatment to solidify as a political cause and a feasible project goal. At the same time, the United Nations General Assembly (UNGASS) was preparing a special declaration of commitment on HIV/AIDS, to be endorsed by all member states. This marked a profound shift in support for scale-up, whereby support for comprehensive, well-funded HIV programs moved beyond activist, research and NGO communities, and into the realm of national governments and international institutions. By 2001, the UN convened a special session dedicated to HIV/AIDS, issuing the *Declaration of Commitment on*

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<sup>8</sup> In focusing on the advent and development of “scale-up” as a social and political phenomenon, this analysis woefully excludes much of the rich history of the early HIV response from within institutional structures like the Global Programme on AIDS (GPA), which was formally replaced by UNAIDS in 1996. For a short history, see Lisk, 2010.

*HIV/AIDS*. The meeting recognized HIV/AIDS as a “global crisis” requiring “global action”; the resulting declaration included language about access to prevention, care, and treatment, and solicited global funding commitments for HIV/AIDS programs in developing countries (UNAIDS, 2002, p. 4).<sup>9</sup> Most importantly, member states committed themselves to significantly funding the Global Fund for AIDS, Tuberculosis and Malaria (GFATM), which was formally launched in 2002 as an innovative, multilateral funding mechanism designed to reduce administrative costs, streamline global funding, and increase accountability (Lisk, 2010).

Beyond the corridors of the UN, other funding streams were also gaining momentum. The World Bank, which had been funding HIV projects since the 1980s, launched its sizeable new HIV funding initiative, called the Multi-country HIV/AIDS Program, or MAP, in 2000 (Harman, 2010; Lisk, 2010). In 2001, the Gates Foundation announced a \$60 million grant to support microbicide research, and began to be more directly involved in funding HIV research and programming (Bill and Melinda Gates Foundation, 2012). In 2002, Botswana became the first African country to provide ARVs through its public health system, doing so with support from Merck and the Gates Foundation (Carpenter, 2008). In 2003 the WHO announced its “3 by 5 Campaign” (WHO, 2003, 2004), which laid out goals for treating 3 million people with HIV/AIDS by the end of 2005; this was the first time the global community had set explicit treatment targets. Also in 2003, the US Congress set aside \$15 billion to be spent on global HIV, TB, and Malaria programs – an enormous commitment of funding, but also a direct institutional challenge to the Global Fund – which became the President’s Emergency Plan

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<sup>9</sup> Transcripts of country statements at the UNGASS meeting are available here: <http://www.un.org/ga/aids/statements/>; Kofi Annan’s initial speech proposing a global fund to fight HIV/AIDS and other infectious diseases available here: <http://www.un.org/News/Press/docs/2001/SGSM7779R1.doc.htm>.

for AIDS Relief, or PEPFAR (Dietrich, 2011). In total, global funding for HIV and AIDS activities expanded astronomically, from \$1.6 billion in 2000 to \$8.9 billion in 2006 (Lisk, 2010, pp. 93–94).

The scale of these funding increases and disbursements was exceptional, and often so rapid that a primary concern among donors was the “absorption capacity” of recipient governments and agencies. For example, Zambia received the most HIV funding from the US government in 2000, prior to the major global scale-up of HIV programs, reaping about \$0.73 per capita from all US government sources (Alagiri, Collins, Summers, Morin, & Coates, 2001, p. 5); by 2009, the Obama administration announced a new global health initiative that would be giving Zambia \$28.20 per capita—amounting to \$289 per HIV-infected individual in the country—for a single program initiative (Michaud & Kates, 2011). Dramatic increases in funding could create enormous inequalities between countries, between regions within countries, and ultimately, between those with HIV and those with other health conditions that were of less interest to global donors. As a case in point, Zimbabwe was able to disburse \$98.35 per person living with HIV in 2008, while Rwanda disbursed \$2015.79 per person despite its much smaller HIV epidemic (Cohen, 2008). Shiffman and colleagues (2008) reported that between 1998 and 2007, funding for HIV/AIDS as a portion of all donor health aid rose from 5.5% to nearly 50%, and during the same period, the proportions of funding for health systems strengthening and population health were reduced by more than 50%.

There are two intertwined aspects of HIV program scale-up essential to its character across diverse country contexts. First, scale-up is a global process. From its very beginnings, scale-up not only encouraged the participation of diverse global actors, but required them. Governments of the global South, national and transnational activist

groups, NGOs, international organizations, donor countries, and even transnational public-private partnerships all contributed in essential ways to the process of scale-up; as a social phenomenon, scale-up represents a convergence and production of these global actors' diverse interests, values, and senses of responsibility. And it orbits around a particular, universalizing aim: To achieve "drugs for all" (Biehl, 2008) as well as access to care and prevention throughout the developing world. Its benchmarks of success and principles for implementation, while varying by country, are guided by international agreements, policies, expertise, and advocacy. And because it is embedded within transnational networks, scale-up is enabled by movements of policies, values, people, and programs through those networks. As a result, its reach is shaped by the gaps, hierarchies, and exclusions of such transnational dynamics as well (see Ferguson, 2006). Though scale-up aims for universal access to treatment, participation in the processes of priority-setting or policymaking—which are dominated by powerful agencies, is hardly universal—a highly sought after, but rarely granted, privilege.<sup>10</sup>

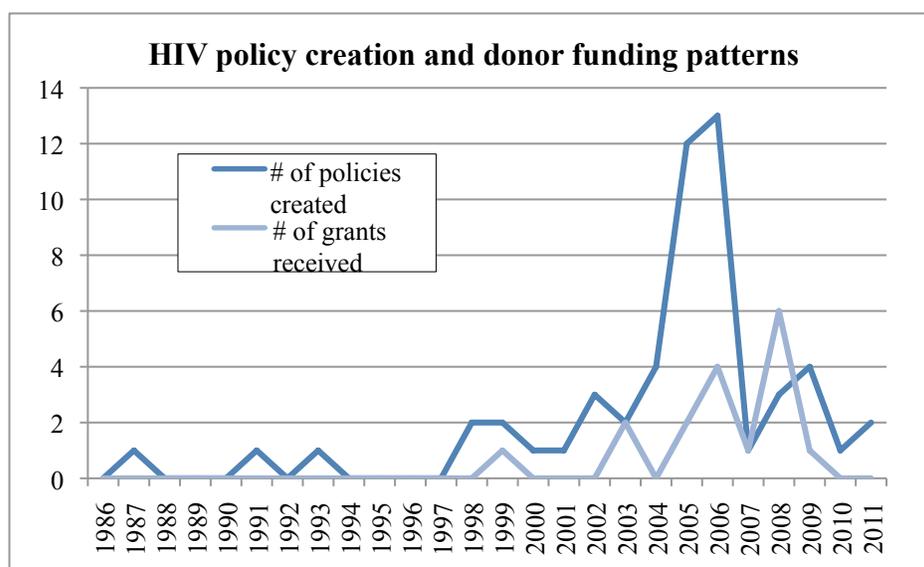
Second, since scale-up is embedded in global social fields shaped by relations of power, it demands not only shifts in policies, but changes in the ways that nations make decisions, and alterations of the very institutions responsible for programming and funding disbursement. The scale-up process in many recipient countries can be measured as much by policy deployment as by the expansion of access to medicines. Table 1.3 reflects data amalgamated from the HIV/AIDS timeline in Lesotho included in Appendix A. In it, I have tallied the number of HIV policies created each year, and the number of major grants reported by the Government of Lesotho. One can clearly see, particularly in the early years of scale-up (2000 – 2006), that efforts in policy creation directly preceded grant funds

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<sup>10</sup> The representation of individuals and groups from the Global South is particularly poor.

awarded; a massive policy deployment effort in the years directly prior to Lesotho’s scale-up of HIV treatment (2004 – 2007) is followed by two waves of funding commitments to support treatment programs (see Appendix A for more details on policies and grants).

Global discourses about the importance of “political commitment” and “good governance” for obtaining funds convey important messages about the ways in which governments must submit themselves to institutional and procedural changes, as well as display evidence of conformity to global “best practices,” in order to receive (or continue receiving) funding. Decisions about countries’ eligibility for grants are dependent, at least in part, on their successes in policy development and their efforts to deploy procedures that are in line with global best practices. A primary measure of these efforts are the UNGASS reports regularly submitted by all member countries. These outline countries’ policy, procedural, legal, and institutional efforts relevant to HIV; in response, key stakeholders rate country progress (see NAC, 2010b; UNGASS, 2008; additional reports available at <http://www.unaids.org/en/dataanalysis/knowyourresponse/countryprogressreports/2012countries/>).



**Table 1.3: Patterns of HIV policy creation and donor funding received in Lesotho, 1986 - 2011.** See Appendix A for further information on events, funding, and sources.

Some of the most remarkable political legacies of HIV scale-up in recipient countries are the changes elicited in institutions and in the power of certain agencies and individuals. Funders (with the support of NGOs and activists) have encouraged, and in many cases required, the establishment of new institutions—most notably the National AIDS Commissions (NACs, set up as independent, national HIV programming bodies responsible for coordinating a multisectoral response to HIV) and cooperative councils organized by specific granting institutions, like the Global Fund’s CCMs (Country Coordinating Mechanisms, responsible for setting funding agendas and coordinating applications for Global Fund grants among private, public, and civil society partners). Of course, creating entirely new governance structures in recipient countries does not occur without considerable tension. National AIDS Commissions, which donors such as the World Bank and UNAIDS emphasized should be independent of Ministries of Health (MOHs), frequently come into conflict with health ministries and executive branches because of tensions over whether or not NACs are politically independent entities, questions about how their work intersects with that of the MOH, and conflicts over control of grant resources (Cassidy & Leach, 2009; Putzel, 2004). Lesotho’s Ministry of Health and Social Welfare (MOHSW), with help from others in the ruling political party, effectively dissolved the National AIDS Commission in 2011 (discussed in chapter 3). Rumors had long circulated that the MOHSW leadership resented NAC’s primary position in distributing grant resources, and that there was debilitating confusion over NAC’s purpose and role. Observers of CCMs in a number of countries report considerable concerns about the extent to which they remain independent of national governments. In a number of countries, the principle recipients of Global Fund grants are also the core leadership of the CCM, and the government dominates priority-setting and decisions about which



organizations will receive grant funds (Akoku, 2009a; Biesma et al., 2009; Cassidy & Leach, 2009; Putzel, 2004). In 6 out of 7 of Lesotho's Global Fund grants, a government ministry has been the principal recipient; the remaining grant was disbursed to "civil society," which in fact was the Lesotho Council of NGOs, an umbrella organization for NGOs in the country that is closely aligned with the ruling party.

It should be emphasized that none of these entities—not NAC, the CCM, nor even the national Ministries of Health (which have also gained considerable power throughout scale-up)—have directly elected representatives, nor is it quite clear who their constituents might be, and how representatives are made accountable to them. A number of scholars have argued that, despite the emphasis on civil society partnerships and strategies for the greater involvement of people with AIDS (GIPA), institutions like NACs and CCMs (and the structure and flow of HIV funding more broadly) tend to promote tokenism in civil society representation, encouraging the involvement and funding of large "umbrella" organizations at the expense of smaller, community-based entities, and dis-incentivizing civil society activism by involving organizations as service providers (Biesma et al., 2009; Cassidy & Leach, 2009; Fisher, 1997; Rau, 2006). When umbrella organizations serve as representatives for all citizens, or a single person living with HIV is put on a committee to represent the interests of all people living with HIV/AIDS, forms of representation and political processes are unfair and undemocratic. Few citizens even know who represents them on such committees, nor are representatives easily accessible. Structures of accountability hardly exist, representatives are not obligated to report back to constituents (if they even perceive themselves as having constituents), and there is no systematic means for having representatives nominated or elected that allows the participation of the

constituents such persons or bodies are intended to represent.<sup>11</sup>

Funding flows within countries – which often emanate from entities like NAC and the CCM – have the power to elicit paradigmatic changes among community organizations, citizen associations, and what is typically termed “civil society” as well. This is most noticeable in the devolution of state responsibilities and grant resources to NGOs of all kinds. As Ferguson and Gupta (2002) note in their description of what they, drawing on Foucault, term “transnational governmentality,” these patterns are foundational practices that shape our contemporary world: “The outsourcing of the functions of the state to NGOs and other ostensibly nonstate agencies, we argue, is a key feature, not only of the operation of national states, but of an emerging system of transnational governmentality” (p. 990). The devolution of state functioning to NGOs tends to elevate select organizations into positions of considerable power: In 2005, the top 20% of civil society organizations (CSOs) in Lesotho controlled and disbursed 80% of the funding, and it is likely that this trend was exacerbated as PEPFAR and Global Fund disbursements heavily favored more professionalized NGOs (Birdsall & Kelly, 2007, p. 64). Large umbrella organizations – such as the Lesotho Network of Persons Living with HIV and AIDS (LENEPWHA) or the Lesotho Council of NGOs (LECONGO) – now dominate the political landscape of HIV programming in Lesotho, and citizens’ ability to access these organizations or understand their representative structures is extremely limited.

Despite these vast political shifts—of which I have only given the briefest of overviews—global health and HIV programs continue to be portrayed as distinctly apolitical, requiring government partnership and support but somehow above the purview of citizens and democratic process. They continue to be perceived as biomedical, clinical,

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<sup>11</sup> For further information on representation and accountability in Lesotho’s CCM, see Akoku’s stellar exploratory study (2009).

or programmatic interventions without distinct political effects or aspects. Nevertheless, the ways in which citizens are asked to engage in such programs, and their perceptions of them, are deeply political, intimately bound up in ideas about membership, social contracts, state power, inequality, recognition, and the disciplinary practices of contemporary HIV treatment modalities. It is the 'felt' politics of everyday engagements with, or abandonments by, HIV programs among citizens (patient and non-patient alike) that becomes the primary focus of much of the research here. I have chosen to hone in on elements of everyday political life in the context of HIV programming in part because it is a story less often told, even as there has been significant focus on political leadership and global institutions in HIV response. I also prioritize this aspect of citizen experience and perspective because I feel it gives some small measure of voice where more formal methods of representation and participation are largely absent. I have no illusions that this somehow makes up for much-needed systems of political engagement; but, nevertheless, this is perhaps the most that raw empirical research can offer.

### **Scale-Up's Disciplinary Logics**

HIV scale-up elicits changes in much more than political institutions and the structures of civil society; much recent scholarship has extensively studied its impacts on citizen subjectivities. In her compelling overview of research approaches to understanding the ways that health regimes and experiences shape identity and subjectivity, Susan Reynolds Whyte (2009) lays out two major trajectories of anthropological engagement: research on health identities and the politics of identity in health movements; and biopower, along with the increasing attention to various biological citizenships and subjectivities. In many ways, the scholarship of social scientists examining power, politics and HIV/AIDS has

followed a trajectory from a focus on identity politics (engaging in research on social movements, treatment activism, patient identities, and stigma and discrimination) to a focus on biopolitics. In recent years, research utilizing a Foucauldian, biopolitical framework has grown exponentially, led by a number of scholars whose work examines how health systems and services have become a prominent, if not the primary, force shaping citizen subjectivities and survival, spawning various theorizations of biological citizenship, biosociality, therapeutic citizenship, responsabilized citizenship, and health governmentality (Biehl, 2007; Nguyen, 2010; Petryna, 2002, 2004; Rabinow, 1996; Redfield, 2005; Robins, 2008; Rose & Novas, 2003). In many ways, this evolution is not surprising; the expansion of scale-up breathed new life into concerns about the disciplinary practices of public health agendas, the power of global institutions and governments in determining how and under what conditions citizens will survive, and scale-up's own prominent concerns with counting and documenting patients and their infections. It is also worth noting that this theoretical evolution—from an emphasis on identity and social movement politics to an overriding focus on biopower, discipline, and subjectivity—is not solely limited to health studies or medical anthropology, but represents a profound shift across the social sciences (Brass, 2000). In many ways, HIV programs encapsulate the most defining elements of this new scholarship—from the burgeoning presence of support groups and other biosocial associations, to the discursive means by which clinicians and counselors shape the ways patients see themselves, behave, and engage with therapeutic regimes. Studies of HIV have been central to this theory development (Biehl, 2007; J. Comaroff, 2007; Nguyen, 2010).

Beginning with *The Birth of the Clinic* (1973), Foucault's canon of work displays a remarkably sustained and vigorous concern with modern forms of power over life—in

biomedical practice (1973), in totalizing institutions (1975, 1989, 2003), and perhaps most extensively, in diverse and dispersed forms of governmentality in an increasingly neoliberal world (2008). This scholarship stems from a simple but extremely potent idea: Whereas the enlightened state form was ostensibly established in such a way that it could let citizens live, but withhold the potentiality of taking life (making death through execution) as emblematic of sovereignty, the modern state could “foster life or disallow it to the point of death”—that is, *make* life, and *let* die (1980b, p. 138). In doing so, it combines two distinct disciplinary practices: the “anatomo-politics” that polices the bodies of citizens, making them more efficient, healthy, effective, pure—and, in essence, treated—and the “biopolitics” of the population, that counts, specifies, examines, and organizes the population’s health in such a way as to “invest life through and through” (*ibid.*, p. 139). Strangely, as Foucault points out, this creates a situation in which, despite the many diseases and biological risks ravaging the poor of the world, “what might be called a society’s ‘threshold of modernity’ has been reached when the life of the species is wagered on its own political strategies...modern man is an animal whose politics place his existence as a living being in question” (*ibid.*, p. 143). Life is now integral to the exercise of power, and the preservation of life is the seat of power for the modern state.

For Foucault, the exercise of such power over life takes the particular form of “governmentality,” a dispersed, insidious set of practices for the “conduct of conduct” that is particularly well-suited to the neoliberal world, with its proliferations of civil society, NGOs, and humanitarian projects. Governance takes two primary forms: that of legitimating discourses, which determine and convey what is right, rational, proper, and expected; and that of the structuring of possible forms of intervention—the procedures, institutions, processes, and legal geographies that allow new forms of governing to take

place. Governmentality creates new political subjectivities, in both senses of the term: It demonstrates and reinforces for citizens their subject-positions as forms of power shape their possibilities for survival; and it shapes the mindscapes of citizens—their identities, their perceptions, and most importantly, their ways of behaving and crafting survival in the world. Foucault is particularly interested in how governmentality elicits “technologies of the self”—the projects of self-fashioning as healthy, productive, responsible citizens that are so strongly incentivized and produced by neoliberalism. Discipline, we can begin to see, takes nearly invisible, but far-reaching forms, entering the most private reaches of citizen subjectivity. Foucault’s work begins to disabuse us of the faulty notion that there are distinct private and public worlds in politics, showing how power seeps into private actions, personal behaviors, and individual outlooks (though this dichotomy is thoughtfully and thoroughly contested by feminist political scholars as well).

If, as Foucault argues, the defining power of the modern state is executed at the level of life itself, then surely the scale-up of HIV programs—and following that, the vast mobilizations of resources for global health—represents the vanguard of this new power. Though surveillance, data, and discipline have long been a feature of public health programs within state regimes (Bayer, Fairchild, & Colgrove, 2007), in HIV programs and global health initiatives they take on an entirely new scale. HIV education programs and treatment regimes explicitly aim to reformulate patients’ ideas about their bodies, the nature of infection, appropriate behaviors, respect for therapies, and even the epidemic itself. Rhetoric about HIV-positivity, in particular, promotes very specific ideas about how HIV patients should conduct themselves, and how engaging in the *proper behaviors* of self-care, responsibility, appropriate eating, pharmaceutical adherence, and psycho-therapeutic optimism can preserve and prolong life (Finn & Sarangi, 2008; Nguyen, 2010; Robins,

2008). In resource-constrained contexts where access to ARVs has never been guaranteed, and was extremely hard to secure prior to scale-up, Nguyen (2010) writes that a politics of triage incentivized technologies of the self and projects of self-fashioning in order to access much needed treatment. This creates a kind of “therapeutic sovereignty” – a “republic of therapy” whose logics are driven not only by scarcity, but also by therapeutic goals and rationalities. The forms of governmentality expressed in HIV programming mirror, almost exactly, those highlighted by Foucault: the emphases on personal responsibility, the delegation of state powers to flexible, shifting non-state entities, the replacement of political morality with a governance of rationality and cost-effectiveness, technologies of the self to access and secure goods (which reinforces individual responsibility), and the obfuscation of real forms of structural injustice and the workings of power in driving infections and impeding survival.

Nevertheless, as Swidler (2009b) points out, despite these acute extensions of governmentality in the form of HIV programs, considerable evidence from within sites of the epidemic seems to indicate that programs have much less extensive reach into personal behavior than we might initially assume. Infection rates appear to be stubbornly entrenched in many areas; sexual practices and patterns of behavior show a robust ability to resist influence; and when logics of behavior change are imposed, any decreases in risk are slow and hard-won. Rather, “the one area in which global models have penetrated,” Swidler writes, “is at the level of rhetoric and ideology” (p. 195). HIV services seem to be most successful in communicating to citizens what it means to be a good and deserving patient, and eliciting the kinds of labor required for participation in therapeutic regimes—the training, self-monitoring, disclosing, and acceptance that are essential to accessing treatment. The question, then, is how these messages—which convey wide-reaching

values about citizens' moral obligations as public and private individuals, and their place in new hierarchies of bureaucratic functioning—change citizens' outlooks regarding the state, and themselves as citizens. In addition, global health discourses convey powerful ideas about what is deserved, and the very nature of what constitutes rights in a changing world. For example, even as scale-up legitimized the “right to treatment” discourse, patients accessing treatment across Southern Africa complained about debilitating hunger that impeded their ability to survive, and the concept of a “right to food” has failed to materialize, even as food insecurity appears to inhibit adherence to treatment (Alex de Waal & Whiteside, 2003; Jones, 2011; Maclean, 2012; Mangili, Murman, Zampini, & Wanke, 2006; Tang et al., 2002). As a result, amidst Lesotho's debilitating and severe food crisis during 2012, a United Nations Children's Fund (UNICEF) representative confidently reported that UNICEF was helping out by providing food packages, but that their organizational strategy was to fail to provide enough to nutritionally support each household: “It doesn't even cover 40% of household needs...and it's on purpose, by the way. Because we don't want to create a welfare state” (Magubane, 2012). Statements such as these convey powerful normative discourses about the relationships between citizens, NGOs, and the state, and the changing (or even nonexistent) social contracts through which such relations are executed. They reveal deep moral sentiments about the value of citizens, who primarily fail to qualify as the kind of persons deserving of social protection or continued access to the goods necessary for survival.

Rabinow and Rose (2006) caution that it is easy to see everything in today's world as imbued with biopower, to perceive it as an all-consuming kind of sovereignty over everyday life. They argue that much work extending theories of biopower—including that of Hardt and Negri (2000) and Agamben (1998)—tends to overreach in its assessment of



biopower's scope, and overgeneralize the ways in which biopower controls life, departing from detailed genealogies of how power operates in specific institutions, situations, and populations. Without discounting the enormous value of these works as tools through which we can re-examine and re-think the meanings of state, sovereignty, power, and bare life in the contemporary world, it is also important to focus on research efforts that endeavor to elaborate specific, ethnographic explorations of power (and resistance), discipline (and its limitations), and the multiple forms of subject-belonging and subjectivity that emerge from health regimes. In doing so, it is also important to observe the inequalities in how biopower and therapeutic sovereignties are applied and executed (Nguyen, 2010; Sparke, in press). Within the interstices of everyday life, we can observe that HIV programs pick and choose recipients and areas of discipline, and that their reach does not always extend far beyond clinic walls, as patients build therapeutic itineraries that include a wide variety of services and forms of care and healing (Klein, 2007; Samuelsen, 2004; D. J. Smith & Mbakwem, 2007; Taylor, 2010).

Recent work in medical anthropology has drawn on ethnography to focus on the ways in which biopower and governmentality produce new forms of "biological" or "therapeutic" citizenship, studying how modern citizens are recognized, attain services, and are treated by the state as biological entities. Adriana Petryna's (2002, 2004) groundbreaking work on biological citizenship in the wake of the Chernobyl disaster explored the treatment of the biologically-damaged status of citizens, and the science of *knowing* about citizens' exposures as a form of suffering. This was constructed as a lens, through which Petryna examined how citizenship, the politics of recognition, and the political economy of care were changing during a crucially important sociopolitical shift in eastern Europe: its transition from socialism to market capitalism. Similarly, Aiwah Ong (1995) examined how

refugee medicine in the US served to socialize subjects of a modern welfare state: constructing a particular population, creating the means for governing them, and serving as an interface between modes of cultural performance. But Ong's work also details the many ways in which the reach of biopolitics is limited, examining how patients themselves draw in the medical gaze, revert it, and ultimately deflect biomedical control. These views of biological citizenship highlight its mutability in specific contexts, its situatedness within specific regimes of governmentality and political conditions, and its dynamic, relational nature.

In response to work on biological citizenship that takes root primarily in places where access to live-saving therapies can be negotiated, Nguyen proposes that a different dynamic of "therapeutic citizenship" holds sway in contexts of acute resource-scarcity. Studying the pre-HIV scale-up politics of triage in West Africa, Nguyen (2010) argues that therapeutic citizenship is an especially "thin" form of citizenship, where entitlement is disease-specific, and where a positive diagnosis can provide access to a means of bleak survival that nonetheless is unavailable to sufferers of other diseases (p. 109). In addition, Nguyen's (2008) work highlights the workings of a now global "therapeutic economy" in which therapeutic citizenship becomes "a form of stateless citizenship whereby claims are made on a global order on the basis of one's biomedical condition, and responsibilities worked out in the context of local moral economies" (p. 142). It is the disjuncture between these two worlds, and their moral logics, that places such material and social strain on his informants and their experiences of citizenship.

Biological citizenship allows us to focus on some dynamics amidst HIV scale-up that are particularly important to understanding the powers that shape everyday clinical and non-clinical encounters. Biopolitics fuels the emergence of patient-consumerism, as an

outgrowth of contemporary biopolitics that emphasizes self-monitoring, responsibility and good behavior (Correa, Petchesky, & Parker, 2008; Paiva, 2003; Rose, 2007).

Consumerism is touted as a form of patient empowerment, yet it emanates from, and reinforces, strong patterns of anti-politics and capitalism: Rather than recognizing a right to health, it creates a right to *buy* health. In sites of acute resource scarcity, the dynamics of patient-citizenship are shaped less by modes of capitalist consumption and more by humanitarian gift economies (which nevertheless remain rooted in capitalist logics) (Bornstein & Redfield, 2007; Stirrat & Henkel, 1997). Claims become requests, 'empowerment' is often reduced to quiet subversion, and entitlements become handouts. Expectations – of what will be given, and what is expected in return – are muddy, difficult to navigate, and often contested. In chapter 6, I describe how such dynamics are taken to even stranger levels amidst garment factory workers producing Product(RED) t-shirts for “humanitarian consumption,” who gain the “gift” of HIV services while offering, in return, a silence about labor abuses and occupational health concerns in order to preserve the imaginary of an ethical industry.

Amidst resource scarcity, struggles to access goods for survival alters how we might perceive governmentality. There seemed to be many among my informants who would have happily enrolled in ARV training classes or disclosed their status on the radio if it could have meant they had consistent access to food. I encountered not one, but many, mothers who brought their malnourished children to the fancy, privately funded pediatric HIV clinic to be tested over, and over, and over again, always hoping that their children might qualify for the high-quality health care offered there and gain access to scarce stores

of Plumpy'nut® (a nutritive supplement for the treatment of severe acute malnutrition).<sup>12</sup> Is this evidence of the disciplinary reach of HIV scale-up? Perhaps, in part. But in a more immediate sense it is evidence of the bizarre forms that struggles for survival take in these neoliberal, global economies of suffering. I began to think of such forms of engagement as a kind of *politics of reciprocity*, rather than a blind, willing subjugation to biologic regimes. Recipient politics (among other dynamics I discuss later in this chapter), appears as a strategic eking out of survival through mediated engagements with therapeutic regimes and state and non-state entities. It involves a careful calculus among patients and citizens about what they could offer such therapeutic regimes, and what they might gain in return. In chapters 4 and 5, I discuss how such dynamics play an essential part in the way that support groups engage with the state and funders, and in the ways that HIV patients construct discourses about hunger, food insecurity, and the toxicity of ARVs.

What the accounts of Petryna (2002, 2004), Ong (1995), Nyguen (2010) and others demonstrate is that experiences of biological forms of citizenship are diverse and context-specific, and that understanding the parameters of such forms of political subjectivity requires a close examination of political context, modes of governing, inequalities of access, forms of resistance, and the dynamic engagements of different citizens and patients. The term's expansive applicability may encourage such wide usage that it empties out or leaves behind the ethnographic moorings of citizenship in context. In this research, I became concerned that the predominant focus on biological citizenship might prematurely curtail explorations of other forms of citizenship, political engagement, and nascent political movement, particularly as many studies situated inquiry firmly within the bounds of the clinic and its gaze. By and large, though my informants could regurgitate all manner

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<sup>12</sup> At the same time, MOH officials reported that stores of Plumpy'nut® intended for the public sector were rotting at the national drug supply offices, awaiting distribution. This is not an uncommon phenomenon.

of catch-phrases about HIV prevention and proper behavior, such discourses were a means to an end, as what really concerned them were broad sociopolitical issues about the power of government, its engagement with citizens, their struggles for material and social survival, and their fights for meaningful recognition from the state or its partners. In watching my informants' quite exceptional endeavors to establish themselves as fully-fledged citizens with a wide set of political and social concerns, I began to wonder if frames of biological citizenship might reinforce the partitioning of the modern citizen into biological pieces, becoming overly focused on citizenship as biologically- and biomedically-determined. In doing so, it could cause us to lose sight of other forms of politics, sites of resistance, and expressions of citizenship. In this I do not propose that we ignore the pervasive effects of governmentality on modes of political engagement, or that we downplay the pernicious ways in which global health programs reduce citizens to biological entities. But it seems perhaps premature to then *only* study forms of biological citizenship, and ignore the other forms of political life that our informants, against all odds, are attempting to establish, protect, and reinvigorate.

### **Addressing Scale-Up's Predecessors**

In their introduction to the 2001 special issue of the *Review of African Political Economy*—an issue dedicated to taking stock of contemporary political and economic developments emerging throughout Africa—Carolyn Baylies and Marcus Power (2001) offered the following synopsis of the research included in the issue. It is worth repeating in its entirety:

Among [the themes of this issue] are the complicity between local elites and international capital and the use of public office to consolidate positions of privilege. Another [theme] is the consequent tendency for those at the bottom to continue to lose out and in some cases to become brutalized in their pursuit of survival, finding themselves pitted against one

another rather than in unified opposition to the external forces which constrain them. A third [theme] is the scrambling for position and economic security between these extremes, with structures ostensibly created to promote community participation and collective gain subject to manipulation to augment private incomes or used for individualized ends. A fourth [theme] is the difficulty faced by organizations within civil society, lauded as crucial to the building of democratic societies, but led by financial fragility to dependence on donor purses, in ways which undermine their autonomy and displace their aims (p. 5).

It should come as no surprise that, even prior to the advent of HIV scale-up in African states, political society struggled with acute inequities and competition, power was divided between local elites and external forces, civil society's independence was questionable at best, and citizens faced major barriers to fair and open participation. I place this text here to remind us that HIV scale-up has certainly not occurred in a political vacuum, nor is it wholly responsible for the dismantling of democratic structures in Africa. Instead, HIV scale-up unfolds amidst already tense and even beleaguered political systems and populaces; it is layered on top of the rich, troubled histories of colonialism, post-colonialism, and development politics—histories that are ubiquitously in attendance in everyday life, haunting the politics of the present. HIV initiatives—and global health endeavors more broadly—seem to operate with a particularly ahistorical viewpoint, which is perhaps fueled by their relentless attention to present emergencies and future goals. Thus, it is not that scale-up has happened in a vacuum, and that its effects on politics operate singularly and alone; rather it is that scale-up has been undertaken as if in a vacuum. This, in turn, has a range of political consequences.

The political histories into which contemporary HIV programs have been inserted could fill entire libraries, and I make a very limited attempt to elaborate Lesotho's political history in chapter 2. In what follows here, I will highlight a few of the most important political dynamics with which HIV scale-up has come into contact, namely: the legacies of development; the patterns, perceptions and usages of "civil society" in a neoliberal world;

and the reinvigoration and rewriting of patrimonial dynamics by flows of funding from development and health projects. Finally, I will discuss why a study of HIV scale-up's political impacts is essential—even given these earlier legacies, the decidedly imperfect democratic forms in many sites of scale-up, and their inevitable impacts on the study methodology.

### *Legacies of Development*

Perhaps no single phenomenon has had as much impact on post-colonial African states, nor taken so many different forms and undergone so many reincarnations, as development. The disciplines of anthropology, history, sociology, geography, and African studies have produced some of the most important critiques of development (Cooper & Packard, 1997; Escobar, 1995; Ferguson & Gupta, 2002; Ferguson, 1994; Hardt & Negri, 2000; Igoe & Kelsall, 2005; Mercer, 2002; Watts, 2001); taken together the literature is extremely diverse and multi-sited. Many of these works provide a crucial grounding for understanding some of the defining dynamics of HIV scale-up. One of the most pivotal early accounts of a development project from an anthropologist was Ferguson's (1994) work in Lesotho, *The Anti-Politics Machine*. In it, Ferguson examines a single development project carried out by the Canadian International Development Agency in the district of Thaba-Tseka in Lesotho. Taking a Foucauldian frame, this detailed study builds a critical understanding of the very project of 'development' by examining: the ways in which Lesotho is bestowed a status as a "less developed country"; how knowledge about its poverty is constructed and disseminated; the disjunctures between perceptions of livestock economies among Basotho and the development experts who attempt to 'modernize' this sector; and the technocratic, expert-driven, and power-laden processes that obscure the

real drivers of Lesotho's poverty and inequality.

One of Ferguson's most compelling and central arguments concerns the ability of development projects to act as a machinery that obscures the political origins of underdevelopment, and therefore mobilizes a kind of "anti-politics" in and of recipient countries. This approach brings into stark relief some of the similarities that development shares with HIV programming—in particular, the ways in which an expert-driven approach and powerful knowledge-production practices obscure more political understandings of how and why HIV epidemics persist. In addition to the power to define epidemics, a focus on HIV can create an anti-politics that obscures other political and social issues—a dynamic I discuss in much further detail in chapter 6. Many other scholars have also discussed the preeminence of science and expertise in modernity and efforts at modernization. (see, for example, Giddens, 1990). In particular, the search for singular, simple, or cheap solutions to complex patterns of social disenfranchisement, abandonment, and impoverishment has defined cycles of thinking in both development and global health programming (Easterly, 2006; Severino & Ray, 2010; Shiffman, 2006). This anti-politics also extends to development agencies' engagement with democratic institutions. Given their interest in outcomes—from structural adjustment policies to HIV treatment—they tend to see politics as a means to an end (Bartlett, 2001). Donor aid can have the pernicious effect of propping up less than democratic regimes, and even in democratic states like Lesotho it seems to give undue power to the ruling party, not only in the form of resources with which to execute public programs and also run campaigns, but also in the forms of symbolic legitimacy and power over life (Bayart, 2009; Ferguson, 2006; D. J. Smith, 2008). Thus, even as donors place an increased focus on accountability, good governance and transparency in development schemes, they emphasize



accountability to donors and global institutions, but less often to citizens and society, for whom development still looks very much like an anti-democratic enterprise.

Amidst this cyclical, trend-driven thinking, a few tenets have persisted throughout the latter decades of development planning, thoroughly influencing approaches to HIV scale-up. First among these are tropes like “sustainability,” “accountability,” and “participation,” which have been emptied out and co-opted by successive waves of planning and programming (Cooper & Packard, 1997; Hintjens, 1999; Peters, 1996; Pfeiffer, 2004). Participation, for example, has come to mean something decidedly apolitical, such that organizations and initiatives depend on recipient “participation” but often mean by this their willing submission to external priorities, and the multiple forms of volunteer labor they provide in return for membership or goods. One African minister was reported as touting his country’s democratic participatory approach as the following: “We decide what is to be done and then we tell the people to do it” (Peters, 1996, p. 22). The question, following a Foucauldian approach, is to ask what such discursive efforts accomplish, and how ideas like these travel, shape programs, and impact citizen subjectivities. In chapter 3, I attempt to explore one such trope—that of a “competent citizenship” in the time of HIV/AIDS—which is especially prominent in Lesotho, and particularly relevant to the ways that HIV programs are reconstructing citizenship. Even in the furthest reaches of programs, citizens understand the importance of, and adhere to, such discourses. “We want to be developed—” one man in a very rural village told me during a community meeting, stopping himself midsentence before he provided a more correct framing of the community’s desires: “We want to develop ourselves.” In doing so, he reflected, and responded to, the prevailing discourses in Lesotho about poverty, rural recipients of aid, and the goals of development: that citizens should promote

“sustainability” by shouldering the responsibility for their own development, that aid should only help them along such a path, and that deserving citizens were those who rejected the “lazy,” “dependent,” hand-out seeking practices of their neighbors. At more senior levels of bureaucracy, ideas about “best practices,” are grounded in such tropes, which take on the weight of core political and social values, written into policy, and forming the basis for decisions about resource distribution, priorities, and programs.

Finally, it is crucial to note that development projects take on specific endeavors to document, understand, capture, and count populations. These documentation practices, of course, do more to rewrite perceptions of citizens than to shed light on much of their reality, as is noted extensively by Ferguson (1994). Interestingly, such efforts are no less apparent in HIV programming, where program documents, policies, and bureaucratic discourses can have the effect of stigmatizing populations, “othering” certain already second-class citizens, blaming groups for the spread of infections, or associating those more likely to be infected with HIV with amoral practices, low intelligence, or exotic behaviors (Farmer, 1992; Parker & Aggleton, 2003). Interestingly, in Lesotho, discourses about HIV risk and epidemiology frequently categorize rural, poorly-educated populations as a reservoir for persistently high HIV infections, though these populations tend to have much lower rates of infection and overall prevalence than more urban districts (Bulled, 2012). But the discursive itself is important here, and development or public health “knowledge” serves to delineate different kinds of deserving and undeserving, innocent and blameworthy citizens—a phenomenon that Charles Briggs (2004) refers to as “sanitary citizenship.” In this sense, programs can reproduce and reinforce inequalities and hierarchies, even as they set out to ostensibly address them. This can even be observed in efforts at building community “empowerment” in HIV programming, where even well-

intentioned efforts can have the unintended consequence of exacerbating social hierarchies (Campbell, Nair, & Maimane, 2007). And at a national level, development and health funding elevates local leaders into power and promotes the professionalization of experts and service providers, which can exacerbate national power and income inequalities (Cooper & Packard, 1997; Swidler, 2009b).

### **Scale-Up and “Civil Society”**

Concerns about the definitions, purposes, and uses of civil society have been heard repeatedly from Africanist and development scholars in the wake of neoliberalism. These critiques include: concerns about the emptiness of the meaning of the term civil society; the uses to which CSOs are frequently put by funders and states; the eclipse of state power, the emptying out of the social contract, and the privatization of essential state services through the deployment of NGOs; the conflation of NGOs with more robust, democratically-sound, and politically active forms of civil organization; and the embeddedness of NGOs and the very concept of civil society within transnational processes of neoliberalization (c.f. Comaroff & Comaroff, 1999; Fisher, 1997; Igoe & Kelsall, 2005; Mamdani, 1996; Mercer, 2002). As Ferguson and Gupta (2002) demonstrate so forcefully, “civil society” is intimately bound up in patterns of corporate wealth, state violence, and Western values:

“One is never quite sure: Is the Anglo-American Corporation of South Africa part of this “civil society”? Is John Garang’s army in Sudan part of it? Is Oxfam? What about ethnic movements that are not so much opposed to or prior to modern states, but ...produced by them? And what of international mission organizations...?” (p. 991).

As they argue, it is no longer sufficient to view the state as “up above” and civil society as “down there,” among the “grassroots,” though these spatializations still hold considerable productive powers in how we think of and address contemporary states. Rather, as a

number of scholars note, civil society has become a problematically diverse conceptual category. It is productive (in the Foucauldian sense) in that it allows distinctly apolitical administrations, representations, and provisions to seem politically safe and meritorious simply because they carry this appellation. Civil society can be uncivil, it can be unrepresentative, it can be apolitical, and it can be extremely unfair. It is also, almost always, under-defined.

Nevertheless, it would be erroneous to dispense with the entire notion of civil society because of recent misappropriations or abuses. Tocqueville's (1994) detailed exploration of the power of associational life in early America is enjoying a resurgence, as is attention paid to the benefits of social capital embedded in much of civic and collective life, advanced most notably by Robert Putnam (2001). For many of the grassroots, democratizing mobilizations of the 1980s and 1990s in Latin America and Africa, the instrumental power of civil society movements was genuine, a crucial beachhead against the entrenched powers of dictatorships and autocracies. Civil society may be more in need of defense than critique—requiring a reclaiming of its anti-establishment, associational, and activist roots. Following this line of thinking, scholars like Arjun Appadurai (2002) have defended the emancipatory possibilities of grassroots organizations, entities enacting “globalization from below” (see also Edwards & Sen, 2000; Edwards, 2009).

In the wake of colonialism in Africa, civil society presents unique theoretical challenges. As Mamdani (1996) explains, colonial rule essentially “bifurcated” the state, between an urban civil society speaking the language of political rights, and a rural, communal society adhering to custom and the leadership of local “traditional” leaders (whose power was granted and reinforced by colonial rule). Such bifurcation reached its nadir in South Africa, but is apparent elsewhere as well. It was this divide that Mamdani

argues impeded democratization, and allowed “decentralized despotism” to survive decolonization and destabilize urban civil society movements. Political society is divided among tribalized, territorialized zones of belonging: “a tribe for the subject, a nation for the citizen” (p. 292). Thus, Mamdani concludes:

...democratization cannot just be a simple reform of civil society. It also has to be a dismantling of the mode of rule organized on the basis of fused power, administrative justice, and extra-economic coercion, all legitimized as the customary....Faced with a power that fragments an oppressed majority into so many self-enclosed culturally defined minorities, the burden of resistance must be both to recognize and to transcend the points of difference (p. 296).

Mamdani’s work highlights the persistent tensions between a liberal, equal rights-bearing, enlightenment vision of civil society, and the kinds of “civic-republican” forms of political sociality—ethnic, traditionalist, communitarian, patron-clientelist—that continue to flourish in many African states (Chabal & Daloz, 1999; Ramphela, 2001). In Lesotho, the division between those who can claim citizenship in the nation and subjecthood in the tribe seems to be traced along the line between those involved in the giving of aid (civil servants, NGO workers, consultants, and bureaucrats) and those who are its recipients. A view of post-colonial political bifurcations helps us to understand tensions and resentments between these groups, as well as common discourses that portray recipients of aid as traditional, ill-educated, and diseased.

Partha Chatterjee (2004) expands on this notion of a partitioned civic sphere, arguing that modernization has created a situation, especially in developing states, where the populace is effectively divided between a “civil society” and a “political society.” Civil society remains an enclave of the elite, for whom the entitlements of citizenship and access to political rights are possible. But for the vast majority of the (poor) population, modernity and neoliberalism have rendered them objects of policy, “populations” to be

technologically governed, whose participation is reduced to providing numbers for surveys and receiving, if they are lucky, occasional benefits as clients. For these subjects, survival is eked out through semi-illegal practices as their true political rights go unrecognized by a state that cannot afford to appease their demands without infringing on the property rights of its elite civil society. Chatterjee is particularly critical of NGOs, who are “likely to reflect the locally dominant interests and values...[and can] ignore and even suppress demands of locally marginalized interests” (p. 74). In this way, NGOs create a false consensus, and dampen the voice of the governed. Though Chatterjee nonetheless sees spaces for opportunity and mobilization in political society—amidst its forms of nascent and often “illegal” political action (p. 59)—his discussions of the acute separation between civil and political society, and the roles of NGOs and governmentality in supporting such a division, are especially relevant to examinations political functioning in the time of HIV scale-up.

As Ferguson points out in *Global Shadows* (2006), in the context of neoliberalism, NGOs become a kind of “surrogate demos,” as “substantial matters involving the policies of external donors have tended to be insulated from processes of representative democracy, often via the use of nongovernmental organizations” (pp. 12-13). Similarly, Petchesky (2003) writes that the patterns and objectives of many NGO and civil society mobilizations have created a situation in which, “with regard to global health crises, rights and initiatives, the void in democratic governance is the most serious neglected disease” (p. 113). As a result, we are losing sight of values about public obligation, mutual support, specific and enforceable social rights, and ultimately, social contracts, that are the fundamental building blocks of social democratic politics. Ferguson (2006) proposes,

It is not that states have disappeared, or even simply that they are, as it is often put, “weak.” It is, rather, that they have increasingly gotten out of the business of governing, even as they (or rather, the politicians and bureaucrats who occupy their offices) retain a lively interest in

other sorts of business. In this new era, it is not the organizations of “civil society” that are “nongovernmental”—it is the state itself (p. 39).

HIV programming has not fundamentally altered this apolitical architecture; it has simply funneled inordinate amounts of money through it, and created new, powerful institutions to manage the flow of this money. The net effect, then, is that HIV becomes a distinct and extremely fruitful kind of apolitical “business” which reinforces, rather than challenges, the disjuncture between citizens and state, between bureaucratic politicians and their obligations to the populace, and between the inconstant, unpredictable provision of resources and the recognition of meaningful social rights and entitlements.

### **Power, Democracy, and Patronage**

The forms of democracy so forcefully promoted throughout Africa and other developing regions since the early 1990s represent, themselves, the globalization of a particular neoliberal ideology. During the dismantling of state services associated with IMF-led structural adjustment programs, the promotion of a particular vision of civil society was seen as a strategy for shifting services away from state purview and strengthening institutional structures that were independent of governments presumed to be bloated and corrupt. This aggressive promotion of “democratization” equated NGOs with civil society, and civil society with participatory democracy. As a result, it was a thinly-veiled but wide-reaching shift towards privatization. As Igoe and Kelsall (2005) describe it, this put well-meaning but perhaps not always critically-minded NGOs “between a rock and a hard place”—stuck at the intersection of donor and global interests and their genuine desires to “do good” (see also Fisher, 1997). The “NGO-ification” of the African political sphere may be the most pronounced characteristic of contemporary sociopolitical life on the continent.

Mbembe (2003) has argued that both “civil society” and democratization are concepts central to the “authentication” of “subjection” (p. 35), and the process by which both ideas became distilled into the promotion of NGOs is certainly central to his claims. In this dissertation, however, I begin from a potentially hazardous position, in that I am unwilling to dispense with democracy altogether. Rather, I seek a nuanced but hopeful assessment of political possibility in Lesotho, attendant to the forces of power and ideologies shaping it, but also to the opportunities for citizen participation, collective solidarity, and emancipatory structures.

A number of scholars of contemporary African politics—including Mamdani (1996)—note the predominance of patterns of patrimonialism and patron-client relations, and the trajectories of power in African states under colonialism and development schemes that favor the power of chiefs and local elites (Bayart, 2009; Bird, Booth, & Pratt, 2003; Chabal & Daloz, 1999; Ferguson, 2006; D. J. Smith, 2008). With their emphases on developing rural areas, utilizing local elites as power brokers and representatives of the community, and doling out goods through hierarchical networks, NGO initiatives and development projects can exacerbate state bifurcation and patronage politics. In additional ways, however, they also corrupt these patronage systems. Where once a chief might be held responsible for providing for his constituents’ long-term well-being, NGO programs and development practice disrupt networks of accountability, making responsibility for well-being a temporary, fleeting arrangement, and distributing goods in unexpected and unsystematic ways. Bayart (2009) and others (c.f. Ferguson, 2006; Smith, 2008) have focused on the ways in which metaphors of “eating” are foundational to portrayals of politics in Africa, where a “politics of the belly” (Bayart, 2009) dominates political life. Ferguson (2006) describes how the metaphor of eating is bound up in both “good” and



“bad” patronage politics in contemporary African states:

It is often possible to discern an underlying contrast between powers that create social prosperity versus powers that destroy it....On the one hand, [chiefly power] can provide for the people and bring peace and prosperity; on the other, it can destroy the land and feed off the blood of the people. Key metaphors appear again and again: the chief as both man and lion, rainmaker and witch, feeder of the people and eater of the people. These two modalities of power usually correspond to two kinds of wealth—broadly, the kind that feeds the people, and the kind that eats them (p. 73).

At the level of citizens and the communities in which they are embedded, HIV resource flows have the power to remake dynamics of patronage, create jealousy and distrust of groups and individuals receiving support, and elevate certain individuals into powerful new positions. Swidler (2009b) has shown how funding flows to NGOs—and through them, into the hands of individuals and groups in communities—create new patterns of patronage, whereby NGOs and lucky community leaders become new patrons. Daniel Smith (2008) notes that the “workshop mentality” of global health and family planning programs in Nigeria is a primary method for extending and replicating patron-client relations. While donors prefer workshops for their easy measurability, local organizers use them to mete out privilege and “cultivate networks of clients and reward patrons” (pp. 712-3). Meanwhile, participants rely on per diems, lunch, and other benefits in lieu of salaries, and such benefits become a modern form of resource distribution. In the context of such dynamics, we should ask what is exchanged: What are patrons expected to “give” to recipients, and perhaps more importantly, what is expected of recipients in return? Swidler (2009b) comes to the conclusion that

Perhaps what really matters is not whether NGOs enter, despite themselves, into patron-client relationships in which they are cast as patrons. Instead the question is whether NGOs institute social practices that make patrons more responsive to their clients. Those who administer NGOs should be asking whether the concrete social practices they put into effect give clients leverage to keep their patrons aware of their responsibilities to consult, to consider their clients’ well being, and to redistribute resources, or whether local NGO staff consider themselves the end of the patron-client chain, monopolizing access to those external agencies that provide the resources (p. 212).

In essence, then, we should be assessing to what extent these dynamics allow for any semblance of democratic accountability and meaningful participation. And we should attend to the ways in which new kinds of social contracts – between citizens and NGOs, between NGOs and the state, and between citizens and a fundamentally different sort of (neoliberal) state – are executed, called into meaning, and rewritten. This opens up room for understanding how NGOs, states, and citizens fit into new sociopolitical logics, a question which is central to the ethnographic project I have carried out in Lesotho.

### **New Patrons, Same Clients?**

Certainly, development initiatives, earlier health campaigns (like population control initiatives), and, even prior, colonialism, were not lacking in acute concerns about citizen bodies, the threat of infection from black populations, or reforming the behaviors, beliefs and practices driving disease rates (J. Comaroff, 1993; Livingston, 2005; Packard, 1989). If HIV scale-up has a historical rooting in earlier colonial and postcolonial health campaigns, and the many procedures and anti-politics of the development initiatives that precede it, how are we to differentiate the effects of HIV programs on politics from the impacts of earlier development and health campaigns? In some ways, we can't: The historical embeddedness of HIV programs allows us to perceive them as part of broader global processes, but also muddies the waters in such a way that attributing all effects to a single variable is quite impossible. Instead, we should ask how the machinations of HIV scale-up are different—in size, scale, values or procedures—than campaigns that precede it. I will argue that the effects of HIV scale-up cannot be disaggregated from these broader trajectories of globalization, development, and the historical legacies of health campaigns in Lesotho, but that they are different in crucial ways. In addition, HIV scale-up represents

an important symbolic apogee of the trends and processes that precede, and in part create, its existence. Even as such, scale-up is a foundational pre-cursor to the emergence of global health as a contemporary cause, movement, and phenomenon (Crane, 2011; Erikson, 2008; Lewis, 2007; Macfarlane, Jacobs, & Kaaya, 2008). Finally, I posit that HIV scale-up is perceived by citizens themselves as a paradigmatic shift in the way that it has rapidly changed powers, procedures, resource distribution, social contracts, forms of representation, and the forms of citizenship valued by the state and its partners. These are excessively palpable and apparent changes for citizens: that alone should indicate to us that HIV scale-up represents a break with the past, a change in the order of things, and a disjuncture between the politics before scale-up and the politics of a post-scale-up world.

A number of the trends in globalization, neoliberalism, patrimonialism, civil society, and representation that I discuss above are all markedly exacerbated by HIV scale-up. But in another way HIV scale-up comes to encapsulate the outermost boundaries of such movements, symbolizing their most fundamental values. HIV scale-up became the perfect conveyance mechanism for neoliberalism, globalization, and celebrations of civil society--ideologies that are coming under more and more strident attack. Not only did it swiftly carry these ideologies into the heart of state programming across Africa, but it did so in such a way that they were normalized, masked by the seemingly value-neutral and quite laudable goals of providing treatment access, protecting people from infections, and caring for the sick. HIV reified trends and norms that development and neoliberalism had first put into practice: the importance of civil society; the reliability of consumerist, individualized, responsabilized forms of citizen engagement; the equating of service provision and volunteerism with robust forms of political participation; and the broad acceptability of public-private partnerships. In addition, the emphasis on multisectoral HIV initiatives

ensured a kind of mutual survivability for HIV and development, as they were construed as dependent on, and beneficial to, each other. Nor were those who labored to carry out such ideology in practice nefarious in their intent; rather, they were quite well-meaning about the lofty goals of treatment and prevention programs. But that is the pernicious nature of such values, and points to the effectiveness of HIV scale-up as a vehicle for their normalization.

On another level, however, HIV scale-up provided a template for new ways of doing business in African states, legitimated calls for “good governance,” and in doing so, seemed to justify the wholesale revision of state institutions and processes of representation. It was the feeling of emergency—the sense that HIV was somehow extraordinarily exceptional in both its pathological spread and the responses necessary for curtailing infections—that legitimated rapid and broad-based changes in political structures and processes, with many systems for oversight and representation simply being ignored or subverted by early organizational activities. The contemporary political philosopher Giorgio Agamben (1998) has reminded us that such states of emergency create “spaces of exception” in the normal order of things that allow gross incursions into the rights of individuals and citizens, and reduce them to a form of “bare life,” stripped of political protections. But he takes this observation much further, noting that the machinations of state sovereignty are *entirely dependent* upon such spaces of exception, and that these are foundational to state functioning, even though they are construed as exceptional. “At once excluding bare life from and capturing it within the political order, the state of exception actually constituted, in its very separateness, the hidden foundation on which the entire political system rested,” he argues (p. 9). It is the phenomenon of the simultaneous centrality and abandonment of citizens, their exclusion and their imprisonment, and the

necessity of exceptionality for the execution of state power, that holds essential lessons for understanding how HIV scale-up contributes to political sovereignties. Its emphasis on emergency, on exceptionalism, on the dire, bare need of the lives it is trying to save, perfectly justifies and reifies the power of HIV actors—from states to NGOs to global institutions—to administer life.

In the chapters that follow, I attempt to document the exhaustive ways in which HIV scale-up seems to have taken a great toll on citizens' lives and opportunities. In doing so, it may compound the earlier impacts of health and development campaigns, but any observer in Lesotho understands that HIV is a striking social and political phenomenon unto itself. Part of this is the way in which (at least in this period) every discourse, every initiative, and every dialogue about behavior refers in some capacity to HIV. Scale-up is an all-encompassing phenomenon in citizen lives, percolating into everyday life through radio programs and clinic speeches, community meetings and the distribution of local resources. It becomes embodied in the forms of labor citizens undertake and their understandings and interpretations of hunger. I have heard HIV called "the unwanted guest" in Lesotho, from families who recount stories of how HIV infection consumes not just family members, but household resources and family labor and the childhoods of youngsters. No one would dispute that the availability of HIV treatment has dramatically improved the lives of those living with HIV in Lesotho—and decreased the severity of the visits of that "unwanted guest." But we can imagine that some of the political outcomes of HIV programs have themselves become a unique kind of unwanted, unasked-for guest—the kind that eats up resources and speaks out of turn and shows little interest in what others have to say.

## **Emergent Themes**

In doing this research, and later, in writing it up, I came to rely on a few crucial ways of thinking about the processes unfolding as part of HIV scale-up and the changes it was eliciting in the lives of citizens. These “themes” (for lack of a better word), emerged, in many ways, directly from the stories my informants were telling me, what they revealed to me about their lives in conversations, actions, and ways of being-in-the-world. They provide a thread that can be traced throughout the chapters that follow, and a set of frames for thinking about how the data fits with the broader social dynamics and constraints of my informants’ lives.

### *Politics of Reciprocity*

I argue throughout the chapters that follow that HIV scale-up has elicited new forms of political engagement and dis-engagement, new patterns of interaction for states, citizens, and nonstate entities. These new dynamics include changes in understandings of the social contract and departures from traditional state – citizen relations, alterations in the expectations of states, citizens, and nonstate actors, and new strategic interactions between these entities in order to ensure survival, or prosperity. I came to think of these new dynamics as a *politics of reciprocity*, which, at its most fundamental core, is marked by the positionality of donors and recipients, the givers and receivers of aid and goods. I am sure some of these dynamics existed between donors and communities in Lesotho long before HIV arrived, but HIV scale-up has increased the intensity with which nonstate entities and funders seek “community partnerships,” request labor from participants, and demand accountability from communities. I became increasingly aware that the politics of reciprocity in the time of AIDS involved a carefully orchestrated theatre in which donors,

local elites, and recipient-citizens played proscribed roles, though much of the script for this play was unspoken, and participants were obliged to act as if there were no play at all. This theatrics of giving involves discursive efforts to establish the deserving neediness of recipient-citizens, and to ensure the appearance of accountability and transparency on the part of donors. Ironically, however, the “dependency” of recipients is mirrored by the dependence of donors on the presence and willing participation of recipients.<sup>13</sup> Typically, this involved obsequious citizens expressing their gratitude while hinting at all of the other needs the donor had ignored, while the donor spoke at length about the importance of “sustainability” and the evils of “dependence” and citizens nodded eagerly. This was almost always followed by jubilant celebrating on the part of citizens and earnest efforts to document (in photos or videos) the handing over of resources, donations, gifts—and then, of course, once the donors had gone, recipients’ expressions of disappointment, distrust, and suspicion. I discuss the parameters of such encounters in more detail in chapters 4 and 5. What is important to note here is the way in which such an exchange is a gross inversion of a political encounter, in which every action is intended to mask true discourse while endeavoring to demonstrate values of “accountability,” “transparency,” “community partnership,” and “sustainability.”

A politics of reciprocity shapes citizen subjectivities in other ways as well. It impacts the knowledge and information to which citizens have access, what they are able to demand of NGOs and institutions, and the forms of citizenship which those institutions expect from them in return. The reduction of politics to a set of recipient exchanges between “patients” and “providers” (and in this, I mean providers not in the clinical sense, but in the sense that they provide goods, resources, and services to the population) is

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<sup>13</sup> For an entertaining unveiling of these arrangements, see Amina Sow Fall’s *The Beggars’ Strike* (1981).

emblematic of the broader elimination of politics from health endeavors and HIV programs. Most importantly, these recipient exchanges—which are such a residual, broken form of political engagement—nevertheless form the basis of citizens’ most visible, important, and, to them, emblematic encounters with NGOs, state institutions, and donors. Thus, I spend considerable time examining such encounters from the perspective of citizens, interrogating what is expected and what is delivered, and how such recipient exchanges are interpreted by citizens who are struggling to understand the new logics and rules of their political worlds.

### *Political Geographies and Forms of Membership*

The preponderance of NGOs, and the rapid political changes at state and local levels, prompts me to also pay close attention to the structure and layout of citizens’ political worlds. In doing so I make reference to the work of Deleuze and Guattari (2009) on the importance of cartography for understanding contemporary social systems, and maps as temporal, open articulations of the world. Deleuze (2006, p. 21-38) draws on Foucault to demonstrate how diagrams of power can gain new meaning as cartographies, or in the hands of Elyachar (2003), “mappings of power.” They are not alone in such an endeavor, as geographers like David Harvey (2005) and Manuel Castells (2000) have emphasized the importance of geographic, spatial, topographical conceptions of social worlds. Ferguson and Gupta (2002) introduce the spatial imaginary of states as “above” and “outside” as a predominant mode of thinking about neoliberal state forms, where the state is not absent, but takes on new “spatializations” as both “vertical” (up there, not down here) and “encompassing” (in a far outer ring of society, but still enclosing and controlling the population) (p. 983). These ways of thinking about the political world were



invoked by my informants again and again, as they constantly referred to the distant but powerful bureaucrats and experts “up there.” When they spoke of the state’s services or its attentions as absent—as when services mysteriously disappeared, or the state deliberately ignored their calls for assistance—citizens referred to God as a last recourse for provision and attention. God is the ultimate entity “up there” and “outside” the citizenry, but is sometimes the only power to which citizens can appeal. “Even if the government does not see you,” one community leader said in trying to reassure members of a far-flung support group who bemoaned the sense of abandonment they felt at the hands of the government, “*heaven does.*” For Lesotho, as in many postcolonial zones, the historical, colonial legacies of maps hold acute power: Maps are the tangible scratchings upon which the state was stripped of its most fertile lands (see chapter 2) and its citizens marooned inside of South Africa’s economic and political dominion (Ferguson, 2006, ch. 2).

It is through political geographies that we can come to understand the spatial nature of Lesotho’s citizens’ abandonment, but also the ways in which such abandonment is situated amidst the relentless counting, claiming, and mapping activities of NGOs (see, for example, Elyachar, 2003). Among today’s NGOs, geographical claims form a considerable basis for legitimacy: Note the ubiquitous and prominent descriptions of “where we work” on almost all NGO websites. These are space-claiming endeavors that echo earlier colonial mappings of territory, population, and resources. From Biehl’s (2005) “zones of social abandonment” to Agamben’s (1998) “spaces of exception,” non-belonging is increasingly territorialized, and it is this spatiality—and the power over life even amidst abandonment that is wielded within such spaces—that consecrates new forms of sovereignty. In response to the imagery of globalization—which too often presents the world as infinitely connected, with resources and ideas “flowing” from one site to

another—a few scholars have instead emphasized the cartographic potholes in an imagery of global space. Ferguson (2006) calls up images of “global shadows” and Ong (2005) refers to the “checkerboard patterning of the national terrain” and a resulting “variegated sovereignty” (p. 697). “Networks of political and economic connection,” Ferguson (2006) writes, “...hop over (rather than flowing through) the territories inhabited by the vast majority of the African population” (p. 14).

These uneven cartographies force us to confront the exigencies of life in spaces of abandonment. Ferguson is concerned with what this means for *membership*, and highlights the strange and at times heart-breaking efforts of African citizens to claim a meaningful global membership. In developing this work, and in hearing so frequently about informants’ failed or insufficient efforts to claim membership (and thus, a residual kind of social contract) with NGOs, state institutions, and donors, I began to think of their positioning as a peculiar *dis-membership*, both in the sense that they were effectively banned from membership in most kinds of entities and institutions, and in the sense that the political effect of this abandonment—and its felt impact for citizens—was a kind of dismembering of the citizenry. It is only through understanding the political geographies of citizen worlds—by which I mean the myriad institutions, programs, NGOs, and donors with whom they attempt to build membership and craft social contracts—that we can begin to grasp the full extent to which HIV programs effect a dis-membership of populations in places like Lesotho.

Finally, a note is necessary about the use of the term “citizen” throughout this work. I frequently refer to individuals as citizens (rather than as patients, recipients, or community members). This is not meant as a claim that my informants always retain and assert particular forms of democratic citizenship. Nor is it necessarily meant to juxtapose

more enlightened, democratic ideals of citizenship with the forms of engagement more commonly observed in Lesotho, including through patronage politics, cosmopolitan strivings, or aid recipiency—decidedly political strategies of engagement that, while crucial to this study, nonetheless fall beyond more traditional conceptions of citizenship. My use of the term “citizen” is meant in a more universal way, a marker that serves as a reminder—of the focus of this study, of the importance of political recognition in these new political terrains, and of the ways in which the engagements and conversations of everyday life are inherently part of what constitutes the political in this study. Rather than asserting that all informants and subjects in this study are fully-fledged, rights-bearing political citizens, my use of the term highlights the importance of the political as well as the incompleteness of political membership and social contracts for many citizens. It ensures that readers remain aware of my informants’ striving for political agency even under unpropitious circumstances. Finally, it is intended to counter dominant narratives in public and global health literature that portray individuals primarily (and at times, only) as patients—when I do use the term “patient,” it is intended to highlight the subject-status of individuals receiving goods and services within the clinical environment.

### *Survival*

Finally, in the spaces of dis-membership created in the wake of HIV scale-up, survival becomes a unique challenge—as the social contract is emptied of states’ responsibilities to the poor, and as biomedical treatments increasingly replace social protection schemes. Even while seeking HIV services, patients showed that multiple forms of survival could be in play at any single time, and that each of these aspects of survival contributed to a very complicated calculus influencing how and where they negotiated

care. Relevant forms of survival include: economic survival (involving considerations of economic benefits of support group membership, or economic costs of disclosing status or attending clinic regularly); social survival (involving stigma, discrimination, and jealousy, but also the social support or collective vulnerability involved in support groups); spiritual survival (involving the many forms of healing and cures offered by traditional healers, faith healers, church services, and the importance to many of maintaining faith); and network or familial survival (involving the maintenance of family networks, support networks, and obligations of support to others). These comprised prominent concerns for my informants, but were largely seen as risks to adherence, or sources of clinical support on which patients could rely. Outside clinic walls, the disjunctures between biomedical and other survivals were particularly acute, as when patients refused to take treatments without food, claiming that treatments had a toxic power that could kill them in the absence of nutritional stability (see chapter 5).

Critiquing the tendency of literature on biopolitics and biological citizenship to inflate the dualism between “giving life” and “letting die,” Fassin (2010) points to the eminent importance of “survival” as an intermediary and agentive space, particularly when looking at HIV in South Africa. Rather than a “bare” or biologic life form, survival is a robust, active form of living. It is also a struggle, and in Fassin’s mind, a political and ethical one. Fassin sees the assertion of survival “as an ethical gesture through which life is rehabilitated in its most obvious and most ordinary dimension—life which has death for horizon but which is not separated from life as a social form, inscribed in a history, a culture, an experience” (p. 83). It is, after all, the *struggle* for survival in which our informants are most thoroughly engaged. I began to think of my informants’ endeavors in this regard—their efforts to establish forms of survival that encompassed a whole host of

belongings, protections, and meaningful engagements—as an antithesis to the “technologies of the self” or the emptied, partitioned, temporary memberships that abound in a post-scale-up world. As Nguyen (2010) comments in reference to the demands of HIV programs in West Africa, “self-fashioning could be powerful, but it was about [biological] survival, not belonging” (p. 7). How might we re-imagine robust forms of survival and belonging as meaningful, moral projects towards which our informants are continually, doggedly striving? In paying attention to these strivings, my research reclaims them as important fields for political mobilizations and demands, even when they are woefully unsuccessful: for they express a sense of how things ought to be, and in doing so, articulate a moral world that is not, but should be.

### **Why Lesotho?**

This project’s choice of site and subject is, like many, an outgrowth of both personal experience and methodological consideration. In 2005, I moved to South Africa to work with a community-based HIV NGO supporting prevention of mother-to-child transmission (PMTCT) in clinics and hospitals across the country. The program at the time was quite small, but it has since grown, expanding into countries across sub-Saharan Africa. In 2005, however, our concerns were more proximate, as we attempted to build effective PMTCT programs amidst the considerable government efforts to impede HIV treatment scale-up. Though the African National Congress (ANC)-led government, led by President Mbeki, had acceded to the roll-out of ART beginning in 2003 and 2004, progress was slow to reach more rural areas, especially in under-funded provinces. The government’s AIDS denialism remained a considerable barrier for the millions of patients who needed treatment, and for the efforts of activists with the Treatment Action Campaign

and the HIV/AIDS Law Project, who asserted that access to treatment was a fundamental human right. Among the clinics in which I worked, and among the young patients I befriended—first in rural Mpumalanga Province, and later in KwaZulu-Natal—the human toll of these policies was gut-wrenching and relentless. For anyone working in South Africa at the time, the driving questions underscoring HIV programs were political ones: What was fueling the state-sponsored denialism in South Africa? How could we explain the differences between the responses to HIV in places like Uganda, Brazil, Botswana, and South Africa? What lessons could be learned from the extraordinary, transnational social movements to secure treatment access and articulate the right to health as a fundamental human right?

Over the past decade, a number of scholars addressed many of these questions (Barnett & Whiteside, 2002; Bayer & Oppenheimer, 2007; Berkman et al., 2005; Alexander De Waal, 2006; Fassin, 2007b; Heywood & Altman, 2000; Lieberman, 2009; Nattrass, 2004; Parker, 2011; Parkhurst, 2001; Petchesky, 2003; Poku & Whiteside, 2004). As the phenomenon of HIV scale-up fully took root, however, and HIV treatment access became a reality across many countries, the political questions shifted. The experiences in places like Uganda, Brazil, and Botswana—in the sense that they were driven by *internal* political initiative—began to look exceptional. So too did South Africa's denialism, which went largely unrepeatable in other countries with generalized epidemics. For many other states, particularly in Africa, providing ART treatment on *any* scale would require the considerable assistance of bilateral and multilateral donors, as well as clinical experts. Beyond a few lucky activists who raised money to pay for treatment, found compassionate supporters in other countries, or cobbled together treatment through donations, schemes and sheer will (Nguyen, 2010), most countries lacked any considerable HIV/AIDS

treatment plans, and prevention efforts were minimal (until HIV scale-up began in earnest). Thus, when global money for HIV began to grow exponentially and programs such as PEPFAR, the World Bank's MAP and the Global Fund began dispersing funds, scale-up occurred as an externally-driven initiative, often in the absence of vibrant civil society responses or internally-funded initiatives (Lisk, 2010; Parker, 2000). International donors and organizations crafted rapid, technical deployments of services in response to global initiatives and extra-state priorities (Edström & MacGregor, 2010). It became apparent that the driving questions in HIV policy were no longer about "political will," but about global power, organizational structures, and patterns of aid. As a result, I became committed to exploring the research possibilities of examining these processes from within a "recipient" country.

Lesotho, then, was a new sort of emblematic case, with its history of rapid, but late-coming, funding advances, and its willingness to align itself with international policies (Kimaryo, Okpaku, Githuku-Shongwe, & Feeney, 2004; Owusu-Ampomah et al., 2009). Of course, it was not the only country I could have chosen—Malawi, Rwanda, Kenya or a number of others could have been promising options. But Lesotho offered a few additional advantages. First, as I will discuss in chapter 3, Lesotho undertook an unprecedented initiative called the Gateway Approach that was designed to raise awareness about HIV and to incorporate the priorities of communities into the national HIV and AIDS plans and policies. Surely, if there was a country where the political impacts of HIV scale-up had been *positive* rather than *negative*, and had involved the voices of citizens, Lesotho would be it. Second, Lesotho's small size and the accessibility of various organizations and leaders made the research project's scope more feasible. I was able to quickly gain a sense of the relevant organizations, agencies, funders, and partners; the community of

individuals working on HIV-related projects was small enough that I was able to get to know a great many people individually, and see them often. This proved particularly helpful in ensuring that my sampling frames for key informant interviews and my choices of field sites were not grossly skewed in one direction or another. Finally, I was able over successive summers in 2008 and 2009 to travel to Lesotho to work on various projects, network with clinicians and HIV program staff working in sites across the country, and begin developing a sampling and methodological strategy. These experiences provided a great deal of familiarity with various health systems, organizations, and key contacts, and provided a sense of the feasibility of the project I envisioned.

## **Methods**

From its very beginnings, this project drew on two primary methodological approaches: first, the practice of political ethnography as promoted by political scientists, sociologists, anthropologists, and feminist scholars; and second, Buroway's "Extended Case Method" (2009). As anthropologists have increasingly turned towards studying elements of political worlds in their attempts to grapple with the rapidly changing forms of states, institutions, social movements, and citizenship (c.f. Comaroff & Comaroff, 1999; Das & Poole, 2004; Mamdani, 1996; Ong, 2006; Paley, 2002; Shore & Wright, 1997; Tsing, 2004; Vincent, 2002), some scholars in political science and sociology have responded to the overwhelming turn towards quantitative and economic methods in their disciplines by re-examining what grounded ethnographic methods can contribute to scholarship on political forms, systems, and actions (Baiocchi & Connor, 2008; Tilly, 2006; Wedeen, 2002). Together, these trends have produced a growing awareness that the political—in its broadest sense—is manifest not simply in structures, institutions, or rational behaviors, but



through dynamic, contingent, socially-embedded meanings and actions among individuals and groups. This has led to a number of groundbreaking works that test our thinking about core political forms, and allow researchers to confront and interrogate the challenges to states, institutions, and citizenship presented by neoliberalism, globalization, transnational movements, and contemporary aid practices (Appadurai, 2002; Chatterjee, 2004; Das & Poole, 2004; Escobar, 1995; Ferguson & Gupta, 2002; Mbembe, 2001; Nguyen, 2009, 2010; Tsing, 2004). Ethnography in the realm of politics can remind us that the everyday lives of citizens and informants lend meaning to their (and our) political and legal realities (Das, 2007). This approach also allows us to embrace a far more expansive definition of what constitutes political action, institutions, or the state, at a time when much research in politics relegates citizenship to certain categories of belonging (citizens, non-citizens), discrete forms of action (voting, rioting), or sets of preferences that influence measurable political choices (as in rational-choice theory).

The work of studying everyday politics heralds from an even more prominent tradition in feminist political theory that challenged the bifurcation of private and public spheres (see Butler and Scott, eds., 1992; Elshtain, 1993; Fraser, 1990; Pateman, 1983; Rosaldo, 1980). The prominent dichotomy in political thought between the public (male) sphere of political action and the private (female) sphere of social relations reinforces a political patriarchy that not only legitimizes the exclusion of women from the public sphere, but delegitimizes labor, contracts, and even forms of violence that ensnare women in the private sphere (Pateman, 1983). Feminists have been at the vanguard of examinations of these “private” politics, emphasizing their centrality to understanding contemporary politics.

How do we then capture and understand politics from an ethnographic

perspective? Surely not all life is political, nor can all our informants' actions and desires be considered politically-motivated or reflective of politics. And particularly in settings (like Lesotho) where expressing discrete political views can lead to retribution from political agents, patrons, or sources of support, informants may remain deliberately unengaged with politics in order to preserve their survival. As this project evolved, I began to think of the data of political ethnography as arising from three foci. The first was an emphasis on examining the dual forms of political subjectivity. As Good and colleagues argue in *Postcolonial Disorders* (2008), the focus on subjectivity in anthropology is a focus on both *subjection* to structures of power and *subjective* modes of being in the context of hierarchy, violence, and politics (p. 2). Subjectivity is inherently political:

Subjectivity denotes...an urgent sense of the importance of linking national and global economic and political processes to the most intimate forms of everyday experience. It places the political at the heart of the psychological and the psychological at the heart of the political. Use of the term 'subject' by definition makes analysis of the state and forms of citizenship immediately relevant in a way that analysis of the 'self' or 'person' does not (pp. 2-3).

Second, and linked to this emphasis on subjectivity, was a focus on what I call the "politics of the everyday." Drawing on ethnography's already rich attention to everyday life, it seemed natural to ask how politics, power, and discourse were represented in everyday life. This meant emphasizing my informants' ongoing encounters with institutions, NGOs, programs, and other citizens, as well as the ways in which the patterns of their lives and livelihoods were shaped by the prevailing political environment around them. In doing so, I began to move away from what I think is an overemphasis in political science (and, perhaps, in our own public lives) on overt, but relatively rare, forms of political action: voting, protesting, rioting, or violence. Rather, we form ideas about who we are as citizens and our position in the political world through the encounters and

mundane patterns of everyday life. It is here that the persistent effects of power and resistance—as well as history—are made evident.

Finally, while I share the considerable criticisms of “civil society” as a conceptual category discussed earlier, Tocqueville’s (1994) original emphasis on “associational life” is richly productive as a tool for thinking about and observing diverse forms of cooperation, movement, and collective effort in the field. Associational life came to represent not just the work of support groups or the presence of local NGOs, but the efforts of women to care for the sick and orphaned, communal concerns about how to feed the hungry, the collective vulnerability of support groups who struggled to take responsibility for one another, and the informal gatherings of neighbors and citizens while waiting for services or NGO goods at clinics and government buildings. These were spaces where forms of solidarity and social life were being reworked and challenged, where collective ideas about responsibility, rights, and justice were repeatedly taken out, examined, and discussed. They were important social and political spaces, and to the extent that I was invited to participate in them, I did so eagerly.

The Extended Case Method is an approach to ethnographic research that allows the researcher to examine a social sphere through the lens of existing theory, leveraging in-depth examinations of carefully chosen cases to challenge or reconstruct those theories (Burawoy, 1998, 2009). This method allows the researcher to see theory as closely connected to social reality, and to carry theory into the field site, utilize it, re-examine it, and, eventually, revise it (Burawoy, 2009, p. xi-xvii). And it allows the research project itself to remain in productive conversation with other scholarship that may assist in reading, or reconsidering, the data at hand. The Extended Case Method moves between minute data and broad social structure, between an informant’s daily challenges and the

social conditions in which he lives his life, and between everyday political interactions among citizens and the broad changes occurring in their political universe. Given the broad questions asked by this study, this methodological frame provided a way to maintain a bifocal view of the evolving project findings, shifting constantly between the minutia of everyday data and the tectonic shifts occurring at state and transnational levels that were shaping my informants' subjectivities, survival, and social worlds. Finally, the Extended Case Method provides a more thorough means of conducting the "ethnographic revisit" (Burawoy, 2009, p. 72) whereby the researcher returns to the site of a previous, often archetypal, ethnography to re-evaluate the social theory it produced. I cannot claim that this project accomplishes even the beginnings of a thorough revisit of James Ferguson's (1994) ground-breaking study of development and politics in Lesotho, nor have I aimed to undertake the same approach, or endeavored to situate the study in a truly similar geographical or social context. Rather, I consider this an ethnographic "elaboration," attempting to evaluate how and in what ways the "anti-politics" of the aid and development machinery have been re-tooled, updated and redeployed in HIV scale-up processes. This study is carried out against the backdrop of a markedly changed social and political world for Basotho. Particularly relevant for this work is that it takes place after the beginnings of the global health boom and the initial commitments of funding for HIV treatment scale-up, and at the peak and initial decline of HIV program funding (2008 – 2011).

### *Research Sites and People*

As a result of these approaches, I conducted research in two primary sites. Preliminary research trips were taken between 2008 and 2010 to finalize research sites,

and then intensive field research was carried out over 15 consecutive months from 2010-2011. At the center of the project were two programs providing clinical care for HIV: The first was a government clinic providing primary care services in addition to donor-supported HIV treatment and care; the second was a workplace-based HIV prevention and treatment program run by an international public-private partnership named ALAFA. Government clinics operate decentralized HIV programs with a mix of public and donor support and funding, and are broadly integrated into the public health system of the country. ALAFA (the Apparel Lesotho Alliance to Fight AIDS) operates within the primarily Chinese- and Taiwanese- owned garment industries, which comprise Lesotho's single largest privately-owned industry. It is cooperatively supported by (primarily US) garment buyers, Lesotho's government ministries, NGOs, and private industry partners. For the government clinic site, I selected a medium-sized community-based clinic in the peri-urban town of Ha Mamello, located about 30 miles from the capital city of Maseru. For the ALAFA clinic site, I chose a clinic within the New Century Factory, a larger and well-established garment factory in the outskirts of Maseru.<sup>14</sup> This case selection allowed an assessment of how and whether the political impacts of scale-up differ across institutional and project settings. Given the broad array of public, private, and public-private institutions involved in HIV scale-up and service delivery, it seemed insufficient to focus on only one model of care: By specifically selecting clinical programs whose purposes, interests, values, and services differed dramatically, I would be able to also evaluate how variations in services, and the ethics and values that underscore them, impact on political subjectivities among patients. Table 1.4 shows the differences between these two sites according to the primary variables of interest.

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<sup>14</sup> For reasons of confidentiality, and to ensure against any negative consequences for any of my informants or the organizations with which I have worked, the names of the town and the factory have been changed.

| <b>Criteria</b>      | <b>Government Clinic Site</b>   | <b>ALAFA Clinic Site</b> <sup>5,16</sup>   |
|----------------------|---|--|
| <i>Site name</i>     | <i>Ha Mamello</i>   | <i>New Century Factory</i>   |
| Location             | Peri-urban community  | Urban garment factory  |
| Institutional Type   | Public facility w/ limited NGO assistance   | Public-private partnership   |
| Services             | Primary care + HIV services   | HIV services, limited primary care   |
| Patient Demographics | Mix of community, seeking primary care  | 80-90% women, seeking HIV care   |
| Medical Staff        | Foreign doctor provided by int'l org.<br>Government nurses, most from Kenya<br>Village health workers | Private sector, contracted doctors<br>Peer advocates from factory                          |
| Additional Support   | Network of international NGOs may provide training, supervision, add'l services                       | Limited partnerships provide some supplies, materials.                                     |
| Principal Oversight  | Ministry of Health (MOHSW)  | Project Management Committee <sup>15</sup>   |
| Secondary Oversight  | Int'l orgs;<br>MOH protocols set by board consisting of ministers, experts, orgs.                     | Partnership of: factory owners, labor, government ministries, US corporations, Int'l orgs. |

**Table 1.4: Comparative criteria for clinical research sites.**

Most ethnographic research to date on HIV and citizenship is primarily situated within the environments of the clinic or the support group, focusing on the subjectivities and emergent forms of citizenship among patients and those living with HIV/AIDS. In addition to hypothesizing that not all clinical regimes are identical in their institutional design or their impact on political subjectivities and articulations of citizenship, I also endeavored to examine the political impacts of HIV scale-up as more than a clinical intervention. I wanted engage with the effects of scale-up well beyond the walls of the clinic, and beyond the populations of citizens who were aware of their status and were living with HIV/AIDS, or the limited sample of individuals who actively sought and maintained care as patients within a largely biomedical system of care. Because HIV services have been implemented in a more streamlined, technical, and well-funded fashion, the experiences of patients seeking HIV care can be worlds apart from the

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<sup>15</sup> The Project Management Committee consists of two representatives from the garment industry, the medical director of the program, and one representative from a bilateral development organization.

experience of those seeking health care for other conditions. Investigating political subjectivities among non-HIV patients, and among non-patients, seemed essential. I was also interested in examining the political lives of individuals at the tense interface between their status as patients and as citizens. These sites—where citizen and patient identities, and HIV patients and their fellow citizens, encounter one another—seem a place of “friction” (Tsing, 2004) where ideas about belonging, rights, the social contract, and forms of survival that matter most are reforged.

As a result, it was especially important to interview individuals falling outside the scope of clinical HIV services to see how they viewed HIV services, the government’s responsibilities, and themselves as citizens. I primarily used the initial clinical sites as launch pad for a far broader investigation of HIV scale-up into the diverse surrounding communities. In Ha Mamello (the government clinic-affiliated site), this meant working throughout the town and communities surrounding the clinic; at New Century (the ALAFA site), it meant situating the research within the broader contexts of labor, production, the factory environment, and a transnational garment industry. In practice, this meant: working with support groups both affiliated with, and unaffiliated with, the clinics in both sites; interviewing a broad spectrum of patients coming for services other than HIV/AIDS care, testing and treatment; spending a great deal of time visiting the sick with community health workers; working with traditional healers seeing patients who utilized traditional forms of care—either in conjunction with, or instead of, care from the clinic; and attending a number of political and communal gatherings that had little to do with HIV or health care, including monthly meetings of the community council. In order to contextualize data from both field sites, I participated in and observed a host of national and regional policy dialogues and meetings among government ministries, NGOs, donors, and civil society

organizations throughout the research period. In addition, I conducted archival reviews of news sources from before and during the process of HIV scale-up, comprehensive reviews of policy documents, grant applications and awards, and reports from donors and NGOs about HIV, scale-up, and health services in Lesotho. Finally, I conducted interviews—both informal and formal—among more than 75 NGO and donor representatives, civil society leaders, and other key informants throughout the research period.

Nevertheless, I remained painfully aware that research in the garment industry site presented particular methodological challenges, both inside and outside the factory walls. I chose to work primarily within a single factory—the New Century Factory in urban Maseru, the capital city—rather than across multiple factory sites.<sup>16</sup> Accessing workers outside of the factories was difficult, as they lived throughout a broad urban area, and tracking workers from a single factory to be interviewed would require obtaining addresses and names from management, thus compromising confidentiality. Furthermore, factory workers worked such long hours in addition to shouldering domestic duties that I often found they were more willing to speak at work than at home. But conducting interviews within the factories meant contending with managers, who might either begrudge workers leaving work to be interviewed, or keep track of those who came to speak to us in order ensure workers were not giving unfavorable accounts of working conditions.

Thus, I found the research contending with the two driving forces that shape life for factory workers: the constant, grueling demands for worker productivity, and the equally

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<sup>16</sup> Factories in Lesotho are primarily located in two different urban areas, Maseru (the capital), and Maputsoe, a manufacturing city located in the north of the country. These towns have some salient differences, as do the factories and workers within them. Workers in Maputsoe tend to emigrate with families and partners, while workers in Maseru are more likely to travel for work alone, though more workers in Maseru appear to emigrate from closer towns and cities. Workers in Maputsoe tend to be older, and are slightly more likely to be married, though these demographics are changing at both factory sites. In the end, I visited with workers from both towns, and ultimately decided that the differences impacted minimally on the research questions, and that the access provided to me at New Century in comparison to other factories far outweighed the potential impact of any sampling bias.



inescapable surveillance by factory management to ensure that workers remained silent about labor violations and worked to preserve the delicate image of the factory as a zone of “ethical production” (see chapter 6). Providing a safe space for any research activities and ensuring confidentiality for informants was a considerable hurdle. Ultimately, the clinic space at the factory offered a partial solution. Since many workers came to the clinic regularly, and could access it with minimal oversight from upper management, I was able to recruit workers for interviews within the clinic. This did mean, however, that the interviews with this population were limited to those who came to the clinic, and were often hurried. While I was able to interview a diverse group of workers who came to the clinic seeking all kinds of care—from bandages and analgesics to TB and HIV treatment—I certainly missed speaking to those who avoided the clinic.<sup>17</sup> There were, however, ways around this limitation. I developed focus groups with workers who were already away from work for ALAFA events or other trainings, and I was also able to interact with workers within the Ha Mamello community (see below). And once my presence was established at the factory, workers who wanted to speak to me would visit the clinic of their own volition in order to be interviewed, even if they did not need to use the clinic’s services. As for the time limitations, while workers appreciated the time away from the production lines, they were also under pressure to return and complete their “score” for the day. I allowed workers to stop interviews at any time, and if they wanted to return for follow-up interviews we were able to do so by having a clinic worker call them from the production

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<sup>17</sup> This likely meant that I was able to interview fewer men than I might have if I were recruiting from the factory floor. While 80-90% of the workforce of the factories is female, men tended to use clinic services less often. (Gathering exact numbers on the gender balance in factories is difficult, due to short-term hiring, under-reporting of statistics, and frequent changes in the overall workforce. But it appears that more and more men are joining the once female-dominated workforce as mining jobs in South Africa disappear and miners are retrenched.)

line on another day.<sup>18</sup> Nevertheless, I frequently dealt with attempts by upper management and even clinic staff to tamper with sampling strategies and recruit workers for interviews who would offer narratives approved by management. As a result, I attempted to remain as flexible as possible in this setting, offering to end interviews early and conducting more interviews than was necessary, while managing as much of sampling and recruitment as possible on my own.

Research in the factory setting included participant observation of health-related activities both during and outside of work hours for workers. I never succeeded in gaining access to the factory floor as a participant, but only as an observer. This is a significant shortcoming of the research, though other rich ethnographies in the field provide a more close-up look at garment factory work itself (Plankey-Videla, 2006, 2012; Ong, 1988). I often had to rely on secondary accounts of factory floor relations, but pooled these from a wide array of sources. In addition to interviewing a broad spectrum of workers at the factory, I worked with and interviewed shop stewards, labor union representatives, independent factory inspectors, doctors, nurses, case managers, HIV counselors, and factory management. More importantly, I set up additional interviews and focus groups with workers from 3 other factories, and interviews with clinical staff from multiple factory sites, in order to gain a broader perspective on factory work, clinical services, and perceptions of HIV and health policies. These interviews and focus groups were held off the factory grounds, and also provided an opportunity to assess the differences in how workers spoke about labor issues and health services when inside and outside of factory walls.

The two primary research sites—Ha Mamello and New Century—shared a

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<sup>18</sup> This is the same way that workers are brought in for regular visits to the doctor or nurse, so they faced minimal stigma or questioning from managers or co-workers.

considerable cross-pollination of informants that I had not initially expected but which ultimately became very beneficial for expanding the sampling frames of each site. This should not have come as such a surprise to me, as Lesotho is a very small country (so small that it is not uncommon to find that two people know at least one person in common, if they do not know each other) and its population, especially factory workers, is highly mobile. In addition, Ha Mamello was only about 30-60 minutes from New Century by car or minibus taxi. I interviewed workers at New Century who came from, or still lived in, Ha Mamello, and patients at Ha Mamello clinic who worked at New Century or other nearby factories. At the home of a traditional healer in Ha Mamello, I met factory workers seeking care who came not only from New Century and Maseru, but from as far away as the factories in Maputsoe, on the far northern border of Lesotho. In visiting patients in Ha Mamello, I encountered those who had once worked in the factories but were now too sick or weak to work. The proximity of the two sites allowed me to conduct multi-sited research simultaneously (even attending events and interviews on the same day) and keep tabs on informants in both locations for the duration of the research period. Encountering factory workers in and around Ha Mamello also allowed me to supplement the highly workplace-based data from New Century with observations and encounters that fell well outside the watchful eyes of managers and factory security. Because these sites shared a fair degree of proximity, however, I attempted to broaden this data with intermittent visits to much more rural clinics and towns.

One potential critique of this methodological strategy is that the research has not engaged fully with the particular issues and concerns one might observe in Lesotho's very rural areas, which are expansive, frequently under-serviced, and severely marginalized. Life is unmistakably harder in these areas: Poverty is far more entrenched, food insecurity

is common, access to basic goods and services is limited, and education rates are lower. Though only about 25% of Lesotho's population lives in urban areas, urbanization rates have increased significantly over the past decade (Crush & Frayne, 2010). Nor can the remaining 75% of the population be considered purely "rural," though it almost always is classified as such (Bureau of Statistics, 2009). Peri-urban towns and villages dominate the densely populated lowlands region of the country. Because the lowlands zone of Lesotho includes the bulk of Lesotho's arable land, it also houses 70% of the population (Ministry of Health and Social Welfare [MOHSW], 2003). The common bifurcation of Lesotho's population into "rural" and "urban" areas masks these significant peri-urban areas, as well as the considerable internal migration of the population. This bifurcation stretches well into the psyches of both development experts and Basotho themselves, and the image of the poor, uneducated, diseased rural peasant is a common one—so much so that even a person's food choices or clothing can immediately identify him as rural or urban in the minds of onlookers. This divide, as is all too common in health policymaking (see Briggs & Mantini-Briggs, 2004), also leads to considerable blame of Lesotho's rural populations for the spread of diseases, including HIV, despite the fact that HIV prevalence rates are far higher in urban, lowlands areas.

In crafting a sampling strategy for this project, I was reticent to immediately embrace, and therefore reify, these divides, but I also remained acutely aware of the marginality of Lesotho's more rural populations. The dense concentration of development and global health aid apparatuses within Maseru, the capital of Lesotho, as in many recipient countries, is a powerful geographic example of the hierarchical "spatialization" of

states fueled by development practices (Ferguson and Gupta 2002).<sup>19</sup> As a researcher it is all too easy to be drawn into the centripetal forces of Maseru's centralized aid architecture. Nevertheless, I worried that if I sampled heavily from rural areas and found vast evidence of political disenfranchisement, I would be told that this was simply a byproduct of the rural areas' lack of communication, poor education, and limited contact with government. Ultimately, I chose to purposively sample from both urban and peri-urban sites that would be much more likely to have ample opportunities to participate in, communicate with, and observe government and its partners. Thus, if I found considerable evidence of marginality and disenfranchisement, it could easily be hypothesized that these trends were worse among more rural populations. In order to gauge the rough differences between more rural and urban and peri-urban populations on the variables of interest, I also conducted focus groups and worked with support groups in far more rural areas from time to time.

The methodological plan for this project, as in most ethnographic undertakings, evolved as the research unfolded. Both the Extended Case Method and political ethnography emphasize that research questions should remain dynamic, changing in response to new data and reconsiderations of theory that occur in the field. As a result, the methodological means by which we pursue those questions should also remain flexible. Given the relatively short time frame for the research, I engaged in bits of methodological opportunism—when doors were open to new sources of informants or new sites for research, I tended to take them, while attending to the broad sampling strategies I had initially laid out. This approach, while requiring a fair measure of flexibility, generally, I believe, resulted in more diverse data and the sorts of happy coincidences and lucky breaks that can elevate research findings from the mundane to the surprisingly

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<sup>19</sup> A 2007 paper on civil society and HIV/AIDS in Lesotho reported that 85% of civil society organizations were located in Maseru (Birdsall & Kelly, 2007, p. 47)

transformational. For example, while I intended for one of my two primary research sites to be located within an ALAFA program site, I did not initially expect to have such considerable access to a factory that was also integrally involved in Gap's Product (RED) initiative. While this site added more diversity of data and thematic content than I had initially planned on gathering—and at times even challenged the core research questions in that field site—it provided a truly remarkable opportunity to examine transnational humanitarian consumption campaigns from the perspective of laborers who were both producers and recipients of such humanitarian commodities.

Ultimately, in addition to the more than 75 interviews conducted with NGO staff, local experts, and clinicians, I recorded and transcribed close to 100 interviews in the two clinical sites and among patients and family members in the community. In each site I had key informants with whom initial interviews turned into long, wide-ranging conversations that spanned many encounters. A key portion of the fieldwork, especially in Ha Mamello, was long-term observation of, and participation in, multiple support groups. With one group in particular, this engagement stretched over a number of years. Clinic-based interviews were complemented by numerous visits to patients in their homes, and engaging in the practice of accompanying patients in seeking care outside the clinic site—most often at secondary and tertiary care facilities. Finally, I frequently visited with and observed a well-known traditional healer in Ha Mamello, and interviewed patients who sought out her services.

### *Ethical Considerations and Challenges*

In addition to the considerable ethical challenges posed by research within Lesotho's garment factories, research with populations of patients and persons living with

HIV/AIDS (PLWHA) is widely recognized as involving additional ethical challenges. One paramount concern for HIV research, particularly in community-based clinics, is the inadvertent discovery of participants' HIV status through association with the research and the researcher's relationship with clinical and support programs for community members living with HIV. My primary approach to avoiding these associations was to relentlessly describe the research with informants as a project to explore the following two questions: First, what were citizens' perceptions of health services and politics in Lesotho? And second, what did *all* citizens think about HIV, HIV policy, and HIV services? In doing so, I went out of my way to publicly interact with, and interview, a wide array of citizens not seeking HIV treatment or involved in HIV activities. While I faced many erroneous presumptions during the research, the perception that everyone speaking to me had HIV was not one of them.

Another key ethical strategy was to never ask about HIV status directly. In many instances, informants either offered information about their status, or used local colloquialisms (e.g., "I am taking the treatment") to hint to me that they were living with HIV. This prevented overstepping basic boundaries of comfort in interviews. Other topics of conversation, however, were equally sensitive, and I had to adapt interview protocols to these unanticipated discomforts. Foremost among these were direct questions about politics. Informants often worried that expressing political opinions would result in retribution from local government representatives, clinic workers, or even non-governmental agencies (as I discuss in chapters 2 and 4). Of course, additional precautions to protect identities and confidentiality were necessary, and these protocols and measures were approved by the Columbia University Institutional Review Board (IRB), the national Lesotho IRB for health research, and the Lesotho MOHSW's research ethics board.

### *Positionality*

In his research on HIV treatment, support groups, and the politics of ARV-related hunger in Mozambique, Ippolytos Kalofonos (2008) reported that he found it almost impossible to avoid being perceived as someone working on health programs, responsible for bringing “help” and “development” to those with whom he was trying to conduct research. He writes:

I occupied an odd position. Rather than implementing projects and interventions, I was interested in how people interacted with them, and I did not have many jobs to offer. I was frequently approached for favors...I felt it necessary to somehow distinguish myself from development personnel and missionaries because I saw those relationships as characterized by conventional or institutional hierarchies....During my training I also developed the distinct impression that relationships in the field were contaminated and polluted by payment and material exchange, and the proper ethnographic relationship should somehow be more organic. How could I reciprocate without turning into a ‘*patrão*,’ a boss?...For me, the ethnographic experience was characterized by relationships of dependency, obligation, and misunderstanding (pp. 23-25).

I believe these impressions and concerns are not unique, and I have frequently encountered them among colleagues and fellow students struggling with relationships in the field. But the prevailing writing on ethnographic methods—which both deconstructs the research encounter as hopelessly burdened by power relations that always impact the dialogue between researcher and informant, and projects an idealized vision of the proper research encounter as one of genuine solidarity—provides little guidance for navigating the everyday awkwardness and severe moral discomfort of these engagements.

These reflections point to two intertwined issues for researchers like myself: First, as a young, white researcher from the US with considerable expertise in health programs, my informants’ confusion over why I am *not* working with an NGO or a funder is justifiable. I was unmistakably a white outsider (*makhooa*), and in a small, insulated country like Lesotho this outsider status was frequently and publicly pointed out to me. My means of



addressing this was to do what ethnographers do best—to build lasting relationships, to become embedded in social relations, and to allow my informants to know me, my intentions, and my project on an intimate level. This was the only way I knew how to combat such misperceptions. The second issue concerns expectations of gifts, goods, resources, and other forms of assistance: In many ways, the solution to the first problem provokes the second problem. Entering and exploring social networks, particularly in Africa, means becoming embedded in dynamics of reciprocity, assistance, and resource-sharing. The extent of expectations that relatives, neighbors, and more well-off community members will share resources with those in need can be jarring to a first time visitor or researcher. As Nguyen (2010) succinctly points out, for many in Africa, their “number of dependents is directly proportional to income rather than actual kin relations” (p. 200). In Lesotho, the social good and the individual good—and social and individual well-being—cannot be disconnected from one another. The selfish accrual or hoarding of resources is seen as a social transgression, a violation of moral order.

The refusal to participate and become enmeshed in networks of reciprocity by many international health and development workers in Lesotho only feeds communities’ distrust of them. But the disparities in income between myself and my informants was so extreme that the expectations of what I might be able to give and share were a considerable burden, and a minefield of ethical issues. As I spent more time in communities, I became better able to separate out the requests that arose from a misconception that I was connected to NGO and therefore had access to all kinds of project resources, and those that arose from expectations that I participate in a meaningful way as a member of a community. I developed ways of sharing with members that attempted (not always successfully) to show generosity without showing favoritism, and

gave “gifts” without tying them to certain forms of participation in the research. Often this took the form of giving goods or services when they were most needed, and with the advice of key informants. I kept a garden whose meager harvests I brought with me when visiting sick patients and key informants. I occasionally intervened to assist patients in getting services, and frequently gave advice about where certain services could best be accessed. I gave money to, or arranged transport for, very ill patients when I could, and when it was badly needed. When I returned to the US, I collected donated and unwanted medical supplies—especially gloves and home-based care supplies—to bring back to support groups, care workers, and clinics. And while I relentlessly reminded people that I was not affiliated with any NGO or international donor, at times I was able to use my considerable knowledge of funding and organizations to assist support groups in writing a grant application, connecting with a donor, or preparing a report—though I only did these things at the explicit request of groups. At a certain point in the research, I realized that these “gifts” were frequently categorized by my informants as “given with love.” So when I brought medical supplies to an under-resourced support group and apologized that I was not able to bring more, I was told, “no. Because you give it with love, it is not small.” In this way, my informants subtly communicated that they understood my efforts were given with love—as part of a social network—rather than through obligation, or programmatic agendas. In doing so, they also demonstrated that such efforts were received in a fundamentally different way than the efforts of NGOs, donors, or HIV programs.

Nevertheless, there were times when my informants firmly believed that I was affiliated with an NGO or a funder and I was unable to convince them otherwise. Often this occurred when I met with a new group, or was poorly introduced by another community member. At times, members would deliberately portray me as a “helper”

(*mothusi*) rather than a “student” (*moithuti*) (as I was usually identified), hoping that I would not notice the somewhat subtle difference between the two words, and hoping that this identification would put significant pressure on me to produce goods or services for the community. When this misperception occurred, the appeals for resources or assistance became much more forceful and direct. At other times, it felt as though I was being held responsible by informants for all prior wrongs, all promises unfulfilled by other NGOs and foreign workers. “You come from America,” one elderly woman I was interviewing said to me at one point, “and there are some Americans who came here and they said they would give us some t-shirts that say, ‘know your status.’ So I’m telling you, we *do* like to know our status. We know our status.” She spent the better part of the interview asking me why I had not brought her a t-shirt. The tenor of these appeals reflected broader perceptions of the unfairness and corruption inherent in HIV funding. Sometimes they revealed the extant wounds of unfulfilled promises; sometimes simply the perception that NGOs, government officials, and powerfully networked individuals are keeping resources to themselves, and preventing goods and services from reaching citizens. Though these encounters never became comfortable, I learned to view them as an important aspect of the data, showing in unmistakable terms how citizens perceived those involved in HIV scale-up. Because NGOs and funders were also not known to just appear in villages and initiate open-ended conversations—and because official NGO and government visits prompted a complex theatrics among recipients, intended to demonstrate their gratitude and worthiness of assistance—these misperceptions also allowed me an important opportunity to experience communities’ claims-making towards NGOs, as well as perceptions of what they deserved and what forms aid should take.

*Looking Forward*

In what follows this lengthy opening, I attempt to describe the political changes I have observed in multiple sites across Lesotho. Chapter 2 provides a more comprehensive introduction to Lesotho: in particular, its political history and the most salient aspects of the contemporary political field. Chapter 3 introduces the context and unfolding of HIV scale-up in Lesotho, focusing on the development of a few crucial policies that provide insight into how citizens are reconceived and politics rewritten under HIV programming. Chapter 4 brings us for the first time to the clinical context in Ha Mamello, providing an intimate view of how clinical practice, patient subjectivity, and the constraints of the health system intersect in affecting how patients view and seek services from the government. Chapter 5 extends the focus in Ha Mamello outside clinic walls, examining the inner workings of two competing support groups, whose labor and purposes differ but who nonetheless struggle with the same problems of collective vulnerability and a politics of reciprocity. Chapter 6 contrasts the data from Ha Mamello with the challenges posed by HIV treatment and “humanitarian consumption” in Lesotho’s “ethical” garment industry, where humanitarian, public-private partnerships to supply HIV programs can occlude attention to labor violations, poor working conditions, and occupational health concerns for workers. Finally, a brief conclusion points towards potential policy solutions and future trajectories of research given the urgency of the findings reported here.

## 2. The Setting

*“What are you saying about the government, my dear?”*  
—HIV patient, in response to questions about  
how HIV services could be improved

In an edition of Lesotho’s *Public Eye* newspaper in October 2010, commemorating the country’s annual Independence Day celebrations, a columnist asked whether independence day should even be celebrated, given the country’s current political problems (“Not quite,” 2010). The Lesotho Congress for Democracy (LCD) was enjoying the fruits of what was beginning to look like one-party rule, and few citizens were optimistic about upcoming election prospects. The columnist wrote that the best political change Lesotho could hope for would be an opening of the border with South Africa, which would allow Basotho to seek further economic opportunities in the neighboring state.<sup>20</sup> The journalist’s suggestions are less radical than those of his contemporaries, who propose that the country be annexed into South Africa altogether. Another columnist (Motsoeli, 2010) argued that the country should abolish its national anthem, a song written by French missionaries and put to the tune of an old Swiss children’s song. The anthem’s middle three verses (already omitted from contemporary usage), are a relic of colonialist propaganda intended to quell Basotho anger over the loss of their most fertile lands to South Africa: *“Some say our land is very, very small / we think it is large enough / we need no more at all / have we not our pastures, flocks and herds of cattle? / Does that not*

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<sup>20</sup> Prior to the 2010 World Cup, South Africa unceremoniously closed the border with Lesotho to all Basotho who did not have passports, which meant that the vast majority of Basotho citizens could no longer seek economic opportunities in South Africa. Border security was tightened. South Africa cited potential security threats as their reason for these actions (Peta, 2010).

suffice?” He suggested that Lesotho adopt South Africa’s national anthem—*Nkosi Sikelel’ iAfrica*—instead.

Lesotho’s political and economic fates have long been determined by exogenous factors, and in this sense, the country’s Western-led, externally-accountable HIV response is nothing novel. But Lesotho’s colonial and post-colonial history creates a complicated set of conditions under which contemporary political subjectivities take shape. And these conditions—like the ever-present border with South Africa that appears so prominently in the *Public Eye*’s Independence Day musings—constrain social and economic possibilities as well. Any discussion of changing political landscapes and subjectivities in Lesotho must begin by examining history, and so this chapter begins with a brief political history from the early 19<sup>th</sup> century onwards. Others have transcribed this history more eloquently, and in far more detail, and so I refer readers seeking a more complete account to these fine works.<sup>21</sup> I will then turn to the primary conditions of life for today’s citizens—including struggles with economic inequality, gender inequities, migration, and questions of statehood—and the constraints the state faces in delivering services amidst the pressures of neoliberalism. I then discuss data indicating that HIV scale-up processes are having a noticeable impact on political institutions and citizen outlooks in Lesotho. Finally, in a short post-script, I analyze how the research project was received by the government of Lesotho, and use this data to reflect on the meaning of participation for today’s citizens. The situation highlights the effects of an emphasis on documenting program success and

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<sup>21</sup> The history presented in the following section is compiled from myriad sources (Aerni-Flessner, 2011; Bardill & Cobbe, 1985; Casalis, 1861; Coplan & Quinlan, 1997; Eldredge, 2007; Epprecht & Natrass, 2000; Epprecht, 1993, 2009; Ferguson, 1994; Fox & Southall, 2004; Hamnett, 1971; Maleleka, 2009; Murray & Sanders, 2000, 2005; Murray, 1981; Olaleye, 2004; Poulter, 1972; Southall, 2003; Tsikoane, Mothibe, Ntho, Maleleka, 2007; Turkon, 2008, 2009). Facts and figures were triangulated across multiple sources. Where deviations occur or there is some dissent in the literature, I cite the primary source(s) used.

state accountability to funders.

### **Political History**

Basotho date the origins of their modern state to the 1820s, a period during which Chief Moshoeshoe, the widely recognized “founder” of Lesotho and its later king, consolidated smaller tribes under his control. A keen leader and son of a smaller chief (*morena*), Moshoeshoe rose to power amidst the fighting, starvation, and vast population movements that marked the period widely known across Southern Africa as the *mfecane*, or in Sesotho, the *lifaqane*. For the people who gathered around Moshoeshoe in the high grassland region that now encompasses Lesotho, this was a time of enormous political and social change. They faced threats from the Zulus and other warring groups, felt the influxes of Boer settlers and British colonialists moving onto their lands, and sought protection from, and alliances with, new emerging leaders. In 1824, Moshoeshoe moved his large extended kin network and other followers to a plateau in what are now the western lowlands of Lesotho called *Thaba Bosiu* (“Mountain of the Night”). From this broad plateau, Moshoeshoe and his followers were able to successfully defend themselves against attacks, while expanding their ranks through more peaceful negotiating with clan groups wishing to gain protection.

Moshoeshoe’s consolidation of power did not go uncontested. He faced acute challenges from *Voortrekkers* (Boer settlers) who were at the time seizing vast portions of fertile land in what is now Free State, as well as the British, who were also fighting to gain control of the region. Moshoeshoe took on an evangelical French missionary named Eugene Casalis with the intention of gaining his assistance in charting a way through the churning political waters of the time. A true diplomat, Moshoeshoe relied on Casalis and

other missionaries who followed in his wake to advise him in the ever-changing negotiations with the British that continued throughout his lifetime. Though the British, who shared his desire to limit Boer settlement, marginally supported Moshoeshoe, they offered little protection in practice (Coplan & Quinlan, 1997, p. 31). Beginning in 1868, Lesotho became a British “protectorate,” which allowed it to be governed by indirect rule and placed significant authority in the hands of chiefs. Tensions over authority at times erupted, as in the Gun War of 1880-1881, a standoff between Basutoland and the Cape Colony authorities. Lesotho retained only minimal independence as a protectorate of the British Empire (Poulter, 1972), but as Eldredge (2007) argues, Lesotho’s leaders showed a considerable capacity for working within the structures of power imposed by colonialism, engaging in a strategic acquiescence that employed tactics of what she calls “dissembling” and “disguise” (p. 29). Thus, even as Lesotho’s leaders seemed to capitulate to colonial demands, they retained strategies for subverting, lessening, or circumventing colonial authority.

Over a period of decades, ongoing threats from Boer settlers, negotiations with the British, and numerous treaties and agreements slowly stripped Moshoeshoe, his followers and his heirs of their most fertile and productive lands. Ultimately, more than two-thirds of Moshoeshoe’s realm was ceded to the Free State (Coplan & Quinlan, 1997, p. 31). Where once Lesotho was a surplus grain producer for South Africa, the loss of this land and subsequent impositions of protectionist trade measures to support the farmers of the Free State wholly undermined its agricultural production (Ferguson, 1994; Turner, 2005, p. 4). Turner (2005, p. 4) argues that the trade measures were a pointed attempt by the colonial government to assist the burgeoning mining industry in accessing cheap labor. And so the Basotho farmers who had once produced grain that sustained the mining areas like



Kimberly now became migrant miners themselves, and Basotho became dependent on wages and remittances for economic survival.<sup>22</sup>

The political legacy of Moshoeshoe enshrined local chiefs as the primary representatives of their people. Nevertheless, these structures of authority were not as hierarchical and patrimonialist as we might assume: “BaSotho relations with their chiefs were moderated by a political discourse among commoners and intellectuals, and not by a hegemonic ruling class ideology,” Eldredge (2007, p. 9) writes. *Pitsos*—local community gatherings called by the chief to discuss matters and make collective decisions—were understood as a forum in which individuals could speak openly and even criticize the chief’s decisions. In his own memoirs, Casalis (1861) describes the political openness and the structure of dialogue that marked the *pitso*:

The... chiefs are bound to consult their subjects on occasions where the public welfare requires the adoption of important measures. These assemblies, called *pitso* (convocation), are always held in the open air.... The orators generally express themselves with the greatest freedom and plainness of speech. It is understood that on these occasions the chiefs must hear the most cutting remarks without a frown. Here, as everywhere, there is always a party for and a party against the government. The chiefs, therefore, when they have much opposition to fear, endeavor to gain beforehand those men of who support they are most in need. They also avail themselves, during the session of every little means in their power to influence the assembly.... The chiefs generally speak when all the others have finished; they commence with an exordium, setting for the legitimacy of their claims to authority.... The opening of the discourse is generally of an historical nature, and in the absence of all written documents the memory of the sovereign is subjected to the closest criticism. He must, therefore, first prove that he has a lucid idea of the concatenation of the facts to which the debate refers. “One event is always the son of another,” said a Mochuana prince to me on one of these occasions, “and we must never forget the genealogy.”...Then follows the declaration of the royal opinion, and the refutation of contrary ideas; and woe to any who have been imprudent enough to take undue advantage of the liberty of speech! If the potentate they have attacked happens to be a witty and sensible man, he will make them pay dearly for the impunity on which they reckoned. This is the fatal hour which gives birth to nicknames, which cling with the tenacity of a shadow to those on whom they are bestowed (pp. 233-6).

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<sup>22</sup> For a fascinating discussion of how the shift toward mining incomes impacted social organization and perceptions of the body in Botswana, see Livingston, 2005. For more information on how these economic flows impacted rural sustenance and family relations in Lesotho, see Murray, 1981. For a comparison between Lesotho’s economic situation in relation to South Africa and that of the “homeland” of the Transkei under apartheid, see Ferguson, 2006.

Nevertheless, as the colonial era progressed, the British had a heavy hand in promoting the “traditional” authorities of local and sub-national chiefs over the rights of citizens or more democratic forms of rule, as was their practice in other colonies (Coplan & Quinlan, 1997; Mamdani, 1996). Customary law was codified (in Lesotho, this became the Laws of Lerotholi), and used by chiefs to assert local power and penalize citizens (Poulter, 1972). At the same time, the colonial architecture of governance made chiefs accountable to colonial authorities, rather than to the people; this created fertile conditions for patrimonialism, greed, and abuses of power (Coplan & Quinlan, 1997, p. 36). As colonialism continued, chiefs proliferated, which meant, at the level of everyday citizen politics, an “all-encompassing presence of authority, down to the smallest hamlet, authority both accessible and immediately understood” (Coplan & Quinlan, 1997, p. 37).

As Lesotho entered the post-colonial period, legacies of chieftaincy and political patronage clashed with independence movements sweeping across Africa, which frequently aligned with anti-traditionalist, communist-leaning, independence candidates. By the 1950s, the Basutoland Congress Party (BCP) emerged, calling for self-determination and an end to the current system of traditionalist rule in Lesotho. Led by Ntsu Mokhehle, the party called for more representative rule, and by 1960, the National Council, which was originally made up of appointed chiefs, included members elected from the 9 districts, with an overwhelming representation from the BCP. In 1961, King Moshoeshoe II appointed a commission to develop a new constitution and make plans for an independent state, a process that took more than two years. The resulting constitution supported a Westminster-style system, with an upper house (consisting primarily of chiefs) a lower house (with representatives appointed through elections), a prime minister, and an independent judiciary. The constitution greatly constrained the king’s power, though to this

day he retains a surprisingly powerful symbolic and cultural authority (Coplan & Quinlan, 1997, p. 40; Epprecht, 2009; Maleleka, 2009, p. 2).

In Lesotho's first elections in 1965, the Basotho National Party (BNP), which was more aligned with the chiefs and the country's sizable Catholic population, won a narrow, and surprising, victory. The BNP leader, Joseph Leabua Jonathan, became Prime Minister, and Lesotho gained independence on the 4<sup>th</sup> of October, 1966. Given the BCP's ties to the South Africa's African National Congress (ANC), the apartheid government supported Jonathan and his BNP party, whose platform was decidedly anti-communist, and friendly to the South African government. In the following elections, in 1970, the BCP claimed a majority, but Jonathan, citing the interference of "communists" (Ferguson, 1994, p. 106; Southall, 2003, p. 254) and sure of the support of both British security officers in the country as well as the South African government, refused to cede power. After the coup, Lesotho was swept with violence, and BCP members faced repression; Mokhehle was jailed, and later fled the country. What followed was a period of 16 years of uninterrupted rule by the BNP and Leabua Jonathan.

Over the next decade, Jonathan shifted his alliances, realizing that a more oppositional stance towards the apartheid government could open up new opportunities for global partnership. As development aid blossomed, this anti-apartheid stance became much more lucrative. Over time, Lesotho became known as a crucial geographic haven in the anti-apartheid struggle: it provided space and support for exiled leaders and intellectuals, like the writer and activist Zakes Mda. As Coplan and Quinlan (1997) tell it, the resulting aid "was made to serve the ruling party and its clients. Foreign governments were the ultimate guarantors of Leabua's rule" (p. 41). Foreign aid was so crucial to the Jonathan's continued hold on power that communities came to associate development

(*tsoelopele*, lit. “civilizing”; later, *ntlafatso*, lit. “betterment” or “beautification”) with power and government (*muso*) (Ibid., p. 41). These perceptions continue to persist today, with aid associated with the power of the ruling government. Meanwhile, in a truly ironic twist, the South African government began funneling money to the BCP leader in exile, Ntsu Mokhehle, as Leabua courted Eastern Bloc countries such as North Korea and Cuba.

After more than a decade of Jonathan’s rule, unrest was mounting, particularly in the army. In 1986, Major General Lekhanya led a coup to overturn Jonathan that enjoyed the broad support of the South African government. What followed was another decade of tempestuous politics and power-grabs by competing elites. King Moshoeshoe II challenged Lekhanya, and Lekhanya in turn deposed the King in 1990; the King abdicated to his son, who became King Letsie III. In 1991, Colonel Ramaema toppled Lekhanya in another military coup, and more political oppression followed. Finally, civilian anger boiled over in May of 1991, when rioting broke out after security guards at a South African-owned clothing shop beat a young mother to death after accusing her of shop-lifting. The rioting had an acute xenophobic fervor, turning not against the government but against businesses owned by Asian and Indian immigrants; citizens felt they had overtaken local business opportunities (Tangri, 1993; Turkon, 2008, pp. 213-14).<sup>23</sup> Violence spilled over into a period of labor militancy among the workers employed in garment factories owned by foreign investors, many of them Chinese (Tangri, 1993). Frustration seemed to emanate from multiple grievances, relating simultaneously to the failure of government accountability to citizens, the long history of poor development and misuses of external development aid, and the abysmal treatment of Basotho workers by foreign-owned

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<sup>23</sup> In many accounts of the event told to me by my own informants, the shop owners responsible for the beating were described as Chinese, not South African. This is an important rewriting of popular history, one that reflects a shift in concerns about foreign others and owners of capital, from white South Africans to Asian immigrants.

factories and shop-owners (Tangri, 1993). Ramaema agreed to a revision of the constitution, which took two years, after which new elections finally took place in March of 1993. A now elderly Ntsu Mokhehle—the one-time independence activist, exiled under Jonathan’s rule, who had been in politics since the 1950s—won a landslide victory for the BCP.

Peace, however, did not follow. Less than a year later, the heavily BNP-aligned army was again threatening to replace the government, and then factions within the army clashed—violently—over who should replace Mokhehle. South Africa intervened, again protecting Mokhehle, but violence continued. The army took four ministers hostage and demanded pay raises; police strikes destabilized matters further later the same year. In 1994, King Letsie III, angry at his newly circumscribed role in the constitution, suspended the government in a “palace coup” that quickly deflated as neighboring countries intervened against him. Moshoeshoe II, his father, was reinstated as king. Less than 2 years later, however, King Moshoeshoe died in a car accident, and his son once again regained the throne as Letsie III. In the lead-up to the general elections in 1998, Mokhehle responded to the unrest and criticism against his government with a bold move: Abandoning his party, he formed a new party, the Lesotho Congress for Democracy (LCD). The BCP was sidelined in the following elections, and the LCD won in a landslide victory. Due to Mokhehle’s poor health, Pakalitha Mosisili was named Prime Minister.

Peaceful elections again eluded the nation. Opposition parties claimed election fraud, and brought complaints against the first-past-the-post election system, which they said favored the ruling party (Fox & Southall, 2004; Turkon, 2008, p. 209). Rioting broke out again, with considerable destruction and casualties in urban areas. South Africa intervened to restore order, though skeptical observers in Lesotho still claim that this

intervention was primarily motivated by South Africa's concern for its own economic interests. Primary among these is the Lesotho Highlands Water Project, a dam and water project that represents Lesotho's most valuable export and largest foreign investment project, providing water to key urban areas in South Africa (Hatchard, 2009).<sup>24</sup> An Interim Political Authority was formed to revise the electoral laws, and with the help of external mediators and political experts, revised the electoral system into a mixed, partly-proportional system. Under the new system, 80 seats in parliament are elected through first-past-the-post constituency elections, and 40 seats are allocated on a proportional basis, allowing smaller opposition parties to maintain a voice in parliament (Fox & Southall, 2004). This system was first used in 2002, and though Mosisili still won by a considerable majority, the election seemed to restore some faith in the electoral process.

By the time of the run-up to the elections in 2007, it seemed as if Lesotho might be settling into a pattern of more peaceful elections. The country's first local government elections had been successfully carried out in 2005, and it seemed that citizens understood, and had some faith in, the new electoral system (Cho & Bratton, 2006; Fox & Southall, 2004). But by late 2006, Tom Thabane—a long-time politician who had served under Jonathan, Lekhanya (the General who overthrew Jonathan), Mokhehle, *and* Mosisili—broke with the LCD party to start a new party, the All Basotho Convention (ABC). While Thabane spoke of the new party as an alternative to the long-drawn-out political fights between the BNP, the BCP, and the LCD, and as a means of creating a new political trajectory for the country, his own resumé indicated that he might be more of a political survivor than a true reformer. A number of MPs (Members of Parliament) followed him,

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<sup>24</sup> This project has been mired in corruption, and many Basotho cite it as the foremost example of the gross misuse of development funding. See: Hatchard, 2009.

however, and the ABC won 17 seats, carrying the vote among urban and younger populations who had long been underrepresented in, and disappointed by, national politics. This left the LCD with a considerably slimmer margin of victory than they had hoped for.

Though international observers have declared Lesotho's elections since 2002 "free and fair," most local commentators are quick to explain that the ruling party still holds a remarkable advantage in any election. In the run-up to the 2007 elections, Mosisili called for the dissolution of the current government and scheduled new elections months ahead of the planned election date—a move that many believe helped the LCD to retain members in the wake of the ABC's emergence. Given the country's small size and limited election budgets, the incumbent party is able to control or influence much of the print, television, and radio media. It is not uncommon for government cars and other resources to be used in campaigning. Many have taken to calling the elections "free, but not fair," and in 2007 Thabane contested multiple aspects of the election vote counting and proportional seat allocation (Turkon, 2008, p. 209). There is great distrust regarding the Independent Electoral Commission (IEC), whose employees I spotted driving the streets of Maseru prior to 2012 elections in brand new luxury cars with vanity plates like "IEC 1" clearly marking their affiliations.<sup>25</sup>

In the run-up to elections in 2012, students, workers, and taxi drivers engaged in strikes, protesting poor economic and working conditions. Many in the country felt that Mosisili, who had held office since 1998, had been in power for far too long; but few held

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<sup>25</sup> Luxury cars are given to MPs and other leaders at a grossly subsidized rate, and are one of the most visible signs of government nepotism. Those I spoke to about the IEC cars readily concluded that they had been purchased or subsidized for the IEC by the government, i.e., the LCD, in order to secure influence.

out hope that he would be replaced in the coming elections. Mosisili looked more and more intent on holding onto power by whatever means, and a well-timed publication of the *Wikileaks* state department cables regarding Lesotho confirmed these suspicions for many citizens. The leaks contained diplomatic memos citing Mosisili's "dictatorial" and "authoritarian" tendencies and made clear he had no intentions of stepping down—providing what seemed like clear evidence of his anti-democratic intentions to already dissatisfied citizens ("Wikileaks hit Lesotho," 2011). Meanwhile, a split was brewing within the LCD, with part of the party opposing Mosisili's re-election. Just at the moment when it seemed Mosisili would face a no-confidence vote brought about by a faction in his own party, he borrowed a trick from Mokhehle and formed a new party, the Democratic Congress (DC) of Lesotho, just prior to elections. Ironically, it was this same trick that had formed the LCD in the first place, and citizens joked that Mosisili had done nothing more than rearrange the letters of his party's acronym. Despite the long history of successful election-tampering in Lesotho, the electorate in 2012 seemed savvy to Mosisili's tricks. Though the DC won 48 seats and 39% of the votes, it did not secure a majority, and the ABC and LCD refused to form a coalition with the new party. Tom Thabane and the ABC were able to successfully form a majority coalition with the LCD and lesser opposition parties, and he was elected Prime Minister. Thabane's rhetoric since forming the ABC party has been that of a populist, and once elected he spoke about the importance of improving job opportunities, schools, health care, and services for the poor. It remains to be seen whether his fragile coalition will hold in order for him to achieve these objectives, and furthermore, whether these goals will stay central to policy in the new government. Nevertheless, the successful—and peaceful—change of power brought to an abrupt halt the era of Mosisili's apparent despotism by democratic means, and allowed citizens to see



that peaceful, uncontested, true transfers of power were possible.

Nevertheless, there are ways in which Lesotho's political history since independence largely makes a farce of legitimate democratic consolidation. In Przeworski and colleague's (2000) celebrated discussion of democratization across the globe, they develop a measure of democracy that focuses on successful contestation between multiple parties: As Przeworski argued in an earlier work (1991), "democracy is a system in which both parties lose elections." Such a barometer of democratic process teaches important lessons in Lesotho, which is one of those rare states in which the parties change, the rules change, and somehow the leading characters remain the same. A political scientist in Lesotho once quipped to me that the same four old men and their cronies had been fighting over the nation since the 1960s. Thus, Mokhehle was able to represent the BCP and then the LCD, and Mosisili to represent the LCD and the DC; Jonathan sided with the apartheid regime and the ANC, the Eastern Bloc and the West; and Thabane held posts under every major ruler since independence. While Lesotho's history seems marred by the constant (and often violent) opposition between BNP and BCP, BCP and LCD, and LCD and ABC, to Lesotho's savvy citizens it seems, in hindsight, like a long, drawn-out shuffle of a very short deck of cards.

### **Nation, Identity, and Citizenship**

Statehood and nationality remain fuzzy categories in Lesotho (Mokuku, 2000). It is a country within a country, and a country that is formed of, and produces, migrants. Over the past decades scholars have noted with some surprise that Lesotho—though it appears to be a homogenous, culturally cohesive nation—is beset by divisions and bouts of political violence (Coplan & Quinlan, 1997; Turkon, 2008). Aerni-Flessner (2011) is quick

to point out that, while Lesotho is today considered a rare example of a culturally and ethnically “homogenous” African state, “the history of the creation of the Basotho nation is one of amalgamation, with ethnic, cultural, and social diversity coming together under the welcome and open aegis of Moshoeshoe” (p. 11). Hypotheses to explain persistent, and at times destabilizing, divisions abound: Some blame the duress and external pressure under which Lesotho was formed (Coplan & Quinlan, 1997); others cite Lesotho’s decades of “dependence” on foreign assistance as undermining national cohesion (Weisfelder, 1977, cited in Coplan & Quinlan, 1997); and (more recently) Turkon (2008) has argued that class divisions, not political tensions are the true source of tension in the social fabric. Too often it seems that Lesotho’s persistent, exogenously-driven poverty somehow brings into stark relief its hopeless divisions, disqualifying it from true statehood. Yet the same divisions—class inequalities, political tensions that can boil over into occasional violence, and some persistent religious differences—hardly disqualify many Northern societies from full and unfettered statehood.

What is perhaps more interesting, as Aerni-Flessner (2011) notes, is that the Mosotho identity seems to transcend politics, defy national boundaries, and persist despite all of these divisions: but neither is it simply a “cultural” label. A self-identifying Mosotho can as easily be found growing up in Soweto, crossing the border for informal work in South Africa, or in a heated debate with friends at a bar in Maseru, discussing whether or not Lesotho should be incorporated into South Africa. The Sotho identity is not just defined by common language, culture, heritage, nationality, kinship, politics, or ethnicity. It is—as one respondent on a local online forum wrote in response to the question, ‘What makes me a Mosotho?’—“the love of Lesotho and Basotho” (“What makes me,” 2007). This is a more ephemeral quality of belonging, one that speaks to pride, but also the solidarity of

people who identify as Basotho but are frequently separated by borders or misrepresented by their government. While commentators may continue to presume that Lesotho's national cohesion is unlikely given its inability to escape the shackles of underdevelopment (a discourse that closely echoes talk of "failed states" in Africa), the fuzzy boundaries of Sotho identity are surely a product of imposed circumstances that curtail the chances of survival. Citizens of Lesotho emigrate in great numbers because they are hard-pressed to find economic opportunity in the country's curtailed markets; they rail against the government because decades of structural adjustment programs and "development" politics have stripped it of the ability to provide basic services and encouraged graft, corruption, and infighting over the remaining resources. That cohesive identities and sources of social solidarity persist in this environment points to the strength of the political society, not its weaknesses.

One identity that does seem an emerging fissure in social life, however, is that between rural and urban—a divide that was certainly reified through historical and colonial practices, which identified the "local" as a fundamentally separate zone from the "national" (see Mamdani, 1996). This divide is influenced as well by the persistent isolation of rural areas in Lesotho today. Current state practices of social service provision, resource distribution, and political outreach further reinforce rural citizens' sense of geographic and political marginality. These divisions are socially prominent today, such that a person's dress, manner of speaking, or even his preference for a particular type of bread might label him "rural" (and therefore a traditional, poorly-educated, member of the culture) or "urban" (and therefore a modernized, well-informed, cosmopolitan consumer). The caricatured divide between rural and urban – and between traditional membership and cosmopolitan consumption highlights the two primary means of engagement available

to citizens in Lesotho today. Cultural members claim political legitimacy only through their place of birth (at the heart of Lesotho) and their attachment to norms and practices that the nation claims as its own at crucial moments of collective nostalgia. Beyond that, they are largely ignored—by programs, practices, and patterns of implementation—and therefore only enjoy moments of cultural, rather than fully-fledged political, citizenship. The cosmopolitan consumer, by contrast, is a modernized political subject whose primary forms of participation in political life are enacted through supplication to political powers and various strategies of consuming public funds and services. Beyond certain moments of collective anger (rioting, protests, or some of the actions of youth league participants), citizens lay claim to little that looks like the rights and participatory benefits. But these caricatures also mask the many postures and survival strategies of individual citizens in places both urban, and rural, and anywhere in between. Most citizens lead lives complicated by mobility, migration, cross-border kinship, and struggles for survival in either state or geographic zone. Claims of a rural or an urban identity have less to do with rigid identity categories, and much more to do with aspirational strategies for gaining membership in a shifting political landscape. In the research that follows, I try not to reify these divisions between local and national, rural and urban, preferring to understand subjectivities in reference to a more complicated political and social topography than these overly dualistic locatives.

### **Life in Lesotho Today**

Custom in Lesotho holds that once an infant has reached a few months of age, female relatives will place the child outside during a gentle rain storm. As the baby inevitably begins to wail and cry, his relatives will stand inside and cajole him, saying, “we

are making you strong! We are building you up! You should not be weak!" This custom teaches a perfectly clear lesson about the inevitability of hardship and the importance of resilience that is central to the ways that many Basotho view the world. For the vast majority of citizens in Lesotho, life is extremely difficult. With little upward mobility, constrained by the economic conditions imposed by Lesotho's place in the world, Basotho face the unremitting, demoralizing stress that arises from knowing their chances of escaping poverty are extremely slim. But as is true in many underdeveloped countries, it is not simply poverty that inhibits citizens' life chances and binds their life choices: poverty is structured by history as well as contemporary political conditions.

With 56.6% of the population living below the poverty line, and a gross national per capita income of \$1,220 (current US), Lesotho ranks 153<sup>rd</sup> out of 180 countries in terms of per capita income (The World Bank, 2012), and 160<sup>th</sup> out of 187 countries in terms of overall development according to the United Nations Development Program (UNDP) (United Nations Development Program [UNDP], 2012). With few employment opportunities and significant concentrations of wealth among a select cadre of leaders and professionals, Lesotho is one of the most unequal nations in the world, with a Gini index of 63.2 (Central Intelligence Agency [CIA], 2012). The country is small and landlocked, but with 1.8 million people spread over 30,360 square kilometers—an area about the size of Maryland—it is more densely populated than some of its neighbors (CIA, 2012).<sup>26</sup> Much of the country is mountainous, high, and poor for farming. Those who live in mountainous areas are isolated, carving livelihoods from livestock grazing, minimal subsistence farming, and (when possible) sending migrants to work in South Africa or urban Maseru, the capital.

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<sup>26</sup> The population density is 73. South Africa's density is half that; Namibia and Botswana both have less than 3 people / square km (CIA, 2012).

As a result, and because the opportunities for miners are dwindling, the country has seen increased pressure towards urbanization. While 27% of the population currently lives in urban areas, which form a ring of towns and cities along the country's lowland borders (CIA, 2012), this figure is expected to rise quickly, reaching more than 40% by 2030 (Crush & Frayne, 2010).

Until recently, Lesotho was a major supplier of manpower to the mines in South Africa. In 1990, at the peak of mining migration, 130,000 men were involved in mining, and nearly 50% of households claimed at least one member who was involved in mining (and therefore, likely providing remittances) (Crush, Dodson, Gay, Green, & Leduka, 2010, p. 8). In less than two decades, the number of miners dwindled to 48,000, driven by declining work opportunities for miners from Lesotho. Remittances from migrants made up as much as 60% of gross domestic product (GDP) in the 1990s, but have since declined to about 30% (Romero-daza, Himmelgreen, Noble, & Turkon, 2009, p. 25). While Murray (1981) and others (Van den Boogaard, Slater, Gugushe, & Phakoana, 2004) reported in the 1980s that remittances were invested in agricultural capital, thereby supporting food production for families at home, more recent research (Crush et al., 2010) indicates that remittances are a source of much-needed cash for families, who use them to purchase necessary household items, including food. Three-quarters of households do *not* invest remittances; this is a rough indicator that the likelihood of longer-term security arising from mine labor is slim, and becoming more so all the time (Crush et al., 2010).

The same is true of work in Lesotho's fledgling garment industry. Since the early 1990s, foreign-owned garment factories producing for US and European clothing labels have employed primarily young, urban women (or recent urban migrants) (Gibbs, 2005). These jobs—which at their peak numbered more than 50,000—are back-breaking,

requiring little training and great patience (Bennet, 2006). Jobs pay poverty wages with little hope of promotion (Raworth & Harvey, 2004). While Lesotho has invested heavily in this industry, and US trade representatives tout incentives for garment manufacturers as a key development strategy, it is unlikely to provide lasting benefits for either workers or their families. Wages are so low that supporting families with remittances is nearly impossible (Crush et al., 2010, pp. 21-22). And as I describe in Chapter 6, many female workers struggle to invest in things like children's education, and commonly engage in transactional sex or second jobs in order to secure additional resources.

Though high rates of education (particularly among women) and new job opportunities in the garment industry have given Lesotho a reputation for achieving considerable gains in gender equality, recent history might argue otherwise (Hausmann, Tyson, & Zahidi, 2010). "Political modernisation in Lesotho has brought little or no significant improvement to the social status of Basotho women," wrote a political scholar at the University of Lesotho in 1997 (Makoa, 1997, p. 12). Under customary law—which gained much more legitimacy under British colonialism—women were treated as perpetual minors, unable to own or inherit property, obtain a divorce, enter into contracts without a husband's permission, or have a prominent voice in decisions regarding where or how children should be raised. It was not until 2006 that these laws were repealed and the "Legal Capacity of Married Persons" act was passed. Pressure from the UN and donor countries promoting gender equality as a multi-sectoral HIV response strategy was an important factor in the creation of the law; so too was the role played by local activists. The Federation of Women Lawyers (FIDA) in Lesotho was crucial to efforts to pass the legislation and educate women about the new law; nevertheless, some members of the group admitted to me in 2008 that knowledge remained low, and education was mired in

difficulty. Despite legal changes, women still face entrenched inequality in gender norms, practices, and perceptions (Lesotho Planned Parenthood Association, 2009; Makoae, 1997). Intergenerational relationships, high rates of partner abuse, and considerable power inequalities in relationships fuel HIV infections (Khobotlo et al., 2009). My own research also indicated that women's employment in garment factories did not earn them economic freedom, and at times exposed them to further violence, stress, and potential infection in relationships.

Many have argued that Lesotho's long-term patterns of migration contributed to high rates of partner concurrency, and to increases in HIV prevalence throughout the country (Murray, 1981; Romero-Daza, 1993; Spiegel, 1991). Today's epidemic—which is concentrated among urban, female populations with more access to income (MOHSW, 2010) —presents a set of prevention challenges with which the country has not yet fully come to terms.<sup>27</sup> Many in the government still speak of the epidemic as fueled by “ignorance” and “traditional values” among rural, mountainous populations. Persistent gender and income inequalities drive the epidemic, and these, in addition to migration patterns, increase the likelihood of multiple, concurrent partnerships that increase risk of HIV infection. Intergenerational relationships, high rates of partner abuse, and entrenched, negative gender norms further fuel infections. HIV stigma, as discussed in other chapters, is significant, and tends to arise from the perceived shame of promiscuous and extramarital sexual partnerships (Holzemer, Gree, & Makoae, 2007; Holzemer, Uys, et al., 2007; Mothibeli, 2009, p. 62). Openness in discussing sexual matters is lacking, but grassroots education campaigns are slowly opening up public discourse to issues of safer sex.

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<sup>27</sup> HIV prevalence remains highest in the urban district of Maseru (26.5%) and lowest in rural Thaba-Tseka (15.9%); it is higher in women (26.7%) than in men (18%); and higher among women and men who have higher income levels are employed (MOHSW, 2010).



Nevertheless, HIV has had an extraordinarily deep impact on life in Lesotho. Life expectancy at birth is 50 for men and women, down from 65 in 1990; the female adult mortality rate has risen from 171 to 573 per 1000 persons (WHO, 2012, pp. 54–55). Improvements in life expectancy, mortality rates, and basic health that should have occurred with considerable investments in health systems strengthening have been stymied by the effects of HIV on maternal and child mortality, TB rates, and secondary diseases, and by task-shifting of already slim human resource capacity towards vertical HIV initiatives. TB, once fueled by migration and mining, is now made more intractable by HIV prevalence. Chronic health problems—hypertension, diabetes, stroke—are also on the rise (WHO, 2012). Finally, food security and access to proper nutrition is a constant difficulty in Lesotho, and one that has become markedly worse over the past few years, as food prices have risen (See, for example, Initiative on Soaring Food Prices, 2008; Romero-daza et al., 2009; Turner, 2009). As Whiteside and de Waal (2003) first pointed out, HIV has a multi-pronged and sinister effect on food production capacities, household purchasing power, and vulnerability to starvation: The epidemic in places like Lesotho has created a second layer of hunger—a “new variant famine”—in addition to long-standing difficulties in achieving food security. In addition, Lesotho’s national insecurity as an agriculturally-poor area and net importer of food means that families are less able to produce for subsistence and are more dependent on purchased food—though poor households lack access to much, if any, steady income. In addition, food prices are presently so high in Lesotho that urban households are reported to spend 75% of household income or more on food alone (Romero-daza et al., 2009, p. 26). As a result, more than 45% of children under five in Lesotho are stunted, the product of chronically insufficient access to food (WHO, 2012, p. 112).

As Ferguson (1994) so eloquently demonstrates, Lesotho's poverty is hardly the result of unhappy circumstance, but rather the product of a colonial history that stripped the country of its most fertile lands, and a post-colonial period of "independence" whose development projects construed endemic poverty as a problem of "dependence," poor development, and national policy. "Poverty in the independent nation-state ...has long been formulated in insistently national terms, as "*Lesotho's* poverty—and thus, implicitly, Lesotho's problem" (Ferguson, 2006, p. 60, emphasis original). Of course, Lesotho's poverty is very much a problem of South Africa, colonial geographies, and world economies. Survival in Lesotho always seems to be carved out in reference to forces *outside* and *beyond*: the factory worker employed in the Chinese-owned factory that exploits US trade rules; the miner who spends half a lifetime in the South African mines; and the HIV support group participant who cobbles together a "salary" from the trickle-down commodities of donor-funded projects. In comparing Lesotho with the *bantustan* of the Transkei under apartheid, Ferguson (2006) argues that the imposed circumstances of poverty in both places were strikingly similar. But whereas black South Africans could recognize the imposed "independence" of the *bantustan* as, in the words of Steve Biko, "the greatest single fraud ever invented by white politicians" (quoted in Ferguson, 2006, p. 59), Lesotho's internationally-recognized political independence only *depoliticized* its poverty and occluded the (decidedly political) conditions of its underdevelopment. As Ferguson (2006) writes, "through its very international respectability, Lesotho was rescued from P.W. Botha's envisioned 'constellation of states' but simultaneously incorporated into a much larger constellation: the world community of nations, within which it occupies an equally powerless position" (p. 64).

More recently, it has been the policies of neoliberalism, structural adjustment, and

obligatory austerity that have placed additional limitations on Lesotho's ability to provide services, and which represent the new political chains of its underdevelopment. Meanwhile, development projects, as Ferguson's (1994) work makes clear, act as a depoliticizing force, obscuring the (external) conditions that create underdevelopment while prioritizing values of self-sustainability, responsibility, and independence. Other scholars (Van de Walle, 2001) have demonstrated the ways in which neoliberal policies in Africa have increased (if not incentivized) rent-seeking, corruption, and neopatrimonialism. The reliance on NGOs to provide essential state services, and their resulting proliferation, shunts the most talented staff away from government institutions and pays them higher salaries. As Ferguson (2006) notes, the residual government work force is less capable and lower paid, which creates "the inevitable consequences of corruption and an explosion of 'parallel businesses'" among civil servants (p. 39). Liberal economic reforms, claim scholars Jean-Francois Bayart, Stephen Ellis, and Béatrice Hibou (1999), shepherd African states along a pathway from privatization to criminalization.

NGOs, meanwhile, have a limited ability to change livelihoods through policy and political change—say, by enacting national pro-poverty schemes like pensions, or by making the hard, sector-wide improvements that enact positive change for all citizens, not just recipients of limited programs. NGOs are inadequate to pick up the roles that states can no longer fulfill (Fisher, 1997; Pfeiffer, 2003). States have been variously described as emptied, hollowed out and marginalized—and it is apt to question their capabilities for producing and carrying out policies under the circumstances by which they are bound. But in another sense African states simply have another set of priorities and purposes: They attend to the business of getting grants, appeasing funders, and marketing natural resources and poor people, and attempt to reap what benefits they may from these activities. "It is

not the organizations of ‘civil society’ that are ‘nongovernmental,’” Ferguson (2006) observes, “it is the state itself” (p. 39). So when citizens say that the state is absent, what they mean is that they feel the state is broadly absent from *their lives* as citizens—no longer accountable to their needs, attendant to their visions of the future, or mournful over its failures to protect them. Though international agencies comment tirelessly on the need for “good governance” in African states, it seems that many are primarily interested in promoting “good governance” in the service of their priorities, grants, and outcomes. Even for those whose genuine interest lies in improving democratic politics and policymaking in African states, efforts are often stymied by leaders’ own resistance to such modes of governing (since they reap the benefits of such neoliberal systems) and the practices of neopatrimonialist governance which have gained such momentum in the wake of neoliberalism (see Bayart, 2009). As Daniel Smith (2008) points out in Nigeria, many good faith efforts at building better democracy fail to fully acknowledge the ways in which “elites and ordinary citizens live simultaneously” in multiple political worlds: traditional patron-clientelist, liberal democratic, and neopatrimonialist (p. 12).

A simple example from Lesotho will help explain the realities of policymaking in the time of HIV scale-up. As I was finishing my fieldwork in 2011, international agencies were consumed with interest in medical male circumcision (MMC) as a prevention strategy, and pushing heavily for its adoption within a number of African states (see, for example, Bollinger & Stover, 2009). Ministers and other government leaders in Lesotho were less eager to implement such a strategy. The verb used for circumcision in Sesotho (*ho bolotsa*) referred to a great deal of practices surrounding traditional circumcision—including attending an initiation school, undergoing a full set of initiation rights, and the traditional practice of circumcision (which is different from medical circumcision and can

either involve no foreskin removal, or only foreskin cutting, both of which are inadequate in protecting against HIV [Auvert, Lissouba, Geffen, Fiamma, & Heywood, 2009; Thomas et al., 2011; Wilcken, Keil, & Dick, 2010]). It was clear that HIV experts and ministry staff in Lesotho needed a different term, but more importantly, they needed a different practice. After all, a voluntary, medical male circumcision for the purposes of reducing HIV infection would be far different from initiation school rites. And traditional leaders were not likely to view a biomedical distilling and usurping of their complex cultural practices favorably. The Minister of Health, Mphu Ramatlapeng, a savvy and well-spoken woman, admitted at a major national meeting that circumcision was fast becoming a “major issue.” She reported that a politician had recently held a rally in his district in which he lambasted her for engaging in “cutting of foreskins” that had nothing to do with cultural practices. As a woman, and without a male child of her own, he said she had little right to speak of these things at all. “So you all know,” she warned the ministry staff, “...we are going for elections soon as you are all very aware. You will have all kinds of detractors [on this issue].” Throughout her speech she refused to use the term “circumcision” but admitted that they had no appropriate term for this new practice. By renaming the practice “cutting of the foreskin” they might be able to forestall some of these divisive political issues. But renaming a medical intervention did not address, nor even invite discussion of, the broader tensions in MMC between the science of risk reduction and the social practice of initiation, or between (already politicized) “tradition” and (aspirationally-apolitical) medical practice.

The choice about whether or not to promote circumcision came down to the interests of funders. A few months later, I attended an event with many country heads of various health and development agencies at the house of the US Ambassador. The talk at the table focused on circumcision, and those present eagerly wanted to know whether or

not the Lesotho government would capitulate to demands that it initiate MMC. Additions to the current prevention plan were only making room for nationalized neonatal circumcision. Not to worry, reported a few of the experts present: The Global Fund had simply made it a requirement for receiving future funding, and the government was expected to add MMC to its prevention plan promptly. Because public health work—and HIV policy, in particular—proceeds according to the moral logic of getting the most desirable health outcomes in the quickest way possible, little attention is paid to the means, and great assumptions are made about the justifications which a positive ‘end’ can bring. But if we examine this from the standpoint of political process—or better yet, political ethics—the balance of ends and means is much less clear. The government isolates and marginalizes citizens who may or may not feel that such rituals are important. Co-opted as a biomedical procedure, circumcision policies prematurely curtail a public conversation about difficult compromises between ritual and medicine, tradition and technology. The government chooses a policy option not because it is clearly the will of the people, or even because it is the will of the government, but because it is the will of international funders.

HIV scale-up has impacted other processes of government as well. It has vastly expanded the power of ministries in carrying out policies and programs, managing major finances, and working with funders and international institutions. Ministers are strongly-affiliated with the party in power, and are typically appointed from the ranks of the most loyal party members. They are not subject to the direct appraisal of voters, but appointed (and fired) by the Prime Minister. Institutions like the National AIDS Commission and the Global Fund Country Coordinating Mechanism are poorly democratic at best (Birdsall & Kelly, 2007; Cassidy & Leach, 2009; Edström & MacGregor, 2010, p. 7; Godwin et al.,

2010). Representation tends heavily towards international and non-governmental agencies as well as government ministries (Akoku, 2009a). Citizen representation often takes the form of tokenism: one or two persons from a certain identity group (persons living with HIV, or LGBTQ populations) representing the interests of a diffuse set of individuals who have little contact with representatives and whose interests do not always align with those who represent them (Akoku, 2009b; see also Cassidy & Leach, 2009, p. 22). Others are represented through national umbrella organizations (Lesotho Network of People Living with HIV/AIDS, LENEPWHA, for example) that, as secondary recipients for large grants managed by government agencies, are in an attenuated position to advocate against government policy decisions. Both of these types of representatives are in a poor negotiating position, and meetings and policy dialogues are power-laden spaces (Akoku, 2009b; Birdsall & Kelly, 2007).

Though the National AIDS Commission (NAC), established in 2005 in Lesotho, is meant to act as an independent coordinating body for the AIDS response, it struggled in practice to create a comprehensive area of work and implementation separate from the country's Ministry of Health and Social Welfare (MOHSW), which grew more and more powerful during scale-up. Both the MOHSW and the NAC were keen to control access to external funding and distribution of grants to smaller NGOs, and fighting over legitimacy and fiscal control came to a head in late 2010. MOHSW commissioned a "report" (authored by hired consultants) on the effectiveness of the NAC that turned out to be a scathing assessment of the agency's role, determined to paint the NAC as unnecessary and out-of-step with current HIV policymaking practices (Matope, 2010). After a very public dissemination of the report's findings, the MOHSW embarked on a systematic dismantling of the institution. Only a handful of civil society or international partners even had the

courage to remark negatively on the dismantling of the NAC. Most international partners were heavily reliant on the participation and cooperation of the MOHSW, and felt that coordinating activities with two agencies was tedious anyways. Internal civil society organizations feared that, with NAC dismantled, MOHSW would control all internal grant-making processes, and reasonably assumed that contesting MOHSW's stance would likely inhibit their access to life-sustaining grants in the future. Thus, in 2011, the very public and unapologetic closure of Lesotho's only independent HIV policymaking body elicited almost no response from civil society or international partners.

Much like their colonial predecessors (Aerni-Flessner, 2011, pp. 4–5), international HIV policymakers and their in-country partners place a great deal of emphasis on political stability and such euphemisms as “order” and “unity” (see Kingdom of Lesotho, 2004). This is a thinly veiled “anti-politics” (Ferguson, 1994), in which the government eagerly takes part, more than happy to oblige international partners in achieving “stability”—preventing political power change—by whatever means necessary.<sup>28</sup> The money from HIV scale-up, even when not directly used in political campaigning, more subtly supports incumbents. Leaders are quick to claim HIV and health successes as their own, and HIV funding appeases lower-level civil servants and young professionals by providing jobs to an intelligentsia that otherwise would likely protest the government.<sup>29</sup> In a telling moment during Lesotho's negotiations for an enormous new development contract with the US Millennium Challenge Account (MCA), opposition parties and workers in Lesotho demonstrated in the streets, demanding that Lesotho *not* receive the grant. Their reasons were two-fold: First, they felt that levels of government corruption should have disqualified

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<sup>28</sup> For a more extended discussion, see chapter 1.

<sup>29</sup> In fact, as HIV funding declined in 2010–2011, students at the National University of Lesotho engaged in repeated action to protest the declining availability of (government) jobs and poor educational resources.

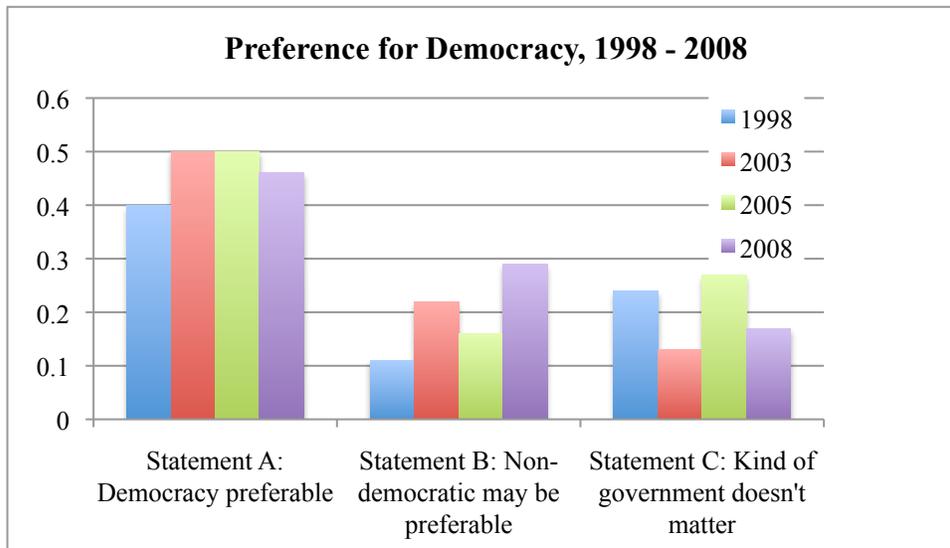


the country as a recipient, arguing that the MCA and the government of Lesotho colluded to cover up practices of nepotism and corruption. Second, the opposition forces feared that such a large grant in the hands of the LCD would make it impossible for them to ever mount a significant challenge to the party in future elections.

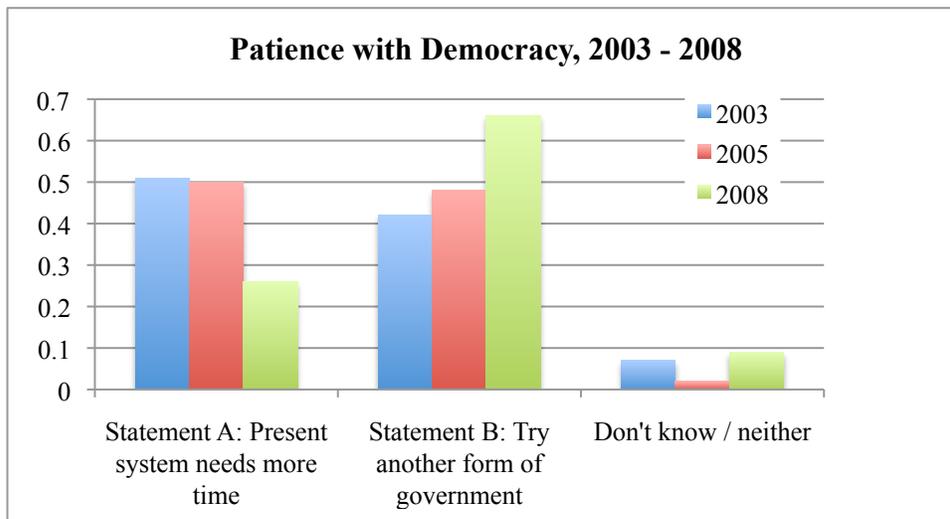
### **Democracy: A Measure of Faith**

The Afrobarometer project, which conducts randomized, cross-sectional surveys of African citizens in countries across Africa, has measured aspects of political and economic life in Lesotho since 1999, a year after the first (relatively) peaceful elections were held in the country. Since then, surveys have been conducted in 2003, 2005, and 2008. Taken together, these surveys provide a portrait of citizens' opinions of the government, political parties, and democratic institutions over a ten-year period. The survey includes a large number of questions about democracy—what it means to citizens, how successful politicians are at upholding it, and whether or not citizens support various elements of a participatory democracy. At the most basic level, the picture that emerges from this data is that, from 1998-2003, citizens in Lesotho were developing, albeit slowly, a growing faith in, and support for, democratic institutions (Afrobarometer, 2009). But by 2008, following the elections in 2007, these measures once again dropped, with a growing percentage of voters (29%) responding that non-democratic forms of government could be preferable to their current situation (Table 2.1) (Afrobarometer, 2009, p. 3). Sixty-six percent of respondents indicated that if the current government could not produce results in the near future, another form of government would be preferable (Table 2.2) (*Ibid.*, p. 4); 51% of voters thought the country was not a democracy, or was a democracy with major problems, up from 30% in 1998. Voters' willingness to reject overt forms of non-

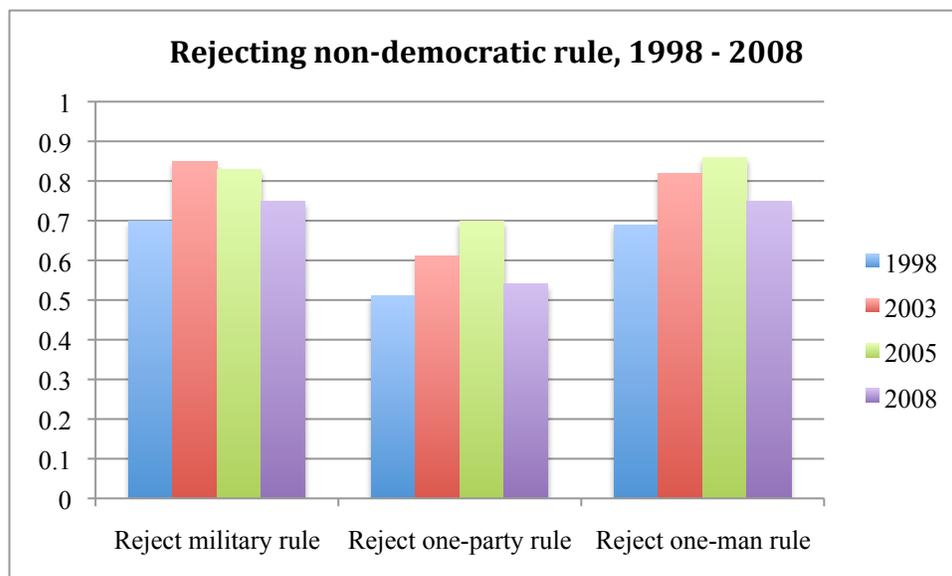
democratic rule, which had risen from 1998-2005, declined significantly by 2008 (Table 2.3).



**Table 2.1: Preference for Democracy, 1998 - 2008:** Percentage of respondents who agree with the following statements: Statement A—“Democracy is preferable to any other kind of government”; Statement B—“In some circumstances, a non-democratic government can be preferable”; Statement C—“For someone like me, it doesn’t matter what kind of government we have.” Source: Afrobarometer, 2009, p. 3.



**Table 2.2: Patience with Democracy, 2003 - 2008:** Percentage of respondents who agree with the following statements: Statement A—“Our present system of elected government should be given more time to deal with inherited problems”; Statement B—“If our present system cannot produce results soon, we should try another form of government.” Source: Afrobarometer, 2009, p. 4.



**Table 2.3: Rejecting non-democratic rule, 1998 - 2008.** Percentage of respondents who reject the following statements: “The army comes in to govern the country”; “Only one political party is allowed to stand for election and hold office”; “Elections and Parliament are abolished so that the Prime Minister can decide everything.” Source: Afrobarometer, 2009, p. 3.

What, then, was the driving force behind these figures in the 2008 survey? Poor opinions of the election seemed to play a part: More people felt elections were not free and fair, but also expressed disappointment and frustration with the opposition parties, who were increasingly playing an obstructionist role. Citizens thought that freedoms of speech, association, and voting had improved, but there was increased confusion over other procedural elements of democracy. Should the president be limited to two terms? Those who agreed declined from 85% in 2003 to 51% in 2008 (Afrobarometer, 2009, p. 5). Should the president pass laws without interference from parliament? Those who agreed increased from 17% in 2003 to 37% in 2008 (Ibid, p. 6). In some sense, the data seemed to reflect not how things *should be*, but how, pragmatically speaking, they *already were*. When citizens in Lesotho spoke to me about the condition of politics in their country in 2008-2011, they often cited the same aspects of politics—too much power in the executive, elections are free but not effective in changing power—as the defining

conditions of their current system.

What is surprising is that these declines in democratic measures occurred at a time when, by all external indicators, Lesotho's democracy was becoming more entrenched and stable. Though the 2007 elections had resulted in some violence, it paled in comparison to the 1998 elections, when troops were brought in from South Africa to "restore order" (Fox & Southall, 2004). Given Lesotho's lengthy history of political abuses, corruption, and coups, we might expect that a series of relatively peaceful elections with evidence of a growing opposition might gradually restore faith in democracy. Instead, it seemed the initial optimism regarding democratic institutions (if we could call it that—Lesotho ranks consistently low in support for democracy across the region) quickly waned.

It is immediately apparent in the survey data that frustration with the poor provision of public services is a crucial source of declining faith in democratic institutions. After all, if the institutions of the state are not able to protect and provide for citizens' most basic needs, what use is there in continuing to build democratic institutions? The influence of such citizen disappointment has been evident across African countries that enacted neoliberal reforms and harsh austerity measures at the behest of donors and international financial institutions throughout the 1980s and 1990s (see, for example, Bond, 2003; Ferguson, 2006; van de Walle, 2001). These measures, not surprisingly, have provoked citizens to look elsewhere for the fulfillment of basic needs—towards traditional leaders and neopatrimonialist solutions—while states have increasingly turned towards privatization of services (van de Walle, 2001). A certain nostalgia for patron-clientelism can be heard amongst citizens, who comment that at least that system provided *something*. In Lesotho, this is observed in the 79% of respondents who support traditional leaders having more influence in governing (as opposed to only 6 percent who say their influence

should decrease) (Hall & Leduka, 2008). Privatization has come late to Lesotho, with an array of new initiatives to privatize various aspects of public services, particularly health care. Some citizens, frustrated by decades of poor service delivery, told me during the research that they would prefer privatization: at least they would know the cost of services, and have the rights of a “consumer” to demand services. Troublingly, such statements point to the sense among citizens that without state services rights have little meaning, and that an emergent, market-driven concept of entitlements may be obscuring struggles for more fundamental social rights.

It is important to note how HIV scale-up has altered opinions of government service delivery, and therefore, broader faith in democratic institutions. Table 2.4 presents public opinion of how the government handles various economic and social services for citizens. As is not surprising, markers of economic performance—job creation, living standards, and food accessibility—indicate vast dissatisfaction with the government. A second tier of public services—fighting corruption, providing water and sanitation, reducing crime—gets middling grades. These are not seen as successes, but neither are they outright failures. The services that get the highest ranks in Lesotho are health, and more specifically, HIV initiatives. These are broadly supported by external agencies and donors, and represent the result of considerable policy efforts. But performance on HIV seems to have little bearing on overall satisfaction with the government; and approval of basic health services is considerably lower. It appears that general approval over how the government is handling HIV is not driving poor overall opinions of democracy in Lesotho. Nevertheless, in the chapters that follow, I explore the ways in which the institutional and social practices of HIV scale-up have vast impacts on how citizens view and participate in democratic politics. Thus, even as approval of HIV services remains high, HIV scale-up has

vast secondary effects on social and political processes that are difficult to assess in surveys such as the Afrobarometer.

| <b>How well is the government handling...</b> | Very badly / fairly badly (%) | Very well / fairly well (%) | Don't know / haven't heard enough to say (%) |
|---|-------------------------------|-----------------------------|--|
| Creating jobs                                 | 80                            | 18                          | 2  |
| Ensuring enough to eat                        | 78                            | 18                          | 4  |
| Narrowing income gaps                         | 77                            | 14                          | 9  |
| Improving living standards for poor           | 69                            | 29                          | 2  |
| Managing the economy                          | 62                            | 32                          | 6  |
| Fighting corruption                           | 56                            | 35                          | 9  |
| Providing water and sanitation                | 56                            | 44                          | 2  |
| Reducing crime                                | 50                            | 48                          | 2  |
| Improving basic health services               | 34                            | 64                          | 2  |
| Combating HIV/AIDS                            | 17                            | 77                          | 6  |

**Table 2.4: Government performance ratings on public services, 2008.** Source: Hall & Leduka, 2008, pp. 30-33.

Almost as striking as citizens' lack of faith in democracy is their sense that non-state actors wield far too much power in government. In particular, 69% of respondents thought international donors and NGOs had too much influence over their government, and 60% felt that local NGOs and civic organizations also had too much influence (Hall & Leduka, 2008, p. 62). In order to test whether or not opinions of NGO / donor influence had any bearing on faith in democracy, I ran a series of simple correlation tests which showed that perceived non-state actor influence was strongly associated with perceptions of democratic functioning and value across a number of variables (see Table 2.5 for summary statistics). In further exploring the cross-tabulation of these variables, it seems that perceptions of non-state actors having too much influence were more strongly correlated with perceptions of, and a preference for, non-democratic institutions, and perceptions that non-state actors had "about the right amount of influence" were more strongly correlated with a preference for democracy. This data indicates that while HIV services may not directly impact on

opinions of democracy, the dynamics associated with HIV scale-up (expansion of international / local non-state actor influence, for example) are correlated with markedly declining opinions of, and faith in, democracy.

|  | Patience with democracy <sup>30</sup> |                                     | Level of perceived democracy <sup>31</sup> |                                     | Preference for democracy <sup>32</sup> |                                     |
|--|---------------------------------------|-------------------------------------|--|-------------------------------------|--|-------------------------------------|
|  | $\chi^2$<br>Chi-square<br>value       | <i>p</i><br>Sig. level<br>(2-sided) | $\chi^2$<br>Chi-square<br>value            | <i>p</i><br>Sig. level<br>(2-sided) | $\chi^2$<br>Chi-square<br>value        | <i>p</i><br>Sig. level<br>(2-sided) |
| <b>Influence of international donors and NGOs</b>        | 55.880                                | .000                                | 105.182                                    | .000                                | 56.676                                 | .000                                |
| <b>Influence of Lesotho civic organizations and NGOs</b> | 57.415                                | .000                                | 101.979                                    | .000                                | 63.757                                 | .000                                |

**Table 2.5: Chi-square correlation of perceptions of non-state actor influence with democracy variables.** Source: Hall & Leduka, 2008.

Of course, it is equally possible that citizens' current frustration with democracy influences their (negative) feelings about how much influence other institutions have, and their suspicions that such institutions directly or indirectly boost the power of corrupt politicians, and in doing so, buy influence. There is too little data in the Afrobarometer survey regarding HIV and scale-up to assess causality in much depth. My suspicion is that falling faith in democracy and increasing external influences in the government feed into one another. Furthermore, the survey includes a subtle but extremely influential validity problem: more than half of respondents to the survey (55%), when asked who they thought sent the interviewer to conduct the interview, responded that they thought it was the government, the Prime Minister, a political party, or another government agency (Hall &

<sup>30</sup> For further information on variable "Patience with democracy," see Table 2.2.

<sup>31</sup> "Level of perceived democracy" reflects responses to the question, "In your response how much of a democracy is Lesotho today?" Responses were categorized into the following variables: (A) Not a democracy / a democracy with major problems; (B) A democracy with minor problems / A full democracy; (C) Don't understand / don't know.

<sup>32</sup> For further information on variable "Preference for democracy," see Table 2.1.

Leduka, 2008, p. 63). In Lesotho, where citizens are still afraid of retribution for voicing political opinions or concerns (see Turkon, 2008, p. 209), we can imagine that this has a dramatic impact on how citizens respond to many of the questions on the survey. I encountered similar misconceptions when entering the field and first meeting participants—deeply entrenched skepticisms that persisted long after I explained (and re-explained) who I was and what interests I represented. Prolonged contact, frequent and open discussions about my research, subjective empathy for participants' fears, and simply being there were the only tools I had to counter mis-perceptions. These tools are fundamentally missing from quantitative survey techniques.

Finally, these data paint a crude picture, and it is difficult to assess exactly *why* citizens are so skeptical of democracy, *how much* of a role HIV scale-up has played in the midst of broader political dynamics in reducing citizen faith in democracy, and *how* perceptions of the processes and changes of scale-up (like expanding influence of external organizations) are influencing appraisals of democratic functioning. In order to answer these questions, I use the remainder of this dissertation to explore qualitative, ethnographic, and observational data gathered from specific spaces of encounter, between citizens and clinics, between HIV patients and NGOs, between communities and donor agencies, and between the government, its partners, and citizens. I will attempt to use this field-based data to paint a rich, detailed picture of how political worlds, citizen-state relations, and everyday political life is changing in the wake of the scale-up of HIV programs.

### **A note on “politics”**

Given Lesotho's tempestuous political history, and the power that political parties



still wield, citizens view political participation with a level of skepticism that often borders on fear. Turkon (2008) reports that his informants in rural areas of Lesotho are perennially “anxious” about the possibility of political persecution, recalling the violence they experienced during political campaigning in the 1980s and 1990s (p. 209). In addition, the long history of ruling party-run development projects has exacerbated the sense that access to development aid is dependent on one’s political affiliations (Turkon, 2008; Ferguson, 1994). Even today, citizens reported to me their suspicions about which political or religious affiliations were preferred by various international NGOs operating in the country. In addition, citizens’ calls for equity in development schemes or government projects are frequently met with punitive measures (Turkon, 2008, p. 211). “Here in Lesotho, people are scared of responsibility,” a factory worker told me, “we are scared to voice our opinions, because we know that the government will abuse us—like, we know the police will always be there, and it’s going to be bad. We just keep quiet because we are scared, even if we know who should be [held] responsible.” Many informants in clinics and communities told me that if they spoke out to criticize a public service or policy—or even expressed an opinion about it—they feared they would no longer have a chance of participating in that service or program. This sentiment was so common that in about a third of all clinic-based interviews I was never able to get patients to reflect on what they wished the clinic or government would improve in health or HIV services. One respondent eyed me suspiciously when I asked her how she thought the government could improve HIV services at clinics like the one she attended. “What are you saying about the government, my dear?” she asked, cautiously. “Politics” was variously described to me as “a bind,” and “a trap.” It is “like having your toe stepped on,” one university student told me. “You don’t engage [in politics] because you *want* to, you engage because someone is

stepping on you and it hurts and it is an instinctive response... But *no* engagement is a good one [here]." To be "political" is to criticize the government or the ruling party, at one's own risk; it also means engaging in the kind of mud-slinging, counter-productive party infighting that occurs relentlessly in Lesotho and at election times leads to murders and rumors of party-affiliated "hit squads" (Zihlangu, 2012).

Thus, when I began the process of receiving government approval for my research on the political impacts of HIV programs, I was hardly well received. Before I even submitted the proposal, I was warned by the head of the in-country Institutional Review Board (IRB)—who was not Mosotho but, in his words, "sort of here long-term"—that Basotho are a "passive people" whose apolitical stance "makes them victims." He asserted that this passivity and apathy among citizens was "just part of their worldview" and that "they don't care" what happens to them politically. This discourse on the presumed "passivity" of Lesotho's citizens creates an image of those who lack power in Lesotho as willfully poor, ill-educated, and unconcerned with advocating for themselves. Talk like this represents the apogee of the impacts of neoliberal thinking in Africa: After decades of externally-imposed policies and plans which leave little room for citizen input, incentivize lacking accountability and corruption among leaders, and turn a blind eye to poor democratic process and political oppression in the interest of preserving "stability" in the state, should it be any wonder that citizens are skeptical about the impact of their participation, and worried about whether criticism or advocacy will bring punitive measures?

As my research proposal underwent review, I faced considerable pressure to leave the country entirely, and few in the ministry would speak to me directly. When I asked for information about why the proposal had been rejected, I was rebuffed with claims that I

was trying to bribe public officials. My Basotho colleagues who had connections to the government all attempted to get information for me—the message I received was that the government was afraid I would be investigating corruption in the Ministry of Health and its partners. Finally, I secured a meeting with one of the ministry officials in charge of research, and he indicated to me that the research was suspicious because it seemed that I was intent on criticizing the government. Political, he explained, meant critical. Wasn't it true, he said, that if I requested to do this research in the US, with such an interest in politics, that it would be like criticizing the performance of President Barack Obama? Surely I could understand why they could not approve this project, he explained. In the end, I made appeals, as an ill-informed student and anthropologist, that I had not intended to criticize the government, but only to study the social impacts of HIV programs on the lives of citizens. From this point onwards, this would have to become the primary focus of my research with any participants, and my ability to interview any politicians or high-level government employees was severely constrained.

I recount the difficulties of this process for two reasons. First, I want to make clear the positionality of the research in relation to the current political situation in Lesotho during the time I conducted my research. I believe it is methodologically and ethically important to write about how the research was perceived, and under what unhappy compromises it had to be carried out. As a result, I limited the extent to which I asked informants directly about political perceptions, participation, or opinions of the government. An unintended benefit of the limitations placed on my project was that it forced me to have faith in the ethnographic method, to reveal to me what my informants felt was most important, to demonstrate through the observance of actions and life trajectories the true nature of informant opinions, and to reveal through the fabric of

everyday life broader social phenomena. Happily, these examinations revealed a rich set of information about broader political and social changes—a finding that is especially important for future work in political ethnography. But I am certain that there are issues about which, had I felt able to ask more direct questions, I would have learned quite a bit more.

Secondly, the ethical approval process allowed me unique insight into the interests, concerns, and fears of Lesotho's bureaucratic and political class involved in HIV programming. From these conversations it became clear that maintaining credibility, minimizing any information leakages about corruption or misuse of funds, and ensuring that research reflected positively on the government were central goals. In private conversations with NGO staff and other researchers who had attempted to obtain research approval for what seemed like far more innocuous projects than mine, I learned that the government was suspicious of any research that might reflect negatively on HIV outcomes.<sup>33</sup> This extremely tight control on information—in a country with a healthy public discourse among local scholars and certain media outlets—was surprising. Certainly, it was incentivized by the grant-making processes and priorities of Lesotho's international partners in HIV scale-up, whose own reporting and monitoring and evaluation systems incentivized and even required that Lesotho portray itself as reliable, honest, stable, and extremely capable at producing positive results when needed. One of the most important impacts of HIV scale-up on political functioning is that national

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<sup>33</sup> A prime example of this defensive stance on independent research is a project sponsored by ALAFA (see chapter 6) to study how its factory-based, public-private model for HIV treatment delivery might compare in terms of cost-effectiveness to public sector programs. This was a reasonable research question for an NGO, and their goal was to demonstrate to industry partners that the program was extremely cost-effective, and thus, to secure long-term commitments of funding from within the industry. According to staff at ALAFA, the government turned down their proposal for research because of fears that they would demonstrate that their program was cheaper than the public sector services, and thus undermine the government's likelihood of securing future funds.

governments' pressures of accountability to funders and agencies create a situation where negative feedback about programs and criticism of government handling of HIV cannot be tolerated.

## 3.

### When Driving on Mpilo Boulevard: Competent Citizenship and the Politics of Scale-up

*“We are determined to use this crisis as the opportunity that forces us to ultimately catapult this nation from the shackles of poverty and under-development into a prosperous and peaceful nation.”*  
Prime Minister Pakalitha Mosisili,  
*Turning a Crisis into an Opportunity* (Kimaryo, 2004, p xxii)

Two different roads lead a traveler across Lesotho’s small but hectic capital city, Maseru. The first, Kingsway Bypass, is a two-to-four lane road through the heart of the downtown area. A cacophonous, busy series of lights and roundabouts, Kingsway can be maddeningly congested with cars at lunch time; at other times it drives like a hair-raising obstacle course, with taxis and mini-buses darting in and out, young hawkers stepping dangerously close to car tires, and Maseru’s notoriously insensitive civil servants driving government vehicles with an abandonment that only comes from not owning the car you operate. By contrast, Mpilo Boulevard traces a path across the hills south and above the downtown area. A newer highway, it benefits from on- and off-ramps and a divider, as well as a long, high, cement-reinforced wall against the hills. These features only seem to encourage Maseru’s motorists, however, to drive faster and with more abandon than they do on Kingsway—and though there are fewer obstacles, the accidents on Mpilo are frequent and terrifying. I once stood with onlookers and contemplated in sheer wonder how a mini-bus taxi had managed to arrive at a 90-degree angle to the road, perched atop a cement barricade, and teetering perilously above a 30-meter drop to a parking lot below the highway.

These two roads appear prominently in Basotho colloquialisms for safe and unsafe sex. To “drive on Mpilo boulevard” is to have sex without a condom; whereas to stop and

wear a condom, like Kingsway, is to take the trying, but safer route. One of my closest friends in Lesotho, Lebohang, laughingly explained the extended metaphor to me:

[On Kingsway] it's the first robot [traffic light] and the second robot down there and the third robot down there, and then the traffic circle. But with Mpilo, there's no traffic circle, there's no robots. So they say...Mpilo is living the fast life. So you drive over Mpilo, you're driving your life very fast. And they normally say, when you take Mpilo road, you drive around [the] mortuary on the left, and Queen II [the major tertiary hospital] on the right. They say when you take Mpilo, either you land in Queen II, or you land in [the] mortuary. But they say when you drive through the robots [on Kingsway], you take a pause—they say you are doing it safe, you are using a condom—you take a break, your life goes on, you get to the second robot, your life goes one, you go on to the third robot, and they say before you get to the traffic circle, you [smell] the smell of bread [from the bakery] and know there's life. But they say, on Mpilo, you're driving your life at 220 [kilometers per hour].

In Lebohang's description, "to drive on Mpilo" takes on a set of rich but accessible metaphors about sexual behavior, using the gentle admonishments of imagery and language to show how risk-taking can lead to death and illness, and how safe sexual practices can have their own sweet but subtle rewards. While I cannot judge its efficacy or impact on actual sexual practices, this seems to be the kind of HIV messaging that so many organizations and entities have tried to foster in the wake of Uganda's success in its "zero grazing" policy: culturally-relevant, localized, easy to understand, and firm without being punishing.

Mpilo Boulevard is home to another AIDS message as well, and one with which I became much more intrigued as my time in Lesotho went by. Painted across the huge cement-block retaining walls on the hillside beside Mpilo is a message that stretches for the better part of a mile, so large that it can be read from across the city: "WORKING TOWARDS AN HIV AND AIDS COMPETENT SOCIETY." Written in English, followed by the emblems for UNAIDS and the Maseru City Council, and bracketed on each side by enormous red HIV awareness ribbons, the sign is a far cry from the other message affiliated with Mpilo Boulevard. This slogan is vague, hard to understand, without any indications

about *who* is working, or what an “HIV and AIDS competent society” might be. In what follows, as I trace the emergence of Lesotho’s HIV policy environment and the major moments that preceded program scale-up, I will return repeatedly, much as I did throughout my research, to examine this troubling message of a “competent society,” and the “competent citizenship” upon which it is built. I argue that understanding what competent citizenship means, and the objectives it serves, is essential to comprehending how HIV programs are altering democratic life and political subjectivity in Lesotho. In order to understand this concept, we must step back and re-examine the most emblematic moments in Lesotho’s brief journey towards scale-up. These include the government’s first major policy documents, which outline a strong “political commitment” to addressing HIV/AIDS; the Know Your Status campaign, a universal testing campaign spearheaded by the King and the Prime Minister; and the Gateway Approach, designed to utilize local government structures as “gateways” to HIV program implementation, decentralizing the HIV response and increasing in local community ownership of policies.

### **The Second Wave**

Like a number of other African nations, Lesotho achieved neither an early response to the epidemic, nor a groundbreaking approach to treatment or prevention. Nevertheless, the pace and scale of HIV program deployment between the years of 2003 and 2010 is remarkable, and reflects an extraordinary global shift in the momentum and philosophy of HIV program support during that time period—a shift felt by a great number of countries at the receiving end of HIV money and support during those years. Lesotho’s experience with HIV scale-up is emblematic of a “second wave” of HIV interventions across the globe, which emphasized large-scale, biomedical treatment and prevention programs, resource-



intensive projects, a focus on accessing as many beneficiaries as possible in order to show outcomes, and a period of at times intense competition between various funding bodies and implementing organizations (see, for example, Biehl, 2008; Cohen, 2008; Hirsch, Parker, & Aggleton, 2007; Merson, 2006; Schneider & Garrett, 2009). The policies and programs that arose during this period are a reflection of national outlooks on the epidemic, but also of international forces and global dynamics; thus, as I describe the scale-up process within Lesotho, I will attempt to link its emergence to global powers and processes. By necessity, these descriptions will be painted in broad strokes, and in doing so I defer to other scholars whose long-term research provides a remarkable record of various phases in the global development and deployment of HIV programs, as well as the values and powers that shaped them (Barnett & Whiteside, 2002; Bayer & Oppenheimer, 2000; Bayer, 1991; Biehl, 2007; Fassin, 2007b; Heywood & Altman, 2000; Hyde, 2007; Lieberman, 2009; Lisk, 2010; Parker, 2000, 2009, 2011; Petchesky, 2003; Poku & Whiteside, 2004; Treichler, 1999).

The first case of AIDS in Lesotho was documented in 1986, and by 1987 the Ministry of Health had responded by putting together a small National AIDS Prevention and Control Program (Gayfer, Flint, & Fourie, 2005; Kimaryo, Okpaku, Githuku-Shongwe, & Feeney, 2004). More than a decade later, however, few significant strides (in terms of policy or programs) had been made, even as occasional data indicated that the virus was continuing on a path of destruction through the population: a 31.3% prevalence rate among antenatal clinic attendees at the national referral hospital in 1994 (UNAIDS & WHO, 2008, p. 15); the quadrupling of the number of persons reported with full-blown AIDS in a single year (1996-7) (Ambrose, 1998); and in 1999, evidence that more than 11% of students at the national university were already infected with HIV (Ambrose, 1999).

National HIV statistics, though rough, show the prevalence among adults jumping from 4% in 1993 to 25% in 1999, and to 31% in 2002 (Kimaryo et al., 2004, chapter 4). In the meantime, the government, like many in the region, did not seem to know how to respond: AIDS committees were formed in the districts but quickly fell into disuse; government plans called vaguely for action on HIV/AIDS but little came of it (Gayfer et al., 2005). Finally, in 1999, with help from UN agencies, the government developed its first HIV and AIDS Strategic Plan, and Prime Minister Mosisili declared HIV a national emergency (Kimaryo et al., 2004). In the year or two that followed, Lesotho seemed to pick up some momentum on HIV and AIDS policy, forming the first national body to address HIV and AIDS, the Lesotho AIDS Program Coordinating Authority, roughly modeled on UN recommendations, and situated within the Prime Minister's purview (Gayfer et al., 2005). The first HIV-related grants also began to trickle in: a tiny (by today's standards) grant from Irish Aid for 2 million Maloti (about \$230,000 at current exchange rates)<sup>34</sup>, and small contributions from other bilateral aid partners such as DFID (UK) and USAID (Babich, Nthunya, & Bicknell, 2006; Gayfer et al., 2005). These were matched by a commitment from the all government ministries that 2% of budgets would be dedicated to HIV and AIDS-related activities, a clear move towards establishing the kind of "multi-sectoral" approach to HIV and AIDS heavily promoted by UNAIDS (WHO, 2005). At the time, development partners such as DFID commented that despite these policy advances, uptake and availability of services like voluntary testing and counseling remained poor, and most efforts were directed towards information campaigns and basic prevention activities (Gayfer et al., 2005; Kimaryo et al., 2004). The major developments in Lesotho's HIV response are outlined in Appendix B.

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<sup>34</sup> Calculated on January 18, 2013, at an exchange rate of 8.58 Maloti to \$1.

During this same time, something unexpected was taking place north of Lesotho, in Botswana. In 2001, President Festus Mogae announced that the country planned to implement a national HIV treatment program with heavy input from private and international partners, aiming to offer treatment to any person living with HIV/AIDS who qualified for it. Though the program initially struggled and faced considerable skepticism, it represented the first attempt at a nation-wide treatment program by any African country (D'Adesky, 2006; Rollnick, 2002; WHO, 2006). It was a bold move: The program would be deployed amidst a population with the highest HIV prevalence rates in the world, and it would be funded in significant part by the government. In addition, after 2004, the program was paired with an aggressive initiative to offer routine, universal testing for HIV—which also met with significant concerns from onlookers, but did allow a greater number of persons living with HIV to be identified and initiated on treatment (Curran et al., 2005; WHO, 2006). By 2004 or 2005, despite so many doubts, Botswana had unequivocally proven that universal treatment was not just within reach for African nations, but a moral priority (d'Adesky, 2006). By that point, as well, the world had witnessed an extraordinary outpouring of support for comprehensive HIV programs for Africa—as the Global Fund, and then the US President's Emergency Plan for Aids Relief (PEPFAR) initiated a competitive, but virtuous, cycle of funding outlays. Donors became eager to demonstrate that universal treatment access could be achieved in a cost-effective manner—and preferably by a single large donor—in other countries (Schneider & Garrett, 2009).

Compared with Botswana, Lesotho offered significant draws for donors, as well as some cause for caution. Like Botswana, it had a high-prevalence epidemic concentrated within a small national population (Botswana has about 2 million people; Lesotho has 1.8

million) (Central Intelligence Agency (CIA), 2012). In addition, Lesotho had been working hard to demonstrate that the country had the “political commitment,” as many were calling it, to spearhead a campaign to treat HIV: to think with, and act upon, global principles about how the epidemic should be addressed in all sectors (Kimaryo et al., 2004). The 2000 National HIV/AIDS plan named political commitment as one of Lesotho’s core prevention objectives, and stated firmly, “the Government will continue to ensure that HIV/AIDS and STIs continue to remain in the public agenda by seizing every opportunity to advocate on HIV/AIDS and STI-related issues” (Government of Lesotho, 2000, p. 7). Unlike Botswana, however, Lesotho was and is a much poorer country, with limited sources of national revenue to divert into HIV initiatives. Its public sector health services were in many places abysmal, vastly lacking the capacity in human resources or technology to implement a treatment program (European Commission, 2007; Gayfer et al., 2005). Lastly, the country’s rugged terrain and limited road access meant that even accessing populations for testing, distributing drugs, or transporting lab results from many rural areas would require the use of donkeys, airplanes, or specially-equipped dirt bikes. Despite these challenges, Lesotho, along with Swaziland, offered a prime place for donors to deploy new, far-reaching HIV programs for treatment, prevention, and care.

It seems that these attentions were not at all lost on Lesotho’s leadership. The country had enjoyed a long period of fruitful development relationships throughout the 1970s and 1980s (though these were not always devoid of corruption, or successful in improving Basotho livelihoods), but donor funding had declined sharply since the mid-1990s (Turner, 2009). Under apartheid (as discussed in chapter 2), Lesotho’s geopolitical position had attracted significant development aid (Gayfer et al., 2005). But with the end of apartheid, Lesotho suddenly lost crucial value as an aid recipient—it no longer held the

cachet of an independent, democratic (or semi-democratic) island of land within South Africa. As money for HIV began to increase exponentially, Lesotho's politicians must have played close attention to Botswana's scale-up. President Mogae visited Lesotho himself on a few occasions during the process of scale-up, promoting more aggressive HIV programming. It seems highly likely that Lesotho's leaders looked to Botswana's leadership on HIV and aimed to emulate it.

By 2003 and early 2004, policies began shifting towards treatment access in Lesotho, pushed along by the government's growing realization that demonstrations of political commitment could attract significant sources of support for programming. Maseru hosted the Southern African Development Community's (SADC) conference on HIV/AIDS, and released an early memorandum titled, *Scaling up the Fight Against HIV and AIDS in Lesotho* (Gayfer et al., 2005). Prime Minister Mosisili launched a national PMTCT program, which relied on donated doses of Nevirapine from the pharmaceutical giant Boehringer Ingelheim (Ambrose, 2003). By 2004, the country was developing a rough plan for the scale-up of HIV treatment, and had opened the first ARV clinic in the country—again with the help of a significant pharmaceutical partner, Bristol-Meyers Squibb (“AIDS Treatment Clinic,” 2004). In the same year the country received its first World Bank HIV/AIDS capacity-building project, for \$5 million, and its first grant from the recently-formed Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), for \$35 million, \$29 million of which would go to HIV/AIDS efforts (Babich et al., 2006; The World Bank, 2010).

Throughout this period, policymakers from Lesotho had been working with a group of technical assistants from UN agencies and other international partners to pull together a lengthy document on HIV scale-up. This book, titled *Turning a Crisis into an Opportunity:*

*Strategies for Scaling up the National Response to the HIV/AIDS Pandemic in Lesotho* (Kimaryo et al., 2004), laid out a carefully-crafted vision of how the country could undertake a social and political metamorphosis in order to achieve a universalized, broad-based approach to the HIV/AIDS crisis it faced. More than any other events occurring at the time, this document set the tone for the scale-up that followed, and established Lesotho as a prime candidate for HIV/AIDS funding and initiatives. The document reflects a deliberate effort to re-shape the population and the government of Lesotho in order to make them more worthy and attractive recipients of HIV programs and funds. As such, it deserves some attention as a key marker of the HIV-related changes that followed.

### **Turning a Crisis into an Opportunity**

*Turning a Crisis into an Opportunity* (Kimaryo et al., 2004) is infused with calls for change, but also a sense of *mea culpa*, as Lesotho's leaders indicate that the time of crisis brought about by HIV is an opportunity to change governmental bad habits; it calls for a new dynamic of thoughtful and effective partnerships between recipients and funders. "We simply do not buy the mantra that 'Lesotho has no implementation capacity' as has often been said by some in the international community and, yes, even at times by ourselves" Prime Minister Mosisili asserts early in his introduction to the book (Kamaryo et al., 2004, p. vi). "It must be that the problem lies in the way we perceive development challenges—like HIV/AIDS—and the kind of solutions that we devise for addressing them..." (Ibid., p. vi). Here, Mosisili refers to long-standing criticisms and fears about Lesotho's ability to efficiently absorb development funds and put them to use: a "capacity" which was of particular concern to HIV funders. Assertions about Lesotho's "absorptive capacity" reappear throughout the document, which its authors believe will help pave the way for

“increased collaboration and higher absorption of existing and future funding”:

This is very important, because up until now, the Government has, on the one hand, felt that this country is not receiving enough resources to enable it to effectively tackle the pandemic whereas, on the other hand, the donors and other members of the international community have felt that it will be difficult to make the case for additional resources for Lesotho unless it can be demonstrated that it is possible for the country to absorb such additional funds.” (Ibid., p. xxx)

Even as the authors struggle elsewhere in the text to define Lesotho’s lack of capacity as a “myth”—a problem of perspective and labeling—discussions of capacity deficits lead to calls for very real and transformational change:

Often, the issue of capacity building is approached from the perspective of change, with approaches that do not bring change but are dressed up in the language of change. In the end, they contribute to strengthening the *status quo*. Transformational change, on the other hand, must start with clear political commitment at the top and be implemented [by] change champions in all institutions...” (Ibid., p. 35-36)

Key to this conceptualization of transformational change is building an HIV response that is linked to fundamental democratic ideals and institutional improvements that “should be based on the evolution of new values...as well as using every available opportunity to promote participation” (Ibid., p. 58). Here, *participatory* democracy rooted in grassroots mobilizations is considered crucial to deploying a new kind of HIV scale-up effort: “It is a well-known fact that public debate and dialogue—including the identification of needs as well as solutions to societal challenges like the HIV/AIDS pandemic, permitted by political freedoms and civil rights, can play a major part in the formation of a country’s democratic values” (Ibid., p. 58).

Equally crucial to these efforts to build a fundamentally different environment for HIV scale-up is a re-conceptualization of the drivers of the epidemic and the necessary areas for intervention:

The challenge facing countries like Lesotho is...to shift and deepen the conceptual

understanding underpinning the national response to a more comprehensive understanding, and...to reflect this conceptual shift in HIV/AIDS related programs and interventions (Ibid., p. 46).

The authors speak about the importance of addressing the underlying factors of HIV/AIDS, focusing on socio-structural drivers of the epidemic: power, gender relations, food insecurity and unemployment, lack of housing and basic services, social networks, migration and mobility, urbanization, and displacement.

Despite the far-reaching, progressive vision deployed in this document, few of its principles have held true in the HIV response that emerged from it. Rather than speak of socio-structural factors of the epidemic today, the government tends to focus on a decidedly behavioral approach, locating responsibility for HIV infection rates in the individual and his or her choices. Rather than speak of the impacts of urbanization and economic dislocation as drivers of the epidemic, and despite undeniable evidence of the high prevalence rates in Lesotho's most urbanized districts, government officials speak openly about the "ignorance" among rural, "backwards" populations as a cause of persistently high prevalence rates (Bulled, 2012). Along with NGO partners, they blame not the conditions of factory employment or economic migration for HIV rates in urban populations, but the behaviors and indecencies of young female factory workers (see chapter 6). And despite the emphasis on building a grassroots democratic base for HIV policies, rooted in political freedoms and rights, the government and its partners have tended to promote a decidedly top-down approach with power over policymaking concentrated in institutions subject to little democratic scrutiny, and an absence of grassroots civic participation (see chapter 2).

Nevertheless, *Turning a Crisis into an Opportunity* was enormously successful in attracting the attention and funding of donors and NGOs. Institutional changes quickly

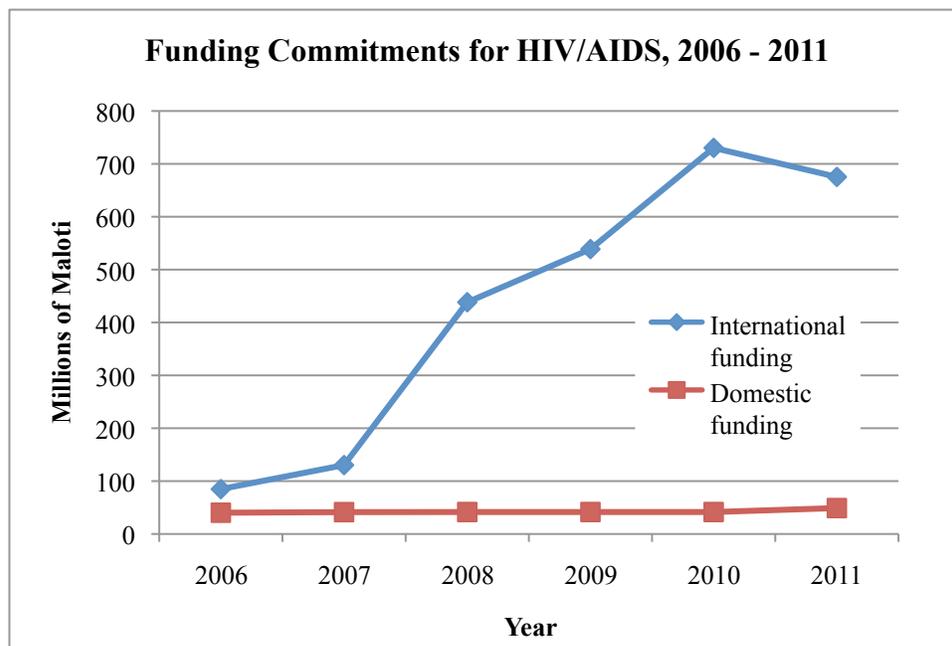


followed its publication: the formation of a National AIDS Commission and an HIV and AIDS forum; a national testing campaign; and the establishment of a new, national association of PLWHA. At the end of 2005, Prime Minister Mosisili announced a new testing campaign—the *Know Your Status* (KYS) campaign—modeled after Botswana’s universal testing initiative. KYS was introduced as a bold new attempt to test every person in the country over the age of twelve, using door-to-door testing efforts and improved access to voluntary counseling and testing (VCT) services in clinics (WHO, 2008). In addition, Lesotho developed a provider-initiated testing protocol, which meant that testing was offered as part of all routine services, and certain at-risk groups (women attending antenatal clinic, for example) would need to opt-out of HIV testing rather than opt-in for it. Thousands of lay counselors were trained in basic HIV testing methods and deployed throughout the country; nevertheless, many counselors did not receive test kits, were not properly trained, or were not deployed to all areas (Human Rights Watch [HRW], 2008). In a 2008 report on the KYS campaign, Human Rights Watch (2008) investigated widespread concerns about rights violations in the program—including lack of adequate consent procedures and forced testing. But as one of the report’s authors told me, the far greater ethical dilemma was that Lesotho lacked the capacity to provide any follow-up services (D. Lohman, personal communication, April 22, 2008). Without a comprehensive treatment program in place, counselors had no way to refer those testing positive to further care. It is not clear, however, that the objectives used by onlookers to evaluate KYS were even remotely similar to the objectives that drove the program’s development in the first place. Instead, it seems the initiative was deployed with two goals in mind: first, to attract global attention to Lesotho’s large population of patients in need of care and treatment; and second, to test and document that population, and in doing so, demonstrate that Lesotho’s

citizens were medically accessible, ready for treatment, willing to submit to regimes of biomedical testing and treatment. Know Your Status created a cadre of patients-in-waiting for donors eager to deploy treatment programs across a significant, but manageable, national landscape.

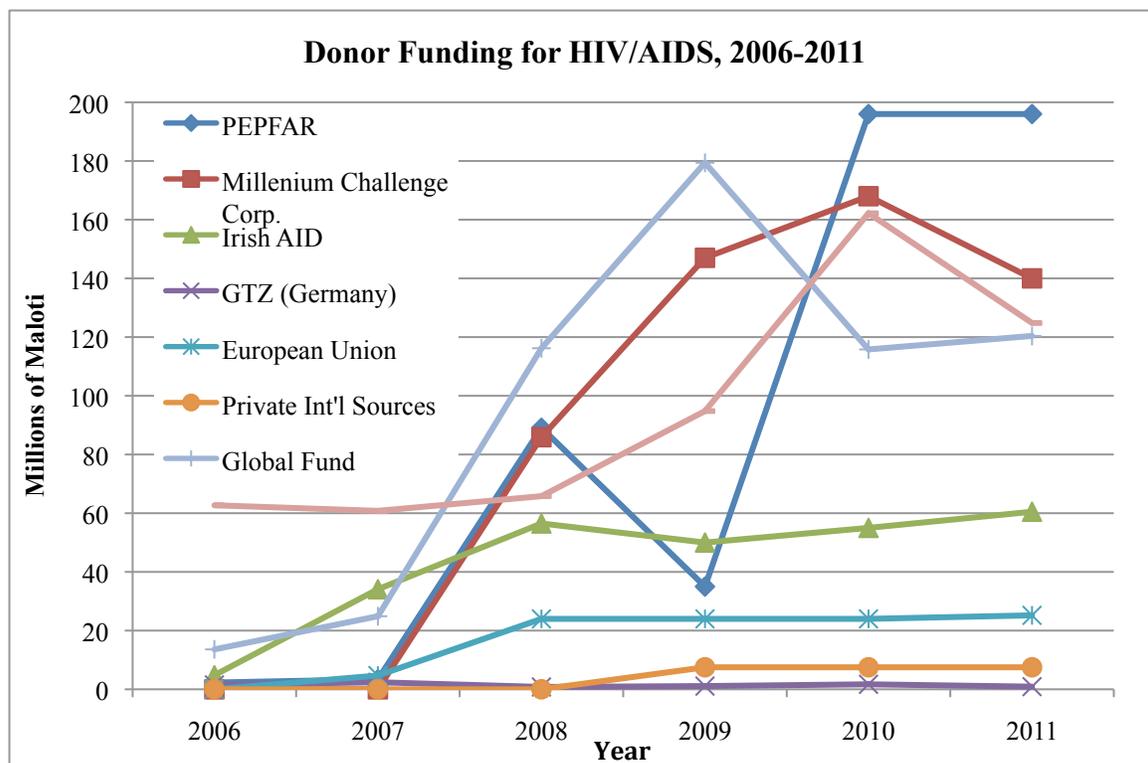
By 2006, grant money and support had begun to flow in earnest (see Figures 3.1 and 3.2 below)—and not only from the Global Fund. Numerous international organizations involved in global health and HIV/AIDS—like the Clinton Foundation’s HIV/AIDS initiative, Population Services International, and with funding from PEPFAR, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) and Columbia University’s International Center for AIDS Care and Treatment Programs (ICAP)—were now fully engaged in service delivery or capacity-building in Lesotho. Bill and Melinda Gates, Bill Clinton, Bono, and Stephen Lewis all visited the country within a 2-year time span. By 2007, funding had spiked upwards (NAC, 2011). With money came pressure to enact more institutional change—a host of laws and policies related to HIV prevention, the protection of vulnerable populations, and persons living with HIV/AIDS (NAC, 2011). In the past, perceptions of Lesotho as “good on policy, poor on implementation” had inhibited its attractiveness as a funding recipient (Gayfer et al., 2005). But now it seemed that declarations of commitment, policy development, and institutional change were the country’s winning characteristics, and a convincing measure of “capacity” and “political commitment.” This was not only true for Lesotho: The UN’s most comprehensive measure of HIV/AIDS response for quite some time has been the UNGASS “Status of the National Response” reports prepared by participating countries. This is an evaluation instrument that puts overwhelming emphasis on advances in policy, law, institutions, and civil society participation without evaluating the positive, material impacts of these developments for

citizens or PLWHA (NAC, 2010b; UNGASS, 2007).



**Figure 3.1: Total funding commitments for HIV/AIDS, 2006-2011:** Source: NAC, 2011.<sup>35</sup>

<sup>35</sup> Data on funding reported in Figures 3.1 and 3.2 is collected from the National AIDS Commission report on the national response (2011). The quality of data, however, is only as good as the efforts to collect and report it among government and its partners. There is significant room for confusion in accounting for funding and disbursements, and efforts have only recently been made to encourage public, consistent reporting among international donors about country-specific commitments. A number of informants expressed skepticism about the quality of government budget reports on HIV/AIDS spending in Lesotho; UNAIDS reports higher government commitments than are represented here (UNAIDS, 2012).



**Figure 3.2: Funding for HIV/AIDS by donor, 2006-2011:** Source: NAC, 2011.

### Competency as Virtuous Citizenship

What, then, allowed for such an extraordinary shift from the language and goals of a vision-defining document like *Turning a Crisis into an Opportunity* to the pragmatic realities of scale-up only a few years later? Some conceptual pathway must have provided a link across this disjuncture of policy. A notion of “competent citizenship” is established in *Turning a Crisis into an Opportunity* that demonstrates how discourses of participatory democracy and socio-structural causes evolved into the top-down, individualized approaches that actually occurred during scale-up. The specter of the “competent citizen” is centrally embedded in the policy and programmatic advances that follow. Its presence reveals how success in obtaining and maintaining global support for Lesotho’s HIV programs was indelibly linked to a project to reconfigure Lesotho’s citizens as ideal subjects for participation in HIV interventions. The subtle re-making of Lesotho’s public as

competent citizens demonstrates how HIV programs—even those determined to build “empowerment” and “capacity-building” among citizens, can end up marketing a national population as a reservoir of pliable, eager, subservient and diseased subjects for the scale-up of HIV interventions.

A core component of Lesotho’s approach to HIV—in *Turning a Crisis into an Opportunity* and elsewhere—is the effort to make citizens and communities “AIDS competent.” Developed by UNAIDS and partner organizations around 2000, AIDS competence initiatives aim to build local community capacity to recognize the threat of HIV/AIDS, account for community strengths and weaknesses to address this threat, and build resources and efforts to respond to HIV and AIDS (Lamboray & Skevington, 2001; UNAIDS, 2001). The initiative emerged from (well-founded) fears that HIV messaging that emphasized behavior change education and top-down prevention strategies was largely ineffective in reaching and speaking to target audiences. The objective was not only to develop more community-oriented discussions about the causes and effects of HIV/AIDS, but also to develop local human capacity to respond to the challenges presented by the epidemic (Lamboray & Skevington, 2001). In Lesotho, AIDS competency became firmly linked to principles of citizenship. *Turning a Crisis into an Opportunity* speaks about the role of individuals in HIV/AIDS competencies as a set of civic rights and responsibilities: “Every Mosotho should know what his or her rights and responsibilities are...every individual is not only able to lay claims on society to have his / her rights respected in the context of this emergency, but also accepts that he / she has a duty to contribute to the fight” (Kimaryo et al., 2004, p. 5). Beyond stating that citizens have a *responsibility* to become competent, however, this text and others remain relatively silent about what becoming competent actually entails. Nevertheless, the text does emphasize the

importance of strengthening local systems of government and forums for popular participation, creating a “more accessible government, which is more knowledgeable about local conditions and more responsive to people’s demands” (Kimaryo et al., 2004, p. 91). Nor were these entirely empty promises: Lesotho is engaged in a long, painful process of health system decentralization spurred by these goals, and community and district levels of local government have taken on additional roles in HIV planning and processes (see below).

In practice, HIV competence approaches set the stage for shifting the responsibility for care-work and even for HIV infections onto citizens and communities. This led to expectations that citizens would provide free labor in carrying out care work, joining in community associations and support groups, and providing support to those on HIV treatment. Such expectations were spoken of as volunteerism, but in the context of poverty, lacking government support, overwhelming need, and the extraordinary funding for HIV entering the country, citizens perceived these expectations as unjust. Finally, HIV competence approaches marked a subtle change in perceptions of HIV that resulted in vast discursive changes: If citizens are made responsible for HIV, then their behaviors, outlooks, and levels of knowledge are to blame when they become infected—rather than social drivers of the epidemic like inequality, gender discrimination, and poor government policies. Given that South Africa’s President Mbeki was, at this same time, asserting to a world audience in Durban that poverty caused AIDS, governments, development planners, and global institutions faced a potential source of strife, or even civil unrest, if the notion took hold that poverty, not pathogens, was to blame for the millions of deaths due to AIDS in Africa. But rather than address the daunting challenges of tackling social inequalities, governments and international institutions turned towards competency, focusing on

behaviors, individual responsibility, and knowledge about HIV. Approaches use the language of “empowerment” and “citizenship” to mask a great shifting of responsibility from governments to citizens. A handbook on HIV competence for local government went so far as to tell community councilors that “competence entails being aware of the importance of culture and its positive and negative impacts on HIV and AIDS and accepting the presence of HIV in your community” (GIZ, 2006, p. 11). Messages like these seem to encourage citizens to police the effects of “culture” on HIV spread.

Competency efforts are not unique to HIV, dating back to post-colonial, neoliberal development initiatives across Africa that emphasized individual capacities rather than the sculpting conditions of colonialism or poverty as the determining factor of development success (see, for example, Ferguson, 1994). The dismantling of the African state brought about by the rise of neoliberal approaches to health and development placed an increased reliance on individual responsibility, market freedoms, and citizen competency. These foci depoliticized poverty and ill-health, and turned landscapes for political engagement into spaces of blame for citizens (Pfeiffer and Chapman, 2010).

In Lesotho, efforts to build a “competent citizenship” in the time of HIV/AIDS focused on “decentralizing” responsibility while undermining communities’ senses of agency and voice. Calls for competence emphasized the importance of biomedical expertise among citizens about risk behaviors and prevention strategies, instead of strategies to foster accountability and participation in policymaking. Though materials spoke about citizens’ rights, discourses often offered only a right to freedom from discrimination, and did not include broader discussions of civil or social rights. Discourses of HIV competence allowed HIV to overtake broader spaces and practices of engagement between citizens and government. This was most evident in the use of *pitsos* to spread HIV

education messages. *Pitsos*—community meetings called by a chief or high official—are the most prominent and important forum for participation and voice for citizens in Lesotho. As discussed in chapter 2, *pitsos* allow citizens to express opinions and make requests of leaders that they might not otherwise feel comfortable voicing, and the meetings often conclude with voting and consensus-building that leads to collective decisions about resource distribution, community endeavors, and future goals. But under development initiatives, and much more prominently during HIV scale-up, *pitsos* became forums for NGOs and local leaders to deliver messages about what NGOs would be doing in the community, and for HIV counselors to spread information about HIV within communities. These uses of the *pitso*, while efficacious to NGOs and government attempting to carry out HIV projects, subvert an important form of political engagement, turning it into a top-down space for disseminating information and telling communities about HIV and initiatives.

This tendency is not unique to Lesotho, and it is difficult to overcome: Even amidst Brazil's quite radical state activism on HIV, Joao Biehl (2007) notes the ways that patients are drawn into the state as service providers and "biological citizens," speak in dialogues that that reassert the power of pharmaceutical medicines, and become obedient to biomedical regimes of regulation and salvation.<sup>36</sup> Nikolas Rose and Charles Novas (2000) have written about how ideas of personal responsibility for biomedical futures arise as a central effect of contemporary regimes of biopower—even among those suffering from genetic diseases, which are the by-products of chance and ill-fated parental pairings. Even here, we can observe citizens engaging in projects of "prudence and obligation" (p. 487), policing their very own bodies and their biological risks. In contrast, Steven Robins (2008) extends this analysis in his discussions of the political subjectivities of treatment activists

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<sup>36</sup> This tendency is also reflected in Nguyen's (2008, 2010) discussions of "therapeutic citizenship" in West Africa (see chapters 1 and 4).



and support group members living with HIV in South Africa. For them, responsabilization is hardly a product of “the cultural hegemony of biocapital,” Robins argues, “and the downsizing neoliberal state’s imperatives of governance-at-a-distance,” but rather a form of empowering knowledge and action (p. 128). Particularly in the wake of these activists’ near-death experiences with AIDS (many of them at a time before ARVs were made available by the South African government), treatment adherence and biomedically-responsible behavior is part of an awakening of new political subjectivities. These born-again citizens, are “the product of more than HIV/AIDS awareness campaigns, sex education, treatment literacy and rational choice,” Robins argues (p. 142). Responsibilization becomes part of “hybridized” subjectivities used by citizen-patients to make claims to state resources and forms of belonging.

In Lesotho, I observed more troubling patterns of subjectivation, particularly in the absence of any meaningful patient-activism around HIV. While responsabilization is a form of governmentality in Lesotho that subtly and subversively encourages citizens to govern themselves, their bodies, and their pathogens, it has hardly been successful in this capacity—as even a cursory glance at Lesotho’s persistently high HIV infection rates will show. The only thing that seems truly self-governed is, as Swidler (2009b) notes, the discourse of a citizen when speaking to a well-heeled foreigner about HIV—citizens are adept at knowing how to say the right things in the right language about HIV “acceptance,” “stigma,” and “risky behaviors.” Instead, I am interested in responsabilization as a form of blame-shifting. In addition to discourses of responsabilization that markets citizens as self-governing subjects and ‘good’ recipients of HIV programming, talk about responsibility and obligation, in conjunction with program decentralization efforts, allows blame for poor or insufficient outcomes to be routed towards citizens rather than implementers or

governments. This tendency to shift blame towards the poor (even as structural inequalities limit their choices, and policies are deeply inadequate) is common—from blaming welfare mothers for their own poverty in the US (Reese, 2005) to “unsanitary” indigenous citizens for cholera outbreaks in Venezuela (Briggs & Mantini-Briggs, 2004; see also Farmer, 1992). Here, however, citizens are not just blamed for their own infections, they are held responsible for inadequacies in *program* outcomes, gaps in implementation, and policy failures. Responsibilization as blame shifting creates a troubling, but (for the government) productive, double-bind for citizens: The more they take action, responsibility, agency in responding to the presence of HIV (and at the request of the government and donors), the more likely they are to incur blame when outcomes are insufficient.

Like many tools, HIV competency’s ability to create social empowerment and local political enfranchisement depends, to a great extent, on how it is wielded. Catherine Campbell and colleagues from the University of KwaZulu-Natal’s HIV/AIDS Network have engaged in a long-term, community-based participatory research project to build HIV/AIDS competence in a rural, marginalized community in South Africa (Campbell, Nair, & Maimane, 2007; Campbell, 2009). In contrast with discourses of competency elsewhere, their vision of competence is an ambitious and progressive one, drawing on Freire’s (1970) strategies for building communal *critical thinking*, and Habermas’ ideal-typic *public sphere* (Habermas, T. Burger, & Lawrence, 1991). Campbell and colleagues (2007) identify six key characteristics of an AIDS competent community: 1) expanded knowledge and skills related to HIV/AIDS; 2) positive social spaces to foster critical thinking and dialogue about HIV/AIDS; 3) ownership and responsibility for drivers of and responses to HIV/AIDS; 4) confidence in local strengths; 5) solidarity and common purpose regarding HIV initiatives, even despite natural community diversity and divisions; and 6) ability to foster bridging

social capital in order to link to sources of support and funding.

Troublingly, despite long-term, concerted work to foster these forms of “competence” in the community, Campbell (2009) faced numerous barriers: gender and age discrimination undermined efforts to spread knowledge and build solidarity; powerful community members used HIV initiatives as opportunities to reinforce, rather than deconstruct, persistent inequalities; older women bore the vast burden of responsibility for HIV care and prevention work; and despite broad connections to sources of funding through the researchers, the community did not succeed in securing sustainable funding for its projects or efforts. Women, who already occupied a weak position in the community, continued providing care and educational work unpaid, while unfulfilled promises soured hopes. Among Campbell’s (2009) conclusions is this troubling observation: “our experiences highlight the irony that many of the most powerful members of the Entabeni community have a vested interest in preserving the very social relations that facilitate HIV-transmission and undermine the well-being of people with AIDS” (p. 17).

Writing on the impact of HIV programs on citizen subjectivity in Brazil, Vera Paiva (2003) differentiates between “consumers” and fully-fledged citizens. Drawing on Freire, she explains that HIV programs have a tendency to turn agentive, participating citizens into consumers through a “banking style practice” in which information and instructions are “deposited” into the person so as to encourage him to consume products and practices (p. 113). For consumers (as opposed to citizens), “social and economic rights...including rights concerning faith and culture, all fall into the black hole of individual achievement...of empowerment considered to be a...compensating factor” for structural constraints like inequality and injustice (Ibid., p. 114). In this context, such constraints are

“perceived as the outcome of individual will, willpower that remains unconscious of the collective and contextual constraints [to health] (Use a condom! Take your medicine correctly! Convince yourself that you can do it! Be efficient! Improve your self-esteem!)” (Ibid., p. 114). Emphasizing the agentic aspects of true citizenship, Paiva (2003) asserts that a citizen in the time of HIV

...is conceptualized as the starting point for a lively *interaction* and not a consumer of a finished *product*... The *individual/citizen* in fact...follows a path of reconstruction or deconstruction of individual and collective appropriation of a range of proposals placed before him, by public services, community leaders, academics and the media, involving prevention or care (p. 114, emphasis original).

Thinking of citizens as consumers and of HIV services as products, she argues, erodes our ability to think of patients as citizens and as health services as rights (p. 115). More fundamentally, however, it limits thinking about citizens as agents interacting in their own social worlds, whose collective agency itself can be a protective force against HIV (Berkman, Garcia, Munoz Laboy, Paiva, & Parker, 2005; Parker, 2011).

Paiva's (2003, 2007) work in HIV education draws on Freire's *Pedagogy of the Oppressed* (Freire, 1970) to “conscientize” (p. 109) citizens about the structural factors of their vulnerability to illness, challenges in adhering to medicines, or inability to access health services (see Paiva, 2007). The challenge of conscientizing health services, she writes, is “to waken the ‘sleeping’ public citizen inside every private consumer, by transforming care and prevention activities into spaces which can embrace and foster psycho-social emancipation” (Paiva, 2003, p. 115). HIV efforts can lead to a process of *conscientization* (Freire, 1970) of citizens about the structures of power in their lives and

encourage natural solidarity and capacities.<sup>37</sup> But an emphasis on “competency” seems to more often lead to a process of *responsibilization* of the public, in which education efforts presume citizens’ natural *incompetence*, and where communities are asked to contribute labor, resources and effort to addressing HIV without gaining access to a means of changing structures of power that contribute to vulnerabilities.

I am interested here in how *conscientization* can provide a useful foil to *responsibilization*, and how these concepts are emblematic of different approaches to engaging communities in HIV projects. Here, a careful consideration of alternative futures—and of the conditions that produce this alterity—is essential to understanding not what is *wrong* with current approaches, but how they do not have to be as they are. The chapters that follow highlight this contrast between *conscientization* and *responsibilization*. *Responsibilization*, as made emblematic in Lesotho by discourses of “competency,” is linked to short-term *HIV projects* with pre-determined goals and outcomes, and tends to decentralize blame for poor outcomes to citizens and their communities. Even if it has short-term positive impacts—on the knowledge base of citizens, or their ability to adhere to medical regimes—these come at the expense of more transformational changes. *Conscientization*, by contrast, is linked to long-term *life projects*. It reflects the priorities and goals of citizens, recognizes the multiple forms of survival for which they are striving, and addresses the structural limitations on their ability to achieve the things they have reason to value (Sen, 2001).

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<sup>37</sup> I take the term from Freire’s *conscientização*, which is also referred to as critical consciousness-raising. For applications of conscientization in HIV prevention, see Paiva’s (2007) work with teens and HIV risk in Brazil.

## Decentralizing Competence

Soon after HIV treatment became available in Lesotho, the government, in partnership with the German Technical Cooperation (GIZ, previously recognized as GTZ, a branch of Germany's bilateral development aid institutions), and with assistance from UNAIDS, announced a new initiative called the Gateway Approach. As a formalization of the plans for decentralization and community-mobilization outlined in *Turning a Crisis into an Opportunity*, the Gateway Approach announced that communities—community councils, specifically—would now be the “gateway to fighting HIV and AIDS” (German Technical Cooperation [GIZ], 2006). This vague slogan enabled the Gateway Approach to become a kind of umbrella concept for a number of different interventions, decentralization strategies, and ideas about the role of local government in HIV scale-up efforts. Nonetheless, the Gateway Approach did, in many ways, represent a concerted effort to put HIV priority-setting in the hands of communities, to build community engagement in HIV projects, and to change the everyday politics of how HIV scale-up occurs. In this regard, it was a novel and promising strategy: If any country was going to succeed in utilizing HIV scale-up to build, rather than dismantle, democratic participation and civic action, Lesotho's Gateway Approach seemed likely to provide the fertile conditions for such a development. The Gateway Approach led to two primary initiatives aimed at decentralizing power and priority-making processes: first, community councils were engaged in an HIV priority-setting process to determine “Essential Services Packages (ESPs)” and possible areas of community intervention in HIV (Ministry of Local Government and Chieftainship [MOLGC], n.d.); and second, district and community AIDS Committees were established to coordinate the response to HIV in communities and improve “HIV competency” at community levels (Chiyoka & Hoohe-Nonyana, 2010). The

Gateway Approach's original stated goal was to establish community councils as a "gateway" for the AIDS response—with implementing partners working in the community (NGOs, but also government agencies like Ministry of Health) obligated to work through and with councils. This would involve tailoring programs to meet council priorities, updating them on activities, drawing on their local expertise, and reporting back to them about project outcomes. In this original vision, community councils could have emerged as local-level institutions for coordinating the response, making community priorities heard, and holding implementing partners accountable to communities. Yet much like the goals laid out in *Turning a Crisis into an Opportunity*, policy objectives tended to be radically dismantled by reality, replaced with programs that hardly even resembled their originating conditions.

The Gateway Approach represented an ambitious vision of how HIV scale up and grassroots democratization processes could mutually benefit each other. It emerged from the idea that HIV interventions would be most effective, and most meaningful, when they arose from community consultations about needs and vulnerabilities, and when they enjoyed the thoughtful engagement of citizens. In fact, the Gateway Approach was one of the primary reasons I chose to conduct research in Lesotho—it seemed that if any place could succeed in harnessing HIV scale-up to positive political change, it would be Lesotho. From the beginning, however, the program struggled with the tensions already highlighted earlier in this chapter: tensions between conscientization and responsabilization, between meaningful participation and service provision, and between the decentralization of political power and the delegation of labor and blame. These tensions are evident even in the manual developed to explain the Gateway Approach to Community Councils (GIZ, 2006). Staff of the Ministry of Local Government and Chieftainship (MoLGC) and GIZ

developed the manual in 2006, and excerpts of the English version are included below. It is designed like a photographic comic book, with staged pictures presented along with brief dialogue that tells a story about how the Gateway Approach unfolds in one community.

The booklet (GIZ, 2006) opens with women gathering water at a dirty stream near a village. One woman complains to another that her child is sick with diarrhea from the water, and others agree that something must be done about it. A third woman (see Figure 3.3, below) says that they can vote in upcoming community council elections, “and then we can have clean drinking water, which is what we need” (p. 5). Villagers vote in the elections, saying they will be good for addressing problems in the country. Later, the newly-elected councilor reviews community priorities: “Electricity, roads, drinking water, clinic,” she says, “this is like a wish list....it’s hard to know which priority to start with” (p. 8). Then “HIV and AIDS Competency Training” facilitators arrive on horseback at the village: “Achieving an HIV and AIDS competent society is the key to a community and individual response towards the pandemic,” readers are told (p. 9). They host “Competency Trainings” for the community council, talking about what HIV is, how it infects the bodies, whether there is a cure for HIV. They are then told about competence—that it involves knowing about HIV/AIDS and supporting those who are affected by it, as well as being aware of “culture” and how it affects risk for HIV (see Figure 3.4 below). They are told that the council is the “Gateway” to fighting HIV and AIDS, that this means “showing responsibility” and sharing this knowledge with others (pp. 10-11, see Figure 3.5 below). The language becomes technical:

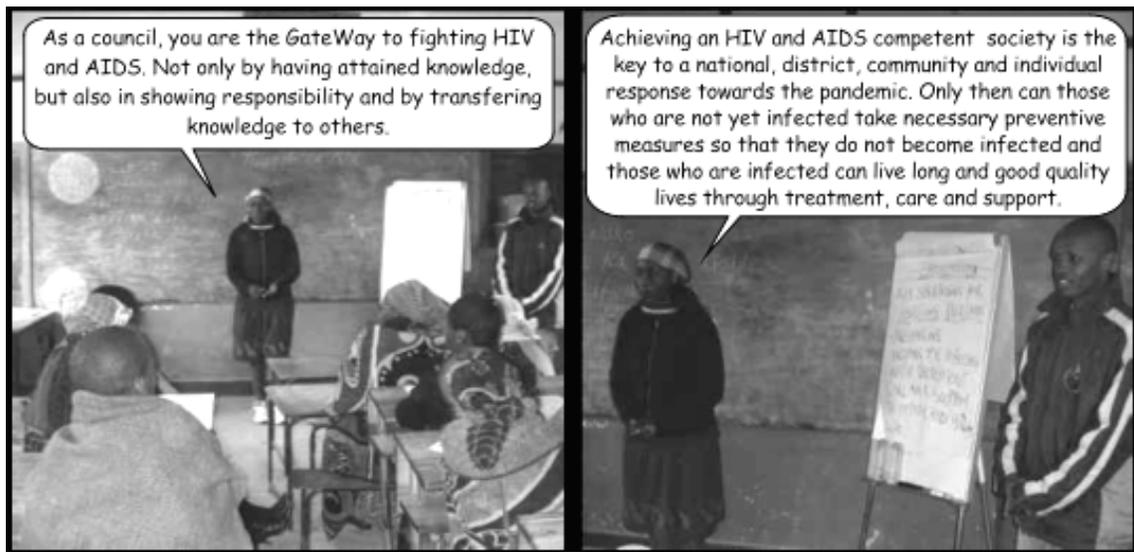
Achieving an HIV and AIDS competent society is the key to a national, district, community and individual response towards the pandemic.... Obtaining HIV and AIDS competence is the basis and starting point to maintain the flow of the mainstreaming process through the different phases of the Gateway Approach (p. 12).



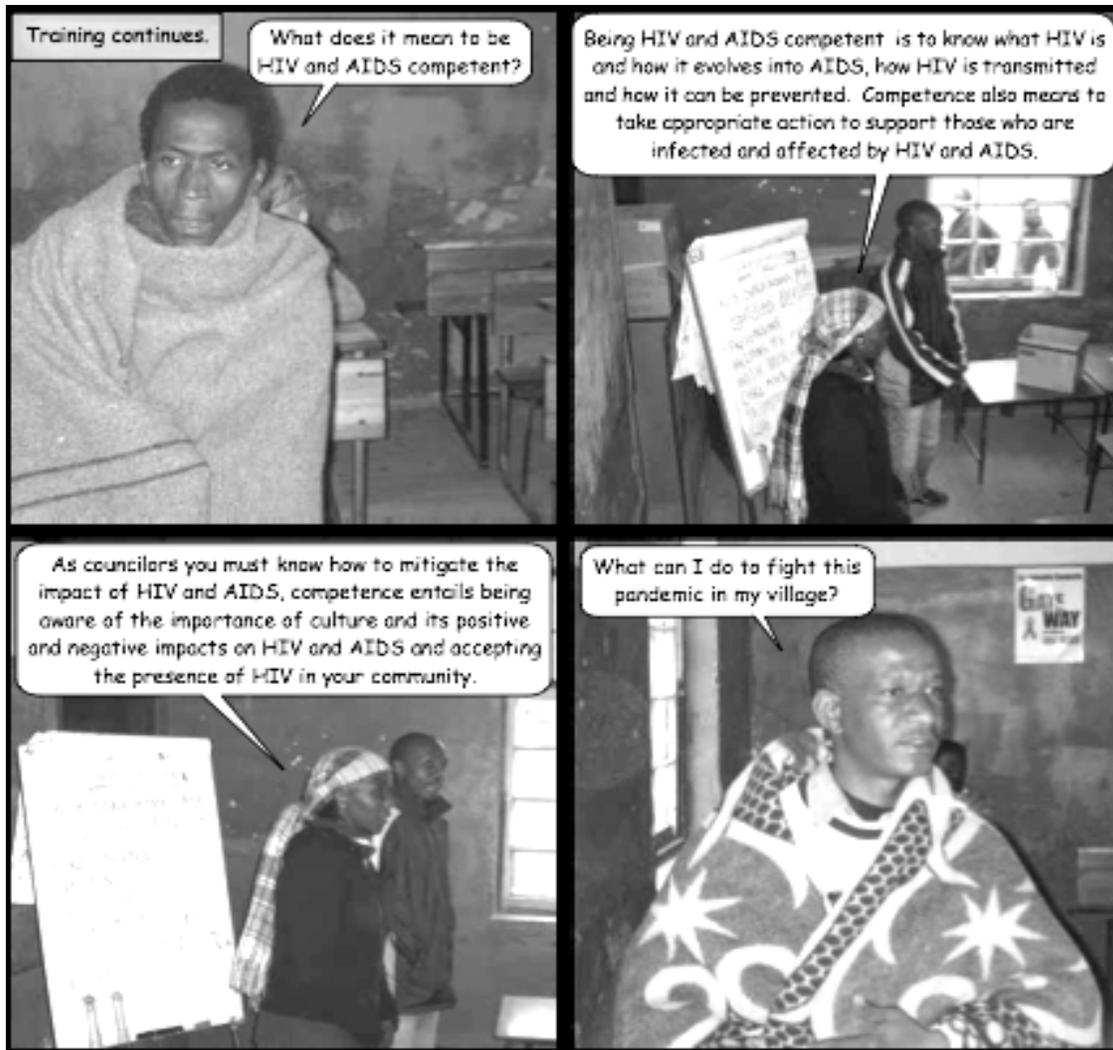
The councilors are told that once they become “competent,” they will “integrate the work of HIV and AIDS into all our daily activities” (p. 12). Trainings continue for public servants, chiefs, and traditional healers, encouraging them to incorporate HIV into their work, and to think about HIV in each of the problems they face professionally. At this level, “mainstreaming” represents an interesting recalibration of how citizens think about and perceive problems in their community. Unclean water becomes a problem related to HIV and AIDS—clean water is needed for *patients* and *caregivers*—not as an element of primary health care for all villagers. The manual clearly conveys the message that, under this approach, community councils will take on responsibility for HIV in the communities, but does not discuss whether, along with these responsibilities, they gain any rights. It also fails to discuss how councils can increase their advocacy in dialogues with NGOs or the government.



**Figure 3.3: A community council manual on the Gateway Approach: Contemplating the impact of elections.** Source: GIZ, 2006.



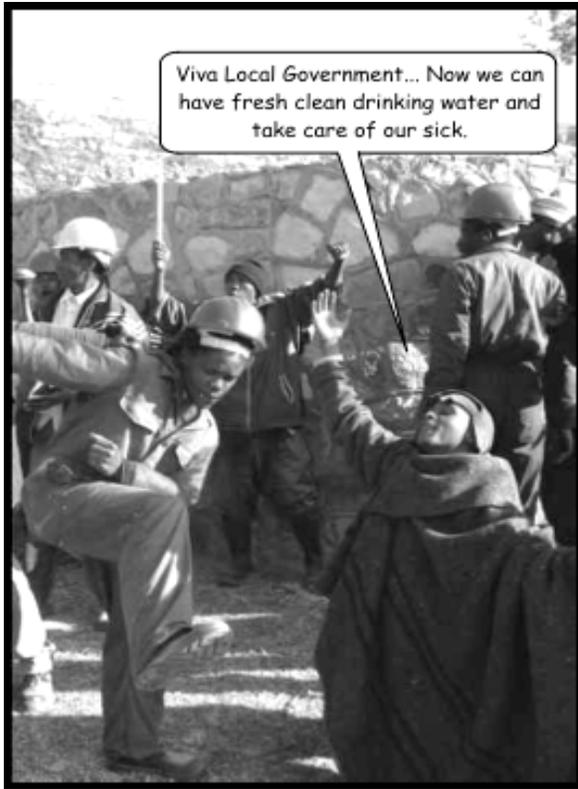
**Figure 3.4: A community council manual on the Gateway Approach: The gateway to fighting HIV and AIDS.** Source: GIZ, 2006.



**Figure 3.5: A community council manual on the Gateway Approach: The meaning of HIV Competence.** Source: GIZ, 2006.

After the trainings, the manual depicts the community and district councils undergoing a priority-setting process for HIV and development goals. Projects to address needs are separated into three categories: those that have an impact on HIV and AIDS (for which funding has been set aside), those that are “self help” projects which do not require external funding or support, and “development projects” which ostensibly do require outside support (GIZ, 2006, pp. 24-26). In the village, clean drinking water gets the most votes; money is collected from villagers to fund the construction of a water tank. Priorities

and budgets for projects are sent up to the District Council, which decides on district priorities. It is not clear from the manual whether these priorities impact national planning processes, nor is it clear if the village gets financial assistance for its water tank, and if so, where it comes from. Nevertheless, the community builds the tank and the villagers are happy about the results. It is clear that the community has achieved its goal, but it has done so largely of its own accord—through its own funding and labor. What is seen here is how decentralization re-locates the onus of responsibility for problems and their solutions within communities—not an entirely detrimental goal, if communities are endowed with the resources and capabilities to develop those solutions. But without a clear vision of how communities are impacting broader national dialogues about HIV and development, nor of how communities can gain a foothold in discussions with NGOs about their priorities and needs, it is unlikely that these resources and capabilities will simply materialize as a result of the decentralization process. Ultimately, what impact does this new process have on citizens' political subjectivities, and on the ways they view themselves and their roles as citizens?



**Figure 3.6: A community council manual on the Gateway Approach: Viva local government.** Source: GIZ, 2006.

In 2007, Community Councils across the country were led in an HIV/AIDS priority-setting process that was a loose re-enactment of the one outlined in the Gateway Approach manual. This process, referred to as the “Essential HIV and AIDS Services Package”—more commonly, the ESP—allowed councils to choose priorities in five different categories of “objectives” in the HIV/AIDS response: “Prevention through change in sexual behavior”; “access to HIV testing and health services; prevention of mother to child transmission”; “orphans and vulnerable children”; and “support for people who are HIV+” (MOLGC, n.d.). Councils could select and rank their top three priorities from predetermined lists of between four and eight interventions that had been drawn from the National Strategic Plan on HIV and AIDS. These interventions were laid out for the councils in a handbook that included specific formats, outcomes and benchmarks for each intervention (MOLGC, n.d.). The intervention choices are listed in Appendix C. After choosing priorities, councils were

given small grants as part of a pilot program to be used to implement their chosen interventions.

While the priorities selected by the councils offer a rough ranking of some of the more important HIV needs in their communities, it is difficult to see how the process truly gave councils an empowered role in priority-setting, especially when the priority choices are pre-selected. The National Strategic Plan (NSP) is a document that broadly reflects global funding and intervention priorities. It is in the government's interest to reflect these priorities in order to attract funding, and international partners contribute heavily to the creation of the NSP. The distilled choices offered to councils were even more limited. As a result, councils scoffed at the choices they were given, and said the process "could not accommodate some of the issues they would have wanted to include" (Chiyoka, 2009, p. 10). Other councils simply listed the additional interventions that they felt were important. These additional interventions showed surprising similarity, and reflected many of the most pressing and under-acknowledged needs that communities face in the time of HIV: acute food insecurity; a concern about vulnerable populations often overlooked by formulaic HIV policies, like "herdboys" (young men who spend months at a time tending cattle with little access to education or services); and educational and training needs for additional/nontraditional groups in HIV/AIDS (Community Council Plans, n.d.). These additional priorities are outlined in Table 3.1. Finally, some of the most commonly-selected priorities, which spoke to deficits in the health sector like lack of trained staff, lack of transportation, and the need for PLWHA to work as expert patients, were later dismissed by national stakeholders and the ESP organizers as "not within the scope of [Community Council] work and therefore ill-advised." It was "generally agreed" that these priorities were the responsibility of the Ministry of Health and that some priorities were

“not...entirely realistic [or] sustainable” (Chiyoka, 2009, p. 23).

| <b>Additional Community Council HIV Priorities</b>                         | <b># of councils listing priority</b> |
|--|---------------------------------------|
| HIV education needs of special groups:                                     | 99                                    |
| -herd boys   | 38                                    |
| -traditional healers   | 15                                    |
| -support groups  | 13                                    |
| -public servants (teachers, council, police)                               | 12                                    |
| -elderly   | 11                                    |
| -disabled  | 10                                    |
| Agricultural/nutritional needs of patients, orphans, affected families     | 55                                    |
| Income generation or vocational training for vulnerable—especially orphans | 14                                    |
| Need for first aid kits/gloves in homes of sick and public places          | 10                                    |
| Develop traditional/herbal medicines to treat HIV                          | 5                                     |
| Human rights and gender equality campaigns                                 | 4                                     |
| Other improvements in clinic service/infrastructure                        | 4                                     |
| Need to train men in home-based care                                       | 2                                     |

**Table 3.1: Additional community council priorities on HIV:** not included in pre-determined priority lists for councils. Source: Community Council Plans, n.d..

The grants for councils to work on interventions, though they did not go far, did result in a great number of small-scale interventions, mostly in terms of registering patients or orphans, coordinating trainings, and organizing condom distributions. Some councils succeeded in working with NGOs to assist them in service delivery, on projects like condom distribution campaigns. Others were less successful: A great number struggled to work with NGOs at all, and a few were actually charged exorbitant fees by the Ministry of Health for basic trainings on HIV and AIDS that ate up the majority of their budgets. An assessment of the project reported that only “a few” councils were able to leverage the program in order to establish better coordination with NGOs and service providers in their area. But blame for these insufficiencies was placed squarely on the shoulders of the councils: “the roll-out of the Gateway Approach is yet to be fully understood and ‘accepted’ by all players... [as a result] stakeholders continue to implement their interventions with no consultations or communication with the [councils]” (Chiyoka, 2009,

p. 16). Nevertheless, many councils reported that the process had helped them, that they felt better able to speak about HIV in their communities, as if they had been granted a small space for agency in addressing the epidemic: "Our communities feel for the first time HIV has been brought to their doorstep," one councilor reported, "[we] now know that the prevention of HIV and care for the affected is not [just] the work of NAC..." (Ibid., p. 32). Perhaps this delegation of responsibility, no matter how daunting, felt refreshing in its novelty, even if the scope of action was limited by a lack of change in the structures of power or processes of decision-making. Ultimately, the councils' grants were not renewed, and had been dependent on external funders in the first place. There were accusations of corruption and mismanagement of money, with councils saying that the National AIDS Commission had never released their funds, and funders accusing councils of pocketing the money. It is difficult to assess which, if any, of these accusations is true. In many cases, councils, faced with a renewed awareness of the enormity of economic vulnerability and food insecurity in their communities, chose to allocate the funds on food packages and small gifts of goods and medical supplies to sick patients, their families, and orphans. This was deemed a misuse of funds by the program organizers (Ibid.).

Following the ESP process, AIDS committees were established in conjunction with councils at district and community levels in 2009. The purpose of these committees was to establish a local, standing body responsible for coordinating the HIV response in communities. It was hoped that these bodies, made up of representatives from sectors and groups relevant to the HIV response (clinicians, PLWHA representatives, traditional healers, support group representatives) would be more knowledgeable about HIV and better able to coordinate with NGOs, clinics, and the National AIDS Commission to continue working on the priorities set forth in the ESPs. Trained coordinators were



deployed to all districts as Community Council Support Persons to assist committees in their first few years. In October 2010, I attended a meeting of AIDS committee members from across the country; the meeting was convened to review a recent assessment that had been conducted of the committees (Chiyoka & Hoohle-Nonyana, 2010). The news was not good: Though committee members were extremely enthusiastic about their positions and expressed sincere desires to address HIV issues in their communities, they were not clear on their roles or responsibilities, lacked basic knowledge about HIV, and frequently had no idea what they were actually supposed to do in their “coordination” role. In discussions at the meeting it emerged that many committees had been hurriedly put together, with representatives selected ad-hoc. Both representatives and their intended constituents were unaware of representatives’ intended roles. One attendee at the meeting explained:

I don't even know where the idea itself came from that such committees should be established.... They went to the clinic and they told the nurse, 'we are establishing a committee of the council, we need a person living with HIV, can you give us a person living with HIV?' ....Even the nurse does not even know what that person is going to do in the committee.... The only thing they [said] is that they are establishing a committee, but it's not clear what this committee will be working on...or what their role will be on the committee...

Thus, rather than bringing democratic decision-making and participatory processes to a local level, AIDS committees’ confusion about their roles and mission complicated the local political terrain around HIV and AIDS responses.

Though AIDS committees were intended to fill a coordination position between local government, service providers, and citizens, official documents explaining their actual duties emphasized their obligations as local implementing agencies. They would design and carry out small projects, collect data, submit reports on activities and data to national entities, raise and budget funding, and develop and carry out monitoring and evaluation (M&E) in their areas (Chiyoka & Hoohle-Nonyana, 2010). The committees

lacked the specialized skills necessary to do much of this work, and were not trained for it. But Community Council Support Persons and other policymakers often blamed their lack of knowledge on “illiteracy” and poor education among members, even though literacy rates are very high in Lesotho. Despite these apparent limitations, and without significant training, members made efforts to index and address HIV needs in their communities. Though they struggled to fulfill their “advocacy” roles without training and support, and though many remained unaware of how to engage in law or policy reform, they were quite active in their communities in mobilizing support from neighbors for orphans and patients in need of care. Without training in how to solicit funding or support from donors or NGOs, councilors appealed to community members themselves for financial assistance during funerals, school meetings, *pitsos* (community meetings called by the chief), and church services (Ibid.).

Neither the ESP nor the AIDS Committees succeeded in dramatically, or even incrementally, altering how the politics of HIV programming plays out in Lesotho. By and large, these institutions emphasized a set of localized strategies for implementing policy and channeling information upwards without giving citizens opportunities to impact policymaking, or access new forms of knowledge and information about donors, policies, government, or even the epidemic. Sometimes the key players involved in driving the Gateway Approach seemed painfully aware of these insufficiencies; at most other times, it seemed as if these original objectives had been forgotten, washed away by the rising tides of scale-up. These cases highlight crucial differences between meaningful and token participation, between shaping and implementing initiatives, and between setting and picking priorities. While councils welcomed the opportunity to take action on HIV, their efforts to do so were clearly constrained by their lack of real capabilities that would enable

them to take part in planning, policymaking, and participating in scale-up, and by the structures of power within scale-up processes to which communities were already tightly bound.

### **Negotiating the right to govern**

As institutions caught between NGOs, funders, initiatives, and recipient communities, councils and AIDS committees struggle to fulfill their roles. In addition to a lack of capabilities or training, my observations and discussions with councils revealed that their primary obstacles were their unequal relations with those executing HIV programs. HIV program staff, NGOs, funders and government officials all seemed to use councils only when they needed something, like data on orphans, condom distribution, or a building site. This inversion of the original intent of the Gateway Approach was well known, even a source of jokes: When Bill and Melinda Gates and Bill Clinton visited Lesotho, a local newspaper ran a picture of the trio with the caption, “The *Gateway* to Treatment,” a play on words that emphasized the Gates’ influence over Lesotho’s access to HIV treatment.

Even though many HIV programs seemed extremely sincere in their commitment to community partnerships and their emphasis on getting buy-in from the community, when observed from the perspective of citizens and councils, these exchanges were unequal, at times dishonest, and often extremely stressful. Councilors and citizens felt that “these people” just came and went, often “disappearing” for long periods of time. When I first began working with the community council for Ha Mamello, we spoke at length about my project and my desire to sit with the council for their meetings over the course of a year. But as the first meeting came to a close and we packed up our things, one of the councilors

said to me, “so now you are just going to disappear?” Even despite my lengthy reassurances to the contrary, the council believed that I would arrive, speak to them, and disappear for months on end, much as so many other people (particularly those from my own country) had done before. This constant movement of NGOs and programs in and out of council areas causes considerable problems for communication and mutual accountability. An AIDS committee member from another district explained:

[As a committee member] you don't know who is in charge of what. The NGOs and the committees, they are never sure who is responsible because today they come with one guy, and the next time they come with another guy...and there is no follow-up of issues. Now we are getting confused because today we go [to meet the NGO] and we find one person; next time we meet them again, and it's someone else entirely, and it really seems confusing.

This also means that committees and councils have no idea who they work with on a long-term basis, which means that when they have questions or problems with a program they have no one they can contact, no means of getting in touch with the program's managers. This compounds their sense that programs arrive and subsequently “disappear.”

Even when programs have a presence in the community, the power inequalities between councilors and NGOs can utterly corrupt decisions about how programs will be run, as well as councilors' own mandates with their constituents. During the time I worked with the Ha Mamello council, they were having difficulties with an American volunteer who was working for a small NGO I will call the Lesotho Community Development Society (LCDS). Their interactions with this volunteer provided a striking, almost haunting contrast to the dynamics envisioned in the Gateway Manual. LCDS had decided they wanted to undertake projects in a village near Ha Mamello, and approached the council. The American volunteer proposed conducting a needs assessment of the village that would highlight areas for possible intervention. He had told the council that LCDS expected to bring in grant funds for the project. Despite the relatively small stature of LCDS and its

young American volunteer, the council was eager to attract grant funds that might be available to help the community, and so they deferred to his leadership. They seemed to have consented with little input, eager to appear willing and flexible given the possibility of grant support. By the time I began meeting with the council, a mere few months later, the relationship had soured considerably. After conducting a needs assessment in the village, the volunteer had decided—largely on his own—that water access was the most important issue, and had approached the local village’s water committee [a sub-committee of the community council] about designing an intervention. While the volunteer felt that he had never promised grant funding, both the village and the community council felt that he *had* made promises, and when funding did not materialize, frustrations mounted.

“Initially, when you came [to us] we saw that you had your own funds and were going to help the community, and you were going to start working with [this village],” one of the councilors reprimanded him, “and I was even jealous that [this village] was going to receive that help [when my village would not]. But now it’s like you are wanting help [from us]!” Adding to the mounting frustrations at this meeting, the volunteer then explained that “the [water] committee had to be restructured. There was a problem with it, [the members] weren’t showing up. So then we had to restructure the water committee.” It appeared that he had taken on this “restructuring” of a community-appointed committee largely on his own, and of his own accord. The councilors were, understandably, incensed that they were not consulted during the restructuring.

After “restructuring” the committee, the volunteer decided that, in the absence of any grant funds, the project could best move forward if it gathered a small operating budget from the community. Along with the new water committee, he implemented a

village tax, charging each adult in the village 20 Maloti—or about \$2.30.<sup>38</sup> This was no insignificant amount for people to pay, especially on a per-head rather than a per-household basis. Not only had he restructured a local government committee, but he had essentially imposed a community tax without any council involvement; he even had the gall at the meeting to request further funds from the council. “You’re overtaking the role of the council,” one member explained to him with what seemed like a generous amount of patience. Another councilor continued:

Our concern is that if you are making development projects in the village, the councilor should be the one going to the village and collecting funds in the community. *She should be the one collecting funds in the community.* If people contribute, she should be in charge, and then come to you and say, this is the amount that we have, and there should be some *agreement* between you guys [about what to do with it.]

The council had clearly lost face with the community, and was worried about the fact that they would be held accountable for the results of the project—or even be accused of stealing the money for it—if their constituents were unhappy. Furthermore, they had little say in the project, let alone its identified “priorities” in the community.

The ease with which this young volunteer was able to restructure a local government committee and impose a village tax was dizzying. He was surprised by the council’s response—it seemed as if he thought he had done what was necessary to “get things done,” and viewed the council as an obstacle to community development. In return, the council was relatively unsurprised by his transgressions; his was not an uncommon perspective among NGO workers. (Indeed, we can see how, from a development perspective, the volunteer’s actions reflect concerns with sustainability, efficiency, and community ownership.) But what troubled me more was the sense I got from council members that, had the volunteer succeeded in bringing in grant money, they would never

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<sup>38</sup> Calculated on January 18, 2013 at an exchange rate of 8.58 Maloti to \$1.

have questioned his actions or the intervention he wished to carry out, even if he had persisted in collecting a village tax. By their reckoning, his failure to bring in grant money changed the power dynamics of their relationship with him, and the unspoken rules about how they would interact with NGOs and funders. I realized, with a considerable level of distress, that I was witnessing a moment of relative empowerment for the council, as its members clarified their roles, reprimanded the American volunteer, and clearly discussed how they wanted the project to proceed in the future.

The incident laid bare the ways in which the Gateway Approach underestimated the power imbalances between councils, citizens, and those involved in and orchestrating HIV scale-up and other initiatives. It placed the onus of responsibility on councils to change the way that NGOs and donors interacted with them, while those entities continued to circumvent councils, pay them minimal lip service, and wield great influence over them because of existing power dynamics between funders and recipient communities. Many agencies persisted in interacting with councils in this way even as they praised the Gateway Initiative at national-level meetings as a new way to achieve good governance. At the same time, citizens in communities like Ha Mamello took on more and more responsibilities for HIV—not only in terms of caring for the sick, and in managing their own treatment regimes, but internalizing discourses about their own responsibility for infections, for their inability to “accept” HIV’s presence in their lives, and for a persistent “culture of hand-outs” and “dependency syndrome” in their society. In chapter 4, I examine the impact of discourses of *responsibilization* on citizen subjectivities, and the effects of HIV scale-up dynamics on support groups and associational life in Ha Mamello. Chapter 4 provides a more comprehensive view of the changes discussed in this chapter,

working from the perspective of recipient-citizens and their interactions with the institutions and organizations that shape their lives.



#### 4.

### **Patient Citizenship: Navigating Institutions and Obtaining Care**

The most consistent interaction with government entities for many citizens in Lesotho occurs while seeking care in the public health system. This is true for HIV patients, but also for a vast number of people who regularly, or semi-regularly, seek services at clinics: for other diseases (diabetes, high blood pressure, tuberculosis); for reproductive health care (family planning services, care for sexually-transmitted infections [STIs], and all maternity services); or for pediatric services (routine immunizations, childhood diseases). Citizens in Lesotho do, of course, come into contact with the government in other ways—the elderly receive small pensions monthly through the local post office, citizens appeal to the community council to resolve land disputes or problems in local services, and citizens occasionally (resources permitting) apply for passports, government jobs, or government assistance. But in this chapter I will demonstrate how citizens' increasingly consistent contact with clinics shapes—and is shaped by—their political subjectivities and their expectations of the state. By changing the way that citizens interact with the clinic, as well as the ways that clinics handle, educate, and discipline patients, HIV programs are altering forms and functions in everyday political life for citizens.

Recent literature on biological citizenship in the space of the clinic explores how the experiences of individuals who become immersed in biomedical regimes of treatment, cure, or care create new, emergent forms of citizenship that are indelibly rooted in biological identities, disease symptomologies, and clinical strategies of discipline (see, for example, Biehl, 2007; Fassin, 2007a; Nguyen, 2010; Ong, 1995; Petryna, 2002; Rose, 2007). This research has been instrumental to helping social theorists to once again

understand the clinic and medical programs as political endeavors (Comaroff, 1993; Foucault, 1973; Scheper-Hughes & Lock, 1987). Studies of HIV treatment regimes describe how recovery creates new political subjectivities (for example, Robins, 2008), how treatment institutions create new boundaries of belonging and abandonment (Biehl, 2007), and how access to precious medicines amidst scarcity and inequality imparts specific lessons for “therapeutic citizens” (Nguyen, 2010). These studies tend to focus primarily on HIV patients, rather than on the broader community of citizens of which they are a part. But HIV is also changing the way that those without HIV perceive the state and its roles. In addition, I am not just interested in how HIV medicine is altering *biological* forms of citizenship, and citizenship within biomedical regimes, but also how, within the context of HIV programming, broader political forms and *conditions* of citizenship are changing dramatically.

HIV programming within clinics is changing the ways that citizens think about government responsibility, and ultimately, the faith they have, or do not have, in democratic systems. These effects are intensified by the broader institutional contexts through which HIV programming is deployed: How do citizens interact with, and perceive, the dispersed webs of non-governmental organizations operating amidst, and above, their communities? The political terrain of HIV programming is a landscape populated by numerous NGOs whose presence *fractures* responsibility for public services even as they are routinely absent from everyday political life. This dynamic—of shaping political life but not existing in it, also has dramatic effects on how individuals embody and act upon citizenship and their faith in state institutions. Throughout this chapter and the next, I will explore how these changes are unfolding in citizens’ lives: in this chapter, by focusing on the institutions of the clinic and NGOs; and in the following chapter, through an

examination of two community-based support groups and their attendees. As all of these entities are largely located in, or affiliated with, a town I call Ha Mamello,<sup>39</sup> there is considerable overlap between ‘community’ and ‘clinic,’ much as there was during my research. I do not attempt to impose an artificial barrier between data that belongs in one ‘site’ and data that belongs in another ‘site,’ instead allowing these spaces and dialogues to percolate into each other, much as they did in my own fieldwork and in my informants’ everyday lives.

As I describe in chapter 1, my choice of Ha Mamello as one of two primary research sites was due to strategic methodological choices, some of them difficult. Ha Mamello is a medium-sized peri-urban town, which is actually made up of a few smaller villages in relative proximity to each other. It lies outside of, and is considerably smaller than, Lesotho’s capital and its larger “camp towns” established by colonial administrators in each district to act as administrative and trading hubs. Ha Mamello is not, though, one of Lesotho’s tiny mountaintop villages, nor is it in one of the inaccessible rural areas. Ha Mamello provided easier access to the community council (whose members met in town), and a variety of support groups and other HIV-related initiatives. Crucially, it contained multiple support groups whose work I contrast in greater detail in chapter 5. Overall, however, the town remained small enough that I was able to repeatedly encounter informants with whom I had previously met, and to visit the households of most local patients on foot.

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<sup>39</sup> In order to protect the identity of individuals and identities with whom I worked during the research, the name of the research site has been changed. “Ha” means “place of” in Sesotho; for clarity’s sake I refer to the town as Ha Mamello and to the clinic as Mamello clinic.

## Clinics and Citizens in Lesotho

Lesotho's public health care system consists of 191 health centers and filter clinics, 18 secondary care centers that could best be described as "mini-hospitals," and one tertiary hospital, colloquially called "Queen II," and named after Queen Elizabeth II (Mwase et al., 2010, p. 13).<sup>40</sup> With limited professional education in the country and no medical school, Lesotho struggles to train and retain health workers of all kinds. In 2010, there were 64 doctors working in the public sector in the entire country, amounting to little over three public sector doctors per 100,000 patients (MOHSW, 2011).<sup>41</sup> In 2005, the Ministry of Health reported that 80% of the doctors whose training it had sponsored in other countries over the past 20 years (with the agreement that they would return to practice in Lesotho) had nonetheless left the country to practice elsewhere (MOHSW, 2004). Many of the best-trained local doctors decide to work in the private sector or are hired by international organizations or funders to run in-country programs—positions in which they can earn significantly more money. In an effort to address "brain drain" and perennial understaffing in the health sector, numerous international partners have contributed to schemes for boosting human resource capacities. The Clinton Health Access Initiative (CHAI) funds salaries and incentive packages for 257 nurses to be placed in the most hard to reach (and therefore most unpopular to work in) public clinics, and donors have supported numerous efforts to improve nurse training in the country (MOHSW,

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<sup>40</sup> Lesotho also has three specialty hospitals: a psychiatric hospital, a leprosy hospital, and a TB treatment center which, in partnership with Partners in Health, administers TB and MDR-TB treatment.

<sup>41</sup> This figure comes directly from the national annual joint review; I have tallied all health workers reported in various health centers. Unfortunately, most figures, including this one, are rough estimates. But all available figures show extremely low levels of physician coverage. Mwase, et al. (2010) report that, in 2003, there were 89 doctors and 1123 nurses and midwives in public sector, which amounts to about 5 per 100,000. In 2009, Mwase et al. (2010) estimated that there were 134 doctors and 1770 nurses.

2011). Despite efforts to retain local health staff, however, a large percentage of health workers (including most doctors and many of the nurses sponsored by Clinton Foundation) are from other countries: Doctors hail from Cuba, Nigeria, India, and the US; nurses are predominantly from other countries in Africa. For patients, the impact of this resource shortage is that they rarely, if ever, see a doctor, and if they want to see a doctor who speaks their language, they must turn to the private health system. Within primary care clinics, patients are likely to encounter a nurse who does not speak their language. This means that a defining element of health care in Lesotho is the feeling of not being heard, and of not being able to express complaints or ask questions except for in gestures or poorly cobbled-together English.

Because most health services offered in local clinics focus on primary, pediatric, and maternal care, children, women, and the elderly are most likely to attend clinics. Men, particularly young men, tend to avoid services until they are acutely ill. This is partly due to men's perceptions of health as a female domain, partly to their discomfort with nearly all-female clinic nursing staff, and partly a result of additional challenges men face in accessing clinics when working outside the country, on part-time jobs away from home, or when farming and herding animals high in the mountains. Like the rugged, weatherworn, long-suffering livestock many men herd as adolescents, Basotho often say that "a man should die like a sheep—without crying," meaning that he should die without complaint or signs of weakness. These are social expectations that can deter men from seeking care until it is urgently needed. But HIV treatment has brought even men into clinics on a regular basis, and men constituted nearly 40% of those I interviewed at Mamello clinic who were

on treatment.<sup>42</sup> In some ways, the presence of HIV treatment has re-acquainted men (or at least some men) with the public health system, but women remain the primary targets of disciplinary practices related to health, and HIV policies can exacerbate this. Women are largely responsible for children's health, and attend clinic more regularly than men do for pre- and post-natal care. After Lesotho adopted its provider-initiated testing policy, women attending clinics were the primary subjects of this policy, particularly during antenatal care, when the importance of testing is emphasized as part of PMTCT efforts. Many citizens reported to me that they were under the impression that HIV testing was mandatory for pregnant women—some even said it was mandatory for anyone attending the clinic. Even if this was not true in practice, the perception of forced testing has far-reaching effects among potential clinic patients—detering some from attending, and making others agree to testing even when they do not want it. Such a policy—and its public reputation—places an undue “responsibility” on women for testing and knowing their status, one that is not equally shouldered by men who do not require maternity services, and find it easier to avoid attending the clinic.

About 40% of public facilities in Lesotho are run by the Christian Health Association of Lesotho (CHAL), a long-standing Christian aid association in the country that is slowly being integrated into the government-run clinic system (Mwase et al., 2010). CHAL clinics do not compete with public clinics; rather, they are part of the public clinic system. Patients rarely choose between one clinic and another; they typically seek care where it is closest, most available, or least stigmatizing (Mwase et al., 2010). As a strongly Christian country, abortion is illegal everywhere in Lesotho, and causes significant

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<sup>42</sup> Lesotho does not publish statistics on ART enrollment broken down by gender, so it is difficult to estimate national treatment uptake inequalities.

problems for women's health.<sup>43</sup> In many CHAL clinics family planning is also not offered, and condom education is discouraged. Nevertheless, recognizing the significant need for these services within the patient population, many nurses and counselors at clinics endeavored to find ways to counsel patients about family planning and condoms, even though they cannot be distributed on site.

The clinic that serves Ha Mamello and the surrounding areas is a small but relatively well-functioning CHAL clinic, which is loosely affiliated with the Catholic Church nearby. The clinic is simply referred to by its location—Mamello clinic. It consists of a few small, rectangular brick buildings arranged around a small garden, and surrounded on all sides by a chain-link fence. The front building is the main clinic building—consisting of a few consulting rooms for nurses serving primary care patients, at least one room crammed with beds and other supplies that tend to go unused, and a kitchen for the staff. Another two buildings on the site are primarily used for meetings and patient education. At least a few days a week the larger of these buildings is crammed full of new or expectant mothers and their babies, as they attend prolonged group antenatal care sessions or well-baby appointments. Patients line up along the sides of these buildings, waiting for appointments. Many arrive at six or seven in the morning, and the nurses try to see the bulk of their patients prior to 2 PM. Patients who arrive “late”—that is, after eight or nine in the morning—are not seen. In the back of the clinic lot, another small rectangular building with two tiny offices comprises the “HIV Corner,” where all HIV services are provided. During my time at the clinic, another tiny building—a temporary round hut made of particle board—was donated through funds from the Clinton

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<sup>43</sup> The most common reason for hospital admissions among women aged 15 and over is complications from abortions sought outside the formal medical system (MOHSW, 2011)

Foundation, and used as additional counseling space. While the “HIV Corner” was likely intended to offer some privacy to patients seeking HIV services, it instead had the effect of making it very clear who was seeking HIV services at the clinic, and who was not. HIV patients waited in a separate area, and nurses and counselors often shouted out their names to call them up to receive medicines, CD4 counts, or test results. Unlike private clinics, where providers take pains to make the experience of getting care a private one—offering covered windows, private consulting rooms, and smaller waiting rooms—seeking care at public-sector clinics is a decidedly public venture.

In 2008, Lesotho decided to abolish user fees for all services in its primary care facilities—health centers and filter clinics. This was a positive step towards providing more universal access to health care, but it is not clear that it has significantly improved overall health care access. Health clinics are routinely understaffed and under-supplied, and even on the best of days only able to provide very basic services. If patients in most areas require an X-ray, need to start TB therapy, or want any kind of obstetric services, they end up going to one of the district or tertiary hospitals, which still charge fees for services.<sup>44</sup> Frequent scarcity of basic drugs (often called “stock-outs”) results in patients being referred to pharmacies where they can buy their own medicines, or seeking care from other secondary or tertiary facilities. Lastly, because many individuals still live quite far from health facilities, transportation is a significant health care cost that is never reimbursed, and rarely acknowledged, by the health system. The cost of getting to and from a regional hospital can be between 20 and 40 Maloti (\$2.30-4.70); the cost of getting to Queen II in

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<sup>44</sup> Fees for these services can be waived—sometimes—if patients meet particular criteria for free services (orphans, some elderly, and some destitute, among others, can qualify) (Mwase, et al., 2010). In order to qualify, patients must first seek a letter from the Ministry of Health. Informants reported to me that Ministry officials often charged for these letters, so they didn’t see the point of trying to get them.



the capital for any serious care can be far more expensive, from 40-200 Maloti (\$5-23).<sup>45</sup> These prices are prohibitive for many patients.

With HIV, clinicians' burdens have grown exponentially. Access to HIV treatment and PMTCT services in the country ballooned over a very short period of time, concentrated between 2006 and 2012 (see chapter 1, Figures 1.1 and 1.2). In 2009, the government of Lesotho decided to decentralize HIV treatment services to health centers, eventually expanding the program to enable access to ART at nearly all health centers in the country. In 2010, more than 80% of women had access to PMTCT services, and 58% of eligible patients had been enrolled on ART (MOHSW, 2011). These represent significant increases, but enrollment of patients has tapered off in recent years, even as services have been decentralized, and there is a vast deficit between the numbers of patients who qualify for such services, and those who actually access them. After 2008, the government also implemented WHO guidelines which recommended that patients be able initiate HIV treatment at a CD4 count of 350, rather than 200. This has added to the considerable burden clinics already face in meeting patient needs. When Lesotho decided to decentralize HIV treatment to health centers, nurses were given primary responsibilities for initiating patients on treatment, addressing side-effects, and monitoring adherence. Counselors, in addition to providing HIV counseling and testing (HCT), also became involved distributing CD4 count results, educating patients about treatment, providing ongoing treatment counseling, and organizing support for patients struggling with adherence or side-effects. While access to treatment expanded rapidly, the work of clinicians and counselors in the clinic shifted noticeably towards managing and triaging treatment regimes for patients with HIV.

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<sup>45</sup> Calculated on January 18, 2013, at an exchange rate of 8.58 Maloti to \$1.

HIV is also accompanied by a great deal of other medical needs, conditions and diseases—including appetite and weight loss, TB, shingles, and more prevalent but harder-to-treat STIs. All of these conditions are first seen, in all likelihood, at the primary clinic level, adding to clinic workloads. In addition, the influx of funding and supplemental programs from outside partners has meant that nurses and counselors are asked to help manage, or provide support for, food aid initiatives, additional staff training, support groups and patient education. Finally, HIV scale-up has meant a vast increase in the amount of data collected at local clinics, as governments, NGOs, and funders all require various “monitoring and evaluation” (M&E) efforts in order to document their program successes and worldwide impact. In clinics, this responsibility falls to already over-burdened clinicians with limited training, and becomes quite time-consuming. As a result, even at a relatively well-staffed clinic like Ha Mamello with comparatively easy access to Queen II, nurses estimated that each one of them saw and treated seventy patients a day. During well-baby clinics, nurses will often see between fifty and seventy patients in the clinic *in addition to* their regular caseload. Nurses typically work from 8 AM until 4:30 PM, but often do not start seeing patients until 9 AM and stop accepting patients between 1 and 2:30 PM. While some are critiqued for not working hard enough, the remaining hours are often filled with paperwork, sorting medicines, collecting lab results, ordering supplies, and dealing with acutely ill patients who need to be sent to another hospital. With nearly seventy patients squeezed into a 4-6 hour time frame, nurses will spend little more than three to four minutes with each patient. That is not the amount of time that they will spend talking with a patient; it is the time they will spend diagnosing, treating, administering drugs to, and fielding questions from, a patient.

Despite these difficulties, Lesotho’s health system seems to function relatively

well—if not with ease, then at least at a level that frequently meets basic health care needs. Beneath this relatively functional surface, however, the statistics are grim. Even as health care access grows, Lesotho is one of the only countries in Africa to show signs of worsening maternal and child mortality in recent years (see chapter 7) (WHO, 2012). Obtaining any care beyond the most basic services is fraught with difficulties, and patients die not only from treatable diseases, but from treatment itself—from misdiagnosis, lack of therapies, or simple neglect. Services at Queen II are so abysmal, and so many patients die from poor treatment at the hospital, that for many years Basotho have claimed that certain nurses simply kill sick patients to make space for new ones, operating like a kind of triaging death squad. “*Ngoan’eso, Queen II b’a u qetela,*” people are known to comment: “My brother, at Queen II they finish you off” (Selinyane, 2001). Certainly, the stress and lack of resources that health workers face contributes to exhaustion and poor outcomes, but these are not only the fault of health workers. Much of the national health budget is consumed within the Ministry of Health, and patients rightly attribute poor health care to the government’s mishandling of budgets as well (see below, and chapter 5).

### **Arranging Care in Times of Crisis**

The tensions and inadequacies of the health system were often revealed to patients—and to myself—in times of acute illness, rather than in the context of routine care. On a sunny, but brisk, day at the clinic, I stepped out of a series of interviews to discover an extremely ill and wasted woman curled up in a wheelbarrow that had been parked just outside the clinic door. Like so many patients with end-stage AIDS, Mme ‘Mats`epo appeared easily 20 years older than she was. Curled up in the small wheelbarrow, however, tucked amidst an old blanket, her bare feet dangling over the

sides, she also looked childlike, like one of the wild-eyed neighborhood boys who would take turns riding and driving wheelbarrows at break-neck speeds down the hill to pick up sacks of mealie-meal. 'Mats`epo's son had delivered her to the clinic from many miles away: Too sick to walk, she was hardly the first patient to arrive by wheelbarrow. It had taken her son most of the morning to get to the clinic. Once they got there, the nurses chided 'Mats`epo for having stopped taking her medicines. Rather than consult with her privately, they grew angry and made a public example of her on the lawn between the regular clinic and the HIV corner. "This lady says she stopped taking her pills because she had no food. Is that true?" The other patients regarded her silently. A woman who had arrived with 'Mats`epo asserts that she did have food. "Did she stop taking her pills because she 'forgot'? No! It is because she has not accepted her status. She wants to hide. She is a *defaulter*. She has stopped because she is a *defaulter*." 'Mats`epo lays on the wheelbarrow, prone, a thin jacket and a stray hand resting on top of her face. I don't know if she hears this, but it is likely she does, and I can't read how it makes her feel. Amidst a dialogue about ARV adherence that blames 'Mats`epo and pays little attention to the real reasons why she did or did not have stop taking her medicines, a strange kind of care is played out in public by the nurses and the patient-onlookers.

The causes of 'Mats`epo's inability to adhere to her medicines do not concern the nurses or the counselor for very long. They briefly make an example of her, and then the moment of shaming seems to pass: They get down to the business of trying to find care for her. 'Mats`epo's family, realizing how ill she was, had transported her to Queen II, at significant cost, the previous day. When she got to Queen II she was turned away. Due to a new decentralization effort in the health system, all patients have to follow a referral process from their local clinic. They are first required to attend their local clinic in order to

obtain a hospital referral, usually to their local secondary care hospital: Anyone just appearing at Queen II would be turned away unless they required emergency care. In a country like Lesotho, 'Mats`epo's condition, though immediately life-threatening, was not an emergency. But patients still routinely sought care at Queen II because it was the only hospital with many of the things they needed, and because they knew it offered the best chance of getting high-level care (even despite rumors about murderous nurses). The nurses at Mamello clinic could tell with a single glance that they would not be able to care for 'Mats`epo on-site. She was in critical condition, and would need to be admitted to a hospital. They suspected she might also have TB, and would need to be tested. They were supposed to then refer her to Scott Hospital, in Morija, a town that was, ironically, considerably further away than Queen II. By this point many of the ladies waiting outside the clinic also began to chime in, asking whether she had had a TB test, and what kind. A few, including the HIV counselor, commented that Scott Hospital had "many problems," especially since the programs run by Médecins Sans Frontières (MSF) at the hospital were turned over to the government. Another woman pointed to the young woman sitting beside her—one of her daughters-in-law—and said that she had been "much sicker than this lady," referring to 'Mats`epo. "And I took her to Scott for HIV and TB, and look at her now!" Her daughter-in-law looks perfectly healthy, if somewhat mortified.

'Mats`epo's son returns to the clinic, forehead gleaming with sweat, his clothing ragged and his feet bare. He has been going house to house in the nearby villages begging people they know for a bit of money to pay for transport to the hospital and medical care. What little resources the family might have had are clearly drained at this point, and he returns back empty-handed. One of the nurses and a counselor give him small bits of money. The transport to Scott is prohibitively expensive—20 Maloti one way, and

'Mats`epo will need someone to accompany her so that she can be lifted in and out of the taxi, and be taken care of at the hospital. The outspoken mother-in-law in the crowd reassures 'Mats`epo's son that once 'Mats`epo has taken the TB test, and started on treatment, he will be able to pick it up for her from Scott if she is too sick to get it. Her advice attempts to lessen the anxiety of mounting financial tallies that seem to be running through his head. I give him the rest of the money he needs to get to the hospital, but he'll have to wait another day. It's after 1 PM; by the time he gets 'Mats`epo there the nurses may turn them away. He picks up the handles of the wheelbarrow and begins to make his way back home, one of 'Mats`epo's feet dragging lightly on the ground as they head towards the road.

Patients in need of care that transcends the rote doling out of pills, or the scripted education sessions about ARVs or TB, often find themselves caught within the strange institutional logic of a beleaguered, strained health system. The encounters can be simultaneously dehumanizing and compassionate—as the nurses publicly chide 'Mats`epo for being an irresponsible patient, and then give her taxi fare from their own small salaries. Both of these forms of treatment were common, and patients often reported that they trusted the nurses to know what was best for them, even if it sometimes involved rituals of public shaming. One patient reported to me that she liked the care at Mamello quite a bit, because “even when the nurses shout at us, we understand why. They aren't just shouting at us because we are sick.” Within these new care regimes, nurses struggle to meet the biomedical needs of patients amid pressures to alleviate their social and economic needs. New treatment regimes encourage nurses to depart from more social—and socialized—forms of care, streamlining patients and emphasizing education as a means of addressing social ills. While Cartesian dualism—which marks the separation between the material

body and the immaterial mind—is elemental to Western medical thought, the fundamental rupture for clinicians here seems not between the human mind and the patient body, but between the biomedical practice and the social world (Scheper-Hughes & Lock, 1987). This disjuncture is best represented in the figure of the nurse—a disjuncture made all the more acute when the nurse shares neither language nor culture with her patients (as is frequently the case). Attempts to streamline and standardize care—particularly as HIV treatment has come under the purview of nurses—mean that patients taking treatment are quickly acclimated to a medical regime made up of rules and policies that are rarely negotiable. Most patients accept these rules gracefully, but those who cannot accept the rules—for reasons of circumstance, debility, or stigma—usually end up voluntarily exiting from the clinical care system. Some of these cases will be discussed in further detail in chapters 5 and 6; for the purposes of this chapter, I focus on the subjective worlds of clinic workers and patients amidst HIV treatment decentralization.

### **HIV Knowledge and Political Subjectivities**

A number of anthropologists have begun paying closer attention to the ways that forms of HIV knowledge, particularly in HIV treatment education initiatives, remakes patient subjectivities. These changes—combined with patients’ experiences with support groups, activist initiatives, NGOs, and transnational HIV efforts (forms of “biosociality,” to use Rabinow’s [1996] term)—have fueled the emergence of new forms of biological or therapeutic citizenship (see, for example, Biehl, 2007; Kalofonos, 2008; Nguyen, 2010; Rose, 2007). Following Foucault (2008), a crucial ingredient in the making of these new citizenships are forms of authoritative knowledge that subtly discipline the conditions of citizen agency, and influence citizen subjectivity. Vin-Kim Nguyen (2010) describes how a

politics of triage determined access to scarce ARVs in West Africa, where patients were encouraged to use “confessional technologies” in order to demonstrate that they were living “openly” and “positively” with the virus. The considerable and entrenched stigma surrounding HIV can inhibit patient success in adhering to ARV treatment regimens. But the messages and strategies used to confront stigma, particularly in the context of treatment, are value-laden and prescriptive. So, too, are the messages to patients about how to maintain their health. Kalofonos (2008) notes the ways in which HIV education in Mozambique, intended to ensure adherence to treatment regimens, in fact inculcates ideas about the ideal patient-citizen: modern, rational, educated, open about his status, and biomedically-savvy. In a context where treatment scarcity is still the norm, values such as these become standards by which good, deserving, responsible patients are parsed out from bad, “lazy,” “ignorant,” or irresponsible patients who are less deserving of treatment.

Combined with strong messages about the dangers of herbal or traditional medicines, these discourses often encourage a turn away from what patients and practitioners perceive as “traditional,” “cultural,” and “rural” mindsets, and towards a modern, rational, urbanized patient identity. Such dichotomies were commonplace in the treatment programs at Mamello, and in national dialogues about HIV treatment and prevention. Because these forceful messages are also tied to goods (ARVs, certainly, but also services, food packages, and money), they demarcate, and oversee access to, zones where survival is considerably more likely and more comfortable. In these zones, a certain kind of biomedical, physiological survival is promoted—and only for those who suffer from a certain disease (see Nguyen, 2010). In Lesotho, as elsewhere, however, each individual requires survival in multiple domains. These include: social survival, where one’s social and familial relationships are intact, where one has care from kin, and where one retains



social standing and “face” (see Benson, 2011) in the community; economic survival, where one is able to retain work, continue bringing in income, or able to maintain relationships that provide monetary support; spiritual survival, in which one’s belief systems are kept intact, or even strengthened; and what we might call moral survival, where one’s values are preserved, and one is able to retain those things one has reason to value.

HIV treatment, then, has fostered a considerable social division in Lesotho between modernist / urban / biomedical and more traditional / rural / cultural ways of thinking. The divisiveness of this discourse prompted traditional leaders and healers in Lesotho to form their own political party prior to the last round of local elections. One of the party leaders said that they felt traditional values like *care* and *respect* were not being served by current government policy, and that the party was a response to “the growing contempt towards cultural beliefs” in Lesotho, the “despicable attitude towards traditional circumcision” as HIV prevention initiatives remade this cultural rite into a medical procedure, and “the continuous clash between traditional healers and medical doctors [and] the lack of respect for traditional doctors.” Among the urban elite the party platform was met with derision (Lesotho News Agency, 2010; Ntsukunyane, 2010).

In Sesotho culture, as in many African ontologies of health, well-being is located in the social and relational world as well as in the individual body (see, for example, Comaroff, 1985; Germond & Cochrane, 2010; Levi-Strauss, 1974; Livingston, 2005). *Bophelo*, which in Sesotho means both “health” and “life,” refers to social and physiological harmony; the search for health can involve social and spiritual interventions; and illness can be the result of social transgression or disruptions in the social world (Germond & Cochrane, 2010; Romero-Daza and Himmelgreen, cited in Livingston, 2005, p. 174; Romero-daza & Himmelgreen, 2004, pp. 959–960). In my discussions with

informants, they often projected a modified set of disease etiologies, wherein illness seemed to arise less from disappointing ancestors and spirits (*balimo*) and more from social injustices. It is not uncommon, then, to hear that “people with HIV die of hunger,” not AIDS, and that the stress of poverty and everyday struggles to survive causes chronic illnesses. As Adam Ashforth (1998, 2005) notes, contemporary life for many Africans is shaped by “spiritual insecurities” as well as material ones, and it is these feelings of dual vulnerability that figure prominently in belief systems. In addressing illness, and seeking various forms of treatment, my informants relied heavily on kin (rather than looking to ancestors), and examined the strengths and weaknesses of their social relations when crafting care-seeking strategies. Echoing the findings of other anthropologists who document the diverse forces at work in patients’ “therapeutic itineraries” (Klein, 2007; Samuelson, 2004; Smith & Mbakwem, 2007) my informants’ perceptions of both illness and the systems to address it were shaped by diverse strategic negotiations with belief systems, disease etiologies, kin networks, economics, and forms of survival.

HIV infection still comes with its own set of stigmas, as it echoes older disease etiologies which stated that sexual infidelity and promiscuity, particularly on the part of a woman, would result in illnesses similar to AIDS, or the birth of a disabled or weak child. *Senyeha* refers to children who, literally, become “spoiled”—suffer “weight loss, severe diarrhea, lack of appetite and failure to thrive,”—because of their mothers’ sexual promiscuity (Romero-Daza and Himmelgreen, cited in Livingstone, 2005, p. 174). For many in Lesotho, disclosing an HIV-positive status is tantamount to admitting that one has been promiscuous, a charge still laden with immorality and social shame. The primary stigma of HIV, therefore, is a stigma of moral transgression—the physical evidence of social misdeeds. As a result, stigma feeds on and exacerbates existing social and gender

inequalities: As these same inequalities drive infections, they reinforce the perceived veracity of stigmatizing beliefs (Parker & Aggleton, 2003). As a result, social, relational, and economic survival factor heavily in individuals' decisions about whether, and how, to seek care for HIV.

Nurses and counselors struggle to integrate these other forms of survival into their rhetoric about treatment. Their messages are frequently boiled down to the most basic components of patient responsibility, particularly as counselors became more and more integrated into treatment (rather than prevention or care) modalities. Since I was not able to sit in on individual patient counseling sessions, I met with the clinic counselors—many of whom were living with HIV themselves—to ask them about the messages they tried to convey to patients. In the dialogue below, we can observe the strong emphasis placed on biomedical treatment regimes during patient counseling:

NK: So, in counseling people who have tested positive...what do you think is the most important thing for them to know?

'Mampho: [The most important thing] is for that particular person [with HIV] to go for blood tests and get their CD4 count.

NK: What else is it really important for people living with HIV to know, from you?

'Mampho: [They should know] how they should protect themselves [from reinfection], and [for] those who are already on treatment, how to take their treatment. And how to live positively.

NK: How do you explain to patients what it means to live positively?

[Silence]

'Mampho: The main thing is that they should know what HIV is.

NK: So to be educated, to be knowledgeable?

Puleng: —and also how to take their treatment, how they should take care of themselves, how they should eat, how they should avoid reinfection...

Palesa: The major thing is that they must start by accept their status. To take responsibility for themselves.

It is difficult to see how this kind of education effort imparts the kind of agentive, empowered ideas about citizenship and "treatment literacy" promoted by organizations like the Treatment Action Campaign (Heywood & Altman, 2000; Robins & von Lieres, 2004). While counselors use phrases like "living positively" and "accepting their status,"

they seem to mean that patients should have successfully absorbed the information provided in the clinic's three-week "school" for those starting ARVs, and should adequately follow the "rules" of a treatment regime. In fact, the final step towards enrolling on ARVs at Mamello was to pass an oral "test." During ARV "school" the counselors repeated treatment information over and over again to prepare patients for the test. They warned patients about the consequences of failure, saying that they felt "ashamed" when patients did not pass.

Frequently, when I asked about the presence of stigma in communities, or about why a certain person had not started taking treatment, the answer I received was that "so and so has not accepted her status." I was confused, though, about how adherence, or more importantly stigma, could be explained by such a vague measure of patient psychology. I asked the counselors, as I did many other people, what they thought "accepting one's status" meant. Palesa replied, "it means you keep on coming to the clinic. A patient has accepted her status if she keeps on showing up." "And taking care of yourself," Puleng added. These messages clearly impart the notion that "acceptance" is a process of coming to terms with medical obligations and responsibilities, not with the disease itself. To accept one's status, then, is to accept one's place in the new order of things brought about by HIV treatment regimes—to become modernized, to leave behind tradition, to submit to the rules and expectations of biomedical rationality. It is accepting a reordering of the hierarchy of forces of survival that orders citizens' lives. It is also, of course, the acceptance of a certain social status that comes with HIV treatment. Finally, such messaging overlooks the ways in which stigma is rooted in, and exacerbates, existing socio-economic inequalities and injustices (Parker & Aggleton, 2003).

In his book on contemporary social movements in South Africa, Steve Robins

(2008) concludes from his studies of the Treatment Action Campaign and other HIV support groups that a new kind of citizen-subjectivity emerges from the transformative experience of taking treatment and regaining health after being “near death.” This pathway—from death’s door to a new, robust life—creates a cadre of born-again citizens for whom survival is the result of patient responsibility and pharmaceutical thaumaturgy. In the context of South Africa, where treatment access was a hard-won victory for grassroots activists, and those near-death experiences were the result of government malfeasance, it is not surprising to see that treatment creates strategic and productive new forms of citizenship. But elsewhere this was not the case. In Mamello clinic, discussions of rights and responsibilities were hardly emancipatory, and treatment initiation yoked patients to changes in citizen subjectivity that seemed imposed, not embraced. During ART training for new patients, counselors emphasized that patients were not being “forced to take this treatment; rather, you make an informed decision.” In practice, training served to weed out those who were unable or unwilling to learn about HIV, adhere to treatments, and “accept their status”—in essence, those patients who were a poor investment of donor dollars, and would ultimately taint the scale-up statistics.<sup>46</sup> It was more likely that training enabled clinicians to make an informed decision about patient eligibility, rather than enabling patients to make emancipated choices. The choice to initiate treatment is, in fact, always a decision made under duress—whether it is the duress of a pathogen or that of a physician seems to matter little to patients in Lesotho.

Nevertheless, nurses emphasized that patients had a right to ask questions about their treatment, and to speak up if they felt they were not getting the right treatment. “These ARVs are very dangerous, and they can kill you! So you have a right to ask questions.

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<sup>46</sup> Kalofonos (2008) reports a similar process of triaging in ART training in Mozambique.

Never be quiet, because if you are quiet, you are the one who's going to suffer." Even descriptions of rights seemed to have more to do with patient responsibility given the dangers of ARV resistance. I asked Mampho, a counselor at the clinic, about whether she thought patients had a right to access HIV treatment. She responded:

Sure. that's why we offer trainings on adherence, so that people can know more about treatment. After that, they can always let us know whether they are ready or not to start the treatment. It's their own choice. Our responsibility is to make sure that they have enough information.

Talk about patient knowledge and education echoes broader national discourses about HIV competence, and citizens' responsibility to be informed. In this context, accepting one's status and becoming educated about HIV treatment is framed as a choice between biological survival and death. By making treatment a choice, and distilling rights into measures of patient knowledge and "acceptance," this discourse portrays the lack of universal access to treatment not as a systemic or political failing, but as a personal one. In doing so, it loosens the bonds of obligation between patients, the health system, and the state, ignoring the social protections that may be necessary in order to secure biological survival.

### **Knowledge, NGOs, and Power**

If HIV treatment in the clinic emphasized a transformation of citizens into patients versed in particular forms of knowledge, I was also interested in the forms of knowledge that were missing in the clinic and the community. Citizens were broadly knowledgeable about government services—they knew the details about pensions for the elderly, and were aware of new social welfare programs that gave out small cash grants to extremely vulnerable households supporting orphans. Patients generally knew which clinic services

were offered on what days, and knew when to seek services from another hospital or clinic because Mamello could not provide them. When the clinic ran out of stock of common medicines, many patients were aware of which medicines were out of stock, as information filtered through networks of neighbors and fellow patients. This information was accurate enough that patients would simply not attend the clinic when the drug they needed was out of stock, and would get medicines from another clinic or a pharmacy, finances permitting.

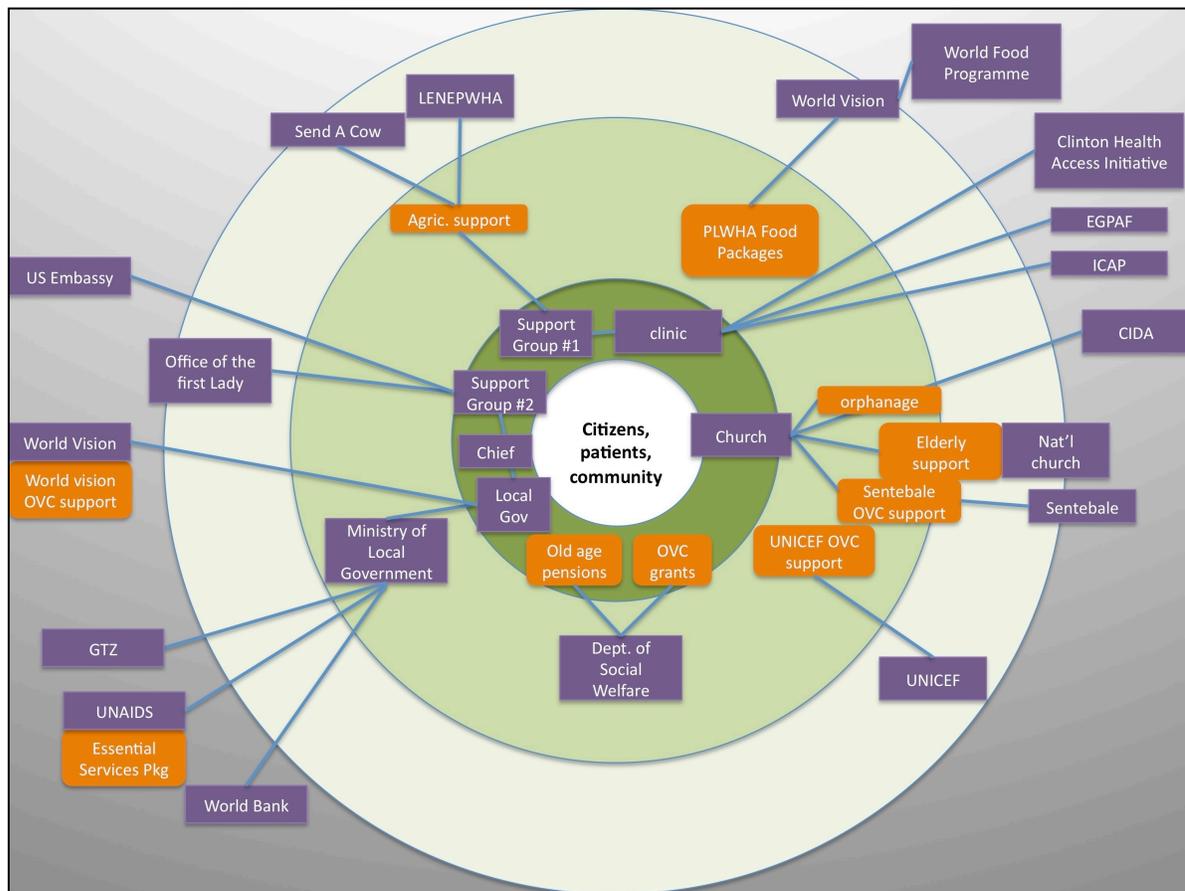
Nevertheless, when it came to the myriad NGOs working with institutions in their community and providing various services, I was repeatedly struck by the utter lack of information available to citizens, even when they were directly benefitting from those programs. When I asked those receiving HIV treatment at the clinic whether they knew of any organizations, churches or groups providing additional services to people living with HIV, they were rarely able to reply in the affirmative. Those who knew of programs had only vague ideas about what they did or where they came from, as shown by the following responses:

-There are some people here [at the clinic] who are getting help, and get food from the clinic...sometimes I hear they [those bringing the food] come from America. I'm not sure.

-You want to know about people who are helping with HIV? I guess I know that there are people who are helping...like there are some [local] businessmen who make some donations, but I honestly can't figure out who is doing what. But I see that people are being helped.

In an attempt to better capture and understand citizen and patient perceptions of the impact of NGOs in their community, I amalgamated data from interviews and conversations with patients into a “knowledge map” of various HIV-related institutions and programs. In Figure 4.1, below, the knowledge map depicts all key institutional actors in Ha Mamello—NGOs, government programs, clinics, church programs, local

government—arranged in concentric rings according to the depth of knowledge most citizens had about each entity. Institutional actors, in purple, are linked to, and differentiated from, specific programs, in orange. The inner dark green ring houses entities and programs in Mamello with which a majority of interviewees had a good working knowledge—they knew where to find these things, how to access them, and had an idea about the status of services. Even if they didn't know much about the entity or program directly, they could easily find someone who did know more. In some cases—as with awareness about stock-outs of drugs in the clinic—this knowledge is quite sophisticated. It is notable that most local government entities, as well as both community support groups, are found in this central ring.



**Fig 4.1: Knowledge map of HIV programs and institutions in Ha Mamello**



Moving outwards, knowledge becomes more scattered and limited. The second, lighter green ring houses entities and services about which there is some general knowledge, and typically, markedly uneven knowledge among the general populace. In these cases it was difficult but not impossible for a citizen to find someone else who knows something about the entity or program, but there was also considerable confusion or conflicting stories about what the entity provides, who is responsible for the service, or whether or not the service is still available. Further out, in the lightest green ring, citizens have only the remotest familiarity with programs and entities, meaning that very few were able to name the program or give a vague description of the populations being assisted (“there is someone who is helping with orphans”). Among key contact persons for these organizations in the community (if they have them), there may be more knowledge. The area outside the rings, in grey, includes programs and initiatives about which citizens I interviewed had no direct knowledge. Often these are programs that have secondary links to Ha Mamello through local institutions or indirect forms of support. More proximate entities and programs are linked to relevant partner institutions in the community with lines. For example, the Clinton Health Access Initiative provides technical support to Mamello clinic, but no one in the community was aware of this linkage. I have only included those with linkages to community entities or programs, but this grey area could also include institutions like the National AIDS Commission, the Lesotho Council of NGOs (LCN), or the Global Fund’s Country Coordinating Mechanism (CCM).

Lack of knowledge among citizens was not for want of trying, and I often fielded questions about which NGOs had different programs, and how they could be contacted. Knowledge about NGOs was not inconsequential: Citizens and patients were eager to “know” NGOs in the hopes that these programs could provide for their survival. Given the

myopic focus on treatment within the clinic setting, NGO programs provided additional services like child support grants, food packages, condoms, agricultural support, small grants and various donated goods that were extremely valuable to those who could access them. World Vision, for example, provided much sought-after food packages to patients currently on ARVs at the clinic. Only a tiny fraction of those patients who were on treatment actually got the food packages, and it fell to the nurses and HIV counselors to devise some kind of fair system for distribution. Since they were unable to divide up the packages (World Vision delivered them and oversaw their distribution), and because it seemed almost impossible to choose the most needy or deserving of those among the hundreds of patients who were food insecure and without work, the clinic staff decided allow each person to access the food packages for 3, 6 or 9 months, in order to allow each person to have a turn. Midway through my research, the food packages stopped coming. No one knew why. Patients were mid-way through their time allotments, were waiting on the packages without any other source of food. A month went by, then two, then three: Patients were desperate but no one seemed to do anything. I probed the HIV counselors: isn't there anyone who knows anything? No. "Isn't there some way to call World Vision?" "Really, nobody knows," Puleng answered in a resigned tone. They had no phone number for World Vision, and it seemed like every time the packages were delivered, someone else brought them, so they had no ongoing working relationship with anyone at the NGO.

Finally, at a policy meeting with national stakeholders in Maseru months later, I happened to hear that World Vision's distribution of food packages had ceased for the foreseeable future—it had only been a two-year program. Ironically, the cancellation of programs is often said to be done in the name of sustainability, as NGOs assert that the only "sustainable" way for their programs to be run is for the government to take them

over, and bemoan the “dependency” that might be created among recipients should food distribution be continued. These concerns may be valid, but in practice, and from the perspective of these recipient-citizens, “sustainability” looks very much like inexplicable abandonment, as they are food insecure and dependent on aid whether or not an NGO is giving them food packages. The banality with which such abandonment is executed—or simply allowed to take place—echoes the increasing banality with which the HIV epidemic itself is addressed, and the changing values driving response, as ideas like sustainability, rights, and partnership are emptied out and inverted.

Citizens were so accustomed to programs coming into the community and subsequently “disappearing” that most reacted to the disappearance of food packages with resignation, and decided they would simply “wait” until packages arrived again. While Lesotho’s citizens do seem to have a long-suffering patience when it comes to politics, their resignation is much more acute when dealing with NGOs or their programs. As NGOs take what could be state functions and turn them into temporary provisions of goods according to mysterious criteria and amidst competition from other organizations, responsibility for core and peripheral state functions with regards to citizens fractures and disperses.

In the midst of this fracturing of responsibility, citizens grasped at various strategies for forging meaningful bonds with the myriad entities upon which they depended for survival. Pointing to the multiple small gardens in her yard, one woman told my research assistant, Ponts`o: “this is my garden for CRS [Catholic Relief Services], this is my Send-A-Cow garden...” Each represented a separate bond of membership, however small, and a separate hope that a more permanent social safety net might be formed. ‘Malefu, an older woman who had been on food packages, reported to me that prior to my arrival World

Vision had lined up all the current recipients and asked them to pose for pictures, to be used on IDs for those who received food packages. As she understood it, the workers from World Vision had created discrete expectations by promising ID cards:

[They] promised us, as people living with HIV, that we would be given money. And we believed we were going to be given IDs, those things that you put here, around your neck, IDs. And our hopes were so high, really, that we might be given support. And we felt that maybe this disease of ours was important and worth something. We were told we would be given those IDs so that they could help us to get payments. And they *lied*.

For 'Malefu and others, World Vision's failure to deliver ID cards was an even greater injustice than the constant unpredictability of the food packages. 'Malefu did not just want a 10 kilo bag of maize meal; she wanted access to the social protections and safety nets that are fundamentally absent in interactions between citizens and NGOs and the state in Lesotho. ID cards promised membership, belonging—in a place where citizenship offered few entitlements. The goods and initiatives brought about by HIV scale-up have the capacity to reduce the social contract to a set of recipient exchanges which are unpredictable, mystifying to recipients, and lacking in guarantees.

It was often difficult to engage patients in lengthy conversations on the subject of NGOs—how do you, after all, talk about things about which you have no knowledge? Refiloe, a schoolteacher in a neighboring area who was taking HIV treatment from the clinic was more outspoken than most, and the excerpts below provide one example of what citizens' viewpoints were like. As we talked about the rights he thought he had as a patient, he asserted that patients *did* have rights, though he could not specify what they were. But, he insisted, "we don't normally *exercise* these rights, such as they are!" I asked him why he thought this was the case. Citizens are to blame, he said, because "we are not aware of the rights that we have." These contradictory statements point to the muddied terrain between citizen knowledge and the exercise of rights. In a context where

knowledge is established as the responsibility of citizens, any failings to seek rights on the parts of citizens are seen as the failings of an “ignorant” and “passive” population. Refiloe argued that part of the problem in understanding rights was that it remained hard to tell which entities are responsible for what: “The problem is that I am not aware of most of these NGOs...they may be playing greater roles...” He puzzled through the question aloud:

...Because, I mean, if an NGO is playing a role...in any given community—if there is someone who is playing a very, very large role, you will know a lot about that individual, or that NGO. [But] you only hear about these UN organizations and all these things, so I don't think I can say that there are any NGOs *here*.

At this last realization he slammed his hand down on the table. What he meant was that, surely, if someone were playing a significant social or political role in the community, he and others would know about them, much as everyone knows who the “big men” are in the community. But he had only heard about “these UN organizations”—those that exist in a kind of intangible place outside of, but for, the country. He seemed to be trying to figure out what being *here* meant, trying to reconcile his lack of knowledge about the local NGO presence with his knowledge that somewhere in the country, all those NGOs he'd heard about were carrying out projects. “They are here, probably, but tell me about that *particular* NGO that is *here*, playing a big role.” He wasn't able to identify a single NGO by name. I responded that I did know that World Vision had been delivering some food packages to the clinic for patients on ARVs. “Okay, yeah, World Vision....World Vision...All I know is that there is World Vision. Sure, I can see the cars, which have the World Vision logos on them. But what do they do? I have no idea, I tell you!” He was laughing by this point, as was I. “Red Cross?” I probed. “Red Cross? Haha! No, Red Cross is—*no!* Is it still in existence?” he asked incredulously. I told him he was not alone in

feeling this confusion. “Honestly,” he replied, “if the NGOs play a role, it should be an active one, which the community can actually be aware of!”

Many NGOs in Lesotho, and elsewhere, speak of their work with an abundance of nouns like “participation,” “community partnership,” and “accountability.” Without reifying the divide between the “top” and the “bottom,” the “local,” and the “global,” it should be noted that the reality of these discourses—in practice, as observed by citizens—seems like a stark inversion of such principles. World Vision, whose cash and in-kind fundraising in 2011 netted a staggering US\$2.79 billion, has been at the forefront of a movement towards what it calls “transformational development” (Kelsall & Mercer, 2003). The organization’s vision of development relies on three defining characteristics of the relationship between donors in the Global North and recipients in the Global South. All of these characteristics are suffused with Christian ideas about charity and biblical metaphors. First, World Vision encourages practices of “Christian witnessing” and the forging of personal bonds between donors and recipients through individual child sponsorship, efforts to connect donor and recipient church congregations, 30-hour fasts for fundraising, and its experiential story telling exhibits on display in its headquarters. Second, it emphasizes accountability to individual donors by providing pictures of recipients and extensive accounting of gifts received—efforts that aim to build bonds of “trust” between World Vision and its supporters. Finally, World Vision endorses partnership with communities—a guiding doctrine that has become so strong within World Vision that Alan Whaits (1999) surmised that the organization’s original “evangelical” philosophy had been replaced with an “ideology of partnership” (p. 421). Through “transformational development,” and an “ideology of partnership,” World Vision’s approach relies on community-focused interventions, and principles of “empowerment” and self-sufficiency

(Kelsall & Mercer, 2003).

It is not clear, however, that these principles gain any traction in citizen-recipient experiences on the ground—at the least, they were not observable in my time at Ha Mamello. Food packages were intermittent and untrustworthy, and the distribution of donations in the context of acute scarcity never seemed fair. Citizens who had walked past World Vision’s offices in Maseru referred to them as “the parking lot,” commenting that the organization must spend all of its funds on the emblazoned cars, trucks and SUVs that litter its headquarters. Occasionally World Vision would visit the community council and ask for a new list of names of destitute orphans; often the request was passed on to Mme ‘Mats`eliso, an older community leader who worked with orphans throughout the surrounding area. She would call *pitsos* [community gatherings] and gather the names of orphans in need, but she rarely got her hopes up that help would arrive. “It would be good if they would do anything to help, but they never do,” she said to me once. “We keep calling the *pitsos*, calling the children, and they [World Vision] take their names, but they are just toying with the orphans...we are now so discouraged.” Whatever World Vision’s reasons for helping or not helping the community, these perceptions reflect the lived reality of relations with NGOs for communities in Lesotho.

James Ferguson (2006) reminds scholars of African politics in this global era that, even as African citizens see the potential of becoming connected to the global system, that system remains full of gaps and exclusions. He describes the relationship of citizens to the West not as a network, but as a pattern of shadows and light, of opportunities and marginalities. This produces “new kinds of more or less desperate claims to membership and recognition at a supranational level,” he asserts (p. 14). Pleas for membership arise and intensify in the context of waning state resources and the increase in NGO provisions of

basic services. They are fueled by the fickle nature of aid money, and, in the time of HIV, the increasingly stringent criteria by which it is decided who will obtain resources and who will not. World Vision attempts to create “relationships of belonging” between individual givers and recipients, recasting ties of kinship and obligation for those lucky sponsored children (Bornstein, 2001, p. 614); but in doing so, it also erases more hallowed social contracts between citizens and states, replacing politics with the kindness and “Christian love” of strangers, rewriting entitlement and rights as gratitude in the form of thank-you letters sent from the sponsored to the sponsor. Survival in Lesotho, as elsewhere in Africa, is now a game of meeting the criteria of membership and belonging set out by extra-state entities. For citizens, these relations have reduced the social contract to what seems like a set of promises with fast-approaching expiration dates, written in pencil, carried about on multiple slips of scrap paper.

These socio-political relations have a direct impact on how patients and community members conduct themselves as citizens. This was most evident in the way patients approached the clinic when it ran out of medicines. While I was working with Ha Mamello, the clinic ran out of blood pressure drugs and other primary care medicines, and was forced to tell patients to go buy the medicines they needed for a few months. Stock-outs are hardly uncommon in Lesotho, but for those who require consistent drug access (like those with high blood pressure), they were stressful, and placed an additional and unexpected strain on household finances—that is, if households could afford the drugs at all. Rather than blame nurses, most patients simply accepted that stock-outs were a problem of “suppliers”; though they had little idea who was responsible for supplying the drugs. I had many conversations with patients about the situation, receiving answers to my questions about whether or not they would personally do anything to try to rectify the



situation that were very similar:

Mme Molapo: They [the nurses] just tell us that there are no pills....it's very frustrating.

NK: Do you think there's anything that you could do about this, or anyone you could talk to about it?

Mme Molapo: About the pills? ... With someone inside the clinic or outside?

NK: With anyone.

Mme Molapo: Honestly, it hasn't occurred to me that I can talk to anyone.

NK: ...Would you ever think of going to the community council to say, "hey, there are no medicines in the clinic?"

Mme Molapo: No, really.

NK: Why not?

Mme Molapo: No, I think this is a very good question. [Laughs.] Most of the time, we Basotho don't have the light [information / knowledge]. I never go up there [to government, officials], because I am always down here, hoping that they [the pills] will just arrive...These questions are very interesting. I wish I *had* done something so that I could answer [you] affirmatively. But I haven't, unfortunately. I haven't gone there. I never thought about [doing] it. I am not activist about these things. Because I just remain here, hoping that next time there will be pills available.

This kind of hopeful, patient resignation was common among citizens. In light of this, the frequent admonishment that patients should "accept their status"—which itself strays so far from rights-based dialogues about HIV—takes on an additional, poignant meaning. Those who live with HIV in the time of scale-up find themselves both privileged and damned, entitled to occasional handouts but forced to recognize their own marginal place in the transnational hierarchies of care and treatment. Yet when citizens become resigned to their marginal status, policymakers identify this not as the result of an unfair and unrepresentative new political system, but as the sign of citizens' own political deficiencies: they are passive, uneducated, irresponsible.

"Maybe I am a very shy person," Mme Molapo tried to explain to me later, even as she was criticizing the government in our interview for not doing more for orphans. "It's not that I hate [the government], it's just that I fear them, especially if I don't know anyone [in government, personally]...I fear these people because they are in very high positions. I have high expectations [for what the government should be doing], but I am very scared."

As discussed in chapter 2, any citizens in Lesotho believe that engaging in politics—and in particular, publicly complaining or speaking out about poor services—will result in them losing what little access they have to goods and resources. HIV and other development funding channeled through central governments—and in particular, through the institutions of government that are not subject to direct elections by the people (ministries, National AIDS Commissions)—increases the virulence of neopatrimonialist relations. HIV funding has replicated and shifted patron-client dynamics in Africa (Swidler, 2009b). But as I will argue in chapter 5, HIV scale-up elicits new dynamics between donors and recipients that extend beyond what we tend to recognize as patrimonialism. I call these dynamics a “politics of reciprocity”—and they are fed by the fracturing of state responsibilities, a distilling of politics into dynamics of resource-seeking and giving, and hierarchies in relations between citizens, NGOs, the state, and funders.

The reigning dynamics of citizen - state relations in the time of HIV scale-up indelibly shape citizen subjectivities. They reflect the replacement of citizenship with temporary forms of membership in state or NGO short-term projects, and of the social contract with a politics of reciprocity. As I will show in the chapters that follow, citizens in various settings continue to search for more meaningful means of engagement with state and non-state institutions, attempting to forge durable conditions of belonging. But in the contemporary political landscape in which citizens eke out the conditions of survival (material, spiritual, medical, and social), one of the most prominent elements of political subjectivity for citizens is the experience of temporary belonging, and the eventual, inevitable, loss of membership in state or NGO projects. This is reflected in the constant “disappearance” of food packages, pills, and NGOs, as well as the felt impact within communities of the rapidly shifting priorities of HIV policymakers. In the wake of HIV

scale-up, citizens experience acute periods of *dis*-memberment—an experience marked by the loss of membership in social programs, but also reflective of the broader dismemberment of the “body politic” (Scheper-Hughes & Lock, 1987). Amid such experiences of dis-memberment, and the sense that no one is truly responsible for their survival, patients turn inwards. Mme Moipone, another patient on blood pressure medicines who had not received them for 3 months when I first spoke to her, told me that she could not possibly speak to anyone about the situation, comparing the act of “becoming political” with *itlama*: being tied up, or bound, tying something around oneself. “So the best thing to do,” she said, “is to keep quiet. You’ll just say, ‘when they [the pills] are there, they are there. When they are not there, they are not there.’” She had no money for transport, or for purchasing the pills from the pharmacy. “I don’t know how I manage” to survive, she said: “It is only God up there who provides.” It is only with God that the social contract remains in the hands of citizens; prayer becomes the final act of negotiation and appeal with the myriad conditions that impinge on survival.

## 5.

## Support, Support Groups, and Survival: The Basotho Hat Turned Upside Down

*“Ngoan’a salleng o shoela tharing”*  
 (“The baby girl who fails to cry dies strapped to her mother’s back.”)  
 —Sotho proverb

I met Mme ‘Mats`eliso on one of my earliest trips to Lesotho, and she quickly became a champion of my research within Ha Mamello. She is a formidable presence—outspoken, confident, vibrant—and these qualities easily elevate her to the level of community leader. By trade, she is originally a traditional healer, but in the time of AIDS her work has become centered on the disease and its social consequences. For a long time now, she has been leading a group of community members—mostly older women—in providing home-based care and support to families suffering with illness and orphans. In English, they identify themselves as a support group; in Sesotho, they are sometimes an “association” (*mokhatlo*), sometimes a “group for support” (*sehlopha sa ts’ehetso*). They are not a support group in the sense imagined by global AIDS experts, who, drawing on the traditions of Alcoholics Anonymous and on strategies of “confessional technologies” (Nguyen, 2010) emphasize socio-psychological support as a means of achieving mental well-being and “acceptance” amidst illness. They consider themselves a support group because they provide support in the form of material goods (when they have them), care, and failing these, prayer. In their work, they don’t ask whether orphans have lost parents due to HIV, and don’t serve only those with AIDS. For them, the disease’s impact is such that it is present in every illness, every sick or emptied household. For these workers, care is an engagement in everyday politics, a form of social solidarity that attempts to fill the spaces of need left by clinical services and HIV programming. Their work deals in hunger

as often as it deals in drug regimens. This form of care attempts to address the broad spectrums of survival (social, economic, familial, spiritual, subjective, political) that are under threat in the weakening of bonds between states, citizens and the institutions of HIV scale-up. In doing so, it also draws attention to the insufficiency of such care work to address these needs and overcome the many challenges to collective efficacy arising from HIV scale-up processes in Lesotho.

In the everyday work of groups like this one, the mandates set forth for them by funders, the government, and global modalities for HIV care and prevention are integrated into long-standing patterns and practices of neighborliness, social support, maternal caregiving, and communal redistribution of goods. Without romanticizing these earlier forms of support and exchange (which can and do lead to marginalization, stigma, or unfair patronage—see Campbell, 2009; Rau, 2006; Turkon, 2009), it is important to realize that the new ethics of “care” and “support” being taught to citizens in places like Lesotho are understood as an extension or modification of older practices—and long-standing forms of membership in local political worlds (Bowsky, 2004; Germond & Molapo, 2006; Makoae & Jubber, 2008). HIV initiatives have added new equipment (gloves, condoms), vocabularies (“accepting one’s status,” “risk behaviors”), skills (positive prevention, infection control), and incentives (stipends, small grants, supplies) to existing practices of care and social solidarity. But in the everyday work of caregivers and support groups, these new modalities are often pushed into the background by the broader social ills that they confront on a daily basis, and which they are still poorly equipped to ameliorate. HIV initiatives have frequently emphasized the importance of community-based responses to HIV, asking citizens to devote considerable (and often unpaid) labor to care and prevention work; yet these citizens remain highly marginalized within HIV scale-up

processes, and unable to obtain the forms of support (for themselves or others) that would provide a means of long-lasting survival. Contemporary support groups in Lesotho find themselves at tense junctures between *survival* and *support*, between *belonging* and *abandonment*, and between *desert* and *dependency*. It is these junctures that I explore below, and which, I argue, shape the political subjectivities of engaged citizens in the time of HIV scale-up.

In this chapter, I explore and contrast the work of two support groups in Ha Mamello: Mme 'Mats`eliso's group of home-based carers, which I will call Bahlokomeli Support Group, and a support group of persons living with HIV/AIDS sponsored by the clinic, whom I call the POSWA (People Openly Surviving With AIDS) Support Group.<sup>47</sup> I am particularly interested in how these groups define themselves, and how these collective identities are at points challenged or reinforced by national ideas about the meanings of care, support, desert, and collective efficacy. These groups reflect the ways that HIV scale-up is changing and remaking associational life in recipient countries. The challenges faced by each group are worlds apart, though they occupy the same community space. These differences reflect the diversity of possible experiences for citizens at the center of local efforts to address HIV. Finally, by observing the challenging, difficult, uncomfortable day-to-day dynamics of these two groups, we are able to witness the fissures in social solidarity which are emerging in the midst of scale-up, and to pay careful attention to the possible ramifications of these social tensions. In what follows, I will first describe the work and evolution of Bahlokomeli, and then turn to a discussion of POSWA. The chapter ends with a discussion of the ramifications of HIV scale-up's project culture and politics of reciprocity

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<sup>47</sup> I use pseudonyms for both groups for their protection. Both groups receive occasional help in the form of small grants and NGO partnerships, and I do not wish for the data presented here to inadvertently jeopardize these sources of support for either group. *Bahlokomeli* means "caretakers" in Sesotho.

for the broader community.

### **A House Full of Patients**

I came to know Ha Mamello best through Mme 'Mats`eliso, who allowed me to follow her volunteers around the villages as they bathed patients and changed dressings, provided treatment support to those with HIV and TB, and shared food or soap with orphans and the destitute. I learned village gossip sitting outside her house on sunny days, as neighbors and patients came to ask for help or advice. And on my walks through the village with her, her encyclopedic memory of social relations helped me to understand the landscape of social suffering brought about by poverty, hunger, and AIDS. Though she had begun her care work decades ago as a traditional healer, her contemporary role in the village combined leadership, healing, and HIV advocacy. Over time she came to see the purpose of her traditional healing work as a means of supporting and filling the gaps in the biomedical HIV system, and she became widely known as for her work with HIV patients. She never claimed to be able to cure HIV, and was quick to reprimand sick patients for failing to get an HIV test, or not seeking ARVs through the clinic. She generally would not give any ingestible treatments to those on ARVs, for fear of liver damage and drug interactions, but would offer topical, and sometimes spiritual, balms. She provided healing services that addressed the opportunistic infections of HIV (especially shingles, "*labanda*" in Sesotho) for which the clinic's services offered little reprieve, and she tried in many different ways to ease the pains of hunger that inhibited so many patients from adhering to their treatment. Combined, her traditional healing and care work represent "hybrid strategies" (Decoteau, 2008; Robins, 2008) common in contemporary public life in Africa, in which identities and roles which we might otherwise perceive as contradictory coexist

and become symbiotic advantages. In many ways, Mme 'Mats`eliso is a classic "organic intellectual" (Gramsci, 1971)—able to understand, and give locally relevant and eloquent articulation of, the structures and possibilities of social life.

A few weeks before Christmas, in the depths of Lesotho's short but intense summer, I found myself following Mme 'Mats`eliso as she set a mean pace up one of the hills outside of Ha Mamello. The thick, tall summer weeds slapped against our faces and arms as we made our way up a narrow footpath. The previous day, Mme 'Mats`eliso had used up precious airtime on her cell phone to call me, frantic, at 7 AM on a Sunday morning. She had just visited an elderly man who was very ill with a lung infection, she told me, and who was unable to take his medicines because he and his wife had no food. Chronic illness in food-insecure contexts tends to trigger conditions of starvation: a patient gets sick, and the household shifts resources to care for them; fewer family members work or are able to tend fields and gardens; the household loses its already tenuous foothold in the margins of food security; the patient is unwilling or unable to take medicines without any food; the patient becomes sicker because of lack of food and medicines, and other family members are more likely to become ill. If the patient is lucky, he somehow survives on occasional handouts and sheer will, and may after some time regain strength enough to work and no longer require round-the-clock care. If he is unlucky, he will die, either from starvation itself, or from the infections or diseases that might have abated had he been able to take his medicines. Death causes further financial woes, as funeral expenses cause families to go into great debt; worse still is the shame of families who cannot afford to bury their dead. More debt, less food, followed by more sickness: without proper nutrition other members of the household succumb to illness, and the cycle deepens.

Ntate Khotso and his wife were in the midst of this cycle when Mme 'Mats`eliso



met him. He had initially been diagnosed with TB, and had taken a full six months' treatment for TB with no improvements in his health. Finally, when he failed to recover, his family pooled its resources to bring him to another doctor at the TB hospital, who said he did not have TB, but instead had a lung infection, and started him on antibiotics. Ntate Khotso had been sick for so long that he and his wife had both lost any sources of income—they had no fields, and they were unable to work in anyone else's fields for food. He claimed he could not take the antibiotics without food, as they made him nauseous and he only lost what little was in his stomach when he vomited them up again. So 'Mats`eliso and I made a visit on Monday morning to the small *malaene* [a low, rectangular building comprised of single-room dwellings] where Ntate Khotso and his wife had a room.

First, though, 'Mats`eliso had someone else for us to meet. Just next door, the other half of the *malaene* was occupied by Mme Lerato, a TB patient. 'Mats`eliso stood in the grass outside the *malaene* and hollered at its occupants to open their windows, chiding them about the risks of infecting their families, and us. It was her best, and often only, protection against this occupational hazard. Mme Lerato had become gravely ill with severe back pain while working part-time jobs in South Africa, and was diagnosed shortly thereafter with spinal TB. She started treatment in South Africa but did not get better. By the time she traveled back across the border to take up a full time position as a patient in her aunt's house in Ha Mamello, she was paralyzed from the waist down. Inside the house, Lerato was cheerful, excited at the rare luck of having visitors despite her grim surroundings. She lay naked under a blanket in a dark back room, which smelled of urine and feces, and a fat catheter drained into a bucket on the floor. Though she had been on TB medicines when she returned home to Lesotho, the clinic had refused to continue her treatments, because she was unable to show up in person, and her aunt had lost her

prescription bottles. Though she had a clinic booklet and a TB care record which showed which medicines she had been prescribed, and for how long, the clinic had *rules*: patients who did not present their empty bottles as evidence of adherence could not be given new prescriptions. This policy is a corollary of the work burdens at clinics and attempts to streamline the endless flows of patients. But in the absence of a sense of rights within the clinic, such rules resulted in patients being turned away with little or no recourse. Break the rules, and you were out of luck; after being turned away, your best option was to show up at the clinic in your needy, pathetic state and hope that the nurses would help you, or go to another clinic and plead your case to a new set of ears. Neither of these options was available to Lerato, of course, who was stranded on this rugged hilltop where taxis would not go.

Mme Lerato was also HIV-positive, which at the time I met her seemed a mere footnote to her other health problems. But this meant she was also not accessing her ARVs, and I worried constantly after meeting her about those half-treated, persistent diseases raging in her body. While visiting Lerato, 'Mats`eliso and I strategized ways to get her care from a clinic. Lerato held out little hope about her chances, seeming more interested in strategizing about how to get me to visit her more often, offering Sotho lessons and further interviews. Ultimately, I ended up orchestrating her transport to the clinic myself—in an old station wagon and with the help of those strong enough to help me load her into and out of it. Each trip was excruciatingly painful for her, and a full day's effort.

The scene at Ntate Khotso's house was much less hopeful. He was barely conscious when we arrived, emaciated and attended by a lazy chorus of flies. He was too sick to strategize, and his wife was sick as well. She sat in the tiny room sweating profusely, the symptom of an infection in her foot that had gone untreated. What time did

she have for herself, after all, when she and her husband were locked into this private, hellish fight for survival? There was little food, and what there was, she gave to her husband, and they hoped he could keep it down with his medicines. Often he couldn't. Without food, the medicines always made him feel sicker, and what was the point of taking pills if he was likely to die of hunger anyways? Later in the day after visiting their house, I brought by maize meal, and they treated the small gift as if it was medicinal, though maize is the staple of the diet in Lesotho. How much should he eat, they asked? How much water should we prepare it with? How many times a day? There was no mistaking that the real medicine here was food.

A few days later Ntate Khotso was a bit better, well enough that he wanted to go to the national TB hospital with Lerato, in the hopes of getting better treatment. He walked away hours and hours later, exhausted, holding medicines but of course no food. He and his wife were depleted by the trip, and I wondered if it was worth it, he seemed so far gone. A few days later, I received a text message from Lerato on my phone: "oh dear Nora I am very sorry to tell you that Ntate has passed away."

After the Christmas holidays and Ntate Khotso's funeral had passed, I traveled again up the hill to his house with 'Mats`eliso, and another support group member, a smiling and ever-jovial woman named Mme 'Mathuso. Ntate Khotso's widow sat outside the house, and I told her again how sorry I was for her loss. She looked at me, smiled, and shook her head slowly. "Mme Nora, Mme Nora..." she said quietly. Things were equally grave at Lerato's house. She had sent a family friend to the TB hospital to pick up her second month of her (renewed) prescription, and he had returned empty-handed. Though we had previously gotten a nurse at the hospital to agree that Lerato could send someone to pick up her medicines, it seemed that the nurses had either forgotten her situation, or that

another nurse on staff was less willing to bend the rules. None of us was eager to repeat the struggle involved in getting Lerato to the clinic. "I don't know what to do now," she said to 'Mats`eliso, sounding angrier and more hopeless than I had ever heard her. Her face was half buried in a pillow as the conversation about her fate circulated above her. I volunteered to go to the clinic and appeal to the nurses again, but none of us were hopeful about the outcome. 'Mats`eliso muttered that "we must have faith" and began to pray quietly. Lerato placed an arm over her face and quietly cried while 'Mats`eliso and 'Mathuso prayed. She seemed to think that death was near; Ntate Khotso's quick passing must have made her vulnerability that much clearer to her. As we left and walked back down the hill, 'Mats`eliso kept repeating, "what is there to do? What is there to do?" Again she turned to prayer. "We can only pray for wisdom."

In Mme Lerato and Ntate Khtoso's world, survival requires much more than pharmacology. Those like 'Mats`eliso who step in to assist them confront the gaping needs in their lives, and face pressure to fill them with their own scant resources. Lerato, as it turned out, did not die. Assisted by Mme 'Mats`eliso's persistence and my own resources, she eventually got two different clinics to provide her with regular medicines for TB and HIV, but it was a monumental struggle. Four months later, she could move her toes; a few months after that, she could lift her legs. And there it was: survival. In Lesotho it often seems like a random and miraculous feat when patients shake off death's dogged pursuit. Survival in these contexts depends on chance, but also on social networks—on sewing fragile webs of support from the fragmented and unpredictable systems of health care and social assistance in Lesotho. Support groups face—and are often held accountable for—the unfair patterns of death and survival in communities. Though their work seems to mediate the space between certain death and circumstantial survival, they remain aware that the

entities which fund HIV programs ultimately set the rules of the game, determining which conditions of life merit assistance, and which do not. Finally, though money seems to pour into the country, many support groups perceive these funds as remaining “up there”—with government, bureaucrats, and experts—rather than being sent “down here” to where needs are acute. After Lerato recovers, Mme ‘Mats`eliso narrates her story for others in the group: “The clinic did not help...The American grants did not help...funding comes for TB, for HIV, but it goes for their fancy hairstyles in Maseru,” she says, referring to the intricate, frequently changing hairstyles of civil servants and local professionals in the capital (Maseru) who seem to profit so visibly from the funding of HIV and AIDS.

### **Bahlokomeli**

Mme ‘Mats`eliso and the Bahlokomeli support group members often give conflicting accounts of their group’s origins. For ‘Mats`eliso, the group began to coalesce as she and others were trained in HIV prevention and care strategies, and more recently, when they became community-based workers for the Know Your Status campaign, going door-to-door in surrounding communities and offering HIV testing. For other women in the group like ‘Makabello, a community health worker affiliated with Mamello clinic, the group emerged in direct response to their struggles with the burden of HIV: “we were struggling with all of the sick, and we ended up realizing that we had to come together to stand up on our own feet, and figure out how to help ourselves and our families [in the face of the disease]. There are so many patients, there are so many orphans...that is why we are doing all of these things.” A few older women in the group claimed it started much earlier, and gave hazy accounts of earlier epidemics that spurred its growth: locusts that destroyed crops and homes, and TB among the miners who returned sick from South

Africa. In many ways, the group had not formally started, but had always been: it was less a group than an amorphous collection of community members helping the sick, trading acts of neighborliness, and building social solidarity as a poor person's insurance against troubles that would, inevitably, arise. Various forms of associational groups are common in Lesotho—ranging from rotational savings groups, to farming collectives, to charitable projects organized by chiefs (African Religious Health Assets Programme [ARHAP], 2006; Turkon, 2009).

Most group members recalled that the group had become an “official” HIV support group in 2000, when the government first put out a call for community groups to help in addressing HIV in their communities. By 2002, the group members attended a government training for care-takers, learning about routes of HIV transmission and strategies for preventing infections and protecting themselves while caring for sick patients. They were also given caregiver “kits” at this time that included gloves, soap, and basic first aid supplies. But many group members insisted that they had been doing care work—without gloves or other materials—for years before they received these kits. With the increases in HIV funding for community-based care and support efforts in Lesotho, beginning around 2005-2006, these robust forms of associational life were largely overwritten by the particular vision of community-led support networks advanced by global HIV policymakers (Kimaryo, Okpaku, Githuku-Shongwe, & Feeney, 2004; Rau, 2006). In this vision, civil society groups provided a cheap source of (largely) volunteer labor for the implementation of HIV initiatives, turning potential sources of grassroots HIV activism into lay service providers (Bowsky, 2004; Lesotho News Agency, 2005; UNAIDS, 2001). Support groups would provide peer education about prevention and treatment, serving a crucial role in the process of building “HIV Competent Citizens” (chapter 3); community-

based care workers could, with minimal inputs of training and supplies, provide care and support to the sick and orphans, and implement campaigns like KYS [Know Your Status]. In many places in Lesotho, citizens enthusiastically responded to demand for community-based organizations (CBOs), either forming new entities or revamping old associations to meet new HIV objectives (Bowsky, 2004). Though their emergence was incentivized by newly available resources (and some group leaders could be heard saying they wanted “a piece of the cake [of HIV money]”), many others were genuinely grateful to be included in efforts, having sat by empty-handed as relatives and neighbors died and orphans multiplied. HIV had strained all social support networks beyond the breaking point, and any assistance in addressing need was welcome. The sense for groups like Bahlokomeli was that they would do what funders and donors needed in order to simply get any supplies and resources into their communities.

Being the object of new financial flows could suddenly place groups at the center of tense conflicts over who deserved, and had access to, HIV money. When more than fifty of Bahlokomeli’s members came forward to volunteer for KYS in 2007, Mme ‘Mats`eliso reported that by that time the clinic staff didn’t “like [outside] people helping with HIV and AIDS in the clinic,” because, among other reasons, “we can see what they [clinicians] do.” What she means is that their presence as part of clinic activities provided another layer of accountability that was uncomfortable for clinic workers. Resources can cause tension as much as they address need, and some clinic workers feel that they are in competition with community-based groups for limited funds and assistance. One nurse in particular, Bahlokomeli members claimed, withheld the stipends they were meant to be paid for their work with KYS—whether for her own benefit or simply to punish the KYS workers is difficult to say. But ‘Mats`eliso reports, with disappointment, that the nurse became one of

many people who, after the HIV money began to flow into clinics and communities, “took off” and “then...were running the *business* of HIV.” This is when things began to be “political” and she realized that “HIV and AIDS is for the politicians”—that is, for people who are interested in gaining power and resources from HIV, who can succeed at such “political” games—not for those who are interested in helping the sick.

In addition to training as KYS volunteers, the Bahlokomeli members attended numerous trainings for community health workers and HIV educators. After their extended efforts to test people in their communities, they now were faced with the additional psychological and material burden of those who they had identified as HIV-positive. As those patients and others became sick, Bahlokomeli focused its attentions on two primary activities—home-based care (HBC) work, and caring for orphans. For a long time, the government had suggested that it intended to pay community health workers (CHWs) and those providing HBC—not a full wage, but what was termed an “incentive” to acknowledge their efforts (“Global Fund Round 6 Proposal,” 2006). Years went by without Bahlokomeli’s volunteers receiving any assistance.<sup>48</sup> They poured their own resources into feeding and caring for patients, borrowing gloves and first aid supplies from clinics and organizations, and failing that, purchasing them on their own. Then, in late 2010, the government finally began to pay community health workers incentives, and even paid an amount of “back pay” to make up for the delays in funding. But in what seemed like an exceptionally arbitrary rule to community-based caregivers, only a handful of the

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<sup>48</sup> It appears that many competing programs for the training and payment of CHWs were at work in Lesotho over the past decade, some sponsored by NGOs, some by the government, and some through Global Fund grants. But even those CHWs in Ha Mamello who worked through the clinic reported to me that they had not received payment for their work in the past 3-4 years. While the Round 6 Global Fund proposal sought to streamline the “bewildering array of working arrangements and incentive systems” for community-based care workers, it only made clear provisions for stipends for certain cadres of community health workers, most of whom had been trained and retained under the Family Health Division of the Ministry of Health and Social Welfare (“Global Fund Round 6 Proposal,” 2006).



Bahlokomeli volunteers were “chosen” to be official CHWs and to receive incentives. The rest could continue their work, but without payment or recognition.

To Mme ‘Mats`eliso and the volunteers, this was a terrible outcome, forcing an arbitrary division between paid and unpaid volunteers, fostering jealousy and anger among the group’s members. Suddenly, some in the group had “jobs,” and others didn’t, and the labor of some was more valuable than the labor of others, though they did the same work. Paid CHWs felt pushed out of the group by other members’ jealousy; unpaid members quit in frustration; ‘Mats`eliso was barely keeping what remained of the group together. “Where are these other [community health workers] supposed to go?” ‘Mats`eliso asked me angrily one day while we were meeting with members on her porch and she was intermittently seeing patients who were arriving at the house seeking assistance. “Because they are living *here*, in Lesotho, where they are helping people, all these affected and infected.” She means that, because they live in communities with the sick, members have no choice but to help them, and they are indelibly part of the communities that they serve. “That’s the main problem of HIV and AIDS,” she continues, “*hobane ba bang ba rua, ba bang futaneng*”—“because the rich are those that inherit, and everyone else becomes poorer.” She points towards a child, skinny and wasted, who has been brought to her house by his grandfather; they are sitting nearby in the yard, waiting silently. She explains that they have come to her begging for transport money to get to the pediatric HIV hospital in Maseru, where the child is hoping to get assistance. Two years prior, I had interviewed the grandfather, a sweet, shy man who had disclosed to me at the time that his daughter was very sick with AIDS. His wife was gone: he talked about the shame he felt as he bathed and cared for his own daughter, having to see her naked body, but he had no one else. She died not long after I interviewed him, and ‘Mats`eliso confides to me that he and

the child are also living with HIV. “Look at this child now,” she says, “they”—the government, the clinic, the people with money—she doesn’t specify, but it’s always the same batch of culprits: “they don’t care about him, they don’t care about this lady [his mother], no, no, no...so I told him he should come here, and he came. They don’t have food, so I share my maize meal with them. We share our meals together. We share soap. How can we do otherwise?”

In the aftermath of the government’s decision to pay some CHWs, the anger of Bahllokomeli’s members festered; they began to speak openly about what they felt they had sacrificed to engage in this care-work. “I am still crying,” Mme ‘Mats`eliso said to me many months later, “If I had the strength or the capabilities I would go outside to these countries [that are funding Lesotho] and tell them about this.” Members of the group emphasized that they had been “hurt by caring”: they identified themselves to me as living with HIV, and claimed that they had been infected while caring for patients. Such claims are not uncommon in Lesotho, and I frequently encountered elderly men and women at the clinic who were HIV-infected and presumed their infection was acquired while caring for children or partners with the disease.<sup>49</sup> This is a population about which few statistics are collected, and so it is difficult to say how prevalent HIV is among older populations.<sup>50</sup> It is

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<sup>49</sup> It is hard to determine the veracity of these statements, as almost no studies have been conducted on the likelihood of caregiver infection in settings where sick patients are sent back to homes with inadequate supplies and limited resources to require long-term, intensive care (Negin & Cumming, 2010; Negin et al., 2010; Makoae, 2009). In these contexts, even a task like washing frequently soiled bed linens is a monumental effort—as water has to be fetched from far away and the linens have to be scrubbed by hand. Many families with sick patients cannot afford washing powder, bleach, or gloves (see also Makoae, 2009). Care work in these situations is messy, and contact with bodily fluids becomes an everyday part of care. Infection among older adults and even the elderly is surprisingly common, but poorly documented, in Sub-Saharan Africa (Negin & Cumming, 2010; Negin et al., 2010; Ng’ango & Diwouta, 2011).

<sup>50</sup> Recent modeling by Negin and Cumming (2010) estimates that the prevalence rate among older persons in Lesotho (ages 50 and up) could be as high as 27.8%. At Mamello clinic, 5 of those I interviewed were over the age of 60 and HIV-positive, and fully a third of those I interviewed at the clinic who were living with HIV were *above* the common age range for data collection on adult prevalence, of 15-49 years of age.

harder still to assess how many in this population are infected through care-giving efforts. Such explanations certainly offer an easy escape from the stigma of HIV, which in Lesotho is strongly associated with promiscuity and sexual immorality. I am not sure (for the purposes of this inquiry) if it matters how these elderly caretakers became infected. Rather, what I find striking is how they spoke about their HIV infection, and the meanings it held for them. In discussions with caretakers, I did not hear the apologetic discourses of people trying to explain away their stigma; I heard talk that was infused with anger and a sense of injustice. Care-givers talked about their lack of knowledge and supplies like gloves, of their children's fear of stigma. "What was I to do?" one woman said about her daughter, who had been severely ill with AIDS. Referring to her lack of gloves, she said, "was I not supposed to touch her? She is my *child*. And so I would be touching her carelessly [*tlapurela*; lit., to hold carelessly; also, to cling to]." Whether or not it was epidemiologically accurate, claims by caretakers that they had been "hurt by caring" were a means of drawing attention to proper ways of caring for the sick, and thereby highlighting how the government and its partners were failing patients and their caretakers. By emphasizing that infections were a direct outcome of the lack of government support for those who were sick and their families, talk of care-giver infection highlighted the broken ties of obligation between government, funders and citizens.

These claims about infection are related to support groups' acute concerns that HIV money does not reach them, and that their labor is under-valued. When Bahlokomeli care workers were initially called on by the government to volunteer their time, they were not

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This means that they were not included in the national prevalence projections (Negin & Cumming, 2010). While caregiver infection is possible—and certainly merits more research into infection routes and rates—it is erroneous for researchers to presume that the elderly are not sexually active or are an insignificant population of those with HIV.

promised wages, but “they [the government] said there would be incentives [with which] to buy soaps and other supplies...Because they talked about the Global Fund money” which they had received for this purpose, one member told me. Instead, it seemed “the government is making use of the Global Fund for its own benefit [only].” But she emphasizes that they were never told they would get real pay for the work, “we were just told to volunteer, that there was no pay, they just said we would get the [caregiver supply] kits, but [then] we never got those either.” Support group members sought incentives or salaries as form of recognition, rather than reimbursement—payment as a form of respect, not of reparation. Monetarily, their expectations were quite low. I spoke to a support group member from a neighboring village during the research who insisted to me his group was paid for its work. By whom? I asked him, how often? After a drawn-out period of questioning, it became clear that what he meant by getting payment was that the group had once attended a nationally-sponsored, week-long training event, for which their transportation was reimbursed. And if members did not eat the lunch provided, they were given an additional M40 (about \$5) at the end of the week as meal reimbursement.

Though donors and supporting NGOs frequently selected support groups to receive ‘incentives,’ packages of goods, or small grants, these donations were paltry compared to the labor value that support group members invested. Often—as with a small grant to support group activities in the area of prevention education, or income generation projects, for example—the grants themselves required support groups to take on whole new areas of work for which the labor was rarely, if ever, reimbursed. Bahlokomeli received a small U.S. Embassy grant while I was working with them, but the grant rules clearly stipulated that it could not be used for any salaries, or for building any structures. Instead, it was intended for income generation projects and community HIV education—projects that

required vast inputs of time, effort, and supplies on the part of volunteers. And because the income generation arm of the project could provide more flexible funds to spend on community needs, the group spent most of their time on income generation, to the detriment of HIV prevention activities. When I spoke to group members, they emphasized again and again that they wished the group could have funding for two things: some small stipend with which they could buy supplies for care-giving and food for the patients they visited, and materials with which to construct a small building in the community where they could meet, hold education sessions, and most importantly, provide meals and life skills education to the ever-growing population of village orphans. Building, in particular, is a crucial means of achieving legitimacy as a person, family, or entity in Africa,<sup>51</sup> and it is likely that the group wished to build in order to create a long-standing resource that would remain after their short-lived grants were gone, and so as to establish roots and acceptance in the community.

Thus, by refusing to pay for either labor or building, funding parameters for community-based support groups deprived them of the two forms of support that would provide the most reliable sense of legitimacy. Since the support of donors is also inconstant, unreliable, and mysterious, groups like Bahlokomeli feel as if they are laboring without recognition, invisible to those who hold the purse-strings. Mme 'Makhotso, an energetic group member, explained it this way:

As we look at the media on the television, and on the radio, we see that there are people [in

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<sup>51</sup> Julie Livingston (2005) describes building, or *boaga*, in Botswana as a crucial “life strategy”: “Building continually reaffirms personhood by forging connections over time and across generations—linking the doing of today and yesterday with tomorrow... In Botswana, where personhood is understood to be a process, building is what one continually strives for. Through building, or self-making... people create and reinvigorate social relationships. They develop moral, economic, political, social or spiritual capital. It is the primary means through which the promise of liberal individualism... can be harnessed to the making of social selves” (p. 15)

support groups] who have achieved so many things that we have not achieved. And we wonder how they were able to accomplish those things, because we know that support group members are those people who are not *working* [i.e., they are not paid for the work they do, they have no other jobs]...so we wonder how they can accomplish these things [without salaries, or other funding]. So our intention—our *desire*—when you see us meeting here and there *every day*, is that ultimately we want somebody to see us and to help these people—the orphans and the vulnerable children and of course the patients. But I suppose we are lucky, because there are villages that have *no* support groups at all.

Support groups thus remained caught in webs of illegitimacy, where their labor was not valued and funders insisted that they would not pay salaries, promoting instead values of community support, social solidarity, and volunteerism. Support groups often demonstrated these qualities almost to a fault, but lack of material resources, as I will continue to discuss below, caused undue strain among members and between groups and the citizens they assisted. Even when “incentives” finally came from the government, they had the pernicious effect of damaging solidarity, and devaluing the work of certain members.

Bahlokomeli’s lack of material resources led to difficulties with patients as well. Those whom members visited at home often bristled at the idea that care workers would enter their homes and provide “care,” but come empty-handed, without offering groceries, soaps or small gifts. Like Ntate Khotso and his wife, many patients and their families remained marooned in a chronic state of food insecurity and hunger. Pharmaceuticals from the clinics and the care offerings of poorly-equipped neighbors are often perceived as insufficient medicine. As in Nancy Scheper Hughes’ (1991) accounts of the “madness of hunger” in the shantytowns of Northern Brazil, medicines and biomedical discourses in contexts of severe resource scarcity and socioeconomic oppression become tools for masking hunger and its causes. But patients in Lesotho spoke of hunger forcefully and frequently with those who offered them care. Rather than turn their frustration towards those entities who might be able to alleviate hunger, patients expressed their anger towards

care workers. Mme 'Mats`eliso spoke often about her struggles with patients in this regard:

I tell people not to be bitter [when we cannot bring them food]; I tell them not to be bitter, because we can't do otherwise. Because we still have nothing to [offer to] help them, you see? Nothing [with which] to help...some [people] they don't want these groups of ours to go see them. Because they will say, "you are always coming, with no food, nothing! No food, nothing!"...they say, "we are hungry, we are hungry, we have to make food, but we are always crying [for want of food]." So we tell them, "we don't have food, either, to give you"....but we always share together what we have. What we have we share.

Mme 'Mathuso tried as well to explain why people became angry at them:

People feel like the support group is failing to do its duty when we cannot bring them anything. We try so hard, but the problem is not between us, the problem is between the clinic, and the funders, and the government. They [the patients] blame us, they think maybe we are practicing favoritism...they think it's a sign that we don't care for them.

What is tragic about these responses is that Mme 'Mathuso, Mme 'Mats`eliso, and the other women in the support group truly offered care sincerely. Perhaps they took some pride in being trained as HIV counselors, or in offering home-based care, but anyone who watched them engaging in their work could see that it was selfless. Often the group members and their patients would contrast true charity as assistance "given with love" from aid as "handouts." But as aid and neighborliness became conflated, patients struggled to understand why caregivers could not provide better connections to the networks through which HIV resources flowed.

Mme 'Makabello told me a story about one of her neighbors, who was on TB treatment, and for whom she was a treatment supporter, overseeing him take his medicine daily as part of directly-observed therapy approaches.

So sometimes he arrives at my place...and he tells me that he is very hungry. I haven't even eaten any *leshelehele* (porridge) yet, but I know that this patient shouldn't take the treatment without eating, on an empty stomach. So now when you don't have any food, what are you going to give this patient? I enter inside my house, and share the bread I have made for my children, which is not even enough [for them]. I will give him tea or coffee, and he eats. I have already dipped into the share for one of my kids—so that he can eat, take the medicine, and go. And I am left there with the drama of replacing the share for this child. He is taking the treatment, and you understand it makes him hungry, and you know [patients] become worse when they take the medicines without food... [otherwise the pills]

make them sick and kill them, I swear!

For 'Makabello and the other volunteers, offering care also meant becoming embedded in new networks of obligation. Acts of care stretched their social safety nets to the point of breaking, as their care work bound them to more and more patients who were hungry, needy, or dying. Because HIV scale-up created expectations among patients that they would receive the help they needed, they were far less reserved about asking directly for assistance. And because support group members were sometimes their only meaningful point of contact, patients articulated their needs to them, and vocally.

In a time of rapid HIV scale-up, money abounded, and therefore schemes to access HIV money did as well. Other support groups were less well-intentioned, and citizens suspected many groups of secretly hoarding HIV monies or using the names of the sick (or falsifying their own HIV statuses) in order to obtain funds. And so this source of true social solidarity and collective efficacy became an object of mistrust and derision. Citizens, unable to hold governments, clinics, or NGOs accountable, and with little reliable information about where funds went or why, turned their anger against those most accessible to them, those whom they did know. As a result, some support groups became more secretive about their work, guarded their activities more closely, and blamed patients around them for being "lazy" and relying too heavily on handouts and charity. "These blessed patients," one of the Bahlokomeli members explained to me, exasperated, "they begin to believe that they are sick, that they should just sit and be *sick*. That is the problem...FAO [Food and Agriculture Organization], World Vision...World Food Program...these people who give them food packages...and even when they have recovered, you find that they are now not willing to do anything. They are lazy!" Of course, these changes among support groups only fuel distrust between members and



citizens in the broader community.

In this climate, support groups could be held accountable to communities for programs, goods or services over which they had little control, even as funders were also holding them accountable. Efforts to provide this kind of dual accountability took up a great deal of effort. When I visited her, Mme 'Mats`eliso was as likely to be engaged in efforts to build trust, both with fellow community members and various donors and agencies, as she was to be engaged in care work. As the most educated member of the group, and the most outspoken, these responsibilities fell to her. With donors, 'Mats`eliso went to pains to document funds and group work. To improve trust with group members she would always make and receive important phone calls surrounded by group members, her small cell phone set to speakerphone so that everyone could listen in on her conversations. She was quick to understand that data was the currency of HIV initiatives, and kept messy, but dutiful, logs of patients and orphans in the community. With the community, building accountability was tougher, especially as the years of HIV scale-up wore on. During the research, and just months prior to national elections, Bahlokomeli received gifts of food packages from a national NGO that was run by the Prime Minister's wife, 'Mathatho Mosisili.<sup>52</sup> A large event was held in the community, and 25 large, 25 kilogram food packages were distributed to the elderly in the village—"too much, really!" the Bahlokomeli members commented afterwards. They had been asked to identify the most needy in the community to receive the packages. Gifts of food are a common tactic used by the ruling party to garner votes in Lesotho (Bird, Booth, & Pratt, 2003), and it

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<sup>52</sup> Lesotho is not alone in having a powerful political leader's wife founding and running a national charity in her name (see Smith, 2008). In endemically corrupt countries, these entities have been used to siphon off public funds. In Lesotho, the organization took its mandate for charity quite seriously. Nevertheless, it remains a telling example of how HIV funding disbursements can circulate through the hands of various powerful, politically-connected individuals. The organization received the bulk of its funding from the National AIDS Commission.

would not be surprising if this was their ultimate purpose. A few women from Bahlokomeli excitedly talked afterwards about the First Lady's appearance, and the presence of a television crew from the national television station. During the event they looked jubilant, dancing and singing praise songs for the First Lady and her entourage.

Later, Mme 'Mats`eliso wearily told me, "we promised we would be back with more." I was confused by what she meant, until she explained that "a few" remaining elderly in the village had not received packages, though they were equally needy, and they had originally been on the list of eligible recipients submitted to the organization. Then there were the orphans, she said, who of course also needed food. She insisted that those who had gotten food today were only "the first group" to get aid, and that Bahlokomeli could make up the difference, providing the extra bags needed. After quite a bit of prodding, I got her to admit numbers: 25 bags had been originally distributed, but she still had 28 more on her list who were in dire need. "So we are thinking that as a support group, we should buy things for those others, with money from our own pockets. Maybe we can at least get 12.5 kilos for everyone...we will do that to make sure that things are transparent...and fair...we will contribute from our own pockets...and perhaps we will invite the First Lady, so she can observe this as well." As she spoke, determination evaporated into exhaustion. Of course she wanted to be able to provide enough to everyone in the village who was truly needy, not just those who had been chosen, but her impetus was also fear—fear that neighbors would think they were hoarding the additional packages, or that they were to blame for the deficit. To keep peace between Bahlokomeli and the community, the members would have to pay for additional food packages—more than were originally given—out of their own pockets. I had been with them long enough to know they would never have enough money for it. I pressed on: wasn't she frustrated,

angry? “It’s more difficult nowadays because donors have policies and laws, and when they say 25 [people] that’s *it*...It’s painful for us because the donors have their own policies, which we can’t influence.” My research assistant, more attuned to the potency of jealousy in Lesotho, asked, “won’t people just complain about getting different packages?” “Yes,” ‘Mats`eliso replied, “but half a loaf is better than no bread at all.”

Mme ‘Mats`eliso and the Bahlokomeli members were hardly immune to feelings of distrust and embitterment when it came to NGOs and funders. ‘Mats`eliso was by far the most outspoken about these feelings, and our conversations would frequently trace a circuitous, but familiar, route between the illnesses of those around her, to her ideas and efforts about what could be done, to the unfairness and corruption of aspects of HIV scale-up. Early on in the research when I brought up the Global Fund, she said to me conspiratorially, “we know that they came here [to Lesotho], we know the *secret* that they were coming here to help *everyone* with HIV and AIDS.” She spoke of this as a secret because, by her reasoning, no one would want Lesotho’s citizens to know about Global Fund’s true intentions of helping everyone, since the government had done such a poor job of distributing the funds and implementing the programs. Of course, these perceptions—the acute disappointment at the lack of government “implementation” of projects, the suspicion that HIV money was stowed away somewhere in the capital making civil servants ever richer, the sense that nothing good or truly *visible* had come of HIV money—was shared by many I interviewed in Ha Mamello. And ‘Mats`eliso did not only reserve her derision for the Global Fund. Once when I was attempting to assist Bahlokomeli in obtaining a small grant from a foundation in Canada to continue its work, ‘Mats`eliso quipped, “Canada is okay, but not those *tsotsis* [gangsters, thugs] from UNICEF.”

Over the two years I worked with Bahlokomeli, I watched the group collectively

shift its identity in response to funding availability and the expectations of government, donors, and fellow citizens (see Table 5.1, below). In some ways these shifts were simply pragmatic; but in other ways they seemed to reflect deeper, and more troubling, shifts in how citizens perceive the opportunities for self-making and collective efficacy amidst the shifting winds of HIV scale-up. When I first met Bahlokomeli they identified as a support group, and the members were mostly older women living with HIV. They were working on community education, the national testing campaign (KYS), and assisting families of patients and orphans. The work touched on a broad range of issues, from a standpoint of solidarity with those living with HIV. That the group members were mostly upstanding, older citizens added credibility to their work and reduced the stigma surrounding HIV. As treatment efforts unfolded in communities, and as funders focused more on engaging community organizations as lay service providers, the work shifted more towards care for the sick, treatment support, adherence education, and identifying and serving orphans in the community. The group's members more often referred to themselves as *workers*, and labor was organized around treatment outcomes and monitoring patients. Finally, as the research came to a close, 'Mats`eliso attempted to heal the rifts among members caused by the payment issues for CHWs by once again shifting the group's focus and identity. Frustrated by their experiences with governmental and non-governmental sources of funding, she now believed that more steady, and flexible, funding for projects could come from income-generation projects. At the time, the government had been increasingly frustrated by the "dependence" groups had on external funding, and emphasized values of self-reliance, accountability, and economic acuity. These messages echoed broader value shifts in the global HIV funding discourse, as funders became frustrated with poor outcomes and misuse of funds (Godwin et al., 2010; Schneider & Garrett, 2009; Swidler &

Watkins, 2009). Following the global financial crisis which began in 2008, funding commitments waned, and shifted even further away from resource-intensive, long term commitments to objectives like treatment assistance and community support, and towards biomedical and technological innovations which they believed were a more efficient use of funds (Institute for Health Metrics and Evaluation, 2010; Medecins Sans Frontieres, 2011; Parker, 2000; The World Bank, 2009; UNAIDS & The World Bank, 2009).

As 'Mats`eliso and the other Bahlokomeli members poured resources into income generation projects, and embarked on trainings in micro-lending and small business ownership, they began to speak of themselves as "entrepreneurs" and "empowered women." I asked 'Mats`eliso directly if she saw the group as a business or a support group anymore; she responded, "we can do these things equally...we are empowered women, [but] we will not just focus on the business." She said that with many members of the group "crying" because they were not being paid (as the new official CHWs were), she needed to find a way to create income for their work. Redefining the group's *work* was a strategy for increasing their sense of ownership and empowerment: engaging in income-producing projects and identify as "empowered women" owner-workers would give them control of goals, finances, and future projects. She characterized their previous care work as a work of *death*, whereas entrepreneurship was a labor that was life-affirming:

"especially in regards to HIV...our minds have to be focused on *work*, rather than on *mafu* (disease, death)." This also meant many group members no longer saw value in publicly identifying as PLWHA. "They don't want to be PLOWAs anymore" 'Mats`eliso said to me, using the colloquial term for PLWHAs: "they know they're positive, but they don't want that identity." Time will tell how this shift in identities impacts HIV stigma and discrimination in the broader community. What this shift does make clear is that openness

about HIV status is flexible and subject to change, driven by external incentives as well as solidarity with other PLWHA. It is important to note that, even after this change, Bahlokomeli still sought to assist community members struggling with illness (primarily HIV) and its social effects. The shift towards entrepreneurship was not simply driven by selfishness, nor did it represent the group turning away from community needs, though this might be a likely long-term outcome of the changes. Even as Bahlokomeli seeks increased funding and independence in order to better serve community needs, it is likely that these new routes to acquiring funding will be viewed by fellow citizens as self-serving undertakings. Furthermore, if the group is successful in obtaining resources in this manner, it is likely that the presence of these private funds in sight of needy citizens will increase patron-client dynamics between support group members and their neighbors.

|                             | <b>Community Association</b>                            | <b>Support Group</b>  | <b>Home-Based Workers' Group</b>   | <b>Women's Cooperative</b>   |
|-----------------------------|---|---|--|--|
| Era                         | Pre-HIV Scale-up  | Early HIV Scale-up  | Mid HIV Scale-up   | Late / Post (?) HIV Scale-up   |
| Member Identity             | Community members                                       | PLWHA   | CHW / home-based carers  | Entrepreneurs  |
| Primary Objective           | Assist sick / needy in community, all-inclusive         | Assist with HIV testing, education, care, orphans   | Provide care to patients and orphans infected / affected by HIV                                | Develop income generation activities to build funds for community projects                                     |
| Funding Sources             | Self-assisted; members' savings                         | Intermittent pay for campaigns; some small grants   | Intermittent grants for supplies; donations; NGO support                                       | Limited; some funds for starting income generation projects  |
| Plans for Future            | Draw attention to need, obtain donations to assist work | To get funds from NGOs, NAC, to support HIV work as support group members                         | To get payment / incentives as promised from government for care work                          | To secure micro-loans and earn profits through selling products.   |
| Reasons for Identity Change |   | Incomplete funding; tensions with clinic staff; disappointment with funding prospects and process | Government decides to fund only some CHWs, not support groups or all care workers, as promised | Possible future outcome: limited skills for business, difficulty accessing markets, lose interest in HIV work. |

**Table 5.1:** Bahlokomeli support group's changing role in response to HIV scale-up.

Bahllokomeli's evolution over the years conveys lessons about the challenges to solidarity that local, community-based groups face in the context of HIV scale-up processes. Though classic studies of collective action (c.f. Olson 1971) make grim predictions about its likelihood of success or survival, it is evident here that collective action proliferated in the early years of scale-up. Olson's (1971) theory of collective action allows that collective action for the provision of public goods (like caring for the sick) will be more likely in small groups where individual incentives (like payment for labor) are provided. Bahllokomeli is a smaller group, but its members continued work for more than half a decade without any individual incentives materializing. Even if the impacts of its work were meager given their limited resources, the effort expended and the collective efficacy demonstrated in their day to day work was very considerable. Similar findings have been reported by researchers, working in Lesotho (ARHAP, 2006; Bowsky, 2004) and elsewhere (see Robins, 2008; Parker, 2000, 2011; Petchesky, 2003) who argue that robust forms of associational life and collective endeavor are a rich but under-appreciated social resource in addressing HIV/AIDS. My intent here is not to romanticize African forms of "civil society"—an approach that has been thoroughly and adeptly critiqued by other scholars, whose views I share (see, for example, Comaroff & Comaroff, 1999; Mamdani, 1996). Rather, I am interested in how these nascent but important forms of collective action in the face of AIDS—which represent crucial aspects of citizen participation and everyday political life in Lesotho—have been challenged, not by the ravages of disease or the poverty of their participants, but by the machinery of HIV scale-up, which itself frequently claimed to assist, fund, and support such community-based groups.

New Social Movement theorists overturned skepticism about the potential for collective action in contemporary life, emphasizing the emerging promise of such

dynamics as identity politics and transnational networks for social movement mobilization (Castells, 2000; Tarrow, n.d.; Touraine, 1981, 2000). But as Steve Robins (2008), a South African anthropologist studying social movement-NGO partnerships, reminds us, “for the vast majority of poor people in the developing world the benefits of global civil society seem elusive, and their social lives remain as parochial and isolated as ever” (p. 85). Nor is the community a space of comfort or easy collectivism—inequalities and unfairness abound amongst the poor, exacerbated by the kinds of individualistic strivings for survival fostered by global neoliberal realities (Biehl, 2005; Boo, 2012; Roy, 2011). The sculpting conditions of everyday life in Lesotho still gravely inhibit the success of collective efforts, and are more likely to create feelings of marginality and dislocation than a sense of participation and belonging. In contrast to studies by scholars like Appadurai (2002), which celebrate a “grassroots globalization” crafted by partnerships between local social movements and transnational NGOs, recent work from South Africa (Robins, 2008) and India (Roy, 2011) emphasizes the shifting bonds of partnership and boundaries of identity in such projects and the pitfalls of inclusionary politics amidst development agendas. Such partnerships in Lesotho remain flimsy and power-laden: they did not improve Bahlalomeli’s access to information, policymakers, or national conversations about HIV. When support was provided (as in the form of salaries for CHWs, or food packages from the Office of the First Lady), it often unintentionally posed striking challenges to group solidarity and, more importantly, to relationships with other citizens. Collective efficacy here is constrained by external factors and resource availability, but also by strains between support groups and the citizens they ostensibly aim to serve. Negative perceptions and suspicion of national HIV programs among citizens are directed at local support groups, which are simultaneously held responsible for poor policy and implementation,



and sought out for goods they do not have.

## **POSWA**

Whereas many PLWHA groups in other countries formed to foster patient activism and awareness in order to hold governments accountable to the needs of those affected and infected by HIV (Berkman, Garcia, Munoz Laboy, Paiva, & Parker, 2005; Fassin, 2007b; Parker, 2000, 2011; Petchesky, 2003), most groups in Lesotho emerged in the absence of any meaningful activist movements regarding HIV. What is the nature and political subjectivity of groups that have formed as a response to the delivery of HIV programming, not as a driving force in creating or demanding such programming? Unlike Bahllokomeli, many groups in Lesotho emerged after the arrival of material support and even ARVs for HIV sufferers. As such, these groups are organized around a galvanizing HIV identity, but an identity that underscores mutual efforts to access the resources necessary for social and material survival, not participation in activism and social movements. This is largely the case with POSWA (People Openly Surviving With AIDS), which started during my research in 2010, a year after ARV treatment had been decentralized to clinics across Lesotho. POSWA was started at Mamello clinic, encouraged and fostered by the clinic's HIV counselors. As one of the counselors, Mme 'Mampho, related to me, the people in the group were "people living with the virus. And in that group we give each other advice, because sometimes it's the case that a person is living with the virus but she really fails to accept her status. So we give each other psychological support." This view of the support group's purpose—which emphasizes *accepting one's status* and *psychological support*—reflects the intended roles of support groups as envisioned by Western HIV experts and many international NGOs. Yet as 'Mampho continues, her

discussion of the support group role evolves: “yes, we have a support group here and we give each other advice on how to survive [*mekhoa ea ho phelisana*]...we make projects, we develop projects...because it is said that when you are living with HIV you have to be self-reliant; you can’t depend on others.” As it turns out, ‘Mampho’s second statement about the group was far more reflective of reality. Despite the attention paid to visions of psycho-social support, mutual support, and a kind of “talk therapy” for PLWHA within and beyond Lesotho, when POSWA’s members spoke about support, they most often meant material support, and communal projects that could provide for their collective and individual survival.

Despite the fact that many support groups in Lesotho have never succeeded in accessing funding to support their activities,<sup>53</sup> the perception among patients and citizens was that PLWHA groups existed to assist their members in accessing resources. Though most agreed that Bahlokomeli was a fundamentally different kind of group than those designed to obtain resources for PLWHA members, I encountered community members and even NGO staff who skeptically dismissed Bahlokomeli as corrupt and presumed its members were only after donor funds for themselves. Thus, whereas support groups (as imagined by development and HIV experts and policymakers) were intended to provide the conditions for psychological well-being and improve treatment and prevention outcomes at a grassroots level, they were perceived by patients and citizens as a crucial social safety net amidst the economic and social vulnerability brought about by HIV/AIDS. Leabua, a middle-aged man getting treatment at the clinic, told me he would “love” to be a

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<sup>53</sup> In this regard, my selection of two support groups that have access to funding and support is misrepresentative of the typical experience of support groups. Many groups without funding or support dissolve quite rapidly. I was also able to work, for shorter periods of time, with a support group located in a tiny village in a rural area in central Lesotho. They had been working as a support group for almost a decade, though they had no material support.

member of a support group “because we [PLWHA] are living such stressful lives. There are a lot of things that cause our stress, and the associations can help even in cases where a patient dies—your kids will have a means of survival.” Though Leabua talks about stress, the stresses in his life are decidedly material; he worries about how he can provide for his children if he dies. For him, the support group, which fosters bonds of obligation among members, might provide an answer to his concerns. Interestingly, however, even when support groups offered potential access to HIV funds, they also required an investment of resources from group members that could be considerable, and is often overlooked by Western policymakers. Within POSWA, members paid dues that were intended to operate as a rotating saving association (*mokhatlo*) among members (similar to a South African “stokvel”). But instead of putting members’ dues towards capital for projects or loaning them out for interest, as is usually the case in such associations, dues were used to pay for members’ transportation to the hospital when sick, for funeral fees, or to support dead members’ families.<sup>54</sup> Even among groups that did not collect dues, like Bahlokomeli, membership required investments of time, materials, food, and money for transportation. Thus, when I asked Letsie, a young man who was unemployed and living with HIV, if he wanted to join a support group, he replied, “I don’t think I can afford it.” As a result, support groups, especially those like POSWA, do not represent the most needy populations of patients; rather they represent those who have enough financial cushion to invest bits of money into the group and commit time to group activities and meetings.

POSWA had been started in the tense aftermath of World Vision’s introduction of food packages at the clinic. Because the clinic had so many patients in need of food

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<sup>54</sup> A key difference here is not about the distribution of funds—there are even *mokhatlo* that operate as informal funeral schemes—but the rules and practices for distribution. Here, distribution is determined by need, not through a rotational order that distributes resources equally among participants over time.

packages, and packages were limited, they rationed the food packages by giving them to patients for three-, six-, or nine-month periods, an attempt to rotate as many patients as possible through the experience of *receiving* food packages, a strategy that likely did little to improve their long-term nutrition. Though the process for ranking patients on the list of the needy was shrouded in secrecy, most informants reported that those who had appeared first on the list were those who had been taking ARVs the longest—not patients in the most acute need of nutritional assistance. Unfortunately, when the clinic moved to take the first group of patients off of the food package recipient list, the patients complained about suddenly losing access to the packages. The clinic counselors instead encouraged them to form a support group in the hopes that they could start an agricultural or food cultivation program, and assisted them in reaching out to various sources of support. Ultimately, the group became connected with Send a Cow, a smaller NGO that was promoting household gardening schemes and livestock husbandry among community groups in Lesotho. As Send a Cow took on the group as part of its community food sustainability program, the group's labor and purpose shifted noticeably towards developing household gardening systems and learning about nutrition.

Because Lesotho is perennially food insecure (Makenete, Ortman, & Darroch, 1998; Mphale & Rwambali, n.d.; Turner, 2009), particularly among patients and families affected by HIV and AIDS (Drimie & Casale, 2009; Drimie, 2003; Himmelgreen et al., 2009; Romero-daza, Himmelgreen, Noble, & Turkon, 2009), a number of household gardening and food security schemes have proliferated in recent years, spearheaded by different NGOs. At the centerpiece of most strategies is the “keyhole garden” approach, which encourages participants to build round, elevated household gardens—a design that promoters say is more resistant to weather, easier for elderly and the ill to access and tend,

water-conserving, and a source of more diverse nutrition for families (Romero-daza et al., 2009; Turner, 2009). NGOs promoting such gardening schemes compete with one another, each claiming a more effective or successful strategy. For Send a Cow, the guiding objective of the project was to use a stepwise training process with communities that focused on building sustainable gardening and agricultural skills as well as on instruction to “change recipients’ mindsets” and address what the program director called “dependency syndrome” among Basotho. At the end of this process of training, groups were guided in giving “gifts” of young chickens or livestock that they had raised to other members. In this way, the program made recipients into “donors themselves.” By “creating donors...and beneficiaries” in communities, the program director reported to me, members become empowered: “now they are EUs, UNDPs, don’t you see?” (M. L. Lepele, personal communication, January 18, 2011).

Ultimately, the group’s interaction with Send a Cow (SAC) wavered between frustration and confusion. Lack of clarity about what the NGO was going to give them, and at what times, led to accusations of hoarding and corruption against the group’s leaders. SAC emphasized productive labor on projects as evidence of commitment to the program, and as a rough measure of group participation. Most support group meetings started off with a tallying of whose gardens, trenches, and other projects had been completed. Among HIV patients—a number of whom were dealing with the symptoms of AIDS or bouts of severe illness—this measure of success produced tensions and anger towards members who could not pull their weight, even as the group struggled to acknowledge that as a support group they should be supportive of all members.

Motsumi was a member of the group who also worked as the clinic’s gardener. He had acquired TB multiple times, was emaciated, and seemed stuck in a cycle of illness

during the time I worked with POSWA. As POSWA's partnership with SAC continued, his frustration mounted. When I first met him at the clinic, he said to me bluntly,

Maybe you are just like these people, who are just using us—saying you are doing things for the sake of people with HIV, talking to us, and maybe you are going to get some funds and they will be of no use to us! ...It's because Send a Cow—these people came here and registered our names, and they were asking us how they could help us. I have pigs already so I said, "you can help me with feed, and help me understand how I can develop this thing, and sell things and get something." So you understand that they are *promising* us [things], and making it seem as if we are going to get something. And in the end there is *nothing*.

Motsumi continued to be very vocal about the fact that he felt NGOs were using support groups like theirs—and in particular, the names of people living with HIV—to get grant funds, and then failing to distribute those funds to communities in ways that actually assisted them. "When you look at all of these organizations coming here, when you take a close look at them, you realize that these are the organizations that want to use us to become rich themselves." He uses the phrase, "*ba ja ka rona*," which literally means, "they eat through [or because of] us," but plays on a second meaning of the organizations eating *from* the patients, literally growing fat from their flesh. (Below, I further discuss the meanings of discourses of "eating" among patients in Lesotho.) Motsumi was also outspoken about the fact that he expected to get resources in return for participating in a support group. For him, the support group was the "group of Send a Cow" (emphasis added).

Motsumi's perspective was both refreshing and distressing to hear. On the one hand, he gave voice to common, but often unspoken, fears among HIV patients that they were being used by the government and NGOs. Often these fears were fueled by lack of access to information about HIV programming, and the common perception that no one was implementing anything with the funds received.

This is why we are living under oppression [*khatello*], because you know that when these people [the government and NGOs] come and tell us, “we’ll do this and that,”...They come to us—and we realize that this is the way that they eat from us. Because the money that they received will be coming from other countries and they will be saying that they are doing something for us, but these are just empty promises...these other countries think they are giving aid [*phallela*] to these people [living with HIV], but the aid never reaches them.

On the other hand, however, Motsumi also gives voice to widely-held but typically unspoken presumptions among community members that HIV will bring aid, money, and resources into their communities. He, along with others, assumes that support groups are established in order to obtain money from the government. Despite the fact that he has a job, and even has livestock (which, by local standards, makes him better off than many—certainly not at risk of starvation), he believes membership in a support group should provide him with goods and resources.

Why are discourses like these so uncomfortable for those in the development industry to hear? I believe it is because they disrupt a set of core presumptions about the meanings and purposes of HIV programming and aid: that support groups should arise organically, operate selflessly, and respond to patients’ psychological needs; that HIV programming and “development” are different programs, with different purposes; that the largely biomedical provisions for persons living with HIV have the power, alone, to ensure survival; and that recipient populations should respect the priorities and programming decisions of HIV experts, government planners, and funding agencies. Of course, from the perspective of patients and citizens in Ha Mamello, it’s not difficult to see why they would assume that HIV money would improve their lives, why their survival would necessitate more than tests and drugs, and why they would use any means possible to transform HIV from a life-threatening illness into a condition of survival.

It was not long before Motsumi was kicked out of the group, but not because he expressed these views openly; other members of the group were also outspoken, and in

more disruptive ways. Motsumi did not see the benefit of being in the group, but neither did he want to quit—he held out hope that funds would eventually materialize. Instead, his fellow group members pushed him out of the group in the middle of a meeting, after he had reported that he was struggling to build his own gardens and work on others' gardens because of his failing health, and his responsibilities as the clinic's gardener. His inability (and perhaps, to some degree, his unwillingness) to contribute enough labor to the group disqualified him from membership in the eyes of the group. It is labor that concerned POSWA's members, and I attended many meetings where HIV was not even mentioned, except amidst bickering over the consequences of a sick or dying member not paying their dues.

When HIV finally did come up at a meeting, it arose because the group had renewed its connection with LENEPWHA, the national association of people living with HIV, which serves as an umbrella body for support groups of PLWHA scattered across the country. Though POSWA paid dues to LENEPWHA, contact had been limited until its members were invited to attend a national training on Positive Prevention for persons living with HIV. At this meeting, POSWA's leaders proudly reported to LENEPWHA that they had formed a partnership with Send a Cow and were involved in many agricultural activities. In response, they were reminded, firmly, that they were not just some *mekhatlo* [village association] intended to raise pigs and have cooperative gardens and save money for themselves—they were a *support group*. LENEPWHA had recently gone through changes, having lost funding and then acquired a new director from Uganda. Priority shifts had been enacted as well, and relayed to support groups through district LENEPWHA councils. Income generation projects (like gardens) were being discouraged, and groups should instead pursue business plans (dress-making, selling eggs, hosting local concerts) to



bring in income for activities. In addition, they embarked on a new positive prevention strategy, encouraging PLWHA to be “catalysts for prevention” in their communities, and asking groups to engage in prevention education among themselves, but also with the broader community. Drawing on the language of transnational patient-activists, LENEPWHA’s director spoke about the principles of Greater Involvement of People with AIDS (GIPA) and about activism, but harnessed these principles to the objectives of positive prevention: the most important way to involve PLWHA, he said, was through their participation in prevention activities. Involving support groups as service providers was re-imagined, by LENEPWHA, as the embodiment of patient activism (J. Taineomwangire, personal communication, 4 June 2011).<sup>55</sup>

I sat with POSWA’s members in their monthly meeting following the LENEPWHA event. The discussion that unfolded, over the course of a few hours, reflects a dense web of tensions and concerns in the group that deserve further attention. Like Bahlokomeli, the group was on the cusp of an identity shift, and also faced internal struggles over resources, labor, and their collective and individual vulnerabilities. Though they faced similar constraints, the group’s goals and understandings of their role were markedly different from those of Bahlokomeli.

POSWA’s leader—a forceful, sometimes dismissive older man named Ntate Moeletsi—cautioned members that they must “change the form of our group. We are not a *society* [*mokhatlo*], are we? We are a *group for support*, aren’t we?” Here, he tries to draw a comparison between the tradition of *mekhatlo*—societies—in which community members pool resources in order to start a business or make money, and support groups,

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<sup>55</sup> This observation echoes earlier research on HIV and grassroots organizations, particularly by Biehl (2007), which argues that support groups and activist organizations are increasingly co-opted by states intent on using their labor for service provision. In this case, however, the limited engagement of activists in HIV policymaking in Lesotho makes this re-packaging of activism easier and more extreme.

for which he uses the English phrase, “group for support.” A support group is less about mutual accountability (which is a driving force in *mekhatlo* or “stokvels,” as they are known in South Africa) and more about mutual assistance. Yet the group struggled with this differentiation between two forms of support [*ts`ehetso*]: how are they to practice mutual support if they do not have resources with which to assist one another?

LENEPWHA had also conveyed to support groups that they should not concern themselves with activities like taking care of orphans and vulnerable children (OVCs)—these fall outside the scope of what a support group should be doing. This advice hardly even makes sense to the group, and many of the older female members are outraged: “the orphans come from us, from this group! Because we are the ones who die and leave them behind!”

Josefa, an often outspoken, and at times confrontational, young member, has attended the meeting, and reports back his reactions to what they were told by LENEPWHA. His anger—which at other times would be considered rude by the older members of the group—opens up a space for honest dialogue about painful group dilemmas, dilemmas which are often only manifest in terse silences and frequent bickering among members. “So I emphasized [at the meeting] the major problem we are facing as a support group...I asked whether LENEPWHA can actually help us if we have a problem here.” He goes on to ask, “what if we have a corpse?” using a derogatory term for the dead. He asks what LENEPWHA would do if they had a member who had passed away and had no funds with which to bury that person. He talks about how the group struggles to pay for the death and illness of its members:

Sometimes we have to break our own wardrobes [to make a coffin]. So we [members] are not working [we don't have income], and this member of ours who is dead was living in a rented apartment. Maybe she doesn't have relatives [who support her] anymore. It's a huge problem for us. [So I asked LENEPWHA] can we come to you here to see that we get those bones out of the *malaene* and into the grave? And they said no. And I said, okay, so let's talk about the orphans that are left behind by this mother of ours who is dead...these

orphans who are left by us [as support group members] and left to us directly [to care for, as support group members], not those that we are helping as a support group more generally [in the community]. Where are the orphans going to stay now that they are living in a rented apartment? ...[So I said to LENEPWHA], are you not going to answer me this question? And they said they were not going to say anything.

Josefa continues, emphasizing that he is not begging LENEPWHA for help, but asking because “the funds are coming into the country! Yet they are not reaching down into the community the way they were meant to.” He mentions with disgust that LENEPWHA’s leaders told him they should be able to earn their own money; someone else tells him they should take the children to the office of Social Welfare, an answer he finds similarly insufficient.

I said, I have been going for more than six months now requesting assistance from Social Welfare for my crippled child [without getting help]! Yet [from those offices] we always hear, “The government has nothing! The government hasn’t received anything!” ...How can we wait for the government to receive [funds] while we have a corpse waiting in this house?

He asks where the HIV money has gone, if it has not gone to the government, and not gone to the support groups, and not gone to the communities. He tells the group that LENEPWHA’s response was, “our assistance is only in the form of psychological counseling trainings, and workshops like this one. That is what LENEPWHA is accountable for.”

By speaking about what LENEPWHA will and will not do for them, Josefa touches on deeper issues regarding the meanings of support for the group. In recent months the members have seemed to realize that being part of a support group binds them through ties of obligation to other members. In this, it acts as a second family in Lesotho—it is obliged to help when members are sick, and resources must be shared among the group. For those group members who have been pushed out of their family homes, or lost family support as a result of their status, these bonds of obligation are all the more important. But bonds of

obligation can quickly become bonds of mutual susceptibility, as the sicknesses and deaths of other members demand material assistance from those that are well, and members take on the considerable financial responsibilities of other members' funerals, families, and illnesses. Group members can quickly become resentful of those binds when support or resources are not provided by the government or NGOs, particularly for groups that have formed at the behest of these entities.

Ntate Moeletsi is frustrated by Josefa's outburst. "Let me tell you something," he says firmly to the group, as other members also begin to complain about LENEPWHA's indifference. "Some members have shown us that there are problems they have with the organizations [like LENEPWHA] that [we] are accountable to...The only way to overcome these problems so that the government can know what we want and what we don't want is through LENEPWHA, because it is like our mother. It is the mother of all of these organizations. Unless we stand up on our feet to make this right with LENEPWHA, without LENEPWHA, there's nowhere we can go. We have no other channel except LENEPWHA." Later on Ntate Moeletsi tells the group that one of LENEPWHA's leaders had recently been threatened by a government minister [he does not clarify which one], who chided her for criticizing the ministry's work, and warned her not to "talk about him or her in a bad way on television, or talk about any of the ministry's issues....this minister got offended when she told the public, 'these are some of the challenges,' and even threatened to disband LENEPWHA, saying, '*nka se qhala seranthana sena*' ['I can break up this whole useless piece of trash'].'" He cautions the group that, like them, LENEPWHA also has to "remember its place," and though he emphasizes that it is an "independent association in the country" and "only pointing out our rights," it is obvious that he is trying to convey a lesson about the care that must be taken in speaking out against the government, or those

in power. His speech is cautionary, but not just about the role of the government. If the government can break up LENEPWHA, then LENEPWHA can break up POSWA. He emphasizes, “it is only through LENEPWHA that the government and the funders will listen to us.”

Josefa responds, still angry. “We should meet with the leaders, with our complaints and our cries...I’m trying to say to you, that with all of our concerns, as long as we are just shutting our mouths, nothing will work for us, because we are saying nothing! *Ngoan’a salleng o shoela tharing!* [The baby girl who fails to cry dies strapped to her mother’s back]”<sup>56</sup> This interchange between Ntate Moeletsi and Josefa gets to the heart of the danger and frustration groups encounter in a context where activism is punished. As an umbrella organization and service provider, LENEPWHA operates with broad assistance from the government and ministries, which allow it to be a recipient on large grants from the Global Fund and other agencies. In return, LENEPWHA serves as the token representative of PLWHA in Lesotho on committees, at national meetings, and in policymaking sessions. It’s a dangerous bargain they’ve struck with the government—and one in which the government can easily strike down their funding or replace them with another organization if they criticize government services.<sup>57</sup> Similarly, groups like POSWA view LENEPWHA as a gatekeeper to resources and grants, and are loath to forfeit that source of support, paltry though it may seem at times. Since LENEPWHA speaks for support groups at a national level, they are afraid of losing membership in that voice, and so refrain from speaking out

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<sup>56</sup> This is a rough translation. *Tharing* refers to the cloth that women use to carry their children on their back.

<sup>57</sup> Funding structures and international organizational practices have incentivized the emergence of national-level umbrella groups like LENEPWHA, which are politically powerful as representatives of interest groups, but as service providers, are poor activists because they are also dependent on governments for funding and grants.

against government policy themselves, even when it seems that LENEPWHA has served them poorly. These clientelistic relations—between support groups and national advocacy bodies, and between LENEPWHA and the government—undermine the possibilities for real activism on HIV policy, and citizen participation in national dialogues. Despite Josefa and other POSWA member’s awareness that failing to cry out may result in their eventual ruin, there is little likelihood that these words will translate into action.

### **Project Culture and a Politics of Reciprocity**

What emerges from the experiences of these two support groups, despite their clear differences, is a story about how citizens craft survival, mold political identities, and interact with powerful institutions amidst HIV scale-up. Even as NGOs and governments tout community-based responses to HIV and ask citizens to devote considerable labor to their initiatives, citizens and groups remain highly marginalized within HIV scale-up processes. The changing dynamics between citizens, support groups, NGOs and the state are also changing broader patterns of citizenship and democracy, altering trust in institutions, expectations of the state, strategies for survival, and opportunities for collective engagement and solidarity. HIV scale-up has created a “project culture” that permeates both the structure of work for NGOs and governments and the structure of everyday life for recipient-citizens.<sup>58</sup> Yet Bahlokomeli and POSWA are primarily engaged in projects for community, group, and individual survival and membership. Amidst the project culture in which they are ensnared, such groups struggle to create *life projects* (see chapter 3) that

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<sup>58</sup> In her work, Jane Galvão (2000) describes the “dictatorship of projects” that emerged in Brazil following the waves of radical democratization that marked the earlier years of epidemic response, as organizations sought and received more formal sources of financial support, becoming subject to a new kind of “dictatorship” even as the country was democratizing.

provide for legitimacy, belonging, and long-term access to social and material capital. One survives in this social landscape through engaging in a *politics of reciprocity*. By this I mean a set of actions, discourses and orientations towards institutions that may provide temporary resources and membership. This includes group and individual efforts to remake identities (over and over again) to meet changing priorities, various strategies of seeking and obtaining resources from funders and institutions, and work undertaken during and in the aftermath of projects to translate project goods and priorities into useful and equitable social goods.

The politics of reciprocity occurs in the midst of prevalent discourses about the Mosotho citizen as someone dependent on aid, unable to provide for his or her own welfare, whose abilities have atrophied due to years of “charity.” It is not uncommon to see citizens turn this discourse inwards, towards themselves, their neighbors, or fellow support group members. Citizens bemoan a “culture of hand-outs” and blame others for a “dependency syndrome” even as they are reduced to supplicating themselves to NGO workers and begging for basic goods whenever they have a chance to do so. At a high-level, national HIV policy meeting in mid 2011, a leading representative of the National AIDS Commission began the meeting by speaking about the global economic crisis, its impact on HIV funding for the country, and his fears that this would mean disruptions in treatment for PLWHA. He chided the audience that the country had become “dependent” on external funding, cupping his two hands together in a gesture of begging. “What are we going to do to stop wearing the Basotho hat upside down? Because we know that when you are wearing it upside down you are getting all of the donor money, right?” The Basotho hat (*mokorotlo*) is a conical-shaped hat woven of grass that is one of the most ubiquitous symbols of national pride and culture. It is said to evoke the shape of the

mountain near which King Moshoeshoe settled with his displaced followers and established Lesotho, but it also reflects a more contemporary set of symbols central to national pride and political identity. Its shape recalls the shape of the roofs of Lesotho's traditional round houses (*mekhoro*), which symbolize shelter, but also kinship, community, and neighborliness. If the *mekhoro* and *mokorotlo* are essential national symbols, then the Basotho citizenry can be said to reside under a single roof, and he who wears the *mokorotlo* shows a pride in the self-sufficiency, unity, and collective solidarity of the nation. Speaking of the "Basotho hat turned upside down" creates an image of an inverted cone, whose shape the speaker compares to two hands cupped in a gesture of begging. But there is a deeper inversion here—a loss of culture, and a symbol of a house upended. In place of a roof there is a vessel, but one that evokes a sense of collective vulnerability. This metaphor is emblematic of a current Basotho crisis of identity, in which a nation which is dependent for survival on "hand-outs" and "charity" nonetheless sees these resulting in an inversion of national values. Even as the speaker reprimands his audience for their dependence on foreign aid for HIV, he speaks in the second person, indicating that he and his listeners are all guilty of these practices.

Kalofonos (2008) reports similar dialogues about laziness and the search for truly "deserving" recipients of aid among PLWHA in Mozambique. He rightly points out that these discourses trap recipients in a double-bind where they will never be truly deserving of aid:

Association members and people living with HIV/AIDS were accused of having become accustomed to and dependent on aid programs, and as their stated needs were therefore not real, they could be dismissed as the products of laziness. In the clinic, on the other hand, those with too much agency were not deemed worthy of receiving food aid because they were not helpless enough. The search for the worthy beneficiary, the passive and authentic sufferer, the innocent victim that could be saved by humanitarian aid, was fruitless (p 211-12).



But fears about “dependency” and “cultures of handouts” in a time of AIDS are emerging at the same time as institutional changes that are dismantling the links between state and citizen. Bonds of civic obligation between institutions and citizens and the recognition of the basic elements of social survival—the very core of social contracts—are being replaced with projects, poor information, lack of recognition, and broken dialogues. Even as HIV scale-up conditions create perceptions of aid dependence by disrupting the social contract between states and citizens, the architects of HIV programming ask citizens to be self-sufficient, “sustainable,” individualistic, and deserving consumers of program services (Kalofonos, 2008; Nguyen, 2010; Swidler & Watkins, 2009; UNAIDS, 2001). Nor is aid dependence simply a financial matter: dependence reflects deeply-embedded forms of governmentality, hierarchy, and control between donors and recipients, subjectifications that are too often overlooked amid perceptions of “giving” as inherently good (see Galvão, 2000).

As a result, citizens experience acute feelings of invisibility and *dis*-membership. Those I interviewed, visited and spoke to in Ha Mamello and other villages constantly asked where the money had gone; certainly, they felt they had never seen it:

- The government is above us, but the money never comes down and reaches us!
- The government reports these statistics to funders and other governments, but we never get any of the money!
- We see the cars driving around that are for the Ministry of Health, but they never come here!

I am less concerned with the objective accuracy of these statements,<sup>59</sup> and more concerned with what they reflect about citizen subjectivities in the time of HIV scale-up.

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<sup>59</sup> For, certainly, HIV money had expanded HIV treatment into clinics across the country, broadened the health care workforce, trained nurses and doctors to manage HIV and AIDS, and funded programs for pediatric AIDS, TB and MDR-TB treatment, and numerous prevention strategies.

First, distrust regarding the way money is spent and suspicions of corruption are most frequently turned towards the government. This likely contributes to the declines in democratic faith that are evident in the Afrobarometer data discussed in chapter 2. NGOs, funders, and international organizations are rarely held responsible to the extent that the government is, despite frustration over how programs are carried out. Second, as citizens gaze out the windows of public taxis at trendy, well-designed ad campaigns promoting condoms and safe sex, or stand on street corners and watch fancy new government vehicles drive past them, they become more and more aware that HIV money has not reached their lives in meaningful ways. Though ARVs are available in clinics, and clinicians are far better trained to dispense them, and programs abound for those living with HIV or orphans, the palpable sense among citizens is that they are being cheated of the funds intended to *help* them. This is likely in part because the average citizen sees little impact of such funds on his or her daily life. Furthermore, even citizens who lack knowledge about specific programs are capable of identifying unfair distribution when they see it. Regardless of the extent of its validity, it is the perception itself that should concern us; if citizens feel there has been no implementation, if they see no value in the services being deployed, and if they sense that nothing has been done with the money the country has received, then an ever-widening chasm opens up between citizens and the state, and between recipients and donors of such aid.

### **To Eat and Be Eaten**

Though citizens are often afraid to speak openly about their disapproval of HIV scale-up, for fear that they will lose what little access they have to programs, they are not entirely without strategies of engagement. Some strategies are more effective than others,

but none constitute truly bold and effective forms of participation. Rather, they are “weapons of the weak” (Scott, 1987), discursive guerilla warfare that relies on metaphor, masked claims, and calculated appeals (see also Swidler, 2006). In this final section, I discuss the most prominent of these strategies of engagement—talk of hunger, eating, and the bodies of the ill and dying—as evidence of a discursive resistance and veiled engagement among citizens who see the processes of HIV scale-up as damaging and insufficient.

“Eating” and “hunger” occupy a prominent place in the African political lexicon. Bayart (2009) drew attention to “the politics of the belly” as a prime condition of African statehood after colonialism, identifying “eating” of state resources and the rotund bellies of prominent statesmen as a currency and symbol of political power. To “eat,” to “have a slice of the [national] cake,” or to “get fat” are phrases used across African countries to describe the actions of those who are more powerful and consume more than their fair share of resources, typically through processes we in the West would consider corrupt (Smith, 2008; Bayart 2009). HIV/AIDS funding initiatives open up new opportunities for “eating,” for politicians, but also for new AIDS entrepreneurs: Epstein (2007) reports on “fat AIDS” in Uganda, where HIV has been transformed from “the slim disease” into an opportunity to acquire vast resources. “Fat AIDS had become so common in Uganda...that if you said you were working on HIV, people thought you were a thief,” she writes (quoted in Kalofonos, 2008, p. 213). Nearly every discourse about eating is also about unfairness and inequalities, and in Lesotho, patients, support group members, and even political leaders spoke to me in the language of eating as well. When I spoke to a community member about whether she thought POSWA would allow new members to join, she responded skeptically that if they did, “they would never know how to eat with that many

people!"; when I asked a longtime patient from Mamello clinic what has been the most noticeable change since ART was introduced, her only answer is, "some people have gotten fat."

In his landmark work on hunger and ARVs in Mozambique, Kalofonos (2008, 2010) explains how hunger among PLWHA is simultaneously a physical condition caused by HIV treatment and the often myopic focus on biomedical services at the expense of attention to social needs in HIV programs, as well as a metaphoric discourse that contests the marginal position of Mozambicans amidst scale-up. In addition to Lesotho's lengthy and worsening patterns of food insecurity and periodic famine,<sup>60</sup> it is unquestionable that HIV thrusts individuals and families into acute and chronic episodes of hunger—what De Waal and Whiteside (2003) term "new variant famine." The wasting caused by AIDS and the subsequent metabolic changes brought about by HIV treatment also cause acute hunger among HIV patients (Kalofonos, 2008; Mangili, Murman, Zampini, & Wanke, 2006; Tang et al., 2002). Finally, patients in Lesotho and elsewhere constantly complain

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<sup>60</sup> Lesotho faces persistent, long-term food insecurities that have recently been seriously exacerbated by HIV-related illness and death. Anthropologists and historians have described how Lesotho's food insecurity is the result not of bad luck, poor farming skills or unhappy circumstance, but of the absorption of its most fertile lands into South Africa (Ferguson, 1994). Whereas Lesotho was once considered the breadbasket for South Africa, exporting grains and staple foods to the mining and industrial areas, it is now entirely reliant on food imports. While history has not been kind to food production, increasing population density, overgrazing, erosion, and drought have further inhibited families' abilities to grow their own food. Research in the 1960s-80s documented the increasing risks and decreasing returns involved in food production in Lesotho, with Colin Murray (1981) pointing out that it was only cash income from deployed and returning labor migrants to South Africa that made farming a feasible investment, and allowed rural families to eat. Poverty has increased dramatically since the 1980s, following successive waves of mining retrenchments. Currently, only 10.87% of land in Lesotho is arable, and the country is a net importer of food, getting nearly 70% of food from imports (Romero-Daza et al., 2009, p. 24). The diet of most Basotho is also markedly over-reliant on cereals, primarily maize meal, and lacking in variation (FAOSTAT, cited in Romero-Daza et al., 2009). More than 45% of children under 5 in Lesotho are reported to be stunted, a major indicator of severe and chronic nutritional deficiencies (WHO, 2012). Those who subsist daily on *papa* and *meroho* [pap and green vegetables] are keenly aware, in such a strikingly unequal society, of the nutritional and symbolic inadequacies of such a diet. Food is an extremely salient marker of class inequalities. Because the price of food is so high, and opportunities for subsistence production are rife with difficulties, many Basotho spend the vast majority of any cash income they have on food. Poor households in a recent survey reported that they spent 75-80% of their collective income on food (Romero-Daza et al., 2009, p. 26).

that taking ARVs on an empty stomach causes nausea and stomach cramps, and inhibits their ability to adhere to medication regimes.

Discussions of HIV and hunger were, by far, the most common topic of concern among my informants in all research sites. Comments about hunger were strikingly similar across different contexts and groups, and always focused on the following argument: 1) I am hungry, and I do not have enough to eat; 2) I am on ARVs, and the doctors tell me to take these pills with food; 3) If I do not take these pills with food, I will die. In each and every case, patients attributed vast power to their ARVs, speaking of ARVs as agentive:

- The pills want us to eat [*lipilisi li batla re je*]...otherwise you will die...I'm scared of these pills...so if I don't eat, I won't take them.
- The pills force us to eat [*lipilisi li re qobella ho ja*].
- The pills eat us from inside [*lipilisi li ja ho rona*].
- The pills force me to steal.

In Sesotho, eating takes on additional meanings. In common lore about witchcraft and Satanism, powerful individuals are said to consume the body parts of strong, young victims in order to gain power and economic wealth (sometimes bodies are burnt, and the ashes consumed).<sup>61</sup> Through occult, evil practices, eating bodies is seen as a means of gaining power one has no right to have. When Mme 'Mats`eliso and her support group members tell me of their anger at the government for not paying them for their work, they assert, "yet we are the ones who are bringing [the government] the blood!" In a literal sense, they are speaking about the spots of blood on the HIV tests they collect during community testing campaigns, and of the blood of the patients they send to the clinics to be tested. Yet they

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<sup>61</sup> These stories are so ubiquitous that my research assistant recalled, as a child, attending public assemblies at her school at which teachers warned children about Indian shopkeepers who were said to trap children in their stores and consume their body parts in order to become rich. And I was often told a widespread rumor about Prime Minister Mosisili, which held that he had been able to stay in power for so long because he had sacrificed his son to the devil (his son was shot and killed by an unknown assailant while Mosisili was in office).

also speak about “blood” in the sense of the infected blood of the patients whom they send in to the clinics. This way of speaking about “bringing [the government] the blood” draws on more sinister perceptions that the government is consuming the diseased blood of patients in order to obtain further funds for HIV.

In addition, the passive verb form of “to eat” (*ho jeoa*, “to be eaten”) is used in Sesotho as a common expression of illness. A sick patient is often asked, “*u jeoa ke eng?*” or, where are you eaten? The sick are eaten from inside out: such expressions gain even more symbolic weight in the era of rampant HIV and TB, where wasted bodies look distinctly as if they are eaten away by illness. And, of course, patients’ ‘eating’ and consumption of medicines has the dual purpose of not just healing the body, but feeding it, restoring it to its fattened status.

What are we to make, then, of these prevalent discourses about ARVs, and the forceful role they play in creating patient hunger, and even causing patients to steal food, or die from the toxicity of drugs? First, we should not underestimate or overlook the very real experiences of hunger among patients affected by HIV, and the vast insufficiency of current food aid programs in Lesotho to address the current crises of food insecurity. As Vinh-Kim Nguyen asserts, ARVs and food packages serve primarily as “postcolonial palliatives while the rich continue to eat the poor” (quoted in Kalofonos, 2008, p. 218). But given the rich meanings attributed to “eating” across African polities, these discourses cannot simply be read as commentaries on material deficit and physiological experience. Rather, they *simultaneously* speak to broader concerns among PLWHA and other citizens in Lesotho about the redistributive insufficiencies of HIV programs and the injustice of HIV scale-up processes. As political leaders and civil servants get fat off of AIDS money, the bodies of patients waste away, no longer because of AIDS, but because of lack of food and

basic resources. When patients speak about “being eaten” by ARVs, they use a phrase that typically describes physical illness (*ho jeoa*) to highlight the insufficiency of pharmaceuticals, the way they make them sick in the absence of other resources for survival. These claims also speak to the feeling of being eaten by those who have gotten fat off of AIDS money—as their diseased and wasted bodies are counted, treated, and used to bring in funding. Talk of hunger, then, is a decidedly political endeavor, and eating becomes a language, a lexicon, of the experiences of marginality and injustice that citizens struggle to express in political terms.

## 6.

## The Body Sac(RED): Public Treatment and Private Interests in the Transnational Garment Sector

*“Even if your father is used to whipping your mother,  
he doesn’t do it in front of visitors.”*

—HIV counselor, New Century factory clinic

I arrived at New Century factory<sup>62</sup> on a cold, rainy morning in February 2011 to find a crowd of workers forming a recalcitrant line against the drab outer wall of the on-site clinic. I was surprised to find so many women waiting for services. Whereas queuing up for services in Lesotho’s public clinics constitutes a kind of patient labor—and a labor of patience—that can stretch on for days, the factory management frowned on workers lingering too long at the clinic. Their time was more valuably spent laboring on the “lines”—row upon row of sewing and cutting stations where they worked 10 to 12 hour shifts producing garments for US labels. Nevertheless, workers, especially those on ARVs, would arrive at the clinic early for appointments, or request doctors on already crowded clinic days, so as to afford themselves a moment of respite waiting in the cramped hallway outside the examining room. Sitting on hard benches, heads resting on the wall behind them or on a neighbor’s shoulder, they collected and bartered these quiet spots of time away from the machines, the noise, the constant moving and making of the factory floor.

This day felt eerily different. The hallway of the clinic was empty but for a few patients holding their treatment cards, and a floor manager was blocking the doorway to the clinic, shouting at the soggy and perturbed workers outside to “shut up” and “stop

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<sup>62</sup> To protect workers from harm—either from their bosses, or from their factories losing contracts—the name of the factory has been changed. This likely does not offer full factory anonymity, but offers some measure of protection. This is buttressed by withholding any personal, identifying information about any individuals included in the chapter. Data includes information provided by workers from other factories, whose names have also been concealed.



being rude.” Inside the clinic, the normal shuffle of patients in and out of the nurse’s office was absent. Workers were being shuttled into another consulting room by the manager, where, beyond the tightly shut blinds, they were asked to submit themselves to a vaginal examination, conducted by the clinic staff and overseen by the factory management. The exam was intended to determine whether or not they had recently had a baby.

In order to explain how this deeply troubling incident came about—how a factory clinic and its clinicians were co-opted into performing forensic investigations of female workers’ bodies, and how female workers were successfully coerced into submitting to such investigations—it is necessary to trace a recent history of the global forces shaping Lesotho’s garment industry. Though the focus of this chapter is a factory-based HIV treatment and care program, the politics of treatment provision in this case are situated within much larger spheres of interest—those of a highly flexible, global industry; of the markets for “humanitarian consumption” it created; and of the “sweat-free” zone of production fostered in Lesotho to meet these consumptive desires. In examining these dynamics, the mechanisms and tools of HIV treatment and care, no matter how clinically successful, become visibly situated within global networks of production, consumption, and inequality. Ultimately, by detailing these private and public histories of labor and industry, this chapter will explore the fragility of rights beyond HIV programming and the challenges for HIV politics when embedded within corporate concerns and priorities.

As global funding for HIV programs tapered off in the wake of the 2008 financial crisis, corporate social responsibility (CSR) arrangements and public-private partnerships (PPP) for health gained considerable popularity, as well as the attention of anthropologists concerned about trends in privatization and the conflicting interests of corporations in global health endeavors (see, for example, Blowfield & Frynas, 2005; Fig, 2005; Gitari,

2007; Newell, 2005; Ponte, Richey, & Baab, 2009). This research provides a timely case study, situated at the confluence of these trends—a public-private partnership for providing HIV treatment and care in factories as part of global corporate social responsibility efforts. This initiative does not deal extensively with occupational health and safety issues, but instead centers HIV treatment as part of a global strategy to brand Lesotho’s industry as ethical, and utilize its products in retail humanitarian marketing for the Product (RED)<sup>TM</sup><sup>63</sup> initiative, whose products were manufactured, in part, at New Century factory. I propose that efforts like these comprise new patterns of humanitarian consumption<sup>64</sup> and commodity fetishism; because HIV is central to such initiatives, they compel us to also challenge the ways in which HIV programs can occlude, and even subvert, the pursuit of broader rights and recognitions.

In what follows, I first trace the evolution of Lesotho’s garment industry, and efforts to brand the country as an “ethical” production zone. I then examine how HIV became central to CSR schemes for companies like Gap, and document the creation of an industry-wide PPP for HIV prevention and treatment within Lesotho’s factories. Extended qualitative research within a single garment factory producing for Gap’s RED line reveals a range of labor, workplace, and health concerns for workers, including the central roles that bodily strength and vulnerability play in their efforts to maintain economic and biological survival. Importantly, factory-based HIV programs—though they show overwhelming clinical success—reconfigure perceptions and discourses of HIV risk in the workplace,

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<sup>63</sup> Also known as (RED), Product RED, and (PRODUCT)<sup>RED</sup>. For simplicity’s sake, I use RED or Product RED in the text that follows.

<sup>64</sup> Richey and Ponte (2008, 2011) call this “compassionate consumption.” I prefer the term “humanitarian consumption,” as it highlights the ways in which corporate production and marketing are now centrally involved in humanitarian efforts. This term has been used by Schultheis (2008) to describe the (slightly different) phenomenon of Western marketing and consumption of narratives describing African child soldiers.

erasing awareness of the social, economic, and industrial drivers of HIV infection among workers, clinicians, and the broader public. Finally, I examine how HIV initiatives in the factories intertwine with, and also undermine, many of these concerns, obscuring broader issues of workers' rights and health by providing biomedical services that are deeply embedded in the networks of power and interests that make up this transnational industry.

### **The Making of an Ethical Industry**

Employing approximately 40,000 workers, more than 80% of whom are women, Lesotho's garment factories constitute the country's single-largest private-sector industry (International Labour Office [ILO], 2009). Garment manufacturing enjoys a long history in neighboring South Africa, where Hart (2002) describes its origins and emergence as a nexus of movement and policy, involving the emigration of Taiwanese factory owners, apartheid policies of industrialization and dispossession, decided shifts toward neoliberalization in the wake of apartheid, and US trade policies. Lesotho's earliest garment producers were primarily Taiwanese and Chinese immigrants, who had been operating factories in South Africa. After being driven out of their home countries by rising wages, decreasing returns, and the quota constraints imposed by the Multi-Fiber Agreement (MFA), they sought out places like Lesotho (Hart, 2002). The MFA encouraged small and mid-sized firms to relocate their production to countries with low manufacturing costs. Because a sizable portion of the cost of garment manufacturing is labor, producers sought out poor countries with low (if any) minimum wage restrictions and relatively lax labor laws (Raworth & Harvey, 2004; Seidman, 2009). Simultaneously, US garment labels began sourcing the bulk of their stock from external factories, preferring to allow cut-throat competition among smaller second or third-tier producers in developing countries to keep

prices extremely low (Hart, 2002; Seidman, 2009). This had the added advantage of distancing buyers from accusations of labor violations and sweatshop conditions in their factories, as supply chains became more difficult to trace—though this did not succeed in isolating major brands like Levis, Gap, or Nike from harsh interrogations of their labor practices.

South African firms relocated to Lesotho during the end of the apartheid era to escape the trade sanctions placed on South Africa by the US and European nations (Edwards & Lawrence, 2010; Hart, 2002). After apartheid—as labor union strength grew, minimum wages rose, and labor laws were more strictly enforced—factories found a willing, and cheaper, workforce across the border in Lesotho. In the early years of its industry growth (1980- early 1990s), Lesotho enticed factory owners with a set of incentives that emphasized tax breaks, low wages, and support from the Ministries of Trade and Labour. By far the most attractive incentive at the time, however, was its lax enforcement of labor laws:

Throughout the 1980s and 1990s, there was little motivation for manufacturers to improve working conditions.... The government was either unable (because of a lack of resources) or unwilling (for fear of losing one of their few sources of foreign direct investment and jobs) to enforce existing labor laws. Unions were actively suppressed by manufacturers who severely limited the ability of workers to collectively lobby for improvements.... During this period, the companies sourcing from Lesotho had minimal on-the-ground compliance presence in the country (Foreign Investment Advisory Service [FIAS], 2006).

In this early period, strikes were commonplace, though often disorganized, and frequently met with violent crackdowns from police, military, or private factory security forces (Baylies & Wright, 1993; Gibbs, 2005). In 2001, Lesotho's public image was rocked by a Clean Clothes Campaign report ("Producing Garments in Lesotho," 2001), which lambasted the country's factories for their poor working conditions, and the lack of legal enforcement, calling conditions "appalling" and wage levels "inhumanly low." The report

found widespread evidence of harassment and abuse by managers, repression of union activities and membership, health and safety violations, and forced overtime. Protests of brands sourcing from Lesotho ensued, driven in Lesotho by labor union representatives. Brands in the US, already damaged by reports of sweatshop conditions elsewhere, began to take notice of factory conditions in the country (FIAS, 2006).

In 2000, President Clinton signed into law the African Growth and Opportunities Act (AGOA), which allows duty- and quota- free access to the US market for manufacturers based in sub-Saharan Africa, with special provisions for the garment industry. With AGOA, industries became much more profitable, and the garment sector in Lesotho blossomed. Between 1999 and 2004, production exports increased from \$100 million to nearly \$460 million, employing more than 50,000 workers at peak levels (see Table 6.1). In 2004, the industry accounted for 75% of overall exports in Lesotho, the vast majority of which were intended for US markets (Bennet, 2006; FIAS, 2006). Yet as Seidman (2009) tells it, the movement of garment factories into more and more impoverished countries created a strange new development opportunity for US policymakers that was embodied in AGOA: “Trade deals were re-imagined as a form of development aid...US trade rules could provide incentives for manufacturers to invest in the country’s allies and create new jobs in poor regions, while lowering prices on imported goods for US consumers” (p. 583). It was this strategy of “trade as aid” which laid the groundwork for the garment industry’s considerable growth in Lesotho, but also the shift towards “ethical industry” in later years.

|                             | 1999          | 2000          | 2001          | 2002          | 2003          | 2004         | 2005          |
|-----------------------------|---------------|---------------|---------------|---------------|---------------|--------------|---------------|
| US garment exports (in USD) | \$111 million | \$140 million | \$214 million | \$321 million | \$393 million | #456 million | \$322 million |
| Workers employed            | 9,847         | 16,417        | 23,518        | 33,140        | 44,345        | 53,087       | 40,364        |

**Table 6:1. Growth of Lesotho garment industry, 1999 – 2005.** (Adapted from Bennet, 2006; FIAS, 2006)

Unfortunately, Lesotho experienced a series of setbacks in 2005 from which the industry never fully recovered. First, the MFA quotas, which protected Lesotho and other countries with smaller industries from competition from China and India, expired. In addition, the South African rand, to which Lesotho's currency is pegged, began to grow stronger against the US dollar, thereby undermining the favorable export conditions which Lesotho had enjoyed for the previous years (Bennet, 2006). Overnight, the industry was transformed: In the first half of 2005, exports dropped by 25%, and 10 factories closed, some shutting their doors and fleeing the country without notifying employees or paying them the salary or severance they were owed. Remaining factories operated at limited capacity, implementing what workers call "short time" practices, whereby they are cyclically put on short periods of unpaid leave, often with little warning (FIAS, 2006, p. 16; MFA Forum, 2006). Trouble was also looming with AGOA: One of its requirements stipulated that countries must develop the capacity to manufacture their own fabrics in order to maintain AGOA eligibility past 2007. Though the expiration was later postponed through 2012, Lesotho has proven unable to accomplish in-country fabric manufacturing, despite ample warnings about these deadlines (CNN, 2011). The industry, whose foothold in the global garment markets was always tenuous at best, remains tethered to the risks of the market, which constantly threaten to drive factories elsewhere. The garment industry in Lesotho accounts for an enormous portion of the country's economy. In 2006, it constituted 20% of overall GDP, and more than 70% of all exports (MFA Forum, 2006). This puts Lesotho's government in a difficult negotiating position when it comes to incentives or labor regulations: With the threat of factories moving elsewhere, government and other stakeholders frequently cite factories' thin profit margins in capitulating to their demands with little negotiation.

In the face of these constraints, and in the interest of buttressing Lesotho's struggling industry, global partners, the World Bank, and buyers pushed Lesotho to streamline production and further reduce costs (MFA Forum, 2006). Acknowledging the hurdles Lesotho faced in lowering costs, however, they developed an alternative plan for Lesotho to market its industry as a kind of "ethical trade zone," with garments produced in Lesotho labeled "sweat-free." This proposal enjoyed the enthusiastic assistance of the International Labour Organization (ILO), US buyers, and trade representatives (Seidman, 2009). Emerging from more than a decade of serious criticism about labor practices, a "sweat free label" manufactured in a developing country with high rates of HIV offered a new, potentially quite profitable form of corporate social responsibility. In many ways, it was a startling move for a country entrenched in poverty. Rather than engage in a "race to the bottom," Lesotho's factory owners would appeal to a new kind of market: ethical consumers concerned enough about factory conditions to pay a premium for ethically-sourced garments (Seidman, 2009). This plan played nicely into the concerns of US buyers about conditions in their factories and the potential public relations disasters they could unleash; buyers like Gap, Inc. were increasingly relying on codes of vendor conduct and factory audits to ensure factories met core labor standards and avoided health and safety violations. The Minister of Trade, Mpho Malie, told international stakeholders in 2006, "I am confident that we can one day soon announce to the world...that Lesotho is the "Destination of Ethical Choice" (MFA Forum, 2006, p. 11).

These initiatives encouraged a broad shift in how Lesotho perceived its obligations to industry, allowing the country to implement revisions to the national labor code: It has ratified 23 international labor conventions, and is a signatory to additional ones, with broad support from the ILO and buyers (ILO, 2009). Today, there are consistent dialogues

over wages and policy between the Ministries of Trade and Labour, factory owners, and union representatives. Union action has lessened considerably, and workers have access to dispute resolution processes. Lesotho has also recently joined the ILO / International Finance Corporation (IFC) Better Work initiative, which invests in training for workers and aims to “improve competitiveness of the industry...by improving compliance with Lesotho labor law and the principles of the ILO...” (ILO, 2009). One aim of the initiative is to build collective cooperation between industry, unions, and government to meet labor standards. It provides for ILO inspections of all factories, with an aim of streamlining and integrating inspections (ILO and International Finance Corporation [IFC], 2010). The program, however, is not without its critics, who often point to the ILO’s increasing role in economic development and cozy familiarity with finance organizations, whose interests may significantly conflict with those of unions or workers. Sunny, optimistic reports from Cambodia, where the pilot project was located, failed to divulge that union activists had recently been murdered and imprisoned by the government (Seidman, 2009, p. 588).

It is essential to note that events in Lesotho represent pronounced shifts towards privatization of the creation and enforcement of labor regulations across the globe. These shifts tend to weaken union activities and limit public regulation of factories while upholding the image of an “ethical” industry. Is the industry any more ethical in practice? In reviewing these developments, Seidman (2009) predicted that “branding an entire national industry ‘sweat-free’ might silence workers’ voices, rather than encouraging them, if the entire country’s exports depend on presenting production as problem-free” (p. 594). His predictions were chillingly accurate. Voluntary, private audits of factories by international brands pose problems: In addition to well-documented patterns of monitors being unable to recognize and report hazards and rights violations in factories (O’Rourke,



2000), companies have little incentive to hire highly critical monitors. In addition, as I will describe below, factory inspections often elicit a ritualistic theatre of compliance from workers and managers that has little bearing on everyday factory practices. Workers remain aware of the fact that their jobs are dependent on maintaining an image of an ethical industry, and engage—sometimes willingly, other times under duress—in *producing and performing* the “ethical” for fear of losing their jobs.

### **HIV Treatment as Corporate Social Responsibility**

HIV initiatives in the factories are intimately bound up in this history—and in current efforts to maintain Lesotho as an ethical production zone. By 2005, labor representatives, the Government of Lesotho, and external partners were becoming acutely aware of the HIV rates in the factories. Demographics alone—workers tend to be young, female, urban, unmarried migrants—did not bode well for infection rates. Today, the HIV prevalence rate among factory workers remains above 40% (ALAFA, 2010). At New Century and a few other factories, cursory programs and policies were in place to assist workers to test, access treatment, or return to work after becoming ill. But many workers struggled to access HIV services during working hours, or missed days from work to go to local clinics.

All seemed aware that HIV threatened already declining worker productivity, and therefore the viability of the industry in Lesotho.

For buyers, HIV presented a timely opportunity to engage in CSR that had little to do with working conditions, factory pollution, or other potential reputation-tarnishing issues. No one took better advantage of this situation than Gap, whose leadership on CSR meant that its activities constituted more than 40% of overall industry output; Gap was instrumental in the leadership of AGOA and the MFA forum (Edwards & Lawrence, 2010). In 2006, Gap partnered with Product RED, a campaign spearheaded by Bono to market

special “RED” products that give a portion of profits to the Global Fund. The campaign encourages participation through consumption in forms of “charity” and “consciousness” that are celebrity-laden, glitzy, and expertly-branded (Ponte et al., 2009; Richey & Ponte, 2008, 2011). Nowhere was the campaign more visible than in Gap stores across the US, where shoppers could, for the (slightly inflated) price of a t-shirt, re-brand themselves as caring, liberal-minded, and somehow (no matter how elusively) connected to Africa (Richey and Ponte, 2008).<sup>65</sup> Through what Richey and Ponte (2011) term “Brand Aid,” “international development assistance becomes another marketable product,” enabling Western consumers to participate in HIV scale-up and donor culture (p. 13). Gap’s RED line was produced at New Century Factory, which Bono visited in 2006, while he and his wife, Allie Hewson, were also visiting factories that produce for her ethical clothing line, Edun. In the years that followed, workers at New Century cut and sewed RED clothing, RED promotional posters decorated the walls, but none I spoke to recognized the links between the shirts they produced and the pills they consumed. For them, (RED) was just another logo. But the choice to have the campaign’s t-shirts produced by a highly HIV-infected population is crucial to the campaign’s broader humanitarian production enterprise: Lesotho, unable to offer cheap production, instead provided the advantage of a workforce infected with HIV.

ALAFAs, the Apparel Lesotho Alliance to Fight AIDS, was launched during the same period, following the release in 2006 of a detailed report commissioned by ComMark Trust exploring the viability of various workplace HIV care and treatment programs for the industry (Colvin, Lemmon, & Naidoo, 2006). Soon afterwards, in 2006, ALAFAs was

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<sup>65</sup> Richey and Ponte (2008, 2011) point out that Bono successfully affiliated the campaign with *African* beneficiaries and *HIV*, though the Global Fund supported many other regions as well as TB and malaria programs.

formally launched as a public-private partnership forged between US Buyers, local garment industry representatives, and the Lesotho Ministries of Health and Social Welfare (MOHSW) and Trade and Industry, Cooperatives and Marketing (MOTICM). ALAFA would offer a new form of public-private HIV prevention, care and treatment—an industry-wide commitment to providing care—supported by international funders as well as by US buyers.<sup>66</sup> Bono was present at the launch, as were key representatives from Gap. Gap committed to funding the pilot project for ALAFA at one of its own factories, New Century; Bono announced that proceeds from Edun’s “ONE” campaign t-shirt would also support ALAFA (Gilden, 2009).

At the launch of RED in Davos, Bono described these new HIV initiatives as integral to the production of RED in Lesotho:

A woman working in a Lesotho garment factory that produces Gap products becomes part of a cycle of hope.... She works for an employer that offers her services and support and access to HIV testing and treatment. And she’s making a product that will be sold around the world, the profits from which will be invested back into her country (quoted in Richey and Ponte, 2008, p. 722).

Thus, from its very beginnings, ALAFA was central to these intertwined agendas, and the workers at New Century were engaged in multi-layered labors. In addition to working long shifts under hard conditions for marginal wages, they were making products that, through a unique form of humanitarian consumption, would ostensibly fund part of their own treatment. They were also engaged in the patient-labor of adhering to a regimen of pills and behaviors intended to make them more productive, efficient, and valuable workers.

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<sup>66</sup> Dagmar Hanisch, an early director of the program, described it as follows: “The ALAFA model has been drawn from these recommendations, and may best be described as a private sector-drive, industry-wide, comprehensive HIV prevention, treatment and care intervention that will be managed by a small core of professionals under the control of a management board. Actual services will be provided by a variety of service providers drawn from the private and NGO sectors” (MFA Forum, 2006, p. 28)

Finally, their work—both as patients and as workers—helped sustain Gap’s image as a responsible, socially-engaged, and humanitarian company. ALAFA, aligned closely with the association of factory owners—the Lesotho Textile Exporters’ Association (LTEA)—is explicitly tied to efforts to “produce” an ethical industry, and thereby, increase profitability. Dagmar Hanisch, who directed ALAFA’s earliest efforts, justified the program to industry representatives by reassuring them that it would “contribute to building the Lesotho apparel industry’s image as an ethical sourcing destination. The intervention should therefore bring financial benefits to the industry” (MFA Forum, 2006, p. 29).

ALAFA is part of global trends towards privatization in humanitarian initiatives. In the past few years, global health initiatives have embraced PPP strategies, and more and more entities like the World Bank, the US Millennium Challenge Account (MCA), and multinational corporations are taking on health projects as core areas of their work. While privatization gives many academics and health activists pause, it has been embraced by a number of NGOs and governments, who see it as a key strategy for making health projects and funding more efficient, accountable, and productive. In Lesotho, for example, a new, public tertiary care hospital (the only one in the country) was launched in 2011-2012, the product of a public-private partnership between the MCA, the MOHSW, and a private South African health corporation, Netcare. Arrangements like these are rapidly changing the dynamics for how health care is provided, to whom such care is accountable, and how health priorities are established and met in resource-poor countries. Far too little scholarly research has critically engaged with such endeavors, and while this chapter hardly constitutes a full appraisal of them, I hope that it will point towards some of the advantages and pitfalls of such an approach.

## ALAFa

It is essential to highlight two key elements in ALAFa's mission and services. First, in achieving what it sets out to do—to provide high-quality HIV, STI, and TB care in factory settings, and in doing so, to ensure workers are healthier and HIV prevalence is less severe than they would otherwise be—ALAFa succeeds in spades. Second, ALAFa is a product of the industry and its partners, and as such, its services and approach reflect the broader interests of its creators. ALAFa's work is perennially negotiated, carved out from the spaces between private and public, factory and clinic, worker and patient, and industry and labor. Its mandate is forged through partnerships with industry (US buyers, the LTEA, and factory management in Lesotho), government (the Ministries of Health, Trade, and Labour), donors (UK aid agency DFID, PEPFAR, Global Fund, and others), and labor representatives (unions, the ILO, and organizations like ComMark Trust).

Though a complicated public-private partnership, ALAFa's day-to-day work is executed by a staff of managers, nurse case managers, and counselors who monitor activities within particular factories. Each factory also has an appointed HIV coordinator who is responsible for all care, treatment, and prevention services at their factory. ALAFa's work is roughly divided between prevention services (support groups, testing initiatives, condom distribution, and peer education [*meruta methaka*]) and treatment services (a full ARV treatment program, as well as STI and TB care provided on site). Some factory sites have both programs, some only have prevention services, and some (about 10%) do not participate in ALAFa at all, though the goal is to achieve both prevention and treatment programs in all factories. In order to qualify for a treatment program, a factory must allot space for a clinic somewhere on the factory grounds. This space allows a doctor to privately consult with patients. At other times factory-paid nurses will offer basic palliative

care and assist with treatment provision, while counselors offer HIV tests. The range of services varies at factories depending on the size of the clinic, the availability of nurses, and the investment by factory ownership.<sup>67</sup> Nevertheless, all factories with treatment programs provide free, on-site HIV, TB, and STI care. Rather than place additional strain on the public health system, ALAFA contracts with local private doctors to provide care, which most workers strongly prefer to the services at public clinics. Workers can also see the doctor on-site for other primary health care services, but fees for those services are deducted from their pay; no free, comprehensive primary health care is offered. If workers struggle with stigma, they can see doctors at their private practices instead of at the factory clinic, and there is no charge for this service.

New Century has ALAFA's oldest and perhaps its best treatment and prevention programs, which are housed in a small, multi-roomed clinic on factory grounds. Doctors come for some time nearly every day of the week to see new and old patients. A full-time nurse, who also acts as HIV coordinator, assists and provides basic care to workers—prophylaxis for pain and headaches, first aid for injuries, and directly-observed therapy for TB. An HIV counselor is also available; she assists in getting patients from the factory floor, providing HIV testing, distributing free formula to new mothers who have HIV, and directing once-weekly support group meetings. Workers with chronic illnesses (HIV, but also TB and diabetes) are allowed a short break at 10AM to eat a snack and take their medicines.

Apart from the relatively small contribution of the factory, ALAFA obtains funding for its services from international donor agencies, but also from US garment buyers like Gap,

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<sup>67</sup> Variation in services is usually reflected in the number of hours or days a week a clinic is staffed by a nurse, doctor or counselor. At some factories, management offers extra services or entitlements to workers, like “tea breaks” for workers who take daily medicines for HIV and TB.

Wal-Mart and Levis. ALAFA strategically leverages partnerships to pressure recalcitrant factories to open clinics and support programs. When US buyers are in town visiting ALAFA, program staff will sometimes make a point of taking them to visit one of their factories that does not yet have a comprehensive program. US buyers are eager to see HIV programs in place, and their disapproval is often enough to pressure factories into participating in ALAFA. But these productive partnerships also position ALAFA firmly on the side of the garment industry when it comes to labor concerns, wage negotiations, or union-factory disputes. While ALAFA staff members sincerely want the best for workers, especially given their frequent contact with them, their program prioritizes HIV treatment and prevention above other services for workers or broader labor issues.

ALAFA's success as an industry-wide HIV program model is unparalleled, and it has received international recognition for its innovative program design and success with multiple stakeholders. Though many workplace HIV initiatives have emerged in the past decade—most prominently, in Southern Africa, among Anglo American and other mining companies (see Rajak, 2010)—ALAFA is unique in its approach to provide and manage an industry-wide HIV program. Its example has helped build momentum for workplace HIV policies in other industries in Lesotho. The program's efforts in HIV prevention are remarkable: 94% of workers have been reached with preventative services; condom distribution and usage has been normalized across the population; 75% of workers have tested for HIV at least once; and a majority of workers are aware of ALAFA's peer education programs and support groups. Treatment and care statistics are equally impressive: Because testing rates are high and workers are encouraged to test regularly and before getting ill, those who test positive remain aware of their CD4 counts, get regular check-ups, and enroll on ARVs early. With more than 7,000 workers on treatment, ALAFA

created a unique patient tracking system to monitor adherence and assist in keeping track of workers who leave factories or move between factories. Overall, ALAFA reports a treatment uptake rate of 83% (ALAFA, 2010).

The program enjoys broad approval and support among workers, who are grateful that they no longer lose paid hours visiting public clinics, and enjoy their access to ALAFA's clinicians. "There's good care for all of us in there" one worker commented to me, "even the doctors that work in there are special. They will talk to you and make you feel counseled." Being able to make appointments, ask a doctor questions, request additional tests or treatments, or simply have a conversation with the provider are unheard-of luxuries in a public health system that is vastly over-worked and understaffed, reliant on clinicians who do not speak Sesotho. ALAFA's treatment program is in most respects superior to that of the public health system, where HIV care is largely orchestrated by nurses. Many workers reported that they feared losing their jobs because they would have to return to the public sector to get services, and one worker even reported to me that she had decided to apply for work at New Century after leaving another factory because she knew that at New Century workers were getting HIV treatment. These are powerful endorsements of the program's efficacy and success.

In addition, the focus on HIV treatment within the factories has enabled workers who qualify to access certain *comforts and entitlements*—tea breaks, waiting time in the clinic, formula for newborns—that are precious goods in such a setting. Comforts and entitlements, however, point to undeniable limitations in what the program can provide. Treatment exists primarily for people living with HIV/AIDS, TB, and STIs, and many



primary health care services are not available.<sup>68</sup> Working mothers who do not have HIV complain that their babies starve while they are at work, because they do not have access to formula; other workers request family planning, which is not currently available. At HIV prevention and testing rallies workers wondered to me why tests for diabetes or cancer were not being offered. The lack of these services highlights the ways that vertical global health programs can unintentionally exacerbate social inequalities. ALAFA, of course, would like to provide these services, but building momentum for them is difficult. In the fall of 2010, funding fell short as current grants expired, and workers feared the program would close and leave them without access to medicines. During national wage negotiations this year, ALAFA proposed a contributory health scheme between labor and industry, both of whom seemed to support the idea. It is unclear whether such a scheme, either for primary health or for HIV services, would be popular with workers, who would be asked to pay for services that are available for free in the public sector. But wage negotiations fell apart when one union made demands for a living wage for workers, which was met with dismissal and criticism by factories, ALAFA, and other unions.

Given that ALAFA is a public-private partnership and an industry-level intervention (rather than a private, factory-level program), we might expect its mandate to be independent of factory interests. But as a partner of industry, and as a program indelibly shaped by global interests, ALAFA's independence from concerns about worker productivity and industry value is fragile. Its justifications for treatment and prevention programs for factories are couched in the language of business: "We know from extensive research within other workplaces that this type of intervention will improve the morale and productivity of employees," Dagmar Hanisch told industry representatives just after ALAFA

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<sup>68</sup> New Century was considered one of the most progressive factories because it also allowed workers with chronic illnesses like diabetes to also take tea breaks in order to take their medicine.

was formed (MFA Forum, 2006, p. 28). Today, ALAFA's justifications of its HIV treatment programs to donors and the international community are similarly situated within a discourse about industry, development, and costs and benefits:

The care and treatment component of ALAFA increases the sector's productivity by reversing adverse effects such as progressing illness, increased absenteeism, increased staff turnover, presenteeism, and general human suffering. Securing the industry's future combats two of the key long-term drivers of the HIV/AIDS epidemic: poverty and gender inequity (ALAFA, 2010).

While ALAFA does address, as in the quote above, the "suffering" of workers, they speak to a particular form of suffering—that from specific illnesses—and they rarely use rights discourses about HIV treatment or working conditions. Instead, ALAFA talks numbers: "The apparel industry provides around 40,000 jobs, mainly for relatively unskilled women...producing 19% of the country's GDP.... 47% of employees are the only breadwinners, and 95% regularly send money to the extended family" (ALAFA, 2010). By treating the bodies of workers, ALAFA "secures" a tenuous industry, promotes development, and supports impoverished networks of kin. Nor are workers oblivious to management's attention to productivity. Workers like Amohelang, a peer educator, assumed ALAFA's work was bound up in these interests as well:

All they care about is production, not the health of the workers. As long as there is an increase in production, whether [or not] it's increased by sick people—as long as there is production. If people don't get counseling [about HIV], they will die, [and then] where will the production come from?

While ALAFA's goals should not be trivialized, they create and uphold a certain set of values about what workers contribute and why they deserve treatment.

### **The Clinic as Between and Among**

In the context of ALAFA's negotiated position between factory and workers, the

space of its clinical services deserves more attention. The clinic simultaneously offered a space of solace away from the factory floor, and a space situated firmly within the disciplinary research of the factory. Exploring these tensions helps to explore the political positioning of HIV services within the factory, as well as the constructed divisions between worker and patient bodies. In discussions with workers, my research attempted to tease out answers to two questions: what realms of the factory/clinic space are safe, or promote health, and how are the clinic and factory spaces differentiated? This helped to build a sense of how spaces and bodies functioned, and served functions, within the broader factory.

For many workers, the clinic offered a space of respite, and even safety, from the grueling work and intense pressure of the production lines. "This clinic is where I find my safety...it the place where you get relief," one worker said. Another commented to me wryly, "I feel like I could get sick more often [so that] I could stay here in the clinic." Yet these strategies for seeking care and respite were frequently frowned upon by factory managers, who saw the clinic as a potential barrier to productivity. Workers admitted that overuse of the clinic could result in the management refusing to allow anyone to see the doctor. If a manager noticed that a worker was frequently going to the clinic, they might use this information to publicly ridicule or threaten him. HIV coordinators complained that factory management harassed them to disclose the names of workers living with HIV. Discrimination against sick workers, despite workplace HIV policies, seems commonplace. Thus, a young male machine worker related the following story about a co-worker who was sick with HIV:

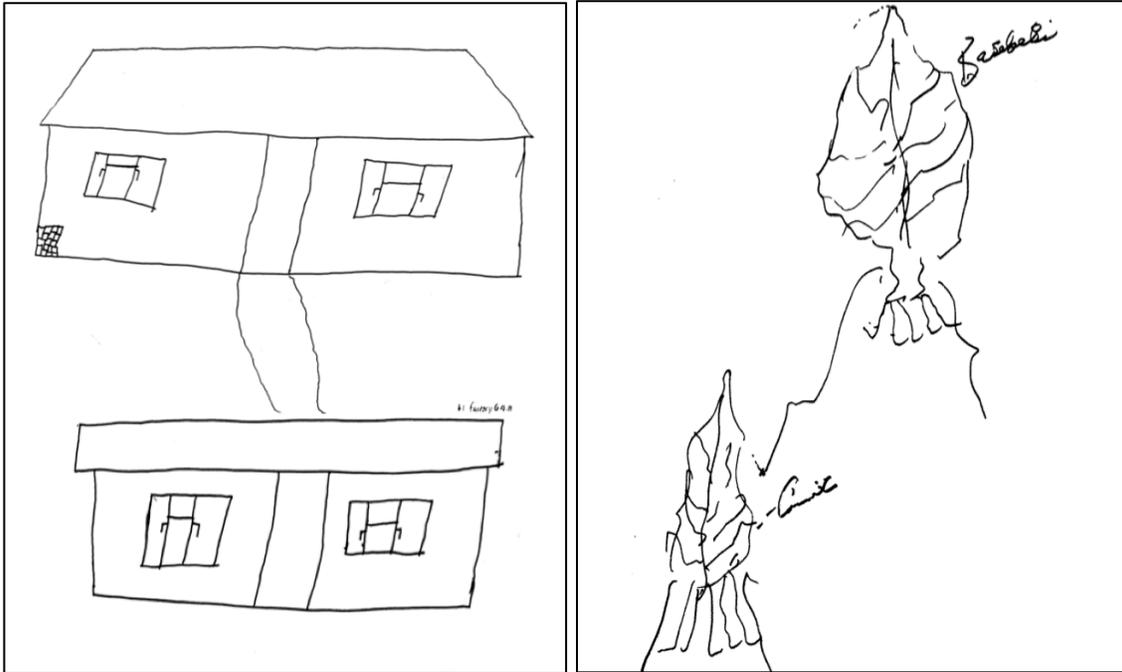
He wasn't able to do his work anymore... he was too weak to work... [But the management] didn't fire him. The workers ended up discriminating against him, along with the Chinese [management]. The Chinese would laugh at anyone who would have to share the same loaf of bread with him, because everyone gets half [a loaf, provided by the

factory]. The Chinese knew what was happening with that person, and everyone else ended up knowing too. They all discriminated against him. There was no one who was on his side.

In this way, discrimination and stigma could be leveraged by troublesome managers to pressure poor-performing employees to quit of their own accord, even if they could not be fired.

On a few occasions, informants were patient enough with my questions about clinic space to allow me to engage them in projects to diagram and draw the clinic and its relationship to the factory. I encouraged them to depict how they perceived the clinic and the surrounding factory; mostly, however, they focused on the similarity and relationships between factory and clinic. Though my informants spoke of clinics as safe spaces, their visual depictions of these two spaces told a different story. In the two drawings below (Figures 6.1 and 6.2), constructed by two different informants, we can see an emphasis on the *pathways* between the factory and the clinic, and the *similarities* between the shapes and dynamics of each entity. The first artist (left image) depicts her sense of the factory and clinic buildings—each a near replica of the other, but with the clinic noticeably smaller. She emphasizes their connection to one another through the pathway drawn between them. The drawings by a second artist (right image) depict the flow of workers and labor within the factory and the clinic, and between each site. The two leaf-like shapes are nearly identical; again, the clinic is a smaller replica of the larger factory structure. What is interesting here is that in two different renderings, intended to depict different aspects of space (structure and movement), the overall message conveyed is strikingly similar: The structure and flow of life in the factory is repeated, on a smaller scale, within the clinic. Interestingly, workers at New Century as well as at other factories often assumed that HIV and clinical services were provided by the factory management, and that HIV prevention

activities were run by ALAFA. One informant reasoned that factories ran clinics: If ALAFA ran the clinics, they would be in every single factory; because they are not, it must be up to the factories. Of course, this is not erroneous—but the confusion between these institutions impacts workers' perceptions of services.



**Figures 6.1 and 6.2: Picturing clinic and factory spaces.** Two informants' depictions of clinic / factory spaces. In each depiction the factory is rendered on top. The writing on the right image reads “Basebetsi” (“workers”) and “clinic.”

### When the Work Makes You Weak

Work in garment factories is widely acknowledged to be repetitive, exhausting, and painful (Lashuay et al., 2002; Ong, 1988; Prentice, 2007; Raworth & Harvey, 2004). While I was aware that conditions in these factories could be poor prior to starting the project, I did not intend to make them the primary object of study, wanting to focus instead on the HIV treatment programs. How naïve—to think that working conditions could be delicately overstepped in the pursuit of a different research question. As it was, the conditions of work shaped not only how care was sought, but defined much of life itself for my

informants. Dimensions of coercion, discipline, and productivity permeated every conversation, every body presented for care, and each patient's subjectivity. Given Foucault's (1975, 1980a, 2008) preoccupation with surveillance, punishment and discipline in institutional spaces, and his argument that such spaces exude forms of discipline that structure and reshape subjectivities as well as bodies, it should not be surprising that this was the case. An important lesson from this subset of the research is that HIV programs cannot be lifted from the social conditions which surround them—and that the politics of treatment in any place are defined by the porous membranes between the treatment world and the social world in which care is embedded.

The conditions that shape everyday life on the factory floor also shape workers' conceptions of health and illness. Pain and exhaustion are a constant presence in the factory, where work involves exposure to occupational hazards that cause health problems ranging from the chronic (stress injuries and lung diseases from particulates) to the acute (injuries from cutting machines, for example) (Raworth & Harvey, 2004; Lashuay, et al., 2002). Everyday health complaints like headaches, stomachaches, nausea, aches, light-headedness, and common colds are so common as to be a constant source of low-level misery. Pain has its own vocabulary: Workers often complain of *lehlaba*, a sharp, stabbing pain in the back or chest, which can arise from the strain of sitting hunched over machines for long periods, but is also linked to lung diseases and TB in local illness taxonomies. Occupational health and safety is a primary concern for workers, but is rarely discussed in the clinical setting. Patients who complain of headaches, chest pain or *lehlaba* are given ibuprofen or aspirin, perhaps some water, and returned to work. Medicines rarely ease acute and chronic pains, and more severe illnesses cannot be addressed in the clinic.

Without a clear knowledge about the health dangers their work exposes them to,

workers talk incessantly about the smell and feel of “bad air” from chemicals, waste, dust, or smoke—diagnostic discourses that echo a pre-germ theory science of miasmas and toxic air. Recent work in anthropology has highlighted how space, place, and exposure reorient our thinking about bodies and health, breathing a strange new life into the plausibility and use of miasma as a conceptual device for those who inhabit or study “inescapable ecologies” (Nash, 2007; see also Petryna, 2002). These ways of thinking are especially salient in the factory, where dangers are unknowable and minimally-controlled. Workers expressed fears about developing cancer from the chemicals; heart disease or diabetes from the sedentary, stressful work; or lung diseases from the air. “We have heard we are very vulnerable” to cancer, one patient said, while requesting screenings for cancer and diabetes.

In garment factories, the air literally can be toxic: The chemicals used to treat and dye fabrics, the particulate dust created by cutting fabrics, and the smoke generated by incinerators and trash fires are all capable of causing cancers and lung diseases if proper methods and protective gear are not used. After spending only a few hours visiting the floor of a denim factory, I left with a severe migraine and pain throughout my sinuses and lungs; for days afterward when I sneezed or blew my nose my tissues turned a bright, indigo shade of blue. Workers are poorly-equipped with masks—not only are the ones they are given to use on a daily basis not up to industry standards, but they are rarely replaced. “The masks are not safe at all, it’s not a proper mask, it’s just a light material,” Tlali, a peer educator, said to me. The mask, he said, acts “like a sponge,” soaking up the bad air and toxins from the factory air. “Now you can imagine, because you’re actually breathing [through] it, it’s right next to your nose and your mouth, you’re breathing that bad smell. There’s no other air that penetrates. You’re just breathing the same bad smell [each and

every breath].”

Illegal factory waste dumping is widely acknowledged, though after international news agencies reported on the issue a few years ago, efforts were made to change practices (McDougall, 2009). Residents of Ha Thetsane, one of three primary industrial areas in Lesotho, still refer to their local river as “the blue river” because of all the dyes dumped into it. Residents recounted stories of a toxic, foul smelling cloud of gas which emits from factories at night and seems to hang over the valley. Locally, Lesotho’s factories have a dubious reputation for health and safety violations (Matope, 2012; Motsoeli, 2011; “Sebapo’s death,” 2012). A factory monitor whom I interviewed reported that he frequently caught managers hurrying into the factory ahead of him to distribute the proper masks that are required by buyers. Inside the factories, managers engage in various strategies for hiding their health and safety code violations from inspectors—strategies described to me in great detail by workers, ALAFA staff, and even factory inspectors themselves. Everyday work on the factory floor thus consisted of a *normal* workflow—that was dangerous, unhealthy, and damaging—punctuated by orchestrated moments of *abnormal* workflow—that was safe, healthy, prescribed, and performed—when inspectors, buyers or visitors arrived.

To locals and workers, these were open secrets; but factories went to considerable lengths to keep me<sup>69</sup> or factory inspectors from finding them out. Informants reported that

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<sup>69</sup> Managers tampered with my sampling strategies, and on one occasion, upon closing a window in the clinic before starting an interview, I was startled to find a manager crouched outside it, ear pressed to the glass. Some workers said little in interviews, which were often ended early, for fear of the authenticity of consent; with others, it was as if the floodgates had opened, and they were half relieved, half thrilled, to tell these stories. I had considerable worries about revealing these truths here, for fear of retribution against the workers who spoke to me. Ultimately, in extended conversations with workers and factory inspectors, I was strongly encouraged by them to tell these stories, as workers believed in their importance and were aware of the risk; key industry informants were consulted on strategies for ensuring managers would not trace the sources.



factory managers coached them about what they should tell inspectors, and they complied because they knew they could lose jobs, or the firm could close:

When there are people visiting, workers are called to be interviewed about how things are going...[and] they usually hide the things that are happening [in the factory] so that the factory won't be closed. You won't benefit from that [the firm closing], so it's usually best just to hide the corruption that has been happening.

'Malineo, a shop steward at New Century, explained how workers were co-opted into participating in factories' arts of deception:

For example, buyers come—maybe the big buyers of the factory are the ones coming. Normally, [the management] will assemble the workers outside, they...choose workers [who will talk to buyers]—they are the ones picking, right? And when they pick and choose for themselves, [we are told], “do not tell the buyers that this and this and that happened, because you will not be able to find work [afterwards].” But we are laboring for these buyers *ka pelo tse seng monate* [with hearts that know no joy].

'Malineo goes on to clarify that management enlists union representatives in ensuring that workers conceal factory conditions.

We don't want to say to the workers that they shouldn't express their opinions. But the management come to us as shop stewards, asking us to tell the workers. They know it's through us that the workers will do what they ask... Here, every time you voice a complaint, there is no response except a promise that you will lose your work, or that, “you better leave!”—they want us to say good things about them to the buyers.... So the workers cry constantly to us as shop stewards that they are not satisfied, but every time the buyers come, for the sake of saving our jobs, they end up providing information to the buyers that is not true, because we are trying to keep our jobs. But the truth remains: We are not working under acceptable conditions.

Later in the discussion I ask if workers feel scared. “In all of these factories—all of them—the cry of the people is that they are scared.” But she is quick to note that the factories are also scared of the buyers. “It's because...the buyers do not want workers who are working under oppressive conditions.” Thus, in factories beholden to a branded image of ethical clothing, a collective theatrics among workers and managers *produces* a temporary construction of a safe and healthy workplace. In this way, fearful of losing their jobs or

their factory's contracts with buyers, workers labor knowingly to fabricate the ethical perceptions upon which buyers' brands (and the RED campaign) are dependent.

### **Managing Workers, Managing Health**

While management strategies vary, they are often a source of considerable conflict in the factories, and impact how workers seek care and maintain their health. In the general hierarchy of Lesotho's factories, Chinese or other foreign nationals occupy management positions, but line supervisors—who enforce production quotas, ensure discipline, and implement policies for management on the factory floor—are typically older and better-educated Basotho women. These supervisors occupy an unenviable position between the expectations and policies of upper management, and the often angry and over-worked young women below them. Some supervisors were caring and even maternal towards workers. One worker who was hospitalized for many months explained that her supervisor came to the hospital to feed her, bathe her and care for her when her young children were unable to do so. More often, though, workers spoke of a generalized “oppression” (*khatello*) that trickled down from management to supervisors. One frustrated supervisor, Nthabi, confided in me that she thought the workers made mistakes on purpose, and then gave her “attitude.” “I get sick of these workers,” she said. “...Sometimes I wish they were my own children so I could just take them and whip them.” The maternally-tinged relationships between female supervisors and workers occupy a spectrum between care and coercion, and in doing so, thrust care practices in the factory into suspicion. In contrast with Mme 'Mats`eliso's maternal care work in chapter 5, the “care” in the factory is tinged with considerations of productivity, with shades of discipline, and with the tense bonds between workers and management that are suffused with racial and gendered

tensions.

There were other casual references to workplace abuse in my conversations with workers that revealed its normalcy and acceptance. 'Mampho said to me dismissively in one of our conversations, "sometimes we are hit, sometimes we are not." Another time, I asked 'Malineo, the shop steward, what she meant by *khatello*—oppression—and she responded by explaining that there were distinct rules about punishment and abuse in the factory. A Chinese manager could act with impunity to discipline a worker by hitting her, but "we are told that when you have a conflict where a Chinese person beats a Mosotho [worker], the Mosotho [worker] shouldn't hit him back. We are trying to educate the workers, so that they understand [not to hit back]. You know, it's not easy when somebody hurts you, to just let it go, to endure it."

At other times, punishment was less physical, but no less severe in the minds of workers. A few reported that Chinese managers would draw on Basotho notions of illness etiologies to mete out punishments. Among Basotho, exposure of body parts to cold air or surfaces is seen as dangerous to one's health. On numerous occasions during the research when I absent-mindedly sat down on cold concrete walls or benches without a blanket or a notebook to protect my hindquarters, it would elicit shouts from nearby women who worried for my health. At the factory, a common punishment required factory workers to sit outside in the shade of the roof's awnings, on the cold benches that lined the factory walls, for hours on end.

Lesotho's labor laws are intended to protect workers from physical punishments, and an independent labor board has been established to deal with disputes and challenge unfair firing. Nevertheless, workers felt that unions and labor laws had limited capacities to assist them with everyday injustices. Shop stewards were rarely able to prevent or

successfully address the more mundane and common practices of oppression, rights violations and punishments within the factory. For example, one common punishment strategy involved forcing workers to sign warning letters detailing their misbehaviors and violations (either real or contrived), and then ordered unpaid suspensions as punishment. Workers can be suspended with little oversight, and suspensions then go to an internal disciplinary committee. Ideally, disciplinary committees are able to resolve such disputes, but management could deliberately delay committee appointments while the unpaid worker was obligated to remain at home without pay, travelling back and forth to the factory to check on her case. The financial strain this imposed usually drove workers away from the job before they ever had an opportunity to appeal. And the factory avoids facing fines and inquiries for unfair firing: “She just ends up giving up the job, and leaving the money [she is owed]...” ‘Mathabo reported.

From time to time, this strategy was used on sick workers, who were supposed to enjoy special protections against unfair firing under HIV workplace codes. ‘Mathabo explained,

I saw a woman who was sick one morning, and when she was not done [with her work], the supervisor was called. She showed the supervisor her *bukana* [her clinic booklet] showing that she’s sick—she’s coughing and the supervisor doesn’t want to understand that. And since this patient did not meet the score, the supervisor took her again to upper management. They were forcing her to resign. They told her that she might be trying, but that she was only hurting other people, and that she should stop [working] so that she could spare everyone the pain of her failures, so she would be the only person feeling this pain.

At other times, however, workers reported that management were understanding about their periods of illness and allowed them to take time off from work (see below).

Ultimately, workers remained aware that the law was of little help, and their fates left up to the inclinations of management. Legal provisions, ILO conventions, and union support offered little protection. One worker explained:

I've observed that the management uses the power they have, not the laws and the policies that are there.... The management uses their own power. They are not held to the policies that are in place, the policies that are there to protect the workers, because they don't want to work according to the policies.

And workers are aware that buyers' codes of conduct for factories also have little bearing on reality. Thus, the conditions of work which workers found most harmful—low wages, backbreaking work, unhealthy conditions, lacking protections—were viewed as unchangeable realities, indelible parts of the work itself. In light of this—and because they were unable to voice frustrations to visitors or buyers—workers felt decidedly silenced. “Even if we cry out” about the conditions, I was told, “nobody can hear us.” As I will demonstrate below, the contours of oppression (*khatello*) and struggle (*sokolang*) on the factory floor influence how workers understand their bodily health—and ultimately, what place ARV treatment plays in their lives.

### **Weak Bodies, Empty Pockets**

Because workers are physically and politically vulnerable, bodily strength or weakness becomes a particular concern. Despite the vast cultural differences between Basotho workers and their Chinese managers, both share an interest in extending the stamina (and therefore the productivity) of bodies. To this end, “boosters”—commercialized variations on more traditional *muti* or types of *meriana* (herbal mixtures developed by traditional healers)—are often peddled among workers. A popular brand from South Africa called Positive Life (the reference to HIV is overt, and intended) was marketed at a discount to workers at New Century, who could purchase products and have the price deducted directly from their paychecks. Some of the most popular formulas included “Mixture of Life” an herbal mix whose advertised benefits included “extinguishing pain and fatigue” and boosting the immune system; and “Power Mix - The

Strong One” designed to “restore stamina to people burdened by exhaustion.” While ALAFA staff worked hard to dispel beliefs that boosters could cure HIV, their persistent appeal among factory workers is driven by more than erroneous beliefs about HIV cures. Even though many taking boosters were living with HIV, their more prominent concerns were about bodily strength and stamina in the face of exhausting, but necessary, labor.

Witchcraft also becomes involved in the quest for bodily strength, though often in the most mundane ways—used to boost the strength of workers so they could survive their shifts intact, or protect them from succumbing to the lung diseases or chronic pains that were so endemic. ‘Mathabo, who worked in quality control as a “checker,” told me that she had tried to become a supervisor. When she was promoted, she succumbed quickly to illness. She explained that she was not strong enough to withstand the witchcraft used against her by jealous fellow workers, and had neglected to solicit the skills of a traditional healer to protect her. ‘Mathabo spoke of her inability to become a supervisor as a physical, bodily failure: “I couldn’t make it,” she said, “I was too weak for [the job].” Without proper (legal) protection and knowledge about occupational exposures, workers rely on herbal boosters and forms of spiritual assistance to defend weakened and vulnerable bodies. Similar beliefs fed into the tragic massacre of striking mine workers (many of them Basotho) at Marikana in South Africa in 2012. They were reportedly given *muti* that was intended to shield them from bullets only hours before being gassed and gunned down by a heavily-armed special police force (Conway-Smith, 2012). One can only imagine the severity of powerlessness and lack of legal protection that might drive workers to embrace such forms of protection.

While workers are provided some paid sick leave under national law, many reported that, in reality, they were rarely paid when they became sick. Sometimes this was because

chronic pain and illness put them well above their allotted days; at other times they failed to produce proper documentation; still more often, managers denied requests for various reasons. In interviews and informal conversations, the mantra of “no work, no pay” was repeated over and over again. Even when workers did access paid sick leave, the prevailing moral world was one in which only a full day’s work would result in pay.

Nthabiseng, who worked on the line and served as a peer educator at another factory, described the perils of becoming weak or sick:

The health of the factory worker is never safe. Because as long as you are in the factory, you are told, “no work no pay.” If you are somebody who is careful about your health, if you feel like you’re not feeling well, you know that you need to do something about it...[which] means staying home from work [to rest]. But now *u lula naheng e sokolang* [you are living in a struggling country]—or I can say that *bophelo bo re sokolang* [life in general is a struggle]—situations force you to go to work while you are still sick...and regardless of whether you are sick or not, if he [the manager] wants you to make a certain score [quota], you have to do that! So in that case you are not safe.

Sick workers also felt that they constantly risked angering managers because of their declining productivity, trapped in a double-bind between the risks of taking time off to seek care, and the risk of becoming more ill while continuing work. ‘Mathato explained that management was unhappy when workers spent too much time at the factory clinic, but:

Even if you go to the clinics outside and miss work, they are still not satisfied with that. And if you feel like, no, I’m not feeling well, I need to rest for the day, they’re still not satisfied....so I really don’t know what makes them happy! When you are healthy, they love you, but when you are sick, they don’t...you will see that they are impatient and untrusting with you. But in this kind of work, you will find that your sickness is caused by your work...and if you just suffer through it, after that, when you become terribly sick, you’ll see that they are still not satisfied with you!

Ailing workers seemed to be regarded with distrust: a threat to productivity and a source of draining resources.

In a country where chronic illness is largely the norm (whether TB, HIV or another

condition), and in an environment where bodily weakness adds another layer to physical vulnerability, the provision of ARVs and other medicines becomes a means of boosting the body, restoring it to its previously robust state. It is also valued as a means of restoring productivity. Weakness and exhaustion are paramount concerns for workers because they cannot afford the loss of pay should they need to take leave. Despite the financial hardship it poses, more than a third of workers interviewed at New Century had taken at least a month's leave in the past, and some had "resigned" for longer periods.<sup>70</sup> Often these resignations were due to exhaustion or ill health—some named conditions; others simply said they were "tired." "I know the work is heavy, but I have to do it anyway, because that is the only thing I know how to do," Mathato, a widowed mother of three, told me. "But it is good here at New Century because we are given time for sickness. We can go home and recover and come back to work. But it is also stressful because we are not earning any money when we are at home." A number of workers reported that they did not come back to work because they felt physically recovered, but because they were overwhelmed with financial worries and obligations. More than a few women also temporarily resigned after the death of a partner or a child. In fact, more than 40% of workers interviewed had lost a child or a husband, a psychosocial toll from poverty and HIV/AIDS that was not always visible in the factory, but affected far too many workers.

Despite these multiple constraints on workers' efforts to forge their own bodily wellness, their talk about bodily suffering and workplace illness constitutes an important strategy for challenging the authoritative knowledge and clinical silences regarding occupational health that workers confront in the clinic and in HIV programs. These dialogues strove to re-forge linkages between factory exposures, illnesses, and violations of

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<sup>70</sup> This figure does not include maternity leave.



workers' rights that are left under-recognized by the clinical care available:

*Kananelo:* And now when you get sick because of the dust in there, they fire you. Yet they are not even giving you the appropriate safety gear...

*NK:* Is your sick leave paid [for this]?

*Kananelo:* It's there, but they [the management] get tired of it. When you're always bringing the sick leave [letters], they get tired and can just fire you... But you are sick because they are not providing the appropriate attire for the workers! For protection, against all of these things that *they know* are dangerous. [My emphasis]

Workers emphasize that the difficulties of getting sick leave are compounded by the injustice that the work itself seems to make them sick: "It means you get sick at work!" Lefa emphasized. "*U seqhoala sa feme.*" *Seqhoala* is a crippled or disabled person, in this case made disabled by illness. But the emphasis is on *sa feme*—by the factory: You are disabled *by the factory*, your disability *belongs* to them. This rendering draws on beliefs about caring and responsibility for the sick that are deeply rooted in Basotho social organization and culture. By speaking this way she creates a notion of obligation and responsibility—not just for the illness itself, but for the care it necessitates.

For some workers, the broader injustices of their lives confronted the limits of clinic services, and this clash was most clearly expressed, as it was in Ha Mamello, through claims of hunger. For 'Mamohau, a widowed mother of four who was in serious financial straits when I spoke to her, hunger threatened to boil over into action:

I am happy with the services [here in the clinic]...but the pills force me to steal....Sometimes I fall down [from exhaustion], I am very weak. The services here tempt us to steal...[Because] these pills I am taking...you have to eat a lot of food. They tempt me to steal, because they demand more and more food.

When 'Mamohau spoke of her hunger, she drew a line connecting the pharmacological effects of her treatment ("the pills...demand more and more food"), her financial situation (being unable to buy enough food to satisfy her hunger), and the clinical services (which promote HIV treatment—pills that create hunger but do not satisfy it). Her discursive

emphasis, again and again, is on stealing—stealing because she cannot afford food, stealing from the factory simply because she can, stealing because she is desperately hungry. In doing so, ‘Mamohau speaks of pharmaceutical treatment as the agent driving her actions (“the pills force me to steal”). We could read this as an excuse: or, we could read it as an accurate appraisal of the social conditions of care on the factory floor, where treatment only seems to exacerbate injustice, social ills, and unmet needs.

### **Braai Packs and Bad Behavior: Conceptualizing HIV Risk**

Despite the grim descriptions factory workers offered about their working environments, conditions for factory workers have in fact improved in the past years. These improvements have occurred both in and out of work: wages have risen and acute labor violations have abated; and as the worker population ages, more workers are married, have developed firmer community support systems, and have built up financial savings schemes. Regardless of these improvements, however, female workers continue to embody a set of extensive, interlocking social vulnerabilities that threaten their health and survival. A common, derogatory saying about female factory workers in Lesotho is that, when coming to visit a factory worker, “a man should knock her door with a braai pack.” A braai pack is a bag of cheap chicken parts, usually intended for grilling, and despite its poor quality, outside the budgets of poor families in Lesotho. Nevertheless, it is valued—craved, even—as a source of meat. The saying indicates that a man who visits a woman in the *malaene*—the cramped, single-room apartments factory workers usually live in—with the intention of having sex with her must bring her food in order to have sex with her. It points not only to the social expectations that sex for factory workers is often transactional, but to the presumptions that factory workers are promiscuous, *and* poor. Assumptions

about workers, their sexuality, and their economic vulnerability further imperil their safety, social standing, and ability to negotiate for safer sex. These vulnerabilities are widely known. For example, all workers are paid at “month-end,” and as the days of the month go by, their money dwindles, going to food, rent, taxi fare, school fees for children, and to pay the interest on already existing loans (see Table 6.2, below). Late in the month, cars and taxis line up at the factory gates, knowing many women can no longer pay for transport, offering rides in exchange for sex. At month-end, after workers pull cash from ATMs in town to pay rent and loan sharks, thieves try to rob them on their way home or alone in their homes, knowing they are flush with cash.

|  |                       |
|--|-----------------------|
| <b>Typical Salary:</b>                 | <b>863M – 968M</b>    |
| Food costs: <sup>71</sup>              | 431.5 – 484           |
| Rent:                                  | 100 – 300             |
| Medical bills:                         | 0 – 400 <sup>72</sup> |
| Taxi fare:                             | 150 - 200             |
| School fees, 2 children: <sup>73</sup> | 5 – 100               |
| <b>Total living costs:</b>             | <b>686.5 – 1,484</b>  |

**Table 6.2: Typical factory worker’s salary and expenses**, in Maloti (approx 8.58 Maloti = 1 USD in January 2013)

It is likely that these vulnerabilities contribute to further HIV infections in workers. A rich literature across the globe has established the linkages between social and economic inequities, migration, structural violence, and HIV/AIDS (see, for example, Barnett &

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<sup>71</sup> Food costs are a sizeable portion of salaries in Lesotho. Among the urban poor, they have been estimated to be as high as 75% of monthly salary; here they are estimated at 50%, which is probably a very conservative estimate.

<sup>72</sup> Workers spend varying amounts on health care, depending on their health status, their family’s health status, and their preferences for care. One informant reported casually that she spent approximately 400M on medical care for herself and her family each month—this amounts to about 2 visits with a private physician, and nearly 50% of her salary. A visit to the on-site doctor at the factory clinic for a patient receiving primary care services (which are not funded by ALAFA) cost 85M.

<sup>73</sup> Lesotho offers free primary school education for children, though school fees and supplies must still be purchased. Secondary school is prohibitively expensive (often much more than what is reflected here), as is any private schooling. As is shown here, even a “cheap” private / secondary school fee for workers is out of budget. Many are eager to educate their children, but feel that their salaries are simply too low to successfully save anything.

Whiteside, 2002; Farmer, 2001; Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008; Parker, Easton, & Klein, 2000). A 2008 study (Makoae & Mokomane, 2008) of Lesotho garment workers' vulnerability to HIV transmission reports that low pay and migrant status, along with gender inequities, are major drivers of women's susceptibility to HIV infection. Specifically, the study reports:

Women's low wages and the resultant shortfalls in their monthly budget, particularly led many women to engage in sexual behaviors such as concurrent multiple partnerships and transactional sex as a coping strategy. The need to work overtime to augment the low wages [and thus travel home after dark] also indirectly increased their risk of being raped, thus [decreasing] their chances of negotiating condom use (p. 6).

While many citizens in Lesotho simply assume that women in the factories get HIV because they are promiscuous and suffer from too much independence because they are factory workers who earn salaries, ALAFA takes a firm stance that higher rates of HIV prevalence among workers is purely a product of demographics—they are young, often unmarried, urban-dwelling, migrant women. ALAFA also makes the argument that the garment industry supports women and the poor by employing them, and therefore *reduces* some of the social drivers of the epidemic in Lesotho. But a study commissioned by the Health Economics and AIDS Research Division (HEARD) and carried out by researchers at the National University of Lesotho concluded that Lesotho's garment industry created and exacerbated four core population risk factors that are known to fuel HIV infections: labor migration, insecure employment, material poverty, and the additional health and social problems that women face in the context of these other vulnerabilities. The report argued that garment industry policies—particularly those that increased the unpredictability and insecurity of employment and kept wages extremely low—were thus at least partly responsible for the exceptionally high HIV prevalence among factory workers.

Not surprisingly, ALAFA's education programming largely omits discussions of, or

attempts to address, workers' social vulnerabilities. HIV messaging for factory workers emphasizes their personal responsibility over sexual health, and encourages them to negotiate for condom use. Education campaigns and support group discussions focus heavily on individual behavior and convey the message that workers must take responsibility for their own sexual and reproductive health. Primarily as a result of its negotiated status as a public-private partnership, this silence augments, and deepens, ALAFA's reluctance to address working conditions and factory workers' perceived health vulnerabilities due to workplace hazards.

Support group meetings at the factory—led by the HIV counselor or a dynamic ALAFA staff member—were run like patient education sessions, assisting workers to understand how to manage illness and prevent HIV infection and STIs. Support group leaders openly emphasized personal responsibility and workers' abilities to manage their own sexual health:

One thing you have to know, again, is that *I* have a choice. Who? *Me*. Not other people. I have a choice to use a condom. I have a choice to use a condom or to not use a condom... When you go to your bedroom, who is making decisions? It's me. But if you are only going to listen with your ears [not take this to heart], when you are somewhere else, you're only going to do what you want to do. And who will get sick? You. Hence, I'm sounding a call for all of us to take responsibility.... It's true that now we are educated. And I should do what now? All of us should do what?

At this meeting, the group responds enthusiastically that they should "take responsibility!" Only twice did I hear talk about rights among factory workers, and both times this talk occurred in the support group meetings. The first was in this discussion about condom use and STIs. Because STIs are not airborne, the support group leader said, and because one had condoms, STIs would not automatically infect anyone. "Because I have a *right*," the support group leader said, "it's not like STIs are a disease that is transmitted through the air, and I don't have a way to protect myself."

The second time rights were mentioned was in another support group meeting some months later, and again the notion of rights was strangely bound up in a discourse about personal responsibility and being “educated” about one’s health. The group leader was encouraging the group to talk to their doctors and ask questions, to become knowledgeable about their treatment. “Why don’t you ask the doctor?” she chided them, “You see now [that when we do not ask questions] *litokelo tsa rona tsona re hana ka tsona* [we deny ourselves our own rights].” While we should applaud efforts to engage workers in their care and in asking questions about their treatment, such discourses—either about rights or behaviors—are inconsistent with the broader structures of inequality in women’s lives. Surely, many women learned through these discussions how to circumvent such structures in order to protect themselves or their health. But women also took conversations about behavior and responsibility to heart in such a way that they were unable to fathom how their work might put them at risk for HIV. These conversations undermined the fragile linkages workers attempted to build between workplace conditions, illness, and injustice.

It is far easier for factories to distance themselves from the factors that contribute to the markedly high HIV infection rates among this population than it is for them to deny the workplace exposures that increase debility among workers. Yet, strangely, it is the provision of HIV services that enables these occupational health concerns to subtly fall by the wayside. The overall emphasis on HIV within the factory setting—talk about it, services oriented around it—may obscure worker claims about broader bodily ills and occupational health. Certain factories—particularly those with more dangerous production processes—have not allowed ALAFA to provide treatment services, though they demonstrate support for the program in other realms. It is presumed that these factories are afraid that the

presence of an on-site clinic would lead to a documentation of worker injuries and illnesses that might draw attention to occupational hazards and poor conditions. But for the majority of factories, ALAFA's services have not caused significant tensions or drawn attention to broader factory responsibility for worker health. While it is still possible that the clinic site will prove to be fertile ground for building recognition of and agitation against occupational hazards, there were no signs during the research that this was the case. Discourses about HIV and factory workers' risk reinforce this inertia, and also reinforce ideas among workers that health problems are theirs alone—in cause, and in consequence.

### **When Your Father is Whipping Your Mother**

The events that occurred on and prior to that rainy day when I encountered the factory management conducting vaginal inspections on workers are intimately bound up in efforts to produce and maintain the industry's "ethical" image. It had been a terrible week at the factory: On the previous Thursday, I had arrived to find the clinic deserted, the HIV counselor absent for hours before she returned to convey, hesitatingly, that a newborn baby had been found dead in the bathroom of Area 4, purportedly left there after delivery by a night shift worker. The staff hadn't wanted me to find out: "Even if your father is used to whipping your mother, he doesn't do it in front of visitors," I was told brusquely. While the HIV counselor admitted that there were many "scandals" at the factory, and that it was not uncommon to hear that women had absconded to the toilets during shifts to try to perform abortions on themselves, "this is worse," she said, "than anything we can have [or tolerate] here." Abortion is illegal in Lesotho, and female factory workers find that, despite their wages, they either cannot afford to support another child, or can't afford the loss of

wages due to enforcement of mandatory, but unpaid, maternity leave. Hiding their pregnancies until the very last moments, factory workers were known to go into labor on the factory floor, or even complete a shift before taking the taxi to the hospital for delivery.

In subsequent days, the clinic staff suspended their daily work to unfold what seemed to be a practiced—and to them, practical—course of action. Clinic workers told me that it would be easy to find the woman who did this. All they had to do was “inspect” those who worked in Area 4 that night: check who was bleeding, who looked to have just delivered, whose breasts were producing milk. The police were only tangentially involved—the management led the search, and the clinic workers assisted in inspecting suspects. The violation was portrayed as a moral transgression that besmirched the factory’s ethical reputation and required internal policing, rather than a crime violating local law and falling under the purview of local authorities.

By the time I arrived on that rainy morning and was squeezing my way through the clinic door, the workers outside begged me to help them—but not to stop the inspections; to get them done more quickly. They had worked the nightshift and were held for hours afterwards to be inspected; it was now past 9 AM, and they wanted to go home. Afterwards, few workers were willing to speak to me about the incident or the inspections that followed. Those who did traded gossip about who might be guilty. If they mentioned the moral or legal parameters of the inspections, it was only to point out that the inspections were “not good,” because the culprit was never found, and could have easily eluded detection by staying home from work.

In his work on biopower, Agamben (1998) presents the figure of *homo sacer*, the sacred man. An obscure figure from ancient political theory, *homo sacer* represents an individual who, under sovereign law, can be killed but not sacrificed. Brought under the



purview of punitive law, but never protected by it—defined by law, but only to be banned from membership—the “sacred” man is not saintly, but an entity that sits outside society, who has been exiled from full political life. He is left, in the “space of exception” created for him, bare—a life that can be taken with impunity. Agamben’s work holds particular poignancy when applied to spaces of humanitarian action, those realms in which discourses so often hold up the humanity of the Other for inspection and compassion. Here, as Feldman (2006) describes it, the ambiguity between the sacred and the profane in the image of *homo sacer* allows for a “politics of compassion” to engage in “saving a bare life that has been prepared for rescue by the sovereign ban,” which has created it in the first place (p. 17). Therefore, “humanitarian discourses that proclaim ‘the sacredness of life’ do not oppose punitive and violent forms of political power; they are embracing a bare life that has been constituted by sovereign power” (p. 17). In corporate social responsibility and humanitarian consumption schemes, the very act of “doing good” occludes a broader attainment of, or attention to, rights—in particular, rights relating to other health and occupational issues. For workers, even as ARVs give biological life, they inadvertently strip away one’s status as a fully-fledged, rights-bearing citizen.

For Agamben, the work of humanitarian initiatives not only depends on the presence of bare life, but in providing assistance, further reifies life itself as bare. This approach has been critiqued for creating an overly bifurcated division between political life and the life rendered bare (see Fassin, 2010) . What seems more likely is that moments of stark nakedness, emerging within humanitarian projects, reveal the spaces of exception hidden amidst the mundane and dismal locations of everyday struggles to survive. These moments in turn reveal the structures of power and instruments of sovereignty, as well as the moral systems that justify and disguise them, that are so central to biopower (Foucault,

2008). Here, a clinical space is co-opted in the execution of a kind of industrial vigilante justice; the clinical inspection of bodies also reinforces the strange moral order of a globally entwined workplace. The guiding principle of this moral world is not to build a truly ethical industry, but to construct the image of one, to brand it, and market it. In this world the worker body is divided in two: the ARV-treated body held up as sacred even as the damaged worker body is concealed and violated. In this schizophrenic duality, each part enables the other. Without efforts at ethical branding, ARV treatment would not exist; ARV treatment, however, assists in propping up ethical imaging, which in turn ensures a silencing of workplace rights violations.

The difficulty here is that no single entity creates this situation, and responsibility is refracted through the myriad facets of a global network of actors. Who might we hold responsible? The factory managers, who are pressured by US buyers to keep prices unrealistically low, and repeatedly told that ethical branding sells? The clinicians, whose space of biomedical practice is such a thin peninsula of sovereignty, bordered on all sides by the factory's practices of productivity and discipline? ALAFA, whose entire mandate for work is shaped by, and responds to, a web of private interests over which it has little control? What is clear is that the global network of interests that turned US trade policy into a form of development aid, created markets for new practices in humanitarian consumption, and placed HIV initiatives at the center of these new practices, deliberately chooses to prioritize HIV above labor issues. "We do not think that trade is bad," Bono stated at the RED launch. "We are for labor issues. Labor issues are very serious but six and a half million Africans dying is more serious" (quoted in Richey and Ponte 2008, p. 723). The implication, of course, is that labor rights and treatment for HIV are somehow mutually exclusive, that the workers of New Century can have one, but not the other.

While Richey and Ponte (2011) emphasize the ways in which celebrities like Bono become “emotional sovereigns, mitigating the threat to capitalist accumulation posed by the need to display corporate social responsibility,” here Bono demonstrates a more stark political sovereignty as well (p. 12). The vague network of forces for which Bono acts as spokesperson decides that HIV treatment is more important, and by extension, that labor violations, worker rights, poverty, occupational health risks are less urgent forms of social suffering.

When I spoke to ALAFA’s director about the labor violations I was observing in the factories, he said with resignation that “we” had learned “time and again that once living standards improve, manufacturing and garment industries move elsewhere...but as long as people want to buy cheap jeans, sweatshops will exist.” Workers and labor advocates frequently reminded me that a bad job was better than no job at all. But this is not simply a story about another sweatshop and another impoverished industry; it is a story about corporate social responsibility schemes and the fabrication of ethical industries, about a highly successful HIV treatment program that shifts attention away from social and occupational health issues that are much harder to address. In “campaigns” like RED, a new kind of *commodity fetishism*—per Marx (1990), the ways that capital strips products of the signifiers of the social conditions in which they were produced—is being born. What is especially dangerous about *humanitarian fetishism* is that it elevates the purchaser into the role of one who is “doing good” (Richey and Ponte, 2011). Whereas commodity fetishism strips products of their negative (unethical) ties to labor, humanitarian fetishism obscures the social conditions of production while simultaneously adding a perceived positive (charitable) outcome from the purchase.

Finally, Bono's trademark ambiguity about who "we" are and how we came to decide that HIV is more important than labor issues points to a second set of concerns about membership and belonging in global movements, and how they leave behind genuine aspects of rights and citizenship. On another occasion, again speaking about RED and its impacts in Africa, Bono commented, "I represent a lot of [African] people who have no voice at all...They haven't asked me to represent them. It's clearly cheeky but I hope they're glad I do" (quoted in Richey and Ponte 2008, p. 721). Humanitarian initiatives assume a voice that speaks for their recipients; they also reconfigure the categories of belonging, claiming constituencies of recipients who may or may not share their priorities. HIV programs unintentionally re-shape the possible bounds of citizenship entitlements and rights engagements in realms well beyond the clinic or public health practice. Such revisions in the political worlds of workers and citizens have very tangible impacts on rights and well-being, but they are rarely attended to in public health practice. Presumptions about the inherent "goodness" of initiatives like HIV treatment programs ignore the social conditions under which they are produced, and the consequent political futures that they shape. For workers at New Century, violations and treatments of their bodies are intimately bound up in one another, as is the persistent weakness and danger they feel.

## 7. Conclusion

In May 2011, I find myself on a windswept hill in rural Lesotho, accompanied by Mme 'Mats`eliso and Mme 'Mathuso. We are visiting the Mapoteng<sup>74</sup> community association, which is part of the larger network of “support groups” that Mme 'Mats`eliso fosters across the country. On a day when the mountain air is so clear and cold that the sky looks the color of lapis lazuli, we sit on a congress of battered chairs and benches, wrapped in the thick woolen blankets that are the chosen uniform in Lesotho's cold climate, and listen to the group's frustration about their lack of support, their feelings of invisibility. They report a remarkable level of participation, including leadership from the village chief and his wife, and a long-standing history of solidarity in helping the sick in their community. Across town, they have carefully laid out 25 or more garden plots, each one assigned to a sick patient or family and tended by group members in order to ensure some level of food security. But the group is struggling without some level of external support.

Some members of the group are infected; many are not. Some report that they joined because they simply did not know what else to do—to stem the tide of deaths, to help decimated families. Women describe the terrifying early years of the HIV epidemic, speaking of it as a time when “the coffins came out from the houses and twos and threes, one after another.” In small villages like Mapoteng, where entire families have crumbled due to illness, surviving community members find themselves trying to support orphans, sick adults, widows, and elderly grandparents off of meager pensions, scant remittances

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<sup>74</sup> This name, like others, has been changed to protect identities.

from working relatives, and what remains of livestock and seed supplies not already used up or sold off to pay hospital and transport fees. The extent of this burden threatens the survival of entire communities. Support groups begin to look like sandbag levies erected on the eve of a hurricane's arrival: a desperate attempt to preserve a doomed town's survival.

The advent of HIV funding raised hopes and reinvigorated worn-out groups;<sup>75</sup> the failure of that funding to reach many groups like this one creates resentment, distrust, disappointment, a sense of collective moral failure. The Mapoteng group has found little support from the government, its donors, or NGOs, despite the fact that they live close to a well-regarded clinic that receives international and domestic support. They hope that Mme 'Mats`eliso can help them come up with new ideas for attracting NGO or government assistance. She has few suggestions, though she often tries to get her own funders to accompany her on visits to these more far-flung rural associations. She talks about income-generation projects and is willing to share her skills, to teach them how to make various products, but they lack any start-up capital, or the means to market and sell products once they are produced.

As we sit on this hillside ringed with mountain aloes the size of small buildings, the conversation is occasionally punctuated by the far-off noise of a car passing by on the dirt road below town. Each car is white—the ubiquitous color of government- and NGO-owned vehicles—and they are all that pass by on the road. “We are working all alone,” one man says in frustration. “We are working hard but the government is just closing its eyes.” It is as if the government knows they are there (indeed, can see them out the windows of their vehicles as they pass by) but refuses to acknowledge them. And what is

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<sup>75</sup> As I note in earlier chapters, not all support groups are like this one; many emerged after funding became available, and, having been organized in order to obtain grant funds or material goods, tend to lack long-term sustainability and solidarity.

the point of being seen anyways if nothing results from it? “We should be seen with eyes that are *helpful*,” he insists.

It is clear that Mme ‘Mats`eliso is at a loss for ideas that will help. The conversation has ranged from the need for job creation, to a washed out bridge that prevents patients from reaching the clinic. ‘Mats`eliso tries to emphasize that some issues must be taken into their own hands as citizens—brought to community counselors and government ministries. An older, retired miner stands up and speaks to me. “I understand this, but I, as one of the people who went to the mines to earn a living, I know that it is not easy for me to have a voice in that country [South Africa]. It is difficult to have a voice abroad the way you do as a citizen in your own home [country].” He looks to me and explains that much in Lesotho is decided by my own government, by the US. He asks me to return home and say, “I went to Ha Mapoteng and I saw these problems.” He wants to tell me that my citizenship matters more than his does in fixing these problems. It is hard to argue with him: His perception is a powerful and common one in Lesotho, difficult to overturn in the minds of citizens—in large part, because it is true.

Mme ‘Mats`eliso tries another tactic. If anyone can build a sense of optimism and empowerment, she can. She speaks to crowds like a preacher, drawing on religious metaphors and the call-and-response patterns used in many African churches. Her speech is worth repeating in its entirety here, as it gets to the heart of citizen subjectivities in a time of HIV scale-up in Lesotho. The responses of the group are italicized in brackets.

I believe everything is good here, because everything is good in heaven, and so on earth it shall be good!

Because the government is your children, isn't this so?

*[yes!]*

It's not Ntate Mosisili [the Prime Minister].

*[It's not him].*

It's not these other guys.

*[It's not].*

It's not Mme 'Mathatho [the Prime Minister's Wife]. It is your own children. Your children are being sent out but they never fulfill their duties. As we have talked, the cars have been going by. The cars are passing us by time and again. Do you think they don't see you?

[No.]

Don't they know that you are there?

[They know!]

Why is it that they are doing nothing about anything? It's because of their hearts—they don't have generous and good hearts. And yet we are even taken care of by people from other countries! There—over there—are your children! [She points to the road.] Right now I have already seen about three cars [passing us by, on the road]! The government cars, they are just passing by aimlessly, and not entering into the villages! But when you come to the places where they have claimed to be going [and giving services], then you find only *mashata* and *mahlomola* [unbearable situations of suffering].

But you shouldn't be discouraged, you should refuse to be discouraged, because everything is going to work out. Even *thokolosi* is running out of power.

'Mats`eliso tries to convince her audience that the government is "your children," a repositioning that inverts the power structures of government, placing the responsibility in the hands of parents (citizens) for ensuring that their children go out and do their bidding. She compares a government that does not see suffering, does not recognize its people, to a naughty child that must be lovingly, but firmly, brought under the control of his or her parents.

*Thokolosi* is a well-known evil spirit, a sly, tricky little gremlin of a creature blamed for mishaps ranging from the minor (broken windows), to the considerable (an unwanted pregnancy, bad luck in relationships), to the catastrophic (death). Mme 'Mats`eliso jokingly shouts at *Thokolosi*, "Now there is no one you can strangle and kill!" What happens next in the dialogue, however, is unexpected. A woman from the audience, following the call-and-response pattern of the speech, shouts out a retort: "Because AIDS has killed us all!" There is laughter but the response has a macabre humor to it that is deeply unsettling.

'Mats`eliso continues undaunted.

So we should now meet, hold each other's hands, and do this great work. I like this phrase I have been hearing—*muso ha o re tsoelle* [the government does not care for us]—because it is also our cry in my home village...Maybe if I was the only person who was crying, they would think, "oh, this woman never stops crying." But we find the same thing—the very same thing—here.



At this point she seems at a loss for how to continue. It is not enough to simply say that they all feel the same way, but remain invisible together. She is grasping at ways to convince her audience that they can bridge the gap between the government, its far-flung funders, and this gathering of well-meaning but downtrodden villagers. She sighs, and concludes: “Even if the government doesn’t see you, heaven does.”

The extent of felt invisibility among populations experiencing HIV scale-up is profound. It is an invisibility so pervasive that when citizens appeal to forces “up there” (see Ferguson & Gupta, 2002) they are speaking about God, not government. In 2008, when I was just beginning this project, I met with a doctor working with an NGO in Lesotho and asked him about how decisions on HIV policy were made in the country. “We have a second government here in Lesotho,” he said, “an NGO government.” While it may appear to NGOs, donors and experts that Lesotho has a second government in which they are key participants, I have come to understand that for most citizens the concern is not about a second government, but a separate one—one that exists far beyond their reach. In this dissertation, I have attempted to sketch out the parameters of citizen subjectivity and political worlds amidst HIV scale-up, where citizens engage primarily through a “politics of reciprocity”; where patients and support groups struggle to craft survival through temporary, intermittent and broken forms of social contract; where faith in democracy is in the decline and perceptions of corruption are rampant.

For many who work in places like Lesotho, among NGOs, government programs, or as researchers, the data in these pages will be all-too-familiar. I tell these stories in the interest of painting an honest portrait of the political fallout of global health programs, but at the risk of repeating what others have observed, what in fact hides in plain sight. Nevertheless, in the context of other research these conditions, so familiar to many, have

mostly remained a backdrop to other questions; here, I attempt to bring them into the foreground, and in doing so, to give them a full airing as defining social dynamics of HIV scale-up. In addition, I would not be surprised to find that the issues and trends I report on here represent only a small fraction of the evidence that could be brought to bear in answering the question of how HIV scale-up is affecting political worlds and subjectivities. This is an exploratory analysis; my hope is that it might be the basis for a much larger, more generalizable, and perhaps multi-country, multi-investigator project of research. And I hope that the questions I raise here might encourage other ethnographers to reexamine their field data for additional evidence that might more fully answer these questions. In what follows, I briefly describe the research's implications, in particular its lessons for ongoing quandaries about aid effectiveness, citizen empowerment, and the effects of political dynamics on population health. I then discuss potential policy options for addressing some of the concerns about citizen participation, state-citizen relations, and NGO conduct.

### **Making Aid Work?**

A country like Lesotho will continue, at least in the coming decades, to be reliant on significant flows of aid to maintain a minimal level of survival for its citizens. Overhauling health care access and quality will require a much more intensive influx of aid money. Surprisingly, Lesotho funds more of its health system than other African countries, spending more than 10% of total government expenditures on health (WHO, 2012, p. 136). Nevertheless, this amounts to less than a quarter of what South Africa spends per capita on health expenditures, and even less than half of that spent in Swaziland (WHO, 2012, p. 141). Downturns in donor funding for HIV in the wake of the

global financial crisis in 2008 threatened to cause serious disruptions in treatment for patients living with HIV/AIDS because of the government's reliance on donor funding and declines in South African Customs Union revenue that provides the bulk of the government's operating budget (Medecins Sans Frontieres, 2011). And in late 2012, Lesotho sent out an urgent appeal to the donor community asking for support in addressing a mounting food security crisis, estimating that up to 725,000 citizens (40% of the population) would need food assistance in the coming year (Government of Lesotho, 2012).

Events in the past decade have reignited a fierce debate among economists and Africanist scholars about whether aid works, why it doesn't, and how to fix it (Easterly, 2006; Hanlon, Barrientos, & Hulme, 2010; Moyo, 2009; Sachs, 2006; Singer, 2010). I have intentionally steered clear of these discussions, although it is not because they don't concern me; they do. Much of this literature, however, seems to earnestly march down a one-way road towards ever more neoliberal and market-based options, using the troubles of development aid to justify the failures of anything not tied to, and guided by, the capitalist market (see, for example, Moyo, 2009; Sachs, 2006). While these critiques highlight the very powerful disappointments with development present in recipient and donor communities, they easily lead us into a moral zone where forfeiting responsibility for the suffering of others to the forces of capitalism seems like the most just option. This research brought me face-to-face with very broken, and troubling, forms of claims-making: the patient who stood in a neighbor's house demanding food from her children before he would take his treatments; the elderly grandmother who insisted that I, as an American, must have a t-shirt for her because she indeed knew her HIV status; the factory workers in line for vaginal inspections who begged me to help them get done more quickly. But

amidst these broken forms of request are very real desires and needs. How do we reconcile our informants' acute social suffering and desires to achieve better forms of survival with critiques that throw the entire development enterprise into question?

One answer seems to be allowing citizens a greater deal of voice in the aid that enters their countries, making sure that institutions (NGOs, funders, ministries) are more democratically administered, and acknowledging that global health projects are inherently political. Some strides have been made in the form of SWAps (sector-wide approaches to health) that place more funding under the purview of national governments, and efforts to build accountability through increased participation in health (Bjorkman & Svensson, 2007; Jesper & Kerstin, 2006; Rosato et al., 2008; Tandler & Freedheim, 1994). These approaches are partial ones, however, and pose additional difficulties. SWAps ensure government agencies have more say over how funding is spent, but still place a great deal of funding in the hands of government ministries, not necessarily citizens. As discussed in chapter 3, funding to government ministries can increase the power of ruling parties and unelected officials, thus reducing the likelihood and effectiveness of free and fair elections. Efforts to improve participation tend to place the onus of responsibility for accountability on citizens, without necessarily ensuring citizens have the capabilities or power to enforce good governance: They remain forms of self-governance and individualized responsibility, rather than emancipatory, collective, and transformative politics. In addition, increased participation often includes participants as consumers, not citizens, and overlooks potential inequalities in elevating the voice of ill-defined "communities," trends I describe in more detail in chapter 3 (see also Campbell, Nair, & Maimane, 2007; Paiva, 2003). Efforts to increase the voice of Lesotho's community councils in HIV priority-setting and programming, as I describe in chapter 3, have thus far been largely ineffective because

they place responsibility on councils without providing the knowledge needed to build responsive policies and without attenuating the power of NGOs and funders in communities—forces that are difficult for councils to confront, let alone control.

The politics of reciprocity reinforces citizen silence and broken forms of participation, and in doing so, reduces the likelihood that citizens will be able to play meaningful, agentive roles in future health initiatives. Yet even in Lesotho ripples of citizen response can be observed. In earlier chapters I have shown how support groups, community associations, factory workers and everyday citizens still strive to make meaningful connections with each other and their government, and do so against great odds. In recent years a new citizen-led group has emerged in Maseru. Called “Voice of the Voiceless,” it has participated in many recent protests and citizen demonstrations against the government. It aims to draw attention to citizen groups and issues that are not typically heard in Lesotho. There are other signs as well that the government must come to terms with constituencies it has repeatedly ignored or discounted in the past. During Prime Minister Mosisili’s reelection campaign in 2012, he visited factories and appealed to workers for their support, realizing he could not win reelection without this constituency. He was shouted off the stage by angry workers, who claimed that he had abandoned their interests throughout his two terms in office and had turned them into “slaves” (Zihlangu, 2012). It was their support for Tom Thabane, and his attention to labor issues, that helped him win the 2012 election. And in 2011, I met with a Chief’s wife in Lesotho whose aim is to install innovative computers in every village that are linked by radio and internet connection, in order to increase citizens’ access to information about the government and their communication with other villages and the state. Though the pilot project’s demonstration computer languished in a neighborhood outside of Maseru, she remained

committed to building technologies to better connect citizens who were too often isolated from political and social processes in the country. But even as new groups and movements emerge, others disappear. As I describe in chapter 5, Mme 'Mats`eliso and her group of community health workers seem, today, wholeheartedly committed to building business enterprises, rather than continuing as a community-based support group.

And what about signs of resistance, those weapons of the weak (Scott, 1987) that leave room for hope—if not for overt social mobilization, then at least for nascent forms of agency in the face of powerful structures of constraint? Lesotho's cultural and geographic proximity to South Africa makes the absence of citizen activism on HIV like that of the Treatment Action Campaign all the more noticeable. Experts and government administrators are quick to dismiss the populace as "passive," while simultaneously demanding of citizens that they become "competent" as part of HIV scale-up (see chapter 3). In the face of considerable hurdles to participation—lack of knowledge, broken social contracts, the fracturing of responsibility among myriad actors, rapid overturn in programs and policies—the discourses offered by citizens come across as crucial political dialogues about the programs and forms of survival that matter most to them. Talk of hunger, for example, speaks simultaneously to multiple fears: about the toxicity of ARVs in the absence of proper nutrition, about real food insecurity, especially in the context of HIV, about corruption and unfair distribution of AIDS funding, and about the power of the state to administer and take citizen life (see chapter 5). Speaking of hunger and refusing treatment in the context of food insecurity has become an important means of making claims—but like self-immolation or hunger strikes, it is a strategy of last resort, and one that has tragic consequences.

Nevertheless, discourses like these comprise speech acts that have the effect of reorienting talk about HIV towards issues that are of the most concern for citizens. They open doors to broader political discussions about issues that citizens feel are under-represented in the wake of HIV scale-up, as a kind of political “redistricting” captures broad social issues and rezones them as constituents of an HIV/AIDS policy program. The tireless efforts among citizens to change the conversation and give voice to acutely felt needs are important, though at times futile, forms of resistance—discursive “weapons of the weak.” Unfortunately, like the patient who demands food from his neighbors, they are too often misdirected, turned inwards on other community members. As we saw in chapter 5, forms of solidarity can, under the pressure of resource scarcity and unfair distribution of public goods, turn into social tensions and collective vulnerability. Citizens turn towards, or on, one another as the gap between citizens and the state grows wider, and as those responsible for administering programs (NGOs, donors, the state, etc.) seem more and more inaccessible to citizens. The more that citizens are treated and perceived as part-time patients, recipients, clients, or orphans (rather than as citizens), the further the space for meaningful engagement as citizens shrinks. Expecting individuals to act, collectively or individually, as citizens—that is, to mobilize, communicate, speak out, protest—when they are in fact treated more often as clients or recipients, is akin to asking someone who has been raised speaking English to suddenly start speaking Sesotho. We must begin by thinking about changing the structures that shape citizen subjectivities and limit their field of participation and engagement.

### **Bad Politics is Bad for Your Health?**

In previous chapters I have refrained from explicitly exploring the connections between political subjectivities, changing political landscapes, and the health of my informants. In many ways, this final connection was beyond the scope of an already broad research project, but it may be the most important direction for future research. Sen and Derezé's (1991) exploration of hunger and public participation in India opened doors to a renewed recognition of the linkages between political form and function and the health of populations. The data here, though not explicitly intended to answer such questions, indicate that the quality of citizens' relationships with the state, its partners, and clinics may dramatically impact how, where, and how often they seek services. It is not unsurprising to find that in Lesotho, as elsewhere, the ability to interact as a rights-bearing individual with the health system improves individual outcomes and broader shifts in health service provision (Bjorkman & Svensson, 2007; Rosato et al., 2008; Tandler & Freedheim, 1994). The case of Mme Lerato, presented in chapter 5, demonstrates the pitfalls of a public health system in which patients do not feel able to advocate for, or articulate, health rights. Paralyzed by spinal TB and reliant on family members to advocate for her at the clinic, Mme Lerato was particularly at the mercy of clinicians' whims. Their strict adherence to procedural rules in the midst of burdensome patient loads and inadequate institutional support meant that Mme Lerato was not able to access the medicines or care she needed, and dramatically increased her risk of becoming resistant to both HIV and TB medicines. Unfortunately, she is not alone. Patients' widely reported reticence about speaking to clinicians and fear of retribution when lodging complaints about government services create a host of poor service outcomes, and appear to deter patients from seeking care when they need to advocate for themselves, may disappoint



clinicians,<sup>76</sup> or must ask for services that are not immediately available. The persistent popularity of traditional and faith healers—as well as my own research with Mme ‘Mats`eliso and her patients—indicates that therapeutic itineraries are heavily influenced by these dynamics between patients and clinicians.

More broadly, reticence about speaking to clinicians, government agencies, or NGOs, and fear about retribution if complaints are lodged means that meaningful feedback about the quality of services is rarely received. Yet as data from chapter 4 show, patients are very aware of the quality and availability of services at their local clinics. This creates an information deficit between citizens and clinicians, government agencies, and NGOs that impedes the ability to make services more responsive. Nevertheless, it is essential to point out that incentive and power structures make it difficult for citizens to speak out. Retribution from petty bureaucrats or clinicians for criticism *is* quite common; the politics of reciprocity structures citizen interactions with NGOs and funders; few citizens have access to information about how to contact NGOs; and top-down priority-setting processes curtail and limit opportunities for citizens to give meaningful feedback. Studies have shown how patient “empowerment” is associated with better uptake and use of health services (Bjorkman & Svensson, 2007; Rosato et al., 2008), but empowerment, as I argue in chapter 3, can be a nebulous and incomplete measure of full citizen participation and mobilization (see also, for example, Finn & Sarangi, 2008; Petchesky, 2003).

Is it possible that these political dynamics have a visible impact on broader population health? Maternal and child mortality across HIV endemic nations remains

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<sup>76</sup> Fear of facing clinicians when patients have not adhered to medicines or clinic instructions is particularly acute. This happens even when patients have strong reasons (such as hunger, migrancy, or inability to travel to the clinic) for treatment lapses. Additional research I conducted in 2008 on childbearing choices among women living with HIV indicated that when women become pregnant while on HIV treatment they avoid the clinic for fear of facing clinician anger and disappointment.

persistently, shockingly high (WHO, 2012). Much of this mortality is attributable, experts agree, to the secondary effects of HIV (Hogan et al., 2010; WHO, 2012). But recent health surveys in Lesotho have shown rising mortality figures, despite efforts to expand access to free primary health care and vast increases in government health expenditures between 2000 and 2010 (from \$14 to \$56 per capita) (WHO, 2012, p. 137). For example, cause-specific mortality in children under 5 declined between 2000 and 2010 for HIV/AIDS but increased for other common diseases, including measles and pneumonia (*Ibid.*, p. 70-1). Even as HIV treatment has expanded rapidly over these years and HIV incidence has declined, mortality remains so high that Lesotho ranks among the worst countries in Africa for improvements in child and maternal mortality (*Ibid.*, p. 19-21). The most recent Demographic and Health Survey (DHS) in 2009 provoked particular concern in Lesotho, showing that even between 2004 and 2009 child mortality showed an upward trend, and all-cause adult mortality increased by 22% (MOHSW, 2010, p. 257). Mortality estimates are problematic, even where statistical reporting is much more robust, but there are some signs that the quality of primary health services and interventions might be struggling even as HIV care and treatment improves. The WHO reports that the percentage of the population with access to improved drinking water actually declined between 2000 and 2010 (WHO, 2012, p. 112), and maternal mortality rates are rising even as reports of births attended by a health professional increased significantly (MOHSW, 2010).<sup>77</sup>

Figures such as these, though exploratory, indicate that there is significant room for further study as to the drivers of persistently poor public health in places like Lesotho even

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<sup>77</sup> There are enormous discrepancies in Lesotho's reported maternal mortality figures over the past few years. The WHO *World Health Statistics* report (2012) shows the maternal mortality ratio per 100,000 live births as 690 in 2000 and 620 in 2010. But in recent discussions on MDG progress in Lesotho, WHO representatives have reported that the maternal mortality ration increased from 419 in 2000 to a shocking 1165 in 2010, according to DHS reports.

as HIV services have improved. Experts have worried about HIV scale-up's effects on task-shifting (incentivizing shifts in resources away from primary care and towards HIV programs, and moving human resources out of the health system and into NGO and bureaucratic positions) (Callaghan, Ford, & Schneider, 2010), and a now robust literature is exploring the capacity of HIV programming to build more long-standing improvements in health systems (El-Sadr & Abrams, 2007; Hafner & Shiffman, 2013). This leaves a great deal of room, however, for studies exploring how citizens' relationships with health providers, government, and NGOs impact health outcomes, and how HIV scale-up is changing the way that patients seek and utilize various health services and public health interventions across the board.

### **Finding a Way Forward**

It is clear from these research findings that HIV scale-up processes, despite the strong relationships between activist movements and global HIV institutions throughout the past decades, have, in countries like Lesotho, largely left citizens and participatory politics by the wayside. This is despite very well-meaning efforts to build community participation and the greater representation of persons living with HIV/AIDS. An emphasis on administering a primarily biomedical program of action to address HIV has excluded everyday citizens and elevated the power of government agencies. And the vast size and scope of HIV scale-up has eclipsed other health, rights, and social issues. It is important not to romanticize democratic or participatory politics, especially in this neoliberal and globalizing age. But given the tendency of HIV programs to disrupt systems of participation and citizen access to government even despite the best intentions to do otherwise, and given indications that the quality of citizen engagement is linked to health outcomes, it is

clear that we need to reexamine strategies for meaningful participation and true transparency and accountability.

A simple case in point is Lesotho's *pitso*. As described in chapter 2, the *pitso*, or community meeting, is easily the most recognizable and robust form of public, deliberative, political participation in Lesotho. Accounts of the *pitso* from the 19<sup>th</sup> century indicate that, while led by local chiefs, they provided opportunities for public discourse that transgressed social hierarchy, questioning those in power and attending to the preservation of collective well-being. This form of public discourse is reflective of the sort of deliberative democracy promoted by Rawls, Habermas, and Sen, among others. For Sen (2009) in particular, it is "government by discussion" that enables a public, collective accounting of what might ensure the kinds of lives citizens "have reason to value"—or in the language of this work, pursue the forms of survival that matter most. HIV initiatives, building on the tendency of development initiatives to use *pitsos* to disseminate information about projects, have employed the *pitso* as a platform for HIV education and testing, or for the performance of donor aid as goods are handed out to community members. This is a vast departure from the original purpose and procedure of the *pitso*. In many ways, the change is emblematic of broader political shifts during HIV scale-up, and demonstrates the need for a return to more participatory, discursive politics.

How might we move towards deliberative democracy in HIV programming? Taking our cues from Sen (2001, 2009), we might think in terms of building capabilities, those "substantive freedoms" that would enable more meaningful participation. For Sen, democracy is essential to efforts to achieve the kind of life one has reason to value; his vision of democracy is associational, discursive, and driven by citizens. Sen's capabilities approach has been extended to health (articulating types of "health capabilities" and the

ways in which they might be achieved), as well as to recognitions that full public participation as citizens is essential component of psychiatric recovery (Hopper, 2007; Ruger, 2010; Sen, 2002; Ware, Hopper, Tugenberg, Dickey, & Fisher, 2007). Sen's more recent work (2009) has reemphasized the centrality of deliberative democracy in ameliorating injustice. He argues that a view of democracy as rooted in human interaction and public discourse, rather than in the organization or procedures of specific institutions, allows us to pursue democracy more vigorously, and flexibly—and at global as well as national levels (p. xiii). Where Sen falls short is in helping societies to confront the powers embedded in institutions that limit participation and curtail the pursuit of just and meaningful futures (c.f. Deneulin, Nebel, & Sagovsky, 2006). Thus, there are two broad levels at which we might aim to implement feasible changes. The first is at the level of large institutions and structures of power through which global health programming is executed. Changes in the ways that NGOs, institutions, and government branches set policy, develop priorities, and carry out everyday business can begin opening up more space for citizen involvement. The second is at the level of increasing citizens' political capabilities. At this level, I discuss potential changes that would create the kinds of enabling conditions that allow citizens to participate more fully and forcefully. A capabilities approach helps us in avoiding the pitfalls of hoisting further responsibilities and expectations on citizens without changing the fundamental political conditions under which they live their lives.

At the level of institutions and structures, we can imagine a great many possibilities for change. National AIDS Commissions (NACs), Country Coordinating Mechanisms (CCMs), and other institutional bodies intended to represent citizens in setting HIV priorities must become more representative. Tokenist representation by individuals living

with HIV/AIDS or umbrella organizations must no longer stand in for more accountable and fair forms of representation.<sup>78</sup> Representatives must be held accountable to clear constituencies and report back to them regularly. Even if positions are not elected, they should rotate on an ongoing basis. More fundamentally, Lesotho must reinstate its National AIDS Commission and ensure it is a strong and independent voice in HIV policymaking and funding decisions. Institutions like the CCMs must undertake a broader recognition of the hierarchical tensions between funders and civil society organizations reliant on such funding, as well as between themselves and government ministries. Funders, NGOs, activists, and government should engage in annual priority-setting processes that will fundamentally shape all HIV-related activities, and such processes must be driven not by external priorities, but by closer attention to citizen desires, needs, and concerns. As they stand now, joint annual meetings tend to present already agreed-upon priorities and policies, and primarily serve as information-dissemination opportunities. In addition, Lesotho's effort to decentralize some HIV priority-setting to community councils through the Essential Services Plan and the Gateway Initiative is laudable, though unfortunately relatively unsuccessful. But this should not discourage the possibility of community council engagement in priority-setting in the future. In fact, community councils provide a promising structure for information exchange on HIV priorities and policies between citizens and government and its partners. A less top-down and more community-driven priority setting process on HIV and health initiatives is certainly possible. But to work effectively, citizen and council perspectives on HIV priorities must influence national

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<sup>78</sup> It is worth noting that the forms of representation engendered by the GIPA principles tend towards tokenism at multiple levels (including regional and global bodies), not only within national civil society bodies.

policy, rather than just providing a framework for council-led work in communities (for a further discussion, see chapter 3).

NGOs and funders must also alter the ways in which they work with citizens, endeavoring to build better transparency and accountability with communities, not just governments. Any discussion of how these processes may be improved must include a significant caveat: that there is a great variety among NGOs and funders, in terms of how they interact with communities, set priorities, and build processes for better accountability and participation. The recommendations here derive from my own observations of how various institutions engaged with the communities with whom I worked; as such, it is an inherently limited one, which must be complemented by studies conducted elsewhere, and among other communities and NGOs.

A primary step is improving the information provided to citizens and community councils about ongoing projects, allowing opportunities for open and honest feedback from citizens, and ensuring that NGO staff are far more accessible to citizens. Building this kind of accountability will require efforts in multiple areas. First, Memorandums of Understanding commonly drafted between NGOs and the government can firmly stipulate specific expectations for NGOs, including obligations to work through community councils and/or to report back to all communities in which they have programs about ongoing projects and plans for the future. Explicit in these dialogues would be the mutual understanding that citizens could provide feedback and influence priorities for the future without facing any retribution, and that such a dialogue would be separate from any resource distribution among citizens. In order to ensure that NGO programs do not exacerbate inequalities or favor certain geographic areas, government and civil society should encourage NGOs to implement programs throughout the country equally, or

explicitly target the most needy, rather than populations that are most accessible. Governments can also require NGOs and funders to undertake longer-term contracts and programs in country—from 5-10 years rather than 1-3 years—since short-term programs create so much confusion among citizens and impede knowledge accumulation in communities about available services and resources. Longer-term programs may be more reliable, allow citizens to engage more fully in providing feedback that actually impacts program priorities and delivery, and enable relationships and mutual trust to build between citizens and NGO staff. It is also abundantly clear that citizens need more impartial bodies to assist them in communicating with NGOs, funders, umbrella organizations, and government agencies. Building more independent activism in civil society will assist in this process, but in order for those groups to remain independent they must access funding that does not require them to become primary service providers. An intermediary step might be to establish a national ombudsman office intended to assist citizens in understanding rights, resolving disputes, and ensuring they do not suffer punitive action.

Clearer messaging is required about the kinds of labor expected of patients, participants and support groups involved in clinical and NGO programs, as well as in the care of the sick. How are individuals to be reimbursed, if at all? What is expected of them? What benefits and resources might they expect to receive? Governments and funders will have to set clear policies as to whether and how care-givers and support groups will be supported, with considerable input from citizens. And NGOs should distribute easily-understood information to participants, patients, or support groups about what “participation” in their programs includes, what benefits may be expected, what will not be provided, and what efforts, risks, and costs may be involved for any participants. Though consent in research processes has been shown to be, at best, a very flawed process



in such contexts, it may be time to consider some kind of ongoing consent process between NGOs and participants. Such a tool would ensure that both parties clearly acknowledge and come to a shared understanding of expectations, commitment, and program objectives. But even more important is ensuring that NGOs provide ample and fair opportunity for dialogue with citizens and participants about all aspects of their programming and priorities, and use such dialogues to shape future work. Doing that will require a fundamental re-thinking of how NGOs and even governments are funded—an approach that has started with broader acceptance of SWAps but that has much further to go.

Nevertheless, a caveat is necessary. NGOs—and more importantly, CBOs—still provide an important alternative voice on policy in many countries. Especially where government approaches are authoritarian or discriminatory, non-governmental entities can play an important role in activism. As more and more organizations are absorbed as service providers, they tend to become more politically docile. Maintaining and supporting independent, activist-leaning organizations is important, and too much regulation by governments (either through funding arrangements or accountability measures) may limit the scope of productive political critiques in public health programming. In recent years, the Government of Lesotho has shown its ability to arbitrarily shut down or take over independent programs which it deems a threat to its influence over policy and provision, including its closure of the National AIDS Commission. While a number of initiatives like SWAps attempt to build better accountability between central governments and NGOs and funders, what is perhaps more important is to build better systems of communication and accountability between *citizens* and NGOs / funders. As the discussion of Lesotho's

Gateway Approach demonstrates, even concerted efforts in this domain can be swallowed up by global funding hierarchies, NGO mandates, and existing priority-setting processes.

How can we develop the democratic capabilities of citizens more directly?

Lesotho's citizens rank quite high on core capabilities: The population has very high literacy rates, takes interest political issues, and most citizens have access to radios (Hall & Leduka, 2008; Tsikoane, Mothibe, Ntho, & Maleleka, 2007). Despite these capacities, however, acute deficits in basic needs demonstrate a powerful ability to distort political engagement and the articulation of rights and concerns. Sen (2001) and Nussbaum (2000) have referred to the self-damaging or seemingly irrational decisions of agents under the long-term duress of poverty as "adaptive preferences." The term particularly refers to the tendency of citizens—long imprisoned by the lack of choices imposed by poverty—to struggle in articulating preferences, let alone expansive rights and desires, even when given a chance to do so. This inability to imagine the many parameters of a good and decent life, or to see one's treatment as a violation of one's rights, is often taken as a sign of passivity and acceptance among Lesotho's citizens. As demonstrated by my informants, issues like chronic hunger or persistent economic insecurity show a striking ability to damage claims-making, social solidarity, and public participation. Addressing and providing for citizens' most basic needs—and doing so in a way that is neither temporary nor dependent on participation in or endorsement of other programs—is the most important building block to democratic capabilities.

Moving beyond basic needs, Sen (2009) argues that democratic participation involves "the capacity to enrich reasoned engagement through enhancing informational availability and the feasibility of interactive discussions. Democracy has to be judged not just by the institutions that formally exist but by the extent to which different voices from

diverse sections of the people can actually be heard” (p. xiii). This means providing the information and knowledge to citizens that allows them to engage meaningfully, and creating the enabling conditions that allow voices to be elicited and heard. At the most basic level, data in this dissertation has demonstrated that citizens have an acute desire to know more about NGO programs and services in their communities, but lack access to basic information. Public institutions—clinics, community council buildings, post offices—should have postings about all NGO projects going on in communities. NGOs should be required to provide clear, concise, widely-accessible information on a regular basis, and all information must include the contact information for a staff member whose primary role is to interface with citizens and community groups. Ironically, Lesotho does have a vast online database of NGOs working in the country that includes detailed information on projects, intended beneficiaries, funders, and contact details ([www.letsema.co.ls](http://www.letsema.co.ls)). Ironically, this information is inaccessible to almost all citizens, even as it enables NGOs and governments to be highly aware of activities throughout the country.<sup>79</sup> These kinds of information deficits among citizens are easy to address, especially given citizens’ keen interest in having more information about NGOs and high literacy rates. Another basic intervention would be ensuring that providers speak the language of their patients, or requiring the availability of trained interpreters in clinics where international doctors and nurses are providing care. Being able to speak to clinicians, ask questions, and provide feedback is foundational in building broader citizen capabilities.

Undertaking a capabilities approach also means acknowledging that citizens’ interests may not align with those of funders or NGOs, and in particular, that they may

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<sup>79</sup> Information is primarily available through the website. Binders for each district were at one point provided to district councils, but I never heard anyone mention awareness of their existence—even community councils with whom I was working were not aware that this information was available.

prioritize other needs above HIV interventions. On one hand, it is essential that we pay attention to citizen priorities, especially given the tendency of HIV programs to overshadow other issues and rights in places like Lesotho. Ultimately, if citizens do not see the value of yet another HIV prevention campaign, it is unlikely to have any great impact. But on the other hand, public health policymaking tends to involve a fair measure of paternalism—enacting policies that are good for society but may not be in the interest of certain individuals. Public health policies like motorcycle helmet laws and indoor smoking bans limit individual freedoms in order to promote population health, and they can provoke the anger of interest groups and citizens. Over time, they tend to gain broader public acceptance. Crafting balanced policies like this is always difficult, but implementing paternalist policies at the behest of global institutions or to meet obligations from funders is sure to alienate citizens and patients. Increasing public discourse and deliberative democracy to set policies and balance individual and collective rights is crucial, and likely to create better public health outcomes in the long-term.

Finally, new technologies are emerging that promise to change citizen participation in public discourse, allowing citizens to engage more easily and through mobile platforms and crowd-sourcing technologies (Zambrano & Seward, 2013). UNAIDS recently began using crowd-sourcing technologies to influence its policies on youth and HIV/AIDS, and recognizing the need for new strategies of participation and engagement (Sidibé, Piot, & Dybul, 2012). While the proportion of people in Lesotho with access to mobile phones is increasing, many lack the funds to pay for data or air time in order to participate, and only 1.3% of the population reported access to the internet in 2009 (MOHSW, 2010). As a result, new technologies may create new forms of disenfranchisement and inequality. They also require additional citizen capabilities—and in addition to other lacking capabilities,

may contribute to rather than diminish existing democratic deficits. Nevertheless, such strategies remain a promising area for future research, and hold the potential for much greater information exchange between citizens and the state.

Activist movements in countries like Brazil and South Africa have shown that confronting HIV can also provide an opportunity to destabilize hierarchies, articulate rights, and reenergize citizens. Despite the global emphasis on community empowerment and patient participation in many HIV initiatives, however, citizens in countries like Lesotho have not shared these experiences. More than anything else, citizens need more recognition from the government and its partners that they can be meaningful participants in new global health processes, not just bodies to be treated, or recipients to be handed goods. If we fail to recognize the dramatic political impacts of global health programs, or the distrust and invisibility felt by citizens, we risk destabilizing political futures in states with an already tenuous relationship with democracy. Democracy itself is no perfect solution, either—and it faces considerable challenges in Africa, and in the current global era. But enabling citizens to act as agents in their own futures and to engage in public and meaningful deliberation about what those futures should look like is far from impossible. We should not leave those like the support group described at the beginning of this chapter—whose houses and communities bear the scars of AIDS, and who labor so earnestly to carry these burdens—feeling that only heaven hears them.

## Bibliography

- Aerni-Flessner, J. (2011). *"If we govern ourselves, whose son is to govern us?": Youth, independence and the 1960s in Lesotho*. Doctoral Dissertation, Washington University in Saint Louis.
- Afrobarometer. (2009). *Popular attitudes toward democracy in Lesotho: A summary of Afrobarometer indicators, 1999-2008*.
- Agamben, G. (1998). *Homo sacer: Sovereign power and bare life*. Stanford, CA: Stanford University Press.
- AIDS treatment clinic opens in Lesotho. (2004, July 2). *Public Eye*, p. 6.
- Akoku, D. (2009a). *Civil society involvement in the Global Fund to Fight AIDS, Tuberculosis and Malaria: What difference does it make in Lesotho?* Maseru, Lesotho: Lesotho Network of AIDS Service Organizations. Available from: [http://www.gfcu.org.ls/ccm/Research\\_Report\\_Civil\\_Society\\_and\\_the\\_Global\\_Fund\\_Country\\_level.pdf](http://www.gfcu.org.ls/ccm/Research_Report_Civil_Society_and_the_Global_Fund_Country_level.pdf)
- Akoku, D. (2009b). *Towards effectiveness and accountability: Donor-civil society partnership in combating HIV/AIDS in Lesotho*. Maseru, Lesotho: Lesotho Network of AIDS Service Organizations.
- ALAFa. (2010). *ALAFa: An industry model for fighting HIV/AIDS and TB*. Maseru, Lesotho: Author.
- Alagiri, P., Collins, C., Summers, T., Morin, S., & Coates, T. (2001). *Global spending on HIV/AIDS: Tracking public and private investments in AIDS prevention, care and research*. San Francisco, CA: Progressive Health Partners and UCSF AIDS Research Institute.
- Altman, D. (1999). Globalization, political economy, and HIV/AIDS. *Theory and Society*, 28(4), 559–584.
- Ambrose, D. (1998). Summary of events in Lesotho (Vol. 5, iss. 3). Maseru, Lesotho: Transformation Resource Centre. Retrieved from <http://www.trc.org.ls/events/events19.983.htm>
- Ambrose, D. (1999). Summary of events in Lesotho (Vol. 6, iss. 2). Maseru, Lesotho: Transformation Resource Centre. Retrieved from <http://www.trc.org.ls/events/events19.992.htm>
- Ambrose, D. (2003). Summary of events in Lesotho (Vol. 10, iss. 1). Maseru, Lesotho: Transformation Resource Centre. Retrieved from <http://www.trc.org.ls/events/events20.031.htm>
- Appadurai, A. (2002). Deep democracy: Urban governmentality and the horizon of politics. *Public Culture*, 14(1), 21–47.
- Ashforth, A. (1998). Reflections on spiritual insecurity in a modern African city (Soweto). *African Studies Review*, 41(3), 39–67.

- Ashforth, A. (2005). *Witchcraft, violence and democracy in South Africa*. Chicago: University of Chicago Press.
- Auerbach, J. D., Parkhurst, J. O., & Cáceres, C. F. (2011). Addressing social drivers of HIV/AIDS for the long-term response: Conceptual and methodological considerations. *Global Public Health*, 6(sup3), S293–S309.
- Auvert, B., Lissouba, P., Geffen, N., Fiamma, A., & Heywood, M. (2009). Key facts on male circumcision. *SAMJ: South African Medical Journal*, 99, 150–151.
- Babich, L. P., Nthunya, M. A., & Bicknell, W. J. (2006). *Lesotho health sector: A rapid donor survey*. Boston: International Finance Corporation and Boston University.
- Baiocchi, G., & Connor, B. T. (2008). The ethnos in the polis: Political ethnography as a mode of inquiry. *Sociology Compass*, 2(1).
- Baldwin, P. (2005). *Disease and democracy: The industrialized world faces AIDS*. Berkeley: University of California Press.
- Bardill, J. E., & Cobbe, J. H. (1985). *Lesotho: Dilemmas of dependence in Southern Africa*. Boulder, CO: Westview Press.
- Barnett, T., & Whiteside, A. (2002). *AIDS in the twenty-first century: Disease and globalization*. New York: Macmillan.
- Bartlett, D. (2001). Human rights, democracy & the donors: The first MMD government in Zambia. *Review of African Political Economy*, 28(87), 83–91.
- Bayart, J.-F. (2009). *The state in Africa: The politics of the belly* (2nd ed.). New York: Polity.
- Bayart, J.-F., Ellis, S., & Hibou, B. (1999). *The Criminalization of the State in Africa*. London: International African Institute.
- Bayer, R. (1991). Public health policy and the AIDS epidemic. An end to HIV exceptionalism? *New England Journal of Medicine*, 324(21), 1500–1504.
- Bayer, R. (1992). *AIDS in the industrialized democracies: Passions, politics, and policies*. New Brunswick: Rutgers University Press.
- Bayer, R., Fairchild, A., & Colgrove, J. K. (2007). *Searching eyes: Privacy, the state, and disease surveillance in America*. Berkeley: University of California Press.
- Bayer, R., & Oppenheimer, G. M. (2000). *AIDS doctors: Voices from the epidemic*. New York: Oxford University Press.
- Bayer, R., & Oppenheimer, G. M. (2007). *Shattered dreams? An oral history of the South African AIDS epidemic*. New York: Oxford University Press.
- Baylies, C., & Power, M. (2001). Civil society, kleptocracy & donor agendas: What future for Africa? *Review of African Political Economy*, 28(87), 5–8.

- Baylies, C., & Wright, C. (1993). Female labour in the textile and clothing industry of Lesotho. *African Affairs*, 92(369), 577–591.
- Bennet, M. (2006). Lesotho's export textiles and garment industry. In H. Jauch & R. Traub-Merz (Eds.), *The future of the textile and clothing industry in sub-Saharan Africa*. Bonn, Germany: Friedrich-Ebert-Stiftung.
- Benson, P. (2011). *Tobacco capitalism: Growers, migrant workers, and the changing face of a global industry*. Princeton, NJ: Princeton University Press.
- Berkman, A., Garcia, J., Munoz Laboy, M., Paiva, V., & Parker, R. (2005). A critical analysis of the Brazilian response to HIV/AIDS: Lessons learned for controlling and mitigating the epidemic in developing countries. *American Journal of Public Health*, 95(7), 1162–1172.
- Biehl, J. (2005). *Vita: Life in a zone of social abandonment*. Berkeley: University of California Press.
- Biehl, J. (2007). *Will to live: AIDS therapies and the politics of survival*. Princeton, NJ: Princeton University Press.
- Biehl, J. (2008). Drugs for all: The future of global AIDS treatment. *Medical Anthropology*, 27(2), 99–105.
- Biesma, R. G., Brugha, R., Harmer, A., Walsh, A., Spicer, N., & Walt, G. (2009). The effects of global health initiatives on country health systems: A review of the evidence from HIV/AIDS control. *Health policy and planning*, 24(4), 239–52.
- Bill and Melinda Gates Foundation. (2012). Foundation timeline. Retrieved November 28, 2012 from <http://www.gatesfoundation.org/about/Pages/foundation-timeline.aspx>
- Bird, K., Booth, D., & Pratt, N. (2003). *Food security crisis in Southern Africa: The political background to policy failure*. London: Overseas Development Institute.
- Birdsall, K., & Kelly, K. (2007). *Pioneers, partners, providers: The dynamics of civil society and AIDS funding in Southern Africa*. Johannesburg: CADRE/OSISA.
- Bjorkman, M., & Svensson, J. (2007, June). *Power to the people: Evidence from a randomized field experiment of a community-based monitoring project in Uganda* (World Bank Policy Research Working Paper No. 4268). Washington, DC: The World Bank. Retrieved from [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=996174](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=996174)
- Blowfield, M., & Frynas, J. G. (2005). Setting new agendas: critical perspectives on corporate social responsibility in the developing world. *International Affairs*, 81(3), 499–513.
- Bollinger, L., & Stover, J. (2009). *The potential cost and impact of expanding male circumcision in Lesotho*. Washington, DC: USAID Health Policy Initiative.
- Bond, P. (2003). *Against global apartheid: South Africa meets the World Bank, IMF, and international finance* (Second ed.). Cape Town, South Africa: University of Cape Town Press.



- Boo, K. (2012). *Behind the beautiful forevers: Life, death, and hope in a Mumbai undercity*. New York: Random House.
- Bor, J. (2007). The political economy of AIDS leadership in developing countries: An exploratory analysis. *Social Science & Medicine*, 64(8), 1585–99.
- Bornstein, E. (2001). Child sponsorship , evangelism , and belonging in the work of World Vision Zimbabwe. *American Ethnologist*, 28(3), 595–622.
- Bornstein, E., & Redfield, P. (2007). Genealogies of suffering and the gift of care (SSRC Working Papers, June). New York: Social Science Research Council.
- Bowsky, S. (2004). *Matla ea Lesotho ke sechaba: Hlahlobo ea kokelo ea bakuli ma haeng / Lesotho's strength is its people: A rapid appraisal of home and community based care*. Maseru: CARE Lesotho and Family Health International
- Brass, P. R. (2000). Foucault steals political science. *Annual Review of Political Science*, 3, 305–330.
- Briggs, C. L., & Mantini-Briggs, C. (2004). *Stories in the time of cholera: Racial profiling during a medical nightmare*. Berkeley, CA: University of California Press.
- Bulled, N. (2012). *(Re)distribution of blame: The politics of biomedical HIV knowledge among youth in Lesotho*. Doctoral Dissertation: University of Connecticut.
- Burawoy, M. (1998). The Extended Case Method. *Sociological Theory*, 16(1), 4–33.
- Burawoy, M. (2009). *The Extended Case Method: Four countries, four decades, four great transformations, and one theoretical tradition*. Berkeley: University of California Press.
- Bureau of Statistics. (2009). "Analytical report, volume IIIB: Socio economic characteristics." *2006 Lesotho Population and Housing Census (Vol. III)*. Maseru: Author.
- Butler, J., & Scott, J. (Eds.). (1992). *Feminists theorize the political*. New York: Routledge.
- Callaghan, M., Ford, N., & Schneider, H. (2010). A systematic review of task- shifting for HIV treatment and care in Africa. *Human Resources for Health*, 8(1), 8.
- Campbell, C. (2009, March). Building AIDS competent communities : Possibilities and challenges. *AIDS2031*. Salzburg, Austria.
- Campbell, C., Nair, Y., & Maimane, S. (2007). Building contexts that support effective community responses to HIV/AIDS: A South African case study. *American Journal of Community Psychology*, 39(3-4), 347–63.
- Carpenter, E. A. (2008). *The social practice of HIV drug therapy in Botswana, 2002-2004: Experts, bureaucrats, and health care providers*. Doctoral Dissertation: University of Pennsylvania.
- Casalis, E. (1861). *The Basutos*. Berkeley: University of California Press.

- Cassidy, R., & Leach, M. (2009). AIDS, citizenship and global funding : A gambian case study (Institute of Development Studies Working Paper, No. 352). Brighton: University of Sussex.
- Castells, M. (2000). *The power of identity* (2nd ed.). Malden, MA: Blackwell Publishing.
- Central Intelligence Agency CIA. (2012). *The World Factbook*. Washington, DC: Retrieved June 18, 2012, from <https://www.cia.gov/library/publications/the-world-factbook/index.html>
- Chabal, P., & Daloz, J.-P. (1999). *Africa works: Disorder as political instrument*. Bloomington, IN: Indiana University Press.
- Chatterjee, P. (2004). *The politics of the governed: Reflections on popular politics in most of the world*. New York: Columbia University Press.
- Chiyoka, W., & Hoohle-Nonyana, N. (2010). *Capacity assessment report for District AIDS Committees (DACs) and Community Council AIDS Committees (CCACs)*. Maseru, Lesotho: Government of Lesotho and National AIDS Commission
- Chiyoka, Wedzerai. (2009). *External review of the Essential HIV & AIDS Services Package*. Maseru, Lesotho: National AIDS Commission and Ministry of Local Government and Chieftainship.
- Cho, W., & Bratton, M. (2006). Electoral institutions, partisan status, and political support in Lesotho. *Electoral Studies*, 25(4), 731–750.
- CNN. (2011, April 2). Lesotho plans for life without US trade lifeline. *Friday Flyer*, p. 4.
- Cohen, J. (2008, 25 July). The great funding surge. *Science*, 321, 512–519.
- Colvin, M., Lemmon, G., & Naidoo, J. (2006). The private sector response to HIV and AIDS in Lesotho. London: ALAFA / ComMark Trust.
- Comaroff, J. (1985). *Body of power, spirit of resistance: The culture and history of a South African people*. Chicago: University of Chicago Press.
- Comaroff, J. (1993). The diseased heart of Africa: Medicine, colonialism, and the black body. In S. Lindenbaum & M. Lock (Eds.), *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life*. Berkeley: University of California Press.
- Comaroff, J. (2007). Beyond bare life: AIDS, (bio)politics, and the neoliberal imagination. *Public Culture*, 19(1), 197–219.
- Comaroff, J. L., & Comaroff, J. (1999). Civil society and the political imagination in Africa: critical perspectives. Chicago: University of Chicago Press.
- Community council plans, Essential HIV and AIDS Services Package*. (n.d.). Maseru, Lesotho: UNAIDS & Ministry of Local Government and Chieftainship.
- Conway-Smith, E. (2012, August 21). South Africa: Striking miners “thought they were invincible” after taking “muti.” *GlobalPost*. Retrieved January 9, 2013 from <http://www.globalpost.com/dispatch/news/regions/africa/south-africa/120821/south-africa-striking-miners-thought-they-were-invincible-muti>

- Cooper, F., & Packard, R. M. (Eds.). (1997). *International development and the social sciences: Essays on the history and politics of knowledge*. Berkeley: University of California Press.
- Coplan, D. B., & Quinlan, T. (1997). A chief by the people: Nation versus state in Lesotho. *International African Institute*, 67(1), 27–60.
- Correa, S., Petchesky, R., & Parker, R. G. (2008). *Sexuality, health and human rights*. New York: Routledge.
- Crane, J. (2011). Scrambling for Africa? Universities and global health. *The Lancet*, 377(9775), 1388–1390.
- Crush, J., Dodson, B., Gay, J., Green, T., & Leduka, C. (2010). *Migration, remittances and “development” in Lesotho*. Cape Town, South Africa: IDASA, Southern African Migration Programme.
- Crush, J., & Frayne, B. (2010). *The invisible crisis: Urban food security in Southern Africa* (Urban Food Security Series, No. 1). Kingston, Australia and Cape Town, South Africa: Queen's University and African Food Security Urban Network.
- Curran, J., Debas, H., Arya, M., Kelley, P., Knobler, S., & Pay, L. (2005). *Scaling up treatment for the global AIDS pandemic: Challenges and opportunities*. Washington, DC: Institute of Medicine.
- D'Adesky, A.-C. (2006). *Moving mountains: The race to treat global AIDS*. New York: Verso.
- Das, V. (2007). *Life and words: Violence and the descent into the ordinary*. Berkeley: University of California Press.
- Das, V., & Poole, D. (2004). *Anthropology in the margins of the state: Comparative ethnographies*. Santa Fe: School for Advanced Research Press.
- Deneulin, S., Nebel, M., & Sagovsky, N. (2006). *Transforming unjust structures: The capability approach*. The Netherlands: Springer.
- De Souza, H. (1994). *A cura de AIDS / The cure of AIDS*. Rio de Janeiro: Relume-Dumará.
- De Waal, Alex. (2006). *AIDS and power: Why there is no political crisis--yet*. New York: Zed Books.
- De Waal, A., & Whiteside, A. (2003). New variant famine: AIDS and food crisis in Southern Africa. *The Lancet*, 362(9391), 1234–1237.
- Decoteau, C. L. (2008). *The bio-politics of HIV/AIDS in post-apartheid South Africa*. PhD Dissertation: University of Michigan.
- Deleuze, G. (2006). *Foucault*. New York: Continuum.
- Deleuze, G., & Guattari, F. (2009). *Anti-Oedipus: Capitalism and schizophrenia* (6th ed.). New York: Penguin Classics.

- Dietrich, J. W. (2011). The politics of PEPFAR: The President's Emergency Plan for AIDS Relief. *Ethics & International Affairs*, 21(03), 277–292.
- Drimie, S. (2003). HIV/AIDS and land: Case studies from Kenya, Lesotho and South Africa. *Development Southern Africa*, 20(5), 647–658.
- Drimie, S., & Casale, M. (2009). Multiple stressors in Southern Africa: The link between HIV/AIDS, food insecurity, poverty and children's vulnerability now and in the future. *AIDS Care*, 21(sup1), 28–33.
- Easterly, W. (2006). *The white man's burden: Why the West's efforts to aid the rest have done so much ill and so little good*. New York: The Penguin Group.
- Edström, J., & MacGregor, H. (2010). The pipers call the tunes in global aid for AIDS: The global financial architecture for HIV funding as seen by local stakeholders in Kenya, Malawi and Zambia. *Global Health Governance*, 4(1), 1–12.
- Edwards, L., & Lawrence, R. Z. (2010). AGOA rules: The intended and unintended consequences of special fabric provisions. Cambridge: National Bureau of Economic Research.
- Edwards, M. (2009). *Civil Society*. Malden, MA: Polity Press.
- Edwards, M., & Sen, G. (2000). NGOs, social change and the transformation of human relationships: A 21st-century civic agenda. *Third World Quarterly*, 21(4), 605–616.
- El-Sadr, W. M., & Abrams, E. J. (2007). Scale-up of HIV care and treatment: Can it transform healthcare services in resource-limited settings? *AIDS*, 21 Suppl(5), S65–S70.
- Eldredge, E. A. (2007). *Power in colonial Africa: Conflict and discourse in Lesotho, 1870-1960*. Madison, WI: University of Wisconsin Press.
- Elshtain, J. B. (1993). *Public man, private woman: Women in social and political thought*. Princeton, NJ: Princeton University Press.
- Elyachar, J. (2003). Mappings of power: The state, NGOs, and international organizations in the informal economy of Cairo. *Comparative Studies in Society and History*, 45(3), 571–605.
- Epprecht, M. (1993). Domesticity and piety in colonial Lesotho: The private politics of Basotho women's pious associations. *Journal of Southern African Studies*, 19(2), 202–224.
- Epprecht, M. (2009). Women's "conservatism" and the politics of gender in late colonial Lesotho. *The Journal of African History*, 36(1), 29–56.
- Epprecht, M., & Natrass, A. (2000). *"This matter of women is getting very bad": gender, development at politics in colonial Lesotho*. Pietermaritzburg, South Africa: University of Natal Press.
- Epstein, H. (2007). *The Invisible Cure: Africa, the West, and the Fight Against AIDS*. New York: Macmillan.
- Epstein, S. (1996). *Impure science: AIDS, activism, and the politics of knowledge*. Berkeley: University of California Press.

- Erikson, S. L. (2008). Getting political: Fighting for global health. *The Lancet*, 371(9620), 1229–1230.
- Escobar, A. (1995). *Encountering development: The making and unmaking of the third world*. Princeton, NJ: Princeton University Press.
- European Commission. (2007). *Kingdom of Lesotho--European Community country strategy paper and national indicative programme for the period 2008-2013*. Lisbon, Portugal: Author.
- Farmer, P. (1992). *AIDS and accusation: Haiti and the geography of blame*. Berkeley: University of California Press.
- Farmer, P. (2001). *Infections and inequalities: The modern plagues*. Berkeley: University of California Press.
- Fassin, D. (2007a). Humanitarianism as a politics of life. *Public Culture*, 19(3), 499–520.
- Fassin, D. (2007b). *When bodies remember: Experiences and politics of AIDS in South Africa*. Berkeley: University of California Press.
- Fassin, D. (2010). Ethics of survival: A democratic approach to the politics of life. *Humanity: An International Journal of Human Rights, Humanitarianism, and Development*, 1(1), 81–95.
- Feldman, L. C. (2006). *Citizens without shelter: Homelessness, democracy, and political exclusion*. Ithaca, NY: Cornell University Press.
- Ferguson, J. (1985). The bovine mystique: Power, property and livestock in rural Lesotho. *Man*, 20(4), 647–674.
- Ferguson, J. (1994). *The anti-politics machine: "Development," depoliticization, and bureaucratic power in Lesotho*. Minneapolis: University of Minnesota Press.
- Ferguson, J. (2006). *Global shadows: Africa in the neoliberal world order*. Durham, NC: Duke University Press.
- Ferguson, J., & Gupta, A. (2002). Spatializing states: Toward an ethnography of neoliberal governmentality. *American Ethnologist*, 29(4), 981–1002.
- Fig, D. (2005). Manufacturing amnesia: Corporate social responsibility in South Africa. *International Affairs*, 81(3), 599–617.
- Finn, M., & Sarangi, S. (2008). Quality of life as a mode of governance: NGO talk of HIV "positive" health in India. *Social Science & Medicine* (1982), 66(7), 1568–78.
- Fisher, W. F. (1997). Doing good? The politics and antipolitics of NGO practices. *Annual Review of Anthropology*, 26, 439–464.
- Foreign Investment Advisory Service. (2006). *Lesotho corporate social responsibility (CSR) in Lesotho's apparel sector*. Washington, D.C: Author.

- Foucault, M. (1973). *The birth of the clinic: An archaeology of medical perception*. New York: Vintage Books.
- Foucault, M. (1975). *Discipline and punish: The birth of the prison*. New York: Random House.
- Foucault, M. (1980a). *Power / knowledge: Selected interviews and other writings, 1972-1977*. (C. Gordon, Ed.). New York: Pantheon Books.
- Foucault, M. (1980b). *The history of sexuality*. New York: Vintage Books.
- Foucault, M. (1989). *Madness and civilization: a history of insanity in the age of reason*. London: Routledge.
- Foucault, M. (2003). *Psychiatric power: lectures at the College de France, 1973-1974*. New York: Picador.
- Foucault, M. (2008). *The birth of biopolitics: Lectures at the College de France, 1978-79*. New York: Palgrave.
- Fox, R. C., & Southall, R. (2004). The general election in Lesotho, May 2002: Adapting to MMP. *Electoral Studies*, 23(3), 545–550.
- Fraser, N. (1990). Rethinking the public sphere: A contribution to the critique of actually existing democracy. *Social Text*, 25/26, 56–80.
- Freire, P. (1970). *Pedagogy of the oppressed* (30th Anniv. ed.). New York: Continuum Press.
- Fullwiley, D. (2004). Discriminate biopower and everyday biopolitics: Views on sickle cell testing in Dakar. *Medical Anthropology*, 23(2), 157–94.
- Fullwiley, D. (2011). *The enculturated gene: Sickle cell health politics and biological difference in West Africa*. Princeton, NJ: Princeton University Press.
- Galvão, J. (2000). *A AIDS no Brasil*. Rio de Janeiro: Relume-Dumará.
- Gayfer, J., Flint, M., & Fourie, A. (2005). *Evaluation of DFID's country programmes: Country study Lesotho 2000 – 2004*. Maseru, Lesotho: DFID.
- German Technical Cooperation. (2006). *The Gateway Approach: Mainstreaming HIV and AIDS using local authorities*. Maseru, Lesotho: Decentralized Rural Development Program, GTZ Lesotho.
- Germond, P., & Cochrane, J. R. (2010). Healthworlds: Conceptualizing landscapes of health and healing. *Sociology*, 44(2), 307–324.
- Germond, P., & Molapo, S. (2006). In search of Bophelo in a time of AIDS: Seeking a coherence of economies of health and economies of salvation. *Journal of Theology for Southern Africa*, 126(November), 27–47.

- Gibbs, T. (2005). "Union boys in caps leading factory girls astray?" The politics of labour reform in Lesotho's "feminised" garment industry. *Journal of Southern African Studies*, 31(1), 95–115.
- Giddens, A. (1990). *The consequences of modernity*. Stanford, CA: Stanford University Press.
- Gilden, D. (2009). *Lesotho apparel industry unites to fight AIDS. Case Studies for Global Health*. <http://casestudiesforglobalhealth.org/post.cfm/lesotho-apparel-industry-unites-to-fight-aids>. Accessed August 12, 2010.
- Gitari, F. A. (2007). *Investigating the potential role of corporate social responsibility (CSR), in management of HIV/AIDS at workplace: A case study of garment industries in Thetsane, Maseru*. Masters thesis: University of Stellenbosch.
- Global Fund Round 6 Proposal: Lesotho's coordinated proposal for preventing the spread and mitigating the impact of HIV/AIDS on orphans and vulnerable children and enhancing community involvement in TB control*. (2006). Maseru, Lesotho: Global Fund Country Coordinating Mechanism.
- Godwin, P., Morah, E., Nitzsche-Bell, A., Orago, A., Kalomba, D., Van Renterghem, H., Misra, S., et al. (2010). Enhancing accountability in HIV programs: Lessons from the Global Fund's first learning wave of National Strategy Applications. *Global Health Governance*, 4(1), 1–14.
- Good, M.-J. D., Hyde, S. T., Pinto, S., & Good, B. (2008). *Postcolonial disorders*. Berkeley: University of California Press.
- Government of Lesotho. (2000). *Policy framework on HIV/AIDS prevention, control and management*. Maseru, Lesotho: Author.
- Government of Lesotho. (2012). *Appeal for humanitarian assistance, September 2012 to June 2013*. Maseru, Lesotho: Author.
- Gramsci, A. (1971). *The prison notebooks*. New York: International Publishers.
- Gupta, G. R., Ogden, J., & Warner, A. (2011). Moving forward on women's gender-related HIV vulnerability: The good news, the bad news and what to do about it. *Global Public Health*, 6(sup3), S370–S382.
- Gupta, G. R., Parkhurst, J. O., Ogden, J. a, Aggleton, P., & Mahal, A. (2008). Structural approaches to HIV prevention. *Lancet*, 372(9640), 764–75.
- Habermas, J., T. Burger, & Lawrence, F. (1991). *The structural transformation of the public sphere*. Cambridge, MA: MIT Press.
- Hafner, T., & Shiffman, J. (2013). The emergence of global attention to health systems strengthening. *Health Policy and Planning*, 28(1), 41–50.
- Hall, D., & Leduka, R. C. (2008). *Summary of results: Round 4 Afrobarometer survey in Lesotho* (Vol. 3, p. 63). Lansing, MI, and Maseru, Lesotho: Afrobarometer.

- Hamnett, I. (1971). Some notes on the concept of custom in Lesotho. *Journal of African Law*, 15(3), 266–273.
- Hanlon, J., Barrientos, A., & Hulme, D. (2010). *Just give money to the poor: The development revolution from the global South*. Sterling, VA: Kumarian Press.
- Hardt, M., & Negri, A. (2000). *Empire*. Cambridge: Harvard University Press.
- Harman, S. (2010). *The World Bank and HIV/AIDS: Setting a global agenda*. London and New York: Routledge.
- Hart, G. (2002). *Disabling globalization: Places of power in post-apartheid South Africa*. Berkeley: University of California Press.
- Hatchard, J. (2009). Combating transnational corporate corruption: Some further lessons from Lesotho. *Journal of Commonwealth Law and Legal Education*, 7(2), 155–163.
- Hausmann, R., Tyson, L. D., & Zahidi, S. (2010). *Global gender gap report*. Geneva: World Economic Forum.
- Heywood, M., & Altman, D. (2000). Confronting AIDS: Human rights, law and social transformation. *Health and Human Rights*, 5(1), 149–79.
- Himmelgreen, D. A., Romero-Daza, N., Turkon, D., Watson, S., Okello-Uma, I., & Sellen, D. (2009). Addressing the HIV/AIDS-food insecurity syndemic in sub-Saharan Africa. *African Journal of AIDS Research*, 8(4), 401–412.
- Hintjens, H. (1999). The emperor's new clothes: A moral tale for development experts? *Development in Practice*, 9(4), 382–395.
- Hirsch, J. S., Parker, R. G., & Aggleton, P. (2007). Social aspects of antiretroviral therapy scale-up: Introduction and overview. *AIDS*, 21 Suppl(5), S1–S4.
- Hogan, M. C., Foreman, K. J., Naghavi, M., Ahn, S. Y., Wang, M., Makela, S. M., Lopez, A. D., et al. (2010). Maternal mortality for 181 countries, 1980-2008: A systematic analysis of progress towards Millennium Development Goal 5. *Lancet*, 375(9726), 1609–23.
- Holzemer, W. L., Gree, M., & Makoae, L. N. (2007). Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public Health Nursing*, 24(5), 389–399.
- Holzemer, W. L., Uys, L., Makoae, L., Stewart, A., Phetlhu, R., Dlamini, P. S., Greeff, M., et al. (2007). A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6), 541–51.
- Hopper, K. (2007). Rethinking social recovery in schizophrenia: What a capabilities approach might offer. *Social science & medicine* (1982), 65(5), 868–79.
- Human Rights Watch. (2008). *A testing challenge: The experience of Lesotho's universal HIV counseling and testing campaign*. New York: Human Rights Watch and Aids and Rights Alliance for Southern Africa.



- Hyde, S. T. (2007). *Eating spring rice: The cultural politics of AIDS in southwest China*. Berkeley: University of California Press.
- Igoe, J., & Kelsall, T. (2005). *Between a rock and a hard place: African NGOs, donors and the state*. Durham, NC: Carolina Academic Press.
- Initiative on Soaring Food Prices. (2008). *Lesotho: End of mission report*. Geneva: Food and Agriculture Organization.
- Institute for Health Metrics and Evaluation. (2010). *Financing global health 2010: development assistance and country spending in economic uncertainty*. Seattle, WA: Author.
- International Labour Office. (2009). *Decent Work country programme: Lesotho*. Geneva: Author.
- International Labour Organization and International Finance Corporation. (2010). *Better Work Lesotho project summary*. Geneva: Author.
- Jesper, S., & Kerstin, S.-A. (2006). Translations of health sector SWAps: A comparative study of health sector development cooperation in Uganda, Zambia and Bangladesh. *Health Policy*, 76(3), 277–287.
- Jones, C. (2011). “If I take my pills I’ll go hungry”: The choice between economic security and HIV/AIDS treatment in Grahamstown, South Africa. *Annals of Anthropological Practice*, 35(1), 67–80.
- Kalofonos, I. A. (2008). *“All I eat is ARVs”: Living with HIV/AIDS at the dawn of the treatment era in central Mozambique*. PhD Dissertation: University of California, San Francisco.
- Kalofonos, I. A. (2010). “All I Eat Is ARVs”: The paradox of AIDS treatment interventions in Central Mozambique. *Medical Anthropology Quarterly*, 24(3), 363–380.
- Kelsall, T., & Mercer, C. (2003). Empowering people? World Vision & “transformational development” in Tanzania. *Review of African Political Economy*, 30(96), 293–304.
- Khobotlo, M., Tshello, R., Nkonyana, J., Ramoseme, M., Khobotle, M., Chitoshia, A., Hildebrand, M., et al. (2009). *Lesotho HIV prevention response and modes of transmission analysis*. Maseru, Lesotho: National AIDS Commission.
- Kimario, S. S., Okpaku, J. O., Githuku-Shongwe, A., & Feeney, J. (2004). Turning a crisis into an opportunity: Strategies for scaling up the national response to the HIV/AIDS pandemic in Lesotho. New Rochelle, New York: Third Press Publishers.
- Kingdom of Lesotho. (2004). *Kingdom of Lesotho poverty reduction strategy 2004/2005 - 2006/2007*. Maseru, Lesotho: Government of Lesotho
- Klein, T. (2007). Selecting therapies in Benin: Making choices between in- formal, formal, private and public health services. *Afrika Spectrum*, 42(3), 461–481.
- Lamboray, J.-L., & Skevington, S. M. (2001). Defining AIDS competence: A working model for practical purposes. *Journal of International Development*, 13(4), 513–521.

- Lashuay, N., Burgel, B. J., Harrison, R., Israel, L., Chan, J., Cusic, C., Pun, J. C., et al. (2002). *"We spend our days working in pain: " A report on workplace injuries in the garment industry*. Oakland, CA: Asian Immigrant Women Workers Clinic.
- Le Marcis, F. (2003). The suffering body of the city. *Public Culture*, 16(3), 453–477.
- Lesotho News Agency. (2005, January 21). Carers reminded of responsibilities. *Public Eye*, p. 8.
- Lesotho News Agency. (2010, November 5). Traditional healers form political party. *Public Eye*, p. 14.
- Lesotho Planned Parenthood Association. (2009). *Violation of rights a threat to development: A collection of "I" stories by LPPA*. Maseru: Lesotho Planned Parenthood Association.
- Levi-Strauss, C. (1974). *Structural Anthropology*. New York: Basic Books.
- Lewis, B. (2007). New Global health Movement: Rx for the World? *New Literary History*, 38(3), 459–477.
- Lieberman, E. (2009). *Boundaries of contagion: How ethnic politics have shaped government responses to AIDS*. Princeton, NJ: Princeton University Press.
- Liese, B., & Dussault, G. (2004). *The state of the health workforce in sub-Saharan Africa: Of Contributing Factors*. Washington, D.C: The World Bank.
- Lisk, F. (2010). *Global institutions and the HIV/AIDS epidemic: Responding to an international crisis*. London: Routledge.
- Livingston, J. (2005). *Debility and the moral imagination in Botswana*. Bloomington, IN: Indiana University Press.
- Macfarlane, S. B., Jacobs, M., & Kaaya, E. E. (2008). In the name of global health: Trends in academic institutions. *Journal of public health policy*, 29(4), 383–401.
- Maclean, S. (2012, February 28). HIV-positive mother forced to eat COW DUNG with her medication because she's too poor to afford food. *Mail and Guardian*. Retrieved March 7, 2012 from: <http://www.dailymail.co.uk/news/article-2107229/HIV-positive-mother-forced-eat-COW-DUNG-medication-s-poor-afford-food.html>.
- Magubane, K. (2012, November 6). SA to prevent Lesotho famine? *iAfrica*. Retrieved November 8, 2012 from <http://business.iafrica.com/businessday/825733.html>
- Makenete, A., Ortman, G., & Darroch, M. (1998). Food-aid dependency in Lesotho: Issues and policy implications. *Development Southern Africa*, 15(2), 251–266.
- Makoa, F. K. (1997). Gender and politics : A note on gender inequality in Lesotho. *Journal of Social Development in Africa*, 12(1), 5–14.
- Makoe, M. G. (2009). The phenomenology of bodily care: Caregivers' experiences with AIDS patients before antiretroviral therapies in Lesotho. *African Journal of AIDS Research*, 8(1), 17–27.

- Makoae, M. G., & Jubber, K. (2008). Confidentiality or continuity? Family caregivers' experiences with care for HIV/AIDS patients in home-based care in Lesotho. *Journal of Social Aspects of HIV/AIDS*, 5(1), 36–46.
- Makoae, M. G., & Mokomane, Z. (2008). *Examining women's vulnerability to HIV transmission and the impact of AIDS: The role of peer education/peer support in Lesotho's garment industry*. Cape Town: CARE Lesotho / Human Sciences Research Council.
- Maleleka, D. (2009). The impact of democracy in Lesotho: Assessing political, social and economic developments since the dawn of democracy (Research Report No. 115). Johannesburg, South Africa: Center for Policy Studies.
- Mamdani, M. (1996). *Citizen and subject: Contemporary Africa and the legacy of late colonialism*. Princeton: Princeton University Press.
- Mangili, A., Murman, D. H., Zampini, A. M., & Wanke, C. A. (2006). Nutrition and HIV infection: Review of weight loss and wasting in the era of highly active antiretroviral therapy from the nutrition for healthy living cohort. *Clinical infectious diseases: An official publication of the Infectious Diseases Society of America*, 42(6), 836–42.
- Manning, R. (2002). AIDS and democracy: What do we know? *AIDS and Democracy: Setting the Research Agenda* (Health Economics and AIDS Research Division Working Paper). Durban: University of Natal.
- Marx, K. (1990). *Capital: Volume I*. New York and London: Penguin Books.
- Matope, T. (2011, May 27). Youths savage AIDS response. *Public Eye*, p. 4. Maseru.
- Matope, T. (2012, February 3). Masowe industrial waste dumpsite "a keg full of dynamite." *Public Eye*. Maseru, Lesotho.
- Matope, T. (2010, October 8). Damning NAC report...govt tears into National AIDS Commission, calls for its restructuring. *Public Eye*, p. 2.
- Mbembe, A. (2001). *On the postcolony*. Berkeley: University of California Press.
- Mbembe, A. (2003). Necropolitics. *Public culture*, 15(1), 11–40.
- McDougall, D. (2009, August 2). African dream turns sour for orphan army. *Sunday Times*, pp. 4–8. Maseru, Lesotho.
- Medecins Sans Frontieres. (2011). *Reversing HIV/AIDS? How advances are being held back by funding shortages* (Briefing note December 2011). Paris: Author.
- Mercer, C. (2002). NGOs, civil society and democratization: A critical review of the literature. *Progress in Development Studies*, 2(1), 5–22.
- Merson, M. H. (2006). The HIV/AIDS pandemic at 25 -- The global response. *New England Journal of Medicine*, 354(23), 2414–2417.
- MFA Forum. (2006). *Destination Lesotho: On the road to responsible competitiveness*. Maseru, Lesotho: Author.

- Michaud, J., & Kates, J. (2011). *The U.S. Global Health Initiative: A country analysis*. Menlo Park, CA: Kaiser Family Foundation.
- Ministry of Health and Social Welfare. (2003). *Lesotho national health and social welfare policy*. Maseru: Author.
- Ministry of Health and Social Welfare. (2004). *Human resources development and strategic plan 2005-2025*. Silver Spring, MD: Medical Care Development International and Ministry of Health and Social Welfare, Lesotho
- Ministry of Health and Social Welfare. (2010). *Lesotho Demographic and Health Survey 2009*. Maseru, Lesotho: Ministry of Health and Social Welfare & ICF Macro.
- Ministry of Health and Social Welfare. (2011). Annual joint review report, 2010-11. Maseru: Author.
- Ministry of Local Government and Chieftainship. (n.d.). *Guidelines for implementation of interventions in the Essential HIV and AIDS Services Package*. Maseru, Lesotho: Author.
- Mokuku, M. (2000). Dr. Jeckyll and Mr. Hyde: Basotho citizenship and national identity strategies across the Lesotho - South Africa border. *NUL Journal of Research*, 8(1), 75–103.
- Mothibeli, L. (2009). *Factors influencing utilization of voluntary counseling and testing of HIV among pregnant women in Lesotho*. Masters thesis, University of KwaZulu-Natal.
- Motsoeli, N. (2010, October 13). Little to show after 44 years of independence. *Lesotho Times*, p. 5.
- Motsoeli, N. (2011, April 20). We are over-worked and under-paid, say textile workers. *Lesotho Times*, p. 8. Maputsoe, Lesotho.
- Moyo, D. (2009). *Dead aid: Why aid is not working and how there is a better way for Africa*. New York: Farrar, Straus and Giroux.
- Mphale, M. M., & Rwambali, E. G. (n.d.). *Lesotho Food Security Issues Paper*. London: Forum for Food Security in Southern Africa
- Murray, C. (1981). *Families divided: The impact of migrant labour in Lesotho*. Cambridge: Cambridge University Press.
- Murray, C., & Sanders, P. (2000). Medicine murder in Basutoland: Colonial rule and moral crisis. *Africa: Journal of the International African Institute*, 70(1), 49–78.
- Murray, C., & Sanders, P. (2005). *Medicine murder in colonial Lesotho: The anatomy of a moral crisis*. Edinburgh, Scotland: Edinburgh University Press.
- Mwase, T., Kariisa, E., Doherty, J., Hoohlo-Khotle, N., Kiwanuka-Mukilbi, P., & Williamson, T. (2010). *Lesotho health systems assessment*. Bethesda, MD: Health Systems 20/20, Abt Associates, Inc.
- Nash, L. (2007). *Inescapable ecologies: A history of environment, disease, and knowledge*. Berkeley: University of California Press.

- Nathanson, C. (2007). *Disease prevention as social change: The state, society, and public health in the United States, France, Great Britain, and Canada*. New York: Russel Sage Foundation.
- National AIDS Commission. (2010a). *UNGASS country report, Lesotho: Status of the national response to the 2001 Declaration of Commitment on HIV and AIDS*. Maseru, Lesotho.
- National AIDS Commission. (2010b). *UNGASS Lesotho survey response details*. Maseru, Lesotho: Author.
- National AIDS Commission. (2011). *Report on the National Response to HIV and AIDS*. Maseru, Lesotho: Author.
- Nattrass, N. (2004). *The moral economy of AIDS in South Africa*. Cambridge: Cambridge University Press.
- Negin, J., & Cumming, R. G. (2010). HIV infection in older adults in sub-Saharan Africa: Extrapolating prevalence from existing data. *Bulletin of the World Health Organization*, 88(11), 847-53.
- Negin, J., Wariero, J., Cumming, R. G., Mutuo, P., & Pronyk, P. M. (2010). High rates of AIDS-related mortality among older adults in rural Kenya. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 55(2), 239-44.
- Newell, P. (2005). Citizenship, accountability and community: The limits of the CSR agenda. *International Affairs*, 81(3), 541–557.
- Ng'anjo, M., & Diwouta, C. (2011). *HIV and AIDS and the older adult*. Pretoria: Governance and AIDS Programme, IDASA.
- Nguyen, V.-K. (2008). Antiretroviral globalism, biopolitics, and therapeutic citizenship. In S. J. Collier & A. Ong (Eds.), *Global assemblages: Technology, politics and ethics as anthropological problems*. Malden, MA: Blackwell Publishing.
- Nguyen, V.-K. (2009). Government-by-exception: Enrollment and experimentality in mass HIV treatment programmes in Africa. *Social Theory & Health*, 7, 196–217.
- Nguyen, V.-K. (2010). *The republic of therapy: Triage and sovereignty in West Africa's time of AIDS*. Durham, NC: Duke University Press.
- Not quite the rollercoaster Basotho expected. (2010, October 4). *Public Eye*, p. 4.
- Novas, C., & Rose, N. (2000). Genetic risk and the birth of the somatic individual. *Economy and Society*, 29(4), 485–513.
- Nussbaum, M. C. (2000). *Women and human development: The capabilities approach*. New York: Cambridge University Press.
- Ntsukunyane, L. (2010, November 26). Party born out of a vision: Liau. *Public Eye*, p. 6.
- Ogden, J., Gupta, G. R., Fisherc, W. F., & Warner, A. (2011). Looking back, moving forward: Towards a game-changing response to AIDS. *Global Public Health*, 6(sup3), S285–S292.

- Olaleye, W. (2004). Democratic consolidation and political parties in Lesotho (EISA Occasional Paper No. 15). Auckland Park, South Africa: The Electoral Institute for Sustainable Democracy in Africa.
- Ong, A. (1988). The production of possession: Spirits and the multinational corporation in Malaysia. *American Ethnologist*, 15(1), 28–42.
- Ong, A. (1995). Making the biopolitical subject: Cambodian immigrants, refugee medicine and cultural citizenship in California. *Social Science & Medicine*, 40(9).
- Ong, A. (2005). (Re)articulations of citizenship. *PS: Political Science and Politics*, 38(4), 697–699.
- Ong, A. (2006). Mutations in citizenship. *Theory, Culture & Society*, 23(2-3), 499–505.
- O'Rourke, D. (2000). Monitoring the Monitors: A Critique of PrivewaterhouseCoopers (PwC) Labour Monitoring. Boston, MA: Department of Urban Studies and Planning, Massachusetts Institute of Technology.
- Owusu-Ampomah, K., Naysmith, S., & Rubincam, C. (2009). *Reviewing "emergencies" in HIV and AIDS-affected countries in Southern Africa: Shifting the paradigm in Lesotho*. Durban: Health Economics and AIDS Research Division.
- Packard, R. M. (1989). *White plague, black labour: Tuberculosis and the political economy of health and disease in South Africa*. Berkeley, CA: University of California Press.
- Paiva, V. (2003). Beyond magic solutions: Prevention of HIV and AIDS as a process of "psychosocial emancipation". *Divulgacao em Saude para Debate*, (27), 107–115.
- Paiva, V. (2007). Gendered scripts and the sexual scene: Promoting sexual subjects among Brazilian teenagers. In R. G. Parker & P. Aggleton (Eds.), *Culture, society and sexuality: A reader* (Second ed.). New York: Routledge.
- Paley, J. (2002). Toward an anthropology of democracy. *Annual Review of Anthropology*, 31(1), 469–496.
- Parker, R. G. (2000). Administering the epidemic: HIV/AIDS policy, models of development, and international health. *Global health policy, local realities: The fallacy of the level playing field*. Boulder, CO: Lynne Rienner Publishers.
- Parker, R. G. (2009). Civil society, political mobilization, and the impact of HIV scale-up on health systems in Brazil. *Journal of Acquired Immune Deficiency Syndrome*, 52(S1), 49–51.
- Parker, R. G. (2011). Grassroots activism, civil society mobilization, and the politics of the global HIV/AIDS epidemic. *Brown Journal of World Affairs*, 17(2), 21–37.
- Parker, R. G. (2012). The politics of AIDS: Lessons learned from the first 30 years of the epidemic (and their implications for the fourth decade). *Seminar on ensuring a supportive environment for an effective long-term HIV response: Social and political challenges pre-conference*. Washington, DC: International AIDS Society, July.

- Parker, R. G., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57(1), 13–24.
- Parker, R. G., Easton, D., & Klein, C. H. (2000). Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS*, 14(S1), S22–S33.
- Parkhurst, J. O. (2001). The crisis of AIDS and the politics of response: The case of Uganda. *International Relations*, 15(6), 69–87.
- Pateman, C. (1983). Feminist critiques of the public/private dichotomy. In S. I. Benn & G. F. Gaus (Eds.), *Public and Private in Social Life* (pp. 281–303). New York: St. Martin's Press.
- Patterson, A. (2005). *The African state and the AIDS crisis*. Burlington, VT: Ashgate.
- Peta, B. (2010, August 15). Zuma visit: Basotho banned from protesting. *Independent Online*.
- Petchesky, R. (2003). *Global prescriptions: Gendering health and human rights*. New York: Zed Books.
- Peters, P. (1996). "Who's local here?": The politics of participation in development. *Cultural Survival Quarterly*, 20(3), 22.
- Petryna, A. (2002). *Life exposed: Biological citizens After Chernobyl*. Princeton, NJ: Princeton University Press.
- Petryna, A. (2004). Biological citizenship: The science and politics of Chernobyl-exposed populations. *Osiris*, 19, 250–65.
- Pfeiffer, J. (2003). International NGOs and primary health care in Mozambique: The need for a new model of collaboration. *Social Science & Medicine*, 56(4), 725–738.
- Pfeiffer, J. (2004). Condom social marketing, pentecostalism, and structural adjustment in Mozambique: A clash of AIDS prevention messages. *Medical Anthropology Quarterly*, 18(1), 77–103.
- Pfeiffer, J., & Chapman, R. (2010). Anthropological perspectives on structural adjustment and public health. *Annual Review of Anthropology*, 39(1), 149–165.
- Piot, P. (2003). AIDS: The need for an exceptional response to an unprecedented crisis. *Presidential Fellows Lecture*. Washington, DC: The World Bank, 20 November.
- Piot, P. (2008). AIDS: Exceptionalism Revisited. London: London School of Economics and Political Science, May 15.
- Poku, N., & Whiteside, A. (2004). *The political economy of AIDS in Africa*. Cape Town, South Africa: Ashgate Publishing.
- Ponte, S., Richey, L. A., & Baab, M. (2009). Bono's Product (RED) initiative: Corporate social responsibility that solves the problems of "distant others." *Third World Quarterly*, 30(2), 301–317.

- Poulter, S. (1972). The place of the Laws of Lerotholi in the legal system of Lesotho. *African Affairs*, 71(283), 144–162.
- Prentice, R. (2007). Knowledge, skill, and the inculcation of the anthropologist: Reflections on learning to sew in the field. *Anthropology of Work Review*, XXIX(3), 54–61.
- Producing Garments in Lesotho. (2001, July). *Clean clothes*. Retrieved February 9, 2012 from <http://www.cleanclothes.org/newslist/278>
- Przeworski, A. (1991). *Democracy and the market: Political and economic reforms in Eastern Europe and Latin America*. Cambridge: Cambridge University Press.
- Przeworski, A., Alvarez, M. E., Cheibub, J. A., & Limongi, F. (2000). *Democracy and development: Political institutions and well-being in the world, 1950-1990*. Cambridge, UK: Cambridge University Press.
- Putnam, R. D. (2001). *Bowling alone: The collapse and revival of American community*. New York: Simon & Schuster.
- Putzel, J. (2004). The global fight against AIDS: How adequate are the national commissions? . *Journal of International Development*, 16, 1129–1140.
- Rabinow, P. (1996). *Essays on the anthropology of reason*. Princeton: Princeton University Press.
- Rabinow, P., & Rose, N. (2006). Biopower today. *BioSocieties*, 1, 195–217.
- Rajak, D. (2010). “HIV/AIDS is our business”: The moral economy of treatment in a transnational mining company. *Journal of the Royal Anthropological Institute*, 16(3), 551–571.
- Ramphele, M. (2001). Citizenship challenges for South Africa’s young democracy. *Daedalus*, 130(1), 1–17.
- Rau, B. (2006). The politics of civil society in confronting HIV/AIDS. *International Affairs*, 82(2), 285–295.
- Raworth, K., & Harvey, C. (2004). *Trading away our rights: Women working in global supply chains*. Oxford, UK: Oxfam International
- Redfield, P. (2005). Doctors, borders, and life in crisis. *Cultural Anthropology*, 20(3), 328–361.
- Reese, E. (2005). *Backlash against welfare mothers*. Berkeley: University of California Press.
- Richey, L. A., & Ponte, S. (2008). Better (Red)<sup>TM</sup> than dead? Celebrities, consumption and international aid. *Third World Quarterly*, 29(4), 711–729.
- Richey, L. A., & Ponte, S. (2011). *Brand aid: shopping well to save the world*. Minneapolis and London: University of Minnesota Press.
- Robins, S. (2008). *From revolution to rights in South Africa: Social movements, NGOs & popular politics after apartheid*. Rochester, NY: James Currey.



- Robins, S., & Von Lieres, B. (2004). Remaking citizenship, unmaking marginalization: The Treatment Action Campaign in post-apartheid South Africa. *Canadian Journal of African Studies*, 38(3), 575–586.
- Rollnick, R. (2002). Botswana's high-stakes assault on AIDS: An African test case for wide distribution of life-prolonging medicines. *Africa Renewal*, 16(2-3), 4.
- Romero-Daza, N. (1993). *Migrant labor, multiple sexual partners, and sexually transmitted diseases: The makings for an AIDS epidemic in rural Lesotho*. Doctoral dissertation, State University of New York at Buffalo.
- Romero-Daza, N., & Himmelgreen, D. (2004). Sotho. In C. R. Ember & M. Ember (Eds.), *Encyclopedia of medical anthropology: Health and illness in the world's cultures, Volume 2* (pp. 957–964). New Haven, CT: Human Area Relation Files.
- Romero-Daza, N., Himmelgreen, D., Noble, C. A., & Turkon, D. (2009). Dealing with the global food crisis in local settings: Nonintensive agriculture in Lesotho, Southern Africa. *NAPA Bulletin*, 32, 23–41.
- Rosaldo, M. (1980). The use and abuse of anthropology: Reflections on feminism and cross-cultural understanding. *Signs*, 5(3), 389–417.
- Rosato, M., Laverack, G., Grabman, L. H., Tripathy, P., Nair, N., Mwansambo, C., Azad, K., et al. (2008). Community participation: Lessons for maternal, newborn, and child health. *The Lancet*, 372, 962–971.
- Rose, N. (2007). *The politics of life itself: Biomedicine, power, and subjectivity in the twenty-first century*. Princeton, NJ: Princeton University Press.
- Rose, N., & Novas, C. (2003). Biological citizenship. In A. Ong & S. J. Collier (Eds.), *Global Anthropology*. Princeton: Princeton University Press.
- Roy, A. (2011). Slumdog cities: Rethinking subaltern urbanism. *International Journal of Urban and Regional Research*, 35(2), 223–38.
- Ruger, J. P. (2010). Health capability: Conceptualization and operationalization. *American Journal of Public Health*, 100(1), 41–9.
- Sachs, J. (2006). *The end of poverty: Economic possibilities for our time*. New York: Penguin Books.
- Samuelsen, H. (2004). Therapeutic itineraries: The medical field in rural Burkina Faso. *Anthropology & Medicine*, 11(1), 27–41.
- Scheper-Hughes, N. (1991). *Death without weeping: The madness of hunger in everyday life*. Berkeley: University of California Press.
- Scheper-Hughes, N., & Lock, M. M. (1987). The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly*, 1(1), 6–41.
- Schneider, K., & Garrett, L. A. (2009). The evolution and future of donor assistance for HIV/AIDS. New York: Costs and Financing Working Group, Council on Foreign Relations.

- Schultheis, A. (2008). African child soldiers and humanitarian consumption. *Peace Review*, 20(1), 31–40.
- Scott, J. (1987). *Weapons of the weak: Everyday forms of peasant resistance*. New Haven, NJ: Yale University Press.
- Sebapo's death should serve as a wake up call. (2012, January 25). *Lesotho Times*.
- Seidman, G. W. (2009). Labouring under an illusion? Lesotho's "sweat-free" label. *Third World Quarterly*, 30(3), 581–598.
- Selinyane, N. (2001, November 9). Is Queen Elizabeth II a slaughterhouse? *Public Eye*, p. 8.
- Sen, A. (2001). *Development as freedom*. New York: Oxford University Press.
- Sen, A. (2002). Why health equity? *Health Economics*, 11, 659–66.
- Sen, A. (2009). *The Idea of Justice*. Cambridge, MA: Harvard University Press.
- Sen, A., & Dereze, J. (1991). *Hunger and public action*. New York: Oxford University Press.
- Severino, J., & Ray, O. (2010). The end of ODA (II): The birth of hypercollective action (CGD Working Paper Series, No. 218). Washington, D.C.: Center for Global Development.
- Shiffman, J. (2006). Donor funding priorities for communicable disease control in the developing world. *Health policy and planning*, 21(6), 411–420.
- Shiffman, J. (2008). Has donor prioritization of HIV/AIDS displaced aid for other health issues? *Health Policy Plan.*, 23(2), 95–100.
- Shore, C., & Wright, S. (1997). *The anthropology of policy: Critical perspectives on governance and power*. London: Routledge.
- Sidibé, M., Piot, P., & Dybul, M. (2012). AIDS is not over. *Lancet*, 380, 2058–60.
- Singer, P. (2010). *The life you can save: How to do your part to end world poverty*. New York: Random House.
- Smith, D. J. (2008). *A culture of corruption: Everyday deception and popular discontent in Nigeria*. Princeton, NJ: Princeton University Press.
- Smith, D. J., & Mbakwem, B. C. (2007). Life projects and therapeutic itineraries: Marriage, fertility, and antiretroviral therapy in Nigeria. *AIDS*, 21(Suppl 5), S37–41.
- Smith, J. H., & Whiteside, A. (2010). The history of AIDS exceptionalism. *Journal of the International AIDS Society*, 13, 47.
- Sontag, S. (1990). *Illness as metaphor and AIDS and its metaphors*. New York: Farrar, Straus and Giroux.
- Southall, R. (2003). Between competing paradigms: Post-colonial legitimacy in Lesotho. *Journal of Contemporary African Studies*, 21(2), 251–266.

- Sow Fall, A. (1981). *The beggars' strike, or, The dregs of society*. London: Longman.
- Sparke, M. (n.d.). Health. In R. Lee, N. Castree, R. Kitchin, V. Lawson, A. Paasi, S. Radcliffe, & C. Withers (Eds.), *The SAGE handbook of progress in human geography*. London: Sage Publications.
- Spiegel, A. D. (1991). Polygyny as myth -- towards understanding extramarital relations in Lesotho. *African Studies*, 50(1), 145–166.
- Stirrat, R. L., & Henkel, H. (1997). The development gift: The problem of reciprocity in the NGO world. *Annals of the American Academy of Political and Social Science*, 554 (The Role of NGOs: Charity and Empowerment), 66–80.
- Strand, P. (2010). Making accountability work for the AIDS response. *Global Health Governance*, 4(1).
- Swidler, A. (2006). Snycretism and subversion in AIDS governance: How locals cope with global demands. *Journal of International Affairs*, 82(2).
- Swidler, A. (2009a). Responding to AIDS in sub-Saharan Africa: Culture, institutions, and health. In P. A. Hall & M. Lamont (Eds.), *Successful societies: How institutions and culture affect health* (pp. 128–150). Cambridge: Cambridge University Press.
- Swidler, A. (2009b). Dialectics of patronage: Logics of accountability at the African AIDS - NGO interface. In D. C. Hammack & S. Heydenmann (Eds.), *Globalization, philanthropy and civil society*. Bloomington: Indiana University Press.
- Swidler, A., & Watkins, S. C. (2009). “Teach a man to fish”: The doctrine of sustainability and its effects on three strata of Malawian society. *World Development*, 37(7), 1182–1196.
- Tang, A. M., Forrester, J., Spiegelman, D., Knox, T. A., Tchetgen, E., & Gorbach, S. L. (2002). Weight loss and survival in HIV-positive patients in the era of highly active antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndrome*, 31, 230–236.
- Tangri, R. (1993). Foreign Business and Political Unrest in Lesotho. *African Affairs*, 92(367).
- Tarrow, S. (1988). *Power in movement: Collective action, social movements and contentious politics*. New York: Cambridge University Press.
- Taylor, T. N. (2010). “Because I was in pain, I just wanted to be treated”: Competing therapeutic goals in the performance of healing HIV/AIDS in rural Zimbabwe. *The Journal of American folklore*, 123(489), 304–28.
- Tendler, J., & Freedheim, S. (1994). Trust in a rent-seeking world: Health and government transformed in Northeast Brazil. *World Development*, 22(12), 1771–1791.
- Thomas, A. G., Tran, B. R., Cranston, M., Brown, M. C., Kumar, R., & Tlelai, M. (2011). Voluntary medical male circumcision: A cross-sectional study comparing circumcision self-report and physical examination findings in Lesotho. *PLoS ONE*, 6(11), e27561.
- Tilly, C. (2006). Political ethnography as art and science. *Qualitative Sociology*, 29(3).

- Tocqueville, A. de. (1994). *Democracy in America*. London: Everyman's Library.
- Touraine, A. (1981). *The voice and the eye: An analysis of social movements*. New York: Cambridge University Press.
- Touraine, A. (2000). *Can we live together?: Equality and Difference*. Stanford, CA: Stanford University Press.
- Tsikoane, T., Mothibe, T. H. ., Ntho, M. E. N., & Maleleka, D. (2007). Consolidating democratic governance in Southern Africa: Lesotho (EISA Research Report No. 32). Johannesburg, South Africa: The Electoral Institute for Sustainable Democracy in Africa.
- Treichler, P. A. (1999). *How to have theory in an epidemic*. Durham, NC: Duke University Press.
- Tsing, A. L. (2004). *Friction: An ethnography of global connection*. Princeton, NJ: Princeton University Press.
- Turkon, D. (2008). Commoners, kings, and subaltern: Political factionalism and structured inequality in Lesotho. *Political and Legal Anthropology Review*, 31(November), 203–223.
- Turkon, D. (2009). Modernity, tradition and nuances of class in Lesotho. *City and Society*, 21(1), 82–107.
- Turner, S. D. (2005). *The underlying causes of poverty in Lesotho* (January 12). Amsterdam, Netherlands: CARE.
- Turner, S. D. (2009). *Promoting food security in Lesotho: Issues and options*. Maseru, Lesotho: Priority Support Programme.
- UNAIDS. (2001). Local responses to HIV/AIDS: A strategic approach toward an AIDS-competent society. Geneva: Author.
- UNAIDS. (2002). *Keeping the promise: Summary of the Declaration of Commitment on HIV/AIDS*. Geneva: Author.
- UNAIDS. (2012). AIDSinfo. Geneva: Author. Retrieved October 18, 2012, from [www.unaids.org/en/dataanalysis/datatools/aidsinfo](http://www.unaids.org/en/dataanalysis/datatools/aidsinfo)
- UNAIDS & WHO. (2008). *Epidemiological fact sheet on HIV and AIDS: Core data on epidemiology and response Lesotho, 2008 Update*. Geneva: Authors.
- UNAIDS & The World Bank. (2009). *The global economic crisis and HIV prevention and treatment programmes: Vulnerabilities and impact*. Geneva and Washington, DC: Authors.
- UNGASS. (2007). *Lesotho UNGASS country report*. Geneva: Author.
- UNGASS. (2008). Lesotho UNGASS report: Status of the national response to the 2001 Declaration of Commitment on HIV/AIDS. Geneva: Author
- United Nations Development Program. (2012). Lesotho country profile: Human development indicators. Retrieved August 15, 2012, from <http://hdrstats.undp.org/en/countries/profiles/LSO.html>

- USAID, UNAIDS, WHO, & The POLICY Project. (2003). *The level of effort in the national response to HIV/AIDS: The AIDS Program Effort Index (API) 2003 Round*.
- Van den Boogaard, R., Slater, R., Gugushe, M., & Phakoana, M. (2004). *Review of the Government of Lesotho Emergency Response and suggestions for future programming to address food insecurity in Lesotho* (February). London: Review Task Force, Overseas Development Institute. Retrieved August 14, 2012 from <http://www.odi.org.uk/resources/docs/3962.pdf>
- Van de Walle, N. (2001). *African economies and the politics of permanent crisis, 1979-1999*. New York: Cambridge University Press.
- Vincent, J. (2002). *The anthropology of politics: A reader in ethnography, theory and critique*. Malden, MA: Blackwell Publishing.
- Ware, N. C., Hopper, K., Tugenberg, T., Dickey, B., & Fisher, D. (2007). Connectedness and citizenship: Redefining social integration. *Psychiatric Services, 58*(4), 464–474.
- Watts, M. (2001). Development ethnographies. *Ethnography, 2*(2), 283–300.
- Wedeen, L. (2002). Conceptualizing culture. *American Political Science Review, 96*(4), 713–728.
- Whaites, A. (1999). Pursuing partnership: World Vision and the ideology of development: A case study. *Development in Practice, 9*(4), 410–423.
- What makes me a Mosotho... (2007). *Topix Forum*. Retrieved October 6, 2010, from <http://www.topix.com/forum/world/lesotho/TGG1BP5S088GU2570>
- Whyte, S. R. (2009). Health identities and subjectivities: *Medical Anthropology Quarterly, 23*(1), 6–15
- Wikileaks hit Lesotho. (2011, October 25). *Lesotho Times*.
- Wilcken, A., Keil, T., & Dick, B. (2010). Traditional male circumcision in eastern and Southern Africa: A systematic review of prevalence and complications. *Bulletin of the World Health Organization, 88*, 907–914.
- The World Bank. (2009). *Averting a human crisis during the global downturn: Policy options from the World Bank's Human Development Network*. Washington, DC: Author.
- The World Bank. (2010). *Project performance assessment report, health sector reform project; HIV and AIDS capacity building and technical assistance project*. Washington, D.C: Author.
- The World Bank. (2012). *Lesotho*. Retrieved August 14, 2012, from <http://data.worldbank.org/country/lesotho>
- World Health Organization. (2003). *Treating 3 million by 2005: Making it happen; The WHO Strategy*. Geneva: Author.
- World Health Organization. (2004). *World health report 2004 - changing history*. Geneva: Author.

World Health Organization. (2005). *Summary country profile for HIV/AIDS treatment scale-up: Lesotho*. Geneva: Author.

World Health Organization. (2006). *From access to adherence: The challenges of antiretroviral treatment - studies from Botswana, Tanzania and Uganda, 2006*. Geneva: Author.

World Health Organization. (2008). Know Your Status Campaign review. Maseru, Lesotho: Ministry of Health and Social Welfare.

World Health Organization. (2012). *World Health Statistics*. Geneva: Author.

Zihlangu, B. (2012, March 28). "We are marked for death." *Lesotho Times*. Maseru.

## **Appendix A. Timeline of Political Shifts and Party Rule in Lesotho, 1950-2012**

### **1950-1960: Nearing the end of colonial rule**

The Basutoland Congress Party (BCP) emerges, calling for self-determination and the end of colonialism in Lesotho. Efforts to reduce the power of the colonial-backed system of chieftaincy.

BCP led by Ntsu Mokhehle.

### **1961 – 1965: Constitutional development**

King Moshoeshoe II appoints the Constitutional review Commission to develop plans for an independent state.

**1963:** the council submits its report, supporting a Westminster style constitution with a lower and upper house. The lower house is to be appointed through elections by universal adult suffrage, and the upper will consist of chiefs and some members nominated by the monarch. The constitution greatly constrains the king's power.

**1965:** In Lesotho's first elections, the Basotho National Party (BNP) wins an unexpected majority.

BNP led by Leabua Jonathan, enjoys support from South African government.

### **4 October 1966: Independence Day**

Lesotho gains independence.

### **1970 – 1985: BNP's authoritarianism**

**1970:** In the country's second elections, the BCP takes back a majority, drawing on disappointment from rural areas with the BNP's performance. But the BNP refuses to hand over power, with support from the South African government.

BNP continues to be led by Leabua Jonathan. He shifts alliances towards anti-apartheid forces.

BCP leader, Ntsu Mokhehle, remains in exile.

**1985:** BNP pressured into holding elections, threatens all other parties so severely that there is little competition, and declares an "overwhelming victory" for itself.

### **1986 – 1997: A decade of coups and chaos**

**1986:** Major General Lekhanya, with support from the South African government, leads a successful coup against Leabua Jonathan. South Africa blockades the border, angry at the growing ANC presence in Lesotho.

**1989 – 1990:** King Moshoeshoe II then challenges Lekhanya, and is given executive powers. Lekhanya then deposes the King, and the King abdicates to his son, King Letsie III.

**1991:** Colonel Ramaema topples Lekhanya in another coup. Civilian anger boils over, with rioting and factory strikes in Maseru and other towns. Ramaema agrees to a revision of the constitution, which takes two years.

**1993:** New elections take place; Ntsu Mokhehle, the long exiled BCP leader, wins a landslide victory.

**1993 – 1994:** More instability follows the elections. The army threatens to overthrow Mokhehle, and much violence follows. King Letsie III, angry at his limited political powers in the new constitution, suspends the government in a coup. He receives little support from Lesotho's neighbors, and the coup is soon over. Moshoeshoe II reinstated as king

**1996:** King Moshoeshoe II dies in a car accident. His son is reinstated as King Letsie III

**1997:** lead up to the general elections is marked by infighting in the BCP. Facing criticism, Mokhehle abandons his party and starts the Lesotho Congress for Democracy (LCD).

### **1998-2012: Attempts at democracy**

**1998:** LCD, led by Mokhehle, wins a landslide victory. Pakalitha Mosisili (LCD) appointed prime minister due to Mokhehle's failing health. Rioting breaks out, as opposition parties claim unfair elections. South Africa restores order.

**1999:** Interim Political Authority established to review electoral laws. Electoral system revised to ensure more proportional representation of opposition parties.

**2002:** LCD, led by Mosisili, maintains a considerable majority in elections.

**2006:** All-Basotho Convention, a new party led by Tom Thabane, is formed, having broken away from the LCD.

**2007:** Mosisili and the LCD still hold onto power in the elections.

**2011:** Mosisili perceived to have more and more authoritarian inclinations, but is losing support within his own party. Facing a no-confidence vote, Mosisili abandons his party and forms the Democratic Congress (DC) party.

**2012:** Prime Minister Mosisili finally overturned at the poll, as the ABC wins a slight majority in the elections by forming alliances with other opposition parties.



## Appendix B. Timeline of HIV-related events in Lesotho, 1986-2012

**1986**

- 1st HIV case identified in LS

**1987**

- National AIDS Prevention and Control Program (NAPCP) established within the Ministry of Health and Social Welfare (MOHSW)

**1988**

**1989**

**1990**

**1991**

**1992**

- AIDS Committees established in districts

**1993**

**1994**

- GoL Medium Term Plan (1994-1999) calls for multi-sectoral work on HIV/AIDS activities

**1995**

- 31.3% HIV prevalence rate reported among ante-natal clinic attendees at national referral hospital

**1996**

**1997**

- Number of people reported with full-blown AIDS quadruples between 1996 and 1997

**1998**

**1999**

- UN reports that 11.6% of university students in Lesotho are living with HIV
- HIV/AIDS policy framework developed
- National AIDS Strategic Plan (2000-2004) developed and endorsed by government

**2000**

- Prime Minister Pakalitha Mosisili declares HIV/AIDS a national emergency
- Irish Aid contributes 2.4 million Maloti for combating HIV/AIDS
- National Policy on HIV/AIDS Prevention, Control and Management announced
- Adoption of a Health Sector Reform Program which includes multi-sectoral approach to HIV/AIDS

**2001**

- Lesotho AIDS Programme Coordinating Committee (LAPCA) established, under Prime Minister's office.
- Principal Secretaries Task Force on HIV/AIDS established, to guide LAPCA
- National AIDS Committee established to advise LAPCA and NASP
- Ministries decide to allocate 2% of budgets to HIV/AIDS
- Multi-sectoral Task Force established as well as District AIDS Task Forces

**2002**

- HIV prevalence rate reaches 23.6%
- Vice Chancellor of national university addresses community on risks and impact of HIV/AIDS
- Prior to elections, most political parties mention HIV/AIDS in party manifestos

**2003**

- Prime Minister Pakalitha Mosisili receives gift of Nevirapine from Boeringer Ingelheim
- Launch of national PMTCT program by Prime Minister Pakalitha Mosisili
- Maseru host to SADC Conference on HIV/AIDS
- Assembly HIV/AIDS committee established to mainstream HIV into government activities
- Cabinet memorandum released, *Scaling up the Fight against HIV and AIDS in Lesotho*

**2004**

- Plan for ART scale up developed
- First Global Fund grant received, Round 2, for \$29 million
- World Bank HIV/AIDS Capacity-Building and Technical Assistance Project approved, for \$5 million
- Senkatana Clinic, the first ART clinic in the country, opened by Prime Minister in partnership with Bristol-Meyers Squibb
- *Turning a Crisis into an Opportunity: Strategies for Scaling Up the National Response to the HIV/AIDS Pandemic in Lesotho* published after adopted by cabinet as an official working document

**2005**

- National referral hospital gets its first CD4 count machine, the third in the country
- LENEPWHA formed
- National AIDS Commission Act passed
- National HIV and AIDS Forum established
- National AIDS Commission established
- HIV/AIDS Treatment Centre for Children opened in Maseru in partnership with Baylor College of Medicine and Bristol Meyer-Squibb
- Know Your Status Campaign announced on World AIDS Day

**2006**

- Phase I Round 5 Global Fund Grant approved for scale-up of care and treatment \$10 million
- Launch of the CHAI-MOH Rural Health Initiative
- Development and launch of National M&E Framework
- Passage of the *Legal Capacity of Married Persons Act*
- *National Blood Transfusion Policy* adopted
- Implementation of Child and Gender Protection Units (CGPUs) in Police Service

- Introduction of high school bursaries for OVCs
- Launch of National Action Plan on Women, Girls, and HIV/AIDS
- *National Adolescent Health Policy* enacted by MOHSW
- No. 5 Labour Code Amendment Act 2006: to make provisions for HIV and AIDS in the workplace
- Development of National Strategic Plan 2006-2011
- Ministry of Health and Social Welfare (MOHSW) develops the *National HIV and AIDS Testing and Counseling Policy*
- *National HIV and AIDS Policy* drafted and enacted by NAC
- Institutionalization of the Gateway Approach to decentralize the response to HIV/AIDS
- Bono visits Lesotho to promote Red campaign and to support the launch of ALAFA
- Bill Clinton, Bill and Melinda Gates, and Steven Lewis undertake joint visit to Lesotho
- Launch of the Know Your Status Campaign (KYS)

## 2007

- Phase II of Round 5 Global Fund Grant begins for \$5.8 million
- EU grant 11 million Euros received for OVC programmes
- Signing of World Bank-GoL-Netcare Public-Private Partnership agreement for new tertiary referral hospital, worth \$113 million.
- Round 6 Global Fund Grant for \$5.5 million approved
- National consultations convened in preparation for AIDS Bill
- National Operational Plan 2007-2008 developed and adopted
- Protection of OVCs against property-grabbing instituted by Master of the Court
- HIV/AIDS Committees established in National Assembly and the Senate.
- *Education Sector Policy on HIV and AIDS* developed by Ministry of Education and Training
- National Coordination Framework adopted
- National HIV and AIDS Partnership Forum launched
- Joint review of PMTCT programs, Introduction of plan to scale-up PMTCT programme
- Institutionalization of umbrella bodies for all civil society organizations
- Thematic working groups for Programme Management, HIV Prevention, Treatment, Care and Support and Impact Mitigation were formed and operationalized
- 21 Line ministries, departments or agencies trained on HIV/AIDS and developed action plans for mainstreaming HIV within their sectors.
- Ministry of Gender, Youth and Sport launches *National Action Plan on Women and Girls and HIV/AIDS: Facing the Future Together*
- Launch of Essential Services Package (ESP) and start of 128 community councils implementing the ESP on HIV/AIDS at community levels.
- Church leaders sign Statement of Commitment to focus on HIV and AIDS
- ALAFA Launched

## 2008

- Round 7 Global Fund grant agreement signed for \$18 million
- Mid-term review and revision of National HIV/AIDS Strategic Plan
- Roll-out of life-skills curriculum in primary, secondary schools
- *Modes of Transmission Study* completed
- Launch of Red Ribbon Media Award
- Launch of the Child Help Line
- UN launches Joint UN Programme of Support on AIDS in Lesotho: Delivering as One

## 2009

- Approval of Millennium Challenge Account support for \$362.6 million over five years
- GOL-PEPFAR Agreement for support worth \$27 million a year for five years
- Renewal of World Bank \$5 million grant for HIV/AIDS Technical Assistance Project

- Approval of Global Fund Round 9 grant for \$8 million
- Global Fund Round 8 grant for \$50 million agreed
- Global Fund Round 8 grant Phase 1 for \$6.8 million agreed, Lesotho Council of NGOs appointed as Principal Recipient
- National Behavior Change Communication strategy developed and launched
- Passage of Legal Capacity of Married Persons Act
- District and Community Council AIDS Committees established
- Training and Capacity Building on HIV/AIDS Competence and Mainstreaming for the Private Sector and Civil Society Organizations
- Initiation of full decentralization of ART and TB treatment to 200 health centres

## 2010

- Global Fund Round 8 agreement to support MDR/XDR-TB and HIV management signed for \$7.7 million
- Enactment of Child Protection and Welfare Act
- Harmonization and development of the workplace policies and strategic plans by public, private, civil society actors and implementing partners
- National Affirmative Action Plan for Gender, HIV and AIDS for Women and Girls launched
- National HIV Prevention Strategy developed
- Lesotho Output Monitoring System for HIV and AIDS (LOMSHA) developed and rolled out to 10 districts
- KYS evaluation undertaken and completed
- Second Demographic and Health Survey completed
- Initiation of National Health Decentralization Plan
- DFID ends future support to Lesotho for HIV/AIDS programs
- Internal audit of NAC undertaken, with subsequent cutbacks in funding
- Global Fund Round 10 proposal rejected, first Global Fund proposal denied

## 2011

- New MOHSW prevention strategy announced
- Irish Aid announces no longer supporting HIV/AIDS programs in Lesotho
- NAC National Partnership Forum held to review National HIV/AIDS Strategic Plan 2006-2011
- NAC dissolved

### Appendix C. Community Council HIV Priorities

| <b>HIV Priorities from 128 Community Councils in Lesotho</b>  | First Priority (%) | Second Priority (%) | Third Priority (%) |
|---|--------------------|---------------------|--------------------|
| <b>Objective 1: Prevention Through Change in Sexual Behavior</b>  |                    |                     |                    |
| Male-focused discussions  | 29.6               | 20.8                | 8                  |
| Facilitation of regular activities for youth such as football, volleyball, dance groups, drama groups and life skills groups                            | 26.4               | 18.4                | 22.4               |
| Distribution of male and female condoms and proper usage education  | 20                 | 20                  | 10.4               |
| Building the capacity of traditional community leaders in HIV and AIDS and in implementing related initiatives  | 11.2               | 14.4                | 18.4               |
| Parent involvement in shaping the behavior of children on HIV and AIDS related issues   | 8                  | 15.2                | 8.8                |
| Registration of initiation schools and facilitating adherence to best practices within the schools  | 4                  | 8                   | 18.4               |
| Building the capacity of church leaders in HIV and AIDS and in implementing related initiatives   | .8                 | 2.4                 | 8.8                |
| Facilitating the capacity building of business leaders in HIV and AIDS and in the implementation of related activities                                  | 0                  | 1.6                 | 4                  |
| <b>Objective 2: Access to HIV Testing and Health Services</b>   |                    |                     |                    |
| Support mechanism for critical patients to [access] hospital/health facility (council to agree on the mechanisms)                                       | 25.6               | 27.2                | 17.6               |
| Registration of chronically ill patients  | 24.8               | 20                  | 14.4               |
| Facilitate and ensure provision of HBC supplies and gloves and limited training to registered HBC groups  | 24                 | 20.8                | 27.2               |
| Registration of home-based care (HBC) support groups  | 9.6                | 11.2                | 11.2               |
| Facilitate and ensure training of at least one health facility worker per facility to do HIV counseling and testing                                     | 8.8                | 8.8                 | 12                 |
| Facilitate provision of testing kits to trained community HIV&AIDS counselors   | 7.2                | 12                  | 11.2               |
| Advocacy for provider-initiated testing at health care facilities   | 0                  | 0.8                 | 4                  |
| <b>Objective 3: Prevention of Mother-to-Child Transmission</b>  |                    |                     |                    |
| Provide training to at least on health facility worker per facility to do PMTCT and testing and ART/PEP support   | 36                 | 18.4                | 16                 |
| Train CHWs to test and support prevention of mother-to-child transmission   | 33.6               | 28.8                | 24                 |
| Establish referral system for emergency delivery for mothers  | 16                 | 29.6                | 36.8               |
| Conduct door-to-door / community education campaigns and male involvement on PMTCT + exclusive breastfeeding  | 16                 | 22.4                | 21.6               |
| <b>Objective 4: Orphans and Vulnerable Children</b>   |                    |                     |                    |
| Registration of orphans and vulnerable children   | 38.4               | 17.6                | 8                  |
| Ensure that registered orphans and OVCs have access to basic services such as education, nutrition and food security and health care                    | 33.6               | 37.6                | 20.8               |
| Capacitate and empower Councilors, Chiefs and community members in protection of orphans and vulnerable children and ensure access to required services | 16                 | 26.4                | 45.6               |
| Facilitate counseling services for orphans and OVC including support/play therapy   | 12.8               | 16.8                | 24.8               |

| <b>Objective 5: Support for People who are HIV+</b>  |      |      |      |
|--|------|------|------|
| Sponsoring HIV+ facilitators to do door-to-door, community gatherings and small group meetings /speeches/discussions on living positively with HIV/AIDS, stigma and discrimination | 30.4 | 32   | 24   |
| Placement of one "expert" or HIV+ patient at each health facility  | 27.2 | 14.4 | 14.4 |
| Organized transport for patients, treatment supporters and medications pick-up to hospital / health facility   | 25.6 | 23.2 | 25.6 |
| Training of and sustaining of treatment supporters for PLWHA on ART  | 16.8 | 28.8 | 33.6 |