

UNMAKING ACTIVISM:
POLITICAL AND PRACTICAL AIDS PATIENTHOOD
IN NORTHERN MOZAMBIQUE

By

Joel Christian Reed

A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Anthropology — Doctor of Philosophy

2016

ABSTRACT

UNMAKING ACTIVISM: POLITICAL AND PRACTICAL AIDS PATIENTHOOD IN NORTHERN MOZAMBIQUE

By

Joel Christian Reed

This dissertation is about the side effects of HIV/AIDS treatment activism, its dysfunction and legacy in Mozambican everyday life. Working with AIDS support groups in northernmost Cabo Delgado Province, I problematize the utopian depiction of patient groups as a forum for infusing political subjectivity. Prone to internal conflict and hijacking by careerists, members compete for resources and inclusion in formal development projects. This antagonizes the relationship between civil society and the communities it presumes to serve, fostering distress and instability between and among groups. Poor treatment adherence and biomedical skepticism, alcoholism, and economic desperation pose serious obstacles to social solidarity and progress. In the name of “health systems strengthening” and the “decentralization” of clinical services, AIDS-specific treatment centers known as “day hospitals” were closed down nationwide. The discouraging state response to organized protests exposed the fragility of a rights-based approach to political oppression, suggesting that the broadly resonant “master frame” associated with AIDS activism—more treatment, for more people, in more places—has been successfully absorbed into wider governance structures.

No longer victims in global health parlance, the patient voice has become diluted and devalued. Allowing itself to be defined by political process theory, I argue, AIDS activism has become unmade. A focus on its emergence, rather than the viability of its forms and strategies, has created an academic blindspot, contributing to activism’s obsolescence, and relocating it from streets and communities into multinational institutions and the offices of government

contractors. Due to selection bias and a poor diversity of case studies, anthropology finds itself enamored with sweeping and invariant models of social movements. Ethnographic data presented here suggest that political involvement and demands for treatment alone are insufficient for sustainable patient mobilization, and that we may not be learning about biosociality from enough sources. Creating a safe haven for the common HIV/AIDS patient begs renewal of the concept of therapeutic community, and a reformulation of patient rights that is more practical than radical, and more local than transnational.

Copyright by
JOEL CHRISTIAN REED
2016

To sufferers of chronic illness—
viral and otherwise—
sempre estamos juntos

ACKNOWLEDGEMENTS

This is the culmination of a long history of experiences in Africa that began in 1999. Since I first set foot on the continent, in Zambia with a cohort of fellow Peace Corps volunteers, I'm not entirely certain that I've ever really left, at least not concerning matters of the heart. Set in motion was a slow, but constant and progressive, detachment from self and embrace of the 'other' that, upon close inspection, seems like it *had* to happen. Villagers of Kapundu, I pray for you often. We bonded by chance. Thank you for the *storgē*, for shaping my conscience, keeping me safe, and teaching me how to survive just about *anywhere*. For my family, apologies for the missteps. We bonded by design. Thank you for the *agape*, for shaping my personhood, fixing the breakage, and teaching me how to survive just about *anytime*. For everyone involved in my conversion, some realize and others don't the absolute value of our connectedness. We bonded by providence. Thank you for the *philia*, for shaping my soul, for the authentic witness, and teaching me how to survive just about *anything*. For Anne Ferguson and all of my committee members past and present, whose protection and advice has been angelic, I owe you all much more than you know. Thank you for the patience, for shaping my mind, and lighting the path. To those in Mozambique, without whose reckless kindness my life would be even more impoverished, perhaps we will meet again. When we do, we'll laugh a lot and cry a little, just like before. *Por favor, olha para o futuro, e vai com Deus.* Antonio, Mwako, rest in peace. For the rest of us, *a luta continua*.

PREFACE

The impersonal hand of government can never replace the helping hand of a neighbor.

~Hubert Humphrey

The same thing that makes the rural population live on tradition makes the urban population live on rumour.

~G.K. Chesterton

Always do a little work. The wise man praises the valiant woman. Her fingers, he says, worked the spindle. Your distaff is the sum of your desires. Spin a little therefore every day; make your design thread by thread till they are all used up and you shall infallibly see their completion. But see that you do not hurry, because you might twist the thread with knots and you would entangle your spindle. Work, therefore, and though you keep on advancing slowly, you will nevertheless go a long way.

~Saint Padre Pio

Revolution begins with changes in the individual.

~Jenny Holzer, Truisms

TABLE OF CONTENTS

LIST OF FIGURES	x
KEY TO ABBREVIATIONS	xi
Chapter 1-Introduction.....	1
Central Research Questions.....	10
Ethnography – Reassembling the Support Group.....	11
Fashioning AIDS Activists - Biosociality and Biopolitics	19
Chapter II-AIDS Treatment and Activism in Mozambique	30
Welcome to Caridade.....	30
Demands for Treatment.....	34
Day Hospitals and Therapy.....	40
First Impressions – Getting to Know Caridade.....	46
AIDS Associations, Socialist Legacies.....	57
Chapter III-AIDS Associations in Cabo Delgado Province.....	62
Introduction	62
Of Offices and Organigrams.....	63
Reputations – Meetings, Conflict, and Slander	70
Standardized Civil Society	83
‘Little’ Protests and the Workshopocracy	91
Civil Society Existentialism.....	96
Chapter IV-Challenges to AIDS Activism in the ‘Subuniverse’ of Cabo Delgado	101
“Common” Activists.....	101
Lingering Confusion about AIDS and Activism	105
Ineffective Home-Based Care Programs.....	110
Treatment Illiteracy and Abandonment	120
Alcoholism and ART Patients.....	134
Still Missing - Practical Activism for the Man in the Street.....	144
Chapter V-The (Dis)Integration of the Day Hospitals	148
Protests in Pemba	148
Day Hospital Closures	153
Health Systems Flattening – the Failed Promises of Decentralization.....	166
“Slacktivism” and Rabble Rousing in Northern Mozambique	177
The Knife in a Gun Fight – AIDS Treatment Activism after Health Systems Strengthening.....	187
Chapter VI – Unmaking Activism	192
Biosociality as Civilizing Mission	192
Caridade’s Final Election.....	203
Where Now Are the Biological Citizens?	210

BIBLIOGRAPHY	218
--------------------	-----

LIST OF FIGURES

Figure 1: Map of Mozambique, Pemba Circled	14
Figure 2: Formally Registering a Civil Society Association	86
Figure 3: Levels of an Association	87
Figure 4: Rights and Responsibilities of Associations	88
Figure 5: Action Plan for Change in Associations	89

KEY TO ABBREVIATIONS

ACT UP – AIDS Coalition to Unleash Power

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral Therapy

ARVs – Antiretrovirals, Antiretroviral pills or medication

CD4+ – T-cells, helper cells, also refers to a common laboratory test (CD4 count)

CDC – Centers for Disease Control and Prevention

CNCS - *Conselho Nacional de Combate ao SIDA* (Mozambique’s National AIDS Council)

EGPAF – Elizabeth Glazer Pediatric AIDS Foundation

FRELIMO – Frente de Libertação de Moçambique (Mozambique Liberation Front, Mozambique’s ruling party)

HIV – Human Immunodeficiency Virus

MATRAM – Mozambican Access to Treatment Movement

MISAU - *Ministério de Saúde* (the Mozambican Ministry of Health)

MONASO - Mozambican Network of AIDS Service Organizations, a government NGO

MSF - Médecins Sans Frontières, or Doctors Without Borders

NGO – Non-governmental organization

Núcleos - *Núcleos Provinciais de Combate à Sida* (Provincial AIDS Offices)

PEN - *Plano Estratégico Nacional de Combate ao HIV/SIDA* (Mozambique’s National Strategic Plan to Combat HIV/AIDS)

PEPFAR – President’s Emergency Plan for AIDS Relief (an American AIDS treatment initiative)

PWAs – People with AIDS

RENSIDA – *Rede Nacional das Pessoas Vivendo com HIV/SIDA* (National Association of People living with HIV/AIDS)

UNAIDS - Joint United Nations Programme on HIV/AIDS

USAID – United States Agency for International Development

TAC – Treatment Action Campaign

WHO – World Health Organization

Chapter 1-Introduction

“My husband was a big drunk. We point to him as an example of how *not* to behave,” replied Fatimah to my question concerning people who stop taking their AIDS medications in her support group. Fatimah is the president of her group, the second “AIDS association” formed in Cabo Delgado Province, called *Ajuda à Próxima* (Help your Neighbor). The group is a recipient of project donations from the government in the form of farming implements, seed for planting, a plot of land, several goats, and a chicken coop. Fatimah’s husband, also HIV infected, had recently died. “He was on a drinking binge,” she told me, “leave home early, and come home late. He stopped [treatment] for 27 days before he finally died last January. He had the human right to *not* take his pills, you know.” I frequently heard ‘human rights’ statements like this in Pemba that seemed out of place. One patient told me he had the human right for the government to buy him a house, another, to get a monthly stipend for being HIV positive. Another man said he had the human right to divorce his wives, which he had done on seven separate occasions, each time marrying a younger one and paying the appropriate bride price. This reflected the common belief that sex with a virgin could cure someone of HIV infection.

Fatimah continues. “Now that he’s gone, I’m doing my own experiment.” I leaned forward a little, expectant and wide-eyed. “My health is improving and my CD4 is normal,” she says, “and I don’t miss a single pill. Sex with my husband was reinfecting me! It made my viral load increase, and I felt sicker. Without our sex together I’ve had no reinfection and am starting to feel better.” It took a moment for me to realize that the experiment she referred to concerned her own chastity, so I didn’t challenge her conclusions. “But there are always problems, you know. The problem now is that these pills make me forget things all of the time.” She glanced down at her cell phone and keys resting on the glass table between us as if she was worried about them, then

looked back up at me. Patients often complain about medication side effects. Forgetfulness isn't all that common, but probably preferable to some of the other ones, like persistent fatigue or nausea. Seated with Fatimah in the lobby of Hotel Cabo Delgado on comfortable chairs seemed a far cry from her village, about 20 kilometers away. My interviews with others in her support group occurred on wooden stools in their abandoned chicken coop, which, now that the chickens had all died was isolated enough to be considered a safe enough place to answer AIDS questions from an inquisitive white foreigner. The chicken coop, also the missing goats, and the overgrown plot of land that produced no food were all evidence of failed support group projects, hardly morale boosters for patients who had hoped, as the promise went, to 'generate' their own income.

I was happy to finally meet Fatimah because I had heard a lot about her. She was considered a great leader. Several members of her AIDS association told me she saved their life, taught them how important it is to take the pills, and encouraged them to have patience with their families and others in the community who 'talked bad' about AIDS and the people who have it. Fatimah was in Pemba City for a government-hosted training to educate support group leaders on the new "Law 12/2009," related to the rights and responsibilities of people living with HIV/AIDS in Mozambique (República de Moçambique 2009). There were quite a lot of trainings for AIDS associations lately, an effort to manage the burgeoning number of such groups in the country. When I first came to Pemba in 2007 there was one AIDS association in the province. Two years later there were twelve officially registered with the government, and several others that were attempting to do so. On one hand, the new law seems well timed, coming along with government efforts to distribute treatment in more clinic facilities and locations than ever before. On the other hand it seems tardy. Article 4 of Law 12/2009 guarantees the right to free treatment in the country, but anti-retroviral medication (ARVs) had already become much more accessible over the past five or six years in places far from Maputo, places like Pemba, in the Provinces. This

happened particularly quickly through the “day hospitals,” or AIDS specific treatment facilities with their own pharmacies, health care staff, and waiting areas. Another component of Law 12/2009 also requires patients to comply with their treatment regimens, a stipulation that provides good guidance, but hardly seems enforceable.

Just then, Fatimah said something else unexpected. “You know, [AIDS] patients go and fuck whoever. The association has a big problem with this—policing sex. You just can’t monitor these things, it’s too difficult.” On the table between us her cell phone buzzed and she excused herself to take the call. After a quick discussion she put it down again and said “this man who keeps calling...he wanted to ‘cleanses’ me after they buried my husband. I was freed from this tradition, because of my HIV status. Everybody knows about this, but this man, he still wants to try anyway.” Widow cleansing is a cultural practice in many parts of Africa. It involves sexual activity between one or more relatives of the dead man and the surviving wife in an effort to stake a claim, in order to break the spiritual bond or any remaining supernatural attachment between the dead man and his wife. “Normally, anyone who wanted to pay could have done this. There were many of them. I took some men to the hospital and did a [HIV] test for them so they would stop asking, but this one [calling her on the phone], he won’t stop.” I asked no further questions about this. No other interview participants had mentioned widow cleansing before, but then again, Fatimah was not a typical interview participant. Completely comfortable, unreserved, she was also the largest Mozambican woman I had ever met, easily over 230 pounds—a desirable feature for most men. A decade ago HIV was known as ‘the thinning disease’ in southern Africa. Treatment has certainly changed that classification. Not only do people generally retain their weight, they often gain some as well.

Her cell phone buzzed again, and she picked it up to type a message. “Now most people use condoms to do the cleansing, or just let the sperm fall outside of the female,” she stated rather

lackadaisically, distracted and staring into the phone screen. She locked stares with me again. “Women are weaker than men, you know? Biologically, our CD4 is very undeveloped...we all suffer a lot. My husband’s CD4 was always lower than mine, but I had more symptoms. I never understood this. ” The interview was almost over. “You should keep going with your reports. Tell them there in your country that we want a vaccine. The government has to find a cure so that our children don’t grow up with this virus.” I thanked her and began to pack up my things when Fatimah cast her gaze to a man who had just come up the stairs and was looking around the lobby. She said goodbye to me, got up, and went to greet him. This was the man who was calling and texting her phone, the one who had wanted to ‘cleanse’ her back in February. They started together down the stairs to leave the hotel, and I couldn’t help wondering if this was some sort of date. I noticed then she had left her keys and phone on the table. Her side effects must have kicked in again. I picked up the items, shouted her name and ran down the stairs after her. As I handed them over, she smiled at me one last time before they went out onto the street.

Before his death her husband had been a co-founder of Ajuda à Próxima. They had started the support group together, facilitated meetings, and recruited new members. Trained in how to conduct home-based care for other AIDS patients, and a regular attendee at the day hospital, he was aware of what would happen to him when he ceased to take his pills. He and Fatimah had come to revelation about their condition together, and saw rapid improvement in their health as they began their pharmaceutical treatment. Not even Fatimah could explain why he did what he did. It wasn’t for lack of food, the most common complaint patients have—Mieze is a farming village. It wasn’t poor clinic access—healthcare staff, aware of what he was doing, had even brought pills to his front door. This man’s decision wasn’t a rational one, but it was a conscious one. He had *let* AIDS kill him. Everyone, including Fatimah, watched it happen, but couldn’t change his mind. With all the support available to him—the clinic, the group, his own activist

wife—what else could possibly have been done to save this man’s life? Perhaps the prime suspect in his killing was the *nipa* he drank constantly as his health slipped away—the clear, corn-based moonshine that is a cheap and available option in towns and villages all over Mozambique. In my own AIDS association, Caridade in Pemba City, I saw the same process unfold with numerous group leaders and members.

The *nipa*, however, points to another set of problems, the preexisting conditions that medicine can’t address. The patient reflects these, serving as a mirror, a living representation, an example of society’s challenges to care for itself. He is the “suffering body of the city” (Marcis and Inggs 2004). It is becoming obvious that treatment alone, access to biomedical healthcare—the mantra of political AIDS activism—is not sufficient for a total restoration to health for some patients. Technoscience has its limits, and the dissemination of *some* kinds of moral messages needs to accompany it in order to move beyond them. This is a sensitive topic for anthropologists, who look upon the deployment of certain terms, images, and concepts with immense skepticism—particularly if they result in the molding of populations into efficient and adaptable subjects. We had to be careful about this, especially at first in the AIDS era. The imposition of risk categories—homosexual, Haitian, poor, African—threatened to displace the exposition of structural violence occurring en masse (Farmer 2006). There was a strong sense that victims were getting blamed for being victims in the early days of the pandemic (Sabatier 1987). Anything less than treatment access, for getting drugs into bodies, was viewed as woefully inadequate. Just prevention, just education, or just trainings were considered mere distractions. Now that there is widespread consensus and focus on the issue of universal treatment coverage, it’s clearer that the support group, an actor and entity all its own, has not received enough attention and remains underdeveloped. An understanding of activism’s after effects is not well elucidated.

Mozambican AIDS associations are examples of the after effects of activism. Called into existence well after the introduction of treatment into the public square, they agitate the presumed link between activism and treatment access, and represent a social contract between state and citizen. Patients join AIDS associations not because they fear death. Medication is available to anyone who visits the clinic. Patients join AIDS associations because they want, or have been promised, something extra—involvement in a project, a handout or payout, a job or a salary. These associations are wondrously ambiguous. They are supposed to act like little NGOs, but also as spaces for emotional support and advice. They are supposed to apply for project funding, but also be self-sustaining and collect membership dues and fees. They are supposed to create their own action plans, set goals, and adhere to fiscal budgets. Yet, they must also deliver on the demands of their partners, provide cheap labor, and answer to the needs of NGOs or state programs relying upon them for data collection and service delivery. They are supposed to be open to anybody for membership, but still remain patient-centered, and choose leaders to make decisions for them in a presumed atmosphere of egalitarianism. The bureaucracy involved in running and participating in an AIDS association is reasonable for a secondary-school educated Mozambican, but just complicated enough to preclude subsistence farmers, or those living in isolated, rural areas, from getting involved and seeing any tangible results from it. Some members get paid, others don't. The interactions that occur at the group level can generate solidarity, along with greed and jealousy. These AIDS associations are shining examples of neither civil society nor a therapeutic community, yet contain the seeds of both. They are uniquely Mozambican, pieced together from components of a socialist past, nominally 'of the people,' yet also hearken to the global community of AIDS patients that social scientists praise and tout as naturally occurring, ubiquitous, and unstoppable.

Anthropologists are now beginning to note the trouble with portraying AIDS civil society as utopian in nature (Bähre 2007; Marsland 2012; Le Marcis 2012). Initial enthusiasm about patients coming together in protest against poor drug availability and perceived unfair government policies sparked a high level of interest in the concept of social solidarity. Famous examples of this emerged in the headlines and drew worldwide attention—ACT UP in the United States, TAC in South Africa—that portrayed AIDS patients as a united front, politically combative ideologues formed and shaped by overly bureaucratic institutions whose inaction was letting people die unnecessarily. To describe the phenomenon theorists latched onto the idea of biosociality, a concept that emphasizes patient mobilization and highlights the formation and activity of groups of people who identify with one another based on a common genetic or biomedical illness. Patients latched onto the idea of human rights, positioning AIDS treatment as foundational to the physical and mental well-being of high numbers of people and thus covered under international treaties and agreements, of which most African nations are signatories. The struggle for AIDS treatment, in this light, was a political one, a function of overcoming stigma and seeking inclusivity in healthcare and government programs.

The AIDS patient support group was supposed to be a breeding ground for this approach, a site for the stimulation of demand and the realization of benefits owed to affected persons on the part of states and institutions responsible for their protection and welfare. From this perspective, it is social recognition, from the state or similar authority, which mitigates powerlessness. It is social recognition that legitimates the person and his group, drawing attention to the issue, inviting concern, assistance, and intervention. Social science has labeled this *biological citizenship* (Rose and Novas 2005; Petryna 2013), the claiming of resources as recompense for a chronic illness or genetic condition through appealing to objective or expert evaluation in order to save life or meet basic needs. The results of this can manifest in a number of different ways. In a perfect

world it would level the playing field, allowing those most severely impacted to live as healthily as possible. It would speak to the fruits of patient advocacy, overturning misconceptions and dispelling ignorance. It would also legitimate efforts at empowerment and facilitate fellowship amongst those affected. AIDS patient support groups were supposed to be the site for the practical application of activism, holding government accountable, taking charge of their lives, managing the impressions that others have about them and offsetting stigma. In popular imagination, these groups came to be recognized as something both old and new, civil society but with humanitarian features, a privileged kind of social movement, deserving of encouragement and even financial support—if they fulfilled the roles set out for them.

This dissertation is primarily about dysfunction—of AIDS associations, of the utility of rights-based demands and calls for social transformation. Expectations about political AIDS activism first made AIDS patienthood cogent, then led to yet another example of “dysappearing bodies” (Imrie 2001)—patients appear to disappear into the framework of national health systems. Once taken for granted, everywhere highly visible, AIDS activists have now demanded themselves out of existence, barely able to claim special privileges anymore. AIDS activism, its short term goals, its consumability and expendable nature, manifested itself in Mozambique as just another kind of “governmentality” (Lemke 2001; Ingram 2010; Foucault 2010), allowing for the imposition of certain morals, attitudes, and modes of living onto entire groups of people without their obvious and active consent. Gone are the grassroots ‘movements.’ Still remaining are the multinational institutions and bureaucracies that rose up around them. Now part of an antiquated system, the Mozambican AIDS associations never really achieved what they wanted, which was to participate in the AIDS industry, to be fully vested in the programs taking place around, for, and with them. They were provided a model with which to do this, and it did not suffice. The reasons why are informed by the contours of history and the parameters of a global health industry that leaves no

corner of the world untouched. During my time with Caridade¹—the group that took me in, allowing me to live and work with them as if I were a member myself—AIDS activism in Mozambique rose and fell, decidedly, in relation to the operation of the AIDS-specific treatment clinics called day hospitals. The response to the closure of these centers, with patient-activists losing the “fight,” exposed the fragility of a rights-based approach to AIDS activism as well as its entrenchment in mostly foreign modes of thought.

Delving further into the life cycle of the group itself, and those which splintered off from it, problematizes the relationship between the group and the community it claims to represent and serve. Extremely relevant is the fact that AIDS patient-activists were state and NGO funded, expected to officially register, attend trainings and workshops, and carry out projects. Even as this goes on today, some very basic and standard problems persist in Mozambican society which complicate hopes for lasting success. Poor treatment adherence and biomedical skepticism, alcoholism, familial strife and economic desperation all pose serious obstacles to the potential for unity or social progress commonly ascribed to the forward thinking AIDS patient and his or her support group. What I will conclude is that if biosocial collectivities and biological citizens do indeed exist, if these concepts are universal and good, then perhaps the impetus and drive to consult widely outside of their social groupings in order to solve their own problems is not. The success of the group may not, in fact, derive from social recognition—this is the hypothesis that I intend to test. Detachment and avoiding interruption, helping members to manage their old lives rather than forge new ones, these are the battle-tested tactics for crisis intervention that AIDS patients who needed them most never had the opportunity to sample. Avoiding and helping others avoid disease relapse, and embracing private rather than public commitment to a cause,

¹ I worked with 8 different AIDS associations in Cabo Delgado Province. Names of associations have been changed to protect their identity. Names of informants, likewise, have been changed for purposes of confidentiality.

are likely the least developed elements of AIDS activism. The weakness and, at times, absence of these basic and desirable elements of the support group prohibits its meaningful sustainability.

Central Research Questions

What is the role of HIV/AIDS activism and advocacy in the lives of patients in Northern Mozambique? Some patients in this region organize themselves into support groups in order to share their experiences with this condition. Do the associations cultivated among them represent a moral and therapeutic struggle, or the extension of technocracy? Does their existence and proliferation signify collective resistance to or amelioration of the stigma, poverty, and feelings of powerlessness often associated with AIDS patienthood, or are they forums for the ambitions of a privileged few and the techniques of neoliberal governance? Social science theory on this phenomenon hovers around the concept of biosociality, a term emphasizing the exchange of information and technologies on the part of chronically ill persons in order to cope with the effects of illness. From this perspective, patient support groups can be therapeutic communities and sources of healing. Yet, these groups often also seek benefits from the state and its partners and inclusion into NGO economies.

Within anthropology, the study of persons who leverage disease diagnoses in order to access resources from the welfare state further designates them as biological citizens. In many settings people seek official disability status out of financial interest. Depending on what resources are available and how they are obtained this can unhinge patienthood from programmatic benefits, leading to exaggerated or even false claims of eligibility or need. In Mozambique, where testing positive for HIV yields access to treatment but not always the resources necessary for survival, is AIDS activism, when connected to material gain, likewise subject to predation? Does careerism within civil society imbalance its potential for furthering human rights, or even basic medical progress? Problematizing these questions is the relationship between the governing and the

governed, the regulator and the regulated. In Africa there are high rates of program dropout for those enrolled in treatment. From this perspective, the success and survival of global or humanitarian initiatives depends just as much upon the patients as the patients depend upon them. What are the results of programmatic interventions when patients are poorly consulted about service and treatment delivery models which affect them? Here I address the integration of AIDS treatment clinics, known as day hospitals, into Mozambique's national health system. Activists lost the fight to maintain their own clinics, amidst government and expert claims that the model wasn't working. Nominally involved and participating in their own treatment, to what extent can patient-activists successfully make demands upon a state which in turn depends upon international actors and external processes of decision making in its capacity to care for and protect its citizens from this epidemic?

Generally speaking, and within a long history of public sector AIDS treatment provision, if civic groups initially had an important role to play in abrogating poor treatment access, to what degree does there exist an indigenous or natural version of activism originating in the minds and lives of individuals themselves? This question becomes particularly salient in post-socialist Mozambique, where the orientation of support groups—known as AIDS Associations—has predominately been state-chaperoned and non-oppositional, based on the agricultural farming cooperative model laid out by the ruling party just after independence. Is it possible that civil society AIDS activism, while not as associated with treatment access, solidarity, or community representation as previously thought, nevertheless potentiates immense psychological value for those who still require it and need it the most?

Ethnography – Reassembling the Support Group

Answering these research questions involves a task that is simultaneously simple and complex, the examination of a particular 'slice' of a society—the AIDS patient support group—as

if it were both a discrete unit of measurement but also a multifaceted web of persons and their relationships. This is an exercise in identifying what set of 'rules' the support group obeys. Is it autonomous and able to define itself, bound more or less by the very same principles which guide any other aspect of culture and human relations? Or, does it demonstrate the presence and influence of something 'new,' suggesting that other unique factors are at work? That might mean that the support group possesses specific properties, ones which set it apart from being purely social, and maybe even redefines the terms for what should be considered 'purely social' to begin with. Other anthropologists working in this topical area have claimed as much (Nguyen 2007).

AIDS activists, in this view, comprise "much more than a new social movement pre-articulated around explicit objectives," argues Nguyen. Those on treatment make up "a vanguard...a complex biopolitical assemblage, cobbled together from global flows of organisms, drugs, discourses, and technologies of all kinds" (Nguyen 2007: 125). If that is the case, then perhaps the anthropologist, with a wide angle lens and academic insight, is privileged, finding him or herself in a position to decode, demystify, and explain these groups and these people better than they themselves can (Robins 2006). There is ritual here, we are told, which can escape them. For example, AIDS patients may experience a rite of passage, which takes place within and through the group as people espouse and live out the techniques relevant to restoring health. According to some, the patients themselves don't recognize this. Robins (2006:313), working with AIDS activists affiliated with South Africa's Treatment Action Campaign (TAC), contends that they "cannot grasp the radically transformative character of the new biosocial subjectivities and HIV-positive identities" that spring forth of their own accord, unbridled and inherent, as it were, and waiting to be documented, described, and categorized in books or articles (and dissertations).

When I entered the field it was my second time in Mozambique. I first came for a brief stay in 2001, on vacation from my Peace Corps post in Zambia. I was struck by the differences between

the two countries, particularly the reliability of the Portuguese language for communicative purposes in Mozambique as compared to the scarcity of English speakers in rural Zambia. With only this cursory experience I may have concurred with what the Brazilian historian Gilberto Freyre terms “Luso-Tropicalism,” the claim to a greater blending of cultures in what the Portuguese empire dubbed not as overseas colonies but as ‘provinces’, extensions of the nation (Castela 2010). The Salazar dictatorship would later use this theory as an excuse for justifying its continuing rule in Africa long after independence was gained in neighboring nations, supporting the claim that the Mozambican indigenous were on a road or pathway to assimilation, and thus cultural evolution or advancement (Bastos 1998). This speaks to the misapplication of ideas, as experts, theorists, or analyzers see trends in diverse locales which may or may not be as uniform as expected. We should be mindful of abused concepts like this when carrying out ethnography. Similarities may apply to theories like biological citizenship. I will elaborate on this below.

To study AIDS activists in Mozambique, as a student at Michigan State University, in 2007, I spent three months in country collecting pre-dissertation data, working closely with the *Movimento para o Acesso ao Tratamento em Moçambique* (Mozambican Access to Treatment Movement, or MATRAM) and the *Rede Nacional das Pessoas Vivendo com HIV/SIDA* (National Network of People Living with HIV/AIDS, or RENSIDA) to identify sites and groups for a longer return visit. In 2009 I returned for one year on a Fulbright-Hays Doctoral Dissertation Research Award and stayed in Pemba, Cabo Delgado Province, in the far north of the country (see Figure 1: Map of Mozambique). This province has the lowest rate of HIV/AIDS in the nation, at 9% as compared to 21% in the South (MISAU 2013). It has the second highest rate of treatment abandonment. Official figures suggest a 22% dropout rate (MISAU 2011). AIDS activism got a late start here. Pemba City was the last provincial capital to register an AIDS association. Cabo Delgado is a unique Mozambican province because, along with Nampula, it forms part of the

Swahili Coast. It is matrilineal (Bandali 2011) and also mostly Muslim (Bonate 2006). The average life expectancy is only 36 years, compared with 53 in Maputo (Instituto Nacional de Estatística 2015). The long distance from the capital has impacts. There is less of a governmental and NGO presence, and this antagonizes formal health care logistics. People here suffer from many ailments and frustrations. Malaria and cholera are endemic, and infant mortality is high, but HIV/AIDS is the only illness that has its own ‘social movement.’ The virus causes 20% of hospital deaths (MISAU 2009).

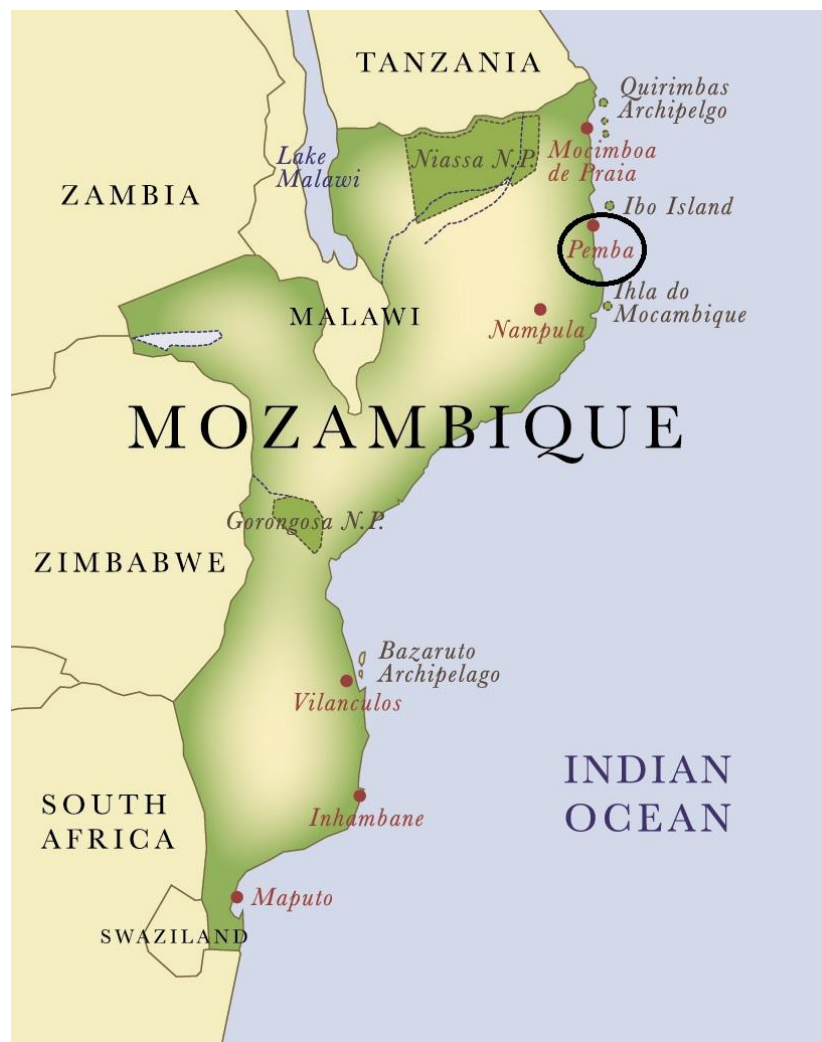


Figure 1: Map of Mozambique, Pemba Circled

During my time in Mozambique I interviewed 75 AIDS patients in 13 different AIDS support groups or associations. The questions I asked focused on their diagnosis, how they came to be on treatment, and what kind of help they received from other patients and the group itself. I also asked about their domestic life, who shared knowledge of their illness and why, and how they cope with everyday challenges. Many became my friends, and formed a kind of cohort panel. Through our work together, my frequent visits in their homes and in the offices of their civil society associations, I was able to interact with about 20 people on a regular basis. Keeping track of the ups and downs of their lives, we were resources for one another. I was expected to contribute, just as any friend or family member in this culture would, to the circulation of social and economic capital. They, in turn, and in time, did not treat me very differently than any other member of the support group. In this way, I gained access to group meetings, as well as the workshops, trainings, and conferences that formed the basis of ‘partnership’ with NGO donors, government ministries, and clinic staff and the various AIDS associations in and around Pemba City.

I shadowed AIDS association members as they did their work, assisting new patients in the day hospital, or teaching about HIV in schools and community centers throughout Pemba City. I documented these encounters and spoke to persons I met along the way. The Mozambican health care system relies on doctors and nurses, but also *técnicos de saúde* (health technicians), who had much to say on the subject of AIDS patienthood. The *Ministério de Saúde* (MISAU, the Ministry of Health) is supported by NGO funding, and encompasses AIDS specific interventions through what are called the *Núcleos*, short for *Núcleos Provinciais de Combate à Sida* (or Provincial AIDS Offices). The workers at the Núcleo were intimately familiar with AIDS association funding and politics. In Pemba, the Mozambican Network of AIDS Service Organizations (MONASO), a government organized NGO, was heavily influential in civil society activities, including the

creation, formation, and formal registration of AIDS associations. These are some of the institutions most relevant to AIDS patients and activists in Cabo Delgado. I made regular visits to these sites—clinics, NGO, and government offices—for observational purposes and to have discussions with those directly involved with AIDS care, AIDS associations, and related policy decisions. I eventually established contact with AIDS activists in other associations and support groups, visiting hospitals and civil society groups in other districts in the province, and participating in programmatic activities such as ‘home-based care,’ where volunteers visit the homes of patients to help them maintain their treatment regimen and contact with clinicians.

Studying activism or activists of any brand, careful attention must be paid to the use of analytical categories. There tends to be, in particular, an overreliance on shared vocabulary which lends itself well to a subtle yet dangerous blindspot reflecting “atmospheric hegemony” (Cunningham 1999). This refers to the potential for truancy in the scholarly imagination of ideas or practices which disagree or inconvenience mainstream intellectual consciousness.

Cunningham (1999) mentions this in the context of evolutionism in Victorian anthropology, where a paradigm of thought dichotomizing civilization and savagery was legitimated through the domination of certain theoretical influences. Applying this to African AIDS patients raises warning flags regarding the purity of a “global civil society” (Corry 2006). While AIDS groups everywhere may share some specific features, and activists may exhibit similar behaviors, regardless of the apparent burgeoning of interest and attention to such groups, researchers tread in risky territory whenever we attempt to dissolve the role of the state or the agency of actors.

To counteract this it may be necessary to challenge implications that political action occurs outside of national frameworks, or that networks of knowledge cross geographic boundaries as if they do not exist. Activism does not uniformly constitute a challenge from below (Lipschutz 1992). Ascribing this status in one place may create undue targets of patients and of activists in yet

another. Here, I would like to remain cautious of following in the intellectual footsteps of social scientists who emphasize the ‘newness’ of most facets of AIDS patienthood. It may be a disservice to evaluate and measure activism by standards originating out of context, in terms of its capacity for political resistance, or the informant’s willingness or ability to link his or her struggle with the international language of human rights. The authenticity of a social activist is not limited to those who undergo a political transformation or subjective rebirth.

This points to the reliability of social science data, our ability to generalize, and the imposition of flawed orders or categories—like Luso-Tropicalism, or biological citizenship—that can stem from ethnographic bias, rushed, or multi-sited research. One of the most neglected issues within cultural anthropology is that of quality data control (Owusu 1978) which results, most often, from the distorting effects of cultural theory, but also from the poor choice of informant on the part of the ethnographer (Naroll 1962). Particularly relevant in the African context is the notion that some informants may intentionally mislead the ethnographer, especially when financial resources are at stake or careers on the line. Owusu (1978), speaking to early African ethnography, notes that ethnographers who report on the presence of certain factors and events in the lives of those being studied—such as warfare (conflict) and witchcraft (accusations or rumors)—tend to be “long stayers” rather than “short stayers” in the field. Certain facts and opinions remain off limits and escape the notice of researchers who make quick trips, or who else occupy additional roles such as that of auditor, doctor, or teacher.

In his analysis Naroll (1962) suggests that ethnographers who master the culture and the native language are more likely to have a superior rapport with their informants, are more likely to report deception, and less likely to be imposed upon or have their disposition swayed by a single informant. In reporting my own data, I rely very much on “native” language—Portuguese and African tribal dialect—and in the classifications offered and expounded upon by research

participants to describe their own situations, attitudes, and feelings. Moreover, I approach the topic of “the informant” through an explication of the group itself, without relying on any one particular activist. This is a macro level perspective but in a micro level context. Pemba is not a cosmopolitan urban center, which, in some respects, serves to correct the potential for distortions in the conceptual and practical application of AIDS activism. In capital cities and other ‘fast paced’ environments the influence of transnationalism is ubiquitous and authoritative. Such sites are more easily influenced by NGO or humanitarian cultures, workers, and ideas from abroad. This presents a bias. The details of the support group are likely to be glossed over. As I will explain, in Pemba not only is there a good deal of conflict within and between groups, there is also a good deal of misinformation which belies the assumption that AIDS activism ‘works’ really well or translates the same in each and every place that it visits.

Bruno Latour (2007) reminds us, however, not to tear down or disperse what others have made or constructed. Stressing the utility of what he terms “actor-network-theory” we are encouraged to reassemble pieces of the whole, to retrace and reassess the associations between various parts of the object of study under consideration as we encounter them and see them at work in the field (Latour 2007). The AIDS support group, and AIDS patients, thus remain legitimate entry points for the researcher, and to deny what has been proposed—theories related to social solidarity, biosociality, the necessity and relevance of activism—would be disingenuous and pedantic. Good methodology involves approaching them again, triangulating data, and seeing if the results align. Such a conception makes it much less risky to work within already proposed frameworks than either nullifying suggestions or accepting them wholesale as fact. Following Latour’s advice, I do not set out to find actors who fit neatly into well known types. If the biological citizen or her biosocial collectivity are to appear, they will do so without intense exegesis on my part. While patient-activists and their groups may indeed be, as Nguyen (2007)

tells us, “complex biopolitical assemblages” (p. 125), then in order to carry out honest ethnography on and about them we “have to grant them back the ability to make up their own theories of what the social is made of” (Latour 2007: 11). If, as Robins (2006) tells us, there is ritual in successful AIDS patienthood—universality in the support group and its rites of passage—then by definition it must be repetitive and ever present. If these kinds of assessments are not controversial, if we can take AIDS activism at face value, then nobody should mind if, in this dissertation, I abandon the shortcuts and undertake again the task of “assembling the collective” (Latour 2007: 16), in this case, the biosocial collective, all over again from the ground up.

Fashioning AIDS Activists - Biosociality and Biopolitics

Theorizing AIDS patients and their place in the expansion of AIDS treatment in southern Africa calls to mind two concepts that are historically and theoretically well grounded—the support group, and civil society. The support group is a treatment model, a “therapeutic community” (Doherty and Harry 1976) that relies on psychiatric models and group psychology to stimulate improvement in the patient’s condition. Most often utilized in residential drug abuse settings (Huey 1971), the support group often uses current or former illness sufferers as models and examples of successful behavior to prevent disease relapse among new members (Gardner 1971). It also provides a forum for relationships between members and formal medical authorities or other experts—case workers, treatment providers, counselors, or crisis intervention experts, for example (Crane 1968). Civil society is a classical political science term denoting voluntary associations among groups of persons seeking social solidarity and cooperation with each other to address a common concern or cause (Boyd 1999). It is traditionally considered a naturally occurring feature of democracy, “civitas” (Oakeshott 1991), an area of life in between the state, the family, and the market (Beauclerk 2011), and a defense against political aggression or manipulation (Almond and Verba 1989). The relationship between human rights law and AIDS

activism positions it well within the political philosophy of Hegel, who identifies civil society motivations as stemming from the need for social recognition and mutual respect between the governing and the governed (Honneth 1996).

Comprised of patients who meet together for therapeutic purposes, but also advocate for their cause, the Mozambican AIDS associations combine these two concepts. They hybridize the support group with civil society, and even seek inclusion in government and NGO projects based on and because of their illness. In anthropological and social science theory, they embody “biosociality” (Rabinow 2005) and “biological citizenship” (Rose and Novas 2005). The concept of biosociality denotes groups of persons who meet together to discuss their experiences of coping with a chronic illness. Biological citizenship refers to the leveraging a disease diagnosis to access resources or compensation, especially from the state. AIDS patients are relative latecomers to this theoretical framework, which was initially applied to sufferers of rare genetic illnesses (Rajan 2007) and persons much more obviously impacted by state inaction—like victims of the Chernobyl nuclear disaster in the Ukraine (Petryna 2013). What sets biosociality apart from the support group is the focus on identity formation at the hands of or in relation to biomedical science (Dimond, Bartlett, and Lewis 2015). What sets biological citizenship apart from civil society is the notion of a collective and shared experience that directly impacts on the human body (Alcano 2009), where the claiming of one’s illness—the very identity of being sick or infected—serves as a kind of “path to cure” or “path to citizenship” (Callon and Rabearisoa 2008:235) that makes patienthood alone into a type of social justice. The biosocial collective, like AIDS patients who join groups and sign rosters, parallels that of a patient advocacy organization (Panofsky 2011). This is the arena in which biosociality most clearly begins to cross over and cross-pollinate the world of HIV/AIDS, particularly concerning patient rights and social relations between the afflicted and others with whom they might interact.

The biosociality framework also implies the need for protection and the seeking of safeguards from those who can provide it, experts like medical researchers, lawyers, or economists capable of objectively evaluating and addressing the needs of victims or sufferers (Heath, Rapp, and Taussig 2007). The accommodation of illness becomes intertwined with politics such that the two interests overlap, and patients themselves are drawn into patterns of participation (Taussig, Rapp, and Heath 2001), “responsibilization” (Robins 2006:314), and, in the case of HIV/AIDS patient groups “confessional technologies” (Nguyen 2010) that impact on the self, reshaping and redefining everyday “moral economies” (Nguyen 2007). In this manner, patients seek to act upon those who in turn seek to act upon them—influencing decision makers, making demands regarding their own treatment, and helping determine funding streams and research goals or objectives. Biosociality and biological citizenship acknowledge such spheres of human organization and even the array of regulatory, economic, and legal concerns that seem to be rather messily involved and attached.

Wehling (2011) mentions a group of *pseudoxanthoma elasticum* patients who convinced the National Institutes of Health to let them co-invent a blood and tissue bank. Epstein (1996) highlights similar outcomes between homosexual lobbyists and the Food and Drug Administration where activists pushed agendas for AZT clinical trials in the 1980s, early in the AIDS pandemic. Theorizing AIDS patient groups as biosocial collectivities recognizes that not only are patients less “helpless” when they support one another (Parr and Davidson 2009), but also when they negotiate for resources—like antiretroviral therapy (ART)—that make their condition more manageable, extend their lives, making them more a part of the establishment, less medically isolated, and increasingly interdependent with the institutions and societies that can or should care for them.

On the topic of treatment access, African AIDS patients have managed to insert themselves so successfully into policy discussions and international interventions as to receive widespread attention and credit for influencing the trajectory and nature of the global ART scale-up (Iliffe 2006). As I will discuss in the next chapter, AIDS activism served as a catalyst for the introduction of ART in contexts where experts previously deemed it economically unfeasible and medically undesirable. Biosociality and biological citizenship, the shared identity of AIDS patients and their demands to be on treatment, led not only to the establishment of nationwide networks of people living with the virus, but also to what Biehl calls “activism within the state” (2006) and the “pharmaceuticalization” (2007) of the epidemic among populations that before were not considered treatable. The overemphasis on pills makes patient groups “biovaluable” (Rose and Novas 2005), their existence and proliferation another way of generating additional treatment subjects and foreign aid recipients, and a support network more for products than for patients—a kind of “commodity fetish” (Marx 1909). This raises the question of whether the expansion of AIDS activism is based on the successful spread of political ideas, like human rights, or good marketing, harkening more to patterns of consumerism than to healthcare freedom and liberty (Millikan 1987).

Now that AIDS treatment is widely available patient groups find themselves in contexts of “extractive approaches to HIV/AIDS” (Marsland 2012). NGOs, multinational institutions, governments, consultants, and think tanks have also taken up the “fight” for ART (Epstein 2008; Johnson 2008). With the “scale-up” (Mugenyi 2004) or “rollout” (Andrews et al. 2007) of treatment in the public sector now a global concern, AIDS patient groups occupy the role not of agitators, but of partners in an international development industry. The funding, projects, and resources infused into this setting can result in conflict (Le Marcis 2012) and a type of “reluctant solidarity” (Bähre 2007) that is far from utopian. Understandings about biosociality may

contribute to the tendency to perceive of the AIDS support group as being static, but, as this ethnography shows, there is no lack of competition between and within these groups. Members may not even share the same goals. Intergroup dynamics (Miller and Rose 1994) can impact the group's relevance, making it more useful to some than to others. The "particularities of daily life," side effects of medications, temptations to give up, and other personal struggles (Alcano 2009) make the support group appealing, yet their success is not automatic. This is especially the case in Africa, where the "primordial public" (Ekeh 1975) of reciprocal, clientelistic, and informal networks of support complicates the assumed purity of civic associations. The group can be hijacked, it is a target for careerists and the self-interests of many (Keane 1988). The mythical figure of the African "big man" (Cabassi and Wison 2005) ensures that the role of activist, advocate, and leader is itself a manipulable resource.

Noting the environment of development workshops, trainings, and service-work, Le Marcis (2012) suggests that support groups are pulled into "structures of in/action," which allow members to get swept up in projects that are usually not innovative, transferring their accountability from that of the community to that of donors. This is one way, according to Marsland (2012), for the state, the government, and other institutional partners to begin to penetrate the imaginations of members. She mentions that in Tanzania the history of civic association, and the formation of fake self-help groups, inhibits the biological citizenship that others suggest occurs naturally in other settings. This is no different in Mozambique, where civil society, including AIDS associations, serves as a very practical means not only for the cultivation of biosociality but for the extension of the state as well. Between the public and the private, tied to the clinic and also government projects, the AIDS association becomes a site for the state to intervene and reproduce itself in society. Anthropologists like Nguyen (2010; 2007) and Robins (2006) mention the support group as a place where "technologies of the self" (Foucault 1988) are freely espoused as members

attempt and are encouraged to self-govern. Faced with the reality of a state that spends too little to repair damaged lives, being responsible for one's own health becomes, to some degree, an expectation and a requirement. Seeking to take part in what the state is doing, a lot of responsibility falls onto the group as well.

Faced with a lack of AIDS medications—a commodity that only the state could provide—the goal and aim of AIDS patient-activists during the pre-treatment era was to avoid becoming part of a “discardable population” (Santos 2005: 36). That kind of civil society, following the work of Antonio Gramsci, posits only two actors—the state versus the excluded (Hall 1986). Civil society's role in this case is to make certain its members are not ‘selected out’ of the political process. This requires participation with the state, because without participation there are no benefits. Closely and even directly related, the political resistance that we saw from early AIDS activists—picketing government offices in the U.S., staging die-ins and marching in the streets of South Africa—is also very Nietzschean, involving resistance to the domination of one's will by others through efforts at inserting oneself into the fabric of society (MacIntyre 1995). Yet, as this dissertation will show, we now find AIDS civil society losing power, losing funding, and becoming obsolete. The reason why is that it has been absorbed. Hall (1986) tells us that the easiest way to contain political resistance is to approve it, grant it the social recognition it wants, and incorporate it into the rest of society. In what is now a post treatment era, the state can claim that it has done its part, treating AIDS patients with equality, agreeing to their demands. The strategies of the early AIDS activists no longer work, and that brand of civil society is no longer in a position to threaten those in power, but to be used by them instead. The result of this kind of political resistance, in the Gramscian or Nietzschean tradition, is that “those who make the conquest of state power their aim are always in the end conquered by it and [become] the instruments of one of the several versions of modern capitalism” (MacIntyre 1995: xv).

AIDS activism, and its practical implementation or manifestation in the AIDS support group, becomes just another tool for the modern state, and a site for the imposition of certain morals, attitudes, and modes of living onto the daily realities of entire groups of people without their obvious and active consent. The effects of such efforts can be contradictory to their original intentions. Referring to the subtle ideology behind the promotion of self-help techniques and efforts toward personal empowerment—like the “self-esteem” movement—Cruikshank (1993) identifies the circulation and adoption of the techniques involved as “liberation therapy” (1993:232), a “social vaccine” that empowers people to live responsibly and inoculates them against the dangers of helplessness, poverty, and stigma. This is useful not only to the patient, but to the state as well, because a citizen or group that is more empowered—to adhere to AIDS treatment, to carry out community service projects, and to recruit other members into a movement that encourages this behavior—makes them more productive, or even a source of labor, as it also absolves the government of some of its responsibilities and obligations. This parallels what Illich (1982) calls social and cultural “iatrogenesis.” The attempt to produce activists, while outwardly oriented toward better community health, leads to widespread acceptance of management techniques just as likely to be harmful as helpful. Orchestrated in the name of progress, as a necessary remedy, the by-products of approaches intended to modernize or transform often entail some form of pollution, indirectly limiting personal autonomy and contributing to preexisting vulnerabilities. Activism, a form of self help, becomes one path for enforcing and reinforcing behavior stemming from a source with possible ulterior motives. The community, the biosocial collectivity, ‘the group’, is opened up, penetrated, and available for interventions and experiments.

Since this is the case, the state has a vested interest in the promotion of AIDS activism just as much as the patients themselves. Yet, because we live in an era of what theorists call “neoliberal

governmentality” (Harvey 2007)—which points to the market as the basis of and reason for government—AIDS activists, patients, and their support groups will find it difficult to escape the dominant logic that they, along with the state, exist to serve ‘the market,’ in this case, the industries that spring up around solving the crisis of HIV/AIDS in economic and technological ways rather than social ones. I will discuss this in terms of the projects that support groups are expected to adopt or carry out. These entail conformity with an external rule of law, but appeal to patients as biological citizens in an environment where, other than the meager salaries and defrayment of select other costs associated with being HIV positive and in a successful AIDS association, no other form of compensation for their illness truly exists.

Yet, other social scientists working with Mozambican AIDS associations presume that political activism is the highest form of AIDS citizenship (Fenio 2011), and that engaging with the government is an advantageous strategy for support groups (Kalofonos 2008). By this logic, AIDS support groups are “biopolitical” (Foucault 2010)—serving an underlying rationality of modern capitalism—due to their poor influence in society and subsequent lack of power. But the original Foucauldian concept of “biopower” (Foucault 2003) has less to do with attaining social status than with pinpointing subtle mechanisms of population control. Connecting politics with life with the manipulation of physical bodies, biopolitics and biopower are favored theoretical staples for anthropologists, who draw parallels between biomedicine and the expansion of colonial empire (Nguyen 2010), or relate humanitarian efforts to limitations on personal freedom (Mckay 2012) and processes of undemocratic decision making (Redfield 2005). I believe anthropology as a discipline may be ‘stuck’ in this mode, fixated on the power dynamics between authority and subordination. Much like Foucault himself, as theorists we see no way out of neoliberalism—the extension of the economic into the realm of the social. This is due to its seeming ability to jump from locus to locus and to exercise sovereignty, usually based on numbers and other supposedly

neutral and objective measurements, regardless of the “milieu” (Canguilhem 2008) in which we work or operate. Like biomedicine or humanitarianism—efforts that are somehow ‘good’—political activism, and AIDS civil society, are also useable by neoliberalism.

Ironically, social science on HIV/AIDS interventions may be contributing to a “sociology of absences” (Santos 2005:35), the ‘selecting out’ of some valid modes of social relations. It is worth considering, in relation to AIDS support groups, whether the theoretical framework of biosociality adds to this. Working with these groups, we toggle between an emphasis on cosmopolitanism (Singer 2002)—the idea of a “global village,” where a borderless and unmitigated transnationalism is encouraged to thrive—and communitarianism (Rawls 2001)—where, without high functioning local systems, a global one has no opportunity to take root. The impetus and desire to paint AIDS civil society in broad strokes may reflect little more than an “artificially created solidarity” (Cruikshank 1993:242), where, in the name of globalization and the perceived critical need for universal human rights to be applied sooner than later, patient groups which don’t conform to a political life are subjected to an “invisible governance” (Cruikshank 1993:245), a gentle tyranny, an erosion of leadership and accountability, on the part of others who believe that they should.

While there appears to be plenty of empirical evidence for biosociality, for the claim that communities can form around biomedical categories, we should be cautious about where it might lead us theoretically (Dimond, Bartlett, and Lewis 2015). It may turn out that the concept wears thin, especially if basic or classical social theory, like the utility of the support group, or the proper functioning of civil society, eventually appears equally useful for explaining what draws members of a group together and how they respond to new knowledge. Analyzing the situation of the Mozambican AIDS associations, and the patients or communities that they claim to serve or represent, from the Foucauldian viewpoint of “governmentality” (Lemke 2001)—looking for

continuities in logic and the deployment of governing tactics through various institutions and policies—may reveal that theories about biosociality do not add much to what we already know.

This gives credence to one of the most common criticisms of biosociality to date, that it privileges supposedly ‘new’ experiences of health and illness over possibly historic and deep rooted ones (Lock 2008). I would add another criticism: that biosociality privileges transnationalism and cosmopolitanism over and above communitarian understandings of what a support group is and does, distorting or presuming a link between successful patienthood and political subjectivity, or even a foreign or Western notion of what is ‘therapy’. If this is true, biosociality and biological citizenship may cover up a process of “hijacking” AIDS activism (Faundez 2003), giving it over and linking it to an agenda not originally or foundationally its own. The question that needs to be addressed, then, is whether the biosocial collectivity is better off seeking approval and benefits from the state and its partners, or within the communities from which they spring and, assumedly, serve or represent.

What I will suggest here is that these early forms of AIDS activism have not necessarily missed the mark, but neither have they been well permitted to develop. They were or are merely an antechamber for a more full and authentic version of civil society which, due to recent events in global health politics has been squelched or even cannibalized. The deepening of AIDS civil society will involve giving “priority to culture” rather than states or institutions, and influencing “the subjectivity of society” (Pope John Paul II 1991) in such a way that more than just a few benefit from its existence. The story of the AIDS associations in Mozambique is in some ways tragic, as they lose the fight for their AIDS clinics, and their relevance both in politics and the communities in which they are embedded. The result is that biopolitics overcomes biosociality, neoliberal governance overcomes AIDS activism, and a ‘social’ movement is overcome by what Sundell and Wärngård (2013) refer to as the “evidence-based policy movement”. Yet, many of the

changes that have occurred cannot be reversed, and there is reason for hope in the resilience and continuing contributions of patient-activists in the future.

Chapter II-AIDS Treatment and Activism in Mozambique

Welcome to Caridade

You don't just pass through Pemba City, at least not in a bus or a car. It's at the end of a peninsula, which makes it something of a dead end in terms of land transportation. The airport stays busy, and the port does a good deal of trade, even though it's second to Nacala in Northern Mozambique. Tourists pass through usually on their way to even better beaches on the islands off the mainland coast, but other than that, Pemba City is not really 'on the way' to anywhere else. Rather, if you're in the city for the kind of work I'm interested in—exploring the experiences of AIDS patients—chances are it's your intention to be there, and not elsewhere. Pemba is not some convenient stopover for collecting data, evaluating, and then deciding if it's a good idea to stick around. That's not to say that it's not worth a trip, or isn't an interesting place—far from it. Instead, it is rather isolated, at least from the busyness often associated with major African highways, transport hubs, or destinations that are stopovers to other destinations. It's a good 60 kilometers even from the paved road heading further north, making it in some ways an illogical destination for those who don't have specific reasons to get here.

That is definitely the sense I got at a restaurant in downtown Pemba sitting across the table from Antonio, the president of Associação Caridade—a support group, or association of people living with HIV/AIDS in the city. One could even say that at that time Caridade was *the* AIDS association in town, there were no others. This was in 2007, and the trend of AIDS associations in this area was only beginning. No foreign student or anthropologist had ever yet approached Caridade with the kind of request I was going to make. I made contact with the group through RENSIDA, Mozambique's official network of people living with HIV/AIDS. Talking with them in Maputo, I had secured Antonio's phone number and was hoping to set up formal interviews with Caridade's members as an exploratory exercise, to see how open the group might be to

collaborating with a foreign researcher. Antonio had arrived with something of a cadre, two women who sat on either side of him, drinking coca-cola and looking in opposite directions at the activity going on around us at the outdoor café. People were passing by on the sidewalk carrying on daily business, some getting money from a nearby ATM, others going into a neighboring supermarket, still others entering the Mozambique Airlines kiosk attached to the same building. Cars were swerving through roundabouts in the road up and down the hill from where the restaurant was located. I had been staying at the beach a few kilometers away, so was still getting used to the comparatively un-lazy atmosphere of the downtown area.

“So, what are some of the activities of your association?” I asked him, after our initial exchange of formalities. I knew very little about Caridade. I was aware that Antonio himself was a nurse in Pemba’s day hospital, the AIDS clinic, meaning he must be more educated than many of the patients I interviewed in Maputo. He had his hands clasped on the table, and his brow was a bit furrowed, giving off a concerned and serious vibe. “Well..Seu Cristiano, is it?” He confirmed my name, and I nodded. “We are still new, I guess you could say, still in the process of being really recognized by most of the patients who come to the hospital. But, *graças a deus* (thanks be to God), we do have funding, so some of our members are able to be activists.” He was referring to a conceptual divide among association members. ‘Activism,’ in Mozambican AIDS associations, doesn’t mean thinking in a particular way about one’s treatment or disease status. It doesn’t even mean being trained by an NGO or the government in a particular activity, like home-based care, or having some certificate stating that one has completed a course in the significance and meaning of human rights, for example, although those items bring one a step closer. Activism, for those involved with the AIDS association, means having a paid position within the group. Anyone else is considered a member, something akin to an activist-in-waiting, because the goal for most members is to eventually see financial compensation for their involvement. This meant that some

partner was financially and programmatically supporting the association, because while everyone, even members, were entitled to handouts—for example, if a local NGO or church or even the hospital decided to give out free food to AIDS patients—being an ‘activist’ signified receiving a *subsídio* (a salary) in the form of *Meticais*, Mozambique’s currency.

“Basically,” he continued, “we have three programs. Some work in the hospital...” I interrupted, “opening *processos*?” I asked, referring to new patient case files. “Yes,” Antonio replied, “helping new patients accept their [disease] status, talking to them about the medication, offering support. Then, some work with Medicos del Mundo.” This is the Spanish-based NGO that was involved with Pemba’s day hospital from the beginning, providing drugs and logistical support, but had begun to focus on activities outside of the city. “These activists do home-based care.” “So,” I asked, “visiting patients in their homes...” “Yes and finding those who don’t return to pick up their medications, the abandoners. Then, we also have activists in the schools. They visit and talk about prevention, awareness, *esse tipo de coisa* (that kind of thing).” “With the primary schools?” I asked. “Yes, but some are in the secondary schools, too, it’s a partnership with the Ministry of Education,” “and UNICEF?” I asked. “Yes, and UNICEF.” Antonio paused, “So, you know about that? That is a new one.” “Maria told me about it in Maputo,” I responded. I heard about that project at RENSIDA’s office—the national network of people living with HIV. It was, in fact, the project that brought Caridade into RENSIDA to begin with. The association previously had no relationship with this UNAIDS funded entity, whose leadership was appointed by the ruling FRELIMO political party.

At this point, I still had not visited Caridade’s office. Earlier, on the phone, Antonio told me to meet him here because finding the office would be too difficult, because I don’t know the city. I had seen the day hospital, though, the local AIDS treatment center. It was a busy place, located in a building separate from the main hospital, but within the same compound. It had its own

entrance on a side street. The waiting room was full, and people moved in and out of the doorways at a dizzyingly high turnover rate. I spoke briefly with a Mozambican health technician there who told me the Cuban doctor on staff was too occupied to stop work for a discussion. I meant to return later, hoping to track down Antonio there, but when he responded to my phone call I didn't make it back there until later in the week. "Antonio," I questioned, "what do you think about me spending more time with Caridade? Right now, I've only got a couple of weeks, but I hope to come back for a longer period later. I'm trying to learn more about treatment, what people think about it, and how exactly it's helping them. I'd like to sit down with some of the members, individually, and do interviews with them. I've got the questions right here, if you want to see..." Antonio interrupted, "I think, Cristiano, I think that's fine. We are very open to visits like this. There is no problem." He then began addressing the women in Makua, and while I was unable to follow the conversation precisely I could tell it was about logistics. Turning his attention back to me, he asked, "when do you want to start?"

That afternoon I was escorted to Caridade's office, and Antonio crafted a schedule for me to interview a couple of people a day. I spent the next two weeks with Caridade members, mostly in a formal interview setting, but also visiting people in their homes, strolling through parts of Pemba that are off the beaten path, joking, and talking about life in general. One day I traveled with a few of them to a village called Mieze to visit a neighboring AIDS support group, Ajuda à Próxima, which splintered off from Caridade because of the distance from that village to Pemba City (about 20 kilometers). Participation in Caridade meetings was difficult because of the 20 kilometer distance, and this support group was seeking to get officially registered as a new AIDS association with the government. There seemed to be a rising tide of AIDS patients organizing themselves into support groups. I was told about others that may be starting up. Everywhere I went in Pemba, whether to interview NGO or government staff, go shopping in the market, and

even walking on the beach, I ran into Caridade members. The group seemed integrated into the fabric of daily life in the city, the members stayed busy, and were respected in the more formal institutions, like Medicos del Mundo, and in the day hospital. The kind of work they did there was as Antonio described—close to the new patients in the hospital and ready with advice, and frequently fetching people from their homes when they didn't show up for clinic visits sometimes with the help of the hospital's ambulance. Antonio himself could be found in the back of the hospital with rubber gloves on, prepping patients for a visit with the doctor. Pemba City itself, in spite of the crumbling classical Portuguese architecture, seemed full of hope through the lens of Caridade members and activists who were happy to have a day hospital, proud to have NGOs and government staff interested in including them in programs and activities to help other patients and community members.

What historical and cultural factors contributed to the existence and formation of AIDS patient groups like Caridade? How are they expected to function? How do they fit into the global and Mozambican responses to the crisis of HIV/AIDS? AIDS patient groups form part of a wider effort to help normalize the virus in their societies. This mission springs from and capitalizes on the successes and intentions of earlier AIDS activists from all over the continent and the world. What makes the Mozambican AIDS associations similar and yet different? In this chapter I will situate AIDS associations in an historical context, and provide an initial sketch of the main one that informs my research on the topic.

Demands for Treatment

Caridade, and groups like it in Mozambique and other southern African nations, owe their existence to what is now a long history of social activism for people living with HIV first in developed nations and now all over the globe. Caridade began as a support group of less than 15 people in 2005, and a little more than a year later found itself signing contracts with NGOs,

paying office bills, and filling out reports with data and deliverables like ‘number of people served’ or ‘number of AIDS educational activities performed or carried out.’ Caridade is, perhaps in many ways, a direct descendant of ‘People with AIDS’ (PWAs) groups and organizations dating back to the late 80s and early 90s (Vugt 1993). In other ways, it is a distant relative. Some of the first such groups that emerged around having a seropositive status did so as a result of widespread deaths within the homosexual community in places like New York City (Shilts 1987). AIDS identity, early on, was associated with particular ‘high risk’ groups, risky sexual behavior, and subcultures that were not only rebuffed for their unfortunate medical state, but also blamed outright for perpetrating and spreading the virus (Sabatier 1987). Sufferers were assigned an almost criminal status for this unwanted affliction. Compared to a medical or epidemiological approach to understanding AIDS, with its focus on sexual and other kinds of risk taking behavior, anthropologists contributed to the study of HIV/AIDS by bringing to light stories that might otherwise never have been told. Explaining how large-scale social forces impact viral transmission on a wider scale—like politics and the economy and “structural violence” (Farmer 1996; Scheper-Hughes 1993)—social science also helped make the perspectives of ‘people with AIDS’ more clearly relevant, turning exclusion into inclusion, and reconciling the world with the dispossessed.

In actuality, however, the world needs them, those who are infected, and especially those who are dispossessed, in order to even leverage the kind of action needed to make this problem stop or slow down. AIDS patients, early on, fought for the ‘right’ to be included in clinical trials, or for the kind of social justice where drugs would be available to those who needed them within reasonable time frames and at fair prices (Epstein 1996). Now, the world—governments, biomedical experts, multinational institutions—are fighting not only to get more HIV infected persons on treatment, but to get them to stay on treatment once they start. From the first efforts at minimizing the impact of the virus in various societies and contexts—the campaigns for basic

prevention education emphasizing condoms, abstinence, and monogamy in sexual relationships (Piot 2000)—it was quite clear that AIDS could never be completely solved just within the context of the clinic. That is more, not less, evident now with the advent of widespread treatment. This concern, on the part of experts toward the patients, is somewhat but not entirely altruistic. AIDS is so widespread as to be considered a biosecurity threat, an ever-looming potential economic disaster, a governance issue and threat to the stability of entire regions of the planet (Ingram 2010). Groups like Caridade may be direct descendants of early AIDS activist groups but with at least one major difference—the tables are now rather turned around. They are not social outcasts, at least not theoretically. The world *wants* people to get AIDS tests and it *wants* them to take their medicine. This is not a task for which doctors, scientists, or bureaucrats are very well suited.

However, that is not an acknowledgement that any less faith is being placed in the possibility of a mostly technical solution, or that any more is being placed in the capacity of AIDS support groups to help solve the crisis either. “Treatment as prevention” (Sigaloff, Lange, and Montaner 2014) is a very recent focus. It is a worthwhile endeavor, but also a subtle nod to the fact that attempts to change behavior at the social level are not as simple as throwing condoms at people during parades, commissioning billboard slogans, or other ‘social marketing’ techniques. It is great news that whenever there is a 10% increase in the number of people on treatment in any given area the incidence of HIV falls by 17% (W.H.O. 2013). Access to treatment is at an all time high, and has averted around 4 million deaths since it was widely introduced in developing nations in the mid 2000s (Fox and Rosen 2010). It is bad news that the abandonment of treatment by patients who start is also at an all time high. Not only are our statistics on this less well tabulated than our statistics on enrollment numbers, the reasons why it happens are also poorly understood. Entire segments of the AIDS patient population seem to just disappear, about one quarter of them, within about three years, on the global level. In Mozambique one third to almost

half go unaccounted for within a year or two, depending on which set of clinics or provinces are being assessed (Decroo et al. 2014; Cumaquela, Sidat, and Sousa 2012).

To address problems like this governments and multinational institutions call upon people living with HIV to become more involved, to be active on the community level, and to be part of special efforts to help health service facilities identify factors contributing to slow treatment uptake and program dropout (UNAIDS 2012). Yet, there is a question of patience, of unaddressed or failed expectations from support groups, and also of who is really in charge. AIDS civil society support groups in Africa, like Caridade, rise and fall in relation to the presence and funding level of donors (Marsland 2012). This makes them, perhaps, quite unlike the early AIDS activist groups, not only in places like the U.S. or Europe, but in Africa as well. Those early AIDS groups absolutely refused to go away, no matter the odds or challenges; nowadays—as I will discuss here—patient-activists seem to expect money or other compensation. Anthropology on this topic, the field level concerns of individual patient groups, is relatively undeveloped. There has not been a great deal of detailed ethnography on AIDS support groups. The brief histories and short details of early African groups and activists suggest that they were important actors in proving to the world and the medical establishment that AIDS treatment could be carried out with hard-to-reach populations in difficult settings. Part of the problem now could be that, in the opinion of much of the world, their identity never evolved much beyond that.

The first and most famous African activists tried to draw attention to themselves and others like them, through public speaking, gaining media attention, and living ‘positively’ in society. The goal was advocacy, to get funded, to lead by example, and to warn others about an illness that many Africans did not believe actually existed. Before free treatment was even considered a possibility in Africa, as far back as 1991, groups like Zambia’s Positive and Living Squad attracted several hundred members (Zulu 1993). Some activists, like Dominique Esquail from the Ivory

Coast, who could have gotten treatment because of his outspokenness and connections to doctors, died (in 1996) out of refusal to take the pills until everyone had equal access (Lumiere Action 2015). This same strategy was used by South Africa's Treatment Action Campaign and its first leader Zackie Achmat, along with a united effort to smuggle in AIDS drugs from abroad in order to skirt government bans on AZT and other pharmaceuticals that were proving effective in American and European clinical trials (Nattrass 2007). While South Africa was a special case—the government there latched onto the claims of AIDS denialists and refused to acknowledge that HIV causes AIDS—there was tangible fear among the international medical community that more deadly strains of HIV could result from patients who failed to comply with treatment regimens or that interrupted access in poor countries could result in viral mutations that could threaten the global North (Huber 2007).

Decision makers then, in the late 1990s, did not want to “waste” expensive AIDS drugs on possibly non-compliant patients (Sontag 1997). Even when the costs of AIDS medications started to drop, making them more affordable for free public provision, African patients were stereotyped. It was believed they would not be able to adhere to the complexities of the ART regimen because they were not sophisticated enough. USAID's director Andrew Natsios captured this sentiment well, appearing frightfully out of touch for an international program coordinator, during the International AIDS Conference in 2000 at Durban, South Africa:

“Many Africans don't know what Western time is. You have to take these (AIDS) drugs a certain number of hours each day, or they don't work. Many people in Africa have never seen a clock or a watch their entire lives. And if you say, one o'clock in the afternoon, they do not know what you are talking about. They know morning, they know noon, they know evening, they know the darkness at night” (Donnelly 2001).

Research on adherence in low resource settings helped to reverse this bias, even to the point of suggesting that patient compliance was worse in some North American settings (Mills et al.

2006). Another turning point came when the international humanitarian organization Doctors without Borders teamed with Treatment Action Campaign (TAC) activists on service projects in the Eastern Cape of South Africa—where the local government agreed with defying the national bans on medications—to deliver ART in informal settlements and shanty towns (Cohen et al. 2009). TAC's ranks continued to grow. The movement claimed 110 branches in South Africa by 2004, and garnered the attention and support of academics, lawyers, politicians, biostatisticians, and international development organizations and donors (Grebe 2011). The group became an icon, fusing service provision with political mobilization, and demonstrating that AIDS patients could work to help other AIDS patients, especially by knowing the neighborhoods and communities where they dwelt, in ways that foreign NGOs couldn't.

United around the concept of free and widely available AIDS treatment, TAC also drew attention to international treaties and charters that justified their cause and held their government accountable. The Universal Declaration of Human Rights, states that “everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services” (W.H.O. 1948). The United Nations’ International Covenant on Economic, Social, and Cultural Rights (ICESR), Article 12(1) recognizes the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (OHCHR 1966). The African Charter on Human Rights and Peoples’ Rights states that “every individual shall have the right to enjoy the best attainable state of physical and mental health” and that signatories to the charter “shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.” (OAU 1981). TAC paved the way for wider recognition of AIDS treatment as a human right (Hayden 2012), merging the needs of patients at the lowest levels of the social ladder with the interests of international policy makers, pharmaceutical companies in India and China

that began manufacturing generic AIDS drugs for African consumption, and the practicalities of carrying out AIDS treatment programs in areas where it was previously not thought possible.

Prior to this, ART in Africa was limited to those who could pay for it, such as political or business elites, and those enrolled either in clinical trials or private health insurance schemes such as those provided by multinational corporations (Reed 2005).

Day Hospitals and Therapy

Prior to ART, 80% of those infected with HIV died within about 2 years. On treatment, a patient's chance of survival within that same time frame skyrockets to more than 80%, especially if the virus is caught before progressing to full blown AIDS (W.H.O. 2013). In southern Africa, ART has reduced mortality by 62% in the late 2000s alone. AIDS related deaths here peaked in 2005 and continue to drop, from 2.3 million per year to 1.3 million on average (Fox and Rosen 2010). Patients now have life expectancies on par with healthy people, but with a crucial caveat—adherence to treatment must be sustained. This is because antiretrovirals do not cure people of the virus, rather, the pills work to lower the body's viral load so that it can continue to produce CD4+ cells. These are necessary for a healthy immune system to ward off the opportunistic infections that we all regularly encounter but which disproportionately threaten the lives of the immunocompromised. AIDS drugs are broken down into different classes, and each class intervenes at different points as the virus attempts to replicate itself on the cellular level and infect additional cells. Patients do best when they ingest drugs from all three classes of antiretrovirals, or one pill that contains a formulation of each drug. These are the 'fixed-dose' combinations to which most Africans now have access, and are taken, ideally, twice a day.

It's not always easy for patients to tell how well their body is doing on the drugs without consistent clinical contact. Being on ART is a different sort of experience than getting better from taking a round of antibiotics, for example. For one thing, the pills are not a cure. This can be

difficult to explain to new patients, especially if their understanding of biomedicine is limited. Also, patients should not gauge their level of health based only on how they feel. Regular laboratory tests must be done to measure viral load and count CD4+ levels. Side effects can make treatment a very unpleasant experience, particularly upon initiation, making people feel worse after taking the pills than they did before, with symptoms like nausea, diarrhea, dizziness, hunger, or fatigue. With persistence, however, viral load suppression can be achieved. Patients feel better and can work again. They will even start to look better, what some call the “Lazarus effect” (Walton et al. 2004), regaining weight and energy, and seeing rashes, sores, and wounds disappear. Still, many people do stop treatment, and if they don’t start again this always leads to disease relapse. There may be some very practical reasons for this, like poor patient counseling, transportation, or drug availability (Groh et al. 2011). It may also be a kind of compromise or loss of the patient’s resolve or willpower, similar to what happens to soldiers experiencing “combat fatigue” (Jones 2006). That is when non-clinical help, like a support group or a devoted caregiver, perhaps is most helpful.

At the time when TAC was making headlines in South Africa, the Republic of Mozambique and its international partners were just beginning to make provisions for the introduction of ART into the national health system. The government issued Ministerial Diploma Number 183-A/2001 on December 18, 2001, which regulated the process of officially introducing ARVs into the country. It limited distribution to a couple of hospitals, and formalized a request for the involvement of other organizations, because government-run clinics reached only 30% to 40% of the country’s total population (Kula 2008). From 2001 to 2003 fewer than one thousand patients had access to treatment, and only in the two biggest cities of Maputo and Beira. In 2003 and 2004 Doctors without Borders and the Catholic charity Saint Egidio became involved, expanding the model that some Cuban doctors had adopted from their country and were implementing in

patchwork fashion across Mozambique—giving AIDS patients their own buildings and related services, completely separate from the other hospitals and other patients (Eade and Smith 2011). This served as the blueprint for the “day hospital” system in the country, a treatment unit dedicated entirely to HIV/AIDS services. As NGOs became more and more involved with AIDS care the day hospital (*hospital de dia* in Portuguese) became a privileged place for them to carry out their work.

Day hospitals were usually isolated from other hospitals and clinics. They typically had their own waiting areas, consultation rooms and hospital beds. Patients had access to their own pharmacies, well trained staff, and even expensive equipment unavailable in most other clinics, like laboratory machines and ambulances dedicated specifically to day hospital work. Initially, AIDS patients could get everything they needed at the day hospital—an AIDS or lab test, a doctor’s appointment or physical exam, medications such as ARVs or analgesics, and education on living with the virus. Videos were often shown in the waiting areas of day hospitals, and nurses or AIDS patient-activists had a captive audience for carrying out activities like nutritional cooking demonstrations or water sanitation techniques. During the pilot phase of the day hospital system, from 2004-2005, about 30 were in operation. The number of patients on ART rose from 7,200 to 19,000. In 2006, 120 more HDDs were opened, and the number of beneficiaries reached 44,100 patients, or ten percent more than initially planned for that year. By 2007, 211 day hospitals were seeing patients in every corner of the country, and the number of patients reached 88,211, only about 6,000 less than the total number of patients in the country estimated to be in critical need of antiretroviral therapy (Kula 2008).

The government played a role in this as well, accepting the day hospitals as part of what it calls the *Rede Integrada* (Integrated Network) of its national health system (MISAU 2004). This made day hospitals into other points of triage within the overall hospital network, just like

maternity or pediatric wards, surgical units, and blood banks. The Mozambican Ministry of Health (MISAU) included the day hospitals in their second *Plano Estratégico Nacional de Combate ao HIV/SIDA*, known as PEN II (the second National Strategic Plan to Combat HIV/AIDS). The series of PEN plans—PEN I, II, and III—were the results of governmental and donor negotiations, spearheaded by the World Bank, that included recommendations on reducing the impact of AIDS along with specific objectives for NGO and government healthcare programs (Wamba and Loga 2008). Besides the day hospitals, the PEN plans guided the involvement of governmental ministries besides MISAU—like the Ministries of Education, Youth and Sports, and Agriculture—to conform to what the World Bank and other donors termed a ‘multi-sectoral response’ to AIDS. The plans also oversaw the creation of additional AIDS-specific bodies, in particular, the *Conselho Nacional de Combate ao SIDA* (CNCS, or the National AIDS Council), and its provincial subsidiaries, the *Núcleos Provinciais* (referred to simply as Núcleos, or Provincial AIDS Offices). In addition, the PEN plans called for the creation of civil society groups—the AIDS associations—under the purview of a new government organized NGO known as MONASO (the Mozambican Network of AIDS Service Organizations).

Heavily funded, issued under the guidance of the World Bank, and inviting increased involvement from international institutions like UNAIDS, the PEN plans saw renewed interest in the AIDS response on the part of national political leaders, and was raised, in many ways, to a bureaucratic level higher than the Ministry of Health itself (Harman 2007; Hanlon 2004). The justification for this, that AIDS was an international development issue and a challenge to the governance of the nation, placed the AIDS response firmly on the agenda of Mozambique’s ruling FRELIMO party. As a former Marxist-Leninist regime, FRELIMO has a long history of orchestrating centralized planning programs for the nation. Since independence from Portugal, FRELIMO has remained in presidential and parliamentary control of Mozambique. The projects

the party pursues have always tended toward “high modernism” (Harvey 1991) and, particularly before the civil war with the armed guerilla movement known as RENAMO, included previous successful efforts at universalizing education and primary health care on a national level (Chabal et al. 2002). FRELIMO was one of the first to adopt the WHO’s recommendations on Primary Health Care in developing nations in the late 1970s, making Mozambique a leader in immunization campaigns against diseases like smallpox, tetanus, and measles, and with about a 90% coverage rate for the nation’s population—a figure almost unheard of in the region (Isaacman and Isaacman 1983). The day hospital system, likewise, was unique in southern Africa. Like cancer units or children’s hospitals in developed nations, where specialized treatment can be provided for select populations, AIDS patients in Mozambique had their own wards, what might loosely be called ‘centers of excellence’.

It was in the real world setting of the day hospitals that AIDS support groups first began to appear. Already a privileged site for partnerships between the government, NGOs, and multinational institutions, the AIDS clinics served also to bring patients together on a regular basis and enabled the formation of the kind of civil society called for in the country’s strategic plans. Multinational institutions purport that AIDS patients are useful in the clinic. UNAIDS calls on them to advocate for themselves, to assist in the delivery of services, and to mobilize communities, especially to facilitate faster treatment uptake and less program dropout (UNAIDS 2012:36). Clinicians believe they contribute to ‘task-shifting’ (Bemelmans et al. 2010) alleviating the burden on healthcare staff by counseling new patients and preventing service related bottlenecks in overcrowded clinics. It is commonly suggested that AIDS patients can be treatment supporters, and assist with a range of clinical duties including the filling out of forms, counting patient’s pills to measure adherence, and providing ‘directly observed therapy’ for one another—the so-called “buddy” system (Brinkhof et al. 2010; Harries et al. 2010). A couple of AIDS patient

groups had been around in Mozambique since before treatment was available. Kindlimuka in Maputo and Kubatana in Beira were formed in the late 1990s. However, limited to large cities, predominately with a prevention-oriented agenda, the day hospitals were the real seedbeds for the additional growth of similar groups. Treatment, and its expansion, gave them a better defined meaning and purpose. NGOs, like Doctors without Borders, who were familiar with the activities of South Africa's Treatment Action Campaign, and government bodies, like Mozambique's National AIDS Council, under pressure from the government to carry out "dynamic projects" (Matsinhe 2008) and make civil society happen according to plan, pushed for the creation of more Mozambican AIDS associations, and they began to grow in number.

Encouraged by NGO and healthcare staff, Mozambican AIDS associations began to form in the day hospitals. When I first arrived in 2007 there were more than a dozen of them in Maputo. Most of these were small, consisting of 10 to 20 members. They had meetings at their local day hospitals, and worked within the bounds of their neighborhoods. The Military Hospital and the Alto Mae Clinic (run by Doctors without Borders) are two examples of where small AIDS associations sprang up. Others, larger groups, like Kindlimuka, the country's first AIDS association, have their own office and run several projects for their members, for income generation, and for home-based care of patients on ART. Mozambican AIDS associations, especially the ones affiliated directly with RENSIDA (the national people with AIDS network, funded by UNAIDS) operate under a state-imposed structure. They have reports to fill out and data to submit. They have what are called general assemblies, where leaders including presidents, vice-presidents, secretaries, and treasurers are elected. This is the model set out for AIDS civil society in Mozambique. It is bureaucratic and formalized. Because it lends itself better to funding, AIDS patients who form support groups often seek to become official AIDS associations, to be

recognized by the state, and therefore capable of participating in state or NGO sponsored projects.

First Impressions – Getting to Know Caridade

Throughout this dissertation I draw on data from many AIDS associations, eight, to be exact, just in Cabo Delgado Province. Yet, they all echo and mirror what occurs within Caridade, the region's first AIDS association and the one with which I had the most intense and secure relationship. I present Caridade as the prototype, and indeed the default leader of these other splinter groups. Many basic traits remain the same across them all. The situations I discuss can safely be extrapolated to the national context as well, particularly for the smaller groups not operating as 'flagship' examples of AIDS associations in larger cities. According to this formula, the Mozambican AIDS association is both support group and civil society, oriented toward mitigating the impacts of the virus for its members. One of the biggest concerns for AIDS patients everywhere is the threat of stigma from the community and from families. As a support group, the association exists to offset the danger posed by being socially outcast and the fatalistic outlook on life that can result from that (Roberts 2008). For AIDS activists, the association is supposed to be a harbinger of human rights, to function independently from the state, and be self-sustaining (Grebe 2011; Hayden 2012). My first encounter with Caridade, in 2007, involved only a brief introduction of two weeks. During my interviews with members I asked a series of questions about the AIDS patients in the area and about the group—how it came about, its relevance in their lives, how they helped each other stay on treatment. What I found was that these dual roles—of support and activism group—were more difficult to reconcile than it might seem.

Statements made during these initial interviews echoed a theme of hope, but to varying degrees. Some people benefitted more or less than others from the work and efforts of the association. Caridade had about 60 enrolled members at the time. Antonio, the president,

provided me with a list of interviewees representing a wide range of members, of various ages, genders, and lengths of affiliation. Solidly connecting members' experiences was a change from poor to good health once treatment began. The sense that there are many other people 'out there,' in the city but especially in rural areas, suffering the same kinds of tragedies that Caridade members did—laying in bed for months or even years completely unaware of what ails them—was strong and provided purpose and direction to the group. There was an atmosphere of gratitude, to the hospital, the government, and NGOs, accompanied by a commitment to recruitment, equally shared by group members, paid and unpaid. Financial and other opportunities opened up through the association. Besides small salaries (ranging from US\$50 to US\$100 per month, depending on the activity), there was a communal garden, and the group was raising goats for sale. Talk of a reduction in stigma around the virus and people who live with it was common.

Several members stated that encouraging other AIDS sufferers to get tested, start treatment, and stay on it had become a personal goal for them and a responsibility:

“Before, people were scared. If you were positive, it meant death. ‘AIDS kills,’ that’s what the billboards [along the highways] said. Now people are opening their eyes and are thankful. They are following the path to the day hospital. Discrimination is reducing, it’s not like it was before, back when people thought that you can’t eat together. There are people who don’t want treatment, and the association [Caridade] is charged with helping to find them. Some try to hide, but we talk to them. It has to be like this—‘let’s go to the hospital together’—to advance treatment. With our help the numbers are rising. In ten years, they probably will have already cured this [HIV/AIDS], that’s what I think. Caridade exists so that we can show our faces. Some people here that you talk to [in the association] will tell you that they don’t receive anything. They do it for the love of the job.” (Interview July 25, 2007, Pemba)

“A long time ago, people did not want to go to the hospital—*nada!* (no way!). But we got used to hearing it on the radio. We didn’t have support [funding or jobs] then, we would just go to the hospital and educate people. We sat together for so long, then we thought ‘let’s make an association, as positives.’ We had heard that in Maputo, there is an association, in Quelimane, there is an association, in Nampula, there is an association, so that’s also why we’re here. At first, we were just ten people. We presented ourselves to the government, and they accepted us.

We first got help from the Núcleo [Provincial AIDS Council], from a Portuguese woman there. The governor's wife was like our mother, encouraging us, helping us with projects. Now, discrimination has stopped, it's not a big problem, but that doesn't mean people are taking the pills. The number of people on treatment is low because everyone thinks HIV means death. They don't know that the pills can make you *bom mesmo* (very healthy). Like me, I stayed in the bed one year, basically dead, unable to move, like this [he feigns collapsing in his chair]. We are asking for more help, to expand treatment. Things like our garden, because it helps to expand treatment. For Caridade, we can't get tired, we have to support people not to stop treatment, not to refuse to get tested. Partners [the government and NGOs] need to help us not to get tired, so that people don't abandon their treatment." (Interview, July 25, 2007, Pemba)

Further conversation revealed a different conception of stigma, specifically concerning what a 'reduction' in stigma was intended to achieve.

The man just quoted, when asked if his family knew about his illness, told me "No! They do not know. That would not help anybody." Stigma reduction and social acceptance of persons living with the virus are separated out:

"Stigma is decreasing, but I live with this as a secret, my family doesn't accept it. Our province is the last one to get this [an AIDS association]. We feel discriminated because of this. And some [in the community] say that this association is a joke, that it means nothing. So, this is the kind of discrimination we are fighting against—not the virus, but our right to meet together, to discuss our illness." (Interview, July 25, 2007, Pemba)

Attempting to further understand the reasons why Caridade existed, its purpose and how it functioned as a source of support, members continued to identify solidarity among patients as a tangible result:

"Caridade is the focal point for all of the other groups that are starting to appear now—in Mize, in Montepuez, in Moçimboa—they all started here and their leaders used to come to our meetings. They are all part of Caridade. We are in these groups to share. There is no competition among us." (Interview, July 26, 2007, Pemba)

"The objective is to associate, otherwise, people have no place to talk, to learn. We formed this group to help with these necessary things—because many people died before, when they would arrive too late at the hospital. There were few of us when we started, but the government saw the advantages of working with us and began to warm up to the idea. The Núcleo gives us money to feed members, to plant in our garden, to buy goats, and sewing machines. So, it is good. We get to work

together, to teach children in the schools, and to give lectures in the communities.” (Interview, July 26, 2007, Pemba)

Members spoke highly of the hospital, emphasizing the consistent availability of ARVs that had enabled all of them—without exception—to maintain their treatment regimen for several years without any shortage of pills. Any treatment interruptions identified among these interview participants had occurred before they were aware of how important the pills were to their health, or due to logistical challenges such as being far away from the city or other hospitals. Praise for the health care staff was common: “In counseling [at the hospital], they tell you not to stop taking the medication, and the meaning of CD4. Maybe counseling in some places is bad, but not here” (Interview, July 27, 2007, Pemba).

However, maintenance of life through the support group was far from perfect. Complaints centered on access to resources for daily survival, including money and food. ‘Partners’ and other patients were targeted for criticism:

“Now, we have this problem of few donors. People want to come and be members and get something for their lives. They join the association, but then they stay in the home if they don’t get paid. I don’t get paid. I only get a little bit of money from UNICEF for my monthly rent. When I need money for food, where will I find it? The government should find a way to get food to us. With these donors they can get medicine to people, why can’t they get food to them too? I am working to teach these kids [through the UNICEF school program], so I should be getting paid just like a government worker gets paid. I should be getting paid for being HIV positive. This is my opinion. The government needs to look at this. I feel this poverty deep in my heart. How can a girl survive living in a two room house, with a crying baby, and no money?” (Interview, July 30, 2007, Pemba)

“The biggest problem for members is food. Ninety percent of us are unemployed; women are abandoned by their husbands. People live without hope. It is a mentality approaching craziness. Even if you are well educated you have little chance. The donors should give us a little stipend. They trained us as activists, so they owe us that. And, each donor brings their own policy. Some put us on contracts, and we have to be in the office all day, which is not always possible. Others pay small stipends only during a project, when that is over there is no more money for that activist. I think they are scared we will use money poorly, if we have extra. But that is impossible, because you need three signatures just to get the money out of the banking account. There is plenty of oversight in that regard, we

can't steal it. So, now each one fights for themselves." (Interview, July 30, 2007, Pemba)

The idea of being paid to be HIV positive was presented in tandem with the idea that AIDS treatment is a human right, and should therefore be free for patients. Yet, in the opinion of the support group members, there just wasn't enough of an effort on the part of the government and donors:

"The government should pay us—it is our father, the father of us as patients. And, we are poor. We know that we have human rights. This is a big topic. Treatment is a necessity and so also is a human right. It needs to be free because it costs too much. The same thing with food, and a house, we should receive incentives for those things too. Our projects stop because the donors stop funding them. Our garden stopped when the Núcleo stopped funding it." (Interview, July 30, 2007, Pemba)

When I asked more about the Association's garden, it became clear it was a project that hadn't worked out.

The goats, also, had disappeared. Demands from the group to the Núcleo that the government should pay for a night watchman to keep thieves from stealing goats and produce went unanswered. People stopped working in the project because there were no benefits. Members stated that without more money, and more help from donors, Caridade's chances of success were slim: "If Medicos del Mundo (an NGO) leaves, Caridade will fail. It would completely collapse" (Interview, July 31, 2007, Pemba). It was common for people to report shortages of non-ARV AIDS medications, such as antibiotics and anti-fungal prophylaxis, that were not available in the hospital, but only in private sector pharmacies. As one member told me, "I've never had to stop treatment, but sometimes I go without other medications, like antibiotics, for months" (Interview, July 30, 2009, Pemba). Still another, "at times I have prescriptions for medications that are neither in the hospital or the pharmacy, they're just not anywhere" (Interview, July 27, 2009, Pemba). Members of the group felt powerless over the pharmaceutical access situation in Pemba.

Talking with Caridade members and activists in these initial stages of research yielded a mixture of the expected and unexpected. Statements about working together for the good of the community were met with claims that there was not enough compensation or benefit within the association. Claims that stigma and discrimination against AIDS patients was decreasing were met with others claiming that seropositive status was something to be kept secret. Likewise, impressions of group solidarity began to change further when I met one of its most vocal members—Luisa. She had been at an out of town training during the first week of interviews, but would later become one of my main contacts in the group. In the beginning, Luisa seemed to epitomize the prototypical HIV positive human rights activist. When I first met her for an interview, she arrived in a Medicos del Mundo hat—she worked as a home-based care volunteer for the NGO—wearing a t-shirt with the slogan ‘HIV Positive’ written in large letters across the front. Luisa explained to me how the founders of Caridade—those who had been members since its inception, in 2004—were “stuck in their ways, old in years, and afraid to live openly with the virus” (Interview, July 31, 2007). They were often demanding of or oppressive toward newer members, like her. She accused other members of being greedy. “There are some people who just want money,” she said, blaming this problem on the donors. “Before the donors came, we talked to each other, after that [the group] just fell apart. Funds create problems,” she told me during our first interview, looking stern and concerned.

Her awareness of human rights differed from some of the other members interviewed. Without claiming that she had a human right to a stipend or a free house, her interview answers to my human rights questions were textbook material. “The government is very corrupt,” she told me. For Luisa, human rights meant countering the effects of this on AIDS patients by attending government meetings, and speaking out on behalf of those who otherwise wouldn’t in order to maintain the current momentum toward treatment access and equality for poor,

underrepresented people. This kind of attitude was in stark contrast to the impressions I had thus far gotten from Caridade members about the meaning of human rights. Luisa made her colleagues appear unsophisticated. I had previously been told by one man that “the government brings money for us to survive, so we like the kinds of business they do here in the city. Human rights are for me to treat my own things, like my house, or putting things in my store [his personal business], or the government to feed my children. This is human rights” (Interview, July 26, 2009, Pemba). Others suggested that they had the human right to a cell phone. Luisa’s ‘subjectivity’—critical of the government, moving around the city without hiding her HIV positive status—reminded me of interviews I had done with Maputo-based activists, those who were more in touch with international activists and who attended a wide variety of NGO trainings.

Luisa confided in me that she had been unfairly discriminated against by her husband, a man from the Tanzanian island of Zanzibar, who, after having a daughter with Luisa, kicked her out of his home, forcing her return to Pemba. She lamented being away from her only child. “Caridade is my family now,” she told me, and began listing the names of others in the group who she considered her adopted brothers and sisters. Luisa had been in the association for only a year, and already seemed more involved than some of the original members. I believed that Luisa would make a good informant, because she conformed to an idea that I had about ‘proper’ AIDS activists—that they are politically savvy, and outspoken. When she invited me to her home for dinner, I accepted. But, when I insisted that we include Caridade’s president, she told me, “you know, he’s on his way out.” She made a fist, put up her thumb, placed it against her lips, and took a swig from the fake beer bottle that her hand had formed. This was my first clue that Antonio was an alcoholic. Regardless of Luisa’s objections, we made plans to buy some shrimp and crab from the local fishermen, and I invited Antonio to diner with us.

At the dinner the next day, Antonio arrived on his motorcycle and was already inebriated. As Luisa and her sister cooked, he told me how badly both of the women ‘wanted’ him (sexually). “As the president of the Association,” he said, “all of these women (in the group) want me.” Luisa’s uncle, an elderly man, seemed very amused with Antonio’s discussion, smiling and laughing at his words and behavior. The kinds of statements the president was making must have been typical and expected. “You know,” continued Antonio, “Seu Cristiano...we are very poor here. We don’t have anything. I don’t even have enough petrol to get home on my motorcycle.” At this, I became better acquainted with what Mozambicans refer to as a *pedido*—a polite version of begging, particularly targeting someone who is perceived of as having more power, resources, or money than the beggar. To *pedir*, in Portuguese, means ‘to ask.’ A *pedido*, then, is the event or act of asking for something. Either in person or on paper, it is a frequent feature of social relations in Mozambique. It is not uncommon for this to be tempered with *quid pro quo* characteristics—an assumption that some related favor has been or will be done—which serves as a justification for the request.

A *pedido* is formalized and summarized in the common statement, “*estou a pedir...(e.g.) dinheiro*,” or “*estou a pedir...(e.g.) um cigarro*” (lit. I am asking for money, or a cigarette). Culturally speaking, Antonio’s *pedido* for petrol for his motorcycle could not go unanswered on my part—a yes or no was required. The quandary in which this put me was concerning, because as Caridade’s president, Antonio had some power to impact future research with the association. Risk to my relationship with the group was an implication of refusing his *pedido*. Antonio continued to drink, pulling sips from a small bottle of clear liquid that he kept in his pants pocket. A couple of times through the evening, he fell going up and down the stairs into Luisa’s home. I was hesitant to, in any way, enable this man to drive home on a motorcycle. At the end of the evening, I offered to pay for a taxi but he refused. I ended up conceding, giving him money for

fuel, and he left in the dark on his motorcycle which had a busted headlight. Knowing Antonio as I do now, in hindsight, it is highly unlikely that the money I gave him actually went to petrol, but rather to more rounds of *nipa*, the moonshine he liked to drink, instead.

Luisa and I became well acquainted that evening, discussing our lives and dreams with each other. I learned that Caridade would hold a general assembly in October of that year (2007), and she had hopes to win the presidency from Antonio. I told her my intentions to return to Mozambique for a longer stay, and verbally agreed with her to make Caridade a part of the research. She told me more about the battle within Caridade between its founders (like Antonio, and a few of the activists I had interviewed) and its *novos membros* (the new members), some of whom I had also interviewed and spoken with. According to Luisa, the concerted effort on the part of the founders, to keep new members from climbing the ladder of hierarchy within the association, could only fail. She told me that the new members have more education, are more committed, and would not stay *sentado* (sitting around) in their homes, waiting for free handouts from the government. The NGOs that Caridade worked with knew this, Luisa said, and slowly but surely the old would give way to the new.

My initial encounter with this AIDS association yielded several conclusions. Among these, there was the idea that presenting oneself at the hospital and taking pills on a regular basis was not such an easy thing to do. New and undiscovered patients needed active encouragement from other patients in order to start treatment. In addition, the number of those on treatment was steadily increasing. Association members felt responsible for that and proud. Also, other associations were being formed and Caridade's influence was visible. Hence, there was some type of organic growth of these groups occurring, and a place for them was being carved out with more formal institutions—NGOs, and the Provincial AIDS Office (the Núcleo). Caridade had a number of partners to work with, and the types of jobs activists were undertaking varied considerably.

What began in the hospital among a small group of people had expanded into neighborhoods and schools.

However, the picture that was painted for me remained in many ways unverified. A brief visit with Caridade would not have been enough to know the truth. Professed humanitarian motivations—wanting to help others get on treatment, wanting to help the community—were tainted by claims of personal vulnerability, making the association, for some, a type of welfare network. Claims of selflessness, combined with notions of unrealized donor responsibility, seemed to warrant further investigation in light of the understanding that ‘help’ seems to always come in the form of funding or money rather than from within the group itself. Projects, such as the community garden, were presented as happening now and yet already failed, and so caution had to be exercised before ascribing either revolutionary or sustainable potential to them on my part. While I had heard of the camaraderie among association members, and their desires, intentions, and history of helping one another, the formal interview setting and the fact that my trip was quick meant I had yet to witness how this component of the association truly functioned.

Comparing Caridade members with those of the associations I interviewed in Maputo and associated with MATRAM, the fact that Caridade had so many concurrent projects was striking. This has several implications. For one, as alluded to by one of the members quoted above, the group had more than one boss. With plans, budgets, meetings, and activities dedicated to such disparate interests—the hospital and government, the NGO, and RENSIDA and UNICEF (a project which also included the Ministry of Education as co-coordinator)—who is answerable for what and when can become a bit of a mess. I would later find out that these relationships were only the tip of the iceberg. Three other NGOs regularly sought out partnerships with Caridade. One was Action Aid/Pemba, who paid for the office space and other logistical infrastructure such as the two computers the group had. This NGO also sponsored short-term activities in the

community, hiring Caridade members to speak at community meetings and gatherings. This project was called ‘Stepping Stones’. It was intended to diminish stigma by having HIV-positive persons tell their stories and educate local leaders on what it was like to live with HIV.

MONASO also regularly included Caridade in public presentations. As a government-organized NGO in support of AIDS civil society, MONASO would regularly pick up Caridade members and take them to villages or schools in order to participate in meetings, carry out drama skits and theatre, or speak on the behalf of HIV-positive persons. Then, there was FOCADÉ, a branch of the national LINK Forum of NGOs. FOCADÉ worked with Action Aid to ensure that Caridade—and other associations in Cabo Delgado—remained relevant and legitimate. They demanded reports and data from Caridade on a regular basis, attendance at their meetings, and sponsored trainings where members would be sent to other towns and provinces in order to participate in skills transfer seminars, called *trocas-de-experiências* (information exchanges), with other AIDS associations in Mozambique.

This level of apparent sophistication could mean multiple hypothetical realities, and the true ones would have to be teased out by additional research on my part. Either member claims that donors don’t support the association enough were false ones, or the donors were taking advantage of the members and activists by requiring them to spend their time in various activities for which they weren’t well compensated. If neither of these were true then additional explanation on the part of Caridade leaders would be necessary as to why only certain members had jobs or opportunities, and others didn’t. In any case, it was apparent that the abstract concept of activism may have taken a back seat to one of commerce—but this was difficult to tell, because members expressed an interest in both. Certainly, from what I had seen of the multiple and small AIDS associations scattered throughout Maputo and essentially unfunded, Pemba’s AIDS activists’ understanding that their province was somehow behind in progress seemed unjustified.

The coordinator of the Mozambican Access to Treatment Movement in Maputo once told me “we recommend that an AIDS association do one thing only, but do it very well” (Interview, July, 10, 2007, Maputo). But, Caridade was doing many things, almost anything they could to get project funding. One realization from this initial research with Caridade was awareness that this group was not, and would likely never be capable, of funding itself. Caridade, as an association, did not write grants, apply for projects, or compete for funding opportunities based on its own merit. Instead, Caridade looked to other organizations and groups capable of providing the resources it didn’t have, and those organizations that needed a community partner looked to Caridade. The group was not generally antagonistic or critical toward the government. Caridade may not have been as independent as the concept of a free civil society might indicate. Like President Antonio asking for fuel for his motorcycle, the group may, as well, thrive on the concept of the *pedido*.

AIDS Associations, Socialist Legacies

AIDS associations are not the only civil society associations in Mozambique. There are many other kinds—associations of women, of schoolteachers, religious adherents and leaders, retired military, and young persons. Upon independence, the Mozambican FRELIMO government derived many of its political practices from the Russian revolution. The ideal was for the political party to become a ubiquitous presence and, like the political commissar in Russia, for a party member to be present in all activities in order to ensure the proper (non-revolutionary) orientation of any particular group. To achieve this end, FRELIMO activists were installed in the towns and villages of Mozambique. These were the *Grupos Dinamizadores* (Dynamic Groups), party affiliated “community” groups, comprised of FRELIMO enthusiasts and given objectives like organizing the collection of taxes, policing the streets, or promoting health and hygiene in their neighborhoods. Representatives were sent into all areas of the country, and forcefully integrated

into all working environments—supervising surgeons in hospitals, monitoring teachers in classrooms, introducing party politics to soldiers.

At the core of this, one of FRELIMO's many modernization projects, was party control and imposition from the top down. Some branches of the FRELIMO party that still exist today got their start in this manner, with the same function now as in the past, of communicating the party's intentions or desires, and educating the populations they serve—like the Organização da Mulher Moçambicana (OMM, or the Organization of Mozambican Women), the Organização da Juventude Moçambicanos (OJM, or the Organization of Mozambican Youth), and the Organização dos Trabalhadores Moçambicanos (OTM, or the Organization of Mozambican Workers) (Munslow 1986). Drawing on this socialist model, FRELIMO embraced a marriage between nation-building, community intervention, and socio-economic change, but with the political party as the leading force, over and above the individual and even the state itself. Many of FRELIMO's policies were unpopular, which is part of what contributed to a 20 year long civil war (Chabal et al. 2002).

The number one industry in the country, agriculture, was, like all of the others, state-chaperoned as well. There were state-run farms, with inputs like tractors, seed, fertilizer, and pesticides paid for by the government. Many of them were located on the same large plots of land where colonial farms, using *chibalo* (slave labor) from Mozambican indigenous, were owned and operated. Then, there were the farming cooperatives—the closest the government ever came to a national system of communal labor—comprised of volunteer workers who shared farming equipment and implements to work large shares of government provided land. What they produced was the property of the state. The farming cooperatives were considered to be a “movement” (Wardman 1985), bound together by what the government termed *cooperativismo*, literally meaning “cooperationism” (O’Laughlin 2009). Salaries were paid to members of the

cooperatives, who also had access to literacy classes, shops, bakeries, and projects, like brick making, for them to build their own personal economies and homes. The Cooperative Law of 1979 stated that each cooperative should have a constitution, which set out the roles, obligations, and functions of its members. Just like AIDS associations, farming cooperatives had general assemblies and members could run for governing positions.

Wardman (1985) notes that members clung strictly to the benefits of the cooperative, but rarely fulfilled work obligations. Organized into 'brigades,' those in charge were hesitant to carry out sanctions against family members and friends or to mark those who did not show up to work as absent. Many worked just a few hours a month but got paid as if they were full time. Mobilizing people for important work proved difficult and the organization of the cooperatives were poor. Compared to the crops on private, individual plots of land, the cooperative farms were not as well watered, weeded, or harvested at appropriate times. Plans made within the cooperatives were often left unaccomplished. There was an obsession with bookkeeping, with registering the movement of money, sales, and debts, but it was usually inaccurate. Harvests rarely produced a profit. Workers had no significant incentives, and the character of the president often determined the success of the cooperative. FRELIMO possessed a paternalistic attitude toward them, and provided more assistance to pilot or flagship cooperatives, closer to towns with greater traffic and economic activity, in order to show the success of the system. People tended to care much better for their own private farms more than the cooperatives. Producing for others and for the state did not seem to motivate efforts toward quality control.

Skipping ahead 30 years, Wardman's observations appear prophetic. They speak to the dysfunction of state-sanctioned solidarity, and the challenges of implementing a standardized system oriented toward the organization of workers, especially at the community and village level. To include the nation and its people in radical, transformative plans, notes Pitcher (2008:

77), positions the state as “demiurge” over some of the most basic concerns. The focus on big projects, valued symbolically more than practically, allows all parties to turn a blind eye to poor oversight. Plans are centralized, but mismanagement is not, and so there seems to be no one to blame when things fall apart. The AIDS associations would not escape a similar fate. Seeking and claiming insertion in state and also international endeavors seems to carry great potential for adverse effects.

There are, in fact, an inordinate number of parallels between the farming cooperatives of the past and the various Mozambican associations of today. It is even safe to link the AIDS associations more to the farming cooperatives of socialist Mozambique than to the AIDS activist groups in neighboring postcolonial countries. Some of these parallels include a reliance on external inputs—donors, now, as well as the state—and on the driving personalities of leaders such as the presidents. The emphasis also on projects, such as prevention education, public or hospital lectures, home-based care, or the distribution of medications or products to sick people, suggests that AIDS associations must be ‘productive,’ fulfilling a specific role for the state. AIDS associations in the larger cities or towns—flagship projects for their partners—receive the most attention, visits from foreign dignitaries or program coordinators in order to make a good impression. Representatives of these associations have seats at the figurative tables of decision making, at the donor sponsored meetings in Maputo and at trainings abroad, as community representatives, stand-ins for the nation’s population of seropositive persons. The associations that participate in this, and toe the party line—like Kindlimuka in Maputo—are ‘selected in’ to this process. Those that don’t, like MATRAM, the Mozambican Access to Treatment Movement (Høg 2006), whose only project is holding the government accountable for treatment provision, are ‘selected out,’ barely known by the donors and multinational institutions because of poor visibility at governmental functions.

Like Mozambican citizens just after the country's independence, AIDS patient-activists now are under the influence of similar types of *grupos dinamizadores*, state supported community interventionists that emphasize and insert the ruling party's ethos into everyday life. These include RENSIDA (the National Network of People Living with HIV/AIDS) and MONASO (the government-organized NGO overseeing AIDS civil society). AIDS associations are expected to strive for and conform to a national system of *associativismo* (O'Laughlin 2009), which literally means "associationism," encouraging them to band together around a cause, which is in this case the empowerment of AIDS patients, or AIDS activism, for the better functioning of healthcare efforts on the part of the state and its partners. Experts and trainers on how *associativismo* should work in the country are sent to educate AIDS associations on how to relate to one another, and how to lobby the state for their needs. NGOs are asked to participate by offering AIDS patient groups projects, salaries, and benefits. These influences have the effect of shaping AIDS civil society, absorbing it, and reissuing it back into society after it conforms to a particular standard. Like the farming cooperatives before them, there is deference to this paternalism—a lack of local level motivation—leading to absolution of responsibility such that projects do not produce as they should. Patients take what they can get and do not complain. They have little vested in the venture, because what binds them is not so much their illness as allegiance to an external power, one that appeals to the building of their own personal economies rather than to the moral economy or success of the group itself. *Associativismo*, as we will see, puts AIDS activism on the fast track to obsolescence, making it a cog in the wheel of state interests, and appealing to desires of careerists.

Chapter III-AIDS Associations in Cabo Delgado Province

Introduction

In this chapter, I focus on the AIDS association as an institution by delving further into everyday life for the group called Caridade. I will describe and analyze some meetings, trainings, and encounters that occurred for the group, using these data to highlight certain findings about AIDS civil society in Pemba City. This chapter contests understandings that civil society groups are united, that its members act in solidarity, and that the group can be independent from prevailing structures and ideologies. While AIDS associations form part of the city's "therapeutic landscape" (Gesler 1992) they are, through involvement with particular development or health projects, drawn into an organizational culture that parallels that of the state and its partners—what DiMaggio and Powell (1983) call "institutional isomorphism." While the group should be free to pursue advocacy, social support, and political expression for people living with HIV in the area, its usefulness to a variety of actors rather enslaves it, limiting its organic growth. Efforts by donors, decision makers, and leaders to capacitate the group lead to conflicts, arguments, and fission. External interference—efforts to 'help' the group—might be welcome if it wasn't as inappropriate, superficial, or misplaced as it seems. Instead of contributing to or empowering the situation of AIDS patient-activists in the city, the group's involvement in projects and politics leads to what I will call "civil society existentialism." Expected to 'run' itself, but also respond and conform to assistance from others, the group and its donors both become disenchanted. Yet, they all continue on the same path—toward bureaucracy and economic goal setting—expecting different yet better results from preconfigured formulas which link political progress, practical forms of activism, and international development together in ways that limit the potential of each.

Of Offices and Organigrams

Arriving back in Pemba and becoming reacquainted with Caridade after almost two years away, I discovered that Luisa had lost her bid for the presidency. Antonio, the day hospital nurse who helped found the group, won a second term in office. I was a bit surprised to hear that. “At first, we tied,” Luisa told me, “wow, did he cry. Everybody felt very sorry for him. When the votes were recast, he won by one vote.” “So, you are the vice-president now?” I asked her. “I am the vice-president,” she replied, “but we will have another *assembleia* (election) this year, and there is a two term limit. So, he has to step down.” Luisa told me that everything was going well for Caridade, that the projects were continuing to develop and partners continued to fund the group. I knew, however, from conversations I had with activists in Maputo, that funding for civil society groups like Caridade was diminishing. The coordinator of MATRAM, César, also told me about how the closures of day hospitals happening in the country were creating problems for treatment access. Soon there would be no day hospitals—this is one important place where activists have jobs and carry out their work. Patients were also affected. “Some have already stopped coming for treatment,” said César, referring to clinics in Maputo (Interview, February 18, 2009, Maputo). So far, Pemba had been spared. Nobody was certain when the AIDS clinic here would close.

If you’re looking for the AIDS association called Caridade, the office isn’t easy to find. It is surrounded by a tall, white-washed cement brick wall with the words ‘*Latrinas Melhoradas*’ (VIP Latrines) painted on the outside. It is housed in the same compound as a state-run initiative designed to help city residents upgrade their outhouses with concrete floors, asbestos roofing, and deeper pits. The entrance is guarded by a large solid metal gate. Upon entering, immediately on the left are three model latrines, used to show off the handiwork of the *Latrinas Melhoradas* project. In the back rests a fleet of broken down vehicles—some lorries and military jeeps. A businessman pays the government to house them here so that he can use them for spare parts. In

the late afternoon, after Caridade closes its office, the compound also hosts literacy classes for adults, an educational initiative to make up for internal displacement and scholastic face time lost during the civil war. To the right is the single-story, tin-roofed facility in which Caridade rents two rooms, one for members, and another for management. There is a cement patio, well shaded by trees, just outside of the door for members. Nailed to it is the only indication that an AIDS association operates here—a piece of construction paper with the words “Associação Caridade” (Caridade Association) in wide tipped black magic marker.

Inside there is a telephone that works intermittently, depending on whether the bill has been paid. Sitting on a desk is an old computer that doesn’t turn on. It’s a metal shell, a monitor, and keyboard. The last man who came to repair it stole all of the parts inside but sent a bill to Action Aid, the NGO who pays the rent and utilities for the office, as if he had actually fixed it anyway. There’s a trash can in the corner with Action Aid’s name on it, and no other indication of the NGO’s involvement. Taped to the walls are AIDS awareness posters and ads for condoms. One of them features an oversized, smiling cartoon condom handing out smaller versions of itself to teenagers on a soccer pitch. On a table in the corner sits a shoebox with a slit on the top, always empty, where members can insert money to pay for “*cotas e joias*” (membership dues and fees). There are a couple of wooden benches and a few plastic chairs around. Carlitos, Caridade’s spokesman and my research assistant, brings them out onto the patio when he opens up the office in the morning. It is there, under the shade of palm and papaya trees, where members and visitors are received, usually first by Carlitos. The other room, the one for management, is usually locked. That’s where the money for salaries and project expenses is kept, and two working computers, one for balancing the budget, and another for entering data and writing reports. Bakari, the accountant, and Fevereiro, the group’s secretary, spend the most time in this room, at their desks. There are some books and training materials on a shelf in the corner, a couple more posters on

the walls, another bench, and a reed mat. The group sometimes hosts small trainings or meetings in here if the weather outside is uncooperative.

Caridade's office, in the Latrinas Melhoradas compound, is nestled in the center of bustling *Bairro Natite* (the neighborhood of Natite), close to downtown Pemba and not far from a small health clinic and a Ministry of Health training center. It's often relatively quiet. But in spite of how cozy one might feel seated on Caridade's patio discussing Mozambican politics or some such topic, the noise just over the wall can occasionally be deafening. It rises and falls in relation to the volume and speed of motorized traffic passing by on the road outside, and according to the level of music blasting from the roadside *barracas* (small stores) just across from the entrance gate. The road is only wide enough for one car, or two motorcycles and some pedestrians. The latter have to dart out of the way whenever a car horn sounds or risk getting struck, as visibility through the winding network of unpaved roads is poor. The road is mostly sand, but that doesn't keep small rivers from forming on it and running downhill toward the ocean (only a kilometer away) during rainy season, crafting pitchfork-shaped ravines and making the paths difficult to navigate and unpredictably uneven from day to day.

A lot of what seem like small and disconnected events occur in Pemba's *bairros*. Foot traffic is heavy in Natite because it is on the way to Pemba's largest open-air market, Banguia. But, this bairro and places like it are more than just crossroads where people travel from point A to point B. With all of the bamboo fences and concrete walls one might get the impression that privacy is respected, but that's something of an assumption. A lot of visiting, a lot of *bate-papo* (casual conversation) goes on behind these walls. Walking or driving along, there are gaps or cracks and you can usually catch a peek through to the other side, into people's homes and yards. People stop and *do* things around here. It's a thriving community rather than a simple thoroughfare. The houses and businesses—barber shops, bike and motorcycle repair huts, women roasting snack

food and selling home-made brews on the street corners—represent data points and destinations in people’s lives. Those who are supposed to know about it know that Caridade’s office is located here. For some, it is on their list of places to go. For others, unaware but seeking, they find their way to the association in what Mozambicans refer to as *qualqueira maneira* (in whatever way)—asking around, being brought or referred by a friend. But, there is no publicity about Caridade, no signs or advertisements that might signal its existence or purpose to the outside world.

The office compound, in fact, functioned very much like a drop-in center for the association’s members and their neighbors and friends—something like a social club but with pamphlets and booklets on HIV/AIDS. A steady stream of one, two or more people could always be found conversing on the patio. Conversation topics did not always have to do with AIDS. Most centered on other aspects of survival and life in the city and the province. Women arrived and discussed their home life, including arguments with husbands and boyfriends. Men talked about their wives, children, and girlfriends, or how a particular job search was going. Complaints about the government, NGOs, or certain people working with the association were common. Caridade’s office, in many ways, was a valid part of Pemba’s “therapeutic landscape” (Gesler 1992; Bell et al. 1999). As an in-between place, not the clinic but not the home either, it served as another “sphere of the life world” (Kearns and Collins 2000) for members to sustain their personhood. While Pemba’s day hospital was certainly a part of people’s medical lives, the office served as a site for addressing other, more mundane, and less formal topics related to living with HIV/AIDS in Pemba City. It formed part of what Parr and Davidson call “lived geographies” (2009:263), a place where people find inspiration and develop coping mechanisms within their own small, personal, and transitory “niches” of survival.

On my first full day with the group, I was in Caridade’s office when a Landcruiser stopped and a couple of doors slammed shut on the other side of the wall. Luisa and the others had just

said goodbye to Ana, from MONASO, the state-run NGO, who stopped by under the premise of learning more about the association's action plan for the next year. During that brief meeting she prepared the group for what should have been a surprise visit from Pemba's newest, wealthiest, and most influential NGO, the PEPFAR-funded Elizabeth Glazer Pediatric AIDS Foundation (EGPAF). It's common practice in Pemba for people to give others notice when something either promising or threatening is looming. Ana's visit should have been sufficient preparation for the upcoming encounter, but it wasn't. EGPAF was seeking a suitable community-level partner to continue, and even expand, a home-based care program in the city. Another association was being considered—Bem Vindo, which had splintered off from Caridade a few months back—and this visit was intended to clarify which one had the capacity to do the work.

As the representatives of EGPAF and Caridade sat down to talk about the association's achievements, Luisa told them about the UNICEF-funded school project that the association was conducting. It had expanded into other districts, making Caridade a province-wide association. The EGPAF workers listened to her summary, and then proceeded to ask a series of routine questions, focusing on the association's demographics, budget, and number of people served through its projects. One of them then presented an organigram in the shape of a pyramid. Showing this to the Caridade as an example, it had at the top a fictional president. One level below were the positions of vice-president and president of the assembly. Other positions, including the secretary, treasurer, vice-secretary, and vice-treasurer occupied lower levels on the pyramid. Members formed a generic base block at the bottom. EGPAF asked Caridade to provide its organigram. Could they have a copy for their files? Where was the association's president—this man, Antonio—and could they speak with him?

The reactions of Luisa and the others consisted mostly of nervous glances and a brief period of silence. Falume, the President of the Assembly, walked over to another area with a couple of

members and began to talk quietly in a kind of huddle. “For us,” responded Luisa to EGPAF, “the president is in the middle.” She pointed to the center of the paper. Looking at the organigram she said, “We don’t have one of these yet.” She began drawing a make-shift version of the association’s hierarchical structure on a blank sheet of paper. As the EGPAF staff watched her, some brows furrowed. “This isn’t possible,” replied one. Luisa had drawn the chart with the president and the members in the middle, with all other elected positions in a circle around them, and no lines connecting to the president. It was explained that he wasn’t here to talk because he is a nurse in the day hospital, and was currently at work. In reality, he was at or near his home, drunk.

The air was palpable with tension as the association realized that the absence of president and the lack of an organigram were two strikes against them at the outset. The conversation—what really amounted to an interview—continued but changed slightly to the form of an audit. Fevereiro was asked to produce the reports of activists and examples of documents turned in to UNICEF and Action Aid. Bakari was asked to produce printouts of the budget from the past few months, receipts from purchases, and bank account statements. At this point, questions became more specific. Why are some reports completely filled out and others are not? Why are there no minutes from the group’s meeting last January? At these targeted inquiries, Luisa appeared visibly angry. Her answers became curt, and it seemed she would be happy to just walk away from the scene.

That’s what a few Caridade members did, including Falume and Carlitos, who I saw stroll out of the gate and onto the street. As the questions continued and they didn’t return, I too went out of the compound to see what was going on. I found them at the *barraca* across the road—a bar-like structure complete with stools for clients on the outside—talking to the owner and drinking bottled beers that he kept out of sight for them behind the bar. He would hand them over when requested for the two of them to take quick sips before returning the bottles to their hiding

places. Falume began complaining to me about the meeting. “These people are not serious,” he told me, “they’re just trying to catch us in a lie.” Carlitos told me what he thought as well. “They already have all of this information,” he said, “They can get it from Action Aid, or from FOCADE, or MONASO, or Medicos del Mundo [all partners and donors of the group]. This is more of a formality for them to be able to tell us no.”

While the group’s response seems immature—Luisa’s impatience, the president’s absence, leaders like Falume and Carlitos abandoning the discussion—it may also qualify as an act of resistance to what DiMaggio and Powell (1983:150) call “coercive isomorphism.” This refers to the formal pressure placed on less powerful groups by more powerful ones, so that they adopt the same structures as other ‘units’ similar to them in purpose or function. In this encounter between donor and local group, the implication is that a contract and related financial graces could be provided, if the group conforms to outside expectations. Whether or not the structure suggested—the organigram, with its theoretical hierarchical pyramid—is appropriate for the group or not, Caridade’s inability to produce anything like it is an indictment. It means the group does not meet the same environmental conditions as others, and, perhaps cannot be trusted. If Caridade doesn’t conform to this specific programmatic regularity, it may not be likely to conform to others either. This type of direct imposition, this “coercive isomorphism,” is just one way in which groups tend to become like other groups—what DiMaggio and Powell (1983) call “institutional isomorphism.” Groups, like Caridade, can become standardized and less diverse in other ways as well.

One other way is through “normative pressure” (1983: 152). This refers to how socially embedded mechanisms—education, professionalization, and political influence—dominate and define the accepted methods and conditions of particular lines of work. When “normative pressures” are at play, those groups with better visibility, more wealth, donors, projects, and

partners hold significant sway over the development and evolution of others, who are under pressure to conform in order to meet with equal success. Normative pressure is the realm of careerists. Those with more impressive titles, name recognition, branding, or marketing tactics attract more attention and generate more ‘work’. ‘Selected in’ to a particular industry—like AIDS activism—the structure of the group and its techniques for problem solving become the accepted standard. For other groups to deviate from this is risky, because alternative methods are not believed to be effective. What this means for Mozambican AIDS associations is that the drive and motivation to become involved with NGO or government projects is viewed as healthy and helpful to the group. This can not only be divisive—inspiring allegiances outside of the group itself—it can also create an environment positioning the group as a resource for opportunists. What we will see is that in Pemba, where wealth and opportunity are scarce, normative pressures allow the group to orient itself more toward benefits or commerce than to solidarity, handicapping its ability to adjudicate or moderate internal conflict.

Reputations – Meetings, Conflict, and Slander

As it turned out, Caridade would not be awarded EGPAF’s home-based care contract. The new association, Bem Vindo, would be the recipient. As other AIDS associations sprang up with whom they could work, NGOs in Pemba were beginning to cut ties with Caridade, Pemba’s first AIDS association. The group was not perceived as very hard working. The coordinator of Medicos del Mundo, the NGO that initially worked closely with Caridade and even helped fund its startup, had, just a couple of years ago, encouraged me to come back and study the AIDS association. Now I was being told that it had irresolvable internal problems, and that I shouldn’t work with them at all. “There are certain members who we believe are crooks,” he told me (Interview, Pemba, April 28, 2009). The NGO had even banned some Caridade activists from attending their trainings, and funded the startup of the new association, Bem Vindo, to work in their community service

projects as an alternative. The head of MONASO blamed Caridade's downfall on project funding. He had seen it before with associations in other provinces, and told me that "these groups tend to be torn apart as they come into money, especially if the projects are big enough to where people can choose camps" (Interview, Pemba, May 12, 2009).

It wasn't always like this; Caridade used to have more respect. The president, Antonio, in spite of the alcoholism, was considered a brilliant day hospital nurse. Fevereiro and Bakari appeared on Mozambican television, letting journalists into their homes to report on the situations of AIDS patients. Carlitos had regular engagements on the local radio station, talking about the importance of AIDS testing and the effects of treatment. Luisa attended Ministry of Health meetings as a stand-in for AIDS patients, and appeared on stage at political rallies, giving speeches about how the government needed to treat AIDS patients better. Members often reminisced about the old days. Fevereiro recounted this story about the association before they had NGO funding:

"Brada (brother)! Back in those days Dr. Cesário would come here and pick us up, three, four or five of us, and take us to the [provincial health] training center. This was what he did when the new nurses didn't believe anyone with HIV would actually tell someone else that they had it. We would sit in front of the class, drinking coca-colas, and answering their questions. How did we get it? What do we do about it? How is it possible that we're even surviving?! I tell you, it really opened their eyes [he gestures as if he is opening his own eyes with his fingers]. This is what we liked to do, be seen and open up people's eyes" (personal communication, Pemba, July 12, 2009).

Talk of what Caridade used to be was common. "People, residents from this neighborhood, used to bring their children to us," Falume told me, "and we would take them to the hospital because they were scared to go." The subject came up because we had a small visitor who had wandered into the office compound with a couple of his friends. Motioning for the child, who was maybe eight or nine years old, to come closer to where we were seated, he put his arm on the boy's shoulders and continued:

“This youngster here almost didn’t make it. His very father is a member of this association—HIV positive—but wouldn’t take the child for treatment. Now look at him! [The child smiles at Falume and glances sheepishly at me] Look at his arms! He’s healthy. Now, bring me some of these people who say Caridade never did anything for anybody” (personal communication, Pemba, April 2, 2009).

After a few weeks with the group, I began to understand more about what happens, on a daily basis, around Caridade’s office. Some activists only showed up on payday. Others, usually unpaid, treated the office like home. Formal meetings rarely happened. The monthly meetings that the association claimed on its progress reports were fabrications. By the time an association-wide meeting was called I had been in Pemba for three months. A supervisor from RENSIDA in Maputo was coming to collect data on the UNICEF project, and expected to attend a group meeting. It was the morning of May 9, 2009. Most members were there, but neither the President nor the Vice-President was present. Falume, President of the Assembly, laid out the agenda. First, talk about Action Aid money and a new project that would be implemented. Second, talk about Christian (me) and the purpose of his research. Third, discuss the UNICEF project with Gibson, who was here from Maputo—but, like the other leaders, also wasn’t present at the meeting.

The yard was full of about 50 people, some crowded onto the few benches and chairs, but most of them standing. I recognized about half of these, who made regular appearances at the office. Many others were familiar from my pre-dissertation research in 2007. I was offered a place on a bench because I was going to be speaking. The atmosphere was peaceful as Falume told the group about ‘Stepping Stones,’ an Action Aid-sponsored program for members to have meetings with neighborhood associations all over the city. Invitations would be sent to the *Presidentes dos Bairros* (neighborhood presidents), who would set up locations for the meeting to occur. The topic would be ‘living positively with HIV/AIDS,’ and Caridade members would facilitate the discussion. Drinks and snacks would be provided. So far, the members were quiet and there were no questions. Falume asked me to introduce myself, and I gave a brief summary of my research

goals—to investigate the importance of HIV treatment, and the role of the association in the lives of its members. I discussed my nationality, university, and role as a student and anthropologist. Some people nodded their heads, and others appeared completely disinterested. I sat down and Falume asked if there were any comments.

Hands shot up and murmurings came from the crowd. At first I wondered if the comments would be about me, but they weren't. Simao, one of the association's founding members, stood up and spoke:

“There are some people in this association who think they are better than others. Let me just remind everybody that activists are not members, so they shouldn't get the same things that members get. We don't need this kind of language where people put each other down. What I mean is that some activists have said ‘I am the coordinator of such and such a program, and others don't mean anything to this association, and I can take money when I want.’ Some of us have been here for a long time, and we are being left out when we are supposed to get things.”

The previous evening, Simao had called what he termed a “founder's meeting,” that took place at the office, where only original members of the association were invited. It was about some bicycles that were given to Caridade by Action Aid, and distributed to certain members without the consent of the entire group. Simao and his friends didn't get one, but others, including the leaders and the activists, did.

A number of people at the current meeting were upset about this perceived unfair transaction, and the noise level rose considerably after Simao's comment. As Falume tried to quiet the crowd, the association's president, Antonio, walked in the entrance to the compound. He was wearing a white shirt with the phrase ‘follow the leader’ in red written in English across the front. Antonio's gait made me suspect what I later confirmed with Carlitos—that he had been drinking. He took a seat next to Falume up front, aware of the nature of the protest but not of Simao's exact comments, and began directing the meeting:

“What we need here is honesty and equality, and for people to be serious about the work we are doing in my, I mean our, association. I say our association because we

all know that associations are composed of many people. Now, normally there is no way to know if people are lying until we catch them. But, I am the president here. I know things that others do not, and I have certain rights that others do not. I happen to know that there are some people robbing money [He looks directly at the accountant, Bakari]. When this sort of thing happens, they will be taken out of the association, just the same way as it happened last time.”

At this statement, shouts of anger arose from the group that elevated emotions even higher than before. In part, this was a direct response to the threat of removing people from the association. It was, additionally, outrage at a direct violation of what Simao had just acknowledged—that some people think themselves better than others. The president himself had received one of the bicycles in question. Zealous, Bakari the accountant stood up and accused the president of walking directly into his office and taking money out of the association’s coffers. He was rebuked by the president and stormed off of the patio into his office.

Another member, Ana Maria, stood up and began denouncing what she claimed to be unfair treatment. Returning from visiting family in Maputo, her paid activist position was taken by someone else and she found herself unemployed. “I told Luisa [the coordinator of the UNICEF school project] that I needed to take this month off, but when I got here this one [she points to Bryson, seated next to me] was doing my job.” Bryson, not HIV positive, and new to the association, was Luisa’s younger brother. The implication was that his appointment to her paid activist position was an act of nepotism. As Ana Maria continued to defend herself, Bryson asked to borrow my phone and sent a text message with it. A few minutes later Luisa, who had been absent from the meeting (Bryson told me she was sleeping), stormed into the compound, fingers raised, and shouting. She directly confronted Ana Maria and the two traded remarks in Makua. Others had to break the two women apart, and palpable tension grew throughout the yard.

Because of this confusion I slinked off of the patio and joined the crowd of youngsters in the back near the latrines and farthest away from the melee. There were about eight of them, all teenagers, who had joined Caridade as a drama group for AIDS prevention education. They had,

in fact, just won an award for a skit they carried out at a government function on Mozambican Women's Day. The prize was a length of *capulana*, that colorful and patterned African material so commonly seen wrapped around the waists and heads of women. It was enough to either make a series of matching outfits for the drama group, or sell in the market for a small sum. However, President Antonio had stolen it from the office. Against the protests of Carlitos and Falume, he had strapped it to his motorcycle and driven away with it a few days ago. The President frequently helped himself to items in the office if he could sell them to fund his drinking habit—phones that people left in the office to charge, notebooks, power cords, an electric fan. He had, in the recent past, helped himself to project related items also, a soccer ball and a box of pens otherwise destined for schoolchildren in one of the northern districts. Given his behavior, it wasn't difficult for me to believe Bakari's claim that Antonio helped himself to the money in the office as well.

It wasn't difficult for me to believe that Ana Maria had been unfairly removed from her activist job in favor of Bryson either. Over the couple of months I had been conducting ethnography with the Association, Luisa's absence was more common than her presence. Seeing her or speaking to her required going to her home or calling her phone. She showed up in the office predictably on payday, or when important visitors made appointments with her. When letters arrived to the office, she demanded they be brought to her home for her to read, responding directly in the name of the group and without consulting others. I would occasionally run into Luisa at government meetings, or in the offices of the Núcleo or of MONASO, talking with the bosses. She could also be seen taking taxis around town, and sometimes would disappear for days. We would later discover that she had been sent for some kind of training in another district or another province, in the name of Caridade, but never reported back to the group about the results or information being passed along. The normal process for the group to select who was chosen for these kinds of engagements was always bypassed. In order to continue spending time

with Luisa I visited her frequently in her home, where discussion centered on AIDS politics in Mozambique. However, I noticed she also had developed a steady drinking habit. One evening, she tried to sleep with me and I refused. After that, our relationship never fully recovered. Ana Maria's complaint against her today was a synthesis of what the group wished they could tell Luisa—that her antics were obvious and that she was using the group to install her own friends and family members into paid positions. When the president, Antonio, wasn't treating the association as his own personal bank and private resource, then Luisa, the vice-president, was busy driving the group into a state of oligarchy.

As I pouted in the back with the teenagers, I realized that Gibson, the boss from RENSIDA in Maputo, had quietly joined the meeting. It seemed that others began to recognize his presence around that time and the loud, disrespectful remarks ceased. He didn't speak at first, he just leaned against the wall. I thought he was playing with his phone but later realized he was taking notes. As attention settled on him he began to speak to another conflict, one he must have already known about because it wasn't brought up in the meeting. It involved an accusation from Antonio that Luisa had stolen money from him. Gibson addressed this by grilling Antonio about particular budget numbers, which resulted in the president floundering on all types of information, destroying his legitimacy relative to the money in question. The President looked foolish, and said nothing in reply. "*Somos iguais* (we are all equal)," said Gibson, speaking again to the whole group, "so what is the fighting really about?" He went on to explain that the association needed better reporting or risk losing UNICEF funding, and appointed three people to collect and compile reports from the school initiative. Later, in a private conversation, Gibson told me that these internal conflicts are not RENSIDA's problem, that they have no control over these issues, and that they are to be worked out on the local level. RENSIDA, even with such interest in the

group's data and project success, apparently espoused a 'hands off' approach to the type of internal conflict that Caridade was experiencing.

Commenting on the famous Northfield Experiments, a study on group psychology that took place during World War II in England, Miller and Rose (1994) suggest conflict within the therapeutic community can be productive for someone—but rarely for the group itself. These experiments were geared toward reintegrating soldiers with neurotic casualties back into the military. The first Northfield Experiment, intended to be an indication of what occurs 'naturally' and without the imposition of structure, involved what were called 'leaderless group tests'. These included the intentional absence of appointed leaders, external direction, or authority, to allow, ostensibly, the qualities of undiscovered or unrecognized leaders to emerge. One unique finding was that the most effective leaders were those more in tune with the needs of the group, and not those with simply the highest military or educational rank (Kraemer 2010). In addition, observers (or really, interventionists) found that by coaching certain individuals—those with stronger wills, or who felt they deserved to lead— they could send them back into the group and repurpose its activities according to their own advantage. The end result was anarchy, infighting, and a more, not less, dysfunctional group than before. Because solidarity was unattained, and group goals warped, the experiment was deemed a failure. This first experiment was aborted after just six weeks. But, as Miller and Rose note, a new type of insight was exposed—"the understanding that the group and its dynamics could now be acted upon and used by others both to reveal and to transform the individuals who comprised it" (1991: 41).

It is striking, in Caridade's case, that the group's top leaders were also the apparent top sources of angst and distress. Antonio, a nurse and an employee of the state, and Luisa, a veteran of AIDS association and activist trainings in the country, were also both most frequently at the center of group conflict. Their motives were highly questioned by the group, leaving it in an

unstable emotional state. It was through its leaders that the group appears most penetrable from the outside. Their positions as program coordinators made them vulnerable to criticism, as they made decisions and statements that came across as nondemocratic and authoritative. The leaders appeared to occupy a rank second to none in a kind of pecking order, and it is this that drew the ire of other members. This feature of the group effectively contradicted the statement of Gibson—undoubtedly an authority figure, and flown in from Maputo—that everyone here was equal. His stance, that RENSIDA did not interfere in these situations, positions Caridade in many ways as its own little Northfield Experiment, complete with the ‘leaderless group test’—the noninvolvement of the country’s national AIDS association leaders in this intragroup conflict.

Another important finding from the Northfield Experiments suggests that the group is not isolated from its surroundings, but that therapeutic communities “have a defined direction of activity which is determined by the social system in which they are located” (Miller and Rose 1994: 44). This is another way of stating that the group is under normative pressures, but takes the concept further—the group is absorptive of and serves to reflect the culture and social forces which surround or inform it. This has obvious applications for AIDS activists in relationship with the state. If the state wants the group to be productive, then that line of thinking will be pursued. If, on the other hand, the state wants an unorganized group—and this actually may have been the case in Mozambique, such that a countercultural activism could not flourish—then the chances the group will be maladjusted are much higher. Wilfred Bion, directly involved with the designs and chronicling of the Northfield Experiments, tells us that the task of those who want to work with the group, in these instances, is to pursue it to the point of disturbing its dynamics and performance (Bion 1991). When that happens, the group ceases to evoke therapy. Instead, it evokes “primitive psychotic anxiety” (Bion 1991:39). In that sense, the shouting, posturing, and arguing over benefits and bicycles in Caridade is incriminating both of the group itself, and those

who support it or use it for the data it provides. The group ‘absorbs,’ to some extent, the practices of African elites—the government. There are normative pressures for the group to *not* be unified, and even for members to cheat or cut corners in their efforts to survive or get ahead.

As I came to work with and know more about Caridade it became clear that some group members engaged in practices of fraud. Two accountants had pilfered the group’s bank accounts and left. Leaders and program coordinators regularly forged receipts for project expenses, pocketing the money. They would claim travel money when travel was never performed. They would punish lower level activists by withholding salary and keeping it for themselves. Income generation projects were pillaged. Community gardens were razed overnight, goats stolen from the project pens, chicken raising projects staged and money claimed, in order for individual members to pay for meager expenses, including household rent or even alcohol drinking sessions. Notebooks, pens, and pencils—supplies for members to attend adult education courses—were sold by the box or packet in the local markets. If indeed the group codifies or mirrors what goes on around it, then, like the Mozambican state itself, and even some of its donors (Hanlon 2004), Caridade promoted and lived a lifestyle of corruption. All of this was considered not only relatively normal and socially acceptable, but even enviable. Other AIDS associations and support groups wanted to be like Caridade. What the group did, its practice of fraud, embodies what, in Mozambican Portuguese, is called *to mafiar*—to defraud others for personal gain. It is a technique, a concept on par with the *pedido* I described in Chapter 2. Both the *pedido* and *mafiar* are frequent practices in Mozambican society. They point to insecurity, what Bion (1991) calls “primitive psychotic anxieties.” Caridade espoused them both, and espoused them well.

It is important to understand the term *mafiar* in order to contextualize Caridade’s position, and that of other AIDS associations, in this society—this is what AIDS activism passes for and consists of on the ground and in the field. *Mafiar* is a slang Portuguese verb in its infinitive form,

derived from what we know in English as ‘the mafia.’ It literally means to deceive others via illegal or questionable practices—but in a particular manner. It implies a concerted effort on the part of a network of individuals, and so differs from the basic concept of being deceived, lied to, or fooled—the term in that case is *enganar*. It differs also from *robar*, the simple act of robbing or being robbed. Let me explain how *mafiar* is different. If I get charged too much from the woman selling tomatoes in the market, this is simple deception. I got fooled—*ela me enganou* (she deceived me). If people break into my house and steal my radio, *eles me robaram* (they robbed me). If, on the other hand, an enterprising businessman buys up a section of beach property that was previously considered off limits to others, and is able, with the blessing of the government and other local businesses, to acquire the proper permits and materials needed to construct a profitable hotel or restaurant, *ele nos mafiou* (he ‘mafiared’ us). He both deceived us, and robbed us, collectively, of something that is not just mine, but ours—the ancestral land in and around Pemba City that is rapidly being taken up for private gain. *Mafiar* combines the arts of deceiving and robbing, and applies it to teamwork. Caridade, and AIDS associations like it in and around Pemba City, were considered by some to be mafia-like organizations. This has to do with their involvement in government and NGO-funded projects—the “institutional isomorphism” of the group with other groups, including the state, viewed as predatory or poised to empower personal economies over collective ones.

If there are indeed “normative pressures” at work on Caridade, we do not need to look far to discern their origin. Jason Sumich’s description of Mozambican parliamentary procedures—complete with aggressive posturing, finger pointing, yelling, and walkouts (Sumich 2008)—is not a far cry from the scene I just described during Caridade’s meeting. In spite of sharp personal disagreements, leaders of the ruling FRELIMO political party maintain their power via access to outside networks of influence, and defending the interests of an upper middle class vis-à-vis other

social and political groups. It is the unspoken claim of these, as Sumich describes them (2013), ‘African elites’—those with the ability to continue developing relationships with lucrative political and foreign actors—that if they lose power then the alternative (RENAMO, or another less well connected political party) would be more corrupt, more disastrous, and less able to negotiate well for the productivity of the country and the lifting up of the masses from poverty. Pitcher (2008) adds to this by suggesting that the Mozambican elite, despite party rhetoric appealing to equality and power to the people, performs well due to back door deals and questionable marriages between government and private sector interests, what she terms “smart partnerships” (2008:140). This refers to the capacity of the government to *mafiar* in Mozambique, as those in power broker deals to sit on the boards of companies invited in to develop the nation’s resources or financial sectors. Like the wider culture around it, Caridade is something of a mafia.

What the Northfield Experiments suggest—that the group is penetrable from the outside, especially through its ‘leaders,’ and that the group is absorptive, displaying or reflecting the society in which it is entrenched—may be evidenced in groups like Caridade and its tendency toward “institutional isomorphism.” But what about conflict? How is that, as the Northfield Experiments also suggest, productive for others, those outside of the group? Why would any entity or actor want to disturb the group’s dynamics or impact its performance? How and why might evoking ‘primitive psychotic anxieties’ be desirable, helpful, or contributory to some other agenda or project? Thinkers and philosophers on neoliberal governance have the answers here: the group does not exist to serve society, or even the group itself, but rather, it exists to serve the market. Criminality, efforts to *mafiar*, and examples of dissent and fission within the group, are perfectly acceptable. As long as it is well regulated, conflict and criminality are just smaller markets within other, bigger ones (Lemke 2001). Certainly, a penal code exists to catch those who break the rules, but punishments meted out are geared toward controlling the environment

rather than the moral inclinations of guilty offenders. The result will be more civil society and not less, more AIDS associations and not fewer, because as long as these groups exist to serve the market—from the perspective of neoliberal governance—they are not at all problematic. Their proliferation, well regulated, controlled, filtered or funneled, is a boon to industry.

Caridade's situation had serious implications for the traditional goals of AIDS activism in the area, revising the evangelistic nature of the enterprise and how civil society transforms the rest of society. When new associations began to form in and around Pemba City they, in many ways, modeled themselves on Caridade, the first group they knew that experienced 'success'. Caridade's many projects and the group's capacity to gain funding, along with its immature capacity for social solidarity, stifled the reasoning of later groups and their innovation in the realm of organizational modeling. A high profile, low functioning group like Caridade may have helped seal the fate of others that were to follow. The president of a group in nearby Mecufi, vying to register with the government and become an official AIDS association, told me that "we want to be like Caridade, at all of the [government] meetings, able to ask for things...they have a good *mafia*, we want to be part of this *mafia*" (Interview, September 15, 2009, Mecufi). Other new groups, like Bem Vindo, who was awarded the EGPAF home-based care contract, took action plans and project proposals from previously successful Caridade documents, substituting their name for Caridade's when submitting them to donors and funders.

Continuing with DiMaggio and Powell's framework for institutional isomorphism, what occurred was "mimetic isomorphism" (1983:151), where organizations model themselves on those they perceive to be more successful or legitimate. This is especially likely when the goals of a group or movement, like AIDS activism, are poorly understood, ambiguously defined, or hedged in by uncertainty. The three facets of institutional isomorphism discussed here—coercive isomorphism, normative pressures, and mimetic isomorphism—were encouraged and supported

by the state and its partners. This is clear from encounters shared during trainings and meetings that associations were expected to attend. What these next encounters that I will describe suggest is that the state does what Wilfred Bion (1991) proposes is necessary to effectuate an unorganized group—pursue it to the point of disturbing its dynamics and performance, in this case by inserting itself only in select ways, but also by withdrawing and being absent in others.

Standardized Civil Society

For government, part of the problem with AIDS associations is that they do not function as well as expected. The state was well aware of the kinds of problems that Caridade and groups like it were having. Manuel, the director of the Núcleo (Pemba's provincial AIDS council office), blamed it on the naiveté of group members. Caridade, he told me one day in his office, “never did understand the meaning of *associativismo*” (Interview, Pemba, April 13, 2009). “People form these associations for money and they never learn how to live,” he said. “But it’s not just Caridade, it’s all of the associations. Cabo Delgado is very behind with associations and *associativismo*.” Curiously, the intervention itself, the injection of *associativismo* into the daily lives of average persons, despite causing friction, remains valid and free from criticism. This brings into focus the “social iatrogenesis” that Illich (1982) describes. When misinterpretation or misapplication is labeled deviant rather than part of models presumed to be pure and free from defect, it’s clear that a monopoly has been established. Bureaucracy does not tolerate complaints, but turns them into either opportunities or misdemeanors. The result is a disqualification of whatever doesn’t fit, mediated through processes dubbed value-free and non-subjective.

The experts and specialists enforcing such processes seem to be imposing a burden, but not very strictly. There are half-hearted attempts to transpose poor performance into a better system. More and more partners are introduced to assist the group, but none are directly responsible or charged with making substantive changes. There is both more and less supervision. Excuses can

be made for failures, success celebrated, and certain people promoted or rewarded. Mozambicans are familiar with this configuration. Discussing the establishment of democracy and democratic governance in Northern Mozambique, Harry West (2008) emphasizes this troubling paradox. In the transition from socialism to democracy people here are simultaneously more *and* less regulated. Just like the post-independence era, the presence and influence of administrators and bureaucrats is ubiquitous, even expanded. However, what is new with democracy is the hesitancy on their part to take sides and their refusal to adjudicate, for fear that blame will be passed on to party political representatives or others in decision-making power. Mozambicans, West notes, are increasingly expected to ‘govern themselves’ (West 2008). The social space provided by *associativismo* is primed for experimenting with what does or does not work in the community, but with nobody to blame for what goes wrong besides the beneficiaries, the victims. The intervention, despite at times being the very cause of more chaos, remains whole and intact. Repair efforts are directed toward the group, not the model, not toward the concept of *associativismo* or those who promote it.

A plethora of groups and persons are ‘in charge’ of overseeing AIDS associations in the country—the Núcleo, MONASO, the various foreign NGOs like EGPAF and Medicos del Mundo in Pemba. But, adhering to this laissez-faire approach, they provide only frameworks, suggestions, and ideas intended to help or assist AIDS activists with carrying out their duties. They rarely, if ever, become personally involved. Meanwhile, technocrats remain largely irresponsible for the effects of this approach, which typically involves providing trainings or workshops to civil society groups. When convenient, credit can be taken for the impacts of this. When inconvenient, hands can easily be washed and new groups created out the ashes of failed ones. Like the agricultural farming cooperatives of old, civil society associations in Mozambique are given plans and

structures to which they are told they must conform in order to be recognized as approved partners of the state.

There are also loose guidelines—laid out in what is called “Ministerial Diploma no. 40/2003 of April 2nd,”—which govern civil society in Mozambique. This Diploma establishes two principles to be followed. The first is called “the Principle of Complementarity” between the government, donors, and civil society associations. This principle allows citizens to create civil society groups, as long as they ‘comply’ with legislation. The Diploma also establishes “the Principle of Collaboration,” allowing civil society groups access to existing state resources and the decision making processes of the national health system. This is what justifies AIDS activists sitting in on the meetings of government health committees, for example. This Diploma and the Principles laid out in it allow, and even demand, that civil society and government be intertwined with each other. Civil society’s access to state resources is dependent on the state’s access to civil society. This Diploma serves as a blanket proclamation that the government has a role and the final say in designating and approving what it considers to be legitimate or official civil society.

The government, then, has the right and duty to train and inform civil society as to how it can be considered legitimate. The preferred method for this involves the use of ‘experts’ who work for FRELIMO or one of the state-organized NGOs. These experts are flown in to Pemba from Maputo, and lodged, usually, in the Pemba Beach luxury hotel for the training period. The standard medium for communicating between these experts and local, sometimes illiterate or uneducated activists, involves laptops, PowerPoint presentations, and screen projectors—all tools to which local associations have little or no access. The format for these trainings involves lectures and small groups. Facilitators ask participants to answer questions—like “what are the requirements to register as an association with the government”—and the people respond. They may be asked to define certain terms—such as “ethical,” “monitoring and evaluation,” or “good

governance,”—and then congratulated when correct, or corrected when wrong. I will present now some slides from one such training, translated from Portuguese, which dictate to the associations what they must do and how they are to behave in order to receive recognition from the government. These slides are taken from the “Good Civil Society Governance” training, hosted by the *Mecanismo de Apoio à Sociedade Civil* (MASC, or the Mechanism for Civil Society Support), at the FRELIMO party headquarters in downtown Pemba City.

Figure 1 defines the stages through which associations must pass in order to officially register their group. It is presented as rigid; groups are advised not to stray from this path:



Figure 2: Formally Registering a Civil Society Association

Here, groups are told that the first step to becoming a civil society group is to hold elections in the context of a general assembly, then pick a name for their group. The name must be unique, because it will appear in government records and files. The group must then develop what are called “statutes.” These expound a mission statement for the association, and list out its goals and objectives. The group may then present these to the government—in the case of AIDS

associations, the NGO known as MONASO—for approval. A contract may then be signed between the association and the public, for which the government is signatory. After this, a constitution may be written, laying out the rules by which the group will function. At this point the group may become officially registered. Their name will be published nationally in the government bulletin—the *Boletim da República*—the same publication that lays out new laws and directives between from the government to its citizens. At this point, according to the diagram, “the association has the right to be recognized by the government.”

This next slide, Figure 2, harkens back to the organigram presented to Caridade at the beginning of this chapter. Here, the association is educated on the acceptable structure of the group:



Relationship Between Management Levels and Governance

- **The Institutional/Strategic Level:** The highest level of governance, shaped by the constitution, vision, and mission of the association, the rights and responsibilities of its members. This is where decisions are defined and taken.
- **Organizational/Tactical Level:** This level unites the others, drives actions, and settles disputes between them. It reconciles the Institutional and Operational levels with one another.
- **Operational/Technical Level:** This level is linked to the daily problems of the association. It is the level where all of the association's activities are carried out, and is the level responsible for the proper functioning of the association.

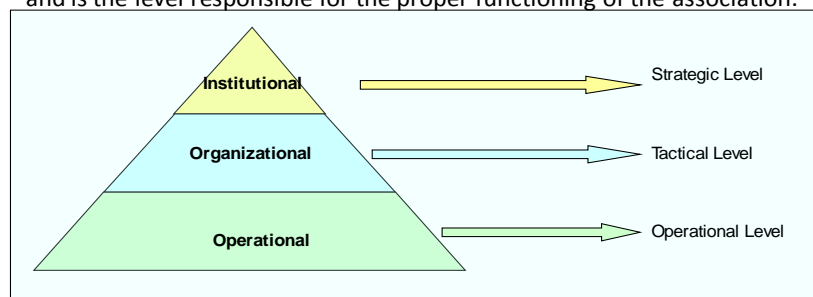


Figure 3: Levels of an Association

The group is expected to have three levels, with workers on the bottom, leaders on the top, and another set of managers in the middle. Interestingly, “all” of the association’s activities belong on the bottom level, but the decisions are to be made on the top. The slide dictates that the group should be divided into hierarchies.

Members have rights and responsibilities, as laid out in Figure 3. This slide suggests that members must participate in order for the group to succeed. Voting and elections figure prominently into the formulation. It is recommended that the group function like a little version of FRELIMO or another political party, with stipulations that members must try hard to agree with one another, make financial contributions, and share their viewpoints:



Rights and Responsibilities of Associations

- **Member responsibilities and participation** – the members of the association must actively participate in the association’s activities to help it reach its objectives.

Rights

- To vote and to be elected.
- To participate in all of the association’s activities.
- Access to all files, books and documents.
- Call together a meeting or assembly when necessary.
- Ask for clarification from the administrative council and/or the executive director.
- Share and give opinions and ideas.

Responsibilities

- Contribute to the association’s success.
- Participate in meetings and elections.
- Comply with decisions made by the majority of members.
- Vote in elections.
- Adhere to pledges made to the association.
- Remain informed about the activities of the association.
- Denounce failures when they occur.
- Pay dues and fees to the association.

Figure 4: Rights and Responsibilities of Associations

In this, the final slide presented in this three day training, associations are asked to fill in an action plan for the changes they identify as necessary for the group to improve. Figure 4, the

“Action Plan for Change,” requires the group to identify a problem, followed by ways it can be resolved:



Action Plan for Change

Association Name: _____

PASSO V – Formulação de um Plano de Mudanças

Question to Address	Actions to Begin Taking	Responsible Persons	Time to Execution	Necessary Resources

Figure 5: Action Plan for Change in Associations

During this session of the training, members were divided into groups according to their associations. In my group, Caridade members identified the need for the purchase of their own office, so that rent would no longer have to be paid the government agency who owned the current space. When the groups came together again to present our action plans to the room, not a single plan, including ours, failed to list money as the main resource needed. The other groups had also identified material needs as their question to address—a car, a computer, a latrine or other building—in order to develop their association.

In “The Anti-Politics Machine,” James Ferguson (1994:259) notes that “development” of the nation comes as a package of standard available inputs, entailing lack of diversity, locked into unimaginative or misleading action plans. The reasons as to why address management concerns

more than social or economic progress. Any deviation from a pre-approved standard becomes more difficult for a routinized bureaucracy to implement and evaluate. The training of civil society in Mozambique, just like many other ‘project’ in this context, encourages institutional isomorphism. Any version of civil society unlike that put forth in these kinds of trainings is less likely to be recognized by the government, less likely to get funded, less likely to have needs met or be seen as a legitimate ‘partner.’ While Ferguson reminds us that the precedence for applying formulas and proscriptions to international development projects in southern Africa is well entrenched, what may be unique in Mozambique is the extent to which the state goes to treat civil society as part of the bureaucracy rather than an alternative to it, or as an extension of governance rather than a compass for it.

What the state intends by this maneuvering is impossible to discern from my data alone, however, the effects of it are clear. Given what has occurred between governments and AIDS activists in other countries—TAC in South Africa, for example—it may not be a coincidence that the Mozambican state carries through with a long-standing tradition of close involvement with special interest groups—the agricultural farming cooperatives, the imposition of party officials into the realm of workers and women (the *grupos dinamizadores*)—especially during a time when local level motivation and donor interest in AIDS patients organizing themselves was at an all time high. Articulated as *associativismo*, the result is certainly “anti-political,” since by doing this the state appeals to the same values espoused by politically resistant AIDS activists—to their inclusion rather than exclusion, acknowledging their right to lobby and approach the state with their concerns—but in a way that is pre-ordained to be manageable and tolerable for bureaucrats and elites. The effect is regulation, the containment of AIDS activism within a box of apparent equity that does not, on the surface, seem unreasonable. However, the requirements given by the state for the official recognition of AIDS (and other) associations acts as a kind of glue to bring

together and harden the trinity of institutional isomorphisms—coercion, normative pressure, and mimeticism. Stressing this uniformity stifles and chokes off diversity, discourages innovative or entrepreneurial alternatives to the accepted standard, and impacts competing visions for the future.

The next training that I will describe highlights the non-response of the facilitator to the felt needs of the group, sharing, reemphasizing, and reinforcing a conclusion drawn from the last encounter—that associations are, in some ways, not much worse off without the trainings and government ‘experts’ than with them. It is natural, I think, to wonder about the resources invested in these attempts to ‘educate’ or raise ‘awareness’ of what associations are and do on the part of government-hired technocrats, especially to an audience of persons who have already bought into and accepted a scheme of organization and structure that doesn’t seem to be producing what they believed it would. It is interesting to note that, despite having a budget that is predominately funded by other nations and development assistance, the state still attempts to position itself as the primary benefactor and provider of skills and resources to its citizens—a type of “neo-patrimonialism” (Pitcher, Moran, and Johnston 2009) that tries its best to solicit consent and obedience, expecting compliance and acquiescence from structural subordinates like AIDS activists, but without the real right to demand it or the resources to back it up. Here, I try to draw attention to how inelegant this proves to be on the ground and in actual practice. The ‘little’ protests in the following scenario are the seeds of the bigger one to be described in Chapter 5.

‘Little’ Protests and the Workshopocracy

“Conflict can lead to war, so we must avoid conflict in our associations,” said the government-hired trainer that nobody knew, who flew in from Maputo for the day. I wondered if he used these words on purpose, given Mozambique’s twenty-year long armed struggles, to evoke images arousing nationalist emotions. He represented the FRELIMO party, and arrived just a

couple of months before the next presidential election. The title of this training was “Effective Association Building, Management, and Leadership” (held on August 12, 2009). “And what is the cause of conflict?” he asked. One person shouted back, “Gender inequality! Women have too much power in the home.” Another remarked, “Troublemakers! Too many people want to help themselves and not others!” Still another said, “The President!” Positive group consensus developed around this last suggestion, and a symphony of heads nodded yes. One person shouted out “Uhemia hemia!” (which in Makua means “authoritarianism”). He continued, “The president forgets he is a member of the association, and thinks he is above everyone else.” Grunts of agreement and approval echoed through the room. The trainer nodded and said thank you, then clicked a button on his computer forwarding to the next slide in his PowerPoint presentation. Neither the word ‘president’ nor ‘authority’ was on it. “Transparency is the problem,” he said, as if no comments were even given.

This statement made me think of the World Bank’s focus on transparency and accountability as defining features of good government, and as essential to economic reform (World Bank 1992). Perhaps some of the Bank’s ethics—demanding disproportionate accountability from below than from above—had arrived at this level of society. He continued, “We must show the available resources and how they are used. Look at Mama Fatimah here. When I saw her exit the taxi this morning, as an association member I could have thought she was using our resources for her own benefit; that she was stealing when actually she is not. Assuming she used the association’s money is bad accountability. Good accountability reduces conflict and bad thinking.” He went on to talk about the importance of submitting receipts to justify daily expenses. This tendency was common in the trainings I witnessed in Pemba. After soliciting the group’s opinion on a topic, the trainer barely addresses it and moves on to another issue.

In this case, the group moves on as well. There are other concerns to bring up. “When we submit documents to the government, it always takes them so long to respond,” mentions one participant. The trainer smiles, “that’s because you don’t understand. You have no comprehension of sectoral interdependence. They will tell you to expect the issue to be resolved in 45 days, but it will often take longer because there are a lot of people who have to approve your request, make sure it is safe, not threatening to others.” One man stands up. “We have been waiting for one and a half years to hear back about running a minibus transport business out of our association!” Another participant says “our association has been waiting two years for permission to put a sign up in front of our office to be officially recognized by the government.” Still another, “when we need the ambulance from the hospital to pick up a sick patient, we find it is stopped at a bar.” “So, there is conflict here?” asks the trainer. “Yes!” comes a unison response from the group.

For a brief moment the trainer looks out the window. I believe I saw a quick look of exhaustion sweep across his face as he exhaled. He then turns back around and advances his PowerPoint slide, never responding to any of the concerns just mentioned. Instead, he continues defining terms. “A leader,” he says, “is someone who influences others, while a manager is an implementer.” Seemingly undeterred, someone brings the topic back to conflict, “it is these very people—leaders and managers—who want money without doing any work.” “Ah, but this is interpersonal conflict,” says the trainer, “We think it is not group conflict but it is. We think it is not a problem.” The emotional distance between the trainer and the group grows as he ignores their comments, and the ‘we’ statements make the exchange seem like he’s talking to children. He sticks to his slides and definitions, and enters into a rehearsed speech about Samora Machel and Eduardo Mondlane. According to the trainer, these founders of FRELIMO and heroes of Mozambican independence knew that “when confronting your enemy, you must have a plan, a strategy.” He picks up an orange. “One association member wants to make a cake with this

orange, the other wants to make fruit. What do we do? Do we split it in half, or do we do something with the orange that the other member doesn't want to do?"

Perplexed by this nonsensical example, the group remains stoic. No answers come forth. "This is the kind of thing we must think about," continues the trainer. "Do we confront this problem right now, as it is? Or do we delay and postpone the debate?" Time moves slowly as vocal participation on the part of the group dwindles. It starts to seem like the trainer is trying to train himself. Grasping for straws, he asks, "Why should the president have to ask someone to clean, when that person should already know her role? She should clean without being asked! We must reinforce our roles in our associations." As the day winds down he again touches on a sensitive topic. "What about membership fees and monthly dues, can we kick someone out of the association for not paying these?" "Yes," says the group, unenthusiastically. By now, there is little effort to call attention to the white elephant that the trainer just let into the room—associations are unable to either make ends meet with monthly dues or enforce their payment. Even before the training is over, people begin to filter out of the room. Some don't even return for the free coca-cola and snacks at the end of the day.

Commenting on the rise of civil society in Tanzania, Kelsall (2002) suggests that the governmental response has been to institute a "workshopocracy" (2002:604)—the use of forums like trainings and workshops to address the needs of grassroots groups but in ways removed from authentic public interests. This works well for the government, which uses them to demonstrate its apparent support of civil society initiatives. Every training or workshop carried out justifies the state in the eyes of donors. Regardless of how hollowed out the subject material may be, or how vacant the substance of discussion and debate, what is important is that the training be done, implemented, noted on official forms, spreadsheets, or reports. Trainings and workshops become window dressing for what Kelsall calls "politics of the veranda" (2002:598). Figuratively speaking,

fundes, managers, and administrators walk by, catching glimpses of civil society involvement, and see politics being aired in public, even though on the inside of the building the room is empty and devoid of any real political change. This is one way to think about ‘bad’ workshops.

Another way to think about workshops is as an imposition on the concept of ‘self.’ Discussing the use of workshops with AIDS activists in West Africa, Nguyen (2010) points out how they resonate with neoliberalism because they ‘steer’ activists in particular directions—toward processing their feelings, engaging with self-help literature, motivating participants to approach life in a more positive light, and to debrief with others to remold their perceptions of bad experiences. The implication of some anthropologists studying the dynamics of testimonials and confessional technologies among AIDS patients (Robins 2006; Robins 2004) is that initiatives geared toward skills-building or crisis alleviation are an overstepping of boundaries, subtle means of thought control, limiting in scope. From this perspective, any outside effort to ‘transform’ the ‘subjectivity’ of AIDS patients comes across as not good enough, too uniform in its application, less effective than enabling group participants to become politically savvy and engage the governance structure as well-educated activists. What I would like to suggest, however, is a slightly different approach—the trainings and workshops which cause the most damage dash people’s hopes by mocking their choice to become involved with civil society in the first place. The most distressing manifestation of a ‘neoliberal workshopocracy’ is devoid of any useful techniques at all.

Besides emboldening the state to treat all civil society unimaginatively and uniformly, what the “workshopocracy” really brings into focus—what truly needs to be addressed—is any element of nondemocracy at work. This has less to do with whatever icebreakers, group discussion techniques, or lay psychotherapy exercises are being used than it does with treating participants like children or worthless, passive consumers. What the poorly implemented workshop

demonstrates to civil society groups is how limited their options are, how little effort the state has to put forth in order to dismiss them. This is a function of poor quality, bad design, and the reckless selection of facilitators or implementers. It carries with it an enormous weight—of fatalism, discouragement, and frustration—for activists who are now led to believe that, in terms of ‘partnering’ with their government, this is as good as it gets. Association members in Pemba City would have been much better off *with* workshops that successfully diffused proven self-help techniques than with ones feigning government interest and guidance. It is, in a word, dehumanizing to make workshop participants feel as if all current and future efforts of their association or group might ultimately come to naught. Trainings or workshops which deepen the reach of the state by infusing self-governance techniques or superficial notions of self-esteem deserve scrutiny in their capacity to require participation in exchange for benefits. However, the most disempowering trainings of all exclude even those who attempt to be included, robbing even those who choose to participate of their benefits, making even their self-determination—often times this is the most people can offer—into just another tool for deradicalization and instrumentalization.

Civil Society Existentialism

Caridade’s formation, not as a support group, but as a state-recognized AIDS association, has been more harmful to the group than it has been helpful. Rendered more visible to the state through its voluntary participation—it’s adoption and allegiance to particular projects and activities, it’s agreement to be a partner (in principle) but subordinate (in reality) to other, more powerful actors—make it a target among other targets similar in function and status who acquiesce to this type of oversight and management. The impotence of the group appears in some ways balanced by its prior and continuing potential efficacy, its rise from the recesses of the bairro and the clinic, its composition primarily of authentically uneducated and promisingly passionate

activists, members, and volunteers. Its original orientation as community-centered and patient-powered characterizes the group as a very real and tangible version of civil society—at its best, a true success story. The challenge is not how to move beyond this, but how to regain it.

A victim, in many ways, of central government planning, the apparent dichotomy of traditionally imposed categories of analysis—the tension between the government and the individual (or in this case, the individual ‘group’)—are not really of principle concern, nor the ultimate malefactor. The disaster here is not outside influence, it is the incapacity for all involved to follow a singular rule of law. The group’s freedoms, its ‘rights’ and ‘responsibilities’ are presented as limitations, but the government (and its partners), in contrast, gives itself free reign, positioning itself as answerable to none, a minor God, a demiurge. It is in the abstract concept of civil society that this is most damaging. The group is treated as existential, set in motion but with undetectable, invisible, imposed boundaries—given ‘help’ that is meticulously interested, but also coldly detached. The group, in actuality, need not consent, agree, or obey, unless it really wants something in return—a contract or a deal.

The typical anthropological fascination with “technologies of the self” as a brutal imposition is misplaced here because it is not the primary mechanism of control. People do not ‘give in’ all that easily to targeted attempts at channeling their behavior, attitude, or lifestyle. Instead, this is achieved by the state (or its partners) in the self-appointed role of overseer, regulatory commissioner, and provider of favors. Ironically, more, not less, discipline is needed on the part of some actors. Those who *mafiar*, conduct bad trainings, and control the group via external and elite alliances devoid of merit but not influence actually *do* need to ‘govern themselves’ better. Doing so would allot them more, not less, freedom. The subtle process of integration, of civil society becoming more like government, of individuals becoming leaders or getting trained, is not to be resisted if it leads to better overall accountability. If it doesn’t, however, then it must be

altogether rejected. If anyone can break the rules then everyone must start again, until some system or another actually works. We may be in a phase where this is warranted. It is really the only way out of a 'neoliberal' confluence, when the group finds itself hopelessly answerable and subservient to others.

This, then, is civil society existentialism: groups such as AIDS associations represent, presumably and in the abstract, automatic freedom from despotism and tyranny, yet their *laissez-faire* existence is mythical and impossible to attain. The group cannot be wound up, like a clock or a watch, and left on a table alone to do its work. Someone or something will always stop by to try and tinker with it. The group, then, may be better off in a protectionist or isolationist mode, set apart from development projects, action plans, experts, and funding. Otherwise, from the point of view of the state or other regulator, it not only needs but also deserves some form of external guidance, and will never truly function on its own. Since that is the case, when a third party inevitably comes into play, it is often able to flout all of the rules. Skirting along the periphery of regulation, trainers, association presidents, African elites, paid consultants, and others who come across as 'in charge' are equally capable of both subterfuge and empowerment. The choice is largely theirs, and not the group's.

This third party continues not only to present but also justify itself as some form of interference, making the power of the state visible but in various other questionable ways and venues. Civil society's supposed natural occurrence does not escape the place and time in which it is embedded. The battleground, in such cases, is the concept of 'partnership.' Therefore, for groups caught up in the throes of civil society existentialism, the way out is to ignore the ruling powers and carry on alone—in a word, to disengage. When both participation and non-participation yield the same results, the answer is a return to an original state, the same one which drew attention to the group to begin with, and supplied it with its initial credentials as

grassroots, a worthy ally, and a visible target. The process may be painful because it involves culling and sacrifice—of apparent progress, of projects and salaries, of faux coalitions and haphazard training regimens—in order to return to a stable state, even if appears to be a step backward. The answer for Caridade, and other Mozambican AIDS associations, is simple but unlikely to be sought. It is to make demands on one another rather than outsiders, and to consult and negotiate mostly within the group itself, staying true to original goals and objectives.

The impetus for such a strategy is evident in the nature of works undone or as yet unaccomplished. While chasing funding and approval from bodies and entities higher up on the economic food chain, momentum subtly shifts away from the reasons why the group was crafted or called into existence to begin with, toward ever more bureaucratic tasks and purposes which chip away at the group's meaning and pragmatic function. Having achieved some success and obtained some recognition, the right kinds of thirsts are slaked, particularly those of leaders and decisions makers. Data are exchanged, but reported up a ladder of reverse accountability, such that field-level realities get obfuscated or even ignored. Projects which work well in one context are presumed to work equally well in another, such that oversight or needs for adjustment become less of a priority. Efforts break down which never get repaired, and progress falters. The group, if it so chooses, rests comfortably on its laurels while society around it continues to crumble. Challenges persist which under better circumstances could have worked themselves out. To evaluate AIDS activism and civil society groups we need not look to government bookkeeping, the amount of money allocated to civil society coffers, levels of publicity and public relations success, or how far and wide the name of some community based organization or NGO has spread. We need only further examine the communities themselves, where such groups are situated and active. In this next chapter, I further focus attention on the local situation, the world and culture in which Caridade is embedded, the microcosm where AIDS activism is presumed to

be hard at work. The litmus test for civil society—and those who claim to fund and support it—is read and assessed at the heart of the people, towns, and villages of Cabo Delgado Province.

Chapter IV-Challenges to AIDS Activism in the ‘Subuniverse’ of Cabo Delgado

“Common” Activists

“This rain is for the mango trees, to make their flowers bloom,” said Susanna, as the drops began to pelt the tin roof of the of the association’s abandoned chicken coop where we were conducting our interview. The chickens were all gone. That project hadn’t worked out well for the association. I very much appreciated this sentiment from her, a welcoming statement that taught me something about her culture and land. We sat there together, caged in, getting to know one another as the rain grew heavier. When Susanna was diagnosed as HIV positive it was because her constant uterine pains caused her to seek help at the hospital. Before that, for six years her period never seemed to stop, but she didn’t really know what was wrong. “I thought that maybe I didn’t have any blood left!” she said. The pain caused her be sexually abstinent, and as she got skinnier, her first husband left. Now, because of the illness, she had entered menopause at the early age of 25. “When you tell people about the virus, it is strange, they think you are nothing.” She adjusts the bracelets on her arm with her other hand, maybe 9 or 10 of them. They are made from parts of unused female condoms, fashioned by removing the synthetic material that normally cups the cervix upon insertion, leaving rings that are almost indistinguishable from some of the cheap imported jewelry found in local markets. Most people here don’t like to use condoms, especially the female ones. They often end up as bracelets, and as material for making toys like soccer balls.

“My husband doesn’t want to accept that I am positive, I’m certain of this, even when he sees the medicine. I asked him to do a test and it was negative. Still, sometimes I divorce him, but we always come together again.” She refers to a common practice in the area of informally and temporarily separating from a lover, as a result of some frustrating aspect of the relationship. Susanna was in what people call a “traditional” marriage. Having lived with the same man for

many years, the community viewed them as husband and wife. About her AIDS association, and her medication, she had this to say:

“When I take the medicine, it is very strong. It helps a lot. But sometimes I can forget, for two or three days, then I really feel terrible. If you can eat well, then the medications are no problem. Otherwise you feel drunk [she rotates her head, mimicking dizziness]. The association helps, certainly. We can talk together. We are all sick, so nobody is scared. Mama Fatimah mobilized us, saying that if we join, the government will help us. We only got food one time, but they gave us *katanas* (machetes) for working in the garden, and some mosquito nets. The most difficult thing for me is the poverty. If we had money, we could buy nutritious foods. In the city it is different. There they are fat!” (Interview, August 9, 2009, Mize).

Her history of long suffering, concerns about relationships, stigma, and daily survival are common themes for AIDS sufferers in this region, and, in a village as small as Mize “everyone knows you are ill.” She continued, “but that doesn’t seem to matter to most of these young girls. They say there is no virus, and go with many men. As for me, I have no farm. I am just waiting for God to call me...*pronto* (I am ready).”

Activists like Susanna are the most common ‘type’ of activist in Cabo Delgado Province. Her statements indicate above average interest in her own condition as well as that of others. She is concerned about HIV in her community and the status of those who are affected—her AIDS association and similar groups. She wishes the situation was different, expresses hope and fears over her future, and identifies specific problems that need to be addressed, namely poverty, and access to other resources that are valued but also scarce not only for her but for most other Mozambicans as well. Not particularly well educated, or politically savvy, Susanna is not famous, or even the leader of a local AIDS association. No newspaper articles have been written about her. Neither she nor her group is the subject of books on AIDS treatment activism. She is, however, in many respects, representative and symbolic—an ‘everywoman’. There are more Susannas in the world than there are Zackie Achmats or Magic Johnsons. For her, and others like her, to not be included or considered a part of the world of activism is more than just disingenuous, it would be

an indication that the ranks of so-called AIDS activists are much thinner than we might suppose or are led to believe.

Susanna does not occupy the same world as the stereotypical, cosmopolitan, urban-based version of ‘the activist’. She passively waits for help, and is more of a consumer than a producer. She has medication, and now she wants other *things* from her government—food and tools. She does not broadcast her AIDS status. She may even be putting her husband at risk, who is either in denial or unaware of his chances for becoming infected. But this does not devalue her existence, contributions, or potential to enact change or social justice. Instead, it indicates a hidden world, one unsensationalized and not held up to the public as exemplary, maybe because it doesn’t support the preferred narrative in exactly the right way. Susanna, and many other activists in Cabo Delgado—especially those who do not travel or attend workshops and conferences—occupy a “subuniverse” (Berger and Luckmann 1967:84) of the world of popular, politically-motivated AIDS activism, an endeavor that may in some sense be global or universal but is certainly not uniform or ubiquitous. To suggest that it should be makes it into yet another ‘technology of the self’ (Foucault 1988), an attempt on the part of empire to mold and conform others at a distance and without their consent.

AIDS activism is not a given, objective, independent reality but rather is quintessentially human—a social construct and intellectual territory that is not, as some might like to believe, either inevitable or naturally prone to *novo* conceptions of social evolution. Susanna may never—as Ida Susser predicts—transition from being a mere “adaptive” activist into a “transformative” one (2009) due to some latent ability to organize others and become an ‘organic’ intellectual. But that does not make her ‘less than’ other, better connected AIDS activists. Her story matters. Cabo Delgado Province matters, not because it is front and center of the AIDS activist movement but for opposite reasons—as neutral territory, where people are not as exposed to predeterminations

about what is and is not the acceptable role of an activist. Less touched by the world, more isolated and nondescript, Cabo Delgado is a laboratory for testing the limits and claims of AIDS treatment activism and for evaluating its reach. Treatment alone—more clinical facilities, better so-called ‘access’ to medication, or even the government’s signature on more laws and human rights agreements—won’t save Cabo Delgado. Change must continue to occur locally. For this, no clear cut trails have been blazed. Relatively unstructured, support groups flounder for opportunity and meaning.

Subuniverses of AIDS activism are segmented and segregated, highly contextualized and structured by a variety of criteria—education and the circulation of knowledge, values that may be spiritual or traditional, aspirations for money, resources, or prestige, and aesthetic tastes, for food and drink, for social relations and (dis)unity, and even different kinds or types of healing. This chapter is devoted to the subuniverse of AIDS activism in Cabo Delgado Province, particularly through an explication of the challenges AIDS patients and activists face in regards to their condition and what they can and cannot do about it. Reality in this context—*reality sui generis* (Durkheim 1982)—is ladled with contradiction, misunderstandings, and subjective viewpoints about HIV/AIDS and even activists themselves that threaten to disarm the apparent gains of a dominant mode of activism that has emphasized, perhaps to its detriment, the virtues of treatment alone. These are the views of “the man in the street” (Berger and Luckmann 1967:vi), taken for granted, dismissed, or ignored by the wider world because of their perceived inaccuracies.

Occupying a world that is real to him, for *the man in the street*, abstract notions of illness and social solidarity are often little more than reifications, even presumptuous impositions. Biomedical facts and clinical evidence have little sway over his thoughts and actions. He requires an activism that is more practical than it is radical. The challenges faced by AIDS activism that I

will discuss here are situated in the beliefs of *the man in the street*. They include: lingering confusion about the virus, ineffective home-based care programs, antiretroviral treatment abandonment, and alcoholism. None of these are easily solvable simply in the context of the clinic, but they might be in the context of a high functioning support group—a model for which we still, after all of the political hype and international interest, have no clear blueprint or standard. AIDS activism is relevant here, present and at work in its own way, and continues to be sorely needed, not for establishing ephemeral or imagined connections between persons living far apart, but especially for the promotion of resilience and inner strength for the *man (or woman) in the street*.

Lingering Confusion about AIDS and Activism

“AIDS is many things that never stop. It is just another one of those *doencas incognitas* (unknown diseases)” (Interview, September 8, 2009, Mecufi). According to Martinez (1989), for the tribes of Northern Mozambique—the Makua, the Mwani, and the Makonde—*doencas incognitas* (unknown diseases) are considered to be the worst types. They are more deadly even than “very serious illnesses” because they are “imported from whites” (1989:154). Disease is often considered to be disgraceful, the result of existential aggression (on the part of God, ancestors, or jealous persons—witches) or a life out of balance:

“AIDS comes from God, whatever thing you find comes from God. God gives us everything, including disease and death. The government didn’t bring AIDS here, and the government is good. It gives us pills and food. But God and the government are like this [he crosses his fingers and holds them up, indicating togetherness]. It helps God to provide for us. AIDS came here from a white man, a doctor here in the hospital” (Interview, Pemba, July 28, 2009)².

For many Africans, including AIDS activists, disease is a social experience, a mystical rather than biological occurrence, and HIV/AIDS—because of the myriad symptoms it presents—is likely to

² This statement is partly true. Mozambique’s first AIDS case was diagnosed in 1986 in Pemba. However, it was a black Haitian-American man, not a white man (Matsinhe 2006:36).

be misdiagnosed or treated in non-clinics settings. What the patient's family is likely to suspect is that a ritual prohibition, on food, hygiene, or sex, has been violated. What the patient is experiencing—partial paralysis, vertigo, rheumatism, or *ekhumelo ya emphome* (bad blood, as suggested by Susanna, above)—can be resolved by bathing in roots and herbs gathered from the bush, by drinking a similar concoction, or being 'vaccinated' with razor blades by a traditional healer:

When I got sick my son took me to seven curandeiros (traditional healers). They gave me roots, I took a bath, and it helped a little bit. Those who don't believe the government and don't like the hospital say that HIV is just witchcraft. [I ask her if that is what she thinks] No, but I used to, and many people still do. They don't listen to us when we tell them what we know" (Interview, Pemba, July 31, 2009).

Also, HIV/AIDS is not a local term. It is commonly referred to as *kidudu*, a Makua word designating worms or gastrointestinal stress, and an illness caused, purportedly, by bugs or insects in the body. *Kidudu grande* (big kidudu)—an even worse version of the original—is said to be imported from whites. AIDS in Northern Mozambique fits into the common plague metaphor described by Sontag (1989:89)—visited upon a society by outsiders, AIDS "is understood in a premodern way."

Activists that I interviewed often first heard about AIDS from government outlets, like newspaper articles, radio programs, and educational brochures or pamphlets. These sources mention routes of AIDS transmission other than sex, but by drawing equal attention to them many patients are encouraged to deny that sex was ever a factor in their infection. One man told me that he got ill after stepping on a dirty syringe and his foot started itching. Another blamed a blood transfusion in the hospital. Another man believed he got infected through a bloody workplace accident, and that HIV entered by air through his open wounds. Several patients told me that they got HIV from the unsanitary treatment of a traditional healer. Some, less than half of those interviewed, mentioned sex. One woman believed that her baby may have given her HIV:

I could have been infected through the umbilical cord of the baby. We were both infected in the same day [her and the baby]. There is no control in the hospital with blood safety. That day the beds were full, so I could have been stuck with used needles” (Interview, August 3, 2009, Pemba).

Other AIDS association members suggested that cholera, malaria, and Tuberculosis were possible ways to acquire HIV. Efforts to educate people, even ‘activists’, about the virus have been insufficient. An enormous gap exists between knowledge that is passed on—by clinicians and educators, in literature and media—that if it hasn’t been addressed by now may simply never be, at least not in the same old ways.

Some activists in Cabo Delgado intellectualize the virus as a conspiracy theory, a government project designed and generated to bring in money and kill off unwanted populations:

“We hear on the radio that *such and such* number of dollars has come to the government to help people with AIDS. Where is this money? Why don’t we get it? Because it stops in Maputo! Some say that the whites brought [HIV] here. Why don’t they have it? Because they brought it for us! The government talks about it, but they [the Ministers of Parliament] don’t have it. That is because they knew about it before, when it was a secret. The last time they came here [to Macomia], they said HIV would be finished by 2010. They can say that, because they can control it” (Focus group, October 17, 2009, Macomia).

“This disease is new. It doesn’t come from here. Nothing the government does seems to help. For them, it is producing money. In this district, we hear that people in that district are getting money. In that district, they hear that we are getting money. We are always told that it is coming, but it doesn’t, and they expect us to stay blind about this? What is happening is this virus is balancing out the country, it lets the government kill people they don’t want. What they tell these other countries, there [gesturing far away with her hand] is they are helping us. Does it look like I’m being helped to you?” (Interview, September 8, 2009, Mecufi).

In Moçimboa da Praia, some passersby of the local AIDS association *Desafio Jovem* (Youth Challenge) believed Americans brought HIV/AIDS to Mozambique, because the sign outside of the office, which the association was required by its funder to display, read “AID from the American People.” In Cabo Delgado AIDS is very much associated with money and influence. The theories people propagate indicate their unique grasp on the global AIDS industry. This is not up for much debate or argument, and people are not easily swayed on these points.

Activists are considered to be a part of this government project. Enlisted to 'work' in their AIDS associations, members of the community do not trust AIDS activists and believe they joined their association out of self-interest:

"Some of my neighbors say that we (association members) write our names down and the government brings us money. I look healthy, so they don't even think the virus exists, or is a problem. When I encourage them to get a test and visit the hospital, they tell me that this is my *negocio* (business), that I get paid when they join the project" (Interview, September 9, 2009, Mecufi).

Some do become activists out of self-interest, so when projects die down so does the association:

"This association used to be for projects. That is why I joined. They told us if we did this then we would get money from raising chickens. But what we also know is that the government must give us medications. They won't let people with HIV suffer anymore. We had a garden, and we had goats, but now we don't and nobody comes anymore to the meetings. Now nobody works. They just come sometimes, sit around like this, and then go home" (Interview, Pemba, August 5, 2009).

There is also competition between associations and jealousy, especially based on expectations that the government owes something to the association:

"In Mizeze, we are always told to do 'sustainable projects, sustainable projects.' Well, I never see Caridade doing sustainable projects! In our village, everything falls into the category of *machamba* (garden). The associations in the city have more opportunities, even though they do lousy work. They all get paid, and we can't even get a tractor" (Interview, August 11, 2009, Mizeze).

Activism becomes an aspect of the activist's personal economy, a way to get money and survive on a regular basis. They feel dependent on the government, and NGOs like MONASO:

"Here we only have land for the garden, but nothing else to make it, no seeds, no hoes. We created this group because MONASO told us to. When we got the land, people said 'this garden is for people with AIDS.' But we still don't have a constitution or statutes, and MONASO won't give us anything else until we do. We want to be like Caridade, at all of the meetings, able to ask for things. [I tell her that Caridade members are also upset with funding and assistance] Yes, I know but they have a good *mafia*, we want to be part of this *mafia*" (Interview, September 15, 2009, Mecufi).

This may serve as evidence that for an AIDS association to be involved at all with generating income puts it at odds with others and even with the community, and leads to a focus on commerce rather than disease alleviation.

Stigma against HIV positive persons—what Mozambicans call *vergonha* (lit. shame)—remains a significant obstacle in Cabo Delgado. When one's HIV positive status is well known:

“People won't buy things from you when you are selling in the market. This has destroyed our AIDS association, because when we make charcoal or cement blocks [for housing and building construction] people pass us by. They go to the others around us and buy what they need. They do not want to support our association. They call us *infectados* (infected). Everyone there talks bad about us” (Interview, August 3, 2009, Pemba).

Stigma keeps many people in the area from getting tested. According to one activist they are “scared of being contaminated, but they don't want to do a test. When you suggest it, they insult you” (Interview, July 30, 2009, Pemba). When asked to elaborate on why *vergonha* is problematic for patients, that concept was frequently linked to the Portuguese word *desprezar* (lit. to despise). An activist told me:

I stopped taking my medication because I stopped going to the hospital. I stopped going to the hospital because my neighbor *me desprezou* (despised me). She talked bad about me, and told everyone she met about my (AIDS) condition. I was ashamed to show my face or even step outside at daytime. This went on for months (Interview, August 1, 2009, Pemba).

While stigma—the proliferation of spoiled identities (Goffman 1986)—is a common experience for many AIDS patients, more distressing even than its presence is, perhaps, the incapacity of AIDS patients in this context to construct a counter narrative. The implication that while stigma happens nothing can be done about it is an indication that the achievements of AIDS activists in this regard are very likely less than ideal, and perhaps even subpar. The ‘newness’ of AIDS associations, and AIDS activism here has been unable to address this, and may never be able to do so.

While the misinformation in circulation about HIV/AIDS—where the disease comes from, the nature of the government’s involvement, and confused ideas about who activists are and what they do—certainly makes it seem as if activist efforts to change the society around them have failed, they also serve as a map and compass for where they could or should head in the future. There needs to be a reorientation, first among activists themselves. Their empowerment does not lie in seeking the same kinds of resources as the society around them but in addressing crisis recovery in their own lives, to serve as examples not just of good patients but as good residents and citizens overall. They need skills to avoid disease relapse and to manage their situations better, not opportunities for obtaining ‘new’ jobs, or philosophies for developing ‘new’ selves, but the chance for regaining what was lost and reintegrating well in society. For attitudes and knowledge in society to shift, for *the man in the street* to embrace accurate structures of plausibility concerning HIV/AIDS, AIDS associations must be stronger and more effective, but not necessarily more politically active or culturally obvious. They must be able to convince one another of objective truth without falling prey to substandard ‘knowledge.’ These changes are not likely to come from NGOs or the government but from activists themselves. If they are unable to generate relationships rather than income, and dignity rather than competition, they may remain sidelined and grow increasingly irrelevant, even becoming—in and of themselves—obstacles to patient rights and progress.

Ineffective Home-Based Care Programs

“We want to extend home-based care to another ten districts this year,” said Manuel, the coordinator of Pemba’s District AIDS Council. A map of the province flashed from the projector onto the white screen at the front of the room in *Bairro Natite’s* training center for health workers. Color coded, the key at the bottom indicated that districts were divided between the NGOs and organizations present at the time. “But,” he continued, “this won’t be possible for us,

from a logistical perspective. It's only from the level of coordination that it can happen. That's why you're all here." He gazed over the audience, comprised of 30 people, mostly coordinators and AIDS activists, volunteers of home-based care programs throughout the province. "I want you all to know that at the Núcleo, we are working in a political box. Things are being decided in Maputo over which we have no control. In particular, activists are supposed now to work across all health areas, not just HIV/AIDS. Things are changing. We don't know where they are going." As Manuel stepped aside to speak to an expatriate seated at the front of the room, I turned to Carlitos. "Do you know what he's talking about?" I asked. Carlitos shrugged his shoulders. Manuel continued, "Since last year, in Maputo, we haven't been able to settle the issue of incentives for activists doing home-based care. It seems like nobody can decide whether providing them is a good idea, or not. Some say it's not fair. In some cases, two NGO's are working in the same place, and one person is working for both NGOs, taking home a double salary. In other cases, some NGOs pay better than others. People leave one NGO and go to work for another only for the money. People get trained, and then disappear."

At this, the coordinator for Medicos del Mundo, a Spanish NGO, stood to comment. "This is the problem we find across the board, and often we can't even verify if the work is getting done. It's not just with the activists that we already have. We tried to train 25 traditional birth attendants in Metuge, but from day one they wanted to get paid, so they abandoned the training. Many even refused to take an AIDS test. We can train them, and give them tools, but they shouldn't be doing that kind of work if they are HIV positive. What we've found is that the easiest thing is just to pay for these women to attend school." The man continued to speak on the problems associated with activists—they're untrustworthy, don't report for work, and often demand more money after they're hired. The organization was leaning toward disbanding their team of activists entirely. "The problem with doing that," he said, "is that we have no other way

now of knowing which AIDS patients are still taking their medications, and which have stopped. We used to get the register from the hospital for this, but not anymore.”

The meeting continued with presentations from other coordinators of home-based care programs. AMODEFA—the Mozambican Association for the Defense of the Family—said they trained 74 activists in Nangade, Palma, and Mueda, focusing especially on adherence concerns. “One of the things that we have them do,” said the AMODEFA coordinator, “is go door-to-door of those homes where we suspect the patient hasn’t been to the hospital in some time. It’s guess work, primarily.” He showed his own PowerPoint slide, a map of the town of Palma, with some areas shaded out. “Just months after the training we lost half of our activists in Palma because of the issue of payment, leaving these few locations [pointing at the map] where the program continues.” He cited the additional barrier of long distances and poor transport, causing the remaining activists to spend more time walking between homes than working with patients. “We’re guessing that almost half of patients who start treatment don’t go back after the first month. This is what we are trying to attack.” He began to list the names of organizations that provided funding support, “It’s not enough...[turning to face Manuel] there’s really no way we can expand the program in this situation, as it is.”

The last NGO to present the results of their home-based care program, the Spanish Medicus Mundi, working in the district of Montepuez, had the clearest data on the subject. “We have 173 beneficiaries. Half of them are HIV positive, some of these and another ten percent suffer from psychiatric disorders, like schizophrenia and depression. There are a lot of alcoholics. We’ve dedicated a small room in the hospital to these psychiatric and substance abuse patients, and have begun to treat them.” The coordinator, Isabel, mentioned that turnover in the program was high. There were a lot of deaths. Others disappeared, probably going to other villages or towns. She continued, “we have 82 new patients just this month, so there is a continuing need. We have

only 34 patients on ART, and 5 of them abandoned their medications last month. We know this is not good, and are working hard to educate people about this.” After the meeting and her discussion, I approached Isabel about her statistics, and she invited me to spend some time with her and the NGO’s activists in Montepuez.

About 200 kilometers from Pemba, Montepuez is not densely populated. The entire district is inhabited by an estimated 187,000 persons, but has the second highest AIDS prevalence in the province, just after Pemba City, at about 8%. Isabel knew of my interest in gauging the number of *abandonos*, or those on ART but lost to follow up. She told me that “the hospital officially records zero of these cases, but our records indicate it is much more than that, because only about two-thirds of the patients actually come to pick up their medications every month” (personal communication, August 20, 2009, Montepuez). Riding through the town of Montepuez on my first morning with her, she had to stop the Landcruiser on three separate occasions because somebody was walking or lying in the middle of the street. The activists in the car with us recognized each of them as AIDS patients, each time descending to query the individual and either point them in the right direction, accompany them home, or take them to the hospital. After delicately chaperoning one of these cases into the back of the car where I was seated, an activist told me that “this woman is on phenobarbitol and haloperidol,”—antipsychotic medications—“when we first found her, her family had left her at the curandeiro’s (traditional healer’s compound), where she tested negative for *majinni* (evil spirits).” I glanced at the woman, who was wearing a white, but extremely dirty, full blown wedding dress. She mumbled occasionally as we got closer to the hospital. “She stays alone?” I asked. “She moves around,” replied the activist, “we never know where she might show up!”

Medicus Mundi had 20 activists on the payroll, carrying out home-based care duties in each section of town. As we dropped off the patient in the wedding dress and her activist guide at the

hospital, we encountered Bento, one of the male activists, waiting for us outside of the day hospital. He had trouble that morning getting a patient to be seen by one of the doctors, and the man remained collapsed on a reed mat outside of the entrance, having waited all night for the place to open. Isabel told me her opinion that “the female activists really work much better. But, Bento is very good. The problem with the women is that sometimes their husbands forbid them from working. We train them, and then they’re gone after a month.” I waited as Isabel went to talk to one of the hospital staff. I noticed she had to raise her voice, but then someone came out to fetch the man on the reed mat. After this, together with Bento, we entered the Landcruiser again to begin the day’s rounds. Isabel was going to introduce me to some of the beneficiaries of the home-based care program.

Just off the main streets of Montepuez are neighborhoods with many homes not on the electrical or water grid. In these cases, other than proximity to certain services or businesses, the residents may as well be located in rural Mozambican villages. We parked the vehicle in the yard of a home constructed in the pique-no-pão style—a bamboo frame, with rocks packed in between to form walls, and a mud layer covering them to provide a finished look and seal the cracks. It was thatching season. Nearby lay a pile of grass destined for that purpose, tied neatly in man-sized bundles and stacked into a pyramid shape. An older woman came out to greet us, and I could barely see anything in the dark interior of the home as she shut the door behind her. After exchanging pleasantries with Bento in Makua, she went back inside and came out again with a small girl, of maybe 6 or 7 years, in her arms. “This is the patient,” said Bento, “we have known her for about 4 months.” The girl had just woken up, but smiled widely, extending her hand to shake mine and Isabel’s. “Her mother and father are dead, so her grandmother here takes care of her,” he said. He pointed inside the house and the girl went back in, emerging quickly with a large envelope and a pill bottle.

Spilling the pills onto a tray he began to count them—triomune, a common fixed-dose ARV tablet—while the girl pulled what turned out to be an x-ray from the envelope. “She also had Tuberculosis, but it’s clear now” said Isabel, holding the x-ray up against the white washed back drop of the house’s mud wall. She motioned for the girl to pull off the head scarf she was wearing, revealing patchy skin and not very much hair. The girl herself hadn’t spoken, and I was beginning to pick up on the fact that she was deaf. “What happened to her hearing?” I asked. Bento responded, “when she was very little she was treated for malaria with quinine. Deafness sometimes results. There is another boy inside, also with TB, and we think he is positive also, but the grandmother here doesn’t trust Isabel and won’t let us treat the boy. She said that she doesn’t want a white woman telling her how to take care of the child, and that the hospital hasn’t done well with the other one. We haven’t been able to get him tested.”

The next home we went to was a government constructed one, with cement blocks, glass windows, and asbestos roofing. We circled around to the back yard. The patient’s husband, a former civil servant, had died, and she lived alone. On her arms were spotty, red, and irregular shaped lesions—Mycosis. Bento pulled a vial of medicine from his bag, and we waited as he used a q-tip to paint her tongue with a purple liquid, an antiseptic, intended to help treat the Candidiasis that covered the inside of her mouth. As she sat down, Isabel began to question her. “We heard you were having some problems, what happened?” In Portuguese, the woman began to explain that her allergies were very bad, and the worst one was her allergy to water. She couldn’t take a bath because of it. “You’re not bathing?” asked Isabel. The woman shook her head, and told us that she didn’t have any soap. Seeing us, a neighbor shouted something to Bento in Makua. “I think she’s been robbed,” he said. At this, the patient became more animated, and explained that a robber had entered her house as she slept, stealing her food (maize flour), cooking pans, and a blanket. Isabel became visibly angry. “We’ve talked about this before!” She stood up and began

pacing. “Every time you get something, it’s gone the next day. You can’t keep track of your (health) papers, and now you’re not even bathing. I’m not even sure that you want to be our patient...do you want to be our patient?” The woman nodded yes.

Isabel continued, “then you have to take responsibility for your own health, you have to bathe...ok?” Again, the woman nodded yes. Also suffering from a pink eye infection, Isabel donned a pair of rubber gloves and asked the woman to lie down on the reed mat where she was sitting. Bento had to hold her arms to her side to keep the woman from fighting as Isabel held the woman’s eyes open and inserted eye drop medication. Clearly frazzled, she poured water from a jug into a shallow pan. At this, the patient broke Bento’s grip, stood up, and moved quickly toward her house. She entered and slammed the door. As we went back to the car Isabel explained to me that the woman had worsening AIDS dementia. “I don’t know how long we can keep doing this with her...it’s terrible. I don’t know if she can stay in our program, our level of care isn’t high enough, and she needs somebody with her all of the time.”

The next place we stopped was the local Assembly of God Church, close to the center of town. We didn’t go in, but went around to the side of the building, where a tarp was erected, finding a man roasting cassava and boiling a small pot of water over a fire. “This man is positive, but also is an epileptic,” said Bento, as we greeted him. He told me that his name was Vasilio, and he came here from Mesa, about 30 kilometers away. He wanted to go back, but his daughter and her new husband kicked him out of their home. His wife had done the same thing a few months ago, now he was homeless. “They let me sleep here, in the Church,” he said, “but they still haven’t given me a bed. I have to sleep on the floor.” He explained that he got some food from a government program for AIDS patients, “but it’s not enough.” As Bento counted his pills, and filled out the home-based care form, Isabel stepped away from us to attend to a phone call. At that point, among men only, Vasilio explained even more of his story—that he was impotent, and

his wife left him for that reason, leading eventually to their separation and his current lack of family. After we left him with his cooking fire, Isabel and I discussed the man's needs. In our own countries—the United States or Spain—the government cannot subsidize everyone who needs food or housing, and we have our own homeless populations. How is it possible that Mozambicans expect this in their own nation, with even fewer resources? Vasilio's story, hardly unique, was nevertheless common in his insistence that he be even better housed and fed than what was currently provided.

At our next stop, the patient had been given her own room—outside of the family's house, in the backyard, in what looked to be a simple storage space. Upon entering the compound, the family barely greeted us, stayed seated, and kept shelling peas. Noticing our arrival the female patient came outside for what was probably the first time that day, looking sleepy or groggy. The family—her sisters, cousins, and children—took no notice and seemed to want nothing to do with her. Her eye was swollen, and Isabel sat down to have a closer look. The patient had recently recovered from measles. Speaking Makua, with Bento translating, the woman told us that some man had broken into her room last night and had sex with her. She was tossed off her mat, and her pillow was thrown to the other side of the room. "She says it was an evil spirit," said Bento. Complaining of stomach aches, Isabel asked how she was taking the anti-inflammatory that she had been given. "She's taking too many of them," Bento told us. While that probably accounted for the stomach ache, the woman insisted that she had a cobra inside of her, and when it moved it caused her pain. Glancing inside the room, Isabel asked her why she wasn't using her mosquito net. She told us it was because there are no mosquitoes this time of year, but when Bento asked her to show us the net, it was still inside of the original packaging. During the visit, the family continued to ignore our conversation, avoided eye contact, and acted as if we weren't there. Close to her family, yet separated from the home, it wasn't clear she was even getting enough to eat.

The woman appeared skinny for an AIDS patient actively on treatment. Isabel asked for her health card, to see if she was attending the day hospital and picking up her medication on time, but the women told us that she didn't have either—her card or her medications—because her usual visiting activist, who wasn't Bento, had stolen them.

As we departed from that home, Isabel and Bento told me about Ricardo, an activist that had worked with the program for some time before disappearing. During his tenure, he gained the trust of Medicus Mundi and the patients he served through near perfect attendance at meetings, in the clinic, and at appointments in patient's homes. By the time Isabel started hearing negative comments from other activists about him, he had already caused a lot of damage. Because he filled out fake reports, Medicus Mundi was unaware that his visits were less frequent than they should have been. He also violated protocol by keeping the patient's health cards and medications on his person or in his own home, presumably in order to sell the medications. In Pemba, I had seen firsthand tables in the markets stocked with AIDS medications, even entire bottles with the Ministry of Health logo on the front. Some people did access treatment in this manner, even buying one or two pills at a time. Seeing the educational level of many patients in Montepuez, and their incapacity to care for themselves, Ricardo's affront was a serious one. In many cases, people depended on activists to provide accurate information and guidance on what to do in certain situations, how and when to take medication, and what events should trigger a visit to the clinic. The last patient that we visited was not alone in having her health card and medications go missing, Ricardo was in charge of nine or ten other patients who had also not been well attended to in recent times.

In Montepuez, Cabo Delgado's most sophisticated home-based care program, activists provided hands-on care and were well stocked with medications. They depend on an NGO—Medicus Mundi—for success, and still faced drastic challenges getting patients to maintain their

own health. AIDS patients, found in their own homes and enrolled in these kinds of programs, occupy the role of *the man in the street* in this case. Berger and Luckmann (1967:2) note that the intrusion of experts—like Bento the activist, or Isabel the NGO nurse—into the territory of *the man in the street* is likely to cause him to “raise his eyebrows”. Freedom, knowledge, and reality cannot simply be brought or handed to him, and those who like to do so have a responsibility to try and understand what methods are required, what other settings are appropriate, to begin to educate or sway the perhaps inaccurate worldview of *the man in the street*. The socially-constructed ‘realities’ of common and average patients, like those described in these encounters, cannot be simply dismissed, but should be better described and documented, pondered over and grasped at, so that more appropriate solutions can be crafted that might better fit their needs. The home lives and domestic situations of these kinds of patients—far from inculcated into an activist lifestyle—is a subuniverse that often goes unexplored.

Before I left, Isabel explained further that the home-based care program is seen as an NGO initiative, and that the government is uninvolved. If the NGO were to leave, the program would likely stop. Because Montepuez had no AIDS association or support groups, many of the activists carrying out home-based care were not HIV positive, rather, they were appointed by the *presidentes dos bairros* (neighborhood presidents), meaning they were most often the friends or relatives of local political elites and upper middle class families. Isabel, an expatriate and the sole coordinator of the program, was unable to oversee the activists properly. She lamented the lack of a local AIDS association able to help her with this aspect of the job, but did not want to create one herself for fear it would not be sustainable.

Treatment Illiteracy and Abandonment

It is easier to enroll patients in treatment programs than it is to keep them enrolled. In September of 2008 there were 5,557 people on ART in Cabo Delgado, and this number increased to 7,745 in just one year. Not once during that time period does the system fall short of its expected goals, with the number of newly enrolled reaching greater than 100% of the target number every single month, climaxing at 125% in October, 2008. Yet, around that same time the number of people who abandon treatment rises steadily, from 14% in September, 2008 up to 17% in September, 2009. It continues to rise after that, up to 20% in December, 2009 and to 22% in February, 2010. As more people enroll, patient retention is a more significant problem than it ever was during the initial phases of free AIDS treatment in sub-Saharan Africa. Once they start, about one quarter of patients disappear within three years (Fox and Rosen 2010). Some claim this number is as high as one-third (Decroo et al. 2014; Luque-Fernandez et al. 2013), or even up to 40% (Harries et al. 2010). In Cabo Delgado, official estimates vary. The best guess—and it is a guess, because the metrics for program retention are not standardized or easily measured—is that about one in three patients abandon treatment within the first few months of initiation (MISAU 2011). Combating this requires addressing the patient's desire and ability to adhere to the prescribed pharmaceutical regimen.

Treatment adherence is mostly a psychological struggle, one that has less to do with clinic access than previously thought (Ware et al. 2009). The most commonly cited reasons for poor adherence and program abandonment, the only ones that most clinic-based programs are able to address, include distances to facilities, funding for or access to transportation, bad patient counseling, and drug availability (Groh et al. 2011). But, many other barriers exist that are less well acknowledged and more difficult to target. Some people stop taking the pills because they feel healthy and believe they are cured. Others stop because they feel unhealthy and believe the pills

are making their condition worse. Some are hiding their HIV status and fear the discovery of pills by others in the home, being seen picking them up at the pharmacy, or making frequent visits to the hospital. Other factors may breakdown a patient's resolve to be compliant. ARVs are highly toxic, making them difficult to tolerate and resulting in headaches, exhaustion, increased hunger, vomiting, or diarrhea. Patients may try to minimize uncomfortable side effects by voluntarily interrupting treatment, but compromise their immunological status and recovery in the process (Msellati et al. 2003). Adherence is also not easy to measure. There are some laboratory tests that can do this—blood reference ranges, viral load, and CD4+ T-cell counts can provide reliable assessments—but the most common way to gauge patient compliance is by counting the number of pills left over in the pill bottle. Adherence, therefore, is usually self-reported (Denison et al. 2015; Simoni et al. 2006). The risk factors most frequently associated with bad adherence include unemployment, low income, low education, substance abuse, younger age, and an unstable home environment (Heath et al. 2002; Norton et al. 2010).

In Cabo Delgado, an important contribution to patient adherence is for the family or caregiver to be aware that the patient has HIV, and to know how the treatment works. AIDS is seen as a new disease and different from many others because it is chronic and incurable. This poses an obstacle for people unused to being on medication for extended periods of time:

I have this epidemic [meaning HIV/AIDS]. And it is not like malaria, it doesn't go away, ever. I can't get my family to understand this, and so, the medication itself is not the same either. If you have TB they give you pills for a certain time period and tell you that when you have taken them all, then you can stop. This virus is so different. We can't stop the pills! My mother doesn't believe that I can't just get an injection and stop the (hospital) visits. I tell her that with ART the bugs that are inside my body stop moving, and rest instead, but never die, and this is the only way to keep them from killing me. I tell her that I am always sick, so I must keep going to the hospital. That is what sick people do, right? (Interview, August 30, 2009, Pemba).

Activists believe better family involvement is essential to keeping patients healthy and in programs:

When we are visiting the homes of patients we find families that tell us the patient is already dead, when they are not. The patient is just in recovery, but it's not clear to them what is happening. They don't even know the name of the illness that the patient is suffering from. They just see reactions (from the pills) and say 'ah, these medications are not good!' They see vomiting, and maybe the patient is acting silly from being light-headed, or the legs are itching. It doesn't matter how many times you counsel them, or the patient, you can talk to them 1,000 times, but until they see the improvement themselves, it doesn't make any difference. These cases are just complicated (Focus group, October 20, 2009, Moçimboa da Praia).

Families may even be involved in keeping patients off of treatment:

Here the family is usually responsible for making people stop their medication. They complain about the price of transport. They tell us that since we feel better, it's time to quit taking the pills. I could have listened to my aunt, but instead I went on my own. These are the same people who told me not even to get a test, that the needles they use are the same ones that gave me the virus, even the cotton they put on your finger is infected, or that the blood they have taken out of others is just passed on to you. They will even tell you that the medications themselves cause AIDS (Focus group, October 17, 2009, Macomia).

These types of statements reinforce what many researchers already acknowledged, that families and caregivers—particularly when they can help make sure that patients take their medication—should be included in HIV/AIDS programs (Walton et al. 2004). Western understandings of confidentiality may inhibit this at the village level.

Such mistrust of biomedicine is common in Cabo Delgado. The hospital and the clinic are relatively recent historical introductions to Mozambique and to the Province (Bastos 2007). Some people believe that health facilities are under the control of foreigners and white colonizers, and that doctors and nurses intentionally give illnesses to patients in order to control the population. Health care workers are, according to some of my interviews, "*donos de doença*" (the owners of disease), tricksters who seek to harm people, destroy families, and fragment society by spreading diseases (Interview, July 29, 2009, Pemba). For some patients even visiting the hospital is a psychological battle:

For me, I have no problem going to the hospital because my father, when I was a child, worked for whites and always told me that it was ok to do that. Others don't think so. My friend still thinks that the nurses here are tricking him, that the

reason the government is giving away medicine is because it is a government project (Interview, August 5, 2009, Pemba).

Some patients are quick to try and end their relationship with the clinic, and do so as soon as they begin to recover:

When you go to the hospital you find good things, not bad ones. I didn't know this before! So, when some people get tested and get their (HIV/AIDS health) card and their medications, and they start to feel better, they return to the hospital and try to hand the card back to the nurses. They tell them 'here is your card back, I don't need it anymore' (Interview, August 1, 2009, Pemba).

On other accounts, patients insist that they have, upon occasion, been given the wrong kind of medicines, or medicines that don't really work (Interview, Mecufi, September 1, 2009). In some cases, concerns about the integrity of health care staff are warranted. Some health workers 'go rogue' and operate personal businesses out of their homes:

A nurse who was here (at Pemba's hospital) used to treat patients in his own home. You could pay him less, and instead of waiting in line it was faster. He used to give injections of aspirin. While he had a lot of customers, it was later we found out he did not know what he was doing and that he stole supplies from the hospital for this business [I ask her why people went to see him at all]. Because he would tell you what is wrong with you and give personal advice, while in the hospital you just got pills. If you were very sick you could sleep in his home (Interview, July 31, 2009, Pemba).

Treatment literacy in this area is also very low. Few patients are able to name their medications, and describe them instead by their color—white, brown, pink, etc. When asked about what ARVs they were taking, occasionally someone would pull out their HIV/AIDS health card and read the name of the medication written there in order to respond to my question. A common misconception about AIDS activism is that it helps patients feel a sense of ownership over their own health care and pharmaceutical regimen. In Pemba, the government, rather than AIDS activists, gets credit for providing drugs to patients, who feel indebted as a result, and possibly even insecure about the future of their treatment:

Please don't stop bringing these medications here! My health is guarded there in these pills. I started taking them so that I could be a human being again! So, I am

glad that people have arranged this, when we, the patients, weren't even thinking about it. They will decide what to do next. [I asked her who she was referring to] Our government and people like you (Interview, September 8, 2009, Mecufi).

Patients are not always able to cope with the side effects of their medications. These range from constant hunger (the most common complaint), to partial paralysis of body parts (such as the feet), to an overwhelming feeling approximating drunkenness or intoxication, to even a loss of eyesight or blurred vision. Certain rashes, sometimes painful, itchy, or ugly, come and go as they please. For many patients "the reaction to the medication is very bad, and some people abandon them because they are afraid to die, and think that the pills will kill them before AIDS does" (Interview, July 28, 2009, Pemba). It's a shock, to some, to find out that what is supposed to make one feel better has the opposite immediate effect, and being told by the provider that side effects will wear off doesn't make the experience any easier to tolerate.

AIDS associations, and informal support groups, are important for patients to work through some of these issues. When they are able to meet together patients recognize that they are not alone:

I used to forget at first (to take the pills), but I'm very well accustomed now. I used to vomit, all of the time, because I had a lot of saliva in my mouth and my throat. Now, I can't see very well. I think that is because of the pills. My left arm has no strength, so I come here (to the day hospital) for massages twice a week. I also have trouble reading—and that's not just because of my eyes, it's like I can't think sometimes, I feel a little stupid, like my brain can't function. I know this is caused by the treatment, because others (in the association) have the same problem (Interview, August 3, 2009, Pemba).

The relationship between ART and the body is summarized most frequently in statements about insufficient amounts or varieties of food worsening the experience. Many discussed the fact that, when unable to eat at medication time, they felt "drunk" and suffered more intense reactions and side effects than when taking medications on full stomach (Interviews, July 27-29, August 1, 4, 5, 12, September 9, 12, Pemba, Mize, Mecufi). Many refuse to take pills without food as a result. The uncomfortable nature of side effects, given their clear relationship to the medication itself, is an

abrogating factor to adherence, particularly for patients who have not suffered more intense AIDS symptoms, and may be tempted to quit because they haven't yet experienced what happens when they do. Many patients credit that kind of personal experience—a frightening and near deadly disease episode or relapse—as the reason why they are able to maintain adherence to ARVs later on in their life. Making a clear connection between treatment and health is helpful for personal resolve:

The first 14 days are very tough. If you aren't well educated, you can believe that you are cured within one week. There is a lack of information about this, and those of us who join (AIDS) associations are easier to help. Otherwise, you just don't know where some of these people live. It's easy to talk yourself out of coming back to the hospital. You've just found out you have this virus, it costs money to take transport, and you start to think that the government doesn't know what they are talking about (concerning treatment for life) because you feel great! Look, the nurses don't have the 30 minutes to do proper counseling in the hospital, so the biggest problem is starting the medications when you don't even think you have a serious illness. For me, I was so sick when they found me that I knew ARVs saved my life, *sem duvida* (no doubt) (Interview, August 11, 2009, Mize).

When I started ART in 2006 I got much better, and quickly. I was playing football and was very healthy. I was given two months worth of the pills, but I only took a few of them. I put them on my shelf and left them there, started drinking again, and in a few weeks ended up with TB and so sick I couldn't leave the bed, again. Now, I would never abandon these medications, and I don't drink. The others in my association (he is the vice-president) look to me on this issue, so when someone wants to stop I go and talk to them. [I ask him if that helps people continue] In most cases, yes, but we have one or two who keep dropping out (of treatment) (Interview, September 15, 2009, Mecufi).

One such example—of AIDS association members stopping treatment—is Eliza, a member of the association Nashukuru who showed up for an interview with me in Mecufi. When I asked her about her own adherence to medication she told me she never questioned the efficacy of the medications, and never quit taking them. My standard questions about side effects, stigma, and other challenges to her compliance didn't inspire any discussion. However, in later interviews with other association members her name was often mentioned. I was told by several other members of her association that she was stubbornly non-adherent, that they had to keep watch

over her daily in order to try and keep her on schedule. On three separate occasions she was admitted to the hospital because she quit taking her pills and never told anyone. Each time, her health deteriorated to a level more threatening and dangerous than before. When I asked these other association members why she let it happen, nobody could tell me. She lived alone, her children had left the area and she had no husband. She also had no income, and no regular way to obtain food. Other association members had to bring her meals. The woman did not care for her own hygiene and rarely bathed. Others in the village accused her of being a witch and treated her as an outcast. Even though her trips to the clinic after stopping her treatment restored her to health each time, she continued to falter and miss doses. Her reasons for this may be complicated. Perhaps, regardless of her experiences in the clinic, she did not believe she was HIV positive. Or, perhaps she had no reason to live. Socially abandoned, able to rely only on others in her AIDS association, she spent her days isolated or depressed, which spurned her poor adherence.

One Caridade activist, Reggie, insisted to me that he never stopped taking his medications. However, when he was away from the group people talked about his non-compliant behavior. Reggie was newly married to a woman who, as far as we knew, was not HIV positive. She was considered overbearing, mean-spirited, and difficult to deal with. In spite of being an active member of Caridade and a vocal participant in meetings, Reggie had not told her, his third wife, about his own HIV positive status. The two fought constantly. His neighbor, also a Caridade member, related these incidents. Plates and food would fly across the yard at mealtimes. Loud shouts could be heard from the bedroom at night. Reggie's movements were monitored intensely, because his wife feared he had other lovers. Reggie lied to his wife about the nature of Caridade, telling her that it was a FRELIMO political party association. He also had to visit the day hospital unnoticed, and keep his pills hidden. The result of this was more than just an occasional missed dose. At times, he pawned his pill bottle off on his neighbor, asking him to hide it so that his wife

wouldn't find out his secret. He went days at a time without asking for his medication back, skipping doses because of this domestic situation. When, one day, he finally was caught taking pills by his wife, he told her that he had a headache and that the pills were Tylenol rather than ARVs. Fortunately for Reggie he never suffered a disease relapse. His non-compliant behavior probably wouldn't have stopped. One day, however, his wife showed up at the Caridade office looking for him. With a triomune 30 pill bottle in her hand, which she claimed to have found in their latrine, she told the group present at the time that she finally knew they were all HIV positive. From that point, she tried to prohibit Reggie from participating in Caridade meetings, or from taking his pills. The relationship ended in divorce. Reggie remained in Caridade, but was transferred to a distant village for his own protection. When I saw him months later, he was healthier looking, and told me he was much happier working at his new post.

Another Caridade activist, Armando, stopped taking ARVs because the clinic in his home village refused him service. When he was diagnosed in Pemba he was given several months of medication. But when he arrived home, he found that his patient file hadn't transferred. When his prescription ran out, the clinic refused to give him medications because his CD4+ cell count was above average. The workers there did not want to enroll him in their ARV program until he met the requirements of less than 500cells/mm³. They did not believe Armando, who claimed that he had already initiated treatment in Pemba and just ran out of medication. He was told he would have to go back to Pemba and find his patient file before they would administer ARVs to him. Unable to pay for transport back to Pemba, Armando stayed home. After several months off treatment his condition began to deteriorate and he came close to death. His neighbors and other villagers became aware of his HIV positive status. At the insistence of AIDS activists working for an NGO there, Armando was driven to Pemba and nursed back to health in the hospital. As a result of everyone knowing his AIDS status, he did not feel safe or welcome going back home. He

joined Caridade and stayed in Pemba, and became trained as an activist. He eventually began to work and got paid for coordinating other activists in Caridade programs. Armando's story is, on one hand, unique. Most patients who want to be on treatment can usually obtain it from the clinic. However, others may find themselves in similar circumstances. Bureaucratic inefficiency and miscommunication poses a legitimate threat to patients when protocol and standards are too inflexible to take special cases into consideration.

Even living near to a clinic—where patients are more likely to have drug on hand—does not guarantee high treatment adherence. Clinical data as well as home based care visits in Pemba and Montepuez, cities that had day hospitals close to patient homes, reveal that treatment abandonment is just as bad if not worse in urban areas than in rural ones (MISAU 2011). Patient travel is likely not the most significant obstacle to treatment adherence. It is not at all unusual to find patients in the middle of urban *bairro* enrolled in an ART program who, when asked the question of why they aren't taking their pills, simply shrug their shoulders and provide no answer. Even the best efforts of a local volunteer, one who lives in the same neighborhood and speaks the same language as the non-adherent patient, fails to convince him or her that the pills are life-saving, that the hospital offers the best treatment compared to any other option that might be pursued—usually alternative means like traditional healing or prayer. A simple or mundane excuse is sometimes all that's necessary to rationalize one's way out of medical treatment—the healthcare staff isn't friendly, the patient no longer gets free food rations, pills are not well tolerated, or the patient feels better—these are all easy ways for people to lose heart in a biomedical approach. On multiple occasions I found myself without a response to those patients most socially isolated and most forlorn when they said that the pills make them hungry, that they can't afford anything to eat, and that they preferred to just die now rather than later.

One case that was particularly striking involved a woman with a six month old baby, who moved to Pemba seeking to become employed as a cleaning maid in a wealthy household. Her husband had abandoned her and the baby, and after leaving her village she found herself living in a broken down hut a five minute walk away from the provincial hospital. When we arrived at her home during a home-based care visit, her pill bottle was empty. She asked me to buy a candle for her. This woman—who spent her nights in a dark home while the city around her teemed with electricity, loud music, parties, busses and cars, minutes away from an international airport where tourists arrive, ready to spend US\$1000 a night staying at nearby luxury island resorts—had no light, no matches, no food, and no help from her neighbors. She became distraught during our visit with her, as the activists asked questions about her health and welfare. Holding her newborn baby by the wrist like a ragdoll, she insisted that their lives were worthless, and threatened to kill herself that night. She was literally dragged the kilometer uphill to the hospital, where she received a thorough scolding from a worker in a hospital uniform who forced her medications down her throat. Distance did not threaten this woman. Had the hospital been any closer it would only have been a little bit more tolerable for the activists to drag her there. More invested in projects than patients, the local AIDS associations couldn't offer much help in the form of a well functioning support group. The parameters of this situation are not at all unusual.

Anthropologists studying these phenomena—patient non-compliance, resistance to taking medication, and poor treatment adherence—place them in the category of biomedical skepticism, and question whether it is even possible to address this in the context of the clinic. The social factors of poor treatment adherence—overcoming stigma, persevering through difficult cycles of side effects, combating fatalism, or not trusting authority—are considered problems unsolvable given only the brief periods of patient-provider interaction (Whyte, Geest, and Hardon 2003). Like Eliza, some patients may simply tell the provider that they are compliant when in fact they

are not. This has been documented as very likely in situations where medicines, like ARVs, are not cures but only treatments, temporary, in constant need of replacement. Studying the use of benzodiazepines, Britten (1996) notes dissatisfaction among patients who feel that the drugs do not address the root causes of their anxiety and refuse their medications. Studying the use of antabuse, a drug used to make heavy drinkers sick so that they cannot feed their habit, Steffen (2005) equates refusal to take the pills with disobedience to authority. Studying epileptics, Conrad (1985) notes that some patients associate the drugs with the illness, and assume, incorrectly, that by not taking the drugs the illness will fade or go away. Others note how daily routines and work necessary for survival can take precedence over adherence, especially when physical labor—as in African subsistence farming—is negatively impacted by side effects (Trostle 1988; Alcano 2009). In other cases, patients stop taking pills after a certain period of time because it is a habit that they simply choose not to maintain (Hunt et al. 1989).

The most common reason for AIDS treatment abandonment in Cabo Delgado approximates what soldiers experience from overexposure to combat, war, and death. Most patients who stop their AIDS treatment, or are tempted to do so, go through a personalized version of “combat fatigue” (Jones 2006). Fighting with their own negative and destructive thoughts and actions, or with others in their same household or society, several causes and factors contribute to a breakdown in the psyche—a stress disorder, a response to anxiety, fear, and hopelessness. The way to engage this is by developing strength and resiliency in all aspects of life—at work, at home, and at play—to keep this from taking such a toll on the patient’s willpower and resolve to keep living and fighting the persistent battles necessary to keep a relentless virus at bay.

From visits to clinics and hospitals all over Cabo Delgado it is obvious that rampant treatment abandonment is a serious concern in the province. In the rooms where patient files are kept, stacks of them are set aside and marked in red with the word ‘abandonado’ across the front.

The responsibility of tracking down these patients is not usually a government task. It is left to volunteer AIDS activists, who have the difficult assignment of finding the patient at home and recording their status in official log books. If the patient is deceased, he or she will be removed from the registry. If not, the activist attempts to link the patient with services again, bring the patient in to the hospital for reevaluation, or continue to visit the patient—possibly taking medications to them in the interim, if the clinicians are willing to bend the rules—until the patient agrees to be seen again by health care staff at the facility. It is a difficult job, some NGOs hire staff and coordinators specifically for this task. They are always overworked, because the number of patients who do not report back to the clinic is overwhelming and never seems to go down.

Good adherence is a function of determination. Those patients who are most successful have others encouraging them and providing “social capital” for maintaining their regimen (Binagwaho and Ratnayake 2009; Ware et al. 2009). What needs to be targeted—a patient’s fortitude and capacity to maintain it via the moral and emotional support of those around them—is equally as important as drug availability and distribution at point of service. Some programs and researchers have tried to incorporate methods for strengthening this in the clinical setting. These tend to involve the utilization of non-medical help—like the use of “treatment supporters” (Kranzer and Ford 2011; Bärnighausen et al. 2011)—to provide a range of counseling services to patients. These interventions fall into the category of “task shifting” policies (Bemelmans et al. 2010) intended to unburden doctors and nurses by devolving some duties to lower level staff. But formalizing social support in this manner tends to be small scale and limited to a few select clinics or sites. The successes entailed, the results of initiatives carried out for evaluative purposes, or as pilot projects, may be difficult to reproduce and not funded over the long term. The recommendations which come forth emphasize the need for tailoring services more to the lives of the patient, pinpointing

barriers to adherence that impact them in their homes and various locales, educating them more thoroughly on the nature of ART, setting up reminders—via cell phones or mnemonic techniques—for patients to take their pills regularly and obtain refills when needed (Harries et al. 2010).

Surveying the literature on improving patient adherence, articles on this topic tend to provide exhaustive but overly generalized recommendations that, quite likely, are too comprehensive, logistically challenging, or require more advanced resources for tasks like data management than is likely possible in most African contexts. Bärnighausen (2011:944) suggests the incorporation of “behavioural, cognitive, affective, and biological interventions through combinations of treatment supporters, nutritional support, financial support, psychosocial support, and education sessions”. Brinkhof (2010) recommends tracing patients lost to follow up in order to ascertain their vital status, and more diligently recording transfers in and out of programs. In a recent document, the WHO (2013) prescribes addiction counseling, mental health support, and targeting services based on gender to address treatment program attrition. These kinds of questions—of how to provide services that cater to specific locales and for as many patients as possible—are really best addressed outside of the clinic rather than in it, and by patients themselves.

But groups like Caridade, with conflict, in-fighting, and competition over resources, have not gone unnoticed. No small amount of frustration is felt by those in close contact with malfunctioning civil society groups. This has led to alternative efforts to get treatment to people, still in nontraditional ways, but doing away with those civil society elements that seem so problematic in favor of strictly ART-oriented services. Luque-Fernandez, et al. (2013) discuss “adherence clubs” in South Africa. Facilitated by trained counselors, nurses visit with groups of 15-30 patients who meet the inclusion criteria for participation, having been on ART for at least 18

months. Basic health assessments are done during the meetings, and short discussions on AIDS related topics take place. Decroo, et al. (2014) discuss “Community ART Groups” in Mozambique—a model that is being increasingly embraced by the Ministry of Health—which involve groups of up to six members who verify one another’s adherence and send a representative to the clinic to collect medication for the entire group. The representative relates important information to clinicians during the trip, which is documented on a shared group health card. Models like these have yielded substantially high rates of adherence, generally over 90% after a year or longer. If these types of initiatives become standard or more efficient than working with support groups, they might easily replace or compete with AIDS civil society projects and efforts in southern Africa.

Berger and Luckmann (1967:2) mention that “*the man in the street* does not ordinarily trouble himself about what is ‘real’ to him and about what he ‘knows’ unless he is stopped short by some sort of problem. He takes his ‘reality’ and his ‘knowledge’ for granted”. Biomedicine is not automatically given a high place of authority in southern Africa. In regards to patient compliance and ART program abandonment, there is persistent evidence that people cannot simply be educated or told to take their drugs properly. Many who do comply with their regimen have previously suffered dramatically from symptomatic AIDS episodes, or have bounced back from severe disease relapses, and so are able to make clear connections between their own health and a commitment to the drugs. There are obvious facets of lay psychology at work here that can be better transmitted and shared by and between patients themselves rather than clinicians, politicians, or humanitarian workers. There is therefore a continuing need for non-clinical models and options for patients to sustain their treatment access and maintain the willpower or personal resolve required to stay on treatment.

Alcoholism and ART Patients

It should come as no surprise that AIDS patients who regularly partake of alcohol suffer higher risk of defaulting on treatment than those who do not (Huis In 't Veld et al. 2012). While this outcome may be reserved for those who drink to excess, in the southern African context, these are a majority over only social drinkers (W.H.O. 2014). Moreover, beer and wine, the more expensive and less intoxicating options, are not as frequently consumed or as readily available as hard liquor. Home brewed spirits and uncontrolled brands of clear gin that are ubiquitously present. That Mozambicans, even in the mostly Muslim north of the country, participate regularly in heavy episodic drinking is quite obvious, especially during the night. More alarming than that is the fact that, moving through Pemba's *bairros* and alleyways, a considerable amount of it occurs when the sun is up as well. In general, heavy drinkers are 50% as likely to be classified as adherent to their treatment as non-drinkers, and missed doses of ARVs occur most often on drinking days (Hendershot et al. 2009). For some people in Caridade, and other AIDS associations in the area, every day is a drinking day, and the question is not when to stop, but how much can be obtained.

Of course, the official stance on mixing ARVs with alcohol preaches abstinence. During counseling sessions patients, particularly men, are warned against alcohol as a threat not only to adherence, but to the efficacy of the pills as the body breaks them down chemically. However, there is no follow up to this information from the clinic. Unless a problem case emerges uncontested, someone with a drinking problem is unlikely to be confronted on it. Moreover, according to the published literature, interventions on this topic are scarce, or otherwise only brief and cursory in nature (Parry et al. 2014). One of the biggest problems with this situation—the combination of telling patients to abstain with little guidance on how to manage it—is that patients can believe they must make a choice between the alcohol or the treatment (Kalichman et al. 2013). But besides that, drinkers in general display overall sub-optimal adherence and higher

mortality than other ART patients, making this topic one of increasing interest to those who work in the disease area of HIV/AIDS (Nachege et al. 2006).

It seems that the attention being paid to alcohol abuse and ART is relatively new in the southern African context, which makes sense, because the effort to treat those with the virus has thus far focused on access and standard issues of recruitment and retention. It is, of course, appropriate to research this link. We have known since the start of the AIDS epidemic that substance abuse forms part of a wider web of risk taking that, apart from the obvious (and even well studied) connection between intravenous drug use and HIV infection, places people at greater risk for contracting the virus through increased and dangerous sexual activity (Needle et al. 1998). Alcohol use, though, compared to using dirty syringes to get high, isn't exactly some kind of outlier, unusual, or culturally unacceptable behavior in which to engage. Not only is alcohol popular and easy to obtain, it is marketed by national and international companies in a sophisticated manner (Casswell and Maxwell 2005). These include strategic product placement and other unmeasured promotions like sponsorships and point of sale materials.

It isn't unusual in Pemba to find people wearing free t-shirts distributed with the "2M" logo, the national beer. *Barracas* and other types of stores not only carry wide varieties of alcohol, some are also decked out with the brands and insignias of beer or dry gin companies, having received in-kind donations such as paint or signs with which to fix up the establishment. In addition, during my stay Pemba City only had 5 billboards—one near the airport, a couple in the center of town, and the rest near the beach—and four of them advertised alcohol like Johnny Walker Red Label Whiskey and Heineken Beer. Inevitably, the scenes depicted there highlight smiling faces, well dressed but tightly clad women, or young men (next to their automobiles) enjoying one another's company with a drink in hand. These marketing tactics, however, are simply confirmation of a more obvious reality that alcohol and drinking are at the confluence (and

sometimes center) of many people's lives as a vehicle for pleasure seeking or entertainment during free time. Alcohol also has its place in gender relations (Ray and Gold 1996), as a sign of masculinity, or a proxy indicator for wealth that is meant to attract members of the opposite sex. Apart from being a drug in its own right, with the capacity to influence sexual decision making, alcohol in southern Africa is a basic and prolific cultural placeholder. In Pemba, this manifests most accessibly on the strand of Pemba (Wimbe) Beach, where tourists, politicians, business people, prostitutes, and many others mingle especially on Fridays and Sundays to wind down (or wind up) the week. Some take advantage of the opportunity by stocking up small coolers and selling individual beers, or sachets of gin or rum, by the roadside.

As night falls, the main drag along the beach becomes particularly attractive to the party-goer. The expensive hotels and restaurants that normally stand out seem practically unimportant. The crumbling walls built during colonial Portuguese times which separate the road from the start of the sand get subsumed and disappear behind the bodies of street hawkers and socializers as people sit, congregate, or display their wares on or by them. Cars parked alongside blast rhythms loud enough to spur impromptu dances. Meet and greets dominate the landscape, as people catch up with one another at the conclusion of the work week. Besides alcohol, other things are sold here. Grilled chicken, samosas, cigarettes, and fruit, for example, are also available. Women, their bodies for sale, are also publicly displayed, in short shorts, tight t-shirts, and with hairdos that would put some movie stars to shame. As the night progresses, so does the collective level of intoxication, and inhibitions drop. As the size of the crowd waxes it becomes clear that for those who have the means—cars or motorcycles—the beach is the primary one-stop shop on a circuit of bars and restaurants that create a welcome escape and diversion from the drudgery of workaday life in the city.

Often, on Friday nights, I would make the typical sacrifice of a full night's rest in order to absorb the goings on of night life on Pemba Beach. Sitting there along the wall, chatting with my neighbors, beach boys who frequented the area at all times of the day or night in order to prey on tourists (mostly by selling arts and crafts, other trinkets, or marijuana), a dazzling array of vehicles stop and go along the strand. Some of them, mostly Landcruisers, are clearly emblazoned with the logo of the Republic of Mozambique. Others belong to USAID, or NGOs in the city headed by Mozambican national staff, such as Population Services International (an NGO that prides itself on AIDS education and prevention, mostly through distribution of condoms). Some belong to well-to-do residents, others to international businessmen on their way to or from Tanzania. The drivers of these vehicles stop, one to all of the people in the car get out, buy a beer or two, pick females to accompany them, then get back into the car and drive away. Motorcycles buzz back and forth as well, carrying on the routine. The same drivers sometimes reappear and repeat the process as the night goes on. The conversations between men and women as they barter on a fair price for sex are not secret and can easily be overheard. The *quatorzinhas* (14 year old girls) are the most expensive.

On the other side of the wall, on the beach side, small groups of mostly local people form circles of conversation, sitting in the sand and exchanging visitors back and forth. Along the seashore, couples walk, sometimes hand-in-hand, sometimes smoking or drinking. It is not unusual to see groups of teenage or young adult boys loudly pursuing one attractive female. Sex on the beach is common at night. So are reports of gang rape. As the night drags on, fights often break out, and people haul each other into the nearby police station to settle what would otherwise be petty or resolvable arguments, if alcohol wasn't involved. As the outdoor scene becomes more and more anarchic, those who can afford it migrate into the discotech at the end of the beach, remaining there until the sun comes up. Mozambicans—from Maputo to Cabo

Delgado— know very well this practice of what can only be referred to as *uma festinha* (a little party). If one should move from the beach to the other bars or restaurants around the city, drinking (excessively) is the glue that holds the city together on the weekends—or tears it apart, depending on one's perspective.

Not to be outdone, those of lesser means, in the yards, housing compounds, and *barracas* of the bairros, also have their fill of alcoholic substances, and partying. A stroll through any neighborhood reveals, especially on the corners of paths and unpaved roads less frequented by cars and trucks, brightly colored plastic buckets full of the yeast-heavy maize drink known as *cabanga*. This drink, less powerful than others, lends itself well to all day drinking sessions and is particularly favored on national holidays when nobody works, and for weddings or funerals. Often brewed by women trying to make money on the side, it takes at least a liter to even get a good buzz. Because the belly swells, locals claim that one need not eat when partaking of that much *cabanga*. The opposite of this drink, the clear, distilled, corn-based moonshine known as *nipa*, ranges from 180 to 190 proof pure grain alcohol. For half a dollar, less than a half pint, one can obtain a successful high. For an entire dollar, or a whole pint, one can forget what happened during the course of several hours. For those who buy in bulk, or for those who brew *nipa* themselves, the scene around the home can become not only sad or frightening, but disastrous. The neighborhood of Chipapwale, the poorest and most inaccessible of Pemba's central bairros, located on the opposite side of the bay from the beach and where the sewage and runoff water from the city gathers during flood times, is absolutely devastated by a *nipa* epidemic. Drunks literally crawl from drinking spot to drinking spot, from one yard to another, in search of the substance required for them to continue to stay inebriated.

I regularly interacted with and followed the lives of three Chipapwale residents who were also Caridade members— the treasurer, Fevereiro, the president, Antonio, and an activist named

Rita. During my time with them, none of these people managed to escape the clutches of *nipa*. Fevereiro's girlfriend, his second after his divorce and a schoolteacher, once received a loan from the Agha Khan Foundation in order to fix up her home, a house that she shared with the treasurer. But, rather than using the money for what it was intended, she bought supplies to manufacture *nipa* in their spare bedroom—a homemade contraption, a moonshine still complete with pipes, glass jars, and a heating source. The children who slept there now had to sleep in the sitting room. After her first batch, she got so drunk that she tried to pull down the electrical wires strung up through the rafters of their home in order to shock and kill herself. Both of them *nipa* addicts, the couple fought constantly. My visits there, subsequently, revealed the kinds of people that *nipa* attracts. At least one tried to sleep with Fevereiro's girlfriend while he was passed out drunk. Another stole their small television from inside of the house. Whenever I found people gathered there, half of them would be passed out, sometimes having soiled themselves, only to wake up occasionally for another drink. If payment was overdue and service was refused, voices were raised. The alcoholics would then move on, presumably to a location where one more cup could be had.

Antonio, Caridade's president, lived just around the corner from Fevereiro. He had a wife and two children, and previously owned a number of expensive objects and furnishings. He had, over the course of several years, bought and later sold a number of refrigerators, televisions, and motorcycles when funding was too short for him to drink. Regardless of the fact that Antonio had a government salary, as a nurse in the day hospital, as well as NGO money as the president of Caridade, his children slept on reed mats instead of even the cheap, locally constructed sisal bedding that most families could afford. Whenever I visited, he would beg money from me for a drink, and send one of his children to a nearby *nipa* salesman to buy a small bottle for himself, which he would sip on as we talked.

He treated the small plastic bottle like someone would treat a whiskey flask—tucking it into his shirt or pants pocket when not in use, and revealing it on a whim and whenever the urge struck him. Often he told me “*seu Cristiano...cabanga não dá* (doesn’t work for me), I need *nipa*.” Whenever he visited my house, he would search through it looking for alcohol, and drink whatever he found. One time, this included an entire fifth of imported whiskey. Not only did everyone in Caridade know of Antonio’s addiction, but the rest of the NGO and AIDS world in Pemba did as well. In spite of Antonio’s occasionally poignant observations and criticisms of the government and medical establishment during district level meetings, his behavior in other contexts infamously indicted Caridade as ineffective or not to be taken seriously. Within Caridade, we all wondered how it was possible that Antonio still held his official position as nurse, when his attendance at work was atrocious. Remember that Antonio is an AIDS patient, and was by this point on ART himself for several years. Falume, Caridade’s President of the Assembly, had this to say about Antonio’s drinking behavior:

Tem bom organismo, o gajo (the motherfucker has a strong body)! Very healthy! Without that, he couldn’t keep up this *vicio* (vice). He hardly eats, drinks *nipa* all of the time, and rarely gets sick (with AIDS symptoms). He is also smart, a very good nurse. He could be treating people in his own home if he wanted to. Instead, the only time you can catch him sober is if you get to his house as soon as he wakes up. Otherwise, it doesn’t matter what he does or doesn’t plan on doing that day. If he starts out for work, all it takes is one stop somewhere, anywhere for a drink. From that point on, he won’t appear at work, he just goes from drinking spot to drinking spot. When he starts this, you can see it happen, as if he changes into someone else. He takes the entire bottle of *nipa* in one gulp [Falume swallows harshly], then the eyes get bloodshot, and droop a little bit. Then, his body goes rigid [Falume locks his arms down at his side], and finally loosens up [Falume slumps on his stool]. At that point, he starts talking nonsense, and you know that he’s gone (personal communication, April 28, 2009).

This, of course, explains Antonio’s under interest in Caridade’s regular activities and his over interest in paychecks.

On days when salaries were given out, if he couldn’t show up, he had another member walk the sum of money down to his home in Chipapwale. When he did show up to collect money, he

usually didn't make it back home until the next morning. The drinking would begin immediately, first with a celebratory 2M beer, followed by barraca-bought gin, and finally his favorite substance, *nipa*. Carlitos would bring a reed mat outside for him to pass out on before he closed the office. One time, some Caridade activists were taking pictures of a passed out Antonio on that mat after he had soiled himself, lying in dirty clothes directly in the sunlight in the middle of the day next to the office wall. From this kind of behavior flowed decisions and actions the results of which were bad for the association as a whole. Antonio hung on to his position as president, refusing to be ousted by other members and reacted violently to such suggestions, so that he could continue to fund his drinking habit. The power that he lauded over other members and activists, as a nurse in the day hospital and the president, de-motivated and discouraged others from participation or from believing that the association would ever improve. When sober, he would make promises to people or commit to decisions that he couldn't keep or would overturn when he got drunk. It's not that members emulated his behavior—nobody's drinking problem was as severe or frequent as Antonio's—but people took advantage of the chaos injected into the group through his poor and lackluster leadership nonetheless. Before losing so much control over the association, Antonio also managed to install a number of his drinking friends (also HIV positive) into certain activist positions throughout the province, including in his home village of Mecufi. This further sullied the name of Caridade as a group of alcoholics, who rarely did their job with precision, but were nevertheless in charge of UNICEF school programs and delivering AIDS education to children.

Rita, another HIV positive *nipa* addict and Caridade activist, owned a house in Chipapwale, but refused to sleep there because of threats from an ex-boyfriend. Instead, she spent her evenings in the homes of other boyfriends all through the city. The NGO Medicos del Mundo, perhaps unaware of Rita's proclivity to drinking, had installed her as an activist working in the

bars and brothels of Pemba City. This position kept her both fed and opportunistically intoxicated as she was offered meals or drinks from bar owners involved with the program. Others in Caridade suspected that Rita sometimes traded her own body for money or other goods when she was off duty. My own interactions with Rita became full of tension, as she invited herself to my home one day under the pretense of an interview. After insisting that I buy beers and cokes for us to drink, she suggested that we sleep together and that she become my girlfriend during my time in Pemba. When I refused, she spread rumors that this act had taken place anyway. Constantly tied up in court battles with ex-boyfriends who she claimed would not return items left at their homes—items like radios, speakers, and clothing—Rita’s social and economic situation deteriorated quickly. Medicos del Mundo found her drunk at an event for AIDS education in a community police station, ending her activist salary and position. Her home in Chipapwale got flooded and was broken into, leaving her truly destitute. As she refused to stop drinking, she blamed her problems on other people in Caridade—some of the same people who could have sheltered her through continuing personal disasters.

Numerous other events raised concerns around the issue of alcohol and AIDS activists in Pemba. When visitors from other AIDS associations came to the area—presidents and vice-presidents from other associations in other provinces, high level activists in RENSIDA or from Maputo—they were courted and serenaded by Pemba-based activists who introduced them to the city’s nightlife. Falume, the President of the Assembly, was usually put in charge of identifying which bars to go to at what time, and which women might be suitable for the men, the *chefs* (bosses) on overnight trips to the area. I accompanied him on some of these outings and have seen, on multiple occasions, Maputo-based AIDS activists take home women from Pemba’s bars. For Caridade, on paydays it was not unusual to find activists spending a good deal of their paycheck on drinks in the local *barracas*. Young females, somehow aware that it was payday,

would show up to drink beer with association members, later disappearing together into alleyways as night fell. Some of the male activists also frequented brothels in Pemba City. There are many of these establishments, masquerading as hotels. Inside are rooms with at least two doors so that people can enter into one side and leave through another. When I visited the homes of female activists, they would ask me to buy beer for them, and would drink as many as I chose to provide to them. Luisa, Caridade's vice-president, was often found in the yard of her home drinking hard liquor. These tendencies and behaviors are not anomalies, instead, they are representative of what is in Pemba a culture of drinking, sex, and escapism.

This aspect of African culture—alcoholism and partying—is an enormous challenge to AIDS treatment activism because it is so entrenched, accepted, and impactful. Clinicians certainly recognize the problem, linking the overconsumption of alcohol with a greater burden of HIV-related symptoms, low levels of social support, new forms of stigma, and the visiting of traditional healers (Denison et al. 2015). The increasing emphasis on the nexus between treatment and alcohol, in mainstream published literature and in clinical studies, strongly suggests and confirms that this is yet another issue that cannot be comprehensively addressed in the clinic. It speaks to the need for effective approaches to addiction at the community level—like Alcoholics Anonymous (Valverde and White-Mair 1999), options that are free, publicly available, and operate independently—to be more widely available in this context. It also speaks to the need for strategizing how the AIDS support group could be more involved with discouraging and limiting alcohol consumption among its members.

Berger and Luckmann (1967:2) mention that “*the man in the street* may believe that he possesses ‘freedom of the will’ and that he is therefore ‘responsible’ for his actions.” They go on to question how it is that ‘freedom’ has come to be taken for granted in a society, and how ‘reality’ can come to be lost to an individual or to an entire collectivity. The ‘reality’ of AIDS is lost, and

takes a back seat to the ‘freedom’ to drink and get drunk in Pemba City. Concerning therapeutics, willpower and intention are both vacant in this context. It may be worth questioning why and how AIDS activism has been unable to address significantly the question of alcoholism—and its associated behaviors, such as sexual promiscuity—in its ranks and among patients and activists in southern Africa. Perhaps this stems from a backlash against earlier presumptions that AIDS transmission is predominately the result of negative risk behaviors, resulting in timidity over prescribing and suggesting that people refrain from them, a hesitancy for controlling or making demands on others. Yet, if we are going to seek out verifiable truths pertaining to the situations that societies racked by HIV/AIDS encounter, assessments on alcoholism and substance abuse should not be off limits for the purposes of analysis and as potential factors promoting the continuation of the epidemic and barriers to treatment adherence.

Still Missing - Practical Activism for the Man in the Street

The stories, statements, and encounters highlighted in this chapter expose topics of concern that are not well studied in the world of HIV/AIDS—lingering confusion about the virus and activism, ineffective home-based care programs, rampant treatment abandonment, and alcoholism in Cabo Delgado Province. These have immense consequences for patients and implications for the future trajectory of AIDS activism as it unfolds in the southern African context. The intricacies and details of what goes on in Pemba and Cabo Delgado—what I suggest is a microcosm, a ‘subuniverse’ of the wider struggle that AIDS patient-activists undergo and face—are not unique or isolated. Likely, similar events are unfolding elsewhere and not receiving much scholarly attention or other publicity. The features of this subuniverse reveal that the provision of AIDS treatment, as well as the work of activists, is dysfunctional on several levels. Patients are not obedient to biomedicine. They do not place much weight in the public work of activists. Their efforts and those of the state are viewed with ambiguity and not always trusted.

Patients and activists—although they will use their HIV positive status as leverage for resources—do not seek to stand out but rather want normality in life, stability in their domestic and social situations, and to be able to carry on with work and other personal endeavors. When treatment fits into this equation it is embraced, not perfectly or consistently, but predictably and reliably for those who ‘know’ that it is effective. There is some degree of treatment ‘activism’ in anybody who fits this description.

Scholars of AIDS activism emphasize its relevance as a human rights struggle and its capacity to transform people from subject to citizen, from a passive recipient to an active participant (Fenio 2011). This narrative takes on an air of civil rights, and, unfortunately, of sociocultural evolution as well. Activists in Pemba are expected to conform to a better model, one that emphasizes outspokenness and the right to be demanding. Academics point to well-known success stories, like South Africa’s TAC, which expanded and thrived on partnerships and the building of international and academic coalitions (Grebe 2011). In this way, AIDS activism gained widespread recognition and legitimacy as a politically-oriented social movement, equipped to be, purportedly, active and present in virtually any setting. It successfully drew upon global agreements and worldwide treaties capable of empowering patients anywhere to make demands on the state and the culture around them, to be, in a word, “transformative activists” (Susser 2009:142).

What happens, however, when chronicling the pursuits and lifestyles of AIDS patient-activists in places like Pemba City is that this narrative either doesn’t fit or begins to break down. The “common” activists described here do not have very clear understandings of human rights. Some default on their treatment. Others haven’t even taken an AIDS test. Groups carry out income generating projects with a tendency to fail, or that end up serving narrow interests. Unless they occupy a lower rung on an imaginary ladder of success—not yet modern or up to speed—

then these activists are not given a clear category to occupy in the world of activism. They are, perhaps, ‘struggling’, ‘imperfect’, or ‘handicapped’ activists whose positive intentions—and, indeed, a myriad of valid attempts and ‘little’ achievements—nevertheless christen them as legitimate.

The subuniverse of Cabo Delgado Province does not flawlessly serve the oft-embraced agenda or stereotypes we have come to associate with AIDS activism—that “some in Mozambique are becoming transnational citizens like their counterparts in South Africa” (Fenio 2011:731), or that “those living with HIV/AIDS remake themselves as both citizens and humans, asserting ‘who’ they are through meaningful appearance in the public realm” (Hayden 2012:587). Such assessments and statements do not apply to everyone and everyplace. It is possible that if and when they fail to fulfill particular criteria, subuniverses like the one in Cabo Delgado get ‘selected out,’ omitted, even dismissed as nonrepresentative or unimportant outliers. Unable to contribute to standard talking points it is easier left unmentioned. Subuniverses, “like all social edifices of meaning,” write Berger and Luckmann (1967:84), “must be ‘carried’ by a particular collectivity.” It only follows that in a world of biosocial collectivities and biological citizens, some subuniverses are more privileged than others. If they resonate in the right way and at the right time they can be taken for granted, permitted or nourished to represent and to speak on behalf of all the rest. Very successful and renowned AIDS activist groups come to be considered the establishment in the world of AIDS activism, and to be taken as its “stable symbolic canopy” (Berger and Luckmann 1967:86). Limited almost exclusively to treatment expansion, and having already done their job relatively well, these models may have little to offer moving forward.

The ‘triumph’ of AIDS treatment activism—getting ART into more and more public health facilities in southern Africa—is also, in some ways, the ‘triumph’ of those who would like to see it end there, who can now claim ‘mission accomplished’ and divert resources or attention to

different emergencies, crises, or other deficiencies in international governance and development. The absorption of political resistance, the adoption of AIDS treatment into mainstream mechanisms of healthcare may—much like other attempts to make civil society voices heard and recognized (Tusalem 2007)—disproportionately favor the needs of the upper middle class over the lower. The evidence for this includes the longevity and persistence of very basic problems and challenges such as those elaborated upon in this chapter. Even with ready access to ARVs in clinics, patient-activists in Cabo Delgado still lack strong support groups and social networks. Average patients could very much benefit by having a greater say in the way the government manages AIDS associations, and in the manner in which they are incorporated (or not) into the projects of NGOs.

Still missing are the practicalities of how to live well with HIV/AIDS in Pemba City and in Cabo Delgado Province. Still missing are examples and models for a free and independent civil society. Still missing are sustained social relationships in a happy and thriving support group setting. Still missing are manifestations of a capable therapeutic community tailored to meet the needs of *the man in the street* so that he can overcome the right obstacles in this environment, where information is skewed and knowledge is too much subject to rumors and miscalculations. The needs and views of *the man in the street* are easily silenced and subsumed simply by placing—or claiming to place—AIDS drugs on the shelves of the clinic. Becoming more political—protests, demands, the elucidation of ‘rights’ claims—as this next chapter will demonstrate, is not a valid strategy for everyone in all contexts. AIDS activism, in order to be successful, requires acknowledgement of its diversity and limitations, and the development of various alternate forms and framings, even if they appear a bit different than what is considered to be the status quo.

Chapter V-The (Dis)Integration of the Day Hospitals

Protests in Pemba

On the morning of September 11, 2009, about a hundred AIDS activists gathered together in Pemba's *Praça dos Herois* (Hero Square), two kilometers away from the Provincial Health Office. Some had flown in from Maputo, others were trucked in from surrounding towns and villages, but most were association members and patients who had once attended Pemba's day hospital, the AIDS clinic that had closed down—or, as the government phrased it, was 'integrated' or 'decentralized' into the central hospital. They planned to march along the city's main street, *Avenida 25 de Setembro*, with a letter to be hand-delivered to the Provincial Health Director alerting him of their grievances. T-shirts with the slogan *HIV Positivo* were distributed to the participants, youth, teens, and adults alike, who had also prepared signs with phrases like "Don't leave us to die!, We are all equal, You and I depend on treatment, and No to Stigma!" The biggest banner, to be held in front of the marching crowd, was the centerpiece and contained the principle theme of the march. It read "March for Life without Stigma—Pemba, 2009." Another one, almost as big said "Stop Stigma and Discrimination."

As people got into position, clustered with their organizations and friends, sirens from the police motorcycles guarding the protesters started sounding. A man with a megaphone—one of the Maputo-based activists—gave a quick speech:

We are all here as equals, and we know that what is happening in our country is wrong. People are suffering! Our brothers and sisters do not have the medical services that they need! So, what are we going to do about it? We are going to tell them what we think! And what do we think? Down with stigma!

At this, the crowd responded, in unison, "down with stigma!" and began marching forward. As the people progressed through the city's main thoroughfare, the administrative and commercial districts, microphones were brandished and the group chanted calls and responses. "We are all

equal, we want better health, don't leave us to die!" People broke into song and danced happily in the caravan. Activists with their own motorcycles (including me) stayed in front, adding to the noise, and buzzing ahead a hundred meters or so whenever the crowd caught up with us. Just prior to ascending the final hill to the Provincial Health Office one song in particular caught everyone's ear, adding much to the level of excitement. It was directed to the nation's Minister of Health, the enemy or villain of this AIDS activist campaign. The group sang "Ivo Garrido, you have really done it this time!"

Stationing themselves on the manicured lawn outside the main entrance to the Provincial Health Director's office, people continued to shout phrases like "better health care!" and "we want more centers!" Some journalists in the crowd started conducting interviews for radio and TV. "We need to see doctors! Down with stigma! We are not dried fish! Where is Doctor Cesário? Where is nurse Inês? Where is the food we have been promised? We want better nutrition!" It was extremely hot, and despite continued attempts to keep energy high—some impromptu speeches, additional singing, brief improvisational comedy sketches of the Minister of Health closing down AIDS clinics—the crowd began to dwindle. After two hours of waiting the director had still not appeared, and people were leaving to seek shade, water, and food. A group of office workers started to gather outside, telling the group to leave the premises. Grabbing a megaphone, Luisa—Caridade's vice-president, who had been appointed leader of the protests—directed her voice toward the building with the intention of being clearly heard. She stated that these same protests were going on right now in other cities. In Lichinga, Quelimane, Xai-Xai, and Tete, activists were marching and gathering this same day and for the same exact cause. "If the director is not going to come outside, I will read the letter to him myself!" she stated. At that, and with the letter in her hand, she motioned for two other activists to accompany her and marched toward the entrance to

the building. They were forcefully stopped by armed guards, and retreated back onto the lawn where most of us were still standing.

We got word that some activists had spotted the Provincial Health Director attempting to leave in a Ministry of Health vehicle, but they had blocked the entrance to the parking lot with their bodies, forcing him to go back inside. A few minutes later he finally did emerge, dressed in a suit and tie, and sweating profusely. Luisa approached him with the letter in hand, but he barely made eye contact with her, and addressed the rest of the crowd instead. “What do you have to say to me, personally?” he asked, “I don’t have time for these *brincadeiras* (games)!” Luisa waved the letter in his face tauntingly. Fuming, he snatched the letter from her hand and said he would read it inside, at his desk, but not here in public. After this, the protest ended, and very disappointingly. Some people trickled out of the crowd and back to their homes. Others returned to the staging area, waiting for the trip back out to their village or town. The Pemba Provincial Health Office never issued a response, but Mozambican news and media took notice. There were headlines in local newspapers and online (IRIN PlusNews 2009b), however, nothing really came from the effort. The day hospitals never reopened, no other show of force was made on behalf of AIDS patients in Pemba. This was the first, and since then last such protest ever in the city.

The Pemba protest was in a sense contrived, coordinated by a small group of activists based in Maputo who dubbed themselves the *Liga contra Discriminação* (or the Anti-Discrimination League). The motivations for the protest, however, were quite authentic, not only here but in the rest of the nation as well. Patients were upset at the integration—or really, the disintegration—of their AIDS clinics, the day hospitals that had been the locus of AIDS treatment distribution since its early stages in the country. Yet, the letter that Luisa handed to the Provincial Health Director, a carbon copy of the one handed to the Minister of Health in Maputo during a similar protest a month earlier, made no mention of day hospitals or the closures. Demands to reopen the facilities

had been removed and replaced with vague ones, requests for better services and less stigma, because the activists had been forewarned—by their own government—that the day hospitals were gone forever. The reason for this was because AIDS treatment, according to the state, should not be limited to day hospitals alone, but “decentralized” to all health units. Ivo Garrido, the Minister of Health, noted that AIDS patients should not be forced to congregate in one place and even went so far as to label day hospitals “foci of discrimination” (Olsen 2013:243). This was an assessment quite opposite that of the patients themselves, who appreciated the convenience and indeed discretion afforded them by having their own facilities. Faced with the state’s claim that more AIDS patients could be reached by devolving AIDS services into the national health system, patient-activists in Mozambique, despite a preference for having their own AIDS clinics, were robbed of their traditional mantra—that AIDS patients are the same as everybody else and that treatment should be provided for free everywhere. The state, apparently, had taken activists up on their goal and request of providing universal health care, but in a way that did not seem to privilege them.

In this chapter, I suggest that the broadly resonant “master frame” (Carroll and Ratner 1996) of politically-oriented AIDS treatment activism—more treatment, for more people, in more places—has failed and even done a disservice to patient-activists in Mozambique. Enormous and disproportionate attention has been paid to AIDS patients and their protests or rights claims, resulting in a preference for a mode of interpretation establishing injustice and victimization as the justification for their existence. What occurs when this justification is taken away from them is the perceived subsequent irrelevance of the movement itself. Since its inception, AIDS activists have been portrayed as being interested primarily in treatment access (Gamson 1989). The wider struggle for social justice, and even for complete unity among the movement’s adherents, is seen as insurmountable compared to just getting a prescription for a drug or a pill. In the second

decade of the 2000's, however, this overarching “mobilizing structure” (Goodwin, Jasper, and Khattra 1999:51)—of poor treatment access and perceived stigma and discrimination—has become impermanent, absorbed, and is beginning to be addressed by the very same entities and powers that were previously considered the movement’s targeted enemies. A poor selection of case studies—a focus on ACT UP, or TAC, and similar groups engaged in open dissent—has lent itself well to imprecision and biases that hindered the further testing and refinement of additional proposals about what AIDS activism is, does, and could be in other real world settings.

Scholarship on AIDS activism is dominated by what Goodwin and Jasper (1999) call “political process theorists,” who view the study of protests, social disruption, and rights-based challenges to political oppression as their end goal. This leads to stagnation, and a focus more on the *emergence* of a social movement than the *viability* of its form, strategies, or impacts. Political process theorists “remain enamored of sweeping, transhistorical formulas and invariant models” (1999:30). Latching on to the “political opportunity thesis,” the main argument of this approach is that “people join in social movements in response to political opportunities, and then, through collective action, create new ones” (1999:30). The inherent implication is that political involvement is sufficient for social movement mobilization. It also presumes a fight, a consistent back and forth between those with and without power. For political process theorists, social movements are “collective challenges by people with common purposes and solidarity in sustained interaction with elites, opponents, and authorities” (Tarrow 1994:3–4). If these elites, opponents, or authorities manage to remove themselves from the fray—by, for example, agreeing on some points with activists themselves—then the movement has nothing against which to struggle and is likely to fall flat.

In this chapter, I will explain how this occurred in the context of the “decentralization” of Mozambican day hospitals. As part of a wider international trend toward “health systems

strengthening” (Abt Associates, Inc 2012; World Health Organization 2007), the traditional “master frame” of AIDS activism—treatment equity, maximizing the number of beneficiaries of ART—was relocated from the street into institutions, and transformed from being radical to mainstream. Health systems strengthening is an example of what happens when the “policy implementation capacity” (Rucht 1996) of the state is too broad and not subject to local-level, democratic discussion or debate. It essentially robbed AIDS activists of their elite allies, who could now support AIDS treatment expansion via ways and means less outside of their comfort zone. This unfolding of events suggests that describing protest should not be the aim of research, at least not without filling in more of the blanks. Protests are easily, and usually, sensationalized. AIDS activism, by allowing itself to be defined by political process theorists, dominated by concerns mostly for biomedical therapy, and by activists interested in airing their grievances more in public than in private, finds itself unable to be shaped by what occurs around it, and unable to adapt to the shifting constellations of change and political processes in which people are inherently embedded.

Day Hospital Closures

The day hospital closures should not have come as a surprise to AIDS activists. It was discussed for years before it occurred. During my first trip to Mozambique, in 2007, the topic came up repeatedly in interviews with activists in Maputo and Pemba. When queried on their opinions, however, the responses were strikingly ambiguous. Patients then were much more open to the idea of a day hospital integration:

The hospitals are full, and the day hospitals are few. They should integrate them because the central hospitals don't have what they need. Also, people really do abandon their treatment because of the day hospital. Nobody wants to be seen there. We are all people, we are all patients, and diseases are diseases. So, it is a good idea to join them together (Interview, July 5, 2007, Maputo).

There was an acknowledgement that resources were not evenly distributed, and that getting rid of day hospitals might be the solution:

There is this big access problem in the rural areas, and no trained health care personnel. So, I see what they are trying to do. Patients should not have to come to the cities just to get treatment, and when they try to get ARVs in a rural area and are not well received, they might not come back again. So, there has to be some equality there (Interview, July 5, 2007, Maputo).

On the point of discrimination, some patients emphasized the desire for confidentiality over simply having their own clinic facility, and the ultimate need to protect their AIDS status from involuntary disclosure to others:

People pass by the day hospital and make nasty comments. They're just not very nice. So, yes, some people are scared to come to the day hospital for fear they will be spotted there. But, in the main hospital, it's obvious to anyone who sees my (health) card that I'm HIV positive. So, it's hard to tell where the discrimination might be worse, here or there.

Yet, patients were also keenly aware that they would lose something along with their day hospitals, in particular, convenience and some degree of specialty care:

Treatment for someone who is seropositive is different than from a normal patient. And if they integrate, the waiting time for us in the hospitals would be intolerable! Now I go to the day hospital in the morning and am finished by 1pm. If they integrate, I would have to come back the next day (for a test or laboratory result) (Interview, July 4, 2009, Maputo).

The doctors in the day hospital know what they are doing and work very well, so integrating them is a bad idea because there the doctors treat AIDS only. I have never heard of a drug shortage in a day hospital, but our other hospitals don't function. If they integrate, there will be nothing there for us (HIV patients). Those other hospitals don't have health technicians or laboratories, stigma is worse there. If this happens, where will we get our medications? (Interview, July 3, 2007, Maputo).

While many people were very aware that an 'integration' was being considered, they did not know when or how it might actually happen.

The order was given to close them in early 2008, and, at least initially, Ivo Garrido denied it was even true. The newspaper report—probably an inadvertent leak by the Ministry of Health—

indicates that discussion between patients and the government on this topic probably should have ensued much earlier:

Mozambican Health Minister Ivo Garrido has denied that he ever ordered the closure of the "Day Hospitals" which cater solely for HIV-positive patients, according to a report in Friday's issue of the independent weekly "Savana". It has taken the Minister a month to deny the story, which first appeared in the 27 February issue of the Maputo daily "Noticias". The paper claimed that Garrido decided to close the Day Hospitals because he regarded such separate treatment as contributing to the stigmatization of, and discrimination against people suffering from HIV/AIDS. "The Day Hospitals have no place in the structure of the Ministry of Health", said Garrido, as cited by "Noticias". Regardless of the beliefs of those who had set them up, they had become foci of discrimination against AIDS patients "and that's why I have decided to abolish them". No letter from the Health Ministry denying this story appeared, and "Noticias" never published any retraction. Furthermore the closure of the Day Hospitals seemed to be in line with Ministry policy. According to "Savana", NGOs that work on HIV/AIDS say that the decision to integrate anti-retroviral treatment for HIV-positive people into the normal services of the health units, rather than keeping it as something separate, was taken over a year ago. Nonetheless, the "Noticias" story created some alarm among the patients who were using the Day Hospitals, who had not been prepared for any change in their method of treatment. Some told reporters they feared for their survival if they had to receive treatment from units not specialised in HIV/AIDS matters. Such concerns may have led to a quiet volte-face. For speaking to reporters last Tuesday, during an interval in a meeting of the Health Ministry's Coordinating Council, Garrido declared that he had not ordered the closure of the Day Hospitals, and that they are still functioning. He added that all measures taken by the Health Ministry "seek to guarantee the well-being of patients and not to damage their interests" (Savanah 2008).

Nevertheless, over the course of the next year day hospitals began closing, slowly but surely. One by one they were 'integrated' into the main hospital, often with no warning or notice given to patients about what was to occur (IRIN PlusNews 2009a). When this began, some patients knew about it, and others found out the hard way. Activists—who, perhaps, should have been aware—were too slow to address what appears to have been a systematic removal of AIDS clinics until much too late. Nobody, including the health workers and day hospital staff themselves, was really prepared.

The way this 'integration' happened differed from site to site. In some cities, like Chimoio, the day hospital doors were locked and patients were redirected to the central hospital waiting

area. In other places, like some sites in Maputo, patients were told to report to other wings—a “Department for Chronic Disease” (Olsen 2013:231). These tended to be dilapidated buildings with a new name, but still devoted mostly to AIDS patients—the most common type of chronically ill person. They often found themselves waiting outside in the sun, and even more exposed to the eyes of passersby than they had been in their original sites. One of the official reasons given for ‘integrating’ the day hospitals was to bring treatment closer to the homes of patients. Olsen (2013), however, notes that attempts to do this failed. In many cases, patients did not want to be seen obtaining treatment close to their homes and went to other neighborhoods, sometimes traveling great distances to do so. Some clinics became congested and others became empty, because patients did not show up where they were always expected to. For the first time in history, since AIDS treatment began in Mozambique, ARV drug shortages became a widespread concern. After the day hospital ‘integration’, providers began filling prescriptions only halfway, requesting patients to come back frequently to check and see if more pills were available (PBS Newshour 2010).

In Pemba, one of the last sites to be ‘integrated,’ the day hospital building remained in use, but was transformed into an auxiliary waiting and triage area for the central hospital. AIDS patients arriving there were surprised to find it overflowing with strangers, and people suffering from a variety of other ailments from broken arms to Tuberculosis to malaria. AIDS work was supposed to continue as normal, but it didn’t. Activists who worked with new patients to carry out treatment counseling, for example, had no space in which to do it. Education on HIV, normally carried out with a TV/VCR or a flipchart of illustrations in the corner of the waiting area, ceased because there was barely any room for a teacher to stand. Noise levels were too high to speak over. Also, the day hospital staff had been split up. Some were transferred to other wings of the hospital, others to entirely different clinics in the city. Patients, who previously knew staff by

name, were now faced with new health care workers not only unfamiliar with their specific cases, but also not well trained (if at all) in the area of HIV/AIDS. Inside the former day hospital, doorways had pieces of paper taped to the front as signs with the words “pediatrics,” “maternity,” or “triage” on them. There was no consulting room only for HIV patients any longer. Laboratory equipment had been consolidated into one room, and the workers were cramped inside. The AIDS testing center, next door, was also shut down. It had been taken over as offices for the Elizabeth Glaser Pediatric AIDS Foundation, a PEPFAR contractor.

Patients had mixed reactions to the loss of the day hospital. Some were in favor of it:

I appreciate the joining of the two hospitals. The changes are good, because everyone used to say that this hospital had AIDS. Now it is better, it eliminates discrimination. In the past, everyone knew that the day hospital was special. Now everyone is together, so I prefer it this way (Interview, July 30, 2009, Pemba).

The day hospital did embarrass some patients, who believed that it was easier for them to hide their status from others according to the new arrangements, and were perfectly happy to not be seen in an AIDS clinic:

Hospitals were not originally integrated into African societies at all! Now, again, we are rid of these outside influences (he refers to the NGOs who ran the day hospital). People still go in, just look at all of the doorways, they can hide in those rooms and nobody knows the difference. Now that there is no separation there is less discrimination, so it is a good thing. The government knows what they are doing. Now you can't tell the difference between patients. There is less suspicion. It was so strange before (Interview, August 3, 2009, Pemba).

It is better now. In order to do anything else in the hospital, people have to get a test first (she mistakenly believed an AIDS test was now required for anyone at all to be seen in the hospital). Now we will know everyone who has the virus, so this is good for the community. The change is normal, I can still hide my medication. My children ask me everyday, ‘Mom you are taking pills,’ but they do not know what the pills are (Interview, July 31, 2009, Pemba).

Not all agreed, however, and spoke up against the day hospital ‘integration’:

It was better to have our own hospital. Everyone is looking at us, they won't eat with us. People have stopped coming for their ARVs. This is a complex disease, it needs to be controlled. This way, there is less control (referring to laboratory tests and patient assessments) (Interview, August 4, 2009, Pemba).

Many people with HIV already are not registered (for ART). They usually arrive too late for treatment anyway. How can this be better for them, who were scared to come even then (before the integration)? If you look around, nobody even does lectures anymore (AIDS education), because they don't get paid. I will still come here, there isn't another option, but I do not think that the government is hearing what we patients are saying (Interview, August 1, 2009, Pemba).

At first this was a discriminatory place, the 'door of AIDS,' people called it. Now it is gone, but for what? Now look, the space is gone, there are no beds, there are longer waiting periods. And the others here now are talking bad about us, saying 'why did they put us here with AIDS patients?' In the pharmacy, too, when you hand over your card you can start to feel ashamed and people talk about it. It was better *entre nos* (between us only)" (Interview, July 31, 2009, Pemba).

Experiences with the 'integration' were highly varied, which suggests that the process was not standardized. There were, most likely, severe deficiencies in its implementation.

In Pemba, for example, the integration was unarguably messy. Attempts were not made to clarify how it would happen, what new roles activists would take on there, or to introduce new staff to them. Activists were questioned about their legitimacy in the new hospital spaces, and found it difficult to do their jobs:

I arrived one day to begin my normal duties, when a health technician I don't know asked me what I was doing here. I replied '*senhor*, I am an activist, and I am here to work with the HIV patients.' One patient waiting for a consultation told me to leave, that we don't need dirty people in the hospital. As I argued with that man, the health worker told me to be quiet, to stop making noise. I didn't go home, I stayed to do my job, but felt ashamed and demoralized. Who are these new people, and why don't they like us? Why are they trying to make us feel isolated and keep us from doing our jobs? (Interview, August 1, 2009, Pemba).

There was also misunderstanding about how far reaching the process had been. Some were unaware that day hospitals were closed down nationally, and blamed it on local authorities:

That Dr. Saúde [the former day hospital health technician] is not doing a good job. Why did he close the pharmacy in the day hospital? And without telling us he was going to do it? [I explain to him it was a national decision, not one made in Pemba by Dr. Saúde]—Ok, but the least they could have done was explain to the patients what was happening. None of us understand what is happening in the hospital (Home-based care visit, August 8, 2009, Pemba).

Some effort could have been made to communicate what was happening so that patients had fewer questions and knew what to expect. This, however, may not have been a priority for the government.

The issue of day hospitals in Mozambique has always been relatively tense. Kalofonos (2008) notes that they were introduced to offset stigma—that AIDS patients did not feel safe in standard hospital environments—but also for surveillance purposes and to control medication stock. HIV was then still very much considered an emergency. ARVs were expensive, and so donors demanded a direct route to patients that was free from government bureaucracy and inefficiency. The Ministry of Health was at first on board with the idea, and at their inception day hospitals were not supposed to be set apart from the rest of the health system. They were initially labeled as “specialty units integrated into the existing network of health services...places for the introduction and control of anti-retroviral therapy” (MISAU 2004: 7). However, their implementation occurred at a time of increased donor interest in AIDS that may have seemed threatening to national sovereignty³. Therefore, the Ministry of Health may have always harbored some mistrust and skepticism about a system not entirely under its control.

Over time, through NGO support, and a disproportionate amount of international funding, many day hospitals became relatively independent. Some—especially those built and run by international medical NGOs—had more reliable services than government hospitals, better equipment, and higher staff to patient ratios. Over time, day hospitals came under fire as NGO creations, poorly linked to other health services and incapable of contributing to the advancement of the nation’s health system (Pfeiffer et al. 2010). Increasingly, it was argued that arrangements such as these—programs and specialty clinics targeting one disease only—are

³ Matsinhe mentions the intense negotiations that occurred over the creation of other specialty AIDS projects—like the National AIDS Council, and the implementation of AIDS only strategic action plans (PEN I, II, and III) (2008 55-73). Day hospitals, likewise, may have been considered unwieldy.

inequitable (Schneider et al. 2006). According this understanding it is preferable to, as much as possible, minimize distances from home to clinic, maximize client usage and the number of beneficiaries, and introduce ARV services in as many sites as possible (Grépin 2011; Van Damme and Kegels 2006). These and similar arguments may have emboldened the Mozambican Ministry of Health to begin doing away with the day hospital system in the country—a system that had seen ART coverage rise from 3% in 2003 to 38% in 2009 (MISAU 2009; MISAU 2013).

Some within the activist community were more in tune with this than other patients. Day hospitals had become, in a sense, political chess pieces in a fight between the Ministry and foreign NGOs. César, the director of MATRAM in Maputo (the access to treatment movement), told me his opinion—that the Ministry of Health was so incompetent and so mal-structured that it could never get AIDS treatment right. NGOs, many of which staffed and ran day hospitals, had to stay and continue with their projects. The Ministry was intimidated by these, and more interested in asserting their domination than with helping patients. Likely, government policy would move in whatever direction necessary to kick NGOs out of AIDS treatment—an intervention over which the government now demanded more control. “Democracy kills,” he told me, “instead of improving things, the people in charge just want to show everybody that ‘I am the boss.’” He lamented the language being used to describe what was in his mind a step backward, and potentially a large scale attack on civil society. The ‘integration’ would concentrate more political power in Maputo, and give politicians greater control over patient’s lives. “When they do decentralize everything,” he said, “it means people here (in Maputo) will have access to everything in the rest of the country” (Interview, July 5, 2007, Maputo).

As I began to ask more questions about the day hospitals and their closures in organizations around Maputo, two main camps continued to emerge—and some continued to throw this word, ‘decentralization,’ around in their dialogue. The first camp consisted of AIDS activists like César

of MATRAM, and those international NGOs working at the clinic level, who found the move disheartening. “We put a lot of time and money into these facilities,” said the Doctors without Borders (MSF-Switzerland) education coordinator. “The patients do well there. It is their place.” She alluded to an army of patient-activists operating with the support of groups like MSF. I asked her what the options were at this point. She responded that:

The government is very clear that [the day hospitals] will close. There is nothing to be done about that. In their place, we are planning to open AIDS “centers”. They won’t have the same types of services—like medication and hospital care—but we can do some things. We are thinking along the lines of nutrition counseling, education, and employment services (Interview, Maputo, February 22, 2009).

The suggestion revealed the perceived benefits of day hospitals as much more than just treatment related. The desire to see these continue served as motivation enough for MSF to begin considering alternatives—AIDS “centers”—to counteract the rapid closing down of day hospitals, which was occurring without warning. An MSF doctor in the Tete day hospital said “they just barged in one day, and we were told to leave by the next.” Faced with, basically, a government-enforced shutdown, they had no time to notify patients, reorganize project staff, or close out basic activities. “It was sudden, and we were anything but prepared,” he told me (Interview, Washington, D.C., March 7, 2014).

The other camp consisted of program coordinators of multinational institutions, like UNAIDS and the CDC. Their opinions about closing down the day hospitals were almost opposite that of the first camp. They embraced the understanding that ART, by any means, had to be provided in more clinic sites. In the name of equity and better distribution, day hospitals had to be eliminated. “The day hospitals are being collapsed as part of an overall project of decentralization,” said the director of UNAIDS, Mauricio Cysne, in Maputo:

“Just with the sheer numbers of people living with HIV here, the day hospitals could even get bigger than regular clinic facilities. It will be easier for the government to better track patients this way. AIDS patients are just like everybody else. They suffer from the same diseases that other people all over the world suffer

from, so they need to be able to access all of the other services in the hospital. The activists are another problem...(Interview, March 11, 2009, Maputo).

When I asked him about that last point, the UNAIDS director began to address the patient's fundamental right to privacy, and to not be identified by any other party as HIV positive:

How would you feel if strangers could go into a hospital and look at your medical records? Such a thing would be unheard of in Michigan [where my university is located]. These AIDS associations, and activists, are not part of the UN system, so we are not particularly interested in working with them (Interview, March 11, 2009, Maputo).

I mentioned to him that the activists, nonetheless, felt insulted, as if their efforts to help get people on treatment went unappreciated. They had frequent contact with other patients, and believed that treatment program retention would suffer if the day hospitals were taken away. His response was that “this integration is going to happen. We don’t know what this will look like on the ground, but the theory is sound.” When told that AIDS activists were complaining about the day hospital closures, an expatriate CDC worker told me “we need data. If they are going to complain about this, we need data because in other places what we are seeing is that putting money just into AIDS doesn’t help the rest of the country’s patients” (Interview, March 12, 2009, Maputo).

Ivo Garrido—the man who, upon ‘decentralizing’ the day hospitals, would soon be the prime target of AIDS activists’ ire—falls firmly into this second camp of opinions. This camp is comprised of experts, of foreign-born workers in charge of large-scale programs and who do not see eye to eye with the smaller, field-based humanitarian NGOs like MSF. It is, perhaps, mildly surprising that Garrido falls into any camp of opinions along with foreigners. A staunch FRELIMO party nationalist, he is famous for enforcing certain parts of the “Kaya Kwanga Commitment” (World Health Organization 2000)—a framework issued by the Ministry of Health—in order to regulate the perceived incursion of NGO interests within the nation’s borders. His efforts to assign foreign health workers to isolated, rural areas of Mozambique were construed as

particularly bold, even dictatorial, by NGOs that had no intention of opening offices or supporting staff in the places he determined were most in need. If by closing down the day hospitals Garrido was carrying on with this type of a mission—controlling foreign interests and ensuring compliance with the needs of the nation—it is one that he never used as a defense. What he does say when finally confronted by AIDS activists, on August 3, 2009 in Maputo, is similar to what the UNAIDS director and the CDC worker told me when I interviewed them almost five months before.

Four to five hundred activists marched in the Maputo protest. Carrying signs, chanting, and wearing ‘HIV Positivo’ t-shirts, they approached the Ministry of Health building where Dr. Garrido, aware of the effort, was waiting to greet them. He stood patiently by as César of MATRAM, on national television and radio, read aloud the letter calling him a “dictator” for closing the day hospitals and not consulting the patients. “We want to express our indignation over the process of these closures,” said César. He mentioned specific cases where patients had been discriminated against, that wait times had increased, and medication in some sites had become unavailable. New hospital staff, he said, did not have the “patience” to attend to cases of HIV/AIDS as they did in the day hospitals (DREAM 2009). Given a chance to respond, Garrido did so mostly in the affirmative. Of course, he said, all of these concerns would be taken into account. Of course, he said, patients would continue to receive the highest possible care that the country could provide. In fact, they had no need to worry because even more attention was going to be paid to them in the near future. But, the topic of the day hospitals was not up for debate, they no longer had a part in the Mozambican HIV/AIDS planning process (Verdade 2009). The word that he used to describe the process was ‘decentralization.’ “If we had to open a day hospital at every place where HIV/AIDS patients are being treated, we would end up with two national health systems. From a public health perspective, this is impossible,” he told the crowd (Agência de

Notícias de Resposta ao SIDA 2009b). Garrido also claimed that the decision to “abolish” the day hospitals was his own, and it was irreversible (Agência de Notícias de Resposta ao SIDA 2009a). Over and over again, in the newspapers, on radio, and TV interviews, Ivo Garrido reasserted that the day hospital closures were his decision, and that they were being “integrated” and “decentralized” into the main hospital system.

Over the course of the next two months the rest of the day hospitals were shut down, including the one in Pemba⁴. Carrying out additional protests, as described at the beginning of this chapter, had no apparent impact on the Ministry’s actions. It was difficult to tell what effect closing the day hospitals had on patients, but universal clinic coverage is still not obtained even today. Activist groups, like MATRAM and its associates, estimated that 40% of patients had at some point either dropped out or interrupted treatment as services changed (IRIN PlusNews 2009c). While the number of people on treatment did continue to rise—up from 38% in 2009 to 52%, or about 300,000 people by 2012 (UNAIDS 2013)—the proportion of clinics providing ART rose by only 7% or 8% during that same time period. In 2009, 222 of Mozambique’s 1,414 health units provided ART to patients. By 2012, the number had risen to just 316, from 15% to 22.5%, leaving 87.5% of health units out of the process (MISAU 2013). Decentralization, while it did not deliver on its promise of putting ART on the shelves of every health unit, did accomplish one great feat—reducing the presence and influence of international NGOs and their involvement in AIDS projects across the country. Coordinators in Cabo Delgado told me they now occupied only a “support role” in the health system (focus group, August 27, 2009, Pemba). They were tasked with diversifying their programming to support other diseases and instructed not to focus on

⁴ There were two exceptions to this. The 1° de Maio clinic in Maputo (run by MSF) and the day hospital at Maputo’s military hospital—both out of the Ministry of Health’s reach—continued to function for a number of years afterward.

AIDS alone. MONASO, the government NGO in charge of administering to AIDS associations, also began to lose funding and influence.

But, while AIDS clinics and the locally based NGOs that worked most closely with activists and patients faded into the background, other features of the AIDS response in Mozambique continued to function unhindered. Targeted AIDS programs, as long as they were government related, were not decentralized. The Núcleos and the National AIDS Council continued to operate and their offices remained open. The Provincial Health Offices retained their strategic plans, AIDS specialty staff, and task force meetings. Select programs, like ECOSida—an AIDS project directed toward the private sector and business community—was more actively promoted after decentralization than before. The number of “community based organizations”, a term given to PEPFAR contractors (a global initiative of the American government), rapidly increased and the scope of their involvement grew as they were planted in provincial capitals all over the country. UNAIDS was not slimmed down, but RENSIDA—the national network of people with AIDS, and a UN-funded project—was significantly restructured, and subject to massive staff changes and reductions.

The implementation of decentralization applied a double standard, one that favored the largest national and international entities over the smallest. The justification for decentralization—doing away with AIDS exceptionalism, and the parallel health system of day hospitals—applied only to patient clinics and their friendly parties, but not to well-funded bureaucratic structures, even if there was overlap between them. Given Mozambique’s traditional reliance on foreign HIV/AIDS strategies, Garrido’s assertion that day hospital closures were only his decision is questionable. Mauricio Cysne, the UNAIDS director, was also quoted at the time making very similar comments as Garrido. “The day hospitals can’t be managed. We can’t confirm

that this is the model for putting 1.5 million people on treatment”, reported IRIN PlusNews (2009c). The report continues:

Following Cysne, the decentralization idea permits the patient to receive services closer to home. The day hospitals are too far away...Decentralization would be, according to Cysne, the only way to transform into reality the guarantee that patients can access universal treatment and a basic health services package (*my translation*).

While Ivo Garrido was certainly the ‘face’ of the day hospital decentralization process, his decision to close the day hospitals did not occur in an information vacuum. Others, at top levels of the nation’s development industry, shared his opinion. About a year later, Ivo Garrido was sacked from his position, and the new health minister continued to struggle with the impacts of the day hospital closures. Drug stockouts and patient complaints never stopped (Suarez 2010).

Decentralization was handled poorly in Mozambique. Making the appropriate connections between what happened and other forces, possibly ones too strong for Mozambique’s AIDS activists to fight, begs delving into the ‘theory’ of decentralization, where it came from, what it did, and how it was made manifest in this country.

Health Systems Flattening – the Failed Promises of Decentralization

The day hospital closures were, in more ways than one, in total lockstep with changes occurring in other developing nations at the time. Concerning the administration of AIDS care, health policy experts and scholars were actively debating the advantages and disadvantages of policies that emphasized the strengthening of national health systems over and above the continued implementation of piecemeal projects. Termed “health systems strengthening,” examples of folding disease-specific interventions into national health systems came primarily from the Latin American setting, where programs addressing bilharzia, maternal and child health, immunizations, vaccines, and malaria were gauged for how well their funding might better be put to use in the public domain (Rabkin and Nishtar 2011). Given the overwhelming amount of money

being spent on HIV/AIDS—which garnered about US\$15 billion in the first decade of the 2000s alone (El-Sadr et al. 2011)—metaphorical votes were being cast in the published literature for how well this might work in the world of AIDS.

The winners of this debate emphasized the futility of short term goals—even before all evidence in strict support of the position was available from real world settings (Atun et al. 2010)—and insisted that funneling HIV/AIDS resources into fewer funding streams would yield better results than the continuation of fractured, small scale efforts operating in isolation or in tandem with one other. “Horizontal” funding, with resources dedicated more to government coffers than anywhere else, was deemed more effective than “vertical” funding, or resources dedicated to smaller projects in fewer locales (Lawn et al. 2008). Decision makers at WHO, the World Bank, the US Government, and UNAIDS had decided—as we saw in the case of Mozambique—that victory in the fight against AIDS lay in the hands of empowered and emboldened national health systems, not with handfuls of NGOs who bypass local structures altogether. AIDS interventions would be unable to progress, and would ultimately be unsustainable, without addressing the systemic challenges common to the environments in which programs and healthcare staff found themselves. Building up the “crumbling core” of health services and facilities in developing nations, many began to argue, should be the top priority (Loewenson and McCoy 2004).

This was, in many ways, a revisitation of some very old and even heated exchanges on whether it is better to fund one disease or fight them all simultaneously, whether it is best to implement “primary health care” or “selective primary health care” in postcolonial, poverty stricken, and even war torn states in southern Africa (Walsh and Warren 1979; Newell 1988). The difference between these strategies, when they were being considered in the latter half of the 20th century, was their potential for different kinds of distortions. Successes associated with a rapid

deployment of clinicians and staff, or pouring money into quick technological fixes—like bug sprayers for killing mosquitoes that spread malaria—had to be weighed against the possibility that local level processes might continue to degrade alongside them. Yet, empowering a nation could also mean a lower quality or even slower response. Governments already struggling with chronic infrastructure and logistical issues—such as being able to maintain a cold chain for vaccine storage and delivery—might only be capable of targeting basic health care issues, useful at the population level but not so much against epidemics or during spikes in the incidences of more virulent and deadly diseases. Tension around the continuing operation of Mozambican day hospitals was, subsequently, marked by very similar concerns. If we consider the facilities only as places for the distribution of pills, then of course folding them into the main hospitals makes sense—especially from the detached, birds-eye perspective of planners and managers.

However, in the developed world—the U.S., Europe, and other nations in the Global North—there are no prohibitions against specialty clinics or programs tailored to serve vulnerable populations. These are hallmarks of civilization, not threats to the system. If the UN, or WHO, or other managing body tried to force a developed nation to ‘integrate’ its cancer units or children’s hospitals, there would be no end to the outrage. Weeding out institutes or foundations that supported them—like what was happening to medical NGOs throughout Mozambique—would be judged as illogical or even illegal. In the majority of settings serving or targeting a population in need is considered a charitable mission, both to the group itself and to the rest of the healthcare system. It allows providers to filter services and to focus on illnesses which cause disproportionate suffering. It decongests other facilities so that a basic level of care can continue unhindered for everybody else. Accusation of brain drain is also misplaced. Studying cancer units, Germain (1979) notes that specialists aren’t ‘stolen’ away from hospitals that need them, they are instead given

opportunities that otherwise wouldn't have been possible to hone their craft. This logic applies to more than just clinics.

Supporting persons at higher risk for being lost to the system or remaining invisible is typically a praiseworthy pursuit, even if such efforts do separate or wall them off from the outside world. Providing at-risk persons with their own spaces is not uncommon. Janovicek (2007) portrays battered women's shelters as homes away from home, spots where women can recuperate and begin to reconstruct their lives after episodes of domestic abuse. Glasser (2010), studying soup kitchens, notes the sense of community that homeless persons developed there served a greater purpose than just the furnishing of basic meals. Clients developed resilience to personal crises through the development of social capital and networks of support. Targeted services, clinical or otherwise, do not have to be a burden, and dismantling them is less, rather than more, likely to strengthen a health system. Specialized services are typical of a well developed health system, and there are some very practical reasons why. The "therapeutic landscape" (Gesler 1992; Bell et al. 1999) of a clinic serving a vulnerable population, or a specific illness, carries with it a clear health promotion message. It can be designed to attract them and keep them coming back (Curtis et al. 2007). The integration of peer support—as in mental health or drug addiction treatment (Wilton and Deverteuil 2006)—becomes more possible. "Personhood" is better sustained as clients are more able to confront and manage issues that apply only to them and not others (McLean 2007). Day hospitals embodied all of this, and so for many Mozambican activists and AIDS patients their "decentralization" bordered on injustice. For them, this was not a sophisticated theory of third world healthcare, it was another word for "defunding".

During a visit to Pemba on September 6, 2009, just days before the protest, the president of MONASO (responsible for doling out funding to AIDS associations) had a sit-down meeting with

AIDS association members from Pemba City and surrounding areas. Her monologue centered on the falling budget of the organization. As NGOs began to “hand over” more and more duties to the government, MONASO had become increasingly responsible for financially maintaining most of the AIDS associations. It was becoming unsustainable. She criticized AIDS associations for being artificial—calling to mind Cruikshank’s concept of “artificially created solidarity” (1993:243). “Especially these newer associations,” the director explained, “they have a tendency to appear and then disappear. Their existence depends on whether or not we give them money. When we don’t, they stop functioning.” She complained that NGOs were shoveling their responsibilities for some AIDS associations onto MONASO, and stated that the problem was “decentralization”. This was the result of the “*crise financeira*” (financial crisis) she indicated, pointing to the global economic recession of 2008 and 2009. She then told everybody—this was the point of her visit—that MONASO would not be able to support all of the associations in the way it had before.

Activists who had worked for MONASO would be dismissed. MONASO would cease to print the books, brochures, and pamphlets that were previously distributed in order to educate people on AIDS prevention and relevant legislation. Instead, those groups that had computers would have to download and print them on their own. “This should give the groups more pride,” she told us, “because they will be acting more independently.” In addition, this year’s national MONASO elections would be slimmed down. Only one activist from each province would be chosen to go instead of the usual five. This and other encounters with coordinators in charge of AIDS projects and programs in the country began to convince us all that the word “decentralization” was being used to signify defunded and broken budgets. Another example involved funding for the December 1st World AIDS Day celebrations that year. Pemba’s Núcleo indicated that the budget had been cut by more than half, from US\$12,000 in 2008 to US\$4,800 in 2009, also because of

what they termed “decentralization.” The term became synonymous with lack of funding, unemployment for activists, and diminished opportunities in the city’s AIDS sector

At the opposite extreme, mainstream literature on HIV/AIDS published around this time used the term very differently. Rather than being synonymous with defunding, it was found alongside helpful sounding words like ‘integration’, ‘health systems’, and ‘strength’:

By placing emphasis on strengthening district-level health systems to provide integrated primary care, the tools [offered in this guidebook] result in improved patient referral, case management and communication between levels of the health system. Strong involvement of people living with HIV as expert patients during training and their participation in clinical teams as community health workers supports effective chronic care. The **decentralization** of services to the community level provides services close to home, supports family-based care and empowers patient self-management. Such community-based approaches to health service delivery not only help to overcome geographical distances but also address social distances by ensuring that health services are responsive to the needs of the community (W.H.O. 2009:119, my emphasis).

Similar excerpts are ubiquitous in official assessments of decentralization, which is offered up as the preferred process for a sustainable agenda of health systems strengthening. These serve as stark reminders of the gap between decision makers and patients, and suggest that those who implement reforms may be severely out of touch with field-level realities. At worst, information which contradicts this narrative may be getting covered up, deleted, or remain unpublished.

In Pemba, from the perspective of patients, decentralization was a bad thing. MONASO was going to stop funding their associations because of decentralization. The pharmacy, waiting area, and even lay activists who worked closely with them were all taken away when their day hospital was closed, also because of decentralization. Many patients—as I am about to describe in the next section—stopped coming for treatment and found medication more difficult to obtain. Experts writing about decentralization and health systems strengthening do not acknowledge such issues, but offer these types of conclusions instead, and often without providing data:

A recent subject of debate concerns the merits of vertical (targeted) versus horizontal (general) approaches to health-care provision. Although a disease-

specific, targeted approach has increased access to ART for millions of individuals worldwide, increasing emphasis is now being placed on general investment in health care systems, infrastructure, and human resources to address a broader spectrum of diseases. **Decentralization** of access to health services, with a shift towards community-based care and task-shifting away from physicians to trained nurses and lay health care workers, has also been shown to increase access to ART and improve adherence and follow-up (Barlett and Shao 2009:638, my emphasis).

When applied to antiretroviral treatment in Africa, UNAIDS (2013:21) agrees that decentralization is “the key factor” in recent rapid expansion of ART services, improving patient retention and various forms of adherence support—including that of support groups. Mozambique is singled out in such assessments, which claim that “all African countries are successfully decentralizing” their ART services (2013:38). Others—like Dr. Decroo of MSF, who was present at the closure of Tete day hospital—note that the decentralization efforts in Mozambique were hampered by a lack of infrastructure, shortages of human resources, organizational challenges, and drug shortages (Decroo et al. 2014). After decentralization in that region, patient attrition under the new system approached two times that of the old one (Decroo et al. 2009).

Most ironic, however, is the use of the term ‘decentralization’ to describe best practices that experts recommend enacting. These are portrayed as new ideas, distinctive, and innovative, but were already happening in Mozambican day hospitals at the time of their closures. Bedelu (2007) suggests that decentralizing services enables “task shifting”, or the use of lower level health care workers and lay “adherence counselors” to cater to higher numbers of patients in South Africa. Day hospitals already did this, however, by using health technicians to prescribe ARVs and perform assessments, and activists to educate new patients and fill out forms. Bemelmans (2010) points out that in Malawi, creating “health surveillance assistants” to work in “improved health posts” allowed AIDS patients to be seen separately and faster than in the main hospital. Day hospitals were already separate, faster facilities, ‘improved’ posts for AIDS care. Long et al. (2011) praised Johannesburg’s Crosby Clinic for building a separate waiting area, consultation rooms,

and pharmacy for AIDS patients independent of other clinic services. Day hospitals already had each of these features. Nearly everything that authors and experts identify as goals and objectives for decentralization to strive for and achieve was previously done in the Mozambican day hospital system as a matter of design, yet, their disappearance and devolution went unnoticed in most mainstream publications—particularly the reports of multinational institutions.

Health systems strengthening—the apparent goal of decentralization—began under the auspices of “performance-based financing,” the main component of a WHO pilot project that experimented with a “pay to play” system in the infrastructure-challenged nations of Rwanda (Bucagu et al. 2012) and the Democratic Republic of the Congo (Soeters et al. 2011). The model divides the health system into six “building blocks” or “pillars,” and embraces the use of standardized “indicators” that can be evaluated over designated time periods for statistical successes (W.H.O. 2007). Financing is given to particular districts and municipalities based on the performance of area health centers. To be rewarded, predetermined objectives must be met, related to (for example) the number of beneficiaries served, number of staff trained, number of successful live births, or number of persons placed on ART. In this data-driven approach, facilities report their results via forms and websites, which are tabulated and monitored from afar, in order to determine how well the clinic or hospital is functioning and meeting demands. Additional programming and more resources are allocated to sites that are high performers. In that sense, health systems strengthening is reminiscent of the American “No Child Left Behind Act” for public education—where schools and teachers are given bonuses for higher student test scores (Lederman 2010). Like critics of that American policy, critics of health systems strengthening suggest that false reporting and fabricated data, in the context of poor monitoring and limited on-site auditing, allow crooks and cheats to “game the system” for higher pay (Kalk, Paul, and

Grabosch 2010; Bucagu et al. 2012). There is, therefore, also a financial incentive for the government to decentralize day hospitals.

The notion that the best practices and efforts toward standardization underscoring health systems strengthening might be birthed from Westernized or even Americanized forms of managed health care and official accreditation opens this collection of policy shifts it up to similar, even more global criticisms. Namely, the questions of who watches the watchdogs, who controls quality control, and if business-related conflicts of interest are a possibility, or perhaps already in play, have to date gone unasked and unanswered. Completely implemented in the health systems of some developed nations, the tying together of payment, patient health, and medical intervention has previously come under fire in a variety of contexts. Investigations into the National Commission for Quality Assurance (NCQA, located in the United States) revealed corporate alliances in the non-profit world facilitated by “interlocking directorships” (McDowell 2004). Shared board membership and institutional sponsorship from pharmaceutical companies, multinational banks, and large health insurance companies caused some to label the NCQA’s supposedly professional regulatory models as self-serving. In 1999, the Lancet exposed attempts on the part of the U.S. Coalition of Service Industries (UCSI) to sabotage national health care in the UK and Canada. The group had links with the World Trade Organization. Conclusions suggested that “health maintenance organizations target the public funding behind foreign health care systems. Multibillion dollar social security or tax pools are effectively redirected through private-sector organizations” (Price, Pollock, and Shaoul 1999:1980). To not have addressed such issues prior to implementation suggests that the architects of decentralization policies are either unaware of them, or not very concerned. A healthy skepticism is certainly warranted pertaining to predictive claims that developing nations can or will prosper from this type of restructuring.

Health systems strengthening therefore resides in a family of policies which assume the mantle of value-free and objective, but surreptitiously lump together clinical issues, management effectiveness, efficiency, and cost. There may, therefore, be very good reasons to question the rights of multinational and non-governmental bodies to demand obedience and conformity from clinicians and practitioners at work in the field. Nevertheless, the most well-funded and widespread bodies and entities—the World Bank, the WHO, UNAIDS—have thrown their full weight behind the implementation of decentralization policies. Day hospitals may be just one form of collateral damage; an erosion of creative work in the health sector which properly belongs to local cultural heritages, and particular therapeutic landscapes, could be another. It would seem, however, that some kinds of testaments and evidence are being taken at face value over and above others. Supporting the moniker of health systems strengthening are manifold articles (Mussa et al. 2013), government contractors (Abt Associates, Inc 2012; FHI 360 2016), think tank analysts, and white papers presented, for example, at World Economic Forum meetings (Sekhri 2006). These defend “horizontal” models and attack “vertical” ones, like Mozambique’s day hospitals. The impact, in social science, may be turning some of us into corporate apologists. The anthropologist James Pfeiffer, who has a long history in Mozambique as an advisor and consultant, also spoke out against day hospitals, portraying them as NGO creations, poorly linked to the rest of the health system, and incapable of contributing to it (Pfeiffer et al. 2010). His “Code of Conduct” for NGOs in Africa—one of which, Health Alliance International, he sporadically heads up—recommended decentralization as the best way forward (Pfeiffer et al. 2008)⁵. He and his team later changed their message, however, after the data came pouring in and the impacts of abolishing day hospitals became more evident. They then suggested that the process was carried

⁵ Health Alliance International (HAI) clearly sees itself as instrumental in developing Mozambique’s health sector, even as a kind of watchdog or overseer. The recipient of multimillion dollar USAID grants, the organization has direct ties to the University of Washington’s Department of Global Health. According to a recent article, after expanding to several other countries over the years, HAI has been focusing on “strengthening health systems of impoverished and fragile nations” (Heim 2011).

out too quickly, that the government wasn't prepared, and that some day hospitals should have remained open (Lambdin et al. 2013).

The damage was done, however, and the lasting effects of decentralization and health systems strengthening hit AIDS activists particularly hard. What happened in Pemba, and in some other cities in Mozambique, with the closure of the day hospitals qualifies for what Dear and Wolch (1987) call a “landscape of despair.” Drawing on theories of “therapeutic landscapes” (Bell et al. 1999) human geographers have cited other examples of what happens when high numbers of service-dependent populations are discharged from programs and facilities in the name of relocating them. Communities often ascribe more stigma to facilities which cater to high risk groups than do the groups themselves. Burnett and Moon (1983) document this in the context of hostels for the homeless in urban America. When beneficiaries are dispersed from places they frequent and consider their own, the effect is one of instability, dismantlement, and reconfiguration. It tends to disorient people, negatively impact their identity, and cause them to feel abandoned. Official processes like these usually rely on variables that turn out to be poor surrogates for equity and fairness—like minimizing distances between services and users, or maximizing the number of recipients. If intentional, this can lead to a “planned shrinkage” (Wallace 1990), a downgrading of services as communities of patients get deconcentrated, fractured, and lose their collective voice. In landscapes of despair, patients are unceremoniously ‘dumped’ onto smaller facilities—like rural clinics in Mozambique now expected to offer ART—less capable of addressing complex issues or organizing effectively to demand resources from the state.

In the case of AIDS patients, and from the point of view of those threatened by activism, this was very effective because it took away political power—the “master frame” of demanding universal treatment. Consequently, it also delegitimized the AIDS treatment movement in the

eyes of the international community. If the goal of the state is the same as the activists, to get as many people on treatment in as many places as possible, then the state is not only in the right to shut down day hospitals, but also to ignore and even shut down projects and programs for activists as well. This is, in part, why complaints about day hospital closures, legitimated because of ‘theory’ and rubber-stamped by expert consensus for widespread deployment and implementation, went unacknowledged in wider circles. But there are also other reasons why this happened. Political AIDS activism was always peripheral in Mozambique, and, at least in Pemba, a good example of the few exercising power over the many. It is inorganic, a garden that was not well tended. Political AIDS activism here is just one of many other industries, a job opportunity and way to get employed. The role of advocate is easily exploited, even if it arises in legitimate contexts. This means that when the time comes to call upon ‘activists,’ they are few and far between. They have to be manipulated, or organized, to stand up and represent what are supposedly the universal values of the AIDS treatment social movement.

“Slacktivism” and Rabble Rousing in Northern Mozambique

“It is already done,” said Dr. Saúde, “the integration has happened. There is no way to change it, and what can we do now? The government *é nosso pai* (is our father) and we must respect our father.” Addressing the association called *Esperanca da Vida* at their usual meeting place on the wooden benches behind Pemba’s former day hospital, Dr. Saúde, the health technician, was referring to the recent closure of the facility. ‘Integration’ was the nicest way of putting it; a total mess was closer to the truth. I hadn’t been to the day hospital in a while. It was never really a calm place, but relatively private, protected by a high wall shielding it from view of the street. One could usually at least find a seat. Now it was overflowing with people, and loud. I had to force my way through the queue formed at the narrow entrance and beg pardon for disturbing people to

get into the compound. I could see why ART patients were complaining, it appeared as if their hospital had been taken over by outsiders. I sat down next to the doctor.

“We have to make our own solutions,” Dr. Saúde continued, “because this is a problem that needs to be confronted and dealt with.” He turned toward me, “Cristiano, what do you think?” he asked. I explained what I had heard about this in other cities in Mozambique—Tete and Chimoio for example—that the changes were implemented quickly, and that both staff and patients were caught off guard. I read online that patients had been complaining about having to wait in the same areas of the hospital with other patients because their health cards were green and not blue. When they presented themselves in a queue or to the staff, others noticed this and it caused tension and fear. “Change the color of the cards, ok,” said Dr. Saúde, writing something on paper. “What else?” he looked around at the group. Somebody suggested that we need to educate people on the virus—the default response to such inquiries. Another member said that everyone should be in the same queue, and that it is perfectly normal for patients to be seen by the same doctors. “No,” one woman disagreed, “a nurse who doesn’t know about HIV could say it is the same thing as malaria! That it is *igual* (equal)!” At this, everyone in the group burst out laughing, Dr. Saúde included. “She said it is *igual*!” he said, catching everybody’s eye and inciting an additional round of laughter. “Look, the problem is,” he continued, “that already people have stopped coming. Normally we have 50 patients per day in the day hospital. Yesterday there were three, the day before that there were only two. My bosses want to know what is happening, and they want a report. What can I tell them?” An association member, a middle-aged man, said that “the ones who are scared are not us, but those outside of the association. They fear being discriminated against when they are in the same room with non-positives.” Dr. Saúde turned to me and said, “What’s going to happen in this country is, we are going to reach a phase where nobody gets a

test, there will be no CD4 counts, we will just write a prescription for triomune and hand it to the patient and say ‘here it is, go and get it.’”

Esperanca da Vida was comprised of all ART patients, about 25 people. Many had been to Maputo and “trained” to carry out home based care, but nobody did. There were no salaries and no spaces for them in formal projects. All they had was a charcoal-making business and a chicken coup. The group said it was waiting for the DREAM program—the Maputo-based NGO initiative that funded their training—to build them a nutritional center in Pemba so they could get free food. Some of the group’s members joined Esperanca da Vida because they didn’t like the way Caridade was being managed. They were particularly critical of Luisa, Caridade’s vice-president, for not sharing information with them, and for kicking some of them out of their paid positions as workers for UNICEF, Action Aid, or other NGOs. Knowing this about the group, I was surprised to see Luisa herself turn the corner of the building and comfortably sit down next to Dr. Saúde. He was expecting her, and after greeting everybody, she launched into what was apparently her assigned lecture topic—*associativismo* and leadership. She began by explaining that the group needed to have an organigram, and that only the president and the vice-president can sign checks, or authorize a dispersal of money. She went on to explain that Caridade had been so successful that HIV patients in Cabo Delgado were not as behind the times as they used to be, that they were more organized, and cited Caridade’s activities in other towns and districts as evidence of the association’s success. “We are known at the national level,” she bragged, and offered Esperanca da Vida membership in RENSIDA, Mozambique’s national people with AIDS umbrella association.

I was surprised to hear this suggestion. Just a few days before, having beers with Luisa in the front yard of her house, she told me that she had RENSIDA *nas palma das mãos* (in the palm of her hands). She didn’t seem keen on sharing her privileges with others. Her frequent trips to

Maputo for trainings and her position as coordinator of the UNICEF program were extremely lucrative for her. She rarely showed up at Caridade's office, but was still somehow the first point of contact whenever someone important arrived in Pemba and wanted to discuss the human rights of AIDS patients here. The latest example of this involved a researcher from the UN who we heard wanted to interview Caridade members about gender equality. We waited around the office all day only to find out she never left Luisa's house, and departed from the Pemba airport after only talking to her, but not to anyone else in the group. Plenty of Caridade members were upset with Luisa—they considered her lazy, and a thief—but there was little they could do about it. Her phone number topped the list in Maputo of people to call in Pemba, and most of the group's reports passed through her hands before going on to RENSIDA. With President Antonio spending most of his days drunk, Luisa had commandeered power over Caridade, the association with the longest history of partnerships and coalition-building in the province. Luisa, after encouraging the members of Esperanca da Vida to open a group bank account, invited them to the meeting that was about to happen for planning the protest against day hospital closures in Pemba, to take place a few weeks later.

Through her Maputo contacts, Luisa became de-facto leader over the Pemba protest as well. Far away from Maputo, activists in Pemba and Cabo Delgado Province had infrequent contact with others throughout the country. The organizers of the protest, the *Liga Contra Discriminação* (the Anti-Discrimination League), had been relying on her organizational abilities to ensure the widespread involvement of as many AIDS associations and patients as possible. Over the course of planning the protest, when the Maputo-based activists flew in to Pemba for meetings, Luisa was the locally appointed representative and did the most talking. In closed-door meetings with members of the *Liga*, Luisa managed to gain access over the protest's resources—boxes of "HIV Positive" t-shirts, crates of bottled water, bags of snacks like potato chips and cookies. Later, we

found she had sold some of these items in the markets—including the t-shirts—and there was not enough for the protesters during the march. She appointed members of her own family and friends as liaisons and persons responsible for various jobs before the protest. Her brother was to contact the police and the city council. Her mother would inform the radio station and NGOs in town. There were per diems, small amounts of money, available for these jobs. Her father would facilitate the purchase of gasoline for the motorcycles, including his own. She also decided who would carry the banners, and the money spent on the materials needed to construct them. It was also decided—between Luisa and the group of activists from Maputo—that she would be the one to hand over the letter to the Provincial Health Director on the day of the protest. Luisa had succeeded in dominating the entire process of planning the September 11 march. She had become the “African big man” (Cabassi and Wison 2005), capable of circumventing AIDS civil society in Pemba. Her reliance on her friends and family is typical of the clientelistic relationships based in the “primordial public” that Ekeh (1975) discusses in his seminal work on this topic.

Regardless, Luisa and the *Liga* tapped into some very real concerns that patients had over the loss of their day hospitals. Luisa did a fine job of identifying speakers for the larger meetings who could rile up the crowd and elicit the kind of reaction appropriate for a political protest against a perceived governmental injustice. At the Red Cross building in Pemba, several activists, including Luisa, gave their testimonies in preparation for the final day. After viewing a video of the August protests, of patients marching in the streets with their t-shirts and signs through closed-off city streets, and of the clip when César of MATRAM read the grievance letter to Ivo Garrido on the steps of the Ministry of Health, Luisa stood in front of the group of about 200 AIDS patients and said:

The bosses are abusing us, and it is the personal problem of Ivo Garrido. Many people already arrive late for treatment, and many think that treatment doesn't exist. This disease can't be treated like all of the others, it requires treatment for life. The patient has a right to the information they need for taking ARVs properly.

And why does South Africa have special treatment centers for AIDS patients but here in Mozambique we must close them? (Public meeting, September 9, 2009, Pemba).

Another activist, a policeman, and one of the founding members of Caridade followed, telling the crowd:

I was the first person on treatment in Pemba City. In the old days we could come only one day of the week to get ARVs, but the old nurses were good. We are going back to how it was before, with limited services, only now the nurses treat us badly. There are other people who haven't been back to the hospital since this happened. If we lost people before, we're losing even more now (Public meeting, September 9, 2009, Pemba).

One man focused on a common complaint among AIDS patients, the rumor that rich people did not have to wait in line at the hospital, and that they had their own "night hospitals" where they could receive their treatment in secret:

The problem here is discrimination, discrimination against poor people! Where are the ministers of parliament getting their treatment? Why do I never see the bosses in line at the hospital? The night hospitals are still open. We are all HIV positive but in different economic classes. We must march and show our force like patients did in Maputo (Public meeting, September 9, 2009, Pemba).

These Pemba AIDS patients were normally cut off from mainstream AIDS activism in Mozambique. Preparation of the crowd began in this room, a couple of days before the march. Various AIDS patients who might never have organized for a protest without becoming worked up like this, and with not necessarily that much in common other than their feelings about losing the day hospital, began to express interest.

This was an indication of how unlikely such an occurrence would have been without some outside organization facilitating it. After the meeting was over, other patients approached me with parallel statements. Without the *Liga's* influence, they would have remained in the dark about the why the day hospital had shut down, and with no direction about how to address it:

I travel here from Mize [about 20km away]. It costs 40 Meticais (US\$1.50). Before, I could come in the morning and get my medications quickly, even do lab tests. Now, I have to wait 4 hours before I can go back into the hospital for the results.

These medications [he shows me his prescription for an antibiotic, B vitamins, and acetaminophen] will cost me 300 Meticaís [about US\$13] in Farmácia Nova (in Pemba). I have severe headaches all day for the past week, and a terrible stomachache. If I can't get my analysis today, I have to pay again to come back tomorrow. Before, things were good, why is the government doing this to us now? (Public meeting, September 9, 2009, Pemba).

Another man, a well-dressed professor who worked at the teacher's training college, but hid his status from his coworkers, told me:

I was always able to get my pills at the day hospital, for years, and nobody ever knew that I went there. Two days ago I was seen in the hospital, and now I am writing letters to my boss to explain why I should be able to continue teaching even with this condition. I didn't expect this, and I may have to get a lawyer. If I get fired, I am thinking of writing my story to put in the newspaper, but I do not know where I am going to live if that happens (Public meeting, September 9, 2009, Pemba).

This next man believed that Pemba's day hospital shut down because of some construction that was going on there. He had no idea it was a nationwide, government policy until he attended the meeting:

I thought that if there was more space [on the hospital's grounds] we could have continued with the separation. I had no idea any of this was happening, talking about policies and rights! All I knew was that the doctors and nurses were gone. Now, hearing about this discrimination against us, I don't know why it has been kept secret and nobody from the government told us about this (Public meeting, September 9, 2009, Pemba).

To influence patients to march was the *Liga's* intent—to correct misinformation and put people on the same page. Yet, I've already described what happened during the protest, and afterward. Nothing changed for these HIV/AIDS patients. By some accounts, treatment access may have even gotten worse than it was before. The political 'action' taken on the part of the *Liga* in Pemba—the protest against the day hospital closure—was fruitless for most of the province's patients. It was, however, profitable for Luisa and a few others. I will comment more on this soon. For now, let's conceive of the day hospital protests not as earth shattering events, but as minor acts of support for the cause of AIDS treatment activism.

Analyzing the concept of “slacktivism,” Kristofferson et al. (2014) note how “token acts of support” of a socially observable nature moderate later involvement in a cause. In this study, individuals who engage in *public* support for a particular cause are less likely to meaningfully respond to follow-up requests, as compared with those who engage in *private* support for the same exact cause. The reason why has to do with self-consistency and the alignment of values. In publicly observable settings, motivations are more likely to be activated by impression-management concerns. For individuals interested in being viewed by others, public support for a cause satisfies the criteria for their involvement. They are no more likely to support the cause in the future than those who did not initially support it at all. Conversely, for those whose involvement with a cause is done in private, values are more likely to be derived from individual attitudes and reasoning, and less prone to social influence. In these cases, subsequent involvement with a cause is more likely to remain consistent, the distance between the self and the cause is diminished, and misalignment between belief and action becomes aversive. In other words, reliable and persistent activism depends on personal commitment, not obvious, outward behaviors. Combating “slacktivism”—an eventual decline in support for a cause, even after high initial interest—values displayed to the world must first be instilled in private. For HIV/AIDS patients, where both forums are essential for the cause as a whole, this points to the need not for more protests or public displays of demands and grievances, but for strong, locally situated support groups capable of voicing and consolidating their views among one another prior to airing them on the street or in the media.

While initial views on “slacktivism” stem from the online world—of consumers ‘clicking’ the ‘like’ buttons on Facebook pages or retweeting within the hashtags of activist Twitter accounts—in the ‘offline’ world of Mozambique, the *Liga*’s sudden appearance in Pemba as organizers of dissent is metaphorically similar. The need for Maputo-based activists to come to the area and fill

a gap in knowledge, about the policies of the government and the rights of AIDS patients, indicates an arbitrary relationship between the signifier and the signified, between politically savvy AIDS activists from the capital city and those who are less aware, comparatively lost in the nation's hinterlands. For them, marching in a protest is clicking on the 'like' button—a token act of support, not likely to develop much further due to foundational lack of initial involvement. Commercializing a protest, the 'social marketing' of activism and human rights, is likely unsustainable and unlikely to lead to subsequent meaningful action, especially if not enough attention was paid to the groundwork for such action in previously and in private.

Unity and social solidarity, therefore, remain elusive, made up, in need of a crafted defense. For the Maputo protests to be reproduced, to be carried out and restaged in other parts of the country is also to treat AIDS patients not primarily as brothers and sisters for a cause, but as consumers of model or brand that needed distribution and publicity. Even though it hooked in to organic complaints, the public platform of rabble rousing was unavailable in the ordinary medium of Mozambican activism without encouragement from idealists and gatekeepers. When the activists of Esperanca da Vida were asking along with Dr. Saúde, 'what do we do now that the integration has occurred,' the answer came from Luisa and other quasi-elites with, perhaps, different or additional motives and intentions. The theme of the protests—down with stigma and discrimination— was, in the end, much too generalized to lend to any particular province, city, or group of patients. It may also have obfuscated other, more practical, locally defined terms of negotiation and retaliation, such as the need for lawyers, local AIDS centers, or private pharmacy stipends for AIDS patients. What else might have occurred without this imposition of the national over the local, of the transnational over the domestic, of the chanting and marching AIDS activist over the problem-solving capacity of particular support groups, we will now never know. If any fruit grew from the protest in Pemba, Luisa consumed most of it. This situation suggests that

activists who seek public recognition may engage in multiple, even contradictory roles—that of challenging neoliberal economic injustices and policies, and also that of obtaining prestige promotions.

Soon after the Pemba protest Luisa created a new AIDS association, with herself as the president. She called it *Si Peke Yangu* (I am not alone), and told me that it was for women only. She invited me over for a meeting one day, which took place at her home in *Bairro Natite*. When I arrived, the women were eating chicken and drinking sodas. Dressed in matching *capulanas*—a waist and head wrap of colorful African material—they were practicing songs and dances for the upcoming World AIDS Day celebration on December 1st. I was asked to take some pictures of them on my camera and record video of the group on my phone. As I did, I noticed that I knew some of the women—they were Luisa’s neighbors, and others were friends of hers, likely not HIV positive. Later I found out that the group had gotten funding from MONASO—for meals during meetings, for the *capulana* material, and even for a computer that Luisa kept in her home to write grants and reports. The pictures and video had been sent to Maputo as part of a project application for a local women’s AIDS group, which up until then, never existed in Pemba. Other AIDS associations had been trying for years to get this kind of attention from MONASO. Luisa’s outspokenness, her willingness to be seen and heard and talk about her illness in public, was a qualification with disproportionate benefits. At the World AIDS Day festivities, her new group sang a song for the governor, his wife, and a minister of parliament that went like this: “We are *Si Peke Yangu*, and our history is a long one.” The association at that time was less than two months old.

In 2011, Luisa was hired as a project manager by RENSIDA, and left Pemba to go and work in Maputo. She continued to remain vice-president of Caridade, and president of *Si Peke Yangu* during her absence. Her time in Maputo was short, however. She was found embezzling project

funds, and using RENSIDA money to support her own lifestyle in the capital. To this day, Luisa remains integral to the functioning of Caridade, but the association is slimmed down considerably. Its members now only include those who get paid for carrying out project work in Pemba's bairros. Other AIDS associations in Pemba have ceased functioning—Esperanca da Vida, Nashukuru, Ajuda à Próxima—no longer meet together or carry out project work in their villages. Kharibo, the home-based care group that got EGPAF and PEPFAR funding, continues to operate, and most of its members are not even HIV positive. Certain other “activists” in Pemba still get visits from important people in Maputo. Recently I came across a photo of Luisa on a social media website with the director of USAID/Mozambique. The caption indicated that he was being briefed on the human rights situation of AIDS patients in Cabo Delgado Province. Luisa's identity as an AIDS activist continues to profit her enormously. As the name *Si Peke Yangu* suggests, she is probably not alone; there may be many activists whose public and private presentations of themselves conflict and threaten to undermine or cheapen solidarity at the local level. Outsiders and visitors must work with wider bases of activists to offset this bias, and to ensure that equal opportunity is given to those who may be rendered hidden or voiceless by a few strong and dominating personalities within specific activist cultures. The greatest “slacktivists” are the ones who fail to take note of these situations or act to resolve them.

The Knife in a Gun Fight – AIDS Treatment Activism after Health Systems Strengthening

What the day hospital debacle in Mozambique suggests is that if AIDS activism is unable to evolve—to move beyond a focus on treatment—it can, will, or may already have become irrelevant in places like Pemba. Since its inception, popular understandings of AIDS activism have centered on its capacity for performance, for theater, for pinpointing, targeting and engaging in smear campaigns against a perceived enemy of one kind or another. This is less useful than we are

often led to believe. Studying ACT UP, in the early days of American AIDS Activism, Gamson (1989) draws attention to how the group's actions sometimes got noticed, but at other times were completely ignored. South Africa's Treatment Action Campaign gained immense publicity with its street theater and legal actions against the government (Nattrass 2007). Today, however, the group finds itself amidst paralyzing budget cuts, abandonment by many of its previous donors, and dropping down the political agenda in South Africa and internationally (Nicolson 2014). The question worth asking is whether or not this model—with its anger, its semi-militant approach to organizing patient demands under the auspices of political resistance—is really all that representative or transferable. Perhaps it is itself the outlier and the anomaly when compared with other, less commonly studied examples of unity and solidarity. Post health systems strengthening political AIDS activism in developing nations is more impotent than ever before. It is obsolete, no longer pivotal, and a relic—the knife in a gun fight, or even the knife in a war with untouchable multinational policies promising to strengthen health systems. The patient voice is now less, rather than more, valuable. What emerged in Mozambique is the idea that patients, supposedly, are now no different than anyone else attempting to navigate the health system. Ironically, the “decentralization” of day hospitals—properly executed—fits perfectly into the “master frame” of fairness and equity that was always at the center of the AIDS activist agenda.

Scholars of social movements interested in “framing processes” and “collective action frames”, like poor AIDS treatment access, note that they are not merely carriers of ideas, or naturally occurring meanings that unexpectedly grow out of events, arrangements, or ideologies. They are, instead, relied upon by “movement actors” and viewed by them as “signifying agents” (Benford and Snow 2000:613). From this perspective, AIDS activists, like members of any other social movement, actively engage in the production of meaning—in its generation, diffusion, its functionality and the way in which it operates among other members and within the movement

itself. There is intention here. Goals and objectives are set and pursued. There is, therefore, also responsibility and culpability. The actions, claims, and demands of AIDS activists in the past were, in essence, tantamount to pre-authorization for this international trend toward strengthening health systems in developing nations. Even though consent was not explicitly obtained from every AIDS patient in Pemba for the closure of their day hospital, those at the highest levels of governance were operating on an implicit assumption—and ultimately, it was a good one—that any complaints about “decentralization” would fall upon deaf and unsympathetic ears. The world was now convinced that AIDS patients are equal. AIDS activism, tied so intimately to notions of injustice as it relates primarily to the availability of AIDS medications, was relatively unequipped to refocus or to shift its master frame appropriately, away from a historical standard and toward other types of ‘therapy’—the virtue of the day hospital as, for example, a drop in center or social club. It was unable to attack the ‘openness’ of health systems strengthening, its inclusivity, its appeal to a revised vision of diversity, not of AIDS patients exceptionalism, but the human rights of everyone else—the rest of the nation’s populace—in their stead.

There are a number of other ways—perhaps more effective than protests—that patients and activists could have approached the package of events described in this chapter. They could have demanded an end to all perceived ‘foreign’ incursions into Mozambique—of PEPFAR, UNAIDS, and the WHO, in the name of ‘fairness’ or even sovereignty. Complaints could have been made against the practices of certain community based organizations and freshly minted contractors carrying out AIDS programs in the country—the ones that the government privileged in instituting health systems strengthening. The double standard applied in this process could have been better explored, and questions asked about why the government was able to retain its National AIDS Council, AIDS-specific task forces, and bureaucratic funding for targeted AIDS programs even as patient clinics and facilities were forced to shut down. Demands could have

been made to incorporate funding for support groups into the framework of health systems strengthening in Mozambique, to make AIDS associations an integral part of the health system. Activists might also have critiqued the attack on small projects, in solidarity with international medical NGOs like MSF or Medicos del Mundo that also felt unduly targeted by sweeping national reforms and state demands for them to change focus. But, AIDS activism, largely writ, is unable to incorporate most of the items in this list. They are too context-specific. Limiting itself to an obstinate form of activist orthodoxy, the only types of considerations able to make the short list—the gold standard used to unite the broadest possible base of people to its cause—concern biomedicine and the state alone. The draw toward a fight and toward war is not a feather in the cap of AIDS activism, it is a bane to its existence, a proclivity that frequently oversteps its bounds by preventing other types of dialogue.

A good deal of reshaping, remolding, reconfiguration, and even exclusionary thought is necessary to point to ‘valid’ forms of AIDS activism and what it portends as its collective identity. The assumption—embraced and developed by political process theory and those who search for the achievement of short term goals—is that social movements must shape public policy and state action to qualify as a force for social change. Consequently, political process theorists, in parallel with popular media, television, newspapers, and journalists engage in a sensationalization or hollywoodization of activism that positions the state as more powerful than it truly is—as target, audience, and arbiter of social movement demands. But the real bias, the flaw in cultural theory, is most blatant and emerges in case study selection, in the kinds of movements examined and the activities observed and explained. A protesting group alone is not good enough data. Treating it as such permits rather than inhibits “slacktivism,” promoting those who seek social recognition over those who do not, threatening the long term stability of the movement itself. The Mozambican protests against day hospital closures did not signify the breaking open of long

bottled up tensions on the part of activists. As a political opportunity, it was short lived, a half-opened window, and even rather pathetic. Instead, the protests were rushed, inorganic, and an exposition of the fault lines scarring the depiction of unity, and of shared understandings, among patients there. The protests were not liberating but constraining, and confirmation of the end of an era, one where states, donors, and others invested in AIDS treatment expansion listened to demands from patients claiming violations of their universal and collective human rights.

Chapter VI – Unmaking Activism

Biosociality as Civilizing Mission

Our idea of what is ‘good’ biosociality may be wrong, even imposing, because AIDS activism is quite a tender topic. Many activists in Mozambique stand in direct tension with the idea of airing their behavior, AIDS status, or concerns in public. An HIV positive woman—a nurse, and well educated, who at one time worked for RENSIDA, Mozambique’s national AIDS association—expressed horror at the ideas generated by a visiting activist from the United States:

“She came to my office [in Maputo] to offer us money, and suggested that we fight with our government. ‘Make some [picket] signs,’ she told us, ‘and march through the streets of the city.’ She suggested that we complain about the way we were being treated. I told her that if we did that our organization would not last long. This is Mozambique, not America! I said to her that here, in Mozambique, we work *with* our government not *against* it. We don’t insult others who we know will help us” (interview, July 09, 2007, Maputo).

This same RENSIDA employee nearly refused me an interview with her, due to a bad experience with a previous anthropologist who had worked with the organization. She referred to him as my ‘friend’ because I said I had heard of him before, and we both came from foreign countries:

“Your friend, when he was here, visited with a lot of AIDS associations. He said that he wanted to ask questions, but what he really wanted was to teach them something. He spent a lot of time talking to them about what is activism. Some of the presidents from the provinces he visited complained to me, said that he was embarrassing them. ‘We don’t want this guy telling us how to do our job,’ that is what they told me. He told them that good activists talk to others about their illness, that they don’t hide or speak quietly, and aren’t ashamed. He insulted me too, told me I was too embarrassed to share my disease status with others. I told him, ‘Sir, what you are going to write in your books is not going to help us’” (Interview, July 09, 2007, Maputo).

What this woman’s statements suggest is that ‘activism’ is a social construct, even a kind of marketing brand that circulates according to exposure or influence. Calling attention to the perhaps unconscious encroachment of Western values upon Mozambican ones exposes a dichotomy that may help contextualize the preference for a global model—one that proliferates in

cosmopolitan or urban areas—over local, small scale, culturally recognizable forms of minimizing the impact of AIDS in less obvious or noteworthy ways.

As a result, theorists and anthropologists writing about AIDS activists have fallen into a trap, one that presumes biosociality should lead to biological citizenship, that the highest purpose of AIDS patient groups is the satisfaction of demands by outside benefactors, states, or others with a greater degree of power. It is certainly the case that pharmaceuticals are a resource that most patients can't manufacture or secure on their own, but there is more to biosociality than a focus on treatment alone fails to capture. The emphasis mostly on politics, and the rather dominant version of activism that has been mistaken for a universal (or desirable) norm, much about 'the group' remains undescribed. The thesis to which many social scientists cling amounts to the idea that progress for AIDS patients lies in how well they are ensconced in politics, that patient groups thrive on this. I believe this is harmful, and here I am going to claim an opposite thesis. In the post treatment era, what AIDS patients need most is to be more divorced from politics in order to remain less affected. To be effective, the support group must attempt to be above the fray, less subject to interruptions to its development by any other actor or party, answerable to no other for its activities. These should be oriented more toward preventing disease relapse than anything else, toward an improvement in quality of life.

Biosociality—a shared social consciousness or identity, with its potential to bind persons together in solidarity and combat against a threat or enemy—is relevant in its potential to create dialogue and facilitate communication. But, we must be aware of how noticeable this is, especially on the part of those in power. Biosociality—describing it, documenting it, labeling it—makes AIDS patients more visible. It also makes them more governable, into better identifiable targets, more directly subject to the confines of what Foucault (and many others) calls "governmentality". My work here is preceded by many colleagues invested in the topic of AIDS support groups. Like

myself, students such as Kalofonos (2008) and Fenio (2009) entered into the field evaluating the integrity of Mozambican AIDS associations. Some of us were seeking evidence that civil society was part of the solution to the AIDS crisis. The environment at the time led to high expectations. The prevailing theory concerning AIDS activism was that suffering, caused by a lack of treatment, stimulates demand and wakes from dormancy politically active creatures that are capable, via solidarity and persistent political resistance, of obtaining what they rightly deserve from corrupt, greedy, immoral states and companies that would otherwise prefer to see them die or simply don't care. All of us, of course, problematize this algorithm. Essentially, like many theoretical constructs, it is porous and not a very good one.

Still, the fissures and cracks inherent in this myth tend to be only tangentially addressed in dissertations and full length books (Robins 2010; Nguyen 2010) in ways that short, high impact articles overlook and fail to make clear (Robins 2006; Nguyen 2007). The valorization of heroics, the intentional depiction of iconic patients or groups as representative of others, as readily generalizable stand-ins and examples of best practices, casts a wide shadow over the realistic situations of the majority of patient groups in sub-Saharan Africa. In very few cases is the AIDS support group an appropriate site for cultivating broader social revolution. Depicting it as such is reductionist, but the highfalutin language involved—sensational, partial, intended to motivate, sway, and influence—strongly resonates with a populist humanist tone easily capable of drowning out competing events and understandings.

At the root of this algorithm and presumption—that biosociality leads to biological citizenship—is the overwhelming flood of literature available about South Africa's Treatment Action Campaign and how tempting it is to compare it with other groups in other places. Likely, the overemphasis on TAC has just as much to do with South Africa's second world status as it does with TAC's apparent successes. The nation's accessibility to researchers, widespread use of

the English language, the availability of respected universities, and the primacy of business markets there are rarely factored into what is depicted as a continent-wide, even global, independent, and grassroots fight for civil and human rights. Despite some very real organizational challenges and performance issues (Le Marcis 2012), TAC is loyally portrayed as powerful, a force to be reckoned with, a model to emulate, a victory over racism, classism and apartheid—a monolith. “TAC employs the political lexicon of the struggle...TAC events commonly start with the right-fisted salute and the cry of ‘Amandla!’ (power)” (Grebe 2011:852). TAC idolizers intentionally conjure such images to paint the situation as a worker’s fight against capitalism and medical inequality. This is partly true, but uniquely South African at many junctures. TAC’s supposed success has impacted groups like Caridade in Mozambique in some ways that are not entirely helpful. AIDS patient groups that do not live up to similar expectations are easily dismissed as ineffective, and lower down on the evolutionary scale than the politically successful TAC.

Scholars tend to rank African AIDS patient groups according to how similar they are to TAC. Says Kalofonos (2008:216), “the tactics of TAC emerged out of the apartheid struggle...there has never been a comparable large-scale, sustained grassroots political movement in Mozambique...The practices and tactics of Mozambican associations emerge out of evangelical church practices and rather than agitating for political change, these groups are more likely to seek accommodation within the status quo, and are more oriented toward daily survival.” AIDS support groups, including Mozambican AIDS associations, are now supposed to facilitate political upheaval. Says Fenio (2011:718–722), “Mozambican associations are *still* fearful of speaking out against the government...South Africans are most free in their ability to critique government and vocalize opposition”. I emphasize the word ‘still’ in this last quote as an indication that

Mozambican patient groups are expected to ‘grow up’, to begin to act more like South Africa’s TAC—to not just be biosocial, but become biological citizens.

Ida Susser’s dichotomy between ‘adaptive’ activists and ‘transformative’ activists is no different. Patients who make and sell products for tourists on the streets of Durban are given less space in her ethnography than patients who speak openly about their illness and attempt to recruit others into their group (Susser 2009). This selection bias is evident in much writing about AIDS activists. There is an expectation that patients conforming to a political mind, a political subjectivity are more valuable, better off, with apparently higher potential than others. Again from South Africa, “experiences of illness, treatment, and participation in TAC and MSF can produce radical transformations in subjectivity and identity that go well beyond conventional liberal democratic conceptions of ‘rights’ and ‘citizenship’...TAC and MSF activists argue that they are not only interested in medical treatment but also concerned with creating ‘empowered citizens’ who understand the connections between biomedicine, the wider social world, and the political economy of health” (Robins 2006:312, 315). Perhaps because I did not see these kinds of transformations in Mozambique it is easy for me to eschew this type of language.

This dissertation, on the other hand, has primarily been about dysfunction—among patients, in their communities, and in the overarching mechanisms of governance encompassing them. In the post-treatment era, protests and demands have done little to move the therapeutic needle for activists in Mozambique. It may even be fair to say that AIDS treatment in Mozambique would have progressed about as well without the AIDS associations as with them, according to the state of the science and recommendations of healthcare and development professionals. What we are facing, then, with the Mozambique situation is a set of lost opportunities, the main one being a model of AIDS activism that was superficially supported by the government, financially propped up by NGOs now withdrawn from such activity, and ultimately unsustainable. It had room for

improvement but never very good guidance. It is particularly striking how AIDS associations appeared simultaneously threatening to the state (enough to be targeted for registration and standardization) but still inaccessible to the majority of patients in need of a traditional therapeutic community (inculcated into the world of development projects). Making this possible was an impoverished view of activism—every patient has a right to this, even if just in their own home—and the stunted development of AIDS associations due to unresolved tension between the concepts of altruism and production.

The question I ask in the beginning is: what is the role of HIV/AIDS activism and advocacy in the lives of patients in Northern Mozambique? The short answer is that it does not transform them into biological citizens. The long answer is only slightly more complicated—AIDS activism, largely writ, serves as a complex set of guidelines for a lucky or ambitious few to wrest power and subsequently benefit disproportionately from those without the means, skills, or desire to participate. AIDS activism boils down to just another type of “governmentality” (Foucault 2010; Lemke 2001; Burchell 1993)—the imposition of certain morals, values, and modes of conduct upon entire groups of people without their obvious and active consent. There is an important difference, however, in this kind of governmentality, because it is not evidently neoliberal in nature. It is, rather, underwritten by biosociality, by the expectation that persons sharing an illness condition are bound by it, and so must or should act together in retaliation or other ways viewed (by outsiders) as essential to offsetting its effects. AIDS activism is, to coin a phrase, a kind of ‘biosocial governmentality’, which forms the atmospheric hegemony or academic blind spot that I spoke of in Chapter One. Treating AIDS patients anywhere and everywhere the same, social scientists, academic, progressive thinkers are every bit as guilty of attempting to rule and dictate the future trajectory of mass populations of people as the neoliberal, conservative-minded

thinkers who instituted policies like health systems strengthening in sub-Saharan African nations such as Mozambique.

The hesitancy or failure to describe the in-fighting, conflict, and challenges faced by AIDS patient groups in the mainstream literature amounts either to a cover up and public relations campaign, or it suggests that we haven't been learning about biosociality from enough sources. The unspoken implication is that groups not characterized by solidarity, ones that do not conform to expectations and standards that they live openly in society about their illness, and try to actively and intentionally change it, are not worth our attention, or do not deserve it because they are not exemplary and therefore not in the spotlight either. Nothing could be further from the truth. On the contrary, AIDS patient groups with political motivations, and their individual members, are the outliers when compared to groups like Caridade and others mentioned in this dissertation. There is probably even more to learn from the quiet ones than the loud ones. The stories and events I describe here are comparatively subaltern, forced into the shadows by the very same biosociality that claims to draw them out and cast wide rays of light upon them.

I have tried here to be faithful to the ethnographic data. In Chapter Three, I describe intragroup dynamics, dysfunctional meetings and trainings, and the almost oppressive atmosphere of "institutional isomorphism" and "civil society existentialism" in Pemba City. Opportunities related to AIDS activism form another way for people to *mafiar*—to cheat and to lie—in competition with their friends and neighbors. In Chapter Four, I mention the basic challenges faced by AIDS activists, NGOs, and home-based care workers in the region. In the "sub-universe" of Cabo Delgado Province poor basic health education, biomedical skepticism, and alcoholism threaten the success of AIDS treatment projects. Even in a context of international support for AIDS patient groups, still missing are examples of successful support groups for the most common sufferers and victims of the virus. In Chapter Five, failed protests against day

hospital closures reveal the impotence of rights-based demands and the fractured foundation of the nation's activist community. The presumptions of political process theorists, that engaging in politics is the best way forward for patient groups, is undermined by "slacktivism", which permits the manipulation of the group by those most interested in being seen and heard, and in the hope of commerce and employment. What I attempt to make clear is that the needs of AIDS patients here are both basic and prolific but the Mozambican government is not in a position to adequately respond, and most likely never will be. Interdependence with perpetually failed systems is unhelpful. The answer to the question of who is in control is absolutely nobody. This is, essentially, a dystopia.

When we contrast this with what we think we know about AIDS activism, about the biological citizen, the differences are stark. I fear we are, or were, at a stage where anthropologists mistake speaking the truth with a poor defense of disciplinary values. In choosing to emphasize sharing and oneness over inconvenient details and particulars, analysis and critique are selectively applied. Foremost among these may be Nguyen (2007) and Robins (2006) who I believe have overly romanticized AIDS patienthood. I discussed this in Chapter One focusing on the problematic between biosociality and supposed or apparent 'newness.' Nguyen's attempt to point out "therapeutic citizenship," a 'new' version of biological citizenship uniting AIDS patients everywhere seems to strip biosocial spaces and actors of agency and in the same breath legitimize the action. Such theories privilege transnational perspectives. Most important is treatment and, in the name of solidarity, group consciousness is whitewashed. His overreliance on proxy patients, even in his book (2010), make it difficult to retain a sense of what it is like to be a villager, and also limits any sort of stable focus on the group itself.

The same thing occurs with Robins (2006), who bases his analysis of TAC-affiliated AIDS patients on the concept of identity transformation, positing they go through a "traumatic journey"

from “near death” to “new life” (p. 313). In order to classify this he falls back on the anthropological concept of “rights passages” as a way to underscore aspects of the universal. The newness attached to the supposedly welcomed changes occurring in the support group is something to be interpreted not by themselves, but by outsiders like Robins, whose knowledge of biopolitics makes him more aware of what is happening. As I mentioned in Chapter One, Robins believes patients “cannot grasp the radically transformative character of the new biosocial subjectivities and HIV-positive identities” (p. 313). He has to point this out like an anthropologist studying an undiscovered tribe. “New forms of biological and health citizenship are emerging” (p. 315) that must be publicized, placed on a pedestal, treated as avant-garde. “Calls from progressive public health circles for a ‘new contract’ between provider and client” (p. 313) mean that patients who self-fashion appropriately are more likely to dispel distress and helplessness than those who don’t. The focus on ritual is an abstraction that permits this self-fashioning to occur in ways with which we are comfortable. Symbolism and fictive kinship, the group and its NGO sponsor as mother and father to the new self, displaces the kinds of technologies of the self that we usually eye with suspicion, despite the fact that they are compatriots. Confessional techniques, testimonials, behavior change, all of the by-products of the imposed risk categories that social science prides itself on combating, fade into the background, less important thanks to the availability of all things new—like AIDS treatment, and new groups that appear as pioneers united by political and social resistance.

In my own research, for some members the group does lead to adherence, friendships, and liberation from stigma or anxiety, for others it remains a cognitively empty and meaningless space. For still others, it intensifies distress and fosters jealousy. The ‘ritual’, the meetings, discussions, participation in projects, and the lifting up of the activist mentality are equal part performance and practicality. Observing ritual, even if well executed, even if exciting narratives

are elicited about it, does not always refer to something substantial or equally amazing (Staal 1979). Participants may have nothing in their minds like what we immediately infer. Researchers who are insufficiently embedded with the group and paying attention mostly to surface cues are not likely to notice this. The creation of a new self, without a substantial circling back or reformulation of the old one, can actually pose a risk—of forgetting, of failing to remember, as indication of an underlying resistance to self-correction. The ‘new self’ is a mark of modernity that might not last or stand the test of time. Experimental, it all too easily becomes a temporary assignment not meant to persist. In other words, when the group goes away, then so does the biological citizen. Mitchell calls it just another technology of the self, “reappropriated and reintegrated by modern sociology and anthropology...in what modernity calls ‘the creation of a new identity’” (2007:113). His assessment echoes Foucault, who also warns us about breaking with the past: “from the eighteenth century to the present, the techniques of verbalization have been reinserted in a different context by the so-called human sciences in order to use them without renunciation of the self but to constitute, positively, a new self” (1988:49).

My concern with this is that it may block other biosocial pathways, and lead to disinterest in expanding other bases of knowledge. Questioning whether biosociality must or should always lead to biological citizenship helps us revisit the question of what biosociality is actually for. It is not for explaining cultural evolution. Acknowledging this undermines the idea that there are stages or progressions of biosociality, and it means that what we are dealing with, potentially, are at least two competing biosocialities—one dominant, and the other one not. We have, first, the concept of the new self, of re-creation, of the group and its members hyper involved in facets of lobbying, raising funds, promoting research, or educating the masses. They proudly serve as living, breathing examples of an escape from victimhood. This is the biosociality of the benevolent social actor, whose participation in articulatory politics, even at minimum levels, serves to

redefine perceptions about him, her, or the group in ways intended to build it up from the outside in. We have, second, the concept of taking back a lost life, of picking up where one left off, of not necessarily reaching for something new, but regaining something lost. These seek to reinsert themselves back into society without drawing special attention or making specific demands upon it. This is the biosociality of domestic security, encouraging participation with the group as it is centered on obtaining composure and esteem following a major life disruption. The embrace of either biosociality is subject to personal preference, but also to marketing techniques, the availability of various strains of thought, and the deployment of terms, images, and concepts that brush up against and become tangible in the hearts and minds of the populace.

The challenge for the AIDS patient group, and the anthropologist who works to describe it, is to acknowledge that both of these competing biosocialities are relevant and that partial or fragmentary versions of either will adversely affect the overall vision and trajectory of AIDS patienthood. The threat most obviously faced so far is that of biosociality as a civilizing mission. Like Gilberto Freyre with his Luso-tropicalism, this threat masquerades as a promise, of overturning tyranny, of dissipating ignorance, of seeding and impacting all overarching ideologies equally well. The prototype of the AIDS activist parallels that of the freed slave or the noble savage, not so much in content as in poise, offered up as a literary stock character to which we can point and reference without much thought or wasted space in an article or term paper. But a high price is attached to the use of tropes, paid in myopic snippets rather than kernels of truth, and in the whittling down of activists such that they are no longer determinants of themselves. An obsession with feverishness, of demands and disruptions, has imprisoned us, along with our research subjects, in cell blocks of visceral materialism. Small things loom large, like the distance from home to clinic, the distribution of material resources, or numbers of bodies on treatment. Large things get ignored or even ridiculed, like self-mastery, moral inventories, and the

minimization of harmful behaviors. To truly be counter cultural, AIDS activism cannot embrace the same currency and language of the very institutions it claims to attack. Power, recognition, influence, even employment, these are not lofty goals for the group, but neither are they sufficient means to an end or always worthwhile endeavors.

As anthropologists we are often trying to make connections, looking for assemblages. We value those capable of coordinating similar actions and reconciling values at many different sites and simultaneously. In our selections of case studies and particular narratives within them we intentionally downplay some variables and draw attention to others. Did AIDS patients in South Africa really overturn Ministry of Health policies against the use of ARVs, or was it as much upper class lawyers and intellectual elites bringing their own pressures to bear against authority? The branding of AIDS activism, as if were its own firm or company, has limited the capacity for AIDS patient groups to counter market failures for the most vulnerable in places like Mozambique. The common support group is unable to accomplish the socially and economically desirable objectives that should be within its own reach. Channeled, funded, and forced to operate within externally imposed strictures and limits, we find the topic at a dead end, in the throes of dissolution. By allowing biological citizenship to become the goal of biosociality, therapy is no longer truly the point, and we find ourselves unable to differentiate between capital and hope. Activism as we know it can be expendable, temporary, a mere puff of wind, likewise for many AIDS patient groups in the region.

Caridade's Final Election

"Somos a resistência (we are the resistance)," said Falume, sitting on my veranda in Bairro Eduardo Mondlane the night before Caridade's third and what would turn out to be final *assembleia* (election). He was referring to a faction within Caridade that intended to see Luisa lose her upcoming run for the presidency. This time, the third election for the association, Antonio's

term limits had maxed out, so somebody new would be taking the reins for the first time.

Together with Fevereiro (the other presidential candidate besides Luisa), Carlitos (my research assistant, running for Fevereiro's former position of treasurer), and a new member of Caridade, Fevereiro's drunken neighbor (who would soon be installed as an activist in the group, even though he had never taken an AIDS test), we were doing what men do in the evening with extra available foreign funding—drinking beers. The foreign funding came from my Fulbright award money, of which I had some remaining as the weeks wound down prior to my departure from the country and back to East Lansing, Michigan. Another activist, Hamisi, a member of both Caridade and Bem Vindo, had just joined us, coming from the Medicos del Mundo compound further up the beach and toward town. He was complaining about having to end a recent sexual tryst with an Italian expatriate coordinator because “our relationship was messed up,” he told us. “I left her because I didn't want to be abused by these people...they treat us blacks as if they are colonizers” (personal communication, December 6, 2009).

But, he had other business there as well, that of trying to “*organizar alguma coisa* (organize something)” to eat and drink from that particular donor for Caridade's elections. In Pemba, this phrase is a classic marker of the *pedido*—an “asking,” or a begging. I had been privy to this particular negotiation, which started several days before. The coordinator of Medicos del Mundo approached me during a training they were holding to raise awareness of HIV/AIDS on the part of local male barbers in the area (who, it was assumed, tended to have rather frank sexual discussions with clients and so were supposedly suitable outlets for handing out condoms). Toni, the Spanish coordinator, told me he was very saddened by Caridade's list of requested items for the election, which included 37 chickens, 20 cases of beer, 20 kilograms of maize meal and rice, and host of other goods which he deemed to be excessive or inappropriate to holding a six hour meeting. It occurred to me that he wasn't aware of exactly how these kinds of negotiations work.

People and groups, especially Caridade, try to get all that they can from donors. This is because they have no idea when they will have another legitimate opportunity to ask for things, but also because if you start out big, then the final take is likely to be better than if you start out small. It's always a process, these kinds of negotiations, not much different from any other kind of business deal, just like haggling in a market over tomatoes or bananas, or naming the price to be paid to a day laborer. Each side tries to do the best for themselves that they can. Hamisi, aside from having ditched his relatively new foreign lover, had also just secured what Caridade needed to feed the 60 or so members it had on election day—most of the food, but none of the beer.

Just then, Luisa rang Fevereiro on his cellular phone, who answered and greeted her, then activated the speakerphone, giving us all the signal to be quiet. "We have to punish Teresa," said Luisa. "And why is that?" Fevereiro replied, looking both amused and perplexed. Teresa was one of those activists who worked in programs both for Caridade and Bem Vindo, a long standing member of both associations, whose entire family and neighborhood knew her HIV positive status and her work in AIDS education and home-based care. She got a hefty month's salary from her work with both groups. "She didn't turn in her report last month," Luisa continued, "I'm going to cut one month's salary from her." At this, Carlitos looked at me, and smiled sadly. We both knew that Luisa's intention was to take that money for herself, and if necessary, share it with Fevereiro to get him on her side in any ensuing debate with Teresa as a result of losing the money. "Sister," said Fevereiro, "I have that report. It's on my desk. Teresa brought it to me last week." "No, but that's too late," Luisa replied, "she always does that, and one day it's going to make us lose funding." Fevereiro wrapped up the conversation off speakerphone, telling Luisa that he would come and discuss it with her the next day. The group briefly discussed this exchange. These days, Luisa never came to the office anymore, but instead, just stayed at home, making demands to other Caridade leaders over the phone. If that weren't the case, she would have seen Teresa's

report and wouldn't even have broached this subject with Fevereiro. For his part, Fevereiro asked me if I had any "*agua de papa* (daddy's drink)" in the fridge, because he knew I often kept whiskey in there, and I handed him the bottle.

In the weeks leading up to Caridade's third election, almost all work around the office stopped. However, circulating among the homes of members and activists, it became clear that the energy normally devoted to that was being put into private meetings and even low level bribery. The two running for president, Luisa and Fevereiro, both had "their people." Loyalty to either depended mostly on which one had conferred activist status and salary to a particular person, and in terms of that, Luisa clearly had the majority. Her efforts at campaigning centered on the art of the strategic phone call, coupled with entertaining members she considered to be capable of influencing others by inviting them to her home for dinner or drinks. Fevereiro's approach was much more *laissez-faire*. He allowed others to campaign on his behalf. Because he was more often present at the office, making him more accessible and approachable, and because he was not as high profile as Luisa, who did talks on the radio and headed up city-wide meetings, people considered Fevereiro a safe and non-political alternative. Many feared that Luisa would take the association over completely if she won, by continuing to appoint young, non-HIV positive friends to paid positions. The older, founding members of Caridade saw Luisa as an upstart, and were likely to vote for Fevereiro because he was also a founder. Caridade's policy was that the presidential candidate to receive the second most votes would become vice-president. A third candidate, Zaida, was a relative unknown. Most knew that she ran at the request of Luisa, who was hoping to split the votes so that hers added up to more than Fevereiro's.

Candidates for the other positions—secretary, treasurer, president of the assembly, and porta-voz (messenger)—were a mix of activists who regularly showed up around the office. Some of these were actively buying votes from members in the form of drinks purchased from barracas

across the street, or even giving small amounts of cash to select people. One day, after closing up his office, the accountant Bakari handed me 300 Mozambican Meticaís (about US\$12), and I wasn't even a voting member of the association. He just smiled, and pointed discretely to Falume, who was running again for president of the assembleia, but had his back turned and didn't notice the exchange. There was an obvious rise in the number of private walks that people took together leading up to the elections, where strategies and discussions could be had in secret, away from prying eyes and curious ears, and under the pretense of just catching up. Elected Caridade leaders serve 5 year terms, are guaranteed a salary that whole time, and have the final say in the lives of activists. They approve their reports, their vacation requests, and collectively represent all the supervisory duties common to any other business, company, or organization. Therefore, competition to get elected to these positions is only natural, because jobs of any nature in Pemba City are highly sought after. Unfortunately, Caridade leaders depend on the organizations that finance the group, which included at that time Action Aid, FOCADÉ, RENSIDA, MONASO, and the Núcleo. When any of those donors sneeze Caridade catches the cold. This was the group's eventual fate, almost complete defunding.

The election went off without a hitch. Action Aid paid for the supplies and renting the room at the Red Cross, and there was enough food and soda for everybody. Prior to each round of voting, the candidates were permitted to give a brief speech, summarizing the reason for their interest, their accomplishments, what skills they bring to the table, and how the association would benefit from their service. Many, including Carlitos, my research assistant, employed the language of human rights and the need to fight for better services and more projects. Others stressed their longstanding loyalty to Caridade, having not defected to join or found other AIDS associations. Still others emphasized their educational credentials, their capacity to write proposals, apply and secure funding. Those who had spoken so loudly and boldly in small group

settings leading up to the election seemed tamed and even intimidated in the rather formal atmosphere of the large room in which we sat, 60 to 70 Caridade members, ready to write down someone's name and decide their future. Fevereiro won the presidency, and Luisa became vice-president for the second time. Hamisi became secretary, Carlitos the treasurer, and Falume continued as president of the assembly. Antonio, my first contact with the association, its founder, and two term president, didn't show up to vote. I would only see him again one time before his death in 2013, the result, so I was told, of too much drinking. He left behind a widow and two children.

Over the next few weeks, my last bit of time with the association, Caridade worked as if powered by a million horses. However, the reason for this was not the regime change, it was fear. In nearby Nampula, the Association there had lost its contract with UNICEF through RENSIDA—the primary school AIDS awareness project that also provided support to orphans and vulnerable children. External monitoring of the group's efforts revealed certain irregularities that didn't add up to a justifiable budget, and the program was cut. The very thought of this happening to Caridade was terrifying to everybody. The UNICEF contract made up the bread and butter, the majority of funds, for Caridade, apart from the Action Aid money that paid for the office and some occasional community programs in Pemba City. Loss of the UNICEF project also meant loss of Caridade's presence in the rest of Cabo Delgado Province. What all of this meant is that Caridade had to get its records and its story straight about the UNICEF project in multiple sites. Receipts had to be obtained for purchases, and if that wasn't possible, forged and then re-signed by the appropriate people. Reported calendar dates of implementation had to be correct and correspond to those on submitted progress reports. Evaluations of trainings and projects had to be collected, organized, and appear legitimate. Goods distributed and services rendered had to be

well documented. Transportation for project oversight had to be justified. All of this presented a huge conceptual task to the association because many corners had been cut in the recent past.

There were times, for example, that trips to the provinces simply didn't happen. Caridade supervisors were supposed to make regularly scheduled visits to places like Balama, Montepuez, Chiure, Meluco, and Muidumbe. There were instances when transportation broke down, or somebody got sick, and the visit was canceled. Trainings were supposed to be conducted with new activists or in schools with the beneficiaries. Some of these were cut short. Others had been compromised by Caridade's partner on the project, Pemba's Ministry of Education, who sometimes added new people to the project and tried to insert their own activists into Caridade's activities, leading to shorter or less effective efforts because funding didn't stretch as far.

Surprisingly, though, approval for another three year period was granted in 2009 for Caridade to continue administering the UNICEF project, which was ultimately cut nationwide in 2012. That was the time when everything else began to fizzle out for the group as well. As I write this, in 2015, Caridade still has a rented office, but the door remains mostly shut. Plans to buy land and build a new office to be owned by the group have been abandoned. The association gets funding now from the American Embassy, but the leadership of the group doesn't function as it should.

Somehow, Luisa became the sole administrator of that project. Other Caridade leaders have turned to different kinds of business in order to support themselves, and the only AIDS association that continues to function is the one funded by PEPFAR through the Elizabeth Glaser Pediatric AIDS Foundation—Bem Vindo—whose members are mostly not HIV positive. The other AIDS support groups in the city and surrounding municipalities have completely folded.

Where Now Are the Biological Citizens?

In light of what has happened to Caridade or *insert name of AIDS association here* it is disturbing to see the lip service still paid to groups like these while they are simultaneously disappearing, and AIDS-specific programming and clinics shutting down. A kind of political doublespeak persists at the level of those with the most decision making power that tends to drown out the voices of those to whom they claim to cater. UNAIDS places Mozambique into a category of countries “with generalized epidemics, low antiretroviral therapy coverage (less than 50%) and high gaps in treatment access (UNAIDS 2012: 39). Here, we are told, “special efforts are required to maintain and accelerate scale-up in these countries”. Claiming to recognize an unfinished agenda associated with full ART coverage, the document *Treatment 2015* calls on civil society to be more engaged with advocacy and accountability, service delivery, and community mobilization (UNAIDS 2012). People with HIV are called on to help health service facilities identify factors contributing to slow treatment uptake and program dropout (UNAIDS 2012: 36). Yet, what is actually happening is the opposite of all of these proscriptions. Compared to just a few years ago, in Mozambique there are no special efforts except at the level of bureaucracy and government contracting.

The manner in which people with AIDS were able to persist together in Mozambique, the AIDS association, has been decimated, from both the inside and out. While UNAIDS goes on to talk about the need for the “widest array of partners” including community based organizations and people living with HIV, particularly in order to generate demand for treatment, inform strategy development, and support service delivery (2012: 36), these groups have been cut off from the funding pipeline through what appears to be a well concerted effort. Organizations like Medicos del Mundo, Clinton Foundation, and MSF—the groups that funded and worked more closely with AIDS associations—have been told to move on to addressing the entire patient population. For

the most part, they have complied. Yet, for some reason the large, multinational programs and institutions like UNAIDS and PEPFAR continue their work with AIDS only. The juxtaposition is circumspect in its disregard for average patients, but fits well into the concept of a “planned shrinkage” (Wallace 1990), the “Landscape of Despair” (Dear and Wolch 1987) that might, with different sources of thought and input, have been avoided.

Official reports and mainstream literature acknowledge the fact that the aids activist, as biological citizen, is less and less able to harbor ill will against the system. Programs and projects are able to point to the AIDS activist as included in their plans. This speaks strongly to the viability of productive logic, of the dangers imposed when constitutive labor is mistaken for patient advocacy. It might be that the government and its partners wanted to try their hand at AIDS patient identity formation. This would be useful for later tearing it apart. The AIDS associations provided that platform. Technologies of the self at work on their desires, to be involved by getting jobs and salaries, had a sublimely negative effect on the group’s concepts of fairness and ethics, but had an equally opposite effect on its aggregate potentiality, a safe bet that the proliferation of AIDS associations would yield a positive return on investments and eventual surplus value. AIDS patient groups—and indeed, day hospitals as well—have been excellent sites for venture capital. Indications of success here pointed to more in places and with bodies previously inaccessible but no longer unreachable, the rest of the population. The state, inserting itself into activism and by later silently withdrawing, was able to leave it worse off than if it had never even been involved. AIDS activism, inserting itself into the state, yielded very different results. Its membership base sullied by competition, the presupposed alliance between those sharing the same predicament or illness breaks down, suggesting that biosociality and activism do not always see eye-to-eye.

This ill-founded relationship came to fruition with the decentralization of day hospitals, which was likewise the decentralization of AIDS patient consciousness. The failure here of AIDS activism was not in its inability to silence its critics or speak out, but in its murky capacity for justifying itself through evidence. Had patient-activists observed that their existence was contingent on production, and not really on human rights, then the benefits of non-dominant forms of biosociality, and the imperative for domestic security over benevolent social action, may have assumed a position of authority. In a world that kowtows more to efficiency than ideals, 'movements' besides only social ones carry and disseminate their own messages. The "evidence-based policy movement" (Sundell and Wäringård 2013) permitted Garrido to ignore the gap between his decision and AIDS activist sentiments. Regardless of the fact that sufficient time and effort had not been invested to distill exactly how these wide scale changes might be felt in every context, universal patient rights overtook AIDS activism on the international list of key issues. To stay on the side of management processes politicians respond better to talking points than to demands.

The loss of external support would have been less impactful had AIDS patients been seeking benefits from their collective involvement besides material resources. Were groups more effectively bent on the prevention of disease relapse among their own members, and the dissemination of illness coping or livelihood strategies exclusive from external programs, then the capacity for AIDS activism to drive health data and outcomes in its own right would have been better parsed. Up against 'the market' as a site for doing things quickly and efficiently, treatment as a form of self-improvement is easily withdrawn or transferred out of the group. The project plan, as well, is revealed as a technique simply on loan. The eventual unwillingness to allocate any power to AIDS activism had everything to do with a lack of competing proofs in defense of what the group was always better equipped for than the state. Destigmatizing the virus at the

community level, highlighting the scale of the pandemic in the realm of the social, the circulation of social capital, and inculcation into moral economies are items and tasks less easy to measure than most others, but they are more than mere filler in the lives of the afflicted. We are at a point where logical demonstrations are preferable to demonstrations in the street.

Without rosters, leaders, project money, or talking to the press, Alcoholics Anonymous is the most successful support group model in the world. Reconciling people with life as a safe place, replete with practical advice and social support, these groups do not furnish members with jobs, salaries, or housing. They accept no outside funds nor do they rely on medical professionals and experts for guidance. Yet they proliferate internationally, and each meeting differs according to speakers and content. ‘Sponsors’ care for new members and lead them through standard steps that liberate people from harmful thinking and negative behavior. Rather than seeking out formal programs, formal programs seek out the group, sending sick people to the community for therapy that clinicians can’t provide. Aspects of apprenticeship, addressing the existential vacuum, and exploration of meaning and sacrifice—these are viable goals for the group but less so for the state, and still measurable in number of lives saved (Frankl 2006). Social realism is social justice (Archer 1995), and the promotion of dignity is as practical of a concern as any other (Rosen 2012). In the hyper-politicized world of AIDS care there increasingly seems to be no place for such a model.

There is something to be said, then, for the absence of gatekeepers. It may increase emotional commitment and obligation, and decrease the tension between institutional formation and community loyalty. It may better enable the stabilization of self-consciousness and the transfer of experiential knowledge, and carve out space for appeals that differ from those linked mostly to representation and entitlement. There may be many points of dissonance between ‘expert’ activists and self-advocates which remain obscured out of fear they might upset normality. But this normality is the result of a “looping effect” (Hacking 2000), where activism

becomes self-referential and ceases to align outside of its own expectations. There were different sorts of problems, of affect and mood, difficult to broach in Mozambican AIDS associations at the very outset. Equally accessible and utilized as the language of solidarity is that of disappointment, exclusion, and lost opportunity that indicates politics is no longer fertile ground. AIDS activism is haunted by this lack of foundational emotional and even discursive work. Protests against it have taken the form of apathy, disinterest, and unattachment.

What we have, then, are scores of homeless biological citizens who set their sights on the wrong kind of citizenship. Striving and inspired to become citizens of the transnational, but less motivated as citizens of the local, perceived need for self-enrichment combined with poor guidance and oversight lead to internal group sabotage and professional inefficacy. Activism serves as a distraction and insufficient moral ground for group cohesion. The blending together of projects both public and private is like serving two masters, enabling personal agendas to overtake the common good. By now work on the self, at the level of greed or the slaking of similar unhealthy thirsts, is more than necessary, it's required. The topic of responsabilization, confessional technologies, and testimonials should be revisited. Bereft of lay psychology the group is more likely to become a tool for the elite than a forum for the disadvantaged.

To follow a motto or mantra would have been a good start. The names of AIDS associations encapsulate the mission. *Caridade* refers to unconditional love. *Bem Vindo* means welcome. *Nashukuru* is thankfulness. *Ajuda à Próxima* is help your neighbor. *Esperanca da Vida* is hope of life. These concepts are not foreign, but fail to direct action so long as they remain uninspired. While making connections between politics, projects, and AIDS patient groups is not always and everywhere wrong, the approach has mostly been speculative. "Human existence is always oriented toward the future," writes sociologist (and social constructivist) Peter Berger (1970:61):

Man exists by constantly extending his being into the future, both in his consciousness and in his activity. Put differently, man realizes himself in projects.

An essential dimension of this ‘futurity’ of man is hope. It is through hope that men overcome the difficulties of any given here and now.”

Where the AIDS associations failed was in the project of hope. Every stolen goat, every misspent dollar, every missed chance for a meeting not just about resources and expenses are a slap in the face of the common AIDS patient and his or her hopes and dreams. The groups in Cabo Delgado would have been better off without such projects. Abuse of the project is the doorway to abuse of the group. It is apparent to everybody, the secrets are not easily hidden. This is how AIDS associations failed to impact the society around them, robbing their own future, invitingly taken over by the outspoken, the clever, and the corrupt.

The capitalist rationality fueling the expansion of government into the lives and minds of people has no problem with elements of social conflict. Protests, civil society disruptions, claims made against the state provide less opportunity for social advancement than at first it seems. The ‘opportunity’ of a struggle, even when it results in an apparent accumulation of goods (or access to treatment), signals also the group’s affability at being worked on, defined, and shaped in a manner it might not expect. Aspiring to universality, the global village, or the transnational nature of AIDS patienthood lends itself well to domination by others. Not only is it easy to challenge in terms of practice, but its application requires an attack on diversity, leading to a platform on which all can agree, usually evoking one or another version of *the consumer*. Millikan (1987) posits the consumer as a hungry frog, darting out its tongue to consume any material appropriate in size which moves past its retinas. Unsure of its content—it could be poisonous—we can look to the frog to see if it was appropriate, or not. As the food moves downstream we can also gauge how well it benefits the creatures in different environs. Are the creatures altered, sickly, or more energetic? Does the content have the same effects as it moves farther from its source? The folding of AIDS patient groups at my research sites, and subsequent lack of

replacements, suggest the content did not satiate. Perhaps it was inappropriate; perhaps it satisfied minimally, at the level only of primary desire, of instant gratification.

But it is not wrong to want. MacIntyre offers the concept of enlightened self-interest as not at all incompatible with seeking “the good life” (1999:13), but power, money, and influence alone do not further cooperative pursuits. The figure of the AIDS activist, at the forefront of a vanguard of social justice, offers no way out of ‘the state’ versus ‘the excluded’ dilemma. As this figure draws us more and more into a cycle of participation, it will become less provocative despite its birth in the fire of rights and demands. This biological citizen also offers us no way out of the Foucauldian snares laid out in concepts of governmentality and biopolitical power, perceived as ineliminable life elements and constant disruptions. Displacing (neo)liberalism—as a hindrance to civil society, as constraint on freedom or the autonomy of the group—rests on the practices, rationality, and morality of “plain persons” (MacIntyre 1999:15), those whom Nietzsche identifies as ‘the herd.’ Identities based on biological facts take shape in ways not nearly as unruly as previously thought. The consequences are really rather predictable. Investors want consumers and the state wants participants. Both are happy to intervene because it legitimates their presence, spurring business and politics onward.

Normalcy for the group, and the establishment of effective support networks, was a persistent design flaw for AIDS activism in southern Africa. Attempts to correct it unsurprisingly corresponded to preexisting patterns, the same kinds that often establish themselves after the discovery of an illness, its treatment, and related biosociality. This hasn’t occurred ad-hoc but through highlights of heroism, utopias, and exemplary case studies, simultaneously indicative both of activism’s monopoly on public symbols and their spoliative effects. The failure to communicate worry, distress, fear, frustration, and anxiety eclipses paths for moderation and correction. Bad work and poor performance does not constitute research material to be discarded,

as often thought, and should instead be integrated into the construction of narratives to help us assess the past and plan for the future. But confusion continues. We still believe AIDS activism is more about medicine and complaints than quality of life. The “fourth wave” of AIDS activism (Smith 2013) is attributed once again to patients demanding treatment, this time for pre-exposure prophylaxis, treatment as prevention efforts, and forced taxes on Wall Street to fund progressive causes. Such concerns stand in for and replace the need to rethink relations between governance, society, and AIDS patienthood. Locked in this cycle it is unlikely for biosociality to develop much further. Treatment is for people, not people for treatment, but emerging only for crises or in apparent states of disrepair AIDS civil society and AIDS activism presents itself as destined, if not prepackaged, mostly for consumerism and scandal. We find ourselves still waiting on a satisfactory defense of the local, the average, the common, and the humble.

BIBLIOGRAPHY

BIBLIOGRAPHY

Abt Associates, Inc

2012 Health Systems 20/20: Final Project Report. Bethesda, MD: USAID.

Agência de Notícias de Resposta ao SIDA

2009a A Difícil Descentralização Dos Pacientes Dos Hospitais de Dia, September 23.

2009b CNCS Passa Por Mudanças, October 10.

Alcano, Matteo Carlo

2009 Living and Working in Spite of Antiretroviral Therapies: Strength in Chronicity. *Anthropology & Medicine* 16(2): 119–130.

Almond, Gabriel Abraham, and Sidney Verba, eds.

1989 The Civic Culture: Political Attitudes and Democracy in Five Nations. Newbury Park, Calif: SAGE Publications, Inc.

Andrews, Jason R., N. Sarita Shah, Neel Gandhi, et al.

2007 Multidrug-Resistant and Extensively Drug-Resistant Tuberculosis: Implications for the HIV Epidemic and Antiretroviral Therapy Rollout in South Africa. *The Journal of Infectious Diseases* 196: S482–S490.

Archer, Margaret S.

1995 Realist Social Theory: The Morphogenetic Approach. Cambridge ; New York: Cambridge University Press.

Atun, Rifat, Thyra de Jongh, Federica Secci, Kelechi Ohiri, and Olusoji Adeyi

2010 A Systematic Review of the Evidence on Integration of Targeted Health Interventions into Health Systems. *Health Policy and Planning* 25(1): 1–14.

Bähre, Erik

2007 Reluctant Solidarity: Death, Urban Poverty, and Neighbourly Assistance in Urban South Africa. *Ethnography* 8(1): 33–59.

Bandali, Sarah

2011 Exchange of Sex for Resources: HIV Risk and Gender Norms in Cabo Delgado, Mozambique. *Culture, Health & Sexuality* 13(5): 575–588.

Barlett, John A., and John F. Shao

2009 Successes, Challenges, and Limitations of Current Antiretroviral Therapy in Low-Income and Middle-Income Countries. *The Lancet Infectious Diseases* 9(10): 637–649.

Bärnighausen, Till, Krisda Chaiyachati, Natsayi Chimbindi, et al.

2011 Interventions to Increase Antiretroviral Adherence in Sub-Saharan Africa: A Systematic Review of Evaluation Studies. *The Lancet Infectious Diseases* 11(12): 942–951.

Bastos, Cristiana

- 1998 Tristes Trópicos E Alegres Luso-Tropicalismos: Das Notas de Viagem Em Lévi-Strauss E Gilberto Freyre. *Análise Social* 33(146/147): 415–432.
- 2007 Medical Hybridisms and Social Boundaries: Aspects of Portuguese Colonialism in Africa and India in the Nineteenth Century. *Journal of Southern African Studies* 33(4): 767–782.
- Beauclerk, John
- 2011 A Framework for Understanding Civil Society in Action. *Development in Practice* 21(6): 870–879.
- Bedelu, Martha, Nathan Ford, Katherine Hilderbrand, and Hermann Reuter
- 2007 Implementing Antiretroviral Therapy in Rural Communities: The Lusikisiki Model of Decentralized HIV/AIDS Care. *The Journal of Infectious Diseases* 196 Suppl 3: S464–468.
- Bell, Morag, Eugene Palka, Christopher Thurber, et al.
- 1999 *Therapeutic Landscapes: The Dynamic Between Place and Wellness*. Allison Williams, ed. Lanham ; New York ; Oxford: University Press of America.
- Bemelmans, Marielle, Thomas van den Akker, Nathan Ford, et al.
- 2010 Providing Universal Access to Antiretroviral Therapy in Thyolo, Malawi through Task Shifting and Decentralization of HIV/AIDS Care. *Tropical Medicine & International Health* 15(12): 1413–1420.
- Benford, Robert D., and David A. Snow
- 2000 Framing Processes and Social Movements: An Overview and Assessment. *Annual Review of Sociology* 26: 611–639.
- Berger, Peter L.
- 1970 *A Rumor of Angels: Modern Society and the Rediscovery of the Supernatural*. 1st edition. Garden City, NY: Anchor.
- Berger, Peter L., and Thomas Luckmann
- 1967 *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. New York: Anchor.
- Biehl, João
- 2006 Pharmaceutical Governance. In *Global Pharmaceuticals: Ethics, Markets, Practices*. 1 edition. Adriana Petryna, Andrew Lakoff, and Arthur Kleinman, eds. Pp. 206–239. Durham: Duke University Press Books.
- 2007 Pharmaceuticalization: AIDS Treatment and Global Health Politics. *Anthropological Quarterly* 80(4): 1083–1126.
- Binagwaho, Agnes, and Niloo Ratnayake
- 2009 The Role of Social Capital in Successful Adherence to Antiretroviral Therapy in Africa. *PLoS Med* 6(1): e18.
- Bion, Wilfred
- 1991 *Experiences in Groups: And Other Papers*. 1 edition. London: Routledge.
- Bonate, Liazzat J. K.
- 2006 Matriliny, Islam and Gender in Northern Mozambique. *Journal of Religion in Africa* 36(2): 139–166.

Boyd, Richard

1999 "The Unsteady and Precarious Contribution of Individuals": Edmund Burke's Defense of Civil Society. *The Review of Politics* 61(3): 465–491.

Brinkhof, Martin W. G., Ben D. Spycher, Constantin Yiannoutsos, et al.

2010 Adjusting Mortality for Loss to Follow-Up: Analysis of Five ART Programmes in Sub-Saharan Africa. *PLoS ONE* 5(11): e14149.

Britten, Nicky

1996 Lay Views of Drugs and Medicines: Orthodox and Unorthodox Accounts. *In Modern Medicine: Lay Perspectives And Experiences*. Simon J. Williams, ed. Pp. 48–73. London ; Bristol Pa: Routledge.

Bucagu, Maurice, Jean Kagubare, Paulin Basinga, et al.

2012 Impact of Health Systems Strengthening on Coverage of Antenatal and Delivery Services in Rwanda, 2000-2010: A Systematic Review. SSRN Scholarly Paper, ID 2131112. Rochester, NY: Social Science Research Network. <http://papers.ssrn.com/abstract=2131112>, accessed April 29, 2014.

Burchell, Graham

1993 Liberal Government and Techniques of the Self. *Economy and Society* 22(3): 267–282.

Burnett, Alan, and Graham Moon

1983 Community Opposition to Hostels for Single Homeless Men. *Area* 15(2): 161–166.

Cabassi, Julia, and David Wison

2005 Renewing Our Voice: Code Of Good Practice For NGOs Responding To HIV/AIDS.

Callon, Michel, and Vololona Rabeharisoa

2008 The Growing Engagement of Emergent Concerned Groups in Political and Economic Life: Lessons from the French Association of Neuromuscular Disease Patients. *Science, Technology, & Human Values* 33(2): 230–261.

Canguilhem, Georges

2008 Knowledge of Life. New York: Fordham University Press.

Carroll, William K., and R. S. Ratner

1996 Master Framing and Cross-Movement Networking in Contemporary Social Movements. *The Sociological Quarterly* 37(4): 601–625.

Casswell, Sally, and Anna Maxwell

2005 Regulation of Alcohol Marketing: A Global View. *Journal of Public Health Policy* 26(3): 343–358.

Castela, Tiago

2010 Planning Practices and the Utopia of Lusotropicalism in Portugal and Mozambique, 1945-1975. *Traditional Dwellings and Settlements Review* 22(1): 15–16.

Chabal, Patrick, David Birmingham, Joshua Forrest, and Malyn Newitt

2002 A History of Postcolonial Lusophone Africa. Bloomington: Indiana University Press.

Cohen, Rachel, Sharonann Lynch, Helen Bygrave, et al.

2009 Antiretroviral Treatment Outcomes from a Nurse-Driven, Community-Supported HIV/AIDS Treatment Programme in Rural Lesotho: Observational Cohort Assessment at Two Years. *Journal of the International AIDS Society* 12(1): 23.

Conrad, P.

1985 The Meaning of Medications: Another Look at Compliance. *Social Science & Medicine* (1982) 20(1): 29–37.

Corry, T. Olaf

2006 Global Civil Society and Its Discontents. *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 17(4): 303–324.

Crane, K. W.

1968 Psychiatric Social Workers in the Therapeutic Community. *British Journal of Psychiatric Social Work* 9(3): 145–151.

Cruikshank, Barbara

1993 Revolutions within: Self-Government and Self-Esteem. *Economy and Society* 22(3): 327–344.

Cumaquela, Feliciano Pedro Maurício, Moshin (Supervisor) Sidat, and César Palha de (Co-supervisor) Sousa

2012 Adição a terapeutica anti-retoviral (TARV): Experiência dos serviços farmaceuticos do Hospital Central de Maputo. Thesis. <http://www.saber.ac.mz/handle/10857/3902>, accessed April 28, 2014.

Cunningham, Hilary

1999 The Ethnography of Transnational Social Activism: Understanding the Global as Local Practice. *American Ethnologist* 26(3): 583–604.

Curtis, Sarah, Wil Gesler, Kathy Fabian, Susan Francis, and Stefan Priebe

2007 Therapeutic Landscapes in Hospital Design: A Qualitative Assessment by Staff and Service Users of the Design of a New Mental Health Inpatient Unit. *Environment and Planning C: Government and Policy* 25(4): 591 – 610.

Dear, Michael J., and Jennifer R. Wolch

1987 *Landscapes of Despair: From Deinstitutionalization to Homelessness*. Princeton University Press.

Decroo, Tom, Olivier Koole, Daniel Remartinez, et al.

2014 Four-Year Retention and Risk Factors for Attrition among Members of Community ART Groups in Tete, Mozambique. *Tropical Medicine & International Health* 19(5): 514–521.

Decroo, Tom, Isabella Panunzi, Carla das Dores, et al.

2009 Lessons Learned during down Referral of Antiretroviral Treatment in Tete, Mozambique. *Journal of the International AIDS Society* 12: 6.

Denison, Julie A., Olivier Koole, Sharon Tsui, et al.

2015 Incomplete Adherence among Treatment-Experienced Adults on Antiretroviral Therapy in Tanzania, Uganda and Zambia. *AIDS (London, England)* 29(3): 361–371.

DiMaggio, Paul J., and Walter W. Powell

1983 The Iron Cage Revisited: Institutional Isomorphism and Collective Rationality in Organizational Fields. *American Sociological Review* 48(2): 147–160.

Dimond, Rebecca, Andrew Bartlett, and Jamie Lewis

2015 What Binds Biosociality? The Collective Effervescence of the Parent-Led Conference. *Social Science & Medicine*(126): 1–8.

Doherty, Edmund G., and Joseph Harry

1976 Structural Dissensus in the Therapeutic Community. *Journal of Health and Social Behavior* 17(3): 272–279.

Donnelly, John

2001 Prevention Urged in AIDS Fight Natsios Says Fund Should Spend Less on HIV Treatment. *Boston Globe*, June 7.

DREAM

2009 Doentes de SIDA Acusam Ivo Garrido de Não Consultá-Lo, August 10.

<http://dream.santegidio.org/2009/08/10/diario-de-noticias-mocambique-doentes-de-sida-acusam-ivo-garrido-de-nao-consulta-los/>.

Durkheim, Emile

1982 *Rules of Sociological Method*. New York: Free Press.

Eade, John, and Michael Peter Smith

2011 *Transnational Ties: Cities, Migrations, and Identities*. Transaction Publishers.

Ekeh, Peter P.

1975 Colonialism and the Two Publics in Africa: A Theoretical Statement. *Comparative Studies in Society and History* 17(1): 91–112.

El-Sadr, Wafaa M., Miriam Rabkin, Rifat Atun, and Kevin M. De Cock

2011 Bridging the Divide. *Journal of Acquired Immune Deficiency Syndromes* (1999) 57 Suppl 2: S59–60.

Epstein, Helen

2008 *The Invisible Cure: Why We Are Losing the Fight Against AIDS in Africa*. First Edition edition. New York, NY: Picador.

Epstein, Steven

1996 *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley, Calif.: University of California Press.

Farmer, Paul

1996 On Suffering and Structural Violence: A View from Below. *Daedalus* 125(1): 261–283.

2006 *AIDS and Accusation: Haiti and the Geography of Blame*. Updated with a New Preface edition. Berkeley: University of California Press.

Faundez, Julio

2003 Regime Change and the Governance Agenda—Are They Linked? *Proceedings of the Annual Meeting (American Society of International Law)* 97: 137–139.

Fenio, Kenly Greer

2009 Between Bedrooms and Ballots: The Politics of HIV's "Economy of Infection" in Mozambique. Dissertation, University of Florida.

2011 Tactics of Resistance and the Evolution of Identity from Subjects to Citizens: The AIDS Political Movement in Southern Africa. *International Studies Quarterly* 55(3): 717–735.

Ferguson, James

1994 The Anti-Politics Machine. University of Minnesota Press.

FHI 360

2016 Health Systems Strengthening | FHI 360. Health Systems Strengthening. <http://www.fhi360.org/expertise/health-systems-strengthening>, accessed January 16, 2016.

Foucault, Michel

1988 Technologies of the Self: A Seminar with Michel Foucault. Luther H. Martin, Huck Gutman, and Patrick H. Hutton, eds. Amherst: University of Massachusetts Press.

2003 "Society Must Be Defended": Lectures at the Collège de France, 1975-1976. David Macey, tran. Reprint edition. New York: Picador.

2010 The Birth of Biopolitics: Lectures at the Collège de France, 1978--1979. Reprint edition. New York: Picador.

Fox, Matthew P, and Sydney Rosen

2010 Patient Retention in Antiretroviral Therapy Programs up to Three Years on Treatment in Sub-Saharan Africa, 2007-2009: Systematic Review. *Tropical Medicine & International Health: TM & IH* 15 Suppl 1: 1–15.

Frankl, Viktor E.

2006 Man's Search for Meaning. 1 edition. Boston: Beacon Press.

Gamson, Josh

1989 Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement "Newness." *Social Problems* 36(4): 351–367.

Gardner, Kathryn

1971 Patient Groups in a Therapeutic Community. *The American Journal of Nursing* 71(3): 528–531.

Germain, Carol

1979 The Cancer Unit: A Ethnography. Wakefield: Nursing Resources.

Gesler, W. M.

1992 Therapeutic Landscapes: Medical Issues in Light of the New Cultural Geography. *Social Science & Medicine* (1982) 34(7): 735–746.

Glasser, Irene

2010 More Than Bread: Ethnography of a Soup Kitchen. Tuscaloosa: University Alabama Press.

Goffman, Erving

1986 Stigma: Notes on the Management of Spoiled Identity. Reissue edition. New York: Touchstone.

Goodwin, Jeff, James M. Jasper, and Jaswinder Khattri

1999 Caught in a Winding, Snarling Vine: The Structural Bias of Political Process Theory. *Sociological Forum* 14(1): 27–54.

Grebe, Eduard

2011 The Treatment Action Campaign's Struggle for AIDS Treatment in South Africa: Coalition-Building Through Networks. *Journal of Southern African Studies* 37(4): 849–868.

Grépin, Karen A.

2011 Leveraging HIV Programs to Deliver an Integrated Package of Health Services: Some Words of Caution. *Journal of Acquired Immune Deficiency Syndromes* (1999) 57 Suppl 2: S77-79.

Groh, Kate, Carolyn M Audet, Alberto Baptista, et al.

2011 Barriers to Antiretroviral Therapy Adherence in Rural Mozambique. *BMC Public Health* 11: 650.

Hacking, Ian

2000 *The Social Construction of What?* Harvard University Press.

Hall, Stuart

1986 Popular Culture and the State. In *Popular Culture and Social Relations*. Tony Bennett, Colin Mercer, and Janet Woollacott, eds. Pp. 360–379. Milton Keynes, England ; Philadelphia: Open Univ Pr.

Hanlon, Joseph

2004 Do Donors Promote Corruption?: The Case of Mozambique. *Third World Quarterly* 25(4): 747–763.

Harman, Sophie

2007 The World Bank: Failing the Multi-Country AIDS Program, Failing HIV/AIDS. *Global Governance* 13(4): 485–492.

Harries, Anthony D, Rony Zachariah, Stephen D Lawn, and Sydney Rosen

2010 Strategies to Improve Patient Retention on Antiretroviral Therapy in Sub-Saharan Africa. *Tropical Medicine & International Health: TM & IH* 15 Suppl 1: 70–75.

Harvey, David

1991 *The Condition of Postmodernity: An Enquiry into the Origins of Cultural Change*. Oxford England ; Cambridge, Mass., USA: Wiley-Blackwell.

2007 *A Brief History of Neoliberalism*. Oxford University Press.

Hayden, Patrick

2012 The Human Right to Health and the Struggle for Recognition. *Review of International Studies* 38(3): 569–588.

Heath, Deborah, Rayna Rapp, and Karen-Sue Taussig

2007 Genetic Citizenship. In *A Companion to the Anthropology of Politics*. David Nugent and Joan Vincent, eds. Pp. 152–167. Blackwell Publishing Ltd.

Heath, Katherine V, Joel Singer, Michael V O'Shaughnessy, Julio S G Montaner, and Robert S Hogg

2002 Intentional Nonadherence due to Adverse Symptoms Associated with Antiretroviral Therapy. *Journal of Acquired Immune Deficiency Syndromes* (1999) 31(2): 211–217.

Heim, Kristi

2011 UW International AIDS Nonprofit Hit by Financial Questions in Mozambique. *The Seattle*

Times, February 1. <http://www.seattletimes.com/seattle-news/health/uw-international-aids-nonprofit-hit-by-financial-questions-in-mozambique/>.

Hendershot, Christian S., Susan A. Stoner, David W. Pantalone, and Jane M. Simoni
2009 Alcohol Use and Antiretroviral Adherence: Review and Meta-Analysis. *Journal of Acquired Immune Deficiency Syndromes* (1999) 52(2): 180–202.

Høg, Erling
2006 Human Rights and Access to AIDS Treatment in Mozambique. *African Journal of AIDS Research* 5(1): 49–60.

Honneth, Axel
1996 *The Struggle for Recognition: The Moral Grammar of Social Conflicts*. Joel Anderson, tran. 1st MIT Press ed edition. Cambridge, Mass: The MIT Press.

Huber, Peter
2007 The Coming Plague. *The Wall Street Journal*, April 10.

Huey, Florence L.
1971 In a Therapeutic Community. *The American Journal of Nursing* 71(5): 926–933.

Huis In 't Veld, Diana, Linda Skaal, Karl Peltzer, et al.
2012 The Efficacy of a Brief Intervention to Reduce Alcohol Misuse in Patients with HIV in South Africa: Study Protocol for a Randomized Controlled Trial. *Trials* 13: 190.

Hunt, L. M., B. Jordan, S. Irwin, and C. H. Browner
1989 Compliance and the Patient's Perspective: Controlling Symptoms in Everyday Life. *Culture, Medicine and Psychiatry* 13(3): 315–334.

Iliffe, John
2006 *The African AIDS Epidemic: A History*. 1 edition. Athens : Oxford : Cape Town, South Africa: Ohio University Press.

Illich, Ivan
1982 *Medical Nemesis: The Expropriation of Health*. New York: Pantheon.

Imrie, Rob
2001 Barriered and Bounded Places and the Spatialities of Disability. *Urban Studies* 38: 231–237.

Ingram, Alan
2010 Biosecurity and the International Response to HIV/AIDS: Governmentality, Globalisation and Security. *Area* 42(3): 293–301.

Instituto Nacional de Estatística
2015 Cabo Delgado Province - Mozambique Data and Statistics. Knoema.
<http://knoema.com/atlas/Mozambique/Cabo-Delgado-provincia>, accessed February 15, 2015.

IRIN PlusNews
2009a Fim de Hospitais-Dia Traz Estigma E Mau Atendimento, January 30.
<http://www.irinnews.org/printreport.aspx?reportid=82664>, accessed January 17, 2016.

- 2009b Liga Contra Discriminação Volta a Promover Protestos, September 9.
<http://www.irinnews.org/report/86075/mo%C3%87ambique-liga-contra-discrimina%C3%A7%C3%A3o-volta-a-promover-protestos>.
- 2009c MOÇAMBIQUE: Sociedade Civil Cria Observatório Para Monitorar Qualidade No Atendimento, September 23. <http://www.irinnews.org/printreport.aspx?reportid=86248>.
- Isaacman, Allen F., and Barbara Isaacman
 1983 Mozambique: From Colonialism to Revolution, 1900-1982. illustrated edition edition. Boulder, Colo. Aldershot, Hampshire, England: Westview Press.
- Janovicek, Nancy
 2007 No Place to Go: Local Histories of the Battered Women's Shelter Movement. Vancouver: University of Washington Press.
- Johnson, Krista
 2008 Between Self-Help and Dependence: Donor Funding and the Fight against HIV/AIDS in South Africa. *Africa: Journal of the International African Institute* 78(4): 496–517.
- Jones, Edgar
 2006 Historical Approaches to Post-Combat Disorders. *Philosophical Transactions: Biological Sciences* 361(1468): 533–542.
- Kalichman, Seth C., Tamar Grebler, Christina M. Amaral, et al.
 2013 Intentional Non-Adherence to Medications among HIV Positive Alcohol Drinkers: Prospective Study of Interactive Toxicity Beliefs. *Journal of General Internal Medicine* 28(3): 399–405.
- Kalk, Andreas, Friederike Amani Paul, and Eva Grabosch
 2010 "Paying for Performance" in Rwanda: Does It Pay Off? *Tropical Medicine & International Health* 15(2): 182–190.
- Kalofonos, Ippolytus
 2008 "All I Eat Is ARVS." Living with HIV/AIDS at the Dawn of the Treatment Era in Central Mozambique. Dissertation, University of California, San Francisco.
- Keane, John
 1988 Civil Society and the State: New European Perspectives. London ; New York: Verso Books.
- Kearns, R. A., and D. C. Collins
 2000 New Zealand Children's Health Camps: Therapeutic Landscapes Meet the Contract State. *Social Science & Medicine* (1982) 51(7): 1047–1059.
- Kelsall, Tim
 2002 Shop Windows and Smoke-Filled Rooms: Governance and the Re-Politicisation of Tanzania. *The Journal of Modern African Studies* 40(4): 597–619.
- Kraemer, Sebastian
 2010 "Great Men" need Not Apply. *BMJ: British Medical Journal* 340(7759): 1263–1264.
- Kranzer, Katharina, and Nathan Ford
 2011 Unstructured Treatment Interruption of Antiretroviral Therapy in Clinical Practice: A Systematic Review. *Tropical Medicine & International Health* 16(10): 1297–1313.

- Kristofferson, Kirk, Katherine White, and John Peloza
2014 The Nature of Slacktivism: How the Social Observability of an Initial Act of Token Support Affects Subsequent Prosocial Action. *Journal of Consumer Research* 40(6): 1149–1166.
- Kula, Kula: Estudos & Pesquisas Aplicadas, Lda
2008 Análise da Situação do HIV e SIDA & Acesso ao TARV em Moçambique.
- Lambdin, Barrot H, Mark A Micek, Kenneth Sherr, et al.
2013 Integration of HIV Care and Treatment in Primary Health Care Centers and Patient Retention in Central Mozambique: A Retrospective Cohort Study. *Journal of Acquired Immune Deficiency Syndromes* (1999) 62(5): e146-152.
- Latour, Bruno
2007 Reassembling the Social: An Introduction to Actor-Network-Theory. 1st edition. Oxford University Press.
- Lawn, Joy E., Jon Rohde, Susan Rifkin, et al.
2008 Alma-Ata 30 Years on: Revolutionary, Relevant, and Time to Revitalise. *Lancet* (London, England) 372(9642): 917–927.
- Le Marcis, Frédéric
2012 Struggling with AIDS in South Africa: The Space of the Everyday as a Field of Recognition. *Medical Anthropology Quarterly* 26(4): 486–502.
- Lederman, Josh
2010 A Bill's Name Is Part of the Game. Chicago, IL: Medill Reports.
<http://newsarchive.medill.northwestern.edu/chicago/news-166509.html>.
- Lemke, Thomas
2001 “The Birth of Bio-Politics”: Michel Foucault’s Lecture at the Collège de France on Neo-Liberal Governmentality. *Economy and Society* 30(2): 190–207.
- Lipschutz, Ronnie D.
1992 Reconstruction and World Politics: The Emergence of Global Civil Society. *Millennium Journal of International Studies* 21(3): 389–420.
- Lock, Margaret
2008 Biosociality and Susceptibility Genes: A Cautionary Tale. *In Biosocialities, Genetics, and the Social Sciences: Making Biologies and Identities* Pp. 56–78. Routledge.
- Loewenson, Rene, and David McCoy
2004 Access to Antiretroviral Treatment in Africa. *BMJ : British Medical Journal* 328(7434): 241–242.
- Long, Lawrence, Alana Brennan, Matthew P. Fox, et al.
2011 Treatment Outcomes and Cost-Effectiveness of Shifting Management of Stable ART Patients to Nurses in South Africa: An Observational Cohort. *PLoS Med* 8(7): e1001055.
- Lumière Action
2015 Lumière Action. <http://www.platforme-elsa.org/structure/lumiere-action/>, accessed February 16, 2015.

- Luque-Fernandez, Miguel Angel, Gilles Van Cutsem, Eric Goemaere, et al.
2013 Effectiveness of Patient Adherence Groups as a Model of Care for Stable Patients on Antiretroviral Therapy in Khayelitsha, Cape Town, South Africa. *PLoS ONE* 8(2): e56088.
- MacIntyre, Alasdair C.
1999 *The MacIntyre Reader*. Kelvin Knight, ed. New edition edition. Notre Dame, Ind: University of Notre Dame Press.
- Marcis, Frederic Le, and Judith Inggs
2004 The Suffering Body of the City. *Public Culture* 16(3): 453–477.
- Marsland, Rebecca
2012 (Bio)Sociality and HIV in Tanzania: Finding a Living to Support a Life. *Medical Anthropology Quarterly* 26(4): 470–485.
- Martinez, Francisco Lerma
1989 *O povo macua e a sua cultura*. Lisboa: Ministerio da Educacao, Instituto de Investigacao Cientifica Tropical.
- Marx, Karl
1909 *Capital: A Critique of Political Economy*. C. H. Kerr.
- Matsinhe, Cristiano
2008 *Tabula Rasa: Dynamics of the Mozambican Response to HIV/AIDS*. Kula.
- McDowell, Bernard
2004 National Committee for Quality Assurance. *Social Work* 49(3): 525–528.
- Mckay, Ramah
2012 Afterlives: Humanitarian Histories and Critical Subjects in Mozambique. *Cultural Anthropology* 27(2): 286–309.
- McLean, A
2007 The Therapeutic Landscape of Dementia Care: Contours of Intersubjective Spaces for Sustaining the Person. In *Therapeutic Landscapes: The Dynamic Between Place and Wellness*. Allison Williams, Morag Bell, Christopher Thurber, et al., eds. Pp. 315–332. Lanham ; New York ; Oxford: University Press of America.
- Miller, Peter, and Nikolas Rose
1994 On Therapeutic Authority: Psychoanalytical Expertise under Advanced Liberalism. *History of the Human Sciences* 7(3): 29–64.
- Millikan, Ruth Garrett
1987 *Language, Thought, and Other Biological Categories: New Foundations for Realism*. Reprint edition. Cambridge, Mass.: The MIT Press.
- Mills, Edward J., Jean B. Nachega, Iain Buchan, et al.
2006 Adherence to Antiretroviral Therapy in Sub-Saharan Africa and North America: A Meta-Analysis. *JAMA* 296(6): 679–690.

MISAU, Ministerio de Saude (Mozambique)

2013 Plano de Acelaração Da Resposta Ao HIV E SIDA.

2011 Relatório de Retenção TARV: Analise de Retenção Aos 12 Meses Dos Pacientes Que Iniciaram TARV Em Junho de 2009.

2009 Inquérito Nacional de Prevalência, Riscos Comportamentais E Informação Sobre O HIV E SIDA Em Moçambique.

2004 Hospitais de Dia E Cuidados Ambulatórios Para Pessoas Vivendo Com HIV/SIDA: Guião Para a Organização E Gestão. 2º Rascunho. República de Moçambique.

Mitchell, Nathan

2007 New Directions in Ritual Research. *In* Foundations in Ritual Studies: A Reader for Students of Christian Worship Pp. 103–130. Grand Rapids, Mich.: Baker Academic.

Msellati, Philippe, Anne Juillet-Amari, Joanne Prudhomme, et al.

2003 Socio-Economic and Health Characteristics of HIV-Infected Patients Seeking Care in Relation to Access to the Drug Access Initiative and to Antiretroviral Treatment in Côte d'Ivoire. *AIDS* (London, England) 17 Suppl 3: S63-68.

Mugenyi, Peter

2004 Highly Active Antiretroviral Therapy: We Need To Scale Up Its Use And Reach With Existing Facilities In Poor Countries. *BMJ: British Medical Journal* 329(7475): 1118–1119.

Munslow, Barry, ed.

1986 Africa: Problems in the Transition to Socialism. London ; Atlantic Highlands, N.J., USA: Zed Books.

Mussa, Abdul H, James Pfeiffer, Stephen S Gloyd, and Kenneth Sherr

2013 Vertical Funding, Non-Governmental Organizations, and Health System Strengthening: Perspectives of Public Sector Health Workers in Mozambique. *Human Resources for Health* 11: 26.

Nachega, Jean B., Michael Hislop, David W. Dowdy, et al.

2006 Adherence to Highly Active Antiretroviral Therapy Assessed by Pharmacy Claims Predicts Survival in HIV-Infected South African Adults. *Journal of Acquired Immune Deficiency Syndromes* (1999) 43(1): 78–84.

Naroll, Raoul

1962 Data Quality Control-A New Research Technique. *Prolegomena to a Cross- Cultural Study of Culture Stress*. New York: Free Press.

Nattrass, Nicoli

2007 Mortal Combat: AIDS Denialism and the Struggle for Antiretrovirals in South Africa. 1 edition. Scottsville, South Africa: University Of KwaZulu-Natal Press.

Needle, Richard H., Susan L. Coyle, Jacques Normand, Elizabeth Lambert, and Helen Cesari

1998 HIV Prevention with Drug-Using Populations: Current Status and Future Prospects: Introduction and Overview. *Public Health Reports* (1974-) 113: 4–18.

Newell, K. W.

1988 Selective Primary Health Care: The Counter Revolution. *Social Science & Medicine* (1982) 26(9): 903–906.

Nguyen, Vinh-Kim

2007 Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship. *In* Global Assemblages. Aihwa Ong and Stephen J. Collier, eds. Pp. 124–144. Blackwell Publishing Ltd.

2010 The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS. 1 edition. Durham, NC: Duke University Press Books.

Nicolson, Greg

2014 TAC: Funding, Accountability and the Dire Consequences of Closure. *Daily Maverick*, October 3.

Norton, Wynne E, K Rivet Amico, William A Fisher, et al.

2010 Information-Motivation-Behavioral Skills Barriers Associated with Intentional versus Unintentional ARV Non-Adherence Behavior among HIV+ Patients in Clinical Care. *AIDS Care* 22(8): 979–987.

Oakeshott, Michael

1991 On Human Conduct. n Later printing edition. Oxford : Oxford ; New York: Oxford University Press.

OAU, Organization of African Unity

1981 African [Banjul] Charter on Human and Peoples' Rights.
<http://www1.umn.edu/humanrts/instate/z1afchar.htm>, accessed May 8, 2014.

OHCHR, United Nations Office of the High Commissioner for Human Rights

1966 International Covenant on Economic, Social and Cultural Rights.
<http://www.ohchr.org/EN/ProfessionalInterest/Pages/CESCR.aspx>, accessed May 8, 2014.

O'Laughlin, Bridget

2009 Rural Social Security and the Limits of “Associativismo” in Southern Mozambique. *In* . Maputo, Mocambique.

Olsen, Bent Steenberg

2013 Structures of Stigma: Diagonal AIDS Care & Treatment Abandonment in Mozambique. Dissertation, Roskilde University.

Owusu, Maxwell

1978 Ethnography of Africa: The Usefulness of the Useless. *American Anthropologist* 80(2): 310–334.

Panofsky, Aaron

2011 Generating Sociability to Drive Science: Patient Advocacy Organizations and Genetics Research. *Social Studies of Science* 41(1): 31–57.

Parr, Hester, and Joyce Davidson

2009 Mental and Emotional Health. *In* A Companion to Health and Medical Geography. 1 edition. Tim Brown, Sara McLafferty, and Graham Moon, eds. Pp. 258–277. Chichester, West Sussex, U.K. ; Malden, MA: Wiley-Blackwell.

Parry, Charles Dh, Neo K. Morojele, Bronwyn J. Myers, et al.

2014 Efficacy of an Alcohol-Focused Intervention for Improving Adherence to Antiretroviral Therapy

(ART) and HIV Treatment Outcomes - a Randomised Controlled Trial Protocol. *BMC Infectious Diseases* 14: 500.

PBS Newshour

2010 High Costs of HIV Medication Cause “Terrible Dilemma” in Mozambique.
<http://www.pbs.org/newshour>.

Petryna, Adriana

2013 *Life Exposed: Biological Citizens after Chernobyl*. With a New introduction by the author edition. Princeton, NJ: Princeton University Press.

Pfeiffer, James, Wendy Johnson, Meredith Fort, et al.

2008 Strengthening Health Systems in Poor Countries: A Code of Conduct for Nongovernmental Organizations. *American Journal of Public Health* 98(12): 2134–2140.

Pfeiffer, James, Pablo Montoya, Alberto J Baptista, et al.

2010 Integration of HIV/AIDS Services into African Primary Health Care: Lessons Learned for Health System Strengthening in Mozambique - a Case Study. *Journal of the International AIDS Society* 13(1): 3.

Piot, Peter

2000 Global AIDS Epidemic: Time to Turn the Tide. *Science* 288(5474). New Series: 2176–2178.

Pitcher, Anne, Mary H. Moran, and Michael Johnston

2009 Rethinking Patrimonialism and Neopatrimonialism in Africa. *African Studies Review* 52(1): 125–156.

Pitcher, M. Anne

2008 *Transforming Mozambique: The Politics of Privatization, 1975-2000*. 1 edition. Cambridge University Press.

Pope John Paul II

1991 100th Anniversary of *Rerum Novarum: Centesimus Annus* - Encyclical Letter Addressed by the Supreme Pontiff John Paul II to His Venerable Brothers in the Episcopate. London: Catholic Truth Society.

Price, David, Allyson M Pollock, and Jean Shaoul

1999 How the World Trade Organisation Is Shaping Domestic Policies in Health Care. *The Lancet* 354(9193): 1889–1892.

Rabinow, Paul

2005 Artificiality and Enlightenment: From Sociobiology to Biosociality. *In Anthropologies of Modernity*. Jonathan Xavier Inda, ed. Pp. 179–193. Blackwell Publishing Ltd.
<http://onlinelibrary.wiley.com/doi/10.1002/9780470775875.ch7/summary>, accessed June 3, 2014.

Rabkin, Miriam, and Sania Nishtar

2011 Scaling up Chronic Care Systems: Leveraging HIV Programs to Support Noncommunicable Disease Services. *Journal of Acquired Immune Deficiency Syndromes* (1999) 57 Suppl 2: S87-90.

Rawls, John

2001 *The Law of Peoples: with “The Idea of Public Reason Revisited.”* 1 edition. Harvard University Press.

Ray, Amy L., and Steven R. Gold

1996 Gender Roles, Aggression, and Alcohol Use in Dating Relationships. *The Journal of Sex Research* 33(1): 47–55.

Redfield, Peter

2005 Doctors, Borders, and Life in Crisis. *Cultural Anthropology* 20(3): 328–361.

Reed, Joel

2005 Hiv/aids Workplace Interventions in South Africa and the United States. Graduate Theses and Dissertations. <http://scholarcommons.usf.edu/etd/831>.

República de Moçambique

2009 Direitos E Deveres Da Pessoa Vivendo Com HIV E SIDA.

Roberts, Sandra

2008 Normative Functions of HIV/AIDS Support Groups. *South African Review of Sociology* 39(1): 83–97.

Robins, Steven

2004 “Long Live Zackie, Long Live”: AIDS Activism, Science and Citizenship after Apartheid. *Journal of Southern African Studies* 30(3): 651–672.

2006 From “Rights” to “Ritual”: AIDS Activism in South Africa. *American Anthropologist* 108(2): 312–323.

Robins, Steven L.

2010 From Revolution to Rights in South Africa. Reprint edition. BOYE6.

Rose, Nikolas, and Carlos Novas

2005 Biological Citizenship. *In* *Global Assemblages*. Aihwa Ong and Stephen J. Collier, eds. Pp. 439–463. Blackwell Publishing Ltd.

<http://onlinelibrary.wiley.com/doi/10.1002/9780470696569.ch23/summary>, accessed May 15, 2014.

Rosen, Michael

2012 Dignity: Its History and Meaning. Cambridge, Mass: Harvard University Press.

Rucht, Dieter

1996 The Impact of National Contexts on Social Movement Structures: A Cross-Movement and Cross-National Comparison. *In* *Comparative Perspectives on Social Movements: Political Opportunities, Mobilizing Structures, and Cultural Framings* Pp. 185–201. Cambridge University Press.

Sabatier, Tade Aina, Jon Tinker Renee

1987 Blaming Others: Racial and Ethnic Aspects of AIDS. London; Chicago: Panos Publications Ltd.

Santos, Boaventura de Sousa

2005 Beyond Neoliberal Governance: The World Social Forum as Subaltern Cosmopolitan Politics and Legality. *In* *Law and Globalization from Below: Towards a Cosmopolitan Legality*. Boaventura de Sousa Santos and César A. Rodríguez-Garavito, eds. Pp. 29–63. Cambridge, UK ; New York: Cambridge University Press.

Savanah

2008 Garrido Denies Ordering Closure of Day Hospitals, March 28.
<http://www.clubofmozambique.com/solutions1/sectionnews.php?id=11286&tipo=one>.

Scheper-Hughes, Nancy

1993 *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley, Calif.: University of California Press.

Schneider, Helen, Duane Blaauw, Lucy Gilson, Nzapfurundi Chabikuli, and Jane Goudge

2006 Health Systems and Access to Antiretroviral Drugs for HIV in Southern Africa: Service Delivery and Human Resources Challenges. *Reproductive Health Matters* 14(27): 12–23.

Sekhri, Neelam

2006 *From Funding to Action: Strengthening Healthcare Systems in Sub-Saharan Africa*. White Paper. Becton, Dickinson, and Company.

Shilts, Randy

1987 *And The Band Played on: Politics, People, and the AIDS Epidemic*. Macmillan.

Sigaloff, Kim C. E., Joep M. A. Lange, and Julio Montaner

2014 Global Response to HIV: Treatment as Prevention, or Treatment for Treatment? *Clinical Infectious Diseases* 59: S7–S11.

Simoni, Jane M, Ann E Kurth, Cynthia R Pearson, et al.

2006 Self-Report Measures of Antiretroviral Therapy Adherence: A Review with Recommendations for HIV Research and Clinical Management. *AIDS and Behavior* 10(3): 227–245.

Singer, Peter

2002 *One World: The Ethics of Globalization*. Yale University Press.

Smith, Raymond

2013 Can There Be a Fourth Great Wave of AIDS Activism? *The Huffington Post*.
http://www.huffingtonpost.com/raymond-a-smith-phd/can-there-be-a-fourth-great-wave-of-aids-activism_b_4171233.html, accessed February 7, 2016.

Soeters, Robert, Peter Bob Peerenboom, Pacifique Mushagalusa, and Célestin Kimanuka

2011 Performance-Based Financing Experiment Improved Health Care In The Democratic Republic Of Congo. *Health Affairs* 30(8): 1518–1527.

Sontag, Deborah

1997 Doctors Withhold HIV Pill Regimen From Some. *New York Times*, March 2.

Sontag, Susan

1989 *Aids and Its Metaphors*. 2nd edition. *New York Review of Books*.

Staal, Frits

1979 The Meaninglessness of Ritual. *Numen* 26(1): 2–22.

Steffen, Vibeke

2005 *Managing Uncertainty: Ethnographic Studies of Illness, Risk and the Struggle for Control*. Museum Tusculanum Press.

Suarez, Ray

2010 Mozambique's Health Care Struggles Put Need for Basics Back in Focus. PBS NewsHour, October 22. <http://www.pbs.org/newshour/rundown/mozambiques-health-system-a-maze-of-need/>, accessed January 19, 2016.

Sumich, Jason

2008 Politics after the Time of Hunger in Mozambique: A Critique of Neo-Patrimonial Interpretation of African Elites. *Journal of Southern African Studies* 34(1): 111–125.

2013 Tenuous Belonging: Citizenship and Democracy in Mozambique. *Social Analysis* 57(2): 99–116.

Sundell, Knut, and Lars Wärngård

2013 How Do Government Agencies Use Evidence? Stockholm, Sweden: National Board of Health and Welfare.

Susser, Ida

2009 AIDS, Sex, and Culture: Global Politics and Survival in Southern Africa. 1 edition. Chichester, West Sussex, U.K. ; Malden, MA: Wiley-Blackwell.

Tarrow, Sydney

1994 Power in Movement: Social Movements and Contentious Politics. 3 edition. Cambridge ; New York: Cambridge University Press.

Taussig, Karen-Sue, R. Rapp, and D. Heath

2001 Genealogical Dis-Ease: Where Hereditary Abnormality, Biomedical Explanation and Family Responsibility Meet. *In* . [http://experts.umn.edu/en/publications/genealogical-disease-where-hereditary-abnormality-biomedical-explanation-and-family-responsibility-meet\(9fa0a5a4-e5ad-49e4-a569-093384ff2de6\).html](http://experts.umn.edu/en/publications/genealogical-disease-where-hereditary-abnormality-biomedical-explanation-and-family-responsibility-meet(9fa0a5a4-e5ad-49e4-a569-093384ff2de6).html), accessed December 1, 2015.

Trostle, J. A.

1988 Medical Compliance as an Ideology. *Social Science & Medicine* (1982) 27(12): 1299–1308.

Tusale, Rollin F.

2007 A Boon or a Bane? The Role of Civil Society in Third- and Fourth-Wave Democracies. *International Political Science Review / Revue Internationale de Science Politique* 28(3): 361–386.

UNAIDS

2012 Treatment 2015. Geneva, Switzerland.

http://www.unaids.org/sites/default/files/media_asset/JC2484_treatment-2015_en_1.pdf.

2013 Access to Antiretroviral Therapy in Africa: Status on Report Progress Towards the 2015 Targets.

Valverde, Mariana, and Kimberley White-Mair

1999 "One Day at a Time" and Other Slogans for Everyday Life: The Ethical Practices of Alcoholics Anonymous. *Sociology* 33(2): 393–410.

Van Damme, Wim, and Guy Kegels

2006 Health System Strengthening and Scaling up Antiretroviral Therapy: The Need for Context-Specific Delivery Models: Comment on Schneider et Al. *Reproductive Health Matters* 14(27): 24–26.

Verdade

2009 Hospitais Dia Não Tem Lugar No Ordenamento Nacional, August 5.

<http://www.verdade.co.mz/saude-e-bem-estar/4269-hospitais-dia-nao-tem-lugar-no-ordenamento-nacional>.

Wallace, R.

1990 Urban Desertification, Public Health and Public Order: “Planned Shrinkage”, Violent Death, Substance Abuse and AIDS in the Bronx. *Social Science & Medicine* (1982) 31(7): 801–813.

Walsh, J. A., and K. S. Warren

1979 Selective Primary Health Care: An Interim Strategy for Disease Control in Developing Countries. *The New England Journal of Medicine* 301(18): 967–974.

Walton, David A., Paul E. Farmer, Wesler Lambert, et al.

2004 Integrated HIV Prevention and Care Strengthens Primary Health Care: Lessons from Rural Haiti. *Journal of Public Health Policy* 25(2): 137–158.

Wamba, Lucrecia Jose, and Tiwonge Towera Loga

2008 Southern African AIDS Trust (SAT) Commitment for a Coordinated Response to HIV and AIDS in Southern Africa: The Implementation of the “Three Ones.” *Canadian Journal of Public Health / Revue Canadienne de Sante’e Publique* 99: S11–S15.

Wardman, Anna

1985 The Co-Operative Movement in Chokwe, Mozambique. *Journal of Southern African Studies* 11(2): 295–304.

Ware, Norma C, John Idoko, Sylvia Kaaya, et al.

2009 Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study. *PLoS Med* 6(1): e1000011.

Wehling, Peter

2011 The “technoscientization” of Medicine and Its Limits: Technoscientific Identities, Biosocialities, and Rare Disease Patient Organizations. *Poiesis Prax* 8: 67–82.

West, Harry

2008 Govern Yourselves”: Democracy and Carnage in Northern Mozambique. *In Towards an Anthropology of Knowledge*. Santa Fe: School of Advanced Research.

W.H.O.

2007 Everybody’s Business: Strengthening Health Systems to Improve Health Outcomes: WHO’s Framework for Action. Geneva, Switzerland: World Health Organization.

W.H.O., World Health Organization

1948 The Universal Declaration of Human Rights. <http://www.un.org/en/documents/udhr/>, accessed May 8, 2014.

2009 Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector. <http://www.who.int/hiv/pub/2009progressreport/en/>, accessed June 7, 2015.

2013 Global Update on HIV Treatment 2013: Results, Impact and Opportunities. <http://www.who.int/hiv/pub/progressreports/update2013/en/>, accessed April 25, 2014.

2014 Global Status Report on Alcohol and Health 2014. Geneva, Switzerland.

Whyte, Susan Reynolds, Sjaak van der Geest, and Anita Hardon

2003 *Social Lives of Medicines*. 1 edition. Cambridge, UK ; New York: Cambridge University Press.

Wilton, Robert, and Geoffrey Deverteuil

2006 Spaces of Sobriety/sites of Power: Examining Social Model Alcohol Recovery Programs as Therapeutic Landscapes. *Social Science & Medicine* (1982) 63(3): 649–661.

World Bank

1992 Governance and Development. 10650. The World Bank.

<http://documents.worldbank.org/curated/en/1992/04/440582/governance-development>, accessed June 24, 2015.

World Health Organization

2000 The Kaya Kwanga Commitment.

http://www.who.int/countries/moz/publications/kaya_kwanga/en/, accessed January 16, 2016.

2007 Everybody's Business: Strengthening Health Systems to Improve Health Outcomes. WHO's Framework for Action. Geneva, Switzerland.

Zulu, W.

1993 "Positive and Living" in Zambia. *AIDS Action*(21): 8.