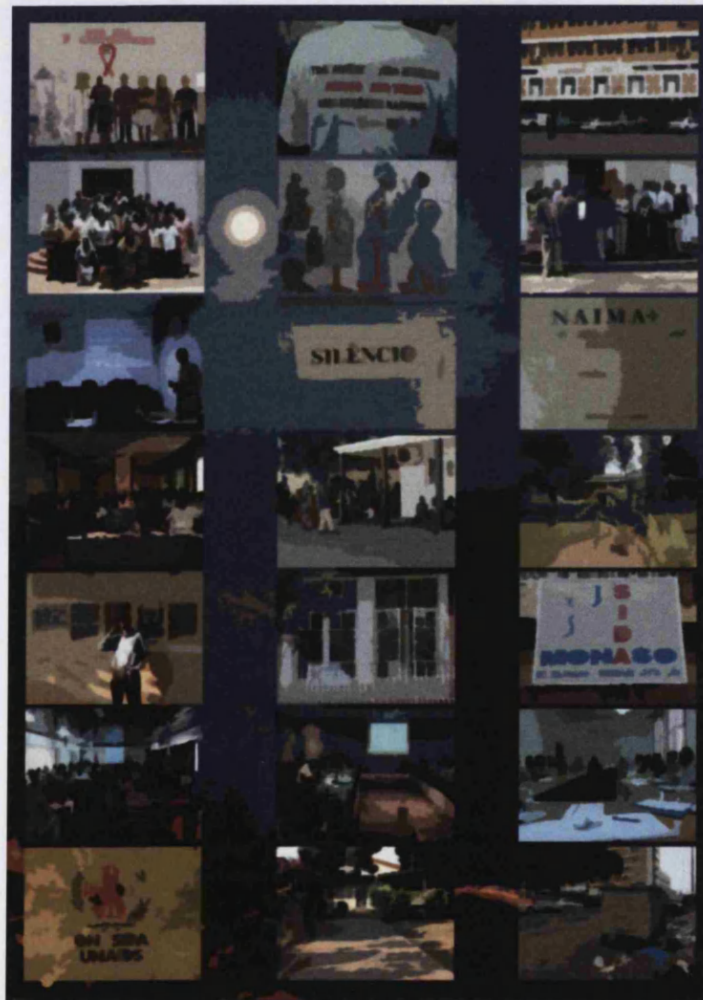The London School of Economics and Political Science

The Process

Experiences, Limitations, and Politics of ARV Treatment in Mozambique

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MPhil Anthropology, MA Human Rights & Democratisation

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Declaration

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Erling Høg

Abstract

I argue in this thesis that successful access and delivery of antiretroviral treatment essentially depends on the interrelatedness between individual, social, and political processes. It takes the case of Mozambique, a hard-hit poor country in Southern Africa, which offers free ARVs on a 'first come first served' basis, supported by all major international donors. The HIV epidemic will be analyzed in a time perspective to show this interrelated process. This entails a move between experience and politics using classical anthropological perspectives on power, politics, social order, taboo, rites of passage, risk environment, and structural, symbolic, cultural, social, and everyday violence. Life story interviews, ethnographic interviews, participant observation, and focus groups are key methods that lead the descriptive and analytical narrative of this particular landscape, which was pieced together by multi-site fieldwork in Maputo City, where all major government, international community, civil society, and treatment implementing actors reside. The outcome is unique and detailed accounts of the reality of ARV rollout in Mozambique, which relates experience living with ARVs, epidemiology, consequences living without ARVs, health worker experience delivering ARVs, health system capacity, advocacy, history, and politics of ARVs, health care, and nation-building. This will show how the individual level of access relates to the macro level of the political struggle for independence and sovereignty, intertwined by ever-changing social constraints that feed on the delicate (im)balance between experience and politics. The study thus deviates from classical adherence, stigma, civil society, and governance studies, which tend to focus exclusively on the patient, society, or political institutions. Such micro-macro anthropology invariably recognizes two sides of the coin: success and failure, which is a constant struggle between the state of endemic socio-structural crisis and (dis)order, political leadership, and international solidarity, against the creeping and concrete reality of normalization of life and death.

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I owe a great debt of gratitude to many people at the Institute of International Health, Immunology and Microbiology at the University of Copenhagen. I first thank the late Anita Rønn, who initially supported my research as co-supervisor, but who left us prematurely due to severe illness. I thank Lene Blegvad, Ib Bygbjerg, Flemming Konradsen, Helle Samuelsen, Peter Kjær Jensen, Britt Tersbøl, Vibeke Rasch, Birgitte Gantriis, Marianne Dithmer, and Hanne Ingvorsen, with all of whom I have engaged in fantastic teamwork since 2002, as I have been involved in the following projects: the Danish Research Network for International Health, ENRECAHEALTH, Centre for International Health and Development, CISU, Master in International Health, MIH, Master of Disaster Management, MDMa, and the Graduate School of International Health. I thank in particular the head of the research unit for international health Thor Theander for supporting my research. Poul Birch Eriksen has always been there with his discrete and deep voice giving sharp comments from a journalist perspective.

Five anthropologists keep inspiring me above all: Mary Douglas, Nancy Scheper-Hughes, Tony Barnett, Susan Reynolds Whyte, and Paul Farmer. Your writings have stayed with me throughout my university years at the University of Florida, University of Copenhagen, University of Padua, University of Coimbra, and the London School of Economics and Political Science. The issues you address, your frankness, intellectual width, and your constant reminders of our responsibilities as public intellectuals and applied anthropologists, have always kept me alert and attentive to the importance of academic life. You have a way with letters and the world like few others.

I thank all people living with ARVs, health workers, policy makers, administrators, advocates, and government staff who spent time with me in Mozambique.

It would be impossible to mention all and possibly an infringement of research ethics revealing your identities, which throughout this thesis have been concealed by the change of name and location. However, I decided to make this story as real as possible by paying attention to minute detail, which preserves authenticity. The personalities presented here in detail have given explicit consent, as they consider it of utmost importance to pass on their life stories beyond their own experience.

However, warm souls opened their professional and private doors to me, without which I would never have enjoyed the level of access to the field as I did. I think in particular of Telva Barros and Ana David, but I also think of Ivo, Gilda, Gaspar, Armando John, Ana, Sansão, Thomas, Américo, Irene, César, Arlindo, Quetelo, Carlos, Atalia, Yassine, Francisco, Florindo, Sousa, David, Joana, Bina, Chiara, Tcheizy, Eva, Katharina, and everyone not mentioned here. This is a greeting of friendship. I will always remember your hospitality and kind ways. I met many people throughout the process, as you will see in the pages to come. You taught me most of what is here. Finally, thanks to Ippolytos Kalofonos and Ramah McKay, field compadres working on similar issues. I hope we will collaborate in the future.

I dedicate this thesis to all brothers and sisters.

Erling Høg

London

24 September 2008

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Tables

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Hosi yamukela kesosi	Deus receba agora	God receive now
Si konsoto swahina	As nossas orações	Our prayers
Hi konsotela amavabyi	Oramos contra a doença	We pray against the disease
Mavabyi ha SIDA	A doença do SIDA	The AIDS disease

Hi li ho ho	*Hi li ho ho choramos*	*Hi li ho ho we are crying*
Who dzila	*Estamos a chorar*	*We are crying*
Hi wulela kuwene	*Glorificamos a ti*	*We bless you*
Hidzilele wene yehova	*Choremos a ti Deus*	*We cry for you God*
Xikwembu xa hina	*Deus nosso Pai*	*God our Father*

Tatana wa hina infuissa	Pai nosso nos oiçam	Our Father listen to us
Swikonfoto swahina	As nossas orações	Our prayers
Reisava hikwaio yadzila	Todo o mundo está a chorar	The whole world is crying
Hi mavabyi ha SIDA	Por esta doença do SIDA	Because of this AIDS disease

Hi phune Tatane hi phune	Ajuda Pai ajuda	Help us Father, help us
Xikwembu xa hina	Deus nosso	Our God
Hi luele Tatane hi lueli	Ajuda a lutar Deus	God, help us to fight
Xikwembu xa hina	Deus nosso	Our God

Movimento das Mães Intercessoras
The Intervening Mothers' Movement

As I was walking down Avenida Cahora Bassa for the first time, I noticed scribbled writing on the surrounding wall of the military area, housing the Military Hospital and its public ARV Day Hospital. Old dark, blackish letters on the crumbling wall under the relentless mid-day sun spelled the heroic motto: 'Defender a Pátria, Vencer o Desenvolvimento, Construir o Socialismo'. A few days later, as I passed by again, four soldiers were whitewashing the barrier. More correctly, one soldier was handling the brush, three were watching. He persistently and diligently covered the wall in white. Every letter received meticulous attention to guarantee it would vanish for good. I figured this was the day of reckoning, leaving behind the past, facing the present, despite the many signs and symbols in the public sphere indicating the opposite. The third time I passed by, I saw a shiny white wall, reinforced by the bright sunlight, yet standing in sharp contrast to the dusty road, the ubiquitous garbage lying around, and the skinny neglected dogs constantly barking, walking in stooping humility. Nevertheless, it was deceptive Fata Morgana. The closer I got, the stronger the inoculating impression. The telling mantra stood out clear in the massiveness of whiteness, my face dripping with sweat: 'Defend your Homeland, Conquer Development, Construct Socialism'. I gazed intensively for an eternity, contemplating the profundity of the Mozambican diction. From then on, I began to understand the process.

<div align="right">Erling Høg</div>

Introduction

Introduction

'People Living With ARVs' show gratitude. Gilberto says: *"Doctors are doing a great job"* and Lídia says: *"I have 200 percent confidence in ARVs"*. 'People Living Without ARVs' say in disappointment: 'they are slow' and 'the hospitals are full'. However, most people do not seek health care and Anísia says: *"I can't tell you who they are."* Epidemiologists annually adjust 'best estimates', which leaves us to contemplate the chain reaction from prevalence and absolute numbers to treatment needs, ARV targets, and ARV coverage. In everyday hospital life, Anabella, a physician, invokes the allegory of a dam: *"I compare this to a huge dam, which is about to explode."* The government continues its commitment to provide access to health care for all Mozambican citizens, as envisioned at independence in 1975. Benedito, the ARV Committee, says: *"We are available to treat everyone... but the big problem today is qualified human resources."* Alfredo Mac-Arthur, the National AIDS Programme Director, says: *"We don't have the health system capacity to inform the general public about treatment."* Paulo Ivo Garrido, the Minister of Health, says about the need to gain work permission in Mozambique: *"It's a matter of sovereignty. It's about respect for human beings."* At the National AIDS Council, Sergio talks about 'shrimps and lobsters' and 'the moon and the bicycle', with reference to absorptive and absorption capacity, proportions, and context. A treatment campaign emerged within the plethora of AIDS NGOs in 2005, supported by international donors. After two months, a campaigner said: *"We need to move forward, but we are not doing anything."* Then eight months into the campaign, Lucas said: *"It is not going anywhere"* and *"We also need connection to the government."*

The Mozambican government introduced access to free ARV treatment within the public health system in 2004, supported by international donors and treatment implementers. This ethnography describes and analyzes access and delivery barriers with reference to the above circular tour of different perspectives on the introduction of antiretroviral treatment in a poor country within the epicentre of the sub-Saharan HIV epidemic. Why do only few people seek HIV related health care? How does health system capacity influence limited HIV disclosure? What are the key obstacles for people in need of health care? Which health system and political obstacles prevent the government from delivering ARV treatment to all in need? How do individual, social, and political barriers interrelate? Which factors influence health seeking behaviour? How do people experience access to treatment? At the theoretical level, it seeks to understand this threefold individual-social-political process in terms of anthropological perspectives on power, politics, social order, taboo, rites of passage, and how structural, symbolic, cultural, social, and everyday violence constitute a particular risk environment.

Fieldwork

Multi-site fieldwork brought me in contact with people living with ARVs, support groups (Kudumba, Pfukauhana, Tinena), Day Hospital health workers (MSF Switzerland, MSF Luxembourg, Italian Sant'Egidio Community, the Spanish Association for Integrated Health and Human Development, ASIDH, and the International Center for AIDS Care and Treatment Programs, ICAP, University of Columbia), advocacy workers (UNAIDS, Mozambican Network of AIDS Service Organisations,

MONASO, the Mozambican Treatment Access Movement, MATRAM, the patient or-

ganisation Kindlimuka, and the National Network of Associations of People Living

with HIV/AIDS, RENSIDA), health politicians and managers (National STI/HIV/

AIDS Programme, Ministry of Health, National AIDS Council), and donors (World

Bank, Clinton Foundation, World Food Programme) (see Figure 1).
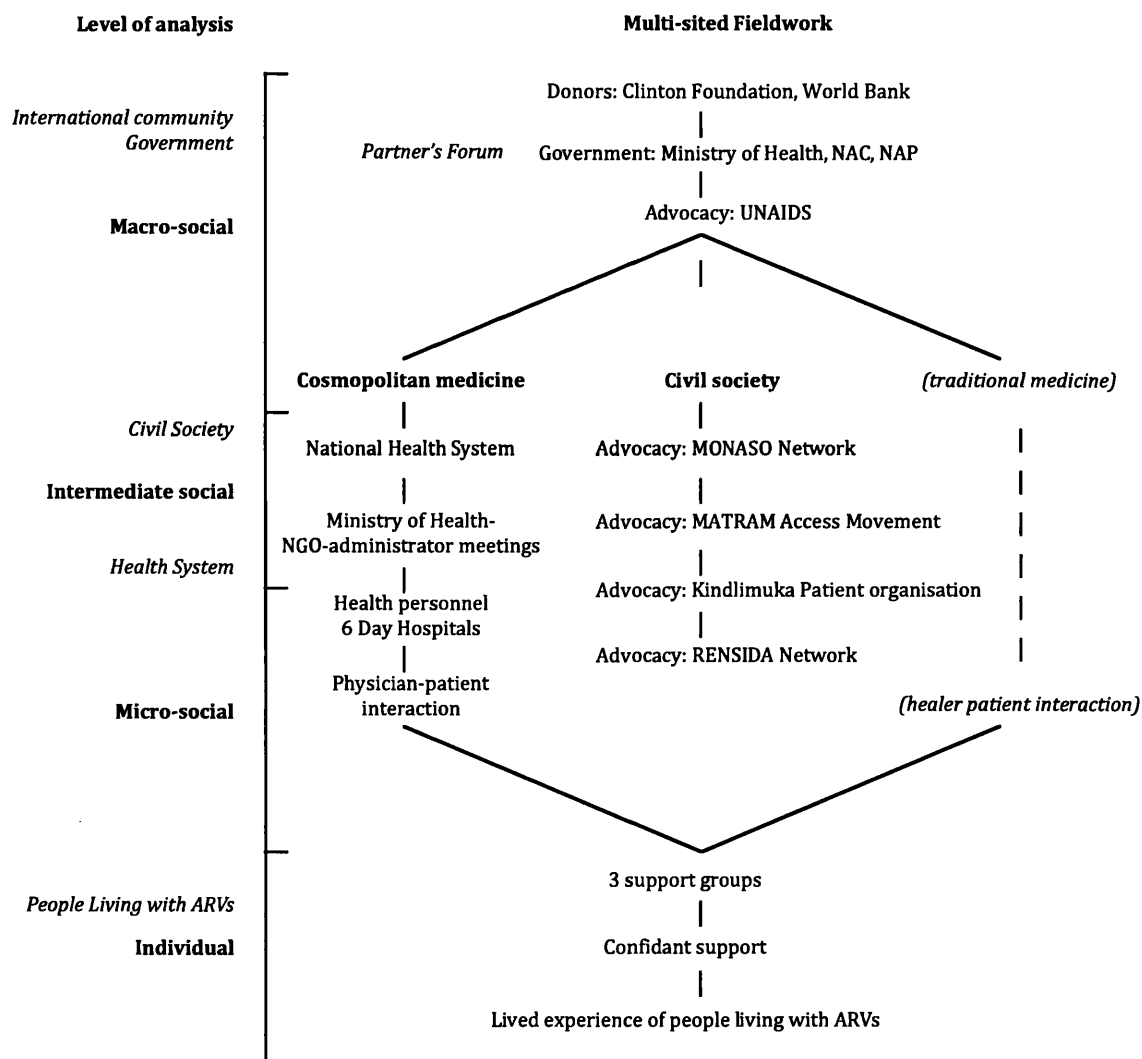
Figure 1: Fieldwork in Health System Perspective
Source: Adapted from (Baer, et al. 2003: 39).

The micro-macro model within the Critical Medical Anthropology paradigm inspir-

ed this (see Figure 2).

Level of analysis   **Social and Biopsychological Relations**

Capitalist world system

|

Corporate and state actors

|

Plural medical systems

Macro-social

Cosmopolitan medicine   Heterodox/ethno/religious medical systems

|

Health institution policy/decision-making

|

Administration-health personnel interactions

Intermediate social

|

Interactions among health personnel

|

Physician-patient interaction   Healer-patient interaction

Micro-social

Patient's personal support network

|

Patient's experiential response to illness

Individual

|

Human psychobiological system

Figure 2: Levels of Health Care Systems
Source: (Baer, et al. 2003: 39).

Critical Medical Anthropology merges theory and social action through processes and interactions between micro and macro levels of social organisation (Baer, et al. 2003; Singer 1998; Singer and Baer 1995). The relevance of such paradigm lies in its emphasis on the political economy of health, critical theory, and Marxist emphasis on power and politics. In particular, the 'three bodies' analytical framework (Scheper-Hughes and Lock 1987) triangulates the individual, the social and the political bodies. In this way, the framework merges phenomenology, symbolic, structural, and post-structural anthropology.

I emphasize the similarities and differences between ethnographic modes of inquiry to qualify the choice of multiple field sites. For the purposes here, micro-macro fieldwork appeals to multi-site ethnography (Marcus 1998), a vertical slice (Nader 1972; Nader 1980), a multilevel perspective (van der Geest, et al. 1990), and transnational power relations (Ferguson 2006; Ferguson and Gupta 2002).

Marcus reminds us that multi-site ethnography involves the entire research process, both in the field when we collect and produce data, and at the desk, when we analyze them and write up our findings. Field sites constitute a horizontal space in which no particular site is given preference or taken as a starting point, which is often the case in studies that take a 'view from below'. Multi-site ethnography thereby differs from Nader's vertical slice, which has become synonymous with 'studying up': this bottom-up approach takes the individual level exposed to systemic domination as the locus of inquiry, which could also be interpreted from the above model (Baer, et al. 2003: 39) (see Figure 2).

Multilevel anthropology was developed during the 1980s to articulate the study of micro-macro level sociocultural phenomena to examine their potential linkages (DeWalt and Pelto 1985). On the other hand, multi-site ethnography grew out of dissatisfaction with traditional anthropological fieldwork limited to the community level, which produces 'partial knowledge' (Marcus 1998). In both cases, such micro-macro perspectives examine how local levels affect and are affected by social, political, and economic processes at the national, international, and global levels, which resonates the call to examine transnational topographies of power relations between state and civil society (Ferguson 2006) and transnational governmentality (Ferguson and Gupta 2002). However, while the multilevel perspective is a reaction against one-sided and one-dimensional research focused on ei-

ther the micro-social (village community) or macro-social (state), towards a 'link-ages perspective' (van der Geest, et al. 1990: 1026), multi-site ethnography readily looks at what is ethnographically 'in the picture' (Marcus 1998: 85). The differences between the vertical slice, the multilevel perspective, multi-site ethnography, and the transnational power relations may appear subtle, but all five approaches require mobile positioning and they challenge the traditional location of the ethnographer among the poor and powerless. This is my intention and I draw inspiration from all five methodological approaches with the small caveats discussed here in mind.

I keep a cumulative focus on 'ART access and delivery' by looking at the experience living with ARVs, the implications living without them through qualitative assessment of epidemiological data, a review of social science HIV studies, experience delivering ARVs, the politics of health and ARVs, treatment advocacy, and the socioeconomic circumstances under which all this occurs. Only one place in Mozambique makes such multi-site fieldwork possible: Maputo City (see Figure 3).[1]

I stayed in the 'HIV community' in Maputo city for the entire 15 months of fieldwork. They called me 'the butterfly researcher' who moves swiftly between the different actors. This proved convenient within a working culture where all meetings and events happen by last minute invitation and it indeed required mobile positioning. I was soon known by all HIV community members, accepted and welcomed, and often greeted with empathy as the 'researcher friend'. Nevertheless, I emphasize an important point: I was one of the very few who had the privilege to be able to move swiftly between actors and organisations. This is not the reality on the ground among people who work and live with HIV.
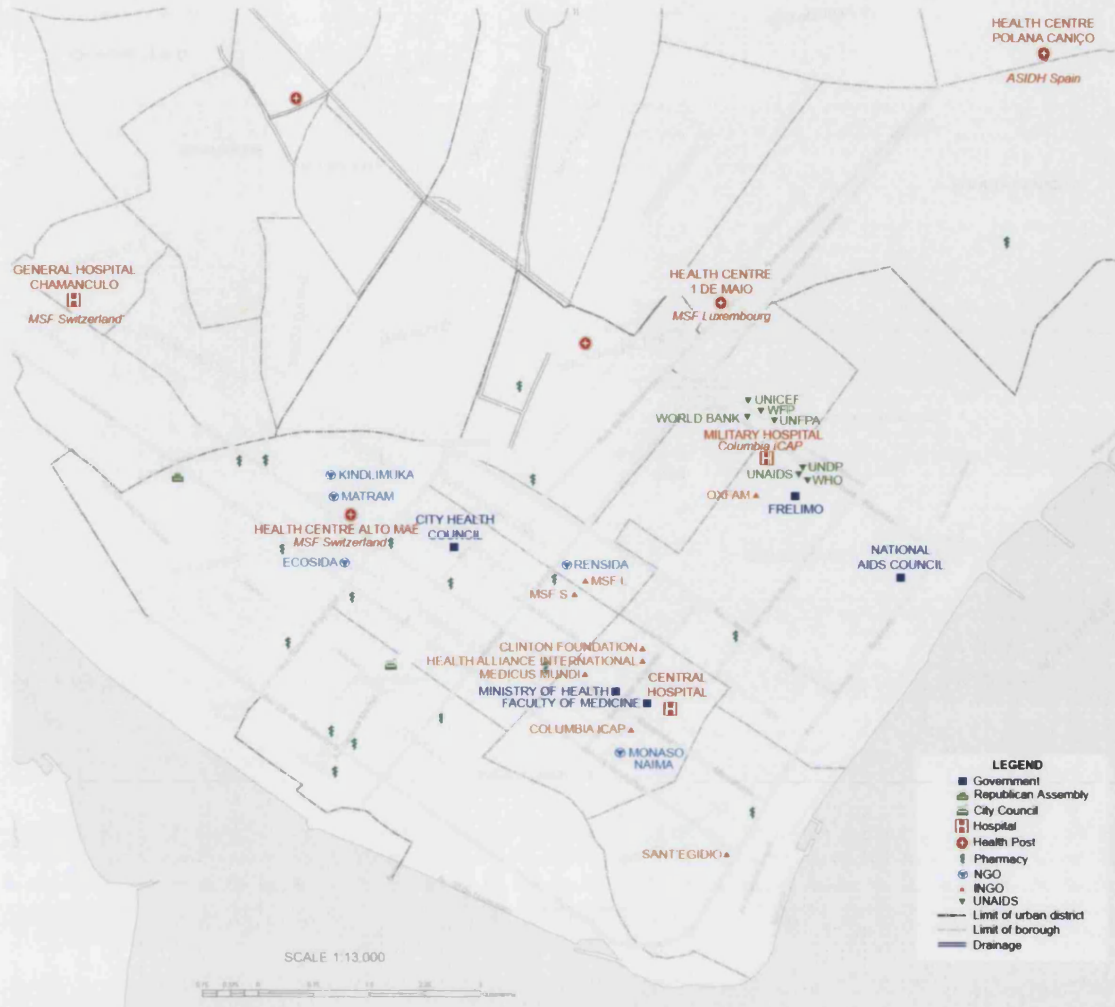
Figure 3: Multi-site Fieldwork, Maputo City, 2005-2006
Source: Fieldwork.

The 'linkages perspective' (van der Geest, et al. 1990) in my experience soon became a 'gaps and linkages perspective'. Despite the close proximity of actors (see Figure 3), many people admitted that they continue to work in isolation, despite the circulating principles of 'partnerships' and 'multi-sectorial approaches'. This will become evident from reading about the reality of the different implementing treatment organisations supporting the Mozambican health system.

Access and Delivery Channels

The delivery locus necessitates a description of *how* the government manages to deliver ARVs and the chosen *ARV model.* I focus on the medico-cultural *Mozambican model,* which differs from the *public health model* applied in Malawi (Harries, et al. 2006) and the *mandatory testing model* applied in Botswana (Weiser, et al. 2006). Sant'Egidio and MSF Luxembourg were the first treatment organisations that provided small scale ARV treatment from 2001 onwards. MSF Switzerland came in 2003. The Mozambican government started a harmonization process in 2004 to integrate free ARV treatment into one unique public health system, supported by the international community. This was made possible by an ambitious treatment plan initially supported by the Clinton Foundation and Health Alliance International, and later by the Global Fund, the World Bank, and PEPFAR. The Mozambican model was established on this basis. The Ministry of Health leads this process, except for the Military Hospital services under the Ministry of Defence. Major supporting treatment providers include Health Alliance International, HAI, the International Center for AIDS Care and Treatment Programs, ICAP, MSF Luxembourg, MSF Switzerland, the Sant'Egidio Community, and the Association for Integrated Health and Human Development, ASIDH.

Access studies have different focuses, decided by sex, age, comprehensiveness, and the service or commodity in demand. Human beings of all ages and both sexes need access to treatment of HIV related diseases: the unborn, children, adolescents, adults, and the elderly. The idea of 'access to comprehensive treatment' has emerged along 'universal access', yet both remain ill defined and contested. Access to ARV treatment cannot be seen in isolation from broader issues of access

to health care, access to information, access to education, and access to food and water, all subsumed under the right to health. Additionally, the access locus necessitates a description of *how* people gain access to ARV treatment and related services and how these modes of access have changed over time. This approach has been applied in a few anthropological studies, for example in Uganda (Whyte, et al. 2004) and Senegal (Egrot, et al. 2004). Such studies reveal layers of social injustice through *unequal* access to medicines.

I have uncovered seven access channels in Mozambique: Mozambican private pharmacies, the South African health system, social triage, the Mozambican public health system, preferential treatment of pregnant women and health workers, health insurance, and corruption. First, social triage may determine access to ARVs. Those who have the means and connections purchase the drugs in private pharmacies in Mozambique and through the South African health system, particularly in the city of Nelspruit. Mozambicans are less concerned about stigma and discrimination in a South African clinic, and they benefit from the fact that many Portuguese doctors who left Mozambique at independence practice there. That is, patients and doctors can communicate in Portuguese. However, those who can afford it go to South Africa for any kind of health care. Many Mozambicans unabashedly say that health care is much better in South Africa than in Mozambique. Mozambicans experience long waiting lists and hours, low quality service, and an unclean environment.

Only the privileged few Mozambicans gained access to treatment before the introduction of free ARVs through the public health system. Members of the upper middle class employed in private companies and public functionaries in the state apparatus used private health care in Mozambique and the South African health

system. Mozambican anthropologist Cristiano Matsinhe raises issues of an exclusive selection process under circumstances of scarce goods, and the reproduction of differences with a view to the history of Mozambique. In times of economic crises, the socialist regime introduced 'governors' shops' and 'co-operators' shops', in which the powerful kept exclusive access to food and other daily goods, as opposed to the 'masses', who struggled to gain access to the scarce or non-existent goods in 'peoples' co-operatives' (Matsinhe 2005). Socially structured hierarchies have been maintained during the introduction of ARV treatment, but interestingly, the government did not deny such division. The government arguably took its measures as part of a natural process of differential treatment along the lines of culturally inbuilt perceptions of entitlement, class, and ethnicity.

However, the role of private clinics and pharmacies changed upon the introduction of free ARV treatment in the public health system in 2004. First, the private sector is not obliged to provide information about ARV treatment to the government. Therefore, state ARV statistics do not include the private sector. However, I talked to a few pharmacists in Maputo about the availability and sales of ARVs over the counter to get an idea of their market share: ARVs are no longer in demand. They refer the few pharmacy customers to the public health system. At the same time, pharmacies keep selling many drugs against opportunistic infections, as they are not universally available in the public health system. A Day Hospital may herald the principle of free drugs for all HIV related diseases, but such medicines are often out of stock. Nonetheless, one pharmacist claimed that private health care offers higher quality treatment, both in terms of medicine and service. This pharmacist did not think highly of generic drugs and the 'low quality services in the public hospitals.' However, this is of course professional jealousy.

The third channel is the subtle kind of social triage by which access to treatment may only be a phone call away. Many private companies have set up HIV services for their employees, but they do not have government permission to create their own private ARV sites. Good connections may facilitate employees in need of ARVs to jump the waiting list to get immediate health service. This is covert preferential treatment given to company employees.

The fourth access channel is through the public health system, governed by the 'first come first served' principle. Treatment is free. The Mozambican government has managed to increase ART coverage from 4,000 adults and 1,700 children in 2004 to more than 88,000 adults and more than 6,000 children by the end of 2007 (Ministry of Health 2008a; Ministry of Health 2008c). Indeed, international partner organisations delivered 96 percent of the ARVs by February 2006 (Marsh 2006), but this delivery is based on government priorities to integrate ARV provision within one unique Mozambican public health system. This harmonization process is part of the Mozambican model.

The fifth access channel is through globally accepted preferential treatment of pregnant women and health workers. In Chapter 2, I discuss some of the ethical issues related to the policy to ensure HIV free babies with no guarantee of ARV treatment for the mothers when they need it. Health workers have become the second politically correct target for ARV treatment. This policy choice maintains their utilitarian value in society. Other targets, like teachers or police officers, remain controversial in times of the 'access for all' rhetoric.

The sixth access channel is through private health care in or out of Mozambique sponsored by medical health insurance, which may include family coverage. Employees in international organisations mainly benefit from this.

Corruption creates the seventh access channel. A USAID corruption report claims that substantial amounts of drugs and supplies are diverted, stolen, and resold in Mozambique (USAID 2006). Corrupt souls use public facilities for private gain. Health workers charge patients for services that are free. Drugs go missing and remain unaccounted for at all types of pharmacies. The lack of control mechanisms, including recording and tracking systems may explain this (ibid.) However, we need evidence for the specific corrupt behaviour related to antiretrovirals. This could be a black box access channel.

Further research into this would 'follow the drugs' by applying biographical approaches to medical commodities (Appadurai 1986; Whyte, et al. 2002), combined with multi-site modes of construction (Marcus 1998) in order to follow their trajectories. This would entail fieldwork that follows ARV drugs from production to consumption. Where were the drugs produced? How were they manufactured, imported, and exported? What is the time span between production and consumption? Do drugs disappear? Where, how, how many, why, and by whom? Are free drugs resold on the market? Which markets?

Access and Delivery Barriers

This study 'follows the people': People Living With ARVs, People Living Without ARVs, biomedical health workers, policy makers, politicians, treatment activists and advocates. The first chapter presents and discusses some of those who have surpassed all barriers and thus benefit from ARV treatment: Gilberto, Edmundo, Alicia, Beatriz, Daniela, Evaristo, Ângela, Marco, Teresinha, Bianca, Odolina, Geisa,

Nisalda, and Fátima. Their life stories reveal the oral history of people living with HIV and point to double meanings of salient topics known in many countries: silence, taboo, sensitization, voice, stigma, and discrimination. The chapter begins with a view from a Day Hospital, Gilberto's life story and support groups, followed by an analysis of individual and shared experience living with ARVs. The analysis of silence, sensitization, and voice shows how the government's past 'AIDS kills' campaign and the weak health system fuel and produce stigma and discrimination at the social and individual levels. In other words, limited access to ARV treatment produces inequality and links to the reproduction of social difference.

Specifically, I will explain enculturated silence aided by anthropological insights from the study of taboo (Douglas 1979; Douglas 1992; Douglas 2002 (1966); Leach 1979), social memory (Connerton 1989), and embodied experience (Fassin 2003; Fassin 2007; Kleinman and Kleinman 1994). The advent of HIV falls within a social order in which few other social issues are challenged and change. Why and how could it be different in the case of HIV? The ARV era provides a case to show how the present links to the past socially, culturally, and ideologically: the challenges of the past manifest in the struggles to overcome treatment access barriers. Finally, the 'three bodies' analytical framework (Scheper-Hughes and Lock 1987) offers the key analytical framework that inspired the development of my own empirically informed access and delivery model exposed in Chapter 3. The 'three bodies' triangulate the individual, social, and political processes.

Chapter 2 provides a qualitative assessment of epidemiological data to answer why the majority of people live *without* ARV treatment. I term this 'epidemiology without faces': the majority in need of ARV treatment remain silent and invisible, and therefore do not come forward to reach out for health care. However, it

would be all too simplistic to blame the victim for this. I think of the therapeutic

process as particular *rites of passage* that hinge on given social and political cir-

cumstances, given the reality of the weak health system capacity. This inspiration

comes from anthropologists Arnold Van Gennep and Victor Turner, who worked

on transitional processes and experience: the silent majority is 'structurally invis-

ible' (Turner 1967: 96; van Gennep 1960 (1908)). They appear as statistical arte-

facts. Mozambique has limited absorption and absorptive capacity to turn 'People

Living Without ARVs' into 'People Living With ARVs' through sensitization and

counselling. Moreover, the epidemiological narrative remains time bound, based

on qualified estimates, yet with little connection to everyday reality. However, this

is part of the argument: the Mozambican model *recognizes* limited absorption and

absorptive capacity. The government argues that it applies a 'gentle, stepwise,

responsible, and pragmatic' approach to expand the availability of ARV treatment

given the socioeconomic, socio-political, and socio-structural circumstances.

An integrated focus on epidemic evolution (Barnett 2006; Barnett and

Whiteside 2006 (2002)), context specific epidemic evolution, and natural disease

history facilitate a qualitative assessment of epidemiology against reality. Towards

this endeavour, I juxtapose prevalence and testing data with treatment needs, tar-

gets and coverage. This leads to a description of the Mozambican model: *o processo

clínico*,[2] initiation and continuation phases, its medico-cultural quality, and the in-

troduction of Mozambican politics of health. The Mozambican government remains

faithful to socialized medicine, which was envisioned at independence in 1975.[3]

Therefore, the government attempts to integrate tertiary curative health

care into primary health care.

Chapter 3 explores the access and delivery model. This model departs from the classical socio-behavioural 'Andersen model', which looks at predisposing, enabling, and need factors, specific to general health seeking behaviour in the United States (Andersen and Newman 1973). This departure seeks to qualify the need to develop a pluralistic health seeking model, specifically adapted to the reality of the unfolding HIV epidemic in a resource-poor setting like Mozambique. I created this model during fieldwork, inspired by the 'three bodies' (Scheper-Hughes and Lock 1987). Marco, Anisia, Saidah, Constança, Isaura, Vítor, Lídia, Fausto, Gilberto, Rosalina, Liliana, Mafalda, and Osvaldo point out the corners of the model. By doing so, I have attempted to look at access to and delivery of ARV treatment from individual, social, and political perspectives to examine how they interrelate.

Two phenomena remain intrinsic among Mozambicans living with HIV: *medo e vergonha*, fear and shame. I relate this analysis to how people talk about limited health system capacity. Mozambicans commonly say with a feeling of resentment: *"estão a demorar"* – *"they are slow."* Delayed access to health care simultaneously reinforces passivity and denial. Major barriers include a 'psychological cocktail of obstacles', which produces silence and secrecy. I analyze these phenomena in wider historical context of social relations, the practice and politics of traditional medicine, poverty, human suffering, colonization, and governance. I term this an 'acknowledgment-denial analysis', which I define as oscillation between the acceptance and rejection of the truth about individual HIV status, which depends on the changing availability of ARV treatment.

Chapter 4 provides a literature review of social science HIV studies in sub-Saharan Africa in general and in Mozambique in particular. I clarify types of studi-

es and qualify the need for anthropological multi-site studies of ARV treatment. I call for studies of access and delivery of ARVs.

Chapter 5 describes the reality of ARV delivery within Day Hospitals and in the communities through home based care. Valter, Clara, and Raisa (nurses), Mafalda (counsellor living with ARVs), Anabella and Duarte (physicians), Guilherme (coordinator), and Miguela (activist living with ARVs) guide us through their everyday experience, complemented by insights into the lives of Rosalina, Paulina, Adelina, Amélia, Rogério, Cláudio, and Patrícia (home based care patients). This is about health worker commitment, vocation, workload and overload, and health system carrying capacity. The need for sufficient health workers has become the most politicized issue since the introduction of ARV in the public health system. Funding was not earmarked 'essential human resources' when 'essential drugs' came into focus. The Mozambican government wants Mozambican health workers to do the job and it strives to decrease reliance on foreign donor aid.

This ties into the politics of development with a view to the government's urge for self-determination. Chapter 6 looks at the Mozambican response to HIV and AIDS within its political history. However, a small caveat: The politics of health analysis excludes issues related to the cost of ARV treatment and politics on an international scale. I focus on the response to the need for ARV treatment in a context of abundant financial resources and generic drugs, when the government introduced ARV treatment in the public health system from 2004 onwards. Neither money nor medicine was a problem at the onset of the Mozambican model.

However, there are significant points to be drawn from the political negotiation over ARV treatment between 2000 and 2004 that support the argument about the impact of HIV on the Mozambican sovereignty process. I analyze four key

themes: a) long-standing commitment to nationalized health care, b) the devastating impact of civil war on the health system, c) dedication to decentralisation without privatisation, and d) NGO competition, internal brain drain and privatisation.

This historical and political perspective explains the government's commitment to national sovereignty. My theoretical take on this relates contradiction, ambivalence, and conflict within political discourse, complemented by governance, human rights, sovereignty and dependency, inspired by Gramscian hegemonic discourse and Foucauldian governmentality (Foucault 1979; Foucault 2000 (1994); Foucault 2008 (1966); Gramsci 1971).

I use historical material and anthropological studies of Mozambican health care and HIV. However, field based material directs the analysis: participant observation and interviews with key people at the Ministry of Health and the National AIDS Council. Benedito (ARV Committee member), Sergio (National AIDS Council), the National STI/HIV/AIDS Programme Director Alfredo Mac-Arthur and Minister of Health Paulo Ivo Garrido lead the way.

This analysis raises an important point in the context of ARV treatment: ARV treatment arrived at a time of political reform and health system transition and it became a political opportunity for this process. This has implications for understanding health care reform, including the expansion of ARV treatment. Thus, the strong emphasis on lack of infrastructure and human resources as the most serious obstacles to ARV provision needs to be seen in the context of Mozambican political history. ARV provision is as much an emergency response to those in need as an opportunity to resurrect the public health care system, which was ruined during the 1980s after a period when the governing political party FRELIMO made important steps towards free and universal primary health care.

To show this, I compare the health development paradigm with the medical relief paradigm with reference to the work of Gorik Ooms (Ooms 2008). This schism shows intrinsic struggles over ownership of the development process. HIV increases government dependency on foreign aid, which adds to the progressive demise of the FRELIMO development agenda. However, the problem cannot be solved without external funding. This creates the basis of a 'culture of contradictions', which helps us to understand 'the process' in terms of nation-building through the urge for self-determination.

I have developed a detailed set of timelines to support this argument: it juxtaposes the evolution of FRELIMO, the war, the health system, HIV and AIDS data, the national response to the epidemic, as well as key civil society and international community events. The lesson is clear: health care is paramount to the identity and politics of the FRELIMO governing party. While lenient and open to negotiation over privatisation in many other areas, FRELIMO stands firm on its politics of social services and health in particular: health care is *the* Mozambican native reserve. Health care is *the* totem that symbolizes the social imagination of a glorious, independent, and sovereign nation state that serves its people. FRELIMO is *the* process. This raises the question how many lives have been sacrificed in the name of nationalized health and the Mozambican ART model, which avoid private health care.

Chapter 7 analyses how advocacy organisations fit into the picture of ARV treatment provision. The Human Rights and Access to AIDS Treatment Campaign 2005-2006 structures this analysis led by advocacy officers: Ângela, Jerónimo, Lucas, and Lúcio. I argue for a division between *intimate, strategic,* and *distant* civil society organisations that determines government recognition and ultimately the allocation of resources. This is about organisational proximity to power.

I apply classical anthropological theory to show this: taboo and classification of the environment (Douglas 2002 (1966); Leach 1979) and silence in relation to ritual performance (Radcliffe-Brown 1979). Other studies focus on vertical relations between civil society and the state: for example Hirschman's analysis of exit, voice and loyalty (Hirschman 1970) and Azarya's analysis of disengagement and incorporation (Azarya 1988; Azarya 1994). Such macro-social studies have paid little attention to horizontal relationships within society and how actors perceive their role in relation to the state. This resonates Marcus' call to look at the 'big picture' (Marcus 1998: 85), but it also recognizes the 'transnational topography of power' (Ferguson 2006: 89ff), which attempts to go beyond the traditional perception of verticality between 'state' and 'civil society'. However, my own approach recognizes how actors in Mozambique have reproduced the common top-down hierarchy ('state-civil society', 'up there-down here'). It takes the myriad of transnational donor-government-civil-society relations into account. This is captured in my argument of the intimate-strategic-distant stratification of civil society, which involves government alignment, donor alignment, and double donor-government alignment. Ethnography of such processes requires sociocultural understanding of stratification, partnerships, and silence. Theories of socio-political order and cultural conduct organize this endeavour.

In Chapter 8, I relate the broader socioeconomic circumstances against the therapeutic, social, and political meanings of what I have termed 'the process'. This analysis integrates a discussion of the circumstances related to human rights education, poverty, basic needs of people *living with or without HIV*, and the sensitization phenomenon. Nuno, Marco and his 8 silent friends, and participants in a workshop on food assistance for people living with ARVs lead us the way.

The government decided to provide free drugs against opportunistic infections and food for the severely ill nationwide in March 2006. I incorporate an analysis of the period between idea and implementation by looking at the lifespan of Global Fund applications and the absorption capacity (ability to digest and consume financial resources) and absorptive capacity (ability to apply and assimilate new knowledge) of Mozambique.

The access and delivery model embraces 'the process' in all three central meanings of the term: individual, social, and political processes. What are the steps and barriers towards access to treatment of HIV related diseases? How can we conceptualize the model and the process in terms of social science theory to advance informed policy choice? To answer this question, I relate the access and delivery model to 'the process' in the therapeutic sense of the term. The Mozambican approach to ARV treatment focuses on individual responsibility and control, less on the need to provide the circumstances for improved livelihood.

I discuss exit, voice, and loyalty (Appadurai 2004; Hirschman 1970) to argue that poor peoples' risk is not organisational membership, but life itself through a downward spiral of destitution, illness and death. This is the structural death living without ARVs. Loyalty through silence is the only option left. This is a consequence of human suffering, deprivation, and structural violence. From here, I draw on anthropological insights on context, development, and food production (Ferguson 1994; Lévi-Strauss 1970; Matsinhe 2005) to connect to the following emphasis on *rites of passage* and the violence perspective.

The therapeutic process constitutes *rites of passage* (Turner 1967; van Gennep 1960 (1908)), which determine who ultimately benefit from treatment. I juxtapose epidemiological individualism (Baldwin 2005; de Waal 2008) and thera-

peutic citizenship (Nguyen 2005) to see the obstacles that people face during the process from testing to living with ARVs. The analytical lens for this combines risk environment (Barnett and Blaikie 1992; Barnett and Whiteside 2006 (2002); Rhodes 2002) and different kinds of violence: structural violence (Farmer 2004; Galtung 1969), symbolic violence (Bourdieu 2000), social violence (Kleinman 2000), cultural violence (Galtung 1990), and everyday violence (Scheper-Hughes 1992; Scheper-Hughes 1996). The violence perspective is one interpretation of the access and delivery model, which points to the dialectic between success and failure as a constant struggle between socio-structural crisis and (dis)order, political leadership, and international solidarity, against the encroaching reality of normalization of life and death.

I discuss four issues in the conclusion: 1) *Uniqueness*: partnerships between the Mozambican government, international donors, and treatment implementers, achievements of the Mozambican ART model, and the introduction of Counselling and Testing for Health, 2) *Policy implications*: how to improve the patient tracking and social support systems, 3) *Future research*: anthropology of life with or without ARVs, and 4) *The Process*: its individual, social, and political meanings.

The therapeutic process relates the individual process (experience of ART), the social process (constraints that feed on the delicate (im)balance between experience and politics), and the political process (sovereignty and the government vision to provide health care for all Mozambicans). Ultimately, the process is about development ownership, but it also points to the question when and whether HIV will convince the world that we need new solutions to respond to the epidemic.

1
Living With ARVs

1: Living With ARVs

"Benfica-Zona Verde, Benfica-Zona Verde" shouts the conductor, standing in the doorway of a *chapa* minibus, casually hanging out, as he waves to the people in the street awaiting their daily means of transportation. We are opposite the Central Hospital crowded with people as usual. We head up Avenida Eduardo Mondlane and pass by the Ministry of Health. After a few minutes, the statue of Eduardo Mondlane becomes visible in the midst of the busy Maputo traffic, standing against the blue sky and a curious mix of hoardings advertising milk, yellow pages, and Coca-Cola. Eduardo Mondlane was the first FRELIMO president until his death in 1969, assassinated by a letter bomb. He would have been sad had he lived to see the reality of the current infectious disease epidemic in Mozambique.

The behaviours of the people who attend the local Day Hospital as they enter and leave the Health Centre are remarkable. Instead of taking the direct way to the Day Hospital behind the Health Centre, many people take a less public shortcut through the Health Centre. Stigma attaches to those who walk directly to the Day Hospital. As someone explained, people will condemningly say: *"It's for those people with AIDS".* On the way out, you see large bins full of ARV cardboard boxes. People living with ARVs try to minimize the visibility of the drugs, before they carry them into the public and private spheres of life. Many carefully scratch off the AIDS ribbon on the ARV plastic container, as it reveals your identity and fuels stigma and discrimination. Ironically, the ribbon was invented for the opposite reason.

I sit inside the ARV dispensary, next to the pharmaceutical assistant who gives out ARVs to people in need. They have all gone through health triage and medical consultation before they come here. Every minute a person knocks on the door with a prescription to receive free medicine for the next 15, 30, or 60 days. Behind us, there is a large stock of ARVs, mainly the triple therapies Triomune 30 and Triomune 40 from Cipla in India. Through the window, you see a beautifully well-kept hospital area with grass, flowers, tropical trees, and consultations organized sequentially. You can hear the birds sing, but also the characteristic and lasting sound of the phlebotomist taking blood samples for CD4 counts, as he hits the arm of the patients with the palm of his hand to make the veins stand out for the needle. People sit in silence with a melancholic sadness awaiting their turn. They are there at different points in their lives with HIV to attend health triage, blood sampling, medical, and psychological consultation, ARV restocking, or ARV counselling.

The pharmaceutical assistant takes notes as she reads the prescription. She asks the patient: *"When do you need to take the medicine?"* The patient replies: *"One in the morning at 8 o'clock and one in the evening at 8 o'clock"*. The assistant replies: *"Here you have ARVs for the next 2 months and a pamphlet to inform you about what to eat and how to remember to take the medicine twice a day. See you next time. Next, please come in."*

The line of people is long. Citizens of Mozambique, young and old, high and low, men and women from all walks of life: migrant workers, security guards, students, drivers, miners, health workers, maids, teachers, police officers, soldiers, farmers, bureaucrats, salespersons, unemployed, and many others. The encounter seems uncomplicated: a short conversation and a transaction of medical supplies for a number of weeks depending on the state of health of the individual.

Gilberto

Gilberto is one of them: a man in his thirties who tells his illness story since the onset of symptoms in 1998. The story represents many of those who have lived with HIV and health problems for many years. The story plot follows treatment seeking behaviour in the pre-ARV era, treatment of other diseases for a long period (mainly malaria and tuberculosis), uncertainty as to the nature of the problem, fear of discrimination testing for HIV, and the complicated ART initiation phase, until they finally gain access to regular ARV treatment – often several years later.

"In 1998 we didn't talk about this problem. We spoke very little about HIV/ AIDS", he recalls, reflecting on how ill he was and on how initially he was unaware what was happening to him. *"I always suffered malaria: constant malaria that never went away."* Gilberto went in and out of the hospital for malaria medication, as the disease periodically worsened and improved. Then in 2000 he suffered from a severe cough, at first seemingly harmless. Gilberto was diagnosed with tuberculosis and he underwent eight months of TB treatment. For two months, he thought he was cured, but then he caught tuberculosis again. The doctor at the local hospital said to him: *"Gilberto, I have to talk to you. Look, this tuberculosis has already been treated".* The clue was to find out why the tuberculosis revisited Gilberto. The doctor told him that such cases would normally indicate HIV, and he recommended Gilberto to take the HIV test. *"I thought a lot about it, because in 2000 we didn't have AIDS treatment in Mozambique."*

The Mozambican health authorities identified the first case of AIDS in 1986. Many years of 'denial', 'ignorance', and blaming 'outsiders', 'others', and 'foreigners' followed. This pattern was seen in many countries. HIV was not recognized as

a major public health problem by the Mozambican government until 2000, when the National AIDS Council was founded. The 2001 HIV surveillance reported 13.6 percent HIV prevalence in the adult population, based on 10,000 pregnant women's antenatal care consultations (National Institute of Statistics 2004). In other words, Gilberto was then one among approximately 1.2 million Mozambicans living with the virus.

Fear: HIV Testing, But No Treatment Available

One day in 2000, Gilberto went to see his doctor to tell him: *"I will take the test!"* Gilberto went straight to a nearby Voluntary Counselling and Testing centre, only to see that his neighbour was working as a nurse there. *"No, no, I cannot enter the VCT. When she sees me, she will think I have AIDS, as I am already ill with tuberculosis, and I am spitting bloody gobs when I cough. That nurse will tell the whole neighbourhood about me, she will spread it all. People will discriminate against me."* However, Gilberto's fear of discrimination was unfounded. He explained his situation to the nurse at the VCT centre and she said to him: *"Gilberto, don't worry. I will arrange some money for you so you can go to a private clinic to take the test".* People paid 150,000 Meticais in 2000 for an HIV test in private clinics (6 US$). This was a substantial amount of money for most citizens, as the minimum wage was – and still is – about 30-40 dollars per month. The clinician put the result in an envelope and asked Gilberto to give it to his hospital doctor.

"There were many patients in line, when I arrived at the hospital. More people joined. Then finally it was my turn. Then I gave the envelope to the doctor. I didn't

like the way the doctor treated me." I asked: *"What did he do?"* Gilberto: *"He opened*

the envelope and saw the result. Then he said: 'Senhor Gilberto, you have AIDS!' Then

I asked: 'Doctor, now that I have AIDS, what can I do? Is there a treatment? Is there

anything I can do?'" The doctor replied: *"No, there is nothing you can do."*

"I felt very sick that day. I felt very, very sick." However, Gilberto insisted by

asking what he could do. He compared AIDS to other diseases with no cure, like

cancer and hypertension. *"Can't you give me some tranquilizing medicine, so I can*

live longer?" The doctor told Gilberto about ARV treatment, but that it was not yet

available in Mozambique. *"But you can try at Health Centre Alto Maé, where Doctors*

Without Borders are working. They attend people in a situation like yours."

Natural History: Old and New Infections in Time Perspective

HIV life stories raise general points about the natural history of the HIV virus. A

few patients started ARV treatment in 2002 and 2003. More have gained access to

ARVs since mid-2004. Many have carried co-infection for several years, mainly

malaria, tuberculosis, and HIV. In any case, people in need or living with ARVs

carry an old infection, which dates back several years (Morgan, et al. 2002a; Porter

and Zaba 2004; Todd, et al. 2007). More than two hundred thousand people were

estimated to be in need of ARVs in 2004 (National AIDS Council 2005: 21), when

the government committed itself to free universal access to health within the

National Health System. The government 'denied' the HIV epidemic and it saw HIV

as a minor problem for many years after the first AIDS case report in 1986. Ineffi-

cient surveillance methods and insufficient resources meant massive underreport-

ing and non-reporting. Citizen ignorance, lack of physical access to HIV and AIDS health care (transport, distance, money), limited health system capacity, and complex psychological sentiments (fear, shame, denial, aversion, scepticism, silence, passivity, and distrust) meant that few came forward for testing.

If we then think of a context half way into the first decade of the new millennium of resource abundance, political commitment, increased HIV awareness and testing, then an alarming scenario can be predicted ten years ahead. More people living with HIV, who were infected in the new millennium, will progress towards AIDS and require ARV treatment. This sets high demands on the health care system. The government is committed to improve health system infrastructure and to train more health workers, but this happens at a slower pace than the increasing number of people in need of ARVs. However, most people infected long ago who do not have access to treatment will and do die. Day Hospital coordinators estimate that 75 percent of the people who test HIV positive do it during the WHO defined third phase (severe symptoms) or fourth phase (terminally ill) (WHO 2005). They are 'late presenters'.[1] This proves to be too late in many cases. There are no systematic studies of this, but a medical doctor at the Central Hospital of Beira, in the high prevalence Sofala province, reported that those who arrive at the Day Hospital in clinical stage 4 die within an average of two to five days (Vitorino 2007). Immediate ARV treatment is not possible at that stage. However, one multi-country study might give us an indication of the problem: it found that out of 3,456 patients in Mozambique, Malawi and Tanzania, who received ARVs for more than 6 months, 72 percent initially had WHO clinical stages 3-4 (Marazzi, et al. 2008).

Scepticism and Discrimination: Facing The Fact and Friends

Gilberto doubted the result of his test. *"Is it really true? Perhaps it is the wrong test. I don't agree".* He went to another VCT centre to test again. *"I liked the way the counsellor treated me. She received me with lots of care."* Gilberto asked: *"What does 'positive' mean?"* The nurse explained the difference between HIV negative and HIV positive, and that positive means that the person has the virus that provokes AIDS. She also assured Gilberto that he did not have AIDS. The nurse told Gilberto the same as what the doctor had told him, but with good manners. The nurse opened a medical record for Gilberto, *o processo clínico*, and assured him that he would be offered prophylactic treatment against opportunistic infections.

MSF was constructing a Day Hospital and would soon be able to offer ARV treatment. *"But is it possible that I will live much longer with this treatment that Miss Counsellor is telling me about now?"* She said: *"Yes. Avoid the dirty life. Skip nightlife. Eat well. Do not go hungry for a long time. Be faithful to your medication. Take your medicine at the hours that I tell you. You will live."* Gilberto started prophylactic treatment in 2001.

Gilberto reflects on his previous life without treatment in a social environment in constant fear of discrimination. *"Life wasn't easy, because a person gets ill, gets very ill, gets very, very ill without proper AIDS treatment. Then, when they look at me they start stigmatizing and discriminating against me. 'What he has, that guy there, that's AIDS. And he is trying to hide it.' People show distrust. They keep a distance – they discriminate against people like me. Even to the point that some people didn't want to talk to me anymore."* Fortunately, everyone within his family understood his situation: his mother, his brothers, and sisters.

ARV Treatment: Courage to Live

From 2003, Gilberto regularly consulted his doctor and his nurse. One day the doctor said to him: *"Gilberto, we need to talk, because we now have a treatment we want to give you. This treatment is not like aspirin or chloroquine. We need to talk a lot with you, before we give you this medicine."* Gilberto then attended the pre-ART counselling sessions to learn about ARV treatment. Gilberto asked the question like many others in the same situation: *"When will the doctor tell me that I don't have to take the medicine anymore?"* The doctor said: *"This medicine doesn't cure AIDS, it doesn't cure the virus. But it is a treatment that gives better quality of life to a person living with HIV."* CD4 analysis was performed after 1 month of pre-ART counselling. Gilberto had 142 CD4 cells per micro litre blood, compared to a healthy person with an average of 1000 CD4 cells per micro litre blood, cells that help the immune system to protect against infection (US DHHS 2005).[2]

Gilberto started free ARV treatment in April 2003. Day Hospital Alto Maé stands behind the Health Centre, linked by the VCT centre. Prime Minister Pascoal Mocumbi officially inaugurated these facilities donated by MSF Switzerland and the Swiss Bachmann Foundation on 1 December 2003.

"First and second month were difficult. Very difficult", Gilberto recalls. He suffered painful side effects. *"A person will drop out by feeling all the pain, if he doesn't have courage. But I had already been counselled, they had explained everything to me, and I had the courage".* Gilberto's condition improved after two months and his CD4 count soon climbed to 245. Then it went down to 180. Gilberto worried about this situation, until his doctor assured him that it would only be a temporary decline. The following CD4 count was at 490.

Gilberto finally says: *"This is more or less the life I have lived since 1998."*

Individual and Shared Experience

Gilberto's life story reveals a difficult path to ARV treatment paved with problems of HIV and AIDS incompetency within the Mozambican health system, years of ill health without knowing his HIV status, and fear and experience of discrimination living with the HIV virus. Three key issues explain his success in overcoming individual and social barriers: information, counselling, and courage. Gilberto was frightened by the prospect of HIV disclosure and the response from society, like other people in the same situation. In the following, I describe and discuss the ethnographic methods applied as the basis for this chapter.

Field Methods: Can You Tell Me About…

I visited six Day Hospitals full time for 5 months. Life story interviews were conducted with 30 individuals living with ARVs (19 women, 11 men). Nine of them were Day Hospital activists (6 women, 3 men). I conducted formal interviews with five key informants between two and five times. Participant observation in support groups complemented the individual interviews (Kudumba, Pfukauhana, Tinena) . In addition, I observed the daily hospital routines, and conducted qualitative interviews with coordinators, doctors, nurses, psychologists, counsellors, and activists. I followed activists, doctors, and nurses on their home based care visits (10 women, 5 men, 6 children) (see Chapter 5). All research activities included indispensable informal networking, chatting, and talking. Informal encounters provided insights

into everyday life at the hospitals, as opposed to the formally staged interviews in which health care workers reflected on the bigger issues of their profession.

Patients had to be sensitized before I could interview them. They seemed more comfortable to the idea the longer I stayed at a Day Hospital. The nurses would talk to patients about my project and suggest an interview. Some days they stood in line waiting to talk to me. At other times, they were not so interested. However, I was surprised to see that many patients liked to talk about their life and problems with ARVs considering the widespread silence. The first impression when you arrive at a Day Hospital with full waiting rooms is an atmosphere of silence, melancholy, and despair. In fact, one doctor told me that the biggest problem in the doctor-patient encounter was communication. I was told that patients did not have much of an idea about their illness and about its past, present and future. However, there I was: patients told me detailed stories from the onset of health problems to life with ARVs.

Three issues made a difference towards successful life story interviews: *information, method,* and *context.* I gave each person a list of ethnographic life story questions, ordered around several key themes of illness experience: *life, Day Hospital, counselling and social support,* and *alternative and traditional medicine* (see Appendix 1). I explained it all for those who could not read. The *life* focussed questions were the most relevant for people living with ARVs: patients had a chance to talk in detail about their experience with HIV over time. Indeed, the suggestive phrase *Can you tell me about...* turned out to be a culturally appropriate key that made them talk openly about their life with the virus. Finally, the given space within the Day Hospital setting among peers and health workers was conducive to talk about life and ill health.

I invented the term 'live focus group', defined as qualitative research in which a researcher interacts with a group of people who talk about a particular issue without guiding them. Live focus group interviews supplemented the one-on-one interviews and participant observation. Orthodox focus groups proved impossible to realize at all levels of fieldwork. In this context, ARV patients came into the Day Hospitals in silence, waited long hours in the waiting room, spent time with a health worker, and then they wanted quickly to leave again. Live focus groups in the support groups offered participant observation without the researcher having to control the situation, which is generally the norm and limitation of ideal type focus groups. I observed participants' interaction and how the they voiced their opinions on specific topics related to ARV treatment. I asked questions, listened, took notes, and participated in the debates. In fact, informants controlled the focus groups, as encouraged in textbooks (Morgan 1997; Spradley 1979). Finally, live focus groups were particularly useful to prove Morgan's simple test (Morgan 1997: 17): Do participants actively and easily discuss the topic of interest? They did.

Storytelling was a key component of my encounters with ARV patients and support groups. Individual life stories reveal the oral history of Mozambicans living with the virus. They give voice to the apparent *silent* epidemic history. Storytelling in support groups provides psychosocial support among peers. However, data validation was difficult: people who live with HIV hesitate to invite strangers, activists, or health workers into their everyday lives in their homes surrounded by friends and family. Therefore, narrative theory is necessary to appreciate the differences between individual and collective storytelling. The validity of the former depends on other pieces of information in social and cultural context, while the validity of the latter resides in the narration itself (Peacock and Holland 1993).

I would have liked to visit patients regularly and systematically in their communities and their homes, but this was quite an impossible suggestion under the given circumstances of perceived and real stigma and discrimination and the underlying and consequential psychological emotions, which produce the ever-present silence and secrecy related to living with HIV. Once you leave the oasis of talk at the Day Hospital, you re-enter the troubled zone of secrecy in public and private spheres. Patients cross these zone every 15, 30, or 60 days on their visits to the Day Hospital for medical and psychological consultation and ARV restocking. However, the individual *life-focused* stories present the struggles of real people, focused on *lived history* (Peacock and Holland 1993: 369-370).

The *psychosocial* life story approach emphasizes the creation and maintenance of social cohesion and collective identity within a therapeutic group (ibid.). Researcher presence is less relevant in this context. The researcher participates and observes group activities. The quality of the psychosocial life story approach resides in the interaction among group members. Group members use stories as pieces of information to create collective identity and they hereby create validity *independently* of other sources of information. The ontological basis is *interpretation* within the group of stories told, as opposed to the objectivist life focussed approach, which insists that the story mirrors reality (ibid.). Empirical detail of collective storytelling ties into the next section, which will show how storytelling becomes meaningful within a peer group.

HIV Support Groups: Oases of Disclosure

Support groups provide moral and psychosocial support, based on the recognition of the importance of such support, but also on the fact that they have no means available to provide economic and social support. Poor people can only afford 'moral' and 'psychosocial' support. There is little if any 'state' support for poor people without the basic material necessities. Yet, support groups are important: they provide a forum where people can voice their concerns and problems living with ARVs. Mozambicans often lack such space elsewhere, due to the silence and secrecy attached to living with the virus. Support group meetings create an oasis of disclosure.

I was talking to Gilberto about the HIV information campaigns in the 1990s and early 2000s. He told me about the slogan in the newspapers, on the radio, and on TV: 'AIDS Kills, AIDS Has No Cure'. *"People received this information and until this very day they don't want to take it away. We have already developed better information. Information is available, but people's consciousness has not yet changed! I decided that I don't want to return to the past, because when I go for a consultation, when I sit at home, or when I go out with friends, then I always have to hear about cases of discrimination."* I asked Gilberto to give me an example why such patient support is important. He said: *"I knew a person who took the test. He was not ill. They counselled him very well at the Day Hospital. Treatment was even available, but he committed suicide, because it reigns in the minds of people that 'AIDS kills, AIDS has no cure'. I feel that we have to work a lot in the area of HIV/AIDS to make people understand that AIDS is an illness like any other illness that doesn't have a cure."*

Storytelling: Letting Others Know

For this reason, Gilberto and others, with support from an MSF coordinator, decided to establish a patient support group. They named it *Kudumba*, a *Shangaan* word meaning: *Let's Speak Reality!* Gilberto looked at me with a stern face and said with a grumbling voice: *"Vamos falar a realidade!"*

The Kudumba group was founded in October 2005 as an association of patients living with HIV 'to support members and their families in need of moral and psychosocial support'. Members pay a 50 New Meticais monthly fee (2 US$). Those with little money can still become a member and pay 10 New Meticais per month. However, only about 50 people had joined Kudumba by mid-2006. Moreover, only a few of them attended the Friday afternoon meetings. Some meetings were even cancelled. In fact, the 'oasis of disclosure' stands in striking contrast to the majority of patients waiting in silence for their medical appointment, supported by the fact that some 3,000 people receive ARV treatment at this Day Hospital. I believe many more would become Kudumba members if they could, but economic, social, and psychological barriers keep them away.

I participated in several Kudumba meetings. They gather under an open shed within the Day Hospital area, sitting on benches and chairs in a circle formation. Every meeting starts with two key activities: animation and storytelling. This Friday afternoon gathered 31 participants (22 women, 8 men, and 1 child). First, the moderator encourages participants to tell knee-slapping jokes to let people have a good laugh. The change of faces before and after these gags is remarkable. From rather empty looking faces, you now see animated and happy people with an incentive to communicate and share their experience living with HIV and ARVs.

Then they tell stories about life before and after the HIV test, before and after they start ARV treatment. This is similar to what I do, when I interview people who live with the virus. This was a pleasant surprise: I had seen some Day Hospitals without support groups. I had visited other support groups that used a different approach to patient sensitization. They perform group-counselling sessions to inform about prophylactic treatment, adherence, proper nutrition, and condom use. With Kudumba I found a methodological two-in-one: a 'live focus group' focussed on storytelling. This approach emphasizes the relevance of ethnographic life story methods and it exposed that Mozambicans love to talk and tell stories – in a comfortable setting. The risks and consequences of voicing the reality living with HIV are included in the following analysis.

Life stories reveal the problems and solutions related to treatment seeking behaviour. *"You can speak!"* says the moderator, each time a persons stops talking. He encourages participants to keep on talking. Some storytellers are blunt and direct: they say what needs to be said. The shortest and clearest testimony I heard went like: *"I took the test, I was positive, and then I started treatment. Now I feel good, I don't have any problems."* Others are shy and afraid of talking about themselves and HIV. For example: *"Telling a story, I talk in third person. I don't say that it is me."* Participants give a big round of applause in a lively and animated way at the end of each story.

A few proactive Kudumba members have no fear: in their own words, they are the 'courageous soldiers'. They become role models to ARV disclosure: those who are afraid or not ready to speak about their HIV status have a chance to listen to others. What problems have they had to face? What were the possible solutions?

Storytelling provides a means of ordering the past to make sense of and control the present to edify and mentally prepare for the future. Storytelling offers audience validation and recognition, which alleviates psychological suffering. People living with ARVs find great relief among peers sharing their stories, particularly as storytellers can conceal their identity and where they live. They enjoy the freedom to speak within an oasis of disclosure. In fact, the chance to speak 'anonymously' and 'out of context of daily life' makes people realize that others have gone through similar social, cultural, and material difficulties. That is, ARV stories, though seemingly idiosyncratic, hinge on a cultural repertoire of shared experience: the pros and cons of HIV and ARV disclosure in private and public spheres, social disintegration, and cultural condemnation. Mozambicans who live with HIV have experienced a difficult life with other diseases, which have become normalized conditions: endemic infectious diseases, destitution, and poor public health.

There is both good and bad news to the prospect that living with HIV may become part of cultural disease normalisation. In particular, I find it relevant to discuss and analyse the reasons and causes for troubled vocalisation and the widespread silence related to living with HIV, which until recently has been publicly declared a death sentence. Reluctance to talk about individual and social concerns living with ARVs through an agency declared as moral support, yet which implicitly proclaims discontent with the social circumstances, points to perceived and experienced consequences of stigma and discrimination produced and perpetuated by the dominant society and political culture. I turn to an intermezzo that describes the foundation of the Pfukauhana support group, the differences in attitude to life this initiative creates, and specifically a phenomenological description of how people living with ARVs experience silence and secrecy.

'Poor People Like Us': On HIV Public Disclosure

Patients and health workers founded the Pfukauhana support group on 29 June 2006, 14 months after the ARV facility opened at the Military Hospital. The silence and despair among ARV patients, which I had experienced until then, transformed into motivated activity as the Pfukauhana group took shape. Edmundo, an ARV patient representing the access movement MATRAM, organized the first meeting, which gathered 17 participants (9 women, 2 men, 3 children, and 3 health workers). Edmundo says: *"Let's talk about HIV!"* He enthusiastically goes on about the differences between RNA, DNA, and CD4, their functions, and how they interrelate. He includes all details of HIV pathology, points of entry, how the HIV virus enters the body, and why condoms are important.

Beatriz, a young woman with no visible symptoms of HIV, cried her heart out among her trusted friends in the support group. She was afraid she would not be able to see her children grow up. Her husband and her daughter are both HIV negative, but her son has also been infected. Beatriz has had no physical problems with ARVs, only psychological. *"You can't live without a heart and mind at rest, which is needed also for ARVs to work well."* Then Daniela joins in with a forceful voice: *"I know I am not alone: there are many more in the same situation. The most important support we need is psychological not medical!"*

Evaristo, the president of Pfukauhana, said at the second meeting: *"The group is open to everyone. We don't select patients and sympathizers."* This time 8 men, 12 women, 2 children, and 2 psychologists showed up. They told stories about denial, discrimination, and secrecy. Alicia was the first to break the silence: *"I didn't believe it. I kept saying 'It is not true' for a long time. I took the test once*

again in 2005 and it was positive. It was true. My husband is also HIV positive, but he continues to drink and smoke and he does not change his behaviour. It is such a joke. I need your help. I have not been able to change his life and my own has been affected. I simply want to feel better."

Others followed Alicia's example. Bianca said: *"I have a niece who knows she is HIV+, she knows her CD4 count, and she is eligible for treatment, but she doesn't believe it. She says 'it's not my analysis!'"* Odolina said: *"My family doesn't give me food. They say the hospital is dirty, AIDS is dirty: 'Wash all your clothes before you enter the house!'"* Geisa said: *"I live my life, the secret stays with me only. No one in my family knows, my mother, my 14 brothers and sisters, only my grandmother in church".* Then Nisalda said: *"Our families need to know that we have organized an association, a support group. Let's invite our families to see what we are doing and that the group also includes HIV negative people."*

Ângela from RENSIDA talked about her experience living with HIV at the next meeting, which gathered 9 men, 16 women, 1 child, and 2 psychologists. *"We are not afraid of living with HIV! This is our goal. Let's live positively".* All members presented themselves by name. Then Ângela continued: *"We learned about AIDS in the 80s. We heard that AIDS kills, simply! Those with AIDS led a bad life. We were isolated and people discriminated against us. In 2000, we were not well treated at the hospitals. We were always the last ones attended to. We had to wait until the end of the day, even if we arrived early in the morning."*

I knew Ângela through several meetings with international organisations, where I never heard her speak a word. She explained that the people from the 'powerful organisations' would never let civil society members speak. If they did, they would never take their side. She often felt muted at these events. However,

here she was 'giving voice' to people living with HIV: she spoke with a strong voice about the needs and problems living with HIV.

Ângela introduced two key issues: silence and sensitization. *"It is difficult to find a state functionary who breaks the silence. Poor people like us break the silence. We are normal citizens, often unemployed, often without money."* Fátima joins in: *"Many people need to be sensitized. Many are still stigmatized and people keep discriminating against us. We need empowerment! We need to work in the city! We need to work in the districts! We need to provide psychosocial support everywhere!"* Ângela replies: *"Everyone of us have a role to play. We need to educate our families. We need to create conditions in which you can learn how to do this work on how to sensitize families about stigma and discrimination and how to break the silence."*

Boaventura Machel, the brother of Samora Machel, died of AIDS in 1999. His closest family, led by his wife and children, Samora Machel's widow Graça Machel, and Eduardo Mondlane's widow Janet Mondlane, decided to 'break the silence' by a public announcement of the death of a prominent public figure in Mozambique. The obituary appeared in the *Notícias* newspaper on 27 November. It reached the New York Times by mid-December (Swarns 1999). The event was seen as a historical turnaround, which would make an end to silence and discrimination. Prime Minister Pascoal Mocumbi lamented the fact that HIV continued to be seen by society as taboo that generates secrecy and marginalisation. Mocumbi pleaded Mozambicans to break the taboo (ibid.), but little happened.

Gossip rapidly spreads the news when people die from HIV, but this information never becomes official through the media. Obituaries of young and old Mozambicans fill the daily newspapers, but without explicit mentioning of the cause of death. I remember my own bewilderment, when I first arrived in Mozambique

and read the newspapers. I flicked through the pages and saw that many people had died recently: page by page filled with photos of boys, girls, teenagers, young and old women and men, complemented with name, age, location, and cause of death. This left me confused and sad. It was difficult to fathom the reality behind it. The cause of death was invariably stated as 'died after prolonged illness'. This is common. 'Died after prolonged illness' is a common dignifying statement, customarily used in many countries to show respect for individual privacy. The unusual and worrying aspect was that there were so many obituaries. Nevertheless, even though many read the newspapers, nobody spoke about the reality. This phenomenon seemed a normalized aspect of everyday life.

Gilberto often commented on this: *"We need to be much more aggressive and tell the truth! Write under each picture in the obituaries that this and that person died of AIDS. Then people will understand that AIDS is part of reality. This will be the most effective prevention campaign too!"* Today, as Ângela puts it, it is 'poor people like us', who break the silence.

Silence, Voice, and Taboo: Reproduction of Social Order

On a visit to the phlebotomist, I saw a message on a notice board: *"Let's break the silence. Silence kills more that AIDS. Let us fight against stigma and discrimination. You are not alone, there is always someone by your side."* Yet, I was puzzled that the discussion soon died out during support group meetings, only kept alive by the few courageous soldiers that no one can silence. That is, talkative storytellers differ immensely from passive listeners.

Though difficult to analyse silence compared to verbally expressed communication, silence per se constitutes a means of communication. A taxonomy of silence among people living with ARVs classifies five key themes: *enculturation, secrecy, despair, statement,* and *choice*. This classification will be discussed with key social science literature on silence in the context of illness experience and taboo.

Function and Enculturation

Individual, social, and political gains and repercussions matter when people living with HIV consider voice or silence. Such considerations may explain why the majority of people estimated to be living with HIV do not come forward for HIV testing, often despite the fact that they have been well informed about the virus and how to control it. Under the circumstances of perceived and real threats of social disapproval and condemnation, limited access to health care, and poor living conditions, then people are right to ask whether one should always follow the good example of the ones who give voice to social suffering and ill health. Social, economic, and political circumstances may tell you that silence makes the better option. In other words, silence has a protective function. Silence and secrecy protect the individual against bias and intolerance.

Taboo and somatization explain silence related to the enculturation thesis. Enculturation implies the process by which people become incorporated into a specific culture: they adapt to cultural norms and social order. Changes in family, community, and political life influence the life long enculturation process. First, the definition of taboo includes reluctance to mention or discuss a particular issue.

Second, silence is caused by or an expression of individual or collective historical experience. We therefore need to analyze silence within Mozambique's social history to explain why its citizens remain unwilling to talk not just about HIV but also about public matters in general. I do this with reference to classical anthropological analyses to argue that enculturated silence depends on taboo (Douglas 2002 (1966); Leach 1979), social memory (Connerton 1989), and embodied experience (Fassin 2003; Fassin 2007; Kleinman and Kleinman 1994).

Gilberto said to me with a sincere voice: *"I am realizing a taboo; that people don't want to talk about HIV and AIDS. For me, this is the danger of more HIV transmission, when people don't talk about HIV and AIDS."*

Taboo refers to explicit prohibitions from the use or mention of things considered sacred or inviolable. Thus, HIV should fall under such definition, but this would question its sacredness and inviolability. Taboo contains the double meaning of *inhibition*, defined not as cultural or legal banning, but as psychological shyness, hesitation, and insecurity. I claim that the cultural and historical dimensions of HIV in Mozambique converge because of this *prohibition-inhibition* dialectic.

In anthropology, taboo defines as avoidance of things that fall between culturally agreed categories and names (Douglas 1979; Douglas 1992; Douglas 2002 (1966); Leach 1979). The language of silence characterizes taboo: the unsaid, both prohibited and inhibited expressions. Thus, the definition of taboo encompasses distinctive qualities of silence. I argue elsewhere that historically constituted inhibition may explain silence in Mozambique (Høg 2006). The forces to inhibit talk about HIV are paramount, as living with the virus associates qualities in life that human beings rarely connect, and which we usually keep separate in most cultures

precisely through systems of taboo and ritual. That is, HIV at the minimum associates the rare cocktail of sex, disease, and death.

However, the prohibition-inhibition phenomenon in the context of HIV is not unique to Mozambique. I would add a clash of cultures component, evident in Mozambique by the massive use of foreign made moral messages and the increasing call to make them culturally appropriate. They call it 'Mozambicanization' of HIV prevention campaigns. HIV information should ideally be adapted to the different linguistic, ethnic, and cultural contexts of the country. However, the reality is different in the context of the 'ARV rollout'. The government vetoes public ARV announcement on the argument that it would be irresponsible public health practice considering the weak health system capacity. Alfredo Mac-Arthur, the National AIDS Programme Director said: *"We don't have the health system capacity to inform the general public about treatment. People would flood our system and we would not be able to treat everyone."* However, information travels fast by word of mouth, both through oral tradition and due to circumstances of illiteracy, weak media coverage, the digital divide, and weak postal services.

Additionally, religious and behavioural components of taboo influence taciturnity. Douglas' work on risk and blame (Douglas 1992) and purity and danger (Douglas 2002 (1966)), provide useful tools to discuss religious, cultural, and political aspects of silence living with HIV. First, the behavioural blame links to the original understanding of breaching a taboo: human behaviour is blamed responsible for a society wrecked *with* HIV, not *by* it. 'Sexual behaviour' and 'culture', both deemed wrong, invariably explain high rates of HIV infection. In other words, the 'blaming the victim' discourse dominates the 'blaming nature' and 'blaming sociopolitical history' discourses. The natural history of the HIV 'long wave event'

(Barnett 2006; Barnett and Whiteside 2006 (2002): 19ff), with its devastating impact through interaction with human beings aided under socioeconomic fragility and disparate cultures of denial, negligence and inaction, remains unfathomable and fuels paralysis. Individual behaviour change remains the preferred policy option to restore society and protect it from additional viral transmission. A paradigm shift is in the making to acknowledge and take action upon the HIV epidemic as a development problem and solution, but it caught a slow train after twenty-five years adhering to the cultural and behavioural models of epidemic explanation and societal response. Nonetheless, some speculative questions remain: Had they worked, then the HIV epidemic would have peaked earlier with much lower HIV prevalence than currently estimated. Had such initiatives not been taken, then the HIV prevalence would have increased to higher levels. It would have been a painful acknowledgment and reminder of failed progress, had development been the answer from day one of the epidemic. Such conclusions were not reached overnight. Therefore, it is hard to determine the success or failure of behavioural campaigns against the natural history of HIV.

However, ideas of risk and blame take over, when the theory of taboo fails its explanatory power, as Douglas herself points out (Douglas 1992). In other words, this line of thought proposes that the pre-scientific taboo approach rooted in the intersections between nature, culture, religion, and language dominates rational reasoning based on centuries of lessons learned in areas of economic development and public health. Without the latter, behavioural restrictions remain the preferred solutions, not based on evidence but on moral and prejudiced perceptions reminiscent of taboo practiced regardless of its cultural environment. Those who have the comfort and security of development and public health are less ex-

posed to the risk of infectious disease contraction. However, such a social paradigm has absurdly been relegated to a controversial position (e.g. Fassin 2007; Stillwaggon 2006), but of course Mary Douglas points to the long established anthropological axiom that 'in all places at all times the universe is moralized and politicized': move ahead and analyse its implications (Douglas 1992: 5).

Embodied History

Such a proposition makes sense in the context of HIV and AIDS in general and in the context of ARV treatment in particular. It needs an examination that traverses social and personal space for which three kinds of analysis on generational reproduction of social order and embodied experience appear relevant. These emerge from sociosomatics, which can be defined as how the social world affects bodily processes (Kleinman and Becker 1998). The first exposes *why* and *what* societies remember (Connerton 1989), the second *how* bodies remember (Kleinman and Kleinman 1994), the third *when* bodies remember (Fassin 2007).

Several sources of vocal oppression in Mozambique may explain embodied silence: historical events (e.g. colonialism, socialism, civil war), social changes and cultural identity (e.g. health system and political transition, social upheaval, forced migration, one-nation-one-language policy), and ethnic, class and gender differences (e.g. people for whom things never change, persistent ethnically determined social networks among the elite despite proclaimed national integration, elite-peasant distinction, and male dominance and privileged position in society).

Connerton claims that people incorporate social memory into the human body. He argues that human experience of the present depends on knowledge of the past. This social remembrance serves to legitimate the existing social order (Connerton 1989: 3). Arthur and Joan Kleinman suggest to study the interaction and processes that mediate and transform the bodily forms of social experience by asking the compelling question *how* sociosomatic processes shape the experience of the body in social context. This would lead us to understand how, for example, atrocities, ill treatment, and disruption are remembered (Kleinman and Kleinman 1994). Such phenomenological processes in social context contribute an understanding of silence and voice in historical and cultural perspective to show that they are not merely discrete events and abstract transitions.

French anthropologist Didier Fassin takes this approach one step further through a phenomenologically grounded social history of AIDS in South Africa (Fassin 2007). The former question *how* bodies remember affirmatively becomes *when* they do so. Fassin explains the AIDS epidemic in South Africa rooted in an embodied history of apartheid and colonialism that fed racism, poverty, and inequality, which then again favours the transmission of HIV. This structural cocktail made unequal access to health care transparent. Fassin's social history perspective makes a compelling argument against the prevailing paradigms, which concentrate on behaviour and culture as causative agents of the epidemic.

Mozambican social history may explain why Mozambicans prefer silence to voice in relation to public matters. Mozambicans have experienced repressed freedom of expression under socialism, the brutalities against civilians during the civil war, discontent with democracy and neoliberal development projects, authoritarianism that kept criticism within the ruling party, and the lesson learned witnessing

the fate of those who challenged this order.[3] Mozambique experiences political convergence between FRELIMO premised nation-building and asynchronous western premised foreign development with its conditionality bound economic aid.

FRELIMO history provides the first example of how and why citizens were silenced. Upon independence in 1975 *"All social thought and action emanated from within the State and the Party"* (Fry 2005). FRELIMO political centralism with its social control system comprised a top-down apparatus, which represented an authoritarian pyramid. Communitarian assemblies forced people to assimilate FRELIMO ideology. 'Dynamizing groups' hunted down the 'enemies within' to eliminate government opposition. This was a systematic social control system to eliminate traditional culture and any 'manoeuvres of the enemy', executed by 'witch hunters', 'dynamizing groups' and 'agents of national vigilance' (Matsinhe 2005: 30).

Additionally, Mozambique experienced a brutal civil war between 1977 and 1992. South African and Rhodesian Apartheid perpetrators targeted the social services. They ignored the Geneva Convention: all the gains of the Mozambican government since independence were systematically destroyed and precious human capital killed or driven to escape. Millions of Mozambicans took refuge in other provinces or neighbouring countries. Schools, hospitals, clinics, and health posts were destroyed. Health workers and patients were killed (Andersson 1992; Christie 1988; Hanlon 1984; Walt and Cliff 1986; Walt and Melamed 1983). We will later see how Mozambicans consulted traditional healers using silence as a means to heal the wounds of war during the 1990s after the peace agreement (see Chapter 3, p. 145).

Moreover, the government imposed five measures to realize the dream of socialist nation-building: 1) deportation of the urban unemployed to Mozambican

Siberia – the Niassa province farthest north, 2) forced migration, 3) assimilation of national culture, 4) adoption of Portuguese as national language, and 5) elimination of traditions and local languages. The dream of modern socialism included a nation 'without racial discrimination', 'without tribalism', 'without regionalism', and 'without obscurantism' (Matsinhe 2005: 30).

No wonder Mozambicans refer to the culture specific phenomenon of *confusão*, which has a deeper and more complex meaning than merely confusion. *Confusão* signifies a state of confusion created by chaos, disorder, and the tumult of everyday life, as well as lawlessness in the case of war. *Confusão* by implication also means dissension, in the sense of conflict, dispute and disagreement.

Political Strategy

The main issues around silence and life with HIV, AIDS, and ARVs point to vital problems related to treatment seeking behaviour and the interrelatedness of individual, social, and political access barriers, as well as solutions. Some of Kudumba's key questions lead the way: Does breaking the silence resolve or increase the problem of discrimination in the family, among friends, and in the community?

Participants found that breaking the silence about HIV, AIDS, and ARVs is possibly *not* a way to fight discrimination (social barrier), but it is a way to pressure the government to create better living conditions (political barrier). Thus, voicing their concerns about life with HIV is not merely a means to influence the social sphere of individual discrimination, but a political strategy to point out the poor living conditions of the majority, regardless of their HIV status.

However, disclosure of HIV status provokes potential social repercussions. The benefits of 'breaking the silence' depend on the situation, influenced by the following elements: 1) sensitization, 2) awareness of the risk of expulsion from home, 3) balance advantages and disadvantages giving voice, and 4) courage.

The group considered the difference between breaking the silence in public and in the family. As the running banner says on the National AIDS Council website: *"People talk about AIDS when they are away from home, but when they are at home they are silent"*, quoted from a speech by President Guebuza during the Presidential Initiative to Fight HIV/AIDS week in February 2006 (Guebuza 2006).

Collective memory emanates from the history of access to public health. Health care before independence almost exclusively benefited the colonizers (Hanlon 1984; Matsinhe 2005). This explains FRELIMOs commitment to social services upon independence. Indeed, the Mozambican government made good progress towards the dream of equal access to health care soon after independence, ahead of the WHO call for primary health care for all (WHO 1978a), but then civil war broke out and hampered this process. However, the government points to the early success story in health care as a historical reference point for the dream of free nationalized health care, which lives on in the social imagination. However, reality proves different: most citizens live far away without means of transportation to gain access to government health care. Many of those who did reach the health services experienced bad services and certainly those with the most severe illnesses, including HIV, have until recently been served last. Moreover, the government started the nationwide campaign from the early 1990s: 'AIDS Kills, AIDS Has No Cure' and 'Those Who Have AIDS Are Awaiting Death'. This left many in despair. Remember Gilberto's words: *"People received this information and until this*

very day they don't want to take it away." The introduction of ARVs circulates by word of mouth, but people keep struggling with the collective consciousness of the past, which I would argue is partly driven by the lack of public announcement of ARV treatment. Yet, I agree that the government faces a difficult dilemma of 're-sponsible public health policy' given the weak state of the health system and the high number of people in need of ARV treatment.

This line of thought affects the analysis of silence: Silence depends on the delicate balance between knowledge and ignorance and it is a sign of deprivation. In recollection, FRELIMO gives highest priority to health care, evidenced in the his-torical liberation narrative, which persists in the social imagination to uphold the dream of a sovereign nation. However, the lack or denial of material benefits con-sidered fundamental to the identity of a people and nation has a numbing effect. Silence simultaneously makes a powerful yet pathetic statement about the poor circumstances as people witness the inability of the international community to bring about development that makes a difference to ordinary citizens. In other words, poverty can be seen as the outcome of longstanding ideological struggles over the development process. In fact, I argue that poverty is a particular sign of ideological *disorder* (see Chapter 5, p. 233).

External factors may explain why development fails to reach the poor. Structural adjustment programs that promote privatisation and fail to keep their recent pro-poor pretension provide a prime example of longstanding criticism of development (Butt 2002; Kim, et al. 2000; Millen, et al. 2000; Schoepf, et al. 2000). The poor are held hostage in this process, left to live as martyrs of development, or as sufferers of external dictate, as argued by Hanlon and Plank (Hanlon 1991; Hanlon 1996; Plank 1993) (see Chapter 6).

Public health awareness should not be underestimated, contrary to common prac-

tice among Mozambicans high and low, who say that Mozambicans are ignorant.

Do Mozambicans get sick from ignorance or poverty? In my opinion, poverty and

the stigma of ignorance form a double insult. However, health seeking behaviour is

an exercise in citizenship ('I have the right'), as state provision of health care is an

exercise in statesmanship and democracy ('we have the duty'). What people have

experienced historically from the state and colonial powers, combined with per-

sonal and cultural preferences, produce a strong sense of pride and dignity that

precludes asking for help, but rather advances abstention from speech and public

discussion. Popular participation in democratic processes is not heaven-sent and

its success awaits people's own claim and ownership.

However, this makes the individual responsible for the lack of access to

health care, not the government, or the state of the health system. The Mozambican

government cannot afford a public health approach to HIV. The government denies

any accusation of passivity on the sound and fair argument that the problem is lack

of infrastructure and qualified human resources.

Sensitization

An analysis of 'sensitization' precedes the analysis of 'voice' versus 'silence'. As

seen so far, silence is not merely a form of denial but a rational choice under the

given circumstances of perceived and real stigma and discrimination attached to

living with the HIV virus. 'Sensitization' is the consciousness-raising factor towards

breaking the taboo around HIV and an informed choice between silence and voice. It primarily divides into *peer education* and *public advocacy*.

People living with HIV, whether or not they have taken the HIV test, still need basic information about HIV, AIDS, counselling, testing, and treatment. Many people do not know about HIV related issues and support groups, even in the capital city. *"Kudumba, you have helped us a lot, because we were in the dark?"* Such gratitude speaks for itself.

However, sensitization in the sense of public information campaigns can be seen as a pragmatic political choice, which depends on health system capacity. For example, an international treatment organisation initiated *'sensitization for the city'* in 2004: a theatre group performed every Thursday in public places of Maputo. During those days, it was easy to get people to test for HIV and to start ARV treatment, but this changed, when the 'sensitization for the city' project stopped its performances. This had to do with the limited capacity of the Day Hospital. Why keep advertising, once the hospital is full? Gilberto participated in the public performances: *"I explained what I have been through, the life I am living now, and the benefits I have accomplished, but the day came when the project stopped. We continue to do our work inside the Day Hospital, because we have seen the great job that the doctors are doing."*

However, a time lapse persists between receiving the information and putting it into action. Sensitization takes time. People living with HIV face individual, social, and system barriers: fear, shame, denial, scepticism, prejudices, stigma, discrimination, lack of social capital, poverty, waiting lists, and scarce infrastructure and human resources (see Figure 3.1, p. 134). This is a crucial finding for the understanding of stigma and discrimination as a social and political process, which

feeds on the changing circumstances of individual and social knowledge, health system capacity, and political response. As Gilberto said: *"The work is very important, because the sensitization we did at market places and other public places was in 2004, but as people are very hard minded they don't come for testing until now"*.

For example, the Alto Maé VCT centre admits a maximum of 10-15 people per day. The Day Hospital transfers patients to other Day Hospitals in Maputo. Many patients can therefore attend HIV/AIDS health services closer to where they live. Additionally, patients with no health complications can come for a short consultation and renew their stock of ARVs through the 'normal' services at the Health Centre. These phenomena point to the patient/personnel ratio: the number of HIV testers increases faster than the number of health workers. As Gilberto says: *"It is not easy to take the test here and it is not easy to start treatment. What was easy earlier is today not easy at all."*

Stigma and Discrimination as Social and Political Process

My analysis of 'voice' among people living with ARVs emphasises two main issues: social condition and social consequences. The former points to the lack of food, the latter how to confront stigma and discrimination. One of the purposes of my fieldwork was to identify barriers to access ARVs at the individual, social, health system, and political levels and to observe and understand how these barriers interrelate and influence treatment seeking behaviour (see Figure 3.1, p. 134). Political decisions, based on economic and resource constraints and the consequent nationwide 'AIDS kills' propaganda, produce stigma and discrimination. This is how stig-

ma and discrimination originate in the mélange of structural, symbolic, social, cultural, and everyday violence, which offers a significant reading of the access and delivery model (see Chapter 8).

Source, Nature and Consequences

The 'AIDS Kills, AIDS Has No Cure' campaign provides a case of how a message from the body politic affects the social as well as the individual body. Ultimately, people end up unwilling to test for HIV or disclose their HIV status. This has profound implications for how the phenomena of stigma and discrimination are manifested, perceived, and circulated. Blaming the discriminator fails to capture the origins of stigma and discrimination beyond the individual and the group in larger social and political processes. Blaming the government implies that it had an alternative solution. Blaming the international community implies that it failed to reach out to fellow human beings as an act of solidarity and human rights obligation. WHO founded the Global Program on AIDS, GPA, in 1986, the year of the first AIDS case report in Mozambique. The GPA proposed a human rights approach to the epidemic. Critical action campaigns, drug price negotiations, and resource mobilisation occurred many years later. These are difficult speculative issues in historical retrospect, but I argue that fine-meshed complex interrelated individual, social, and political processes produce and fuel stigmatizing and discriminatory practices. In everyday life, people feel a cocktail of shame, fear, humiliation, aversion, silence, and distrust (see Figure 3.1, p. 134). However, many assign the responsibility for

such prejudicial treatment both on themselves, their social affinities, community members, and the larger public and political authorities.

For example, Teresinha's health problems began in 1998. She suffered severe coughing, rashes, sores, and weight loss, until she was merely skin and bone, reduced to a body of 29 kilogram. After 4 years in and out of hospitals, she was finally diagnosed with HIV at one of the day hospitals run by an international organisation. The Mozambican public health system did not have the expertise to diagnose HIV or to refer for an HIV test. Teresinha told me: *"That program on the radio said that the disease has no cure and word by word that those who have AIDS are only waiting to die. They said so without giving us courage and without giving us moral support. This is why so many die from this disease. The first propaganda was badly made. The people who knew they had AIDS or symptoms of AIDS, where should they hide? I didn't leave my house to see other people and I didn't go to the hospital: I preferred to die right there, since 'the one who has AIDS is only awaiting death'."*

Teresinha's CD4 was 24 when she started ARV treatment and she soon recuperated. She explained: *"I got better and I managed to leave my house, only to see that my neighbours thought I was a ghost. 'She is already dead: that woman could not recuperate, she has AIDS, and she is dead!' Others said: 'It's not her. She is a new one, she is a new shape among us. She is a bit bright and a bit gloomy'. They were confused. One fine day when I visited the hospital, I passed by the market, where two or three Senhoras had the courage to come and see whether I was a ghost that would disappear, but I didn't disappear, as I am not a ghost. This happened in 2002 and 2003. I recuperated to become a strong woman and I never again appeared that weak woman that I was before. I was full of sores at the age of 41 and I weighed only 29 kilos, but soon again, I became a strong woman. I now weigh more than 60 kilos."*

Rooted in Humiliation and Limited Access

How can we explain Teresinha's experience? Mary Douglas' work on purity and danger may help us to see how HIV as a perceived disorder advances stigma. Mary Douglas argues in *Purity and Danger* that we classify our surroundings to facilitate order, which creates the definition of pollution as *matter out of place* (Douglas 2002 (1966)).

Let us take a walk from the garden into the kitchen. I explain 'matter out of place', typologize the subtleties of order and disorder, emphasize discrepancies between individual, social, cultural, and religious perceptions, and suggest a point about sexual behaviour and HIV transmission. This is about rules, culture, context, dirt, purity, aesthetics, religion, morality, and hygiene. First, I was trimming a flowerbed and I forget to take off my shoes when I entered the house, so whether I break a rule already depends on house rules or culture. Shoes inside the house would break the rules in some houses and cultures and be marked as 'matter out of place'. In my house, I would probably be forgiven for leaving soil in the entrance hall, but would undoubtedly be cursed up and down by my significant others for leaving it on the kitchen floor. Soil is conventionally 'in place' in the garden but an unpleasant and 'out of place' matter in the kitchen. In other places, the difference between 'garden' and 'kitchen' would not be marked by surface. Soil is soil with no connotation like in the English language with its double meaning of 'earth' and 'dirt'. I then grab the dishcloth to clean the floor and immediately I break another rule: dishcloths for dishes, floorcloths for floors. This rule depends on hygiene and/or cultural convention. Some might say that 'a cloth is a cloth' and use it accordingly. I then grab a banana and thereby immediately break the next rule. I

forgot to wash my hands, which is another example of hygienic cum cultural convention. After eating the delicious banana, I carelessly throw the banana peel on the kitchen floor, only to hear my loved one scream at me: *"No, throw it where it belongs!"* Belongs? Yes, I know, it belongs in the waste bin, the stinky plastic bag that we conventionally have put on the inside of the kitchen cupboard door wrapped over the garbage bag skeleton under the sink. *"Thanks honey!"* My partner kisses me and we soon get in the mood for sex. Now, 'my loved one' and 'my partner' are imprecise terms. Breaking the rules having sex with my partner would depend on religious and cultural rules related to sex, gender, and marital status (e.g. homosexuality, sex before marriage). However, conjugal sex is still considered appropriate and thus 'in place' – at 'home', 'in the house'. Indeed, I had sex with my partner, but I was not satisfied. I therefore at some point try to get it 'outside the house'. Presto, this explains the Portuguese cultural dichotomy *casa/rua* and *fora da casa*, the cultural code for extramarital sex (see Chapter 4, p. 192). Consequently, whether this is socially acceptable or tabooed is another matter 'in or out of place'. Do I seek a lover, a dogging partner, a prostitute, or a one-night stand? I will leave at this. The point is, thinking with Gregory Bateson's famous short metalogue between a father and his daughter *Why Do Things Get in a Muddle* (Bateson 2000 (1972)), that one person's sense of order is another person's state of confusion, which in my opinion may explain the cause and effect of a presumably predominantly sexually transmitted disease like HIV. In other words, we would witness fewer HIV infections, if we all shared the same perceptions of purity and danger. I have hereby introduced the discrepancies between individual, social, cultural, and to some extent religious perceptions of order and disorder, which challenge policy makers for the prevention of HIV infection. This raises another point, in my opin-

ion, which does not come out of mere political correctness: levels of HIV infection must have a multitude of explanations beyond sexual behaviour (see Chapter 4, p. 195, and Note 4.3).

Mary Douglas saw taboo as a way to protect society against disorder. It must be emphasized that HIV is a socially undesirable state of being, regardless of its advancement as dormant virus, immune syndrome, or in need of multiplication inhibiting medicine. The impurity and disorder associated with HIV, as it poses a risk to others, in turn facilitates stigma. The virus-infected individual, before being attributed the accepting status as a 'person living with HIV', posed a danger to the norms of society. Reference to the risk of pollution is still widespread: many people refer to family members who avoid eating from the same kitchen utensils, avoid touching the clothes, or avoid using the same toilet as the person living with HIV. Health workers refer to colleagues who do not want to touch the patient or even the patient's protocol in fear of contamination.

I utilize a multi-dimensional stigma theory. Most studies take Erving Goffman's definition of stigma as a starting point (Goffman 1963), whether conceptual or empirical. However, they diverge into two separate paradigms. One focuses on psychological characteristics of the individual and the isolated behaviours of the stigmatizer and the stigmatized. The other one places this behaviour in social context. For example, a social psychology perspective defines stigma as a lasting 'condition', 'status', or 'attribute', negatively valued by society (Herek 2002: 596). The other tendency looks at stigma as a social process and how stigma relates to macro-social inequalities in an attempt to avoid the reification of stigma inferred in the psychological approach. The argument corresponds to the social paradigm that explains the development of the HIV epidemic in historical and structural terms as

opposed to individual behaviour and culture (Fassin 2007; Stillwaggon 2006). However, the particular anthropological crux of the stigma debate insists that perceptions and attitudes are grounded in broader social context, particularly the production and reproduction of social inequality (Castro and Farmer 2005; Parker and Aggleton 2003). The definition of stigma as 'attribute' originates from Goffman, but the anthropological school of thought avoids its essentialist meaning, which objectifies the quality of stigma within the stigmatized person. Link and Phelan suggest the term 'label' to avoid the essentialist terms 'attribute' and 'mark'. They argue that stigmatisation stems from social processes with an emphasis on its temporality: it may come and go (Link and Phelan 2001: 368). This creates a multidimensional definition of stigma:

1. *Labelling*: people distinguish and label human differences.

2. *Stereotyping*: dominant cultural beliefs link labelled persons to undesirable characteristics and to negative stereotypes.

3. *Separation*: Labelled persons are placed in distinct categories to accomplish some degree of separation of "us" from "them".

4. *Status loss*: Labelled persons experience status loss and discrimination that lead to unequal outcomes.

5. *Discrimination*: Stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination (Link and Phelan 2001: 367).

Stigma features, according to Link and Phelan, a co-occurrence of labelling, stereotyping, separation, status loss, and discrimination. Link and Phelan elaborate this

definition within a broader perspective of power, domination, and social exclusion: they emphasise stigma as a form of violence – particularly structural and symbolic violence. Additionally, a synthesising perspective between the individual and macro-social levels of analysis has been proposed as a means to improve our understanding of causes, experience and consequences of stigma over time (Campbell and Deacon 2006; Deacon 2006; Mills 2006).

In the Haitian context, Castro and Farmer found that logistic and economic barriers determine who will have access to health services, not primarily stigma (Castro and Farmer 2005). That is, associated costs (transportation, medicine against opportunistic infections, food and water) during hospital visits limit access to health services. They base their findings on long-term fieldwork in Haiti, one of the poorest countries in the world and comparable to Mozambique. I agree with Castro and Farmer that quality HIV care can lead to a rapid reduction in stigma, with resulting increased uptake of testing. However, my own fieldwork has shown that in such environment of free ARV treatment, a combination of persistent historically based humiliation (e.g. poverty, the development rhetoric, and the 'AIDS kills' campaign) and limited health system capacity perpetuate stigma. I do not see it as an either-or situation or a matter of ranking of access barriers, as implied by Castro and Farmer. Logistic and economic barriers interrelate with and feed different forms of stigma (see Figure 3.1, p. 134).

We see a transitional period between two understandings of HIV in Mozambique: from *lethal* to *chronic* disease. The ARV era in the public health system began in 2004, which promised to give hope and evidence of a prolonged life, but the majority who cannot access these medicines are not ignorant of this event. They are left in disappointment and despair, which feeds humiliation, discredit, and

silence. Castro and Farmer would call this a consequence of structural violence, which they define as social inequalities like racism, sexism, political violence, and poverty, rooted in historic and economic processes that negatively shape society. Structural violence predisposes the human body to pathogenic vulnerability by shaping risk of infection and the rate of disease progression. Structural violence determines access to health services and who suffers from HIV related stigma and discrimination (Castro and Farmer 2005: 54). However, such structural determinism initially fails to see how its effects are received, reproduced, reinterpreted, and communicated in present times. Indeed, I will discuss different types of violence in Chapter 8 as one important reading of my access and delivery model, but before then, there is much first-hand observation to be unravelled.

Individual Access Barriers to ARV Treatment

This leads us to the key analytical tool applied in this study: the interrelatedness of individual, social, and political processes. Anthropologists Nancy Scheper-Hughes and Margaret Lock developed this analytical distinction during the late 1980s as a branch of Critical Medical Anthropology (Scheper-Hughes and Lock 1987). They define the individual body in a phenomenological sense as *lived experience*, a perspective with roots in the work of Mary Douglas and Marcel Mauss. Mary Douglas also inspired the concept of the social body as the symbolic representation by which humans think about nature, society and culture (Douglas 1996 (1970)). The body politic, on the other hand, refers to the regulation, surveillance, and control of both the individual and collective body. Clearly, Michel Foucault's work on mad-

ness, clinical medicine, punishment and sexuality, and power and knowledge inspired this perspective (Foucault 1967; Foucault 1976; Foucault 1977; Foucault 1980; Foucault 1981).

Scheper-Hughes and Lock developed the 'three bodies' as three separate yet overlapping units of analysis, which expose three theoretical orientations and epistemologies: phenomenology (individual body, the lived self), structuralism and symbolism (the social body), and post-structuralism (the body politic) (Scheper-Hughes and Lock 1987).

The purpose of this chapter has been to avoid either/or propositions of how and whether individual and social barriers exist and to avoid any ranking of obstacles to access ARVs. I have instead focussed on the interrelated nature of the complex web of obstacles to access and the agencies of individual and collective groups of people living with ARVs. The empirical access and delivery model exposes the experiences, limitations, and politics of ARV treatment in Mozambique, inspired by the 'three bodies' (see Chapter 3 Figure 3.1, p. 134).

I started out with a view from a Day Hospital, Gilberto's life story, support groups, and a description of individual and shared experience living with HIV, AIDS and ARVs. The analysis of silence, sensitization and voice prepared an inductive pathway towards an understanding that public campaigns about HIV as a lethal disease and the reality of material and human scarcity in the health system fuels and produces stigma at the social and individual levels. It is the sour grapes phenomenon – treatment is available but out of reach – that transforms into increased scapegoating and self-stigmatisation. In other words, limited access to ARV treatment produces inequality and links to the reproduction of social difference (Parker and Aggleton 2003). This is captured in what I see as living *with* or *without* ARV

treatment as the difference between the *fortunate minority* and the *silent majority*. My focus so far has been on the former, while the 'invisible' majority, who do not come forward for HIV testing and treatment, and who are not approached in a public health manner due to capacity constraints of the health system, will be the focus of the next chapter.

One day I met Marco by happenstance at MONASO. Marco asked me what I had been doing for such a long time since last time we met. I said that I was visiting the Day Hospitals in Maputo talking to many people living with ARVs about their illness experience. Marco wanted to know what they told me, and what I had learned, as he looked at me with a somewhat sceptical and challenging face. I cautiously and thoughtfully told him the story I have described in this chapter. Marco smiled, reached out his hand suggesting a friendly greeting, and said to me: *"That is exactly what I have been through myself."*

2
Living Without ARVs

2: Living Without ARVs

One morning I met Marco on my way to a Day Hospital walking the streets of Maputo with clear blue skies, fresh and mild coastal winds. We had talked about this many times, but I asked him again: *"Do you know anyone who has taken the HIV test, is HIV positive, is eligible for treatment, who definitely wants treatment, but does not have access to treatment?"* Marco replied without hesitation: *"Yes, I know many. Some live here in Maputo, others live far away without means of transportation and access to treatment. People want to live! I know several who have even taken the test 4-5 times but still do not have access to treatment. The hospitals are delaying treatment, even the consultation for CD4."* Then I recalled similar stories: *"Oh, because of waiting lists, you mean they come to the day hospital and they are told that the next available consultation is within a month, or perhaps within 2-3 months."* Then Marco looked at me somewhat frightened and insulted: *"No, often up to one year later!"*

However, Marco was reluctant to bring me to the ones in need of treatment. I kept asking around for advice where to go and whom to talk to, but the usual answer would be: *"I can't tell you who they are"*. Anisia, who herself lives with HIV, explained that she often goes to meetings, where they discuss the problem of HIV and everyone would agree that HIV is a problem, but they would mention it in third person neutral, such as: *"There is a problem"* or *"Many people have HIV"*. You never hear personal statements, such as: *"I have a problem"* or *"I have HIV"*. Anisia then explained: *"Therefore I cannot tell you that Isaac, Paula, and Emma have a health problem or have HIV and don't have access to ARV treatment"*.

I sensed Marco and Anisia's reluctance to put me in contact with people who lack access to treatment. I thought they would breach other people's silence and invisibility against their will and I therefore felt that their position was perfectly justified. I decided to tread with caution. An aggressive researcher was the last thing on earth they needed. What else than answers to my questions and their life stories did I want from them? Thirty minutes of talk? What could I give them in return? A conversation with me would not give them access.

How can I represent the people 'living without ARVs'? We see that the majority of people remain 'invisible': they do not come forward to test for HIV. We see limited health system capacity, which means that many of those who do reach out are rejected for testing and/or treatment. The two kinds of people have one thing in common: They fall victim to structural violence and invisibility. Therefore, I analyse the epidemiological data, interpret their meanings, and juxtapose prevalence, testing, treatment need, and treatment coverage data to prepare and qualify the health system chapter about infrastructure and health personnel needs.

Epidemic Evolution

I relate epidemic evolution and the Mozambican response to HIV to explain how and why the majority of people estimated to have HIV go untested for the virus and those in need without treatment. This provides a qualitative assessment of epidemiological data to explain why the majority of people live *without* ARVs.

Access to State Numbers

The following analysis relies on access to information at the Ministry of Health, the National AIDS Council, and the National Institute of Statistics. I met with 11 key persons and asked for information related to prevalence, testing, treatment need and coverage, ART expansion, infrastructure, and human resource needs to compare and contrast these kinds of data over time. Key Ministry of Health sites were: the Board of National Health, Department of Medical Assistance, the Pharmaceutical Department, the National STI/HIV/AIDS Programme, Department of Health Information, Board of Human Resources, and Bureau of Information.

It was at first a Kafkaesque experience to find my way through the maze of boards, departments, and councils, but then an awarding one talking to the right people and the right time. You ask for directions within a ministry: no one is sure where this or that site is located. 'Try on the fourth floor'. There they said: 'No, try on the first floor'. 'No, try on the second floor'. The Ministry of Health is open to visitors, but it is widely known to be difficult to approach for all parties of the partner community in terms of direct communication and getting an appointment. This is common to bureaucratic institutions in many places. Consideration of single cases is time consuming. They are busy. The Ministry is understaffed. Foreign consultants were kicked out in large numbers. Some Mozambicans followed. However, everyone was welcoming and friendly, once I had gone through the rites of formality. I wish I could have stayed longer and more intensely at the Ministry of Health. I would have liked to follow some of the senior members of the ARV committee, who manage the expansion of ARV treatment in specific provinces, to get an insider perspective on health governance in times of HIV.

A Generalized Epidemic

Mozambique is one of the poorest countries in the world, ranked 172 out of 177 countries on the UNDP Human Development Index (UNDP 2007). According to preliminary results of the third census from 2007, the population increased 28 percent between 1997 and 2007 to 20,530,714 inhabitants (National Institute of Statistics 2008). Maputo province experienced the biggest increase at 52 percent, principally by migration from Maputo City, which has experienced the smallest growth at 5.4 percent over the ten-year period. Maputo City had 1,099,000 inhabitants in 2007. Maputo folks primarily move to the new residential zones in the sister city Matola, and in Boane and Marracuene. Almost 40 percent of the entire population resides in the two northern provinces of Zambézia and Nampula (ibid.).

The Maputo Central Hospital began to test for HIV in 1996. The first VCT centres opened in 2001. I include national level testing statistics for the first 4 years they were available: 2002-2005 (see pp. 105-117). In summary, more than half a million people of all ages tested for HIV during this period of which 140 thousand tested HIV positive (Ministry of Health 2006f). In other words, only some 5 percent of the adult population, 2.5 percent of the children, and 2.7 percent of the total population had tested for HIV by 2005. The 140 thousand HIV positive tests account for about nine percent of the estimated 1.5 million HIV infected people by the end of 2007 (UNAIDS 2008).[1] Close to 6 million Mozambicans would need to test for HIV to find the 1.5 million Mozambicans estimated to have HIV, as an average of 26 percent of those who test for HIV turn out HIV positive. This is an unrealistic number of HIV tests, given the limited capacity for population based HIV testing and the limited voluntary testing demand.

We need to look at the course of the epidemic to understand this scenario and the increasing number of people in need of ARV treatment. The first AIDS case was reported in 1986. HIV grew into a generalized epidemic by the end of the decade, characterized by its grip on the general population and HIV prevalence consistently over 1 percent in pregnant women, as defined by the Working Group on Global HIV/AIDS and STI Surveillance (UNAIDS/WHO 2003). Natural epidemic history follows three distinct phases, which follow an S-curve: slow increase, rapid increase, and plateau. There are two distinct epidemic curves, one for HIV and AIDS (Barnett and Whiteside 2006 (2002): 52) (see Figure 2.1).
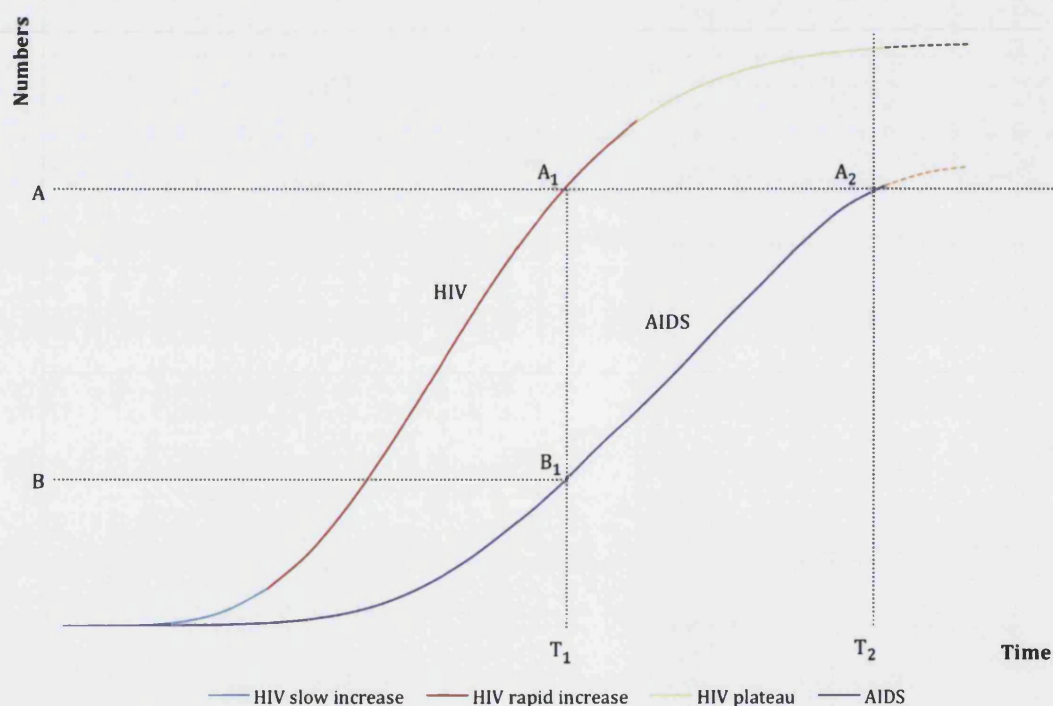
Figure 2.1: Epidemic HIV and AIDS Curves
Source: (Barnett and Whiteside 2006 (2002): 52).

This illustrates the mutual relationship between numbers of infection and time. The number of AIDS cases (B_1) is lower than the number of people infected with HIV (A_1) at a given time (T_1). The number of AIDS cases, corresponding to A_1, will

only be reached much later (T₂), when the number of people infected with HIV in the meantime has grown much bigger (Barnett and Whiteside 2006 (2002): 53).

Infected people live through four clinical stages from HIV infection to AIDS: 1) asymptomatic, 2) moderate symptoms, 3) severe symptoms, and 4) AIDS (WHO 2005). The median time from seroconversion to clinical stage 2 has in one study been found to be more than 2 years (25.4 months) and to stage 3 close to 4 years (45.5 months) (Morgan, et al. 2002b). The median time from seroconversion to death without treatment intervention varies between study cohorts: Uganda 10.2 years (Morgan, et al. 2002a), overall survival in East African studies 10.3 years, South African miners 10.5 years, 2 Thai studies 7.9 years, Haiti 7.4 years (Todd, et al. 2007), Tanzania 11.5 years (Isingo, et al. 2007), Rakai Uganda 8.7 years (Lutalo, et al. 2007), Uganda 9.0 years (Van der Paal, et al. 2007), and Thailand 8.4 years (Rangsin, et al. 2007). This points to the heterogeneity of survival patterns and the need for localised estimates of AIDS mortality and ART needs, according to improved methods from 2007 (Stover, et al. 2008; Wandel, et al. 2008).

A Context Specific Epidemic

An epidemic obviously needs appropriate intervention, but the experience of HIV has shown a nonlinear relation between the natural history of HIV and its responses in poor countries. Appropriate measures were not taken at the right moment. Surveillance, testing, and treatment were introduced at intervals over more than two decades. Health systems across Africa were weak and unprepared for HIV, AIDS, and ARVs. The international community hesitated, remained inactive, and it

was unable to make a difference at the speed normally needed in an emergency. People do not come forward to test for HIV or they test at the very latest stage of the disease. This is a long-wave event that most emergency response mechanisms have not been able to, and still cannot, engage with efficiently. Drug patents and drug prices prohibited dissemination of medicines to those in need. There were not enough health workers to do the job and they are still in demand.

I redefine epidemic evolution as responses over time by people living with HIV, the public health system, the government, and the international community to merge natural disease history with social reality. Eight epidemic phases show the specific epidemic history in Mozambique (see Figure 2.2). These phases comprise an interrelated pattern of HIV epidemic fragilities, which I elsewhere discuss in terms of state fragility and capacity (Høg 2008). This pattern of fragilities includes weak responses from all actors.

Phase 1 began in the early 1980s. There were possibly some unreported cases of HIV and AIDS before the first reported AIDS case in 1986. The Mozambican government believed it came from the outside, as declared in the very first paragraph of the National Strategic Plan from 2005: *"The first AIDS case in Mozambique was diagnosed in 1986. It was a foreign citizen who had already been infected, when he entered our Country"* (National AIDS Council 2005: 5). The epidemic grew steadily during the late 1980s, but people were largely ignorant about HIV. Sentinel surveillance started in 1988 with one site in Maputo City, which increased to 20 sites nationwide by 2000, and 36 sites in 2001. The first national HIV surveillance in 2001 estimated 13.1 percent HIV prevalence (Ministry of Health 2005d).

Figure 2.2: Epidemic Evolution and Response in Mozambique
Source: (Høg 2008).

	HIV Epidemic	PLWA	Public Health System	Government	International Community
Phase 1: < 1986	No AIDS reported Some HIV infections	Ignorance	Not prepared	Ignorance	Inaction
Phase 2: 1986-2001	AIDS reported More people infected	No access to treatment Silence, fear, shame Hopelessness, no expectation	Limited surveillance No intervention Lack of resources	Denial, blame, despair Resouce mobilisation Political response AIDS Commission Epidemic Alert	Some action Drugs too expensive for Africa
Phase 3: 1995 >	Severe illness and death Large number of orphans TB and malaria are major killers	No access to treatment Silence, fear, shame Hopelessness, no expectation	Not prepared Improved surveillance	STD/AIDS Programme	Some action Drugs too expensive for Africa
Phase 4: 2001-2002	A few cases seen by medical services	Affluent get ART In private clinics	Not prepared	National AIDS Council Strategic Plan excl. ART Exclusive selection process Reproduction of difference	ARV price drop
Phase 5: 2002-2004	More people seen by NGOs	Gratitude Low expectation	In preparation	HIV and AIDS Labour Law	Funding Technical assistance
Phase 6: 2004 >	Public Health Services provide free ARVs	Gratitude Disappointment Some expectation	ART expansion begins	Strategic Plan incl. ART	Implementation starts
Phase 7: 2005 >	AIDS cases overwhelm the health services	Gratitude Disappointment, understanding Withdrawal, silence Low expectation	Under expansion, but cannot keep up Overload, absenteeism Brain drain	Capacity building Infrastructure	Capacity building Infrastructure
Phase 8: 2006 >	Loss of human resources in increasingly large numbers	Gratitude Disappointment, understanding Withdrawal, silence Low expecation	Under expansion, but cannot keep up Human resource crisis Increased absenteeism/overload	Insists on Mozambican work force Some expatriate recruitment	Supports the government, but suggests alternative transnational solutions

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Small-scale treatment by international organisations began in 2001-2002 and large-scale in the national health system in 2004. Phase 2 *without treatment* thus lasted about 16 years. Those infected early during this evolution died from the mid-1990s in Phase 3, which left many children orphaned.

The government 'AIDS Kills' campaign from the early 1990s to 2004 left people without hope. Treatment of HIV related diseases was not mentioned in the national strategic plan for the period 2000-2002 (Council of Ministers 2000).

Neither people living with HIV, nor the public health system, nor the government and the international community were prepared, when appropriate action was needed. Immediate public health and political response in terms of health system preparation occurs only in an imaginary scenario. That is, the epidemic would ideally need improvement of health system infrastructure, human resource planning, and drug availability at its inception. Moreover, it would need uninhibited people coming forward for voluntary or mandatory testing and treatment. None of this has been the case in any country in the world.

Phase 4 began in 2001, when a few privileged members of the elite benefited from ARV treatment (Matsinhe 2005). Treatment became available in private clinics in Maputo, and in Nelspruit, South Africa, for the few who could afford it. Phase 5 began when MSF and Sant'Egidio started small-scale ART services in a few provinces in 2001-2002. Phase 6 began by mid-2004, when the government embarked towards free ARV treatment for all within the public health system, supported by the international community. The fortunate minority of people living with ARVs have felt thankful during these phases, while the silent majority have been tormented by fear and shame, been disappointed, and have had low expectation of support from the health system. This leads to the point that treatment

providers have to find ways how to deal with failed treatment expectations (Bernays, et al. 2007), instead of mere rejection that fuels the cycle of depression.

The medical services attended an increasing number of HIV and TB patients during Phase 6. The Mozambican epidemic soon moved into Phase 7 in which the number of AIDS cases overwhelms the health services. This is part of the reality experienced from the beginning of ARV delivery in the public health system from 2004 onwards. Mozambique experiences a human resource crisis, despite capacity building initiatives. It is an enormous challenge.

Phase 3 continues, despite health system improvement, with many people severely ill. They arrive at the health facilities at the last minute (see Chapter 1, pp. 45-46). However, people living with HIV cannot exclusively be blamed for this phenomenon. They are as much victims of structural violence. Their reluctance to come forward for treatment is a mix of psychological barriers, use of alternative therapeutic options, low expectation, poverty, distance and cost, limited health system capacity (see Figure 3.1, p. 134), and lack of nationwide renewal of the old 'AIDS Kills' campaign, which still reigns in the minds of people.

Prevalence projections indicated that AIDS had become one of the main causes of death by 2004. By 2010, one in every three deaths would be due to HIV related diseases. This projection showed an increase from 41,000 deaths in 1999, to 110,000 deaths in 2005, to 169,000 deaths in 2010. The cumulative death toll was estimated to reach 1.2 million by 2010. The number of orphans was estimated to be 441,451 by 2007 (National Institute of Statistics 2004).

A study on the impact of HIV/AIDS on human resources estimated an increase in AIDS deaths in the active labour force from around 300,000 to more than 2 million between 2000 and 2020 (Cohen 2004a). Therefore, Mozambique should

have reached Phase 8. However, exact data on the impact of HIV/AIDS on the la-
bour market are scarce. We only have media reports of the deaths of the work
force. For example, the Minister of the Interior announced in the Savana newspa-
per in 2005 that more than one thousand policemen die each year, which leaves
behind orphans and widows (Lopes 2005).

The eight epidemic phases improve our understanding of epidemic evolu-
tion in context, but I have also developed an assembled set of curves in an attempt
to understand the total picture of projections and the reality on the ground. These
curves juxtapose a series of numbers: HIV estimates, HIV tests, ART needs, ART
targets, and ART coverage (see Figure 2.3).
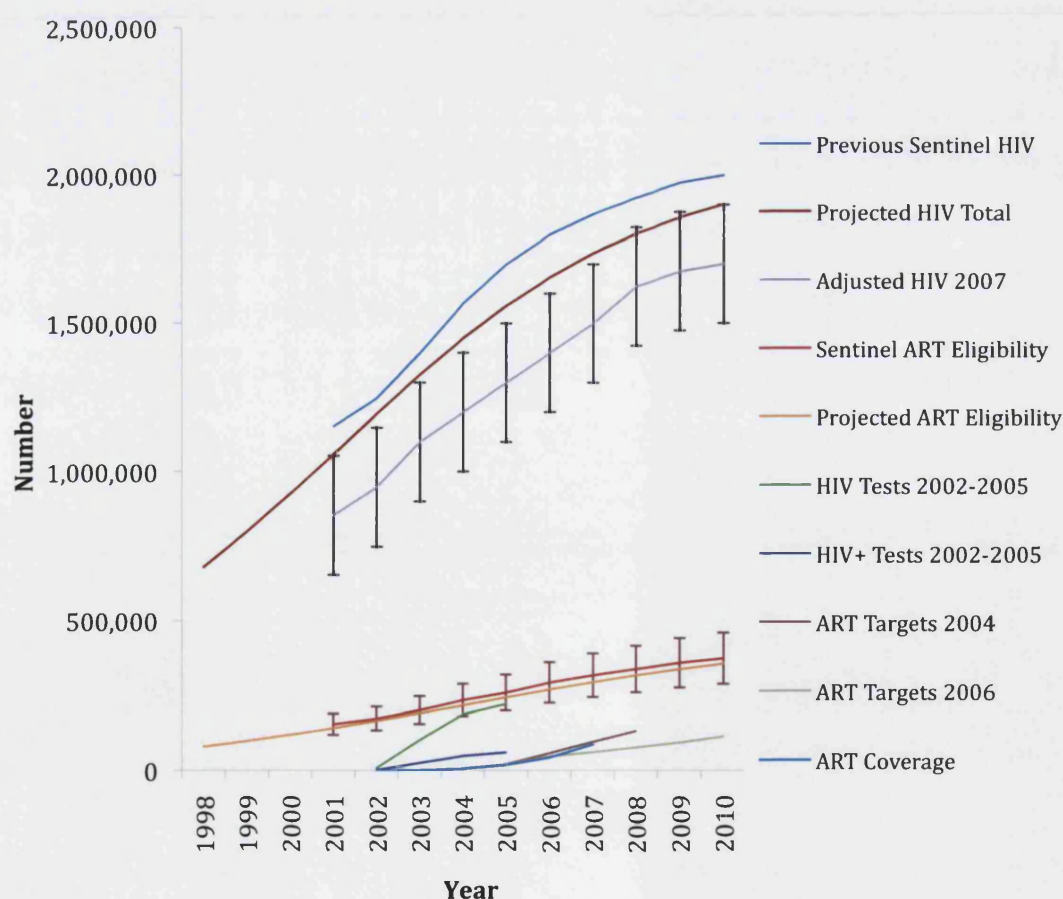
Figure 2.3: HIV Prevalence, ART Eligibility, HIV Testing, ART Targets and ART Coverage
Source: (Ministry of Health 2008b; UNAIDS 2008).

The previous sentinel prevalence data are above the projected prevalence seen over the 12-year period 1998-2010. Then UNAIDS lowered its estimate to 1.5 million (range 1.3-1.7 million) Mozambicans of all ages living with HIV by the end of 2007 (UNAIDS 2008). The 2002 demographic impact study projected that 16.2 percent of the adult population would have HIV in 2009, which in 2004 was adjusted to 16.1 percent in 2006 (National Institute of Statistics 2002; National Institute of Statistics 2004). However, the 2004 sentinel surveillance already showed that 16.2 percent of the adult population had HIV (Ministry of Health 2005d) (see also Prevalence 1988-2007, pp. 101-105). Another example: the original ART target in the National Strategic Plan was lowered in 2006 from 132,000 to 78,000 on treatment by the end of 2008. The real coverage in 2007 was 88,211, thus below the original target at 96,000, but above the revised target at 62,000 (Ministry of Health 2008a; Ministry of Health 2008b) (see Figure 2.3).

Evolution of ARV Eligibility

The sentinel and the projected prevalence give two different estimations of people in need of ARV treatment. Therefore, we need to analyze how treatment needs are measured to understand this in relation to the estimated number living with HIV. The UNAIDS Reference Group on Estimates, Modelling, and Projections decides the criteria how to estimate ART eligibility by differentiating between *new ART eligible patients, annual mortality, incidence dependency,* and *future accumulation.* This reference group worked according to the following assumptions in 2006:

New ART eligible patients
Individuals who progress to a state 2 years from death due to AIDS
need ART

Annual mortality
Those who receive ART are subject to 10% annual mortality

Incidence dependency
Depends on incidence of HIV some years previously, corresponding to
the time of infection

Total number
The total number of people needing ART is the sum of the number of
people newly needing it and the number of survivors from the
previous year

Future accumulation
This total number accumulates in future years and remains dependent
on the number having received treatment in previous years (UNAIDS
2006a; UNAIDS 2006b).

If 100,000 people were infected in 1992, then all of them would need ARV treatment some 8 or 9 years later. With regard to the total number in need of treatment, a WHO plan says more specifically: *"The estimated total number needing antiretroviral therapy is based on the estimated two-year mortality plus 80% of those currently receiving treatment"* (WHO 2004: 62).

These assumptions were updated in 2007 by the UNAIDS Reference Group. Major enhancements were made in response to 1) a review of the US Census Bureau programme, 2) new evidence from cohort studies, 3) revised child treatment guidelines, and 4) a need to produce uncertainty bounds for all estimates (Stover, et al. 2008: i24). Estimates of the time from ART eligibility to death without treatment intervention were longer than previously estimated by Boerma and colleagues (Boerma, et al. 2006). ART eligibility now rests on a CD4 count below 200 cells per microlitre blood or WHO clinical stage 4 or a combination of a CD4 count between 200 and 350 cells per microlitre blood and WHO clinical stage 3. This results in a shorter period between HIV infection and ART eligibility and a longer pe-

riod between ART eligibility and death without treatment intervention (Stover, et al. 2008: i26). This explains why the number of Mozambicans in need of ARV treatment has increased to 370,000 (range 290,000-460,000) by the end of 2007, while the updated adult HIV prevalence was lowered from 16.0 percent to 12.5 percent due to experience from population based surveys (WHO/UNAIDS/UNICEF 2008).

Natural disease history explains the differences between the number of people with HIV and AIDS, and the need for ART. Then keep in mind that many people die without treatment and that incidence remains high in Mozambique: it has been estimated to be 500-700 new infections per day, or 182,500-255,500 per year (National Institute of Statistics 2004). In other words, the fact that 1.2 million people carry HIV does not mean that 1.2 million people need treatment some 9 years later (see Figure 2.4).
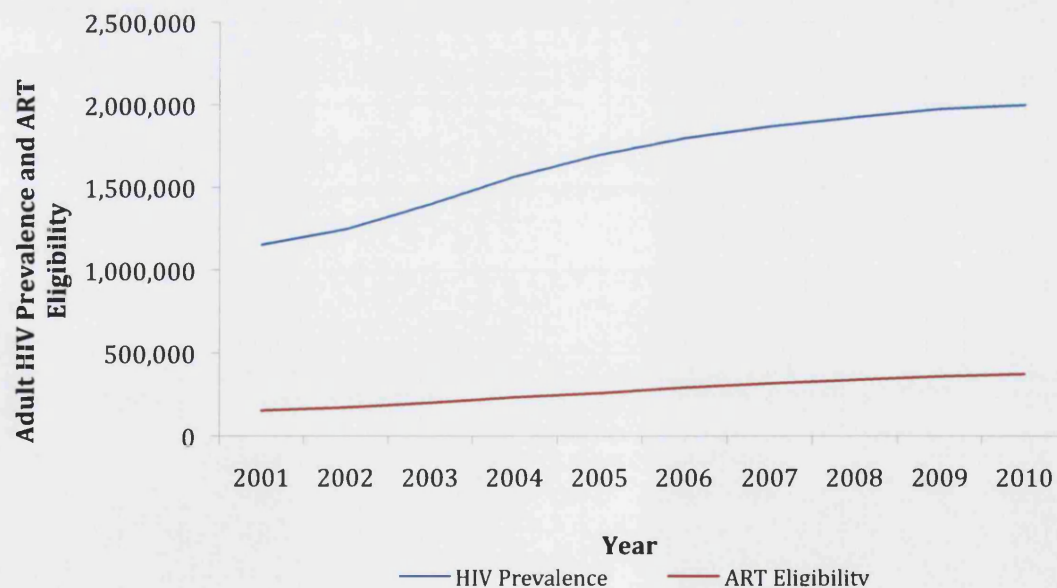
Figure 2.4: HIV Prevalence and ART Eligibility among Adults, 2001-2010
Source: (Ministry of Health 2006d).

However, we do not know the final course of the S-curve. There are only two ways that HIV prevalence can decrease, in this case in the age group 15-49 years: 1) people die, or 2) there are more HIV negative 14-year-olds who turn 15, than HIV

positive 49-year-olds who turn 50. If we then add the fact that only a few of those children who acquire HIV during the peri-natal period survive until the age of 10, then we have the HIV negative age group 10-14 year olds called *'A janela de esperança'* – the window of hope (National AIDS Council 2005).

Prevalence depends on the relation between the number of deaths and the number of new infections, as indicated above. Thus, the number of people in need of treatment depends on the relation between old and new infections and the point in time, when treatment became available and the expansion of the health system. In blunt terms, people fall out of this calculation when they die without treatment.

Adults

The increase in ART eligibility with the added uncertainty range points to profound implications for the need of financial resources to keep up with sufficient health system infrastructure and human resources. However, such estimations matter little to hardworking people on the ground, who can hardly keep up with the increasing demand, yet only caring for about one out of four adults in need of ART. The need for infrastructure and health workers will remain astronomic. No Southern African country has managed to treat the lowest estimated number of people in need of treatment, except Botswana.[2]

Children

Children progress faster from HIV infection to AIDS, primarily due to their weak immune system. About 75 percent of children with HIV need treatment. The number of children living with HIV increased from around 103,000 in 2005 to more than 121,000 in 2008 (Vaz 2006). This means an increase in number of children in need of antiretroviral treatment from more than 68,000 in 2005 to more than 83,000 in 2008 (see Figure 2.5).
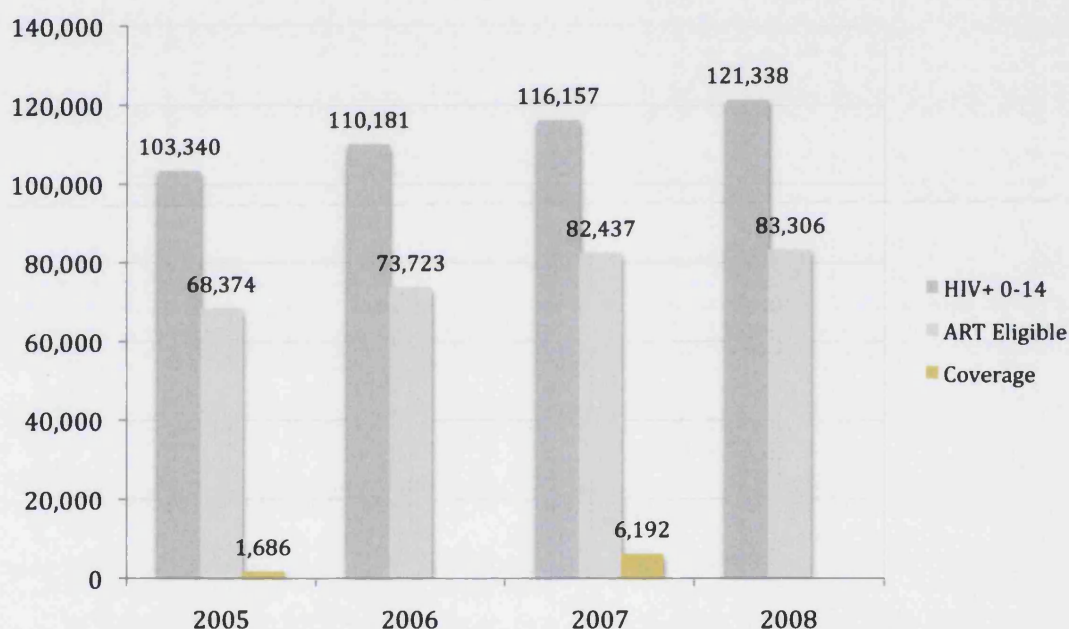
Figure 2.5: HIV Prevalence and ART Eligibility among Children, 2005-2008
Sources: (Ministry of Health 2008c; Vaz 2006).

Only 1,686 children were on treatment in 2005 due to weak health system capacity (Vaz 2006). This increased to 6,192 children on ARV treatment out the targeted 11,820 children in 2007 (Ministry of Health 2008a; Ministry of Health 2008c). The government and donors have taken several initiatives to improve the situation, but the adult-child ratio is telling: adults enjoy preferential treatment with little global advocacy to change this in favour of children.

Evolution of HIV

Synchronous responses remain illusory, given limited local resources, capacity, and absorptive constraints. Affordable drugs were not made available until the beginning of the new millennium. Health systems were weak across Africa. Governance, surveillance, testing, treatment, support, infrastructure improvement, and training of health workers do not run in parallel. A closer look at epidemic evolution reveals evident staggered responses, but more importantly, how response needs accumulate both because of this and the natural evolution of the epidemic. I compare sites (sentinel, testing, and treatment) and numbers (prevalence, HIV tests, ART need and coverage, and human resources) in empirical detail to comprehend the magnitude of the problem and the implications for human and material resources needed to respond adequately (see Table 2.1).

Table 2.1: Sites and Numbers, 1988-2007

Sites	1988	1994	2000	2001	2002	2003	2004	2005	2006	2007
Sentinel	1	4	20				36			
Testing				5	27	84		155	359	
PMTCT					8	17	51	93		386
ART					3		23	38	150	211
Numbers										
Prevalence, %				14	15		16			16
HIV, m.				1.1		1.7		1.8		1.5
HIV tests					9,164	102,487	188,255	222,775		
HIV+ tests					2,353	26,009	49,459	61,346		
HIV+ %					25.7	25.4	26.3	27.5		
ARV need					230,000	250,000	270,000	300,000	330,000	370,000
ARV coverage							7,414	19,726	44,100	88,211
HR need								1,908		

Sources: (Ministry of Health 2004; Ministry of Health 2005c; Ministry of Health 2005d; Ministry of Health 2006f; Ministry of Health 2007b; Ministry of Health 2008a; Ministry of Health 2008b; Ministry of Health 2008f; National AIDS Council 2005; National AIDS Council 2006; UNAIDS 2008; UNAIDS/WHO 2002; UNAIDS/WHO 2006c; WHO/UNAIDS/UNICEF 2008).

Prevalence 1988-2007

The Mozambican government established the National STI/HIV/AIDS Programme in 1988. This was 2 years after the first AIDS case had been reported. Mozambique had only one sentinel surveillance site until 1994, when three more sites opened in the central region. This expanded to 20 sites in 2000 and 36 sites in 2004, dispersed in all 11 provinces. The first national epidemiological survey was conducted in 2001, then in 2002, 2004, and 2007.

The 2007 update was performed with improved surveillance methods. The national adult HIV prevalence was estimated at 16 percent, with some regional variation: South (21%), Centre (18%), and North (9%) (Ministry of Health 2008f). The prevalence was estimated at 16.2 percent in 2004 with regional variation: South (18.1%), Centre (20.4%), and North (9.3%) (Ministry of Health 2005d).

The epidemic seems to have stabilized, as prevalence by means of the new surveillance methods was estimated to be the same in 2007 as in 2004. That is, historical prevalence rates were consequently updated in 2007. Sentinel based prevalence increased from 14 to 16 percent between 2001 and 2007, which replaced the previous estimates from 13 to 16.2 percent. However, the new UNAIDS assumptions mean that prevalence rates have been lowered to approximately 0.8 times the prevalence found in antenatal clinic surveillance in countries like Mozambique without population-based surveys to provide a more accurate estimate of the number HIV infected people (see Figure 2.6, and Note 2.1).
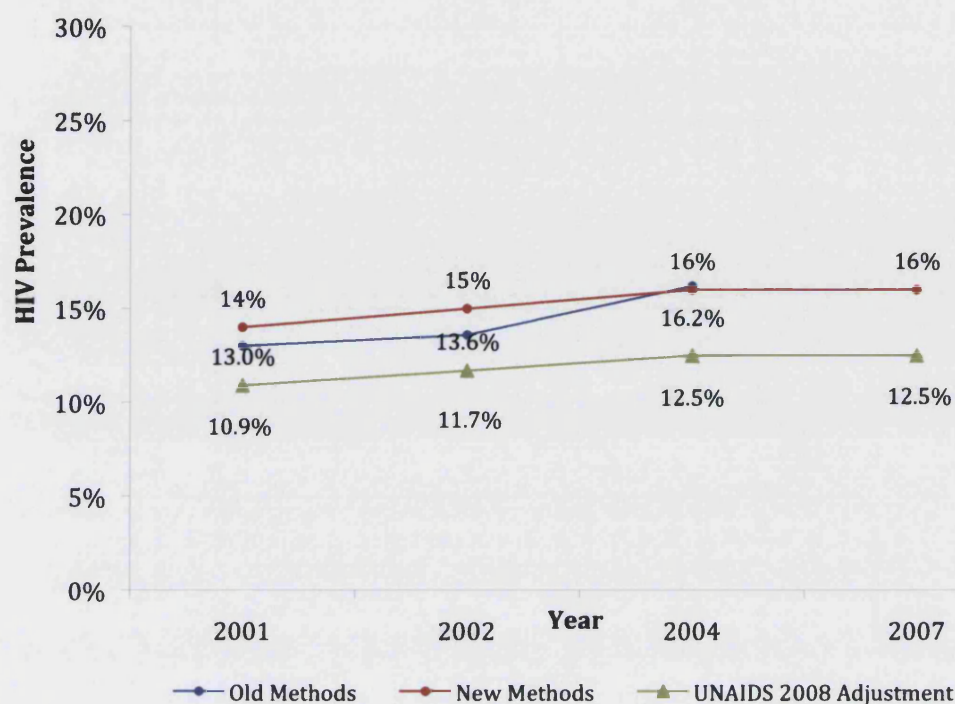
Figure 2.6: HIV Prevalence, 2001-2007
Source: (Ministry of Health 2008f; WHO/UNAIDS/UNICEF 2008).

However, the southern region for the first time showed the highest regional senti-

nel based prevalence, previously found in the central region (see Figure 2.7).
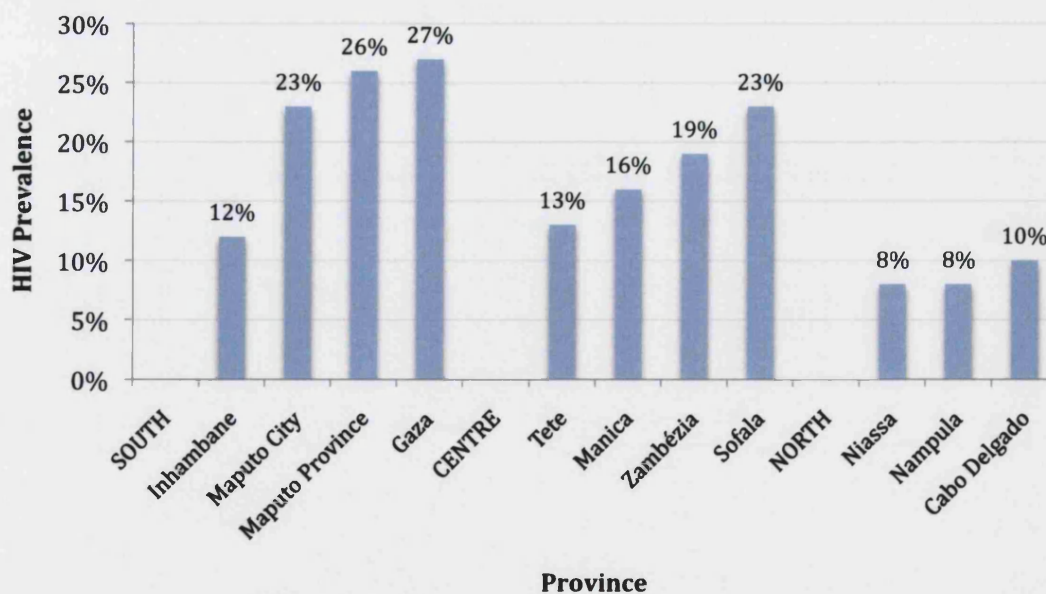
Figure 2.7: HIV Prevalence, South, Centre, North, 2007
Source: (Ministry of Health 2008f).

This could be explained by the coexistence of sub-epidemics, in the North, Centre, and South. The HIV epidemic in the central region can be seen as the oldest epidemic, which would reach its peak earlier than the southern epidemic. Thus, the southern epidemic was still growing in 2007 (see Figure 2.8).

	2001	2002	2004	2007
Gaza	19%	21%	25%	27%
Maputo Province	16%	18%	22%	26%
Maputo City	17%	18%	21%	23%
Inhambane	8%	9%	10%	12%

Year

Figure 2.8: Increasing HIV Prevalence, South, 2001-2007
Source: (Ministry of Health 2008f).

On the other hand, the new sentinel based estimates suggest that the HIV epidemic in the Centre has reached its plateau, indicated by decreasing figures over the 2001-2007 period in three of the four central provinces. Sofala, Manica, and Tete are the provinces with the highest population mobility with the neighbouring countries Malawi, Zambia, and Zimbabwe. Only Zambézia saw an increase in HIV prevalence between 2001 and 2007 (see Figure 2.9).

Coexisting epidemics could be explained by different patterns of migration. HIV started early in the Centre, presumably due to high population movement along the Beira corridor, which connects Zimbabwe and the central coast of Mo-

zambique (Cohen 2004a; Collins 2006). A large population of migrant workers
follow the Maputo corridor linked to the high prevalence neighbouring countries
South Africa and Swaziland. This may influence the spread of HIV.[3]

	2001	2002	2004	2007
Sofala	25%	24%	24%	23%
Zambézia	16%	17%	18%	19%
Manica	18%	17%	16%	16%
Tete	16%	15%	14%	13%

Figure 2.9: Decreasing HIV Prevalence, Centre, 2001-2007
Source: (Ministry of Health 2008f).

UNAIDS/WHO suggests that 1.5 million Mozambicans (range 1.3-1.7 million) were
living with HIV by the end of 2007 (UNAIDS 2008). This puts Mozambique second
to South Africa in absolute numbers of HIV cases in southern Africa. Incidence is
about 225,000 new infections per year, and annual deaths due to AIDS have in-
creased from around 33,000 in 1998 to around 123,000 in 2006 (National Institute
of Statistics 2004). However, the mid-2000s AIDS case notification system captur-
ed only about 9 percent of the number of AIDS cases estimated by epidemiological
impact studies (National AIDS Council 2005), due to lack of physical and human
resources (Chilundo, et al. 2004).

We have seen how HIV prevalence increased – *and decreased* – between 2001 and 2007. Resources were not in place to offer the advocated universal access package of 'testing, treatment, care, and support' within the public health system until 2004-2005. Testing and treatment became widely available during 2006 and 2007, aided by international organisations and external funding to improve the Mozambican health care system, but the late coming of these initiatives in light of epidemic evolution makes it a daunting task to make up for lost time.

Testing 2002-2005

HIV testing is the first crucial step to gain access to one of the 216 treatment sites in place by May 2008 (Ministry of Health 2008a). Testing for HIV beyond the Central Hospital began in 2001, 13 years after the first local sentinel surveillance in 1988. However, few Mozambicans test for HIV. This is a pattern seen across Africa. Moreover, construction of new ART sites does not automatically mean that people confidently and uninhibitedly come forward for testing clapping their hands showing gratitude. Will people come to the mountain or will the mountain come to the people? Ninety-five percent of the adult population stay away from the VCT centres, while the health system and the government remain reluctant to advertise HIV testing combined with ARV treatment.

Five VCT centres opened in 2001: two in Maputo City, two in Sofala, and one in Manica. Then five types of VCT centres evolved: 1) classical, 2) satellite (district service open once or twice a week), 3) prevention of vertical transmission service, 4) youth friendly service, and 5) in-hospital service (Ministry of Health 2004: 30).

84 VCT centres had been established by the end of 2003 and 155 by the end of

2005 (National AIDS Council 2005: 72-73; National AIDS Council 2006: 26).

The Ministry of Health introduced Counselling and Testing for Health, CTH,

in 2006 to advocate provider initiated voluntary HIV testing as part of a compre-

hensive consultation of overall health. This was a move towards normalisation

within the health system to minimise stigma and discrimination associated with

the use of VCT Centres physically separated from the health centres. 359 CTH units

were registered in 2006, including 281 ex-VCT Centres and 78 vertical transmis-

sion units (Ministry of Health 2006k).[4] This is in itself an ambitious challenge. CTH

requires a new health triage structure within the health centres and hospitals after

the five VCT years. This puts more demand on health workers. Successful realiza-

tion of CTH depends whether and how these centres will rely on the old VCT infra-

structure or new infrastructure. It will also depend on training and availability of

health workers. Health triage workers will need specialized skills to diagnose and

refer patients with various health problems.

Only 23 persons tested for HIV during the first six months of 2002 at the 27

VCT centres in 8 of 11 provinces, excluding Inhambane, Gaza, and Zambézia. More

than 9,000 people tested during the second half (see Figure 2.10). The resources

provided by MSF Switzerland, MSF Luxembourg, Health Alliance International,

USA, and Médicos del Mundo, Spain can explain this. They attended more than 90

percent of all those who tested for HIV in 2002 (Ministry of Health 2006e). Seven-

ty-five percent of the tests were taken in Maputo City, Tete, and Maputo provinces,

where the international organisations operated. The large number of women

testing in Tete can be explained by the presence of the MSF prevention-of-mother-

to-child-transmission programme (see Figure 2.10).

Province   **HIV Tests by Sex, N=9,164**
                        ■ Male   ■ Female

Maputo City   1,537   1,722
Tete   749   1,547
Maputo   714   589
Sofala   618   430
Niassa   606   368
Nampula   188   84
Manica   5   3
Cabo Delgado   3   0

0   500   1,000   1,500   2,000
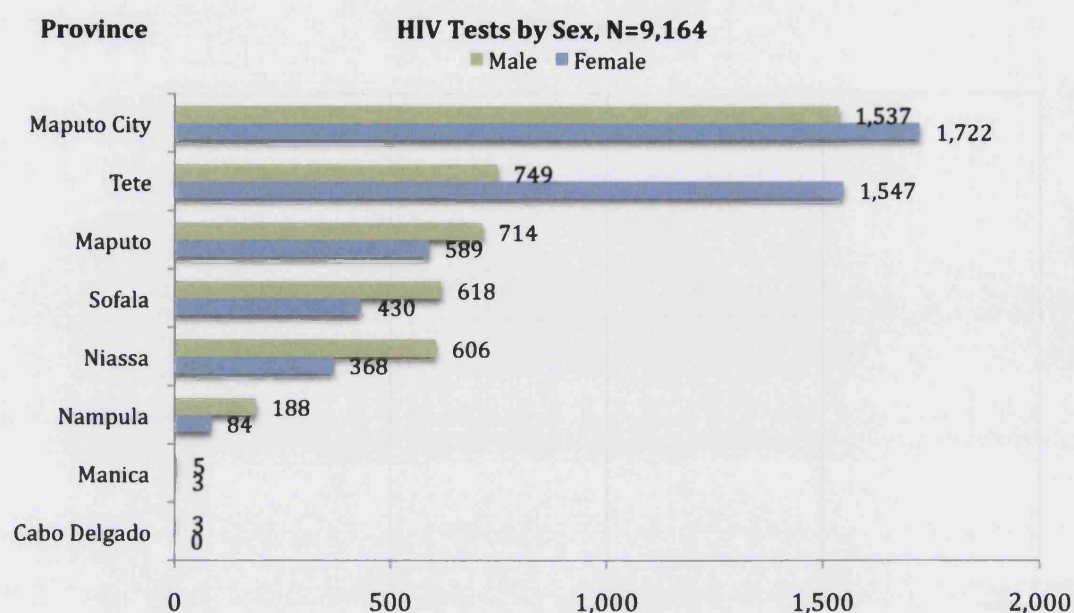
Figure 2.10: HIV Tests by Province by Sex, 2002
Source: (Ministry of Health 2006e).

Testing uptake increased from 102,487 tests in 2003, 188,255 in 2004, to 222,775

in 2005, which gives a total number of 522,681 Mozambicans tested for HIV during

2002-2005. The HIV test-based prevalence was between 25 and 28 percent with a

total cumulative figure of 139,167 HIV positive tests (see Figure 2.11).

Number of tests (N=522,681) and HIV Positive Tests (N=139,167)

250,000

222,775

200,000   188,255

150,000   ■ HIV Tests
                 ■ HIV+ Tests
                   Percentage HIV+

102,487

100,000

61,346
49,459

50,000
9,164   26,009
2,353
25.68%   25.38%   26.27%   27.54%
0

2002   2003   2004   2005
Year
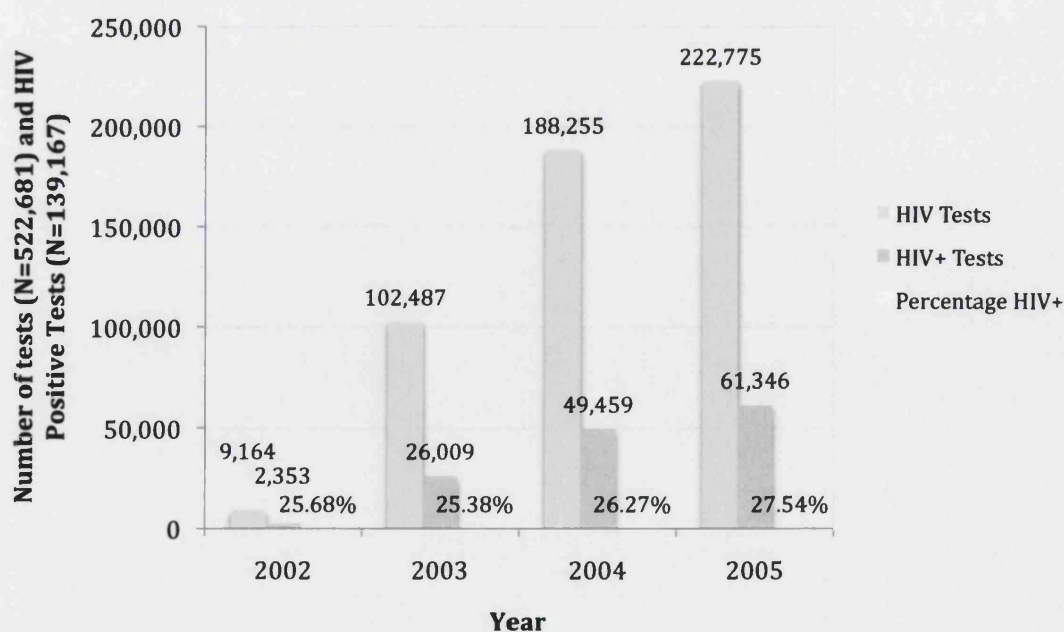
Figure 2.11: Total Number of HIV Tests and HIV Positive Tests, 2002-2005
Source: (Ministry of Health 2006f).

The total number of HIV tests by sex during 2002-2005 shows an increase from roughly 50 percent female and male VCT users in 2002 to about one third men and two thirds women in 2005. PMTCT programmes can explain this (see Figure 2.12).
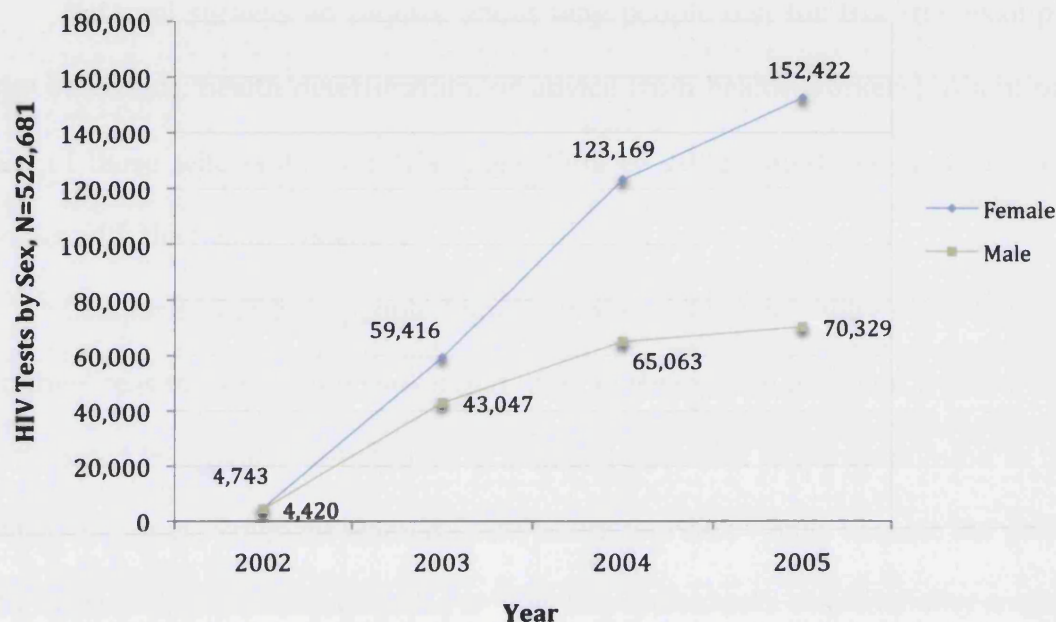
Figure 2.12: HIV Tests by Sex, 2002-2005
Source: (Ministry of Health 2006f).

Sources of Information

Several pertinent questions relate to HIV testing. First, we need to ask how many of those who test negative later test positive. What happened in life between the negative and the positive test? There are few if any studies of this. Could specific preventive measures be taken for those who test negative? Policy makers could target them as People Tested HIV Negative, PTHN, to make sure they avoid HIV infection. Alternatively, do they return to the risky game of eventual HIV transmission? Does life go on as usual? What public health measures could be taken to protect those who test HIV negative from subsequent virus transmission? Is it good health policy to leave it up to individual responsibility? A first step is to ask those

people who test negative what they do to avoid HIV infection. More importantly,

ask them why such avoidance may prove difficult, due to the dynamics of their so-

cial and economic life.

National surveys do inquire about why people test for HIV (for example,

risky behaviour, health deterioration, or advice from health workers). About one

third of those who tested for HIV from 2002 to 2005 found out about it from

contact with the health system.

Comparison of how people found out about the availability of HIV testing

and their reasons for testing shows that most of them were pregnant women who

participated in provider initiated programmes to prevent HIV transmission to the

babies they carry. Pregnant women – and health workers – have become the politi-

cally correct targets. Otherwise, it remains the individual's responsibility to gain

access to health care. In other words, the health system does not advertise HIV

services beyond its doors. The 'counselling and testing for health' principle encour-

ages health workers to inform all patients *within* the health care system about it.

During the VCT years 2002-2005 two thirds found out about testing outside the

health system, at work, in the community, through the media, from family and

friends, etc. (see Figure 2.13).[5]

Barriers remain between the awareness of HIV testing and pro-active

health seeking behaviour. Those who have taken the test have in most cases had

good reason to do so. I have already introduced participation in PMTCT program-

mes as the main reason. Pregnant women have become a global target group. Oth-

er major reasons include severe illness and risk behaviour. Health workers recom-

mended HIV testing for only about ten percent of people testing for HIV, unrelated

to PMTCT programmes (see Figure 2.14).

Source of Information   **HIV Testers, N=522,681**

Source	Value
Health Worker	181,768
Friend/Colleague	115,971
Other	60,310
Family	33,487
Theatre/Dance/Music Group	28,148
Other users	24,957
Pamflet/Activist	18,475
TV	11,287
Community	9,902
School or Church	9,901
Radio	9,155
Partner	7,625
Neighbourhood	4,861
At work	4,322
Blank	1,361
Blood Bank	1,151
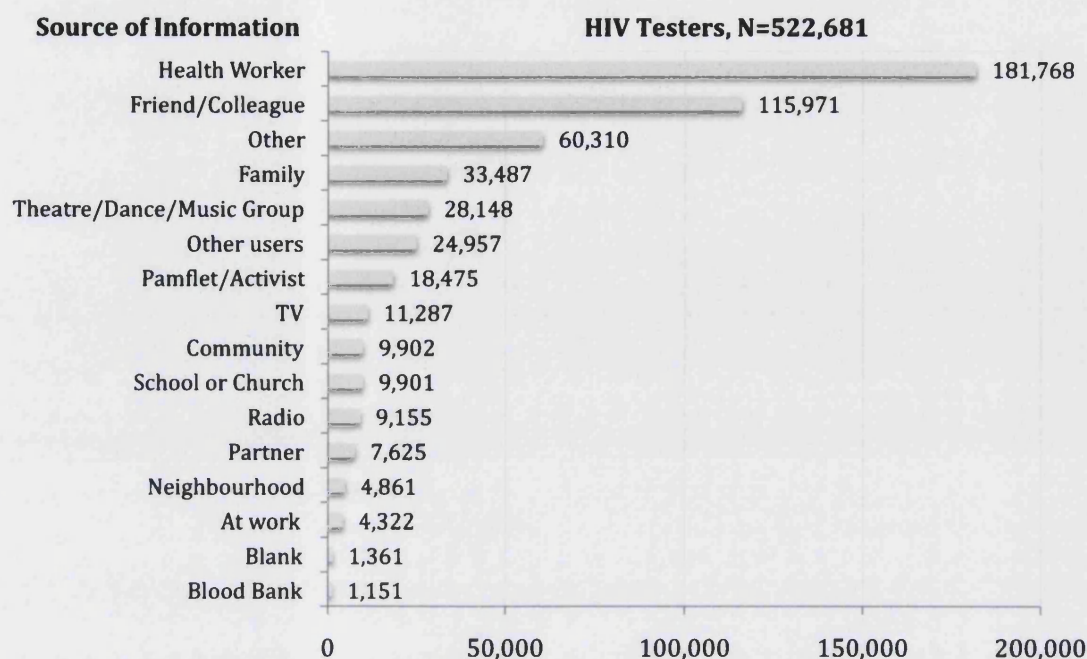
Figure 2.13: HIV Testing: Information Sources, 2002-2005
Source: (Ministry of Health 2006f).

Reason   **HIV Testers, N=522,681**

Reason	Value
In PMTCT Programme	151,027
Own Risk Behaviour	112,697
Feel Ill	74,225
Referred by Health Professional	51,982
Through Counselling	42,190
Distrust of Partner	30,085
Other	25,799
Partner is HIV+	5,820
Family Planning	5,630
Child Is Ill	4,989
Partner's High Risk Behaviour	4,981
Blank	4,853
Partner is Ill	4,625
Marriage	3,177
Sexual Violence	601
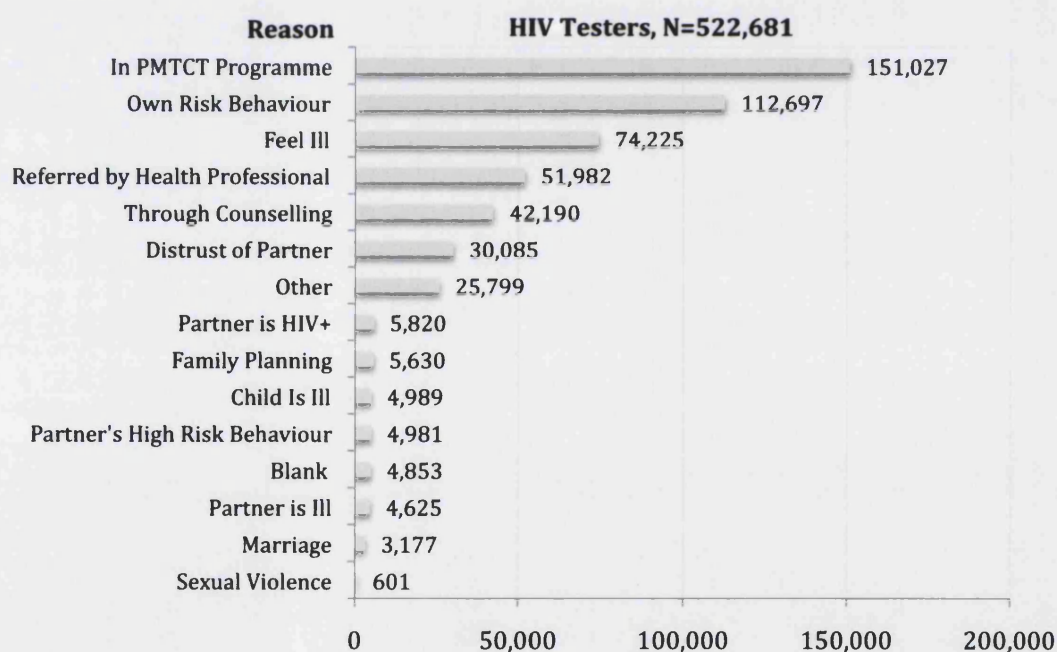
Figure 2.14: HIV Testing: Principal Reasons, 2002-2005
Source: (Ministry of Health 2006f).

From this we need to ask: Can we differentiate risk exposure between those who test positive and those who test negative? In other words: Are those who test negative simply not (or less) exposed to risk of HIV transmission? Alternatively,

are they equally exposed to risk, but lucky to be on the negative side of the probability equation?

Rationally, a person tested negative would try to avoid (or minimise) exposure to risk of transmission, but such change of lifestyle could be difficult if not impossible for the many who leave the CTH Centre HIV negative and re-enter the chains of the social fabric in the community and society. For example, people need to be conscious about the risk of transmission to take action to change their lifestyle. Beyond consciousness, people need negotiating power to practice safe sex or to choose abstinence. In case of illness, people would need to be able to make sure that there is no risk of contamination from consulting biomedical or traditional health services. Biosecurity is an issue for all types of health care. No human being is an island: without such body armour an individual is left to the risks that life bears, including but not limited to the risk of HIV transmission.

Pregnant Women, Insignificant Men

Provider initiated testing is one solution to limited voluntary testing. This is normally done with sufficient health system supply, like in Botswana, the exceptional case in Africa (Weiser, et al. 2006). On the other hand, outreach to pregnant women has become global HIV policy. However, why do we not target men for HIV testing? If it were true that men are the drivers of the epidemic through 'promiscuous' behaviour, or through culturally accepted groups of 'polygamy', that do not function as perfectly closed systems to avoid HIV infection, then a combined prevention and testing intervention for men would seem obvious. Simply focus on the

source of the problem. However, this has not been global policy priority. Moreover, pregnant women have become the correct target based on the human rights principle that we should prevent HIV transmission to newborn babies.

There is less emphasis on the health care of the newly delivered mother. A UNICEF report, which compares data from 71 countries in 2005, confirms this (IATT 2007). The report found weak links between PMTCT and ART programmes. Fewer than 50 percent of the women actually received ARV prophylaxis. Women and children are lost in the process. Very little information exists that evaluates how many pregnant women need ARV treatment and how many of these women actually receive ARV treatment (ibid.).

The feminization of the African HIV epidemic aggravates these problems, evidenced by the estimated 60/40 female-male divide of people with HIV through-out sub-Saharan Africa (UNAIDS/WHO 2006a). Yet, if we look at actual HIV testing in Mozambique, we will see that this was a 67/33 divide by 2005 (see Figure 2.15).
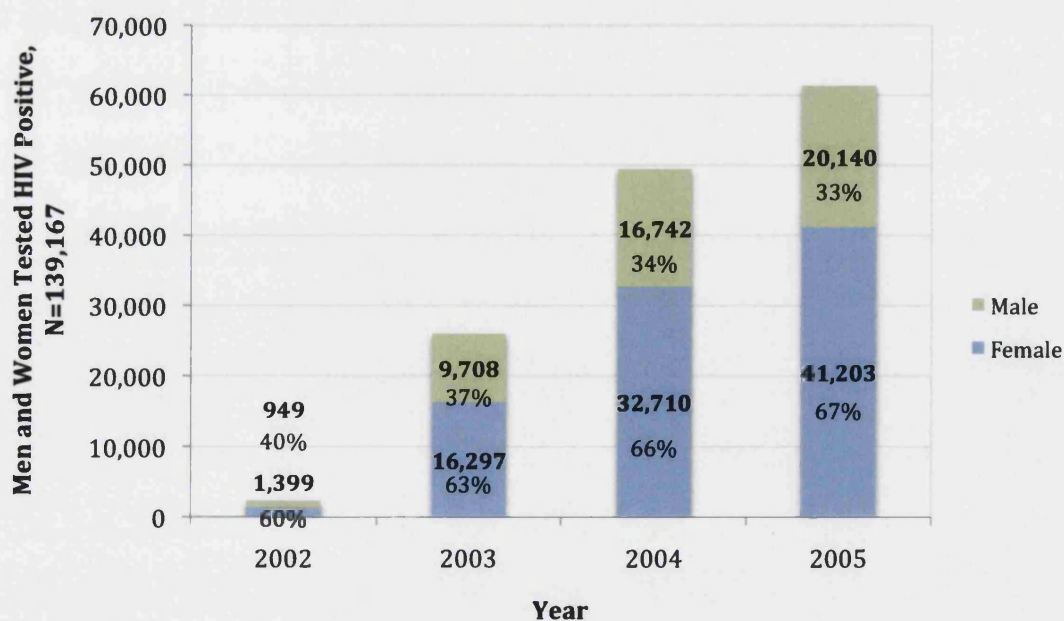
Figure 2.15: HIV Positive Tests by Sex, 2002-2005
Source: (Ministry of Health 2006f).

The percentage of male HIV positive testers was in fact higher than the percentage of female HIV positive testers in 2005 (see Figure 2.16).

	2002	2003	2004	2005
■ Female HIV Tests	4,743	59,416	123,169	152,422
■ Female HIV+ Tests	1,403	16,297	32,710	41,203
Female % HIV+	30%	27%	27%	27%
■ Male HIV Tests	4,420	43,047	65,063	70,329
■ Male HIV+ Tests	950	9,708	16,742	20,140
Male % HIV+	21%	23%	26%	29%
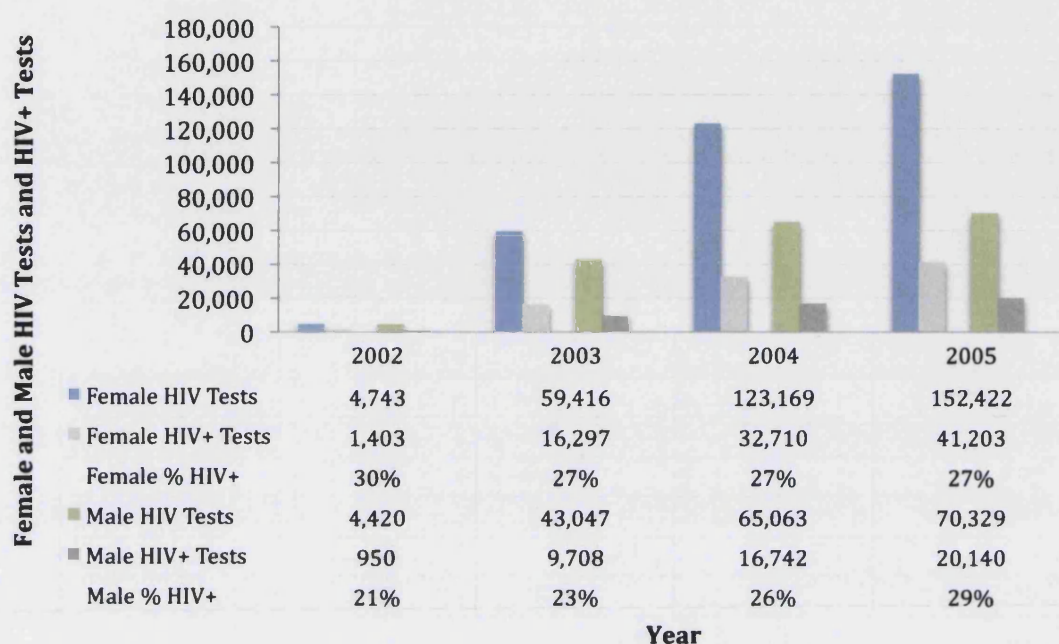
Figure 2.16: Female and Male HIV Tests and HIV Positive Tests, 2002-2005
Source: (Ministry of Health 2006f).

The analysis of the pregnant women target group highlights key problems regarding rights and provision of ARV treatment. Twenty-nine percent of the Mozambicans who tested for HIV during 2002-2005 were pregnant women (see Figure 2.14, p. 110). This explains the increase in testing, but it also hides the fact that pregnant women are not primarily targeted for the sake of treating them with ARVs. Upon giving birth, the mothers are given *prophylactic* ARV treatment to prevent HIV transmission to the baby. This is an effort to save the life of the child and thus a human rights issue of the rights of the unborn to life and health. Yet, these same rights of the newly delivered mothers are less cared for. Albeit, the Sant'Egidio DREAM programme offers ARV therapy for pregnant women until 6 months postpartum, along formula, clean water, nutritional supplementation, and continuing ARV treatment, if necessary (Marazzi, et al. 2007). Nevertheless, I heard health

workers in other programmes mention that mothers are more treated like a 'life saving tube' than a human being. The obligation to save the lives of the unborn seems appropriate, but the quality of health care provided for the mothers is jeopardized and compromised, given the limited capacity of the health system, including qualified health personnel. This is a difficult ethical and material dilemma.

The number of women in relation to men who test for HIV has increased from 52 percent in 2002 to 68 percent in 2005 (see Figure 2.17). PMTCT programmes may explain this and I see one key implication in this scenario: the winners are the newborn babies; the losers are both women and men. Pregnant women lose because there is no guarantee that they will receive treatment and care upon confirmed HIV positivity. Men lose because few of them are offered provider initiated HIV testing. With no testing, there is no treatment. The prospect is a painful death after some 10 years – or less – after infection.
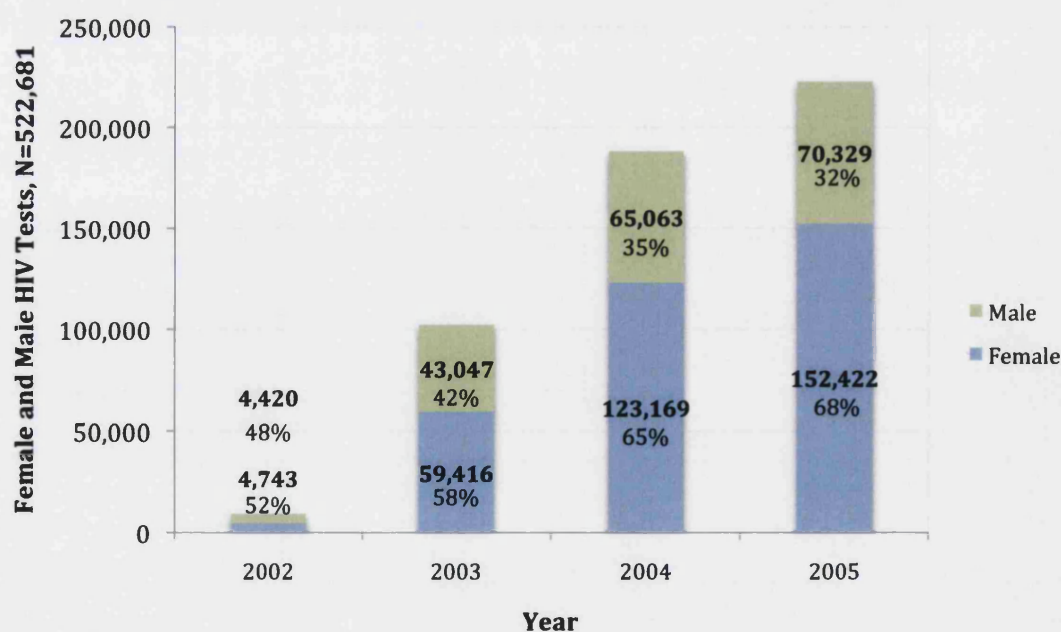
Figure 2.17: HIV Tests by Sex, 2002-2005
Source: (Ministry of Health 2006f).

Do we know how many have died from HIV related complications? Epidemiological counting of 'deaths due to AIDS' remains difficult, given the weak reporting and patient tracking system. One study systematically examined the quality and interconnection between HIV case-detection and AIDS case-reporting in Mozambique (Chilundo, et al. 2004). This found that such data are poor and incomplete. In fact, this is the case in all poor countries challenged by the HIV epidemic. They cannot live up to 'WHO standards', 'uniform electronic information systems', and 'biosecurity precautions'. This produces 'inconsistencies', 'errors', 'iatrogenic transmission', and 'under-reporting'. This is a consequence of poorly equipped health systems and poorly trained and overloaded health workers, but it is also part of the challenge. The impact on the labour force, and ultimately the economy, caused by limited testing and case reporting, may be devastating. It depends on the productivity of the people. Most Mozambicans are poor and unemployed, so how do they count in economic terms? Surely, it is a disaster in humanitarian terms, but it is also a policy choice, given the scarce resources that spell the fact that testing, treatment and care is not yet available for everyone. Human rights may not be affordable, but can we afford not to reach out and test men and women simultaneously? Mandatory testing for couples may be a feasible policy option that would ensure higher gender equity and synchronous testing, care and treatment. This would minimize secrecy around HIV, minimize risk of transmission upon knowing the test results, and consequently improve adherence as individual and social access barriers to HIV care would diminish if not vanish. In other words, you would not need to hide your HIV status and ARV treatment from your partner. This is all theory. We do not know whether HIV testing for couples would bring about these changes. However, it is worth trying.

Moreover, most people with HIV are in the age group 20-24. This is the biggest demographic age group and the group in which most people have tested for HIV. However, it is alarming to see that as the age groups get smaller towards the age of 50, the higher percentage of HIV tests turn out positive. First, they have had a good reason to take the test: most come forward with severe symptoms. All Mozambicans between 25 and 50 years of age lived through the 20-24 age group at some point during the HIV epidemic. Second, it reflects that most people test for HIV at the late or ultimate stage of disease progression, often when it is too late to initiate treatment and death will occur within a few days. Third, from this we can infer that those people have lived the estimated 5-8-10 years with the virus during their 20s and 30s: they have unknowingly put others at risk and in all probability transmitted the virus. They have even had the 'right' to do so, given the policy focus on 'voluntary testing'.[6] The percentage of HIV positive tests increases gradually from age group 25-29 (33%) to age group 45-49 (46%) (see Figure 2.18).

Discussion of HIV testing emphasizes several key points related to the provision of care and treatment: accessibility, patient versus provider initiated testing, supply versus demand, and the impact of the HIV epidemic on society caused by limited testing. Individual barriers include reluctance, low expectation, and implicitly some level of auto-exclusion even under the circumstances, when testing is within reach. Health system barriers include lack of capacity in terms of testing facilities and the long-term resources needed to care for those infected with the virus. Specific target groups means indirect exclusion of others. Health policies need to be carefully redefined with the expansion of ARV treatment. Failure to do so may in fact increase HIV transmission. Mandatory counselling and testing for couples is one key policy implication.

Age Group **HIV Tests (N=522,681) and HIV+ Tests (N=139,167)**

Percentage HIV+   HIV+Tests   HIV Tests

Age Group	Data
50+	37% 7,474 20,369
45-49	46% 7,214 15,718
40-44	44% 11,386 25,657
35-39	41% 15,816 38,177
30-34	38% 21,837 56,979
25-29	33% 28,894 86,535
20-24	22% 30,407 140,115
15-19	10% 11,466 118,047
10-14	11% 615 5,825
5-9	25% 1,302 5,151
1-4	27% 2,573 9,487
< 1	31% 133 436
Blank	50 185

0   20,000   40,000   60,000   80,000   100,000   120,000   140,000   160,000

Figure 2.18: HIV Tests and HIV Positive Tests by Age Group, 2002-2005
Source: (Ministry of Health 2006f).

Time is a crucial factor, as we have seen through the analysis of epidemic evolution, and the specificities of the Mozambican context. Expansion of the weak health system happens against the increasing number of people with advanced disease progression. I therefore turn to the specificities of the Mozambican ARV treatment model to fully appreciate and comprehend the challenges that this slow acting virus presents to us in terms of the multiplicity and farsighted responses needed to make these responses sustainable.

The Mozambican Model

Limited health system capacity emphasizes the need to consider how many pa-

tients it can embrace in light of the duties and responsibilities of the health author-

ities. This is about the risk of empty promises against the obligation to care for the

ill. The case of ARV treatment is a prime example, as the general picture shows

high need, but low demand and low supply. Specifically, the demand easily ex-

hausts the increasing supply, as new ART sites open. Yet, the heterogeneous nature

of the demand-supply balance across Mozambique is still poorly understood and a

question that I cannot answer definitively in this project. Nevertheless, the point of

this analysis is the emergence of a Mozambican ART model, based on Mozambican

priorities and recognition of the socioeconomic circumstances.

O Processo Clínico: Medical Record and Social Contract

People who test HIV positive divide into three patient categories: 1) *asymptomatic*,

not in need of medical attention, 2) *symptomatic*, in need of clinical consultation,

such as prophylactic cotrimoxazol treatment, but not yet in need of ARVs, and 3)

severely symptomatic, in need of ARV treatment decided by level of symptoms, CD4

count, and viral load.

This means a difference between patients enrolled and patients on ARVs.

For example, there were 129,149 patients enrolled into the ART sites nationwide

by September 2006, of which 34,184 were on ARVs and 94,965 patients in other

kinds of care (Ministry of Health 2006i). However, there could be patients in need

of ARVs unable to get them due to limited Day Hospital capacity. Additionally, many arrive very late to test for HIV in clinical Phase 3 (severe symptoms) or Phase 4 (terminally ill). Successful ARV treatment for the terminally ill is often impossible. This is the problem with 'late presenters' (see Chapter 1, pp. 45-46).

An ART medical record is opened in the third case, when the patient is eligible for ARVs. This is called *o processo clínico*, or *o processo* in everyday language. This is the beginning of the *therapeutic process*.

The medical record serves two key functions: systematic documentation of patient medical history and social contract. It establishes obligations on both the health system and the patient. Once admitted, the health system takes on responsibility for continuous care. On the other hand, the patient needs to agree upon the treatment programme. The informed consent contract, issued by the AIDS Control Commission, the National Health Service, lays down the specificities of this mutual commitment. The patient accepts the following: sufficient information about HIV, AIDS and antiretroviral treatment, access to counselling, the palliative nature of ART, possible side effects, the importance of treatment adherence, consequences of non-adherence, the hospitality of the health system, safe sex promise, consent to make personal information available to medical science, and finally that ARV treatment is voluntary (see Appendix 2).

Initiation Phase, Continuation Phase: From Testing to Treatment

The patient, his/her confidant, the doctor, and the counsellor all sign the agreement. The process from first contact with the health system to antiretroviral treat-

ment is a series of consultations: before the test, after the test, the result of the CD4

test, pre-ART consultations, and follow up sessions (see Figure 2.19).

PRE-TEST HIV TEST RESULT   CD4   RESULT PRE-ART PRE-ART PRE-ART PRE-ART   ART   ART   ART   FOLLOW-
                    TEST   CD4   START   UP
   —→   —→   —→   —→   —→   —→   —→   —→   —→   —→   —→   —→
                                                                                          Erling Høg • 2008
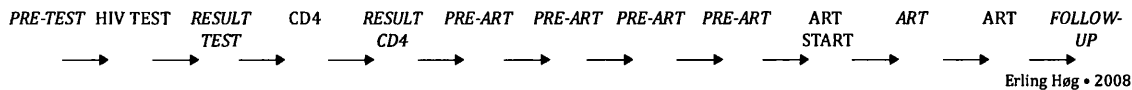
Figure 2.19: Consultations From HIV Testing to ARV Treatment
Source: Fieldwork.

The *initiation phase* consists of up to 10 consultations at the hospital during the

first month between the person enters the HIV testing centre and the beginning of

ARV treatment. The initiation phase starts with a pre-test consultation to inform

the person about the basics of HIV and the prospects towards the syndrome of

AIDS. The next consultation is when the HIV positive status has been confirmed by

a second HIV test. Then the phlebotomist takes a blood sample, which is sent to the

nearest hospital with equipment to analyse CD4 counts. This was highly time con-

suming during the days when only three places had the equipment to analyse CD4,

at the central hospitals in Maputo (South), Beira (Centre) and Nampula (North).

This changed during 2006 and 2007 when new high-technology CD4 software was

implemented at local hospitals. The person is then counselled about the CD4 count.

If eligible for ARV treatment, a series of four counselling sessions take place before

ARV treatment begins. The initiation phase is thus a series of pre-test, post-test,

and pre-ART sessions.

The CD4 count is an important indicator of ART eligibility. One study of pa-

tient flow in Beira found a median of 72 days between receiving the results of CD4

to the beginning of ARV treatment (Ministry of Health 2006a) (see Figure 2.20).

Events between CD4 Result and ART Start	Median Days upon Inscription
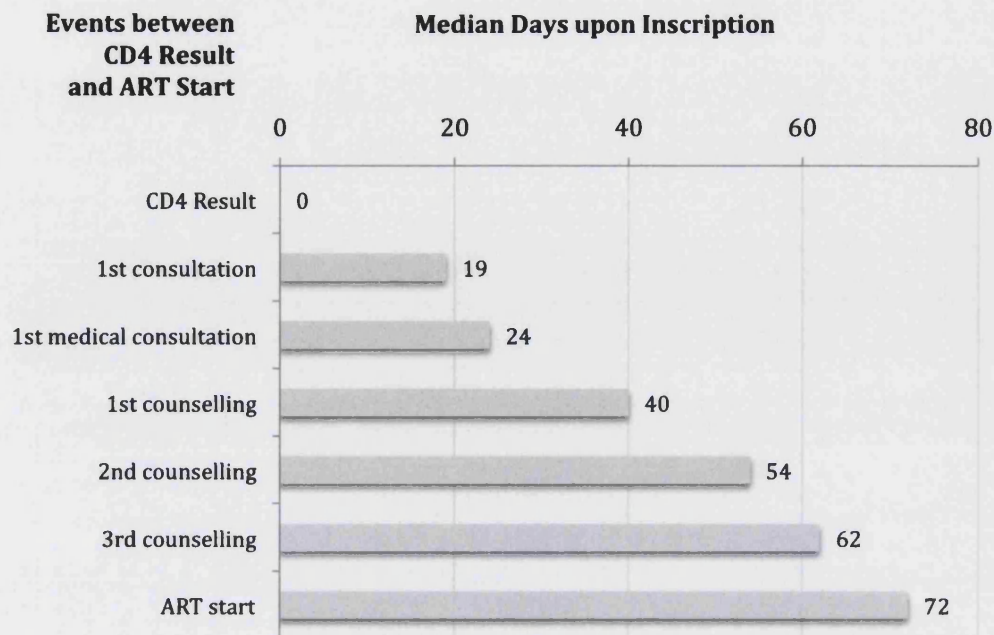
Figure 2.20: Patient Flow Between CD4 Count and ARV Treatment
Source: (Ministry of Health 2006a).

This is a prime reason for the success of the Mozambican model, but the time factor is a cause for concern in an emergency. However, I caution that any compromise to save time, money and human resources may have dire adverse affects on long-term adherence and the very success of the quality of life living with ARVs. I believe that thorough counselling is crucial and that equal human resources are needed for the continuous psychosocial support for chronically ill people who are additionally affected by the social ills that HIV carries.

The first day of ARV treatment marks the beginning of the *continuation phase*. The number of follow-up counselling sessions depends on the person's state of health, but usually he/she needs to visit the hospital every 15, 30 or 60 days. The patient receives a free stock of ARVs to take home sufficient for the respective periods. This means that a model ARV patient with few or no health complications needs six consultations per year. However, an average ARV patient needs 15-21 hospital visits per year. Yet, the hospital will accept a patient, whenever he/she

needs care. The number of consultations needed per patient also depends on the routines of the health workers. One doctor maintained that regardless of profession, a health worker could see a maximum of 15 patients per day. However, this does not correspond to reality.

In other words, treatment expansion happens at the expense of the current health worker force. Health workers were already overloaded, but now they have to run much faster until new ones arrive (Mozambican graduates, upgraded mid-level technicians, and foreign health workers). This is about the fragility of health system carrying capacity. It will eventually collapse, if the only criterion of 'success' is mere 'ART coverage' without an eye to the number and welfare of health workers. 'Essential' drugs have to be accompanied by 'essential' human resources and 'essential' infrastructure. Yet, this 'essentialism' remains highly politicized (see Chapters 5, 6).

Some Day Hospitals register the number of patients who dropout of treatment. However, data are often unreliable for a number of reasons. First, if a patient is a few days late for an appointed consultation, then he/she could be registered as a dropout. Second, some patients may have been transferred to another hospital and/or moved to another province. Third, some hospitals do not keep record of patients who drop out of treatment. The Ministry of Health intends to harmonize all aspects of the process, but different work philosophies among the international treatment providers, different levels of technical and human resources capacities, and general work overload all complicate its achievement.

A Medico-Cultural Approach: Stepwise, Responsible and Culturally Sensitive

Benedito, the ARV Committee, said in August 2006: *"From now on as we get involved with ART, we begin to target the whole process. We now offer ART in all provincial capitals. We have started to create our own model."* This refers to partnerships, decentralization, geographic equity, and ownership. The government applies an ARV treatment model, which they see as stepwise, medically responsible, and culturally sensitive. ARV treatment is announced locally, when the health system is prepared in terms of sufficient health infrastructure, medical equipment, and trained health personnel. This is the disjointed health policy approach, which compares ideal solutions to the practically feasible in a context of scarce but increasing resources. AIDS activists bring the news to the community about the availability of treatment. They use *sensibilização* – gentle 'citizen sensitization' – which serves to inform about the entire process from HIV testing to ART initiation and continuation phases. The overall approach to inform and educate about HIV prevention, testing, and ARV treatment seeks to *Moçambicanizar* – Mozambicanize – the messages to make them culturally relevant. Additionally, they try to send AIDS activists to areas where they can communicate in the local language. This may prove difficult, especially in urban areas inhabited by people from many provinces with different native tongues. Whether and how the Mozambican model creates inequity in access to health care is part of a larger discussion of relations between human rights, public health, and pragmatic engagement with the world. This discussion raises questions of absorption capacity and therapeutic responsibility.

The Treatment Era: 2004 and Beyond

Free large-scale ARV treatment through the public health system started in June 2004. By the end of 2006, 44,100 adults benefited from ART (Ministry of Health 2008a) out of 330,000 people in need (WHO/UNAIDS/UNICEF 2008) (see Figure 2.21). This increased to 88,211 adult ARV patients in 2007 and 104,351 adults by the end of May 2008 (Ministry of Health 2008a). The number in need of treatment had meanwhile increased to some 370,000 by the end of 2007 (range 290,000-460,000) based on updated methodology (WHO/UNAIDS/UNICEF 2008).
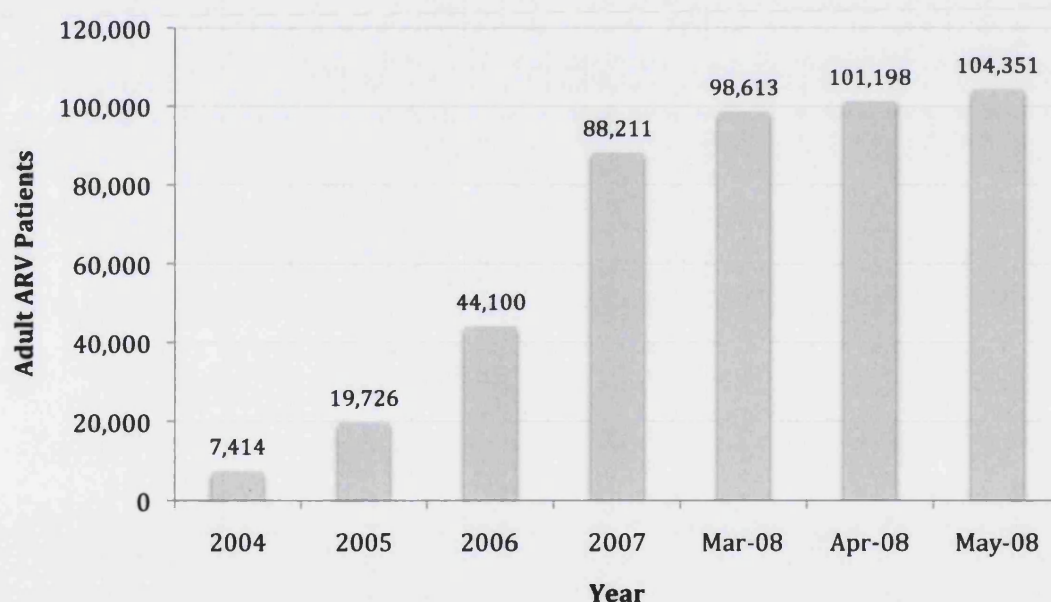
Figure 2.21: Adult ART Scale-Up in Mozambique, 2004-2007
Source: (Ministry of Health 2008a).

Adult ART coverage by province showed a higher degree of geographic equity by May 2008. Still, 53 percent of adults on treatment were in the South, 35 percent in the Centre, and 12 percent in the North (see Figure 2.22).

Province	Adult ART Coverage, N=104,351
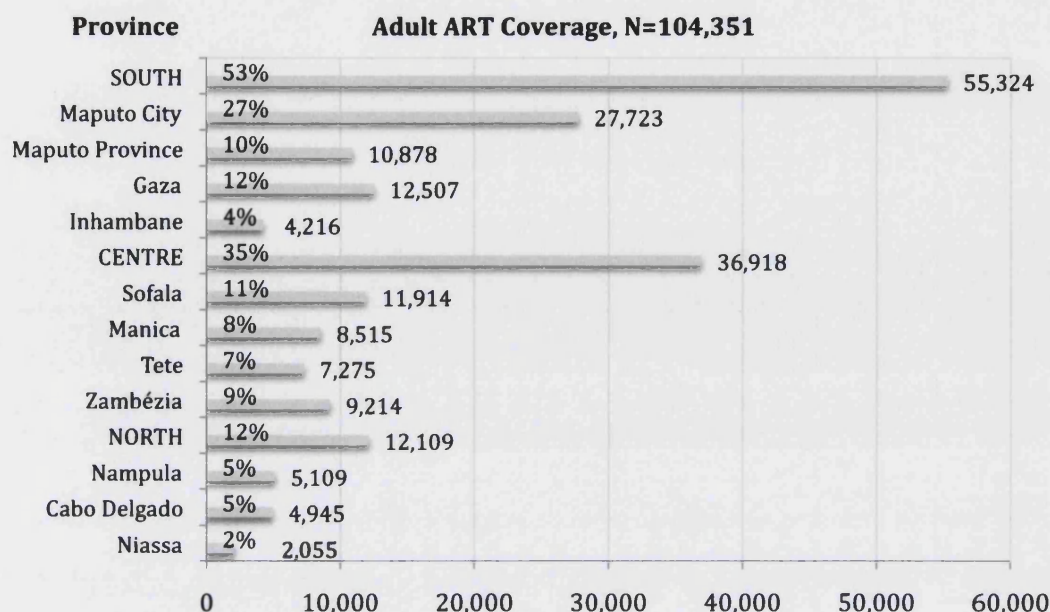
Figure 2.22: Adult ART Coverage by Province, May 2008
Source: (Ministry of Health 2008a).

This should be seen against the number of adults in need of treatment in light of the discussion of three sub-epidemics (see Figure 2.7, p. 102). The need for ART is smaller in the North. It is highest in the Centre, as more people have progressed towards the advanced stage of HIV in an older epidemic. The highest prevalence in 2007 was found in the South: the need for ART will increase, as it is considered a younger epidemic.

Adult ART coverage by sex shows that 64,575 women and 39,776 men were on treatment by May 2008. Women's share was between 54 percent and 70 percent by province (see Figure 2.23). We have seen that the number of women who tested for HIV increased substantially due to the focus on pregnant women (see Figure 2.17, p. 114), and that the double number of women tested HIV positive during the 2002-2005 period (see Figure 2.15, p. 112).

The number of women in need of treatment is obviously higher, caused by epidemic feminization (see pp. 111-115). Pregnant women provide the blood sam-

ples for estimating the prevalence in the general population. PMTCT programs also target pregnant women. However, the question remains, whether the higher number of women on ART correlates with the high focus on pregnant women and their need for ART when time comes (see Figure 2.23).
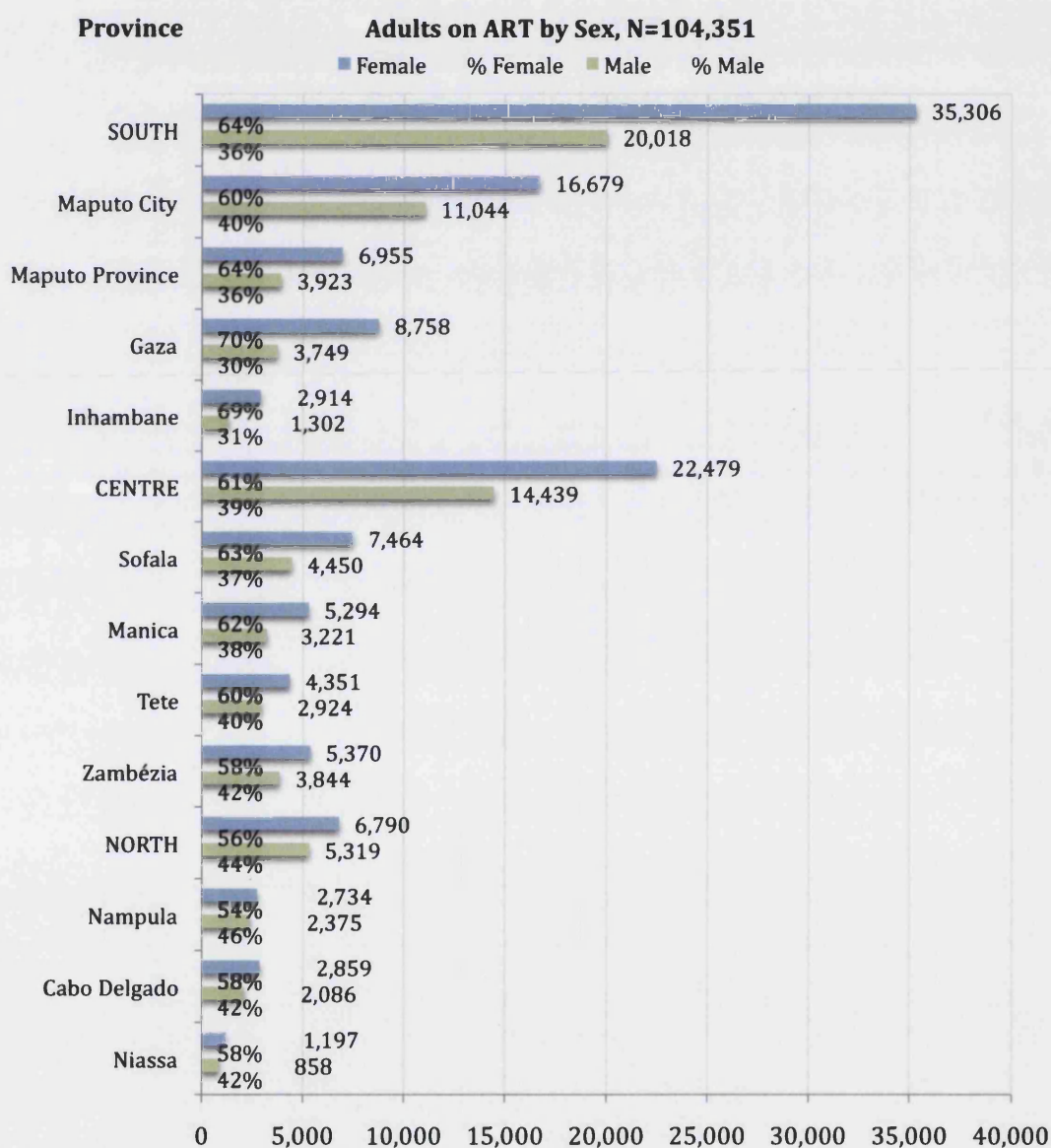
Figure 2.23: Adult ART by Province by Sex, May 2008
Source: (Ministry of Health 2008a).

Alternatively, is the number of women who seek health care higher, beyond the outreach to pregnant women, compared to men? This would be possible, as those who test for HIV divide into three: one third men, one third women, and one third pregnant women (see Figure 2.17, p. 114). Two thirds of those who test HIV positive are women (see Figure 2.15, p. 112). Thus, do the men who do not come forward for testing and treatment constitute the 'invisible majority'?

Additionally, 7,276 children under the age of 15 were in treatment by May 2008 (11% in the North, 32% in the Centre, and 56% in the South) (see Figure 2.24). Again, it would be fair to assume that most children are in need of treatment in the Centre. However, the best facilities for paediatric treatment of HIV related diseases are found at the Central Hospital in Maputo, sponsored by UNICEF. It has become a model for the rest of the country, but the expansion of paediatric ART faces many obstacles, evidenced by the Clinton Foundation, which leads the process towards better facilities for children. A breakdown by sex shows that 3,544 girls and 3,732 boys were on treatment, which is a 49/51 divide, though girls' share ranges between 39 and 55 percent (see Figure 2.24).

The expansion of adult ART has been a remarkable success in face of the obstacles. This success story is due to collaborative commitment by the government and the international community, almost unparalleled in sub-Saharan Africa. The Mozambican government enjoys support from all major international donors like the Global Fund, Clinton Foundation, PEPFAR, Sant'Egidio, the World Bank, Health Alliance International, MSF, ASIDH, governments of Ireland and Canada, and more.
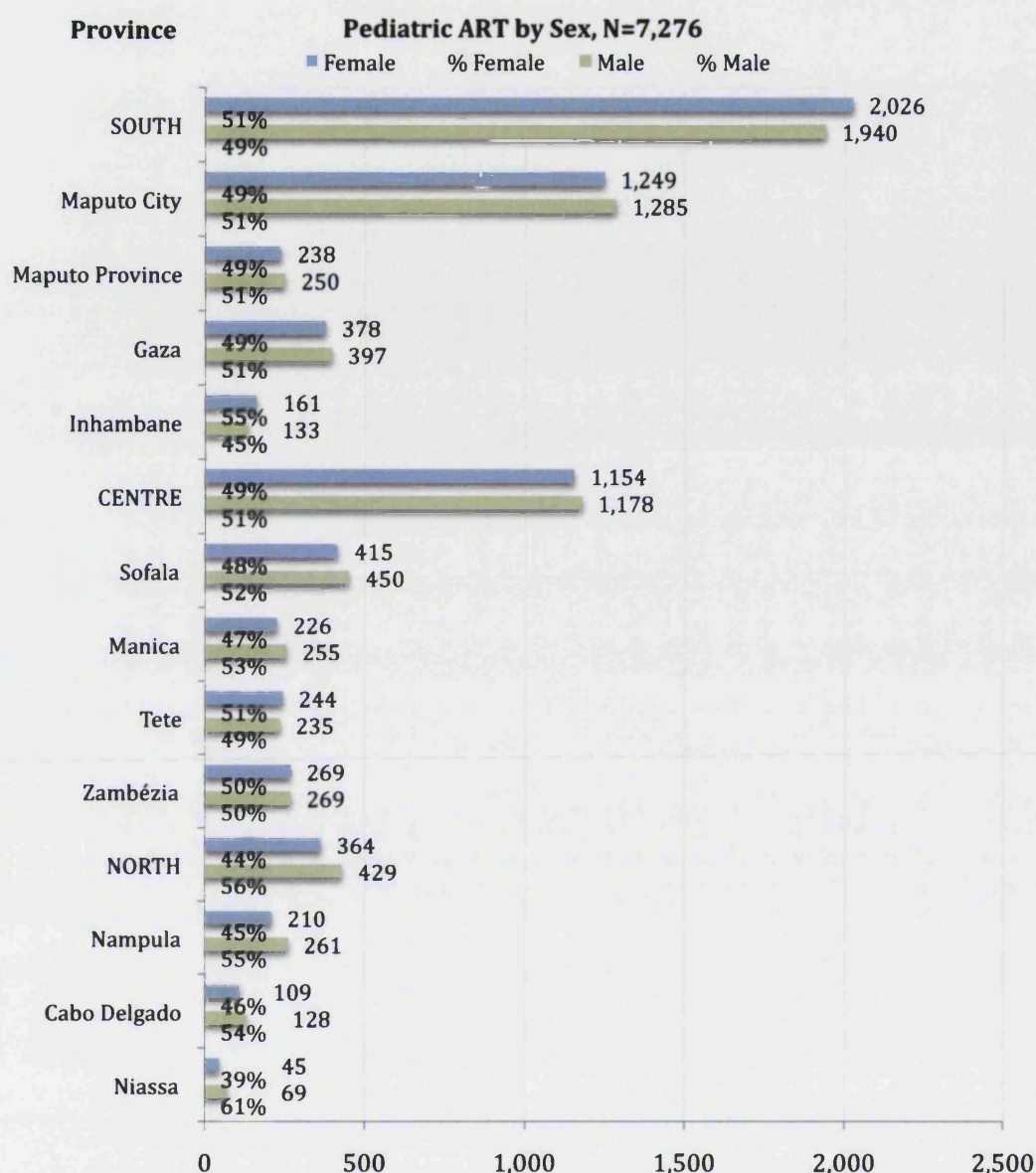
Figure 2.24: Paediatric ART by Province by Sex, May 2008
Source: (Ministry of Health 2008a).

The Minister of Health announced by mid-2007 that more than 150 ART sites had opened and that ART was available in all 128 districts of Mozambique (Ministry of Health 2007b). The number of ART sites increased to 211 in 2007, which almost doubled the target of 112 ART sites for that year, and to 216 sites by May 2008 (Ministry of Health 2008a; Ministry of Health 2008c) (see Figure 2.25).

Epidemic Evolution in Context: Acknowledgment and Achievement

This is a story of acknowledgment and achievement. However, numbers are deceptive. The construction of physical infrastructure is straightforward with sufficient funding available, yet complicated under the circumstances of a demolished health system. The *quality* of ARV treatment is an entirely different matter.

ARV treatment for life necessitates food for life, spiritual and moral support for life, medicines against opportunistic infections for life, and medical and psychosocial support for life. There is not enough of any these elements. Food for ARV patients has become a policy priority, but national and international politics, as well as the lifespan of Global Fund applications, complicate its implementation (see Chapter 8, pp. 356-373).

Medical and psychosocial support systems demand a high number of qualified health workers, which ideally must be Mozambican. Medicines against opportunistic infections are free, but they are often unavailable, or only for sale in private pharmacies. All this adds to health system fragility, which needs proper attention to make the story truly successful. Moreover, the number of people in need of treatment increases rapidly: UNAIDS/WHO estimate an increase from 270,000 in 2004 (range 200,000-340,000) to 370,000 in 2007 (range 290,000-460,000) (WHO/UNAIDS/UNICEF 2008). Therefore, about 350,000 people were in need, when the Minister of Health announced the availability of ART at the district level in July 2007 (Ministry of Health 2007b). More than 50,000 were then on treatment, but how many were rejected at the hospital door? It is life on the ground with ARVs that matters, not solely the construction of physical infrastructure and number of patients in an ART registry.

I have shown how the HIV epidemic progresses over time and the major responses

in Mozambique during 1986-2008. I focussed on *how many* and *why* the majority

of people estimated to be in need of treatment live and die *without* it. HIV testing

began outside the Maputo Central Hospital in 2001. More than 500,000 people

tested for HIV between 2002 and 2005. Close to 6 million HIV tests would be need-

ed to find the 1.5 million people estimated to have contracted the virus – at the end

of 2007 (UNAIDS 2008). Ninety-five percent of the adult population had not tested

for HIV by the end of 2005. More than 104 thousand adults and more than 7

thousand children were on treatment by May 2008 (Ministry of Health 2008a), yet

some 300,000-350,000 people were in need at that time.

To improve our understanding of the complex relations between individual,

social, and political barriers, I will introduce the access and delivery model in the

next chapter to see how these barriers relate to health seeking behaviour theories.

This model explains limited testing and treatment. This is about the *circumstances*

of a poor country in terms of different types of indirect violence: poverty, inequity,

injustice, and deprivation, which frame a particular risk environment (see Chapter

8). Additionally, Chapter 3 will discuss silence and secrecy related to the use, prac-

tice, and malpractice of traditional medicine as a continuation of the analysis of si-

lence and voice in Chapter 1. All this will improve our understanding of how indi-

vidual and social barriers converge, less about political and system barriers, which

will be elaborated in Chapter 5 about health worker experience delivering ARVs

and the patient-practitioner encounter.

3
Access and Delivery

3: Access and Delivery

I have developed an access and delivery model that considers individual, social, and political factors for the successes and failures of ARV treatment provision. Material, structural, psychological, social, and political factors determine health seeking behaviour. Individuals react to changing political and politicized HIV and AIDS discourses, as well as to changing social dynamics, and changing individual emotional and psychological state of mind. This model grew out of my fieldwork experience in Maputo City. Therefore, I do not pretend that this altogether reflects the reality in all 11 provinces and 128 districts of Mozambique. However, I believe this model is sufficiently versatile and generalisable to evaluate ARV programmes in specific contexts across Mozambique and in other countries.

I depart from the classical socio-behavioural health seeking model, which looks at predisposing, enabling, and need factors, specific to general health seeking behaviour in the United States (Andersen and Newman 1973). I qualify a holistic and pluralistic health seeking model, specifically adopted to the reality of the unfolding HIV epidemic in a resource-poor setting like Mozambique. The model divides into *individual barriers* (aversion, psychology, ignorance, and costs), *social barriers* (dynamics, social conditions, prejudices, and charlatanism), and *political barriers* (capacity, infrastructure, governance, and competence) (see Figure 3.1).

Figure 3.1: Access and Delivery Barriers
Source: Fieldwork.

PSYCHOLOGY
Knowledge, Postponement, Fear, Shame, Denial, Aversion
Distrust, Silence, Passivity, Negotiation, Self-stigmatisation, Disregard
HAVE NOT TAKEN HIV TEST

AVERSION
Fear, Shame, Denial, Passivity
Self-stigmatisation, Scepticism
HAVE TESTED HIV+

IGNORANCE
Information, Education, Communication, Denial
Scepticism, Dissemination, Misconception
HAVE NOT TAKEN HIV TEST

COSTS
Transport, OI Drugs
Food, Water
MAY HAVE TAKEN HIV TEST

GOVERNANCE
Priority, Commitment, Leadership, Partnership
Advocacy, Definition, Will, Fear
Silence, Denial, Information, Education
Communication, Dissemination, Coordination
Competition, Implementation, Bureaucracy

DYNAMICS
Gender, Inter-household, Family
Friends, Colleagues
Inter-dependency (unborn, children)

CAPACITY
Human Resources, Patients per Day
Personnel/Patients, Waiting List

CONDITIONS
Poverty, Social Capital,
Culture

INDIVIDUAL

POLITICAL

SOCIAL

INFRASTRUCTURE
Hospitals, Laboratories, Equipment

PREJUDICES
Discrimination, Stigma
Intolerance, Judgment
Myths, Obedience, Pacifism

COMPETENCE
Reference, HIV Knowledge
Disease Integration

CHARLATANISM
Pretension, Knowledge &
Integration of HIV

Erling Høg • 2008

Individual Barriers

Individual barriers include *ignorance, psychology, aversion*, and *costs*. 'Ignorance' concerns people who have not yet taken the test, caused by lack of *information, education*, and *communication, denial, scepticism*, lack of *dissemination*, and *misconception*. 'Psychology' concerns people who may indeed know about HIV testing, but they have not yet taken the HIV test, caused by a cocktail of obstacles: *knowledge, postponement, fear, shame, denial, aversion, distrust, passivity, negotiation, self-stigmatisation*, and *disregard*. 'Aversion' concerns people who know their HIV positive status, but they avert further steps at some stage of the therapeutic process, caused by *fear, shame, denial, passivity, self-stigmatisation*, and *scepticism*. Finally, 'costs' concerns people who may or may not have taken the test. 'Costs' here define as associated expenditures related to hospital visits. Cost barriers include *transport, drugs against opportunistic infections, food*, and *water*.

Aversion: Navigating the Maze of Attrition

Aversion was an issue often brought up during support group meetings. For example, Constança told us about her niece: *"She knows she's HIV positive. She knows her CD4 count. She knows she needs treatment, but she doesn't believe it. She says: 'It's not my analysis'"*. Constança spoke in a voice of despair and she asked for good advice what to do. Her niece has moved back and forth between home and Day Hospital for the series of consultations, which includes testing, CD4 analysis, test results, and counselling. She then ends up denying her medical record. Time spent at

home may be a contributing factor, which builds up anxiety and problems accepting the sick role. Major barriers in the series of counselling – see Figure 2.19, p. 120 – can be differentiated as people who have taken the HIV test:

a. But do not want to know the result
b. Get the result, but do not go for CD4 blood sampling
c. Get the result, go for CD4 blood sampling, but do not want to receive CD4 count
d. Get the result, get the CD4 count, but do not come back for prophylaxis/treatment
e. Begin the series of four ART counselling sessions, but stays away at one point
f. Initiate ARV treatment, but drop out

Depending on disease progression, there may be one hundred or more days between pre-test counselling and the initiation of ARV treatment. Ambulatory counselling leaves the patient with plenty of time at home to worry about the next session (fear, shame, denial, self-stigmatisation, scepticism, and passivity). Anxiety builds up and this may explain, why he or she stays away. All this leads to points of attrition between HIV testing and ART follow-up (see Figure 3.2).

PHASE	INITIATION	CONTINUATION
	TEST•RESULT•CD4•RESULT	ART START•FOLLOW UP
Points of Attrition	● ● ● ●	● ●
Counselling	Pre-Test Post-Test Pre-ART	ART
Capacity	Health workers	Health workers
Purpose	Disease knowledge	Therapeutic knowledge
Location	CTH Centre	Day Hospital

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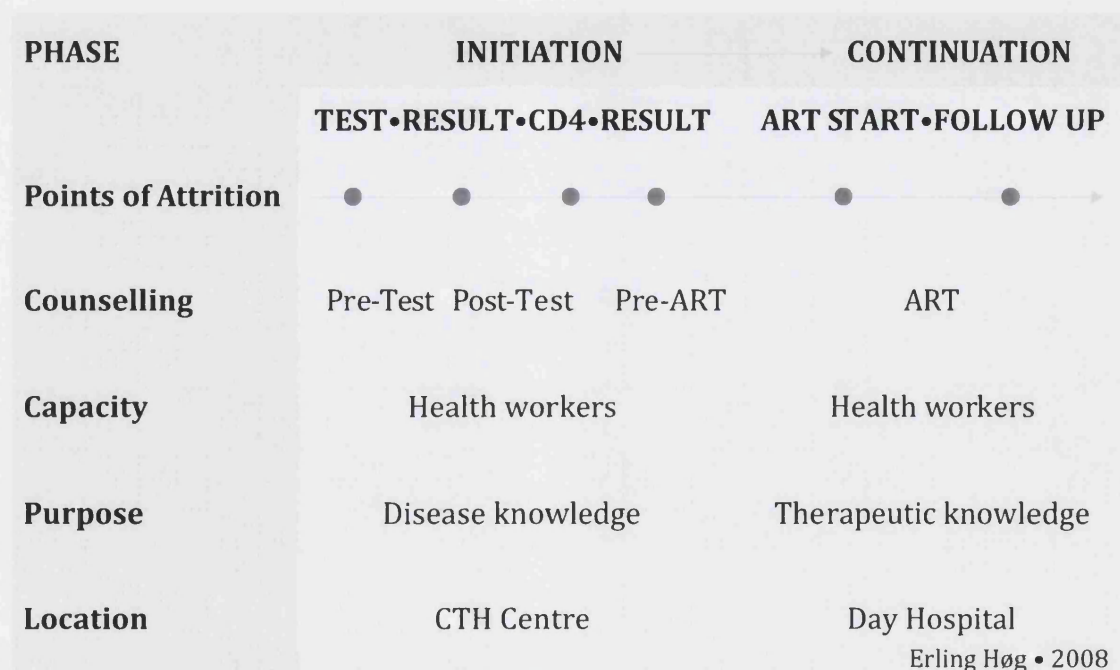
Figure 3.2: Points of Attrition Accessing ARV Treatment
Source: Fieldwork.

Psychology: A Cocktail of Obstacles

Second, those who have not yet taken the HIV test form the largest group of people. They may lead a normal life without knowing they have HIV. They do not come forward for HIV testing. They are entitled to do so in accordance with principles of 'voluntary testing' and the protection of individual human rights. They live on with no illness symptoms often for a number of years. This is the asymptomatic phase of disease progression. Mild symptoms then set in, but many people tend to ignore the problem. Later they begin to suffer a cocktail of psychological obstacles, which sets inevitable barriers to come forward for testing: postponement, fear, shame, denial, aversion, scepticism, silence, passivity, negotiation, self-stigmatisation, distrust, and disregard. These obstacles may be mutually interdependent. It is well known that people in general postpone seeking health care for any illness, caused by high tolerance and threshold of pain. This is the 'let's see' phenomenon ('I don't feel sick this week, let's see next week'). Such attitude continues until it is too late, evidenced by the fact that some three out of four adults come forward for testing with severe symptoms or during the terminal phase (see Chapter 1, pp. 45-46). However, postponement depends on other obstacles. The 'fear and shame' phenomenon stems from anticipated stigmatisation and discrimination. This leads to reluctance to accept the sick role and denial of the problem.

Health Care Utilization Models: Disabling Factors in Focus

Classical health care utilization models lend clarification. Andersen and Newman created a socio-behavioural model in the 1970s to explain factors associated with biomedical health seeking in the United States (Andersen and Newman 1973). They distinguish between three factors that determine individual health seeking behaviour: *predisposing* (demography, social structure and beliefs), *enabling,* (family and community) and *need* (illness level) (see Figure 3.3).

Some individuals are more inclined to use health services than others. Past illness and experience with the health system may explain this. Once willing to use the health services, a person must also be enabled to do so, including consent and support from the family, social security, health insurance and the accessibility of health services. 'Health service accessibility' specifically refers to the density of health infrastructure and the number of health workers available. The idea of illness level concerns proper recognition and acceptance of a given health problem.

Predisposing »	Enabling »	Illness Level
Demographic	*Family*	*Perceived*
Age	Income	Disability
Sex	Health insurance	Symptoms
Marital status	Type of regular service	Diagnoses
Past illness	Access to regular service	General state
Social structure	*Community*	*Evaluated*
Education	Ratios of health personnel and	Symptoms
Race	facilities to population	Diagnoses
Occupation	Price of health services	
Family size	Region of country	
Ethnicity	Urban-rural character	
Religion		
Residential mobility		
Beliefs		
Values concerning health and illness		
Attitude towards health services		
Knowledge about disease		

Figure 3.3: Individual Determinants of Health Service Utilization
Source: (Andersen and Newman 1973: 107).

The Andersen model was context specific and disease-unspecific, but it does provide three critical elements for access to HIV related health care in poor countries. HIV testing is the very gateway into tertiary care of chronic disease. Past illness experience of Mozambicans have given them a high level of pain endurance and tolerance and to some extent low expectations of what the health system can do for them. They may have discrepant ideas about values and health and inadequate knowledge about the disease, much in line with the Andersen model. The access and delivery model relates *disabling* factors, as there are few enabling factors. Most people have low if any income, no health insurance, no social security, weak social capital, weak performance power of human and citizen rights, and often live far away from Day Hospitals. Indeed, ART sites are now available in all 128 districts, which promises higher accessibility. ARV treatment is also free of charge, but there are still several disabling factors to access such services, including limited health system capacity, secrecy and taboos, and the difficulties changing to and accepting the sick role. This is particularly the case related to HIV and AIDS. All the disabling factors discussed so far contribute to the difficulties of accepting HIV.

This is part of individual, social, and cultural denial and involution. Denial and involution both denote action and process and thereby imply adaptation. However, I think there is an important difference: denial is the *act* of refutation of facts and involution is the *process* of transformation.

Alex de Waal defines involution as 'the systemic behavioural counterpart of denial' (de Waal 2005), and Marguerite Daniel defines it, based on Scudder, as a behavioural process in response to rapid social change that results in social denial, thereby matching 'denial' with 'involution' (Daniel 2005: 196).

Reading Scudder, I see a chain reaction: change-response-denial-involution. People respond to stress situations by clinging on to the familiar and Scudder literally called this a *process* of cultural involution (Scudder 1973: 53). The outcome of such process is *in*action: people try to maintain the status quo of normal life, as if nothing ever happened (ibid.).

In epidemic terms, cultural involution makes people pretend that the reality of HIV has no social effect. On the other hand, *individual* involution is the experience of such effects, which ultimately means that a person has nowhere to turn to. Therefore, I define individual involution as an introversion of unsolved social problems, which in the case of HIV invariably is caused by stigma and discrimination (e.g. stay in the house, stay in bed).

However, the definition of social involution suffers the conflation of the 'social' and the 'cultural'. Social *involution* runs counter to social *evolution*, that is, human development. Overall, involution is part of the argument: involution creeps in as an invisible, silent, and indirect violent act of normalization, an omnipresent process that gives adaptation the meaning of reverse change.

Silence, Secrecy and Negotiation: Looking to Therapeutic Options

However, there is more to the story, when we look at silence, secrecy, and negotiation. Later models have taken a pluralistic approach to health seeking behaviour by including traditional medicine and home remedies and paying attention to material, structural, and macro-political factors (Kroeger 1983; Weller, et al. 1997). In fact, Kroeger suggests a holistic model, which integrates socio-medical and anthro-

pological approaches. This would include major parts of the access and delivery model, since it focuses on health service factors and medical pluralism to explain obstacles to health care. Specific studies of health seeking behaviour of people with HIV have indeed looked at the role of culture and traditional medicine in Malawi (Hatchett, et al. 2004) and in Ghana (Awusabo-Asare and Anarfi 1997). However, they have paid little attention to how cultural traditions influence treatment seeking behaviour, how this behaviour depends on and interrelate with social and political access barriers, and the reasons for non-seeking behaviour. I think of traditional healing practices, including psychological and emotional reactions to fears induced by the spiritual realm in times of HIV and AIDS.

I included several questions about traditional medicine in the life story interviews with people living with ARVs (see Appendix 1). There are those people who: 1) have never used traditional medicine, 2) have used traditional medicine at some point, but now exclusively use ARVs, and 3) move back and forth between biomedical health workers and traditional healers.

For example, Saidah, Isaura, and Vítor said they had never used traditional medicine. They seemed straightforward, like Saidah: *"No. I only come here at the hospital,"* and Isaura: *"No, I have never experimented with these things,"* and Vítor: *"No, I am not using any of that."*

Many people living with ARVs maintained that they have abandoned traditional remedies and now exclusively use biomedical treatment. These 'enlightened' ARV users came forward for testing, broke the barriers of silence, and found moral and social support among peers through 'Western' confessional therapies.

For example, Lídia is an extremely confident AIDS activist, who speaks to me up front with clear enunciation. She says: *"To me, I am more level headed with*

ARVs, because before I started treatment, my family made me take traditional medi-

cine, which each time made my situation worse. Now I have 200 percent confidence

in ARVs. The drugs work well for me and I don't have any problems."

I did not manage to interview people who move back and forth between Day Hospitals and traditional healers, only people who previously did this. I believe this was due to the fact that I interviewed 'successful' ARV patients without significant problems. However, I did sense their reluctance to talk about the issue of traditional medicine in general and the mix of therapeutic options in particular. Many insisted they had never tried it and that they were unsuspicious about antiretroviral treatment. This could well be true, but it could also be the wrong place to ask the question inside the Day Hospital dominion. Matsinhe suggests that traditional practices encompass the entire social context, but that many people resort to 'official discourse', when prompted to speak about it. They conceal any involvement with traditional practices (Matsinhe 2005: 151).

Traditional Medicine: Source of Taboo and Power

Traditional medicine encompasses a dynamic mix of distinct, overlapping, and competing healing practices throughout Mozambique. No single entity qualifies as 'traditional medicine'. In other words, the various healing practices share one commonality: they are non-biomedical (van der Geest 1997). However, cultural constructivism defines *all* medical knowledge and systems as 'traditional' under the domain of 'ethnomedicine'. Biomedicine is therefore also traditional medicine. Such perspective emphasises the multidimensional aspect of medicine and healing

in which an ethnomedical system defines an evolving product of cultural history (Feierman 1985; Gaines 1992). However, the term 'traditional medicine', applied to non-biomedical practices, has proven a resilient folk category among people of all walks of life, including those from academia, international organisations, biomedical, development and state institutions (West and Luedke 2006).

Mozambique comprises a diverse pluralistic health care environment with many therapeutic options, in which it is difficult to distinguish between healing systems and apply the term 'system' in the sense of epistemic boundaries and coherence. As West and Luedke point out, traditional healers cross boundaries of ethnicity, language, and religion, between rural-urban, local-global, official-unofficial, traditional-modern categories, and physical borders (West and Luedke 2006). It all appears quite unsystematic.

Curandeiro practice embraces spiritual and social counselling, curing, and sorcery. Sorcery includes the creation of fortune and misfortune. Some operate exclusively with medicinal plants and do not possess powers to communicate with the spiritual world. Others are exactly that: spiritual specialists. Witchcraft is performed by *feiticeiros*, the ones that attend inexplicable and unusual unfortunate events. In the previous chapter I discussed how HIV is an undesirable state of being and how it associates impurity and disorder with reference to Mary Douglas' work on purity and danger. The point is that various rituals need concealment: they need to be tabooed to create and maintain power. That is, traditional medical practices operate by way of secrecy, as opposed to biomedicine characterized by public knowledge (van der Geest 1997). People hide behind this barrier, whether or not they suspect they have HIV, or whether or not they seek health care. Speaking of HIV related health problems put them in danger of bedevilment, social exclu-

sion, and stigma and discrimination. Purification ceremonies, ritual scarification, and 'vaccination' practices seek to restore order, but the advent of HIV remains contested in terms of its nature, origins, causality and cure. The controversial discourse on HIV signals uncertainty, which makes various therapeutic options and family advice proliferate. As long as uncertainty persists, people will install hope and opportunity, even the slightest chance of healing or curing from any source or practitioner. This is the pragmatics of uncertainty (Whyte 1997), which I believe tends towards a universal human characteristic, given the widespread global popularity of traditional and alternative medicine. In addition, hope may turn into fatalism, hopelessness, and despair. Time is here a crucial factor. Many HIV positive people worry how much longer they are going to live and, therefore, about their future prospect. The human- and spirit-induced maladies, perceived or real, contribute to this downward spiral, which may explain the fine line between silence and voice. People who suffer HIV associated symptoms therefore end up tormented between determined requirements to 'maintain the silence' and 'break the silence', which ultimately leads to social involution. Only the *fortunate* minority transgresses the laws of secrecy, maintaining *appropriate* silence.

Several plausible explanations of why people keep the silence and secrecy around HIV can be found here. I initially asked why the majority of people do not come forward for testing. I then cautioned about the representational problems of the silent and invisible majority. Many of the fortunate minority who survive on ARVs underwent significant personal transformation to reach that stage (see Chapter 1). Sudden pro-active, outspoken AIDS activists help their illness peers to 'break the silence' and come out from their hideaway, which may be physical. However, silence and secrecy are not merely products and reproductions of the global

definitions and understandings of stigma and discrimination and the emotional troubles they encompass. Similar 'Breaking the Silence' campaigns, which grew out of the Durban International AIDS Conference in 2000, have kick-started the process in many countries, for example in Burkina Faso (Nguyen 2005), Nigeria (Alubo 2002), Zimbabwe (Duffy 2005; Houston, et al. 2005), Uganda (Witter and Were 2004), Botswana (Heald 2006), and South Africa (Morrell 2003). However, context specific factors that originate in threats induced by spirits, Gods, witchcraft, and sorcery produce and sustain silence and secrecy. Moreover, these phenomena are poorly understood and understudied. I do not pretend to speak with greatest authority on this issue for two reasons: 1) silence may be an unbreakable choice, and 2) my fieldwork did not include visits to traditional healers. An anthropologist must proceed with caution, not to violate the rules and reasons of the unspoken, but I will discuss the historical context of silence within the use, politics, and fate of traditional medicine.

Powers of Spirits and Pastors: Competing over Silence and Voice

There are both functional and ontological explanations for the revival of traditional medicine in Mozambique. First, people turn to traditions to remedy past and current disorders (war, diseases) through cosmological and organic healing and purification. Traditional practices become forms of social reintegration through an essentialized traditional ethos in a post-colonial and post-war context (Passador and Thomaz 2006). Second, revivers attempt to reformulate and search for the essence of 'Mozambicanness' within the tensions between 'African tradition', 'modernity'

and 'civilization' (Fry 2000). Third, traditional rituals are often practiced through nonverbal communication. That is, the person can remain silent, when consulting a traditional healer. Mozambican anthropologist Alcinda Honwana found this to be the case how Mozambicans dealt with healing the wounds of war in the 1990s. Silence became a convenient means in healing the traumas of violence (Honwana 1999). This may also be the case living with the agonies of HIV. Confessional therapy offered by biomedical counsellors and activists implies pouring out your heart about intimate details about your life: sex, whereabouts, illness experience, partners, food and drinking habits, and living with chronic disease. This is not necessarily enjoyable for everyone in the world, but particularly not for Mozambicans who have experienced various forms of silencing and repression from colonizers and government. Thus, silence has become a friend in need: people take refuge and find space of comfort under the wings of traditional healers.

However, we must look behind the widespread phenomena of *medo e vergonha* – fear and shame – to improve our understanding why particularly Mozambican women remain silent about illness problems. Silence is not merely a convenient means of trauma healing. Mozambican anthropologists Ana Maria Loforte and Cristiano Matsinhe have studied this. They expose cultural beliefs about the links between ancestors and women. This is a story about blame, responsibility, impurity, and danger. The belief goes that women are inherently disposed as dangerous, capable of transmitting 'the evil' (Matsinhe 2005: 177). According to Loforte, women are perceived as a 'repository' of infections and diseases, thereby blamed the responsibility for bringing illness to the house. This makes them conceal their symptoms. They feel afraid and ashamed. Social exclusion is at stake. This reinforces what Loforte calls the 'culture of silence' (Loforte 2007: 30).

This 'culture of silence' differs from the ones defined by Freire and Daniel. Freire relates a 'culture of silence' to muted voices within a sociocultural context among the excluded or the ones at the bottom of the hierarchies in society, which well could be applied to the Mozambican history of colonization and centralized socialist government. Freire developed his idea to a Brazilian reality in which the poor lack critical voice to oppose the dominant culture within an extreme class society. This is a different story about dialogue, critical awareness, political education, civic courage, and conscientization (Freire 1972; Freire 1975; Freire 1990; Freire 1998). Daniel defines 'cultural silence', applied to Tswana reality of silence around AIDS deaths in Botswana, as *"a* passive *form of denial, a 'hiding behind' culture, a denial of responsibility"* (Daniel 2004: 37). This does not altogether apply to Mozambican reality.

Loforte exposes one major reason why Mozambican women remain silent about illness symptoms. Women who fail to abide the rules of the group risk 'spiritual' diseases from ancestral aggression. Thus, women fear the repercussions, if they reveal their illness to significant others of this world. It would be a sign of bedevilment. Women would be viewed as both *contaminated* and *contaminator*. Thus, the *curandeiro* becomes the intermediary in order to communicate with the other world to clarify any misdeeds and to seek purification and restoration within the community (Loforte 2007: 30). Such illness consultation includes problems of HIV and other sexually transmitted diseases. Second, pregnancy is perceived a sacred period and therefore may complicate this scenario.

All this may legitimate the focus on pregnant women during biomedical intervention, but the unborn children are the winners, not the women, nor the men. Therefore, there is double good reason to target women and men simultaneously

through coupled counselling and testing, helping them to break this kind of silence, and their fear and shame.

However, this is not the same as neglecting the culture of negotiation with the ancestral other world. The context of illness behaviour inherently comprises a constant struggle between a 'culture of silence' and a 'culture of voice'. This produces a difficult psychological context for making the right choice in times of HIV. For example, storytelling in the context of modern HIV therapy could be colonization of the life world to be avoided at any cost. This is about individual pride and ownership of the body and life, but this also means that you cannot have the best of worlds, when HIV treatment, care, and support remain out of reach. You can hide in silence, but you have to break psychological barriers to enrol the biomedical treatment regimen. In other words, telling significant others – friends, family, health workers – about health problems and the need for HIV testing and treatment establishes one first crucial step, which comes at a cost. This takes *courage*, as Gilberto told us in Chapter 1.

We see two kinds of healing power competing the dominions of silence and voice. Foucault defined pastoral power as Christian servitude in terms of salvation, care for the individual for life, and knowledge about that individual's life world (Foucault 2000 (1994): 333). This requires voice, disclosure, and confession. Confessional technologies happen through various forms of biomedical 'counselling' and biomedical 'traditional rituals', which have become commonsensical and uncontested ways of providing 'global health'. This is evidenced in the rapid extension of patient 'testimonies' and 'support groups', by which patients are expected to 'break the silence' in 'oases of disclosure'. The powers of speech and life stories reveal details and secrets of the past and present. On the other hand, spiritual pow-

er works by way of negotiation, veneration, and worship through community rituals or through intermediaries such as traditional healers. People are expected to appropriately remain silent and keep their secrets. The rights of confidentiality and privacy of people living with HIV literally and ironically mean the right to remain silent. The given social order, of highest relevance in the context of living with HIV, as I discussed in Chapter 1, can explain this. Fear of speaking about HIV stems from fear of repercussive malignant spirits. Malignant spirits would punish individuals for having broken social norms through 'sinful behaviour'. This would show that misfortune had arrived or that someone's bedevilment had been successful. The cycle then becomes threefold: silence, secrecy, and invisibility.

Social Barriers

Social barriers include *pretension, dynamics, social condition*, and *prejudices*. Some barriers overlap with individual barriers through the interplay of individual-family-community and the use of traditional healing practices. However, there are specific social barriers that need separate elaboration. 'Dynamics' is a broad concept that embraces issues of gender, household, family, friends and colleagues, as well as interdependency, by which the unborn and children depend on the voice and choice of others. 'Conditions' concerns how people live under the constraints of poverty, minimal social capital, and the forces of culture. 'Culture' may serve as both a barrier and facilitator, as I have discussed through my analysis of silence and voice. 'Prejudices' means stigma and discrimination, intolerance, judgment,

and the social obedience of the norms of exclusion with all the forms of social paci-

fism it produces, whether ultimately this leads to social denial or involution.

Dynamics: Navigating the Social Spheres

We have seen how significant others become barriers for the individual seeking

health care for HIV related health problems. Lack of communication about sex and

ill health may be one of the root causes. Women face a particular problem: they

often need permission to seek health care for HIV from their male partners. Dis-

obedience necessitates silence and secrecy. Keeping this secret for the entire fami-

ly, colleagues, and community protects against gossip, exclusion, stigma, and dis-

crimination. This is the constructive and protective function of silence and secrecy.

Interdependency concerns the voice, agency, and rights of the unborn and

children. Who decides for them? Who advocates their interests? What are the pros-

pects of the unborn and children when adults face problems of silence, secrecy,

stigma, and discrimination? Indeed, prevention-of-mother-to-child-transmission

programmes reach out to the unborn. Actors now also prioritize paediatric ARV

treatment programmes, but with low success rate, due to lack of infrastructure,

qualified health workers and a complicated treatment regimen.

Conditions: Poverty, Social Capital and Culture

Many people therefore lack social capital to navigate their social spheres in search of solutions for their ill health. They are too poor to embark on a medical regimen, which necessitates a whole range of activities and related expenditures that most can ill afford. The biggest problem is access to food and potable water. Many live far away from Day Hospitals and they cannot afford the cost of transportation, if it is at all available. Food and water for the many travels to the Day Hospital cost extra. Drugs against opportunistic infections are unaffordable. Some organisations provide them free while others do not. Even when free, they might not be available. All this is part of the harmonization process within the national health system, in which both food and secondary drugs are meant to become essentials.

Many people who live under poor conditions turn to pacifism and fatalism, which reveals the fine line between hope and hopelessness. Many access barriers remain weighty and lead to despair and resignation, aided by the cycle of silence. This cycle may lead to individual involution and social invisibility, as I have already shown. The fears of prejudices stem from anticipated and felt stigma and discrimination, which include root causes in both traditional and modern culture, or local and global discourse and understandings of the HIV epidemic. I experienced charlatanism as one of the biggest barriers: some traditional healers pretend they can cure AIDS. Several initiatives have been taken to change this. The government seeks to eliminate ignorance through education and integration of traditional healers in their response to HIV. However, many people are fooled, while they wait for this initiative to become a success. False claims to HIV expertise by traditional healers stand in the way for many people in urgent need of health care.

Pretension: Traditional Medicine and Human Suffering

One of them is Fausto, who works as an AIDS activist at one of the Day Hospitals. Fausto at one point says to me: *"I know that I am going to die one day, but I also know that telling my story to you, it will stay alive. This could help others. And I want to tell you all of it. I don't have a problem with that. I also want to tell you the whole story about my experience with traditional medicine."*

Fausto began as an AIDS activist in 2004. He had lost his job after getting ill, but found opportunity as an activist to help him provide for his extended family of seven children, their partners, and his grandchildren. Fausto works with impressive energy and social conscience, despite the fact he himself lives with chronic disease. *"I visit severely ill patients in their homes, as it's impossible for them to come to the Centre. I continue my own treatment so that I can visit them, teach them, when things look impossible."*

I ask Fausto why HIV is a secret. He says: *"It stems from discrimination. Our society fails to accept breaking the silence, because it depends on each and every family that in case you are out of luck, then discrimination may inhabit your house."* After a rhetorical pause, Fausto continued: *"If my daughter knew that that I am seropositive, she would refuse that I take my granddaughter up in my arms, but as she doesn't know, there is no problem. When I eat soup, or a piece of fruit or whatever, I hold my granddaughter in my arms, and at the same time I manage to feed her soup and eat with the same spoon. I know that this does not cause any problem, but if she knew that I am in this situation, she wouldn't accept it. Discrimination would apply right there."*

Fausto's little secret makes him lead a normal life with his grandchildren. Discrimination prevails, caused by a cocktail of ignorance, misinformation, illiteracy, and denial. Fausto explains in a loud rhetorical manner: *"Who says it doesn't matter? Us here in this suburb, if I one day break the silence, on the way wherever I go, I will only find discrimination."* He looks at me and he repeats: *"Wherever I go I will only find discrimination. This is because of ignorance. Who says it doesn't matter?"*

But where secrets serve a functional purpose, silence may lead to psychological and social deroute. *"You know that the majority of infected people are from the young strata of society. If a girl says that she doesn't have a boyfriend and that she will not contaminate anyone, then all boys would escape! This silence of disclosure, epa, she will stay in her bed and this turns into total and complete involution."*

However, Fausto maintains that people do have options, when life is most difficult. This is about the use of traditional medical and religious practices. Fausto says: *"If I grew up in a society of curandeirismo, and I associated with curandeirismo, I learned what I know today, then I would always return to live with curandeirismo."* I asked him to explain what he meant in more detail: *"There are people who say that the ARV is full of illness. This is true! This is the fruit of illiteracy. It's difficult. This may be ending in society, but there is still much of this in the rural areas. Because people are illiterate in the rural areas, where curandeirismo still exists. Curandeirismo is about people who are playing God and Devil. Each one pulls you, God pulls you, the Devil pulls you. Curandeiros will never say to a person: 'Go to the hospital'. They don't! If they did, they would lose their business."*

I maintained that the Ministry of Health works closely with traditional practitioners by means of information and education campaigns, but Fausto objected: *"This is about sensitization. I would say this is a discourse that the government, the*

Ministry of Health, is creating to associate with them, but practically this is a dis-

course that they only do there above and end it when they come here. It doesn't work.

Because the majority of curandeiros are illiterate." Fausto looks at me with a facial

expression, which says: *'Don't pull my leg'.*

I asked Fausto why he wanted to continue our conversation the next day.

He said: *"You are asking me very important questions. Let's continue!"* Why is it that

people do not come forward for testing? *"There are people who say that the HIV is*

inside the condom. They don't want to take the test." I had heard this anecdote many

times. *"And they have HIV for sure?"* I asked him. *"They do, without any doubt. They*

have it. I was saying that in my family, I have my cousin. I have come to the point I

can see this, I can see that a person has HIV, but she is denying the HIV test. She is in a

bad shape. She has even consulted everyone at the hospital, but they haven't been

able to detect the disease. This person has HIV. It's a big problem."

Fausto's cousin thus experienced the health service incompetence, which

the government has recognized and taken measures against, but this takes time,

further prolonged by individual resistance to HIV testing. *"It's in the head and this*

barrier is supported by the infamous traditional practitioners." Somewhat perplex, I

asked him: *"How?"* Fausto leaned over the table, looked straight at me, and said:

"Because they can see that this person has HIV symptoms. But when such a person

comes to them, all they do is those divinations." Fausto changed into a high-pitched

voice, imitating the curandeiro who says to the seropositive person: *"No, no, no,*

you are not infected, you have problems with your family. Your family is giving you

this, and this, and this." Then he says with his normal voice, with sincerity: *"But, as*

the person is mentally poor, he will accept what the curandeiro is telling him. He will

say 'ah, I don't have HIV, I have this and that, which I will treat and then leave it.'"

The reader might think this is all speculation: Fausto is making things up from the gossip about traditional healers. However, Fausto raised his voice at this moment, looking earnest and grave: *"This is not just an idea that I have. It's not something I'm just thinking: they are concrete and practical. It happened to me! I consulted them for a long time, but no one was able to say to me 'you have to go to the hospital and get tested'. No one. They simply said: 'Hey look, you are ill. But this disease is no problem. I will treat it. Give me so much'. And then I gave him money. But as I am suffering and I am not getting any better, what's my worry?"*

Fausto rested with a rhetorical pause and reciprocated: *"I will leave him and seek another one. The next one says: 'that one did a bad job; I don't know what he is up to. I will treat you, it's not a problem'. I therefore gave him money and even went to the bank to get more money, and I kept paying him. It was all the same after two-three weeks. Then I left him. I looked for another one. This one says: 'Hey, it took you a long time to come to me. This is no problem for me. I will treat it.' Then I gave him money. Time flies. The virus works inside you. It's killing you."*

Fausto coughs a little bit and then catches his breath to say: *"Listen, it was my own initiative to go to the hospital! I began treatment at the local hospital. There they said: 'Hey, we have performed many analyses, but these sores don't go away. It's better that we transfer you to dermatology, because you have a skin disease'."*

This was during the days, when health workers in the national health system were not trained in HIV, AIDS, and ARVs. Health worker training in ARV treatment started within the Ministry of Health in 2004, but problems persist of incorrect diagnosis and lack of reference between specialists.

"I left the hospital to seek a curandeiro again, because curandeiros are more specialized in treating scurf. So, he burnt some roots. Then he mixed them with ani-

mal bones. Then he grated all this. A lot of blood came out, then he applied this thing and it would dry up. But it didn't dry up on me."

Fausto kept moving back and forth between traditional healers and the biomedical doctor. He was not satisfied with treatment of either kind of practitioner. The biomedical doctor finally advised Fausto to go to the beach to bathe in salt water. The sores dried up after one week. *"But, I kept having diarrhea. I had eye inflammations. I was operated 4 times. And I had this cough that never goes away."*

The 'cough that never goes away' is a common expression for one classical symptom associated with advanced HIV. People explain symptoms of AIDS in this way before they find out about its nature. They know other HIV related symptoms like diarrhea, skin rashes, and inflammations from other illness episodes, but the 'cough that never goes away' is an exceptional phenomenon.

Fausto ended up critically ill, when he experienced severe symptoms of AIDS. *"I survived on milk, because my mouth was all inflamed and full of sores. I couldn't even drink out of a cup. I couldn't eat salty food. I could only drink milk."* Then he consulted one of the international treatment providers, which gave him the chance to join the fortunate minority: he entered the initiation and continuation phases – the therapeutic process. *"All these health problems disappeared after three months here. Weight loss and lack of appetite."*

Others like Gilberto, Rosalina, Liliana and Mafalda share Fausto's experience and views on traditional healing. They have one thing in common: they did not know about HIV throughout many years experiencing ill health. I interviewed Osvaldo, who has been a counsellor since the beginning of ARV treatment in Mozambique in 2002. He can clarify why they did not know about HIV.

An Epidemic of Prejudices: Individual and Collective Denial

Osvaldo first told me about the years with HIV before the new millennium: *"To be honest, we had all heard about it, we all lived it, but we didn't believe in the existence of HIV/AIDS. We didn't believe anything about it!"* He then revealed something about the omnipresent accusations and conspiracy theories: *"The white people invented all this. This was a way for the white people to finish us. Many times we interpreted the situation in this way."* Then he continued: *"Also, forms of prevention were not given to us. Many of us didn't use condoms. Many of us knew about sexually transmitted diseases, except HIV/AIDS. It was a logical situation, a characteristic situation, because we were not informed about HIV. We had heard talk about it, but it was at a distance: in Zimbabwe, Kenya, and Uganda, always outside the country."*

Osvaldo continued: *"This was all about prejudices; those things were inside all of us. Even educated people, even at the level of health workers: there was a certain ignorance, which didn't sensitize anyone to care to take preventive precautions. This created all this movement, as the number of infections increased, but it was unknown, as nobody had been proven to have it. Nobody found out whether they were seropositive or not. Even at the big hospitals: they didn't test for HIV."*

This was a case of individual and collective denial, mixed with accusations that 'white man' had an evil master plan, as well as the globally 'blaming others' phenomenon. As Farmer noted in the early 1990s, *"As long as we have known about AIDS, blame and accusation have been prominent among the social responses to the new syndrome"* (Farmer 1992: 244). Specifically, Matsinhe proposes two key aspects of the Mozambican 'epidemic of prejudices': 1) recognition of incompetence

and ignorance within the country, and 2) reluctance to discuss the problem loaded

with negative and stigmatizing connotations (Matsinhe 2005: 40).

However, the epidemic of prejudices reveals a cycle of retaliation, as exem-

plified in the growth of conspiracy theories in response to discrimination. That is,

victims of prejudicial treatment respond by reverse stigmatisation, the rhetorical

weapon of the powerless (Farmer 1992; Link and Phelan 2001). Moreover, these

various forms of individual, collective, and state denial and blame regarding trans-

mission and spread of the HIV virus have had dire consequences in the era of ARV

treatment. The epidemic of prejudices continues, yet alleviated by successful pro-

gress at the interface between historical and personal denial. As sociologist Stanley

Cohen remarks in *States of Denial*: *"As the problem becomes politically fixed, so it*

becomes easier for the individual victim to overcome residual denial, self-blame, stig-

ma or passivity and seek appropriate intervention" (Cohen 2001: 51-52). In other

words, personal bias is contingent on the political power to change the capacity of

the health system. Stigma and discrimination decreases for those who win the lot-

tery in the 'first come first served' game. However, the epidemic of prejudices, in

all its multivariate nuances, worsens for the majority of people in need of ARV

treatment, who find themselves humiliated, numbed, and silenced, yet in sympa-

thetic understanding of the limitations of the health system.

Political and System Barriers

Mozambique was burdened by state denial, influenced by its past political align-

ment to socialism – in particular Russia and Cuba – but certainly caused by the

devastating effects of war. The Mozambican government did not have the resources to adequately respond to HIV. The biggest challenge, which lies at the heart of FRELIMO politics, is how to improve the National Health System. This has been at the core of the political agenda since independence in 1975. The government welcomes those international organisations that agree and sympathize with this goal, but it embraces the ones that agree to end AIDS exceptionalism to improve overall health care delivery. The government does not salute affirmative action for AIDS under the circumstances of high disease burden. AIDS funding has become a pragmatic opportunity to improve, construct, and expand free and universal health care to all corners of Mozambique. Training of health workers and construction of health facilities at the provincial and district levels remain the biggest challenges. This *is* a 'race against time' (Lewis 2006a), as the number of people in need of health care grows faster. The health system is challenged beyond its limits, despite the rapid expansion of ART sites since 2004 and despite the relatively low demand for HIV testing. Finally, reasons for silence and secrecy related to the practice of traditional medicine can be explained by the legacy of scientific socialism, which prohibited all cultural aspects against modern development.

State Denial: Good Faith, Incompetence and Ignorance

Politics of denial may explain reluctance to consider HIV/AIDS a problem for the country, before the arrival of the international community. As evidenced in Farmer's ethnography about blame and accusation in Haiti (Farmer 1992), Mozambicans blamed the United States and denied everything considered 'deviant and dis-

eases of capitalism' (Matsinhe 2005: 41). However, denial may stem from Cohen's

cultural denial from good faith, such as genuine ignorance and lack of resources

(Cohen 2001: 56). Thirty years of war left Mozambique in ruins, particularly the

health infrastructure. The resistance movement RENAMO systematically destroyed

schools and health care facilities. The Portuguese colonial administration left upon

independence. The IMF and the World Bank would not let Mozambique develop by

its own government agenda (Hanlon 1996). This remains an ideological struggle

and a sensitive matter of sovereignty. Insufficient initiatives were taken to resur-

rect the health care system until the new millennium, when the major donors in

the area of HIV and AIDS began to support the Mozambican government towards

preparedness for the HIV epidemic (see Chapter 6).

Health System Challenges: Competence, Capacity, and Infrastructure

System barriers include problems of incompetence within the health system and

limited human resource capacity. The relatively few ART competent health work-

ers can only care for a limited number of patients. To reiterate, some 5 percent of

the adult population had tested for HIV by 2006, of which 26 percent tested HIV

positive. Some 30 percent of the adults and 7.5 percent of children in need of treat-

ment received it by May 2008 (see Chapter 2). This already pushes the health sys-

tem beyond its carrying capacity. The expansion of physical infrastructure is on-

going, evidenced by the 216 ART sites across the country in the 128 districts by

May 2008. However, there are many other challenges ahead. Health workers need

diagnostic knowledge and how to refer patients to proper expertise. Many people

suffer several diseases, evidenced by syndemic co-infection of for example HIV, TB, and malaria. Unilateral health worker training in ART would take away resources and health workers from other parts of the health system, already overloaded by the general burden of disease, experienced for centuries (see Chapter 5).

Silence and Secrecy: The Legacy of Scientific Socialism

I explain the fate of traditional medicine in historical and political perspective to discuss how and why traditional healers and patients hesitate to speak openly about HIV. The revival of traditional values may seem a diametrical turnaround since the days of FRELIMOs scientific socialism, when the government attempted to abandon and prohibit witchcraft and sorcery. This process started in the late 1960s, when FRELIMO changed from nationalist front to revolutionary organisation (Adam 1996). The first constitution endorsed by Samora Machel reinforced the explicit effort to *'realize an energetic fight against illiteracy and obscurantism'* and to *'promote development of national culture and personality'* (Machel 1975a). This was a three-fold project, which simultaneously campaigned against capitalism, colonialism and traditionalism, including the repression of both Christian and Muslim religious practices (Fry 2000). 'Clients' and 'traditional authorities' would be punished for 'counterrevolutionary activities' and 'false consciousness' (West 2005; West and Kloeck-Jenson 1999). All this went on until the beginning of the civil war in the early 1980s. This explicit crusade sought to negate and eradicate cosmological elements, deliberately viewed as archaic and backward values inappropriate and prohibitive in modern society (Matsinhe 2005).

However, the government changed its policy for three reasons. First, the government realized that socialism had failed. Second, it understood the global message that the World Health Organisation recommended to integrate traditional medicine into primary health care, which took form in the 1970s and promulgated through subsequent decades. Third, the government pragmatically embraced the idea suggested by the international community to let 'traditional authorities' form the basis of an emerging civil society for the purposes of the democratisation process, decentralization, and local participation (West 2005: xviii; West 2006: 22). Rights of assembly and association were formulated in the 1990 constitution (Chissano 1990), which soon led to proliferation of development projects and NGOs and new forms of international alliances with the government.

The Ministry of Health created an office for the study of traditional medicine in 1977 to collect information about traditional medical ideas and practices, symptomatology, disease description and classification. The Ministry recognized the Association of Traditional Doctors in Mozambique, AMETRAMO, in 1990 to 'appreciate and valorise their knowledge and action in the fight against disease' (Republic of Mozambique 2004).

The Government's 2004 Traditional Medicine Policy and Strategy for Implementation (Republic of Mozambique 2004) follows the WHO recommendation for integration of traditional medicine into primary health care, which has been WHO policy since the Alma Ata Declaration in 1978 (WHO 1978a; WHO 1978b). The government puts the blame on the Portuguese colonial administration for all issues related to 'obscurantism'. Focus is on active ingredients in medicinal plants. The first laboratory project on this initially failed. Obscurantism then re-emerged in 1980s because of illiteracy and lack of knowledge sharing. Moreover, the govern-

ment policy omitted one important part of the WHO definition of traditional medi-

cine from 1978: *"Traditional medicine might also be considered as a solid amalga-

mation of dynamic medical know-how and ancestral experience"* (WHO 1978b). This

indicates continued commitment to eradicate 'obscurantism'. However, this likely

creates an unofficial domain for such practices, rather than their elimination. In

times of HIV and AIDS, this leads to double silence and secrecy. As Murray Last

asks, *"Is politically orientated professionalization from above compatible with social-

ly sanctioned professionalization from below?"* (Last 1996: 388). In other words,

'unofficial' healing practices find legitimation among their users. 'Unofficial' prac-

tices become tabooed, often via secret societies, and function by nonverbal com-

munication and secret knowledge. HIV and AIDS carry silence and secrecy, as we

have already seen. Together they produce the opposite of government intentions,

focussed on clarity, communication, referral to competent biomedical health serv-

ice, and traditional medical practices limited to primary health care.

A 1991 pilot project, aimed at collaboration between the Ministry of Health

and traditional healers, focussed on how to reduce transmission of HIV and sexual-

ly transmitted diseases. The study noted that the change from prohibition to re-

cognition was slow to reach traditional healers (Green, et al. 1993). I would say

that collective memory reigned, which inhibited the healers from acting in accord-

ance with their newly attained status. Healers therefore remained silent, when

Green's team asked about sorcery and witchcraft. They concluded that there was

no evidence for such practices and they felt safe to deduce that local diseases were

perceived in predominantly natural terms. They consequently prioritized common

sexually transmitted diseases for policy purposes. It was too early to conclude the

same for HIV as a relatively new disease (ibid.). Thus, Green and colleagues do ac-

knowledge the problem of silence and secrecy, but they deny the existence of sor-

cery and witchcraft. This phenomenon is part of what Matsinhe calls the emer-

gence of 'cultural gaps' and how the hegemonic HIV/AIDS discourse neglects dia-

logue with alternative frames of understanding (Matsinhe 2005: 133ff). Sorcery

and witchcraft *do* exist, but in a vacuum of invisibility, silence and secrecy, parallel

to official discourse and policy implementation. Reasons for failed HIV prevention

and treatment programmes may reside in this counter-denial turning a blind eye.

Health Seeking Behaviour and Medical Pluralism

Another important point: the Government continues to integrate traditional medi-

cine according to the 1970s WHO policies. It also recognizes the problem of HIV

and traditional medical practice, evidenced by the initiatives to educate traditional

doctors about HIV and AIDS. However, only about 400 out of 90,000 practitioners

of traditional medicine were trained by 2006 (Ministry of Health 2006j). Yet, the

question remains why so few people come forward for HIV testing. Do most people

living without ARVs hide at home? Do they continue to consult one or more of the

many traditional healers that still lack the information and skills how to handle

AIDS patients properly? The implicit government denial of some forms of tradi-

tional practice may be an indirect reason why so few people come forward for HIV

testing, care and treatment. If both traditional practitioners and their patients hide

in silence and secrecy in fear of authority and they at the same time circumvent the

rules for treating HIV and AIDS, then we have both an explanation and a problem.

Engaging Cultural Context: Dialogue in the Making

However, sociocultural values were considered important for the production of an 'informed basis' for the national response to HIV and AIDS (Matsinhe 2005). Knowledge, Attitude and Practice studies were promoted, but still, *"the policies and strategies reflected more the global focus on forms and methodologies on how to fight against HIV/AIDS, and less about the dialogue with the multiple stereotypes and representations, which circulate about HIV/AIDS among the different groups and population categories in Mozambique"* (ibid.: 186). This is Matsinhe's critique of policy making in its cultural context.

I agree with Matsinhe's point that on one hand we cannot renounce the positive impact of initiatives taken so far that seek to inform and educate people and traditional medical practitioners about HIV and AIDS. However, the numbers, policies, and strategies do not tell us about the coexisting set of values constructed and reconstructed along the implementation of the national strategic plan and the ongoing ARV rollout, which is presented as a biomedical regimen that demands true believers for life. Neglecting half the local practices, mostly the extreme opposites of biomedical thinking, may already have proven the wrong strategy for the success of intended treatment expansion. This may explain problems of ARV dropouts and the lack of patient demand, even when the supply of infrastructure and human resources is in place. In other words, cultural heterogeneity reigns over any attempted national or political project that spells homogeneity. Competing social imaginaries occur within a multiplicity of popular perceptions and political incentives. This is exactly what Matsinhe emphasizes that dialogue is necessary (Matsinhe 2005). People and cultures do not constitute clean slates and docile

bodies on which values, behaviours and codes of conduct can be implanted, engrafted, or even in a medical sense 'inoculated'. The contested discourse on 'civilization' and 'tradition' continues at all levels, which point to tensions between modernity, enculturation, and cultural practices. But, as Peter Fry argues, human *suffering* fuels the belief in witchcraft and sorcery (Fry 2000).

Health Seeking Behaviour: Pacifism Rooted in Human Suffering

This has immense implications in times of HIV, AIDS, and ARVs. The first implication is obviously the one about charlatans (see p. 151). Traditional medical practices imply the risk of HIV transmission from ritual purification ceremonies. Yet, the government educates traditional practitioners about sterilization of their tools to rectify this problem. Thirdly, traditional medical and religious practices provide important resources to maintain psychosocial and mental health. From my own experience, many such beliefs and practices occur within an autonomous space that alleviates psychological and spiritual suffering, which complements the medical antiretroviral therapy. Such activities are mainly practiced through self-government, free from outsiders' intervention. Though differences between 'psychosocial therapy' and religious or authentically Mozambican 'spiritual practices' may be a matter of ideology, I do believe in the liberating powers of the freedom to think, believe and choose. However, it may have inadvertent consequences to be living with or without ARVs in an environment of criss-crossing messages of what is right and wrong, promised and kept, and said and done.

This is about human suffering: the psychological, mental and emotional impact of health seeking behaviour, as people in need of care and treatment experience fluctuations between expectation and disappointment, hope and hopelessness, success and failure. Moreover, postponement and passive health seeking behaviour relate to disease and illness as an enculturated norm. People live with and have died from so many other diseases throughout centuries. Adherents of traditional cosmologies search for comfort, but they also encounter 'barriers' to ARV treatment.

The 'Mozambicanization' and 'sensitization' projects include translation of HIV prevention messages and ART counselling into many of the some 40 local languages. This is an enormous challenge: many languages do not have words for 'HIV', 'AIDS', and 'ARVs'. Mozambicanization and sensitization happen by means of community *palestras* and community radio broadcasting. However, how and why traditional beliefs possibly stand in the way for biomedical treatment remains poorly understood. The predominant paradigm argues that individual or cultural 'denial' explains non-seeking behaviour, not traditional beliefs. However, I do not believe in an either or situation. People live in a context of multiple conflicting messages, both when it comes to HIV prevention and ARV treatment. Negotiation with spirits or Gods of the cosmological realm intersects with the offer made by supposedly neutral biomedical science. Calling upon God to negotiate absolution – the release from guilt and sinful behaviour – may or may not stand in the way in order to face the reality of HIV and AIDS.

However, Pfeiffer reminds us that rising social inequality and economic disparity causes a decline in social cohesion. Mozambicans in fact turn away from harmful and expensive traditional healers in search of alleviation by the 'Holy Spirit' within African Independent Churches (Pfeiffer 2002). Others know the biomedi-

cal story and they may well be in a 'state of denial', evidenced by their shortcuts in life: they take the easy way out in an attempt to avoid the day of confrontation.

However, people engage in syncretic health seeking behaviour, which lends faith to religion, tradition, and science. Mozambicans combine traditional and modern medicine throughout their life cycle in search of equilibrium between magical, spiritual, traditional, and modern dimensions, all perceived as part of the same cosmology (Matsinhe 2005; Ministry of Health and DANIDA 2004; West 2006). Thus, we see the navigation and possible conflicts within one cosmology, rather than conflict between different cosmologies, or ignorance, avoidance, or denial of particular cosmologies. This is nothing new within anthropological studies of medical pluralism. People are practical, not ideological when they seek health care (Leslie 1980: 194). The new is that HIV, AIDS, and ARVs have emerged and now show the importance of taking such pluralism seriously to eliminate malpractice.

These factors need to be taken into consideration to understand why some people fail to take ARVs twice a day. The next chapter reviews social science HIV studies in sub-Saharan Africa in general and in Mozambique in particular. This will show the dearth of ethnographic access and delivery studies.

4
Context

4: Context

This chapter provides a literature review of social science HIV studies in sub-Saharan Africa and in Mozambique in particular. I analyze 1,563 country-specific studies, retrieved from the Social Sciences Citation Index, SSCI, in five ways to qualify the choice of multilevel ethnography of the ARV rollout in Mozambique: by *type, country, language, time,* and the *size of the HIV epidemic.* The second part exclusively reviews HIV studies in Mozambique with a focus on prevention and sexual behaviour, as these are the predominant study types. All this leads to a discussion of ARV studies.

HIV Studies in sub-Saharan Africa: A Review

The Social Sciences Citation Index is a multidisciplinary inventory of published journal articles. It lists more than 1,700 journals across 50 social science disciplines, plus individually selected items from more than 3,300 leading scientific and technical journals (Social Science Citation Index 2007). The SSCI does not index *all* social science studies. Some social science journals do not fulfil its inclusion criteria: blind reviewing and number of international citations (Gogolin, et al. 2003) within an environment dominated by the English language. In fact, the SSCI over-representation of research published in English ranges between 20 and 25 percent (Archambault and Gagné 2004; Sandelin and Sarafoglou 2004). This may reflect the bias towards conducting research in English-speaking countries in Africa, but it

may also hide an unknown number of social science HIV studies published in languages other than English. Moreover, journal articles only account for 45-70 percent of research output in the social sciences (Archambault and Gagné 2004). Nonetheless, the following analysis of HIV studies from the SSCI index provides a good indication of the kinds of social science HIV studies that have been conducted in the period between 1987 and 2007 in sub-Saharan Africa.

A Typology of Country Specific Social Science HIV Studies

I removed 399 comparative, meta-, regional, and continental studies from the references retrieved from SSCI to perform a consistent analysis of country-specific studies. Then I created 17 study categories, informed by disease history, disease progression, health system capacity, research habits, how peoples have reacted, epidemic consequences for society, and epidemic costs and governance.

- *Where did the HIV epidemic come from?*
Aetiological studies focus on conflict, poverty, refugees, culture, politics, and socioeconomic factors

- *How big is the problem?*
Surveillance studies focus on prevalence and incidence

- *How do we develop a biomedical solution?*
Studies focus on social aspects of vaccine development

- *How do we avoid contracting the disease?*
Prevention studies look into sexual behaviour, condom use and promotion, awareness, risk, and risk perception, reproductive health, and biosecurity

- *How is HIV transmitted?*
Studies look at the factors that facilitate and determine transmission

- *How do we find out whether we have it?*
Studies focus on aspects of voluntary and mandatory HIV testing and counselling

- *How do we live with it?*
Living with HIV/AIDS entails attention to disclosure, stigma, and discrimination

- *How and where do we get access to health care?*
These studies focus on health seeking behaviour and barriers encountered

- *How do we treat it?*
Living with ARVs entails a new set of concerns in addition to living with HIV before AIDS sets in. Studies of 'treatment for life' focus on 'adherence' and 'compliance'

- *Who will care for us?*
The need for health workers is an enormous challenge in poor countries. Studies look at aspects related to health care for people living with ARVs: Health care personnel, traditional healers, community health workers, family support, and home based care

- *Where do we get treatment?*
Few studies look at the capacity of the health systems in sub-Saharan Africa, focussed on the lack and need of infrastructure, technical equipment, and private versus public health care provision

- *How do we conduct proper research?*
Studies focus on methodological and ethical aspects

- *What if we cannot get access to treatment?*
Action studies look at action campaigns, advocacy, and human rights

- *What is the harm done and how we can ease it?*
Impact and mitigation studies focus on mortality, morbidity, economic and labour market changes and the growing problem of orphans

- *How much does it cost to respond to the HIV epidemic?*
Cost studies look at country specific aspects of funding sources, expenses, and cost-benefit and cost-effectiveness analyses that try to estimate the costs of responses to HIV

- *How do we control the epidemic?*
Governance studies look at politics and policy

- *How can social scientists describe the entire scenario in a holistic manner?*
Very few studies look at the HIV epidemic in general and at the introduction and expansion of antiretroviral treatment in particular from a historical, sociological, anthropological, or ethnographic perspective

More than half the studies focus on HIV prevention (see Figure 4.1). Health policy and time proportional reasons may explain this. Aetiological studies of how and why the disease spreads predominantly look at individual behaviour of people on the move (migration, refugees) and individual behaviour in circumstances of instability (conflict, war). This is not the same as looking at risk environment for explanatory power.
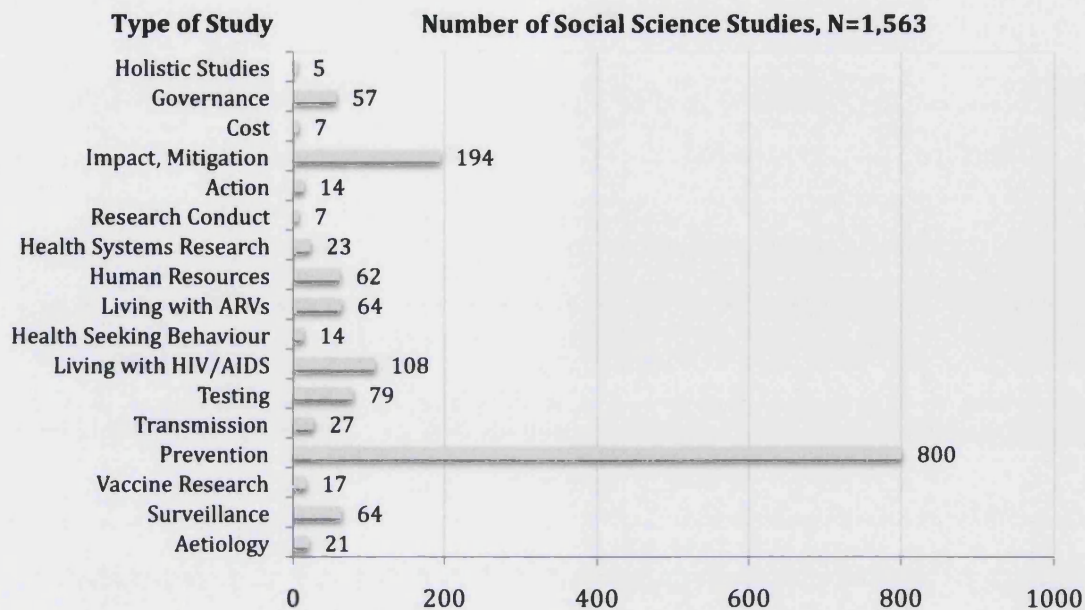
Type of Study	Number of Social Science Studies, N=1,563
Holistic Studies	5
Governance	57
Cost	7
Impact, Mitigation	194
Action	14
Research Conduct	7
Health Systems Research	23
Human Resources	62
Living with ARVs	64
Health Seeking Behaviour	14
Living with HIV/AIDS	108
Testing	79
Transmission	27
Prevention	800
Vaccine Research	17
Surveillance	64
Aetiology	21

Figure 4.1: Social Science HIV Studies, sub-Saharan Africa, 1987-2007
Source: (Social Science Citation Index 2007)

Few studies look at the historical circumstances and social conditions that may favour the transmission of HIV. The tendency to ignore these factors has in fact been worsened by the human rights discourse that tends to focus entirely on the individual. Such focus misses the point that the right to health is an inclusive right, which would cover health care and those circumstances necessary to maintain health. Components of such public health inclusiveness include water, sanitation, food, nutrition, housing, working conditions, a healthy environment, and access to education and information related to health (United Nations 2000).

In reality, social marketing dominates prevention efforts through initiatives such as Knowledge, Attitude and Practice (KAP), Information, Education and Communication (IEC), and Abstinence, Be Faithful and Condom Use (ABC). Lack of resources for treatment in poor countries cannot exclusively explain why prevention has been the favoured policy choice for more than two decades. Indeed, researchers have only been able to do treatment studies since the introduction of antiretroviral therapy in sub-Saharan Africa (5 years over the period 1987-2007). A growi-

ng number of studies focus on 'living with HIV/AIDS', 'health seeking behaviour',

'living with ARVs', 'human resources' and 'health systems research'.

Linguistic Trail: Tracing the Colonial Legacy

The majority of studies were conducted in English-speaking countries. Many studi-

es have been conducted in some countries and few studies in others. This is part of

the colonial legacy. I have divided the countries according to official or predomi-

nant language to support this: there are five Portuguese-speaking, twenty-three

French-speaking, and nineteen English-speaking. This division remains ambiguous

in a few countries. Arabic is the official language in Sudan, yet English remains an

acknowledged principal language in Southern Sudan. Cameroon and the Seychelles

have French and English as official languages, yet French predominates in both

countries. Equatorial Guinea has three official languages: French, Spanish, and Por-

tuguese. Finally, the official language of Somalia is Somali, where other languages

like Arabic, English, and Italian remain secondary (see Figure 4.2) (Central

Intelligence Agency 2008).

Country Specificities

Differentiation by country shows that 1,329 (85%) of the studies were conducted in the 19 countries with more than 10 studies conducted (see Figure 4.4). English-speaking countries hosted 1,197 (90%) of these studies. The remaining 30 countries contribute fewer than 10 studies per country (see Figure 4.5).

Country   **Social Science HIV Studies, N=1,504**

■ English speaking ■ French speaking ■ Portuguese speaking

Country	Value
Madagascar	12
Senegal	13
Burkina Faso	14
Namibia	17
Cameroon	19
Rwanda	20
Mozambique	22
Ethiopia	26
Côte d'Ivoire	32
Ghana	42
Botswana	43
Malawi	62
Nigeria	72
Zambia	89
Zimbabwe	101
Kenya	123
Tanzania	142
Uganda	200
South Africa	455

Figure 4.4: More than 10 Social Science HIV Studies, sub-Saharan Africa, 1987-2007
Source: (Social Science Citation Index 2007).

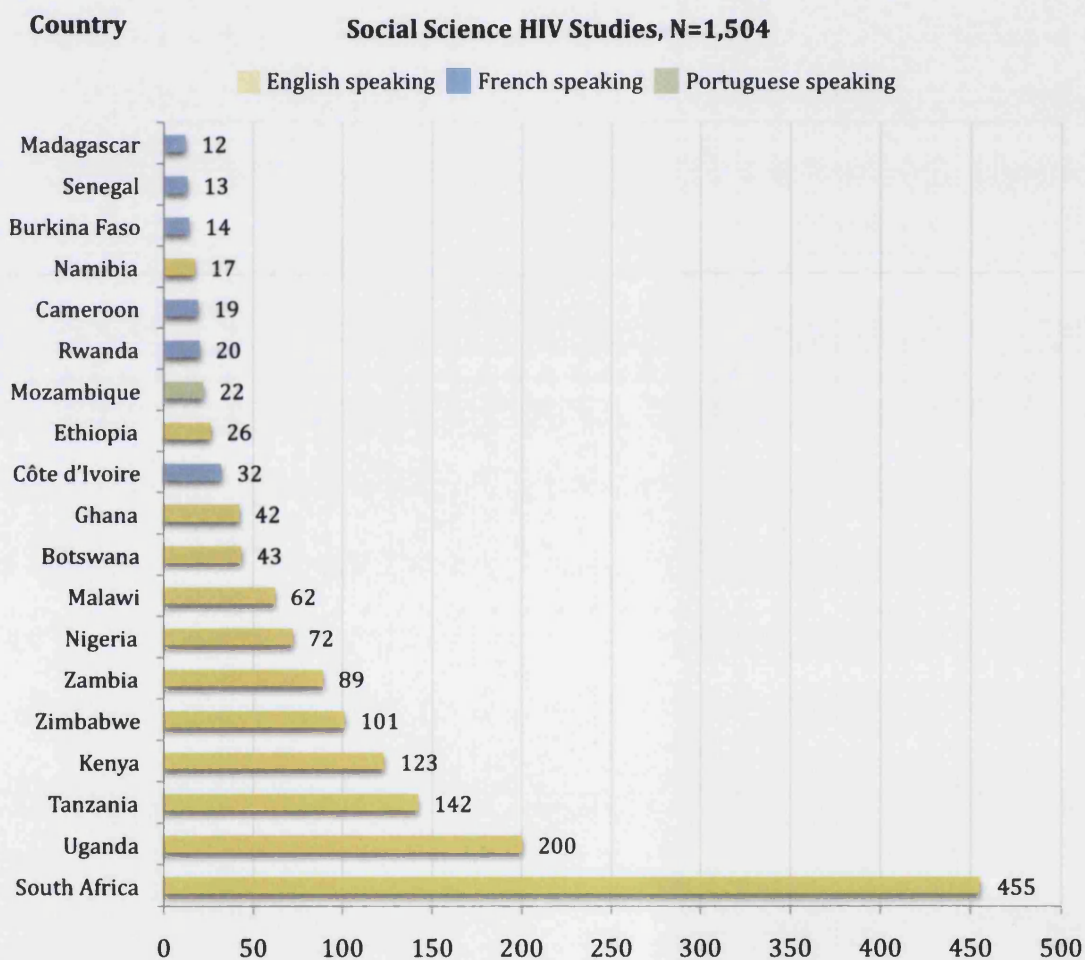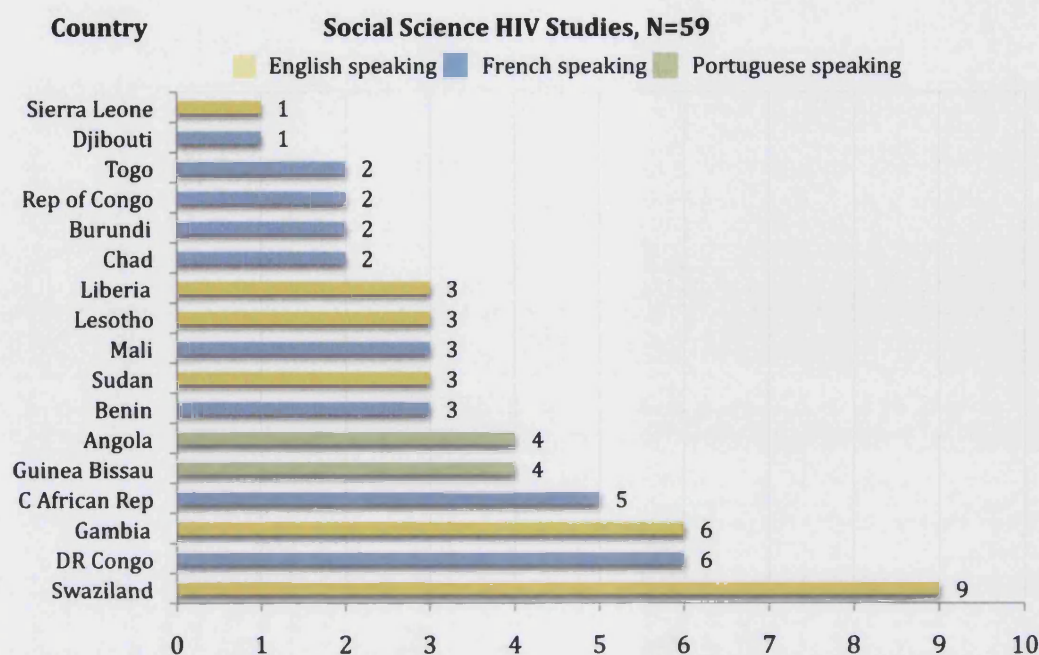**Figure 4.5: Fewer than 10 Social Science HIV Studies, sub-Saharan Africa, 1987-2007**
Source: (Social Science Citation Index 2007).

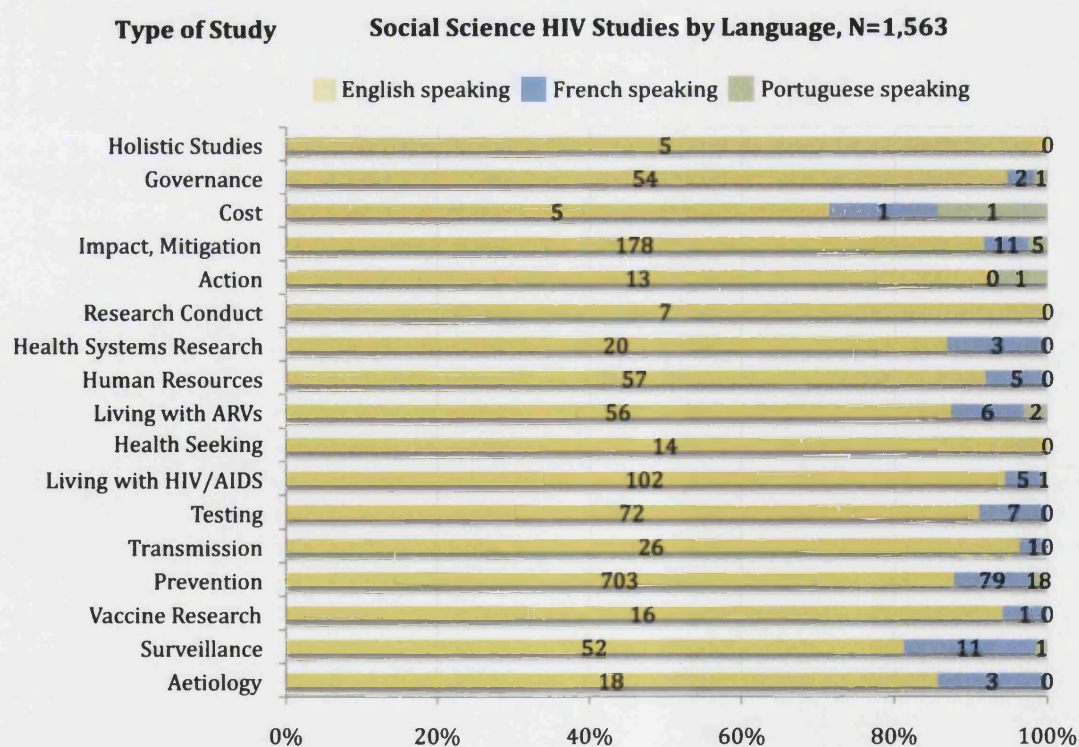This distribution of studies is consistent for all types of study (see Figure 4.6).

Figure 4.6: Social Science HIV Studies by Type and Language, sub-Saharan Africa, 1987-2007
Source: (Social Science Citation Index 2007)

The Portuguese and French speaking-countries comprise 57 percent of all sub-Saharan countries, but they only contribute 10.5 percent of the SSCI social science HIV studies. The English-speaking countries comprise 39 percent, but they contribute 89.5 percent of the SSCI HIV studies. This may, as I indicated in the beginning, say more about this particular index than about the actual number of studies conducted in French- and Portuguese-speaking countries.

I see several reasons for this. English is the predominant global academic language. Researchers competent in the English language take advantage of this situation: they likely choose an English-speaking African country as a matter of convenience. They do not need to learn a foreign language. In addition, native researchers to English-speaking African countries are competent in the English language and therefore have easier access to journal publication.

Foreign researchers who choose French- or Portuguese-speaking countries to do fieldwork most likely come from France, Portugal, or Brazil. Only France has a strong research tradition in Africa. A similar set of reasons explains the few studies in Portuguese-speaking countries. On one hand, few researchers speak, read, and write Portuguese. In Southern Africa, they have chosen Mozambique's English-speaking neighbours, evidenced by this analysis. Of all the studies in sub-Saharan Africa, 858 (55%) were conducted in South Africa, Tanzania, Malawi, Zambia, Zimbabwe, and Swaziland. These countries are part of the English-speaking belt between South Africa and Ethiopia within the epidemic epicentre. The high concentration of studies in this region may therefore seem logical. In other words, researchers go to the countries with highest HIV prevalence. However, the Portuguese-speaking Angola and Mozambique stand out as perfect outliers in this scenario, which supports the point about the bias towards English-speaking countries.

South Africa is a particular case, with its high economic power and academic capacity in the African context, but all Mozambique's neighbours except Swaziland notably make the top ten of the list of HIV studies per country (see Figure 4.4). South Africa strikingly contributes 455 (29%) of the 1,563 studies analyzed here from all countries in sub-Saharan Africa. On the other hand, Mozambique has weak academic structures and Mozambicans have difficulties with the English language. This means few chances of academic publication in leading international journals.[1] Only 15 articles of the 1,563 are published in French. The rest are published in English, except one study published in German.

Category and Time

The evolution of HIV studies by type of study on one hand shows the factual picture of social science contributions over 2 decades, but it also reveals the illogical sequential appearance of responses against an infectious disease epidemic. Better late than never, but why the delay in realising the interconnectedness between prevention, testing, and treatment? Why are we just waking up to the reality of weak health systems and the need to train massive numbers of health workers some 20 years into the epidemic? This is about the politics of preparedness. Treatment was 'unaffordable' in 'resource-poor settings' for the first two decades. Interventions have focussed on prevention. African governments were 'in denial' and lacked the infrastructure. Recently the issues of 'absorption and absorptive capacity' have been invoked to explain the slow ARV rollout.

The trend lines show the evolution of studies during the period 1987-2006 (see Figure 4.7). I have included 'Prevention' and the categories that have experienced an increase to more than 15 studies published in 2006. Prevention studies outnumber Impact and Mitigation, Living with ARVs, Living with HIV/AIDS, Testing, and Human Resources three to ten times.
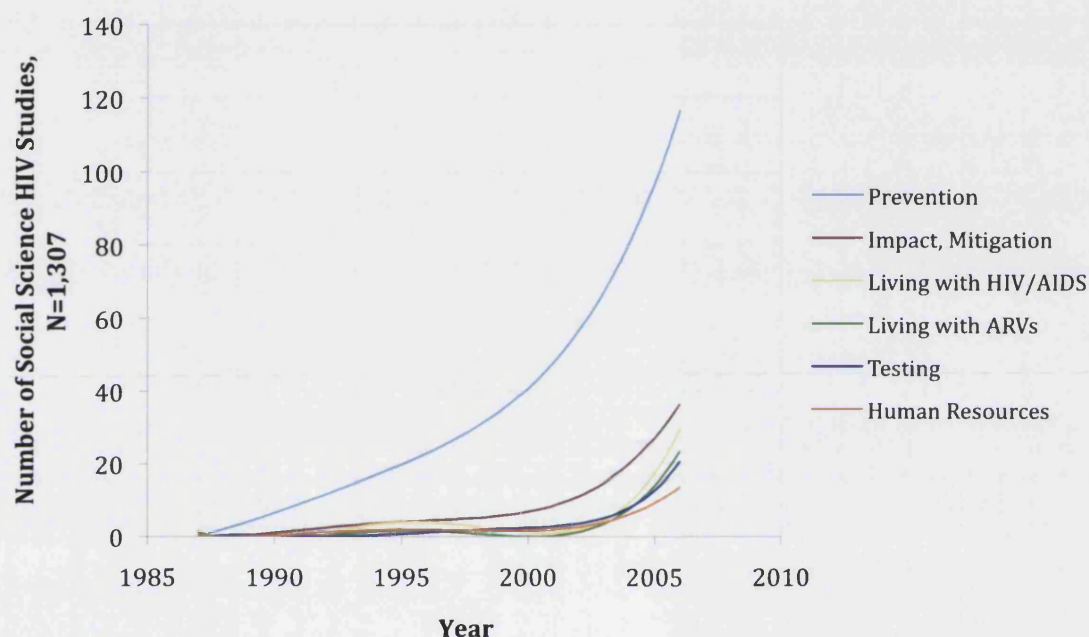
Figure 4.7: Social Science HIV Studies by Study Type, sub-Saharan Africa, 1987-2006
Source: (Social Science Citation Index 2007).

Why ten times more prevention studies than human resource studies? Why not rapidly scale up operational human resource studies to improve health worker conditions, needs, and skills? The remaining 11 themes of this analysis contribute ten or fewer publications per year. Those are Surveillance, Governance, Vaccine Research, Transmission, Action, Cost, Health Systems Research, Aetiology, Health Seeking Behaviour, Research Conduct, and Holistic Studies. As an anthropologist, I choose to highlight the following lessons from this exercise, as they point to operational and academic research areas in which anthropologists must engage:

a) *Prevention studies*: they continue to outnumber all other types of study. Prevention studies focus on individual behaviour as the cause and driver of the epidemic. The need for studies of risk environment is only partly reflected in the studies of epidemic aetiology, as they focus on underlying poverty and socioeconomic factors.

b) *Impact and mitigation*: a macro-study type that grows steadily. They focus on the impact of the HIV epidemic on the economy, the labour market, and mortality and morbidity, particularly orphans.

c) *Living with HIV, AIDS, and ARVs*: People centred studies focussed on the experience 'living with HIV/AIDS' and 'living with ARVs' surpassed HIV testing studies in 2004. This increase will most likely continue in the coming years. This reflects the late coming of the ART era in Africa in the early to mid-2000s.

d) *Health Systems Research*: such studies, including the needs for human resources, infrastructure, and technical equipment, have appeared late on the research agenda with minor increase. Some research is in the making. This also reflects the relatively slow publication process of academic studies.

e) *Governance*: Few have studied health policy and politics comprehensively. Governments are often blamed for lack of response, but few social scientists have actually described and analysed governments' role and power in the control of the HIV epidemic from an insider's perspective.

f) *Action*: There are remarkably few studies of action campaigns, human rights, and the role and accountability of nongovernmental organisations.

g) *Health Seeking Behaviour*: There is a dearth of studies looking at 'life with ARVs'. Anthropologists need to follow people living with ARVs away from the health system, in the communities, in the homes, as life unfolds with changing residence, partners, and social spheres. This is the missing social science contribution to understand why people drop out of treatment and how to improve adherence.

h) *Holistic Studies*: Few studies have provided a time perspective of the HIV epidemic by means of history, sociology, anthropology and ethnography.

The Size of the Problem

How many social science studies do we need of the HIV epidemic in sub-Saharan African countries? Factors such as adult prevalence or absolute numbers of people living with HIV could be decisive for where to conduct fieldwork. Nevertheless, it depends on how we look at it. Take for example Swaziland and Nigeria. Swaziland has the highest adult HIV prevalence at 33.4 percent with 220,000 people living with the disease (UNAIDS/WHO 2006e). Nigeria's adult HIV prevalence is 'only' at 3.9 percent, but 2.9 million Nigerians live with HIV (UNAIDS/WHO 2006d). Swazi society would be closer to extinction given its higher prevalence than Nigeria, but we also talk about the problem of HIV in terms of absolute numbers. South Africa has the highest number of people living with HIV, followed by Nigeria. However, no matter the angle from which we seize the problem, the need for social science studies would ideally be counted by their ability to solve problems. However, the number of social science studies conducted in sub-Saharan Africa is arbitrary in relation to local needs. Choice of research location is rather a matter of colonial language appropriation, convenience, and local economic power and academic structures. South Africa is the perfect outlier compared to the rest of sub-Saharan Africa, but where should researchers go, if the need for research matters? A few studies would suffice, if they solved problems. Why conduct more studies, if for example levels of incidence decreased or if operational research helped solve the challenges faced by the health systems. The focus would probably change, so more studies would still be needed. I suggest looking at the proportion between social science studies and the total number of people living with HIV (see Table 4.1).

Table 4.1: Social Science HIV Studies Related to the Size of the HIV Epidemic

Country	Social Science Studies	Studies/HIV Population (1/Pop)	Adult HIV Prevalence (%)	Total Population with HIV (%)	Adults	Adults and Children	Population
Senegal	13	4,700	0.9	0.5	56,000	61,000	11,658,000
Uganda	200	5,000	6.7	3.5	900,000	1,000,000	28,816,000
Botswana	43	6,300	24.1	15.3	260,000	270,000	1,765,000
Ghana	42	6,400	2.0	2.0	247,220	266,851	13,227,000
Angola	4	8,000	3.7	2.0	280,000	320,000	15,941,000
Rwanda	20	9,500	3.1	2.1	160,000	190,000	9,038,000
Tanzania	142	9,900	6.5	3.7	1,300,000	1,400,000	38,328,000
Kenya	123	10,600	6.1	3.8	1,200,000	1,300,000	34,255,000
Burkina Faso	14	10,700	2.0	0.7	140,000	150,000	22,112,000
South Africa	455	12,000	18.8	11.6	5,300,000	5,500,000	47,431,000
Zambia	89	12,400	17.0	9.4	1,000,000	1,100,000	11,668,000
Namibia	17	13,500	19.6	11.3	210,000	230,000	2,031,000
Malawi	62	15,000	14.1	7.3	850,000	940,000	12,883,000
Djibouti	1	15,000	3.1	1.9	14,000	15,000	793,000
Zimbabwe	101	16,900	20.1	13.1	1,500,000	1,700,000	13,009,000
Ivory Coast	32	23,500	7.1	4.1	680,000	750,000	18,153,000
Swaziland	9	24,500	33.4	21.3	210,000	220,000	1,032,000
Cameroon	19	26,600	5.4	3.1	470,000	505,000	16,321,000
Nigeria	72	40,300	3.9	2.2	2,600,000	2,900,000	131,529,000
Mali	3	43,300	1.7	1.0	110,000	130,000	13,518,000
Central African Rep.	5	50,000	10.7	6.2	230,000	250,000	4,038,000
Togo	2	55,000	3.2	1.8	100,000	110,000	6,145,000
Congo	2	60,000	5.3	3.0	100,000	120,000	3,999,000
Burundi	2	75,000	3.3	2.0	130,000	150,000	7,548,000
Mozambique	22	82,000	16.1	9.1	1,600,000	1,800,000	19,792,000
Lesotho	3	90,000	23.2	15.0	250,000	270,000	1,795,000
Chad	2	90,000	3.5	1.8	160,000	180,000	9,749,000
Sudan	3	116,700	1.6	1.0	320,000	350,000	36,232,000
DR Congo	6	170,000	3.2	1.7	890,000	1,000,000	57,548,000
Guinea	0	-	1.5	0.9	78,000	85,000	9,402,000
Niger	0	-	1.1	0.6	71,000	79,000	13,956,000

Sources: (Social Science Citation Index 2007; UNAIDS/WHO 2006a).

For example, one study correlates to 4,700 people living with HIV in Senegal. At the other end, one study correlates to 170,000 people living with HIV in the Democratic Republic of Congo. If we assume this ratio to be a valid indicator of research demand and obligation, then researchers should consider going to DR Congo, Sudan, Chad, Lesotho, or Mozambique, and so on. The choice of Mozambique relates to the size of the HIV epidemic in the country, the dearth of anthropological ART studies, and my Portuguese language proficiency.

HIV Studies in Mozambique: An Anthropology of Sexual Behaviour

I here review social science studies from Mozambique. The 22 studies from the SSCI index divides into 14 prevention studies, 3 impact studies, 2 adherence studies, 1 governance, 1 cost, and 1 surveillance study. There are no studies of people living with ARVs, health system capacity, human resources, action, or holistic social science studies of the introduction and expansion of ARV treatment. The study of governance looks more at tuberculosis than HIV (see Figure 4.8).
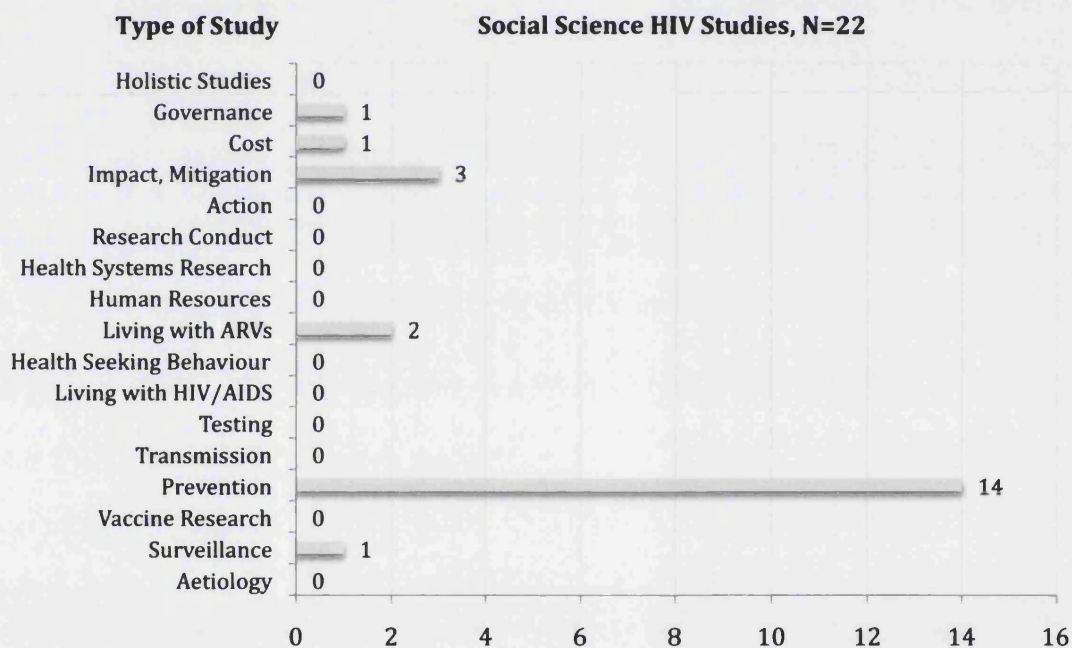
Type of Study   **Social Science HIV Studies, N=22**

Type of Study	Value
Holistic Studies	0
Governance	1
Cost	1
Impact, Mitigation	3
Action	0
Research Conduct	0
Health Systems Research	0
Human Resources	0
Living with ARVs	2
Health Seeking Behaviour	0
Living with HIV/AIDS	0
Testing	0
Transmission	0
Prevention	14
Vaccine Research	0
Surveillance	1
Aetiology	0

Figure 4.8: Social Science HIV Studies, Mozambique, 1987-2007
Source: (Social Science Citation Index 2007).

Thus, Mozambique is no exception. Most studies apply the dominant public health model focussed on individual behaviour with virtually no attention to broader structural factors that may increase the risk of contracting the HIV virus. This suggests that the biomedical ARV solution dominates poverty eradication.

I include an annotated bibliography of HIV studies in Mozambique 1987-2007 (Ministry of Science and Technology 2007), compiled by the Maputo based KULA applied research consultancy. Only 34 of the 450 entries in this bibliography figure in academic journals. The rest belong to the common 'grey area': plans, reports, minutes, memoranda, abstracts, research proposals, guidelines, evaluations, manuals, and enquiries. About 60 percent of these studies focus on prevention, coordination, monitoring, and evaluation (see Figure 4.9).
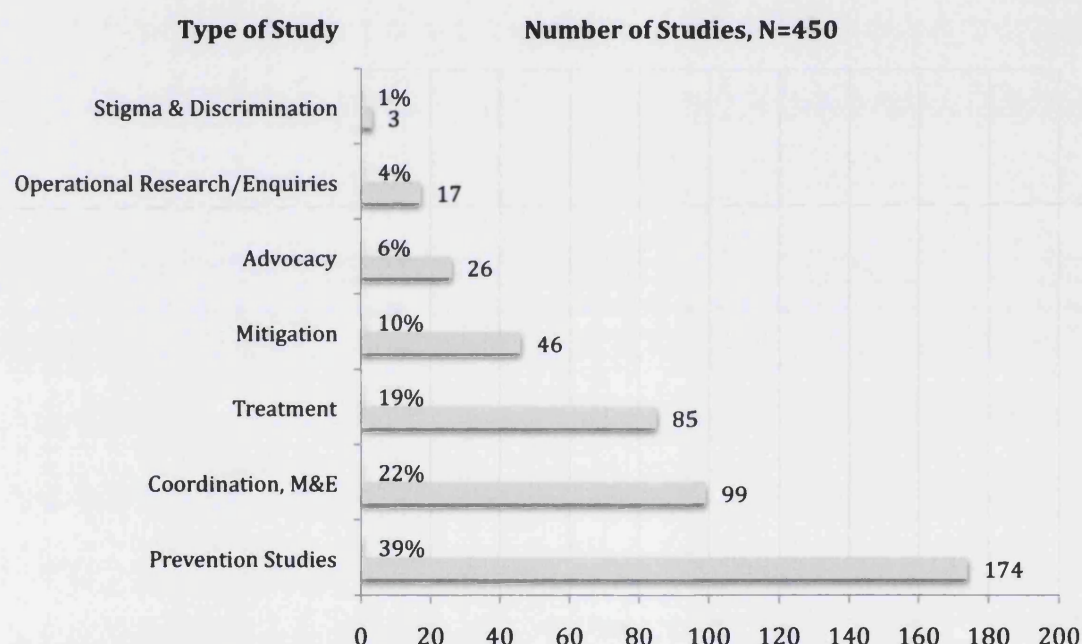

Figure 4.9: HIV Studies by Type, Mozambique, 1987-2007
Source: (Ministry of Science and Technology 2007).

The 85 treatment related studies focus on prevalence, variant types of the HIV virus, efficacy, drug resistance, and medicinal plants (see Figure 4.10). Biomedical studies dominate this picture.
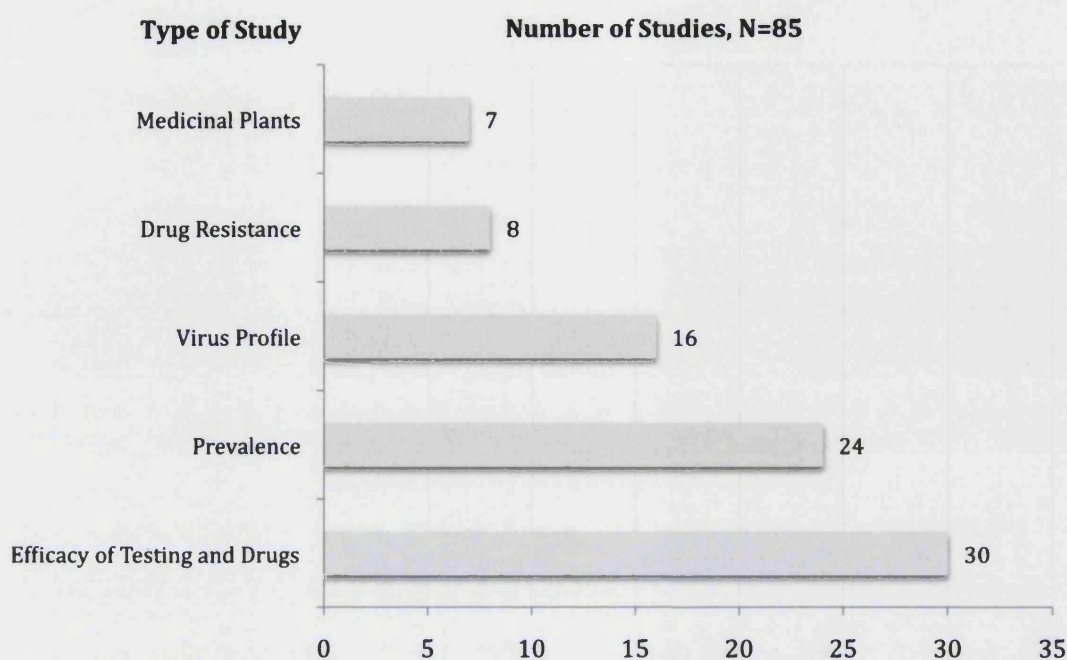
Type of Study   **Number of Studies, N=85**

Figure 4.10: HIV Treatment Studies by Type, Mozambique, 1987-2007
Source: (Ministry of Science and Technology 2007).

For this review, I also include social science HIV studies conducted in Mozambique that have not been indexed in the SSCI. Behavioural studies look at *knowledge and attitude* (Font, et al. 2006), *safety, risk, and social threat* (Domingos Paulo 2004; Machel 2001; Manuel 2005; Prata, et al. 2006), *condom social marketing* (Agha, et al. 2001; Hawkins, et al. 2005; Karlyn 2001; Pfeiffer 2004a), *counselling and testing* (Mola, et al. 2006), and the *initiation of antiretroviral treatment* (Pearson, et al. 2007). The choice of the behavioural lead relates to the fact that most studies in Mozambique have had this focus, but it also promises to lead towards the focus of this thesis.

HIV Susceptibility: Safety, Risk, and Social Threat

Mozambican sociologist Josina Machel asked why young Maputo women 14-20 years of age engage in risky sexual behaviour and whether the spread of HIV is due to socioeconomic factors and/or patriarchal beliefs and mores (Machel 2001). Machel concludes that women lack negotiating power under the constraints of the norms, values, and sexual practices in Mozambique that place women subordinate to men. In particular, Machel argues that patriarchal norms and the need for material support make poorer women more likely to engage in risky sexual behaviour than richer women. Seen in this perspective, middle-class women would then be more courageous and assertive in terms of challenging such norms. They would be at lesser risk of HIV infection.

Risk of infection here depends on power relations decided by gender and class, which leads to an important point: risk of transmission hinges on multiple factors, a sociocultural syndrome, and socio-structural disorder. I find it difficult to believe that HIV aetiologically can be explained by an independent variable like 'poverty' or 'education'.

Machel provides insights into sexual behaviour in Mozambique through a 'safe love' versus 'safe sex' distinction, which captures persisting vulnerability to HIV transmission. 'Safe love' is based on trust and thus in my opinion may harbour increased or continued multi-partner sexual behaviour. The idea that 'love protects us' equals the belief in partner fidelity and as long as this can be trusted, there is no need to use condoms as part of 'safe sex' in long-term relationships, according to Machel's findings (Machel 2001). Thus, condom free sex may become an alibi for

partner fidelity and at the same time a means of getting away with having multiple sexual relations.

Mozambican anthropologist Sandra Manuel found that trust and love provide a sense of immunity to infection (Manuel 2005). Prevention campaigns that advocate condom use in 'occasional sexual relations' reinforced such belief. Manuel uses the concept of 'socio-sexual' scripts to capture the context of sexual normalisation, which took shape before the days of HIV. At worst, there are no behavioural safeguards against HIV transmission. At least, the old behavioural norms dominate the incoming prevention messages and recently incorporated sexual norms in times of HIV.

Knowledge and attitude studies have generally shown that people do have knowledge about HIV, but low risk perception and low condom use. Florindo Martins attempted to find out about knowledge, behaviour and capacity for self-discipline among young adults in Maputo (Martins 2005). Martins found that young adults do know some of the rights and wrongs about HIV, but that they know little about the major factors that contribute to increased risk of HIV transmission and sexually transmitted diseases. These factors include routes of transmission, factors associated with major risk of transmission, the most important means of prevention, and about sexuality in general. As concluded by Manuel (Manuel 2005), Martins found that the level of knowledge about HIV and sexually transmitted diseases and capacity for protection against them increases with level of education. However, young adults have introduced the use of condoms as the panacea against infectious diseases associated with sex. No significant behaviour change complements condom use, like postponement of sexual debut or reduction in number of

sexual partners. Young Maputo adults believe that condoms will solve the problem of potentially intruding microbes (Martins 2005).

We thus see two kinds of trust in the games of sexual behaviour: 'love protects us' (you do not need a condom) and 'condoms protect us' (you do not need behavioural change). One of the consequences is perpetual underestimation of the exposure to the danger of contracting the slow-acting but ultimately lethal HIV virus. How these two kinds of behaviour converge and how they influence the transmission of HIV is still poorly understood.

Two confluent studies support these points. Font and colleagues studied AIDS related knowledge and attitudes among adults in the southern Gaza province. They found that more than 99 percent of the sexually active population knew about AIDS and condoms. More than 50 percent had a good knowledge about prevention methods and of transmission routes. However, 73 percent of men and 91 percent of women did not use condoms when having sex (Font, et al. 2006). In a risk perspective, Prata and colleagues used data from a population based survey of 15-24-year-olds' assessment of their HIV risk to show that 27 percent of women and 80 percent of men who considered themselves to have no risk or a small risk of contracting HIV were actually at moderate or high risk. Condom use at last sexual encounter was only at 14 percent for men and 6 percent for women (Prata, et al. 2006). All this points to the discrepancies between knowledge, risk perception and condom use. People have knowledge, but low risk perception and low condom use. It is the 'it can't happen to me' syndrome of denial.

Another dualism exists between biomedical constructions of risk and social threat perceptions. Mozambican anthropologist Margarida Domingos Paulo studied how people in a Maputo suburb perceive fertility and sexuality in relation to

HIV/AIDS prevention campaigns (Domingos Paulo 2004). In particular, their idea of 'protection' as social capital indicates a communication gap between social and medical threats. Domingos Paulo shows how this group of people maintains social order by paying exclusive attention to the former. 'Protection' starts within the family, as succinctly stated:

> It seems that the perception of threat here is different. For the family, the threat is to reputation, social security and family stability. They are not thinking about a life-threatening disease nor do they want to talk in any specific way about sexual activity, only its social meaning and for young people not to do it (Domingos Paulo 2004: 27).

These perceptions of protection form the basis of behaviour guidance and dominate the biomedical definitions. I suggest that the family and household constitute the last bastions of meaning, power, and control, in which competing definitions of safety will unlikely take over. Unfortunately, the HIV virus has already managed to intrude into the family sphere by its subtle hiding during people's transformative behavioural journeys between private and public spheres.

Behaviour Change: Social Marketing and Structural Determinants

The solutions have been social marketing of behaviour change, the use of condoms, and HIV testing based on human rights norms of 'voluntary counselling and testing'. One health policy study of condom social marketing in Mozambique showed that 'more than half' the adult population knew about the local condom brand *Jeito*

and about condoms in general (Agha, et al. 2001). They found provincial differenc-

es in the use of condoms in *high-risk* sexual behaviour: Maputo City (31%), Sofala

(39%), Manica (46%), and Tete (48%). This means that 69, 61, 54, and 52 percent

of the respondents did *not* use condoms in the respective provinces, which must be

a point for concern, whether this indicates a success or failure of the social market-

ing initiative. Only 23 percent of the respondents in urban Mozambique reported

use of condoms during high-risk sex. However, *consistent* condom use would

change the course of the HIV epidemic (ibid.).

However, an anthropological study in central Mozambique points to the

clash in HIV prevention messages between social marketing, religion and develop-

ment (Pfeiffer 2004a). Pfeiffer argues for a hidden agenda: social marketing pro-

motes privatisation and structural adjustment, not merely HIV prevention. Social

marketing should not come at the expense of community participation and dia-

logue. Religious communities – Pentecostalism and independent churches – pre-

dominate in Mozambique through which people receive an entirely different 'mor-

al' message about sexual behaviour that spells out fidelity norms and the holiness

of the family, as compared to social marketing that carries the 'safety' message that

'you can have sex, but protect yourself'.

From my experience, all these clashing, conflicting, and contradicting mes-

sages, ideologies and interventions coexist in Mozambique. Thinking with Mat-

sinhe, this complexity of messages partly accounts for the lack of direction of the

response to HIV (Matsinhe 2005). One specific policy question for social scientists

to explore is whether and what form of 'single knowledge' or 'one best way' exists

from a local cultural point of view. Simply, how can policy makers create a cultural-

ly informed message and intervention that people understand? They call this 'Mo-

zambicanization' of HIV messages. This is much needed. However, cultural heter-

ogeneity of course complicates this. How many 'local points of view' coexist con-

sidering linguistic diversity and forced and voluntary migration? The current poli-

cy jungle contributes to the ubiquitous phenomenon of *confusão* among the people,

the recipients. Which message is better? Which path in life will provide protection

and security? The contrasting messages may contribute to patchwork behavioural

solutions that increase the risk of HIV transmission.

Indeed, fundamental problems in relation to condom use prevail: insuf-

ficient stock, out of reach, available in the wrong places, and not available where

people have sex. Condom use is a sign of sexual activity, which takes place outside

steady relationships governed by 'love and trust'. The cultural code for extramari-

tal relations is *fora da casa*, or specifically the gendered idiom *mulher de fora*

(Matsinhe 2005: 183), which means men's relations with women outside the home

with reference to the Portuguese cultural dichotomy *casa/rua*, house/street, which

tacitly suggests pleasure, adventure, uncleanliness, prostitution, and street

behaviour. This invokes a change of scene, with a change of risk perception and

behavioural rules, which seems illogical and irrational. Matsinhe found that only a

minority of men and women found it appropriate for women to suggest condoms

at home, whereas a majority found it proper outside the house with *mulheres de*

fora ('women from outside') and *amigas* ('friends') (ibid.). However, the change of

risk perception and behavioural rules is necessary in tabooed relations. Reaching

out for condoms among people with no contact with the health system and HIV or-

ganisations, where condoms are mainly available – and free – means that you need

to reveal your intentions in public. Condoms connote sexual relations *fora da casa*

that easily produce gossip. They may be socially accepted, but highly tabooed. A

Maputo security guard would need to ask around, walk out of his daily routine to get condoms. I talked to some of them about this. There are many guards in Maputo, recognizable by their uniforms. They know each other. They know other workers, drivers, maids, shop keepers, and so on. Thinking with Mary Douglas' definition of pollution as 'matter out of place' (Douglas 2002 (1966)), adventurous sexual aspirations away from your 'loved one' under the constraints of the behavioural norms of society thus becomes 'desires out of place'. This has become a truism. It is part of the kick to break the rules. However, not even a slow acting lethal virus has been sufficiently capable of bending these ingrained games of love and desire. In other words, vigilance contradicts transformation. Alerts, warnings, and posters that remind us of HIV pervade the public landscape of Mozambique. Billboard messages about the right choices in life and the devastating nature of HIV leave you contemplating and perplex. Critical tongues say that such campaigns are too costly and people do not understand the subtle messages invented in an advertising bureau that never considered the cultural context on the receiving end. Yet, people largely *know* about HIV and the dangers it poses to health. This is part of the tragedy. Life goes on, 'as if nothing ever happened', thinking in terms of denial (Cohen 2001; Daniel 2005; de Waal 2005; Scudder 1973). This may be caused by cultural denial (we do not want to change), cultural involution (we do no want to hear more about it) or disability (we cannot change under the circumstances). Consequently, tracing the availability of condoms is a breach of taboo with all the fears of grapevine gossip and social repercussions. Words travel fast. The safer option – for the moment – is to forget about condoms.[2]

Web of Behaviour: An Open System Prone to HIV Transmission

This analysis points to one deep-rooted problem why we fail to stop the spread of HIV: how to overcome socialized behavioural norms, which include the belief in love, fidelity and trust in a context of tacit and cultural acceptance of multiple partners and extramarital relations. In other words, love protects you against disease at home. Condoms protect you away from home – if you can get them. Concurrent partnerships remain poorly understood with regard to factual condom use: do people actually use condoms or do they just say they do? What is the rational logic behind the belief in greater protection from disease infection by means of 'love and trust' over contraceptive means? This is where culture, biology, and medicine converge. Social scientists need to look into this.

I introduce a *web of behaviour*, defined as co-existing sexual behaviours governed by different rules (sex with stable partners, occasional partners, strangers, prostitutes, etc.). People establish rules and perceptions for each kind of sex that viewed in isolation seem to safeguard against HIV transmission, whether these rules and perceptions stem from tradition, social norms, cultural innovation, or medical intervention campaigns. If different sexual behaviours were perfectly closed systems, then the risk of HIV transmission would be minimized, or eliminated. However, the risk of HIV transmission increases, when different kinds of behaviour intersect. In other words, intersection produces clashes and breakdowns of the safety measures discussed so far.

I choose the term 'web of behaviour' as opposed to the more familiar 'sexual networks'. 'Sexual networks' emerge among likeminded people, who share common rules, behaviour, and sexual culture. Each sexual network has its own level of

risk of HIV infection (Adimora and Schoenbach 2005; Frost 2007; Liljeros, et al. 2003; Wohlfeiler and Potterat 2005). A 'web of behaviour' emphasizes the existence and intersection between several social groups governed by different behavioural rules. This is an intrinsic part of the risk environment paradigm that looks beyond *individual* behaviour. A 'web of behaviour' highlights social and discursive disconnectedness, yet simultaneously a crossover connectedness at the level of practice with unintended but drastic consequences. The rising adult HIV prevalence in Mozambique must have more than one explanation.[3] So far, the world has insisted on behavioural solutions and that HIV negative and positive people continue to live happily together, even as virus carriers can live several years without knowing about their infection. Even when symptomatic, many wait until last minute or do nothing at all, as we have seen. Policy makers do not even demand them to find out about it, in the name of human rights governed 'voluntarism'. This scenario is contradictory, in my opinion. Limited behaviour change and HIV testing may explain increased HIV transmission. Thus, the modern public health approach to HIV prevention demands a double individual responsibility: behaviour change and HIV testing. This is an approach against the odds of changing human nature, prone to a certain amount of failure. This is not meant to blame policy makers, individuals or victims for the continued transmission of HIV. Sex, the presumed major route of transmission, does not produce infectious disease transmission in and of itself, only sex between an infected and an uninfected partner. The irony persists, as long as individual free will governs testing for HIV considering the compulsory demand that these same individuals need to change their sexual behaviour to stop further spread of disease. This is a serious dilemma of responsibilities, between the individual human being and public health authorities.

Boundaries of silence, taboo, and lying characterize a 'web of behaviour'. These measures stretch over the entire epidemic evolution into life with ARVs, as I have shown in Chapters 1 and 2. The denial of truth contributes to HIV transmission, as well as failed adherence, and viral resistance: the unsaid, the unspeakable, and the innocent lies – all with drastic consequences. These intricacies of culture challenge public health intervention to prevent continued transmission of HIV. For example, people living with ARVs and Day Hospital health workers explain that lying has become a coping strategy in Mozambique under the circumstances of fragile and vulnerable living conditions. Innocent white lies may solve immediate problems in sexual relationships ('I do not have sex with anyone but you') and encounters with health workers ('I always use condoms, I always take my medicine'). Pregnancy and half empty ARV pill glasses point to the contrary. Silence and secrecy take over, when lying becomes too problematic ('I am taking ARVs, but I don't dare tell my husband or even talk about it. I tested for HIV without him knowing to begin with'). This has implications for treatment adherence and ultimately the cost of drugs as some patients exhaust their tolerance to first line combination antiretro-viral therapies. Second line drugs cost much more.[4]

Sources of Error: Honesty, Denial and Fear of Authority

A few studies look at how sexual behaviour changes with counselling and testing (Mola, et al. 2006) and before the initiation of ARV treatment (Pearson, et al. 2007). On counselling and testing, Mola and colleagues asked 622 participants in VCT groups and 598 participants in non-VCT groups about their use of condoms in

a longitudinal study (Mola, et al. 2006). They conclude: *"People who undergo voluntary counselling and testing for HIV/AIDS change their behaviour, presumably as a result of their counselling"* (ibid.). This is at face value good news. They also note: *"Reported always/sometimes use of condoms for both literate and illiterate subjects was higher and rose over time in the VCT group"* (ibid.)

My concern here is about sources of error. First, Mola and colleagues do admit several limitations of the study. The two groups were not perfectly comparable. Factors like pregnancy, age, religion, and employment status in the VCT group may have skewed the results. The VCT group was also self-selected, as opposed to the non-VCT group. The researchers do acknowledge that people are less honest about sexual behaviour and condom use, but they assume that misclassification would be the same for both groups at entry to the study.

We must scrutinize the issue of honesty and respondents' encounter with state and research authority. Research questionnaires and surveys are often ill suited to capture life as it is. Take the issue of 'white lies': We need to ask whether respondents had any other choice than to claim behaviour change. First, researchers represent authority and respondents may have given the answer they perceived the researchers expected. It may be an example of the denial of truth by the 'little innocent lie that anyone can get away with'. It may be difficult for human beings in general to take a problem by its roots, but I certainly experienced avoidance and evasiveness in Mozambique. That is, it is common to experience people talking about a million other things than the one problem that needs to be solved, even more so when it comes to delicate matters of sex, which is highly tabooed. This manifests as an apparent bigger fear of social than medical consequences getting to truth. The 'white lie' phenomenon may be an indication of an authoritarian

social context, but it may also be a way to safeguard against social repercussions instead of presenting the facts with honesty.

Women's underreporting of concurrent partnerships provides a particular case point. One study found that 21 percent of the women reported multiple partners versus 66 percent of the men (Pearson, et al. 2006). Moreover, the 2003 demographic and health enquiry found even higher levels of fidelity among married and single women and men: married women with one partner (96.2%), single women with zero or one partner (91.6%), married men with one partner (73.8%), and single men with zero or one partner (69.6%) (National Institute of Statistics 2005) (see Table 4.2 and Table 4.3).

Table 4.2: Sexual Behaviour among Married and Single Women

| | Married women | | Single women | | | | | |
Age	Only 1 partner	Number of women	Number of sex partners 0	1	2+	Total	Number of women	Av. no. of sex partners
	%		%	%	%	%		
15-19	93.4	936	51.4	42.3	6.2	100.0	1,517	0.5
20-24	95.9	1,747	31.3	58.3	10.4	100.0	709	0.8
25-29	95.8	1,812	35.4	50.0	14.6	100.0	412	0.8
30-34	96.5	1,495	38.6	53.8	7.3	100.0	297	0.7
35-39	96.6	1,158	47.5	38.9	13.3	100.0	254	0.7
40-44	97.8	872	53.3	39.6	6.7	100.0	254	0.5
45-49	98.2	715	69.8	26.7	3.5	100.0	23	0.3
Total	**96.2**	**8,735**	**45.8**	**45.8**	**8.4**	**100.0**	**3,682**	**0.6**

Source: (National Institute of Statistics 2005: 204).

Table 4.3: Sexual Behaviour among Married and Single Men

Age	Married men 15-49						Single men 15-49					
	Only spouse/partner %	1 %	2+ %	Number of sex partners / Total %	Number of men	Av. no. of sex partners	0 %	1 %	2+ %	Number of sex partners / Total %	Number of men	Av. no. of sex partners
15-19	66.1	17.3	16.6	100.0	33	0.7	39.2	38.6	22.1	100.0	640	1.0
20-24	61.0	25.4	13.7	100.0	196	0.8	11.8	45.4	41.9	100.0	208	1.8
25-29	69.2	22.5	8.3	100.0	293	0.6	6.9	42.1	50.1	100.0	85	1.9
30-39	76.6	15.9	7.3	100.0	528	0.4	30.7	28.8	40.1	100.0	66	1.6
40-49	80.2	14.3	5.3	100.0	416	0.3	46.8	13.7	39.5	100.0	26	1.0
Total	**73.8**	**18.1**	**8.0**	**100.0**	**1,466**	**0.5**	**30.6**	**39.0**	**30.0**	**100.0**	**1,024**	**1.3**

Source: (National Institute of Statistics 2005: 205).

What do these figures tell us? Are men more honest about sexual relations than women? Do men exaggerate? Do women tell the truth? Can the high fidelity rate among women be true, given the higher number of sexual partners among men? Can this phenomenon be explained by linking the high number of sex partners among men to the low number of women who have more than one partner? In other words, do men frequent the same few women who have more than one partner? Therefore, it may be the case that women simply speak the truth. Yet, how can we then explain the ongoing feminization of the HIV epidemic, evidenced by UNAIDS data that 58-60 percent of HIV carriers in all sub-Saharan African countries are estimated to be women (UNAIDS/WHO 2006a)? Moreover, testing data show that 67 percent of those who test HIV positive in Mozambique are women (Ministry of Health 2006f) (see Figure 2.15, p. 112). The figures provide evidence to support the 'vulnerable married wife' thesis, which says that monogamous married women are at high risk of HIV infection. This is the 'love protects us at home' disorder. Men who fool around living out their *machismo* deny the importance of condom use. Following this argument, the men frequent the women who have other partners,

whether they are culturally inclined to do so, 'liberally promiscuous', 'prostitutes', or 'survival sex workers'. Thus, this would entail that the well-known high-risk groups are responsible for the generalized epidemic. The HIV epidemic would not be directly attributable to the number of sex partners that people have, but to the unprotected sex away and at home, as I have shown for different reasons.

However, I have already hinted at the possibility that some respondents, especially women, are lying. They do not tell the truth about how many sex partners they have. The social consequences of doing so could be disastrous. Were the women given the complete anonymous space to provide the answers? Did they fear that their male partners would see their answers on the questionnaires before they handed them in to the researchers? Did they fear what the researchers would think about them? Possibly.

Why these discrepancies? One plausible answer could be that husbands would promptly abandon women who have extramarital sex. The socially accepted *fora da casa* phenomenon typifies a machismo: it is socially unacceptable to see women frequent lovers, male prostitutes, etc. Women would unlikely reveal multiple partners both to spouses, state, and research authorities. Anonymity is at stake. The problem for researchers is also an ethical one: how can we be sure about what respondents tell us? Can we ethically act as flies on the wall in people's bedrooms – or wherever people have sexual intercourse – to witness the moment of penetration with or without condom? The point is that what people say is not always what people do, which is a caveat against taking presumably positive behaviour change results at face value. In a sense, this is another case of trust. Do we trust our results beyond any doubt? Failing to address the sources of error and the truth about sexual behaviour may have dire consequences for policymaking and

the course of the HIV epidemic. We cannot afford to be fooled by elusive truths. The subjective experience of sexual pleasure with or without protection, the cultural subtleties of trust and distrust, the desire to live for the moment, and fundamentally the lack of communication about sexual matters, all run counter to consistent condom use.

The analysis so far shows the need for novel ways to design and implement prevention campaigns. This is meant as a serious reminder of poorly understood loopholes in our intervention methods and understanding of the epidemic.

ARV Studies in Mozambique: Towards Ethnography of Access and Delivery

We have not yet succeeded. The damage has been done. ARV studies have focused on problems associated with *adherence* (Marazzi, et al. 2006; San Lio, et al. 2008), *drug resistance among HIV positive tuberculosis patients* (Mac-Arthur, et al. 2001), and *patient identification* (Gimbel-Sherr, et al. 2007). They do discuss structural and psychological hindrances why only a few people access ARV therapy. However, the anthropological picture of ART expansion progress and obstacles is missing. What are the major individual, social, and health system access and delivery barriers? How do these barriers interrelate and influence treatment seeking behaviour?

The study of sexual behaviour before initiating ARV therapy reveals the presumed power of medical intervention over condom use. A different behavioural pattern emerges at this stage (Pearson, et al. 2006). Pearson and colleagues studied sexual behaviour among beginning ART users in Beira, the central Sofala prov-

ince. By using the Bernoulli process model, they estimated 23.2 new infections per 1000 HIV-positive ART eligible persons per year. The model most significantly demonstrated that medical intervention could reduce HIV transmission by 87 percent as opposed to 67 percent reduction by the use of condoms. They also found that 100 percent consistent and correct condom use only occurred in 20 percent of the relationships between 157 sexually active study participants and their 191 partners (Pearson, et al. 2006). These findings point to the relevance of ARV treatment in poor and resource-limited settings. The introduction of ARVs reduces HIV transmission based on appropriate pre-ART counselling, which is now a given ingredient of the Mozambican model. However, there are several drawbacks. Many Mozambicans believe they can go back to 'normal (sex) life' when health improves from ARV therapy.

Medical Intervention: Modifications in the Mozambican Context

Sant'Egidio was one of the first international organisations to set up ARV programmes in Africa. Sant'Egidio began its DREAM – Drug Resource Enhancement against AIDS and Malnutrition – in Mozambique in August 2001. The DREAM program is based on the principles of free treatment, collaboration with the public health system, and the use of Mozambican health personnel. These are crucial yet political choices in a country struggling to enjoy the fruits of independence. The DREAM programme adherence strategy emphasizes cognitive, emotional, behavioural, and social factors present among people taking ARVs. This has become a model approach to ARV treatment in Mozambique. One study found that out of 154 patients,

127 (82.5%) kept more than 90 percent of their appointments (Marazzi, et al. 2006). Another study found that the mean treatment adherence was 95.2% ±6.9% among 394 patients (San Lio, et al. 2008).

The DREAM programme is a success in Mozambique. However, ART beneficiaries remain the fortunate minority, as health system capacity is limited. The DREAM programme serviced only few people in need of treatment in 2001. The government introduced ART in the public health system in 2004, but the Day Hospitals were soon full. Many more knock on the doors of DREAM, only to walk away in disappointment. Moreover, dropouts often remain a neglected minority. AIDS activists visit ARV patients once or twice a week, but some Day Hospitals do not have the means to attend dropouts. Dropouts need closer attention, especially under the leadership of the Ministry of Health and its principles of 'nationwide harmonization' of ARV treatment within the public health system. The UNAIDS slogan 'make the money work' makes sense in this context, including 'human resources for health' with its double demand of medical and psychosocial support for ARV patients.

An ideal solution would be to have enough health care workers able to sit face-to-face watching each patient taking the medicine correctly at the right time and the right dosage. This would ensure drug compliance and minimize drug resistance. This approach is known as Directly Observed Therapy, applied mainly for TB and HIV patients. This DOT method has been *modified* to fit into resource-limited settings. Modification in the context of ARV treatment in Mozambique entails more than the singular observation of patients taking the drugs. Modifications include moral and psychosocial support, improved patient-health worker communication and confidentiality, the use of community workers and HIV positive people

as supervisors, adapting consultations to patients work schedule and physical condition, and reimbursement of transportation costs (Pearson, et al. 2006). This particular programme was patient-centred, designed to address problems of access to health care, adherence, and side effects. The study points to several issues for further research and discussion. First, Pearson and colleagues point to the need for 'culturally sensitive, feasible and practical programs' in resource-limited countries (ibid.). Second, the use of community workers as AIDS activists is a success and recommendable in other settings. Third, its success rests on whether it will be able to fulfil the ideals of modified directly observed therapy.

However, the need for additional health workers remains the most fundamental challenge for successful achievement of so-called 'universal access' (see Chapter 5). The Mozambican government utilizes its own 'Mozambican model', which initially relied on medical doctors to provide ARV treatment. The Ministry then called upon mid-level technicians for its ART team, based on previous experience with them as surgeons during times of physician shortage.

One study looked at how and whether training of basic level nurses could lead to faster information on patient status, including the identification of ARV eligible patients (Gimbel-Sherr, et al. 2007). This would presumably alleviate the workload of higher-level health staff. This was found to be the case. However, this type of intervention did *not* lead to an increased number of patients on ARVs or a reduction of the time between HIV testing and the initiation of antiretroviral treatment, which had a median time of 71 days. Gimbel-Sherr and colleagues concluded that limited and delayed access to ARV treatment could be attributed to capacity constraints within the health system as the burden of other diseases increases (Gimbel-Sherr, et al. 2007).

Mozambique has a high general burden of infectious disease that already burden

the health system: malaria, tuberculosis, diarrhoea, measles, cholera, tetanus,

pneumonia, rabies, pertussis, polio, meningitis, plague, and sleeping sickness. The

emerging problem of HIV and tuberculosis co-infection is a particular challenge.

Two studies looked at drug resistance and the mutual relationship between the

two diseases (Mac-Arthur, et al. 2001). They emphasize the need to integrate HIV

and tuberculosis programs and the need to find solutions to problems of access to

health care, which invariably means expanding health services to the provincial

and district levels. This expansion now enjoys highest government priority, in line

with the constitutional promise of socialized medicine and comprehensive primary

health care, which has been extended to include tertiary care. The problems of

distance and transportation costs to the nearest health facility remain some of the

biggest barriers for Mozambicans. Mac-Arthur and colleagues conducted their

study over a nine months period in 1998 and 1999 and they found a relatively high

level of anti-tuberculosis drug resistance compared to other countries, but they

found no significant difference by region or rural and urban areas. Drug resistance

was associated with prior treatment history of tuberculosis, while there was no

association between HIV positive status and multi-drug-resistant tuberculosis.

Nunes and colleagues conducted their study some four years later during 2002 and

2003. Unlike the Mac-Arthur study, they found a strong association between multi-

drug-resistant tuberculosis and HIV.

These two studies exemplify the converging HIV-TB problem and the in-

crease in drug resistance to both kinds of treatment. Furthermore, both studies

recognize the problem of limited access to health care and how this influences re-

lated problems of adherence and drug resistance. First, only about 45 percent of

the population have access to TB diagnosis (Nunes, et al. 2005). Second, social and health service barriers may explain incomplete treatment and lead to increased drug resistance (Mac-Arthur, et al. 2001). This HIV-TB analysis provides an example of the relational and linkages perspective between diverse phenomena of the HIV epidemic. I term this perspective 'the epidemic domino effect'.

The Epidemic Domino Effect: From Prevention to Medical Response

This literature review provides an example of an epidemic domino effect from prevention through culture, epidemiology, and medical response. Prevention campaigns inefficiently affect the course of the epidemic. Then culture and socialization affect continued HIV transmission, which affects epidemiology, medical response, and the cost of medical intervention. Epidemic evolution calls for more health workers. Dropouts and adherence problems call for psychosocial health workers. Lack of such health staff means pragmatic compromises not to search for dropouts. Health workers have plenty to do in the hospital setting. Work overload may cause burnout and increase the brain drain phenomenon. Health service abandonment influences the behaviour of people negatively. Lack of health care support means the absence of trusted advice and continuous support on how to survive and prosper with a chronic illness like HIV. Viral resistance, variant strains of HIV, transmission of HIV to uninfected people, and the re-infection of those already living with HIV with a variant HIV type all complicate medical intervention. The HIV epidemic may take a new direction caused by these factors.

Access Studies: Nationwide Context

With this in mind: A comprehensive, yet incomplete, map of social science HIV studies in Mozambique reveals their distribution by province and research topic (see Figure 4.11). Most studies are located in Sofala, Manica, and Maputo City. The long-term presence of Health Alliance International in the central region, and the presence of all major treatment organisations in Maputo City, may explain this. The Clinton Foundation took the lead on paediatric care in 2005. Columbia ICAP and Sant'Egidio initiated activities in Zambézia, the most populous province, and the most underserved in terms of health care. More studies are underway from here. Few studies have been conducted in Tete, despite the fact that MSF initiated treatment projects early on in 2002.

MSF facilitates ARVs in Niassa, but this delivery is understudied by the social sciences. Cabo Delgado has the lowest HIV prevalence, yet 10 percent HIV among adults does not justify the lack of research attention. One study included Nampula (Matsinhe 2005). Ph.D. researchers carry out studies in several provinces: anthropological studies by Ramah McKay, Stanford University (Maputo City, Sofala, Zambézia) and Ippolytos Kalofonos, University of California, Berkeley, (Manica), an international relations study by Kenly Fenio, University of Florida (Maputo, Sofala), and clinical and community psychology perspectives on adherence and psychosocial support by Larissa Polejack, University of Brasilia (Maputo City) (see Figure 4.11).

Niassa

Cabo Delgado

adherence
Meñaca
Lichinga ● condom use
Matsinhe

Pemba

Matsinhe   Nampula

● Nampula

Tete

Zambézia

perception
Matsinhe ● Tete

pregnant women
Cossa et.al.
Matsinhe

Morrumbula   Quelimane
Manica Manga ●   ●
behaviour, ART delivery,   ● prevention   ● behaviour, partnerships, PMTCT
ART access, condom use   de Graça   Bagnol & Chamo, McKay, Novo
Green, Gimbel-Sherr et.al.   Sofala
Kalofonos, Mola et.al.,   Chimoio ●
Pfeiffer, Sheldon   ● ● Nhamatanda
                             mitigation
                             Roby &   Politics, ART delivery, behaviour, PMTCT
                             Eddleman Beira Fenio, Gimbel-Sherr et.al, Pearson et.al., Sheldon

No studies
Inhambane, Cabo Delgado
Few studies
Niassa, Tete, Nampula, Gaza, Maputo
Gaza   **More studies**
prevention,   Inhambane   Zambézia
mitigation   **Most studies**
Agadjanian   Manica, Sofala, Maputo City
Chibuto ●   Inhambane **Ph.D. studies**
Chokwe ●   Fenio, Høg, Kalofonos, Martins,
● KAP   Matsinhe, McKay, Polejack
Font

Maputo
Matola   Xai-Xai
adherence
Marazzi et.al. Maputo City
              ● prevention, politics, ART access, behaviour, condom use,
              partnerships, resistance, adherence, PMTCT, mitigation
              Agadjanian, Domingos Paulo, Fenio, Høg, Karlyn, Machel, Manuel,
              Martins, Matsinhe, McKay, Nunes, Peffer, Polejack, Vaz

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Figure 4.11: Social Science HIV Studies in Mozambique, February 2008

Delivery Studies: Missing Perspectives

I asked the 'who' and 'where' questions to establish the 17 study categories for the review of social science HIV studies in sub-Saharan Africa. I hereby address the challenging issues of human resources and health system capacity. There are few if any anthropological and health systems studies of this. In the context of sub-Saharan Africa, only 62 studies focussed on human resources and 23 on health systems research. The dearth of ART delivery studies stands out. How do health workers experience the patient increase? What is the everyday reality among health workers at the day hospitals? What are the obstacles to quality care? How do health workers living with ARVs experience ARV delivery? How do health workers perceive individual and social barriers? Do health worker concerns match the issues raised by people living with ARVs as we saw in Chapter 1? What is the carrying capacity of the health system? The following chapter is a repositioning from *access* to *delivery*, from the *patient* to the *practitioner*, from this perspective providing an anthropological health system perspective.

5
Delivering ARVs

5: Delivering ARVs

The ARV delivery story is about limited carrying capacity. Health workers have a logical and pragmatic outlook on the situation. They recognize the limited number of patients they can care for, but we will see that they treat many more patients than human resource plans estimate for ideal ART teams. Carrying capacity relates entry and exit criteria, both in terms of patients and health workers. The more patients that enter the system and the fewer that leave it, the faster it reaches its carrying capacity. I discuss the problem of human attrition from the health system in terms of brain drain and deaths due to AIDS elsewhere (Høg 2008). Solutions to limited carrying capacity include transfer of patients to other hospitals, to build more hospitals, train more health workers, and expand health and ART services into the 10 provinces and 128 districts of Mozambique. This would allegedly take away the pressure on the health system in the Maputo capital and ensure the implementation of the principles of geographic equity.

However, there is another side to health worker life. Many health workers live a vocational life that makes it difficult to admit their stress-ridden daily routines. The analysis of ARV delivery provides the story about the beginning of the treatment era late during epidemic evolution within a weak but expanding health system. This is about the socioeconomic context of a poor country, about the successes of the Mozambican government in cooperation with the international community, and about the challenges ahead in terms of the capacity and commitment of health workers. This chapter provides an ethnographic insider perspective of health worker reality.

Maputo Central Hospital

I enter the Day Hospital at the Central Hospital in Maputo in July 2006. An older re-
ceptionist is tidily registering all incomers, as she writes their personal data by
hand into a large black registration book. She asks for name, age, sex, date of birth,
birthplace, address, type of transfer, and whether he/she is attending another Day
Hospital or Health Centre. Central Hospital HIV care at the dermatology section
was the first service in Mozambique in 1996. Few health workers counselled an
increasing number of people about HIV testing, they offered HIV testing and they
were able to open a medical record. Doctors would follow patient symptoms and
do what was clinically possible, but ARV treatment was not available through the
public health system. Doctors referred patients to private pharmacies to purchase
ARVs. Only a few citizens in need of ARVs had the money to do so.

Patient Increase 1996-2006

I met Valter, who started working with HIV patients from the very beginning in
1996. I ask him about the biggest changes since then. Valter says: *"The biggest
change since '96 is, thank God, the availability of free antiretroviral treatment, which
we started at this hospital in 2005. Before then, people had to pay out of their own
pockets. Doctors observed and diagnosed and people then bought ARVs in the local
pharmacies. ARVs were available in 1996, but they were very expensive! Only Minis-
ters could afford it!"*

Mozambican health authorities reported the first AIDS case in 1986. HIV care start-ed in 1996 and free ARV treatment in 2004 within the national health system. About 15 new patients were admitted per month between 2000 and 2004 to the HIV facilities at the Central Hospital in Maputo. Services improved in 2005 by the introduction of ARV treatment. About 150 new patients were admitted per month. With the context specific HIV epidemic evolution in mind, the increase in HIV pre-valence and ART need coincided with the introduction of ARV treatment. The Cen-tral Hospital registered 2,306 new patients between January and August 2006.

I asked one of the doctors how many HIV patients they attend or have at-tended: *"Go and count the records in the archive."* He showed me the way and open-ed the door to the archive. We encountered the characteristic smell of old brown envelopes mouldering in the tropical heat. I spent an afternoon counting with one of the assistants. There were 19,326 medical records of HIV patients for 1996-2006, all neatly stored by number on shelves from floor to ceiling.

Valter says: *"The number of patients is increasing a lot at the moment. We accept 20-25 new patients per day. We have two counselling rooms and two triage rooms and two rooms with beds."* There are about 15 beds in total. I ask him some-what perplexed: *"But do you have capacity to assist so many patients?"* Valter raises his voice: *"No, we don't have the capacity! There is a general lack of health person-nel, but we try to keep up with what the few of us can do. We only have two nurses for the triage section! They are working well beyond what they should be doing."*

This scenario is changing with the ongoing expansion of ARV treatment to the provincial and district levels. That is, ART expansion happens by the principles of geographic equity: a focus on other parts of the country replaced the first years of unfair treatment of Maputo inhabitants. Maputo folks in need of ARVs could

easily push the city health system to its limits for many years, but Maputo will receive fewer resources to keep up with local treatment demand, despite the fact that most Day Hospitals were soon full after the introduction of free ARVs in the public health system by mid-2004. However, the PEPFAR sponsored Day Hospital in connection with the Military Hospital in Maputo, which will be the biggest facility in the country, promises increased treatment capacity in the capital.

Health Triage

Clara, a health triage nurse, says to me: *"I've got a headache from this constant noise of patients around me and all the issues around the disease".* Patients wait in line to talk to her about their health and what to do next. Triage is like a crossroad.

Clara: *"Is this the first time you are here?"*
Patient: *"Yes, first time."*
Clara: *"Have you been informed already about this disease?"*
Patient: *"Yes."*
Clara: *"And your family? You need to talk well with your family. Have you been counselled?"*
Patient: *"Yes, yesterday."*
Clara: *"Do you cough? Do you have headaches? Do you have sores in the mouth? Do you have sores in the genital region? Do you know cotrimoxazol?"*
Patient: *"What's that?"*
Clara: *"It's a prophylactic drug."*
Patient: *"I have never taken that."*
Clara: *"I will give you a prescription."*

Clara takes care of diagnostic analysis based on patient illness narratives and answers to a series of health related questions. Then she refers him/her to proper consultation, like blood testing, dermatology, or gynaecology. Clara drills the advisory mantras for people living with HIV: *advice on dietary regimen* ('what to eat, what to avoid'), *restrictions*, ('stop drinking, stop smoking') and *disease normalisation* ('this disease is just like any other disease'). She evaluates and classifies signs and symptoms to recommend proper treatment. *"Do you have skin problems? For how long? Do you have discharge? Does it hurt? Do other family members have the same kind of problems? Do you have genital problems? Do you have headaches or neurological problems? Do you have diarrhoea? Fever? Problems in the mouth? Did you lose weight? Do you have good appetite?"* The nurse uses clinical criteria and experience to reach proper conclusions.

All drugs against opportunistic infections are free of charge at this hospital, like cotrimoxazol and the antibiotic Clavamox, but some are not in stock. For example, one patient needs the antifungal drug Fluconazole to clean the mouth against oral candidiasis. It needs to be taken for 15 days. It costs 40 MTn per day in private pharmacies, which is about 1 dollar and 60 cents. This person needs to pay about 24 dollars, money she can ill afford, when we consider the chronically sky-high unemployment rate in Maputo. The few ordinary people who do have a job are paid well below the minimum wage, which officially is about 1,400 MTn or 56 American dollars per month.[1]

Lack of space, the high number of patients, and generally bad working conditions make life difficult for the triage nurses. There is lack of space for confidential conversation. There is a constant movement of patients from both sides of the room. Sometimes they attend three patients at the same time. They cannot attend

individual patients without interruption. Patients and personnel constantly enter
and leave the room. The door bangs. The noise increases when the door opens,
letting in talk from next door. Health workers suffer from bad ergonomic position.
Yet, Clara lightens up and says with a tolerant smile: *"But we are used to this and
we adapt to the situation."*

Central Hospital HIV Facilities

There are other weaknesses, despite the extensive renovation of Day Hospital fa-
cilities. One doctor explained lack of logical organisation of consultation rooms ac-
cording to the health care process from entry to exit. They do not register drop-
outs. There is no computerised patient tracking system. The computer literate
pharmacy assistants said they write everything by hand. All they needed was the
hard- and software. The Central Hospital would even provide IT training.

One health worker coyly remarked the need for user services in the waiting
room, like television and magazines. Health workers needed informative TV pro-
grams about higher salaries, and incentives and motivation to do a good job. A full-
time ART physician – and there is only one at this Day Hospital – makes just about
500 dollars per month. Then keep in mind that life is expensive in Maputo.

Then he rejoined with sharp comments about foreign aid and dependency,
which will be discussed in detail in Chapter 6. This is no trivial issue, but intrinsic
to the ambivalent attitude among Mozambicans towards donated money. *"We are
standing with our arms crossed, waiting for foreigners to give us money. When you
give money to people on the street, it will take them away from there, but they will be*

back on the street soon again. What we need is economic investment and develop-

ment! We need to change our attitude. We need autonomy and sovereignty as a peo-

ple and a nation. Look at South Africa! It's a culture of workers."

The paediatric Day Hospital is about one hundred steps away from the adult Day Hospital. UNICEF sponsored all its modern facilities. There is a colour TV in the waiting room, lots of space, and many consultation rooms. All medical record keeping is computerised. This is a model ART site. Now, think back to what I wrote in Chapter 2. The number of children in need of treatment increased from 68,000 to 83,000 thousand between 2005 and 2008. Only 6,192 children were on treatment by the end of 2007 (see p. 99). Two key reasons invoked are lack of infrastructure across the country and lack of donor commitment.

Health workers have their own *palestras.* They receive continuous in-service training related to counselling, HIV testing, biosecurity, hygiene, and cleanlyness. Kindlimuka AIDS activists do the counselling. In fact, they operate at most Maputo Day Hospitals, like Alto Maé (MSF Switzerland), Primeiro de Maio (MSF Luxembourg), Hospital Militar (Columbia ICAP and Sant'Egidio), and Polana Caniço (ASIDH Spain and Sant'Egidio). However, there were no patient support group at the Central Hospital in 2006, like *Kudumba* and *Pfukauhana* (see Chapter 1).

Mafalda: A Counsellor

Valter explained the importance of AIDS activist counsellors. They live with the disease: this is peer-to-peer sharing of illness experience. He adds: *"Often patients don't trust health workers very much."* Mafalda is one of the Kindlimuka HIV coun-

sellors. Let us hear her story, which is about fear, discrimination, silence, invisibility, people living with HIV as expert human resources, coupled testing, transformative agency, hope, and treatment.

Testing

Mafalda discovered she had HIV in 2002. This was right after her husband had been diagnosed with HIV. He died in 2003. He suffered severe fungal attacks on his feet, classical symptoms of Kaposi's sarcoma. This was during the late stage of HIV disease progression. Like many others, Mafalda's husband reached out for health care at the very last minute. He paid 160,000 Meticais, more than 6 dollars, for the HIV test. There was no counselling within the Mozambican health system, so the message was similar to what Gilberto experienced, blunt and relentless: *"You have AIDS!"* This was during the time of the 'AIDS Kills, AIDS Has No Cure' campaign. Mafalda says: *"It was on the radio and on TV. On TV, they showed some of the people with Kaposi's sarcoma, some of the patients from hospitals in a terrible state. We saw all that on TV and this implanted fear in us."* Mafalda kept the envelope with her husband's result, thinking what to do, filled with doubt. Could it be true? Mafalda cannot read, so she had good excuse to feel lack of conviction. She called upon her mother and her husband to verify the result. They cried their hearts out, when they realised it was true. They kept saying: *"We don't believe it."* However, they quickly made up their minds and asked Mafalda to take the test. They recommended her to go to a VCT centre, where it would cost less to take the test compared to the hospitals and private clinics. She had never been to a VCT centre, so on her way she ask-

ed one of the street vendors outside the hospital, where she could *"find this place where they do analyses, so you can know your situation"*. Mafalda says in honesty: *"I always talked like that, without saying 'HIV test.'"*

Mafalda said to the nurse: *"I just want to know my state of health, whether I'm alright or whether I'm already infected."* Mafalda paid 20,000 Meticais and then the nurse counselled her about HIV testing. After the test, the nurse asked: *"Are you ready to get your result?"* Mafalda replied: *"Yes, I am ready to know my result."* The nurse continued: *"Do you agree with all we have talked about since you arrived?"* Mafalda insisted: *"Yes."* However, Mafalda's did not anticipate her own reaction. *"What does this mean? Am I infected? Epa, no way!"* Yet, free ARV treatment had come to town in 2002 with one of the international treatment organisations, so Mafalda knew her prospects and that 'AIDS kills' was no longer the verdict. *"They counselled me about how I can live with it and that it doesn't mean that I would die right there on the spot, but I didn't think in this way at that moment. It didn't enter my mind. Epa, it was not easy. I didn't eat anything for a month. I didn't drink anything. I didn't even take a shower! I thought: 'I'm dead! It's not worth it going on like this. I am already dead! What's left for me?' I was crying and crying, thinking that I was going to die. My husband and I even arranged the money to buy two coffins, one for him, and one for me. We said: 'we are already dead'."*

Her two children tested HIV negative. This was good news. The bad news was gossip and discrimination. Mafalda's sister-in-law gossiped about Mafalda's seropositivity. *"They all believed that I was already ill."* The response from friends and community members was relentless: *"Hey, 'you have SIDA, you have SIDA!' They always said this to me. Many people discriminated against me, when I left my house to go and sell fish on the beach. I ended up very lonely. All the people I used to have*

around me, they all left." Their oppression continued: *"Your husband and your children will soon die, and then you will die too!"* However, verbal abuse was not the worst of terrors. *"No one greeted me any longer. No one greeted me! They only looked at me! They only said things like 'eh, HIV – eh, SIDA'.*

Mafalda lost weight and became weak and feeble. Her husband died. People kept discriminating against her and she was unable to fight against it. She says: *"I could only walk in illness."* She stopped selling fish on the beach. *"They didn't want to buy my fish anymore, because I had 'SIDA'. It was impossible to keep my job. I was so afraid. They even promised to beat me up badly. One of my friends said to me: 'It's better that you don't go there. Because they are all saying that if you come, then they will beat you up, because you have AIDS.'"*

Obviously, Mafalda stayed in her house. This is individual involution, when people turn silent and become invisible. This phenomenon is here caused by the fear of anticipated and felt stigmatisation and discrimination, not by fear induced by spiritual illness or ancestral aggression and bedevilment. Mafalda soon weighed less than 40 kilos. Nevertheless, she curiously says in retrospect: *"But I wasn't ill. I was only losing weight."*

Treatment

"I will never forget Doutora Lauana! She counselled me so well about my future path and all." She said to Mafalda: *"You cannot go on like this. Your husband died because he had a Kaposi's sarcoma for which we had no treatment at that time. You will be*

cared for here and you will soon be able to start treatment. You will not lose your life. You need to gain hope!"

An activist from the patient organisation Kindlimuka came to her house. *"I need to talk to you. I can see you are about to give up. You are thinking too much about what's happening to you. Let's go to Kindlimuka!"* Mafalda was not convinced and ready to go. She then rhetorically says: *"What am I going to do at Kindlimuka? I don't want to see other people. They will see me in this situation and they will say bad things about me. I am very ill. I prefer to stay at home until the day I die."* Mafalda wanted to stay at home, as her entire body was already filled with fear, but the Kindlimuka activist insisted: *"Let's go to Kindlimuka now!"* 'Kindlimuka' means 'Wake Up!' in the local Shangaan language. Thus, Mafalda received a wake up call to come back to life. *"But do you know what?"* she asked me. *"I was so afraid of the people at Kindlimuka the first day I was there. So much afraid! This thing about being afraid of other people crept on me: I was so scared that they would know my situation. I thought 'what are they going to think about me'?*

After a rhetorical pause, she continued: *"I told my story crying to one of the counsellors there."* One of the head counsellors took over to calm her down. *"Don't worry, we are here for you. We know we are HIV positive. You cannot go on like this. Free yourself! You already have two friends here. What happened to you is nothing. Leave those bad people alone, those who discriminate against you. God is not our stepfather, God is our real father!"* Mafalda lightened up. *"I began to think 'she told me that I have more years to live with this situation. Maybe I can live three or four more years.' Anyway, I am still alive until now!"*

Mafalda told me her story in perfectly good condition in August 2006, some four years after she was diagnosed with HIV in 2002, more than two years after

she started treatment in April 2004. She keeps her appointments, well aided by the fact that she is now herself a health worker. She has lived successfully with ARVs since the first full month of counselling, which I described in detail in Chapter 2. *"Nothing bad has happened to me. I haven't had any side effects. It didn't happen to me."* This is what Valter emphasizes: patient counsellors are important, because they live with ARVs themselves. They inspire respect, confidence, and hope for others who experience HIV related illness problems.

Counselling

"It wasn't easy at all when I started working as a counsellor. I was sitting in this room all day and everyone who came to me cried so hard that it was impossible to start a conversation. It was not easy. It is much easier nowadays. People manage to sit down and we start talking. I ask them whether they are ready to receive the result and they say 'yes'. They don't have this fear any longer. This is because they have been counselled before the test.

Mafalda trained to become an HIV counsellor in 2004 and started working as soon as she started ARV treatment. She then contracted tuberculosis, working in 'this room without windows', meaning constant lack of ventilation making her susceptible to airborne diseases. *"I wasn't afraid. I felt good again after six months treatment. Then I was back on ARV treatment."* However, her biggest triumph as an HIV counsellor is to see the bigoted lot of 'friends', who used to terrorize her life, now come to beg her for help. *"The majority of the people that discriminated against me now come to ask me for help! They are already HIV positive. I facilitated their*

entrance to the hospital. I can now see that 'God is not our stepfather, God is our real

father'. They all came to me to apologize and cry. What we did wrong was that we

did not know our path in life. I spoke badly about them. I said many things. I aban-

doned many friends. But I apologize. In fact, I receive them in my heart. Now it's all

'Hello, how are you?' I don't have a problem now. Many neighbours now know that I

am HIV positive. It's normal. I don't have any regrets."

I ask her whether she can see any changes in people since 2002. *"Things are*

changing compared to the past. It's not like before. People manage to come here and

to live life positively. I see many people for whom this is a normal disease, but it

wasn't easy before. People who took the test kept denying the result. I see people in

the communities that now understand that life is normal and that it's a normal dis-

ease. That's because counsellors and activists go there. I see many people who do not

suffer discrimination, when they find out they are in this situation. There are other

places where people don't yet understand, but the majority already understand some-

thing. They accept it. But there are still people who don't understand. It's not easy.

People are very hard headed."

I say to Mafalda that she has gone through so much suffering. I was impres-

sed that she now looks so strong, physically and mentally. I was listening with

deepest respect for her story and the forceful and optimistic way she told it to me.

She took the lead as the storyteller of her own life that only a few did to me. I have

already discussed reasons why people hesitate to talk about life with HIV. If you

recall the advice Mafalda received at her first visit to Kindlimuka, she says to me: *"I*

am free! I feel well! I really feel well! I am no longer thinking that I am going to die

just like that, though I know that death is my destiny. Those that stopped to say hello

now come to me: 'Hi, Dona Mafalda, look at you!' Thank God."

Hospital Ethnography

Valter and Mafalda provide entrance to hospital ethnography: two health workers who have lived through the agonies and progress of HIV services before and after the introduction of ARVs. Valter has seen it all since 1996. Mafalda experiences HIV in her own body and she has lived through all phases of individual and social barriers, as discussed in chapters 1 and 2. Her luck was that she became part of the fortunate minority during a time of ARV expansion in the capital. Few came forward for testing in 2002, when treatment came to town.

International treatment organisations and donors support the Mozambican government, which aims at one unique public health care system, congruent with early FRELIMO promises at independence in 1975. Major and minor international implementing partners are shown in Figure 5.1 and Figure 5.2.

ART Partner	Abbrev.	Origin
Major		
Health Alliance International	HAI	USA, University of Washington
International Center for AIDS Care and Treatment Programs	ICAP	USA, Columbia University
Médecins Sans Frontières	MSF Lux	Luxembourg
Médecins Sans Frontières	MSF S	Switzerland
Sant'Egidio	SE	Italy
Minor		
Asociación Para La Salud Integral y El Desarrollo Humano	ASIDH	Spain
CARE	-	USA, International
Consejo Interhospitalar de Cooperación	CIC	Spain
Cooperação Francesa	CF	France
Dor Sem Fronteiras	DSF	France
Igreja Metodista	IM	England
Irmãs Vicentinas	IV	Catholic Mission
Médicos del Mundo	MM	Spain
Pathfinder International	PI	USA
Solidarnet	-	France

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Figure 5.1: Main Ministry of Health ART Implementing Partners

Médicos del Mundo
Solidarnet

Niassa
MSF S
Columbia ICAP
Switzerland
USA

Cabo Delgado
Pemba
Spain
France

Nampula
Columbia ICAP USA
Sant'Egidio Italy
CARE Spain
CIC Nampula

Lichinga

Tete
MSF Lux
Luxembourg

Tete

Zambézia
Columbia ICAP
Sant'Egidio
USA
Italy
Quelimane

Manica **Sofala**
HAI
USA
Chimoio

Sant'Egidio
HAI
Italy
USA
Beira

Province
● Provincial Capital
ART Partners
Donor Countries

Inhambane
Columbia ICAP
Igreja Metodista
USA

Gaza
Columbia ICAP
Irmãs Vicentinas
Pathfinder
DSF USA
France

Inhambane

Maputo
Sant'Egidio
Médicos del Mundo
Italy
Spain
Xai-Xai
Maputo City

Columbia ICAP
MSF Lux
MSF S
Sant'Egidio
ASIDH
Cooperação Francesa
DSF

USA
Luxembourg
Switzerland
Italy
Spain
France

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Figure 5.2: Main Ministry of Health ART Implementing Partners by Province
Source: Fieldwork.

The private profit and non-profit making sectors complement the National Health

System. There is a large non-allopathic sector of traditional medical practitioners,

herbalists, and some traditional medical practitioners of Indian and Chinese origin

(Ayurveda and Chinese Medicine). Additionally, community health agents may or

may not be affiliated to the National Health System, sometimes the sole providers

of health care in rural areas.

A Five-Tier Health System

The Central Hospital in Maputo is the core of the Mozambican health system, host-

ing the only medical school in the country. Two other central hospitals are situated

in Beira, Sofala province, and Nampula, Nampula province. The Mozambican health

system is a four-level and a five-tier system, comprised by health posts, health

centres, rural, provincial, and central hospitals (see Figure 5.3).

Level	Type
Primary	Health Posts, Health Centres
Secondary	District Hospitals
Tertiary	Provincial Hospitals
Quaternary	Central Hospitals

Figure 5.3: Four Levels of the Mozambican Health System
Source: (Republic of Mozambique 1991a).

The long-term goal is an integrated health care system without external support,

fully managed by Mozambican administration and staff. There are no foreign

health workers at the Central Hospital Day Hospital. Only one international part-

ner has managed to do the same. The Sant'Egidio supported Machava Day Hospital is entirely staffed with Mozambican health workers. This is one of the main reasons why this has become a 'model Day Hospital' for Mozambique. What Marazzi and colleagues in this context call predisposing factors for the Sant'Egidio introduction of ARV treatment include free ARVs, free drugs against opportunistic infections, free food, collaboration with the public health system, and the role of local health care personnel (Marazzi, et al. 2006).

The Day Hospital and the Health Centre

A 'Day Hospital' is an ambulatory arrangement. Day Hospitals are constructed separately, physically located apart from the main health facility. Patients come for treatment during the day and return home before nightfall. Minister of Health Paulo Ivo Garrido sees a difference between Day Hospitals and Night Hospitals. A joyful story circulates about how Garrido says that 'everything is normal at night', compared to 'people are stigmatised during the day.' Garrido intends to integrate treatment and care of people living with HIV and AIDS into the normal health services – *within* the health centre. This is part of the process of disease normalisation to minimize stigma and discrimination, but it also promises to integrate HIV into the broader response needed against the towering burden of disease. This applies to funding and practical response alike.

Health Worker Informants

I conducted participant observation and qualitative interviews at six Day Hospitals. This involved 75 health workers: 60 Mozambicans and 15 foreigners. Foreigners predominantly work as physicians and coordinators. Women predominantly work as nurses, activists, and psychologists (see Table 5.1).

Table 5.1: Health Worker Informants by Sex and Country

Health worker	Total			National			Foreign		
	T	♀	♂	T	♀	♂	T	♀	♂
Physicians	16	10	6	7	2	5	9	8	1
Nurses	14	11	3	14	11	3	0	0	0
Activists	11	10	1	11	10	1	0	0	0
Coordinators	8	3	5	4	1	3	4	2	2
Assistants	6	2	4	6	2	4	0	0	0
Counsellors	5	3	2	5	3	2	0	0	0
Psychologists	5	5	0	4	4	0	1	1	0
Pharmacists	4	1	3	3	0	3	1	1	0
Receptionists	4	3	1	4	3	1	0	0	0
Information Officers	2	1	1	2	1	1	0	0	0
TOTAL	**75**	**49**	**26**	**60**	**37**	**23**	**15**	**12**	**3**

I initially interviewed the Day Hospital coordinator or the key ART physician in charge, using a semi-structured interview guide (see Appendix 3). This provided basic information about the number of patients in care, dropouts, number of Day Hospital health workers, services offered, obstacles, improvements, and human rights issues. This facilitated informed access to the health worker-patient encounter. Participant observation involved observation of activities and interaction between health workers and patients, and I accompanied health workers in their daily routines. 'Participation' was obviously limited, as I am not a health worker. Hospital fieldwork is rather 'engaged observation' or 'empathic observation'. For example, I stayed with physicians and nurses in their consultation, upon explicit con-

sent from their patients, to witness live health care practice. I stayed in every sec-

tion of the Day Hospital to get a good feel of *o processo clínico* and key problems. I

saw daily hospital routines from most angles and I talked to most of the health

workers performing specific tasks. These observations complemented the off-duty

face-to-face interviews in which health workers could only retell stories about pa-

tient encounters. Thus, I spent time with the nurses, phlebotomists, counsellors,

pharmacists, doctors, etc. I also joined medical home-based care teams and AIDS

activists in the communities. This underscores the focus of the project: ARV access

and delivery, different from classical adherence studies, clinical medical anthro-

pology, or community studies. Methodological holism remains the ethnographic

commitment, which differs from the unattainable descriptive holism. As Van der

Geest and Finkler point out, multi-site ethnographers need 'cross-eyed vision',

keeping one eye constantly sensing the context, the other obsessively focused on

the research topic (van der Geest and Finkler 2004: 7).

I presented an informed consent agreement to all health workers and pa-

tients (see Appendix 4). An anthropologist studying both kinds of actors in the

hospital setting, who is neither of the kind, obviously poses a challenge to the par-

ticipatory aspect of research. However, my letter to the Day Hospital coordinator

clearly emphasized that I wanted to talk to patients and practitioners alike. Indi-

vidual interviews with patients were unproblematic to the extent they had the

time to do it. Support groups were easier to join. Many patients saw me both face-

to-face and in the group. Such overlap facilitated my feeling that I was welcome

and accepted. This also influenced my acceptance among health workers, who of-

ten joined the support group meetings. I did at times feel that patients saw me as

'one of them' – the health workers. Indeed, I had no normal sign of affiliation like a

white coat or stethoscope, but I obviously appear foreign to Mozambicans and it would therefore be easy to associate me with one of the international organisations. However, I explained that I was an independent university student. Yet, fieldwork required a good sense of occasion: there are priorities that are more important during daily hospital work than attending to an anthropologist.

Health worker perspectives occupy a different space and signify a different worldview. What are their concerns? How are their concerns similar and different from how patients see life with ARVs? Dominant themes among health workers include infrastructure, human resources and capacity, antiretroviral treatment, community, the reality of Mozambique, work, and patients (see Figure 5.4).

CIRCUMSTANCES

Social security
Poverty
Mentality
Taboo

COMMUNITY

Drop outs
Traditional medicine
Food support
Home based care

CAPACITY

Testing
First consultation
Patients
Patients per day
Waiting lists

ARV TREATMENT

Adherence
Lying patients
Side effects and resistance

HEALTH WORKER THEMES

WORK

Work load
Work related problems
Changes

PATIENTS

Culture
Fear and shame
Food support
Language barriers
Space
Understanding

Lack of staff
ART training
Work authorization

Space
Clinics
Beds
Laboratories

HUMAN RESOURCES

INFRASTRUCTURE

Figure 5.4: Major Health Worker Themes
Source: Fieldwork.

A Day Hospital

"Hulene, Hulene", shouts the conductor: I sit in the Museu-Hulene *chapa* going up *Avenida Kim Il Sung*. The street names all over Maputo City indicate Mozambican history, as they bear the names of important figures that participated in and inspired the liberation of the country during the 1960s and 70s. This 'forest of symbols' (Turner 1967) represents what I call the 'Maputo Manifesto', which is an intrinsic detail to understand 'the process' in ideological and political terms. Along with historical dates of importance, FRELIMO assigned such personalities highest importance upon independence in 1975. They changed the name of the city from *Lourenço Marques* to *Maputo*. Portuguese colonizers were replaced with Mozambican heroes. *Praça 25 de Junho, Avenida Eduardo Mondlane, Avenida Samora Machel, Praça de Independência, Avenida 24 de Julho*: they all signify independence and the liberation front. President Samora Machel declared 24 July 1975 as the Day of Nationalisation of Health, Education, and Justice. Core FRELIMO members embellish the street signs: They herald FRELIMO totems, as the dream of a nation, embodied with spiritual significance (see Figure 5.5). The HIV epidemic has become a devastating shock to the sovereignty process (see Chapter 6).

We cross the *Avenida Mao Tsé Tung* going through the area, where the National AIDS Council resides. We continue to view FRELIMO ideology from street names and plazas: we pass by the FRELIMO headquarter, we turn left at *Avenida Kenneth Kaunda* driving through the area densely packed with international organisations, created to take care of HIV/AIDS advocacy, treatment, development, food provision, family issues, and children. The contrast between past and present is striking in this area.

Figure 5.5: Maputo Manifesto: Street Names, Statues and Plazas
Sources: Fieldwork and (Ministry for the Affairs Related to Old Combatants 2007; Wikipedia 2008).

Person	Life	Deed	Note
FRELIMO			
Statue of Eduardo Mondlane	1920-1969	First FRELIMO President, 1962-1969	Assassinated 1969, letter bomb
Av. Eduardo Mondlane			
Statue of Samora Machel	1933-1986	First President of Mozambique, 1975-1986	Assassinated 1986, plane crash
Av. Samora Machel			
Av. Joachim Chissano	1939-	Second President of Mozambique, 1986-2005	Succeeded by Armando Guebuza
Av. Julius Nyerere	1922-1999	First President of Tanzania, 1964-1985	Co-founder of FRELIMO, died from Leukemia in London
Av. Josina Machel	1946-1971	Samora Machel's first wife, died 7 April 1971, Women's Day	Died from illness
Av. Paulo S. Kankomba	1937-1968	National Adjunct Head of FRELIMO	Assassinated 1968, Cabo Delgado
Av. Romão Fernandes Farinha		Provincial Head of FRELIMO Operations	Died from illness
R. Mateus Sansão Muthemba	1907-1968	National Freedom Fighter	Assassinated 1968, Dar es Salaam
Av. Tomás Nduda		National Freedom Fighter	Died in combat, Cabo Delgado
Av. Armando Tivane		National Freedom Fighter	Died in combat, Tete
Independence war			
Av. 25 de Setembro	25 Sept 1964	Independence War started	Luta Armada de Libertação Nacional, the armed struggle
Av. Guerra Popular		Popular War Avenue	
Av. Acordos de Luzaka	7 Sept 1974	Agreement between Portugal and Mozambique	Took place in Lusaka, Zambia, known as the Lusaka Manifesto
Praça da Independência	25 June 1975	Independence Plaza	Adorned by a Peace Symbol
Av. 24 de Julho	24 July 1975	Day of Nationalization of Health, Education and Justice	
Praça de Heróis		Heroes' Plaza	
African Nationalists			
Av. Agostinho Neto	1922-1979	First President of Angola, 1975-1979	Died in Moscow
Av. Kenneth Kaunda	1924-	First President of Zambia, 1964-1991	Close relationship with Samora Machel
Pr. Robert Mugabe	1924-	First President of Zimbabwe, 1980-	Close relationship with FRELIMO, common liberation struggle
Av. Amílcar Cabral	1924-1973	African Nationalist, Guinea-Bissau	Assassinated 1961, party dissidents
Av. Patrice Lumumba	1925-1961	President Dem. Rep. Congo, 1960-1961	Assassinated 1961, firing squad
Av. Marien Ngouabi	1938-1977	President of Republic of Congo, 1969-1977	Assassinated 1977, suicide squad
Av. Ahmed Sekou Touré	1922-1984	President of Republic of Guinea, 1958-1984	'We prefer poverty in liberty to riches in slavery', declared 1958
Av. Moamed Siad Barre	1919-1995	President of Somalia, 1969-1991	Died in exile, Lagos, Nigeria
Av. Albert Luthuli	1898-1967	Zulu Chief, ANC President 1952-1967, Nobel Peace Prize 1961	Hit by a train and died
International Communists			
Av. Karl Marx	1818-1883	Communist theory, Marxism	Communist Manifesto, 1948, died in London
Av. Friedrich Engels	1820-1895	Communist theory, Marxism	Communist Manifesto, 1948, died in London
Av. Vladimir Lenine	1870-1924	Chairman, Russia, 1917-1924	Assassination attempted twice, died from deteriorating health
Av. Mao Tsé Tung	1893-1976	First Chairman of PR China, 1945-1976	
Av. Oluf Palme	1927-1986	Swedish Prime Minister, 1969-1972, 182-1986	Assassinated 1986, gun shot
Av. Kim Il Sung	1912-1994	President of North Korea, 1972-1994	
Av. Salvador Allende	1908-1973	President of Chile, 1970-1973	Assassinated 1973, infiltration patrol, gun shots
Av. Ho Chi Minh	1890-1969	First President of Dem. Rep. of Vietnam, 1945-1969	

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I philosophized how the streets honour the communist days of glory and the sweets of independence, while the houses accommodate the neoliberal present. We pass by WHO, UNAIDS, UNDP, WFP, UNFPA, UNICEF, CIDA, and the World Bank. This is the foreign forest of symbols. I rejoin Mary Douglas' thoughts about pollution (Douglas 2002 (1966)) to make another exceptional interpretive observation: the ubiquitous uncollected garbage, which can both stick heavily to the ground and whirl lightly with the wind, symbolizes and exhibits ideological disorder. This confrontation produces chaos, confusion, and untidiness, familiar to the Mozambican situation, but the question remains whether this type of violence qualifies as direct or indirect with the discussion of structural violence in mind?

The *chapa* takes a turn at *Praça da Organização da Mulher Moçambicana*, the roundabout plaza created to commemorate Mozambican women and to pay homage to Josina Machel – the second wife of Samora Machel – who died from illness on 7 April 1971 during the FRELIMO fight for independence. Upon independence, the anniversary of Josina Machel's death was consecrated as Women's Day celebrated annually. I enter the Health Centre and Day Hospital on *Rua da Resistência* – Street of Resistance.

An Astounding Silence

It is 8 o'clock in the morning. I see several hundred Mozambicans awaiting their turn. An astounding silence characterizes the atmosphere. A sign on the wall says *'Hospital, Silence'*, but to witness such literal obedience is hard to believe, whether such silence relates to the sign, the dark sides of 'living with HIV', or some general

culturally conditioned and enculturated form of silence experienced in the wider Mozambican society. 'People living with HIV' sit shoulder to shoulder hardly uttering a word with a rather deprived and empty look into empty space. Some take a nap, where they find room for it. No wonder: many rose at 5 or 6 in the morning and travelled long distance to arrive at the Day Hospital before 8 o'clock to hand in their HIV identity card to be in line for their scheduled consultation. They often wait many hours before seeing a doctor or nurse. Few if any brought food or water. Moreover, the Day Hospital does not provide it either, not even a cup of water.

Josina Machel would be in shock were she alive to witness the real life *women's plaza* in a Day Hospital 35 years after her death in the era of HIV, 20 years after the health authorities reported the first case of AIDS in Mozambique, yet just a few years into the treatment era. About 300 patients wait in line for HIV related consultations. The majority of them are women. Another 150 women with babies wait in line for the health programme caring for child growth and nutritional status. Josina Machel fought to emancipate women from their inferior position in society and stood as a role model advocating freedom of expression – in particular public speaking and the liberty to voice personal opinions. HIV arguably negatively affects such progress: it adds to an already difficult life situation of chronic poverty and deprivation.

This Day Hospital employs 28 health workers: 3 full-time foreign doctors, 3 part-time Mozambican doctors, 7 nurses, 3 medical technicians, 3 basic health workers, 3 counsellors, 1 psychologist, and 2 PMTCT assistants. It offers HIV testing, ARV treatment, counselling, and support groups. The reception is the centre point, where patients present their consultation card flashing the word *Esperança*. Every patient is given hope to go along with the therapeutic process. There are 2

consultations for opportunistic infections, 1 ART follow-up office, 3 rooms for counselling, 4 medical consultations, 1 laboratory, 1 pharmacy, 1 PMTCT consultation, 1 home based care office, and the principal doctor resides in the nucleus of the Day Hospital with 5 beds for ambulatory patients.

All patients go through the initiation and continuation phases: pre-test, post-test, CD4, pre-ART, and ART counselling (see Chapter 2, pp. 119-122). Pregnant women are given the choice of pre-natal care before testing. There is an additional consultation to determine whether the patient also has tuberculosis. Those who suffer both diseases receive food support for the first 6 months from the World Food Programme, which in one sense discriminates against those who 'only' suffer HIV. Thorough counselling explains why all eligible patients start ARV treatment. Problems occur afterwards, in the form of side effects, opportunistic infections, and variable adherence.

Additionally, some patients drop out from treatment due to complex causes and consequences, or on physician advice. The entire patient flow included here gives an idea of its complex nature and the kinds of health workers involved at each stage of the medical and therapeutic processes (see Figure 5.6).

Osvaldo explained in an incisive way why patients drop out of treatment: *"It is a consequence of something! There are many reasons. It's not so simple. I say again: it is a complex series of causes and consequences. Prejudices kill. It is a matter of blame. The husband will beat the wife. Exclusion from the family, if a wife tells her husband that she took the test. Illiteracy. Unemployment. Ignorance."* I understood the complexity and seriousness of the matter by Osvaldo's voluminous voice.

Day Hospital
December 2002 - January 2006

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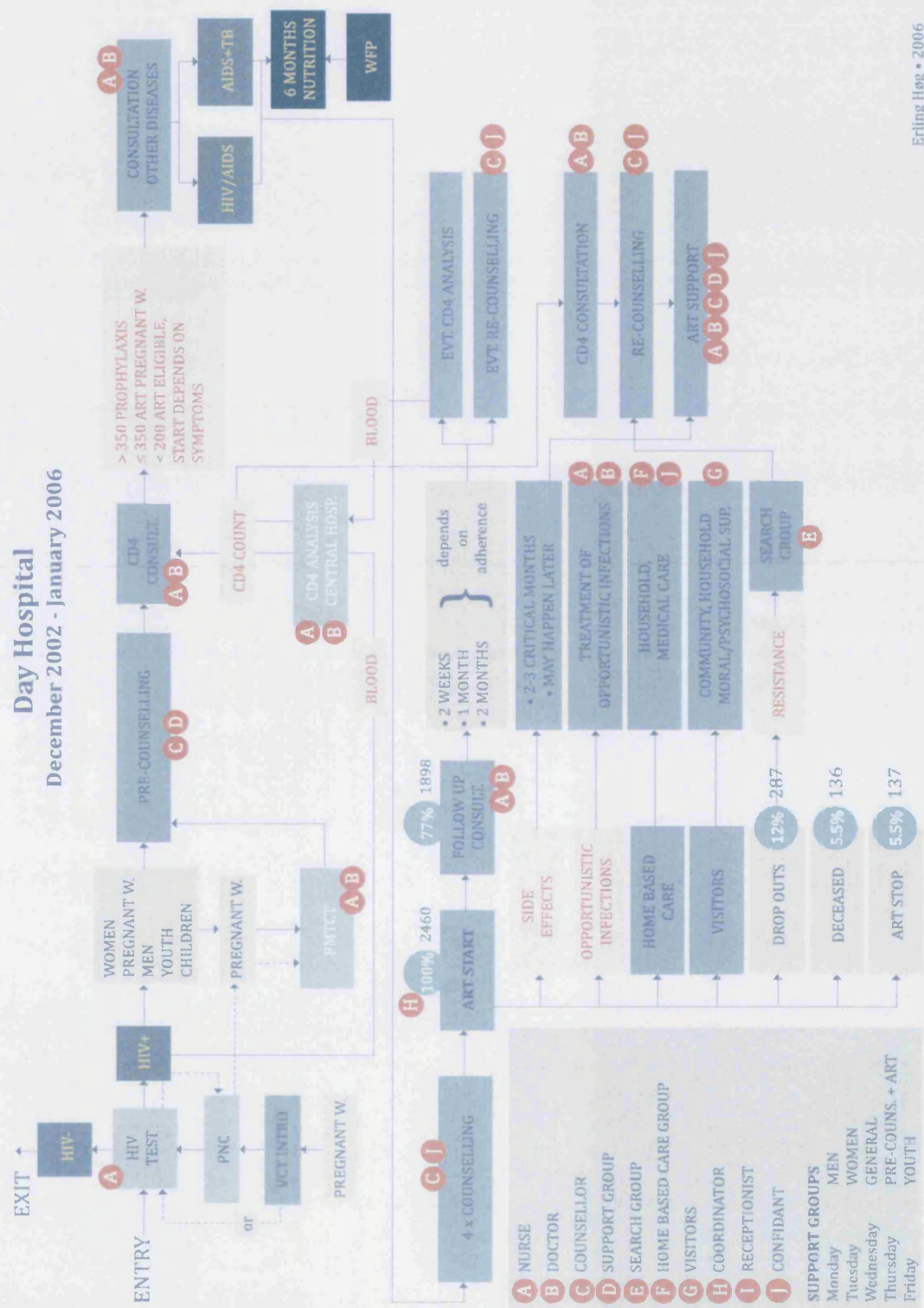
Figure 5.6: A Day Hospital Patient Flow Chart
Source: Fieldwork. *Used for illustrative purposes only.*

Vicente, with whom I talked almost daily at one of the AIDS NGOs, said to me one day: *"How can you know that all these reasons that you hear about are true? Have you been in people's homes? Maybe all this about domestic violence is not true. Have you ever seen a woman being beaten or thrown out of the house, because she reveal-ed her HIV status?"* His rhetoric left me perplexed. I said to him that it remains a difficult methodological and ethical issue on how to provide first hand evidence of a man who beats up his wife and promptly kicks her out of the house.

However, I visited one of the PMTCT Day Hospitals. I witnessed the counsel-ling sessions with nurses, pregnant women and mothers, given that the patients explicitly consented to my presence. I had initially talked with one of the nurses about their work at the hospital in general and about domestic violence and expul-sion in particular. She assured me with a loud confirmative voice that these phe-nomena were not pure discourse, but part of practices that she deals with every day, in the clinic as well as through her home visits. As each woman entered to consult her, she kindly but demonstratively asked the ones she knew had been kicked out by their husbands to tell me their stories. They timidly yet calmly told me about their experiences. Once the husband finds out about his wife having HIV, she is most often beaten or kicked out of the house, or both. I saw the women's bruises and swellings: they tell the truth. In a few cases, the husband chooses to leave the house. Many women now live a homeless life.

Home based care complements Day Hospitalization to improve this situa-tion, given the circumstances of a 'resource-poor setting'. Yet, many patients ideal-ly need hospitalization. This is a delicate medical, social, and ethical question of everyday life delivering ARVs, governed by limited health system capacity. There are not enough hospitals, beds, and health workers. Community outreach is there-

fore necessary, but limited. Community outreach takes three forms: *home based care* (medical support by doctor and nurse), *moral and psychosocial support,* (AIDS activism by voluntary visitors), and *search groups* (activists and counsellors who look up dropouts). I now turn to a descriptive tour to introduce this reality as part of the health system and ARV delivery.

Home Based Care

We drive through the Maxaquene shantytown. This is within spitting distance from the World Bank and the World Food Programme. Many would agree that we here see some of the poorest living conditions in all of Mozambique. The state of public health is deplorable. Mountains of trash accumulated through months and years of inefficient or absent municipal garbage collection surround us as we continue to visit ARV patients. Bairro folks lament the fact that they pay garbage collection fees to the city council. The public space is ruled by dirty, stagnant rainwater and sewage water in one big mess. Children run around barefooted. They pick up things to eat, barely examining their edibility. Rats escape your presence, except for those who area already dead, which speedily putrefy under the relentless sun in competition with an army of hungry insects. The housing standard is low: constructed of a mix of clay, raw cement, straw, and cane. Typically, there is a violent smell of three origins: burning trash, burning coal, and the toxic dust from the raw concrete used for construction purposes. The smell of raw concrete is awful; that heavy material made from gravel, sand, cement, and water. The ubiquitous smoke from burning coal adds to the hostile environment that your lungs must endure. The

floor is made of the bare ground of soil and sand. We visit several patients in their homes this morning.

This was 'slum based care'. Think of 3 days without garbage collection in London or Copenhagen. Citizens would protest and make the ones responsible act immediately. However, this does not happen in Maputo. The things I had read in development plans sounded more relevant than ever, yet ridiculous and useless considering the slow process: 'integrated approaches to development and health', 'Millennium Development Goals', 'poverty reduction', 'the right to health as an inclusive right', and so on. However, many people said that things were worse in the past. A shopkeeper, who has lived through colonialism, civil war, poverty, and wealth, said: *"Mozambique is probably less than 30 percent on its way back to where it was before."* This would indicate that things were better during colonialism. Nevertheless, I kept asking in anger 'why don't they sign the contract and get the job done?' Admittedly, statistics say that 1 billion people live on the margins of survival on less than 1 dollar a day. 2.6 billion live on less than 2 dollars, which is 40 percent of the world's population (UNDP 2007: 25). On the other hand, I had read about Bill Clinton's visit to Maputo in 2005, just after I arrived. Clinton is known as 'the powerful man with the guts to make things happen.' Clinton came up with the idea of 'Project Clean City', with the intention of immediate action. Nothing much had visibly changed one year later. Ideas like 'AIDS exceptionalism' and 'AIDS mainstreaming' promoted worldwide gained new meaning. Doctors and nurses do a terrific job in these communities, like altruistic heroes of health care who take on responsibility beyond their limits.

An Environment Week was held in Maputo, June 2006. Maputo City produces 660 tons of solid waste per day. They only have five vehicles for the renova-

tion business. Maputo City needs 300,000 US dollars per month to respond adequately to this reality. In other words, Maputo needs 3.6 million dollars per year to keep it clean. Lack of qualified human resources was stated as the main problem for the management of garbage collection (Republic of Mozambique 2006).

Citizens do care. People voice their concerns on TV. They write newspaper editorials, articles, and letters to the editor about the problem of garbage in public space, but very little is happening. This is unfortunately part of the normalisation process. People 'give up', 'deny the problem', 'turn a blind eye', 'sigh in resignation', and become 'accepting of the situation'. The problem is astronomical. Public health requires functioning water systems, sewage systems, and a clean environment. International partners know this very well, but what keep them from action? Does public health not figure on their agenda? Is the 'multi-sectorial approach' just another fad? Do they end up denying and turning a blind eye like citizens do? Why not recycle the rhetoric of 'AIDS exceptionalism' and 'human rights' to attract attention, funding, and action in the area of public health? This is what I would call a 'new inclusive exceptionalism'. However, the question is what is so new about it? The 2005 G8 Gleneagles Communiqué promised 'integrated approaches' to development (G8 2005). Was this not an inclusive exceptionalism? Why are other kinds of development not up to speed with investment in health? Medical intervention and cooperation prevail, which make the promises fade into toothless lip service. Alternatively, I simply do not understand the process, obsessed with indignation? Maybe I fail to see the obstacles of the past and the challenges of the present? Yet, the fact that 'the process' is both invoked as explanation and excuse for slow or no progress keeps me exasperated. However, it might be the story of 'too many politicians spoil the broth', rephrasing a well-known food idiom.

What if all the beautiful trees of Mozambique had the AIDS ribbon complemented by public health ribbons and socioeconomic development ribbons? Would things then start to change? Then people would also stop urinating on them. This is no joke. Commonly many households share one latrine: the 1997 census found that 66 percent of all households were without latrine (National Institute of Statistics 1997), which had decreased to 50.9 percent in 2003 (National Institute of Statistics 2005). People take a pee against the trees and the trees are suffering. However, there is no public health campaign to improve water and sanitation, the environment, etc. People told me that campaigns are nonsensical and insulting. As someone pointed: *"You cannot make a living from getting a free t-shirt"*.

All this is harsh reality of everyday ARV access and delivery. Health workers face this reality alone in the field, abandoned by other sectors responsible for the health of body society. They are heroic but gasping, attending poor people on ARVs in bad shape. Let me describe the situation of Rosalina, Paulina, Adelina, Amélia, Rogério, and Cláudio to give an idea of everyday ARV access and delivery.

Rosalina is in bed, unable to get up. She has severe diarrhoea and no appetite. She cannot get up and stand on her feet, when asked to do so by the doctor. Luckily, she has a committed, supportive, and understanding confidant to help her with the daily tasks in life. The World Food Programme supports her living on a monthly basis: we see sacks of maize, corn/soy mix, and split peas.

Paulina suffers HIV and tuberculosis. Her house is simple, made of a mix of raw cement and clay, doorways without doors, windows without glass, and a leaky roof. Mosquitoes have easy access. Paulina is sitting on the floor, wearing her beautiful *capulana*, a traditional sarong wrapped around her body. She suffers tuberculosis with a characteristic heavy cough. Yet, anyone would inevitably cough in-

haling the mix of fumes from raw concrete, dusty floors, burning coal and burning garbage. The smells are unbearable. Yet, the health care team forgot to bring masks, but continues to carry out their duties to assist the ill. The social condition is appalling, as in many other areas of Maputo outside the cement city of Polana and Sommerschield: around us, we see the typical public health chaos. This supports the argument about the consequences of ideological disorder: political transition renders major drawbacks unable to provide the basics in life, even though this has become priority in both socialist and capitalist thinking.

Adelina lies on a simple straw mat on the dirt ground of a small room farthest away in the corner of a large household. The household is relatively nicely kept, as compared to the public sphere. Household members do whatever: they listen to pop music, they fix an old car, and they do laundry. The roof is leaky. The window has no glass. Imagine when it rains. No one has cared for Adelina for quite some time, despite having a confidant within the household. Adelina is skinny to the bone. She has severe bedsores around her hip that need immediate attention. The doctor and nurse blame the confidant: *"Why haven't you done anything?"* The confidant mumbles, unable to provide a credible or clear reason. Anyway, when we leave, Adelina manages to give us a smile and wave at us.

Amélia sits on the floor in her living room. Several members of the household are at home at our visit. We see several empty wine and alcohol bottles. She explains that a family member brings home wine and alcohol from the restaurant, where he works. Amélia has good appetite and no diarrhoea. She suffers HIV and TB, gives us a smile, and says she is all right, under the circumstances.

Rogério sits on a chair in his parents' house, wearing shorts, t-shirt, and sandals. Rogério can hardly breathe and barely walk. He has little or no appetite.

He suffers HIV and TB and advanced Kaposi's sarcoma with lymphoid problems and swollen thighs. They are the size not seen in many other places in the world. We bring him with us directly to the Health Centre in the staff car. We should have called an ambulance, but as most often is the case, the one ambulance they have is not available when needed. The health team is a bit apprehensive about this procedure, therefore pulling up slowly to the Health Centre. They transfer Rogério out of sight of the usual patient reception. The nurse rushes off to inform the Day Hospital manager about the arrival of a patient in urgent need of attention, but her errand drags out. Meanwhile Rogério sits on the stairs at the main entrance to the Health Centre for about half an hour. He is in a bad condition, painfully suffering.

Cláudio is a man in his late 40s, who suffers HIV and tuberculosis. He lives in a small house, fairly well equipped with European style furniture and a double bed, yet the quality of the house itself is not much different from the ones previously described. Cláudio's most recent CD4 count was at 95 and could possibly be lower by now, perhaps at 50, as suggested by the doctor. The doctor tries to persuade him to come to the Day Hospital to initiate ARV treatment. However, Cláudio seems reluctant to take this decision. He says that the TB medicine gives him 'an awfully dry throat' and that he cannot imagine taking ARVs more than once a day. He is not sure whether treatment would help him, as he has seen that 'AIDS has no cure' on TV and he also feels apprehensive about going to a hospital. Cláudio points to his head with his index finger making circular movements, as he explains that his situation, his medication, and level of consciousness about AIDS, make him dizzy, confused, and unable to decide about ARV treatment. The medical team can only professionally and kindly recommend ARV treatment. They cannot oblige anyone to initiate such a regimen. Treatment is first and foremost based on

informed patient consent (see Appendix 2). Such situation points to psychological

barriers, to lack of information and education, and to lack of treatment literacy and

treatment consciousness. As Cláudio in 2006 concludes that 'AIDS has no cure',

with reference to the 'AIDS kills' campaign, this also points to the lack of an updat-

ed public information campaign about the difference between *cure* and *treatment*,

and the availability of antiretroviral treatment.

The following week I saw Cláudio entering a hospital for the first time in his

life. He walked around looking astonished and perplexed with his mouth wide-

open. The place is full of people in a similar situation to the one Cláudio lives.

Cláudio finally sat down to rest and a nurse came to care for him. I talked to one of

the doctors during one of my follow-up visits. Cláudio started ARV treatment and

he was soon in good progress improving his state of health.

Miguela: An AIDS Activist

AIDS activists initially receive short but continuous training at the City Health

Council. An 'AIDS activist' is a reinvention of the 'Communitarian Health Agent'

from the civil war period. One of them is Miguela.

Miguela started as an AIDS activist in 2004. It all started when her daughter

became very ill in 2002. The father of the baby had been beating up Miguela for a

while and now beat her again, indirectly blaming her for the child's state of health.

Miguela then separated from him. They were endlessly trying to solve their social

and domestic problems in court. When her ex-partner last saw her and the sick

child, he told her that he never wanted to see Miguela again.

The child was severely ill, yet undiagnosed. A caring person at the tribunal gave Miguela some money and advised her to take her child to a hospital. Both Miguela and her child tested HIV positive. Miguela went to tell the father of the child: he refused to offer them food at his house. He thought they would contaminate him with HIV.

Miguela had no health problems before or after testing for HIV. She conscientiously showed up for all scheduled consultations and participated in counselling sessions over a 2-month period. Miguela felt completely destitute, when suddenly a caring soul from the Italian Catholic Sant'Egidio Community during a seminar offered Miguela to become an AIDS activist. Miguela started working in 2004 and managed a new life of material dignity and colossal social importance in terms of supporting others in the same situation.

Miguela visits her fellow patients in the community twice a week. She says in a tone full of pride and optimism: *"This work is very important! We provide moral and psychosocial support, because I don't want to hide for any patient the fact that I am seropositive. I don't want to hide it. Also for her: she can take the medicine with her head held up high and I am at her side as she is recuperating."*

We visit Patrícia and her family. Three women of three generations: daughter, mother, and grandmother. Patrícia previously worked as a cook. She sits by a large bucket, cleaning and plucking a big, meaty chicken to be prepared as today's main meal. The activist asks how she is and about her health. Patrícia is skinny and weak. The activist asks her to stand up and to show her whether she can walk. Patrícia takes a 30-meter walk in the yard, stepping with some difficulty, her balance uncertain, then she turns around and comes back to us.

We sit outside the house talking about health and ARVs. The daughter, Patrícia and her mother, the activist, and I. Patrícia says that she is well and that the ARVs work well. The only problem is a chronic and constant tremor of her hands and arms.

The daughter fetches Patrícia's drugs and consultation card to check whether Patrícia has enough drugs until the next meeting at the Day Hospital on 19 May. Miguela explains two ways to renew the stock of ARVs. The daughter may get it for her, or, as is most often the case, the daughter will assist her mother to the Day Hospital. Patrícia needs to see a doctor every 15 days. She is not in a state of health to go there on her own. Moreover, Sant'Egidio does not practice home-based care by doctors and nurses, only moral and psychosocial support by activists.

We leave and walk through the Liberdade *bairro*. We see sandy roads, lush green trees and hedges, chicken, ducks, and well-kept gardens with sprouting vegetables. We see the typical informal street shops selling vegetables and fruit, coca-cola, biscuits, cigarettes, and the like. We also see the typical barbershops and small bakeries. However, you see garbage in the public space everywhere you turn, yet less than in other parts of the city. Another contrast is the absence of car traffic. Hundreds of school children walk the streets, wearing the classical Mozambican school uniform (a white shirt and dark grey or green trousers). Liberdade is a quiet neighbourhood with a mix of Portuguese and African architecture, characterized by both rectangular and round houses and cottages. The gardens stand out as impressive oases with beautiful shady trees with deep dark green leaves.

I talk to Patrícia and her daughter a couple of weeks later at their next visit to the Day Hospital. Patrícia is in a much better shape than last time I saw her. She walks with confidence, though still with some difficulty. Her hands are still shaky. Her daughter explains that this shakiness began soon after Patrícia found out she

was HIV positive. Before that, Patrícia suffered tuberculosis and cerebral malaria. Patrícia had a good life. She was working as a cook and spent much of her spare time in her *machamba* garden. Her health problems began early 2005. Patrícia gets called upon: it is time for her consultation. I talk to Patrícia's daughter, while she is away. *"She had problems with tuberculosis. She was on treatment between May and October. They checked her health and found out she had an infection. Then they asked her to go here to take the HIV test. She turned out to be seropositive,"* her daughter explains. *"She started ARV treatment in December 2005. Initially her health went up and down. After that, she has never had any problems, with the skin or vomiting. As I am always in the house, I can help her remember to take her medicine."*

Patrícia comes back and sits with us again. I ask her, whether she is in a better state of health by now. *"Yes, now I feel better. I had a fever. However, I always take the pills. I get better and I am in better health when I take my medicine. I would like to add that I am also able to work with other people."*

Patrícia and her daughter visit the day hospital once every 15 or 30 days: it depends on the state of Patrícia's health. Two return tickets for the *chapa* minibus cost 30,000 Meticais. Patrícia receives food support from the Sant'Egidio community, provided by the WFP: 36 kilos of flour, corn, wheat, peanuts, beans, sugar, oil and soy. Well, Sant'Egidio does not *deliver* the food. ARV patients have to come get it themselves, carrying it on their heads, walking home, or taking the bus. They say it is sufficient for one month, also in support of the family. However, it is intentionally *therapeutic* food for recuperation purposes for the severely ill, until they are able to work again and carry on with normal life. Sant'Egidio operates with a food support period between a few months and a year.

Feeling Better, Feeling Afraid

I ask Miguela about the problems she faces on her home visits to ARV patients. She says that the biggest problem is treatment adherence. I ask how and why this is so. She says that an ARV patient may have to keep medication a secret or that she only trusts her secret to one or two persons among her family and friends. This secrecy comes from fear of domestic violence, abandonment, and discrimination. Many believe that HIV transmits through touching cups, plates, and clothes that have been in contact with the HIV infected person. Husbands beat up and abandon their wives, when they find out about their HIV status. They leave them with no belongings. Many women worry how to keep ARV treatment a secret – every day, every week, every month, for the rest of life. They live within a family environment of fear of the consequences of breaking the silence. Where can she keep the drugs in the house out of reach of children, husband, and parents? Many women therefore abandon ARV treatment to relieve the psychological pressure.

We take the *chapa* back to the Day Hospital. Miguela then explains in more detail reasons why people abandon ARV treatment. Many patients drop out, when they get better. They think that they no longer need ARVs, despite the fact that they have been counselled repeatedly about the importance of treatment adherence and 'ARVs for life'. Life is complex and memory can be short upon recuperation. Patients may not understand the implications of chronic disease and the consequences of non-adherence and viral resistance to reinitiated treatment.

Miguela explains about the Monday to Friday group counselling sessions. Individual patients come to the Day Hospital once every two, four or eight weeks: it depends on health status and treatment adherence. She also explains that activ-

ists counsel about adherence on their home visits, at best together with the family. However, this may be extremely difficult, when treatment is kept a secret or if the patient has no best friend, the indispensable Samaritan citizen. Individual counselling in the home is possible, but it is often difficult to find space and freedom to speak about such delicate issues. In fact, home based care teams and AIDS activists now wear anonymous unrevealing clothes to prevent showing their errand, which would breach the established secrecy around HIV. AIDS activists often pretend to be 'a good friend from school' and they ask to sit a bit far away in the courtyard of the household. They make sure to talk about the weather, if a family member comes too close able to overhear the conversation about HIV and ARVs.

Community counselling is another option in use. However, this may add to the delicate dilemma between awareness raising and increased risk of stigma and discrimination in the community by exposing those who carry the virus and/or receive virus-controlling medicine. This community tour shows ARV delivery from an outreach perspective, which remains a disproportionate challenge in relation to the mandate and resources of the medical profession.

Anabella: A Family Physician

Everyday ARV delivery inside the Day Hospital is a different story. Let us hear from Anabella, a family physician and Catholic Sister, who first came to Mozambique during the 1990s and later returned in 2003 to become a committed ARV doctor. I spent time with Anabella in her consultation, on her rounds in the observation room, over lunch, in the coordinator office, and through formal interviews.

A Double Silence

Anabella became an ART family physician in 2004. She trained as a physician in Spain, where she also became a Catholic Sister. Then she worked as a doctor in Mozambique in the early 1990s. She recalls that AIDS was then a silenced issue. AIDS was an unrecognized problem. It was not given priority: the country was overwhelmed by the aftermath of 30 years at war and endemic malnutrition, malaria, and tuberculosis. She left Mozambique in 1996 and came back in 2003. *"I could never have imagined the level of HIV which is here, when I came back in 2003"*, she says in retrospect.

This was seventeen years after the first AIDS case had been reported. With my analysis of epidemic evolution in mind, Anabella then says about her experience: *"You need to realize that this is a disease from which we are now seeing the majority of people who got infected. It is inevitable that we are now seeing the consequences. You can live as virus carrier for a long time."* We saw in Chapter 2 how the body remains symptom free during the first wave, which I therefore would call the silent epidemic. Moreover, Anabella reminded me that most of this time was discourse-free. Thus, a double silence characterizes the long latency period: a silent virus and a silent response. Nevertheless, she said that it was a time when Mozambicans always avoided the situation ('we are busy doing other things'). Mozambique experienced post-war recovery, in political, economic, and human terms. Moreover, Mozambicans continually suffer a high burden of disease, eternal poverty, and recurring natural disasters.

A Huge Dam Full of Holes

Then HIV came to the surface. It started in the early 1980s. The first AIDS case was reported in 1986. For all the reasons I have already discussed so far, things did not happen until the beginning of the new millennium. At one point Anabella says: *"I am a doctor and I am working day by day with ill people. Sometimes I compare this to a huge dam, which is about to explode. We stand in front of it all day and see a wall full of holes. Let us fix the holes. Suddenly there are five more holes and then five more, and then ten more. Let's fix the holes! But you can see that the wall is full of holes! This is how we feel sometimes, us who work in health."* The consequences of the epidemic evolution appear as a massive wave (see Figure 2.2, p. 91).

Anabella, like many other health workers in Mozambique, resembles a heroic saint, who believes in miracles and makes them happen. *"I arrived in 2003"*, she says. *"I like this kind of work. I feel a medical vocation to work with this type of patient. I see huge social problems to the extent that I feel like a doctor who also works in the social field. Priests, missionaries, and sisters refer many of them. What if they didn't help them? ARV treatment is fundamental, but if we don't improve the conditions of everyday life, there is no way we are going to defeat this disease."* Let us hear how she copes with such double vision.

Miracles of Hope

Anabella reflects upon the HIV epidemic as a process, not just about a given moment in time, when things may seem manageable and stabilized. This view relates

to her passionate feeling towards her professional vocation. She says about the need for more health workers: *"Yes, we always need more personnel, and when we get more personnel, we always need more personnel! How can I explain? It's like this from 7:30 in the morning! It is a tough and difficult reality. No one is a superwoman or a superman, nothing like that. But I do believe that it's very important that you feel passionate about what you do. Each new day there are more patients, each day is worse, more patients come in every day. And to see that people think that I'm a utopian, an idealist, that I'm dedicating all of my life to a cause that's already lost. But I tell you it's true that I see many miracles as the day passes by. I see miracles of human resistance by people who want to live. People improve a lot with treatment. You have already seen bodies gaining weight, easily from 30 to 80 kilos! People recuperate and they go back to their jobs. Girls are back in school. These are the miracles of hope that I want to continue to see come true. We are human, that's why. The most important is to say 'hey look, don't despair, let's do something!' The ill person will die one day, but at least he or she will die with some dignity with the feeling that someone cared to do something for him or her. Die in a clean bed with clean sheets. It is very, very important to do this for ill people who have usually been rejected."*

Limitless Need of Health Workers

I ask Anabella how many patients she sees per day. She says: *"It's difficult, because there is no limit. I don't mark a number to determine my time. It's impossible to predict the number of daily patients. We get a lot of patients referred by other missions and missionaries. For example, Casa de Calcutta, if they bring twenty today, another*

day they bring ten: it's impossible to predict. They don't know in advance how many

will get sick on a given day. They have to be able to come at the moment they get ill."

Then Anabella commented on the major changes since 2004. *"It's true that*

the number of people who have access is improving. It's better now, but it's not in-

creasing at the speed, which conforms to the size of the epidemic. This is evident. It's

true that we are in a very difficult situation like for most other national systems of

health in the same situation, because antiretroviral treatment is not easy. You need

trained personnel first of all."

Duarte, one of her physician colleagues, agrees with her on the question of

accumulated lack of health workers. I asked him, whether they have sufficient

health personnel to assist people with HIV and AIDS. Duarte replied promptly:

"Never! We seem to have enough until now, but I expect that in another year we need

to recruit more health workers. The situation will become more burdensome for the

centre. This is why the Ministry of Health has decided not only to include doctors to

attend AIDS cases, but also to train paramedical personnel. That is, medical techni-

cians could attend this segment of patients as well. Otherwise, we are very few doc-

tors. It is necessary to involve other kinds of health personnel."

It was difficult for Anabella to directly admit that she was overworked and

overloaded with work. This was the case for most health workers I talked to. Ana-

bella talked in allegoric terms of 'huge dams', 'fixing a hole', and 'tough reality',

mixed with constant reminders that medicine is a vocation.

Health System Challenges

I have by implication discussed key health system challenges through health worker narratives: competence, capacity, infrastructure, and harmonization. The expansion of ARV delivery in Mozambique is a success story against all odds, but by implicit promise of the title *The Process*, this delivery needs to be seen in time perspective as a continuous story linked to the experience living with ARVs, the prospects and consequences living without ARVs, and the reality of Mozambique.

Training of Health Workers

Training of health workers attracts immediate attention. The first doctors went to Brazil in 2001 to receive ART training. The Ministry of Health and Sant'Egidio train ART personnel. They managed to have 230 ART doctors in Mozambique by 2006. Mid-level technicians were then called upon.

I participated in the Sant'Edigio Community DREAM Capacity Course in October 2005 in Matola, the sister city of Maputo. President Armando Guebuza, the Mayor of Matola, the Vice Minister for Health, representatives from Sant'Egidio, the National AIDS Council, the apostolic community, and the RENSIDA association of people living with HIV talked at the opening ceremony. An audience of more than three hundred participants attended.

This full-week course was part of a pan-African initiative to train ART health workers. Health workers from Mozambique, Malawi, Nigeria, Congo, Eritrea, Guinea Bissau, Guinea Conakry, Tanzania, Angola, Ethiopia, Kenya, and Cameroon

participated. The course was taught in Portuguese, English, and French in three separate auditoriums by way of voice-over to an Italian lecturer appearing on a widescreen. Paolo Lombardi, the scientist responsible for the DREAM programme, Department of Public Health, Tor Vergata University in Rome, explains in Italian introductory epidemiology with a Portuguese simultaneous voice-over translation.

The course begins with a general module, followed by specialist modules for DREAM programme coordinators and laboratory technicians. This is where Mozambique with a total of 538 national and 225 foreign doctors (Ministry of Health 2008d), for about 19 million people begins: few Mozambican health workers know about HIV and AIDS and how to treat it. Note also that there are only 107 hospital doctors out the 538 national doctors (Ministry of Health 2008e).

I talked to some of the participating doctors and nurses. This was the first time they learned about HIV and AIDS. The general course starts with the very basics: What is HIV? What is an immune system? What is CD4? What is AIDS? What is ARV treatment? This is an exercise in 'treatment literacy'. Homework included answers to questions like how HIV is transmitted, which sex and age groups are most infected, which are the most hit continents in the world, what is the difference between prevalence and incidence, how many life years you lose caused by HIV, the anatomy of an immune system, and so on.

Carrying Capacity

The second issue is about carrying capacity: how do physical, human and patient capacity fit together? How much longer will health workers last? In fact, they

attend ten times more patients than recommended in human resource plans. Or

did these plans come up with wrong estimates of human resource needs?

The government human resource plan looks at the need for health workers

in relation to ART targets and the extrapolation of human resource needs based on

the basic health team needed to treat 200 patients, as forecast in 2004 (see Table

5.2). Such ART team would care for all segments of HIV patients enrolled at the

Day Hospitals. The recognition is clear, if Mozambique continues to scale up ART

with the limited number of doctors in the country: *"... almost all the medical staff*

available in the National Health System must sooner or later begin to work with

treatment of HIV/AIDS/ART" (Ministry of Health 2005c: 39).

Table 5.2: Human Resource Scenario for ART

	Basic Team	2004	2006	2008
Doctors	1	21	230	526
Medical technicians	1	21	230	526
Counsellors	3	63	691	1,577
General nurses	3	63	691	1,577
Pharmacists	1	21	230	526
Information officers	1	21	230	526
Receptionists	1	21	230	526
TOTAL HEALTH WORKER NEED	**11**	**231**	**2,532**	**5,784**
Number of planned sites		17	112	129
ART target		5,284	57,954	132,280

Source: (Ministry of Health 2005c: 39).

There were 104,351 adults on ART at 216 adult ART sites by May 2008 (see Chap-

ter 2, pp. 124, 129). The number of ART sites doubled the number of planned sites.

ART coverage for 2008 seems to reach the target, but what is wrong with this

picture? True, there were 230 ART doctors in 2006, as targeted, but what about

the need for the other kinds of health workers?

The entire health worker force would not be enough to keep up with the

ART demand. The government simultaneously seeks to decrease its reliance on

foreign health workers. So far, the result is overloaded health workers, despite the fact that training of medical technicians became a priority in 2006. Then what about the need for psychosocial support? Please note that the scenario excludes psychologists and activists. I do not have data on the numbers of trained health workers for 2007 and 2008, but I can show that health workers in 2006 at one particular Day Hospital treated 10 times more HIV/ART patients than recommended. This relates the quality of HIV/ART care to the precarious demand-supply balance.

I visit a Day Hospital with more than 6,600 active medical records. About 4,000 are on ARV treatment. Health workers say they can see a maximum of 15 patients per day, regardless of position. This needs to be seen in relation to patient need of health care. A 'normal' ARV patient needs to visit the Day Hospital 15-20 times per year during the continuation phase. This means that the 4,000 people on ARVs need to visit the Day Hospital between 60,000 and 80,000 times per year. This means that the Day Hospital attends between 240 and 320 ARV patients per day (250 working days per year). The segment of patients in process, but not yet on ARV treatment, adds another 2,600 patients in this case. Every person in need of ARV treatment needs 10 visits the first month (initiation phase). Obviously, the ideal of maximum 15 patients per day does not correspond to reality.

This Day Hospital employs 38 health workers (see Table 5.3). The human resource development plan for 2006-2010 estimates 11 health workers for every 200 ARV patients (Ministry of Health 2005c). The 38 health workers should therefore only treat 691 patients. They treat 6,600 patients. This is 10 times the Ministry of Health 'estimation' or 'recommendation'.

Table 5.3: ART Day Hospital Team

Health worker	No.
Doctors	5
Nurses	14
Counsellors	6
Psychologists	2
Pharmacists	3
Information officers	3
Receptionists	5
TOTAL	**38**

Additionally, two activists take part in *palestras* and counseling. Counselors, doctors, nurses, psychologists, and activists share these tasks. A patient support group is also active. The Day Hospital transfers patients to other Day Hospitals in case of Kaposi's sarcoma. There are about two such cases per month. They refer exemplary patients with no health problems at follow-up session to the Health Centre to ease the workload. Health Centre workers with little or no ART training prescribe ARVs in such cases.

However, the lack of health workers has other dire consequences. This particular Day Hospital does not provide home based care, it does not provide food, and it does not search for dropouts. Local organizations have taken over these responsibilities: the National Association of Nurses in Mozambique, ANEMO, the Mozambican Association for the Development of the Family, AMODEFA, the Lutheran World Federation, and Portuguese and Spanish Doctors of the World.

This may sound like an ideal situation, as Guilherme, one of the coordinators pointed out: *"I think that the HIV/AIDS question is not just about health personnel. It's a social problem that I think needs to be solved in between institutions, where each one contributes in whatever ways are possible. Health provides antiretrovirals. Social action provides psychosocial support, and so on."*

However, most of the patients I talked to did not know about these organisations. Nor had they heard about the patient organisation Kindlimuka. Some of those who had been there could not afford the membership fee.

I arrive early in the morning to talk to Raisa, one of the nurses, who holds a key position with regard to health triage and patient management. Lack of doctors is the biggest problem. They have four foreign doctors, plus the physician coordinator, but they always confront the time consuming problem of work authorization. Foreign doctors stay in Mozambique on short but renewable contracts, or new ones replace them, so the authorization phenomenon is recurring. Foreign doctors *in limbo* do not take decisions in medical emergency cases. For this they need Mozambican doctors, but they are not directly affiliated to the Day Hospital. Mozambican doctors can only occasionally assist the Day Hospital as they work full time at the Health Centre. Raisa says: *"They don't appear, because they are busy. Sometimes we call upon a doctor to assist us, but they also need to be at the first aid section and in the medical urgency section, so we continue without doctors.* This produces frustration and stress among all the health workers at the Day Hospital. Foreign doctors often feel betwixt and between: what or whom should they obey, the Government or Hippocrates? They must follow domestic laws, but they also have an obligation to care for the sick, which brought them here in the first place. Raisa then comments on the workload of the four foreign doctors: *"It is very tiresome. They have to work all day, sometimes until 6 o'clock. Twelve hours is too much. We often get severely ill patients and they need much of their time. They need to see what's happening and attend to the urgency analyses, which is not easy. Each doctor is seeing at least thirty patients per day. And sometimes the doctors also get ill."*

The human resource problem relates to the time consuming processes of work authorization. All nine foreign doctors I interviewed and many of the Mozambican health workers talked about this problem, which they see as a particular stress factor that afflicts all of them. Every emergency call at the Day Hospital causes disruptions at the Health Centre. There are no health workers loitering in the corner. Raisa says: *"We call this a medical vacuum."*

Heterogeneous Realities

Nevertheless, Benedito, the ARV Committee, said: *"We are available to treat everyone, but we know that money is not the only problem at this moment for countries in Africa. Neither is the medicine, because it is also true today that drugs prices have dropped. But the big problem today is qualified human resources, the people's access to the health units, and the quality of those health units."* Donor funding and unique collaboration with the Mozambican government makes expansion of health infrastructure happen. However, the laws and bureaucracy in Mozambique, international bids, and the reality on the ground of weak existing infrastructure, makes this a time consuming process. Human resources continue to be one of the biggest challenges. We can understand this when we think in terms of epidemic evolution and relate the limited number of health workers to the growing number of people in need of ARVs that increases too fast to keep up. Moreover, lived experience is a different story. Nationwide ART expansion remains challenged by heterogeneous realities, influenced by language, culture, tradition, and the staggered response to epidemic evolution (see Chapter 2). Treatment programs arrived at a late stage of

epidemic evolution, when many adults infected during the 1990s had reached the ultimate stages of disease progression.

This points to the lack of synchronicity. People should ideally have been counselled before the arrival of local ART sites to prepare for the therapeutic process – *o processo clínico* – and the double disease (Scheper-Hughes and Lock 1986) of prejudice, stigma and discrimination. This means that people continue to live with feelings of *'no access to treatment, silence, fear, shame, hopelessness, no expectation'* when ART comes to town (see Figure 2.2, p. 91).

It might seem unfair to be wise at a late stage of epidemic evolution, retrospectively saying what we *ought* to have done at the right point in time, but there is still time to catch up from good advice and also lessons to pass on for responses to future epidemics. Successful treatment delivery is about timing and preparedness at all levels. This is not the case in several Mozambican provinces (see Figure 5.7). Anthropological studies in all provinces could verify the heterogeneity of treatment realities to inform policy choices.

PLWA	Health system	Examples
No demand	No supply	-
High demand	Low supply	Maputo City, Sofala
Low demand	High supply	Gaza, Niassa

Figure 5.7: ARV Treatment Demand and Supply
Source: (Høg 2008).

Geographic Equity

ART expansion in numerical terms has been astronomical, given the short period since its large-scale introduction in 2004 under the circumstances of a weak national health system. The number of adults on treatment increased from 4,000 in June 2004 to more than 100,000 in May 2008 (see Figure 2.21, p. 124).

A VCT centre in Maputo typically tests a maximum of 15 people per day due to limited capacity. Many are rejected or asked to come again later. They may have to wait weeks or months. People commonly say in disappointment: *"they are slow"*. All Day Hospitals in Maputo soon reached the limit of their carrying capacity. Then people said: *"they are full."* The transference system to other hospitals seeks to make treatment available closer to where the patient lives. However, the demand is higher than health system supply in Maputo, which is also caused by the fact that more people test for HIV after the introduction of 'Counselling and Testing for Health'. Yet, Maputo has enjoyed preferential treatment due to the presence of all major treatment providers. Provinces were underserved.

The government introduced 'geographic equity' to get ARVs out of Maputo into the 10 provinces and 128 districts. This evidently became necessary, since more than fifty percent of ARV patients nationwide were treated in Maputo City in 2006. The government could reach one hundred percent ARV coverage in Maputo, but it prioritizes distributive justice over urban bias.

The number of adults on ART increased 31 times in Cabo Delgado compared to 4 times in Maputo City between June 2005 and May 2008. ART increased 7 times in the South, 14 times in the Centre, and 22 times in the North (see Figure

5.8). The share of people on ART in Maputo thereby decreased to about a quarter

of the total number on treatment nationwide.

Province	Adults on ART

Increase ■ May 2008 ■ Feb 2007 ■ Jun 2005

Province			
SOUTH	7	31,477	55,324
	8,459		
Maputo City	4	19,989	27,723
	6,993		
Maputo Province	25	10,878	
	4,474		
	436		
Gaza	15	12,507	
	5,050		
	807		
Inhambane	19	4,216	
	1,964		
	223		
CENTRE	14	17,867	36,918
	2,679		
Sofala	12	11,914	
	5,861		
	993		
Manica	19	8,515	
	3,980		
	453		
Tete	8	7,275	
	4,297		
	861		
Zambézia	25	9,214	
	3,729		
	372		
NORTH	22	12,109	
	4,797		
	550		
Nampula	19	5,109	
	2,457		
	276		
Cabo Delgado	34	4,945	
	1,369		
	145		
Niassa	16	2,055	
	971		
	129		

0   10,000   20,000   30,000   40,000   50,000   60,000

Figure 5.8: ART Coverage by Province over Time, Increase June 2005-May 2008
Source: (Ministry of Health 2006c; Ministry of Health 2007d).

Zambézia is the most populous province, a province with RENAMO majority vote,

and the province with least health workers. Zambézia has one doctor for every

75,000 people, compared to Maputo, which has one doctor for every 3,500 people

(see Figure 5.9).

Province   **Inhabitants per Doctor**

Zambézia ▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮ 74,401
Cabo Delgado ▮▮▮▮▮▮▮▮▮▮ 48,144
Nampula ▮▮▮▮▮▮▮▮▮ 46,276
Tete ▮▮▮▮▮▮▮▮▮ 45,677
Inhambane ▮▮▮▮▮▮▮▮ 43,788
Manica ▮▮▮▮▮▮▮ 38,813
Gaza ▮▮▮▮▮▮▮ 37,043
Niassa ▮▮▮▮▮▮ 34,521
Maputo Province ▮▮▮▮▮ 29,855
Sofala ▮▮▮▮ 23,974
Maputo City ▮ 3,487

0   10,000   20,000   30,000   40,000   50,000   60,000   70,000   80,000
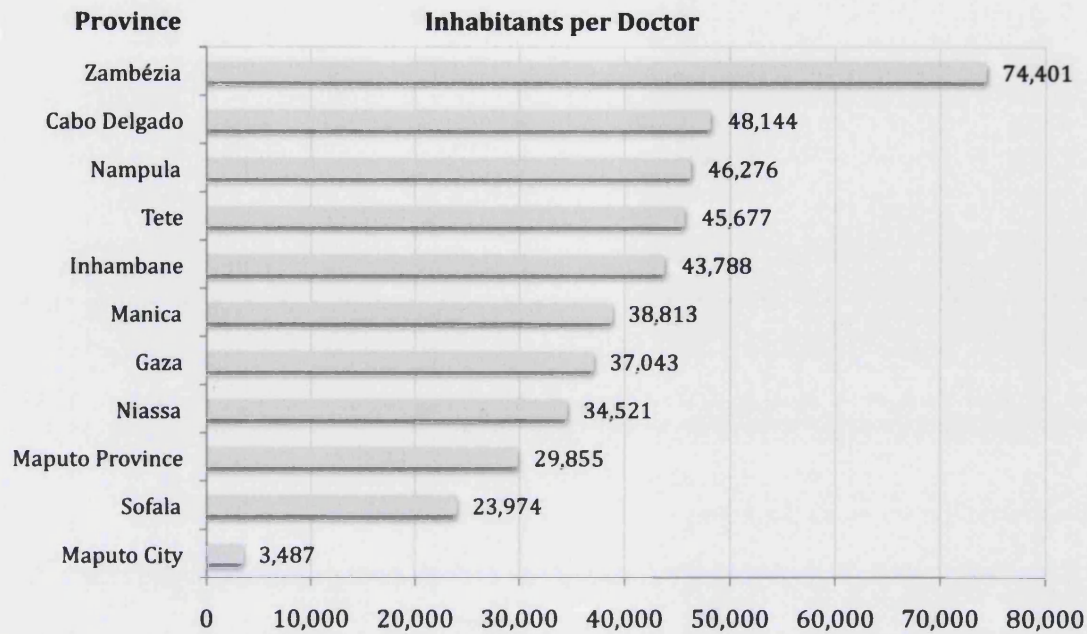
Figure 5.9: Inhabitants per Doctor by Province, 2004
Source: (Ministry of Health 2005a).

The major partners supported between 13 and 30 percent of these patients, al-together providing access for 96 percent of the 21,496 ARV patients nationwide by February 2006 (see Figure 5.10).
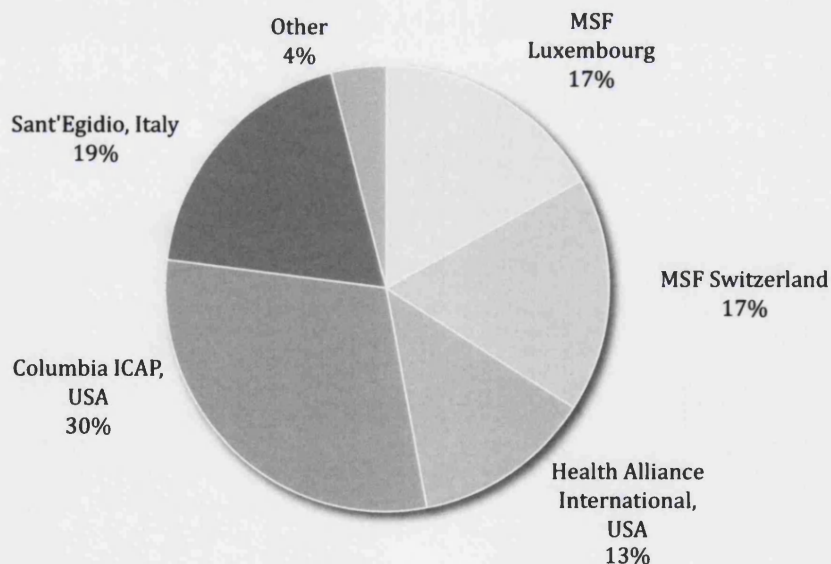
Figure 5.10: Partners' Share of ARV Delivery, February 2006
Source: (Marsh 2006).

We saw in Chapter 2 that as the number of people in need of ARV treatment in-creases dramatically with time, the targets for how many patients the health sys-tem can realistically attend decreases (see Figure 5.11).

	2004	2005	2006	2007	2008	2009	2010
2004 targets	8,000	21,000	58,000	96,000	132,000		
2006 targets		19,000	48,000	62,000	78,000	94,000	114,000
ARV coverage	7,414	19,726	44,100	88,211			
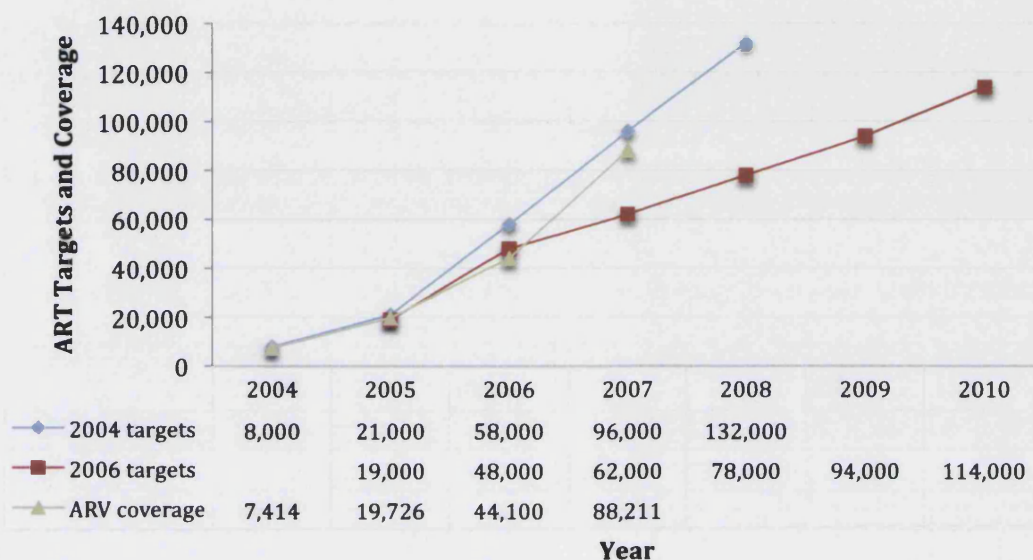
Figure 5.11: ARV Targets 2004-2010 and ARV Coverage 2004-2007
Source: (Assan 2006; Ministry of Health 2008a).

The five-year target was to have 132,000 people on ARV treatment by the end of 2008. The Ministry of Health revised this target to reflect the reality on the ground, based on their experience since 2004. The revised target was set at 78,000 people on ARV treatment by the end of 2008. Yet, ART expansion in 2007 and early 2008 shows that the end of 2008 would reach the original target. On the other hand, the number of people in need of treatment was estimated at 370,000 by the end of 2007 within the range between 290,000 and 460,000 (WHO/UNAIDS/UNICEF 2008), compared to the National Strategic Plan, which estimated 415,000 in 2009 (National AIDS Council 2005).

The point is, for many of the reasons I have discussed in this chapter, that the process teaches us about the 'clean slate': the context for ARV implementation, the obstacles, commitment, solutions, and pragmatic choices. The most important

question remains the need of qualified health workers and the welfare of the hard-

working ones on the ground who attend an increasing number of HIV and ART pa-

tients. I have portrayed significant corners of the reality on the ground, and paid

attention to what health workers have to say about the delivery of ARVs. The gov-

ernment goal continues to be one unified national health system by and for Mo-

zambicans, which echoes the dreams of the social imagination at independence in

1975. However, the human resource question has become highly politicized in the

face of the expansion of ART. This is classical politics of health, which will be dis-

cussed in the next chapter.

6
Politics

6: Politics

The introduction of ARV treatment happened in a time of changes: commitment to sovereign nation-building and health system transition. The sovereignty project dates back to and before independence in 1975. However, the government portrays the old Mozambican system as 'centralized and obsolete', belonging to a state apparatus conceived at a different point in history (Ministry of Health 2005c). However, I argue that ARV treatment becomes politicized exactly as part of the Mozambican sovereignty project established at independence, which in the context of health care reform shows direct affinity to the post-independence successful years of nation-building that included a commitment to the provision of universal access to free health care. The Mozambican government seeks to integrate tertiary care into the otherwise lost goal of primary health care. This chapter therefore explores the Mozambican political response to the HIV epidemic in historical perspective, focussed on the following themes: a) nationalization, b) the impact of civil war, c) funding for ARVs, d) decentralisation *without* privatisation, and e) NGO competition, internal brain drain and privatisation.

The Political History of Health in Mozambique: ART in Perspective

The history of post-independence Mozambique since 1975 has been covered extensively elsewhere (Abrahamsson and Nilsson 1995; Andersson 1992; Christie 1988; Hanlon 1984; Hanlon 1991; Hanlon 1996; Newitt 1995; Noormahomed and

Segall 1994; Pitcher 2002; Walt and Melamed 1983). However, the political history of health care in general and of HIV in particular is missing. The following analysis seeks to clarify the historical links and reasons for the current politics of HIV as ideally yet another disease to be integrated into the National Health Service and as part of the nation-building project.

I use historical material and anthropological studies of Mozambican health care and HIV. However, core material is field based: participant observation and qualitative interviews with key persons at the Ministry of Health and the National AIDS Council: Benedito (ARV Committee member), Sergio (National AIDS Council), the National STI/HIV/AIDS Programme Director Alfredo Mac-Arthur and Minister of Health Paulo Ivo Garrido. I use the real names of the latter two, since they speak officially at seminars and conferences.

Socialized Medicine: A Political Consolidation

FRELIMO cherished free universal access to health care upon independence in 1975. The 1977 law on free health care would ensure health care to all citizens by means of nationalization, in accordance with the first constitution (Machel 1975a; Republic of Mozambique 1977). In other words, socialized medicine would prevent the formation of private health care.

The revised constitution of 1990 reiterated the principle of a health system for the benefit of all Mozambicans: *"All citizens shall have the right to medical and health care, within the terms of the law, and shall have the duty to promote and preserve health"* (Chissano 1990). However, the private sector was authorized for

commercial or non-commercial purposes along with the creation of the National Health Service to realize this objective (Republic of Mozambique 1991a; Republic of Mozambique 1991b).

The creation of the National Health Service emphasizes FRELIMOs commitment to socialized medicine, but the analysis of the politics of ARV funding will also improve our understanding of 'the process' in terms of nation-building, and how the introduction of ARV treatment shattered this project and at the same time became a pragmatic opportunity towards its realization. Mozambique negotiated the introduction of ARVs during the four-year period 2000-2004. This discussion helps us to understand why the Mozambican government insists on the creation of one unique public health system.

Ceilings and Spaces: The Limits of Government Action

Belgian lawyer Gorik Ooms, who worked as Head of MSF Luxembourg in Mozambique 2000-2003, develops the thesis *"can the health-related MDGs be achieved within the conventional health development paradigm"* by looking at the introduction of ARV treatment in Mozambique (Ooms 2008). Ooms juxtaposes the health development paradigm with the medical relief paradigm to show intrinsic struggles over ownership of the development process. HIV provides another case of increased dependency on foreign aid for the Mozambican government. From this view, HIV and associated funding needs have added to the progressing demise of the FRELIMO socialist development agenda. However, while the problem cannot be solved without external funding, the Mozambican government remains am-

bivalent towards development issues since the World Bank and IMF gained foothold in Mozambique during the 1980s.

Twenty-one timelines supports the argument of how the HIV epidemic devastates the sovereignty project. They show the evolution of FRELIMO, the war periods, the health system, and key national, civil society and international community responses to the HIV epidemic within the period 1962-2006 (see Figure 6.1).

FRELIMO was founded on 25 June 1962 in Dar es Salaam, Tanzania, as *the Liberation Front of Mozambique.* FRELIMO then fought 10 years for independence, 1964-1974. Independence Day was chosen as the thirteenth anniversary of FRELIMO, 25 June 1975. The civil war then followed between 1977 and 1992. The National Health System had been declared at independence, followed by a free health care law in 1977. The health system disintegrated during the civil war period, systematically destroyed by the Mozambican National Resistance Movement, RENAMO, supported by South Africa and Rhodesia. The National Health System was then consolidated in 1991, followed by a recovery program in 1995, 3 years after the peace agreement. This programme materialised through a major loan for reconstruction from the World Bank (Lubkemann 2001; Pavignani and Durão 1999). Old health facilities were renovated. New ones were built. More than 400 facilities were created or recreated all together. Health posts were upgraded to health centres. Service outputs of health centres and hospitals increased by 50 percent between 1993 and 1999 (Chao and Kostermans 2002: 6-7).

Figure 6.1: HIV Timelines in Mozambique, 1962-2006
Source: Fieldwork.
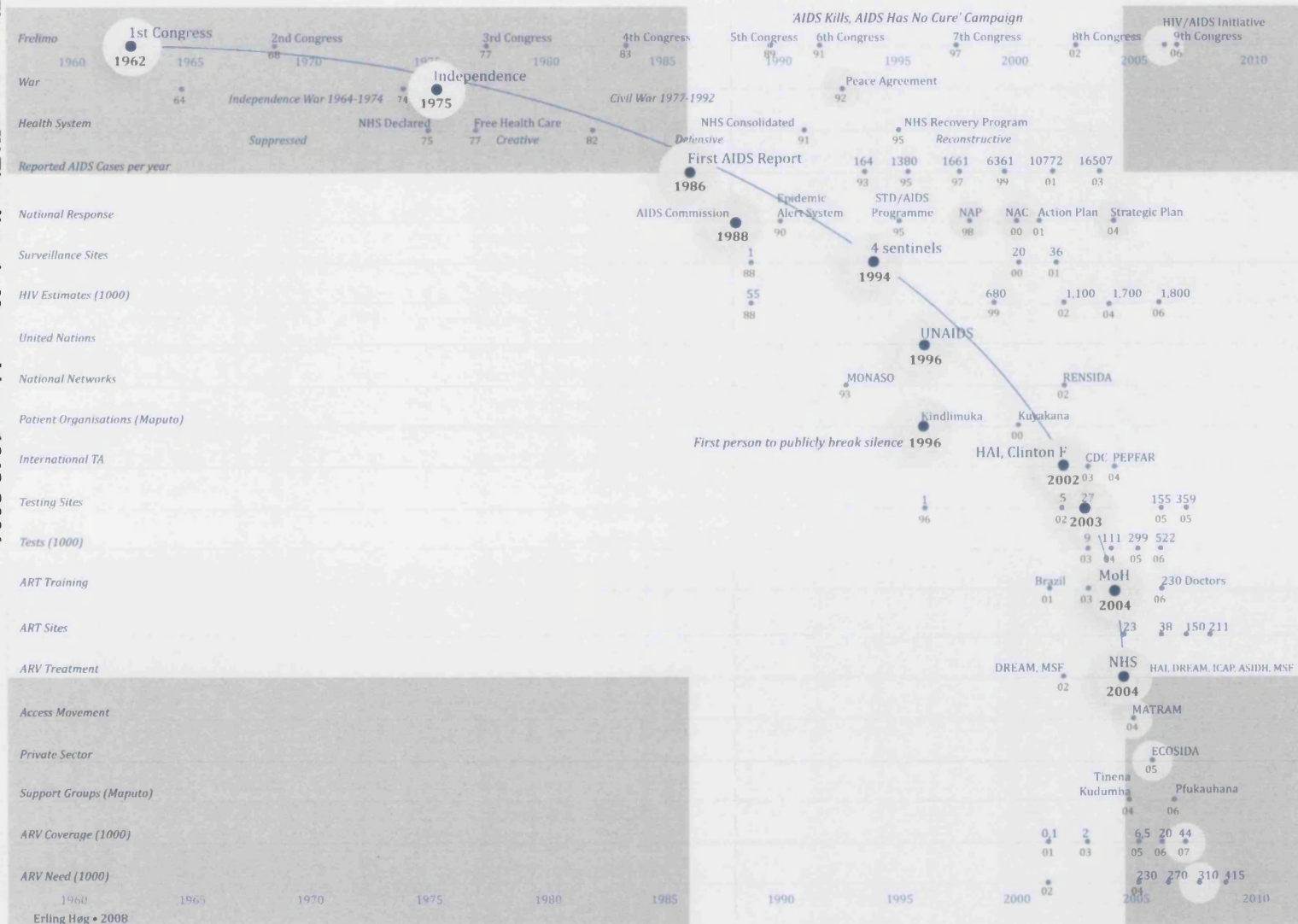
I have included a *dominant timeline*, which shows key events of the political, health system, and epidemic processes between the creation of the liberation movement and the introduction of free ARV treatment in the National Health System. We see 1962, 1975, and 1986: the creation of FRELIMO, independence, and the first AIDS case report (see Figure 6.1). Thus, the first AIDS case was reported during the civil war, when health system was under attack. Second, we see an 18-year period between the first AIDS case report (1986) until the introduction of ARV treatment in the public health system (2004). The government spent the first 14 years of this period on the creation of the following: AIDS commission (1988), epidemic alert system (1990), STI/AIDS programme (1995), National STI/HIV/AIDS Programme (1998), and National AIDS Council (2000). The four sentinel surveillance sites by 1994 increased to 36 sites in 2001. UNAIDS came to Mozambique in 1996. Civil society organisations like the AIDS service organisation MONASO, the patient organisation Kindlimuka, and the women's organisation Kuyakana, were created in 1993, 1996, and 2000 respectively. There was only one HIV testing site in the country until 2001, at the Central Hospital in Maputo. All this was a scattered process. However, the extended 18-year period between the first AIDS case report and the introduction of ARVs within public health system was as much due to local as to global socioeconomic, political, and scientific circumstances regarding the provision of drugs against HIV in resource-poor settings.

The period since the creation of FRELIMO in 1962 can be divided into four phases, which have changed the state of the health system: *repressed* (pre-1975), *creative* (1975-1982), *defensive* (1982-1992) and *reconstructive* (post-1992) – the creative and defensive periods suggested elsewhere (Noormahomed 1991; Walt and Cliff 1986).

I divide the 2000-2004 ART negotiation phase into three constituent parts: 1) the health development paradigm (state budget), 2) the medical relief paradigm (donor aid), and 3) the new health paradigm (exceptional sustained international funding for ARVs). The Mozambican model, which grew out of the new health paradigm, was based on a unique constellation of international funding and national priorities. Funding first paid for drugs. Only gradually did it become possible to pay for infrastructure and training of health workers.

The government initially followed the health paradigm, which implied state budget expenditure. The national 2000-2002 strategic plan did not mention treatment of HIV related diseases (Council of Ministers 2000). A Ministerial Decree, which approved the norms for the introduction of ARV treatment in Mozambique in December 2001, pointed out government limitations under the socioeconomic circumstances:[1] the high burden of disease (malaria, tuberculosis, and cholera in particular), lack of access to health care (only 30-40 percent of the population), side effects, patient non-adherence, the lack of the laboratory infrastructure, and the high costs of ARVs.[2] The government weighed the ethical aspects for the introduction of ARVs under such circumstances against its constitutional duties and responsibilities to care for the sick to 'offer the best services possible' to 'minimize suffering and prolong life'. Therefore, the government pragmatically chose education and prevention in response to HIV (Republic of Mozambique 2001).

Meanwhile, Mozambican doctors went to Brazil in 2001 to learn about ARV treatment, supported by the Ford Foundation and MSF Luxembourg in a discreet and secretive manner, as the official government stance on ARV treatment was negative (Ooms 2008: 132). The Ministry of Health started its own ART training in 2004. Then the expansion of ART sites took off towards the goal of accessible

treatment in all provinces and districts. This was accomplished by mid-2007. This was the evolution of the Mozambican model (see Chapter 2, pp. 118ff).

The ARV funding negotiation provides a story of the independence-dependency dilemma, specifically the choice between the 'health development paradigm' and the 'medical relief paradigm'. In general terms, the health development paradigm implies sustainability, the use of domestic resources, self-determination, and sovereignty. On the other hand, the medical relief paradigm implies dependency, foreign aid, humanitarian assistance, and an exceptional response (Ooms 2008).

The dependency-independency paradox explains the ambivalent resistance-acceptance attitude towards foreign donor aid. We see two interrelated processes at the national level, despite their transnational nature. First, the process of nation-building originates in the early days of FRELIMO liberation movement in the 1960s culminating with independence in 1975 and the constant struggle to 'fight the enemies' ever since, be it microbes, diseases, people, nations, or ideologies. Second, the process to create the National Health System intrinsically links to nation-building. Samora Machel said in his famous 1976 Maputo Hospital Speech that health was important for the revolutionary struggle, which he supported by arguments for equal access to health care, democratic health care, elimination of business medicine and exploitation of human suffering, and the creation of a corporate spirit (Machel 1985b: 142, 147). Health care is at the very core of FRELIMO politics. Health care is the redoubt, the last bastion of socialism, as I will discuss later. I believe this is the backbone of the political discourse and practice in contemporary times of negotiating and implementing ART plans.

I emphasize three issues during the four-year ART negotiation process 2000-2004: 1) the use of existing political structures, 2) the role of the Global

Fund, and 3) the belated attention to the need for human resources. First, the negotiation process over ART funding showed how the Mozambican government and the international community utilized existing buttons on the political dashboard. Was HIV a structural problem or an emergency problem? Should domestic budgets or international funding solve the problem? There was no third way. Ooms eloquently poses this dilemma as a deadlock for many poor countries:

> But what if a problem is structural or chronic, and therefore not exceptional and does not justify a medical relief approach? What if the appropriate response is technically feasible for the affected state, but too expensive? The medical relief paradigm would not be appropriate, but neither is the health development paradigm. This is precisely the conundrum the AIDS crisis created in Mozambique, and other affected states (Ooms 2008: 87).

The question was whether the HIV epidemic is *an exceptional event* or *a structural problem*. The former definition adds to the ambiguity of 'AIDS exceptionalism'. There was and still is no straightforward understanding of this concept. The latter definition supports the understanding of the HIV epidemic as long-term predicament. It also reveals that people with no access to treatment of HIV related diseases fall victims to structural, symbolic, social, cultural, and everyday violence (see Chapter 8). Many people who contracted the virus waited until the very last minute of disease progression before they began to seek health care, only to find out that their country had insufficient health system capacity to care for them.

The Mozambican government pushed the 'calamity button' under the given circumstances, which is common practice in a country with recurrent natural disasters. Calamity funding relates to *exceptional* events with no limit to foreign assis-

tance (Ooms 2008: 93). However, the Mozambican government was confused and frustrated. Disaster funding means that large sums of money enter the country, but it also means more dependency on foreign aid. The health development paradigm would aid the Mozambican process, but 'ceilings and spaces' impeded its advancement. In other words, the government had limited finances for action in favour of its own agenda within its state budget. Outsiders, like the World Bank and IMF, often dictate this.

MSF Luxembourg had been using the medical relief paradigm to support the fight against cholera since the 1980s. The Ministry of Health saw the HIV epidemic as a long-term structural problem and therefore favoured the health development paradigm. Thus, funding had to come from the national health budget, which the government could ill afford (Ooms 2008: 120). This was how fiscal space became a constraint. Common funds for the health sector SWAP, for pharmaceuticals, and for the provinces were developed during the late 1990s. These were not included in the central government budget (ibid.: 123). A central common fund was agreed upon in the Kaya Kwanga Agreement (see pp. 297-304).

The government would ask, whether it had budgetary space to pay for ARV treatment. The answer was in the negative. Heller defines fiscal space as:

> ... the availability of budgetary room that allows a government to provide resources for a desired purpose without any prejudice to the sustainability of a government's financial position (Heller 2005: 3).

Money for ARVs would take away scarce resources from other expenditures. The government was not in a position to borrow the money or to raise taxes to create financial space for ARVs, neither in the short, nor the long-term perspective.

Certain intrinsic characteristics of Mozambican politics have emerged since the coming of the Bretton Woods Institutions. First, ambivalence, paradoxes, and contradictions characterize the political atmosphere. This is about *avoidance* and *need*. The nationalistic Guebuza government remains ideologically distanced from neo-liberal globalism, but it also uses common sense. In other words, pragmatism is the second core of Mozambican politics. Three examples show this: 1) the government's attitude to structural adjustment, 2) its appropriation of how and what qualifies as 'normal' and 'exceptional' in terms of development and relief, and 3) its ways to ensure financial support for both primary and tertiary health care. First, the Mozambican government introduced its own Economic Rehabilitation Programme in 1987, without the approval from the IMF. By trying to avoid structural adjustment, it embraced it (Ooms, 2008: 91). Second, the government began to link normal health expenditure with the war, which was an exceptional event. This meant that it could avoid the limits imposed on the public health budget (Ooms 2008: 93). Third, this is also evidenced in the government's decision to opt for the 'calamity compromise'. The calamity compromise says that when you cannot have access to basic health care for all and access to ARV treatment for some, paid by the state budget, then relief money is welcome, though this means more dependency (Ooms 2008: 116).

HAI, MSF Luxembourg, the Clinton Foundation, the Global Fund, and PEPFAR supported the introduction of ARV treatment, in the order of appearance. The breaking point was the emergence of a new health paradigm, which defined 'sustainability' in a new way that honoured long-term goals of poor countries. International aid would have to pay virtually all expenses in a *sustained* manner (Ooms 2008: 130). This may sound contradictory to the government policy attempting to

reduce donor dependency. The AIDS treatment programme became an *exception*, adding a new dimension to AIDS exceptionalism. *"By the end of 2004, it was clear that funding was no longer the problem. The real bottleneck became the lack of skilled human resources"* (Ooms 2008: 137). Training of health workers cannot be defined as an exception, thus precluding emergency funding. On the other hand, the state budget cannot pay for it either. This creates the *Medicines Without Doctors' paradox*: *"it seems easier to find a lot of money for antiretroviral medicines than to find a little money to train and hire additional health workers"* (Ooms 2008: 140). Health workers would be stuck under the principle of AIDS exceptionalism, which exclusively paid for the medicines.

Other threats to the sustainability of the national health system – with an ARV component exclusively paid by foreign donor money – include NGO competition, internal brain drain, and classical decentralization in the sense of privatisation in health imposed by IMF and the World Bank. All this would go against the Mozambican health care model and threaten the ARV model in particular. I shall return to these issues upon discussing the pragmatic politics of ARV treatment.

Pragmatic Politics of ARV Treatment: A Double Challenge

ARV treatment started in the public health system by mid-2004, eighteen years after the first AIDS case report and many years of campaigning the death sentence of HIV carriers through the 'AIDS Kills, AIDS Has No Cure' campaign. Many people died – and still die – silently from HIV related diseases without access to health services. About 91 percent of AIDS cases go unreported (National AIDS Council

2005). The government faced an ethical dilemma upon the introduction of ARV treatment with regard to public advocacy about its availability. How could they change the old message 'AIDS Kills, AIDS Has No Cure' without misinforming the entire population, as they could not provide treatment for everyone? Global human rights campaigns spelled 'access for all', while the reality on the ground called for 'access for some', based on wise and pragmatic choices.

I talked to Sergio at the National AIDS Council about public ART campaigning and asked why the government refrains from announcing the availability of treatment through the media. Sergio said: *"We are cautious, because we don't want to create a demand just to see social criticism. If you create a demand of what you cannot offer, then this is an irresponsibility of the state. The state cannot do this, going on TV saying: "There is access to antiretroviral treatment". Then people go to get it, just to find out that they cannot get it."*

Thus, pragmatic politics weighs ARV demand against its supply. The capacity of the health system is not in place to universally inform the population about the availability of treatment. Treatment advocacy by the government would be thoughtless public health practice.

However, the message changed from 'AIDS Kills' to 'An Opportunity to Live' within the health system. Benedito, the ARV Committee, first said: *"I agree that until recently – we may say before 2004 – our message was that 'AIDS Kills'."* He explained how the message within the health system needed to change to 'An Opportunity to Live' by the encouraging news: *"You can live!"* Benedito added: *"But the health worker doesn't know this message, because we didn't have capacity to offer ART. The message was that 'AIDS Kills'. It was the message for a very long time. Now we are turning the message upside down: 'An Opportunity to Live' is now possible."*

Benedito said about limited HIV testing: *"Everyone defends his or her argument.*
However, today there is a better offer. You can say: 'I will take the test'. Our idea is
that already by now the message in the VCT centres needs to be different. They need
to say: 'You are taking the test, very well, and if you are positive then your path in life
is still very long. You will keep on going, but you will probably get some infections.
They will be treated and you will have a normal life. You have a life path that will
give you a chance to do many things. It's not just about taking the test, using con-
doms, it's you who denounce it.' I think this will increase the number of people com-
ing to take the test. This is my perception."

The Mozambican model includes proactive health workers who recommend
HIV testing. This is 'citizen sensitization', as opposed to mandatory testing. It is
part of Counselling and Testing for Health, the new approach to HIV testing intro-
duced in late 2006 (see Chapter 2, p. 106). The ARV Committee came up with this
idea. Benedito said: *"Our approach is now to try to say that whenever a patient en-*
ters our national health service, at all points of entry, whether it is in the tuberculosis
ward, at the health centre, an urgent admission, a maternity matter, wherever it may
be, then the test needs to be taken there. We don't want to refer the patient to the
VCT and leave the patient with the huge weight of conscience and the decision to go
there individually. We need to share the burden together."

Benedito explained how ARV treatment is a *double challenge* for Mozam-
bique, in terms of medical and human resource needs. *"ART for us is a double chal-*
lenge, because it is a disease that challenges the conditions that we consider special-
ized at the primary level, and we are not prepared. Today we are working in all of the
system at the same time, trying to improve its quality. However, there is another
thing that needs to happen one day or another: the whole country needs to improve."

This shows the commitment to one unique National Health Service and nation-building through development. Benedito talks realistically about the economic context of Mozambique. He defends the Mozambican response as an emergency plan considering the weak and fragmented health system. In other words, treating more than 40,000 people with ARVs within the public health system between 2004 and the end of 2006 is a success, notwithstanding the fact that more than 230,000 people were estimated to be in need. Benedito explains: *"Our projection for the next years is in accordance with our conditions, not because we don't want to treat all the ill people. We would in principle be ready to treat everyone, but we know that money and drugs is not the only problem at this moment for countries in Africa. It's true that drug prices today have fallen, but the big problem today is qualified human resources. People's access to health care is about their quality."*

Human rights and public health ideals are difficult to summon and to realize in dire circumstances: *"We know that there is a risk also of moving too fast, but we also have people who are dying, who cannot wait until we have created the ideal situation."* It is important to keep in mind that international organisations care for the majority of ARV patients (see Chapter 5, p. 264). They have played an important role for the provision of ARVs in Mozambique, but the Mozambican government aims for a unique national health system without parallel or competing structures. A closer look at the history of the external threats to FRELIMO politics of health explains this tight adherence to nationalized health.

External Threats: Historical Significances of HIV and AIDS Discourses

I discuss the significance of HIV discourses in historical perspective in relation to the fate of Mozambican health care. External threats have impeded the process to improve government social services since independence in 1975.[3] These threats include *civil war backed by South Africa and Rhodesia, privatization and parallel structures, NGO competition, World Bank and IMF policies,* and *the brain drain phenomenon.* The government inevitably succeeded its pursuit of building a nation through social reform before the 1978 Alma Ata declaration. This included an ambitious primary health care plan between independence and the early 1980s (Hanlon 1984; Walt and Cliff 1986). The expansion of ARV treatment provides an opportunity to improve the existing public health system in light of past losses and threats to national sovereignty, whether it has been through destruction inflicted by war, imposed privatization policies, or by NGOs working in the country without caring about the national project.

Civil War: Demolition of the Health System and Health Workers

Post-independence Mozambican history may partly explain the reasons for the current weak health system and the relatively slow response to the HIV epidemic. FRELIMO focussed on nation-building, adoption of Portuguese as the common language, literacy campaigns, democratisation, and access to health and education, which all aimed at a social and developmental revolution.

The RENAMO led civil war, supported by Rhodesia and South Africa, hit the heart of FRELIMO politics and success: the Mozambican social services. Mozambique still suffers from the massive destruction experienced during the civil war, which included demolition of health infrastructure and loss of health workers. In forthright terms: hospitals and clinics were systematically destroyed. Many health workers and patients were killed (Andersson 1992; Collins 2006; Hanlon 1984; Newitt 1995; Walt and Cliff 1986; Walt and Melamed 1983).

Portugal spent almost nothing on health care during colonial rule. The number of doctors dropped from 519 to 86, when the Portuguese left the country at independence in 1975 (Andersson 1992: 40). The number of doctors per rural population dropped from 1 per 161,000 inhabitants to 1 per 443,000 between 1982 and 1986 (ibid.: 84). One thousand health clinics had been destroyed by 1990 (Collins 2006). However, we do not know how many Mozambican health workers have left later. Many of those who stayed, who approach their prime productive years, suffer from a knowledge and skills gap. They had no access to education. Those who could afford it left the country to receive education elsewhere and possibly never came back. This phenomenon has happened in many places that have experienced war and conflict (e.g. Lebanon, Somalia, Croatia, Bosnia).

Key mobility factors possibly facilitated the spread of HIV and the failing response (see Chapter 2, p. 104). Refugees and migrant workers get in contact with high-prevalence neighbouring countries (Collins 2006). Five million people were forced to escape. One and a half million refugees ended up in Malawi, Swaziland, South Africa, Tanzania, Zambia and Zimbabwe (Svarre 1996). The rest were internally displaced, which caused social upheaval. Very little has been done to target these population groups in HIV prevention programmes.

The human resource response to the HIV epidemic in the new millennium relies on the post-independence experience in health. FRELIMO successfully created a primary health care system in the years after independence in 1975, including the rural areas. The government trained a large pool of mid- and lower level health workers, including medical assistants, health agents, mother and child health nurses, and village health workers (Noormahomed and Segall 1994).

Mid-level health workers received in-service training from the early 2000s to mitigate the impact of HIV and AIDS. They were later called upon to join the ART health worker force. I do not have the exact numbers. The government based this upgrading on previous experience with mid-level technicians as *surgery technicians* who performed physician duties. Likewise, the training of AIDS activists relies on previous experience with village health workers.

Nevertheless, the need for health workers to respond to HIV is enormous. I have already pointed to two factors that impede health worker recruitment: 1) the time consuming process of training Mozambican health workers, and 2) the requirement that HIV specialists should not take away human resources from the wider health system burdened as it is with many other disease epidemics.

'Obstacles' and 'constraints' to ART expansion must be understood against this historical background. The existing health infrastructure demolished by civil war and the lack of services and health personnel for the entire population remain the most serious problems faced by Mozambique. However, there are less tangible but equally politicized factors: NGO competition, privatization, structural adjustment policies, and the internal exodus of health workers.

NGO Competition: Intimate and Distant Partners

The Mozambican government seeks to integrate its partners into the national health project and harmonize its procedures through the establishment of 'common funds', 'sector wide approaches to health' and central drug procurement and distribution. This happens in accordance with the United Nations principles of the 'Three Ones', defined as *One National AIDS Coordinating Body* (National AIDS Council), *One Agreed AIDS Action Framework* (National Strategic Plan 2005-2009), and *One Monitoring and Evaluation Framework* (National AIDS Council).
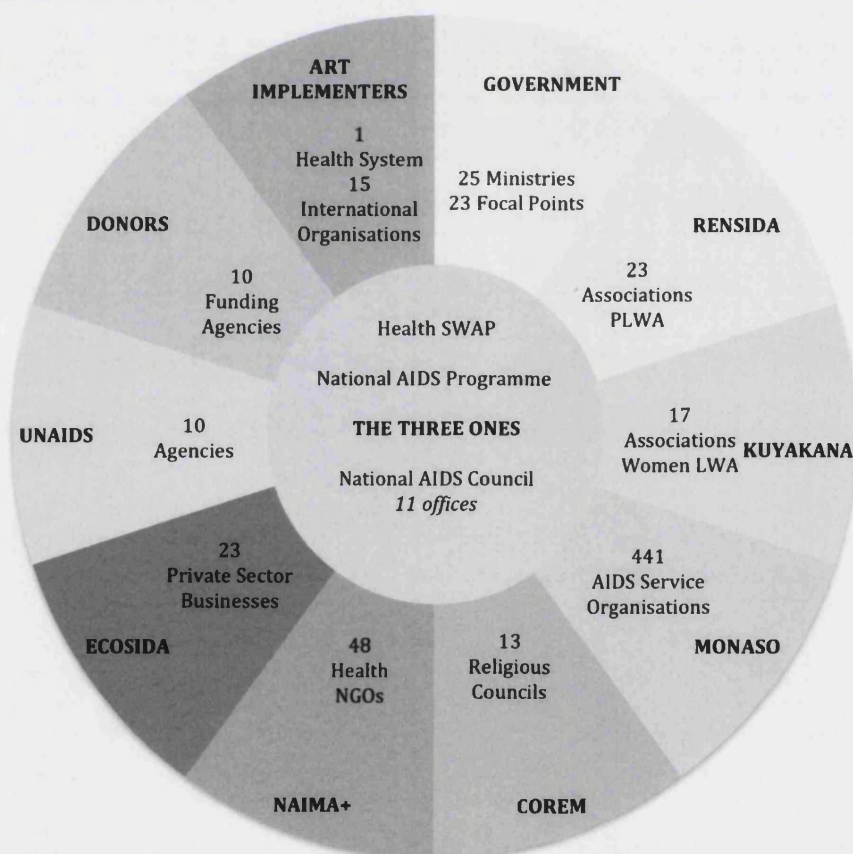
Figure 6.2: HIV and AIDS Partnerships in Mozambique, 2006
Source: Fieldwork.

The National AIDS Council manages the Three Ones, complemented by the National STI/HIV/AIDS Programme, the Sector Wide Approach to Health, and the government, of which 23 of the 25 ministries have an HIV/AIDS Focal Point. Partners include civil society umbrella organisations like RENSIDA, Kuyakana, MONASO, NAIMA+, and ECOSIDA, the international community of UNAIDS, donors, and ART implementers (see Figure 6.2).

However, such centralization challenges Mozambique's absorption capacity (ability to digest and consume financial resources), and absorptive capacity (ability to apply and assimilate new knowledge). Absorption capacity contains a double edge: on one side difficulties in liberating resources from the common fund and, on the other, the time consuming process to realize a given project once the money has been disbursed. In general, money disbursed is far greater than money spent. In other words, the implementation rate is low.

First, treatment providers invariably replied to my question about the most difficult matter under the current system: *"To liberate money from the common fund for any use whatsoever."* This is about slow bureaucratic procedures. They added with a facial expression of hopelessness and disillusion: *"Even when we just need petty office supplies."* Second, the problem is weak capacity to implement the ambitious plans, which are often made in ignorance of the reality on the ground. This is the allegory of the moon and the bicycle, about ambition and realism. Sergio at the National AIDS Council explained: *"The donors keep saying that we need ambitious indicators. It's not enough to have ambitious indicators, when I know that I will not be able to realize them. This is the same as dreaming about going to the moon, when I don't even have a bicycle. Have a dream ambition that doesn't become reality. It is therefore necessary to keep the feet on the ground and say: 'Yes, Sir, if I do five*

today, then for tomorrow I can prepare for 7 or 10. This is not the same as doing five and then saying that I will do 25. It simply isn't. These are the things that we need to work on and articulate for the two plans to harmonize indefinitely."

I asked Sergio what he saw as the most difficult aspect of responding to the HIV epidemic. *"The big problem we have with civil society, as we have with international organisations, is the problem of absorption capacity. Many organisations have good set ups in Maputo, but there is no set up in the periphery. There is a problem of absorption, there is a problem of programmatic and financial management, and there are problems of how to monitor the results. All this has already been questioned. At this moment, we are working seriously in the area of capacity building for programmatic and financial management. We think that this is fundamental. We are preparing a huge piece of work within the area of monitoring, including the indicators and all this. However, we focus on the provincial level to train people in programming and finances through our contracts with Ernst & Young and with KPMG. We also identify local subcontract financial managers. We can subcontract people who have accounting skills, know how to analyse cash flows, know how to make a balance sheet, and know how to do banking reconciliation."*

I asked him whether Mozambique already had people with such skills, and Sergio interrupted me before I finished my sentence: *"It has!"* Then I asked: *"But what is the problem in contracting these people?"* Then he said: *"The problem is that some organisations do have contracts, but some organisations think that they need to hire a foreigner and this can create problems. It is about distrust. This is our reading. We have experience here in Maputo Province, in Sofala, in Zambézia, that this is happening. Look for someone who can oversee the financial part. This would allow the resources to flow rapidly, but we always use them with caution."*

Recipients cannot spend money faster than the conditions allow. Development takes time, especially under the constraints of laws and regulations for constructing new health facilities. Project design, international bids, bureaucracy, project refinement, etc.: it easily takes two years from designing a health facility before laying down the first brick. The problem is also about trust between national and international partners. Trust, knowledge of the context, and solidarity with the Mozambican political process decides whether partner organisations become intimate or distant. Mozambique is *not* a tabula rasa.

The political process is pre-eminently about respect for the Mozambican nation-building project and the longstanding goal of one unique public health system. Benedito from the ARV Committee looked at me with a serious face and then told me with great sincerity: *"All these people that are coming to work for the country need to understand that they come to work within a system."* What did Benedito imply? Were some NGOs developing parallel structures? I distinguish between *intimate* and *distant* government partners to address these questions.

Intimate partners are those that agree to the national health project and/or have worked for many years in Mozambique as government *cooperantes*. Prime examples include MSF Luxembourg, Health Alliance International, and Sant'Egidio. I have already discussed the intimate role of MSF Luxembourg, which participated in the funding negotiation with the government for the introduction of ARVs (see p. 277). HAI was established in Mozambique in the late 1980s after many years of cooperation in the area of health long before the response to the HIV epidemic. North American health workers founded HAI after having supported the Mozambican government during war times in the struggles against external threats (Health Alliance International 2008). HAI people are the good long-standing comrades.

Sant'Egidio facilitated the peace process during the early 1990s. It is therefore a government partner with a unique historical standing, which entrusts Sant'Egidio an indisputable place above the NGO-government polemic regarding proper partnerships. I would argue they have become *untouchables*. Armando Guebuza, then the Minister of Transport and Communications, headed the Mozambican delegation at the joint communiqué at the Sant'Egidio headquarters in Rome in 1990 (Republic of Mozambique 1990). The Peace Agreement between FRELIMO and RENAMO was signed in Rome by President Joaquim Chissano and RENAMO leader Alfonso Dhlakama, in the presence of Sant'Egidio mediators (Republic of Mozambique 1992). These government-Sant'Egidio relations will not be forgotten.

MSF Luxembourg, HAI, and Sant'Egidio exemplify solidarity and respect for Mozambican government priorities. In fact, the Ministry of Health established norms and procedures for NGO activities, specifically planning, implementation, and staff management: 1) follow national strategies, 2) comply with national labour laws and salary rates, 3) affirmative action for Mozambican employment when qualifications are equal to foreigners, and 4) voluntary foreigners are welcome (Ministry of Health 2006h). The government-NGO contract emphasizes respect for government programs, mutual collaboration, transparency, confidence and respect in health service delivery, and respect for the use of medical goods as intended (Ministry of Health 2006b).

Distant partners are those that do not enjoy the trust of the government. The government perceives them as unruly troublemakers, when and if they do not abide the above rules of integration and harmonization. However, they may not yet have understood the process.

The internal brain drain may explain the need for such norms and procedures. The Minister of Health Ivo Garrido told the UN Special Envoy on HIV/AIDS in Africa Stephen Lewis on his visit to Mozambique in July 2006: *"The UN and the NGOs are sucking my blood!"* (Lewis 2006b). Garrido meant that the UN and NGOs attract Mozambican health workers with higher salaries. This leaves the public health system 'anaemic' in its effort to improve its quantity and quality of health workers.

The issue of salary rates continues to be political in international health care relations. The difference between international and national salaries has been shown to be one of the primary factors for lack of motivation to stay within the public health sector (Pfeiffer 2003; Saide and Stewart 2001).

The Mozambican Way: Decentralization without Privatisation

The Mozambican government strives for decentralization *without* privatisation, as shown by the history of nationalised health. From their introduction in the 1980s, the World Bank and IMF made their economic support conditional upon decentralisation *and* privatisation. This discrepancy is not merely about ideological differences, but about ownership of a chosen methodology. This problematic is not new or even unique to Mozambique, but known for decades in the 'developing world' to have counterproductive outcomes. The reform and rehabilitation process in Mozambique focussed on modernisation of port and rail facilities. It paid less attention to the improvement of the health and education infrastructures, because of concern for security in rural areas and distrust whether the government could maintain the health system in shape (Plank 1993: 424).

On the other hand, the government has been willing to privatize other areas, like land, cotton, and agriculture. In fact, FRELIMO has embraced privatization as an opportunity to gain political legitimacy throughout the country (Pitcher 1996: 51). However, health care remains the most highly prized asset that FRELIMO refuses to privatize. As Walt and Cliff suggest, health care continued to be politically important during the years between independence and the civil war: nationalized health became a political response to privatization in health care (Walt and Cliff 1986: 156). I argue that this historical legacy lives on.

However, I often encountered a mixed *centralisation-decentralisation* discourse, when I attended meetings at the Ministry of Health, read newspapers, or watched TV. For example, politicians emphasize the need for social reform, which includes giving political mandate and decision-making power to leaders at the provincial level. Nonetheless, the government repeatedly emphasizes the need for a central authority in a manner that resembles early FRELIMO ideology. In other words, political discourse emphasizes the need for 'decentralisation' as a means towards social reform, but the tone and rhetoric resembles the tongues of Samora Machel and Eduardo Mondlane from the early FRELIMO days. Initially I found such discourse contradictory and ambivalent, but I remained discontent with these concepts to depict what I experienced. Elsewhere (Høg 2006), I emphasise the ability of skilful polyglot actors to change agenda according to their audiences, but I encountered a double-discourse in front of the same audience. However, the literature gave me a clue: the contradictory and ambivalent political discourse remains an intrinsic feature of Mozambican politics (Mackintosh and Wuyts 1988; Saul 1985; Sidaway 1992).

Political commitment to free public health has become a social contract and solemn promise between the government and the Mozambican people. I argue that health care continues to be one of the most politicized areas in Mozambique with its roots in post-independence priorities. This implies negative as well as positive consequences for contemporary and future responses to the HIV epidemic and to ARV treatment in particular. However, reluctance to undertake privatisation is seen on both sides: the government refuses to sell out from its political treasury and the World Bank and IMF show distrust as to whether the Mozambican government could handle privatized health. As shown earlier, the government resists indirect privatisation in health brought by the international NGOs. To this end, it remains important to analyse the introduction of ARV treatment within this politically geared context of public-private and centralisation-decentralisation debates.

Health Care in Mozambique: A Native Reserve

Here I invoke two events during 2006 to develop my argument that health care in Mozambique remains an ideological redoubt: the first national meeting on STI/HIV/AIDS and the signing of the Kaya Kwanga Commitment between the Ministry of Health and NGOs. Health care represents the very identity and success of the reigning party. I have already said that foreign sponsored ARV treatment challenges this ideological position: it is therefore a test of capability and autonomy in the government's relation with bilateral and multilateral donor partners. I draw five lessons from this analysis, which may seem idiosyncratic and even contradictory: 1) The problem is coordination, not partnerships, 2) The problem is diminished

sovereignty, caused by partnerships, 3) Human rights are provocative in a context

of scarce resources, 4) The government insists on national leadership of the devel-

opment process, and 5) The Mozambican government will depend on foreign aid

for many years, aggravated by the increasing need for sustained financial and hu-

man resources to respond to the HIV epidemic

'We Can't Close the Doors': The Ambivalence of Partnerships

The first National Meeting on STDs and HIV/AIDS was held at the Ministry of

Health in Maputo, March 2006. The week was divided into a three-day preparatory

meeting with invited partners, NGOs, and individual civil society members, and a

two-day meeting exclusive for the government and its partners. About 75 partici-

pants attended the first day of the preparatory meeting: 35 women and 40 men. A

quick look at the audience told me that I knew the organisational affiliations of

most participants: Sant'Egidio, Health Alliance International, Médecins Sans Fron-

tières, Clinton Foundation, CDC, DFID, Columbia University, National Institute of

Health, MONASO, Médicos Mundi, provincial health managers, Ministry of Health

staff, the National STI/HIV/AIDS Programme, and the National AIDS Council. How-

ever, I realized the conspicuous absence of people living with HIV, AIDS, and ARVs.

Where was RENSIDA, the national network of associations of people living with

HIV? Who represented the many patient organisations and people living with HIV?

The National AIDS Programme Director Alfredo Mac-Arthur opened the

day. He addressed the issue of partnerships in a sympathetic yet vexed manner by

saying: *"We can't close the doors"*. However, from his facial expression I wondered

whether he was celebrating or lamenting this fact, as I imagined him continue: *"even if we wanted to".* After all, I had heard the politicisation of HIV by the Minister of Health, the President, and the Prime Minister: they insist on national sovereignty. I had also noticed the issue of foreign human resources as one of the most politically sensitive issues of the HIV epidemic. The HIV epidemic not only brought another infectious disease problem to the general population: it initiated a new unprecedented era of foreign aid dependence that the government would prefer to do without in the continued struggle for political and economic independence.

Mac-Arthur then talked about the implementation of the National Strategic HIV/AIDS Plan. He addressed the challenges on how to progressively integrate HIV and AIDS into the National Health System by emphasizing that: *"The problem is not financing and it is not partnerships. The challenge is coordination".* Therefore, the major objective of the National STI/HIV/AIDS Programme was to review and adjust the Mozambican response and targets in relation to accumulated experience and the reality within the country. Notably, the National AIDS Programme Director spoke in the absence of the Minister of Health, who in the specific context of the government-NGO *Kaya Kwanga* meeting problematized partnerships per se.

'Human Rights are Such A Provocation': An Anti-Hegemonic Statement

Mac-Arthur continued: *"Let us not forget that we need to make a quality emergency response."* He finally appeared more human than technocratic the way he addressed HIV and AIDS issues. He appeared impressively talkative as opposed to his silent and subordinate role, when he accompanies the Minister of Health.

What does a 'quality emergency response' mean and entail? An 'emergency' literally suggests a crisis that calls upon urgent and immediate action in which every wasted minute could be disastrous. 'Emergency' spells disaster and catastrophe. By adding the word 'quality', Mac-Arthur implied the biomedical quality of the HIV health care intervention. Such quality response was not possible within the weak public health care system. Mac-Arthur walked up and down the aisles of carefully listening health care professionals and policy makers and at one decisive moment, allegedly with his previous statements in mind, he looked at me and said: *"Human rights are such a provocation"*. That was about those famous 30 seconds worth spending on human rights that week, recalling the eternal rhetorical pause of silence that echoed his statement.

The Programme Director spoke with mixed feelings of optimism, realism, and gloominess, about the major obstacles and challenges: 'insufficient human resources', 'degraded infrastructure', 'vertical implementation', 'centralized management', 'insufficient ARV access and availability', 'lack of biosecurity integration', 'weak links to the community', 'weak public information about available services', and much more. Mac-Arthur's statement about human rights as provocation was a reminder to think in terms of proportions: what can the world expect from a poor country like Mozambique in terms of human rights compliance, especially the social, economic and cultural rights that we call upon in the context of HIV? The Mozambican government ratified the International Covenant on Civil and Political Rights in 1993, but it has not yet signed nor ratified the International Covenant on Economic, Social and Cultural Rights (OHCHR 2006).

Expectations are out of proportions. Mozambique does not have the capacity to realize human rights norms. Sergio from the National AIDS Council explained

the allegory of the shrimp and the lobster: *"This is what I usually say: I cannot get a shrimp to transform into a lobster just because it's hungry. One thing is to define the objectives and another is to see whether I have the resources to realize these objectives. This is happening bit by bit in function of the country's capacity. That's why we have started with community counselling as a pilot project. We still don't have the human resources capable of doing it at the national scale. It has to be done gently at the speed that we move on, training the people and then we can expand more globally. Therefore, the principles are there. What may be missing is material and human capacity to accomplish these principles, as we speak about human rights."*

The Kaya Kwanga Commitment: On Mozambican Leadership in Health

The Ministry of Health leads the process to regulate its relations with its partners. This is called the Kaya Kwanga Commitment. This process began in 1999, after nearly a decade of freedom of association and thus a heavy presence of NGOs. The first code of conduct, signed in September 2000 and subject to joint review every two years, relates four key issues: 1) commitment to the health reform process, 2) no legal implications, 3) existing bilateral or multilateral agreements remain intact, and 4) development of 'a sector wide approach to health' (Ministry of Health 2000). The second code of conduct was signed in July 2003 (Ministry of Health 2003), and the third in August 2006 (Ministry of Health 2005b).

      The three agreements compare in terms of *purposes, commitments, principles*, and *mechanisms* for the relation between the Ministry of Health and its external partners in the pursuit of Mozambican policy goals (Ministry of Health 2000).

The key objectives are: *public health* (health of the population), *capacity* (sustainable health care), and *idealism* (gradual access to health care for all citizens). In other words, the commitment aims at health for all, but the ideal of equity in health can only be progressively realized, given the weak state of the public health care sector. Thus, idealistic objectives should be taken with a grain of salt: action is essentially pragmatic.[4] Nonetheless, the three codes of conduct strongly emphasize Mozambican leadership: *sovereignty, empowerment, trust,* and *capacity*. To this end, the Ministry of Health sets the agenda for all strategies, plans, and guidelines in line with the ideal type of governance defined by Foucault as an interdependent triangular modus of *sovereignty-discipline-government* (Foucault 1979).

'It's About Sovereignty': On National Self-Determination

This assertion can be supported by discourse analysis of the meeting in which the 2006 Kaya Kwanga Commitment was signed. The process of revising the code of conduct is time consuming for two simple reasons: 1) it is difficult to agree on the content of the code between the Ministry of Health and so many partners, and 2) there are more important things to do. This is not to trivialize this agreement, but to emphasize the challenges outside the Ministry of Health across Mozambique.

The meeting gathered about 120 participants, who represented the Ministry of Health and international and national NGOs. The Minister talked for fifty minutes about health and cooperation in Mozambique: 1) coordination between the Ministry of Health and NGOs, 2) respect for the dignity of Mozambique and Mozambicans, and 3) authorization to work in Mozambique.

Garrido initially emphasized: *"We need to work in an organized manner. Someone has to lead the process".* Garrido thereby took on the leadership role of the Ministry of Health. Garrido referred to the 'problem of coordination between hundreds of NGOs', their 'inefficiency', and the 'confusion' that it produced. A reoccurring problem was the *"foreign personnel that work within the National Health System without permission from the Ministry of Health".* Garrido repeated the rules of the process: job protocols need to reach the Ministry of Health at least 45 days before an eventual job contract begins. Foreigners need 'government authorisation' to work in Mozambique. Garrido thundered: *"It's a matter of sovereignty. It's about respect for human beings."* This was loud and serious monologue. The audience listened in complete silence, somewhat perplexed.

The situation could be interpreted in another way: the Minister practiced an authoritarian autocratic management style in front of a plethora of organisational representatives who were afraid to speak against power. More precisely, this political performance resembled 'modern *dedocracy'*, a combination of the two antonyms 'dictatorship' and 'democracy'. The body language of lifted eyebrows and constant gesticulation suggested this interpretation. The Minister keeps the word in his power deciding when and why others should speak. The Minister points his finger at someone demanding him in an intimidating voice to stand up and say who he is and his organisational affiliation. The resemblance to an authoritarian schoolteacher bossing around a flock of docile school children was a tempting obvious.

However, such interpretation might be too far-fetched. The allegoric comparison may be striking at first or second sight for a stranger who is also unfamiliar with live performance of power games in general and politics in the Portuguese aftermath in particular and how that fed into such strong feeling for building a sov-

ereign nation. The Mozambican government spells sovereignty at any cost, but not sovereignty at any cost whatsoever. The neo-liberal dance is after all enticing. Alternatively, was it a dance forced by the World Bank and IMF upon the Mozambican government with its feet tightly tied to the big rubber boots of neo-colonialism and globalisation? The World Bank and IMF lead the dance, the Mozambican government follows their steps? One participant insisted to know why the government does not pay better salaries to health workers. Garrido replied vigorously: *"It is not the government that doesn't want to pay better salaries. It is the World Bank and the IMF that impose limitations and we need to sign to this. This is simply the truth."* The Minister was thus blaming a supra-governmental power for the state of affairs in Mozambique. We all know that rubber boots do not make good dancers.

Governing Mentality: Leadership, Discipline and Sovereignty

The Minister implied that foreign health workers *do not* respect the Mozambican government and Mozambicans, and that they *do not* have sufficient qualifications to work in Mozambique. Garrido referred to his recent dismissal of six health workers, whom he argued did not have sufficient qualifications. Moreover, they had not followed the strict procedures for obtaining work permission. Every health worker contract, job or research application needs the Minister's review and authorisation, but to spend so much time on this issue in a meeting dedicated merely to sign the 'Kaya Kwanga Commitment' seemed out of place.

In my interpretation, Garrido did not have much choice. FRELIMO positioned the Minister of Health within its hierarchy and obliged him to follow the FRELI-

MO political agenda. He could well be instructed to address international and national *non*-governmental organisations in this way. Garrido represents FRELIMO first-line and hard-line politics, which seeks Mozambican empowerment, nation-building, and sovereignty. That is, all FRELIMO politicians of highest contemporary order came into power at independence. The code words in his speech were 'leadership', 'discipline', and 'sovereignty', reading Foucault's renowned essay on governmentality from the 1970s (Foucault 1979). In essence, this is what governance is about. In other words, Garrido followed the nationalistic supposedly uncompromising way of doing politics, which dictates retention of sovereign power to show who is in control governing the Mozambican nation. This is not far from Samora Machel's way with words. Machel spoke of the 'absence of power', 'the lack of authority': *"As there is no power, there is no authority. As there is no hierarchy, there is no authority; there is no definition of remit. As there is no definition of remit, the principal task and the priorities remain unidentified"* (Machel 1985c: 163).

Contemporary discourse eloquently epitomizes the past, even as the government portrays the old Mozambican system as 'centralized and obsolete, which belongs to a state apparatus model conceived at a different point in history' (Ministry of Health 2005c). A strange mix of tongues has emerged with political and health system transition characterized by opposing signifiers that never meet face-to-face, pointing to the future, looking to the past. Indeed, a culture of contradictions characterizes Mozambique, but what is power in such a situation? Is it vertical or horizontal? The decentralization-recentralization process stands out clearly in the politicized discourse on health, perhaps less in practice. In the early FRELIMO days, government enemies included 'liberalism', 'ultra-democracy', and 'absolute egalitarianism': *"Liberalism is a virus that leads to epidemics"* (Machel

1985c: 163-164). However, an ideological hodgepodge now surrounds the government. Think of HAI, World Bank, Sant'Egidio, ASIDH, MSF, UNAIDS, Humana People to People, DANIDA, CARE, HOPE, and many more in the same country: one government against '1001 actors' from all corners of the political spectrum. No wonder they check, whether you are friend or foe. The result is dedocracy, the rule of raised fingers, at least when they play to the gallery. The response to this is complete silence. In fact, foreigners use a code of address long expired in their homelands, when they do speak to authority.

Anthropologist James Pfeiffer, who worked for a USAID sponsored NGO in Mozambique during the 1990s, followed the early *Kaya Kwanga* process. I agree with Pfeiffer's uncertainty as to why the code of conduct was necessary. Pfeiffer suggests two explanations: It could imply a certain level of *mis*conduct and it could be an empty strategic gesture considering its non-legal nature (Pfeiffer 2004b). However, it could signal an ideological compromise between the government, the donors, and implementers. Therefore, it could be another sign of ideological disorder, if we recall an earlier argument (see Chapter 5, pp. 233, 242).

Pfeiffer supports the anti-privatisation argument to strengthen the public sector. Pfeiffer argues that privatisation of Mozambican health care happens indirectly and covertly through international NGOs: they have become the 'velvet glove' of privatisation (Pfeiffer 2004b). In other words, privatisation in this perspective is seen as the inevitable iron hand covered in silky padding. However, it comes at a cost. Pfeiffer conducted an anthropological study of the impact of health NGOs on local communities in the 1990s, which showed that health NGOs contributed to fragmentation and loss of local control of health programs, and rising social inequality (Pfeiffer 2003).

In my experience, the double discourse prevails: the government is against privatisation and parallel structures. However, it cannot save its health care system without external donor support and it cannot pay its health workers salaries that compare to international standards. Health workers lose their motivation to stay within the public health system: they seek greener grass with the NGOs. However, those 'partners' who least understand and sympathize with the FRELIMO project become 'distant troublemakers'.

The Minister of Health finally gave some credit to the international and national *non*-governmental organisations: *"In general we have good and professional relations with NGOs. We highly value the collaboration with NGOs. Let us continue to improve this relation, with respect for the dignity of Mozambicans in mind."* This was to me a surprising change of tone considering the long talk about sovereignty and disrespect. It would have made more sense to begin the meeting giving praise to partnerships considering its nature. The procedure seemed to be: First a slap in the face, then a pat on the cheek.

Participants asked questions related to what the meeting was originally devoted to: the signing of the code of conduct. First, they indicated that the code of conduct was a sign of cooperation, but that the long and bureaucratic process for obtaining a work permit for the health sector in Mozambique was counterproductive. In fact, the process may take four months, divided in three ministries (Health, Immigration, and Work). Foreign workers often begin this process upon arrival in Mozambique. They politely requested the Minister to remedy this problem by organizing a central authorisation unit.

One participant wanted to know the status and progress of the long promised 'ministerial communication unit' to improve communication between NGOs and

the Ministry of Health. *"NGOs need to communicate through the Department of Plan-ning and Cooperation"*, the Minister replied, whereby he emphasized the need to create one single NGO unit. This was taken as an insult by the NAIMA+ network, which was established in 2004 exactly to improve communication and coordina-tion among NGOs to produce 'one voice' for the government.

A few participants doubted the authority of the NAIMA+ organisation. They declared that not everyone wants NAIMA+ membership. *"We have already made the contract and you say that it is ready to be signed. Now there are various doubts and iterations at this meeting between the Ministry and NGOs. What are we supposed to think?"*

The Minister of Health replied promptly: *"Let us sign the conduct with the conscience that it can be improved. It is an imperfect instrument, but we cannot con-tinue without signing it. It is not a bible. NGOs say that the government does not want to sign the conduct, but this is not true."*

Organisational delegates lined up to sign the code of conduct, while others refrained. The Minister had the last word by asking why NAIMA+ still could not represent all international and national organisations. Garrido emphasized that he would not audit any single person or NGO. *"NGOs need to get their act together and elect representatives. Please, define who represents you!"*

The Future of Health Care

In early 2007, the Ministry of Health issued three future health care goals: 1) equal access, 2) improvement of infrastructure and equipment, and 3) the right to health

(Ministry of Health 2007a). This echoes the promise of health care for all set out in the first constitution (Machel 1975a). First, the government seeks quality health care for all citizens. Second, the goal is to have 2000 health units in the country (1 unit/10,000 inhabitants). The government needs to construct 750 health units to reach this goal, in accordance with the Plan to Reduce Absolute Poverty (Republic of Mozambique 2005). This plan includes a general upgrading of health units and health centres (Ministry of Health 2007f). Third, the Ministry of Health released a 'User Rights and Duties Charter' (Ministry of Health 2007c), which specifies the right to health as a given within the 2004 constitution (Chissano 2004). The charter seeks to 'dignify health care users': 1) primacy to the citizen, 2) reaffirmation of fundamental human rights, 3) promote humanisation, especially towards vulnerable groups, 4) improve patient-practitioner relations and active patient participation, and 5) reinforce dialogue (Ministry of Health 2007c). Fourth, a National Politics of Health Declaration seeks to protect the right to health (Ministry of Health 2007e), with reference to the Mozambican constitution (Chissano 2004), and the Universal Declaration of Human Rights (United Nations 1948).[5] In other words, *a luta continua*, the struggle continues, in line with post-independence FRELIMO politics of health towards realisation of free, public, universal, and dignified access to the National Health System. The HIV epidemic would ideally not enjoy exceptional attention towards this goal, but we have witnessed the pragmatic nature of Mozambican politics of health care.

ARV treatment arrived at a time of political reform and health system transition and it became a political opportunity for this process. This has implications for the understanding of the current health care reform, including the expansion of ARV treatment. ARV provision is simultaneously an emergency response and an

opportunity to resurrect the weak public health care system ruined during the civil

war when FRELIMO provided free and universal primary health care.

The Mozambican government continues to demand full sovereignty as set

out at independence. It therefore maintains an ambivalent position towards for-

eign aid, including the funding for ARV treatment. Politicians call for national self-

determination, in my interpretation, *with* or *without* the HIV epidemic. Such a call

for sovereignty would be irrelevant in an apolitical world for the response to the

HIV epidemic. Economic and human resources would ideally come from anywhere

in the world. However, the real world is different: it remains questionable whether

international organisations could recruit the number of health workers needed in

Southern Africa. Yet, the Mozambican government experiences the impact of ex-

ternal threats to Mozambican sovereignty: NGO competition, privatisation and the

internal brain drain. Nevertheless, I have shown the contradictory twist to this

phenomenon: it is part of the political rhetoric to keep the sovereignty discourse

alive and dominant, while in practical terms the real challenge is coordination, not

partnerships. These are some of the key factors that must be kept in mind, when

we try to understand statements such as 'human rights are such a provocation',

'it's about sovereignty', and 'respect the dignity of Mozambicans'. It is the pride of a

government and its governing mentality, questionably the pride of a people.

7
Advocacy

7: Advocacy

This chapter examines what key advocacy organisations do to advance access to treatment within the cultural and socio-political context of Mozambique. It weaves an analytical narrative around the Human Rights and Access to AIDS Treatment Campaign 2005-2006. I follow the 'campaign work' and 'home work' of advocacy organisations, which provides an analysis of civic culture within civil society. I visited UNAIDS, MONASO, MATRAM, Kindlimuka, RENSIDA, NAIMA+, CERPRE, ECO-SIDA, and Oxfam Australia.

HIV Advocacy: Intimate, Strategic and Distant Civil Society

I argue that stratification between *intimate, strategic,* and *distant* civil society organisations in real terms determines government recognition and ultimately the allocation of resources. This is about organisational proximity to power. I focus on advocacy and agency through classical anthropological analyses: taboo and classification of the environment (Douglas 2002 (1966); Leach 1979) and silence in relation to ritual performance (Radcliffe-Brown 1979). Ethnography of such processes requires sociocultural understanding of stratification, partnerships, and silence. Socio-political order and cultural conduct organize this analysis.

Advocacy Informants

I conducted participant observation and qualitative interviews with 32 people in nine advocacy organisations: 21 Mozambicans and 9 foreigners. They worked for MONASO, UNAIDS, Kindlimuka, RENSIDA, MATRAM, Oxfam Australia, NAIMA+, CERPRE, and ECOSIDA. National NGOs almost exclusively employ Mozambicans (see Table 7.1).

Table 7.1: Advocacy Informants by Sex and Country

	Total			National			Foreign		
	T	♀	♂	T	♀	♂	T	♀	♂
Country Coordinators	5	3	2	2	1	1	3	2	1
Presidents	6	1	5	6	1	5	0	0	0
Vice-Presidents	1	1	0	1	1	0	0	0	0
Advocacy Officers	11	5	6	9	3	6	2	2	0
Officers	4	3	1	1	0	1	3	3	0
Interns	5	3	2	3	2	1	2	0	2
TOTAL	**32**	**16**	**16**	**22**	**8**	**14**	**10**	**7**	**3**

I did 4 months full time fieldwork with both UNAIDS and MONASO. I had access to office space, computer, Internet, civil society, and the international community. I participated in all relevant internal and external activities, like meetings at UN-AIDS, MONASO, FAO, WFP, Partners Forum, National AIDS Council, with faith-based organisations, the Ministry of Health, and at the Parliamentary Assembly. The experience of full time fieldwork was about 'letting go to see what happens'. Fieldwork is like a journey: you immerse yourself in the field to gain an insider's perspective. Participate and make yourself useful. Follow the PFP principle: Patience, Friendliness, and Persistence. Meetings are by last minute invitation: each day is a new day, even though I thought I had 'it all planned out'.

The Human Rights and Access to AIDS Treatment Campaign 2005-2006

The country coordinators of UNAIDS and Oxfam Australia conceived a Human Rights and Access to AIDS Treatment Campaign in October 2005. The first meeting gathered 20 participants (11 men, 9 women, 12 foreigners, 8 Mozambicans), who represented Mozambican HIV organisations (MONASO, MATRAM, Kulima, Ntwana-no, and COREMO), the international community (Oxfam JOAP, Family Health International, UNAIDS, NAIMA+, USAID, and Burnet Institute), and the government (National AIDS Council). They brainstormed how to apply human rights in the context of HIV related treatment and finally agreed upon the following core theme for the one-year campaign, starting 1 December 2005: *Access to treatment, lack of access to health services, and related issues of stigma and discrimination.*

The second meeting gathered 12 participants (5 men, 7 women, 5 foreigners, 7 Mozambicans), who represented MONASO, NAIMA+, Sant'Egidio, Project HOPE, Oxfam Australia, and USAID. This time they discussed access barriers and the need for integrated health services, not just access to ARV treatment. 'Integrated health services' would include food, access to information, and free medicine against opportunistic infections. This resembled definitions of 'universal access' that emerged at preparatory meetings for the upcoming global events in Brazzaville, New York, and Toronto during 2006. The campaigners intended to focus on commitments, progress, and obstacles through transparent dialogue between HIV organisations in Mozambique. The campaign agenda, which included constructive suggestions on how to minimize access barriers, would also be an opportunity to promote MATRAM, the Mozambican Treatment Access Movement.

Two observations improve our understanding of the following analysis. First, the division of labour between the National AIDS 'Programme' and 'Council' is clear. The National STI/HIV/AIDS Programme at the Ministry of Health focuses entirely on treatment. The National AIDS Council, located outside the Ministry, focuses on HIV prevention and impact mitigation.[1] The National AIDS Council only participated in the first of the 13 meetings I witnessed throughout the campaign year. The National AIDS Council declared that access to treatment was not a council priority. The inclusion of the Ministry of Health would have minimised the accruing asymmetric knowledge between civil society and the government and it would have been a test, whether the relationship between representatives of civil society and the government is one of collaboration or opposition. However, Ministry of Health representatives never showed up.

Second, all actors lacked wholehearted commitment to implement the access campaign. Oxfam and UNAIDS created the campaign platform. They saw this as a *political* victory. They had to pay for this, directly or indirectly for two reasons: 1) *non*-governmental organisations are not supposed to interfere in domestic politics, and 2) the government in principle disallows treatment access campaigns (see Chapter 1, p. 62, Chapter 6, p. 279, and Chapter 8, p. 391). Government Decree 55/98, which defines the criteria for authorizing foreign NGOs in Mozambique, serves as a control mechanism of NGO action to eliminate segmentation and fragmentation of state action. Specifically, Article 2.3 specifies that *"In the course of their activities, foreign NGOs are forbidden to undertake or to promote any actions of a political nature"* (Republic of Mozambique 1998).

Admittedly, the three UNAIDS full-time staff committed themselves to 16 working groups within the plethora of HIV issues. This was probably the same for

Oxfam Australia. UNAIDS and Oxfam created the platform for the human rights campaign and they expected, perhaps naively, that civil society would take the lead. In other words, the campaign was meant to follow the ABC of political correctness through 'principles of GIPA', Greater Involvement of People Living with HIV/AIDS, invented at the 1994 Paris summit on AIDS, and 'partnerships'. Theories of 'participatory engagement' and 'collaboration' would presumably be applied.

The front seat was reserved for RENSIDA (network of patient associations). MATRAM (access movement), MONASO (service organisation), and Kindlimuka (patient organisation) were then supposed to follow the RENSIDA leadership. However, things turned out differently. RENSIDA folks never showed up. MATRAM and Kindlimuka folks rarely took the scene. This resulted in disjointed campaign efforts by activists with little or no campaigning experience. Yet, the one committed MONASO advocacy officer who kept the campaign alive caused others to accuse MONASO of monopolizing the process. Moreover, Oxfam and UNAIDS retreated, as promised by the imagined correctness of GIPA. On the other hand, the entire purpose of civil society organisations would allegedly be to gain voice, visibility, and influence. Indeed, all HIV advocacy organisations work with 'access to treatment'. Then why the scant attention, sparse commitment, and limited success of the human rights and access to treatment campaign? This emphasizes the paradox between intention, want, organisation, and outcome. Therefore, I will explain political correctness in theory and practice in the Mozambican socio-political context.

A Genealogy of Advocacy Organisations: 1993-2004

MONASO, UNAIDS Mozambique, Kindlimuka, RENSIDA, and MATRAM were founded during 1993-2004 (see Figure 7.1). They share three commonalities: 1) government recognition, 2) advocacy as main objective, and 3) supported by governments and international NGOs.

Figure 7.1: Genealogy of HIV/AIDS Advocacy Organisations, 1993-2004

MONASO was founded in 1993 and officially constituted in 1995. Its main objective is to prevent and mitigate the negative impacts of the epidemic and it leads civil society by creating strategic alliances with the government and development partners (MONASO 2005b).

MONASO has a dual role: *coordination* and *representation*. MONASO complements the National AIDS Council and it represents civil society through the Ministry of Health. Thus, MONASO is positioned within a network of institutions, partners, and working groups, such as the Sector Wide Approach, Partners Forum, the Country Coordinating Mechanism, ministries, donors, agencies, and NGOs (see Figure 7.2).
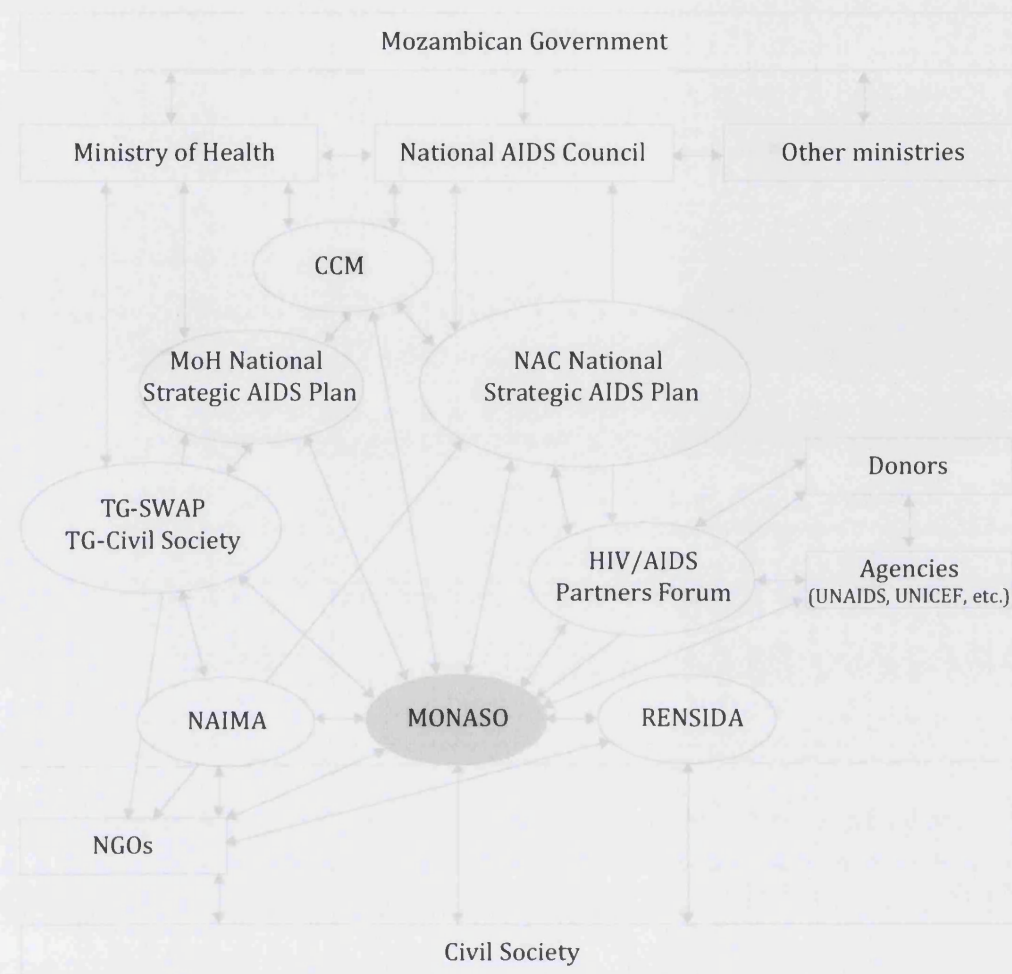
Figure 7.2: MONASO Position within the HIV/AIDS Sector
Source: (MONASO 2005b).

MONASO, Kindlimuka, RENSIDA, and MATRAM descend from the Ministry of Health lineage. The Ministry of Health is on the board of MONASO. MONASO is on the board of the National AIDS Council and the Country Coordinating Mechanism. Kindlimuka is on the MONASO board. RENSIDA and MATRAM are members of MONASO, and vice versa. This would ideally facilitate 'partnerships and collaboration', but it precludes reciprocal criticism, which creates a chain of silent consent. I argue that this lineage mirrors social structure and the chain of command within society.

There are 441 national and international organisations affiliated to MONASO in the 11 Mozambican provinces (MONASO 2005b). MONASO was born out of the lineage of 'AIDS Service Organisations', which emerged from the global net-

work initiative International Council of AIDS Service Organisations, ICASO, in 1991. Close relatives include African descendants like 'AFRICASO' and 'SANASO'.

MONASO seeks to become 'influential', to 'strengthen democracy', and to work towards 'social transformation' (MONASO 2006). Such civic aims would require collaboration with the government, but this would depend on critical rather than compliant voices. I will show how and why this is a difficult aspiration.

Salvador Mazive was the first person that publicly declared to be HIV positive in Mozambique. This was in 1996. This provided the stimulus to create Kindlimuka, the first patient organisation in Mozambique, supported by UNAIDS, which had opened an office in Maputo the same year. 'Kindlimuka' is a Shangaan word for 'wake up!' Thus, the wake up call to break the silence came 10 years after the first reported AIDS case in 1986.

However, 1996 was a significant year for other reasons on a global and local scale. 'Highly active antiretroviral therapy' was marketed, though with prohibitive costs for most countries. UNAIDS was founded. The Brazilian universal treatment access program started, which the Brazilian government later advocated as a model approach for poor countries. The Central Hospital in Maputo began to attend HIV patients.

Mazive's message soon spread to other provinces, but 'Kindlimuka' had no meaning in the many local languages. Therefore, context specific patient organisations emerged that reflected the mosaic of realities. This necessitated a national network of associations of people living with HIV, which culminated in the creation of RENSIDA in 2002.

The RENSIDA network consists of 23 patient associations distributed in all provinces. There are 6 associations in the North, 9 in the Centre, and 8 in the

South. Twenty of them reside in urban areas, which leaves rural areas underserved. RENSIDA therefore aims to have an association in each of the 128 districts. Other objectives include response coordination, advocacy for fair and equitable resource allocation, a space for dialogue, and continued development of associational life (Chilundo and Saugene 2006). Chilundo and Saugene list 4 strengths, 19 weaknesses, 11 opportunities and 9 threats in their analysis of RENSIDA and the women's organisation Kuyakana (Republic of Mozambique 2007). In fact, most organisational assessments frequently mention weaknesses and fragilities in terms of 'weak partnership coordination', 'weak participation in policy processes with government', 'weak capacity', and 'lack of trained individuals'.

Two Kindlimuka members, who returned from South Africa in 2004 with experience from the South African Treatment Access Campaign, TAC, created the Mozambican Treatment Access Movement, MATRAM, supported by Kindlimuka, RENSIDA, MSF, and the Christian Council. MATRAM is a self-proclaimed social movement, which seeks to mobilise communities and political leaders to guarantee treatment of all HIV associated health problems. MATRAM attempts to influence the government's decision-making process about access to treatment through deliberate information use. MATRAM seeks to be 'influential and change the perception, understanding, and behaviour of those in power' (MATRAM 2005a).

Its mission statement also indicates 'collaboration' and 'friendship' with the government: it is formulated in terms of 'working with', 'do advocacy together', 'participate and stimulate processes of taking on responsibility' in collaboration with the government (MATRAM 2005b). Core campaign objectives focus on 'community preparedness' and 'treatment literacy'. MATRAM folks decided to channel

their anger, indignation, frustration, and desperation into constructive action in favour of access to treatment.

The government recognizes MONASO, Kindlimuka, RENSIDA, and MATRAM, which at face value indicates an ideal situation. The four organisations work in 'partnership with the government', which is an admirable aspiration for state-civil society relations in other countries. The recognition process was peaceful, yet bureaucratic. Advocacy organisations maintain a supportive role to the government. In fact, 'best practice' projects and programmes have emerged from this collaboration, but there is more to the story.

First, I apply a FRELIMO spectacle to distinguish between *intimate, strategic,* and *distant* civil society organisations. I argue that this stratification determines government recognition and ultimately the allocation of resources. This is about organisational proximity to power. Second, socio-structural conditions determine Mozambican citizens' acceptance of the socioeconomic and political circumstances and their subservience to the government (Høg 2006). Freedom of expression is a hard choice, given the history of centralized government and the FRELIMO insistence on political debate *within* the party, not in the media or on the street.[2] It remains a slow process to gain and realize the inner freedom to practice the rights of citizenship, even if FRELIMO has become more lenient and democratic. Third, the perceived ideal of a united civil society withers given the reality of fragmentation among its organisations. This is about the lack of social cohesion, if one voice and unity is taken as the yardstick for political success.

Proximity to Power: Shades of Taboo

The proximity to power thesis spells the axiom that affiliation to FRELIMO shapes the socio-political environment and allocation of resources. This is my second application of language and taboo theories (Douglas 2002 (1966); Leach 1979). In short, *intimate* civil society organisations stand closest to FRELIMO. FRELIMO founded and supported its own organisations during the early FRELIMO days of Eduardo Mondlane and Samora Machel. On the other hand, the government and donors 'invented' *strategic* civil society organisations to legitimise policies and plans in the era of donor supported development. In other words, this comprises *political tokenism* and *double patronage*. Intimate and strategic organisations follow the Gramscian definition of civil society as a legitimizing bridge between state and citizens (Gramsci 1971). *Distant* civil society organisations belong to the political opposition and the government consequently see them as 'troublemakers'. This is fundamentally about *distrust*.

Intimate civil society organisations fulfil core FRELIMO criteria: the closer to the epic of heroic liberation the better. This is about *solidarity* with FRELIMO, which resembles the analysis of ideology and authority between the government and *non*-governmental organisations (see Chapter 6, pp. 286-291).

'Mass Democratic Organisations' constituted intimate civil society upon independence. They designate the 'authentic' or 'native' liberation movements. FRELIMO created them as anti-colonial, anti-imperialist, and anti-traditional entities to create the new Mozambique. Such entities included 'dynamizing groups', 'popular tribunals', and 'party cells' (Matsinhe 2005: 31). This legacy lives on. On the other hand, FRELIMO remains ambivalent towards the global ideology of 'democracy',

'civil society', 'rule of law', and 'human rights', with reference to the dependency-independency and nationalism-imperialism dilemmas. The government relies on foreign aid, but the long-term goal is self-sufficiency. Mac-Arthur's statement provides an example: *"We can't close the doors"* (see Chapter 6, pp. 294-295).

All protestant organisations in the South enjoy FRELIMO support. This is no coincidence, as Eduardo Mondlane and Samora Machel were sons of the southern Gaza province. The Swiss-Presbyterian mission influenced Eduardo Mondlane and the Catholic mission influenced Samora Machel. Moreover, FRELIMO proximity was also seen from the beginning of the National AIDS Council in 2000. The first NAC president was Janet Mondlane, the widow of Eduardo Mondlane. A systematic review of all NAC members would probably confirm their FRELIMO background in Southern Mozambique. This may change as part of the process. On the other hand, a systematic review of civil society organisations would probably confirm that AIDS advocacy workers are *not* from a FRELIMO background. The Mozambicans that I knew were from Nampula, Manica, Zambézia, and Cabo Delgado provinces, not from the FRELIMO provinces Gaza and Maputo in the south.

Intimate civil society includes the Mozambican Women's Organisation, OMM,[3] and the Foundation for the Development of the Community, FDC. These organisations associate individuals of Samora Machel's closest family. Informants often said: *"First you see the person, then the name of the organisation."* Women's emancipation was an early FRELIMO promise, personified and practiced by Josina Machel, Samora Machel's second wife. Josina Machel advocated women's public speaking and freedom of expression.[4] Graça Machel, Samora Machel's third wife and the current wife of former South African President Nelson Mandela, personifies the FDC organisation. Graça Machel is the Mozambican woman who enjoys

Josina Machel's dreams of female emancipation the most. This is for a good reason. Graça Machel has by fate become *untouchable*. She can think and say what she wants, without any repercussive consequences: she is part of the establishment. Graça Machel, a first-line member of the FRELIMO Central Committee, was Minister of Education and Culture upon independence in 1975. However, she speaks with two tongues, one for FRELIMO, one for the peoples.

Distant civil society organisations stand in opposition to FRELIMO. They are perceived as distrustful 'troublemakers'. A prime example is the League of Human Rights that primarily works with access to law and justice and violations of human rights (Marques, et al. 2006). Alice Mabote, the leader of the League, enjoys the freedom of expression for a different reason to Graça Machel. Alice Mabote speaks fearlessly as one of the only Mozambican citizens. Letting her talk makes her the token exception that proves the rule. It would be highly unwise of the government to mute her voice, given the sensitive matter of human rights with global attention. Women, Law and Development, MULEIDE, is on the other hand an intimate organisation. The League of Human Rights and MULEIDE work to advance access to law and justice from two different political standpoints.

I analyze the intimate-strategic-distant stratification of civil society in terms of 'shades of taboo'. Taboo can be defined as avoidance of those things that fall between culturally agreed categories and names (Douglas 2002 (1966); Leach 1979) (see Chapter 1, p. 61). The government *is* FRELIMO. FRELIMO *is* Mozambique. FRELIMO is *the* voice of Mozambique. Political rhetoric has made this clear since independence, which opposes or even ignores the on-the-ground heterogeneity in terms of political opinion and affiliation. Distant civil society organisations stand in opposition to FRELIMO. This standing appears logical. The government favourably

supports its own offspring ahead of 'partners', which it perceives as distant or linked to perceived enemies. In discourse and practice, the more distant the organisation, the more tabooed, isolated, and ignored it becomes. With Leach, we may draw a variant social classification of edible parts of the environment in terms of state-civil society relations in Mozambique:

Intimate civil society: Government recognized organisations that belong to FRELIMO, thus part of normal politics, and thus taken for granted partners

Strategic civil society: Government recognized organisations appropriated as possible partners, but they are *consciously* tabooed in daily practice, only to be used under certain ritual conditions

Distant civil society: Government recognized organisations, but they are not recognized *in practice*, thus *unconsciously* tabooed (cf. Leach 1979).

All three categories are 'wholesome' and 'edible' substances, thinking with Leach. The socio-political context determines the specific classification. There is no natural classification of NGO-state relations. However, there are no clear-cut differences between the three stratifications. Their overlap depends on the circumstances of the purpose and process at hand and intimate organisations occasionally associate with strategic organisations. For example, the Mozambican Women's Organisation, OMM, and the Mozambican Youth Organisation, OJM, are members of MONASO. However, this fact only makes the stratification analysis more significant. It identifies the subtle, yet telling differences, whether its implications are historical, political, and/or practical. These phenomena suggest a 'sophisticated diplomatic dance' in which national and international organisations engage with the govern-

ment, both as partners and opponents (Høg 2006: 57). Nevertheless, who leads this dance? I think this is a two-way process.

The stratification of civil society can be seen in a slightly different perspective in which divisions depend on changing ideology. FRELIMO conceived and constituted intimate civil society according to the socialist principles of the first constitution at independence in 1975. Socialism somehow failed, as the government embarked on the neo-liberal path with the IMF and the World Bank in 1984 (Abrahamsson and Nilsson 1995; Adam 1996; Costy 2000; Hanlon 1991; Santos 2006). Strategic or hybrid civil society organisations became an option with the ideologically revised constitution of 1990, which spelled capitalist, democratic development. This camel was hard to swallow. Still, the government was and is diplomatically malleable. FRELIMO simultaneously remains loyal to its past, which is part and parcel of its social imagination as it links past, present, and future to the pervasive mentioning of the process towards a glorious, independent, and sovereign Mozambique. This is why the past matters in the ART era. Despite its chameleon politics diplomatically open to change, FRELIMO retains its core identity, which may explain its unique resilience in the African context.[5] This political constellation creates a vital and quintessential paradox that characterizes this particular African country. I see this as a delicate act of balance between yielding and staying firm on international and national relations in search of stability that gives FRELIMO credibility. FRELIMO is *the* process.

Distant civil society organisations constitute the ones that saw no major change according to these ideological lines. Troublemakers have always been in opposition. They did not emerge from FRELIMO political evolution as the strategic NGOs, regardless of their international donor support.

Partnerships: Chasing the Gaps

MONASO, Kindlimuka, and RENSIDA epitomize strategic civil society organisations. The social movement MATRAM would meet the criteria as distant civil society, as the government sees its treatment advocacy as political interference. However, MATRAM would be a candidate of the 'unnamed' or 'unnameable', thinking with Leach (Leach 1979). MATRAM falls between the three categories, perceived neither as intimate, nor strategic, nor distant civil society. The fact that MATRAM as a self-proclaimed 'social movement' behaves more like 'an NGO' adds to this marginality. These three borderline considerations stem from the nature of political recognition (Englund 2004; Taylor and Gutmann 1992). Otherwise, MATRAM would have become a recognized part of the Mozambican ARV treatment model.

My analysis of partnerships supports the intimate-strategic-distant civil society argument. I will show that failing partnerships among Mozambican NGOs depend on organisational struggle for survival and identity, and, consequently, on mutual rivalry. In fact, each organisation chooses the solitary path, contrary to the partnership principles laid down in their mission statements. Combined with the lack of direct communication with government institutions this produces asymmetric knowledge and asynchronous strategies. Epidemiological HIV data are not fixed in time, as we saw with epidemic evolution. However, organisations create their campaigns on yesterday's data, for tomorrow's needs. Finally, partnerships may be fictive: they serve to legitimate the policy process ruled by the 'international development machine'.

Why Partnerships Fail: Survival, Identity, Rivalry

The third campaign meeting gathered nine participants, who represented MA-TRAM, MONASO, Oxfam, and Sant'Egidio. After a long debate, they once again saw RENSIDA as the politically correct organisation to launch the campaign on 1 December 2005. Would a human rights and access to treatment campaign be possible with or without RENSIDA? There were more problems. The key people from Oxfam and UNAIDS, who came up with the idea, were not present. They were somewhere else in the partnership network. There was still no reply from RENSIDA, despite many attempts to reach RENDIDA folks. One suggested that RENSIDA was busy preparing the GIPA conference. Another one said with some degree of realism: *"We need to move forward, but we are not doing anything."* It would be problematic to change the program by replacing RENSIDA, as donors would be unhappy. This was a difficult situation and a low point of the campaign preparation.

I visited RENSIDA to clarify the situation. First, RENSIDA was fully engaged organising the third GIPA conference in Maputo, a four-day event in late November 2005, just a few days before the launching of the access campaign. Second, REN-SIDA had embarked on its own access to treatment campaign as part of its advocacy program designed two years earlier with support from Oxfam. MATRAM took part in the design process. Then remember that Oxfam finances most of the activities of MATRAM and the access campaign. RENSIDA invited MATRAM to join the RENSIDA campaign as equal partners. MATRAM refused to accept this proposal. According to Ângela, MATRAM responded: *"It is only us who deal with treatment advocacy. You have to follow our plan. No one else can talk about treatment."*

I interpret this as questions of survival, identity, and rivalry. Organisations struggle for survival: they constantly seek new funding and they need to create and maintain their identity. They need to comply with donor conditionality. They navigate limited space of action under the primacy of the government. This is their 'home work'. There is little energy and incentive to engage in constructive partnerships with other organisations. However, we must think of credibility. Organisations *must* prove their commitment to their partners by showing up for appointed meetings. Organisations rapidly lose credibility, if they fail to embody and apply such skill. However, funding agencies never really see the reality on the ground. Most sit in faraway lands, donating money to tabula rasa land. As Fatton reminds us, though civil society inhabits limited space for intervention, civil society in Africa is *not* a *tabula rasa*. Civil society is conditioned by the political and cultural processes that define the state domain (Fatton 1992: 75).

Ângela said: *"As we are not united, I don't see how we can take this question of access to treatment forward. It is such a huge question. I can't do it alone, REN-SIDA can't do it alone, MONASO can't do it alone, and MATRAM can't do it alone. We need to come together, because the problem is the same for all of us."*

In fact, organisations were trying to do things on their own. The 'access to treatment and human rights' campaign was just one among many activities within each NGO. As Jerónimo said: *"I am doing a million things, but nothing at all."* How could they find time and organisation for a united access campaign? Admittedly, Ângela and Jerónimo were certainly not the only ones to reflect in this way. I heard similar remorseful comments from all corners of the HIV community in Maputo.

Ângela raised her voice: *"We have a common objective. It is already defined! But we don't know how to stick together. It's so difficult and I see great difficulties in*

taking this programme forward. Why? We cannot realize programmes on our own. We then drill some of the key partners: 'Oxfam, UNICEF, CARE, Burnet Institute, etc.' *"I have said to my colleagues at MATRAM: 'Imagine, Oxfam is financing RENSI-DA!' The donor of our advocacy programmes is the same, they know our programmes, and they provide technical assistance! Then there is no way we can keep on walking down our own pathway. Every organisation has its own programme and believes that it complements other programmes. Oxfam cannot finance our programme, thinking that we are taking away the work of MATRAM. But they believe that our work complements their work, so they keep supporting us."*

I visit MATRAM 8 months down the road of the one-year campaign. Lucas says with a more saddened voice word by word: *"The human rights and access to treatment campaign started in November, but the campaign has stagnated completely. It is not going anywhere. We need support as well. We have partners who could help us, but it is not moving anywhere. There is no perspective."*

The campaign was confined to the HIV community in Maputo: it never reached the provinces, be it Gaza in the South or Niassa in the North. I ask Lucas about the major difficulties running the campaign. He says: *"It's necessary to have greater motivation. Financial support. This is a provincial campaign! We need to go to the provinces to make it a national campaign!"* I recalled an earlier interview with Lucas in which he compared the South African Treatment Access Campaign budget to that of MATRAM, laughing at the big difference. *"Who knows in Cabo Delgado? No one in Niassa knows about this campaign. We need to reach those places too. We need money. Not just money, but also campaign materials. If you suddenly get a pamphlet about 'Treatment of HIV, Access for All, National Urgency', then you also need information about treatment."*

Failed partnerships essentially rest on benchmarks and money. That is, there are no historical quality indicators for civil society. A previous success story could have been recycled in times of HIV. Second, donors give *money* to raise their own image and goodwill, but they often fail to provide *training* and *skills*. This is like funding agriculture where there are no farmers. In other words, the unsuccessful human rights campaign is not a unique case but a general tendency.

Asymmetric Knowledge, Asynchronous Strategies

Organisations continue to work on their own with small budgets and big ambitions. Recall that Ângela said: *"Every organisation has its own programme and believes that it complements other programmes."* Access to current information is difficult, which makes up-to-date campaigns and common strategies difficult. Organisations often produce the same reports and documentation in several corners of the HIV community, but often with different data. Communication with the Ministry of Health is one of the most difficult matters for everyone in the community, including the National AIDS Council. Written requests pile up at the Ministry of Health. Formal bureaucracy and lack of staff add to extended time consuming procedures. Solicitors get disappointed and frustrated. This produces ghost discourses about government inefficiency and lack of commitment, but it also produces asymmetric knowledge, which soon becomes outdated, collecting dust somewhere in the process. Isolation and inefficient partnerships produce asynchronous strategies, which run counter to the social codes and fundamental principles set in stone.

Let me return to stratification of civil society and argue that partnerships merely

serve to legitimise the policy process led by the international community.

Fictive Partnerships: Appeasing the International Machine

OMM and FDC do not specifically work with HIV. Formal and practical recognition

depends more on political affiliation, less on the task. The government recognizes

MONASO, Kindlimuka, RENSIDA and MATRAM, but for slightly different reasons.

They have become *strategic* civil society organisations, with no pronounced FRELI-

MO alignment or opposition. Therefore, they seem to support the government in

amicable ways. However, the key difference lies in the way the creation and main-

tenance of these organisations serve a political purpose beyond the mere humani-

tarian aspects of their activities. This is how I argue they are called upon only un-

der ritual conditions to legitimise the policy processes as tokens to please the in-

ternational donor machine. This is part of the political fabric and embodied FRELI-

MO culture. Yet, this argument welcomes contestation. Many would disagree, but

this is how hegemony works. I showed this in the previous taboo analysis and by

implication in the later analysis of how its significance lies in the *unsaid*.

Another example illustrates the problem with partnerships: DFID provides

funding for NAIMA+, MONASO, UNAIDS and RENSIDA. Yet, these four organisa-

tions do not have a common forum to coordinate their activities. They rarely meet

face-to-face. They have similar agendas, yet the synergetic effect is extremely low

or undetectable. The consequence is work carried out in isolation and duplication

of specific tasks. For example, all four organisations do lobby and advocacy, yet

complain that they are understaffed and lack competent officers to do the work. Treatment literacy remains an aspiration for all four organisations, encouraged by a Partners Forum/National AIDS Council meeting 9 December 2005, which emphasized the need to educate health personnel and civil society on issues related to the ABC of ARV treatment. Yet, MATRAM takes its own initiative to apply for funding without involving their partners. Lucas explained: *"MATRAM does not like to be a token and does not need partners. MATRAM is an independent movement that dares to speak out and confront others without involving them."* The MONASO treatment literacy campaign did not move anywhere, despite the fact it had given such campaign high priority in 2006. This was explained by the lack of support from civil society and/or international partners. Moreover, MATRAM did not inform MONASO about their funding to have six treatment literacy workshops between April and June 2006, despite their mutual partnership.

Ritualized Events: Patterns of Reappearance

However, campaign events occurred unexpectedly. In fact, NGOs launched them with professional nonchalance. I could provide detailed summaries on the *content* of these events, but that would not support the point of this analysis. Their ritualized *form* intrigued me, how they followed cultural prescriptions. I have pointed to this phenomenon in partnership formation as transactional rituals (Høg 2006), but here I am interested in patterns of behaviour and predictability. A ritualized event follows the symbolic norms of global campaigns, but it also follows the laws of sociocultural prohibition, which include avoiding confrontation and criticism. This

is prescribed by the social order. Silence is gold. These characteristics produce external legitimate feathers, cultural compliance and internal strategic cum embodied silence. Events thereby have both social and ritual *value*, which unintentionally serves to maintain the social order (cf. Radcliffe-Brown 1979).

Ceremonial Rites: Following the Prescribed Order

No one says 'hush, hush, don't say that', as everyone implicitly knows the rules on both sides of the state-civil society dichotomy reproduced in this context. The one who wrote the speech knew all the rules of the ritual. The one who read it aloud knew all about it too, without batting an eyelid. The audience listens patiently without (visible) complaint. Those higher up the social and political hierarchy received the words with tolerance and understanding, showing affection through polite body language. Hence, ceremonial rites follow the prescribed social order.

Ritual events are found throughout the HIV community. As Lúcio said: *"Now it is 'International Testing Day'. Then it is 'Universal Access'. Then it is '3 by 5'. People don't know how to differentiate one thing from another. UNGASS was in the drawer. No one talks about UNGASS. What I am trying to say is that people talk about what's in vogue. Fashion will come to us on '1 December'. 'What are we going to do on 1 December?' Let's go for another ritual."*

The first campaign event took place at the Faculty of Medicine on 28 November 2005. Campaigners had invited the Prime Minister, the National AIDS Programme Director, the MONASO President, the Sant'Egidio Programme Coordinator, the MATRAM Coordinator, and the RENSIDA Executive Secretary. The first and the

last of these did not show up. Thus, we saw representatives from the government, an advocacy NGO, a social movement, and a treatment implementer. About 200 people listened carefully. Symbolic manifestations marked the occasion. Logo symbols that signify context, totem, and predicament decorated the invitations: the Mozambican flag, doves of peace, AIDS ribbons, and the emblematic contours of the territory. Even the notoriously absent RENSIDA organisation was listed as an event organizer. T-shirts exposed the globalized 'access for all' appeal. Candles formed an AIDS ribbon to serve as testifiers of the ongoing epidemic. Moderators passed on microphones to the audience to remind us how important it is to break the silence.

Several events took place in the city on 1 December, Global AIDS Day. Mozambicans marched the streets with banners of righteous claims, like 'Keep the Promise, Stop AIDS'. They gathered to attend cultural activities at the *Pavilhão do Estrela Vermelha*, the Red Star Pavilion, which staged an exposition of HIV artefacts, 'positive gastronomy', basketball, soccer, theatre, dance, and live music. They called it 'Show Vida'. Advocacy officers went to the Parliamentary Assembly to hand over an HIV/AIDS law proposal to protect *all* people living with HIV and AIDS against stigma and discrimination (MONASO 2005a; MONASO/RENSIDA 2005).[6] All these activities were consciously prepared as symbolic manifestations.

The law proposal had been in the making for a couple of years with civil society hearings about their opinions, contributions, and wishes for such law. About 15 civil society members attended the ceremony at the Parliament. They represented MONASO, RENSIDA, MULEIDE, Kuyakana, League of Human Rights, MATRAM, and Kindlimuka. The MONASO president read the prefabricated speech epigrammatically in the way that Mozambicans practice Portuguese formality. Civil

society formally handed over several thousand sheets of paper to the Parliamentary Commission on HIV/AIDS headed by Isaú Meneses, who happens to be a popular musician and the only blind Member of Parliament. Civil society emphasized the importance of symbolic gesture, perhaps in respect of the prescribed social order, as I had heard them wish for a different scenario with thousands of Mozambicans showing their face at the parliament voicing their needs and anger. However, this did not happen. Such desires were retained for the corridor discourse of the imaginary civil society, which would live up to historical definitions as state opposition and critical voices guaranteed by its hard-won autonomy. Even Alice Mabote, the 'fearless' voice, spoke in a tractable tone of her shadow personality. This was perhaps for a good reason: Mabote represented the only distant organisation. Obey the order or stay away. As someone reminded me: 'talk to please' points to the difference between what civil society representatives *say*, what they *think*, and what they *do*. However, this is clever manoeuvring in the political landscape, particularly where the main recipient is a blind man with musician ears who obviously cannot see the external symbolic feathers and their ritual and social value. In other words, there are no visible totems for Meneses, only silence or voice.

Why did RENSIDA stay away from the access campaign? One of the reasons was their commitment to the third GIPA conference. It took place in late November. They say the first two conferences were disastrous. This one was a big success. RENSIDA was the exclusive organizer. Executive Secretary Júlio Mujojo welcomed everyone Monday morning and said goodbye Thursday afternoon. They had invited the Prime Minister Luisa Diogo to officially open the conference, but she did not show up. This was not so surprising. Then at 12:40, Minister of Health Paulo Ivo

Garrido unexpectedly arrived with his retinue, the National STI/HIV/AIDS Programme Director Alfredo Mac-Arthur, and others.

Everyone stood up in silent honour of the Ministerial visitors. The Minister apologized his unpreparedness and asked the audience to accept an improvised speech. The Minister then practiced his customary monologue. *"I would have liked to know about this event somewhat earlier to prepare better. I need to participate in the UNAIDS 2005 Report preparatory meeting. However, let's seriously discuss the issue that is undermining the foundations of Mozambique. What can we do to avoid more infections? We are singing and singing and nothing is happening."* The Minister emphasized the need to make people feel a 'value in life', and how to promote and develop 'self-esteem' and 'dignity' among Mozambicans (cf. pp. 299, 303). Kindlimuka promotes the 'value in life' ethic as a foundational starting point for human rights education, as we will see later. The Minister continued: *"I don't like speaking about numbers, but people living with HIV/AIDS"*.

The Minister left 16 minutes later at 12:56, having said a lot about prevention, but nothing about treatment, though he leads the expansion of the health system in response to the need for treatment of HIV related diseases (see Chapters 5, 6). This was perhaps in accordance with the government stance that treatment publicity would be irresponsible public health policy (see Chapter 1, p. 62, Chapter 6, p. 279), and Chapter 8, p. 391). *"We always keep a door open for you at the Ministry of Health so we can discuss. We are with you day and night. We need to find a solution how to prevent more HIV infections, because we cannot continue like this. I have to leave and I am already late for the next meeting."* Then it was lunchtime.

The workshop on treatment and care highlighted most access and delivery barriers. Moreover, the response by civil society referred, as usual, to the obstacles

and constraints faced by the health system. This was well captured in statements like: *"Our response is limited, but it is better to treat at least two or three people,"* and *"we need to put pressure on the government, but we also know that it is in a difficult situation."* Again, workshop participants begged people to break the silence, but also to 'turn talk into action', with reference to civil society and the government. Then the pre-eminent voices arrived. Graça Machel and Alice Mabote duelling in the same room – the two most outspoken women in Mozambique. Here they spoke with unrestrained tongues on behalf of civil society, one representing the intimate, the other the distant. This would presumably indicate that the third voice of strategic civil society was missing. Would this be mere coincidence? Moreover, Machel and Mabote do not work for HIV organisations. The third voice would ideally represent an AIDS NGO. Alternatively, would lack of political protection explain the absent third voice? Machel and Mabote enjoy such protection, albeit for different reasons, as I indicated earlier. The audience did ask: *"Why is it always the two of you who speak on our behalf?"*

Into the New Year: A Zero Activity Campaign

I gave a talk on HIV/AIDS, Human Rights, Stigma, and Discrimination on 14 December 2005 at the Faculty of Medicine, organized by MONASO, the Southern African Development Community SADC, the European Commission, and *Académicos Juntos*, United Academics.

About 200 students from the 12 major institutions of higher education in Maputo showed up to discuss the theme: *Which role could the student of higher*

education play in the promotion of human rights in the combat against stigma and

discrimination of people living with HIV/AIDS?

I include this event for three major reasons related to surprise, working culture, and audience participation, specifically related to the denial and recognition of the HIV epidemic. First, I was completely taken by surprise. I had no idea about the size of the event until the day before it took place. Fortunately, I was well prepared, as I had been giving a similar talk to law students at the Catholic University in Nampula a few weeks earlier.

Second, this occasion provided evidence of the 'last minute' working culture in Mozambique. It shows the relative ease by which an event can be organised in a professional manner behind the scene, though I would recommend organizers to inform the key speaker in good time. A general point: this was 'business as usual'. Evil tongues call it 'Maputo seminaritis', but it certainly bears witness to what I call 'masters of ceremonial rites'.

The last point is about audience participation and the denial and recognition of the HIV epidemic. I had organised my presentation around seven key questions open for debate, originally prepared for class room teaching:

Discrimination
1. What does this mean to you: 'Stigma and discrimination are the most difficult obstacles for efficient prevention of HIV'. *Use examples from your own life experience, academic literature, and/or Internet sources*

2. How can we convincingly talk about discrimination in the context of treatment? *Use legal and moral arguments. Speak, for example, in terms of equity: inclusion and exclusion criteria for people eligible for antiretroviral treatment*

Stigma
3. Mention 3 stigma related reasons why some patients do not show up for treatment, even as they have been counselled and the Day Hospital expects their arrival

Dissemination
4. How can we disseminate knowledge about the law and human rights of citizens to the provinces and districts? *Give constructive suggestions*

Action
5. How can Mozambicans invoke, claim, and debate human rights in the public sphere? *Use examples from television, newspapers, other countries, academic literature, and/or your own experience*

6. In the context of human rights, action is more important than the law? *Debate*

Conscientization
7. How can we conscientisize people living with HIV/AIDS about the laws and regulations, procedures and human rights in Mozambique? *Debate*

I presented some basic epidemiological data about the state of the HIV epidemic in the world in general and in Mozambique in particular at the end of 2005, as reported by the Ministry of Health and UNAIDS. 1.5 million were estimated to be living with HIV, 200,000 people were estimated to be eligible for treatment, and 16,000 were then on treatment. About 415,000 Mozambicans would be eligible for treatment in 2009. I explained that 16.2 percent of the adult population had HIV, which translates into one in every six adults: seven men and nine women out of every 100 Mozambicans between the age of 15 and 49. I explained that seven in every 100 Mozambican adults living with HIV were eligible for ARV treatment, according to HIV disease progression, as I discussed in Chapter 2. The initial response was unanimous along the lines: 'This is not true. These data are wrong.' Denial was at work, caressing everyone into self-deception. The moderator Gabriel de Barros had to help me out on this. Hardly anyone seemed to believe any of the epidemiological estimates. It took us about 20 minutes to convince the audience. Personal questions convinced them: *"How many of you know someone who has HIV or who died of AIDS? In your family? A father, a mother, a sister, a brother, or an uncle? Among your friends? A colleague? In your neighbourhood?"* The response was unanimous: We saw a forest of hands. The debate could then begin.

The format worked well. I had in mind to avoid talking non-stop from the pulpit with a silent audience listening. I had no intention to become the third voice

of civil society. On the contrary, the seven questions were meant to encourage audience participation and a debate among Mozambicans. We had to stop the discussion at six o'clock, half an hour later than scheduled.

The next meeting took place 31 January 2006, because of Christmas, New Year, and the general holiday season. This was six weeks later. As Lúcio said: *"It's a ritual. Let's do the thing. Let's design a t-shirt. 1 December is a peak event that flattens out and is totally gone by Christmas and at the beginning of the new year."*

The event was organized as a round table discussion for civil society to reach common ground and to establish common and realistic goals for the access campaign. Fifteen civil society representatives showed up. They spent most of the time aligning their understanding of what the HIV/AIDS epidemic is all about. Then they focussed on the contents of the access to treatment campaign and its realization. However, they reached no consensus. They made no concrete plan. Concrete planning was postponed for the next meeting, scheduled for 2 March 2006, five weeks later; three months after the campaign took off. Most partners were browsing their calendars: they said that they had a full schedule doing other things unrelated to human rights and treatment of AIDS.

They cancelled this meeting on 1 March 2005 during the Mozambican pre-consultation for the Universal Access conference to take place the coming week in Brazzaville, Congo. A working group had been established to run the campaign, but most of these were unavailable. Two of them were in South Africa, doing work unrelated to the Mozambican campaign. Another one was in Zambia. Others were busy elsewhere. UNAIDS backed out of the campaign after having facilitated its creation for the reason that it should be Mozambican civil society leading the process. The outcome was a zero activity campaign. There were no meetings for 2 months.

The next meeting gathered 17 participants (12 women, 5 men). They focussed on making an action plan. This was six months into the campaign. One poignantly said: *"The challenge is within the country!"* How can we get the campaign into the districts? What would 'universal access' mean in the Mozambican context? What would an 'UNGASS Movement' entail? How can civil society help the government in terms of human resources, the biggest problem of all? How can we revitalize the community? How can we make 'universal access' a bottom up process?

I divide the 13 participating organisations between 'silence' and 'voice'. The silent ones were MATRAM, Kindlimuka, Kuyakana, CERPRE, and Médicos Mundi España (4 national organisations, 1 international). The voiced ones were UNAIDS, ActionAid, WHO, Oxfam Australia, Sant'Egidio, JOAP, and AMOPROC (6 international organisations, 1 national). The tone was optimistic and foreign, echoing a civil society of distant worlds. They drew attention to the fact that no one raised the issue of ARV treatment during the presidential initiative week in February. *"What is the role of civil society related to access to treatment advocacy? What is the role of each NGO?"* The 2006 objectives were envisioned as the classical rehearsal from the international community: 'action plan' and 'information sharing'. A loud voice with Brazilian syncopation and experience from an altogether different context said: *"Make a public statement! Make it outside these walls! It must come from Mozambican civil society!"* The alleged third voice then left for the next meeting.

What should they concretely do? They decided to follow upcoming 2006 events: the *Global Week of Action for Universal Access* in May and *Global AIDS Day* in December. Remember the statement about the challenge within the country. These events were global in nature. They agreed in chorus: *"Things should continue after May"*. In fact, they made the same statement in November 2005.

The preparatory meeting for the commemorative week gathered seven participants (2 women, 5 men), who represented MSF, JOAP, UNAIDS, MONASO, AMOPROC and, for the first time, RENSIDA. This was another déjà vu gathering. 'Should we do this or that?' No one took responsibility. Instead, they started throwing the ball. They admitted passive participation, lack of information, and limited capacity. One of them explained: *"Civil society doesn't have a common voice or objective. It therefore makes it difficult to have an impact."* This was another low point of the campaign. All meetings were cancelled until 18 May, a week before the universal access action campaign. This was primarily due to frustration and lack of commitment, but also because many were busy with preparatory meetings for the UNGASS session in New York coming up in late May.

The universal access week was officially inaugurated on 20 May 2006 at the Faculty of Medicine. The Prime Minister and the Minister of Health were invited as key speakers, along with UNAIDS, MATRAM, RENSIDA, and Sant'Egidio. Representatives from the government and RENSIDA did not show up. Ergo, this was another déjà vu. The meeting gathered an audience of 71 participants.

I could provide a long summary related to the *content* of this event, but the *form* was once more a fascinating experience. This was another ritualized event. Ten events were programmed for the week, all in Maputo City, most of them attended primarily by people working in the HIV community, many of whom you see at all meetings.

This was the end of the Human Rights and Access to AIDS Treatment Campaign 2005-2006. A preparatory meeting for a new access campaign was held three months later on 22 August 2006. It gathered eight participants (3 women, 5 men, 5 Mozambicans, 3 foreigners), who represented MATRAM, Oxfam, Columbia

ICAP, and MSF Luxembourg. The three strategic HIV advocacy organisations (REN-

SIDA, Kindlimuka, MONASO), and the international one (UNAIDS) did not partici-

pate. The group discussed the question originally intended for evaluation by 1 De-

cember 2006: What have we achieved? They had 21 meetings and events between

October 2005 and May 2006 to reconsider (see Figure 7.3).
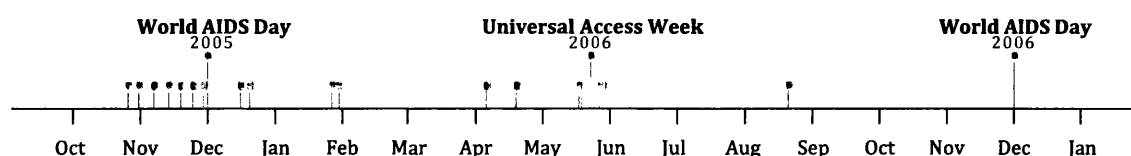
Figure 7.3: Campaign Meetings and Events, October 2005-August 2006
Source: Fieldwork.

They looked back at various fragmented activities and concluded complete lack of

coordination. One of them said: *"We have had weak capacity until now."*

UNAIDS had finally been able to appoint a Social Mobilisation Adviser for

Civil Society in mid-2006. It was a long and bureaucratic process with UNAIDS

Geneva to issue the contract. Civil society at first sized her up and then welcomed

and accepted her and her role. However, she was only offered a six-months con-

tract, which would end in December coinciding with the beginning of the second

campaign year. Moreover, the UNAIDS country coordinator had resigned earlier

during 2006, before the end of her contract to take up a position somewhere else

in the world. She was frustrated with the lack of direct communication with the

Ministry of Health. In fact, there was little if any communication at all between

UNAIDS and the Ministry. The Minister of Health asked 'what is UNAIDS', when the

country coordinator finally obtained a five-minute audience. The Minister later ad-

mitted that he found out about UNAIDS at the 2006 UNGASS meeting in New York.

Indeed, the vigilant reader would wonder how the Minister could announce that *"I*

need to participate in the UNAIDS 2005 Report preparatory meeting" at the GIPA

conference in November 2005. Was he ignorant about UNAIDS going to this meet-

ing? Did he practice a double discourse? Why would he want to provoke UNAIDS?

In fact, the Minister did propose to open a direct line of communication between

the Ministry of Health and UNAIDS upon his meeting with the UNAIDS Mozam-

bique country coordinator. He wanted to receive all new UNAIDS material of rele-

vance to Mozambique. The question remains whether this would be a helping hand

or a means of control.

Moreover, the National AIDS Programme Director looked confused when

given a handful of UNAIDS brochures at an earlier meeting with the UNAIDS coun-

try coordinator and asked: 'what is UNGASS?' Thus, 'partnership frustration' was

one of the main reasons why the country coordinator decided to resign. UNAIDS

was then without a country coordinator for several months. This is inevitably a

point about sustainability and institutional memory.

Oxfam planned to reinforce the access campaign, to recommend reposition-

ing MATRAM as the campaign leader, and to provide more funding. This was done

upon a brainstorming encounter between Oxfam, MONASO and UNAIDS. MATRAM

should ideally lead the campaign and involve other NGOs. What would the role and

responsibility be of each organisation? All organisations were envisioned as *one*

united social movement. They were asked to present a national treatment literacy

plan by World AIDS Day, 1 December 2006.

Ritualized Silence: Cultural Codes of Conduct

I have thus far described and analysed civil society advocacy for access to treatment in terms of socio-political stratification, partnerships, and ritualized events. I argued that *strategic* civil society organisations are often called upon under ritual conditions to legitimise the policy processes. I analyzed the tripartite intimate-strategic-distant stratification in terms of taboo to maintain that hegemony works by means of the *unsaid*. Here I want to match this classificatory analysis with an analysis of how silence works as cultural codes of conduct.[7]

I analyze how the different civil society strata use silence strategically, but for different reasons. This analysis provides an alternative to studies that assume specific connotations: notions of exit, loyalty and voice (Hirschman 1970), and disengagement and incorporation (Azarya 1988; Azarya 1994).

Acceptance and Subservience: Silence As Survival Strategy

I analyze how intimate, strategic, and distant organisations use silence for different reasons. FRELIMO incorporate intimate organisations. Strategic organisations are caught in a double bind between government and international donors. Intimate and strategic organisations show loyalty through silence, which covers the repressed voices of dissatisfaction. The key is to know your place in the socio-political hierarchy and to follow the conditions set by the government and foreign donors. As Chabal points out about Africa, though such generalization is debatable: *"There*

is no self-standing civil society, because vertical ties remain systematically more significant than horizontal (professional or functional) links" (Chabal 2005: 24).

Distant organisations stay silent out of fear. Historical circumstances play an important role. The brutal civil war between FRELIMO and RENAMO is a constant reminder of the past. The new generation is conscious of the fact that one party is in government. This is about habitus and collective memory, thinking with Bourdieu (Bourdieu 1972) and Connerton (Connerton 1989). As Fatton argues: *"The habitus disciplines collective and personal behaviour into codes of conduct that generate schemes generally compatible with the stability of traditional premises and identities"* (Fatton 1992: 76).

Strategic organisations hold prime importance for this analysis, as they are the ones primarily working in the areas of HIV and AIDS. They use silence as survival strategy. NGO workers would often sigh and confess an ethos of acceptance and subservience to power. Ângela said: *"They look at us from up there down upon us. They know our problems, and they even know how to solve our problems, but they don't do anything. It's a bit complicated. And we accept it. We accept everything when they come to us. Everything they say is good for us. It's only when they leave that we change our minds and start saying 'ah, I don't agree with what the Minister says...' This influences the fact that we don't succeed overcoming the barriers. We are not South Africans. We are very pacifist."*

I asked Virginia at MONASO why Mozambicans fear complaining about rights related to poor socioeconomic conditions like employment, housing, lack of clean water, and education. She said: *"Because people are afraid. We have a history of colonialism in this country and of post-war intimidation. A communist government regime was established then. People are frightened here! Absolutely!"* I asked wheth-

er this also pertains to the new generation. *"The new generation knows that one party governs this country. Many things are difficult for people to bring up. I am not saying to you that it is good not to complain about things. I am not saying that this is a cultural thing either, but silence is a way that people try to achieve things. This permeates all these problems. It is very difficult for people to know things, because you need to go to war in order to claim your rights! When you show that you know your rights, then you become demanding. But people don't know their rights."*

Again we see that silence serves a functional purpose: silence is a survival strategy given the hegemonic social structure. Silence is the weapon of the weak but wise and a means of compliance. Silence thus serves the fourth option to Albert Hirschman's exit, loyalty and voice. Decades ago, Hirschman (Hirschman 1970) performed a comparative analysis of 'loyalty', 'exit' and 'voice', primarily within commercial businesses, but applicable to organizations and states. The 'exit' option defines when people leave the organization or the state, which is well captured in the widespread phenomenon of 'brain drain', when skilled workers leave poor countries for a better life in rich countries. The 'voice' option defines when members express their dissatisfaction directly to an authority or through general protest. Hirschman asks *"Under what conditions will the exit option prevail over the voice option and vice versa"* (Hirschman 1970: 5)? Hirschman argues that voice should prevail over the exit option when, for example, public services deteriorate. However, the dilemma rests on the fact that either option comes at a price.

Exit and voice are not viable options for most people or organizations. 'Exit' would mean taking the way out, as we know it in 'brain drain'. Silence is not altogether the same as loyalty. Hirschman does ask the intriguing question: *"Clearly the presence of loyalty makes exit less likely, but does it, by the same token, give more*

scope to voice?" (Hirschman 1970: 77). My analysis shows that Mozambicans use silence as a survival strategy through acceptance and subservience, which follows the Gramscian understanding of hegemony as poor peoples' compliance with the dominant ideology (Gramsci 1971). Thus, there is a reason why there is no third voice for strategic civil society.

In Azarya's perspective, disengagement means withdrawing or keeping distance from the state. Getting closer to the state in search of 'partnerships' and 'collaboration' with the state is called incorporation (Azarya 1994: 83). Azarya does point to the fact that despite wilful attempts to seek incorporation, civil society may operate beyond or on the margins of the state (Azarya 1988). Certainly, the disengagement-incorporation analysis provides a dynamic view of state-society relations in which state hegemony is not taken for granted (Azarya 1994: 83), but its main downside is the lack of attention to how horizontal relations among civil society organisations shape their links to the state. Silence may be an impenetrable concept, but its analysis does invite understanding of state-civil society relations that the ideas of Hirschman and Azarya fail to capture.

Social Cohesion: Fragmented Voices, Fragmented Agency

However, 'voice' may relate to how civil society fragmentation causes lack of social cohesion. The 'one voice' requirement has probably never been part of any of the many definitions of civil society, but civil society may see it as part of a necessary strategy, as the government demands it. We saw this in the previous chapter (see Chapter 6, p. 304). The government knows the game. Would this be a 'divide and

rule, unite and rule' variant of the colonial measure to control its subjects? This would be a double political control mechanism, which produces rivalry among civil society organisations, while simultaneously blaming them for being disorganized.

Nevertheless, Jerónimo maintains that lack of social cohesion explains the lack of success by civil society. *"I think our civil society is very fragile precisely because it lacks the capacity of cohesive collaboration. When you want to negotiate or discuss with other actors, with the government, for example, then it doesn't have sufficient power to be able to argue and defend its points of view. Not only caused by lack of technical capacity, but simply caused by lack of cohesion within itself. This internal fragmentation exists for different reasons. We verify it very clearly by looking at what we call civil society action. We see that the vast majority of organisations want to be the protagonist. 'It was this organisation that did it'. Organisations want to appear so we can see that 'MONASO did it', or organisation 'X' did it. They don't want this protagonism to be shared among them. They don't want to become a cluster saying 'we did this', making this happen as we make other things happen. They always try to appear in isolation as single organisations making and developing this and that. This is one of the biggest problems among the civil society organisations."*

However, the lack of social cohesion is not entirely self-inflicted. A chain reaction causes lack of social cohesion. Lucas says: *"I think that we as civil society have a role in this, because of the problems that I see now. Some civil society organizations receive funding from the government. They cannot criticize the government, because it won't give you money if you violate it. People need to be empowered to do this. They don't have money. They cannot criticize the government, because they know it is a patron that gives you money. This is the reason why civil society is divided. It's a question of survival of the civil society organizations. I cannot criticize*

the person who gives me money. If I do, then tomorrow he will leave me starving. He

will not give me money and I won't able to survive. This is why civil society is so

fragmented. But this is also because our partners don't have capacity to support civil

society."

This seems a classical exit-voice-loyalty predicament of the Hirschman type,

but I maintain that silence causes lack of agency. The difference lies in the think-

say-do differentiation. Loyalty may show in what people say and do, not in what

they think. Voice may be a matter of false faithfulness. Both function to avoid exit.

Silence is the better option towards this end. Islands of silence create fragmen-

tation and consequently lack of social cohesion.

I have analysed the relation between civic culture and civil society. There

are many weaknesses and I have been chasing the gaps. This is not to say there are

no success stories. The MONASO-Kindlimuka-RENSIDA-MATRAM process is ob-

viously one long success story. 'Breaking the silence' has been the key event that

facilitated openness, disclosure, HIV testing, and access to treatment.

Beacons of Hope

The analysis of treatment advocacy reveals three normalized phenomena: con-

stricted voice, blurred agency, and uncertain accountability. This means weak rela-

tion with the government, weak partnerships, ritualized events, and ritualized si-

lence. However, where there is will there is hope. I end this chapter on a note,

which simultaneously relates appeal, quintessence, and optimism. At first, Lucas

says: *"Speaking of universal access, it is necessary that our government looks to all*

aspects and works together with civil society. We need to show all our problems to the government so that it will see civil society as a collaborator. The government would grow itself, if it supported civil society. Civil society and its donor partners are alone. Donor partners are here, but one could doubt why. They never support civil society. They only support small groups of civil society, without empowering civil society as such. We also need connection to the government."

Then he hesitates, weighs his words, and he confesses: *"But for civil society you need people who practically do not criticize the government."* At the end of our conversation, I ask him whether 'universal access' means the same as 'access for all': *"No, it is not the same thing. Universal access is access to various types of care. But we do have beacons of hope, yes, we do have beacons of hope."*

8
Circumstances

8: Circumstances

I relate the socioeconomic circumstances against the therapeutic, social, and political meanings of 'the process'. This analysis assembles the previous seven chapters, which have linked life with ARVs, epidemiology, consequences living without ARVs, the context of social science HIV studies in sub-Saharan Africa in general and in Mozambique in particular, health worker experience delivering ARVs, health system capacity, advocacy, history, and politics of ARVs, health care, and nation-building. Specifically, the triangular access and delivery model illustrates the ethnographic endeavour by comparing and contrasting experiences, limitations, and politics of ARV treatment in Mozambique. This raises a final question: How can we conceptualize the access and delivery model and the process in terms of social science theory to advance informed policy choice?

I do this by relating the model to what I have termed 'the process' in the therapeutic sense of the term juxtaposed with the circumstances of poverty of the majority. First, I integrate this discussion with empirical points about human rights oriented 'community preparedness': the value of life, sensitization, and treatment literacy. Second, the politics of food cannot be ignored within the 'pharmaceuticalization of public health' perspective (Biehl 2007a). Magic bullet solutions to public health stand in sharp contrast to the inclusive ideals of human rights in general and to the right to health in particular. Synoptically, the food problem points to the same political dilemma as the introduction of ARV treatment: the government seeks to avoid more dependency on foreign food aid. On the other hand, poor Mozambicans do not benefit from local food production.

I advance two basic ways of looking at this Catch-22 predicament. First, the need for food and medicines may lead to the development trap. The language of aid proclaims solidarity, while the outcome represents dependency. Second, the government preserves sovereignty *at any cost* to the extent that I would argue they favour the fate of Mozambicans in the name of self-determination – *with or without HIV*.[1] Consequently, poor people living in the martyrdom of failed development suffer different kinds of indirect violence: social condition, context, poverty, deprivation, and injustice. Initially, I draw on anthropological insights on context, development, and food production as a complementary overture to the analysis of indirect violence (Ferguson 1994; Lévi-Strauss 1970; Matsinhe 2005).

I show how the Mozambican approach to ARV treatment focuses on individual responsibility and control, less on providing the circumstances for improved livelihood. The therapeutic process constitutes a series of *rites of passage*, which ultimately determines who benefit from treatment. This analysis draws on insights from classical anthropological studies (Turner 1967; van Gennep 1960 (1908)).

I subsequently juxtapose epidemiological individualism (Baldwin 2005; de Waal 2008) and therapeutic citizenship (Nguyen 2005) to discern the obstacles that people face during the therapeutic process from testing to living with ARVs. The analytical lens for this combines risk environment (Barnett and Blaikie 1992; Barnett and Whiteside 2006 (2002); Rhodes 2002) and different kinds of violence: structural violence (Farmer 2004; Galtung 1969), symbolic violence (Bourdieu 2000), social violence (Kleinman 2000), cultural violence (Galtung 1990), and everyday violence (Scheper-Hughes 1992; Scheper-Hughes 1996).

Human Rights: Self-Esteem and Dignity

In general, Mozambicans know little about human rights and how to put them to use, which I elsewhere discuss in terms of weak performance power (Høg 2006). However, the insistence on the promotion of the 'value of life' among AIDS activists as a starting point for human rights education warrants new consideration. This was one of the main points raised by the Minister of Health on his brief visit to the GIPA conference (see Chapter 7, p. 333). The 'value of life' initiative was invented to promote 'self-esteem and dignity' among Mozambicans (see Chapter 6, p. 303).

The Value of Life: A Starting Point

The 'value of life' initiative originates from the government. On the other hand, the 'sensitization' and 'treatment literacy' initiatives taken by civil society challenge the Mozambican model in general and the appropriateness and efficiency of coun-selling and testing during the initiation and continuation phases. The polemical dif-ference rests on who provides the community support: intimate civil society (com-munity health agents assigned by the government) or strategic civil society (donor sponsored activists). This highlights the dilemma between native and foreign me-thodology: the government seeks ownership of the Mozambican model as part of the process by avoiding competition and parallel systems.

I met Nuno, a Kindlimuka advocacy officer. *"I like what I am doing, because I can see that people pay more attention now. We had problems when Kindlimuka was created, as people came to us for help. People were kicked out of their homes. How*

could we solve such problems? This was linked to stigma and discrimination. In 2002

we created the law that protects workers together with RENSIDA and MONASO. Then

we supported the creation of another law that protects all citizens."

Civil society handed over this law proposal to the parliament 1 December

2005 (see Chapter 7, pp. 331-332), 12 and 9 years after the creation of MONASO

and Kindlimuka respectively. Salvador Mazive broke the silence and founded Kind-

limuka, which sparked social support for people living with HIV and AIDS. The gov-

ernment approved the law on HIV in the workplace in 2002 (Republic of

Mozambique 2002), and drafted the one for *all* citizens with civil society from

2005 onwards (MONASO 2005a; MONASO/RENSIDA 2005).[2] All this is part of the

process. Nuno emphasizes this as a success story: *"Breaking the silence has been a*

success story. This all happened because one person managed to break the silence in

1996 by saying: 'I am seropositive'. I think this is very important. Many things started

to happen because of this. People started to know their situation. Before they walked

in secrecy. They started coming to Kindlimuka when people discriminated against

them in the family and at work. They found out about the support they could get

here."

We see three processes related to human rights and HIV: legal protection,

the emergence of AIDS activists, and public articulation. Success is a relative con-

cept. Ten years passed by between the first AIDS case report in 1986 and the first

person to publicly declare to have contracted the virus in 1996. The number of

people living with the disease in Mozambique was then approaching 500 thousand

(statistics indicated more than 800,000 people living with HIV in 1998) (National

Institute of Statistics 2002). Another ten years passed by before a law proposal to

protect citizens against humiliation and intolerance reached the parliamentary

level. The number of people living with the disease in Mozambique was then esti-

mated at 1.8 million (UNAIDS/WHO 2006c) and later adjusted to 1.5 million

(UNAIDS 2008). Civil society continues to be relatively weak, despite the fact that

hundreds of NGOs work in the area of HIV. However, the point is significant. The

individual, social and political barriers prevented speedier progress. Therefore,

civil society honours any success, whatever the time frame.

Nuno reiterated the fact that few Mozambicans know about human rights.

He was keener on promoting the 'value of life'. This would be the basic starting

point for human rights education in Mozambique. He says: *"We are preparing an-*

other book about human rights. Many people do not understand what they are all

about. We therefore sensitize people. It is a book about the value of my life. We do

this to make an incentive for society in general. What is human life? We need to work

together in the community to understand how people value their lives."

Nuno insisted that the 'value of life' holds prime importance, both in terms

of advocating prevention, testing, and treatment. This is about self-esteem. It is

about fighting against the circumscribed outlook on life, for example the scepticism

and fatalism about the future described by Matsinhe (Matsinhe 2005: 156ff).

Nuno then explained the 'Mozambique is dying' narrative: *"If I am seroposi-*

tive and I don't want to break the silence, not even with my wife, then what will hap-

pen? I will infect my wife and we will have infected children together. We could help

the children with treatment, but this will not happen, as I didn't reveal my state to my

wife. I will disappear, my wife will disappear, and we leave our children for the future

of our Mozambican tribe until we are all gone. Imagine a scenario in one of the bair-

ros or in a village where there are no families. Mozambique is dying. It would be

much easier to break the silence and change many things, if people had this in mind."

Sensitization: Epidemiological Awareness and Responsibility

Sensitization to promote the 'value in life' principle applies to epidemiological awareness and responsibility, but the fine line between knowing and not knowing continues to appear relevant. Indeed, sensitization may 'break the denial'. People need to 'face the facts' to get out of the downward vicious cycle. However, it would be a one-eyed approach without creating livelihood opportunities. This is called 'income generating activities' or in general terms 'socioeconomic development'. 'AIDS mainstreaming' served to include the HIV epidemic within the PARPA, the Poverty Reduction Strategy Plan, which attempts to reach the Millennium Development Goals: cut absolute poverty in half before 2015 (Republic of Mozambique 2005). However, in everyday life, people stand with poverty above their heads, struggling for survival. What is the 'value of life', living with HIV, facing the access and delivery barriers towards ARV treatment? Treatment providers need to find ways how to deal with failed treatment expectations, as suggested in the paradigm that looks at hope, risk and environment (Bernays, et al. 2007). I captured this challenge for donors and policy makers in the sketch of the therapeutic process (see Figure 8.2, p. 385): what is the purpose of 'the first come first served' principle during the entry phase? How do we counsel the increasing number of people who reach out for treatment but find out that the hospitals are full?

The call for individual responsibility raises an important question: Can we command individual control over miserable lives filled with pitfalls of poverty, disease threats, misfortune, and natural disasters? More than half the population is illiterate. What I am challenging here is the isolated focus on knowing about the disease and how to adhere to treatment.

The Food Chain: Unravelling the Web of Reasons

Let me take you through this thinking exercise. Why are the majority of Mozambicans poor? Plausible answers: the country has been unable to grow due to five hundred years of colonialism, regional destabilisation during the civil war, and slow or failed development intervention. However, why are the majority of people living with HIV poor? Because the poor segment of the population is disproportionately large in comparison to any other socioeconomic group.[3] The majority of Mozambicans are poor and hungry, whether or not they have contracted HIV or any other infectious disease. In macro perspective, Mozambique ranks 168 of 177 countries on the UNDP Human Development Index with 37.8 percent of the population living with less than 1 dollar per day in 2004 and 78.4 percent with less than 2 dollars per day. Its GINI coefficient, which measures inequality in distribution of income, is at 39.6, where zero corresponds to perfect income equality and one hundred to perfect income inequality. In other terms, the poorest 20 percent received 6.5 percent of total income, while the richest 20 percent received 46.5 percent of total income in 1996-1997 (UNDP 2006).

Food remains the biggest existential problem for the majority of people living with or without ARVs. Therefore, I chase the food chain: Which aid organisations and treatment programmes donate food? Where is food provided? What kind of food and how much is provided? For how long is the food provided? What are the inclusion and exclusion criteria? Who asks for food? What are the political obstacles to food provision? There are four basic ways to get food: through self-sufficiency, market purchases, social security schemes, or foreign food aid. There is not enough food through any or all of these channels to feed an entire population.

Therapeutic Food

Only Sant'Egidio and ASIDH Spain provided food for severely ill ARV patients at the Maputo Day Hospitals I visited in 2006 (see Figure 8.1). They provide 36 kg of food per person per month – corn, soya, flour, peanuts, beans, and oil – donated by the World Food Programme. The food is stored in a storage room at the Day Hospital. Donors include USA, Germany, and Denmark. Entry and exit depend on health status and social condition. People typically receive food support for 1-6 months, which in rare cases can be extended up to 12 months.

MSF Luxembourg only provides food for those who suffer the double burden of AIDS and tuberculosis. MSF Luxembourg is the only organisation that provides home based care by a medical team, activist home visits, search group tracing dropouts, on site activists, *palestras* to inform about HIV, AIDS and ARVs, and an on site support group (see Figure 8.1).

	Food	HBC	Visitors	Search group	Activists	Palestras	Support group
Sant'Egidio	X	-	X	-	X	X	-
MSF Lux	-	X	X	X	X	X	X
MSF S	-	-	-	-	X	X	X
ASIDH	X	-	X	-	X	-	-
ICAP	-	-	-	-	X	-	X
Central Hospital	-	-	-	-	X	X	-

Figure 8.1: Day Hospital Outreach Activities
Source: Fieldwork.

MSF Switzerland previously provided similar service, but Mozambican NGOs took over this responsibility: the National Association of Mozambican Nurses, ANEMO, the Mozambican Association for the Development of the Family, AMODEFA, the Lu-

theran World Federation, and Médicos do Mundo da Portugal, and Médicos del Mundo España – the Portuguese and Spanish 'Doctors of the World'. MSF Luxembourg and Columbia ICAP were planning to improve their social service.

The food support is meant for recuperation purposes. It is therefore taken away when the patient can go back to 'normal life'. However, food is the biggest existential problem for the majority of Mozambicans *living with or without HIV*. Thus, the therapeutic food basket most often supports an entire family. There are few if any other means of social support. Poor people ask for food at the Day Hospitals. Husband and wife may both be HIV positive, caring for nine children, of which four children are HIV positive. They will need ARV treatment at some point, but they always need food. In fact, Day Hospital coordinators find it difficult to cut the food support for the 'severely ill AIDS patient' under these circumstances.

The capacity to provide food depends on several factors. First, Mozambique experienced severe funding reduction from the World Food Programme in November 2006. Funding had been cut by 77 percent, which forced the WFP to cut its rations by half. This was caused by a good harvest year in Mozambique and the government policy to reduce its dependence on food aid by 10 percent per year over a ten-year period (Ayisi, 2006). However, the funding cut ironically came at a time when food was most needed and most expensive in Mozambique. Moreover, it happened eight months after the Ministry of Health decided to provide food for severely ill ARV patients and just two months after the government asked for 76 million US dollars from the Global Fund. Second, Day Hospitals have limited storage space. Third, this means limited carrying capacity.

However, only a few people living with HIV speak out freely about their problems and discontent, for themselves and for others. Mozambicans remain am-

bivalent whether they should confront the state about their social condition. Many politely support the state and understand the limited services it can provide. However, they remain loyal to the state through silence in fear of voicing their concerns. Many Mozambicans I talked to, including former expatriates, accept the circumstances and they have found a way to get by in life. Others said that Mozambicans are 'accepting and subservient': things do not change for the better for the poor majority (see Chapter 7, pp. 342-345). Many leave the country. Others get stuck in the martyrdom of failed development.

Anthropologist Arjun Appadurai proposes ways poor people may develop capacity to aspire through voicing their concerns inspired by Hirschman: *"How can we strengthen the capability of the poor to have and to cultivate 'voice,' since exit is not a desirable solution for the world's poor and loyalty is clearly no longer generally clear-cut?"* (Appadurai 2004: 63). Appadurai suggests 'voice' as both cultural and navigational capacity. That is, people should engage widely shared social, political and economic issues as a means of upward mobility in society. However, things do not change for the better for poor people. They therefore use *irony* and *compliance* as survival strategies, the former to create distance to maintain dignity, the latter to obey the rules of the dominating social order (Appadurai 2004: 65).

The points about survival strategies make sense in the Mozambican context. However, I challenge Appadurai: his ideas do not make sense in the context of poor people who live outside organised life in an authoritarian state that continues to use its externally and naturally caused weaknesses to excuse its inability to provide its citizens with basic life necessities. Poor peoples' risk is not organisational membership, but life itself through a downward spiral of destitution, illness, and death. In other words, poor people hang on to 'loyalty' as the their best bet. There

is no 'violent protest' or 'total apathy' – two exit options mentioned by Appadurai (Appadurai 2004: 69) – in Mozambique. There is no strong critical voice either.

However, exceptions prove the rule. Marco speaks out like Gilberto. I knew Marco through several meetings as someone unusually outspoken. Marco talks freely in public about the disappointing experiences of individuals in need of access to ARV treatment, the lack and costs of medicine against opportunistic infections, social support, the failures of civil society, the perceived weakness of the state, and the loopholes of the National AIDS Council. Marco is a member of an association of people living with HIV and AIDS, which with few resources is doing a good job supporting its members in a suburban community of Maputo. Admittedly, I never managed to interview Marco formally – a recorded life story interview. However, our informal ways were highly valuable and we met dozens of times.

At first, I sensed his reluctance towards telling me about his life. However, we soon became friends. We stayed in contact and either met, emailed, or sent each other SMS messages several times a week. We often agreed to get together to talk about life with ARVs in more detail. Nevertheless, something came between us each time. For example, Marcos' health often got worse. He had to spent long hours at the Day Hospital waiting for his medical consultation. Marco did not have the energy to talk about it all. Sometimes heavy rain prevented him from getting to the city where he usually goes for medical consultation. The streets easily get flooded. Moreover, Marco was often called for a meeting last minute, as it usually happens in Maputo. Sometimes we had no mobile phone credit to get in contact and sometimes a family member or someone in the community had fallen ill. These are all the little things that change the path of daily life before sundown and contribute to

the state of *confusão*. *Confusão* translates not merely as *confusion*, but as a cultural chaos caused by the tumult of daily life.

I respected Marco's reservations. Our relation was one of confidence and trust, as we talked about all other things possible during our close contact over many months. I rather saw a busy and talkative person with a significant personal shyness, which differed from his enlivened engagement in the cause of human rights to change the difficult social and economic conditions of the majority.

ARV provision cannot be seen in isolation from social circumstances. The rights regime affirms this assertion. The right to health includes health care and those circumstances necessary to maintain health, like clean water, sanitation, food, nutrition, housing, working conditions, a healthy environment, and access to education and information related to health (United Nations 2000).[4]

One example is people on ARVs, who do not meet the inclusion criteria for food support. They are ill, but not 'severely ill' based on specific medical criteria. Marco came to see me shortly after Christmas 2005 with eight of his fellow friends. I faced melancholic sadness and one hour of silence. Marco did the talking, as usual. He spoke as the lighthouse I always saw in him, forcefully and fearlessly about and for the people living with HIV and their poor conditions. His friends sat in silence. Some were wearing sunglasses to cover the blemishes and scars of HIV related symptoms. A private company and a government institution had rejected their application for food assistance. Marco's association applied a Christmas basket for 40 people (see Table 8.1).

Table 8.1: Christmas Food Basket for 40 People

Item	Per person	Total	Item	Per person	Total
Rice	25 kg	1000 kg	Milk	4 litres	160 litres
Peanuts	4 kg	160 kg	Flour	3 kg	120 kg
Beans	3 kg	120 kg	Baking powder	2 packages	80 packages
Sugar	3 kg	200 kg	Tea	1 package	40 packages
Oil	3 litres	120 litres	Chicken	3	120
Eggs	4 dozen	160 dozen	Potatoes	1 sack	40 sacks
Soap	4 bars	160 bars	Butter	2 packages	80 packages
Soup	4 packages	160 packages	Meat	2 kilo	80 kilo
Toothpaste	1 tube	40 tubes	Coolers		
Liquid soap	2 cans	80 cans			

Source: Fieldwork.

No one had the time to take care of their case because of the holiday season. A young man ill with malaria said poignantly, feebly coughing, yet with an ironic smile: *"The country is ill, but the government is on holidays"*. Second, only the World Food Programme provides social support. Third, only associations with high quality storage space remain eligible.

Sacks of maize, beans, and flour need protection against harmful weather conditions. Invariably, the National AIDS Council applies the argument that people living with HIV demand non-discrimination, which then exempts them from positive discrimination. However, ARV treatment is ironically in itself affirmative action: equal access only exists in theory. The limits of food provision are much tighter, determined by the politics of food.

Marco finally asked his friends whether they had anything to say to me. Their silence said it all. It was such a powerful statement. They took off their sunglasses, showing their faces in silence. They left in silence as they had entered.

Affirmative Action

The Ministry of Health had itself decided affirmative action upon the 'severely ill

patients' who suffer advanced HIV. This was in March 2006. The Ministry declared:

"A rapid decision (within 30 days) to be made by the Minister of Health regarding

provision of food to ARV patients" (USAID/Mozambique 2006).[5] This would be food

for recuperation purposes based on certain medical and social criteria. The first

meeting towards this goal was held in late June, more than three months later. As

Gilberto said to me: *"There is so much bureaucracy. This may take 6 months. Maybe*

1 year. Or 18 months. But we know that as each day passes by, people need food."

I 'follow the plan' from idea to inclusion in a funding proposal to the Global

Fund. I decipher five main issues related to the provision of food for severely ill

people on ARV treatment: 1) *collaborative efforts* 2) *programme logistics* 3) *entry*

and exit criteria, 4) *medical versus social intervention,* and 5) *affirmative action.*

The first two issues delineate the split between material and human re-

source needs to implement the proposed programme and the capacity of the exist-

ing political institutions and social support systems. The last three issues relate to

the logic and justification of medical intervention in light of widespread poverty.

What is the logic of advocating the importance of permanent adherence to ARV

treatment among poor people, when food support is temporary? In other words,

medical intervention is ahead of social intervention in the race to beat infectious

diseases and absolute poverty. However, this paradox points to the politicization of

development: the government pleads ownership of the process through increased

domestic production. In fact, the government tends to avoid increasing dependen-

cy on foreign aid and agendas, both in health and agriculture. This is common poli-

tics. Any country would do the same. The message seems clear: 'Do not throw cargo pills and beans on us, make them grow locally'. This is evident in the politics advocating investments in local agriculture and local ARV production. The question remains how and whether external food support or increased local production will benefit the poor majority with or without HIV.

This three-day meeting on food assistance for people on ARVs was held at the fashionable Hotel Cardoso. I came directly from the Kudumba support group, where they discuss lack of food as their major problem. The meeting gathered 30 participants (5 men, 25 women, 11 Mozambicans, 19 foreigners). They represented the Ministry of Health, Ministry of Women and Social Action, Clinton Foundation, International Relief and Development, MSF Luxembourg, World Food Programme Maputo, Johannesburg and Rome, Health Alliance International, UNICEF, Centres for Disease Control, Columbia ICAP, World Vision, World Health Organization, USAID, MSF Switzerland, Sant'Egidio, and UNAIDS. I noticed the conspicuous absence of the Technical Secretariat for Food and Nutrition Security, the National AIDS Council, the Institute of Social Action, and the World Bank. I noticed only one AIDS activist.

First, the meeting was meant as an informal event to encourage inter-ministerial collaboration. Two of the 25 ministries participated. Participants expected a project proposal from the Ministry of Health, which would be the ideal leader of the process. The MoH representative replied that this was an illusory thought, since they did not have the human resource capacity. She said: *"The Ministry does not have a solid plan; nothing has been presented to the Minister. MacArthur wants a proposal from the WFP about what's possible, and a cost and feasibility picture."*

They imagined to create an 'objective', 'viable', and 'simple' proposal, which would define the duration and quality of the support and exemplify 'inter-ministerial commitment' that involved the Ministry of Health, the Ministry of Women and Social Action, and the National AIDS Council. They would also establish concrete partnerships, for example a treatment provider (Columbia ICAP) and a food provider (WFP). However, they pointed to the lack of ministerial coordination. One doctor said: *"Social problems are found in all patients. They have no job, no food, no money, and no security. This is not the responsibility of the Ministry of Health."* An echo followed her statement and serious looking faces understood the gravity of the situation. Then she ascertained: *"I provided treatment, the CD4 went up significantly, and the viral load is now undetectable. I am done! Doctors can't solve social problems. Many patients ask for social help, but it is not the responsibility of hospitals."*

WFP wanted to know the impact of food programmes. Health Alliance International responded by asking how to measure such impact. The Ministry of Health pointed to its extreme lack of human resources to solve the overall problem of food scarcity among ARV patients.

One phenomenon pointed to the schism between theory and practice. The foreigners carried on in English about largely technical issues on how to plan, budget, and implement a medical food support program. Meanwhile, the Mozambicans whispered on the side in Portuguese about on-the-ground issues. Their lightly shaking heads revealed an insider attitude that the plans would not be successfully implemented. However, the two discourses did not merge. The final proposal mirrored the former approach: 'responsibility', 'monitoring', 'ventilation', 'cooling systems', 'lack of reference studies', 'we cannot implement in one week', 'logistics assessment', etc.

They needed a pilot study to fill the gap between theory and practice. On the other hand, the WFP regretted that it had limited resources to realise the plan. Rome sets the limits for WFP in Mozambique. The WFP Mozambique coordinator said: *"We can't move from 21 thousand to 100 thousand, but perhaps stretch to 25 thousand on HBC. We have five thousand patients on food support and can possibly expand to eight thousand patients."*

Second, the proposed programme logistics and implementation challenge the context of malfunctioning social support systems. They need to be established before our friends from the support group meetings can benefit from food support. However, most of them will probably not meet the entry criteria. They are ill, on ARVs, but still too healthy to qualify for recuperative food support.

They saw the biggest problem in terms of 'supply chain feasibility and accountability'. Would it be feasible to have food and medical supply in the same system? Where and how to store the food? What about shelf life and safe packaging material? Who will be responsible? Which ministries would take responsibility?

Third, the discussion about entry and exit criteria produced much controversy. Therapeutic food is often shared among a family of eight, ten, twelve members, which pointed to a much bigger underlying problem of widespread poverty. On the other hand, one participant defended the point that *"not all ARV patients need food, and not all people living with AIDS are poor."* Besides, quantity is a problem: How much food do ARV patients need? How many need it? One participant called for a vulnerability assessment: *"We don't know the patient outside the clinic."*

They discussed 'quantification', 'quality', 'feasibility analysis', 'testing models', etc., but they needed operational research to quantify the effect of food support. However, funding was a problem: *"You need to convince the donor stakehold-*

ers." At this point, hardly anyone mentioned the need for domestic food production, income generating activities, or general socioeconomic development.

Fourth, they pointed to the gap between the provision of health care and the provision of food. In fact, the 'first come first served' principle for access to ARV treatment breads discrimination. Some people are too poor and do not have access to neither ARV treatment nor food. What will happen when patients can no longer receive 'food for recuperation purposes'? What are the medical contra the social entry and exit criteria? The medically inclined proposed to study if and how food makes a difference to adherence. The same entry and exit criteria would be needed for all programs to find out about this. Suggested entry criteria included: mother head of household with low income, widowers with more than three under age children, orphans, and children with body mass index (BMI) lower than eighteen.[6] However, they did not come up with ideas for exit criteria.

Moreover, the discussion about medical versus social solutions produced a political divide. The medically inclined argued that the role of food support should be to improve adherence. The social camp wanted food provision for all poor and malnourished people, regardless of HIV status. One of them said: *"HIV status and a CD4 count below 200, poor health, and poor social condition as inclusion criteria exclude the poor HIV negative people."*

The medical faction replied that 'Food Assistance in Support of HIV/AIDS Care and Treatment' was designed as a health care programme, not as a poverty reduction programme. The WFP representative said that social solutions were beyond the scope of the workshop. Others insisted that access to ARV treatment could not be seen in isolation from wider issues of poverty and lack of access to health care in general.

Fifth, the radical group argued that food support for severely ill HIV patients was unjust affirmative action. Then the WFP representative pragmatically said: *"Let's focus on the HIV entry point – the smaller picture. We need to involve others to solve the bigger picture"*. However, WFP did recognize the need to 'harmonize' and 'streamline' their partner network to be able to succeed 'multi-partner implementation'. At this point, WFP encouraged partners to link medical and social services with livelihood promotion.

In other words, a commodity in high demand given exclusively to severely ill patients produces discrimination against the healthy poor. This suggests the bizarre situation that some people living with HIV would want to become severely ill to get food support. AIDS patients are often better off compared to other people who do not receive social benefits from the state or the international community. The HIV negative do not benefit from food support, they have no NGO affiliation, no micro-credit, and no targeted intervention. Relief food aid provides the exception, but this intervention does not reach all the poor.

Experience from Sofala province shows high demand and low supply. A HAI health worker explained: *"You see poor people, when you visit a poor community. This is your first impression. It is difficult to distinguish between HIV negative and HIV positive target groups. People feel that food for ARV patients discriminates against HIV negative people in general and against HIV negative pregnant women in particular. And those who fulfil the medical and social entry criteria complain when we stop giving them food. There is another problem: the food is not local, but foreign, often of a bad quality."*

Sant'Egidio and MSF Luxembourg pointed to the supply-demand problem by admitting that they often have to choose between equally eligible patients.

Treatment providers cannot treat everyone and they have limited food supply. Transparency problems pointed to the fact that patients lie, cheat, ask for favours, use connections, and resale food through the informal market.

Finally, frustration and disagreement characterized the atmosphere. Participants had little time to reach consensus on programme implementation. They disagreed on the social entry criteria. Then someone suddenly remarked: *"Mac-Arthur expects a proposal for the 6th round of the Global Fund!"*

Food and nutrition components were included in the Mozambican application to the Global Fund, submitted by the government in late August 2006. The government asked for 76 million US dollars. The grant agreement was signed on 21 September 2007. Nearly 23 million dollars were then approved, of which about 2 million had been disbursed (GFATM 2006).

This was 16 months after the decision at the Ministry of Health to provide food support for 'severely ill' ARV patients. The Kudumba group was not successful in its pursuit of food assistance for its members in 2006. Nor were Marco and his friends. A limited yet ambitious number of severely ill patients in need of temporary food assistance for recuperative purposes will one day receive nutritional support. The proposal states within the 'HIV/AIDS section': *"The number of people receiving Home Based Care services is expected to increase from 30,000 in 2005 to 150,000 in 2009, to be sustained in 2010. It is planned to provide food supplements to 95,000 malnourished PLWHA in 2010"* (GFATM 2006: 48).

Beneficiaries will be a few of those who live when the day of delivery comes for people like Gilberto, Alicia, Beatriz, Daniela, Evaristo, Ângela, Marco, Petra, Rosalina, Paulina, Adelina, Amélia, Rogério, Cláudio, Patrícia, and all the ones in the same life situation. There were more than one hundred thousand adults and more

than seven thousand children on ARV treatment by May 2008, who could probably tell similar life stories to the ones told here. At the same time, the number of 'Gilbertos and Petras' in need of ARVs was approaching some three hundred and fifty thousand in 2008, including more than eighty thousand children. This can be compared to the need for food aid for the general population within a time slot of nine months. A FAO/WFP special report estimated that Mozambique needed seventy thousand tons of relief food aid for close to six hundred thousand food insecure people between July 2005 and March 2006. This was due to poorer harvests, combined with the effects of HIV and AIDS, recurrent disasters, lack of savings, weak health services, and limited capacity of community social safety nets. This amount of food was needed in addition to the 'annual recovery, rehabilitation and development food aid', which was forty-four thousand tons (FAO/WFP 2005). Further research would be needed to investigate whether and how the food aid reaches the ones in need, how this provision produces inequality, and how to solve the problem.

The Raw and the Cooked

Petra is an example. Petra is drinking and smoking, sitting on the dusty floor of a small room in poor housing. Half-drunk, Petra complains that she has no money to buy coal to boil the water for drinking and cooking. She receives sacks of maize and beans from the World Food Programme, based on certain medical and social criteria. The food is intended for recuperation purposes, but there is a long way from the raw to the cooked.

My inspiration for such analogy is Lévi-Strauss' raw-cooked dichotomy (Lévi-Strauss 1970). Cooking symbolically marks the transition from nature to culture. This is about processing of raw material. Donor aid provides much raw material, like food, medicines, ARVs, plans, agendas, and information, but logistics and politics complicate taking the goods from Maputo harbour into the hands of people. Mozambique is not a 'clean slate', thinking with Matsinhe (Matsinhe 2005). It is all about context. There is a need for processing of all kinds: the messages, information, plans and agendas, as well as the nature, meaning, and use of ARVs.

One case is HIV prevention campaigns. Why do they fail? Information remains unprocessed and disembodied. Uniform global prevention policies fail to become 'culturized'. We still do not know the recipe. Moreover, food aid is not local. The food is foreign in make and taste, it smells and spells dependency, and the Mozambican government knows this. The Mozambican government seeks sovereignty, but 'it can't close the doors' – yet (see Chapter 6, pp. 294-295).

Another case is local ARV production. Cooperation between Brazil and Mozambique culminated in the construction of an ARV factory in 2008, scheduled to be ready to produce drugs in 2009. The initial negotiations, which started at the beginning of the 2000s, provide an example of a complicated raw-cooked process. I see four key issues for the realization of local ARV production: *feasibility*, *ownership*, *conditionality*, and *trust*. First, project managers faced the weak infrastructure and poor conditions in Mozambique. Pedro Chequer, former UNAIDS Country Program Adviser in Mozambique and National AIDS Program Coordinator at the Brazilian Ministry of Health, at first declared that 'it's not worth building a factory making antiretrovirals in Mozambique for it to become a white elephant' (Notícias 2004). Chequer implied problems of costs and sustainability and that local ARV

production therefore would be impossible. However, they showed renewed commitment just a few weeks later, giving new hope for its realization (Mavie 2004). This was reaffirmed in early 2005 (Notícias 2005). Feasibility studies take time. Brazil reaffirmed its commitment to health in Africa in general, and to the Portuguese speaking community in particular. Specifically, the Brazil-Mozambique partnership rests on mutual trust and the recognition of their common process from colonialism to independence and self-determination. In other words, political congruence facilitates good relations and trust. In fact, a Brazilian Foreign Ministry politician reiterated the political rhetoric of 'democracy-construction-negotiation as process' and the fundamental importance of the conditionality free relations between the two countries (Zenker 2008).

This echoes the Mozambican struggle for self-determination, in my opinion. Mozambican Minister of Health Paulo Ivo Garrido stressed that cooperation between Brazil and Mozambique revolves around the fact that the two countries have common characteristics, such as common history, culture, and the struggle for emancipation (Monteiro 2007). Garrido pointed to their common history of Portuguese colonial domination and the urge of Mozambique and Brazil towards ownership of their respective processes. The key condition in the case of local ARV production would be whether Mozambique could make both a national and international market. This schism exemplifies the raw-cooked dichotomy. Investment in local production would produce competition and cheaper drugs, and it would decrease dependency on foreign provision of raw material. Production, processing, consumption, and profit making would become local. This process took off in 2008 with the support of Brazil, both in Mozambique, Nigeria, and Angola (ibid.).

Petra still faces insurmountable problems cooking the raw goods she receives from the World Food Programme. Moreover, the doctor and nurse could not make Petra understand the importance of taking the ARVs strictly on a daily basis. Yet, alcohol and cigarettes are within her reach, which stands in contrast to the numerous times she has been counselled about the importance of 'treatment adherence' and the need for 'nutritious and healthy food'.

This is a social security problem. It might jar on the ear to mention a government-managed system that provides monetary assistance and social benefits to the unemployed and disabled in an African context. Indeed, Africans welcome the World Food Programme assistance, but it is frustrating to see that the beans are so difficult to turn into edible food. That is, they are so hard that you need to boil them for 2-3 hours. This is not a cost-effective way of cooking. The associated fuel costs for poor people are out of proportion. Moreover, Petra lives a social situation of inextricable difficulties: unimaginable bad housing, surrounded by a heavy disease cocktail of sewage water, garbage, stagnant water, mosquitoes, toxic fumes, and social abandonment. Her daughter, who agreed to be her confidant by signing the informed consent contract – see Appendix 2 – left her in shame and disgrace, in favour of teenage life with her peers, boyfriend and mobile phone.

Tabula Rasa and Anti-Politics Machine

The raw-cooked nature-culture argument closely associates the 'tabula rasa' (Matsinhe 2005) and 'anti-politics machine' (Ferguson 1994) arguments. First, 'tabula rasa' essentially means the absence of preconceived ideas or predetermin-

ed goals. In other words, too many policies and plans spoil real action. This points to the ubiquitous lack of documentation and the intrinsically absent culture of results. To the contrary, a culture of processes dominates the current policy scene. Matsinhe shows how some plans and policies survive from idea to sign off without much concern for their implementation. At worst, doing millions of things at the same time precludes doing any one thing successfully.

Take the example of the early responses to HIV and AIDS by the Global Programme on AIDS, GPA. The Medium Term Plans of Action were criticized for being too standardized with little attention to the context. Indeed, GPA and later UNAIDS changed their plans to meet local needs, but some unintended outcomes keep reverberating in the way local people perceive these plans. This produces countervailing criticism. This is part of Matsinhe's tabula rasa argument (Matsinhe 2005). *Tabula Rasa* evokes the story of how global discourses on HIV have been produced and reproduced in the Mozambican context. *Tabula Rasa* shows the gap between the expectations of donor led intervention and the reality on the ground. Moreover, *Tabula Rasa* exposes the normalisation of governance by exposing how the response to HIV ties into the government's existing elusive discourses and social imaginary concerned with 'nation building', 'development' and 'democracy'.

Admittedly, I also see it in terms of 'ghost discourses'. All actors engage in phantasmal talk. Phantasmal talk recounts how people blame and counter-blame without knowing how things work. Who is responsible for unsuccessful responses to HIV? People typically blame 'civil society', 'the government', 'the Ministry of Health', 'the UN', 'the World Bank', 'the IMF', and so on. Blaming the victim is also fashionable. 'We the people' gossip about our neighbouring tribe, without communicating and understanding how things work 'on the other side'. These *buracos*

grandes, 'humongous gaps', persist caused by insular positions in the age of 'multi-sectorial collaboration' against HIV. However, phantasmal talk should not be belittled but taken seriously as a particular form of grapevine social criticism.

The tabula rasa critic of AIDS responses resembles Ferguson's anti-politics machine argument of development failure (Ferguson 1994). Ferguson's fieldwork in Lesotho during the early 1980s coincided with the time when the virus attacking the immune system was discovered and given the name 'HIV' in the United States. Ferguson looked at development project performance, not at development promises or what development ought to be doing. Ferguson found that development projects in Lesotho do *not* reduce poverty, do *not* transform the country into a modern, capitalistic, and industrial economy, and do *not* facilitate independence. More generally, Ferguson maintains the missing connection between interests and outcomes as the leading thread of the anti-politics machine argument. Thus, Ferguson asserts the unpredictability and uncontrollability of development projects. In other words, the 'anti-politics machine' phenomenon shows how intentional plans transform into unintentional results via unforeseen structures and events.

Matsinhe maintains two specific meanings of tabula rasa related to the Mozambican response to HIV: tabula rasa on the one hand means that we miss a concrete notion of where we are going, despite many years of effort. This is about the lack of benchmarks. We lack historical antecedents of epidemic public health intervention that could be recycled against HIV. However, tabula rasa fundamentally means ignorance of the Mozambican social, cultural, historical, structural, and political context, much along the critic of development in Lesotho put forth by Ferguson. Both criticize donors in particular. Matsinhe uses the allegory of an empty bowl to emphasize this point. Many donors contribute to alleviate suffering from

HIV and AIDS. Nevertheless, they throw money into the empty bowl with one hand, while they keep a list of conditions in the other with little knowledge of the Mozambican reality (personal communication, Maputo 2005). It is a give-and-take situation. Aid for AIDS is not a gift, but conditional, with unrealistic time frames. This contributes to the 'lack of absorptive capacity' phenomenon and funding withdrawal caused by unreasonable deadlines and conditionality. On the other hand, this explains why the Mozambican government insists on its own pragmatic priorities and the need for a Mozambican ART model with all its inevitable limitations.

Ferguson and Matsinhe did not intend to point out the rights and wrongs about development, but the 'anti-politics machine' and the 'tabula rasa' arguments have dissected the development and AIDS apparatuses to improve our understanding of what they do over time. To play with the current AIDS slogan: Do they keep their promises? And in Fergusons' terms: Are outcomes comparable to intentions?

The point of comparing the two arguments here is to emphasize that perhaps nothing much has changed since the 1980s, when Ferguson did fieldwork in Lesotho, despite the event of HIV and the international call for an emergency response. An inbuilt warning appears, thinking with Ferguson: the simultaneous call for mainstreaming HIV and AIDS into development 'thinking' and 'action' may unintentionally result in the 'development as usual' phenomenon, when it *must* be 'HIV, AIDS and development as exceptional'.

Indeed, much *is* happening, as we have seen. The introduction of antiretroviral treatment in Mozambique has so far been a success story. However, the majority live and die without treatment and care. HIV and AIDS now form part of the poverty alleviation plan in Mozambique (Republic of Mozambique 2005), but this 'AIDS mainstreaming' was a slow and difficult political process.

Violence and Risk Environment: Theories of Access and Delivery

I will make the argument more compelling through the concepts of 'violence' and 'risk environment'. I have argued that the majority of people who cannot access medicines against HIV related diseases fall victims of structural violence (see Chapters 2, 3). However, we need to look at structural violence in the context of other kinds of indirect violence to see it as part of a risk environment. I use the access and delivery model (see Figure 3.1, p. 134) to show this. The access and delivery model helps us to understand how the effects of different kinds of indirect violence are received, reproduced, reinterpreted, and communicated. This may lead to solutions how we might break them down to advance access to HIV treatment. In terms of advocacy, this means focussing on individual and social barriers. Mozambicans call it 'sensitization', which pays attention to the 'smaller picture'. Let me turn to the 'bigger picture' through the violence perspective.

Structural Violence

Most Mozambicans cannot escape structural, symbolic, social, cultural, and everyday violence. The idea of 'structural violence' stems from Norwegian peace and conflict researcher Johan Galtung. As Galtung initially wrote:

> We shall refer to the type of violence where there is an actor that commits the violence as *personal* or *direct*, and to violence where there is no such actor as *structural* or *indirect* (Galtung 1969: 170, original emphasis).

Violence researchers have invoked this direct-indirect distinction to avoid mis-understanding. Structural violence is an indirect type. There is no perpetrator. Kohler and Alcock differentiate between 'behavioural violence', which involves an actor, and 'structural violence', which involves attributes of structure, for example 'maldistribution or lack of food, shelter, medical care, education, etc.' People who suffer or die from lack of necessities produce the output of structural violence, which relates structural violence to deprivation and inequity (Kohler and Alcock 1976: 343).

Galtung specifically defined structural violence as *social injustice*, to avoid the connotation of 'exploitation' (Galtung 1969: 171). Galtung thereby emphasized the unintentional nature of structural violence. Thus, structural violence differs from direct, physical violence. Structural violence is indirect, invisible, and *silent*. Moreover, structural violence is a *process*, as opposed to event-oriented direct violence. However, its simultaneous reference to change and status quo points to an inherent contradiction. Galtung initially said:

> Structural violence is silent, it does not show – it is essentially static, it
> *is* the tranquil waters. In a *static* society, personal violence will be
> registered, whereas structural violence may be seen as about as na-
> tural as the air around us (Galtung 1969: 173, original emphasis).

In other words, structural violence passes invisible and silent due to normalisation. This is how I argue that the success and failure of ARV provision constitute two sides of the coin of the constant struggle between the state of endemic socio-structural crisis, socio-structural (dis)order, political leadership, and international solidarity. However, the danger is normalisation: gradual indifference to everyday

violence, everyday death, and everyday loss of productive lives. Structural violence

'creeps in' around us and within us, *as* and *if* we choose resignation to indignation.

Twenty years later Galtung discussed the basic difference between direct,

structural, and cultural violence:

> Direct violence is an *event*; structural violence is a *process* with ups
> and downs; cultural violence is an *invariant*, a 'permanence' (Galtung
> 1990: 294, original emphasis).

Structural violence may take on new forms and become periodically static, which

reveals a slow process with pockets of inertia. The structural violence perspective

ties together much of what I have said about socio-structural (dis)order and (dis-

ease) normalisation. Consider the following definition:

> It is gradual, imperceptible, and normalized as the way things are
> done; it determines whose voice is systematically heard or ignored,
> who gets particular resources, and who goes without. In structural
> violence, agency is blurred and responsibility is unclear; there may
> not be any one person who directly harms another. Structural vio-
> lence normalizes unequal access to such social and economic resourc-
> es as education, wealth, quality housing, civic services, and political
> power (Opotow 2001: 102).

Normalisation involves several phenomena. First, three intrinsic phenomena relate

to normalisation within civil society: constricted voice, blurred agency, and un-

certain accountability (see Chapter 7, p. 347). Second, normalisation applies to

'working culture', 'business as usual', and 'governing mentality' (see Chapter 6, p.

300). Third, the analysis of 'People Living With ARVs' and 'People Living Without

ARVs' points to ARV treatment as a *boundary-making* technology (Biehl 2007b:

283). In other words, we accept the 'first come, first served' principle as the nor-malized way to provide access to treatment. Fourth, limited HIV testing may have become normalized. However, would it be fair to blame the victims who refrain from such testing? People often know the circumstances, trapped in hopelessness when they are rejected by the health system. We have heard that *'they are slow'*, *'the hospitals are full'* and *'it would be better to go home and die in my house'*. We have seen that the current AIDS case reporting system only captures nine percent of the estimated number. We have seen constant limited health system capacity, despite wilful initiatives backed by all the major donors in the world to improve the state of health infrastructure and increase the number of health workers train-ed in delivering ARVs.

Symbolic, Social, Cultural and Everyday Violence

Structural violence theory facilitates one important perspective to comprehend reality on the ground. However, an exclusive focus on structural violence fails to capture the multifaceted nature of how the experiences, limitations, and politics of ARV treatment in Mozambique interrelate. Therefore, I incorporate theories of symbolic, social, cultural, and everyday violence.

Bourdieu pointed to *unvoiced* forms of social and cultural domination as *symbolic* violence (Bourdieu 2000). We saw this in *how* and *why* ritualized events follow the prescribed order (see Chapter 7, pp. 329-342). We saw this in how the significance of hegemony lies in the *unsaid* (see p. 328). We have seen this impli-cated in all forms of silence discussed so far.

Social violence invariably parallels suffering as an effect of structural violence in the normalized sense. Local, national, and global social *orders* produce social violence, and as Kleinman goes on to say, with emotional effects: *"Violence creates (and reemerges from) fear, anger and loss – what might be called infrapolitical emotions"* (Kleinman 2000: 238).

Galtung defined *cultural* violence as those aspects of culture, for example language and ideology, which serve to justify or legitimize structural violence. Cultural violence makes structural violence look and feel right (Galtung 1990: 291). This is what I have suggested by the idea of disease normalisation, not in the senses of integrating HIV into normal health practice or the gradual understanding of HIV as other chronic diseases, but in the sense that HIV is another kind of suffering for which there is limited hope and health system capacity. People have seen so much suffering that they become comfortably numb, turn a blind eye, or develop fatalistic attitudes. This is the denial process. What is the point of testing for HIV, if you know or the rumour tells you that the 'hospitals are full'? This is the process of seclusion. This obviously includes the experience of *everyday* violence, which is the very act of normalisation that causes such violence to become invisible due to its omnipresence (Scheper-Hughes 1992; Scheper-Hughes 1996). Everyday violence in Mozambique includes absolute poverty, food insecurity, recurring drought and floods, some 20 endemic diseases, and sickness as we know it in the definition as *disorder* in its generic sense across a population in relation to macro-social, that is, economic, political, and institutional forces (Kleinman 1988).

All this affects the individual and social bodies. In other words, most Mozambicans living with HIV experience individual or collective deprivation. The types of indirect violence are recurring, if not constant. The question remains

whether 'the process' qualifies as an additional type of violence in light of the fact that Mozambicans invoke 'the process' as both explanation and excuse. Thus, 'the process' would be normalisation par excellence through this perspective.

At another level, the global discourse about 'keeping the promise' resonates the local of a 'prosperous future'. More precisely, the social imaginary of the political rhetoric promises 'progress', 'sovereignty', and 'glory'. FRELIMO has promised 'health care for all' since independence and *the struggle continues*. This is what resembles millenarianism, evading the past, looking to a prosperous future filled with peace, harmony and an environment free of risk and disease, as I analyze elsewhere (Høg 2006). I have no doubts about the good intentions when I see or hear slogans like 'orgulhosamente Moçambicano' – 'proudly Mozambican' – but one question remains inescapable: how many people find it insulting given the circumstances of particularly structural and cultural violence? Which ones can be permanently eradicated? What is the point in promoting personal pride that you cannot eat, whether the locus is sexual behaviour, conjugal responsibility, or living with chronic disease(s)? People want tangible changes, such as education, jobs, buying power, social security, etc. The Afrobarometer public attitude survey confirms this in many African countries (Afrobarometer Network 2004). In other words, 'Poor Pride' makes a virtue of necessity. In parallel, 'natural disasters' characterize the 'normalized' picture of Mozambique, enshrined in the course and lure of nature and in the provisions for donor support under dire circumstances.

The Process: Epidemiological vs. Therapeutic Citizenship

Reality is relentlessly merciless. In times of HIV, the government and civil society require people to take individual control of their lives under such circumstances and to learn the nature of the disease and its treatment. Public health has become individualized, what anthropologist Alex de Waal has coined 'epidemiological individualism' (de Waal 2008), with reference to Peter Baldwin's historical analysis of state responses to HIV (Baldwin 2005). Such rationale demands individual control (life, behaviour) and acquisition of sufficient knowledge about the nature of the disease to be able to move on with the process. Epidemiological individualism has been couched in terms of 'citizenship', which connotes duties and responsibilities more than rights and claims. On the treatment end of the process continuum, such individualism becomes 'therapeutic citizenship', by which physician-anthropologist Vinh-Kim Nguyen originally meant *"the ability to make claims on others for treatment based on one's disease status"* (Nguyen 2001: xiii).

The phrase 'on others' needs further scrutiny. In my opinion, therapeutic citizenship relates national and transnational components, but first a note of caution: the context of limited access to ARVs purchased out of the pocket in the Ivory Coast during the late 1990s differs from the context of free ARVs in Mozambique during the 2000s. Still, the issues at stake remain similar: people continue to make local claims for global solidarity, as patrons within the national boundaries fail to provide public goods. On the other hand, the transnational component relates to how poor people seek therapeutic asylum in another country.

Therapeutic citizenship may indicate the responsibility how to comply with the rules of medicine for life, particularly when seen in relation to the compelling

idea of 'epidemiological citizenship' (de Waal 2008). 'Treatment adherence' has become the mantra criteria for 'good therapeutic citizens'. In other words, the initiation and continuation phases require epidemiological and therapeutic citizens respectively. The initiation phase constitutes the trial of truth and understanding: recognize your disease status and understand its nature. Earlier I analysed these phases in terms of points of attrition (see Figure 3.2, p. 137). Here I expand the picture with *community phase* and *entry phase* (see Figure 8.2).

The community, entry, initiation and continuation phases constitute *rites of passage* in classical anthropological perspective (van Gennep 1960 (1908)). Van Gennep identified processes of socialization as rites of passage: baptism, puberty, confirmation, marriage, and death. Three phases characterize such rites: separation (pre-liminal), transition (liminal), and reintegration (post-liminal) (ibid.). Turner added that *"such rites indicate and constitute transitions between states"*, which includes personal states of health and societies in transition (Turner 1967: 93-94).

This supports the extended argument about the process. In the context of HIV, this means separation from society due to stigma and discrimination, numbed by the circumstance of limited access to health care, and not yet transformed into 'living positively' and 'living with ARVs', a process which gives rise to acceptance and reintegration into society. Thus, liminality relates to the transitional aspect of the process. As Robins notes, the process from 'living with AIDS' to 'living with ARVs' constitutes a near-death-back-to-life transition (Robins 2006).

THE PROCESS	COMMUNITY	ENTRY	INITIATION				CONTINUATION	
	Sensitization	'First Come First Served'	TEST•RESULT•CD4•RESULT				ART START•FOLLOW UP	
Points of Attrition	●	●	●	●	●	●	●	●
Counselling	Mozambicanization	-	Pre-Test	Post-Test	Pre-ART		ART	
Capacity	Activists	Demand/Supply	Health workers				Health workers	
Purpose	Awareness	-	Disease knowledge				Therapeutic knowledge	
Location	Community	Home-Hospital	CTH Centre				Day Hospital	

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Figure 8.2: The Process: Community, Entry, Initiation and Continuation Phases
Source: Fieldwork.
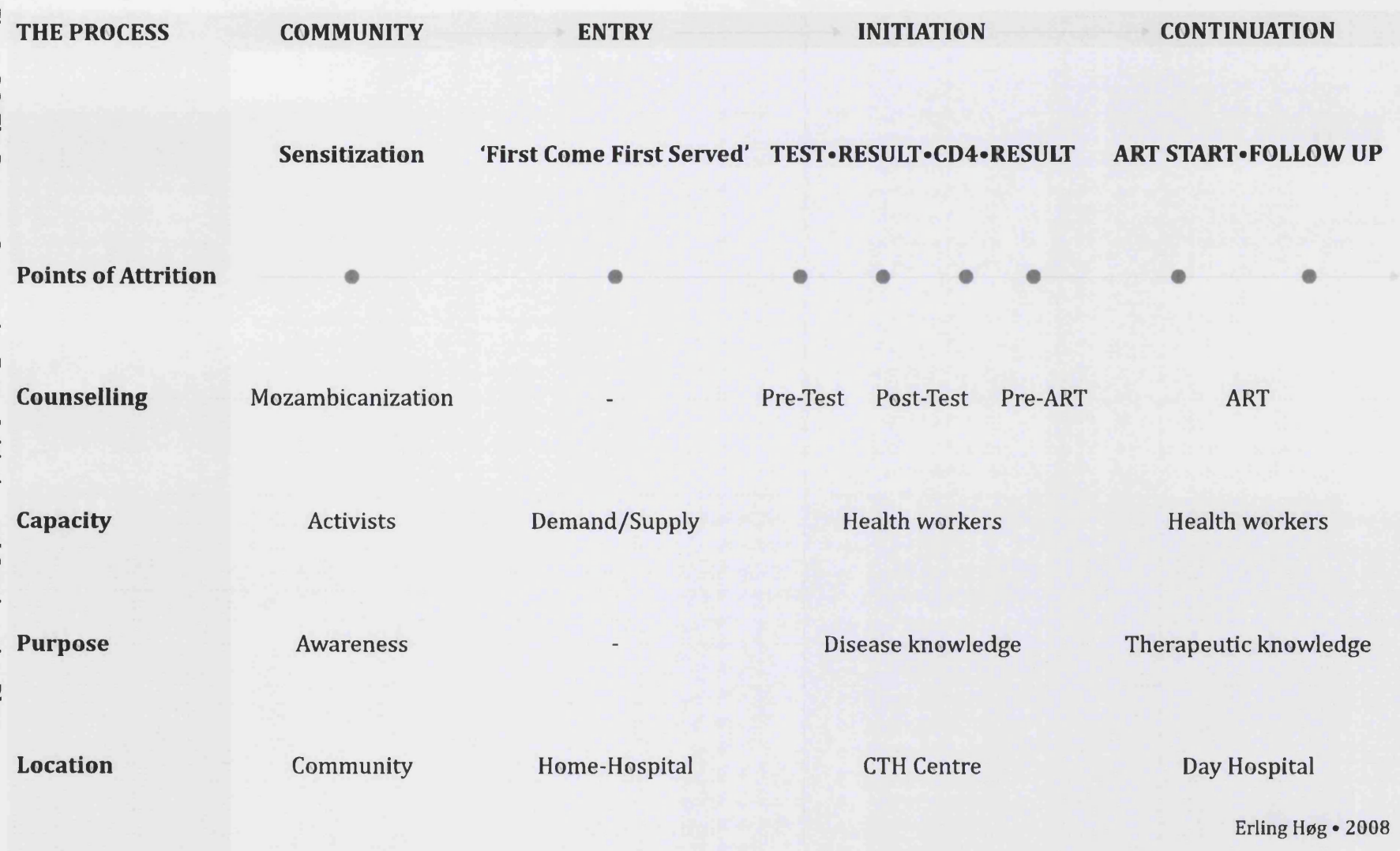
We have seen *rites of passage* throughout this analysis: people go through fire and water to get to the promised land of medical treatment. They will be deemed qualified by individual medical and social criteria, which at the end of the day may not be very transparent. They need to learn more than the basics of disease theory, which indeed has been simplified to fit lay vernacular, but still remains significantly complex. The points of attrition analysis shows how people encounter battlefields of obstructions, between home and clinic, among friends and foes, likely up to three months before the initial trial is over and treatment can begin. Patients need to promise good therapeutic citizenship by signing a contract with the health services. A Samaritan citizen, the good friend, who is not a health worker, nor an activist, but an essential supporter under dire circumstances and complicated medical regimen, will accompany each patient.

The community phase constitutes the separation phase. Infected individuals undergo 'treatment literacy workshops' in discrete location, not entirely in familiar surroundings, towards the discovery of a new identity. The entry and initiation phases constitute the betwixt and between liminal phase, the core of the process. In Turner's definition, the 'betwixt and between' phase separates people from society where they undergo transformation before reintegration (Turner 1967). The successful individual is then reintegrated into a new group and assigned a new social status during the continuation phase: 'Living With ARVs'.

Mafalda is an example. At first she felt like: *"I'm dead! It's not worth it going on like this. I am already dead! What's left for me?"* She struggled with her own inner chaos and her deteriorating health, the violence encountered among friends and colleagues, Kindlimuka sensitization, and her encounter with the health system. Then she said: *"I will never forget Doutora Lauana! She counselled me so well*

about my future path and all." Finally, after a long process facing individual, social, and system barriers, Mafalda expressed her experience overcoming them: *"I am free! I feel well! I really feel well! I am no longer thinking that I am going to die just like that, though I know that death is my destiny"* (see Chapter 5, pp. 217-224).

The process constitutes a series of rites of passages sine qua none. The process is both bottleneck and essence. The question remains, whether the initiatory process is too long in an emergency. A study from Beira shows an average of 72 days between ART eligibility and ART start (Ministry of Health 2006a) (see Chapter 2, pp. 120). Is this acceptable?[7] How do we reconcile time saving procedures and quality treatment? In fact, the initiation phase has been celebrated as the main reason to explain the success of the Mozambican model. However, psychosocial support may become undermined in search of a shorter process, giving priority to medical procedures. This would be a mistake. As Robins argues, it is the very experience of the rites of passage in the process that produce people living with ARVs committed to a new life and social activism (Robins 2006).

Sensitization Revisited

This chapter focuses on circumstances: condition, context, poverty, deprivation, and injustice. I positioned the idea of sensitization within the process constituted by *community, entry, initiation* and *continuation* phases. Sensitization has become an integrated part of the Mozambican model and Mozambican treatment advocacy. The government defines sensitization as a responsible, stepwise approach to community preparedness. The tools are *community palestras* and *community radio.*

Treatment is announced locally, when the local Day Hospital is ready. AIDS activists, who have been trained under the auspices of the Ministry of Health as a reinvention of Mozambican community health agents, communicate the messages. MATRAM – the *'unnameable'* social movement – then joins in to offer its own community preparedness, sponsored by international organisations. MATRAM maintains that sensitization should offer more than counselling and testing.

Treatment Literacy: Towards Universal Access

Patients who succeed the first three phases arrive at the door to the continuation phase: life with ARVs. They need to be well informed about medical treatment of HIV related diseases in order to comply the rules of the regimen. This is called 'treatment literacy', which is part of the process within the Mozambican model, but the access movement MATRAM has taken initiative to do more than that. MATRAM maintains that people are not sufficiently prepared to take ARVs. MATRAM therefore offers treatment literacy workshops to expand the team of activist teachers across Mozambique. As Lucas says: *"We continue to train people. People who sensitize others do not have sufficient knowledge about HIV. Activists receive training, but they don't have sufficient information about what HIV does in the body. People who go through the phases don't have this knowledge either. This is the reason why people do not have this notion when HIV can be treated and when and how you can detect it in the community. People in the bush still have this and that problem without knowing what to do."*

Treatment literacy workshops started with the help of the South African Treat-ment Access Campaign in 2004. MATRAM members received training in Johannes-burg. Then they adapted the new knowledge to the Mozambican context and offer-ed the first treatment literacy workshops in 2006 in six provinces. This was initial-ly a successful initiative, but MATRAM had insufficient funding to sustain it. They also faced a low level of basic knowledge among the workshop participants. Lucas said: *"Local participants don't really understand what this is."* Workshops therefore needed to start out from the very basics of HIV, AIDS, and ARVs, as was the case for the Sant'Egidio ART training programme for health workers (see Chapter 5, pp. 254-255). Lucas said about the MATRAM workshops: *"This is a good programme, because it empowers people with training. This is the capacity building that people need. This is about opportunistic infections. This is a people-led process. The best doc-tor is the patient. The patient knows when it hurts and what he feels, and therefore the one who needs to know what to do. This needs to be managed at the community level. This is very important."*

However, definitions of 'access to treatment', 'universal access', 'access for all', and 'universal coverage' coexist. It is easier to define these aspirations in socie-ties where citizens enjoy social security and a high standard of living. Medical solu-tions are quickly challenged, when poverty and deprivation is the norm. In fact, UNAIDS tried to define what 'universal access' is *not*. Universal access is not about new global targets, it is not about developing new plans and frameworks, and it is not universal coverage. MATRAM understands it as adequate access to information to obtain comprehensive treatment, prevention, care, and support at any service point of the health system. Lucas says: *"If you look at the treatment literacy pro-gram we are doing, then you will see that people need a lot of information. Everyone*

knows what HIV is. There are so many who have it, but you need empowerment to prevent yourself. It is not just about spreading the information and then people will consume it. There is so much work to do. Empower the people."

The advancements in medical treatment and social activism have come together in what Nguyen calls biosocial change, which materialized into therapeutic citizenship. This is the paradox of deprivation. Illness claims seem to be the only way to challenge the uncertainties in life and the violence that people live (Nguyen 2001: 306-307). In other words, people are poor and hungry; they struggle for everyday survival. They cannot survive on ARVs. People who live *with or without* HIV need immediate social support and livelihood improvement.

There are many more advocacy organisations than patient organisations. Most advocacy organisations do not deal with real life on the ground, but they receive more funding than patient organisations and support groups. Thus, the latter ones need a bigger piece of the donor cake. Yet, ARV treatment saves some lives, but socioeconomic development would save most lives. This unfortunately raises questions of affirmative action on behalf of those who live with the virus. Are some people better off *living with than without* the HIV virus?

The New Message: 'An Opportunity to Live'

The Ministry of Health does recognize the need to change the message from 'AIDS Kills' to 'An Opportunity to Live', but the key question remains whether and how such advocacy initiatives will be able to consider the delicate demand/supply balance. The Ministry of Health maintains a 'stepwise and responsible' approach, but

the more infrastructure and human resources, the more people on treatment, the more people know about treatment. Such news travels fast by word of mouth.

We know the numbers of people in need of treatment and on treatment. We have seen how these numbers increase and diverge with epidemic evolution. The number in need increases faster than the number of ARV patients, despite the significant ARV rollout within a limited time span since 2004. Yet, how do we respond to informed structural violence? The fact that many people have died and are dying in ignorance, invisible and silent, points to one moral dilemma, which is partly alleviated by stoic pragmatism. In other words, a commonsensical if not businesslike attitude towards the process prevails and policy makers insist that human rights based voluntary testing is the way forward.

Nonetheless, there are two empty slots in the figure representing the therapeutic process (see Figure 8.2, p. 385). These slots pertain to the 'first come first served' principle: how do we responsibly counsel people who are rejected at the hospital door? Thinking with Turner (Turner 1967: 96), do we pragmatically accept the transition from 'structural invisibility' to 'structural death'? That is, people live and die with HIV on the margins of the successful Mozambican model. The majority of people with HIV fail to join or be absorbed into the fortunate minority 'living with ARVs'. Is this merely an infelicitous but unavoidable outpouring of the Mozambican model of otherwise successful rites of passage? As Biehl reminds us, AIDS therapies are *boundary-making* technologies (Biehl 2007b: 283): People with HIV end up 'living with ARVs' or 'living and dying without ARVs'. 'Come first, be first served' is low cost ethics.

The Mozambican government maintains that a nationwide ART information campaign would be irresponsible public health policy that would invite social criti-

cism. However, such scenario may come closer with ARV treatment available in all 128 districts. Indeed, the rapid expansion of ART to reach more than 100,000 people between 2004 and 2008 deserves to be widely told as a success story. However, the epidemiological narrative reminds us that the number of people in need in 2007 was estimated at 370,000 within the range between 290,000 and 460,000 (WHO/UNAIDS/UNICEF 2008), which equals 667 full Boeing Airbuses, or 4 full stadiums the size of Wembley, or more than the entire population of Nampula City. Numbers fluctuate with changing epidemiological 'best estimates' and it is impossible to count the invisible patients with advanced HIV. However, more people get the message about ARV treatment, when more people gain access to the Day Hospitals. At the same time, the increase in the number of health workers cannot keep up. Health workers on the ground invariably say that the number of people in need of treatment *must* be bigger than what is estimated, though they do not see or deal with the bigger epidemiological picture. What they see is a 'leaking dam full of holes', as we saw in Chapter 5. All this is about health system capacity, the politics of human resources, epidemiological uncertainty, the context and socioeconomic circumstances, the balance between hope and hopelessness, and how to deal with failed treatment expectations. This is why the composite analysis of risk environment, structural, symbolic, social, cultural and everyday violence matters.

Conclusion

Conclusion

This multi-site study looked at what is 'ethnographically in the picture' (Marcus 1998: 85) focussed on ART access and delivery in the context of abundant financial resources and free generic drugs in a hard-hit poor country like Mozambique. The ongoing ARV rollout demonstrates a countervailing process between the experiences, limitations, and politics of ill health. I have shown this by looking at the HIV epidemic as a 'long wave event' (Barnett 2006), utilizing appropriate methods to capture its changing nature in terms of experience living with the virus, natural disease history, epidemiology, health system capacity, advocacy, the political history of health, and socio-economic circumstances. This captures a time perspective of the epidemic, which is convenient for discussing policy implications. In fact, this ethnography provides a unique source of information for improving 'patient tracking and support systems'. The access and delivery model, which embraces all of this, promises a versatile tool for policy makers beyond the Mozambican context.

Uniqueness

The access and delivery model captures the main argument: the interrelatedness of individual, social, and political processes. The study thereby deviates from classical adherence, stigma and discrimination, civil society, and governance studies, which tend to focus exclusively on the patient, society, or political institutions. This

has implications for how we perceive health seeking behaviour. Health seeking behaviour depends on individual circumstances, the social environment, and the political will to improve health system capacity. I analyzed the therapeutic process as a series of rites of passage, in which patients encounter a series of potential points of attrition: community, entry, initiation, and continuation phases. I therefore analyzed 'living with ARVs' and 'living without ARVs' separately. Successful ARV roll-out depends on context, experience, timing, and preparedness considering the socioeconomic, historical, cultural, and political circumstances. Such micro-macro anthropology evidently recognizes two sides of the coin: success and failure, which I have shown to be a constant struggle between the state of endemic socio-structural crisis, socio-structural (dis)order, political leadership, and international solidarity, against the creeping and concrete reality of normalization of life and death. The rapid ART scale-up between 2004 and 2008 is almost unparalleled in Southern African countries with weak health systems. The Mozambican government created its own unique medico-cultural *Mozambican model*, which differs from the simplified *public health model*, applied in Malawi (Harries, et al. 2006), and the *mandatory testing model*, applied in Botswana (Weiser, et al. 2006). Counselling and Testing for Health is the third unique component of the Mozambican response to the need for ART. CTH replaced VCT to advocate provider initiated voluntary HIV testing as part of a comprehensive consultation of overall health. The government aims at AIDS normalisation within the health system to minimise stigma and discrimination. Development partnerships through respect for national priorities, the context specific model, and the innovative 'counselling and testing for health' all deserve to be widely advocated.

The Double Struggle

This relates to the pragmatics of the Mozambican model: it recognizes the limitations of the Mozambican context by proposing a 'gentle and stepwise' process for ARV expansion. The Mozambican government aims at a responsible public health policy under the circumstances of a weak but expanding health system. However, it faces the double struggle to maintain sovereignty in the process of negotiating donor support to resurrect and maintain its health system to service all its citizens. This has been the FRELIMO dream since independence in 1975. However, this process is a double edged sword, as the HIV epidemic arrived as yet another cause of increased dependency on foreign aid, thus with an unwanted impact on the nation-building process. This is not unique to Mozambique. However, the point here is significant: health care remains a native reserve for FRELIMO. Health care provision is not for sale – without proper negotiation towards solidarity with the FRELIMO development project. However, I have cautioned against the difference between discourse, rhetoric, and reality. The idea of 'ownership' remains contested, but perhaps evident from seeing who pays the bill. Nevertheless, I have pushed the argument by taking the politicized discourse at face value: the Mozambican government cherishes sovereignty *at any cost*. The government favours the fate of Mozambicans in the name of self-determination – *with or without HIV*. This raises the question how many lives have been sacrificed in the name of nationalized health and the Mozambican ART model, by which the government seeks to avoid private health care and insists that Mozambicans in the end must exclusively do the job. Foreign health workers, Russian and Cuban *cooperantes* in particular, have been dismissed during this process, while the government simultaneously pro-

claims that lack of health workers remains the biggest challenge for the future sustainability of its ART programme. This may seem an absurd contradiction, but it remains part of the nation-building process.

Nevertheless, the introduction of ARV treatment has been a complicated yet successful fix of the political process. The question remains how to sustain ARV treatment and how to solve the human resource problem in the short and long run. People have indeed come forward for testing and treatment with increased ART availability fighting against stigma and discrimination. I applied a multi-dimensional understanding of stigma that considers its temporality to understand it as countervailing social and political processes that hinge on health system capacity and public information campaigns. On the other hand, I pointed to how the majority of people who cannot access medicines against HIV related diseases fall victim to a cocktail of indirect violence: structural, cultural, social, symbolic and everyday violence. I looked to the history of colonialism, war, and socialism in the context of poverty, deprivation, and inequality to discuss this.

A plethora of 'AIDS NGOs' emerged within this scenario, which from my experience necessitated a new way of perceiving the relations between state, civil society, and donors. I have argued for stratification between intimate, strategic, and distant civil society, caused by government alignment, donor alignment, and double donor-government alignment. Such proximity to power analysis helps us to understand the scaling of recognition and funding.

The access and delivery model helps us to understand how the effects of different kinds of violence are received, reproduced, reinterpreted, and communicated. Indeed, the Mozambican government recognizes the HIV epidemic and it has shown commitment towards ART expansion. However, the human resource ques-

tion remains highly politicized. It must be Mozambican health workers to do the job, but I have shown that 'essential human resources' arrived much later than 'essential drugs' on the donor agenda. Therefore, we have not seen the Mozambican reaction to an eventual dramatic increase in funding for health workers. Would they be as pragmatic as in the case of negotiating medicines and infrastructure, if such funding was earmarked a higher number of foreign health workers? Alternatively, would the Mozambican government stay firm on its Mozambican empowerment project? The human resource issue will remain the key political question in the ART era, as more countries manage to improve health infrastructure. What about the number, welfare, and payment of health workers? Can the world accept that we have to train a new generation of health workers before scaling up quality ARV treatment? Will affirmative action upon Mozambican ART health workers undermine the attention needed to the towering burden of disease? Does the international community have to respect national reservations in the name of sovereignty? Should donors grant unconditional funding for training of local health workers? Scholarships for the medical and nursing schools in Mozambique would be urgently needed. The other side of the coin tells us that the number of people in need of treatment grows much faster than the number of trained health workers. At the same time, I doubt that the international community in an apolitical world would be able to recruit the number of 'volunteering' and 'humanitarian' health workers needed in poor countries.

I say this to point out the versatility of the access and delivery model: it can be evaluated in different contexts. In fact, this already happened during fieldwork. I presented the model at the World Bank Treatment Acceleration Programme, TAP, meeting in Maputo, June 2006. Governments of Mozambique, Ghana and Burkina

Faso participated with all key members of their National AIDS Programmes and National AIDS Councils, as well as the international community, represented by the World Bank, UNAIDS, UNICEF, UNDP, WFP, WHO, Clinton Foundation, CDC, international treatment organisations, and civil society. This was a two-day meeting on the state of implementation of the TAP programme. I presented the model in one of the sessions. Country representatives were given four questions: What are the questions we do not know the answers to yet? What can the countries learn from each other for each of the 12 barriers? How can a patient tracking system improve access in light of the 12 barriers? What are its limits?

The discussion focussed on four related issues: 1) how to guarantee sustainable delivery of drugs for an increasing number of patients, 2) how to integrate treatment and food support, 3) how to guarantee adherence, and 4) how to avoid resistance. This all came together in a discussion how to sustain the finances for ARVs into the future. The Ministry of Finance maintained it had few options of finding or giving money, including lack of taxing systems. The three countries want grants, not loans, in order to avoid burdening African state budgets any further. All this invariably has implications for both social and medical support policies.

Implications

This leads to the policy implications of this study. However, first a relevant question: which policy implications would be approvable for the particular purpose of advancing the quality of ARV treatment without compromising some of the cautions I have made throughout this thesis about the production of social difference

and the inevitable affirmative action bestowed upon 'People Living With ARVs'?

Mozambique needs overall improvement in terms of socioeconomic development,

which would primarily improve the state of public health through immediate

attention to water and sanitation, housing, and garbage collection. Obviously, some

would immediately rebut this assertion on the argument that this is already hap-

pening, but it is a slow process for the majority of poor people. However, the need

to improve the 'patient tracking and support system' is the major policy implica-

tion of this study, focussed on the smaller picture of ARV treatment. In other

words, the Mozambican model needs to be more public health oriented.

The Challenges of A Patient Tracking and Support System

The 'patient tracking and support system' emphasizes the need for socio-medical

improvement of the therapeutic process, which I have shown to include all encoun-

ters with the health system from HIV testing to life with ARVs. Detailed informa-

tion is available to make informed policy choices. First, culturally informed mes-

sages have become paramount. Mozambique has taken the lead through 'Mozambi-

canization' and 'sensitization' (see Chapter 1, pp. 62, 70, Chapter 2, p. 123, Chapter

3, p. 167, and Chapter 4, p. 191). Nevertheless, this process would speed up, if

people of local cultures were involved much earlier producing bona fide prototype

HIV, AIDS, and ARV information instead of troublesome translation of foreign

made material, which at the end of the day ends up diluted and distorted. Second,

the analysis of HIV testing points to four policy implications: target couples (see

Chapter 2, pp. 111, 115, and Chapter 3, p. 148), target men (see Chapter 2, pp. 111,

127), target people tested HIV negative (see Chapter 2, p. 108), and target overall health (see Chapter 2, pp. 106, 109).

Most people would benefit from all kinds of social service, as we have heard that *"Visiting a poor community you see poor people"* and *"Social problems are found in all patients. They have no job, no food, no money, and no security."* Therefore, I do not want to advance policy principles that make people with HIV better off than people without HIV. On the other hand, we want to avoid absurd singularization of the access process, exclusively focussed on access to medicines, which Biehl has coined *pharmaceuticalization of public health* (Biehl 2007a). The truth is that people, whether they live with or without HIV, look for access to a better life.

However, the UNAIDS principle 'make the money work' does make a perfect point towards improving life for those infected with HIV, considering the absurdly huge amount of money that remains unspent at the end of a budget year. The suggestion is simple: spend the money to improve the patient tracking system and Day Hospital outreach activities. Harmonize this across all treatment implementers. Perhaps this is not even a new suggestion: all this may already be part of the harmonization process led by the Ministry of Health. However, I have claimed that the 'process argument' is used as both explanation and excuse for slow progress. The approach to ARV treatment in Mozambique, and other poor countries, is essentially pragmatic not idealistic. Nevertheless, this study shows the fragmentary manner by which outreach activities are carried out at different day hospitals (see Chapter 8, p. 357). The improvement of outreach activities needs involvement of more ministries and a general commitment to improve social services.

However, I see a schism in this scenario between the argument of 'limited absorption and absorptive capacity' and 'limited distributive will'. This stands out

most convincingly in the analysis of social order and inbuilt perceptions of entitle-

ment, class, and ethnicity. People who live with HIV struggle for daily survival

against the social mores and political winds. Individual patients without means for

associational membership have no chance of immediate social support. The prob-

lem is political and logistical (see Chapter 8, pp. 356-373).

Activist home visitors only reach a fraction of those in need of a caring soul.

Day Hospitals need money to purchase vehicles (ambulances, visitor cars) and to

pay for bus tickets for their activists or to buy them bicycles so they can visit those

who live far away.

Mozambique is short of health workers. The entire Mozambican health

worker force would not be able to care for everyone in need of ARVs. However, the

ones trained in ART also need additional skills. They need training how to monitor

drug resistance and how to keep a patient tracking system to systematically follow

the entire therapeutic process of community, entry, initiation, and continuation

phases (see Chapter 8, p. 385). Money and drugs have so far not been the problem

in Mozambique. The big picture reveals the need to channel funding into training

of Mozambican health workers: improve the infrastructure of medical schools and

nursing schools. Provide large numbers of unconditional scholarships. Use the

make-the-money-work principle in pro-active, innovative, and constructive ways.

The relatively few 'patient organisations' in relation to the number of 'AIDS

organisations' is thought provoking. Indeed, some development projects address

the widespread issue of 'food insecurity', but then there are still countless hungry

people turning visible, popping up from their hideaway, begging for food. The

current structures do not allow immediate access for hungry individuals. Would

public soup kitchens be too much to ask in the post-socialist era governed by ego

rules? Would a combined social and medical outreach team at every Day Hospital go beyond budgetary limits? Indeed, words travel fast in Mozambique. Poor people hear the news about food provision at Day Hospitals and thus believe they can receive social support regardless of health status. Day Hospitals are not and should not turn into social offices. Still, the need to improve the patient tracking system requires on site support groups, home based care, home visitors, and a regular search for dropouts. Home based care initiatives are already in the making. In any case, combined social and medical support necessitates political leadership beyond the Ministry of Health, taking the promises of 'Ministerial HIV/AIDS Focal Points', 'multi-sectoriality', and 'AIDS mainstreaming with poverty reduction' seriously beyond mere lip service. Yet, blaming the ministries for lack of commitment would be unfair and simplistic. There is a need to focus attention beyond health to boost other kinds of state services by means of 'ministerial capacity building projects'. The access and delivery model provides a starting point for looking at treatment of HIV related diseases in a holistic manner. DANIDA leads the way by offering a postgraduate course in HIV management in Mozambique from early 2009.

I am short of words how to deal with failed treatment expectations (see Chapter 8, p. 355). The world handles this dilemma hiding behind the 'first come first served' principle. Would the most humanitarian approach be to evacuate the unfortunate ones to countries where they could benefit from health care services, under the wings of therapeutic citizenship? This would be unfair affirmative action upon those infected with HIV. With this comes another full circle: I am back to the wish for socioeconomic development to solve problems within the bigger picture of indirect violence, poverty, deprivation, and injustice.

Future Research

Stop and stay at many of the points of the access and delivery landscape I have visited, described, and analyzed. Anthropological studies would look at adherence, dropouts, absent patients, the patient-confidant relationship, the patient-practitioner encounter, health worker lives, and the role of traditional medicine. These topics could be subsumed under the umbrella 'life with or without ARVs'.

Life With or Without ARVs

This is an undeveloped research area, which requires social researchers to follow the ones living with ARVs and the ones delivering ARVs through extended fieldwork. Follow people on ARVs, as they move on with life in time and space. Research on the patient-confidant relationship could reveal important insights living with ARVs away from the health system, at home and in the community, to improve treatment adherence. We need to examine access to ARV treatment from a community perspective across the cultural heterogeneity of Mozambique. The government offers ARV treatment at 216 sites in all districts of Mozambique. However, the heterogeneous nature of the demand-supply balance across Mozambique is poorly understood and a question that I have not been able to answer definitively. We need a research team in each province to improve our understanding of this phenomenon. The patient-practitioner encounter could tell us about problems of communication to improve services, as well as patient trust and confidence in health workers. Hospital ethnography gives us health workers' points of view: they

are the experts delivering ARVs and thus ought to know how to improve their use.
Failed treatment expectations challenge the anthropological endeavour. Studies
would need to look at points of attrition within the therapeutic process: follow the
ones rejected by the health system and the ones that choose to stay away despite
being well counselled. Additionally, attend to how treatment providers could find
solutions to such dilemmas (cf. Bernays, et al. 2007). 'The absent patient', counsel-
led and ready to start ARV treatment, is a particular phenomenon that would entail
research within the health system and within the community: where and why do
things go wrong?

I have included several research topics that reach beyond the patient focus:
prevention studies, impact and mitigation, health system research, governance, ac-
tion, and holistic studies (see Chapter 4, p. 181). In particular, I emphasize the per-
tinent need for ART governance studies to provide insider perspectives on the
problems and challenges faced by ministries of health. For example, senior mem-
bers of the Mozambican ARV Committee have been assigned responsibility for par-
ticular provinces. An anthropologist could follow them and systematically examine
work at the provincial level, problems, and solutions encountered, and then finally
compare and analyze all the data to improve ART policies.

The Process

"But it's a process." Consider this expression for a moment: *"Mais é um processo"*. It
is simple to say, yet said with such profundity realizing the circumstances, the ex-
periences, limitations, and politics of ARV treatment, a sense of time, and a sign of

hope and confidence. Gilberto, Ângela, Jerónimo, Sergio, Osvaldo, Lúcio, and others: they all said it at some point during our conversations. They initially gave an enthusiastic explanation of the reality of the individual, social, or political barriers to be overcome to gain access to treatment. Then at the end the realization of the circumstances, said with a down-pitched lowering intonation: *"But it's a process."*

Courage to Live

Gilberto said it in relation to having the courage to overcome fear and shame and to break down stigma and discrimination among his social encounters, but also in relation to ongoing bureaucratic and political processes. Fausto talked about how to overcome traditional medical malpractice. Jerónimo referred to the fate of partnerships, civil society, and the course of human rights: *"I prefer to say that we are in a process; a stepping process towards favouring human rights. I really believe that we some day will be able to work in partnership."* Ângela said: *"It's all a process"*, thinking in terms of advocacy.

Lúcio said it relation to how the United Nations is more preoccupied working in processes, less concerned with results. Sergio at the National AIDS Council also admitted working too much in processes, less preoccupied with results. Sergio hesitated at first in response to my question about possible weaknesses of the National AIDS Council, as if this had never entered his mind. However, he then admitted: *"I would say that the big difficulty we have is how to move towards showing results. We are working a lot in processes. We talk a lot about disbursements but not about results x and y."*

Guilherme and others insisted a historical understanding of the process, comparing the development of Mozambique with European countries centuries ago. *"It's a process. We are a growing country. The steps that we are seeing in Mozambique are comparable to situations that developed countries lived one hundred or two hundred years ago. We are unfortunately late, when we talk in historical terms. The circumstances that we live in Mozambique is a situation that Italy lived for I don't know how many centuries ago, which means that it's a process. We need a lot of time to reach the level they have reached. It will take time, it's a process. Do you understand? It is a process."*

Osvaldo also said it in those terms. *"At the bottom of things I would say that this is a process. It's a process that will take many years. Perhaps in 30 years with all the difficulties we have, we will see that this social structure will work well. It's difficult. It's not easy to make it work."*

Many realize the process in this last sense: only socioeconomic development *by and for Mozambicans* will take Mozambique forward. The progress of England was not about advancement in health, they say, but about economic development, hygiene, water and sanitation. Many Englishmen died during this process. Therefore, there is a certain level of acceptance among Mozambicans high and low that many people will inevitably die during the process of the Mozambican HIV epidemic, referring to historical antecedents. However, this turns us back full circle to how I have showed that the political process relates to ownership of the development process. FRELIMO continues to struggle for self-determination as a sovereign nation with the HIV epidemic as a symbolic and concrete reminder.

Notes

Introduction

1 The location of the Sant'Egidio DREAM project is not included on this map, as it is located in Matola, the sister city of Maputo.

2 The medical record is called *o processo clínico* – 'the clinical process' – in Portuguese. In every-day language, this is called *o processo*, the process.

3 In fact, Mozambican primary health care became a successful example of the WHO promoted goal towards "Health for All by the Year 2000" (WHO 1978a) during the creative period 1975-1982 (Noormahomed 1991; Walt and Cliff 1986), yet we can see now 30 years later that both continue to reflect local and global social imaginaries.

1 Living With ARVs

1 'Late presenters' is a phenomenon across the world in varying numbers: Western countries, 10-30%, when CD4 T cells are below 200 cells/ml and symptomatic HIV disease has occurred (Battegay, et al. 2008), England and Wales 2000-2004, 42% (Chadborn, et al. 2006), France 2004, 40% (Delpierre, et al. 2007), Italy 1997-2000, 28.9% (Girardi, et al. 2007), Canada 1996-2001, 39% (Krentz, et al. 2004). A study in Haiti found 65% late presenters, defined as testers with CD4 cell count below 350 cells/ml (Louis, et al. 2007). Studies of this phenomenon are conspicuously absent for African countries.

2 The CD4 count indicates a person's state of health. CD4 cells help the immune system to protect against infection. Generally, the World Health Organisation recommends antiretroviral treatment for people living with HIV, when they have a CD4 count lower than 200 (WHO 2005).

3 The public assassinations of journalist Carlos Cardoso in 2000 and the government's head of banking supervision António Siba-Siba Macuacua in 2001 in connection to major bank scandals serve as reference points for people's reluctance to talk about public and political matters. Such events easily reverberate with a numbing effect among the citizens. The circumstances of these assassinations have been extensively covered elsewhere (Fauvet and Mosse 2003; Hanlon 2004; Hodges and Tibana 2004).

2 Living Without ARVs

1 Epidemiological studies operate with 'best estimates' at any given point in time. For example, UNAIDS revised its assumptions in 2007, based on 30 population-based surveys that found HIV prevalence to be 20 percent lower than sentinel-based surveys. UNAIDS therefore made a downward adjustment to a level of approximately 0.8 times the prevalence found in antenatal clinic surveillance in countries without population-based surveys to provide a more accurate estimate of the number HIV infected people. UNAIDS therefore lowered the number of Mozambicans estimated to be living with HIV from 1.8 to 1.5 million in 2007 (UNAIDS 2008).

2 Botswana had sufficient health system capacity to offer mandatory testing to reach out for people in need of ARVs (Weiser, et al. 2006). 72,000 people were on ARVs by the end of 2005, which was 85 percent of the estimated need (UNAIDS/WHO 2006b).

3 The UNAIDS 2007 epidemic update reveals substantial changes in the number of people living with HIV worldwide, due to improved surveillance methods. Recent data from India and Southern Africa explain the decrease in number of people living with HIV. The exception was Mozambique. Though inconsistent on its analysis of Mozambique, the report specifies: *"Only in Mozambique latest HIV data (in 2005) have shown an increase in prevalence over the previous surveillance period"* (UNAIDS 2007: 15).

4 A higher number of people coming forward for HIV testing would thus be expected for the years 2006 and beyond.

5 Major TV channels like TVM, STV, and Miramar broadcast HIV information almost every day, sometimes several times a day, but almost exclusively about prevention. The 1997 census found that only 5 percent of the households had electricity, but 28.1 percent had radio (National Institute of Statistics 1997). Households with electricity had increased to 8.1 percent in 2003 (National Institute of Statistics 2005). Electrification of Mozambique has been one of the highest government priorities, supported by donors. In fact, President Guebuza proclaimed in August 2008 that the expansions in education, health services, electricity, and telecommunication have been the major factors in overcoming poverty since the end of the civil war in 1992 (AIM 2008). However, at the time of writing, basic services data from the third census in 2007 were not available, only preliminary population results (National Institute of Statistics 2008).

6 It also puts the suggested criminalisation of HIV transmission in perspective.

4 Context

1 Two new exclusive social science HIV journals have appeared in South Africa that have not yet been assigned membership to the SSCI: African Journal of AIDS Research (2002) and Journal of Social Aspects of HIV/AIDS Research Alliance (2004). 191 country specific studies had been published by first quarter of 2008, which show a similar pattern to my SSCI analysis: English-speaking countries (92.7%), French-speaking (6.3%), and Portuguese-speaking (1.0%). Almost half the studies were conducted in South Africa (African Journal of AIDS Research 2008; Sahara Journal 2008).

2 Whether people still decide to have sex without condoms under these circumstances is another question. In other words, how does the availability and unavailability of condoms influence sexual behaviour and thus the transmission of HIV?

3 A composite set of factors influence the rate of HIV infection: nutritional and health environment (Stillwaggon 2006), poverty (Barnighausen, et al. 2007; Booysen and Summerton 2002; Gillespie, et al. 2007; Hargreaves, et al. 2008; Hargreaves, et al. 2007; Masanjala 2007), iatrogenic transmission (Gisselquist, et al. 2003; Gisselquist, et al. 2002; Gisselquist, et al. 2006; Hauri, et al. 2004), concurrent partnerships (Epstein 2007; Halperin and Epstein 2004; Lagarde, et al. 2001; Morris 2001; Morris and Kretzschmar 1997; Watts and May 1992), migration (Collins 2006), host susceptibility (Barnett and Whiteside 2006 (2002); Cohen 2004b; Royce, et al. 1997), stage of infection (Wawer, et al. 2005), and genetic factors (He, et al. 2008). This is plenty of material for a separate social science analysis. It will not be analyzed at length here.

4 The number of people on second line drugs was less than 2 percent in 2005, but their cost took up about 15 percent of the drug budget. The cost per patient per year for first line drugs was at 245 US dollars. Second line drugs came at the price of 2,621 US dollars per patient per year (Pharmaceutical Department 2005).

5 Delivering ARVs

1 Minimum wage provides limited purchasing power. Many rich and poor folks shop in neighbouring countries. Chapa minibuses leave Maputo for Swaziland and South Africa every day, starting at dawn. People mainly purchase large quantities of daily goods for personal consumption or for remarketing.

6 Politics

1 The first statement in this decree resembles early FRELIMO commitment to social services: "Patient Dignity and Satisfaction are the Thermometers of Our Performance" (Republic of Mozambique 2001). Samora Machel says in his 1976 hospital speech: "What was the people's reaction to the nationalizations? The people are our thermometer. This thermometer tells us whether we are right or wrong" (Machel 1985b: 147).

2 The Ministerial Decree was drafted and agreed upon before the price drop of antiretrovirals on the international market in 2001 due to generic competition. The cost of ARV drugs per patient

dropped from around 10,000 US dollars per year to around 350 dollars in early 2001, down to 132 dollars in July 2006 (Médecins Sans Frontières 2006).

3   Possible internal threats include abuse of power, anarchy, violence and corruption, as evidenced in the early post-independence years, which culminated in a speech by President Samora Machel entitled *The Enemy Within* (Machel 1982). Internal causes of the civil war has also been a topic of much debate, but still poorly understood (Saul 2005; Sidaway 1992).

4   The section on foreign technical assistance to the Ministry of Health emphasizes the need to respect that the process *"is driven by Ministry of Health priorities and absorptive capacity"* (Ministry of Health 2000: 6). This indicates that the Ministry sets the agenda and that the Ministry recognizes its limited capacity to efficiently use allocated monetary resources to improve health care.

5   The National Politics of Health Declaration does not refer to the International Covenant on Economic, Social and Cultural Rights, as Mozambique has not yet signed it. I believe there are two plausible reasons for this: 1) Mozambique does not yet have the capacity to fulfil such commitment, and 2) The avoidance is for political reasons: FRELIMO does not want to bind itself to an international treaty that spells some of the core FRELIMO political goals. Thus, I see this as a particular form of Mozambican isolationism, along with a politics of protectionism, which raises the prices on imported goods to avoid foreign competition.

7 Advocacy

1   I met the Norwegian HIV/AIDS Ambassador Sigrun Møgedal, who explained how this division is historically conditioned. National AIDS Programmes emerged during the Global Progamme on AIDS decade 1986-1996, before it was decided that each country should have a commission. Moreover, this decision was taken before the treatment era in poor countries (personal communication, 4 May 2006). In other words, there is an infelicitous disconnection at the level of origin between 'National AIDS Program' and 'National AIDS Council' that none of the international and national parties have yet been able to connect or interested in connecting.

2   The FRELIMO party cell manual on working methods says about criticism: *"The manifestation of opinion is based on the principle of unit-to-unit criticism. Correction of errors is made by criticism and self-criticism. Criticism always takes place within the structures of the party, and always in order to improve the realisation of the party structures and the party members"* (FRELIMO nd: 11).

3   Organisations like OMM and the Mozambican Youth Organisation OMJ were created by FRELIMO in the early 1970s as a 'bridge of legitimacy' between state and population, when realizing that it had lost connection to traditional forms of organisation after having abolished the system of village headmen *régulos*. This was a top-down attempt to introduce civil society (Abrahamsson and Nilsson 1995: 181). Notably, OMM lost state legitimacy for a short period between the year of peace 1992 and 1995, which attracted partnerships with international organisations (Costy 2000: 204).

4   OMM was founded in 1973, 2 years after Josina Machel had died from disease. FRELIMO created OMM committed to gender equality (Newitt 1995: 548). Samora Machel delivered a speech to a women's meeting in Maputo, 1976, in which he formulated the creation of OMM as part of FRELIMO revolution (Machel 1985a: 170).

5   I discuss state resilience at greater length elsewhere (Høg 2008). One of the key questions is when Mozambique will change from being 'weak, but willing' to 'strong and independent'.

6   This was a necessary elaboration of the law created in 2002 (Republic of Mozambique 2002) that protected *workers* from stigma and discrimination. However, legal practice is different: *"So far, it sets the standards of what is desirable and what is condemned, but the country's legal system lacks the appropriate instruments to punish those who discriminate and dismiss workers perceived to be HIV-positive"* (Machel 2007: 24). Civil society wanted a law that protected *all* citizens, especially as only a minority of the population have formal jobs.

7   A code of conduct between state and civil society is less necessary than between state and inter-
     national community. Civil society acts by ingrained cultural codes, knowing its limit set by the
     socio-political order. The international community may read these codes, but their accounta-
     bility and bodies of authority lie elsewhere. Only the ones that understand and make common
     political cause with the Mozambican government count as intimate international partners, as we
     saw in Chapter 6 through the analysis of the Kaya Kwanga Commitment – the *political* code of
     conduct. As Bourdieu notes about state order: *"The social world is full of* calls to order *which
     function as such only for individuals who are predisposed to notice them"* (Bourdieu 2000: 176).

8 Circumstances

1   This resembles Republic of Guinea President Ahmed Sékou Touré's famous yet ambiguous
     dictum from the 1950s, when he claimed sovereignty and independence from French rule: *"We
     will not renounce and we will never renounce our legitimate and natural right to independence.
     We prefer poverty in liberty to riches in slavery"* (Chaffard 1965: 197).

2   Civil society met with the parliamentarian HIV section in February 2008 to adjust it to the model
     created by the Southern African Development Community. The law proposal was expected to be
     approved in March 2008 (Vitorino 2008). However, the law proposal still needed further
     readjustments at the March meeting (PlusNEWS 2008). Moreover, I received information about
     its progress by late August 2008: Civil society called upon many of its international partners to
     point out that the law 'ends up criminalizing people living with AIDS'. One response pointed out
     one of the points I discuss here: the importance that Mozambican civil society organisations
     speak with one voice. However, it strikes me that this protest comes rather late, brought to the
     attention of Oxfam, UNAIDS, the National AIDS Council, SADC, Concern Universal, the Canadian
     HIV/AIDS Legal Network, the AIDS and Rights Alliance for Southern Africa, and others, when we
     recall the participatory draft law process that involved civil society hearings for more than two
     years. The alleged criminalizing elements of the law proposal were not included last minute. The
     late protest implies government responsibility, not poor response by civil society.

3   This is not the same as saying that HIV infection disproportionately affects the poorer in sub-
     Saharan Africa. In fact, a study of this found a positive association between wealth and HIV pre-
     valence, based on data from eight countries, yet explained by other underlying factors, such as
     place of residence and education, and by differences in sexual behaviour, such as multiple sex
     partners, condom use, and male circumcision (Mishra, et al. 2007).

4   Only 2.4 percent of the Mozambican households had water installed within the house in 1997
     (National Institute of Statistics 1997). This had increased to 5.3 percent in 2003. Public wells
     supplied water for 56.2 percent of the population (National Institute of Statistics 2005).

5   Food provision was the 13th out of 14 decisions: 1) ART expansion nationwide, 2) Integration of
     HIV/AIDS services into Primary Health Care and TB services, 3) Training of MoH health workers
     in counselling and treatment, 4) Provincial Coordinators for HIV/AIDS, TB and Malaria to be
     established, 5) Improvement of ARV management by pharmacists, 6) Improve laboratory
     diagnostic capacity, 7) Improve the capacity to use the Health Information System, 8) Give
     priority to Sexually Transmitted Infections, 9) Improve coordination between National AIDS
     Council and National AIDS Programme, especially at provincial level, 10) No VCT centres outside
     the MoH facilities, 11) No Youth Services (SAAJ) outside the MoH facilities, 12) MoH is in charge
     of home based care, 13) A rapid decision (w/i 30 days) to be made by Minister regarding
     provision of food to TARV patients, and 14) TARV and OI medicines will be distributed free
     (USAID/Mozambique, 2006).

6   The BMI calculates the weight-to-height ratio by dividing weight by the square of height.

7   The ones that need immediate medical therapy do exempt the initiation trial, but we do not
     know whether this comes at a cost of lower adherence, poorer understanding, or, on the other
     hand, how the extended length of counselling and testing influences the quality of treatment.

Acronyms

Acronym	Meaning
ABC	Abstinence, Be faithful, use Condom
AFRICASO	African Council of AIDS Service Organisations
AIDS	Acquired Immunodeficiency Syndrome
AMODEFA	*Associação Moçambicana para Desenvolvimento da Família*, the Mozambican Association for the Development of the Family
AMOPROC	*Associação Moçambicana para a Promoção da Cidadania*, Association for the Promotion of Citizenship
ANC	African National Congress
ANEMO	*Associação Nacional de Enfermeiros de Moçambique*, National Association of Nurses in Mozambique
ART	Antiretroviral Treatment
ARV	Antiretroviral
ASIDH	*Asociación Para La Salud Integral y el Desarrollo Humano*, Association for Integrated Health and Human Development, Spanish NGO founded in 1994
ATS	*Aconselhamento e Testagem para a Saúde*, see Counselling and Testing for Health
BMI	Body Mass Index
CD4	Cluster of Differentiation 4 cells, which protect the body against infection
CDC	Centers for Disease Control
CERPRE	*Centro de Relações Públicas Religiosas*, Centre for Public Religious Relations
CIDA	Canadian International Development Agency
CMA	Critical Medical Anthropology
CMAM	*Central de Medicamentos e Artigos Médicos*, Pharmaceutical Department
CNCS	*Conselho Nacional de Combate ao HIV/SIDA*, National AIDS Council
COREMO	*Comité Revolucionário de Moçambique*, Mozambique Revolutionary Committee
CSM	Condom Social Marketing
CTH	Counselling and Testing for Health, *see also VCT*
DAM	*Departamento de Assistência Médica*, Department of Medical Assistance
DANIDA	Danish International Development Agency
DIS	*Departamento de Informática para a Saúde*, Department of Health Information
DNAM	*Direcção Nacional de Assistência Médica*, National Board of Medical Assistance, DAM renamed in 2007 to emphasize its national character
DNS	*Direcção Nacional de Saúde*, Board of National Health
DOT	Directly Observed Therapy
DREAM	Drug Resource Enhancement against AIDS and Malnutrition, project invented by the Sant'Edigio Community, see also *Sant'Egidio*
DRH	*Direcção de Recursos Humanos*, Board of Human Resources
ECOSIDA	*Associação Empresárias Contra o SIDA*, Business Against AIDS

FDC	*Fundação para o Desenvolvimento da Comunidade*, Community Development Foundation
FRELIMO	*Frente de Libertação de Moçambique*, Liberation Front of Mozambique, founded in 1962 in Dar es Salaam, Tanzania, by three leading nationalist organisations, Mozambican African National Union, MANU, National Democratic Union of Mozambique, UDENAMO, and National African Union of Independent Mozambique, lead by Eduardo Mondlane, the first FRELIMO President
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
HAART	Highly Active Antiretroviral Therapy
HAI	Health Alliance International, University of Washington, Seattle
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
ICAP	International Center for AIDS Care and Treatment Programmes, Columbia University, New York
ICASO	International Council of AIDS Service Organisations
IEC	Information, Education, Communication
IMF	International Monetary Fund
INE	*Instituto Nacional de Estatística*, National Institute of Statistics
ICCP	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
JOAP	Joint Oxfam Advocacy Program
KAP	Knowledge, Attitude and Practices
KABP	Knowledge, Attitude, Beliefs and Practices
KAPB	Knowledge, Attitude, Practices and Behaviour
KPMG	Klynveld Peat Marwick Goerdeler: International audit, tax, and advisory service company
KULIMA	*Organismo para o Desenvolvimento Sócio-Económico Integrado*, Organization for Integrated Socio-Economic Development
MAP	Multi-Country AIDS Project, World Bank
MATRAM	*Movimento de Acesso ao Tratamento em Moçambique*, Mozambican Treatment Access Movement, founded in 2004
MDG	Millennium Development Goals. A UN blueprint to halve extreme poverty and halt the HIV epidemic before 2015
MIMAS	*Ministério da Mulher e da Acção Social*, Ministry of Women and Social Action
MISAU	*Ministério da Saúde*, Ministry of Health
MoH	Ministry of Health
MONASO	*Rede Moçambicana de Organizações contra o SIDA*, Mozambican Network of AIDS Service Organisations
MSF	*Médecins Sans Frontières*, Doctors Without Borders

MULEIDE	*Mulheres, Lei e Desenvolvimento*, Women, Law and Development
MZ	Mozambique
NAIMA+	NGO AIDS (+TB, +Malaria) Impact Mitigation Association: Network of NGOs working in Health and HIV/AIDS, international NGOs registered in Mozambique, national NGOs, associations and networks have observational status
OJM	*Organização da Juventude Moçambicana*, Mozambican Youth Organisation
OMM	*Organização da Mulher Moçambicana*, Mozambican Women's Organisation
Oxfam	Oxford Committee for Famine Relief
PARPA	*Plano de Redução da Pobreza Absoluta*, Poverty Reduction Strategy Paper PRSP
PASS	Peculiar Absence of Social Support
PEN	*Plano Estratégico Nacional*, National Strategic Plan
PEPFAR	President's Emergency Plan for AIDS Relief. A US initiative taken by President George Bush in 2003 to respond to HIV and AIDS in 15 African countries
PFP	Patience, Friendliness, and Persistence: key fieldwork principle
PDFH	People Dying From Hunger
PLWA	People Living With AIDS
PLWARVs	People Living With ARVs
PLWOARVs	People Living Without ARVs
PLWH	People Living With HIV
PLWP	People Living With Poverty
PTHN	People Tested HIV Negative
PWF	People Without Food
PWPH	People Without Public Health
PMTCT	Prevention of Mother to Child Transmission
PNCS	*Programa Nacional de Combate as ITS/HIV/SIDA*, National STI/HIV/AIDS Programme
PRSP	Poverty Reduction Strategy Paper, initiated by the World Bank
RENAMO	*Resistência Nacional Moçambicana*, Mozambican National Resistance founded at independence in 1975 as an anti-communist political organisation supported by the white minority government of Rhodesia (today Zimbabwe) to counter the established Marxist-Leninist Mozambican one-party state
RENSIDA	*Rede Nacional de Associações de Pessoas Vivendo Com HIV/SIDA*, National Network of Associations of People Living with HIV/AIDS
RI	*Repartição de Informática*, Bureau of Information
SAAJ	*Serviços de Saúde Amigos de Adolescentes e Jovens*, Youth Friendly Health Services
SANASO	Southern African Network of AIDS Service Organisations
SIDA	*Síndrome de Imunodeficiência Adquirida*, Acquired Immunodeficiency Syndrome. *SIDA* is the Portuguese acronym for AIDS used throughout Mozambique. *SIDA* has a double gender, used interchangeably as the feminine *a SIDA* (the medical disease)

	and the masculine *o SIDA* (the societal problem). This division is however not commonly and consciously used in everyday language
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TAP	Treatment Acceleration Programme, World Bank
TB	Tuberculosis
UEM	*Universidade Eduardo Mondlane*, University Eduardo Mondlane
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund (formerly United Nations International Children's Emergency Fund)
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing, replaced by Counselling and Testing for Health in 2006, *see also CTH*
WHO	World Health Organisation

Glossary

Word	Meaning
a janela de esperança	'the window of hope': refers to the 10-14 year olds who are not yet infected with HIV. The majority of children who acquire HIV during the peri-natal period die before the age of five. That is, few of them survive until the age of 10. However, then the 'window of hope' opens, since they practically live free from HIV until the age of 15 (National AIDS Council 2005).
a luta continua	'the struggle continues': a FRELIMO slogan since independence, enshrined in the Proclamation of Independence in 1975. *Long live FRELIMO! Long live the Popular Republic of Mozambique! The struggle continues!* (Machel 1975b). Used in everyday vernacular by Mozambicans and foreigners to emphasize loyalty and solidarity
a tosse que não passa	'the cough that never goes away': a way people explain one of the classical symptoms associated with advanced progression of HIV
Avenida 24 de Julho	Avenue 24 July, symbolizing 24 July 1975, Day of Nationalisation of Health, Education and Justice
Avenida Eduardo Mondlane	Avenue in remembrance of the first FRELIMO president, President Eduardo Mondlane (1920-1969), assassinated by a letter bomb
Avenida Samora Machel	Avenue in remembrance of the first Mozambican president, President Samora Machel (1993-1986), allegedly assassinated in a plane crash
Avenida Julius Nyerere	Avenue in remembrance of Tanzanian President Julius Nyerere (1922-1999), co-founder of FRELIMO
Avenida Joaquim Chissano	Avenue paying tribute to the second Mozambican president, President Joaquim Chissano (1939-), see also *Maputo Manifesto*
bairro	shantytown, commonly used for the city suburbs
cane city	shantytown, characterized by sandy dirt roads, houses made of sugarcane, or a mix of raw or semi-raw material like mud, concrete, aluminium, tinplates and tin roofs
caniço	sugar cane
capulana	sarong: a large colourful traditional women's clothing used as a skirt and for carrying babies and goods
cement city	area of asphalt roads, concrete pavements, and high-rise buildings at the centre of the major cities. These city centres were constructed by and for the Portuguese during colonial times
chapa	minibus
cimento	cement
confusão	state of confusion created by chaos, disorder, and the tumult of everyday life, as well as lawlessness, and 'all the hell broken lose' in the

	case of war. It also means dissension, in the sense of conflict, dispute and disagreement
cooperante	collaborator; a term used during the 1970s communist period to designate foreign friends and collaborators
curandeiro	traditional healer
esperança	hope; some ART consultation cards carry the flashing word *esperança*
estão a demorar	'they are slow/lingering/delaying'; a common saying about the limited health system capacity for ARV treatment, even under the circumstances of 'rapid ART expansion'
fora da casa	'outside the house/home'; a cultural code for (men's) extramarital relations, originating in the Portuguese cultural dichotomy *casa/rua*, house/street, tacitly suggesting pleasure, adventure, uncleanliness, prostitution, and street behaviour
feiticeiro	performer of witchcraft
home based care	provision of basic care for the sick by formal (doctors, nurses) and informal (activists, visitors) caregivers in the patients' own homes
Kaya Kwanga Commitment	code of conduct to guide the partnership for health development between NGOs and the Mozambican Ministry of Health
Kindlimuka	*Wake Up!* A patient organisation founded in Maputo in 1996. Shangaan word
Kudumba	*Let's Speak Reality!* A patient support group founded in Maputo in 2004. Shangaan word
Kuyakana	*Rede Nacional de Mulheres Vivendo com HIV/SIDA*, National Network of Women Living with HIV/AIDS
Lourenço Marques	colonial name for the Mozambican capital, now Maputo
machamba	small or big plots of land for cultivating cereals and vegetables. Small *machambas* are typically household garden plots, whereas big *machambas* are communal agricultural cooperatives
Maputo Manifesto	Street signs in Maputo commemorate FRELIMO leaders and freedom fighters, key dates and events of the independence war, African nationalists, and international communists. The term 'Maputo Manifesto' is my invention to address the significance of this 'forest of symbols' for the political process. Street signs personify the dream of a nation, embodied with spiritual significance: peace, freedom, independence, and self-determination, with social services in general and health care in particular. Health care is *the* native reserve
medo e vergonha	fear and shame, intrinsic feelings living with HIV, AIDS, and ARVs
Metical	(pl. *Meticais*, abbr. MT) Mozambican currency introduced in 1980, which replaced the colonial Portuguese Escudo currency

Metical novo	(pl. *Meticais novos*, abbr. MTn) New currency introduced in 2006, which replaced the old Metical. 1,000 MT became 1 MTn
Moçambicanização	Mozambicanization: adaptation of matters HIV and AIDS to local social and cultural context, including conceivable translation into local languages. It was invented on the presumption that people fail to understand 'global' or 'foreign' made messages and information. Mozambicanization is diversified across Mozambique to reach different population groups, see also *sensibilização*
Ntwanano	South-South HIV/AIDS project between Mozambique and Brazil. Headquarter in Porto Alegre, Brazil. Activities started in Mozambique in 2002
o processo	the process. *O processo* is the everyday name for *o processo clínico*, which is the individual medical record containing information about life with ARVs. *O processo* is opened when in need of ART. It can be opened, closed, and reopened. I use the term in the clinical, therapeutic, social, structural, and political senses
palestra	discussion forum
Partners Forum	biweekly forum for civil society, business sector, government, and international partners
Pfukauhana	*Get Up and Live!* A patient support group founded in Maputo in 2006. Shangaan language, pronounced *fukauhania* – fukaʊhanɪə
Polana Caniço	a Maputo suburb with the characteristics of a cane city. In 2006, the Maputo City Council decided to turn Polana Caniço into a cement city with modern facilities
Polana Cimento	the city centre of Maputo with the characteristics of a cement city
Praça 25 de Junho	Plaza of 25 June, symbolizing Independence Day 25 June 1975
Praça da Independência	Independence Plaza, symbolizing independence in 1975
Sant'Egidio	Comunità di Sant'Egidio: Sant'Egidio Community, (St. Giles Community), founded 1968 in Rome, Catholic lay society providing service to poor people, with 50,000 members in 70 countries, see also *DREAM*
sensibilização	sensitization: gentle approach to teach people how to prevent HIV transmission, about HIV and AIDS, about HIV testing and ARV treatment. Sensitization can be individual or collective, see also *Moçambicanização* and *o processo*
Tinena	Hero. A patient support group founded in Maputo in 2004. Shangaan word

Bibliography

Abrahamsson, Hans, and Anders Nilsson. 1995. Mozambique: The Troubled Transition. From Socialist Construction to Free Market Capitalism. London: Zed Books.

Adam, Yussuf. 1996. Trick or Treat. The Relationship Between Destabilisation, Aid and Government Development Policies in Mozambique 1975-1990. Ph.D. dissertation, Roskilde University.

Adimora, Adaora A., and Victor J. Schoenbach. 2005. Social context, sexual networks, and racial disparities in rates of sexually transmitted infections. Journal of Infectious Diseases 191(Supplement 1):S115-S122.

African Journal of AIDS Research. 2008. African Journal of AIDS Research. Grahamstown. Centre for AIDS Development, Research and Evaluation, CADRE, Institute of Social and Economic Research, Rhodes University. Electronic document, http://www.ajol.info/journal index.php?ab=ajar, accessed 23 July 2008.

Afrobarometer Network. 2004. Afrobarometer Round 2: Compendium of Comparative Results from a 15-Country Survey. A comparative series of national public attitude surveys on democracy, markets and civil society in Africa. Cape Town. The Institute for Democracy in South Africa. Electronic document, http://www.afrobarometer.org/papers/AfropaperNo34.pdf, accessed 23 July 2008.

Agha, Sohail, Andrew S. Karlyn, and Dominique Meekers. 2001. The promotion of condom use in non-regular sexual partnerships in urban Mozambique. Health Policy and Planning 16(2):144-151.

AIM. 2008. Mozambique: Guebuza Insists That Poverty Has Declined. AIM, Maputo. Electronic document, http://allafrica.com/stories/200808250245.html, accessed 3 September 2008.

Alubo, Ogoh. 2002. Breaking the wall of silence: AIDS policy and politics in Nigeria. International Journal of Health Services 32(3):551-566.

Andersen, Ronald, and John F. Newman. 1973. Societal and Individual Determinants of Medical Care Utilization in the United States. The Milbank Memorial Fund Quarterly. Health and Society 51(1):95-124.

Andersson, Hilary. 1992. Mozambique: A War against the People. London: McMillan Press.

Appadurai, Arjun. 1986. The Social Life of Things. Commodities in Cultural Perspective. Cambridge: Cambridge University Press.

———. 2004. The Capacity to Aspire: Culture and the Terms of Recognition. In Culture and Public Action. V. Rao and M. Walton, eds. Pp. 59-84. Stanford: Stanford University Press.

Archambault, Éric, and Étienne Vignola Gagné. 2004. The Use of Bibliometrics in the Social Sciences and the Humanities. Montreal. Social Sciences and the Humanities Research Council of Canada. Electronic document, http://www.science-metrix.com, accessed 19 July 2008.

Assan, Américo. 2006. Perspectiva da Expansão do Programa TARV (The Expansion of the ART Programme in Perspective). First National HIV/AIDS Meeting, Ministry of Health, Maputo, 2006.

Awusabo-Asare, K., and J. K. Anarfi. 1997. Health-seeking behaviour of persons with HIV/AIDS in Ghana. Health Transition Review 7(Supplement):243-256.

Azarya, Victor. 1988. Reordering State-Society Relations: Incorporation and Disengagement. In The Precarious Balance: State Society in Africa. D.S. Rothchild and N. Chazan, eds. Pp. 3-21. Boulder, Colorado: Westview Press.

————. 1994. Civil Society and Disengagement in Africa. *In* Civil Society and the State in Africa. J.W. Harbeson, D.S. Rothchild, and N. Chazan, eds. Pp. 83-100. Boulder: Lynne Rienner Publishers.

Baer, Hans A., Merrill Singer, and Ida Susser. 2003. Medical Anthropology and the World System. Westport: Praeger Publishers.

Baldwin, Peter. 2005. Disease and Democracy: The Industrialized World faces AIDS. Berkeley: University of California Press.

Barnett, Tony. 2006. A long wave event. HIV/AIDS, politics, governance and 'security': sundering the intergenerational bonds? International Affairs 82(2):297-313.

Barnett, Tony, and Piers Blaikie. 1992. AIDS in Africa: Its Present and Future Impact. London: Belhaven Press.

Barnett, Tony, and Alan Whiteside. 2006 (2002). AIDS in the Twenty-First Century: Disease and Globalization. Basingstoke: Palgrave Macmillan.

Barnighausen, Till, Victoria Hosegood, Ian M. Timaeus, and Marie-Louise Newell. 2007. The socioeconomic determinants of HIV incidence: evidence from a longitudinal, population-based study in rural South Africa. AIDS 21(Supplement 7):S29-S38.

Bateson, Gregory. 2000 (1972). Metalogue: Why Do Things Get in a Muddle. *In* Steps to An Ecology of Mind. Pp. 3-8. Chicago: University of Chicago Press.

Battegay, Manuel, Jan Fehr, Ursula Fluckiger, and Luigia Elzi. 2008. Antiretroviral therapy of late presenters with advanced HIV disease. Journal of Antimicrobial Chemotherapy 62(1):41-44.

Bernays, Sarah, Tim Rhodes, and Tony Barnett. 2007. Hope: a new way to look at the HIV epidemic. AIDS 21(Supplement 5):S5-S11.

Biehl, João. 2007a. Pharmaceuticalization: AIDS Treatment and Global Health Politics. Anthropological Quarterly 80(4):1083-1126.

————. 2007b. Will to Live: AIDS Therapies and the Politics of Survival. Princeton, New Jersey: Princeton University Press.

Boerma, J. Ties, Karen A. Stanecki, Marie-Louise Newell, Chewe Luo, Michel Beusenberg, Geoff P. Garnett, Kirsty Little, Jesus Garcia Calleja, Siobhan Crowley, Jim Young Kim, Elizabeth Zaniewski, Neff Walker, John Stover, and Peter D. Ghys. 2006. Monitoring the scale-up of antiretroviral therapy programmes: methods to estimate coverage. Bulletin of the World Health Organization 84(2):145-50.

Booysen, Frederick le R., and Joy Summerton. 2002. Poverty, Risky Sexual Behaviour, and Vulnerability to HIV infection: Evidence from South Africa. Journal of Health Population and Nutrition 20(4):285-288.

Bourdieu, Pierre. 1972. Outline of A Theory of Practice. Cambridge: Cambridge University Press.

————. 2000. Pascalian Meditations. R. Nice, transl. Cambridge: Polity Press.

Butt, Leslie. 2002. The Suffering Stranger: Medical Anthropology and International Morality. Medical Anthropology 21:1-24.

Campbell, Catherine, and Harriet Deacon. 2006. Unravelling the Contexts of Stigma: From internalisation to Resistance to Change. Journal of Community & Applied Social Psychology 16(6):411-417.

Castro, Arachu, and Paul Farmer. 2005. Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. American Journal of Public Health 95(1):53-59.

Central Intelligence Agency. 2008. The World Factbook. Electronic document, https://www.cia.gov/library/publications/the-world-factbook/index.html, accessed 11 August 2008.

Chabal, Patrick. 2005. Power in Africa Reconsidered. In The African Exception. U. Engel and G. Rye Olsen, eds. Pp. 17-34. Aldershot & Burlington: Ashgate.

Chadborn, Timothy R., Valerie C. Delpech, Caroline A. Sabin, Katy Sinka, and Barry G. Evans. 2006. The late diagnosis and consequent short-term mortality of HIV-infected heterosexuals (England and Wales, 2000-2004). AIDS 20(18):2371-2379.

Chaffard, Georges. 1965. Les Carnets Secrets de la Décolonisation, II. Volume 2. Paris: Calmann-Lévy.

Chao, Shiyan, and Kees Kostermans. 2002. Improving Health for the Poor in Mozambique. The Fight Continues. HNP Discussion Papers. Washington DC. The International Bank for Reconstruction and Development and The World Bank. Electronic document, http://siteresources.worldbank.org/HEALTHNUTRITIONANDPOPULATION/Resources/281627-1095698140167/Chao-ImprovingHealth-whole.pdf, accessed 23 July 2008.

Chilundo, Baltazar, Sundeep Sahay, and Johanne Sundby. 2004. The quality of HIV/AIDS case-detection and case-reporting systems in Mozambique. African Journal of AIDS Research 3(2):145-156.

Chilundo, Balthazar, and Zeferino Saugene. 2006. Mapeamento do Suporte às Associações de Pessoas Vivendo com HIV/SIDA em Moçambique (Mapping of Support Associations of People Living with HIV/AIDS in Mozambique). Pp. 89. Maputo: NAIMA, A Network of NGOs Working with Health and HIV/AIDS.

Chissano, Joaquim Alberto. 1990. Constituição da República de Moçambique (Constitution of the Republic of Mozambique). Maputo. Mozambican Parliament, Republic of Mozambique.

————. 2004. Constituição da República de Moçambique (Constitution of the Republic of Mozambique). Maputo. Mozambican Parliament, Republic of Mozambique.

Christie, Iain. 1988. Machel of Mozambique. Harare, Zimbabwe: Zimbabwe Publishing House.

Cohen, Desmond. 2004a. Mozambique: The Impact of HIV/AIDS on Human Resources. Maputo: Unpublished paper.

Cohen, Myron S. 2004b. HIV prevention: Rethinking the risk of transmission. Electronic document, http://www.iavireport.org/Issues/1104/HIVPrevention.asp, accessed 3 May 2005.

Cohen, Stanley. 2001. States of Denial: Knowing about Atrocities and Suffering. Cambridge: Polity Press.

Collins, Carole J.L. 2006. Mozambique's HIV/AIDS Pandemic: Grappling with Apartheid's Legacy. Social Policy and Development Programme Paper Number 24. United Nations Research Institute for Social Development, UNRISD. Electronic document, http://www.unrisd.org, accessed 23 July 2008.

Connerton, Paul. 1989. How Societies Remember. Cambridge: Cambridge University Press.

Costy, Alexander. 2000. From Civil War to Civil Society? Aid, NGOs and Hegemonic Construction in Mozambique. Ph.D. dissertation, University of Toronto.

Council of Ministers. 2000. Plano Estratégico Nacional de Combate às DTS/HIV/SIDA 2000-2002. Integração, Qualidade e Abrangência (National Strategic Plan to Fight STI/HIV/AIDS 2000-2002. Integration, Quality and Achievements). Maputo. Council of Ministers, Republic of Mozambique.

Daniel, Marguerite. 2004. Beyond Liminality: Orphanhood and Marginalisation in Botswana. Ph.D. dissertation, University of East Anglia.

————. 2005. Beyond liminality: orphanhood and marginalisation in Botswana. African Journal of AIDS Research 4(3):195-204.

de Waal, Alex. 2005. The Challenge of HIV/AIDS. In Towards a New Map of Africa. B. Wisner, C. Toulmin, and R. Chitiga, eds. Pp. 113-131. London: Earthscan.

————. 2008. The Politics of AIDS Exceptionalism. LSE Public Lectures and Events. Hong Kong Theatre. 6 February. Electronic document, http://www.lse.ac.uk/resources/podcasts/publicLecturesAndEvents.htm, accessed 23 July 2008.

Deacon, Harriet. 2006. Towards a sustainable theory of health-related stigma: Lessons from the HIV/AIDS literature. Journal of Community & Applied Social Psychology 16(6):418-425.

Delpierre, Cyrille, Lise Cuzin, and France Lert. 2007. Routine testing to reduce late HIV diagnosis in France. British Medical Journal 334(7608):1354-1356.

DeWalt, Billie R., and Pertti J. Pelto. 1985. Micro and Macro Levels of Analysis in Anthropology: Issues in Theory and Research. Boulder, Colorado: Westview Press.

Domingos Paulo, Margarida do Rosário. 2004. Fertility, Sexuality and HIV/AIDS Prevention Campaigns in Mafalala Barrio, Maputo, Mozambique. MA dissertation, University of Cape Town.

Douglas, Mary. 1979. The Abominations of Leviticus. In Reader in Comparative Religion. W.A. Lessa and E.Z. Vogt, eds. Pp. 149-152. New York: HarperCollins Publishers.

————. 1992. Risk and Blame: Essays in Cultural Theory. London: Routledge.

————. 1996 (1970). Natural Symbols: Explorations in Cosmology. London: Routledge.

————. 2002 (1966). Purity and Danger: An Analysis of Concepts of Pollution and Taboo. London: Routledge.

Duffy, Lynne. 2005. Suffering, Shame, and Silence: The Stigma of HIV/AIDS. Journal of the Association of Nurses in AIDS Care 16(1):13-20.

Egrot, Marc, Bernard Taverne, Mounirou Ciss, and Ibra Ndoye. 2004. The Circulation of Antiretrovirals in Senegal. In The Senegalese Antiretroviral Drug Access Initiative. An Economic Social Behavioural and Biomedical Analysis (L'Initiative sénégalaise d'accès aux médicaments antirétroviraux. Analyses économiques, sociales, comportementales et médicales). A. Desclaux, I. Lanièce, I. Ndoye, and B. Taverne, eds. Pp. 197-210. Paris: ANRS, UNAIDS, WHO.

Englund, Harri. 2004. Introduction: recognizing indentities, imagining alternatives. In Rights and the Politics of Recognition in Africa. H. Englund and F.B. Nyamnjoh, eds. Pp. 1-29. London: Zed Books.

Epstein, Helen. 2007. The Invisible Cure: Africa, the West, and the Fight Against AIDS. New York: Farrar, Straus and Giroux.

FAO/WFP. 2005. FAO/WFP Crop and Food Supply Assessment Mission to Mozambique: Food and Agriculture Organization of the United Nations, FAO, World Food Programme, WFP.

Farmer, Paul. 1992. AIDS and Accusation: Haiti and the Geography of Blame. Berkeley: University of California Press.

———. 2004. An Anthropology of Structural Violence. Current Anthropology 45(3):305-325.

Fassin, Didier. 2003. The embodiment of inequality. AIDS as a social condition and the historical experience in South Africa. Science and Society 4(Special Issue):S4-S9.

———. 2007. When Bodies Remember: Experiences and Politics of AIDS in South Africa. 15 vols. A. Jacobs and G. Varro, transl. Volume 15. Berkeley: University of California Press.

Fatton, Robert. 1992. Predatory Rule: State and Civil Society in Africa. Boulder, Colorado: Lynne Rienner Publishers.

Fauvet, Paul, and Marcelo Mosse. 2003. Carlos Cardoso: Telling the Truth in Mozambique. Cape Town: Double Storey.

Feierman, Steven. 1985. Struggles for Control: The Social Roots of Health and Healing in Modern Africa. African Studies Review 28(2/3):73-147.

Ferguson, James. 1994. The Anti-Politics Machine: "Development," Depoliticization, and Bureaucratic Power in Lesotho. Minneapolis: University of Minnesota Press.

———. 2006. Global shadows: Africa in the Neoliberal World Order. London: Duke University Press.

Ferguson, James, and Akhil Gupta. 2002. Spatializing states: toward an ethnography of neoliberal governmentality. American Ethnologist 29(4):981-1002.

Font, A., R. Puigpinos, I. E. Chichango, N. Cabrero, and C. Borrell. 2006. AIDS-related knowledge and behaviors in Mozambique. Revue d'Epidémiologie et de Santé Publique 54(4):341-354.

Foucault, Michel. 1967. Madness and Civilization: a History of Insanity in the Age of Reason. London: Tavistock Publications.

———. 1976. The Birth of the Clinic: An Archaeology of Medical Perception. London,.

———. 1977. Discipline and Punish: The Birth of the Prison. New York: Pantheon Books.

———. 1979. On Governmentality. Ideology & Consciousness (6):5-21.

———. 1980. Power/Knowledge: Selected Interviews and Other Writings, 1972-7. New York: Pantheon.

———. 1981. The History of Sexuality, 1. An introduction. Harmondsworth: Penguin.

———. 2000 (1994). The Subject and Power. In Michel Foucault: Power. Essential Works of Foucault 1954-1984. J.D. Faubion, ed. Pp. 236-248, Vol. 3. London: Penguin.

———. 2008 (1966). The Order of Things. An archaeology of the human sciences. London: Routledge.

Freire, Paulo. 1972. Pedagogy of the Oppressed. London: Sheed and Ward.

———. 1975. Educação Política e Conscientização. Volume 6. Lisboa: Livraria Sá da Costa Editora.

———. 1990. Education for Critical Consciousness. London: Sheed & Ward.

————. 1998. Pedagogy of Freedom: Ethics, Democracy, and Civic Courage. Lanham, Md.: Rowman & Littlefield Publishers.

FRELIMO. nd. Manual de Célula. Maputo. Frelimo. Electronic document, http://www.frelimo.org.mz, accessed 23 July 2008.

Frost, Simon D. W. 2007. Using sexual affiliation networks to describe the sexual structure of a population. Sexually Transmitted Infections 83:137-142.

Fry, Peter. 2000. O Espírito Santo Contra o Feitiço e os Espíritos Revoltados: "Civilização" e "Tradição" em Moçambique (The Spirit Saint Against Magic and Rebellious Spirits: "Civilization" and "Tradition" in Mozambique). Mana 6(2):65-95.

————. 2005. The Status of Human Rights Organizations in Sub-Saharan Africa Mozambique. University of Minnesota. Electronic document, http://www1.umn.edu/humanrts/africa/mozambiq.htm, accessed 23 July 2008.

G8. 2005. Gleneagles Communiqué. London. Electronic document, http://www.g8.gov.uk, accessed 15 September 2008.

Gaines, Atwood D. 1992. Ethnopsychiatry: The Cultural Construction of Professional and Folk Psychiatries. Albany, New York: State University of New York Press.

Galtung, Johan. 1969. Violence, Peace, and Peace Research. Journal of Peace Research 6(3):167-191.

————. 1990. Cultural Violence. Journal of Peace Research 27(3):291-305.

GFATM. 2006. Global Fund Proposal Mozambique, Round 6. The Global Fund to Fight AIDS, Tuberculosis and Malaria. Electronic document, http://www.theglobalfund.org/en, accessed 24 May 2008.

Gillespie, Stuart, Robert Greener, Alan Whiteside, and James Whitworth. 2007. Investigating the empirical evidence for understanding vulnerability and the associations between poverty, HIV infection and AIDS impact. AIDS 21(Supplement 7):S1-S4.

Gimbel-Sherr, Sarah, Mark Micek, Kenneth Gimbel-Sherr, Thomas Koepsell, James Hughes, Katherine Thomas, James Pfeiffer, and Stephen Gloyd. 2007. Using nurses to identify HAART eligible patients in the Republic of Mozambique: results of a time series analysis. Human Resources for Health 5(1).

Girardi, E., C. A. Sabin, and A. D. Monforte. 2007. Late diagnosis of HIV infection: Epidemiological features, consequences and strategies to encourage earlier testing. Journal of Acquired Immune Deficiency Syndromes 46:S3-S8.

Gisselquist, David, John J. Potterat, Stuart Brody, and François Vachon. 2003. Let it be sexual: how health care transmission of AIDS in Africa was ignored. International Journal of STD & AIDS 14(3):148-161.

Gisselquist, David, Richard Rothenberg, John Potterat, and Ernest Drucker. 2002. HIV infections in sub-Saharan Africa not explained by sexual or vertical transmission. International Journal of STD & AIDS 13:657-666.

Gisselquist, David, Garance Upham, and John J. Potterat. 2006. Efficiency of human immunodeficiency virus transmission through injections and other medical procedures: evidence, estimates, and unfinished business. Infection Control and Hospital Epidemiology 27(9):944-952.

Goffman, Erving. 1963. Stigma: Notes on the Management of Spoiled Identity. Englewood Cliffs, New Jersey: Prentice-Hall.

Gogolin, Ingrid, P. Smeyers, Ángel García Del Dujo, and Diann Rusch-Feja. 2003. European Social Science Citation Index: a chance for promoting European research? European Educational Research Journal 2(4):574-593.

Gramsci, Antonio. 1971. Selections from the Prison Notebooks of Antonio Gramsci. Q. Hoare and G. Nowell-Smith, transl. London: Lawrence and Wishart.

Green, Edward C, Annemarie Jurg, and Armando Dgedge. 1993. Sexually-transmitted diseases, AIDS and traditional healers in Mozambique. Medical Anthropology 15:261-281.

Guebuza, Armando Emílio. 2006. Iniciativa Presidencial de Combate ao HIV/SIDA, 16-20 de Fevereiro 2006 (Presidential Initiative to Fight Against HIV/AIDS, 16-20 February 2006), International Conference Center Joachim Chissano, 2006, pp. 22.

Halperin, Daniel T., and Helen Epstein. 2004. Concurrent sexual partnerships help to explain Africa's high HIV prevalence: implications for prevention. Lancet 364(9428):4-6.

Hanlon, Joseph. 1984. Mozambique: The Revolution Under Fire. London: Zed Books.

————. 1991. Mozambique: Who Calls the Shots? London: James Currey.

————. 1996. Peace without Profit: How the IMF Blocks Rebuilding in Mozambique. Oxford: Irish Mozambique Solidarity & the International African Institute in association with James Currey and Heinemann.

————. 2004. Do donors promote corruption?: the case of Mozambique. Third World Quarterly 25(4):747-763.

Hargreaves, J. R., C. P. Bonell, T. Boler, D. Boccia, I. Birdthistle, A. Fletcher, P. M. Pronyk, and J. R. Glynn. 2008. Systematic review exploring time trends in the association between educational attainment and risk of HIV infection in sub-Saharan Africa. AIDS 22(3):403-414.

Hargreaves, James R., Christopher P. Bonell, Linda A. Morison, Julia C. Kim, Godfrey Phetla, John D. H. Porter, Charlotte Watts, and Paul M. Pronyk. 2007. Explaining continued high HIV prevalence in South Africa: socioeconomic factors, HIV incidence and sexual behaviour change among a rural cohort, 2001-2004. AIDS 21(Supplement 7):S39-S48.

Harries, Anthony D., Erik J. Schouten, and Edwin Libamba. 2006. Scaling up antiretroviral treatment in resource-poor settings. Lancet 367(9525):1870-1872.

Hatchett, Lena A., Chrissie P. N. Kaponda, C. N. Chihana, E. Chilemba, M. Nyando, A. Simwaka, and J. Levy. 2004. Health-seeking patterns for AIDS in Malawi. AIDS Care-Psychological and Socio-Medical Aspects of AIDS/HIV 16(7):827-833.

Hauri, Anja M., Gregory L. Armstrong, and Yvan J. F. Hutin. 2004. The global burden of disease attributable to contaminated injections given in health care settings. International Journal of STD & AIDS 15(1):7-16.

Hawkins, Kirstan, Fátima Mussá, and Sandia Abuxahama. 2005. 'Milking the Cow': Young women's constructions of identity, gender, power and risk in transactional and cross-generational sexual relationships: Maputo, Mozambique. The Implications for Behaviour Change Interventions. Maputo: Options Consultancy Services and Population Services International (PSI), Mozambique.

He, Weijing, Stuart Neil, Hemant Kulkarni, Edward Wright, Brian K. Agan, Vincent C. Marconi, Matthew J. Dolan, Robin A. Weiss, and Sunil K. Ahuja. 2008. Duffy antigen receptor for chemokines mediates trans-infection of HIV-1 from red blood cells to target cells and affects HIV-AIDS susceptibility. Cell Host Microbe 4(1):52-62.

Heald, Suzette. 2006. Abstain or die: The development of HIV/AIDS policy in Botswana. Journal of Biosocial Science 38(1):29-41.

Health Alliance International. 2008. Mozambique. Health Alliance International. Electronic document, http://depts.washington.edu/haiuw/hai/programming/category/mozambique, accessed 13 August 2008.

Heller, Peter S. 2005. Understanding Fiscal Space. IMF Policy Discussion Paper. Washington DC. International Monetary Fund. Electronic document, http://www.imf.org/external/pubs/ft/pdp/2005/pdp04.pdf, accessed 23 July 2008.

Herek, Gregory M. 2002. Thinking About AIDS and Stigma: A Psychologist's Perspective. Journal of Law, Medicine & Ethics 30(4):594-607.

Hirschman, Albert O. 1970. Exit, Voice, and Loyalty: Responses to Decline in Firms, Organizations, and States. Cambridge, Massachusetts: Harvard University Press.

Hodges, Tony, and Roberto Tibana. 2004. Political Economy of the Budget in Mozambique: Department for International Development, DFID.

Høg, Erling. 2006. Human rights and access to AIDS treatment in Mozambique. African Journal of AIDS Research 5(1):49-60.

————. 2008. States of HIV Fragility: Capacity, Vulnerabilities, and Epidemic Evolution in Mozambique. ASCI Research Report No. 11, April 2008, AIDS, Security and Conflict Initiative, HIV/AIDS, Fragile and Crisis States, Social Science Research Council, New York & Clingendael Institute, the Hague. New York. Electronic document, http://asci.researchhub.ssrc.org, accessed 23 July 2008.

Honwana, Alcinda Manuel. 1999. Appeasing the Spirits: Healing Strategies in Postwar Southern Mozambique. In Religion, Health, and Suffering: A Cross-Cultural Study of Attitudes to Suffering and the Implications for Medicine in a Multi-Religious Society. J.R. Hinnells and R. Porter, eds. Pp. 237-255. London: Kegan Paul.

Houston, S., S. Ray, I. Chitsike, J. Mielke, A. Chingono, S. Mutetwa, and I. Gangaidzo. 2005. Breaking the silence: an HIV-related educational intervention for medical students in Zimbabwe. Central African Journal of Medicine 51(5-6):48-52.

IATT. 2007. A Report Card On Prevention of Mother-to-Child Transmission of HIV and Paediatric HIV Care and Treatment in Low- and Middle-Income Countries. Scaling Up Progress 2004-2005. Expanded Inter-Agency Task Team on Prevention of HIV Infection in Pregnant Women, Mothers and their Children. New York. Electronic document, http://www.unicef.org/aids/files/PMTCT_Report_Card_2006_final.pdf, accessed 23 July 2008.

Isingo, Raphael, Basia Zaba, Milly Marston, Milalu Ndege, Julius Mngara, Wambura Mwita, Alison Wringe, David Beckles, John Changalucha, and Mark Urassa. 2007. Survival after HIV infection in the pre-antiretroviral therapy era in a rural Tanzanian cohort. AIDS 21(Supplement 6):S5-S13.

Karlyn, Andrew S. 2001. The impact of a targeted radio campaign to prevent STIs and HIV/AIDS in Mozambique. AIDS Education and Prevention 13(5):438-451.

Kim, Jim Young, Joyce V Millen, Alec Irwin, and John Gershman, eds. 2000. Dying for Growth. Global Inequality and the Health of the Poor. Monroe, Maine: Common Courage Press.

Kleinman, Arthur. 1988. The Illness Narratives. Suffering, Healing, and the Human Condition. New York: Basic Books, Inc.

———. 2000. The Violences of Everyday Life. The Multiple Forms and Dynamics of Social Violence. *In* Violence and Subjectivity. V. Das, A. Kleinman, M. Ramphele, and P. Reynolds, eds. Pp. 226-241. Berkeley: University of California Press.

Kleinman, Arthur, and Anne E. Becker. 1998. "Sociosomatics": The Contributions of Anthropology to Psychosomatic Medicine. Psychosomatic Medicine 60(4):389-393.

Kleinman, Arthur, and Joan Kleinman. 1994. How Bodies Remember: Social Memory and Bodily Experience of Criticism, Resistance, and Delegitimation Following China's Cultural Revolution. New Literary History 25(3):707-723.

Kohler, Gernot, and Norman Alcock. 1976. Empirical Table of Structural Violence. Journal of Peace Research 13(4):343-356.

Krentz, Hartmut B., M. Christopher Auld, and M. John Gill. 2004. The high cost of medical care for patients who present late (CD4<200 cells/µL) with HIV infection. HIV Medicine 5(2):93-98.

Kroeger, Axel. 1983. Anthropological and socio-medical health-care research in developing countries. Social Science & Medicine 17(3):147-161.

Lagarde, Emmanuel, Bertran Auvert, Michel Caraël, Martin Laourou, Benoît Ferry, Evina Akam, Tom Sukwa, Linda Morison, Bertrand Maury, Jane Chege, Ibrahim N'Doye, and Anne Buvé. 2001. Concurrent sexual partnerships and HIV prevalence in five urban communities of sub-Saharan Africa. AIDS 15(7):877-884.

Last, Murray. 1996. The Professionalization of Indigenous Healers. *In* Medical Anthropology: Contemporary Theory and Method, Revised Edition. C.F. Sargent and T.M. Johnson, eds. Pp. 374-395. Westport, Connecticut: Praeger Publishers.

Leach, Edmund R. 1979. Anthropological Aspects of Language: Animal Categories and Verbal Abuse. *In* Reader in Comparative Religion. W.A. Lessa and E.Z. Vogt, eds. Pp. 153-166. New York: HarperCollins Publishers.

Leslie, Charles. 1980. Medical pluralism in world perspective. Social Science & Medicine 14B(4):191-5.

Lévi-Strauss, Claude. 1970. The Raw and the Cooked. Introduction to a Science of Mythology: I. London: Cape.

Lewis, Stephen. 2006a. Race Against Time: Searching for Hope in AIDS-ravaged Africa. Toronto: House of Anansi Press.

———. 2006b. Report on the Mission of Stephen Lewis, UN Secretary-General's Special Envoy on HIV/AIDS in Africa, to Mozambique, 3rd July–7th July, 2006. Pp. 13. Maputo: United Nations.

Liljeros, Fredrik, Christofer R. Edling, and Luis A. Nunes Amaral. 2003. Sexual networks: implications for the transmission of sexually transmitted infections. Microbes and Infection 5(2):189-196.

Link, Bruce G., and Jo C. Phelan. 2001. Conceptualizing Stigma. Annual Review of Sociology 27:363-385.

Loforte, Ana Maria. 2007. Inequidades e Valores em Saúde Reprodutiva: Vulnerabilidade das Mulheres num Contexto de Feminização da SIDA (Inequity and Values in Reproductive Health: Vulnerability of Women in the Context of Feminization of AIDS). *In* Mulher, SIDA e o Acesso À Saúde na África Subsahariana, sob a Perspectiva das Ciências Sociais (Woman, AIDS and Access to Health in sub-Saharan Africa, through a Social Science Perspective). M.C.A. Degregori, E.L. Reguillo, and S. DiGiacomo, eds. Pp. 27-36. Barcelona: Medicus Mundi Catalunya.

Lopes, Carla. 2005. Morrem mil polícias devido à SIDA (One thousand police men die from AIDS). Quelimane. Savana, 2 September.

Louis, Christos, Louise C. Ivers, M. C. Smith Fawzi, Kenneth A. Freedberg, and Arachu Castro. 2007. Late presentation for HIV care in central Haiti: factors limiting access to care. AIDS Care-Psychological and Socio-medical Aspects of AIDS/HIV 19(4):487-491.

Lubkemann, Stephen C. 2001. Rebuilding Local Capacities in Mozambique: The National Health System and Civil Society. In Patronage or Partnership? Local Capacity Building in Humanitarian Crisis. I. Smillie, ed. Pp. 77-106. Bloomfield: Kumarian Press.

Lutalo, Tom, Ronald H. Gray, Maria J. Wawer, Nelson K Sewankambo, David Serwadda, Oliver Laeyendecker, Noah Kiwanuka, Fred Nalugoda, Godfrey Kigozi, Anthony Ndyanabo, John Baptist Bwanika, Steven J. Reynolds, Tom Quinn, and Pius Opendi. 2007. Survival of HIV-infected treatment-naive individuals with documented dates of seroconversion in Rakai, Uganda. AIDS 21(Supplement 6):S15-19.

Mac-Arthur, Alfredo, Stephen Gloyd, Paula Perdigão, António Noya, Jahit Sacarlal, and Joan Kreiss. 2001. Characteristics of drug resistance and HIV among tuberculosis patients in Mozambique. International Journal of Tuberculosis and Lung Disease 5(10):894-902.

Machel, Josina Z. 2001. Unsafe sexual behaviour among schoolgirls in Mozambique: a matter of gender and class. Reproductive Health Matters 9(17):82-90.

————. 2007. Parliament, Politics and AIDS: The Case of Mozambique. IDASA. Electronic document, http://www.idasa.org.za, accessed 23 July 2008.

Machel, Samora. 1975a. Constituição da República Popular de Moçambique (Constitution of the Popular Republic of Mozambique). Maputo. FRELIMO Central Committee.

————. 1975b. Mensagem da Proclamação da Independência Proferida pelo Camarada Presidente Samora Machel no Estádio da Machava, 25 de Junho de 1975 (Message Proclaming Independence Called by Comrade President Samora Machel at the Machava Stadium, 25 June 1975). Maputo. FRELIMO Central Committee.

————. 1982. The Enemy Within. Maputo: Deptartment of Information and Propaganda.

————. 1985a. Defining Woman's Enemy. In Samora Machel: An African Revolutionary: Selected Speeches and Writings. B. Munslow, ed. Pp. 169-178. London: Zed Books.

————. 1985b. Transform the Central Hospital into a People's Hospital. In Samora Machel: An African Revolutionary: Selected Speeches and Writings. B. Munslow, ed. Pp. 142-155. London: Zed Books.

————. 1985c. We Must Strengthen People's Power in Our Hospitals. In Samora Machel: An African Revolutionary: Selected Speeches and Writings. B. Munslow, ed. Pp. 156-168. London: Zed Books.

Mackintosh, Maureen, and Marc Wuyts. 1988. Accumulation, Social Services and Socialist Transition in the Third World: Reflections on Decentralised Planning based on Mozambican Experience. Journal of Development Studies 24(4):136-179.

Manuel, Sandra. 2005. Obstacles to condom use among secondary school students in Maputo city, Mozambique. Culture Health & Sexuality 7(3):293-302.

Marazzi, Cristina M., Paola Germano, Giuseppe Liotta, Giovanni Guidotti, Sandra Loureiro, Aurelio da Cruz Gomes, Maria C. Valls Blazquez, Pasquale Narciso, Carlo F. Perno, Sandro Mancinelli, Annamaria Doro Altan, Karin Nielsen-Saines, and Leonardo Palombi. 2007. Implementing anti-retroviral triple therapy to prevent HIV mother-to-child transmission: a public health approach in resource-limited settings. European Journal of Pediatrics 166(12):1305-1307.

Marazzi, Maria Cristina, Michele Bartolo, Leonardo Emberti Gialloreti, Paola Germano, Giovanni Guidotti, Giuseppe Liotta, Massimo Magnano San Lio, Sandro Mancinelli, Maria Antonia Modolo, Pasquale Narciso, Carlo F. Perno, Paola Scarcella, Graziella Tintisona, and Leonardo Palombi. 2006. Improving adherence to highly active anti-retroviral therapy in Africa: the DREAM programme in Mozambique. Health Education Research 21(1):34-42.

Marazzi, Maria Cristina, Giuseppe Liotta, Paola Germano, Giovanni Guidotti, Annamaria Doro Altan, Susanna Ceffa, Massimo Magnano San Lio, Karin Nielsen-Saines, and L. Palombi. 2008. Excessive early mortality in the first year of treatment in HIV type 1-infected patients initiating antiretroviral therapy in resource-limited settings. AIDS Research and Human Retroviruses 24(4):555-560.

Marcus, George E. 1998. Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography. *In* Ethnography Through Thick and Thin. Pp. 79-104. Princeton: Princeton University Press.

Marques, Maria Manuel Leitão, João Pedroso, André Cristiano José, Boaventura de Sousa Santos, and Terezinha da Silva. 2006. Access to Law and Justice: Advocacy and Legal Assistance Between the State, the Market and the Community. *In* Law and Justice in a Multicultural Society: the Case of Mozambique. B.d.S. Santos, J.C. Trindade, and M.P.G. Meneses, eds. Pp. 187-202. Dakar, Matola and Oxford: Council for the Development of Social Science Research in Africa, CODESRIA, Centro de Formação Jurídica e Judiciária, and African Books Collective.

Martins, Florindo Mudender. 2005. Valoración del comportamiento sexual y de la autoeficacia para la protección de la infección por el VIH/SIDA en jóvenes/adultos, estudiantes de Maputo, Mozambique (An assessment of sexual behaviour and self-efficiency for the protection against HIV/AIDS among young/adult students in Maputo, Mozambique). Ph.D. dissertation, Valencia University.

Masanjala, Winford. 2007. The poverty-HIV/AIDS nexus in Africa: A livelihood approach. Social Science & Medicine 64(5):1032-1041.

MATRAM. 2005a. Estratégia de advocacia para acesso ao tratamento (Advocacy strategy for access to treatment), Vol. 2005. Maputo: Movimento de Acesso ao Tratamento em Moçambique (Mozambican Treatment Access Movement).

———. 2005b. Introdução MATRAM (Introduction to MATRAM). Maputo: Movimento de Acesso ao Tratamento em Moçambique (Mozambican Treatment Access Movement).

Matsinhe, Cristiano. 2005. Tábula Rasa. Dinâmica da Resposta Moçambicana ao HIV/SIDA (Tabula Rasa. Dynamics of the Mozambican Response to HIV/AIDS). Maputo: Texto Editores.

Mavie, Gustavo. 2004. Anti-retrovirais para Moçambique: Brasil reafirma construção de fábrica (Anti-retrovirals for Mozambique: Brazil reaffirms the construction of factory). Maputo. Notícias.

Médecins Sans Frontières. 2006. Untangling the web of price reductions: a pricing guide for the purchase of ARVs in developing countries, 9. Médicins Sans Frontières. Electronic document, http://www.accessmed-msf.org/resources/key-publications/archive/2006, accessed 24 May 2008.

Millen, Joyce, Alec Irwin, and Jim Young Kim. 2000. Introduction: What Is Growing? Who Is Dying? *In* Dying for Growth: Global Inequality and the Health of the Poor. J.Y. Kim, J.V. Millen, A. Irwin, and J. Gershman, eds. Pp. 3-10. Monroe, Maine: Common Courage Press.

Mills, Elizabeth Anne. 2006. From the physical self to the social body: Expressions and effects of HIV-related stigma in South Africa. Journal of Community & Applied Social Psychology 16(6):498-503.

Ministry for the Affairs Related to Old Combatants. 2007. Heróis Nacionais e Combatentes Destacados Depositados na Cripta da Praça dos Heróis em Maputo (National Heroes and

Combatants On Display and Bestowed in the the Crypt of the Heroes Plaza in Maputo). Maputo. National Board of the History and Heritage of National Liberation, Ministry for Affairs Related to Old Combatants.

Ministry of Health. 2000. The Kaya Kwanga Commitment: A Code of Conduct to Guide the Partnership for Health Development in Mozambique. Maputo. Ministry of Health.

————. 2003. The Kaya Kwanga Commitment: A Code of Conduct to Guide the Partnership for Health Development in Mozambique. Maputo. Ministry of Health.

————. 2004. Plano Estratégico Nacional de Combate às ITS/HIV/SIDA Sector Saúde 2004-2008 (National Strategic Plan to Fight STI/HIV/AIDS Health Sector 2004-2008). Maputo. Ministry of Health.

————. 2005a. Balanço do grau de execução do programa quinquenal do Governo 2000-2004 (Balance of the level of execution of the five-year Government plan 2000-2004). Maputo. Ministry of Health, Sectorial Coordination Committee.

————. 2005b. Código de Conduta para Orientar a Parceria entre o Ministério da Saúde e as Organizações Não Governmentais (Code of Conduct to Inform the Partnership between the Ministry of Health and Nongovernmental Organisations). Maputo. Ministry of Health.

————. 2005c. Plano de Desenvolvimento de Recursos Humanos Período 2006-2010 (Human Resource Development Plan Period 2006-2010) Maputo. Ministry of Health, Human Resource Directorate.

————. 2005d. Relatório sobre a Revisão dos Dados de Vigilância Epidemiológica do HIV - Ronda 2004 (Report on the Update of the Epidemiological Surveillance Data - 2004 Round). Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme, National Health Directorate.

————. 2006a. Aceleração da expansão do TARV em Moçambique. Problemática e alternativas de solução (Acceleration of ART expansion in Mozambique. Problematics and alternative solutions). Maputo. Ministry of Health.

————. 2006b. Contrato de Prestação de Serviços pelas ONGs ao MISAU (Service Contract for the Accountability of NGOs and MoH). Maputo. Ministry of Health.

————. 2006c. Data on ART Coverage. Maputo. Ministry of Health, Department of Medical Assistance.

————. 2006d. Data on HIV Prevalence and ART Eligibility. Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme.

————. 2006e. HIV Testing Data 2002. Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme.

————. 2006f. HIV Testing Data 2002-2005. Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme.

————. 2006g. Informed Consent. Maputo. Ministry of Health, National Health Service, AIDS Control Commission.

————. 2006h. Normas e Procedimentos para a Prestação de Serviços pelas ONGs ao MISAU (Norms and Procedures for the Performance of Services by NGOs and MoH). Maputo. Ministry of Health.

————. 2006i. Patients Enrolled versus Patients on ARVs, September 2006. Maputo. Ministry of Health, Department of Medical Assistance.

————. 2006j. Plano Estratégico HIV/SIDA. Componente Medicina Tradicional (Strategic HIV/AIDS Plan. Traditional Medicine Component). First National HIV/AIDS Meeting, Maputo, Ministry of Health, 2006j. National STI/HIV/AIDS Control Programme.

————. 2006k. Relatório Anual da Informação do Aconselhamento e Testagem em Saúde (Annual Report on Information about Counselling and Testing for Health). Maputo. Ministry of Health, Board for the Promotion of Health and Control of Diseases, National STI/HIV/AIDS Control Programme.

————. 2007a. Atendimento hospitalar deve ser igual para todo Moçambicano (Hospital attendance must be equal for all Mozambicans). Maputo. Ministry of Health. Electronic document, http://www.misau.gov.mz, accessed 9 June 2008.

————. 2007b. Boletim DAM de HIV/SIDA em Moçambique, Julho (HIV/AIDS Bulletin DAM in Mozambique, July). Maputo. Ministry of Health, National Administration of Medical Assistance.

————. 2007c. Carta dos Direitos e Deveres dos Utentes (User Rights and Duties Charter). Maputo. Ministry of Health. Electronic document, http://www.misau.gov.mz, accessed 9 June 2008.

————. 2007d. Data on ART Coverage. Maputo. Ministry of Health, Department of Medical Assistance.

————. 2007e. Declaração de Política Nacional de Saúde (National Politics of Health Declaration). Maputo. Ministry of Health. Electronic document, http://www.misau.gov.mz, accessed 9 June 2008.

————. 2007f. Procura-se melhorar a situação de Infraestruturas e equipamento de saúde (We seek to improve the situation regarding infrastructure and health equipment). Maputo. Ministry of Health. Electronic document, http://www.misau.gov.mz, accessed 9 June 2008.

————. 2008a. ARV data, 2004-May 2008. Maputo. Ministry of Health, National Board of Medical Assistance, National STI/HIV/AIDS Programme.

————. 2008b. Data on HIV Prevalence, ART Eligibility, HIV Testing, ART Targets and ART Coverage. Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme.

————. 2008c. Desempenho do sector da saúde sétima avaliação conjunta anual, ACA VII (Seventh annual cluster evaluation of the performance of the health sector). Maputo. Ministry of Health.

————. 2008d. Médicos Estrangeiros. Médicos estrangeiros por região e por província (Foreign Doctors. Foreign doctors by region and province). Maputo. Ministry of Health, Human Resource Directorate. Electronic document, http://www.misau.gov.mz/pt/misau/drh_direccao_de_recursos_humanos/estatisticas/medicos_es trangeiros, accessed 2 July 2008.

————. 2008e. Médicos Nacionais. Resumo dos médicos nacionais existentes por província em 30 de Junho de 2005 (National Doctors. Summary of national doctors by province as of 30 June 2005). Maputo. Ministry of Health, Human Resource Directorate. Electronic document, http://www.misau.gov.mz/pt/misau/drh_direccao_de_recursos_humanos/estatisticas/medicos_na cionais, accessed 2 July 2008.

————. 2008f. Relatório sobre a Revisão dos Dados de Vigilância Epidemiológica do HIV - Ronda 2007 (Report on the Update of the Epidemiological Surveillance Data - 2007 Round). Maputo. Ministry of Health, National STI/HIV/AIDS Control Programme, National Health Directorate.

Ministry of Health, and DANIDA. 2004. Respostas dos Agregados Familiares Face ao HIV/SIDA: Um Estudo de Base. Província de Tete: Changara, Mágoe, Cidade de Tete, Angónia (HIV/AIDS Baseline Study. Tete Province: Changara, Mágoe, Tete City, Angónia). Maputo. Ministry of Health and Danish International Development Agency, DANIDA.

Ministry of Science and Technology. 2007. Bibliografia Anotada. Estudos, Pesquisas e Documentos Relativos ao HIV/SIDA Em Moçambique 1987-2007 (Annotated Bibliography. HIV/AIDS Related Studies, Research, and Documents in Mozambique 1987-2007). Maputo. Ministry of Science and Technology.

Mishra, Vinod, Simona Bignami-Van Assche, Robert Greener, Martin Vaessen, Rathavuth Hong, Peter D. Ghys, J. Ties Boerma, Ari Van Assche, Shane Khan, and Shea Rutstein. 2007. HIV infection does not disproportionately affect the poorer in sub-Saharan Africa. AIDS 21(Supplement 7):S17-S28.

Mola, Olimpio Durão, Mary Anne Mercer, R. Jawad Asghar, Kenneth Gimbel-Sherr, Sarah Gimbel-Sherr, Mark Micek, and Stephen Gloyd. 2006. Condom use after voluntary counselling and testing in central Mozambique. Tropical Medicine and International Health 11(2):176-181.

MONASO. 2005a. Entrega do Anteprojecto de Lei e comemorações do 1 de Dezembro de 2005 (Hand over of a law draft and commemorations of 1 December 2005). Maputo: MONASO, Mozambican Network of AIDS Service Organizations.

————. 2005b. Inicativa para a Prevenção, Combate e Mitigação do Impacto do HIV/SIDA. Programa Quinquenal 2005-2009 (Initiative for Prevention, Fight and Mitigation of the Impact of HIV/AIDS. Quinquenal Program 2005-2009). Maputo: MONASO, Mozambican Network of AIDS Service Organizations.

————. 2006. Estratégia de Advocacia da MONASO (MONASO Advocacy Strategy). Maputo: MONASO, Mozambican Network of AIDS Service Organizations.

MONASO/RENSIDA. 2005. Estudo preliminar sobre um anteprojecto da criação de uma lei que defende os direitos humanos das pessoas vivendo com HIV/SIDA (PVHS) e contra o estigma e a discriminação das pessoas infectadas e afectadas pela pandemia em Moçambique (Preliminary draft study for the creation of a law that defends the human rights of people living with HIV/AIDS (PLWA) and counters the stigma and discrimination of people infected and affected by the pandemic in Mozambique). Maputo: MONASO/RENSIDA.

Monteiro, Denise. 2007. Farmanguinhos/Fiocruz firma acordo de cooperação com Moçambique (Farmanguinhos/Fiocruz signs cooperation agreement with Mozambique). Rio de Janeiro. Ministry of Health. Electronic document, http://www.fiocruz.br/far/cgi/cgilua.exe/sys/start.htm?infoid=256&sid=16, accessed 24 May 2008.

Morgan, D., C. Mahe, B. Mayanja, J. M. Okongo, R. Lubega, and J. A. G. Whitworth. 2002a. HIV-1 infection in rural Africa: is there a difference in median time to AIDS and survival compared with that in industrialized countries? AIDS 16(4):597-603.

Morgan, David L. 1997. Focus Groups As Qualitative Research. Volume 16. London: Sage Publications.

Morgan, Dilys, Cedric Mahe, Billy Mayanja, and James A. G. Whitworth. 2002b. Progression to symptomatic disease in people infected with HIV-1 in rural Uganda: prospective cohort study. British Medical Journal 324(7331):193-196.

Morrell, Robert. 2003. Silence, sexuality and HIV/AIDS in South African schools. Australian Educational Researcher 30(1):41-62.

Morris, Martina. 2001. Concurrent partnerships and syphilis persistence: new thoughts on an old puzzle. Sexually Transmitted Diseases 28(9):504-507.

Morris, Martina, and Mirjam Kretzschmar. 1997. Concurrent partnerships and the spread of HIV. AIDS 11(5):641-648.

Nader, Laura. 1972. Up the Anthropologist – Perspectives Gained from Studying Up. *In* Reinventing Anthropology. D. Hymes, ed. New York: Random House.

———. 1980. The Vertical Slice: Hierarchies and Children. *In* Anthropological Perspectives on Bureaucracy. G.M. Britan and R. Cohen, eds. Pp. 31-43. Philadelphia: Institute for the Study of Human Issues.

National AIDS Council. 2005. Plano Estratégico Nacional de Combate ao HIV/SIDA (PEN II) (National Strategic Plan to Fight HIV/AIDS (PEN II)). Maputo. Council of Ministers.

———. 2006. Relatório de Actividades 2005 (Activity Report 2005). Maputo. National AIDS Council.

National Institute of Statistics. 1997. II Recenseamento Geral da População e Habitação 1997 (2nd General Population and Habitation Census), Vol. 2005. Maputo: Instituto Nacional de Estatística.

———. 2002. Impacto Demográfico do HIV/SIDA em Mozambique. Actualização, ano 2000 (Demographic Impact of HIV/AIDS in Mozambique. 2000 Update). Maputo. National Institute of Statistics.

———. 2004. Impacto Demográfico do HIV/SIDA em Mozambique. Actualização, Ronda de Vigilância Epidemiológica 2002 (Demographic Impact of HIV/AIDS in Mozambique. Update, Epidemiological Vigilance Round 2002). Maputo. National Institute of Statistics.

———. 2005. Moçambique. Inquérito Demográfico e de Saúde 2003 (Mozambique. Demographic and Health Enquiry 2003). Maputo. National Institute of Statistics.

———. 2008. 3º Recenseamento Geral da População e Habitação: Resultados preliminares (3rd General Population and Habitation Census: Preliminary results). Maputo. National Institute of Statistics. Electronic document, http://www.ine.gov.mz/censo2007, accessed 25 May 2008.

Newitt, Malyn. 1995. A History of Mozambique. Bloomington: Indiana University Press.

Nguyen, Vinh-Kim. 2001. Epidemics, interzones and biosocial change: retroviruses and biologies of globalisation in West Africa. Ph.D. dissertation, McGill University.

———. 2005. Antiretroviral Globalism, Biopolitics, and Therapeutic Citizenship. *In* Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems. A. Ong and S.J. Collier, eds. Pp. 124-149. Malden, Massachusetts: Blackwell Publishing.

Noormahomed, Abdul Razak. 1991. Evolution and Future Direction of Health Care Policies and Systems in Mozambique since Independence. Maputo: Ministry of Health.

Noormahomed, Abdul Razak, and Malcolm Segall. 1994. The public health sector in Mozambique: a post-war strategy for rehabilitation and sustainable development. Geneva. World Health Organization. Electronic document, http://www.who.int/hac/techguidance/tools/disrupted_sectors/module_12/en/index7.html, accessed 24 May 2008.

Notícias. 2004. Luta contra SIDA: Brasil já não monta fábrica de anti-retrovirais em Moçambique (Fight against AIDS: Brazil not yet constructing factory for antiretrovirals in Mozambique). Maputo. Notícias.

———. 2005. Fábrica de anti-retrovirais: Maputo e Brasília renovam compromiso (Factory for antiretrovirals: Maputo and Brasilia renew commitment). Maputo. Notícias.

Nunes, Elizabete Abrantes, Eduardo Mello De Capitani, Elizabete Coelho, Orvalho Augusto Joaquim, I. R. O. Figueiredo, A. M. Cossa, A. C. Panunto, and M. Carvalho-Ramos. 2005. Patterns of anti-

tuberculosis drug resistance among HIV-infected patients in Maputo, Mozambique, 2002-2003. International Journal of Tuberculosis and Lung Disease 9(5):494-500.

OHCHR. 2006. Status of Ratifications of the Principal Human Rights Treaties. As of 14 July 2006. Geneva. Office of the United Nations High Commissioner for Human Rights. Electronic document, http://www2.ohchr.org/english/bodies/docs/status.pdf, accessed 9 June 2008.

Ooms, Gorik. 2008. The right to health and the sustainability of healthcare: Why a new global health aid paradigm is needed. Ph.D. dissertation, Ghent University.

Opotow, Susan. 2001. Social Injustice. In Peace, Conflict, and Violence. Peace Psychology for the 21st Century. D.J. Christie, R.V. Wagner, and D.D.N. Winter, eds. Pp. 102-109. Upper Saddle River, New Jersey: Prentice Hall.

Parker, Richard, and Peter Aggleton. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine 57(1):13-24.

Passador, Luiz Enrique, and Omar Ribeiro Thomaz. 2006. Raça, sexualidade e doença em Moçambique (Race, sexuality and disease in Mozambique). Estudos Feministas 14(1):263-286.

Pavignani, Enrico, and Joaquim Ramalho Durão. 1999. Managing external resources in Mozambique: building new aid relationships on shifting sands? Health Policy and Planning 14(3):243-253.

Peacock, James L., and Dorothy C. Holland. 1993. The Narrated Self: Life Stories in Process. Ethos 21(4):367-383.

Pearson, Cynthia R., A. E. Kurth, S. Cassels, Diane P. Martin, Jane M. Simoni, P. Hoff, Eduardo Matediana, and Stephen Gloyd. 2007. Modeling HIV transmission risk among Mozambicans prior to their initiating highly active antiretroviral therapy. AIDS Care 19(5):594-604.

Pearson, Cynthia R., Mark Micek, Jane M. Simoni, Eduardo Matediana, Diane P. Martin, and Stephen Gloyd. 2006. Modified directly observed therapy to facilitate highly active antiretroviral therapy adherence in Beira, Mozambique. Development and implementation. Journal of Acquired Immune Deficiency Syndromes 43(Supplement 1):S134-S141.

Pfeiffer, James. 2002. African Independent Churches in Mozambique: Healing the Afflictions of Inequality. Medical Anthropology Quarterly 16(2):176-199.

———. 2003. International NGOs and primary health care in Mozambique: the need for a new model of collaboration. Social Science & Medicine 56(4):725-738.

———. 2004a. Condom Social Marketing, Pentecostalism, and Structural Adjustment in Mozambique: A Clash of AIDS Prevention Messages. Medical Anthropology Quarterly 18(1):77-103.

———. 2004b. International NGOs in the Mozambique Health Sector: The 'The Velvet Glove' of Privatization. In Unhealthy Health Policies. A. Castro and M. Singer, eds. Pp. 43-62. Oxford: Altamira Press.

Pharmaceutical Department. 2005. TARV Novembro/Dezembro 2005 (ART November/December 2005). Maputo. Ministry of Health, National Health Board, Pharmaceutical Department, Center for Medicines and Medical Articles.

Pitcher, M. Anne. 1996. Recreating Colonialism or Reconstructing the State? Privatisation and Politics in Mozambique. Journal of Southern African Studies 22(1):49-74.

———. 2002. Transforming Mozambique: The Politics of Privatization, 1975-2000. Volume 104. Cambridge: Cambridge University Press.

Plank, David N. 1993. Aid, Debt, and the End of Sovereignty - Mozambique and Its Donors. Journal of Modern African Studies 31(3):407-430.

PlusNEWS. 2008. Moçambique: Novo anteprojecto de lei na defesa dos seropositivos (Mozambique: new law proposal in defence of seropositives). PlusNews. Electronic document, http://www.plusnews.org/pt/Report.aspx?ReportId=77099, accessed 24 July 2008.

Porter, Kholoud, and Basia Zaba. 2004. The empirical evidence for the impact of HIV on adult mortality in the developing world: data from serological studies. AIDS 18(Supplement 2):S9-S17.

Prata, Ndola, Leo Morris, Elizio Mazive, Farnaz Vahidnia, and Mark Stehr. 2006. Relationship between HIV risk perception and condom use: Evidence from a population-based survey in Mozambique. International Family Planning Perspectives 32(4):192-200.

Radcliffe-Brown, Alfred Reginald. 1979. Taboo. In Reader in Comparative Religion. W.A. Lessa and E.Z. Vogt, eds. Pp. 46-57. New York: HarperCollins Publishers.

Rangsin, Ram, Phunlerd Piyaraj, Thira Sirisanthana, Narongrid Sirisopana, Onsri Short, and Kenrad E. Nelson. 2007. The natural history of HIV-1 subtype E infection in young men in Thailand with up to 14 years of follow-up. AIDS 21(Supplement 6):S39-S46.

Republic of Mozambique. 1977. Lei no 2/77 de 27 de Setembro (Law no 2/77 of 27 September). Boletim da República 1(112):503-504.

———. 1990. Joint Communiqué, 10 July 1990. Sant'Egidio, Rome.

———. 1991a. Lei no 25/91 de 27 de Setembro (Law no 25/91 of 27 September). Boletim da República 1(52):13-14.

———. 1991b. Lei no 26/91 de 31 de Dezembro (Law no 26/91 of 31 Dezember). Boletim da República 1(52):14.

———. 1992. General Peace Agreement for Mozambique, 4 October 1992. Rome.

———. 1998. Decreto no. 55/98, de 13 de Outubro (Decree no. 55/98 of 13 October). Boletim da República 1(40).

———. 2001. Diploma Ministérial no. 183-A/2001 de 18 de Dezembro. Aprova as Normas de Organização do Serviço Nacional de Saúde para o Atendimento e Tratamento de Pessoas vivendo com HIV/SIDA e os Princípios orientadores para o Tratamento de Doentes com Infecção pelo HIV/SIDA e os respectivos Guias Técnicos (Ministerial Diploma no. 183-A/2001, 18 December 2001. Approval of the Norms for the Organization of the National Health Service for the Attention and Treatment of People living with HIV/AIDS and the guiding Principles for the Treatment of Patients with HIV/AIDS Infection and Respective Technical Guidelines). Boletim da República 1(50):102.

———. 2002. Lei no 5/2002, de 5 de Fevereiro (Law no. 5/2002 of 5 February). Boletim da República:4.

———. 2004. Política da Medicina Tradicional e Estratégia da sua Implementação (Traditional Medicine Policy and Strategy for Its Implementation). Boletim da República 15(1):5.

———. 2005. Plano de Acção para a Redução da Pobreza Absoluta, 2006-2009 (PARPA II) (Action Plan to Reduce Absolute Poverty (PRSP II)). República de Moçambique.

———. 2006. Necessários 7.5 biliões de Meticais para garantir cidade limpa (In need of 7.5 billion Meticais to guarantee clean city). Maputo. Mozambican Government Portal. Electronic document, http://www.portaldogoverno.gov.mz/noticias/fo_news_saude/junho06/news_023_s_06_06, accessed 23 July 2008.

———. 2007. KUYAKANA – Rede Nacional de Mulheres Vivendo com HIV/SIDA (KUYAKANA - National Network of Women Living with HIV/AIDS). Boletim da República 3(33):5-8.

Rhodes, Tim. 2002. The 'risk environment': a framework for understanding and reducing drug-related harm. International Journal of Drug Policy 13(2):85-94.

Robins, Steven. 2006. From "Rights" to "Ritual": AIDS Activism in South Africa. American Anthropologist 108(2):312-323.

Royce, Rachel A., Arlene Seña, Willard Cates Jr., and Myron S. Cohen. 1997. Sexual transmission of HIV. New England Journal of Medicine 336(15):1072-1078.

Sahara Journal. 2008. Sahara Journal (Journal of Social Aspects of HIV/AIDS Research Alliance). Pretoria. Human Sciences Research Council. Electronic document, http://journals.sahara.org.za, accessed 19 July 2008.

Saide, Mouzinho A. O., and Donald E. Stewart. 2001. Decentralization and human resource management in the health sector: a case study (1996-1998) from Nampula province, Mozambique. International Journal of Health Planning and Management 16(2):155-168.

San Lio, Massimo Magnano, Riccardo Carbini, Paola Germano, Giovanni Guidotti, Sandro Mancinelli, Noorjehan Abdul Magid, Pasquale Narciso, Leonardo Palombi, Elsa Renzi, Inês Zimba, and Maria Cristina Marazzi. 2008. Evaluating adherence to highly active antiretroviral therapy with use of pill counts and viral load measurement in the drug resources enhancement against AIDS and malnutrition program in Mozambique. Clinical Infectious Diseases 46(10):1609-1616.

Sandelin, Bo, and Nikias Sarafoglou. 2004. Language and scientific publication statistics. Language Problems & Language Planning 28:1-10.

Santos, Boaventura de Sousa. 2006. The Heterogenous State and Legal Pluralism in Mozambique. Law & Society Review 40(1):39-76.

Saul, John S. 1985. A Difficult Road: The Transition to Socialism in Mozambique. New York: Monthly Review Press.

———. 2005. The Next Liberation Struggle. Capitalism, Socialism and Democracy in Southern Africa. Toronto: Between the Lines.

Scheper-Hughes, Nancy. 1992. Death Without Weeping: The Violence of Everyday Life in Brazil. Berkeley: University of California Press.

———. 1996. Small wars and invisible genocides. Social Science & Medicine 43(5):889-900.

Scheper-Hughes, Nancy, and Margaret Lock. 1986. Speaking "Truth" to Illness: Metaphors, Reification, and a Pedagogy for Patients. Medical Anthropology Quarterly 17(5):137-140.

———. 1987. The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology. Medical Anthropology Quarterly 1(1):6-41.

Schoepf, Brooke Grundfest, Claud Schoepf, and Joyce Millen. 2000. Theoretical Therapies, Remote Remedies: SAPs and the Political Ecology of Poverty and Health in Africa. In Dying for Growth: Global Inequality and the Health of the Poor. J.Y. Kim, J.V. Millen, A. Irwin, and J. Gershman, eds. Monroe, Maine: Common Courage Press.

Scudder, Thayer. 1973. The Human Ecology of Big Projects: River Basin Development and Resettlement. Annual Review of Anthropology 2:45-55.

Sidaway, James Derrick. 1992. Mozambique - Destabilization, State, Society and Space. Political Geography 11(3):239-258.

Singer, Merrill. 1998. The Political Economy of AIDS. Amityville, New York: Baywood Publishing Company.

Singer, Merrill, and Hans Baer. 1995. Critical Medical Anthropology. Amityville, New York: Baywood Publishing Company.

Social Science Citation Index. 2007. ISI Web of Knowledge. The Thompson Corporation. Electronic document, http://wok.mimas.ac.uk, accessed 10 October 2007.

Spradley, James. 1979. The Ethnographic Interview. London: Harcourt Brace Jovanovich College Publishers.

Stillwaggon, Eileen. 2006. AIDS and the Ecology of Poverty. Oxford: Oxford University Press.

Stover, John, Peter Johnson, Basia Zaba, Marcel Zwahlen, François Dabis, and René Ekpini. 2008. The Spectrum projection package: improvements in estimating mortality, ART needs, PMTCT impact and uncertainty bounds. Sexually Transmitted Infections 84(Supplement 1):i24-i30.

Svarre, Karen-Lis. 1996. Mozambique. En politisk og økonomisk oversigt (Mozambique. A political and economic overview). Copenhagen: Ministry of Foreign Affairs, DANIDA.

Swarns, Rachel L. 1999. A Prominent Family Gives One More Face to AIDS in Africa. New York. New York Times.

Taylor, Charles, and Amy Gutmann. 1992. Multiculturalism and the Politics of Recognition: An Essay. Princeton, New Jersey: Princeton University Press.

Todd, Jim, Judith R. Glynn, Milly Marston, Thomas Lutalo, Sam Biraro, Wambura Mwita, Vinai Suriyanon, Ram Rangsin, Kenrad E. Nelson, Pam Sonnenberg, Dan Fitzgerald, Etienne Karita, and Basia Zaba. 2007. Time from HIV seroconversion to death: a collaborative analysis of eight studies in six low and middle-income countries before highly active antiretroviral therapy. AIDS 21(Supplement 6):S55-S63.

Turner, Victor. 1967. The Forest of Symbols. Aspects of Ndembu Ritual. London: Cornell University Press.

UNAIDS. 2006a. Improving estimates of national HIV burdens and ART need, and modelling the impact of prevention programmes. Report of a meeting of the UNAIDS Reference Group for Estimates, Modelling, and Projections. Geneva. UNAIDS. Electronic document, http://www.epidem.org/Publications/Athens2005report.pdf, accessed 24 May 2008.

————. 2006b. Report on WHO/UNAIDS Meeting on Forecasting ARV needs up to 2010, 7-8 November 2005, Geneva. Geneva. UNAIDS. Electronic document, http://www.who.int/hiv/amds/ReportForecastingMeeting.pdf, accessed 24 May 2008.

————. 2007. AIDS Epidemic Update: December 2007. Geneva. Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO). Electronic document, http://unaids.org/en, accessed 24 May 2008.

————. 2008. Report on the Global AIDS Epidemic 2008. Geneva. Joint United Nations Programme on HIV/AIDS, UNAIDS. Electronic document, http://unaids.org, accessed 16 August 2008.

UNAIDS/WHO. 2002. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Mozambique. 2002 Update. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/emc-hiv/fact_sheets/pdfs/Mozambique_EN.pdf, accessed 3 October 2004.

————. 2003. Guidelines for Conducting HIV Sentinel Serosurveys among Pregnant Women and Other Groups. UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance. Electronic

document, http://data.unaids.org/Publications/IRC-pub06/JC954-ANC-Serosurveys_Guidelines_en.pdf, accessed 24 May 2008.

————. 2006a. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. 2006 Update. All sub-Saharan countries. Geneva. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/globalatlas/predefinedReports, accessed 3 November 2007.

————. 2006b. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Botswana. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/globalatlas/predefinedReports, accessed 30 May 2007.

————. 2006c. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Mozambique. 2006 Update. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/globalatlas/predefinedReports, accessed 3 December 2006.

————. 2006d. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Nigeria. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/globalatlas/predefinedReports, accessed 30 May 2007.

————. 2006e. Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections. Swaziland. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO). Electronic document, http://www.who.int/globalatlas/predefinedReports, accessed 30 May 2007.

UNDP. 2006. Human Development Report 2006. Beyond scarcity: Power, poverty and the global water crisis. United Nations Development Programme. Electronic document, http://hdr.undp.org, accessed 20 May 2007.

————. 2007. Human Development Report 2007/2008. Fighting climate change: Human solidarity in a divided world. Basingstoke. Palgrave McMillan. Electronic document, http://hdr.undp.org/en/reports/global/hdr2007-2008, accessed 26 May 2008.

United Nations. 1948. Universal Declaration of Human Rights. Adopted and proclaimed by General Assembly resolution 217 A(III) of 10 December 1948. New York. United Nations. Electronic document, http://www.unhchr.ch/udhr, accessed 9 June 2008.

————. 2000. The right to the highest attainable standard of health: CESCR General Comment 14. New York. United Nations, Economic and Social Council. Electronic document, http://193.194.138.190/html/menu3/b/a_cescr.htm, accessed 3 July 2008.

US DHHS. 2005. HIV/AIDS Bureau. US Department of Health and Human Services. Electronic document, http://hab.hrsa.gov, accessed 24 May 2008.

USAID. 2006. Corruption Assessment: Mozambique. Final Report. Washington. United States Agency for International Development. Electronic document, http://maputo.usembassy.gov/uploads/images/q3naBGGSYz8BsCXguSD5Pw/Final_Report-Mozambique__Corruption_Assessment-without_internal_rec.pdf, accessed 24 May 2008.

USAID/Mozambique. 2006. Decisions Taken at the National HIV/AIDS Meeting as summarized by the Minister 11 March 2006, Vol. 2006. Maputo: USAID/Mozambique.

van der Geest, Sjaak. 1997. Is there a role for traditional medicine in basic health services in Africa? A plea for a community perspective. Tropical Medicine & International Health 2(9):903-911.

van der Geest, Sjaak, and Kaja Finkler. 2004. Hospital ethnography: introduction. Social Science & Medicine 59(10):1995-2001.

van der Geest, Sjaak, Johan D. Speckman, and Pieter H. Streefland. 1990. Primary health care in a multi-level perspective: Towards a research agenda. Social Science & Medicine 30(9):1025-1034.

Van der Paal, L., L. A. Shafer, J. Todd, B. N. Mayanja, J. A. Whitworth, and H. Grosskurth. 2007. HIV-1 disease progression and mortality before the introduction of highly active antiretroviral therapy in rural Uganda. AIDS 21(Supplement 6):S21-S29.

van Gennep, Arnold. 1960 (1908). The Rites of Passage. M.B. Vizedom and G.L. Caffee, transl. Chicago: University of Chicago Press.

Vaz, Paula. 2006. Tratamento Antiretroviral na Criança (Antiretroviral Treatment for Children). First National HIV/AIDS Meeting, 7 March, Maputo, Ministry of Health, 2006.

Vitorino, Conceição. 2007. "Programa de HIV-SIDA falhou" – afirma o Dr. Josefo Ferro ("HIV-AIDS Programme Failed" – affirms Dr. Josefo Ferro). Maputo. Canal de Moçambique, 8 February.

———. 2008. Parlamentares e sociedade civil concertam ante-projecto lei (Parliamentarians and civil society adjust draft law). Maputo. Canal de Moçambique, 21 February.

Walt, Gill, and Julie Cliff. 1986. The dynamics of health policies in Mozambique 1975-85. Health Policy and Planning 1(2):148-157.

Walt, Gillian, and Angela Melamed. 1983. Mozambique: Towards A People's Health Service. London: Zed Books.

Wandel, Simon, Matthias Egger, Ram Rangsin, Kenrad E Nelson, Caroline Costello, Charlotte Lewden, Tom Lutalo, Anthony Ndyanabo, Jim Todd, Lieve Van der Paal, Albert Minga, and Marcel Zwahlen. 2008. Duration from seroconversion to eligibility for antiretroviral therapy and from ART eligibility to death in adult HIV-infected patients from low and middle-income countries: collaborative analysis of prospective studies. Sexually Transmitted Infections 84(Supplement 1):i31-i36.

Watts, Charlotte H., and Robert M. May. 1992. The influence of concurrent partnerships on the dynamics of HIV/AIDS. Mathematical Biosciences 108(1):89-104.

Wawer, Maria J, Ronald H Gray, Nelson K Sewankambo, David Serwadda, Xianbin Li, Oliver Laeyendecker, Noah Kiwanuka, Godfrey Kigozi, Mohammed Kiddugavu, Thomas Lutalo, Fred Nalugoda, Wabwire-Mangen, Mary P Meehan, and Thomas C Quinn. 2005. Rates of HIV-1 Transmission per Coital Act, by Stage of HIV-1 Infection, in Rakai, Uganda. The Journal of Infectious Diseases 191:1403-1409.

Weiser, Sheri D., Michele Heisler, Karen Leiter, Fiona Percy-de Korte, Sheila Tlou, Sonya DeMonner, Nthabiseng Phaladze, David R. Bangsberg, and Vincent Iacopino. 2006. Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns. Plos Medicine 3(7):1013-1022.

Weller, Susan C., Trenton R. Ruebush, and Robert E. Klein. 1997. Predicting Treatment-Seeking Behavior in Guatemala: A Comparison of the Health Services Research and Decision-Theoretic Approaches. Medical Anthropology Quarterly 11(2):224-245.

West, Harry G. 2005. Kupilikula: Governance and the Invisible Realm in Mozambique. Chicago: University of Chicago Press.

———. 2006. Working the Borders to Beneficial Effect: The Not-So-Indigenous Knowledge of Not-So-Traditional Healers in Northern Mozambique. In Borders & Healers. Brokering Therapeutic

Resources in Southeast Africa. T.J. Luedke and H.G. West, eds. Pp. 21-42. Bloomington: Indiana University Press.

West, Harry G., and Scott Kloeck-Jenson. 1999. Betwixt and Between: 'Traditional Authority' and Democratic Decentralization in Post-War Mozambique. African Affairs 98(393):455-484.

West, Harry G., and Tracy J. Luedke. 2006. Introduction: Health Divides: Therapeutic Border Work in Southeast Africa. *In* Borders & Healers. Brokering Therapeutic Resources in Southeast Africa. T.J. Luedke and H.G. West, eds. Pp. 1-20. Bloomington: Indiana University Press.

WHO. 1978a. Declaration of Alma Ata. International Conference on Primary Health Care Alma Ata, USSR, 1978a. World Health Organization.

————. 1978b. Promotion and Development of Traditional Medicine. Report of a WHO Meeting. *In* Technical Report Series, Vol. 622. Geneva: World Health Organization.

————. 2004. Investing in a Comprehensive Health Sector Response to HIV/AIDS. Scaling up Treatment and Accelerating Prevention. Geneva. World Health Organization. Electronic document, http://www.emro.who.int/aiecf/web23.pdf, accessed 24 May 2008.

————. 2005. Interim WHO Clinical Staging of HIV/AIDS and HIV/AIDS Case Definitions for Surveillance. African Region. Electronic document, http://www.who.int/hiv/pub/guidelines/casedefinitions/en/index.html, accessed 24 May 2008.

WHO/UNAIDS/UNICEF. 2008. Epidemiological Fact Sheet on HIV and AIDS. Core data on epidemiology and response. Mozambique 2008 Update. World Health Organization, UNAIDS and UNICEF. Electronic document, http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epifactsheets.asp, accessed 15 September 2008.

Whyte, Susan Reynolds. 1997. Questioning misfortune. The pragmatics of uncertainty in eastern Uganda. Cambridge: Cambridge University Press.

Whyte, Susan Reynolds, Sjaak van der Geest, and Anita Hardon. 2002. Social Lives of Medicines. Volume 10. Cambridge: Cambridge University Press.

Whyte, Susan Reynolds, Michael Whyte, Lotte Meinert, and Betty Kyaddondo. 2004. Treating AIDS: Dilemmas of unequal access in Uganda. Journal of Social Aspects of HIV/AIDS Research Alliance 1(1):14-26.

Wikipedia. 2008. The Free Encyclopedia. Wikimedia Foundation. Electronic document, http://en.wikipedia.org, accessed 19 July 2008.

Witter, Sophie, and Beatrice Were. 2004. Breaking the silence: using memory books as a counselling and succession-planning tool with AIDS-affected households in Uganda. African Journal of AIDS Research 3(2):139-144.

Wohlfeiler, Dan, and John J. Potterat. 2005. Using gay men's sexual networks to reduce sexually transmitted disease (STD)/human immunodeficiency virus (HIV) transmission. Sexually Transmitted Diseases 32(10):S48-S52.

Zenker, Ana Luiza. 2008. Fiocruz vai se instalar em Moçambique, afirma responsável pela África no Itamaraty (Fiocruz to establish in Mozambique, affirms responsible for Africa in Itamaraty). Rio de Janeiro. Agência Brasil. Electronic document, http://www.agenciabrasil.gov.br/noticias/2008/02/05/materia.2008-02-05.5280184178/view, accessed 24 May 2008.

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Appendix 1: Questions for People Living with ARVs

Ethnographic life story questions

1. Can you tell me about your health before you took the test?

2. When did you take the HIV test?

3. Can you tell me about your life after you tested for HIV?

4. Can you tell me about the counselling you received before you started on ARV treatment?

5. When did you start ARV treatment?

6. Can you tell me about your experience with ARVs?

Day Hospitals

1. Which Day Hospital do you attend?

2. How do you get to the Day Hospital?

3. How far is it in between your house and the Day Hospital?

4. How often do you go to the Day Hospital?

5. How much does it cost you each time you visit a Day Hospital?

6. What is your opinion about the service you receive at the Day Hospital?

Counselling and social support

1. Did you receive counselling before you started ARV treatment?

2. What is your opinion about this counselling?

3. Do you know about how the drugs work in your body?

4. Did you receive information about proper diet?

5. Which type of social support do you receive?

6. Where do you receive social support?

Alternative and traditional medicine

1. Which forms of alternative or traditional medicine do you use to treat AIDS?

2. How much do you pay for each consultation?

3. Where do you go to get these forms of treatment?

4. Who pays these consultations?

Appendix 2: Informed Consent Contract, Mozambique 2006

MOZAMBICAN REPUBLIC
NATIONAL HEALTH SERVICE

AIDS CONTROL COMISSION
Informed Consent

I, _____, confirm that:

- I have received basic information about HIV/AIDS (symptoms, evolution and transmission).

- I have received sufficient information about antiretroviral therapy and had the opportunity to discuss with the HIV/AIDS consultation personnel and to ask whatever I wanted.

- I understand and accept that even as antiretrovirals benefit many of the people that take them, these drugs are not the cure of AIDS and do not guarantee that I do not get ill in the future.

- I understand and accept that antiretrovirals can cause side effects, that they can be severe, and that this was explained to me.

- I promise to do everything necessary to adhere to treatment (taking the drugs every day, showing up for the agreed follow-up consultations and required analyses). If this fails, for medical or other reasons, it will have a very negative effect for the result of the treatment.

- I was informed that the hospital would always be open to receive me, whenever necessary for me, for example when health problems occur or if I have any doubts I want clarified.

- I will engage in practising safe sex (use condom).

- I understand and accept that the personal medical data will be collected and analysed, but that the information that identifies me will be kept confidential and will not be revealed.

- In summary, I confirm that I was sufficiently informed and that I want to initiate antiretroviral treatment, and therefore I sign this commitment voluntarily.

Date: ..../.........../200   Venue: ....

....
Signature and complete name of the Patient   Signature and complete name of the Confidant

....
Signature and complete name of the Doctor

....
Signature and complete name of the Counsellor/Psychologist

Source: (Ministry of Health 2006g).

Appendix 3: Questionnaire Guide for Day Hospital Interviews

Targets: Hospitals, clinics and AIDS treatment projects

Q1   How many AIDS patients do you attend to in this hospital/clinic/treatment project?

Q2   How many patients registered for treatment do not come to the Day Hospital to get treatment?

Q3   How many trained health workers attend these patients?

Q4   Which services do you offer (ARVs, food, water, social support, counselling)?

Q5   What is missing in your health facility to provide AIDS treatment? (medicine, technology?)

Q6   What are the main obstacles to provide AIDS treatment?

Q7   What are the major improvements in AIDS treatment provision?

Q8   Do you know about the human rights approach to AIDS treatment?

Q9   How do you use the human rights approach to AIDS treatment?

Q10   Do you see a potential in the human rights approach to AIDS treatment?

Q11   Have you encountered problems using the human rights approach to AIDS treatment?

Appendix 4: Informed Consent

INFORMED CONSENT
Access to AIDS Treatment in Mozambique:
A Human Rights-Public Health Analysis
Erling Høg
Ph.D. Researcher
MA Anthropology, MA Human Rights & Democratisation
London School of Economics, Development Studies Institute
Email: e.hoeg@lse.ac.uk

Voluntary participation
Your participation in the above titled project is *voluntary* and you can refuse to answer any question. You can also at any time choose to withdraw from the study.

Confidentiality
Any information given by you will remain *strictly confidential*: your name and your information will not be revealed to anyone without your permission. Your information will be combined with information from other study participants and any reader will not be able to identify you or what you said.

Project methods
Research methods includes documental research, qualitative and ethnographic interviews, focus groups, and participant observation with key organisations and persons working on access to AIDS treatment in Mozambique. Fieldwork focuses on policy processes of access to AIDS treatment by following the work of organisations and their partnerships with other organisations. How are they approaching the dilemma between the difficulties of implementing AIDS treatment and the idealistic policies formulated at the national and international levels? Is the demand of human rights in accordance with the reality of access to antiretroviral treatment?

Interviews
Interviews will be a combination of informal interviews, open-ended interviews, and semi-structured interviews based on questionnaires (see questionnaire included with this informed consent). Additionally, new questions will be discovered and used in the research process.

Visits to organisations and Day Hospitals
The methodology emphasizes micro-macro investigation. That is, this approach involves patients, health personnel, and people working in HIV/AIDS organisations, government HIV/AIDS programs, and representatives of international organisations. How are actors working on the human rights approach in the context of HIV/AIDS? What are their points of view?

Purpose
The general purpose of this project is to study how AIDS treatment plans and policies are implemented on the ground in Mozambique, with particular emphasis on the United Nations human rights and partnership approaches to the implementation of AIDS treatment.

The end product is a social science Ph.D. thesis, but the research is also intended to be communicated to a wider audience in the public interest of contributing to access to AIDS treatment in Mozambique.

Justification
The project will contribute to ongoing seminars and workshops and support the body of knowledge for teaching social science of HIV/AIDS, as well as being a point of departure for engaging in development projects. The project could also be a point of departure for development project innovators. The project intends to provide results that will improve our understanding of the practical implications of human rights for public health policies with regard to AIDS treatment. Specifically, the proposed study will contribute to the theoretical and applied sociology of knowledge related to development and HIV/AIDS, primarily in Mozambique but also in other countries in a similar situation. It will be useful for policy, practice, and capacity building in poor countries as they take action against HIV/AIDS. The project is also relevant for teaching anthropology, human rights, development, public health, and international health.

Interpretation
The researcher reserves the right to interpret and analyse freely the data produced in the field, following social science standards of intellectual and academic freedom.

Funding
The project is funded by:
• Danish Social Science Research Council, Denmark
• Department of International Health, University of Copenhagen, Denmark

• ***I have read, understand and agree to the information given on this informed consent form***
• ***I agree to participate in this study***

Date   **Place**   **Signature**