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CONTENTS

Acknowledgements	iii
LIST OF TABLES AND FIGURES	VIII
Tables	viii
Figures	viii
Maps	ix
Acronyms	1
CHAPTER 1: THE SOCIAL CONSTRUCTION OF AFRICA'S HIV EPIDEMIC	3
1.1 The Social Construction of Disease Epidemics	3
1.1.1 <i>Monsterization, Target Grouping and Risk Grouping</i>	4
1.2 Yesterday's Racial Science to Today's 'Racial Metaphors': HIV/AIDS Policy in Africa	17
1.2.1 <i>Institutionalized Racism</i>	19
1.2.2 <i>From Racial Science to "Racial Metaphors"</i>	19
1.2.3 <i>African Promiscuity</i>	22
1.2.4 <i>Briefly Identifying Alternatives</i>	30
1.3 Conclusion	38
Notes	40
CHAPTER 2: THE ILLUSORY TRADE-OFF BETWEEN HIV PREVENTION AND TREATMENT	49
2.1 Antiretroviral Treatment as HIV Prevention	49
2.2 The Prevention Cascade	50
2.3 Focus on the Positives	56
<i>Condoms</i>	56
<i>ART</i>	58
2.3.1 The Financial Reckoning	60
<i>PEPFAR</i>	62
<i>The Global Fund</i>	68
Conclusion	72
Notes	76
CHAPTER 3: HUMAN RESOURCES FOR HEALTH AND ART SCALE-UP IN MOZAMBIQUE	81
3.1 Mozambique's Human Resources for Health (HRH)	81
3.2 Human Resources for Health and ART Scale-Up	85

3.3 Task Shifting	90
3.4 Conclusion	93
Notes	95
 CHAPTER 4: CASE STUDY: THE ROLE OF HIV PREVENTION MESSAGES IN PATIENTS' EXPERIENCES WITH ART IN THE CITY OF MAPUTO, MOZAMBIQUE	
4.1 Introduction to the Case Study	98
4.2 Objectives	102
4.3 Study Design	102
4.4 Study Population	103
4.5 Ethical Considerations	106
4.6 Limitations of the Study	106
4.7 Health Center Malhangalene- Adult ART Patients	108
4.7.1 Human Resources	110
4.7.2 <i>What effect do sources of HIV/ AIDS information and their perceived reliability have on patients' experiences with ART?</i>	110
4.7.3 <i>Do incomplete discussions about modes of transmission contribute to self-stigmatization and cognitive dissonance between patients' 'knowledge' and clinicians' beliefs about patients?</i>	115
4.7.4 <i>How are shame and fear propagated by prevention messages and what effect does this have on patients' experiences with ART?</i>	120
4.7.5 <i>What do patients' and clinicians' impressions of 'HIV Prevention Campaigns: Before and After' reveal about patients' experiences with ART?</i>	125
4.7.6 <i>Do patients and clinicians know that ART functions as prevention and how would that knowledge affect adherence?</i>	131
4.8 Maputo Central Hospital- Pediatric ART Patients	139
4.8.1 Human Resources	142
4.8.2 <i>What effect do sources of HIV/ AIDS information and their perceived reliability have on caretakers' experiences with ART?</i>	142
4.8.3 <i>Do incomplete discussions about modes of transmission contribute to self-stigmatization (of caretakers) and cognitive dissonance between caretakers' 'knowledge' and clinicians' beliefs about caretakers?</i>	147
4.8.4 <i>How are shame and fear propagated by prevention messages and what effect does this have on caretakers' experiences with ART?</i>	156
4.8.5 <i>Do caretakers know that ART functions as prevention and how would that knowledge affect their and the child's experiences with ART?</i>	161
4.9 Conclusions	163
4.9.1 Adult Patients	163
4.9.2 Caretakers of Pediatric Patients	164
4.9.3 Clinicians	165
4.9.4 Decentralization	167
Notes	168

CONCLUSION	172
Notes	179
Appendices	181
Appendix 1	181
Appendix 2	183
References	187
Chapter 1	187
Chapter 2	196
Chapter 3	201
Chapter 4	205
Conclusion	210

LIST OF TABLES AND FIGURES

Tables

TABLE 1. PRE-MARITAL SEX, 15-19-YEAR-OLDS.....	27
TABLE 2. SEX WITH TWO OR MORE PARTNERS & HIV PREVALENCE.....	27
TABLE 3. COVERAGE VERSUS EFFICACY OF PREVENTION INTERVENTIONS, NUMBER OF NEW CASES OF HIV PER 100,000 SEXUAL EXPOSURES.....	54
TABLE 4. REASONS FOR USING CONDOMS BY AGE GROUP, MOZAMBIQUE 2009	57
TABLE 5. REASONS FOR NOT USING CONDOMS BY AGE GROUP, MOZAMBIQUE 2009	58
TABLE 6. TASK SHIFTING IN MOZAMBIQUE.....	90
TABLE 7. ART RECIPIENTS, HEALTH CENTER MALHANGALENE.....	108
TABLE 8. HIV/AIDS INFORMATION: ADULT PATIENTS, HEALTH CENTER MALHANGALENE.....	111
TABLE 9. BELIEFS ABOUT THE EFFECT OF ART ON SEXUAL TRANSMISSION OF HIV, ADULTS.....	133
TABLE 10. EFFECT OF KNOWING ART DECREASES HIV TRANSMISSION ON MOTIVATION TO ADHERE.....	133
TABLE 11. PEDIATRIC ART RECIPIENTS: MAPUTO CENTRAL HOSPITAL.....	141
TABLE 12. HIV/AIDS INFORMATION: PEDIATRIC PATIENTS, MAPUTO CENTRAL HOSPITAL.....	146
TABLE 13. BELIEFS ABOUT THE EFFECT OF ART ON SEXUAL TRANSMISSION OF HIV, CARETAKERS.....	161
APPENDIX 1, TABLE 1. REASONS FOR CONDOM USAGE, MOZAMBIQUE 2009....	181
APPENDIX 1, TABLE 2. REASONS FOR NOT USING CONDOMS, MOZAMBIQUE 2009	182
APPENDIX 2, TABLE 1. ADULT STUDY PATIENT CHARACTERISTICS.....	183
APPENDIX 2, TABLE 2. CARETAKER AND PEDIATRIC PATIENT CHARACTERISTICS.	184
APPENDIX 2, TABLE 3. CLINICAL PROVIDER CHARACTERISTICS.....	186

Figures

FIGURE 1. CATEGORIZATION OF SICK INDIVIDUALS	6
FIGURE 2: TYPES OF HIV/AIDS TARGET GROUPS.....	9
FIGURE 3. PREVENTION CASCADE, ART.....	52
FIGURE 4. PREVENTION CASCADE, CONDOMS.....	53

FIGURE 5. PREVENTION CASCADE, ABSTINENCE.	53
FIGURE 6. NEW INFECTIONS (PER 100,000 SEXUAL EXPOSURES) PER PREVENTION STRATEGY.....	55
FIGURE 7. TOTAL EXPENDITURES ON HEALTH (EXTERNAL VS. DOMESTIC SOURCES), MOZAMBIQUE 1995-2009.....	61
FIGURE 8. PEPFAR FUNDING FY2004-FY2010.....	63
FIGURE 9. PEPFAR PREVENTION FUNDING FY 2010, MOZAMBIQUE	64
FIGURE 10. PEPFAR CARE AND TREATMENT FUNDING FY 2010, MOZAMBIQUE	65
FIGURE 11. PEPFAR ‘OTHER’ FUNDING FY 2010, MOZAMBIQUE	65
FIGURE 12. GLOBAL FUND GRANT AGREEMENTS 2003-2011.....	70
FIGURE 13. DISTRIBUTION OF MOZAMBICAN PHYSICIANS.....	82
FIGURE 14. DISTRIBUTION OF ALL PHYSICIANS IN MOZAMBIQUE (EXPATRIATE AND MOZAMBICAN).....	82
FIGURE 15. INHABITANTS PER PHYSICIAN FOR THE MOZAMBICAN PROVINCES AND MAPUTO CITY.	83
FIGURE 16. CURRENT AND PROJECTED (2015) HUMAN RESOURCE LEVELS BY HEALTH WORKER CATEGORY.....	84
FIGURE 17. CLINICAL WORKFORCE ATTRITION IN MOZAMBIQUE, 2008-2010	87
FIGURE 18. ART PROVISION 2004-2009	99
FIGURE 19. MEDIATION MODEL OF THE EFFECT OF HIV PREVENTION MESSAGES ON ART PATIENTS’ EXPERIENCES.....	102
FIGURE 20. ART RECIPIENTS, HEALTH CENTER MALHANGALENE.....	109
FIGURE 21. PEDIATRIC ART RECIPIENTS: MAPUTO CENTRAL HOSPITAL.....	140

Maps

MAP 1. GEOGRAPHIC DISTRIBUTION OF PATIENTS INTERVIEWED: HEALTH CENTER MALHANGALENE.....	109
MAP 2. GEOGRAPHIC DISTRIBUTION OF CARETAKERS INTERVIEWED: MAPUTO CENTRAL HOSPITAL.....	141



ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Treatment
ARVs	Antiretrovirals
CCM	Country Coordinating Mechanism (Global Fund)
CD4	Cluster-of-differentiation 4 (cells)
CDC	Centers for Disease Control (United States)
CNCS	National AIDS Council of Mozambique
DHS	Demographic and Health Surveys
RNA	Ribonucleic acid
DRH	Human Resources Directorate (Mozambique)
DSMB	Data and Safety Monitoring Board (United States)
GDP	Gross Domestic Product
GHI	Global Health Initiative
HIV	Human Immunodeficiency Virus
HPTN 052	HIV Prevention Trials Network 052
HRDP	Human Resources Development Plan (Mozambique)
HRH	Human Resources for Health
HSS	Health Systems Strengthening
INSIDA	National Survey of HIV/AIDS (Mozambique)
IUD	Intravenous Drug User
LTF	Lost to Follow-up
LTNP	Long-Term Non-Progressor (from HIV infection to AIDS)
MCH	Maputo Central Hospital
MCHN	Maternal and Child Health Nurse
MDGs	Millenium Development Goals
MSF	Médecins Sans Frontières
MSM	Men who have sex with men
MTCT	Mother-to-Child Transmission
NGO	Non-governmental Organization
NIH	National Institutes of Health
PEPFAR	President's Emergency Plan For AIDS Relief (United States)
PLWH	Persons Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PR	Principal Recipient (Global Fund)
PrEP	Pre-exposure Prophylaxis
RCC	Rolling Continuation Channel (Global Fund)

SSA	sub-Saharan Africa
STD	Sexually-Transmitted Disease
STI	Sexually-Transmitted Infection
SWAp	Sector-Wide Approach
TB	Tuberculosis
TEH	Total Expenditures on Health
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

1

THE SOCIAL CONSTRUCTION OF AFRICA'S HIV EPIDEMIC

1.1 The Social Construction of Disease Epidemics

An epidemic is popularly understood to be an outbreak of an infectious disease affecting a wide swath of a population, more or less at the same time or perhaps in a long, contiguous stretch of time. However, this simple definition of what constitutes an epidemic is not particularly useful in the formulation of public policies or in the design of health interventions by a variety of actors. These institutions that act in the domain of public health require an understanding not only of the biomedical and technical characteristics of a disease and its spread, but also of the social dynamics and characteristics that cause or condition the spread of a disease. Often these social dynamics and characteristics, as one might imagine, can be quite difficult to perceive, identify and understand and are infinitely more difficult to act upon. They may even be incorrectly perceived, identified, understood and acted upon, leading to a host of secondary problems which then become subsequently more difficult to address. However, the quest to mitigate or end an epidemic does require that the effort be made and this effort (conscious or otherwise) by individuals and institutions to perceive, identify and understand the social characteristics and dynamics of an epidemic is what I will refer to as the social construction of a disease epidemic.

Study of the social construction of disease traditionally falls into the confines of medical sociology and refers generally to the exploration of “the effects of class, race, gender, language, technology, culture, the political economy, and institutional and professional structures and norms in shaping the knowledge base which produces our assumptions about the prevalence, incidence, treatment, and meaning of disease”.¹ As the social construction of disease clearly has public health policy implications, particularly in resource-poor settings where the effects of epidemic disease are often magnified, it can also be seen to fall within the area of development studies and development policy. It is with this view towards understanding where and how development policies related to public health originate and the nature of their cumulative momentum—or path dependency if you like—that I shall explore the social construction of disease epidemics and of Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

(HIV/AIDS) in particular. I hope to show that, while social constructions are observable, and are indeed endemic to HIV policy and the avenues of HIV research which gain traction, they are rarely explicitly questioned or explored leading to a well-entrenched path of least resistance in research and policy.

This chapter shall explore social constructions of ‘sick’ individuals and how these constructions relate to perceptions of how and why a disease spreads. We will look at how the social construction of sick individuals and beliefs about the transmissibility of their illness aggregate through mechanisms such as target grouping and become entrenched in policy, supporting many misconceptions and leading to path dependency in HIV policy that is difficult to contest, even with empirical evidence in support of alternative paths.

Section 1.2 then addresses the social dynamics behind the transformation of HIV/AIDS into a ‘sexually transmitted disease’ looking back into history and tracing some of the Colonial-era medical and health-related actions that have, arguably, carried over into the HIV discourse resulting in what I call ‘institutionalized racism’ in HIV/AIDS policy within and towards African nations. While others have noted some similarities between for example, Colonial-era syphilis policies and HIV policies in Africa,^{2,3,4,5} I hope to build upon that work by connecting this long history of institutionalized racism with the more modern social constructions of the HIV epidemic which crowd out many avenues of debate about efficacious HIV policy in Africa.

Within each section, discussion of the policy implications of various aspects of social constructions has been integrated in order to demonstrate the relevance of these social constructions to modern public health policy in the area of HIV/AIDS in a pragmatic and, I hope, intuitive manner.

1.1.1 Monsterization, Target Grouping and Risk Grouping

Throughout human history, people suffering from different illnesses – infectious diseases in particular—have played many and varied roles. The stereotypical images of the poverty-ridden and irresponsible consumptive (tuberculosis)⁶, the prostitute as an evil reservoir of ‘The Clap’ (gonorrhea) and the dirty, shunned sufferer of ‘The Pox’ (syphilis) still carry a certain weight in the minds of many people although few people in recent generations have actually had first-hand experience with many of these (in)famous diseases. These so-called ‘metaphorical connotations’⁷ are common and continue to impact persons

living with a plethora of diseases. In relation to HIV/AIDS, though the specific epidemics in developed countries (where HIV remains largely confined to men who have sex with men – MSM – and intravenous drug users) and the generalized epidemics found in many sub-Saharan African countries (where women are at least as effected as men) have little in common, the ‘iconography’ of HIV has made the voyage from the United States to sub-Saharan Africa virtually unaltered. As AIDS was first identified exclusively in MSM in the United States – and was, indeed, named ‘Gay Immunodeficiency Virus’ until 1982—it quickly became known as a sexually transmitted disease (and not, importantly, as a viral infection such as Hepatitis B) which affected gay men due to their ‘lifestyle’ choices and sexual ‘deviance’ which related not only to homosexual activity, but also reports by the early cohorts of AIDS patients in the USA of having had numerous sexual partners.⁸ This early and much-publicized classification of AIDS as a sexually-transmitted disease of promiscuity carried over to SSA regardless of the fact that historical epidemiological accounts are quite clear that AIDS in Africa most probably originated and was disseminated early on through blood exposures (and not sexual exposures).⁹ Though reported sexual behavior in SSA could not hope, in fact, to explain the magnitude of the HIV epidemics nor dramatic differences in prevalence between African countries (as discussed in detail later in this chapter), the imagery of the ‘sexual deviant’ as the reservoir of AIDS has been impossible to purge from both the popular and academic psyche, and has been extended from the homosexual population of the developed world to the heterosexual population of SSA.

Figure 1 illustrates a simple scheme demonstrating how ‘sick’ individuals may be categorized, or in other words, what role they may be assigned in a society. While many other factors can and do contribute to the social construction of a ‘sick’ person (i.e.: extant religious beliefs, socio-economic characteristics of the worst-affected population, availability of a cure or effective treatment, etc...), this figure simplifies matters somewhat by looking at the generic roles assigned to ‘sick’ people based on just two factors: (1) Whether the person is perceived to have ‘caught’ the disease through his/her own irresponsible behavior or if it was presumably someone else’s fault and; (2) the perceived level of danger that the ‘sick’ person poses to uninfected persons.

Figure 1. Categorization of Sick Individuals

		How Person Became Infected	
		Own Fault (irresponsible behavior)	Someone Else's Fault
Perceived Level of Danger to Others	High	Monster	Shunned Victim
	Low	Deviant	Coddled Victim

Source: Author's own presentation

In the social construction of HIV/AIDS, particularly in sub-Saharan Africa, the most commonly claimed modes of transmission are through sexual intercourse and mother-to-child transmission (MTCT) in the case of children. On an individual level, the sexual behavior that is perceived as necessary for one to become infected with HIV (ie: promiscuity, infidelity, multiple or concurrent partners, etc...) is considered 'deviant' as mentioned above in relation to the origins of AIDS iconography in the USA. Those perceived as having become infected with HIV through sexual contact, however, may on the one hand be classified as simply 'deviant' if the perception of the probability of infecting other people remains low. This was often the case during the earlier years of the epidemic in the USA as the majority of the American population did not feel threatened by a sexually transmitted disease believed to only be passed to and from gay men through homosexual intercourse.¹⁰ However, if the infected person is believed to not only have contracted HIV through their own irresponsible sexual behavior, but also to be in a position to infect others in the general population, then this person is perceived as a greater threat and could be categorized as a 'monster'. An example of this type of classification would be the iconography of prostitutes as reservoirs of sexually transmitted infections such as syphilis and gonorrhea and, from the mid-1980's forward, also of HIV.¹¹

Both of these classifications ('deviant' and 'monster') rely heavily on the assumption that the infected person is at fault for his/her infection. If, on the other hand, one falls into a group that is seen as having been infected with HIV

through no fault of one's own (such as children or, at times, women), one may be classified as one of two types of 'victim': the shunned victim is the victim who is seen to have been infected through no fault of his/her own, but is considered a danger to others. This group may include some women who could be seen to have been infected by philandering husbands—this is a topic oft-discussed in the academic literature on African women and HIV^{12,13}—however, they may fall into the 'shunned' group when they bring children into the world as the risk of transmitting HIV from mother-to-child is generally perceived to be very high and HIV-infected mothers who choose to have children may be considered irresponsible.¹⁴ The coddled victim, conversely, is perceived as less of a potential danger to others (less infectious) and deserving of care and sympathy. With the example of HIV given here, hemophiliacs are a perfect example of a victimized group (in the developed world) as they became infected through blood products received in a medical setting to treat a disease (hemophilia) which is acquired genetically. The importance of this perceived threat to others, while not typically discussed in the HIV discourse, has been shown to be significant in the study of tuberculosis patients and their feelings of marginalization or 'demonization'.¹⁵

At the heart of this type of classification is the idea that "more than [being] mere sociological curiosities, these cultural meanings have an impact on the way the illness is experienced, how the illness is depicted, the social response to the illness, and what policies are created concerning the illness"¹⁶ In particular, the aggregation of these categories that is implicit in policy-making becomes of great concern in an area such as HIV/AIDS, with its vast outlays of resources, both human and financial, as well as the complex disease-specific infrastructure that exists in many nations. This phenomenon of aggregation and the concrete policy consequences that follow will be discussed in the following sub-sections dealing with 'target grouping' and 'risk grouping'.

Target Grouping

Schneider and Ingram (1993) succinctly frame the issue of how the social construction of 'target populations' in policy-making shapes both the policy agenda as well as the policies themselves. They point out how social constructions can portray groups of people either positively or negatively as discussed briefly above. Consequently, political incentives are structured so that politicians generally "provide beneficial policy to powerful, positively constructed target populations and [...] devise punitive, punishment-oriented policy for negatively constructed groups".¹⁷ Political science perspectives on social

construction and policy range from the idea of ‘causal stories’^{18,19} to messages sent by policy which explicitly or implicitly communicate “what government is supposed to do, which citizens are deserving (and which not)”.²⁰ They help to effectively identify who is to blame for a political problem and therefore, who is responsible for acting to resolve the problem.

Forming a target group undeniably has political as well as economic justifications, and target populations “are measurable, empirical, phenomena” with policy being the specific tool which creates the empirical boundaries if they did not already exist.²¹ In the case of public health and infectious disease, the formation of a target group implicitly defines and sets apart the people whose behavior has been identified as propagating or advancing an epidemic (or, conversely, who are perceived victims of those who are seen as advancing an epidemic) and whose behavior must be changed through incentives, coercion or punishment in order to address the epidemic (or, conversely, who must be protected from those who are advancing the epidemic). These target groups may or may not have had a distinct and well-defined social construction before a policy was introduced, but surely after the introduction of policy, their social construction is well under way.

In the HIV/AIDS discourse, the social construction of target groups has evolved over time and often different contexts see the ‘same’ people put into different types of groups (i.e.: the political power of gay men as a group is quite different in the developed world vs. in most of sub-Saharan Africa). Though target groups are ubiquitous in HIV/AIDS policy-making, the exploration undertaken here to understand how they are formed and the assumptions (relating to the social construction of HIV-infected people) behind their formation have remained surprisingly free from examination and criticism up until now. Yet, there are some common themes which can be fit within Schneider and Ingrams’s (1993) framework of ‘types of target populations’ (Fig 2) and I shall use that framework to continue the discussion on the pertinence of target grouping in the HIV/AIDS discourse.

The matrix uses two measures: (1) ‘power’ (weak or strong), generally understood as political power but which I will also extend to what has come to be called ‘interpersonal bargaining power’ and; (2) ‘constructions’ (positive or negative), which refer to the way that the group as a whole is socially perceived. The resulting matrix then identifies four types of target groups: ‘Advantaged’ (strong and positively constructed); ‘Contenders’ (strong but negatively constructed); ‘Dependents’ (weak but positively constructed) and; ‘Deviants’

(weak and negatively constructed). You will note in *Figure 2* that in the HIV/AIDS discourse, I have been unable to identify a target group which falls into the 'Advantaged' category; that is, I could not identify a politically powerful group of HIV-infected persons (or a group where HIV infection is particularly high) that is positively socially constructed or positively perceived by society. It is also important in this matrix to understand that we are speaking of the beneficiaries of policies (i.e.: HIV-infected individuals that fall within a certain socio-political group) and not necessarily groups or organizations that lobby for HIV-infected persons. A clear example of this distinction would be the well-known Treatment Action Campaign (TAC) in South Africa. This group has great political power and has lobbied successfully for policies that have benefitted a vast array of HIV-infected target groups, however, they are not listed as a target group in and of themselves as they are generally understood to be a 3rd party political action (lobbying) group rather than a politically or socially-defined group of potential beneficiaries fighting for policies to benefit themselves, personally.

Figure 2: Types of HIV/AIDS Target Groups

		Constructions	
		Positive	Negative
Power	Strong	<p><i>Advantaged</i></p> <p>—</p>	<p><i>Contenders</i></p> <ul style="list-style-type: none"> ○ 'Elite' citizens with HIV (i.e.: politicians, famous athletes, famous musicians, etc...) ○ Gay men in the developed world
	Weak	<p><i>Dependents</i></p> <ul style="list-style-type: none"> ○ Children with HIV ○ People who are believed to have contracted HIV nosocomially (medical setting) ○ Some women with HIV (particularly those who do not have children and are seen to be victims) 	<p><i>Deviants</i></p> <ul style="list-style-type: none"> ○ Intravenous (illicit) drug users with HIV ○ Poor men with HIV ○ Prisoners or ex-convicts with HIV ○ Prostitutes and people who are believed to engage in 'transactional sex' ○ Some women with HIV (particularly those who have passed it to their child and are then seen to be perpetrators) ○ Gay men in most of Sub Saharan Africa

Adapted from Schneider and Ingram (1993)

This categorization of target groups is more than simply a convenient theoretical illustration. The types of policies and the way that they are justified in the political sphere differ widely between the various groups with “rationales for providing beneficial policy to powerless groups [emphasizing] justice-oriented legitimations, rather than instrumental ones”²². In the HIV/AIDS discourse, the prime example of justice-based legitimations can be found in the human rights discourse. Instrumental legitimations would encompass arguments to address the epidemic based upon, for example, potentially broad economic benefits of mitigating the epidemic. Interestingly, “the association of justice-oriented rationales to dependent populations seems to hold even when a case can be made linking the policy to national goals such as economic development”²³.

Justice-based or rights-based legitimations of policy allow for symbolic and rhetorical measures that ostensibly benefit target populations (i.e.: ‘universal access to HIV prevention’) and fall into an altruistic vision of government; while instrumentally-oriented rationales (i.e.: economic benefits for society as a whole) are neither symbolic nor altruistically framed and typically require larger resource investments in the target group.

At this point, an important note should be made: Let us not be led astray by the modern fondness for the phrase ‘universal access’ in the HIV/AIDS discourse which would seem to imply that no target group exists. The target group, of course, is the group that does **not** currently have access based on any number of characteristics such as income, gender, age, geography, etc... When attempting to identify the target group in statements about ‘universal access’, one must simply look at who already has access, and the remaining population then becomes the ‘target group’.

By identifying ways that action towards target groups can instrumentally benefit society as a whole, governments would then be implicitly acknowledging that acting is no longer “altruistic”—in other words, their action would not be based only on helping the target groups themselves out of a sense of goodwill or an abstract notion of justice/rights, but rather on helping the society as a whole—and therefore, it would become more difficult for governments to justify inaction, symbolic action, rhetorical action or under-allocation of resources to the target group.

This byplay can clearly be seen in the arguments surrounding HIV/AIDS policy. All sorts of rhetoric and symbolic action can be seen in the international,

national and local commitments to 'universal access to HIV prevention, treatment and care'. It is difficult to imagine a more perfect example of rhetorical action than a commitment to *universal access to HIV prevention*. This is because it is difficult to find any explicit explanation of what 'universal access to HIV prevention' may imply on a practical or logistical level. As HIV is a blood-borne pathogen, and this policy statement (this 'commitment' on the part of governments) is presumably directed towards governmental/institutional-provided prevention, one could then interpret it to mean, in part, that stringent infection control measures will be adopted in all healthcare settings, with the concomitant investment of financial and human resources, to ensure that no one is a victim of completely preventable nosocomial transmission¹ of HIV (or other infectious pathogens for that matter). Yet, this very resource-intensive interpretation of 'universal access to HIV prevention' is rarely acknowledged or adopted by governments in the highest-prevalence nations (nor by the international organizations working in these settings). The 'universal access to HIV prevention' if it is examined or interpreted at all, is generally considered synonymous with access to condoms and, in some more affluent settings, with access to needle exchange programs for intravenous (illegal) drug users (IUDs). In other words, universal access to HIV prevention does not, in fact, refer to protection of the population from fairly universal, institutional-level threats of infection (i.e.: infection in formal and informal healthcare settings), but rather rhetorically guarantees access to information or interventions meant to bring about individual behavior change.

By basing the universal access to HIV treatment, on the other hand, in a rhetorical and symbolic 'statement' of commitment, governments (and international organizations) simultaneously achieve two ends. First, they ground the universal access to HIV treatment in a human rights discourse (the above-mentioned justice-based rationale), rather than referring to any instrumental rationale (i.e.: immense public health expenditures saved by not having to treat opportunistic infections of AIDS patients, population-level preventative benefits of universal treatment, etc...). This ensures the government's role as the paternalistic and altruistic benefactor of passive HIV-infected persons. Second, through the continued stress put on individual sexual behavior change as the exclusive legitimate prevention strategy, the target group for treatment (HIV-infected persons), is effectively either 'dependent' (weak but positively-

¹ Nosocomial transmission is transmission of a pathogen in a healthcare setting and can include modes of transmission such as injections with re-used needles and/or syringes, blood transfusions with infected blood or non-sterile transfusion equipment, etc...

constructed) or ‘deviant’ (weak and negatively-constructed) which continues to absolve the government and international donors of political responsibility to invest the vast resources that would be needed to provide universal HIV treatment. So, in the end, these ‘symbolic policies permit elected leaders to show great concern but relieve them of the need to allocate resources’.²⁴

An interesting and clear example of the importance of positive vs. negative social constructions in HIV treatment policy can be seen in the debates surrounding antiretroviral treatment (ART) for persons living with HIV (PLWH) and the use of antiretrovirals (ARVs) as pre-exposure prophylaxis (PrEP) for persons who are not infected with HIV.^{25,26,27,28} The financial, logistic, and human resource constraints to providing ART to all HIV-infected persons in need have been discussed extensively and simply broaching the subject of universal ART inspires immediate and interminable diatribes on the infeasibility of this strategy for treatment and prevention with the phrase, “we can’t treat our way out of the epidemic”, habitually thrown in for good measure.²⁹

Let us put this in the framework of social constructions of sick people and target groups. Remember here that people living with HIV are almost invariably negatively-constructed. PrEP, on the other hand, is targeted mainly towards adolescent girls and women (‘weak’ politically but positively perceived in society; in other words, they are generally seen as ‘victims’ of the HIV epidemic). However, we must, of course, note that the financial, logistic and human resource constraints that apply to ART provision for PLWH would necessarily intensify significantly for PrEP provision as ARVs in whatever form (oral, vaginal gel, etc...) would need to be produced and provided on-demand, for the vast non-HIV-infected population for generations to come. Rather than providing ARVs to the 5-20% of the population infected with HIV, the financial, logistic and human resource constraints inherent in ARV provision would have to be overcome in order to provide PrEP to the 80-95% of the population that is not infected with HIV, presumably in perpetuity. And yet, the same people (researchers, politicians, laypeople) who repeat the mantra “we cannot treat our way out of the epidemic” enthusiastically support the idea of PrEP. The question is: why? PrEP is astoundingly impractical and infeasible by any objective measure of feasibility (‘we cannot PrEP our way out of the epidemic’), yet its rhetorical political appeal is phenomenal.

At the XVIII International AIDS Conference (AIDS2010) held in Vienna, a special panel session dealing with PrEP was held.³⁰ The panel of experts (academic researchers, a high-ranking UNAIDS representative, the then-

incoming President of the International AIDS Society, etc...) were asked to comment on the feasibility of PrEP in light of the above constraints to providing ARVs to a much smaller population (namely, as treatment for people living with HIV) and were also asked to comment on the diversion of ARV-related resources from people living with HIV to the uninfected population. Dr. Patrick Ndase, whose presentation had specifically, though very briefly, mentioned concerns about diversion of resources from ART to PrEP, responded and correctly pointed out that ART coverage has increased and continues to increase dramatically in most of sub-Saharan Africa (SSA). However, he did not address the question of feasibility of PrEP in light of the challenges inherent in ARV provision and, not unexpectedly, ended his response: "we cannot treat our way out of the epidemic". Prof. Helen Rees also added a note regarding the target population of PrEP in the context where she works (South Africa), noting that the adolescent girls whom she studies desperately need a way to avoid contracting HIV from their sexual partners without the knowledge of their partners (who presumably refuse to use condoms). These adolescent girls were depicted as vulnerable and innocent, (positive social construction) victims of older, often HIV-infected male sexual partners who refuse to use condoms (the 'monsters' and 'deviants' from our earlier analyses). These girls are voiceless (politically-weak) and must be provided with a strategy to protect themselves from the above-mentioned men as their lack of interpersonal bargaining power (again, 'weak') makes them the archetypal victims of the HIV epidemic. We could not hope for a more perfect example of the social construction of infected people and its interplay with target grouping in HIV policy.

Speaking of ART access in this discussion would have required a politically-dangerous defense, as it were, of the HIV-infected men ('monsters' and 'deviants') whereas, speaking of protecting the 'dependent' (politically-weak and positively-constructed) at-risk adolescent girls and young women is politically noble. Here punitive policies towards the negatively-constructed HIV-infected men are not even necessary as the absence of treatment for them is akin to punishment. The feasibility, epidemiological logic or relative efficacy from a population-level point of view of the one approach (ART for HIV-infected persons) vs. the other (PrEP for uninfected persons) is not up for policy discussion. The policy agenda is unable to consider such dichotomies based strictly on science and evidence as policy is, as the name implies, political; which groups are targeted by policy is perhaps one of the most obvious and intuitive manifestations of the power of social constructions in the HIV/AIDS discourse.

It is important to highlight here that where some might hope or believe that experts may bring a more ‘objective’ (i.e.: apolitical) point of view to the policy-making table, experts inevitably are also vulnerable to the strength and pervasiveness of social constructions and, in fact, often are the parties who define target groups through their research and discourse. This only to say that it would be rather ingenuous to believe that the questions asked by expert researchers are not influenced by “which goals they think are important and which targets they believe are the most logically connected to the goals. The tools that experts think will motivate the targets rest on assumptions about behavior that are influenced by social constructions”.³¹

Risk Grouping

*“...risk, as a form of expert knowledge [...] requires individuals to practice forms of self-regulation”.*³²

The idea of ‘risk’ in the health discourse and of ‘risk groups’ in the health policy discourse has become so ubiquitous as to virtually escape popular scrutiny. Skolbekken (1995), through a series of *MEDLINE* database searches for articles related to ‘risk’, describes what he terms the ‘risk epidemic’ in medical and, especially, epidemiological journals from 1967-1991.³³ Skolbekken went so far as to perform methodical searches for synonyms of ‘risk’ such as “gamble, hazard, danger, probability, uncertainty and odds-ratio” to be sure he was not simply finding a recent change in terminology.³⁴ With the exception of articles in *The Lancet*, he saw steep increases in ‘risk-articles’ with more than 50% of them published in the last 5 years of his study period (1985-1990). He notes, significantly, that not only the absolute number of risk-articles increased, but that their share of the total number of articles published also rose precipitously, reaching an astounding 50% of articles published in epidemiological journals from 1985-1990.

Though the word ‘risk’ is, technically, neutral (i.e.: the statistical probability or likelihood of an occurrence), in public health as in popular usage, it has become synonymous with ‘danger’, implying an increased likelihood of something ‘negative’ happening.³⁵ Rarely do we hear that someone is ‘at high risk’ of living a long and healthy life, for example, though this would be linguistically correct.

In the public health discourse, there are two distinct types of risk. The first deals with personal or, as they have come to be called, ‘lifestyle’ risks. These risks

will be familiar to readers for lifestyle choices such as smoking tobacco which increases one's likelihood ('risk') of developing some types of cancer and chronic obstructive pulmonary disease (COPD) or drinking excess quantities of alcohol, thereby increasing one's risk of developing cirrhosis of the liver. One common attribute of most 'lifestyle' risks was that they traditionally referred to ostensibly rewarding (i.e.: pleasurable), usually addictive and always *optional* behaviors. In other words, 'lifestyle' risk used to be a euphemism for drug usage in all its many and varied forms; legal (i.e.: tobacco, alcohol) or illicit (i.e.: cocaine, heroin). With the introduction of the concept of 'lifestyle' risks to the HIV discourse, however, we have found that sexual intercourse in all its many and varied forms is now considered a 'lifestyle' choice. It began, of course, with the inclusion of sex between men in the United States when AIDS was believed to be a 'gay' disease (and homosexuality was believed to be a lifestyle choice) and quite rapidly spread to the entire heterosexual population of sub-Saharan Africa. To have or not have heterosexual intercourse, previously not considered a 'lifestyle' choice, has now become the main focus of HIV prevention measures, ignoring the quite obvious fact that this 'lifestyle' choice is, in fact, a biological imperative which may not be ignored for the survival of the species. Nor is desiring or enjoying sex an addiction to be overcome (excluding the extremely small percentage of cases of genuine pathological sex addiction). Even the application of strategies that mimic the 'harm reduction' strategy for intravenous drug users (e.g.: needle exchange programs) has crept into the HIV discourse with messages implying that it is better not to have sex at all ('Abstain'), but if you must, then limit yourself to one partner ('Be faithful') or to serial monogamy (i.e.: 'lover' exchange that parallels the needle exchange for IUDs) and use condoms (as realistic an expectation as expecting IUDs to always boil and chemically disinfect their syringes and needles): The infamous 'ABC' approach. Risk groups drawn from this paradigm of 'sexual harm reduction' then become virtually meaningless as all adolescents and adults are then included in 'high risk' categories with shades of nuance based on things like levels of education, geography, etc... The question then is: 'high risk' relative to what or to whom? In other words, when an entire population is classified as being 'high risk' because of a purported 'lifestyle' choice (that is, in fact, a biological imperative), the reduction of that risky behavior is not policy sensitive. People then become part of the 'high risk' group simply by being born in or living in certain geographical regions or socio-economic strata.

Interestingly, the second type of risk that exists in the general public health discourse is rarely discussed in relation to HIV/AIDS. This second type of risk concerns health dangers to populations where "the health threat is regarded as a

hazard that is external, over which the individual has little control”.³⁶ This type of risk will most probably be familiar to readers in the area of environmental hazards such as pollution or toxic waste and the respective risk groups would normally be defined geographically (i.e.: persons living within a certain radius from the source of an environmental risk). Consider, however, that this type of external (or non-individual) risk also exists in HIV/AIDS and is, of course, related to the risk of nosocomial transmission (blood-borne transmission in a healthcare setting), a topic about which little is heard in the African HIV discourse. Were this risk discussed in the HIV discourse, then the resultant risk groups would be defined based upon, for example, likely users of medical facilities with unsafe practices (i.e.: lack of sterilization of equipment, reuse of needles and/or syringes, unsafe blood supply, etc...). Many researchers do not consider this an innocent omission, but rather a coherent political strategy to avoid a popular political mutiny as it were;³⁷ an evasion of the expected response of “anger at government authorities, feelings of powerlessness and anxiety, and concern over the seemingly deliberate and unregulated” dangers posed by institutional-level risks to a relatively powerless populace.³⁸ To publicly acknowledge an institutional-level risk would, therefore, dramatically alter the causal story of the African AIDS epidemics and, consequently, the public perception of who is to ‘blame’ for the epidemics and hence, who is responsible for acting. From this omission of ‘external’ risk in the HIV risk and risk-group discourse we can see the power of the political sphere in risk-grouping much as it exists in target-grouping.

In terms of actual policy-making related to risk groups, this near-complete omission of institutional-level risk and almost-exclusive focus on individual-level risk in the political discourse manifests concretely in the lack of effort that is made to distinguish between potentially policy-sensitive risk reduction and what I will refer to as ‘quixotic risk reduction’. *Quixotic* of course evokes the impossible and ill-fated attempts of Miguel de Cervantes’ 17th century character, Don Quixote de la Mancha, to revive the escapades of chivalry and knights of old, culminating in his now infamous adventures, including his attacks on a group of windmills which he imagines to be giants. ‘Quixotic’, then, has come to mean ‘irrational and doomed-to-failure’. How does this apply to certain strategies of ‘risk reduction’ in health? If public health policy makers were to declare that the best way to fight cholera is for people to stop drinking water, the quixotic (i.e.: irrational and doomed-to-fail) nature of this policy would no doubt be instantly recognized. Cholera is most assuredly transmitted to humans through contaminated water; however, this would be a clear example of a ‘quixotic risk reduction’ strategy as it is aimed at eliminating a biologically-necessary and

natural individual behavior. It is clearly neither reasonable nor rational to expect people to stop drinking water in order to avoid becoming infected with cholera, therefore making this hypothetical risk-reduction strategy quixotic. As Eileen Stillwaggon (2006) so eloquently states:

Drinking contaminated water is a behavior, but one can hardly say that people get sick with cholera because they have a drinking problem. Becoming sick with cholera should not be viewed as the result of drinking behavior but of the infectious dose in the water consumed and the immune strength of the person consuming the contaminated water. Poor people have worse water, and they are less resistant. They probably do not drink more water.³⁹

In just this way, the decades-old classification of risk groups in the HIV/AIDS discourse that hinges upon individual sexual behavior—stating that abstinence is always the best ‘choice’, followed by being faithful to one partner if one must have sex and finally, if one ‘chooses’ not to follow either of the previous mandates, then use condoms—effectively disconnects sexual intercourse from its biological and emotional purposes, attempting to represent it as a ‘lifestyle choice’ over which individuals have complete agency. As engaging or not engaging in sexual intercourse is not, in itself, a lifestyle choice, the continuing and concerted efforts of governments and public health agencies around the world to intervene at the level of individual sexual behavior is quixotic. Though small changes in sexual behavior may be possible through public health education, the defined ‘risk behavior’ (sexual intercourse) can and will never be eliminated (just as drinking water as a behavior will never be eliminated) and as such, efforts to curb the spread of HIV that focus on the least policy-sensitive area of intervention, are doomed to fail.

1.2 Yesterday’s Racial Science to Today’s ‘Racial Metaphors’: HIV/AIDS Policy in Africa

As previously discussed, when examining public policy dealing with HIV/AIDS prevention, we see that policy interventions often remain narrowly focused on individual sexual behavior modification, effectively isolating individual behavior from its social, historical and economic contexts, not to mention marginalizing or disregarding biological and ecological drivers of the epidemic.^{40,41} Often, and unfortunately, when the extraordinarily high rates of HIV infection in several Sub-Saharan African nations are addressed, scholars and policymakers alike begin their work from the implicit or explicit assumption that

the high rates of infection are attributable to individual sexual behavior despite empirical evidence to the contrary,^{42,43,44} and a dearth of cross-country empirical evidence in support of the assumption.^{45,46,47,48} Although recent work abounds as to the social and economic drivers of the HIV/AIDS epidemic in Africa, one will find that the majority of this work consistently positions sexual behavior as a mediating factor. Take, for example, studies of women's economic empowerment that distill the connection between economic empowerment and HIV/AIDS down to the likelihood of a woman 'falling into prostitution' or using condoms.^{49,50,51}

Dozens of dedicated and discerning researchers from medical and social science backgrounds continue to question this paradigm that attributes 50- to 100-fold differences in [HIV/AIDS] prevalence between North America/Europe and southern African nations⁵² to individual behavior differences.^{53,54,55,56} They have pointed out that the over-emphasis on sexual behavior, partially stemming from recent population-control programs and even much further back to 20th century "racial science", has led to a dangerous neglect of institutional and biological co-factors (e.g.: malnutrition, parasitic infections, endemic diseases such as malaria, etc...) that arguably could account for a considerable portion of the difference in infection rates found between Sub-Saharan Africa and Europe/North America.^{57,58,59,60,61,62}

This section examines the persistent racial stereotypes of Africans that are a regrettable holdover from the Colonial period and color not only HIV/AIDS policy in many African nations, but also and importantly, the questions which continue to be asked by countless researchers from all disciplines. Drawing from and expanding upon Packard and Epstein (1991)⁶³, a brief review of colonial and post-colonial medical-racial history in Africa and its ideological contribution to the current dominant HIV/AIDS policy paradigm will be outlined. This will be followed by an exploration of the misperception of extraordinary African sexuality and how this continues to serve as a red herring in the HIV/AIDS policy debate. The section will then conclude with a review of some of the ecological factors that may contribute to high rates of HIV infection in various African nations which receive little attention from the mainstream development community due to the continued focus on what I argue are racially-biased and scientifically-weak arguments espousing extraordinary African sexuality as the primary driver of the devastating HIV epidemic in a number of African nations.

1.2.1 *Institutionalized Racism*

This section seeks to raise awareness regarding institutionalized racism in HIV/AIDS policy in Africa. It does not however, seek to label individual researchers or policymakers as racist. Theories abound as to the nature and origins of institutions and here I will draw implicitly upon Hodgson's idea that institutions "depend upon the thoughts and activities of individuals but are not reducible to them".⁶⁴ To say that racism has been institutionalized is not to say that the individuals whose actions are guided by these institutions are, inherently, in agreement with the institutions themselves and are, therefore, racist. The challenge here, as it were, is to trace the origins and evolution of racist ideology in the formulation of contemporary HIV/AIDS policy in Africa in order to demonstrate two things: (1) that the sexual behavior change paradigm is dangerously detached from reality and, (2) that unless we understand from where this disconnect has arisen, we will not be able to change the general mindset that causes perfectly reasonable and educated people to go along with irrational and empirically weak assumptions.

1.2.2 *From Racial Science to "Racial Metaphors"*⁶⁵

Racism, of course, has a long and ignominious history in Africa, most notably though not exclusively in reference to colonial activities. Without re-cataloguing the entire history of racist intellectual thought and action as evidenced by European colonial powers in Africa, it is useful for our purposes to briefly review some aspects of the explicit racism of the colonial era in Africa and understand how they may create a bridge to implicit racist theories and practices in contemporary African health research and policy-making.

Racial science, politics and medicine have been intertwined in much of Sub-Saharan Africa at least since the early 19th century.⁶⁶ The Colonial establishment in Africa was famously fixated on the idea of "difference" and "otherness", exhibiting a high level of "anxiety over sexuality, and the relationship which develops between sexuality, pathology and 'difference' in the form of skin colour".⁶⁷ Even in areas of disease not related to sexuality, this focus on "otherness" was demonstrated through ostensibly medical practices such as the use of phrenology² in the 19th century South African Cape community to "physically and morally differentiat[e] colonists from their 'savage' neighbour".⁶⁸

² Phrenology is the divination of personal characteristics such as intelligence and propensity to criminal behavior from the physiology of the skull and brain.

These ideas which seem so crude and unscientific to contemporary scholars can nonetheless be seen as dangerous predecessors to newer and more subtle forms of medical racism. As Bank (1996) succinctly states: “phrenology anticipated the scientific racism of the early twentieth century in its doctrines of biological determinism, its interest in skulls and comparative anatomy, its reliance on systems of classification based on broadly defined racial ‘types’ and, above all, in its obsessive preoccupation with the nature of the ‘native mind’”.⁶⁹

The ‘native mind’ – presumably as contrasted with the ‘European’ mind—supposedly gave rise to a morality different from and inferior to the European morality, an idea which shows up strongly even in the contemporary literature dealing with HIV/AIDS in Africa. When transcribed to the issue of HIV/AIDS however, the concept is no longer referred to as the ‘native mind’, but rather as the ‘African system of sexuality’.⁷⁰ We are to understand that this ‘African system’ apparently comprises cultural characteristics that are said to be common to over 700 million people from hundreds of language and ethnic groups; “this supposedly homogeneous cultural zone is coincident in its boundaries with a region identified in the Western view with blackness”.⁷¹ The Caldwells (1987) and their numerous followers in this train of thinking regarding the ‘African system of sexuality’ have even gone so far as to invent a metaphor which classifies Africans as a separate species altogether: ‘*Homo Ancestralis*’.⁷² While some may argue that it is merely a harmless metaphor, the use of a pseudo-taxonomical (and therefore, pseudo-scientific) classification for Africans in a scientific article and specifically, the use of the made-up word ‘*Ancestralis*’, is not only inappropriate, but also naturally calls to mind heavy-browed, physically-powerful but intellectually-weak, primate-like human ancestors. The word ‘*Sapient*’ (obviously, the true classification for our species) in comparison, carries the weight of knowledge and wisdom not only in the original Latin, but in derivative words in most Romance languages (e.g.: ‘wise’ being *saggia* in Italian, *sage* in French, *sábio* in Portuguese, *sabio* in Spanish, etc...). The metaphor, as well as the invention of the ‘African system’ also “assumes that culture is a concept set in stone – fixed, rigid and static”,⁷³ implying that this backwards, ancestral human species living in Africa is a victim of its own “self-destructive incompetence”,⁷⁴ unable to control its basest urges even when the survival of the species is at risk.

The scientific racism of the early 20th century to which Bank refers above is still important exactly because it can be said to have “created scientific justifications for racist practice”.⁷⁵ The recent pseudo-taxonomic label *Homo Ancestralis* creates a scientific sounding name for a bogus, racist idea, again lending the weight of science to racist ideals.

While different areas in Africa experienced very different kinds of colonial rule and it would be impossible to present a homogenous picture, it may be enlightening to focus our attention briefly on the early 20th century British Colonial response to syphilis in East and Central Africa³. While medical racism existed in areas not related to sexually transmitted disease (venereal disease), for our purposes, an examination of Vaughan's historical accounts of anti-venereal policy may be most informative.^{76,77} Through this history we can witness one of the early phases of the racialized discourse in African colonial medicine that may, arguably, still exert the most influence on modern thinking regarding the social epidemiology of HIV in Africa.

Anthropologists and medical missionaries have, for over 100 years, been incredibly focused on “[...] finding social and cultural ‘origins’ for disease patterns”.⁷⁸ In this sense, venereal disease was particularly well-suited to the religious-moralistic-cultural argument, as control of sexuality played such a crucial role in the Euro-Christian doctrine. Early anthropologists found a veritable playground of interesting material in Africa and their work “which documented the customs, beliefs and kinship systems of African peoples, provided a vocabulary with which the African colonial subject would be defined and discussed”.⁷⁹ The British Colonial and medical missionary response to venereal disease in the early 20th century revealed religious-moralistic-cultural undertones in two ways: saving the immortal souls of Africans while simultaneously (and conditionally) freeing them from the ravages of venereal disease which plagued them because of “[...] the essential ‘sinfulness’ of traditional African society”.⁸⁰ The push to tie together sin and disease could be seen not only in the medical-religious conceptualization of disease, but also in the reticence towards using discrete biomedical treatments (injections in this case) to treat disease without simultaneously seeking to convert the afflicted. “Healing, for medical missionaries, was part of a programme of social and moral engineering through which ‘Africa’ would be saved”.⁸¹

Early, uninhibited treatment seeking behaviors of Africans (for syphilis) were appreciated by some British Colonial medical officers who stressed quick and

³ Ironically, it was later acknowledged that much of what was thought to be Syphilis in Africa (*Treponema pallidum*) was actually Yaws (*Treponema pallidum* subsp. *pertenue*). Both are members of the Phylum *Spirochaetes* and are virtually indistinguishable from one another under a microscope. Yaws is passed from any skin-to-skin contact with lesions of an infected person making it a non-venereal subspecies of Syphilis (Dawson, 1987b; Vaughan, 1992)

effective treatment as the best and even only option to combat disease stating that “[.] the only propaganda that was worthwhile was quick and free treatment [and that] nothing could be done with the idea of chastity: it must be treated as a public health problem and when enough of the population has been treated, V.D. [venereal disease] would disappear”.⁸² These same treatment seeking behaviors were instead abhorred by the arguably more influential medical missionary establishment which lamented the lack of shame among Africans and believed that “a sense of shame attached to venereal disease was a necessary step on the way towards the enforcement of a new moral code, and that this would ultimately be the only effective means of control”.⁸³ Again, inherent in the moralistic-religious framing of the syphilis problem is the idea that the uncontrolled, sinful sexuality of Africans underlay the spread of the disease and, crucially, that this sexuality was *different* than European sexuality. Clearly this required a monumental willful ignorance on the part of the medical missionary establishment as the “enlightened” and Christian populous of Europe suffered severe epidemics of syphilis for centuries until the introduction of antibiotics in the 1940s and, in fact, public health departments in all affluent nations continue to battle this old enemy.

1.2.3 *African Promiscuity*

As we have seen with the example of syphilis in the early 20th century, the preoccupation with ‘African sexuality’ (and its alleged difference from ‘European sexuality’) is not a modern phenomenon. One of the striking characteristics of contemporary scholarly works pertaining to HIV/AIDS continues to be the repeated and persistent characterization of Africans as “promiscuous” and further, the use of this catch-all explanation of promiscuity as an explanation for an HIV/AIDS pandemic with infection rates orders of magnitude greater than those that we find in industrialized nations.⁸⁴ In the more recent literature, scholars have dutifully begun disguising the derogatory and value-laden word “promiscuous” with more innocuous-sounding words and phrases such as “people engaging in risky sexual behavior”⁸⁵, “people with multiple sexual partners”⁸⁶ or “people with concurrent sexual partners”. However, what repeatedly escapes mention is the fact that sexual behavior which is common in affluent European nations and the United States, when it occurs in Africa, cannot possibly account for the vast *differences* in HIV infection rates between many African nations and Europe/North America.

With the example of syphilis in British Colonial Africa above we've seen a brief glimpse of the medical and anthropological origins or early manifestations of the misperception of extraordinary African sexuality. However, these inaccurate representations of Africans continue to be recycled in 21st century arguments, most recently in relation to HIV/AIDS.

Before diving into some data on sexual behavior, however, let us deliberate the arguments and concerns that, quite reasonably, circulate regarding methodological challenges in gathering and interpreting this kind of data. When looking at the data on relatively modest levels of sexual activity in many African nations (relative to the USA for example) the common reflexive response is to question the data based on supposed taboos and reticence regarding sex in African cultures. These concerns only become peculiar in scientific inquiry when they are used to precipitously dismiss results which differ from the preconceived notions of researchers. The main issue with this strategy that paints African misreporting with a broad brush deals with magnitude and consistency as discussed below.

Magnitude

The magnitude of the differences in reported sexual activity between many African nations and the United States, for example, is quite striking and would make this degree of misreporting—and the assumption of misreporting only in the African nations, not in the United States—highly unlikely (e.g. adolescent girls reporting sex with two or more partners per year in the USA is almost 9 times that in Swaziland as seen in *Table 2*, below, while Swaziland's HIV prevalence among young people is more than 227 times that seen in the USA). It is true that the demographic and health surveys (DHS) carried out in African nations are face-to-face interviews while the USA data is collected by self-completed, anonymous questionnaires. We could then expect a marginally higher level of misreporting in the DHS relative to the United States due to social desirability bias. The question then is: What would be considered a reasonable level of misreporting? First, let us remind ourselves that HIV is not exclusively (nor efficiently) sexually transmitted but is rather a blood-borne pathogen with other modes of transmission; meaning that we may not assume that all infected persons engage in any sexual activity, let alone 'risky' sexual activity, and have been infected sexually. However, testing for sexually transmitted diseases (STDs, such as chlamydia or gonorrhea) together with administration of survey questionnaires is a quite effective strategy for estimating levels of misreporting of sexual behavior, particularly as it concerns sexual debut.

Drawing on this theme, Eva Deuchert (2011) applies mathematical modeling to DHS data from Lesotho, Zimbabwe and Malawi where a significant proportion of adolescent females with HIV (per the results of concomitant serological testing) self-report as virgins.⁸⁷ Deuchert sets out to calculate what proportion of these reported virgins would have to be lying about their virginity (misreporting) in order for sexual transmission to account for the official UNAIDS claim of 95% of HIV infections⁸⁸ in the three nations. Through a series of adjustments to the model, Deuchert shows that between 40 and 90% of the self-reported virgins would have to be lying (depending on adjustment of other assumptions in the model about background HIV prevalence in virgins relative to the known sexually-active group) in order to reach a level of sexual transmission of HIV of 95%. Deuchert acknowledges that we cannot know *a priori* what proportion of reported virgins are lying, nor can we directly generalize data from other empirical studies, but as an exercise, she makes reference to the Multicentre Study of Factors Determining the Different Prevalences of HIV in Sub-Saharan Africa where STD testing was in fact included for young female (15-24-year-old) respondents in order to more accurately measure misreporting of sexual status.⁸⁹ Using the results of the concomitant testing for STDs, that study's authors then estimate the total percentage of reported virgins misreporting their sexual status to be between 6 and 18%. Introducing, then, a proportion of 20% of reported virgins lying about their sexual status into her model as a high-end example, Deuchert finds that only 34 to 54% of HIV transmission could then be attributed to sexual transmission in the respective DHS data (contrasted with the ever-present official estimates of 95% of transmission being sexual in Africa). Obviously, there are a number of caveats to this type of research and there is great room and need for studies which incorporate ways to verify sexual status into surveys, yet in terms of the data that are rejected by many HIV researchers *a priori* as unreliable, suffice it to say that making the assumption that 40 to 90% of survey respondents are lying when their reported behavior does not support the researcher's preconceived hypothesis or expectations begs the question: then why conduct empirical research in the first place?

The oft-repeated argument that social desirability bias leads to mammoth levels of misreporting (particularly among girls) in Africa, when closely examined, turns out to be quite circular in nature. Take for example a heavily cited study carried out in a rural area of Tanzania several years ago.⁹⁰ The main issue with this study in terms of assumptions about misreporting arises when the authors state: "If sexual partnerships were accurately reported, there should be a positive correlation between seropositivity (prevalence) and sero-conversion

(incidence) and partner numbers” (p 307). The circular nature of this argument is quite conspicuous. In fact, the conclusion should read thus: “With reasonable levels of misreporting, if 95% of HIV transmission were indeed sexual, then there should be a positive correlation between seropositivity (prevalence) and sero-conversion (incidence) and partner numbers”. However, as the authors did not, in fact, find a positive correlation between HIV incidence or prevalence and partner numbers, they immediately (and unjustifiably) assume that misreporting accounts for the lack of a correlation where they had expected to find one. This manipulation of the explanatory story in order to retain an assumption (that HIV incidence and prevalence are affected only by sexual behavior) in the face of contradictory evidence is antithetical to scientific inquiry. Reliable empirical studies that provide reasonable estimates of misreporting exist⁹¹ and there are strong arguments to carry out more studies of this nature. Unless and until reasonable levels of misreporting are included in studies such as the one mentioned above in Tanzania, they remain relatively useless in the debate surrounding sexual behavior misreporting. Studies that pointedly exclude a methodical analysis of misreporting allow researchers to claim any level of misreporting that would be needed in order for their assumptions about sexual behavior and HIV to remain in force. Until the serious issue of magnitude in misreporting (and, specifically, relative to levels of HIV prevalence and incidence) is addressed openly and methodically, we must reject this circular argument that assumes astronomical levels of misreporting (lying) on the part of African respondents *a priori* when their reported sexual behavior cannot explain the observed levels of HIV, assuming nearly exclusive sexual transmission.

Consistency

The second main issue with claims of extremely high misreporting in African nations when sexual behavior does not correlate positively and significantly with HIV deals with consistency. The idea behind social desirability bias deals with culture and taboos about sexual activity. If the argument is that sex is taboo in these African nations, then the idea that extraordinarily promiscuous sexual relations (as would be required to support serious generalized HIV epidemics driven by sexual behavior) are acceptable in these same nations is quite contradictory. If we look at the issue logically, we may either posit that sex is taboo in these nations or that sex is ubiquitous and extreme promiscuity socially acceptable. We cannot argue contemporaneously for two seemingly mutually exclusive social systems in order to discount data that do not match our preconceived notions. Tim Allen, discussing his first-hand experiences as a researcher living and working in Uganda, mentions how, in relation to sexual

behavior studies, researchers assume that subjects are taboo and “it is almost as if international researchers have not wanted to ask ‘indecent’ questions. Information about heterosexual vaginal intercourse [...] seems to be mainly based on assumptions”.⁹² He points out as well that sexual topics (he uses the example of ‘orgasm’) that are frequently and commonly spoken of in popular Kampala newspapers are, incongruously, ‘taboo’ for academic researchers and so not to be found in the academic literature on Uganda.

Moving on then to a relatively early and influential example of the use of the racial stereotype of African promiscuity in the HIV discourse, let us look to DB Hrdy's oft-cited 1987 paper, *Cultural Practices Contributing to the Transmission of Human Immunodeficiency Virus in Africa*:

Promiscuity, especially the total number of sexual partners, is correlated with AIDS in both the United States and Africa. Although generalizations are difficult, most traditional African societies are promiscuous by Western standards[...] For instance, in the Lese of Zaire, there is a period following puberty and before marriage when sexual relations between young men and a number of eligible women are virtually sanctioned by the society.⁹³

Hrdy begins with the unsupported and eminently arguable assertion that promiscuity is correlated with AIDS in the USA and Africa. He then goes on to posit, with no supporting empirical evidence presented, that most African societies are generally promiscuous by Western standards. Let us look briefly to available data and try to understand what “Western standards” might be and how several African nations might compare. We will consider young women as, in high-incidence African nations, they are believed to be at particularly elevated risk of infection, therefore frequently becoming the target group for sexual behavior prevention programs.

We see that in 2006-2008, 38.1% of female 15-19-year-olds in the USA reported engaging in pre-marital sexual intercourse in the 12 months leading up to the survey.⁹⁴ This same figure for Kenya in 2008 was 15.5%, for Zimbabwe in 2005, 8% and Tanzania in 2007-2008, 16.9% as shown in *Table 1*.⁹⁵

If, however, instead of simply looking at young people engaging in sex, we look to the statistics regarding young people engaging in sex with multiple partners (i.e.: “promiscuity”), we find that, among sexually-active females aged 15-19 in the USA, 36.2% reported having multiple sexual partners in the year leading up to the survey.⁹⁶ In Kenya, that same figure is 6.5% (2008); in

Zimbabwe 6.8% (2005); and in Tanzania (2007-2008), 11.2% as shown in *Table 2*.⁹⁷

Table 1. Pre-marital sex, 15-19-year-olds

	Percentage of females aged 15-19 engaging in pre-marital sex in the previous 12 months
United States of America (2006-2008)	38.1%
Kenya (2008)	15.5%
Lesotho (2009)	26%
Tanzania (2007-2008)	16.9%
Mozambique (2009)	52.3%
Namibia (2006-2007)	32.8%
Swaziland (2006-2007)	30.5%
Uganda (2006)	18.2%
Zambia (2007)	26.9%
Zimbabwe (2005-2006)	8%

Sources: Abma et al, 2010 for USA data; Demographic and Health Surveys, respective years for all other nations

Table 2. Sex with two or more partners & HIV prevalence.

	Percentage of sexually active* females aged 15-19 engaging in sex with 2 or more partners within the previous year	HIV prevalence among young people of both sexes (15-24 year-olds)
United States of America (2002)	36.2%	<.1%
Kenya (2003)	6.5%	5.9%
Lesotho (2009)	7.5%	15.4% (2004)
Tanzania (2007-2008)	11.2%	3.6%
Mozambique (2009)	19.7%	11.1%
Namibia (2006)	3.1%	--
Swaziland (2006-2007)	4.2%	22.7%
Uganda (2006)	5.5%	--
Zambia (2007)	9.7%	8.5%
Zimbabwe (2005-2006)	6.8%	11%

*Sexually active is defined as having reported intercourse in the 12 months preceding the survey.

Sources: Abma et al, 2010 for USA data; Demographic and Health Surveys, respective years for all other nations

These data simply and clearly show that, not only do young Americans (females in this example though the relations between the USA and African nations hold for young males as well) have more pre-marital sex on average, but they are also considerably more “promiscuous” than girls in many high-prevalence African nations. A significant minority of young, sexually-active Americans have had multiple sexual partners while having multiple sexual partners among young, sexually-active Africans in various nations, as in this example, is rarer. We must also remember that, even in a nation (such as Mozambique in this example) where one measure of sexual activity (sexually active adolescent girls, *Table 1*) is higher than in the United States, the magnitude of the difference cannot be ignored. HIV prevalence among 15-24-year-olds in Mozambique is over 100 times greater than in the same age group in the USA (11.1% vs. <0.1%). The proportion of sexually active adolescent girls in Mozambique, however, is only 1.4 times higher than in the USA. 1.4 times more sexually active girls cannot explain a prevalence of HIV that is 100 times higher. It is notable as well that the measure of ‘multiple partners’ (promiscuity) is far higher in the USA than in all of the African nations. If, indeed, as Hrdy states, promiscuity and HIV infection were directly correlated, then the young heterosexual American population would have been horribly decimated by AIDS in the previous two decades while many African nations would have relatively low prevalence. Instead, the general population of the USA exhibits an HIV infection rate of less than 1% and HIV remains concentrated mainly among men who have sex with men (MSM) and intravenous drug users, exactly as in other industrialized nations.⁹⁸

Continuing to dissect Hrdy's supposition quoted above, we may move on to his tone of righteous indignation that in Zaire (now the Democratic Republic of Congo), the society reportedly sanctions sexual relations between young men (post-puberty, but not yet married) and eligible (i.e.: unmarried) women. It seems strange indeed that we in Western society would consider pre-marriage dating and sexual activity as acceptable, and even encourage the practice, otherwise known as “playing the field”, in our own nations. Apparently, however, when it occurs in Africa, it is shocking and —far more disturbing— it is used as an explanatory factor for the extraordinarily high rates of HIV/AIDS infection in some African nations.

It would seem then that, rather than relying on empirical evidence, perhaps many policymakers and researchers rely on mathematical, epidemiological

modeling for information on the HIV epidemic, necessitating a critical look at the accuracy of these models. Deuchert and Brody in a 2007 paper question the validity of several extant mathematical models used to simulate the HIV/AIDS epidemic.⁹⁹ These models, rather than using empirical data on sexual behavior, begin with set parameters for the HIV prevalence in a country and the efficiency of heterosexual HIV transmission (probability of transmission per sexual encounter). They then alter the number and distribution of sexual partnerships to arrive at the pre-determined prevalence rate. Deuchert and Brody find that when HIV sexual transmission efficiency is entered correctly, the existing mathematical models significantly overestimate the number of sexual partners as well as misrepresenting the distribution of partnerships needed to reach the HIV prevalence rates that exist in several high-prevalence nations. They find popular models for example, which necessitate 47 sexual contacts per day with an infected partner and others requiring 286 contacts per year with 'casual' infected partners. While these sexual behavior parameters may be mathematically possible, they are exceedingly disconnected from empirical evidence demonstrating that in Sub-Saharan Africa the average number of annual sexual partners in the sexually active population is 1.5.¹⁰⁰

The paradox facing African policymakers is a tricky one: they are seemingly encouraged to base their policy decisions on sound scientific data, yet the international institutional framework within which they find themselves forces them to blindly accept or attempt to manage the deeply ingrained and almost universally accepted pseudo-scientific racial stereotypes of "African sexuality" and accept the myth of extraordinary African sexual activity as driving the HIV/AIDS epidemic. As long as scholars and policymakers (international and domestic) feel free to make ostensibly scientific, yet unsupported comments such as this: "the AIDS crisis in Africa could be brought under control only if Africans restrained their sexual cravings ... it follows that Africans should change their sexual behaviour",¹⁰¹ without facing probing questions as to the scientific basis of the assertion, the individual sexual behavior paradigm will remain dominant in HIV/AIDS policy discourse. Efforts to change this norm and to bring accountability for those who assert such equivocations have been stymied by "[...] the fact that Western research on Africa, especially with respect to sexuality and other aspects of cultural and social life, is not required to conform to conventional standards for evidence in scholarly work. It seems that assertions that would require documentation in scholarly work about people in other parts of the world can be published without support when made about Africans. Racial bias in standards of evidence is a problem of long standing that has lethal consequences in AIDS discourse".¹⁰²

1.2.4 *Briefly Identifying Alternatives*

In discussing the scientific racism which has helped to spawn and continues to support the behavioral change paradigm in African HIV/AIDS policy, it is important to acknowledge that many who work in the field either designing or implementing these programs, most likely have the best of intentions and would be aghast at being labeled “racist”. This is not at all my intention. It was my goal here to show how decades (and, in some cases, centuries) of increasingly subtle *institutionalized* racism have conditioned many to blindly accept the tenets of the behavioral change paradigm: namely, that all Africans, indeed, share a common culture that is highly sexualized in relation to “Western” culture and that their heightened collective sexuality has led to raging heterosexual HIV/AIDS epidemics which can only be stopped by changing said deviant sexual behavior. “The grip of racist intellectual history affects the direction of social science research and the range of policy alternatives that can be considered. The weight of past theories in the popular mind and in the imagery of science is insidious and difficult to counter because so much of racial stereotyping is in the ‘unstated assumptions and unthinking responses’, rather than in explicit postulates”.¹⁰³

If we are to then move away from the injudicious and ineffectual sexual behavioral change approach, the next logical question to be asked by well-meaning researchers and policymakers would be: So where do we go from here? Thankfully, while the sexual behavioral paradigm has been dominant in public policy for decades, researchers in fields ranging from epidemiology to medical anthropology to economics have continued working diligently to identify effective alternative strategies to combat HIV/AIDS. Some of these alternative avenues of research and intervention are discussed below.

Nosocomial Transmission

It is useful at this point to borrow Susan Pedersen’s concept of being “attentive to [the] silences as well as [the] explicit concerns” expressed in policies aiming to regulate public health issues.¹⁰⁴ One might wonder why, for example, a rash of HIV cases in children with HIV-negative mothers in Romania in 1989 prompted immediate and concerted efforts to trace a nosocomial (medical) transmission route which, eventually, was identified and steps taken to avoid future medical transmission;¹⁰⁵ However, the silence in the African HIV discourse

about the possibility of significant levels of nosocomial transmission is quite ominous.

During the previously mentioned XVIII International AIDS Conference, Dr. Jimmy Kolker (then Chief of HIV/AIDS with the United Nations Children's Fund- UNICEF) was interviewed about nosocomial transmission and responded to an inquiry about present efforts to trace modes of transmission in HIV-positive children whose mothers are uninfected (the least problematic population in which to 'prove' nosocomial transmission). Dr. Kolker responded that "[...] we're paying attention to Eastern Europe and Central Asia at this conference, that this nosocomial transmission—transmission in hospital settings— is a special problem in that region because of various pediatric practices and so on and that, tracing the mode of transmission, which is your question, is problematic because there is every incentive by the health care system to deny that this is taking place[...]". When asked about any movement towards acknowledging nosocomial transmission in Africa, Dr. Kolker did acknowledge that "[t]here are obviously examples of contaminated blood [and] contaminated needles", however, he recognized that, in fact, there has not been much movement towards investigating nosocomial transmission in Africa apart from a handful of investigations in the early- to mid-2000s exploring the potential link between routine vaccinations and HIV in children, which were inconclusive. He stated that the difficulty in finding a clear pattern of nosocomial infection in Africa (as a continent) has hindered the effort and expressed openness to future studies to identify clear medical routes of transmission.¹⁰⁶

However, it must be noted that enough evidence certainly exists to justify the launch of outbreak investigations in high-prevalence African nations, particularly where babies and children whose mothers do not have HIV are found to be infected and transmission is most likely due to medical exposure. Gisselquist et al., in a 2004 review article, cite 9 studies where "the proportion of paediatric patients with HIV infections ranged from one to three times the proportion of HIV-infected women in antenatal settings within the same communities" in several African nations.¹⁰⁷ They point out that the pediatric incidence was also quite a bit higher than the estimated one-sixth of HIV incidence in children that would be expected from vertical (mother-to-child) transmission even had all the mothers been HIV-positive. From Mozambique's 2009 nationally representative seroprevalence and behavioral survey (INSIDA, part of their Demographic and Health Survey), babies and children aged 0 to 11 were tested for HIV as well as their mothers. It was found that approximately 31% of the babies and children who had HIV were born to mothers who did not have HIV.¹⁰⁸ A 1985 study in

Kinshasa found that 39% of HIV-positive inpatient and outpatient children 1-24 months old had HIV-negative mothers.¹⁰⁹ A similar study in Burkina Faso in 1989-90 found that 23% of HIV-positive children in the study had HIV-negative mothers. Van de Perre et al. (1987) reported from Rwanda that “[in a] survey among 150 health workers, prevalence for those with STDs and injections for STDs (47%) was almost double prevalence for those with STDs only (24%)”, throwing into doubt the common assumption that HIV-positive persons treated for STDs had unquestionably contracted HIV sexually.¹¹⁰

Contrary to responses seen on other continents, findings such as these have not inspired a concerted effort to rule out nosocomial transmission in African nations and a nominal ‘consensus’ somehow emerged in the late 1980’s that the African HIV epidemic was primarily driven by extraordinary heterosexual activity; consequently, research about nosocomial transmission has become extremely rare and only three nations to date conduct serological testing of babies and children (and their mothers) as part of their DHS survey, and this only in the latest editions.⁴ At the time of writing, no published results of outbreak investigations (genetic sequencing of viral RNA⁵ from different infected persons to trace the source or sources of an outbreak) in high prevalence African nations could be found by this author. Instead, the most common response to calls for outbreak investigations seems to be publications that dedicate ample time and resources to insisting that investigations need not be carried out.

An illuminating and textbook example is Schmid et al., 2004 which attempts to refute claims that unsafe injections (one source of nosocomial transmission) could be a significant source of HIV infection in sub-Saharan Africa. Unfortunately, the authors continue to recycle the aforementioned circular arguments regarding sexual behavior and sexual transmission, for example stating that “HIV-1 is effectively transmitted by sex, as shown by high rates of infection among couples”.¹¹¹ Without further investigation to genetically link viral RNA from both members of the couple, simply the fact of both members of the couple being infected is not evidence of sexual transmission, effective or otherwise. A long-term, rigorous study in Rakai which has become the gold standard for determining transmission efficiency, followed discordant couples, testing viral loads of the infected partner—who was not aware of her/his

⁴ Uganda, Swaziland and Mozambique

⁵ Ribonucleic acid serves as the genetic building block for the functioning and replication of HIV

serostatus as demanded by the Ugandan government—as well as continually testing for seroconversion in the uninfected partner.¹¹² No antiretroviral treatment was available to the infected persons and an average transmission efficiency of .001 (1 in 1000) was calculated. This would not be considered ‘effective transmission by sex’ by any stretch of the imagination. So when circular logic is discarded, we are forced to consider alternative modes of transmission.

Schmid et al., also fall into the trap that many others had fallen into before them, of diminishing the importance of a significant minority. What is meant by this is the habit of many researchers to speak of an issue as unimportant—in this case, non-sexual transmission of HIV—when it *may* not be responsible for the majority of new cases. The authors, while discussing pediatric HIV and the prevalence and incidence among infants and children, cite two small studies in Masaka, Uganda and Cote d’Ivoire which show, respectively, that 60% and 80% of the HIV-infected children had infected mothers and assuming they had contracted HIV vertically through mother-to-child transmission (MTCT). It is intriguing that the authors fail to mention or take into account that the study also shows, conversely, that 40% and 20% of the children had *uninfected* mothers. The authors cite these examples in support of their claim of low levels of nosocomial transmission, yet one must wonder how these percentages of likely nosocomial transmission could possibly be considered low. Pointedly excluded from their discussion as well is the fact that, even in the complete absence of antiretroviral treatment, MTCT of HIV is 25-35% in the developing world.¹¹³ The idea of such nonchalance to 20%-40%+ of infected babies and children in western nations having contracted HIV through healthcare is unimaginable and, again, highlights the disparity, not just in standards of evidence, but also in what are considered acceptable levels of institutional risk between the West and sub-Saharan Africa in both scholarly work as well as global health policy.

Obviously, HIV can be and is transmitted sexually; however, it is a blood-borne pathogen with a relatively low transmission efficiency through heterosexual intercourse, making the lack of debate about nosocomial transmission in Africa inauspicious. One wonders why medical and social science professionals are willing and even eager to look for and stamp out nosocomial transmission routes in Europe, parts of Asia and the Americas, yet continue to insist (with no reliable empirical data this author has seen) that nosocomial transmission is not a problem in Africa, purportedly making up less than 2% of all HIV cases.¹¹⁴

Co-factor Infections

“Between otherwise healthy adults in developed nations, HIV has very low rates of heterosexual transmission”.¹¹⁵

It is no secret that the efficiency of HIV transmission through heterosexual vaginal intercourse is quite low with a probability of infection of approximately 1 in 1,000 between otherwise healthy adults as previously mentioned.¹¹⁶ However, numerous clinical studies have shown that the presence of co-factor infections increases mean plasma viral load⁶ (and therefore, the infectiousness) of persons infected with HIV.¹¹⁷ These concomitant infections also and unfortunately have been shown to increase the susceptibility of non-infected persons to contracting HIV if and when they are exposed.¹¹⁸

Co-factor infections can be sexually-transmitted bacterial infections “both ulcerative and non-ulcerative, [that] increase the likelihood of HIV transmission”.¹¹⁹ These STDs, which are highly common in the West as well as in Africa, such as gonorrhea, chlamydia, bacterial vaginitis and trichomoniasis, are easily treated with antibiotics in affluent nations where access to medical care is virtually guaranteed, but often remain untreated in poor settings, increasing susceptibility to HIV.^{120,121,122}

Co-factor infections may also be viral, bacterial or parasitic infections (not sexually transmitted), often endemic to certain regions (based on climate, geography, local flora and fauna as well as public sanitary conditions), which increase susceptibility to HIV infection and/or increase the infectiousness of HIV infected persons via increased HIV viral loads.^{123,124} These can include infections such as lymphatic filariasis, urinary schistosomiasis, helminthes (intestinal worms) and malaria.^{125,126,127,128,129,130,131,132,133} Again, these infections are curable and, ultimately, public health interventions that lower both infectiousness as well as susceptibility to HIV are a policy-sensitive area which requires further resources and acknowledgement of the various positive synergies possible through addressing ‘health’ in a more holistic fashion.

There is an established literature in public health and long-standing clinical practice demonstrating that persons with nutritional deficiencies, with parasitic diseases, whose general health is poor, who have little access to health services, or

⁶ Plasma viral load is the amount of HIV RNA in blood plasma measured by number of copies per mL of blood plasma. Viral load may also be measured in semen and vaginal excretions.

who are otherwise economically disadvantaged have greater susceptibility to infectious diseases, whether they are transmitted sexually, by food, water, air, or other means. Louis Pasteur characterized the conditions necessary for the transmission of infectious disease with the comment: 'The microbe is nothing, the terrain everything'.¹³⁴

Sawers and Stillwaggon (2010) set out to explicitly identify, not only the drivers of the African HIV epidemic but, uniquely, the driver(s) of the vast difference in HIV prevalence between high-incidence Southern African nations and other sub-Saharan African nations (with low HIV prevalence) as well as other low to middle-income nations outside of Africa.¹³⁵ They performed multivariate, cross-country regression beginning with a 'basic model' which used fairly standard socio-economic control variables such as the Gini coefficient, per capita income, urbanization, a measure of migration, age of the epidemic, literacy, etc. To this basic model they added a measure of nosocomial transmission based on Deuchert and Brody's 2007 study showing a positive and significant correlation between HIV prevalence and unsafe injection practices (it must be remembered that injections represent only one part of nosocomial transmission risk).¹³⁶ They then created a dummy variable which took a one value for the nine high-incidence nations in southern Africa and zero for all other nations. The coefficient for this southern African dummy variable was positive and significant (2.79), but as they point out, simply living in southern Africa as a risk factor for HIV is not a policy-sensitive area; their goal was to test their theory that co-factor infections are "hidden" within that southern African dummy variable. To do this, they add measures of prevalence of five co-factor infections to the model (malaria, schistosomiasis, chlamydia, syphilis and gonorrhea). Using the basic model without the co-factor infections included, they find that HIV prevalence in southern Africa not explained by the model is close to 16 times the level found in the other low- and middle-income nations included in the model. After adding the five co-factor infections to the basic model, they find the coefficients of the co-factor infection variables to be positive and significant at the 99.9 percent level. The R^2 of their enhanced model rose from 66.8% to 80.1%. The model went from explaining only about 10% of the 16-fold difference in HIV prevalence between the southern African nations and the other low- and middle-income nations, to explaining around 70% of the difference. Incidentally, they also find that the coefficient for per capita income in the basic model (without co-factor infections) is negative and significant (-0.486) while after adding the co-factor infection variables, the coefficient for per capita income becomes positive and statistically insignificant. This suggests that

inside the generic ‘black box’ of poverty as a driver of the HIV/AIDS epidemic in Africa, the high disease burden of the poor is cached.¹³⁷

However, though co-factor infections are a sometimes acknowledged issue in the control and mitigation of HIV, policies which target this area must, necessarily, deal with Health Systems Strengthening, arguably one of the most costly and complex types of policy interventions. Apart from the absolute financial costs of these types of interventions though, one must also consider that these interventions that improve general health and/or nutrition, are unattractive to donor and governmental organizations working with HIV-specific funding as attribution of results (i.e.: number of new cases of HIV averted) is virtually impossible, as Hunsmann (2012) describes in detail with a case study in Tanzania.¹³⁸

Antiretroviral Therapy (ART) As Prevention

In September 2009 the American Centers for Disease Control (CDC) published a potentially game-changing review entitled *Effect of Antiretroviral Therapy on Risk of Sexual Transmission of HIV Infection and Superinfection*. The CDC’s report marks one of the first fairly comprehensive summary reviews of clinical trials (including several in Africa) conducted specifically to study this phenomenon. As discussed briefly above, the viral load of an HIV-infected person greatly affects the probability of transmission of HIV to a non-infected person. Antiretroviral medications effectively suppress viral loads, potentially transforming HIV into a chronic rather than terminal illness offering long-term health benefits to infected individuals as well as reducing their probability of infecting others.¹³⁹ The public health benefit of ART is directly related to this viral load suppression and for example, the city of San Francisco’s recent change in recommendations for ART provision is a ringing endorsement of the possible public health benefits. Rather than waiting for CD4 cell counts⁷ to drop to critically low levels (e.g.: updated WHO guidelines to begin treatment once CD4 cell counts drop below 350 cells per mm³), San Francisco’s Department of Public Health is now recommending that medical practitioners begin HIV-infected

⁷ CD4 is short for ‘Cluster of Differentiation 4’ and is represented by the number of these cells per microliter (cells/μL) of blood. CD4 cells are glycoproteins found on the surface of the human immune system’s helper T-cells and serve as a receptor site for HIV. Low CD4 levels are a sign of a weakened immune system and HIV progression. Normal CD4 levels in an HIV-uninfected adult are between approximately 500-1600.

persons on ART as soon as they are diagnosed with HIV.¹⁴⁰ In part the decision came about to improve long-term outcomes of HIV-infected patients, however, Dr. Mitchell H. Katz, director of public health for the city has stated: “I do anticipate it will drive down the rates of new infections [...] It’s a nice, secondary benefit of this new policy”.¹⁴¹

Indeed, a robust combination of clinical studies and mathematical modeling has demonstrated that the early phase of HIV infection, roughly from 0-24 months from seroconversion, is when viral loads are the highest (several times higher even than after the actual onset of AIDS years later and approximately 26 times higher than during the long intermediary, asymptomatic phase); meaning that people are the most infectious to others precisely when they are not eligible for ART in most places.^{142,143,144,145} Of course, any discussion of the use of ART as prevention must necessarily be accompanied by a caveat as concerns about surrounding the question of moral hazard. Simply put, many are concerned that providing a highly effective treatment such as ART will lead to the belief among HIV-infected persons and the general population that HIV is curable and that we will see consequent increases in unprotected sex which will offset the preventative benefits of ART. As people on ART will presumably live longer, they will have the potential to engage in more sexual encounters with a greater potential number of partners. The questions then are: 1) Will patients on ART have more unprotected sex and, 2) will the decreased infectiousness of those on ART compensate for any possible increase in unprotected sexual activity?

The first question has been addressed quite succinctly by Crepaz, Hart and Marks (2004) with a trio of meta-analyses. Using twenty-five English language studies of ART clinical experiments (none, unfortunately, in Africa), they seek to determine whether “(1) being treated with HAART [Highly Active Antiretroviral Therapy], (2) having an undetectable viral load, or (3) holding specific beliefs about HAART and viral load are associated with increased likelihood of engaging in unprotected sex”.¹⁴⁶ They conclude that being treated with HAART and having an undetectable viral load does *not* increase the likelihood of engaging in unprotected sex. However, they did find that “[t]he likelihood of unprotected sexual behavior was significantly higher in people who believed that HAART reduces HIV transmission or who were less concerned about engaging in unsafe sex given the availability of HAART”.¹⁴⁷ This is not an unimportant result; it does highlight the importance of further studies to answer the question of whether the decreased infectiousness of those on ART will, in fact, compensate for this potential increase in unprotected sexual activity. This is an area where

further study is clearly needed and this issue will be addressed in the case study of this thesis.

The history and logic behind ART as prevention as well as the potential preventative externalities of ART on a grand scale are discussed in more detail in the following chapter of this thesis and the case study (Chapter 4) will focus specifically on the effects of the social construction of HIV and specifically of sexual behavior and vertical (mother-to-child)-based prevention messages (in Maputo, Mozambique) on things like patient/provider relationships, enrollment in and adherence to ART; an area that has yet to be studied in Africa and which, arguably, may have a significant effect on the usefulness of ART as prevention.

1.3 Conclusion

It is my hope that, in this introductory chapter, I have been able to guide readers through some of the pertinent literature dealing with the social constructions of an epidemic, as well as the political usage of those constructions which often goes unquestioned in both the popular and academic literature. In addition to the general literature review in these areas, one hopes that my own systemization of the social construction of sick people (*Figure 1*) as well as my application of the classification schemes from part 1.1 to HIV policy (including the introduction of the concept of ‘quixotic risk reduction’) has given readers an intuitive yet clear understanding of the powerful socio-political forces behind HIV policy and, indeed popular thinking, by both experts and lay people in terms of HIV in sub-Saharan Africa.

While HIV is undoubtedly transmitted through sex the world over, it is my hope that readers will begin to question the sexual behavioral change paradigm which attributes the extremely high levels of HIV in several African nations exclusively to ‘extraordinary’ sexual activity. The brief exploration of colonial and post-colonial medical racism in Africa is meant to shed a bit of light on a largely shadowed area of public policy: the institutionalization of racism. This institutionalized racism, apart from being ethically abhorrent, has life and death consequences in the HIV/AIDS policy debate. As researchers and policy makers, we must be attentive to the silences in our avenues of exploration and policy. In the African HIV policy sphere, these silences are particularly profound in the areas of the social construction of HIV-infected (or ‘high risk’) persons, the logic behind the ‘standard’ HIV target groups, nosocomial transmission of

HIV, the role of the burden of disease in many high-incidence nations (co-factor infections) and the efficacy and feasibility of ART for prevention.

The following chapter will concentrate on one of these neglected areas of HIV prevention (ART as prevention), outlining the clinical and epidemiological evidence of its effectiveness as well as financial considerations important to the utilization of this strategy. The role of the social construction of HIV in Africa permeates policy priorities and will be an implicit theme of Chapter 2 during discussions of the dominance of external (international) health financing which brings with it the policy-embedded racial stereotypes of Africans discussed in this chapter.

Chapter 3 will then explore the human resources for health (HRH) situation in Mozambique. These issues will be reviewed in relation to their interplay with efforts to expand ART in Mozambique through the ongoing decentralization of HIV services.

Chapter 4 will then focus on the case study carried out in Maputo, Mozambique from April through September 2011. In 2001 with the introduction of the public provision of ART, the Mozambican Ministry of Health clearly stated its commitment to utilizing ART as prevention.¹⁴⁸ With that in mind, and considering the recent dramatic expansion of ART provision since decentralization of services in 2005 (with actual implementation in Maputo beginning in 2008), the case study will focus on the effect of the social construction of HIV in Mozambique (via HIV prevention messages) on patients' experiences with ART in Maputo City.

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2.1 Antiretroviral Treatment as HIV Prevention

As discussed in Chapter 1, there is great need and potential for implementation of scientifically-sound, alternative HIV prevention paradigms in high prevalence nations. This chapter will focus on the possibilities offered by antiretroviral treatment (ART) as population-level prevention. As Maputo, Mozambique will be the focus of the case study portion of this dissertation (Chapter 4), practical matters and examples will mainly refer to Mozambique from here forward.

Until 2011, the idea of ART to prevent sexual transmission of HIV was mainly confined to epidemiological models and observational studies.^{1,2,3,4} Though some city and regional health departments in developed nations (ex: San Francisco, British Columbia and New York) had adopted early or immediate treatment guidelines to explicitly take advantage of the purported benefits of ART as prevention^{5,6,7}, still there was a lack of what many would consider concrete clinical evidence of the efficacy of this strategy. This all changed in 2011 with the early conclusion of the ‘HIV Prevention Trials Network 052’ (HPTN 052) study. HPTN 052 is a multi-site, randomized clinical trial with the primary objective of comparing HIV infection rates between two groups of serodiscordant couples⁸, enrolling a total of 1,763 couples. All HIV-infected participants had baseline CD4 levels of between 350 to 550 cells/ μ L (for comparison, 2009 WHO recommendations state that patients should begin ART for individual therapeutic purposes at CD4 levels ≤ 350 ⁸). The HIV-infected partner from one group began taking antiretrovirals (ARVs) as soon as the study began (886 couples) while the HIV-infected partner from the second group began taking ARVs only after either developing an AIDS-defining illness or having two consecutive CD4 measurements of 200-250 or below (877 couples) per WHO 2006 recommendations⁹. 278 couples were from study sites in the Americas, 954 from African study sites and 531 from Asian study sites. On April 28, 2011, five years into the study, the Data and Safety Monitoring Board

⁸ Couples where one person is uninfected with HIV and the other is HIV-positive.

(DSMB) that periodically reviews unblinded data for National Institutes of Health (NIH) clinical studies, performed an interim review and called for an end to the trial, recommending that the results of the trial be announced as soon as possible and that all participants be offered immediate ART.¹⁰ The efficacy of ART to prevent transmission was shown to be so dramatic that it would have been unethical to continue the trial.

The entire trial (both groups) saw a total of 28 linked infections (where the previously uninfected partner's HIV RNA was genetically linked to the infected partner's). 27 of these infections were found in the delayed ART group and only 1 in the immediate ART group ($p < .001$). The linked incidence (new HIV infections) per 100 person-years was found to be 0.1 [95% CI: 0.0-0.4] for the immediate ART group and 1.7 [95% CI: 1.1-2.5] for the delayed ART group. The conclusion of the study group's analyses is that "early ART that suppresses viral replication led to 96% reduction of sexual transmission of HIV-1 in serodiscordant couples".¹¹

2.2 The Prevention Cascade

All large-scale prevention policies in high prevalence and high incidence settings historically and currently focus on the seronegative population through sexual behavior change campaigns.¹² In generalized epidemics, the definition of 'at-risk' or 'high risk' groups has become virtually meaningless as HIV prevalence grows in ever-increasing sectors of the population. This means that prevention campaigns that continue to focus on 'at-risk' uninfected persons have an extraordinarily large target population in generalized epidemics and high coverage targets would be exceedingly difficult if not impossible to reach. Kurth, Celum and Baeten et al. 2010 point out that after 30 years of behavior-based prevention strategies, only two nations (Uganda and Thailand) have shown progress in reversing HIV epidemics by targeting uninfected persons (and, in fact, the correlates of Uganda's alleged gains remain controversial¹³).

The issue of target population and subsequent coverage is more than academic. Though much clinical research continues to strive for PrEP interventions (antiretroviral-based vaginal gels, oral ARVs for uninfected persons, etc...) and other preventative measures that are close to 100% effective, public health practitioners are quite aware that when speaking of the population level, coverage is more important than efficacy. In order to illustrate this point, let us look to the prevention cascades in *Figures 3, 4 and 5*. These show a simple

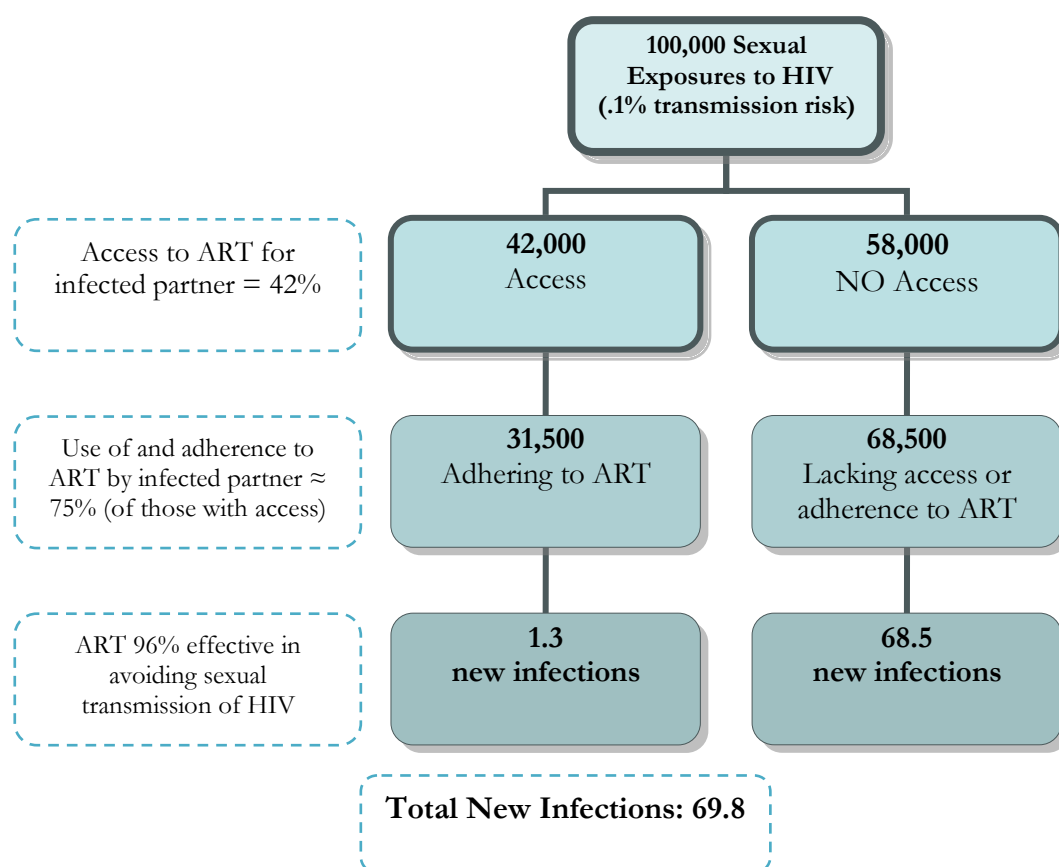
comparison of ART, condoms or abstinence for prevention of sexual transmission of HIV.

Condom coverage and usage is based on Mozambique's 2009 Demographic and Health Surveys (DHS) where 38% of young adults (aged 15-24) report that they are able to obtain condoms and 22.6% of respondents in this same age group who had sex in the 12 months preceding the survey report having used a condom at their last intercourse¹⁴. This age group reports the highest usage of condoms in Mozambique and so presents an upper-bound limit for condom usage in the nation. Condoms for prevention of sexual HIV transmission are approximately 80-90% effective^{15,16} (we will use the upper-bound limit of 90% for this exercise).

Abstinence coverage is based on Mozambique's 2009 DHS data where 6.8% of adult respondents reported not having had sexual intercourse in the 12 months preceding the survey. Abstinence for prevention of sexual HIV transmission is 100% effective.

In regards to ART coverage, by the end of 2009, approximately 42% of adults (aged 15-49) in Mozambique meeting the WHO 2006 clinical standard to begin therapeutic treatment were receiving treatment.¹⁷ Mozambique has a national adherence level of 75%.¹⁸ As mentioned previously, ART as prevention of sexual transmission of HIV is 96% effective.

Figure 3. Prevention Cascade, ART.



“Prevention Cascade” adapted from Patrick Ndase, 2010 (Presentation at the XVIII International AIDS Conference, 19 July 2010)

Figure 4. Prevention Cascade, Condoms.

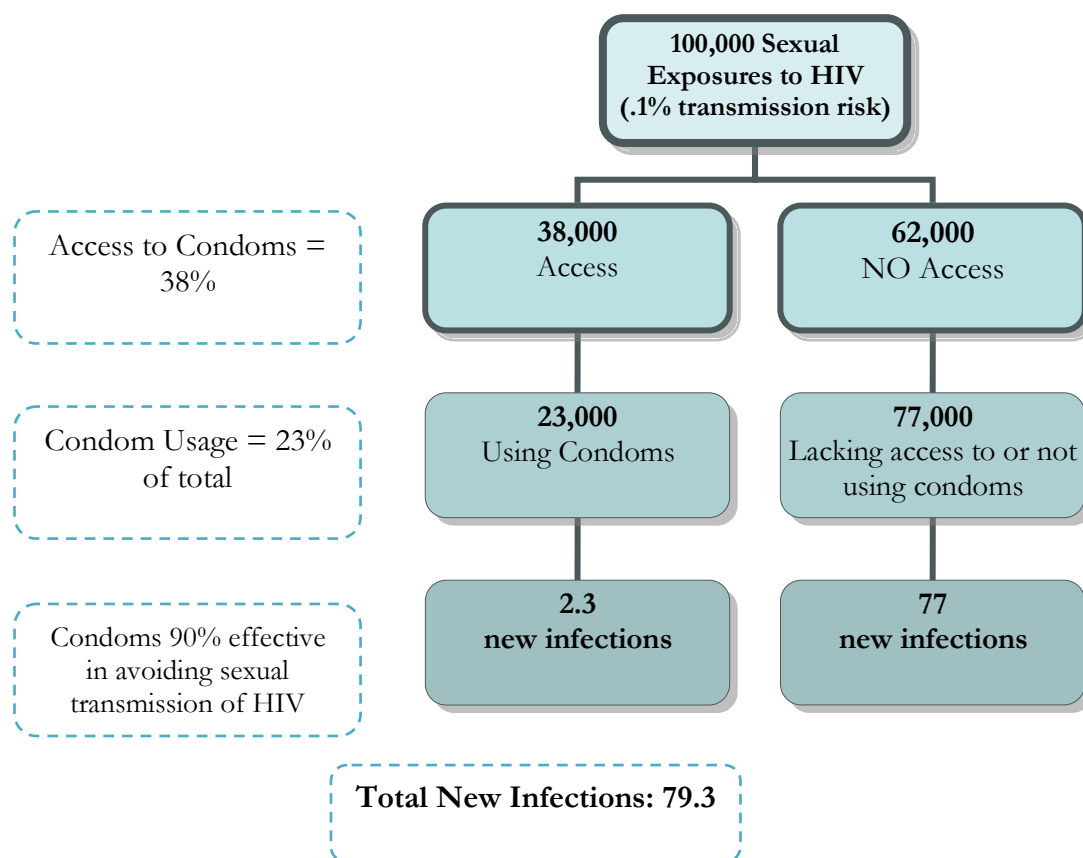
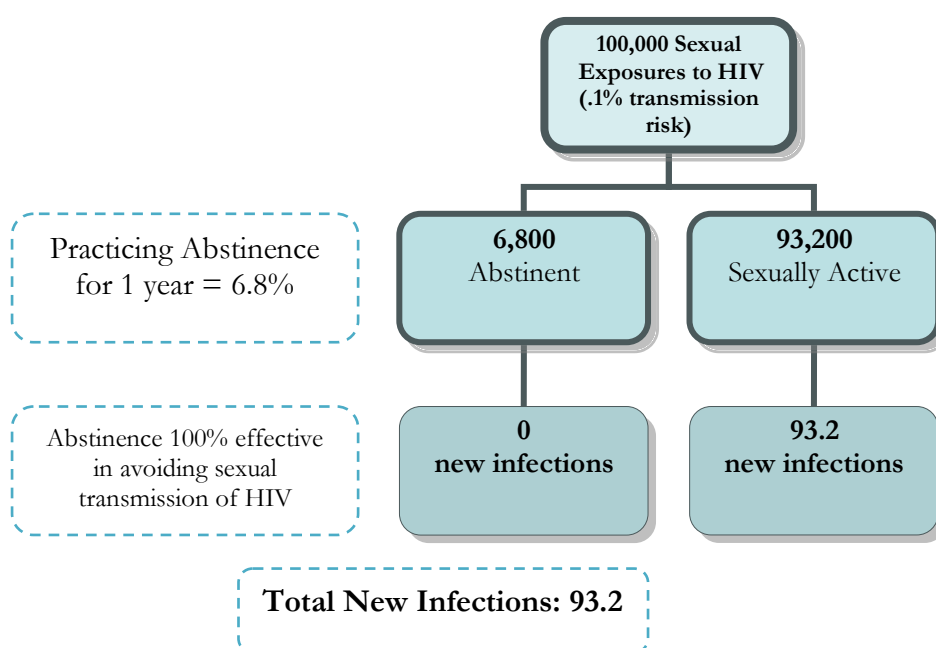


Figure 5. Prevention Cascade, Abstinence.

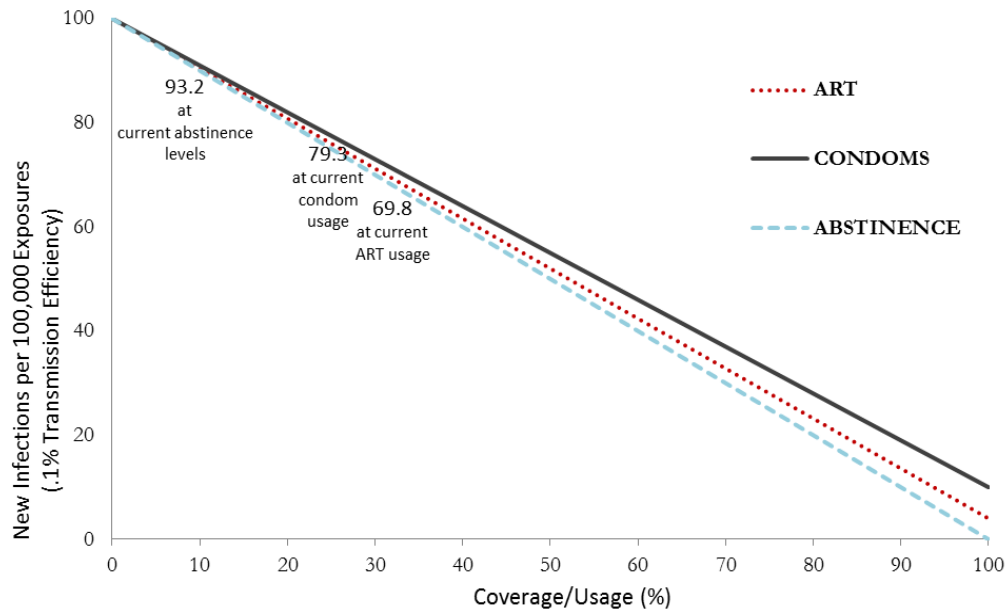


Though these prevention cascades do not consider the nuances of consistent (or inconsistent) condom usage or length of abstinence nor differences in HIV transmission efficiency over time (e.g. HIV-infected persons have the highest viral loads and are consequently the most infectious during the first phase of infection lasting approximately 9-18 months when they are not yet eligible for ART), they still provide a useful illustration of the relative importance of coverage of prevention interventions in relation to efficacy. For example, if condoms (with 90% efficacy) saw an increase to 31.5% usage (the same percentage of the Mozambican infected population that has access to and adheres to ART) the condom cascade would show 71.7 new infections versus 69.8 in the ART group. So this 6% difference in efficacy (between condoms and ART) with equal coverage/usage of 31.5% results in a decrease of only 2 infections (per 100,000 exposures). Whereas, conversely, a 6% increase in coverage/usage of condoms (from 23% usage to 29%) would witness 73.9 new infections, a decrease of 5.4 infections (per 100,000 exposures).

Table 3 provides a visual representation of this. We can see that the decrease in new cases of HIV is much more pronounced along the rows (coverage/usage) than it is down the columns (efficacy). *Figure 6* represents this graphically, again highlighting the importance of coverage/usage over efficacy and showing the number of new infections at current coverage and usage levels of the three interventions (ART, condoms and abstinence).

Table 3. Coverage versus Efficacy of Prevention Interventions, Number of New Cases of HIV per 100,000 sexual exposures

	25% coverage/ usage	35% coverage/ usage	50% coverage/ usage	70% coverage/ usage
90% efficacy	77.5	68.5	55	37
96% efficacy	76.5	66.4	52	32.8
100% efficacy	75	65	50	30

Figure 6. *New Infections (per 100,000 sexual exposures) per Prevention Strategy.*

If then we are to discuss coverage and usage of interventions, we must necessarily return to the idea of target population. As mentioned, the target population of sexual behavior prevention (condoms and abstinence) in generalized epidemics is virtually all adults and, indeed, Mozambique is no exception. Mozambique's 15-49-year-old population is roughly 10,760,000 (out of a total population of approximately 23,400,000)¹⁹. The target population for ART according to WHO 2009 standards for therapeutic treatment is estimated at 570,000 (or 380,000 according to WHO 2006 standards, but we will use the 2009 standard as the importance of early ART for optimal population-level prevention cannot be overstated).²⁰ This means that the target population of sexual behavior prevention strategies is almost 18 times the target population for ART interventions.⁹ Even were we to consider the entire population of Mozambique that is estimated to be infected with HIV (1,400,000²¹), as the target population for ART interventions, the target population for behavioral prevention strategies is still close to 8 times that of ART.

⁹ The same calculus would apply to other interventions aimed at uninfected persons such as PrEP.

2.3 Focus on the Positives

Condoms

Condom coverage and usage has, indeed, increased over the preceding decade-and-a-half. In Mozambique's 1997 DHS, young adults aged 15-24 who had had intercourse in the 12 months preceding the survey reported just 6.8% usage (at last sex with anyone), in 2003 that proportion increased to 19.4% and in 2009 to 23%.¹⁰ Policymakers and donors in Mozambique are optimistic that the proportion of the sexually-active population using condoms will increase rapidly over the next half-decade. Explicit national condom targets refer to condom usage at last sex by 15-49-year-olds who have had sex with more than one partner in the preceding 12 month period, beginning from a reported baseline level of 31% in 2003 and aiming to rise to 60% in 2011, 70% in 2013 and 80% in 2015.²² Actual 2009 DHS figures put the percentage at 22.8%, calling into question the 2003 31% estimate used as a baseline in the national targets, but also the reason for such extreme optimism that endeavors to achieve a stunning 37 percentage point increase from 2009-2011 and subsequent 10 percentage point increases every two years thereafter until 2015.

These targets and their related public health strategies conspicuously ignore the reasons that Mozambicans report for using (or not using) condoms. Looking at *Table 4* below, we can see that the top reported reasons in Mozambique for using condoms are to prevent sexually-transmitted infections (STIs) and to prevent pregnancy. Strangely, the DHS questionnaire includes 'worry about HIV infection' as a reason for using condoms (question number 106, response 'A'), however, this response is not found in the dataset, causing ambiguity as to whether the responses to the separate motivations to use condoms ('to prevent sexually transmitted infections (STIs)' or due to 'worry about HIV') were ultimately combined by DHS staff and included under 'to prevent STIs' in the final dataset. Apart from this ambiguity, however, what we can easily notice is that a very small percentage of respondents across all age groups report using condoms due to public messages advising them to do so. As multiple responses were possible for each participant, the percentages in *Table 4* will not equal 100% and are tabulated as the number of respondents answering 'yes' to each particular reason for using condoms over the number of respondents in each age group who have ever had sexual intercourse and report having used a condom at their

¹⁰ Mozambique's civil war officially ended in 1992 and though HIV was already a significant issue, the first condom social marketing programs only began in 1994 and had national coverage only in 1996.

last sexual intercourse. Complete figures are available in Appendix 1. The most common overlap of responses in all age groups occurred with ‘prevent STI’ and ‘prevent pregnancy’ (ranging from 37 to 59% in the four age groups- shown in Appendix 1). The overlap between the motivations for using condoms of ‘prevent STI’ and ‘due to public messages advising use’ is negligible (ranging from 0 to 1.3% in the four age groups- shown in Appendix 1).

Table 4. Reasons for Using Condoms by Age Group, Mozambique 2009

Reasons for Using Condom at Last Intercourse*	5-Year Age Groups			
	15-19	20-24	25-29	30-34
Public Messages Advising Use	2.0%	3.4%	2.7%	0.7%
Prevent Sexually-Transmitted Infections	87.7%	75.2%	70.4%	68.7%
Prevent Pregnancy	66.4%	67.1%	58.4%	57.5%
Do not trust partner	4.8%	6.0%	7.1%	10.4%
‘Other’ (unidentified) reason	2.5%	3.7%	8.8%	6.0%

Source: Demographic and Health Surveys, Mozambique, 2009

*Individual responses to a series of closed (yes/no) questions; multiple responses possible from individual respondents so that response percentages will not equal 100%. Denominator is the number of respondents in each age group who have ever had sexual intercourse and report having used a condom at last intercourse with anyone.

In terms of why respondents report *not* using condoms, the calculations were performed exactly as with the previous table (reasons for usage) with only the denominator changing to reflect the number of respondents in each group who have ever had sexual intercourse and report *not* having used a condom at last intercourse with anyone. A full breakdown is available in Appendix 1. We can see in *Table 5* below that ‘I trust my partner’ and ‘I’m married’ are the statements with which the most respondents agreed (in terms of their motivation for not using a condom) and that positive responses to both, as we might expect, increase with age. This may indicate that the relatively higher usage of condoms in the 15-19-year-old age group (which steadily decreases with age) may not be exclusively a product of more intense condom social marketing to teenagers and young adults, but may also be related to the decreased usage of condoms by couples in more mature (trusting) relationships and marriages, regardless of how heavily condoms were or are marketed to them. These two particular motivations for not using condoms will be further discussed in the case study in Chapter 4. Interestingly, agreement with the reason, ‘no condom available’ is relatively high

(29.8%) for the 15-19-year-old age group, but falls steadily with increasing age showing the importance of acknowledging motives for non-use (particularly for adult women) rather than simply focusing on coverage/availability of condoms as we currently see in prevention strategies. Unfortunately, the DHS did not include the option of ‘wishing to become pregnant’ as a motive for non-use. However, considering the high percentage of respondents (and the decreasing trend with age) who indicated avoiding pregnancy as a reason for usage, we may postulate that the inverse may be true for non-use. This would indicate that the ramifications of exclusive focus on a barrier method (condoms) or abstinence that we find in HIV prevention campaigns deserves particular attention. It cannot be ignored that both abstinence and condoms have the collateral effect of preventing pregnancy and an HIV prevention strategy that effectively eliminates the possibility to have children is unfeasible at the population level and in the long run.

Table 5. Reasons for Not Using Condoms by Age Group, Mozambique 2009

Reasons for Not Using Condom at Last Intercourse*	5-Year Age Groups			
	15-19	20-24	25-29	30-34
‘I trust my partner’	22.2%	30.2%	28.0%	33.2%
‘I’m married’	27.8%	43.0%	52.5%	53.9%
No condom available	29.8%	15.9%	13.3%	12.6%
Partner did not want to use	13.3%	9.2%	8.8%	7.8%
Used other contraceptive	1.6%	0.8%	1.3%	0.9%
Condom reduces sexual pleasure	10.9%	7.5%	6.0%	4.7%
‘I’m faithful’	8.1%	12.0%	11.7%	13.9%
‘Other’ (unidentified) reason	7.5%	7.1%	6.0%	5.3%

Source: Demographic and Health Surveys, Mozambique, 2009

*Individual responses to a series of closed (yes/no) questions; multiple responses possible from individual respondents.

ART

As demonstrated, ART for seropositive persons has incredible preventative externalities. It is the most efficacious prevention intervention currently in existence (for both MTCT and sexual transmission), has the smallest target population and, importantly, this preventative benefit does not require either the

participation of uninfected persons nor the explicit desire of seropositive persons to prevent transmission. It also does not interfere with conception so that seropositive persons (and their partners) are not forced to trade HIV prevention for the possibility of having a family. Though there are signs that seropositive persons would, in fact, like to avoid infecting others (discussed in Chapter 4), their primary motivation for taking ARVs (with the exception of prevention of MTCT) is to care for their own health. The combination of targeting a much smaller national population – ‘the positives’ – and utilizing a collateral preventative benefit of a personal health-seeking behavior may provide the most pragmatic and effective way forward in generalized HIV epidemics such as Mozambique’s. In terms of concerns about moral hazard or risk compensation behavior¹¹, numerous studies have also shown that HIV counseling and testing often results in risk behavior change (lower risk behavior) in those who test *positive* for HIV while not having any significant effect on behavior for those who test *negative*, further highlighting the secondary preventative behavioral potential of ‘the positives’ as opposed to the difficulty of achieving behavior change in the seronegative population.²³

In terms of coverage, it also must be pointed out that while usage of condoms (or even more rare, abstinence) has slowly crept up over the last 30 years, the coverage and usage of ART in Mozambique has rapidly eclipsed the pace of reported behavioral change in less than a third of the time. As of mid-2011, Mozambique has approximately 220,000 patients on ART, a coverage and usage level of approximately 58% of eligible HIV-infected persons by WHO 2006 standards (and 39% by WHO 2009 standards); this has been reached in just 8 years of ART availability and approximately 5 years into the ongoing decentralization of ART which has greatly increased availability and uptake outside of the capital.²⁴

If then, we are to attempt to harness the preventative externalities of ART and focus on ‘the positives’, there are two main areas where paradigmatic shifts will be necessary. The first is in the calculations performed to judge the effectiveness of specific prevention interventions where ART is currently not included (with the exception, again, of prevention of MTCT) and the subsequent financial allocations for specific interventions. This will be discussed in the following section.

¹¹ This is the phenomenon whereby people may increase their risk-taking behavior when they believe that they are protected from negative consequences, such as the classic example of wearing a seat belt leading to driving at higher speeds.

The second area deals with the socio-political issues discussed in Chapter 1 that have led to exclusive targeting of HIV prevention messages to the uninfected population and an overwhelmingly negative social construction of ‘the positives’. It will be necessary to consider the effect of these sexual behavior prevention messages on people living with HIV and their treatment-seeking as well as ART adherence behavior. This will be discussed in-depth in the case study in Chapter 4 through a qualitative analysis of the experiences of adult ART patients, caretakers of pediatric ART patients and their clinicians in the city of Maputo.

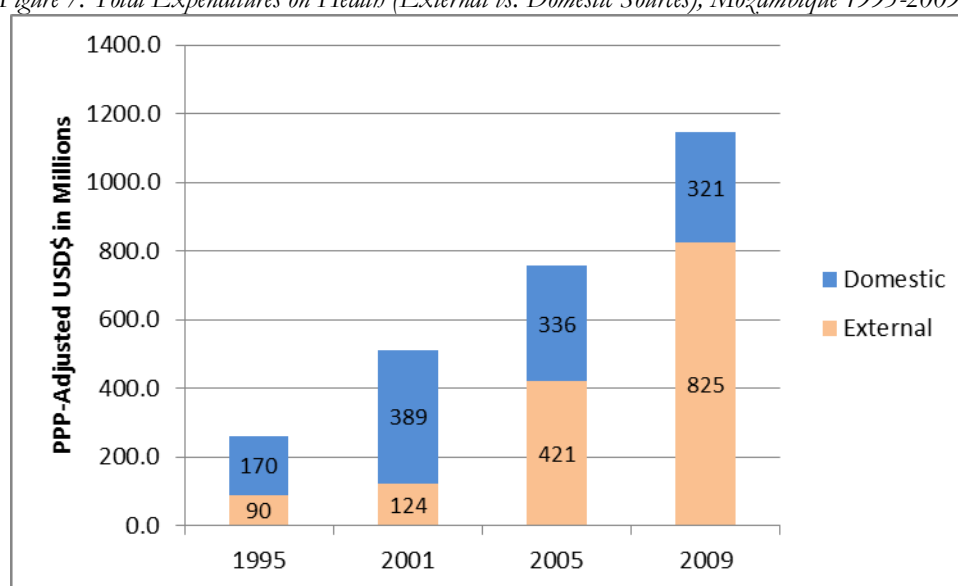
2.3.1 The Financial Reckoning

Though the preventative actions of ART are an externality, and as such, will function whether or not they are explicitly recognized, there is still great need to consider this crucial externality when discussing the allocation of ear-marked funding and the calculations of infections prevented that underlie these allotments. Currently, new cases of HIV that are prevented through ART are not included implicitly or explicitly within international or domestic prevention strategies and therefore ART is not eligible for consideration for funding that is earmarked for prevention.

It will come as no surprise that in developing nations, foreign aid often constitutes a large percentage of health expenditures. Mozambique’s Total Expenditures on Health (TEH)¹² are relatively stagnant, having been 5.1% of Gross Domestic Product (GDP) in 1995 and 5.7% of GDP in 2009.²⁵ To put this in perspective, internationally, this compares to an average of 8.3% of GDP being spent on health in the European Union in 2008; a geographic region not currently experiencing large-scale, generalized epidemics of any infectious disease and one whose expenditures on health are virtually exclusively based on domestic resources.²⁶ Importantly, in 1995, only 34.6% of the TEH in Mozambique came from external (foreign) sources while in 2009 a full 72% of TEH was from external sources showing decreased relative levels of domestic resources going towards health in Mozambique (*Figure 7*).²⁷ Approximately 96% of Mozambique’s HIV/AIDS-specific funding comes from external sources.²⁸

¹² TEH includes all expenditures on health services (preventive and curative), family planning, nutrition and emergency health aid in a nation; both on-budget and off-budget expenditures, private and public.

Figure 7. Total Expenditures on Health (External vs. Domestic Sources), Mozambique 1995-2009



Source: OECD, 2010

Much of these foreign funds are handled ‘off-budget’, meaning that they do not enter into the treasury or working budgets of government ministries and are not subject to parliamentary processes of allocation or monitoring. ‘On-budget’ funds, on the other hand, are channeled through the national government treasury and are subject to the same government allocation and monitoring activities as domestic funds. Mozambique was, in fact, the first country to put Global Fund resources ‘on-budget’ in 2004 (as part of Mozambique’s sector-wide approach, or ‘SWAp’), however, in 2008, Mozambique felt the need to take them ‘off-budget’ again due to the sometimes unpredictable nature of Global Fund disbursements (the bulk of which, in 2007 only arrived in the final month of the year, for example) and the difficulty in harmonizing Global Fund reporting requirements with general government procedures and timing.²⁹ In the 2001 Abuja Declaration, Mozambique (along with another 26 African Union members) pledged to increase on-budget domestic health expenditures to 15% of total government expenditures, however, this goal remains elusive as Mozambique has not, in fact, increased domestic resources for health as a percentage of domestic spending once the Global Fund resources were taken out of the equation.³⁰ Though the temporary inclusion of Global Fund resources into Mozambique’s common budget (through the SWAp) allowed the country to claim an increase of on-budget health expenditures from 11% to 13% of all government spending, this increase has now been lost.³¹

Discussing only on-budget expenditures can be misleading as, for example, exclusive on-budget external health financing in Mozambique is roughly 44% of the country's health budget and domestic expenditures make up the other 56% (compared to 72% of TEH—which includes both on- and off-budget expenditures—being from external resources and the remaining 28% from domestic resources).³² Roughly 78% of Mozambique's HIV/AIDS-specific funding comes from the United States government's President's Emergency Plan For AIDS Relief (PEPFAR) funds which are completely off-budget.³³ However, the importance of on-budget versus off-budget discussions is arguably even more important when discussing public policy decisions as vertical, off-budget resources famously contribute to a weakening of a country's capacity to design appropriate policies and fragmentation of planning efforts.³⁴

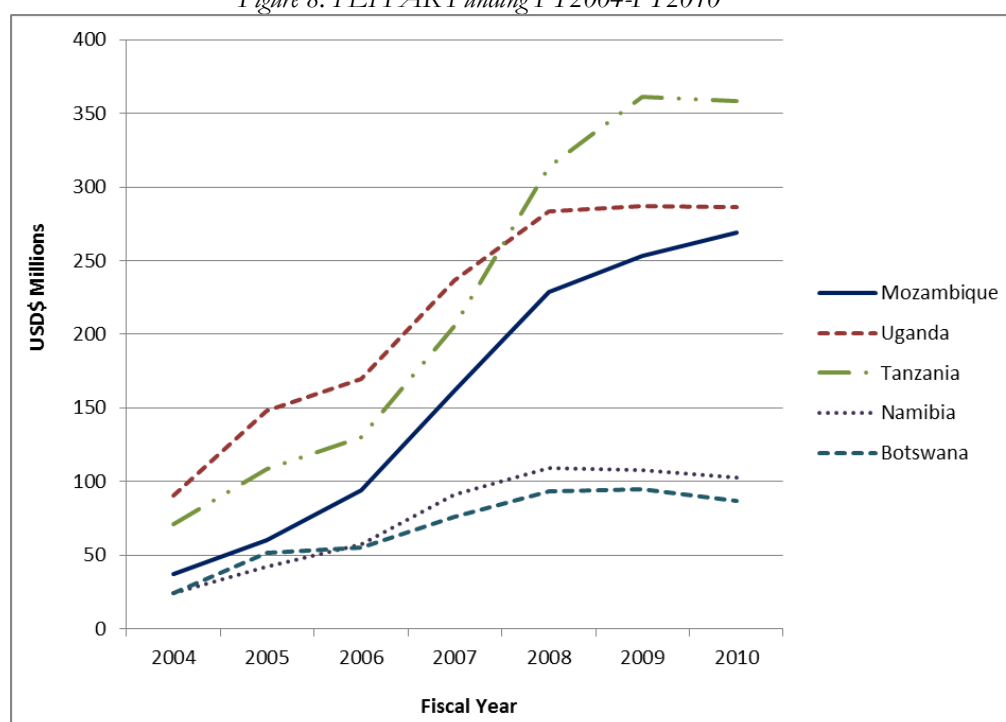
With external (and in particular, off-budget) financing comes, of course, a powerful vertical infrastructure, externally-determined earmarks and regulations on how and where money may be spent as well as the specific division of funds (for example, between various types of prevention and treatment in the case of HIV). These rules, at times, go into assiduous levels of detail and are often cookie-cutter constructs that are applied for all financing from that particular organization to any nation. These vertical structures often also require considerable administrative commitments from target nations, including extraordinary outlays of dedicated human resources (which are already in short supply) and reporting mechanisms that are not harmonized with the nation's domestic mechanisms (nor with those of other international organizations), on the whole increasing transaction costs for target nations. As the two main funding and implementation agencies functioning in the area of HIV in Mozambique are the United States government's President's Emergency Plan For AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria ('The Global Fund'), the following discussion will focus primarily on the mechanisms of these two organizations.

PEPFAR

In 2003, United States President George W. Bush made a commitment to significantly increase American support for HIV/AIDS worldwide, and the US Congress, in May of that year, approved a 5-year USD\$15 billion program that came to be known as PEPFAR.³⁵ The program was re-authorized in 2008 (for another 5 years) with several changes including: an increase in funding from \$15 billion to \$48 billion, a move away from the requirement that 33% of prevention

funds be spent on abstinence-until-marriage programs to a requirement of ‘balanced funding’ of prevention activities for sexual transmission of HIV (to include, but not be limited to, abstinence-until-marriage), as well as new financing for training of health workers in partner nations.³⁶ The new prevention directives also include male circumcision and targeting of multiple, concurrent partnerships as accepted areas of prevention intervention.

Figure 8. PEPFAR Funding FY2004-FY2010



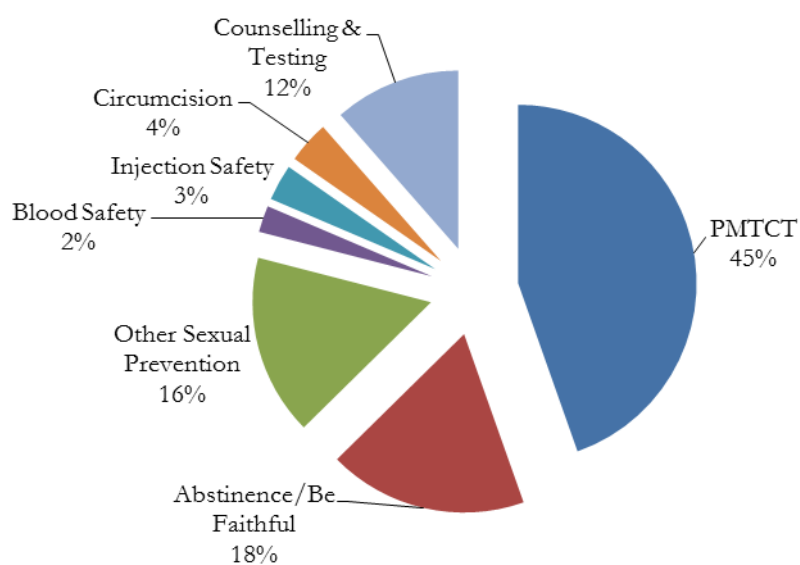
Source: PEPFAR Fiscal Year Operational Plans, Respective Years³⁷

Shortly after PEPFAR was re-authorized, US President Barack Obama created the Global Health Initiative (GHI) whose purpose is to increase coordination of health and development strategies in target nations and focus on health systems strengthening, gender equality in health and development and promotion of country ownership.³⁸ The underlying principle of the GHI is that: “Nations that achieve sustained development gains and tangible improvements in the health status of their populations make more capable partners, can engage in and contribute to the global economy, and provide citizens with the opportunity, means and freedom to improve their lives.”³⁹ Though the GHI purportedly targets issues of family planning, nutrition, HIV/AIDS, malaria, tuberculosis (TB), maternal, newborn and child health, neglected tropical diseases, safe water, sanitation and hygiene⁴⁰, in reality, PEPFAR continues to receive the bulk of GHI funds, totaling 73% of the fiscal year 2012 requests.⁴¹ An enhanced ‘GHI

Plus’ program was initiated in 2010 (with implementation beginning in 2011) and provides additional financial and programmatic resources, however, Mozambique is not among the initial 8 pilot nations chosen to receive the *Plus*’ program benefits.

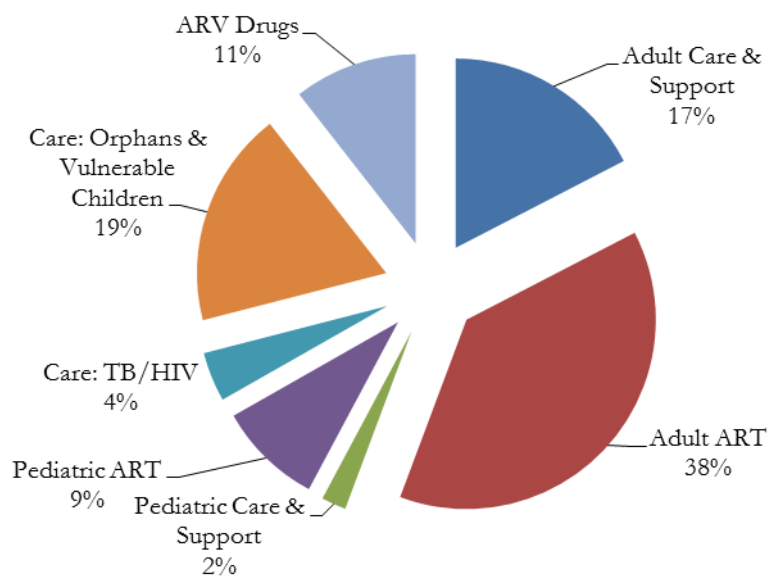
In Mozambique, for FY 2010, PEPFAR committed roughly USD\$269 million (all off-budget), 34% (\$91.5 million) of which was slated for prevention, 35% (\$94.8 million) for treatment and care and 31% (\$82.8 million) for ‘other’ costs which include things like laboratory infrastructure and health systems strengthening as well as management and implementation costs. The breakdown of allocations in each of these PEPFAR budget areas can be found in *Figures 9, 10 and 11* below.

Figure 9. PEPFAR Prevention Funding FY 2010, Mozambique



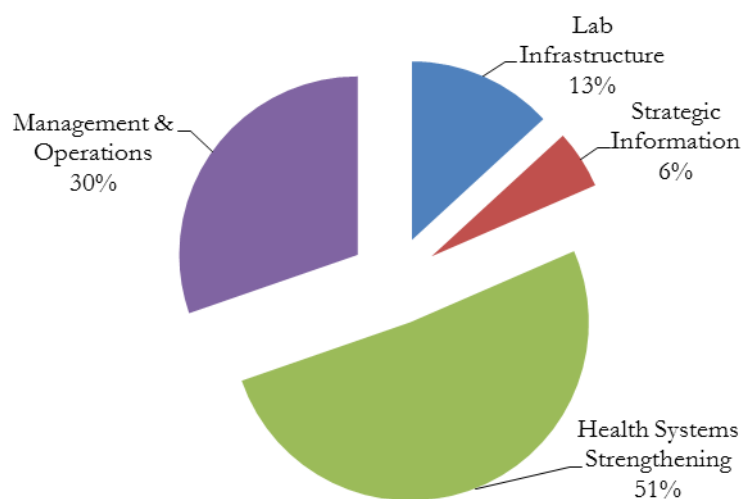
Source: Fiscal Year 2010, PEPFAR Operational Plan

Figure 10. PEPFAR Care and Treatment Funding FY 2010, Mozambique



Source: Fiscal Year 2010, PEPFAR Operational Plan

Figure 11. PEPFAR 'Other' Funding FY 2010, Mozambique



Source: Fiscal Year 2010, PEPFAR Operational Plan

As we can see, 34% (\$31.1 million) of the FY 2010 prevention allocations go towards sexual behavior change in the form of abstinence/be faithful programs, partner reduction and condom usage. It must be remembered that until 2008 a

full 33% of PEPFAR prevention funding had to be used exclusively on ‘abstinence until marriage’ programs. After the 2008 re-authorization, this 33% requirement was removed, however, focus nations must provide a special report to the United States Congress if less than half of prevention funds go to ‘abstinence, delay of sexual debut, monogamy, fidelity, and partner reduction’ (broadly: sexual behavior programs excluding condoms). Presumably, Mozambique will or has provided such a report as they fell far short of this 50% guideline, instead dedicating more prevention funding to prevention of mother-to-child transmission (PMTCT- 45% of PEPFAR prevention funding).

One of the main criticisms of PEPFAR (in both its first phase as well as after the 2008 re-authorization) is the blatant push of an American social conservative agenda in developing nations.⁴² The heavy focus on ‘abstinence until marriage’ in the absence of any scientific evidence that this would help curb a generalized HIV epidemic, even were it a realistic strategy, is the most obvious example. One scholar characterizes PEPFAR’s socially-conservative prevention paradigm thusly: “PEPFAR has utterly destroyed a comprehensive approach in many of the focus nations”.⁴³ Indeed, though it is difficult to quantify actions that are not taken, programmatic evidence from the US Government Accountability Office (which oversees PEPFAR) would seem to support the suspicion that these ideological requirements for PEPFAR prevention funds have forced cuts and reductions in scientifically-sound prevention programs in areas such as blood safety and PMTCT⁴⁴.

As we have seen with Mozambique’s dedication of less than 50% of PEPFAR prevention funding towards sexual behavior programs and more towards PMTCT, focus nations may, in fact, ‘bend the rules’ to some extent, as they feel is necessary, when it comes to PEPFAR prevention funding. In the area of treatment, we have seen the same bending of the rules, only in the opposite direction. In 2006-2007 for example, at least 55% of PEPFAR funding was required to be allocated to treatment (adult or pediatric), however, Mozambique was one of three nations (along with Uganda and Zambia) that fell short of that requirement.⁴⁵ In PEPFAR’s 2008 re-authorization, the treatment requirement was lowered to 50%, yet, in 2010, we find that only 35% (\$94.8 million) of Mozambique’s PEPFAR funds were allocated to treatment and care.

It must be acknowledged that this failure to dedicate 50-55% of PEPFAR funds to treatment has been due, perhaps in large part, to a lack of infrastructure and human resources capable of providing this treatment (this will be discussed further in the following chapter on human resources). The antiretroviral (ARV)

drugs themselves, contrary to popular belief, make up a relatively small portion of treatment costs as can be seen in *Figure 10* above where ARVs are only 11% of the total treatment and care funding allocation (this does not include ARVs used for PMTCT). Though a thorough analysis of ARV and ART costs has not yet been carried out in Mozambique, a comparative study looking at these costs at PEPFAR-supported treatment sites in Ethiopia, Nigeria, Uganda, and Vietnam found average annual per patient ARV costs ranging from USD\$ 472 – 685 and total ART provision costs (including ARVs, all site-level costs for outpatient ART and care as well as administrative costs) ranging from USD\$ 682 – 988, dispelling the myth of exorbitantly high ARV or overall ART costs as the main barrier to ART scale-up.⁴⁶ The same study also demonstrated that per patient ART costs decrease markedly over time with newly-initiated ART patients being more costly than established patients.

The increase in PEPFAR funds in FY 2010 dedicated to laboratory infrastructure (USD\$10.9 million), and Health Systems Strengthening (HSS-USD\$42.4 million) in Mozambique, is, in a sense, an acknowledgement of the importance of general health system integrity as a precursor to successful scale-up of clinical HIV interventions such as ART. Presumably, these investments in the health system as a whole will provide returns later down the road for HIV treatment (and therefore, prevention) as the carrying capacity and efficiency of the health system increases. Once capacity catches up with treatment targets, we may expect to see even greater increases in treatment expenditures, eventually reaching the 50% target of all PEPFAR funds being spent on treatment and care. Though this will certainly help to increase the number of people living with HIV who have access to ART, it would be ideal if explicit calculations of the number of new cases of HIV prevented by providing ART to these HIV-positive persons were allowed to be included in PEPFAR *prevention* calculations. As we have seen, Mozambique has begun to quietly disregard official PEPFAR guidelines for prevention funding by placing heavy emphasis on PMTCT and less emphasis on sexual behavior prevention without any dire consequences from an increasingly-flexible PEPFAR bureaucracy. Were PEPFAR subsequently to move away from its original social conservative ideological slant (with its irrational focus on sexual abstinence) and consider the benefits of ART as prevention when determining prevention earmarks, or simply erase the illusory boundary between prevention and treatment altogether, then nations such as Mozambique would not only be able to provide ART to more HIV-positive persons, but would also be able to reliably estimate the number of new infections prevented through ART provision, creating a righteous cycle of evidence-based prevention and treatment.

The Global Fund

The Global Fund is a multilateral funding mechanism set up in 2002 with a mandate to combat HIV/AIDS, Tuberculosis and Malaria. The Global Fund is not an implementing agency (and so does not have a concrete presence in recipient nations), but rather a very specifically-focused funding agency, providing millions of dollars to recipients to aid in their fight against these three diseases and working through government, nongovernmental (NGO) and private sector organizations through what are called multi-sector partnerships. Requests for funding are written by the country organizations in question (typically in partnership with one another through what is known as a Country Coordinating Mechanism—CCM) with the CCM itself choosing priority areas and The Global Fund independent review panel making determinations on funding. Grant agreements are signed with and funds disbursed directly to Principle Recipients (PRs) who receive an initial evaluation by The Global Fund to ensure they have the capacity and institutional skills to carry out their plans. The CCM system has drawn concerns about fairness and the ability of the CCM to independently monitor PR activity in Mozambique (and other nations) as the Chair and Vice-Chair of the Country Coordinating Mechanism were also the main representatives of the two Principal Recipients¹³ in the country.⁴⁷ The Global Fund does not have explicit rules or regulations to address these types of issues.

One crucial aspect of Global Fund financing is that it is meant to be ‘additional’, meaning that during the application process and again during periodic reviews, recipients must prove that they are not diminishing their own domestic investments and using Global Fund money instead of domestic funds. The Global Fund finances a broad range of activities in relation to prevention, care and treatment of the three diseases, but will not fund basic science nor clinical research (though operational research meant to improve delivery of prevention, treatment and care services may be approved) nor will they provide funding for capital investments such as the building of hospitals. Importantly, The Global Fund does not require that the programs it funds be solely funded by them and, in fact, they prefer to partially support programs in order to encourage the additionality concept and potential sustainability.⁴⁸

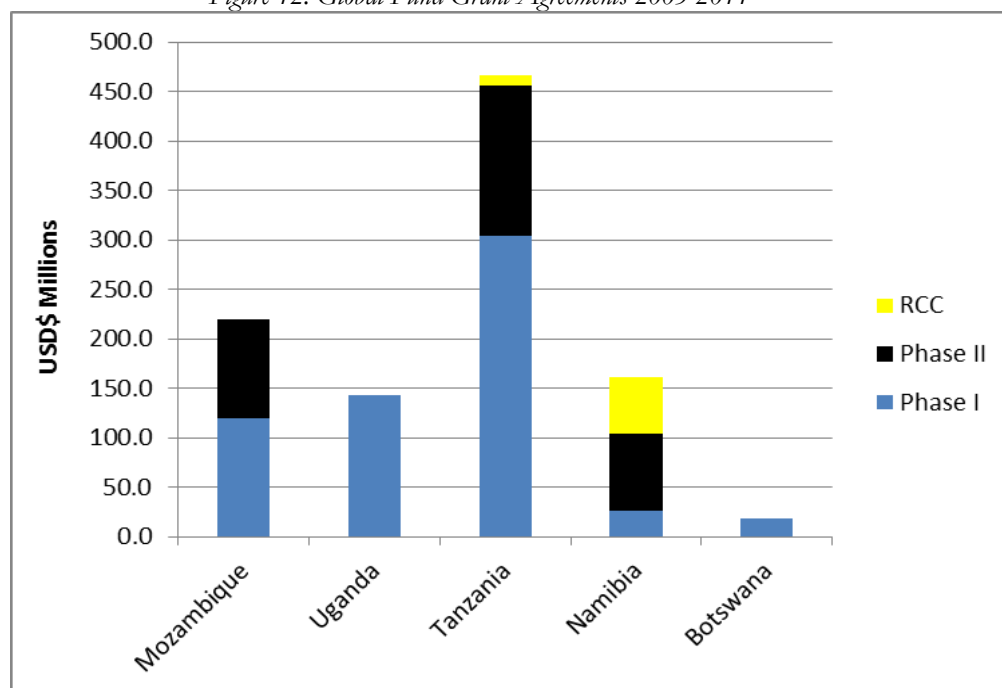
¹³ These two original PRs were the Ministry of Health (MISAU) and the National AIDS Council of Mozambique (CNCS) though World Vision Mozambique and the Fundação Para o Desenvolvimento da Comunidade (FPDC) have now been added as PRs.

The Global Fund raises most of its money from the governments of affluent nations, though private, philanthropic organizations and even corporations and individuals also contribute. As of January 2012, close to USD\$ 30.3 billion has been pledged and close to USD\$ 21.5 billion has been paid to The Global Fund.⁴⁹ The funding gap between Global Fund projections of need, money pledged and money paid is a constant source of concern as the Global Fund works within a strict budget and will only approve funding when it has the money needed ‘in hand’. The Global Fund has not been insulated from the recent global economic downturn and, indeed, in Round 9 (2011)¹⁴, they approved only 90% of total budgets for each of the approved proposals due to the funding gap.⁵⁰ For Mozambique, the Round 9 grant (which began Phase 1 in 2011), totals USD\$ 41.1 million.⁵¹

Proposals to the Global Fund (under the old architecture which is still partially in place and so will be discussed here) are typically for 5 years with an initial two-year funding commitment (Phase 1) and, depending on satisfactory performance, towards the end of Phase 1, funds for the final three years (Phase 2) will be approved. *Figure 12* shows grant agreements from 2003-2011 for selected nations, including Mozambique where USD\$119.8 million was approved in Phase 1 and USD\$ 100.4 million in Phase 2.⁵² The Rolling Continuation Channel (RCC) is an invitation-only mechanism for high-performing grants to be extended for up to 6 years beyond their initial duration and was begun in 2006.⁵³ Mozambique has never been invited to participate in the RCC.

¹⁴ The Global Fund has operated on a Rounds-based system since its inception in 2002, typically holding rounds annually. In 2011 (beginning with the 2012-2016 strategy), The Global Fund has invented a new system which they call “Invest for Impact”. More information on the new strategy can be found at: http://www.theglobalfund.org/documents/core/strategies/Core_GlobalFund_Strategy_en/

Figure 12. Global Fund Grant Agreements 2003-2011

Source: Global Fund Grant Portfolios⁵⁴

The Global Fund estimates that approximately half of its funding goes towards procurement, including ARVs. By mid-2011, Global Fund programs were estimated to be supporting approximately 3.2 million people on ARVs, globally.⁵⁵ In Mozambique, the Global Fund estimates that it supported 220,000 people on ARVs by mid-2011.⁵⁶ It is important to remember that, as The Global Fund does not implement programs and encourages use of its grants to partially support programs, the issue of double-counting tends to arise, particularly between The Global Fund and PEPFAR as many programs jointly support the same public ART programs.⁵⁷ Crucially, the preventative externalities of providing ART to people living with HIV do not appear in any calculations of new cases of HIV prevented. This means that prevention and treatment are handled as freestanding and unattached areas with no spillovers between the two. As we have seen that treatment is, in fact, the most efficacious intervention for prevention of sexual transmission of HIV, the fact that no calculations of the number of new cases prevented through treatment itself means that the vast funding provided for prevention of sexual transmission may not be used for treatment.

As touched upon previously, addressing the issue of vertical vs. horizontal financing (often paralleling on-budget vs. off-budget) is an area where

Mozambique was a pioneer, being the first nation to effectively put Global Fund resources on-budget, including the funds in the SWAp program (in 2004) and, therefore, in their Common Fund for health (PROSAUDE)- an effective horizontalization of Global Fund resources. Though there was much early enthusiasm about this approach⁵⁸, it did ultimately fall apart in Mozambique (in 2008) due to a lack of harmonization between Ministry of Finance fund management processes and Global Fund processes that led to late disbursement of funds in the last two months of 2007.⁵⁹ This caused The Global Fund and external researchers to critically assess how Global Fund mechanisms could more effectively be tailored to country-specific situations, allowing for reliable horizontal financing. More recently, a discourse has developed around the idea of so-called ‘diagonal’ financing where disease-specific results may be sought (typically a ‘vertical’ idea) through health system strengthening (HHS- typically a ‘horizontal’ idea).⁶⁰ Ooms et al. (2008) poetically metaphorize the vertical versus horizontal versus diagonal trichotomy thusly: “While the vertical approach results in fragile, isolated islands of sufficiency, and while the horizontal approach leads to generalised insufficiency, the diagonal approach aims to build islands with a broad and solid base, and to gradually connect those islands, by helping to fill in the swamp” (‘the swamp’ being under- or un-served geographical areas). The Global Fund generally does not require absolute sustainability, stating in their 2007 Call for Proposals that “applicants are not required to demonstrate financial self-sufficiency for the targeted interventions by the end of the proposal term”⁶¹. However, in order to *encourage* sustainability and possibly eventual autonomy (and also discourage ‘crowding out’), The Global Fund does attempt to firmly monitor the aforementioned additionality principle by requiring applicants to “demonstrate that the government contribution to the disease program is greater than or equal to the minimum threshold that applies to the applicant’s income level [and] demonstrate increasing contribution of government resources to the national disease program as well as the overall health sector”.⁶²

Generally speaking, in terms of including calculations of new cases of HIV prevented through ART provision for those infected with HIV into prevention efforts financed by The Global Fund, The Global Fund would seem to be more flexible, in terms of what they will pay for, than PEPFAR. Theoretically, if the Country Coordinating Mechanism of Mozambique were to provide solid reasoning for the use of ART as prevention in their grant request (and therefore, the use of prevention funds for ART), The Global Fund, unlike PEPFAR, has no specific rules or earmarks in terms of particular areas of prevention intervention. In this way, the paradigmatic shift for the usage of Global Fund resources to support prevention as treatment should be less painful than a similar

paradigmatic shift to utilize PEPFAR prevention funds in this way. However, as The Global Fund is not the principal funding mechanism for HIV/AIDS in Mozambique¹⁵ and only partially funds many HIV programs, as well as the fact that they have no implementation arm whatsoever, it would be difficult and unlikely that the Global Fund Country Coordinating Mechanism would drastically depart from principles regarding acceptable areas of prevention intervention as defined by PEPFAR. In this way, the focus of Global Fund resources tends to closely parallel the programmatic priorities delineated by PEPFAR in Mozambique as previously discussed.

As long as PEPFAR retains a strict rhetorical and financial division between prevention and treatment—as well as ideologically-based and rigid regulations on acceptable programmatic areas of prevention—nations such as Mozambique will not have the necessary policy maneuvering space to explicitly account for the considerable number of new cases of HIV prevented annually with effective ART scale-up. Until these financial divisions are taken into account, the preventative externalities of ART will remain unrecognized in terms of the use of prevention funds to take advantage of the most efficacious form of (sexual) HIV prevention currently in existence: ART as prevention.

Conclusion

Chapter 1 focused on the social construction of HIV in sub-Saharan Africa highlighting how the negative social construction of infected individuals combined with their fairly low political and social power has helped lead us to continue with the dominant sexual behavior paradigm in the face of ample evidence showing that sexual behavior cannot explain SSA's HIV epidemics. This path dependence on inefficient and ineffecacious policies has led to rhetorical and policy silence in several scientifically-sound areas of HIV prevention which were briefly discussed in the first chapter.

Chapter 2 then has been dedicated to first laying out the irrefutable clinical evidence of the efficacy of one of these neglected prevention interventions which is the focus of the rest of this dissertation: ART as prevention. The HTPN052 study was the first randomized clinical trial of its kind to prove what 'common knowledge' has known for over a decade, keeping in mind that the mechanisms

¹⁵ For the 6-year period 2003-2009, for example, The Global Fund contributed approximately USD\$220.2 million in Mozambique (for HIV, Malaria and Tuberculosis) while PEPFAR from 2004-2010 contributed approximately USD\$1.1 billion (for HIV/AIDS).

behind ART as prevention of sexual transmission are virtually identical to those in play in prevention of mother-to-child transmission (MTCT) where antiretrovirals have been in use since 1994. Despite this, HTPN052 was potentially game-changing as it used the gold standard in clinical science—the RCT—to show that early ART prevents 96% of sexual transmission of HIV.

As large-scale prevention policies in high prevalence and incidence settings still continue to focus on the seronegative population through sexual behavior change campaigns, it was my goal to show that, not only are these current campaigns fairly ineffective (both in changing behavior and stemming the epidemic), but that, even at current usage/coverage of condom usage, abstinence and ART (access + adherence), we may already be preventing more new cases of HIV through ART in Mozambique than we are preventing with condom usage or abstinence behavior combined. This was illustrated through the ‘prevention cascades’, *Figures 3, 4 and 5*. These cascades and the following visual representations (*Table 3 and Figure 6*) highlight how coverage/usage (or in the case of ART, access and adherence) are, mathematically, more important than efficacy in population-level prevention. Though ART is, in fact, the most efficacious known intervention, it also enjoys higher levels of coverage/usage than both condoms and abstinence, despite decades of policies aimed towards these two sexual behavior-based forms of prevention.

The subsequent section then advocated for a ‘Focus on the Positives’, meaning, a focus on the HIV-positive segment of the population in contrast to the current and historical focus on the uninfected population. Even disregarding the WHO’s guidelines for when HIV-infected persons should begin treatment and considering the entire population of persons estimated to be infected with HIV in Mozambique, we find that the target population for behavioral prevention is close to 8 times the target population of ART. Using the WHO’s 2009 standards on when to begin ART, we find that the target population for behavioral prevention is 18 times larger than the target population for ART. As coverage/usage is crucial to the success of any prevention campaign, the size of the target group is of utmost importance.

With this same dichotomy of target groups in mind we then looked to a disregarded but arguably very important point in prevention campaigns which is the reasons which Mozambicans report for either using or not using condoms. What we find is a preponderance of respondents who report trusting their partner or being married as reasons for non-use and avoiding pregnancy as a reason for use (*Tables 4 and 5* with full pertinent DHS data reported in *Appendix 1*). Though reported access increases with age, usage declines while the above-mentioned reasons for non-usage increase sharply with age. This highlights the importance of considering not only increased availability of condoms and pushing their usage (the current focus of many prevention campaigns), but also the reasons why people report using or not using condoms which is also discussed in the case study in Chapter 4. A very important point which is

neglected in both HIV-related literature as well as in the policy sphere is that the two main sexual behavior-based prevention strategies which advocate condom usage and abstinence are both methods which prevent pregnancy. This makes them not only unattractive to much of the population, but also unfeasible and impractical on a population level and in the long run. HIV-infected individuals on ART, however, seek treatment first and foremost for their own health (not speaking of MTCT) and, as we will see in the case study in Chapter 4, there may be indications that, were they to understand the preventative benefits of ART, they may be more motivated to begin and adhere to treatment in order to protect an uninfected partner. There is also evidence that HIV testing and counselling often results in ‘risk behavior’ change for individuals who test *positive* for HIV while having no effect on behavior for those who test *negative*,⁶³ again highlighting the secondary behavioral potential of ‘the positives’ as opposed to continuing to attempt to change the behavior of the uninfected population. With all of these points in mind, we must critically and thoroughly examine why prevention campaigns remain focused on the uninfected population. As discussed in-depth in Chapter 1, using the framework of the social construction of Africa’s HIV epidemics where infected individuals and groups are negatively constructed and/or weak socially and politically, provides us with an intuitive and insightful lens through which to view the illusory tradeoff that has been created between HIV prevention and treatment.

The subsequent section then focuses our attention on the financial side of HIV policy in Mozambique. Though ART as prevention will function whether or not the preventative externalities of treatment are acknowledged, there is still great need to question the ‘illusory tradeoff’ framework (prevention vs. treatment) that does not allow ART to be considered as an HIV prevention strategy. Currently, new cases of HIV that are prevented through ART (which, as we have seen, may already exceed new cases prevented through abstinence or condom usage) are not included in any prevention calculations and, as a consequence, ART is not eligible for consideration for funding that is earmarked for prevention.

As 72% of Mozambique’s total expenditures on health (TEH) and a full 96% of the nation’s HIV/AIDS-specific funding come from external sources, we then focused on the main HIV/AIDS funding agencies working in the nation: PEPFAR and the Global Fund. The discussion of the social construction of HIV, and, in particular, the importance of ‘Western’ ideas surrounding ‘African sexuality’ are thrown into stark relief in this section as PEPFAR has been accused, not only by some scholars and activists, but also by the US government’s own Accountability Office (GAO) of harming comprehensive prevention efforts which target scientifically sound areas of prevention such as PMTCT and blood safety through ideologically-based requirements (i.e.: large earmarks for abstinence until marriage, partner reduction, etc...). It was also noted that, while a current mandate to utilize 50% of PEPFAR funding on ART is in place, Mozambique has been unable or unwilling to reach this level, possibly

due to a lack of sufficient health infrastructure and human resources (a topic which is the focus of Chapter 3), areas where PEPFAR funds have only very recently been directed. As discussed earlier in this chapter, PEPFAR accounts for 78% of Mozambique's HIV/AIDS-specific funding which has the secondary effect of locking-in policies and strategies which other donors (and the national government) must then work with and build upon. As PEPFAR funds are 'off-budget' and therefore not subject to national policies of governmental approval or allocation, the national government is further disempowered in terms of deciding policy direction and focus. This lock-in of policy direction also becomes particularly salient in the case of the Global Fund. Though the Global Fund does not have ideological requirements for how their resources are spent, they do have a strong 'additionality' principle which requires that Global Fund resources be used in addition to other sources of funding (internal or external), to strengthen existing programs as opposed to creating vertical programs or infrastructure. As the Global Fund makes relatively small contributions relative to PEPFAR and has this 'additionality' requirement, it is unlikely that these funds (or other donor or national funds) would be capable of changing the trajectory of HIV prevention policies without a paradigmatic shift first and foremost in PEPFAR. Therefore, if we wish to harness the externalities of ART as prevention, we cannot ignore the power of social constructions in HIV policy, particularly in light of the clear and explicit connections we have seen between the social construction of 'African sexuality' and the continuing focus of PEPFAR (and, subsequently, all national policies in target nations) on sexual behavioral prevention strategies despite evidence of their continuing failure, not only to change sexual behavior, but also to stem the tide of the HIV epidemic.

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3

HUMAN RESOURCES FOR HEALTH AND ART SCALE-UP IN MOZAMBIQUE

3.1 Mozambique's Human Resources for Health (HRH)

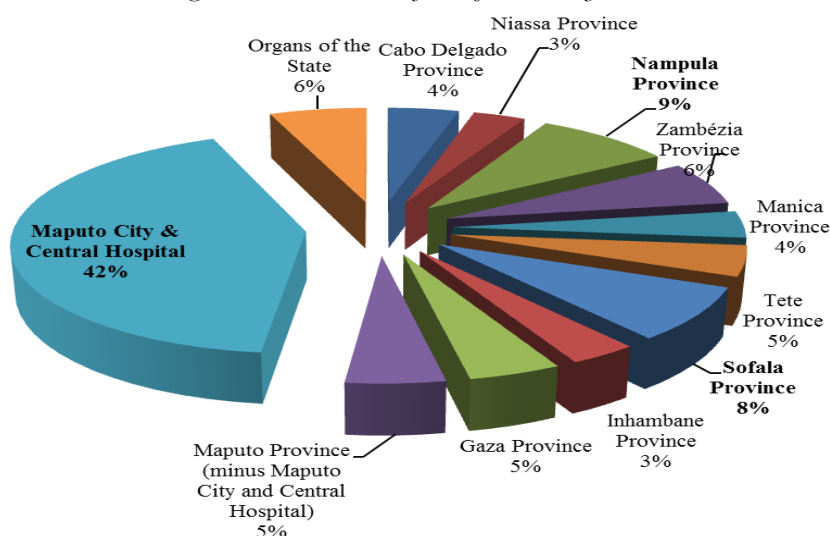
Mozambique is one of the 56 nations identified by the World Health Organization (WHO) in 2006 as having a 'critical shortage' of health workers.¹ The WHO defines the critical threshold for the density of doctors, nurses and midwives (combined) as 23 per 10,000 population, while Mozambique, as of 2010, continues to hover around three per 10,000.^{16,2} According to Mozambique's 2010 Annual Human Resources Report (DRH), as of December 31, 2010, Mozambique counted 863 Mozambican physicians, 76.5% (660) of whom are generalists, 23.3% (200) hospitalists and 0.3% (3) physicians specialized in public health. The capital city, Maputo, contains 42.2% (364) of all Mozambican physicians in the nation though its population accounts for only roughly 5% of the national population.³ Even within Maputo City, we find an imbalance as close to 68% (247) of all physicians in the city work at the Central Hospital of Maputo while the other 32% (117) staff two other general hospitals and close to two dozen health centers.⁴ On a national level, the number of physicians has been growing at roughly 8% since 2008 but again, the growth has been uneven with Maputo City alone recording increases of 14% in 2009 and 39% in 2010.⁵

To put these numbers in perspective, the DRH reports that by the end of 2010, Maputo City (including the Central Hospital) had more Mozambican physicians than the provinces of Cabo Delgado, Niassa, Nampula, Zambézia, Manica, Tete, Sofala and Inhambane combined (the remaining provinces of Gaza and Maputo—excluding the City of Maputo—had a total of 39 and 42 Mozambican physicians, respectively). By the end of 2010, there were 242 foreign physicians working in Mozambique (83% of them as hospitalists), though these 'visitors' and expatriates are not included in Mozambique's national human

¹⁶ Though Mozambique's 2010 Annual Human Resources Report (DRH) puts this ratio at 6.3 per 10,000 population, this is based on considering only children aged 0-5 and women aged 15-45 in the population as can be seen in Table 22 of the report.

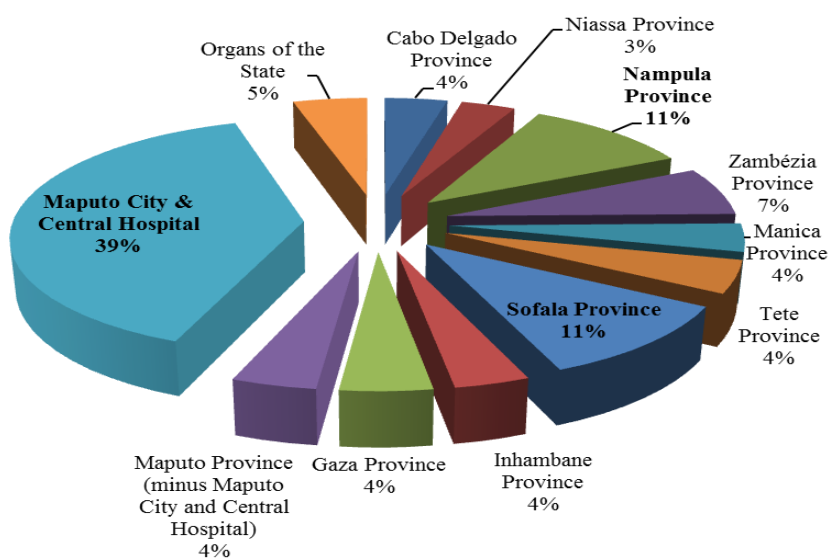
resources plans and projections. *Figures 13 and 14* show a graphic representation of the distribution of Mozambican physicians and all physicians (Mozambican and expatriate) in the nation. The provinces of Sofala and Nampula are highlighted in these figures as they contain the second- and third-largest cities in Mozambique, respectively, after Maputo (Beira and Nampula City). Nampula Province is, in fact, the most populated province in Mozambique with a population of approximately 4.5 million⁶ compared to close to 1.9 million in the province of Sofala⁷ and roughly 1.2 million in Maputo City⁸.

Figure 13. Distribution of Mozambican Physicians.



Source: DRH 2010 Annual Report (2011)

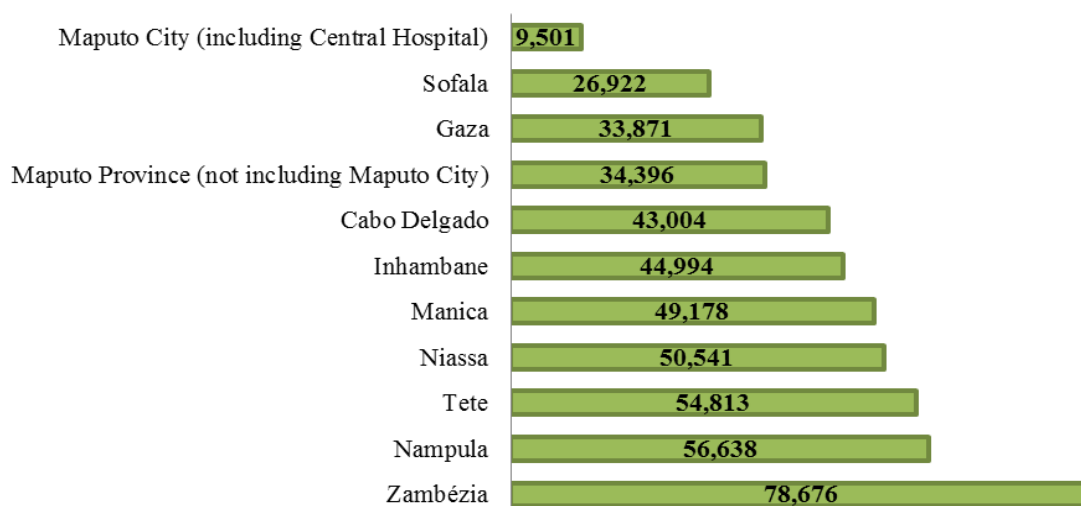
Figure 14. Distribution of All Physicians in Mozambique (Expatriate and Mozambican)



Source: DRH 2010 Annual Report (2011)

Putting the number of physicians in perspective relative to the population of each province and Maputo City, we can see in *Figure 15*, that Nampula province has over 56,000 inhabitants per physician, Sofala (provincial capital: Beira) has approximately 27,000 and Maputo City approximately 9,500.

Figure 15. Inhabitants per Physician for the Mozambican Provinces and Maputo City.



Source: DRH 2010 Annual Report (2011)

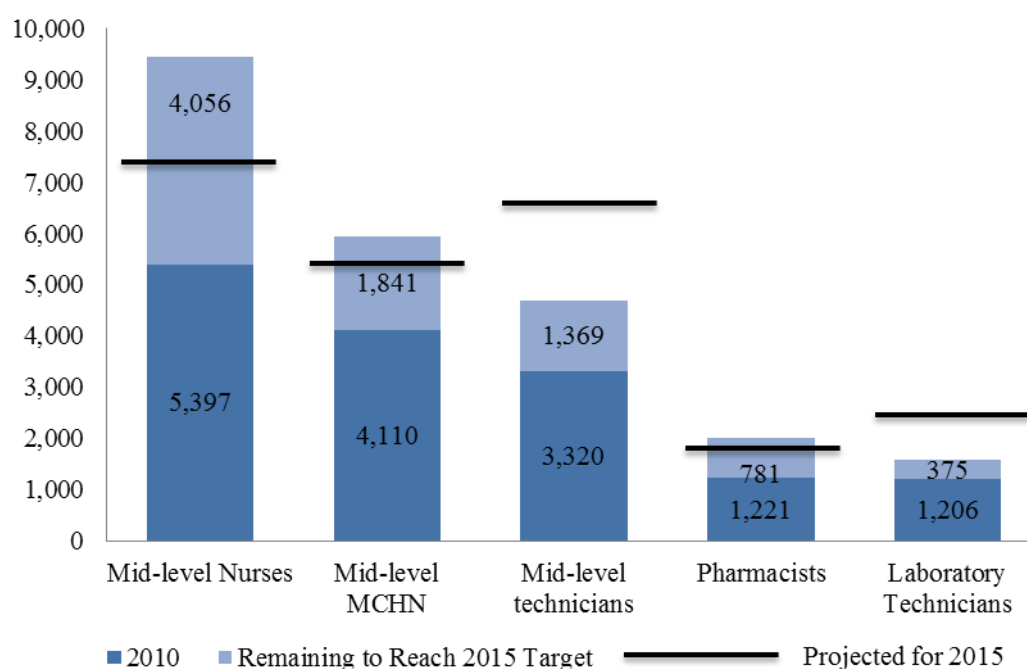
In terms of non-physician clinicians, Mozambique has set explicit targets in their National Human Resources Development Plan (HRDP) 2008-2015 for mid-level¹⁷ general nurses (9,453), mid-level maternal-and-child-health nurses - MCHN- (5,951) and mid-level medical technicians (4,689). By the end of 2010, Mozambique had reached 57% (5,397) of the 2015 goal for mid-level general nurses; 69% (4,110) of the 2015 goal for mid-level MCHN and; 71% (3,320) of the 2015 goal for mid-level medical technicians. However, looking at the rates of growth in these professions, Mozambique expects to fall short of the 2015 goals for mid-level general nurses (23% deficit) and mid-level MCHN (10% deficit), while surpassing the planned number of mid-level medical technicians by 42%.

Mozambique has also set year 2015 targets for pharmacists (2,002) and laboratory technicians (1,581) in the HRDP. By the end of 2010, the nation had 61% (1,221) of the 2015 goal for pharmacists and 76% (1,206) of the 2015 goal

¹⁷ Mozambique disaggregates clinicians by level of education with 'elementary', 'basic', 'mid-level', and 'specialized mid-level' all being included in calculations for so-called 'mid-level' clinicians while 'superior' is the highest level of education and is not specifically targeted or counted in the national goals.

for laboratory technicians. At the current rates of growth in these professions, Mozambique expects a to fall slightly short of the target for pharmacists (2% deficit) but to surpass the planned number of laboratory technicians by 47%. These 2015 targets, the number of health workers to reach the targets as well as the number of projected health workers in each category by 2015 (based on rates of growth in each profession through the end of 2010) can be seen in *Figure 16* below.

Figure 16. Current and Projected (2015) Human Resource Levels by Health Worker Category.



Source: DRH 2010 Annual Report (2011)

The regional imbalance of non-physician clinicians, pharmacists and laboratory technicians is slightly less marked than that of the physicians. By the end of 2010, roughly 17.2% (5,919) of the nation's non-physician health personnel were concentrated in the City of Maputo, however, the Central Hospital of Maputo continues to host the bulk of these health workers with 54.2% (3,207) of Maputo City's non-physician health workers concentrated in the Central Hospital. Not incidentally, this means that the Maputo Central Hospital alone has more non-physician health workers than most of the individual Mozambican provinces (i.e.: Cabo Delgado, Niassa, Tete, Manica, Inhambane and Gaza).

The 2015 goal for all clinical, pharmaceutical, laboratorial and technical staff in Mozambique is 29,333 while, through the end of 2010, Mozambique had reached 63.4% of that goal with personnel numbering 18,587. Tyrell et al. 2010 estimate the total cost of the HRDP (2008-2015) at approximately USD\$ 2 billion with over three quarters of those resources dedicated to the wage bill (health worker salaries), 14% to incentive packages for retention, motivation and deployment of health workers and over USD\$100 million for initial training of health workers (28% of which would go towards infrastructure and equipment) with an additional USD\$11 million earmarked for on-the-job training. It is important to note that the HRDP is generally aimed towards HRH scale-up for health areas considered priorities in achieving the Millennium Development Goals (MDGs), namely: nursing, pharmaceutical management, laboratorial management, preventative medicine, hospitalist administration, anesthesiology, instrumentation and surgery.⁹ However, HRH scale-up as viewed through the lens of ART scale-up, though often on a parallel course (HIV/AIDS is, in fact, the focus of MDG 6), also contains specificities which deserve attention. These specificities will be discussed in the following sections on HRH and ART scale-up and Task Shifting.

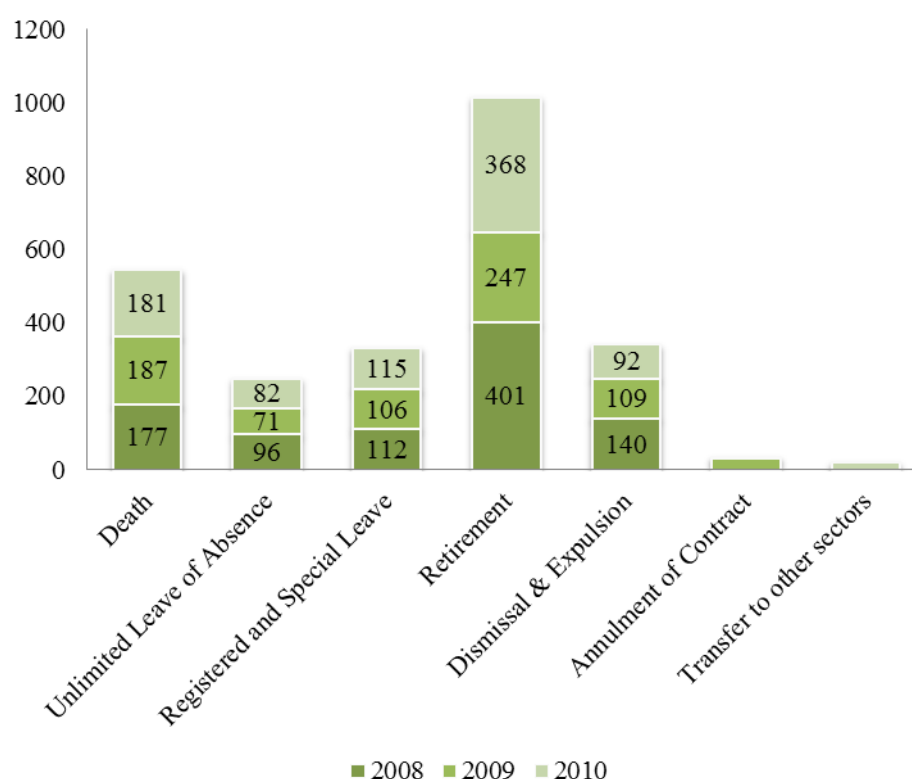
3.2 Human Resources for Health and ART Scale-Up

Though there are many HIV/AIDS-related activities that can be and are carried out by non-health professionals, HIV treatment remains an area which is, understandably, particularly health worker-dominated and the health worker crisis in Mozambique is considered the greatest obstacle to improving the population's health as well as reaching several of the MDGs.¹⁰ Hard and fast recommendations regarding the number or mix of health workers required for effective ART provision in Mozambique have yet to be written. With the rapid move towards task shifting (to be discussed in the following section) and the resulting shifting landscape of health workers qualified and authorized to perform certain HIV-related tasks, recommendations are increasingly more likely to center around the number of health workers needed to provide specific services (i.e. commencement/prescription of ART, counseling and testing, monitoring of CD4 levels, etc...).

The Global Health Workforce Alliance (GHWA), in 2010, published a Rapid Situational Analysis of Mozambique's HRH scale-up as it relates to universal access to HIV-related services. This analysis mainly relied upon HIV epidemiological data, HIV program indicators and key informant interviews to identify strong and weak points in Mozambique's HRH scale-up in relation to

HIV services and to elaborate recommendations to increase the efficiency and efficacy of this HRH scale-up.¹¹ Unsurprisingly, the number, type, level of attrition and geographical distribution of health workers were cited as continuing barriers to universal access. Though the report praised the Ministry of Health's HRDP and the intention behind the accelerated training strategy (2006-2009), a marked trade-off between quantity and quality was identified as the infrastructure necessary (including classrooms, materials, and clinical practice sites) to properly train large numbers and cadres of health workers is still lacking as well as pay, incentives and working conditions conducive to retention in the public sector. All cadres of health workers are seen to suffer from problems of motivation due to a general lack of incentives ('perks'), opportunities for ongoing training and career mobility (particularly for lower cadres of workers), low salaries, difficult working conditions and, ironically, a perception among health workers of very high risk of acquiring HIV on the job through accidents (such as needle-stick injuries). In fact, HIV-related deaths of health workers remain one of the leading causes of workforce attrition, accounting for a large portion of the 19%-25% of the health workforce lost to death each year from 2008-2010 (See *Figure 17*).¹² The relatively high number of leaves of absence (particularly 'unlimited' leaves) tends to reflect the clinical health workers who leave the public sector for 'greener pastures' as consultants and employees of NGOs and donor organizations where pay, benefits, working conditions and opportunities for advancement are considerably more favorable than work in the public sector. These workers have not officially left the public sector by permanently leaving their public employment (they may, indeed, return to their public sector position at the end of their leave of absence), but are considered 'lost' in terms of their concrete contributions to clinical care in public health facilities. Mozambican physicians are particularly coveted by NGOs and, despite the fact that Mozambican physicians represent only 4.6% of all clinical workers (in 2010), they made up 11%, 17% and 13% of all attrition due to registered and unlimited leave in 2008, 2009 and 2010, respectively, and these leaves constituted the primary source of attrition for physicians in all three of those years.¹³

Figure 17. Clinical workforce attrition in Mozambique, 2008-2010



Source: DRH 2010 Annual Report (2011)

Though there are no systematic comparable data from Mozambique, Weller et al, (2011) highlight evidence from several developing nations that shows that donors and NGO's working on the ground tend to "bid" against one another, incrementally increasing salaries for limited health workers and therefore poaching from one another (as well as the public sector) and leading to increasing distortion of salaries. In acknowledgement of this phenomenon, the Mozambican Ministry of Health drafted an agreement that they called the 'Kaya Kwanga Commitment: A Code of Conduct to Guide the Partnership for Health Development in Mozambique' in 1999. Virtually all UN agencies, bilateral donors and NGOs working in the health sector in Mozambique signed the commitment in 2000, pledging, among other things, to "[a]dhere to agreed national rates regarding remuneration and allowances for civil service employees, remuneration of consultants [...and] avoid the departure of qualified personnel through the contracting of civil servants for donor consultancies"¹⁴. The pledge, however, is non-binding and Mozambican government efforts to bring remuneration by international agencies in line with public remuneration have failed to date, perhaps in part due to entrenched expectations of health workers (and those

training to be health workers) as well as escalating competition between NGOs for the limited local, qualified health workers that has led to private sector salaries 5 to 20 times higher than public sector salaries.¹⁵ For example, Ferrinho et al. (2004) found that while medical students in Mozambique acknowledged that they would be needed in the public sector after graduation, one third of the respondents had post-graduation salary expectations ranging from USD\$715-1071 per month and another third of respondents expected over USD\$1,429 per month while, at the time of the survey, newly graduated (public sector) physicians were earning approximately USD\$350 per month. While physicians in Mozambique almost without exception, work at least nominally in the public sector, brain drain can be seen in the tendency towards dual (public and private) practice in order for health workers to gain supplementary income.¹⁶ Dual practice (otherwise known as ‘moonlighting’) is not necessarily negative if properly regulated; Mozambican hospitals, for example, often consider dual practice a necessity in order to retain senior staff.¹⁷ However, due to the potential for conflicts of interest and lessening of hours devoted to public health provision, the Mozambican Ministry of Health stated its intention to firmly regulate dual practice activities in 2008, though by the end of 2010, these planned regulations had not yet been introduced.¹⁸

The Mozambican government, being well aware of this internal, public to private ‘brain drain’ and in addition to planning to regulate dual practice, laid out plans in the HRDP (2008-2015) to increase incentives for retention in the public sector (such as improving public sector career mobility and opportunities for promotion) as well as base salaries of health workers by increasing human resource expenditures as a percentage of health spending. The 2010 DRH reports that, while they Ministry of Health did, in fact, implement competitive promotions throughout the country, due to budgeting difficulties, they were not actually able to increase salaries for these promoted workers, nor for the workers who remained in their previous positions. The report also states that planned differential compensation plans for health workers who were put at higher occupational risk (for example, of contracting HIV on the job) meant to serve as a form of insurance, had also stalled due to budgetary constraints. These failures in terms of increasing financial incentives to retain health workers in the public sector were acknowledged and attributed to an actual decrease (rather than the planned increase) in human resource expenditures as a percentage of health spending in 2010 relative to previous years¹⁹.

Médecins Sans Frontières (MSF) which works extensively in Mozambique, has pointed out the further issue of wage bill ceilings limiting the Mozambican

government's ability to hire new health workers in a timely manner²⁰ (not to mention, limiting their ability to pay competitive salaries for those they do hire). This led, for example, to a support plan beginning in 2002 where MSF, with the encouragement of the Mozambican Ministry of Health, hired and trained newly graduated nurses that the government could not hire itself, sometimes for up to four years, due to the wage bill ceiling.²¹ This mismatch between the HRDP which calls for and projects massive increases in health worker numbers in order to meet the MDGs and the lack of guarantees of public sector jobs for the much-needed, newly minted workers (as well as low salaries and weak incentives for those who are hired) helps to reinforce the public health sector's image as an undesirable sector in which to work.

In terms of donor support for health worker scale-up, most donors (including the major players in HIV services: PEPFAR and The Global Fund) are rarely willing to support public health worker salaries nor their full clinical training, as they are concerned about the 'sustainability' of programs.²² For the relatively short period that The Global Fund contributions were included in Mozambique's SWap ('on-budget', as discussed in Chapter 2), these contributions were, ostensibly, also supporting health worker training, however, this ended when Global Fund contributions were taken 'off budget' again in 2008. What donors do tend to consistently support are short-term, privatized in-service training activities of existing staff to specialize in HIV/AIDS support services (including treatment).²³ Though PEPFAR discontinued the practice in Mozambique (in 2007), the Global Fund also continues to provide what are known as 'top-ups'—often salary supplements—for health workers' HIV/AIDS activities and attendance at donor-funded workshops which have been shown to have the perverse effect of weakening the nation's general health structure by siphoning staff from general, clinical practice to more lucrative HIV/AIDS-specific activities.²⁴ Evidence suggests that, at times, health workers continuously attend these well-paying, donor-funded workshops, further depleting the service delivery in their health centers, in order to gain the significant supplementary income, and failing to then bring that training back into practice.²⁵ This tension between HIV-specific donor initiatives and funding and national attempts to strengthen general health systems so that they are *capable* of dealing with the HIV/AIDS epidemic, but not *limited* to dealing with HIV/AIDS, continues to be an issue.²⁶

3.3 Task Shifting

The deficit in sheer numbers of health workers as well as the ‘poaching’ of the most highly qualified cadres (mainly physicians) by donor organizations working on-the-ground in Mozambique has necessitated concerted efforts to accelerate what is called ‘task shifting’. Task shifting is defined as ‘the delegation of medical and health service responsibilities from higher to lower cadres of health staff, in some cases non-professionals²⁷. In terms of ART scale-up, task shifting is intended to help offset regional imbalances in the health workforce (keeping in mind that physicians are the cadre showing the most severe geographic imbalances in Mozambique) as well as increase the number of patients that can be enrolled in ART per health unit and the number of health units that can offer ART for a fraction of the cost (and time) it would take to scale-up physicians. Though Mozambique introduced the ‘medical technician’ (*técnico de medicina*) cadre shortly after independence in 1975, training of medical technicians was severely reduced in 1986 due to an intensifying civil war and the constraints imposed on the public sector wage bill ceiling by structural adjustment policies.²⁸ Though Mozambique’s civil war ended in 1992, training programs for task shifting only resumed in earnest in 2003, concurrently with the introduction of ART in public facilities. This first wave of new medical technicians (along with existing technicians who had received two weeks of supplemental HIV training) was deployed in 2006 and in February of that same year, medical technicians were authorized to prescribe first-line ART. The number of facilities providing ART tripled in the first 6 months of the technician deployment and a full 45% of rural and peri-urban health centers were (and many, in fact, continue to be), managed by a medical technician.²⁹ Table 6 shows the main elements of task shifting in Mozambique.

Table 6. Task Shifting in Mozambique

Task	Former Cadre	Cadre after task shifting
Prescription of first line ART	Physicians	Physicians and Medical Technicians
ART follow-up and refills	Physicians	Physicians, Nurses and Medical Technicians
Counseling & Testing services and adherence counseling	Psychologists	Medical Technicians, Nurses and lay counselors
PMCT implementation	Physicians	Physicians, MCH Nurses

Bedside Care	Nurses	'Attendants' (similar to nursing assistants)
Taking of blood samples	Phlebotomists (laboratory health workers) and nurses	Phlebotomists, Nurses and Ancillary lab workers (agente de lab)
Patient follow-up and adherence counseling	Psychologists	Psychologists and Peers on ART (activistas)

Source: Jaskiewicz, 2010

Of course, with task shifting, comes the question of quality of services as tasks are delegated to lower cadres of workers. As ART is our main concern, let us focus on the cadre of medical technicians, who now carry out the bulk of ART-related services in Mozambique, including in the health center where interviews were carried out for the fieldwork portion of this dissertation (Chapter 4). Sherr et al. (2010) carried out a retrospective cohort study of patients who initiated ART with either a physician or a medical technician between July 2004 and October 2007 at two public HIV clinics in central Mozambique and examined indicators such as the frequency of clinical visits in the first year post-ART initiation, adherence to ART in the first 6 months of treatment and, whether or not CD4 cell counts were evaluated between 90—210 and 33—390 days post-ART initiation for each group. Their results indicate that patients who began and continued care with medical technicians had similar or statistically better performance measures than patients who had begun their care with physicians for all five of the indicators they had utilized and after controlling for relevant covariables (i.e.: socioeconomic status, CD4 cell count at enrolment, age, education, distance to health facility, etc...). Though patients were not randomly assigned to provider types, those who began care with medical technicians had less education, lived farther from the health facility and were of lower socioeconomic status on average; these factors are generally associated with poorer adherence and care outcomes, however, adherence was slightly higher for the medical technician group (78.9% versus 77% adherence) and the likelihood of death was less for the technician group compared with patients in the physician group (hazard ratio 0.91, $0.79 < HR < 1.06$).

Though case studies such as this show that task shifting holds great promise for ART scale-up in Mozambique, task shifting should not be seen as a panacea nor an absolution of government and donor responsibility to invest in, not only other aspects of the health system, but also in achieving high levels of service delivery within the strategy of task shifting. While task shifting does save

training time (i.e. 6 years for generalist physicians versus 2.5 years for medical technicians) as well as money in the form of training costs and salary, it should not be seen as a permanent solution to health system deficiencies in Mozambique. During the training of medical technicians in ART, there are a number of idealistic assumptions made and included in the curriculum, such as that: medical technicians will only see stable, non-pregnant adult patients in the early clinical stages of HIV (before onset of AIDS); clinical staging of disease progression will be possible in the technicians' future health facilities (clinical and diagnostic tests that determine status of a patient's progression towards AIDS and the need for ART as well as other prophylactic or opportunistic treatments); medical technicians will be supervised by physicians, etc...³⁰ However, as pointed out by Brentlinger et al. (2010), newly-trained medical technicians are often sent to health units lacking in both clinical supervision—recall the high percentage of health facilities that are managed by medical technicians—as well as clinical/diagnostic equipment whose presence was assumed during their training. This same study also found that medical technicians are ill-prepared (and show considerable deficiencies in clinical decision-making as judged by experienced physicians) to deal with patients co-infected with HIV and Tuberculosis (TB), though HIV/TB co-infection is a common challenge in Mozambique. The researchers also found that older medical technicians (those who had been practicing for several years and had completed the 2-week HIV training supplement), show significantly worse performance in terms of correctly identifying opportunistic infections, clinical staging, knowing when to initiate or continue prophylactic treatment as well as when to initiate ART itself, than the younger medical technicians who completed their training after HIV and ART management had already been included and stressed in the full, 2.5-year curriculum. So while task shifting is a useful and, in some cases, revolutionary tool that has indeed, drastically increased access to ART in Mozambique and even patient outcomes in some cases, constant vigilance and improvement of the quality of the health system (including infrastructure, diagnostic equipment and continued scale-up of higher cadres of health workers) is still required in order to avoid the pitfall of trading quantity for quality in our quest to treat as many people in need as possible.

Though here we have focused on task shifting among different cadres of clinicians, it must also be recognized that some tasks have been shifted partially or completely to laypersons (as briefly noted previously). Though 'community-based' care has become popular in policy circles, as we can see through Mozambique's *Cuidados Domiciliários* ('Home Care') program, there is a great need for further research, not only into the quality of home care provided by these lay

caregivers, but also into the quality of their training in terms of minimizing risks to their own health. For example, Mozambique's training manual for these community-based home caregivers only briefly mentions the use of blades by traditional healers and unspecified cosmetic procedures as transmission routes of HIV, but does not include any information, instructions or warnings for caregivers themselves to be vigilant to any and all blood exposures that may occur during their caregiving activities nor does it make any mention of the availability or necessity for immediate post-exposure prophylaxis¹⁸ for caregivers who are inadvertently exposed to infected blood.³¹ These issues are outside the scope of this dissertation, but this is an area which merits explicit study as task shifting (including to these lay caregivers) continues to accelerate to keep up with increasing demand for treatment and care services in Mozambique and other developing nations with extreme skilled human resource constraints.

3.4 Conclusion

This chapter has focused on the 'resources' portion of 'human resources', providing background on Mozambique's numeric, geographic and task-based balance of health workers as well as the reasoning behind recent HRH policies including scale-up and task shifting in relation to HIV treatment. The following chapter, the case study portion of this dissertation, will shift the focus to the 'human' portion of human resources. It will explore the social construction of Mozambique's HIV epidemic as discussed in Chapter 1 through the lens of on-the-ground ART treatment based on patients' and clinicians' experiences with ART. Neither professional health workers nor patients are immune to the effects of the social construction of HIV and the case study attempts to show the very real, if at times ethereal, effects of current and historical HIV prevention messages on patients' experiences with ART. If Mozambique is truly to harness the preventative externalities of ART, the messages communicated to patients through prevention campaigns and through their ongoing communications with clinicians (whether these messages be found in the spoken or unspoken dialogues), must be examined and better understood. We have seen in Chapter 2 that coverage and usage of prevention interventions (including ART) is the most crucial factor in their population-level efficacy. We have also explored the state of Mozambique's human resources for health (and specifically for ART scale-up)

¹⁸ Post-exposure prophylaxis is simply the administration of antiretrovirals (usually for 1-2 months) to a person who is exposed to HIV in order to minimize the risk that they will seroconvert.

in the current chapter. It is now time to turn our attention to not just the numerical and logistical requirements for effective ART scale-up and adherence that have been discussed in these two chapters, but also to the 'human' requirements as they manifest in beliefs and communications regarding HIV.

Notes

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- ⁹ Ministério de Saúde Direcção de Recursos Humanos (DRH) “Relatório Anual 2010,” Maputo: República de Moçambique, XXVI CCS (2011).
- ¹⁰ Ooman, Nandini, Michael Bernstein, and Steven Rosenzweig “Seizing the opportunity on AIDS and health systems,” Center for Global Development (2008).
- ¹¹ Jaskiewicz, Wanda, Maria Ines Tomo, Francisco Langa, Hilde De Graeve, Catherine McKinney, and Lucy Ramirez “Human resources for health implications of scaling up for universal access to HIV/AIDS prevention, treatment, and care: Mozambique. Rapid situational analysis” Intrahelath International (2010).
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²¹ *Ibid*

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4

CASE STUDY: THE ROLE OF HIV PREVENTION MESSAGES IN PATIENTS' EXPERIENCES WITH ART IN THE CITY OF MAPUTO, MOZAMBIQUE

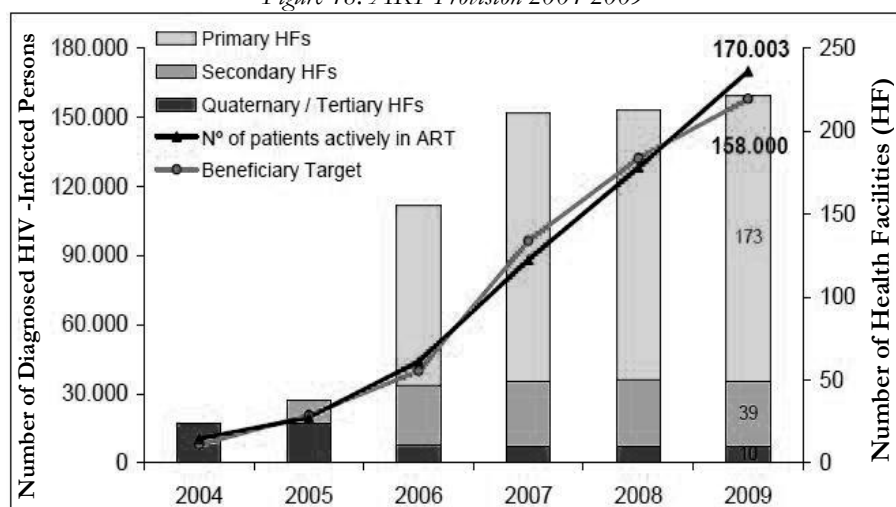
4.1 Introduction to the Case Study

In 2001, with the introduction of Antiretrovirals (ARVs) in Mozambique, the Ministry of Health declared: *“As a consequence of the introduction of therapies using these substances [ARVs], multiple studies have demonstrated their efficacy, drastically reducing patients’ plasma viral loads to undetectable levels, which also brings a great decrease in sexual transmission of the virus [HIV]; in this way, Antiretroviral Therapy is an important contribution in prevention of infections”*.¹

In Mozambique, approximately 1.4 million people are living with HIV/AIDS and roughly 90 thousand of them die of AIDS-related complications annually.² In the city of Maputo prevalence is estimated at 20.7% and just under 20,000 new cases of HIV were diagnosed in 2007 alone, an increase of 15% relative to 2006 (though a portion of the increase may be attributable to the expansion of HIV counseling and testing services).³

In terms of Antiretroviral Treatment (ART), Mozambique continues to make steady progress in expanding its public provision of ART. For example, in 2007, all of the identified newly eligible patients in the city of Maputo (25,123) began to receive ART.⁴ At the national level, as of mid-2011, Mozambique had approximately 220,000 patients on ART⁵.

Figure 18. ART Provision 2004-2009



Source: CNCS, 2010, p. 20

In *Figure 18* we see considerable increases in ART provision with the beginning of decentralization of HIV services, when Primary Health Facilities (Primary HFs) began providing ART beginning in 2006. Until that time, ART had been available only in vertical 'Day Hospitals' dedicated to HIV services (and which fell under the heading of either 'Secondary' or 'Quaternary' Health Facilities). This important progress in ART coverage can, in large part, be attributed to the integration and decentralization of HIV services adopted by the Mozambican Ministry of Health in 2005, with official implementation beginning in 2006 (concurrently with the task shifting strategy discussed in the previous chapter). Recent studies in Mozambique show that the new decentralized system has coincided with a dramatic increase in the absolute and relative number of patients receiving ART, a decrease in the time between HIV testing and commencement of ART and a decrease in the number of patients who disappear or are lost to follow-up.⁶ From the beginning of ART provision in Mozambique in 2003 to the end of 2009, of the 242,854 registered patients who commenced ART for the first time (230,181) or who resumed ART (12,673), 17% abandoned treatment and an additional 8% disappeared or were lost to follow-up.⁷ To put this into perspective, a meta-analysis by Mills et al. (2006) found a pooled adherence (the mean adherence from all studies) estimate of 55% in the North American studies used and a pooled adherence estimate of 77% for the African studies.⁸ This would place Mozambique's 25% of patients who abandon treatment or are lost to follow-up within the normal range for Africa and with much higher levels of adherence than those found in North America. However, though the geographic and distributional coverage of ART services in

Mozambique continues to increase ahead of projections, if ART is to be efficacious, not only for individual treatment, but also for its potential population-level preventative benefits, we must earnestly investigate the experiences of patients on ART to understand how to retain the 25% of patients who abandon treatment or are lost to follow-up (LTF) as well as understand factors that may discourage people from being tested for HIV or commencing treatment. Many studies of ART in the developing world tend to focus on the necessary expansion of the availability of services, highlighting and addressing financial, technical, logistical and clinical issues.⁹ Decentralization in Mozambique has, indeed, helped to address logistical barriers to ART access and adherence, such as distance to health facilities, and in many cases, has eliminated the need for some patients to pay for transport to health facilities in urban settings. The decentralization of, not only patients, but also many laboratory services has shortened wait times between counseling, testing, gauging CD4 levels to determine eligibility for treatment and the commencement of treatment itself.¹⁰ Thanks to the rapid and steady progress in these areas, ART access has indeed increased dramatically in recent years and continues to do so. Now however, it is time to turn our attention as well to some of the sociological aspects of ART within the wider picture of the HIV prevention environment, as ART is a life-long, intensive treatment regimen to which patients must faithfully adhere in order for its individual therapeutic as well as wider preventative benefits to be maximized.

One notable aspect of recent social science-based studies of ART adherence in developing nations is a marked focus on characteristics and behaviors of the patient alone to explain non-adherence, often identifying things like being unmarried, consuming alcohol or having a low level of education as correlates of poor adherence.¹¹ When issues of, for example, the not insignificant effect of stigma on adherence are discussed (such as with infected persons who are afraid to disclose their serostatus to their partners), the concluding recommendation is generally rather vague, stating that efforts to encourage disclosure of serostatus and counsel patients on disclosure are required; isolating the patient and the solution to the problem from the possible source of the stigma.^{12,13} When a social source of stigma is cited, authors invariably refrain from going into detail about either the source of the stigma or the recommendation to address the issue as we can see, for example, in one study that ultimately suggests that what is needed are “changes in the social milieu that make HIV less stigmatized”.¹⁴

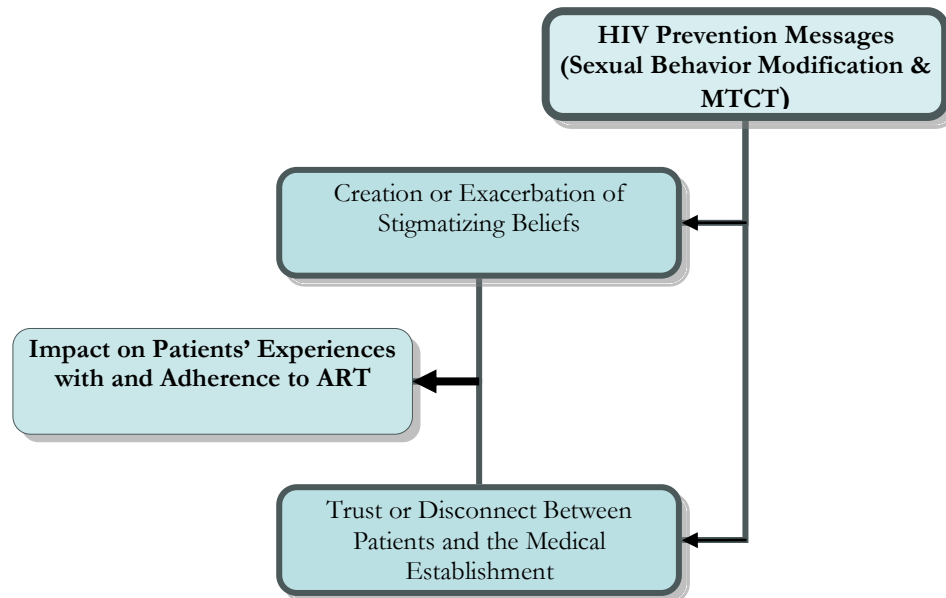
In contrast, one can note that many studies of adherence in more affluent settings focus closely on various aspects of the *relations* between patients and the medical establishment or between patients and providers of information

concerning HIV/AIDS. The dynamics of these relationships between various parties may be a more policy-sensitive area for exploration. Interventions that seek to modify or improve a professional dynamic (as well as modify the information provided within a medical or institutional public health setting) may be more efficacious than attempts to change individual characteristics of patients. Upstream policies also have the potential to pre-emptively combat stigma and fear of disclosure at their possible source.

This study seeks to explore the hypothesis that official HIV prevention messages in Mozambique, with their almost exclusive focus on sexual transmission (and, to a lesser extent, MTCT in the case of pediatric patients), may be a significant source of stigmatizing beliefs, whether these manifest as the internalized stigma of patients themselves or social stigma coming from uninfected (or undiagnosed) persons and clinicians. Several studies conducted in affluent nations which served as a loose basis for this research address issues such as: (1) the effect of the 'deviance' discourse on HIV patients' experiences with medical providers;¹⁵ (2) the importance of the relationship between the patient and the medical provider in adherence;¹⁶ and (3) the importance of trust between patients and providers, particularly in the information and recommendations given by providers.¹⁷

This exploration of the effect of HIV prevention messages on patients' experiences with ART is an area about which, to my knowledge, no research has been done to date and yet, if we wish to understand and harness the preventative externalities of ART, it will be important to understand the effect of HIV prevention messages not only on those who are as yet uninfected, but also on those already living with HIV; in other words, to examine HIV prevention messages in the context of a closed loop, rather than a linear message that exclusively impacts the as yet uninfected population.

Figure 19. Mediation Model of the Effect of HIV Prevention Messages on ART Patients' Experiences



Source: Author's creation

4.2 Objectives

The aim of the study is to explore the possibility that social constructions of the HIV epidemic in Africa and particularly Mozambique, as discussed in Chapter 1, affect patients' experiences with ART and, therefore, the ultimate potential of ART as a prevention strategy. The primary objective is to explore the role of HIV prevention messages in patients' experiences with ART. The secondary objective is to investigate the role of relational dynamics between clinicians and patients on patients' experiences with ART.

4.3 Study Design

Study Design

The study is qualitative and exploratory utilizing semi-structured, in-depth interviews with:

1. Medical providers (physicians, nurses and technicians) who administer ART in the Central Hospital of Maputo (pediatric patients) and the Health Center Malhangalene (adult patients);

2. Caretakers of pediatric patients (under 18 years) receiving ART through the Central Hospital of Maputo and;
3. Non-gestating adult patients receiving ART through the Health Center Malhangalene.

The interviews with medical providers were all conducted by myself in a private examination room at the two medical facilities in question. The interviews with caretakers of pediatric patients were carried out by two members of the research team, one a physician completing 'post-graduate' rotations in the Central Hospital of Maputo and the other in the final year of medical studies at Edoardo Mondlane University at the time of the interviews. Interviews with adult patients were carried out by another member of the research team who was also in his final year of medical studies and by myself. All interviews with patients and caretakers of pediatric patients were carried out in a private examination room at the two medical facilities.

Study questionnaires contained several open-ended questions and patients (or caretakers) and providers were encouraged to speak freely and explain their responses. They were not provided with a list of possible responses to these questions. Interviewers frequently followed-up patients' answers with 'why?' or 'how do you mean?' types of questions to further explore topics. Responses to these questions are characterized as 'spontaneously reported' in the discussion to follow. There were also several 'closed' questions that inquired into self-reported adherence (for the preceding days and weeks) and when non-adherence was reported, interviewers requested further details as to why patients had missed doses and what, if any, self-medicating behaviors they had engaged in (i.e. traditional healers, over-the-counter medicines, etc...). Though this study focuses on sociological aspects of ART, patients were asked about any difficulties they might have in adhering due to logistical or clinical issues (i.e.: unable to travel to health center/hospital; side effects of ARVs; stock-out of ARVs at the pharmacy; need to share ARVs with another person) in order to better understand the relative importance for this population of the sociological aspects in which we are interested versus logistical or clinical issues.

4.4 Study Population

Population

The study population included twenty-six (26) caretakers of pediatric patients aged 3-12 who were receiving ART through the Pediatric Day Hospital of the

Central Hospital of Maputo during the interview period and twenty-two (22) non-gestating adults who were receiving ART through the Health Center Malhangalene. Fourteen (14) medical providers (physicians, nurses and technicians) who were working directly in the provision of ART in both participating health facilities were interviewed. The selection of patients was pragmatic and opportunistic, drawn from patients who presented at the participating health facilities for a clinical check-up and/or to pick up their refill prescription of ARVs during the interview period and who consented to participate in the study. The selection of providers was also opportunistic, based upon clinical staff who were working in the health facilities during the interview period and who consented to participate. Medical providers and caretakers of pediatric patients were interviewed from March through July 2011 while adult patients were interviewed in March and September 2011.

Adult patient characteristics from the Health Center Malhangalene can be seen in *Appendix 2, Table 1*. There were 2,619 adult patients enrolled in ART at Malhangalene as of July 2011, 68% of whom were female (1,793). Of the 22 adult patients interviewed for this study, 77% are female. Four adult men declined to participate after having the study explained to them, citing fears that the audio recording of the interview would be broadcast on the radio. No women declined to participate. The median age of adult ART recipients at the health center as of July 2011 was 35, while the median age of the adult interviewees is 35.5 (the median age of adults in Maputo City in general was 27.5 according to the 2009 DHS). More detailed data on all adult ART recipients at the health center (ie: level of education, profession, etc...) are not available. The median number of years of schooling for Maputo City in the 2009 DHS is 6 years while the adult patients interviewed here had a median of 8.5 years of schooling. 82% of adult patients interviewed identified as Protestant/Zion/Pentecostal and 9% as Catholic and Muslim (each) compared to 48% Protestant/Zion/Pentecostal, 29% Catholic and 6% Muslim in the 2009 DHS for Maputo City. Again in Maputo City, 65% of respondents in the 2009 DHS reported that the closest ART-providing facility to their home was less than 30 minutes away and an additional 26% reported that the facility was between 30-60 minutes from their home.

During the study period, in order to better manage the vast increase in patients as a result of decentralization, the Health Center Malhangalene was beginning a series of initiatives specifically aimed at patients on ART such as the ‘*Community ART Group*’ (CAG) program in partnership with Doctors Without

Borders¹⁹ and a scale-up of the 'fluxo rápido' (rapid flow) program which allows clinically-stable and adherent patients on ART for at least 6 months to present for a clinical consultation only once every six months rather than every month (though they still must pick up monthly medication refills at the pharmacy). No patients participating in the CAG were interviewed so as not to interfere with the monitoring actions of Doctors Without Borders while three patients who participate in the 'fluxo rápido' program were interviewed.

Pediatric patient characteristics (as well as their caretakers') can be found in *Appendix 2, Table 2*. As of September 2011, there were 899 pediatric patients enrolled in ART at the Maputo Central Hospital, 51% of whom were female while 46% of the pediatric patients whose caretakers were interviewed for this study are female. The median number of years of schooling of the caretakers is 6.5 years, slightly higher than the Maputo City median of 6 years. 65% of caretakers identified as Protestant or Evangelical and 23% as Catholic.

It is important to note that the Pediatric Day Hospital of the Central Hospital of Maputo was in the midst of the process of down-referring pediatric patients to their local health centers to continue treatment (the final phase of Mozambique's decentralization) during the interview period and so the interviews with these caretakers will have been just before they were referred to a health center or just before they were permanently assigned to the outpatient pediatric unit of the Central Hospital for the patient's ongoing treatment (if they reside in the geographical jurisdiction of the Central Hospital, they will remain there).

In terms of the representativeness of the clinicians interviewed for this study, all of the interviewees were female. Though detailed data on nurses and technicians are not available for Mozambique, looking at the data on physicians, we see that approximately 67% of the physicians in Mozambique's southern provinces (which includes the province of Maputo) are, in fact, female while, in Maputo City, a full 83% of physicians are female.¹⁸ There was only one male clinician working in the Health Center Malhangalene (a senior nurse) and he does not work directly with HIV patients on ART. At the Day Hospital of the Maputo Central Hospital (pediatrics), only one male pediatrician was identified

¹⁹ The Community ART Group (CAG) project was piloted by Doctors Without Borders in Tete Province beginning in 2008 and arrived at the Health Center Malhangalene in 2011. The program facilitates groups of 6-8 stable patients on ART from the same neighborhood who send one member of the group to the health center monthly to report on adherence for all members and pick up refill prescriptions for all members so that each member goes to the health center approximately once every six months.

during the interview period by our research team and he was not available for an interview. All of the nurses at this facility were female. Clinical provider characteristics can be found in *Appendix 2, Table 3*.

4.5 Ethical Considerations

The study protocol was approved by the Mozambican National Bioethics Committee and the Mozambican Ministry of Health as well as the Maputo City Health Directorate, the Central Hospital of Maputo and the Health Center Malhangalene. Participating hospital and health center clinical staff gave written informed consent. Participating patients gave written informed consent after being read aloud the study consent form. All health provider and patient data are confidential and have been anonymized for inclusion here. All interviews were digitally audio recorded, transcribed verbatim (in Portuguese) shortly after and the voice recordings destroyed 120 days from the date of the interview, per the ethical protocol approved for the study.

4.6 Limitations of the Study

It would be impossible to discuss patients' experiences with ART without pointing out one of the main limitations of this study which is that only patients still enrolled in treatment and with a certain basic level of adherence (who are presenting to the health center for a clinical checkup or medication refill) were interviewed. However, while it may be the case that patients who have abandoned treatment or have been LTF have a completely different set of challenges which determine their non-compliance with treatment, it would seem more likely that the adherent patients have faced or are aware of at least some of the same issues. In this spirit, the challenges and dynamics identified by adherent patients will be discussed. These topics will also be explored from the perspective of the clinicians interviewed who often have valuable insight on both groups of patients that, when combined with patients' narratives, can help us to construct a more complete picture of the dynamics of patients' experiences with ART.

As the study was conducted at only two health facilities in the central area of Maputo, findings cannot be generalized to peri-urban or rural areas where logistical issues may be more likely to affect abandonment and loss to follow-up as well as difficulties in presenting for initial HIV testing. The selection of patients and clinicians was not random nor is the sample large enough to be representative of the participating health facilities and, as such, the data collected

may be used only as an in-depth snapshot of the detailed experiences of some patients and clinicians in order to understand areas that merit further, large-scale study and exploration, particularly in similar urban environments where progress in overcoming logistical hurdles is relatively advanced.

The study also includes a strong sex bias in terms of the caretakers of pediatric patients that were interviewed (all female). Pediatricians mentioned, anecdotally, that they very rarely see fathers or male caretakers of their patients and, when they do, they are virtually always together with the mother of the patient.

4.7 Health Center Malhangalene- Adult ART Patients

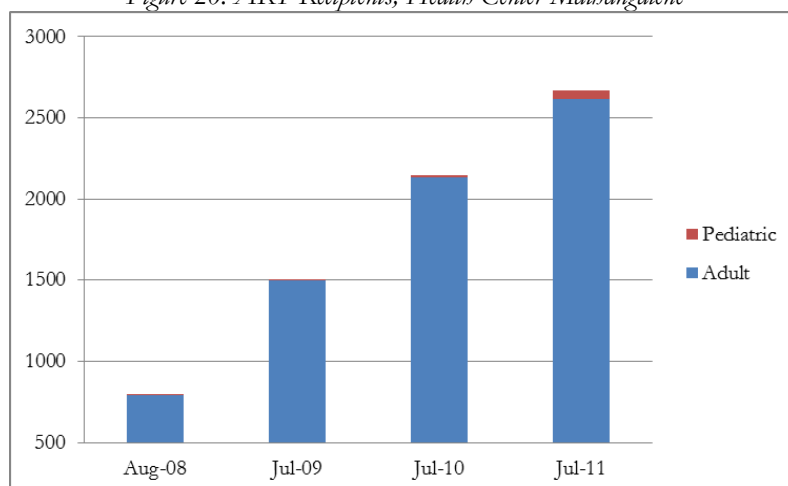
The Health Center Malhangalene is located in the north-central area of downtown Maputo City and has been receiving HIV patient transfers since 2008. It is an outpatient facility where patients are seen in the mornings from approximately 7:30 am until 1 pm (though clinicians remain in the health center until approximately 4-5 pm). Neighborhoods where participating patients live are highlighted on the map (Map 1) in orange and the health center is marked with a large red and white cross. Patients in the outlying neighborhoods highlighted in orange are seen at Malhangalene by request. Some work or have family near Malhangalene while others travel to Malhangalene to avoid seeing neighbors at the health center nearer their home. The national decentralization process has been carried out in phases so that Malhangalene first received adult patient transfers from the Day Hospital of the Central Hospital of Maputo in 2008, the Day Hospital Primeiro de Maio in 2009 and the Day Hospital of the General Hospital of Mavalane in 2010. Adult patients have also been tested and begun treatment at Malhangalene since 2008. Only in late 2010/early 2011 did pediatric patients begin to be officially transferred to Malhangalene and other health centers in Maputo. See *Figure 20* and *Table 7*. The pediatric ART patients listed for earlier years in *Table 7* were seropositive children of adult patients receiving treatment at Malhangalene who requested that their children be able to receive treatment at the same facility to facilitate logistical matters (simultaneous clinical checkups, medication pickup, etc...).

Table 7. ART Recipients, Health Center Malhangalene

Year	Adult	Pediatric	Total	% Increase Adult Patients	% Increase Pediatric Patients	% Increase (Total)
August 2008	794	7	801	--	--	--
July 2009	1499	8	1507	63.5	13.4	63.2
July 2010	2135	14	2149	35.4	56.0	35.5
July 2011	2619	53	2672	20.4	133.1	21.8

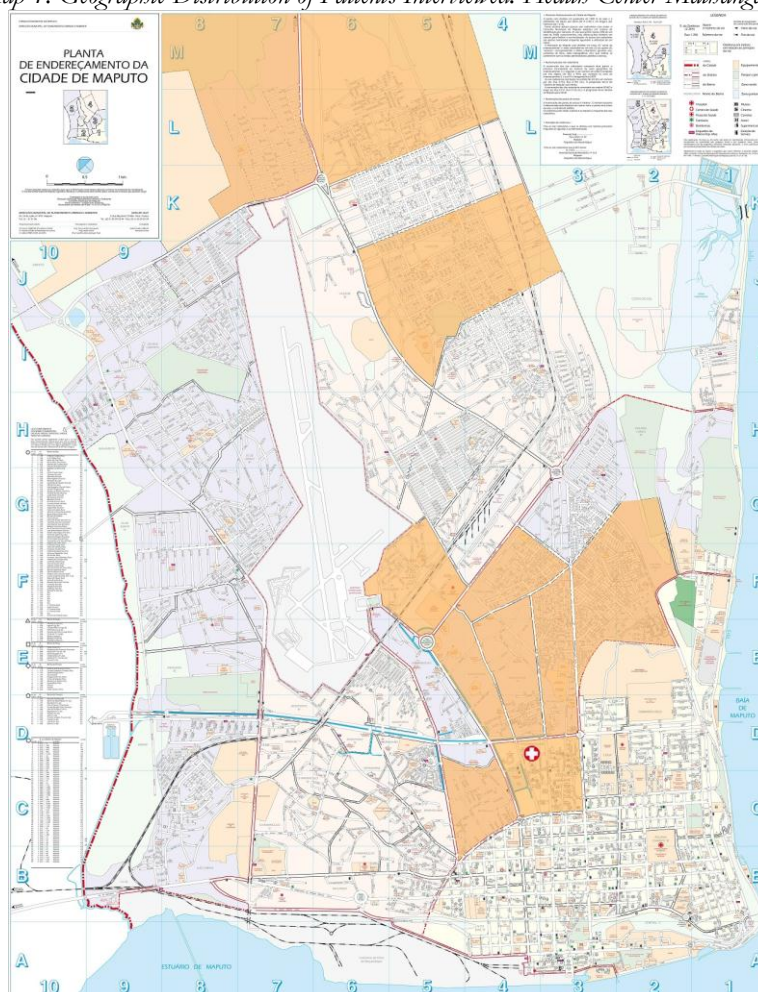
Source: Mozambican Ministry of Health, National ART Database¹⁹

Figure 20. ART Recipients, Health Center Malhangalene



Source: Mozambican Ministry of Health, National ART Database²⁰

Map 1. Geographic Distribution of Patients Interviewed: Health Center Malhangalene



4.7.1 *Human Resources*

In line with Ministry of Health guidelines on decentralization, task-shifting and human resource management as discussed in the previous chapter, Malhangalene assigns adult ART patients to medical technicians who are responsible for chronic disease management (diabetes, hypertension, Kaposi sarcoma and HIV) and are authorized to prescribe ARVs. This is, in part, so that technicians will be prepared for the specific challenges of attending to patients on lifelong treatments, but it is also a strategy to decrease stigma for HIV-positive patients. However, in practice, the director of Malhangalene reports that on any given day, 90% of patients seen at the health center are HIV-positive and though chronic illnesses such as diabetes and hypertension seem to be on the rise, these patients still make up a very small proportion of the patients seen at the center. The director of the health center is also the only physician on staff²⁰. In addition to the administrative duties of the health center director and clinical duties, this physician, at the time of the interviews, was also assigned the role of ‘District Director’ which entails oversight and reporting for five ‘areas’ in the medical district (Malhangalene, Alto Maé, Porto, Maxaquene and Polana Cimento). Three technicians attend to (non-pregnant) adult ART patients, referring complicated cases to the head nurse and/or physician when necessary, based on national clinical guidelines and personal judgment. Two of these technicians were interviewed for this study while the third was temporarily absent from the health facility during the interview period. As many women are diagnosed with HIV during pregnancy (testing is highly encouraged during pre-natal visits), three mother and child health nurses who work specifically with HIV-positive patients in the maternity department were interviewed to better understand the early treatment period for many female ART patients at the center.

4.7.2 *What effect do sources of HIV/AIDS information and their perceived reliability have on patients’ experiences with ART?*

Much focus in the HIV/AIDS literature is placed on ‘knowledge’; what people know. However, relatively little is mentioned in terms of the specific sources of respondents’ knowledge or the perceived reliability of the information received from different sources, with a few notable exceptions in studies conducted in developed nations^{21,22,23}. This study takes advantage of the potential depth of

²⁰ Through a partnership with Doctors Without Borders (Médicos Sem Fronteiras), the health center is assigned a visiting expatriate physician who assists with clinical visits two days per week and brainstorms weekly on complicated cases with the senior clinical staff.

qualitative interviews to explore patients' knowledge about HIV in conjunction with their sources of information and the sources which they consider more or less reliable and why. While the aforementioned studies on the reliability of information sources have focused particularly on sexual behavior change in relation to HIV prevention, this study instead explores the possible impact of reliability of information on the internalization of HIV prevention messages and their effect on patients' experiences with ART. As discussed in Chapter 1, the social construction of the HIV epidemic is powerful, if surreptitious, and it will be important to understand possible repercussions of sexual behavior-based prevention campaigns on persons living with HIV and receiving treatment as well as on clinicians' beliefs and communications about HIV.

Table 8. HIV/AIDS Information: Adult Patients, Health Center Malhangalene

	N	%
Adult Patients	22	
Sources of HIV/AIDS Information (non-exclusive)	18	81.8
Television	15	68.2
Radio	13	59.1
Friends/Family	11	50.0
Health Facility and Workers/Health Lectures ('Palestras')	7	31.8
	4	18.2
'On the Street'	3	13.6
Community Events	3	13.6
Newspapers/Magazines	2	9.1
HIV Activists	2	9.1
School	1	4.5
Church	2	9.1
NGO's	1	4.5
Reliability of Sources of HIV/AIDS Information (non-exclusive)		
<u>Reliable</u>		
Television	15	68.2
Health Facility & Workers/Health Lectures	11	50.0
	7	31.8
Radio	2	9.1
Newspaper	2	9.1
Church	1	4.5
NGO's		
<u>Unreliable</u>	18	81.8
'On the Street'/'person-to-person'	1	4.5

Radio	1	4.5
Church		
Spontaneous Reporting of HIV/AIDS		
Transmission Routes (non-exclusive)		
Sexual Relations	22	100
Blood-borne*	12	54.5
Vertical (Mother-to-Child)	5	22.7
“Tuberculosis” (as causing HIV infection)	3	13.6
Insects, Toothbrush, Food	1(each)	4.5 (each)
How Patient Believes (S)he May Have Become Infected (non-exclusive)		
Sexual Relations	12	54.5
Blood-borne*	4	18.2
‘Don’t Know’	10	45.5
How Patients Report That Their Clinician(s) Believes They Became Infected		
Sexual Relations (unequivocally)	10	45.5
‘Don’t Know/Was Never Discussed’	7	31.8
‘Don’t Know...Probably Sexual Relations’	3	13.6
‘Don’t Know...Sex or Blades’	2	9.1
Patient Reported: Greatest Challenges to Seeking and Adhering to ART (non-exclusive)		
Shame/Fear/Refusal to Face Situation	10	45.5
Lack of Sufficient Food	7	32.0
Discipline/Motivation/‘Self-denial’ (sex, alcohol)	5	22.7
Logistical Difficulties§	3	13.6

* Injections, syringes, needles, cutting instruments, tattoos/scarification, nail clippers, contaminated blood from wounds of infected person, unsterilized materials in healthcare settings

§ Frequency of appointments, distance to health center, waiting time at health center, difficulty remembering to take pills twice daily, missing work once-per-month to attend appointment

As we see in *Table 8*, patients’ reported sources of HIV information are primarily: television (82%), radio (68%), friends/family (59%), health facilities and workers/health lectures (50%) and ‘on the street’ (38%). This is remarkably in line with what we find in the 2009 Demographic and Health Survey for the adult population of Maputo City.²¹ However, patients were also asked to identify which of the sources of information that they consider most and least reliable of those that they had named. The main sources of reliable information identified

²¹ In Mozambique’s 2009 DHS, the following sources of HIV/AIDS information were reported by Maputo City respondents: Television (83%), Radio (69%), Friends/Family (46%), Health Lectures/Health Workers (49%)

are: television (68%), health facilities and workers/health lectures (50%) and radio (32%). 'On the street' or otherwise 'person-to-person' (including friends/family members) was overwhelmingly identified as the least reliable source of information (82% of total respondents, 100% of respondents who identified 'on the street' or 'friends/family' as a source of information). When asked why the above-mentioned sources of information are the most or least reliable, responses mainly centered around the idea of seeing and/or hearing first-hand the 'reality' of HIV on the one hand (reliable) and the existence of widespread denial, rumors and myths on the other (unreliable) as in the examples below:

"I think they [television and radio] show reality...especially television. But as far as the rumors, 'in the neighborhoods', [they're not reliable] because there are a lot of myths out there. Certain people lie and others..." [35-year-old, female respondent- #108, on ART for 10 months]

"Television [is reliable] because on TV, they speak directly. They don't hide that this disease exists. It could be a friend or acquaintance of yours [that talks about HIV], and you can't trust what they say as long as the person doesn't have HIV. Or, whether or not they have it, you're not going to believe in what they say because many people talk a lot about this topic..." [29-year-old, male respondent #101, on ART for 3 years]

"Here in the hospital, yes [the information is reliable], because here we sometimes have lectures on HIV...but out there 'in the neighborhood', from friends, I still haven't heard anyone tell the truth about this disease [...]I think that people are afraid to tell the truth...we're afraid to speak the truth, even if we know the truth....we're afraid to speak the truth and face the truth". [37-year-old, female respondent #108B, on ART for 6+ years]

"From person to person [is unreliable]...like when you meet up with someone on the bus, it's possible that they're giving you inexact information. But if it were a person, for example a health technician, I think that would be an appropriate person to give you precise information." [36-year-old, male respondent #080, on ART for 5 years]

Clinicians' responses in regards to the sources of information that they believe patients find reliable largely matched patients' own responses: television, health lectures ("palestras") and, to a lesser extent, radio. However, some clinicians also

reported that they believe that information from friends, family, ‘people in the neighborhood’ and traditional healers is also reliable for patients, and often more reliable than information from official sources. This contrasts with the patients’ own reports of ‘other people’ as largely unreliable. One possible explanation for this disconnect can be seen in the response of one clinician who spoke of many patients’ initial unwillingness to believe that they are HIV-positive so that, before accepting their serostatus and ‘delivering themselves’ fully over to the medical system, they are more heavily influenced by non-medical people in their lives and less influenced by the medical establishment; a phenomena which this clinician believes reverses once the patient has accepted his/her serostatus. This idea of ‘delivering oneself over’ and fully trusting the medical system is one that echoes through many of the interviews – both patient and clinician – and will be discussed more in the section dealing with respondents’ impressions of HIV prevention messages either before and after HIV diagnosis (for patients) or before and after working with HIV-positive patients (clinicians). As patients were interviewed only after being enrolled in and adherent to ART, it could be that their identification of reliable versus unreliable sources of information had already undergone this transformation as is corroborated by many patients’ narratives regarding their inability or unwillingness to initially believe medical personnel regarding their HIV diagnosis.

“Well, they receive more information from their community leaders, their churches... They trust these people more [than they trust health professionals].” [physician respondent #812. Working with HIV patients for 2 years]

“They trust a lot in information from outside [of formal healthcare settings]...So, for us here, it becomes difficult. Some [patients] go so far as to almost hit us, saying ‘hey! You’re lying! You’re lying! Get real nurse- this is not true!’. So to me, it seems like the information from their communities is stronger, from traditional healers for example. They believe more in traditional healers than they do nurses. It seems like their trust in the community is stronger.” [nurse respondent #808. Working with HIV patients for 9 years]

“I think that the information gets across [to patients] best through television. Many times, with many patients, when they’re still not very informed on the subject [of HIV], they doubt everything that we [health professionals] tell them. Even here in the health center, we’re totally trustworthy, but, at some point, after finding out their HIV test result, they say that the result isn’t trustworthy. This just shows that they’re not yet very informed about the topic.”

[technician respondent #711. Working with HIV patients for 3 years]

The sources of information identified by patients as reliable and unreliable will be a recurrent theme in the sections that follow as self-stigmatization, cognitive dissonance, knowledge and beliefs about modes of transmission and the preventative benefits of ART are discussed. The idea, expressed by both patients and clinicians, of delivering oneself over to the official public health infrastructure in order to successfully adhere to ART becomes particularly important, as we will see, when matters of incomplete information being communicated to patients are discussed.

4.7.3 Do incomplete discussions about modes of transmission contribute to self-stigmatization and cognitive dissonance between patients' 'knowledge' and clinicians' beliefs about patients?

When we consider the importance of sources of HIV information on the perceived reliability of information we can see the central role of official sources (including health workers and health facility communications) in ART patients' ideas about HIV. Though, as mentioned, it may take some time for patients to fully 'deliver themselves over' to the formal health system and prioritize the information given there, it would seem that this 'surrender' may be quite important in order for patients to adhere to ART. As we will see in the following sections, patients often report learning certain, often correct, information from unofficial sources and not receiving this information from official sources. Once patients are enfolded into the health system (beginning with counseling and HIV testing), the pressure for them to accept the extant social construction of HIV which is ubiquitous in prevention messages, as discussed in Chapter 1, becomes very strong. This may lead to high levels of cognitive dissonance between what patients believe to be true of HIV from unofficial sources and possibly personal experience, and what they are being told (or not told) by health workers and official HIV prevention messages.

In terms of the discourse surrounding modes of transmission, looking at *Table 8*, we can note that all patients spontaneously report sexual relations as a mode of transmission of HIV when asked how people can acquire HIV and over 50% of patients spontaneously report knowledge of blood-borne modes of

transmission.²² However, when these patients who reported knowledge of blood-borne transmission were asked about the source of that particular information, they stated that they had heard it ‘on the street’ (or other similar ‘person-to-person’ sources) and, crucially, not from health workers or HIV prevention campaigns (on TV, radio, etc...). So, though they indeed have factual information that HIV is a blood-borne infection that can be transmitted through unsafe injections, cutting instruments, transfusions, etc... they attribute this information to sources which they already identified as being unreliable. When patients were further asked to reflect on their beliefs about 1) how they may have become infected and, 2) how their clinician(s) believes they may have become infected, not only do we find some disconnect, but we also find that many patients report that no clinician has ever discussed with them how they may have become infected.

[in response to question on how patient believes she may have become infected] ***“It wasn’t through sex. It was...how can I say this? I believe that I was infected with HIV through a treatment I received in the hospital”*** [when asked how she thinks her clinician believes she became infected and why] ***“Through sex [laughs]. Since many people are infected through sex... but it’s not always that way.”*** [29-year-old, female respondent #900, on ART for 22 months]

Here we see a marked dissonance between this patient’s beliefs about how she may have become infected with HIV and the way she believes her clinicians think she was infected. When asked the open-ended question of how she believes she may have become infected, the patient begins her response with a nod to the perennial assumption that, as an adult, she was infected through sex, and only after this pre-emptive defense, does she identify what she believes to be the source of her own infection (through a hospital treatment). Then when asked how she believes that her clinicians think she might have been infected, she immediately identifies sex and again, defends her point of view that it is not always that way. It is disturbing that this patient’s very legitimate concerns that she may have been infected in the hospital seem to be disregarded by clinicians. Though this patient has continued with ART, it is not difficult to imagine that others, in a similar situation of dissonance between their own beliefs about how they may have become infected and the health establishment’s stated belief that

²² In the 2009 DHS, 95% and 98% (respectively) of Maputo City respondents report that HIV can be transmitted through vaginal sex and sharing needles or blades with an infected person, however, this was in response to closed questions, rather than spontaneously reported.

virtually all adults are infected due to their sexual behavior, could feel that they had to choose between the official establishment (which includes ART) and what they strongly believe to be correct (that they were infected through a non-sexual route).

"...when it started, I heard in the health lectures that a person becomes infected through sex. Now, they say 'out there' [outside of the health facility], that it may not just be sex... it could be blades, a person who has a wound and you can become contaminated with that blood, blah, blah, blah." [49-year-old, female respondent #110, on ART for 6 months]

[modes of transmission] *"...through sexual relations and contamination through blades, needles. When a person is wounded, and you also have a wound/cut, when it's bleeding, you can be contaminated..."* [in response to how she believes she may have become infected] *I don't know...I don't know...* [in response to how clinicians believe she became infected] *Sexual relations. But my husband doesn't have [HIV]...but they only talk about sex."* [39-year-old, female respondent #100, on ART for 10 months]

In this patient's comments, we can see that she also identifies blood-borne routes of transmission and states that though her husband doesn't have HIV, her clinicians believe that she acquired HIV sexually (as they 'only talk about sex').

"Here, they say you get [HIV] when you have sex. Out there [on the street], they say through blades, needles, and when people have wounds and they touch another person, that blood is contaminated..." [in response to how she believes she may have become infected] *I don't know how I got it [laughs]...I don't 'play around' [have sex outside of the marriage], have lovers/boyfriends, and neither does [my husband]. We're at home together. He always says how people can't play around, that when they do, they pass HIV to other people...That's why we don't play around with other people-not him, not me. We're at home together.* [in response to how clinicians believe she became infected] *I don't know...through sex, through blades...I don't know. They never really said."* [38-year-old, female respondent #908, on ART for 2 years]

[in response to how she believes she may have become infected] *"I don't know...or through food...or...I don't know, it's just me and my husband, alone at home..."* [in response to how clinicians believe she became infected] *I just don't know."* [52-year-old, female respondent #210, on ART for 14 months]

Within these patients' responses, we find a strong dichotomy between modes of transmission communicated to them through official sources (sexual relations) and what they've heard 'on the street'. The blood-borne modes of transmission that they report are, indeed, correct, however, as they already identified this source of information as being unreliable, holding onto these beliefs about blood-borne transmission could create cognitive dissonance between a patient's beliefs and the official message that they are virtually required to internalize in order to adhere to ART.

Respondent #210's response is interesting in that she is an older woman (52 years old) who was diagnosed and began ART only 14 months before the interview. Her only idea for how she may have become infected was through food. Though she did not explicitly express doubt that she may have been infected sexually, she does qualify her uncertainty about how she may have been infected by stating that she doesn't know as she and her husband are always at home together, alone, a kind of refutation of the implicit idea that she may have been infected sexually (which would also imply infidelity by at least one partner). This patient and many others reported that they don't know how their clinicians think they may have become infected; that it had never been discussed.

Simply the absence of discussion on this topic can cause dissonance as the 'default' message of HIV transmission from official sources (including the healthcare system), is that it is almost-exclusively through sexual transmission. The lack of discussion between clinicians and patients on modes of transmission or, when the topic comes up, the focus on sexual transmission, would lead one to believe that clinicians, perhaps, do not understand or accept blood-borne transmission. However, this is not confirmed by the clinicians' responses below. All clinicians spontaneously reported knowledge of blood-borne transmission routes, but here again we find a disconnect, this time between 1) the various modes of transmission identified by clinicians and the modes they discuss with patients and, 2) the official messages on transmission routes to which clinicians are also exposed versus what they see in their daily experience with patients.

[clinician in response to question about the most common mode of transmission of HIV for her patients] *"It's not easy to define the mode of transmission in most patients because, lately, **we're seeing a lot of cases of discordant people, discordant couples for example. So, before they always said that it was through sexual relations, but something, at least for me, is telling me that it's not so much through sexual relations.** Now, as to what the principal mode of*

transmission is...I don't know what to tell you." [nurse respondent #106. Working with HIV patients for 2 years]

[clinician in response to question about the most common mode of transmission of HIV for her patients] "***Sexual relations.***" [in response to question regarding other modes of transmission and if these are discussed with patients] "***...through needles, piercing objects, cutting tools, blood transfusions... no, no, it's not our custom to discuss these [transmission] routes with patients***" [nurse respondent #808. Working with HIV patients for 9 years]

[clinician in response to question about the most common mode of transmission of HIV for her patients] "***The most publicized way, that everyone confirms, is through sexual transmission. Besides that, there are those who may have gotten [HIV] through, for example, transfusions—people who suffer accidents—also through cuts, using the same blade on different individuals. In the hospitals, through injections, needles, if we don't always use disposable materials, we can transmit HIV...Ever since [HIV] became widely spread, they've limited the use of non-disposable materials, though, really, we should be using all disposable materials to decrease even more the probability of transmission through needles. But still, it's a way that a person can become infected. But we don't talk about that.***" [technician respondent #711. Working with HIV patients for 3 years]

"I think for many adults, it's through unprotected sexual relations. [in response to question regarding other modes of transmission] ***... cutting materials, blades, needles, in the hospitals, those that do traditional medical treatments, those that get tattoos [scarification] – it could be with non-disposable materials...***" [technician respondent #605. Working with HIV patients for 2 years]

All of the clinicians interviewed did in fact, identify blood-borne transmission routes. Some (such as respondent #106) explicitly identified their own cognitive dissonance with the official message of predominantly sexual transmission (based on day-to-day clinical experience) after also identifying blood-borne modes of transmission. Others clearly state their belief that almost all adult patients are infected through sex and identify blood-borne routes as rare or negligible. It is significant that these clinicians also specifically stated that they do not discuss these non-sexual modes of transmission with patients. These communications between clinicians and patients regarding modes of transmission may be seen by some as superfluous, in other words: 'Who cares how these patients were infected? They are already infected and we should just move forward with

treatment.’. However, this type of reasoning views HIV prevention as a linear phenomenon where prevention messages (including discussion of modes of transmission) are for uninfected people only and where those who are already infected are those that failed to heed the warnings, and so contracted HIV. If HIV prevention messages provided the general public with information on how to protect themselves from all modes of transmission of HIV, then perhaps this more linear model would be practicable. However, the social construction of the HIV epidemic often ‘monsterizes’ infected adults as discussed in Chapter 1, and this monsterization is built upon the exclusive focus on supposedly deviant sexual behavior as the exclusive driver of Mozambique’s HIV epidemic. This makes it particularly important that we consider the possibility of sexually-focused prevention messages creating dissonance between patients and the formal healthcare system (and to some extent, between some clinicians and the healthcare system) which continues to provide only partial information in the area of modes of transmission.

4.7.4 How are shame and fear propagated by prevention messages and what effect does this have on patients’ experiences with ART?

Though there is much discussion of ‘stigma’ in the HIV/AIDS literature, researchers have little to say in terms of possible institutional sources of stigma in sub-Saharan Africa’s HIV epidemics. Numerous studies, including a recent one in Mozambique, have demonstrated the important role of stigma (as measured by patients’ fear of disclosure, for example) in accessing and adhering to treatment.^{24,25,26} However, to the extent that the sexual behavior causal story of HIV in SSA has largely remained unchallenged, so has the popular idea that the root of stigma is simply an unfortunate collateral effect of an incurable and potentially lethal ‘sexually transmitted’ disease. If, however, one questions the social construction of HIV as an almost-exclusively sexually transmitted disease, this would then imply that the root of stigma in the case of HIV/AIDS in SSA is not necessarily the (scientific) nature of the disease itself, but may rather stem from the social construction of the disease epidemic. As discussed in Chapter 1, HIV is a sexually *transmissible* infection (with modes of transmission including, but not limited to, sex), but in official HIV prevention messages in Mozambique, has been constructed as an almost-exclusively sexually transmitted disease. Also, considering that patients themselves identify incorrect modes of transmission of HIV (i.e.: mosquitos, tuberculosis, food, etc...), and uninfected people’s fear of infection through non-sexual routes is cited in some studies of social stigma²⁷, it must also be recognized that only providing partial information on modes of transmission may feed into stigma in this way as well. A full 20% of Maputo City

adults in the 2009 DHS reported their belief (when prompted by a closed question) that HIV can be transmitted through mosquito bites and an additional 6% were not sure.²⁸ Similarly, close to 9% reported their belief (when prompted) that HIV can be transmitted through sharing a cigarette with an infected person and an additional 11% were not sure.²⁹ If people are only provided with partial information through official sources (i.e. sexual transmission), but their own experience shows them people who are unlikely to have been infected sexually (including, in some cases, themselves), then it logically follows that they would continue to look for alternative explanations; hence, suspicions of transmission through things like saliva (sharing a cigarette) or other bogus sources which leads to increased social stigmatization of HIV-infected persons.

Many of the adult patients interviewed for this study talk of shame, blame and fear of judgment, and several provided in-depth perspectives on these phenomena. An examination of patients' narratives together with clinicians' comments might give us some further insight into how past and current HIV prevention messages focused on sexual behavior may be feeding into deeply-internalized stigma which can affect patients' experiences with ART.

"Before [my husband] knew that he was infected, he would tell me 'if it's with you that this disease begins, I'm going to send you away' [...] That's why I hesitated [to get tested]. [...] What did he expect? That if this disease had begun with me, here [in Mozambique], he would blame me and say that it was ME that brought this disease because it's me who hooks up with men here? When, really, it was HIM who started the disease with this other woman [in South Africa]. Well...God helped me. Because this disease didn't start with me. It started with him." [49-year-old, female respondent #110, on ART for 6 months]

In the above commentary, the patient's fear that she could be diagnosed with HIV before her husband was diagnosed (and consequently be thrown out of her home) implicitly draws on the idea that the only way that either one of them could have become infected is through sexual relations outside of the marriage. For this couple, being tested for HIV became akin to a game of 'chicken' with each partner distrusting the other and fearing that an HIV diagnosis (particularly on the part of the woman) would be the equivalent of admitting to infidelity and would be grounds to end the marriage (throwing the woman out of their home). This patient, in fact, waited not only for her husband to admit to being diagnosed with HIV, but for his death (from AIDS) before she herself would be tested, though she reported that she was also quite sick by the time she was tested.

Clinicians reportedly expressed exasperation that she had put off being tested once they had confirmed that her husband had had HIV, reportedly saying to her: “And why did you wait to come take the test? You were waiting to die?” It is clear in this example how prevention messages that focus exclusively on sexual transmission of HIV can help to create deep mistrust and stigma between couples and seriously impact the willingness of either partner to be tested and begin treatment. Considering the importance of early treatment to the potential of using ART as prevention (as discussed in Chapter 2), this dynamic is worrying. When HIV is characterized as a disease stemming from sexual deviance and infidelity, the consequences in terms of stigma require attention. In the following narratives we will see how HIV prevention messages can contribute to fear of disclosure and the potentially lethal consequences that may follow:

*“[...] there are those who take the [HIV] test and say ‘ah! These nurses are lying!’. **The person is afraid to tell her husband: ‘I have [HIV]’...until the moment arrives to give birth to her baby...the baby dies, as happened to me one time.** [...] I only went to register for pre-natal care when I was 8 months pregnant. I, without knowing, said ‘ah, okay’ [to be tested for HIV]. When I went and took the test they told me I was HIV-positive. I said ‘ah! They’re lying! I don’t accept it! This means nothing- all this that these nurses are saying!’. I didn’t do anything... on the day I gave birth, I went to the hospital [in Maputo], then went home. I never did any treatment, I didn’t do anything, no medications, no nothing. I went home to stay with my baby. **The baby got sick...she died when she was 3 months old.** When I took her to be admitted to the hospital, they came in to ask me [about HIV]. I was afraid to tell them that I had taken the test. I went to take back my baby and they said ‘You didn’t take the test! You see now? The baby is sick’. But I didn’t take any medication during pregnancy...This is how my baby died at 3 months old, here at the hospital in Maputo. They told me it was [from AIDS]. [33-year-old, female respondent #100, on ART 10 months]*

[clinician in relation to a female patient] *“[I asked her] ‘Why don’t you do the treatment like you should? To be able to feel better?’ **She wouldn’t accept it, said that her husband couldn’t know.** So, okay, she decided to become pregnant. [...] We prescribed AZT and she picked it up but wouldn’t take the medicine. There you go. The day of the baby’s birth arrived. Her husband didn’t know any of this. She gave birth. The baby was well for only 2 months. **After that she [the baby] was getting sicker and sicker and after 3 months... after three months the baby went away [died]... When I asked if she [the mother] took her medications [AZT] she said ‘eh no. I was afraid.’ The baby died and she was unable to tell her husband- her first baby died at 3 months old! In the end, she discovered that her husband had already***

*been on ART for 3 years at [another hospital]. But he felt bad in the end too- **he was afraid to tell her and she was afraid to tell him and the baby died.***" [nurse, respondent #808. Working with HIV patients for 9 years]

The two narratives above tell the story of HIV-positive pregnant women who felt such shame and fear to admit their HIV serostatus (either to themselves or their partners) that they allowed their newborn babies to die of AIDS rather than face the perceived shame of being seropositive. In the clinician's narrative (respondent #808), we see that this patient's husband was also keeping his serostatus and the fact that he had already been on treatment for 3 years, a secret. No doubt both partners were aware that they could infect the other (and perhaps the baby) if they did not disclose their serostatus and take protective measures, however, both remained silent (and the woman did not accept treatment, so worried was she about being 'caught'), and they ultimately allowed their infant to die rather than reveal their serostatus or risk being seen taking ARVs (which would lead to involuntary disclosure). Numerous studies have shown that patients who disclose their serostatus at least to their partners, have better adherence to treatment,^{30,31,32} however, if patients are so stigmatized by the purported mode of transmission (deviant/extramarital sexual relations) that they can have difficulty admitting their serostatus to themselves and consenting to treatment, then disclosing to their partner and eventual adherence becomes an even more remote possibility. In the following narratives, we will see how self-stigmatization (also referred to in social psychology as 'perceived discrimination'³³) in relation to involuntary disclosure to neighbors and acquaintances can play out for patients on ART and affect their adherence to treatment as well as people's willingness to even be tested for HIV.:

[in response to a question regarding the greatest challenge to ART adherence] *It's in the person coming here [to the health center] to know that they have HIV. **They're afraid to come here to the hospital, see people from their neighborhood.** Many people don't come. [...] For many people it's difficult. **They're thinking 'that guy is going to see me and is going to tell that other guy and they'll all know that I have HIV.'** [...] The person is afraid to face his reality, afraid that everyone is going to know...* [26-year-old, female respondent #010, on ART 2+ years]

"Other people feel ashamed... 'How are other people going to see me? What will they think of me?'" [27-year-old, female respondent #090. On ART for 1 year]

[In relation to travelling a long distance to the health center when there is a health center near patient's home] *"I leave my house very early, at 6 am, to come here because I think it's better...because of my [female] neighbors. **There's a hospital there [near home] but I prefer to come here...there are always those people. I'm afraid that they'll see me at the hospital there, so I prefer to come here**"* [33-year-old, female respondent #100. On ART for 10 months]

[clinician in relation to challenges to adherence that patients face] *"Another thing is the **fear there at home, fear of family, that someone will see her taking the medication...if her husband doesn't know...if her family doesn't know.** [...] And another part is, for example, having neighbors... running into a neighbor who is HIV-positive. **She's also afraid to show her face [around a health center] because this neighbor is going to know she is HIV-positive... so, this aspect of discrimination between patients...**"* [nurse respondent #510. Working with HIV patients for 11 years]

These four commentaries encapsulate the shame that many patients express in regards to family members, neighbors or acquaintances seeing them going to the hospital or taking medications and deducing that they have HIV.

In all of the above stories, it is not impossible to imagine an alternative scenario. As mentioned previously, stigma has been treated as an unfortunate but unavoidable collateral effect of a 'sexually transmitted' disease and as something that can be combatted by, for example, further education in the form of convincing people that HIV cannot be transmitted by sharing food or utensils.³⁴ It is quite remarkable that, even in such a discussion of stigma that focuses on fear of transmission through casual contact (sharing food in this example) leading to stigma, we still do not see any hint of the possibility that the mode of transmission on which we do, in fact, focus (sex), could be creating the very stigma we purport to want to avoid. If we were to imagine that official sources of information that are generally seen as reliable and truthful by patients (ie: TV, radio, health workers/facilities) included information on all modes of transmission, we can imagine that perhaps some of this overwhelming shame expressed by patients and the stigmatizing beliefs of some clinicians could be mitigated. For example, had the young pregnant patients mentioned here been counseled about non-sexual modes of transmission as a matter of course and had they and their spouses already been exposed to prevention campaigns focused on non-sexual modes of transmission, it then becomes possible to imagine a situation where perhaps these young mothers could have gone home to their husbands and discussed their HIV status without fear of being labeled sexually

deviant or unfaithful. They would have had an alternative explanation for their infection that did not involve deviant sexual behavior. The patients who identified shame and fear as serious barriers to ART adherence and who went on to describe thoughts such as 'what will people think of me?', could, conceivably live in a place where this was not the default and where being tested or treated for HIV would not be an admission of engagement in devious sexual behaviors but would rather be the same as being tested and treated for something as uninspiring of shame as malaria. While causal stories were mentioned in Chapter 1 as a large-scale political phenomenon, we can see with these examples that causal stories can, in fact, be quite pertinent at the inter-personal level, potentially providing an alternative narrative for HIV infection that could help to mitigate the shame and stigma that continue to interfere with, not only efforts to implement so-called 'Test and Treat' strategies, but also individual adherence to ART.

4.7.5 What do patients' and clinicians' impressions of 'HIV Prevention Campaigns: Before and After' reveal about patients' experiences with ART?

Patients were asked their general impressions of HIV prevention campaigns before and after their HIV diagnoses and clinicians were asked the same in relation to when they began working with HIV patients. Their narratives may help us to better understand the ongoing effect of prevention campaigns on both clinicians' beliefs about patients as well as patients' 'relationships' with the formal healthcare system.

[General thoughts on prevention campaigns (before and after diagnosis)] *"Ah- well, to start, it was very much a 'man's thing', you know? For when they had sex, they should use this...condom...thing. But now, for married people at home, we came to distrust this message: 'How are we going to use this condom when we're always together here?' Like, my husband could never tell me 'we're going to use this condom' because I would ask 'why are we going to use this thing?'... This is also difficult for many women, you know? And if he doesn't want to use it [the condom], I can't force him to now can I? [...] These condoms already existed [before HIV] for when they didn't want the woman to get pregnant or whatever. But it was more for sex before marriage, not for married couples at home. But now, with this disease, no one knows anymore why people want to use them [condoms]. He thinks 'when I use it [a condom], then this woman isn't going to trust me [will think I have HIV]' while the problem isn't even that! It could be to avoid other STDs or pregnancy. But now- it's all ruined. Yeah- that's*

it. [Using a condom] sends a signal that ‘I don’t trust you’.”

[49-year-old, female respondent #110. On ART for 6 months.]

This narrative succinctly describes one of the main issues of the perpetual and almost-exclusive promotion of condom usage for HIV prevention. It is notable that this patient is 49 years old and so would have been exposed to these prevention messages (as an adult) from the beginning of the HIV response in Mozambique. There are numerous discussions in the academic literature about women’s interpersonal bargaining power (in relation to a woman’s ability to ‘make’ her partner use a condom)^{35,36}, however, these discussions leave out an important issue, which is that of feelings of trust between partners. This respondent describes how condoms make sense for people (her first impression was, for men) to use when having sexual relations outside of or before marriage. However, she discusses the perverse outcome of constantly linking condoms to HIV prevention in that couples that may have used condoms previously (to prevent pregnancy for example) are now afraid to suggest that one be used because the message sent by condom use these days is ‘I don’t trust you or you won’t trust me: either I think that you have HIV or you will think that I have HIV’. If either partner suggests that a condom be used, thanks to HIV prevention messages that have indelibly linked condoms and HIV, the other partner will invariably believe that one of these statements is true; that the person suggesting condom use is either untrusting or untrustworthy.

This is a sort of collective self-stigmatization where people have been conditioned to believe that a sexual partner (any type, including a husband or wife) is lying and unfaithful by default and is bringing HIV into the home. Either way, trust between partners may have been severely corroded by the decades-old message of HIV prevention campaigns that all people must ‘protect themselves’ at all times, even those in monogamous partnerships. It is very possible that this intense link created by prevention campaigns between condoms and HIV has actually harmed prevention efforts focused on sexual transmission of HIV as it has created this ‘signal’ of either mistrust in one’s partner or guilt about one’s own actions (where the person suggesting condom use must be HIV-positive and was infected sexually outside of the partnership). As discussed in Chapter 2, in Mozambique’s 2009 DHS, we find that respondents in Maputo City who had reported not using a condom in their last sexual encounter commonly reported ‘being married’ and ‘trusting in their partner’ as their reason for not using one. This further corroborates the perverse effect of linking condom usage to promiscuous sexual behavior (which, in this story leads to HIV infection) in that those who are married and/or feel that they trust their partner are unlikely to use

condoms. Looking at widely-acknowledged 'high risk' sexual behavior, we can see that, while only 8% of Maputo City respondents reported paying for sex in the 12 months preceding the DHS, 95% of them reported using a condom during that sexual encounter.

[Before diagnosis] ***"I was always...frightened...to tell my husband that we needed to take the test."*** [Now- after diagnosis and on ART] ***"...I like to be able to sit and watch TV with my husband... they're always saying that to 'andar fora' [be unfaithful or 'sleep around] is very risky, that these days there are lots of diseases around...you can encounter a 'fat' [healthy-looking] woman who tells you that people with HIV are skinny people when it's not like that. Even 'fat' [healthy-looking], a person can be sick, and knowing this, you can avoid many diseases. It's not easy. Even we go for months [without sexual relations] with each other because we're afraid. The way that they counsel us is: 'you're already HIV-positive, so this is the way you need to live if you want to survive for years'."*** [33-year-old, female respondent #100. On ART for 10 months.]

In the response above, the fear inspired by the prevention messages seems to get mixed-in with post-diagnosis 'lifestyle counseling' (which typically includes dire warnings about having sexual relations, drinking alcohol, the need for exercise, etc...) that patients receive in health facilities so that this patient and her (also infected) husband are even afraid to have sex with one another.

[Before diagnosis] ***"I always heard people saying- especially in the hospital- they told me 'You're pregnant- you have to take the test!' It annoyed me! I thought: 'What disease IS this?! ...'"*** [Now- after diagnosis and on ART] ***I was annoyed in those first days when I found out [my serostatus], I wouldn't eat... I didn't believe it. But I got to a point where I said 'sheesh! I have to adhere to this treatment- the people who talk about this stuff aren't crazy'. Now I feel proud because I'm adhering well to the treatment."*** [32-year-old, female respondent #010b. On ART for 16 months.]

[Before diagnosis] ***"I felt horrible."*** [Now- after diagnosis and on ART] ***"In my case, I feel good because I'm receiving treatment."*** [28-year-old, female respondent #808. On ART for 3 years.]

[Before diagnosis] ***"Wow- I felt...like...upset, you know? I felt like...well...like a person who knows nothing. Ignorant..."*** [Now- after diagnosis and on ART] ***"Now...I feel good because I'm already used to it all. It's my life, you know? It's my life. Now that I'm living with the virus and my daughter was born HIV-***

negative... it gave me strength." [26-year-old, female respondent #010. On ART for 2+ years.]

[Before diagnosis] *"Whoa.... [long pause] I felt okay...but on the other hand, I was frightened: 'What kind of mystery is this? This AIDS? Maybe this doesn't even exist!' In another moment I thought 'This is true! It's on TV...'. I felt like that: doubting. But it got to the point where I believed that [HIV] exists."* [29-year-old, male respondent #101. On ART for 3 years.]

[Before diagnosis] *"Wow...I thought that it was...that it was...well- a joke. I thought they were messing with us."* [Now-after diagnosis and on ART] *"I'm...certain that this disease exists. Yeah."* [37-year-old, female respondent #090. On ART for 1 year.]

As briefly touched upon earlier, we again see this recurring theme of initial disbelief in HIV, a feeling that someone is 'playing a joke' on everyone, intense fear, and a sense of dread that 'one day it could be me'; these feelings lace almost all of the patients' responses to the question about how they felt when they saw HIV prevention campaigns before their own diagnosis with HIV. In response to a question about how they feel now that they are living with HIV, many mention that they feel good since they are receiving treatment or because they feel that others can avoid their fate. One woman (respondent #010) ties her newfound acceptance of the disease and in the treatment to the fact that her daughter was born uninfected. It must, of course, be remembered that these patients are, in fact, adherent to ART. In order to attempt to understand what might be happening with patients who drop out of treatment or are LTF, we could conceivably imagine that this leap from disbelief in the disease itself and in prevention messages to an acceptance, not only of the disease, but of the biomedical treatment paradigm and all that it entails, sociologically, is a necessary step in order for patients to adhere to treatment. Clearly this would not be sufficient to ensure adherence, but it would seem to be necessary, nonetheless.

Clinicians' responses in regards to their impressions of prevention campaigns before and after working with HIV-infected patients are also quite revealing. The overwhelming majority report having felt a need for more information and intense fear both due to the apparent scale of the epidemic as well as the fact that HIV has no cure, as in this example:

[Before working with HIV+ patients] *"...When this [epidemic] began, in the world, people first tried to understand 'but what*

IS this?? What's it all about? This pathology that everyone complains about, is infected with...and also, knowing that it's a disease that has no cure... it creates amazing FEAR in anyone... I understood that people really have to learn control over their behavior..." [Now- after working with HIV+ patients] *"... We have to just present this person with another chance to live in a way that the person can accept."* [technician, respondent #711. Working with HIV patients for 3 years]

It is also interesting to note here that this technician credits her understanding that 'people really have to learn control over their behavior' to prevention messages (before she worked with HIV-infected patients) and that her response now that she works with patients centers around presenting patients with another chance to live. Though it is not explicit, this narrative again seems to draw strongly on the idea of HIV patients being those who apparently did not 'learn to control their behavior' and are now being given a second chance at life by the medical establishment (through ART).

Another striking point in many clinicians responses is how many of them immediately equated prevention messages (before they worked with HIV-infected patients) with the idea that 'HIV equals death' as in the following examples:

[Before working with HIV+ patients] *"I heard about HIV in health lectures, theatre performances, TV... it was...I was very afraid of the disease, because right from the start, when I heard about it, I thought HIV equals DEATH...I think this was a lot of people's impression..."* [Now- after working with HIV+ patients] *"Well, changing people's mentality is difficult. Campaigns are campaigns. You have to take the test, because the earlier you do...etc... you have to take your medications at the right time..." All these things. So, yeah. I think that...treatment is difficult, but for that reason, I think we have to continue...continue to do health lectures...campaigns"* [technician, respondent #605. Working with HIV patients for 2 years]

[Before working with HIV+ patients] *"Well. That HIV/AIDS equals death."* [Now- after working with HIV+ patients] *"I think they [prevention campaigns] shouldn't be so pessimistic. It's not all bad. There are good things too- like HIV doesn't equal death. That people get treatment, people live normal lives like any other person."* [physician respondent #812. Working with HIV patients for 2 years]

“Here, it was...how can I say it?... We were really scared. I was also scared because... the publicity that they used back then – it’s different now- but then it was ‘AIDS KILLS’...if you catch it, ‘AIDS kills’. It was the only thing ‘AIDS kills’. But now...it’s different. They say more like: ‘AIDS, you just need to deliver yourself over to medical treatment; there’s treatment’. So now there’s not that same intense fear in the messages that there used to be. Before, if you saw a person with HIV, you crossed the street and let the person with HIV pass by on the other side. You didn’t even say ‘hello’, you couldn’t say ‘hello’. If a person with HIV entered [into a room], everyone went ‘ah! It’s that person with HIV!’ We were all afraid. But that wouldn’t happen today.” [nurse, respondent #510. Working with HIV patients for 11 years]

[Before working with HIV+ patients] *“I think I was still in school when I first began to hear about ‘Jeito’ [the Mozambican government’s condom social marketing program in partnership with Population Studies International] But for me, it seemed like it was more about STDs...I didn’t understand, just thought that AIDS was another STD...So I thought, at the time that it was just about condoms.”* [Now- after working with HIV+ patients] *“Now, working as a physician, I think these campaigns should be carried out, but not only on TV and what not, but in all pre-natal consultations...Because when it’s a public campaign, on TV or whatever, she’s never going to get to the consultation and say ‘look, nurse, I want to take the HIV test’ because if she says that she wants to take the test, the nurse will automatically think that she’s done something bad. So, I think these campaigns are very important, but they have to be integrated in the health lectures for everyone. The person has to already get to the private consultation and have heard them tell EVERYONE to get tested. That everyone should be tested.”* [physician respondent #410. Working with HIV patients for 6 years]

Though the nurse respondent (#510) who has worked with HIV patients for 11 years states that her idea that ‘AIDS kills’ came from older prevention messages that no longer exist, one must wonder as respondent #812 who is over a decade younger and has been working with HIV patients for only 2 years clearly recalls also getting the message that ‘HIV/AIDS equals death’ before she worked with HIV-infected patients. Now that these respondents work with HIV patients, they seem to have moved away from the initial fear that ‘HIV equals death’ and towards a more biomedical point of view that stresses the importance of treatment. However, we still see the recurring idea of people needing to ‘change

their mentality' (in reference to prevention) and 'deliver themselves over' to the medical establishment.

Again, in speaking of their 'after' impressions of prevention campaigns, though it is not stated explicitly, we can see a recognition from some clinicians of the stigmatizing effect of prevention campaigns that focus, for example, on 'risky' sexual behavior and encourage people to ask for testing if they engage in said behavior. As clinician respondent #410 stated, this discourages many people from asking for the test because the clinician receiving the patient's request will think that the patient has 'done something bad' if she is worried about having HIV.

Just as in the patients' narratives, we can see the thread of disbelief in HIV that many clinicians felt upon seeing and hearing HIV prevention messages before they worked in healthcare. Some of the older clinicians remember a time when one could not even say hello to an HIV-infected person on the street. We can also note again the repeated mention of patients delivering themselves over to the medical system, whether this be in the form of presenting to be tested or enrolling for treatment. The importance of patients making this leap from disbelief in the fact that the disease exists at all to fully trusting in the bio-medical system in order to have the possibility of living and long and fruitful life is significant.

Another point worth mentioning in the clinicians' responses is the theme of HIV becoming (or needing to become) 'just any other disease'. Though most clinicians believe that prevention campaigns are generally a good thing and that information about HIV needs to be communicated to the populace, we can also sense from many of their responses, a desire for a little less focus on fear and 'moral censure' and more focus on HIV as a disease like any other. Some of these clinicians, after working with HIV patients have, in fact, come to think of other faster-progressing illnesses (such as malaria) as more worrisome in terms of fears of death and it seems that they would prefer to see more focus on the 'good things' as one clinician phrased it; the idea that HIV is just any other disease and that, with treatment, patients can live normal lives.

4.7.6 Do patients and clinicians know that ART functions as prevention and how would that knowledge affect adherence?

Patients and clinicians were asked if ART (with faithful adherence) has any effect on the probability of transmitting HIV to others and, if so, what effect it has.

Patients were then asked how they would feel in terms of their motivation to adhere to treatment if they were told that adhering faithfully to ART would help protect an uninfected partner. Those who were already in monogamous relationships with an infected partner were asked to think of the question abstractly. Clinicians were asked how they believe that patients might feel in terms of their motivation to adhere to treatment if they were aware of the drastically lower probability of transmission of HIV for patients on ART.

As we can see in *Table 9* below, approximately 46% (10 of 22) of adult patients correctly believe that ART decreases sexual transmission of HIV. Again, it is significant that these patients who thought that ART may decrease sexual transmission of HIV attributed this knowledge to non-healthcare sources.

Incredibly, less than 30% (4 of 14) of clinicians knew that ART decreases the probability of sexual transmission. Of these 4 clinicians who knew the correct answer to this question, 3 were physicians and one was a technician. None of the nurses interviewed believed that ART decreases the probability of sexual transmission—this is notable as these nurses regularly see pregnant female patients and so are very familiar with ART to prevent mother-to-child-transmission (MTCT). The one clinician who reported that ART increases transmission was a physician. Many clinicians, while responding to this question, discussed not only transmission efficiency, but also their concerns about ‘Superinfection’ (infection with more than one strain of HIV) and the possibility of patients spreading more resistant strains of HIV between infected partners. Several patients themselves expressed concern about this same point, suggesting that the possibility of Superinfection and infection with resistant strains is quite effectively communicated to patients.

This becomes important when we consider the idea of moral hazard or risk compensation; the fear that, if patients know that ART decreases the probability of sexual transmission, they will then further decrease condom usage and engage in ‘riskier’ sexual behaviors, effectively offsetting the benefits of ART as prevention. As many patients (including those in monogamous partnerships) qualified their answers to these questions with comments about how they would continue to use condoms so as not to risk infecting themselves with another strain of HIV, it would seem that this fear of Superinfection may, in fact, help calm concerns about moral hazard. It does however, raise interesting questions about the popular argument that if both members of a couple have HIV, then this is a sort of proof that sexual transmission is particularly efficient and accounts for a large majority of cases of HIV with one partner being unfaithful

and bringing HIV into the home and infecting the other. Were that strictly the case, then concerns of Superinfection in monogamous couples would be superfluous as both members of the couple would have the same strain of HIV. Therefore, the stress on Superinfection implies either assumptions of mutual infidelity (the only way that both infected members of a couple could have different sexually-transmitted strains of HIV) or unspoken suspicions that perhaps non-sexual transmission is greater than is officially acknowledged with at least one partner having acquired HIV non-sexually. As HIV prevention messages stress issues of infidelity, it would seem more likely that this is yet another perverse outcome of HIV prevention messages: even within monogamous partnerships where both partners are infected, patients have been taught to always use condoms as their partner could still bring home another strain of HIV, leading to Superinfection.

Table 9. Beliefs About the Effect of ART on Sexual Transmission of HIV, Adults.

	ART Decreases Transmission	ART Increases Transmission	ART No Effect on Transmission	Don't Know
Adult Patients	10 (45.5%)	5 (22.7%)	3 (13.6%)	4 (18.2%)
Clinicians	4 (28.6%)	1 (7.1%)	7 (50%)	2 (14.3%)

Table 10. Effect of Knowing ART Decreases HIV Transmission on Motivation to Adhere.

	Would Feel More Motivated	Same Motivation Because Already Adherent	Would Not Feel More Motivated	Don't Know
Adult Patients	11 (50%)	8 (36.4%)	1 (4.5%)	2 (9.1%)
Clinicians (beliefs about patient motivation)	13 (92.9%)	--	0	1 (7.1%)

“When taking [antiretroviral] medications faithfully, the ‘bug’ sleeps, the virus...It sleeps, falls asleep. But, when it’s asleep, even though it’s asleep, we can’t ever imagine neglecting the methods that they counsel us to use which means, having sex without a condom. But I think that we couples, we don’t always accept condom use [...]. So...I think the best measure to take is to take the medications faithfully.

Why? Because taking them, I think the...‘bug’ decreases and it’s not so easy to make the other person sick. I think it’s better this way.” [37-year-old, female respondent #010c. On ART for 11 months]

“It’s less [the probability of transmission], because if I’m complying with the treatment, at that point, I think the virus is asleep, even though there’s still a risk. It’s still possible to contaminate the other person.” [35-year-old, female respondent #108. On ART for 10 months]

“I think there’s...less risk [to transmit HIV]. Because if the person is adhering to the medications and he has high CD4 levels, there’s less risk to transmit [...] I would feel more motivated [to adhere to ART] to protect the other person. Knowing I could protect the other person.” [40-year-old, female respondent #308. On ART for 4+ years]

“I think that I, taking the medications, have a greater chance of infecting my partner because I’m already in treatment and maybe the other person doesn’t know. Maybe I hid my serostatus from that other person, so the other person doesn’t know. I think it’s very risky, especially if you have sex without a condom because...the medication...I think the medication is cleaning out or... decreasing the intensity of the disease, of the virus. So I think that that ‘stuff’ that’s going to come out of me and go into the other person’s body, my partner’s body... will make it a lot heavier for him...he will get sick very quickly. It would be a lot quicker now that I’m in the middle of treatment...a lot quicker for me to contaminate someone else because the medications are clearing the virus out of my body, so I’m passing more on to my partner. [...] [knowing that ART decreases transmission]...I would feel more motivated to adhere. I really would.” [37-year-old, female respondent #108b. On ART for 6+ years]

“To begin to respond to this question: I’ve never been with any man other than my husband. I’ve never been with another and I’m not with any other... I’ve heard from other infected people...they say that if we’re taking these medications [ART], it will make the virus go to sleep and they say that then you won’t transmit. But, [sheesh], to tell you the truth, I don’t believe it. I have doubts. [knowing that ART decreases transmission]... I would feel really good...proud to be able to protect the other person, not transmit my disease.” [26-year-old, female respondent #010. On ART for 2+ years]

One striking facet of the patients’ responses to the question regarding ART and transmission efficiency is the impeccable logic of many of their responses. The

patients who believed that HIV decreases transmission efficiency correctly and spontaneously identified viral load (metaphorically) as the key factor in the process. Most of them made reference to how ARVs 'make the virus sleep'—therefore lowering the amount of virus in their bodies and the amount that they will then pass on to their partner. The logic of respondent #108 is also well reasoned, even if it is not correct: the patient believes that ARVs function by effectively flushing HIV from the patient's body (rather than the other patients' more correct metaphor of putting the virus to sleep). This then leads respondent #108 to believe that her bodily fluids will actually have more viral material while she is taking ARVs. As previously mentioned, none of the patients had been counseled on this issue in either direction by clinicians and, when some mention an actual source of information here, it is from outside of healthcare settings. However, the remarkable factor here is the excellent reasoning that seems to underlie many patients' beliefs in terms of ART's effect on transmission. Again though, we find that, despite the fact that their own reasoning leads many patients to the correct conclusion that ART decreases HIV transmission, as they have never heard this from a health professional (and, indeed, some have heard it from previously-identified unreliable sources of information), they are unlikely to trust the information that ART decreases transmission.

In terms of moral hazard, it is notable that many patients, without prompting, mentioned their strong belief that even if ART does decrease transmission, it is still not 100% effective as prevention and, as such, patients on ART should still continue to use condoms. This suggests that fears of strong moral hazard expressed by clinicians (and policymakers, both international and domestic) may be overblown. The patients' responses suggest that patients are quite able to hold a more nuanced view of ART as prevention and as a risk-reduction strategy as we see in respondent #101b's response when she explicitly states that, though condom-usage should not be abandoned, ART as prevention would be particularly useful for monogamous couples that will not (or do not) use condoms anyway. As condom usage in Mozambique remains rather low (as outlined in Chapter 2) in spite of intense, decades-long campaigns to increase usage, these responses, and this ability of patients to understand (without information from healthcare professionals) the logic behind ART as prevention—including the fact that it is not 100% effective—is certainly encouraging and should help us to develop a less apocalyptic view of the possibility of moral hazard.

In terms of clinicians' ideas about ART's effects on the probability of transmission, we find several interesting points. First, it quickly becomes clear

that clinicians have not been explicitly taught about the preventative benefits of ART, regardless of the Ministry of Health's 2001 decree that Mozambique would seek to maximize these benefits. The majority of clinicians (seven), believe that ART makes no difference in transmission, with several expressing certainty in this belief as in the following example:

"...the principal is that it [ART] doesn't change anything [in terms of transmission]. I'm absolutely certain that it doesn't change anything." [technician respondent #711. Working with HIV patients for 3 years]

Others expressed a more nuanced view, so that, though they may have said that ART would not affect transmission, they went on to reason through the issue, touching upon analogies between prevention of MTCT and ART as prevention of sexual transmission or recalling patients on ART who, despite not using condoms with their partner, did not transmit HIV, as in these examples:

"I think it [transmission] would happen just the same because there is no cure. Here, we don't have a cure- even taking antiretrovirals, we counsel patients 'even when you're taking antiretrovirals, you have to use condoms'. But there's a patient here in the pre-natal ward, her husband is uninfected, she's infected, they never use condoms....they have 2 or 3 kids, some of them conceived when she already had HIV and, there you go, sometimes the husband ends up infected, sometimes not." [nurse respondent #808. Working with HIV patients for 9 years]

"For me, without knowing which patient it is, without knowing their viral load... the probability of transmitting is the same as if he wasn't taking antiretrovirals. That's my opinion. I've not yet heard anything like 'okay- if you take antiretrovirals, the probability to transmit [HIV] is decreased'...as we see in pregnant women, when they're taking antiretrovirals, they have high CD4 levels, low viral loads... But, in relation to adults [and sexual transmission], no... I've never heard anything about that. I think it's passed on just the same as with a person who's not on ART." [physician respondent #704. Working with HIV patients for 4 years]

Only one clinician reported believing that ART would increase the probability of sexual transmission of HIV. The reasoning, in particular, is slightly disturbing as it shows a lack of understanding that the crucial action of ART is not just to 'make the virus sleep' as it is often simplified for patients, but to keep the virus from replicating, hence lowering patients' viral load over time:

"I think [the probability of transmission] is greater. Because if he's taking ARVs, in his own body, the virus is toned-down/suppressed...this virus is going to be passed to his partner who doesn't take ARVs and it's going to 'wake up'.
[physician respondent #410. Working with HIV patients for 6 years]

And finally, the four clinicians who reported knowing that ART decreases the probability of transmission all included an aside to the perceived danger in telling patients about this benefit, while, conversely, responding that if patients were to be made aware of the preventative benefit, the clinicians believe they would be more motivated to adhere to treatment:

"The chance [of sexual transmission] is decreased. BUT, they can't think like that because infected people have to know that, if they're going to have sex, they always have to use condoms. So, it's not perfectly safe, but the chance of transmission is less. [physician respondent #503. Working with HIV patients for 7 years]

"It [sexual transmission] is decreased. But we're not accustomed to telling them that. Because they might think: 'I'm already taking medication, my partner isn't yet infected...so we have less probability of transmitting'. It's just that we don't tell patients this...because they would think 'If I'm taking medications, why use condoms?' Though their viral load may be low when they're on ART, they always have to use condoms."
[technician respondent #905. Working with HIV patients for 2 years]

In terms of clinicians' beliefs about patients' motivation to adhere to ART if they knew it would help protect uninfected partners, we find that almost all clinicians (13 of 14) believe that the information would improve patient motivation. Most mention that this would be especially useful in monogamous partnerships, and particularly where the couple has children, as in the following examples:

For adults, if it's within a couple, I think it would help because adults always look to the future, if they have kids...they think: 'why let both of us die?'" [physician respondent #410. Working with HIV patients for 6 years]

I think they would be more motivated because I think that we all have that desire to take care of our partner. So, I think if we explained it correctly, they would be more motivated." [physician respondent #503. Working with HIV patients for 7 years]

However, we do find that several clinicians include caveats to moral hazard as well as the idea that it would be complicated to manage this kind of information and be sure that patients understand that ART would not prevent transmission 100% of the time, as in the following examples:

[Thoughts on patient motivation to adhere if they knew that ART decreases transmission] ...*I think if she [a patient] really loves someone and she understands that [adhering] would help to not pass [HIV] on to anyone else, I think that would help her feel more motivated. I also think especially men would be more motivated to adhere because that way they could think ‘hey- I don’t need to use condoms’ and they wouldn’t think about how they could also get another virus from one of the people with whom they don’t use condoms. So...it’s a complicated piece of information. There could be many good things, but also many bad things...*” [physician respondent #704. Working with HIV patients for 4 years]

[Thoughts on patient motivation to adhere if they knew that ART decreases transmission] *I don’t know...maybe for some...for example, couples where one partner is positive, the other negative. Here, it’s generally like this: when a couple has one person with HIV and the other is negative, they usually separate. So, for couples that don’t separate in this situation, you know it’s really about love. The [infected partner] really knows that ‘this person is with me even though I’m seropositive’, so really, there’s a strong motive to take the medications if you really know that they would help you not transmit [HIV to the other partner]...But it’s very complicated. If people already don’t normally use condoms, if this information [about ART as prevention] circulates...I think it’s going to cause a lot of disturbance here.*” [physician respondent #410. Working with HIV patients for 5 years]

4.8 Maputo Central Hospital- Pediatric ART Patients

The Day Hospital of the Maputo Central Hospital (MCH) is located on its own floor within the pediatric ward of the hospital and will be integrated into general pediatrics once the process of decentralization of HIV patients has been completed (projected for 2012). As mentioned earlier, patients who live within the geographic jurisdiction of the Central Hospital will continue to be seen as outpatients at the MCH pediatrics department while the rest will be referred to the health centers nearest their homes.

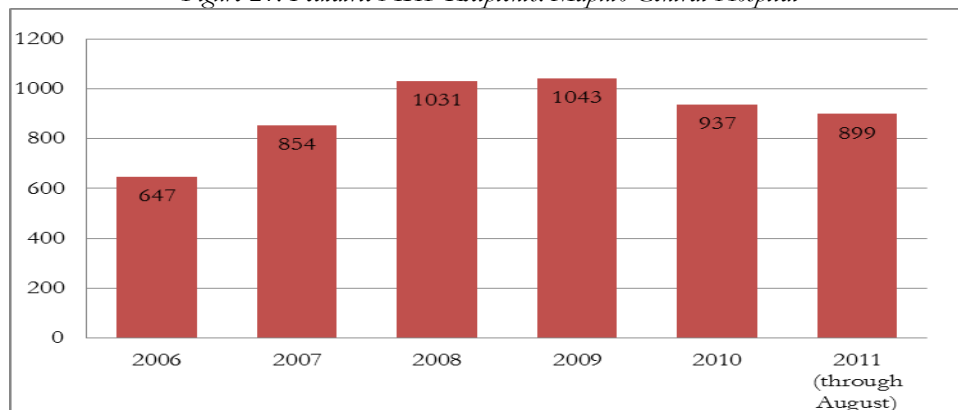
Figure 21 and *Table 11* show the number of pediatric patients on ART at the MCH as well as the number of these patients who abandoned treatment or died while on treatment each year. It is important to note that these deaths are not representative of the number of children who died at the MCH of AIDS in any given year, but rather, only the number of those children who were already enrolled in ART at the MCH. If an HIV-infected child was not officially enrolled in ART at the MCH, then her death would not appear in these figures.

In *Table 11* we can see a spike in the number of patients who were classified as having abandoned treatment in 2008 (22). Not surprisingly, this was the year that adult patients began to be referred to their nearest health centers. As we have seen with Malhangalene, some parents receiving treatment requested at their new health center that their infected child be able to be seen at the same facility. Fearing that the child would fall through the cracks and go without treatment if the requests were not granted, many health centers accepted these children on ART. As children were not yet being officially referred to health centers for treatment (under the decentralization plan), these children would appear in official records to have abandoned treatment at the MCH. From anecdotal evidence recounted by pediatricians in the MCH, it would also seem that the spike in deaths in that same year may have been at least partly attributable to this phenomenon of children being seen at health centers with their parents. Pediatricians recounted stories of these children who had been classified as having abandoned treatment at MCH, later showing up in the pediatric emergency room of MCH with advanced AIDS and their parents reporting that the children were receiving treatment at a health center. Though this study is not clinical and so cannot hope to address the complexities of pediatric HIV relative to adult HIV, both the pediatricians interviewed and the physician director of the HC Malhangalene stressed that pediatric HIV care is considerably more complicated and sensitive than adult care. They generally attributed this to the

fact that HIV, being an immunological disorder, is much more difficult for a child's body to handle, as children have not yet had the chance to develop a mature immune system before being infected. This means that children generally have viral loads an order of magnitude higher than adults and they tend to progress (from HIV to AIDS) much more rapidly than adults. The pediatricians interviewed explained this and attributed the spike in deaths in 2008 to those pediatric patients that were transferred to health centers by their parents before the health center staff had received any special training in pediatric HIV. As no health centers in Maputo have pediatricians on staff and the one physician assigned to each health center tends to have a heavy administrative as well as clinical burden, many MHC pediatricians expressed deep reservations about the health system's readiness to absorb pediatric ART patients into the health centers. The director (and only physician) at the Health Center Malhangalene also expressed the feeling that she, having only received a one-day 'crash course' in pediatric HIV and with the weight of all her other responsibilities, did not feel capable of caring for pediatric ART patients.

As regards the geographic distribution of the caretakers interviewed, we can see from Map 2 below that they travel to the Central Hospital from a greater number of neighborhoods than the adult patients at the Health Center Malhangalene and, in fact, several caretakers live in areas (including the neighboring city of Matola) that are outside of the boundaries of the Maputo City map. This is unsurprising as interviews were conducted before decentralization of these pediatric patients.

Figure 21. Pediatric ART Recipients: Maputo Central Hospital



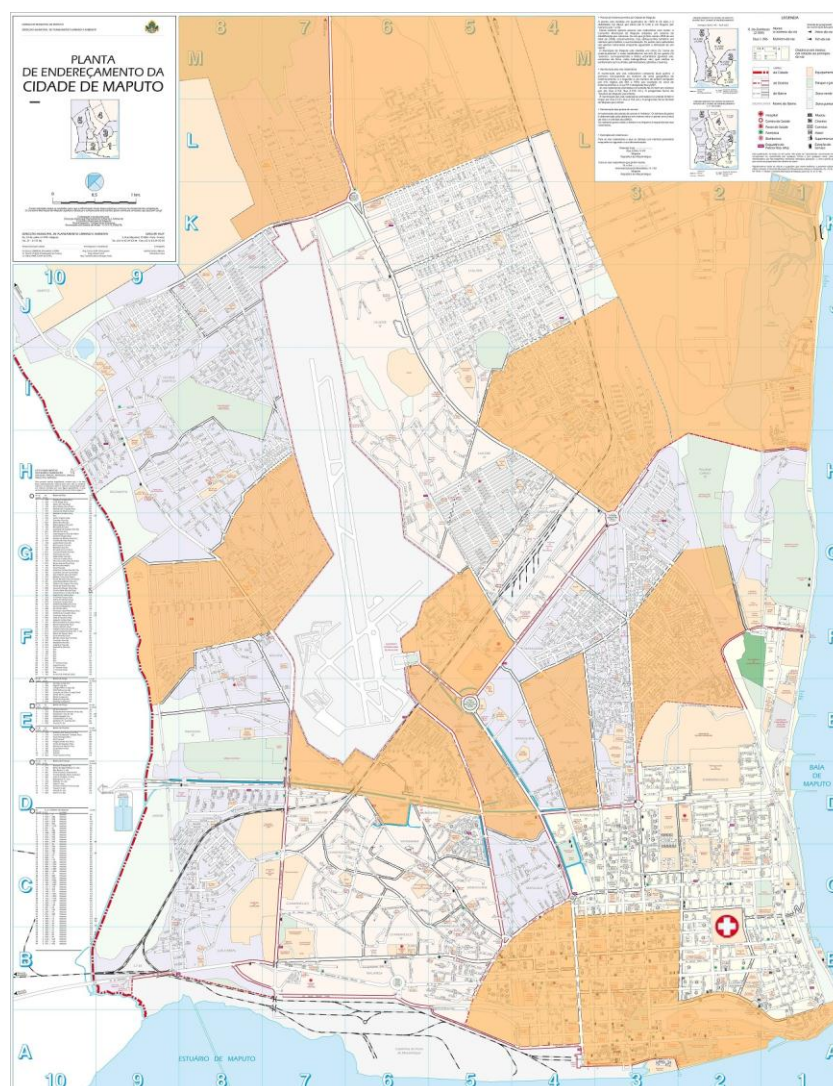
Source: Maputo Central Hospital

Table 11. Pediatric ART Recipients: Maputo Central Hospital

Year	Pediatric Patients on ART	% Change	Abandoned Treatment	Deaths During Treatment
2006	647	--	1	26
2007	854	27.8	1	17
2008	1031	18.8	22	14
2009	1043	1.2	4	4
2010	937	-10.7	0	1
2011 (through August)	899	-4.1	29	1

Source: Maputo Central Hospital

Map 2. Geographic Distribution of Caretakers Interviewed: Maputo Central Hospital



4.8.1 Human Resources

The Day Hospital is assigned three dedicated nurses who do not rotate or change (one was on holiday during the interview period and so was not interviewed), while pediatricians from the Central Hospital pediatrics department as well as ‘post-graduate’ physicians who are completing specialized training in pediatrics serve one month rotations. Pediatric patients are seen twice in their first month of treatment then once per month during the beginning of treatment or until the patient is clinically stable. From there, they have appointments every three months, being seen by a pediatrician each time and, later in treatment, once it becomes clear that adherence is high and the patient is doing well clinically, some patients may be seen as infrequently as once every six months though clinicians must be very certain that adherence is indeed, optimal, in order to recommend this regimen.

4.8.2 *What effect do sources of HIV/AIDS information and their perceived reliability have on caretakers’ experiences with ART?*

We can see from *Table 12* that, in contrast to the adult patients discussed earlier in this chapter, the caretakers of pediatric ART patients are more likely to report friends/family or ‘person-to-person’ as a reliable source of information. All adult patients who reported ‘person-to-person’ sources of information also stated that they are unreliable. 20 out of 26 caretakers reported friends/family or ‘person-to-person’ sources of information in general. Of these, 25% (5 out of 20) consider ‘person-to-person’ sources of information reliable, 55% (11 out of 20) consider these sources unreliable and the remaining 20% (4 out of 20) are indifferent regarding their reliability. It is notable that, as in the examples below, many who identified ‘person-to-person’ sources of information then went on to state that they believe that *all* sources of HIV information are reliable:

[radio, church, friends/family, hospital identified as sources of information] ***“There are no [unreliable sources]. What they say... I believe.*** [35-year-old mother of 8-year-old patient, respondent #677, on ART for 4 years]

[TV, school, health lectures, ‘in the neighborhood’ identified as sources of information] ***“I believe that they’re speaking the truth, that HIV exists. I think that they are all reliable.”*** [42-year-old mother of 5-year-old patient, respondent #419, on ART for 4.5 years]

[TV, radio, health lectures, 'from other people' identified as sources of information] ***"I don't see, I really don't see, sources of information that aren't reliable. They're all reliable."*** [{uninfected} 44-year-old mother of 9-year-old patient, respondent #690, on ART for 3 years]

[friends/family, TV, hospital identified as sources of information] ***"Everyone who talks about HIV is reliable. I believe that HIV exists and everything that everyone says, I believe."*** [28-year-old mother of 3-year-old patient, respondent #568, on ART for 3 years]

While it would be impossible to draw any hard and fast conclusions from these stories, perhaps caretakers of children with HIV may be more likely to believe in 'person-to-person' information, as caring for children is a communal activity to a certain extent. Mothers may have a tendency to rely upon female relatives and other mothers for guidance on raising their children (and several mothers interviewed do, in fact, live with extended family) whereas adult patients may be more likely to discount unsolicited information from sources outside of health facilities. Several pediatricians' responses show that they also believe that sources of information outside of health facilities are reliable for caretakers:

"I think that they believe more in people from their community, their church. They believe more in people from a group where they belong [...] They don't believe much ... in health workers. Maybe it's because of the way that health workers deliver information...the type of language that we use." [physician respondent #410. Working with HIV patients for 5 years]

"Family influence is very strong because we can counsel [patients] to do a certain thing and when they come back here, it turns out they've been doing something completely different because the family influence is what they believe in much more [than in health professionals]. But there also exists a type of patient that I've seen that has been on ART for a long time, knows a lot about this disease and very much trusts what we say. It's mainly when they're beginning treatment and don't understand things very well [that the family influence is strongest]." [physician respondent #704. Working with HIV patients for 4 years]

It is also possible that the caretakers who identify 'person-to-person' sources as reliable have not yet received much 'controversial' information from these sources that contradicts the advice they receive from health workers and official sources. Looking at the responses of the 11 out of 20 respondents who

identified ‘person-to-person’ sources as unreliable, we can see that several attribute pressure to stop taking ARVs to ‘person-to-person’ sources as in the following examples and this could help explain why they do not believe (or no longer believe) in these sources:

[in regards to unreliable sources] *“You have to comply with the medication...**not listen to people from outside [the health facility] who tell you ‘no- you have to stop taking these pills. We can give you a person who can find you a cure...’**”* [33-year-old mother of 7-year-old patient, respondent #736, on ART for 6.5 years]

[in regards to unreliable sources] *It’s people because people are gossips- one says ‘this’, another one says ‘that’, **that these pills [ARVs] will only speed up the disease. That’s why, when it comes to other people, I don’t believe anyone.**”* [38-year-old mother of 6-year-old patient, respondent #706, on ART for 4.5 years]

All caretakers reported health facilities, health workers and health lectures as sources of HIV information—this is in stark contrast with the 50% of adult patients interviewed and the 49% of Maputo City adults in the 2009 DHS who reported these sources of information.²³ It is not clear exactly why we find such a marked difference, however, we could hypothesize that the intense outreach (in particular through health lectures) to educate women about preventing MTCT and encourage all pregnant women to present for pre-natal care (where HIV is invariably discussed) may help contribute to this phenomenon. A full 25 out of 26 caretakers reported that these formal healthcare sources are reliable. Information from churches also figures slightly more prominently in caretakers’ responses than adult patient responses with 5 out of 26 caretakers identifying their church as a source of information (3 as reliable and 2 as unreliable). These reports show that, apart from the 5 respondents who trust in ‘person-to-person’ sources of information (who, in fact, stated that they trust in all the sources of HIV information that they named), the vast majority of caretakers trust in official sources of HIV information including health workers, facilities and lectures as well as, for many, TV and radio. As with the adult patients, we get the sense that the fact of seeing or hearing reality (or ‘the truth’ of what is happening in their

²³ In Mozambique’s 2009 DHS, the following sources of HIV/AIDS information were reported by Maputo City respondents: Television (83%), Radio (69%), Friends/Family (46%), Health Lectures/Health Workers (49%)

lives) underlies the responses of many patients in regards to why these official sources of information are reliable, as in the following examples:

[radio, TV, hospital identified as sources of information] ***“TV [is reliable] because I’ve seen that only people who have this disease are there talking. But for me, all these sources are trustworthy.”*** [30-year-old mother of 7-year-old patient, respondent #930, on ART for 2 years]

[hospital, TV and radio identified as sources of information] ***“The hospital [is reliable] because they tell the truth. TV and radio [are unreliable] because sometimes they lie.”*** [27-year-old mother of 4-year-old patient, respondent #516, on ART for 3 years]

Overall, these caretakers of pediatric patients present a slightly more mixed bag than the adults in terms of the sources of information they find reliable. It is notable that many of the caretakers express greater trust in the formal health establishment than the adult patients interviewed. This will be discussed in greater depth in the sections to follow as we consider how this high level of trust in the formal health establishment and official prevention messages may affect caretakers’ interactions with clinicians as well as their children’s’ eventual relations with the health establishment. These children will, after all, grow up and be absorbed into adult care and will, inevitably have to confront the social construction of adult HIV, but uniquely, they will do so as adults who were certainly not infected through sexual relations. They will be a part of the first generation in Mozambique to do so (as before pediatric ART was available, HIV-infected children would die before becoming adults). It will, therefore, be important for us to gain insight into their current caretakers’ experiences and, combined with the perspective we have gained from the adult patients, attempt to anticipate issues that may arise for these children as they become adolescents and adults.

Table 12. HIV/AIDS Information: Pediatric Patients, Maputo Central Hospital

	N	%
Caretakers of Pediatric Patients	26	
Sources of HIV/AIDS Information (non-exclusive)		
Health Facility and Workers/Health Lectures ('Palestras')	26	100
Television	22	84.6
Radio	15	57.7
Friends/Family	11	42.3
'On the Street'	9	34.6
Church	5	19.2
School	3	11.5
Newspapers/Magazines	2	7.7
Reliability of Sources of HIV/AIDS Information (non-exclusive)		
<u>Reliable</u>		
Health Facility/Workers/Health Lectures	25	96.2
Television	14	53.8
Radio	10	38.5
Friends/Family or 'person-to-person'	5	19.2
Church	3	11.5
Newspaper	1	3.8
<u>Unreliable</u>		
'On the Street'/'person-to-person'	11	42.3
Radio	2	7.7
TV	2	7.7
Church	2	7.7
Health Facilities	1	3.8
Spontaneous Reporting of HIV/AIDS Transmission Routes (non-exclusive)		
Sexual Relations	26	100
Vertical (Mother-to-Child)	22	84.6
Blood-borne*	16	61.5
Mosquitos, Toothbrush, "Tuberculosis" (as causing HIV infection)	1 (each)	3.8 (each)

How Caretaker Believes Patient May Have Become Infected (non-exclusive)		
Vertical (Mother-to-Child including breastfeeding)	15	57.7
Father or both parents	5	19.2
'Don't Know'	5	19.2
Blood-borne	1	3.8
Mother HIV+ during pregnancy (self-reported)		
Yes	16	61.5
No	5	19.2
Unknown	5	19.2
How Caretakers Report that Clinician(s) Believes Patient Became Infected		
'Don't Know/Was Never Explained'	12	46.2
Vertical (Mother-to-Child)	8	30.8
Father or both parents	6	23.1
Caretaker Reported: Greatest Challenges to Seeking and Adhering to ART		
Dedication to Regimen§	11	42.3
Waiting for a cure	5	19.2
Acceptance of HIV as 'just another disease'	3	11.5
Believing mother and child do not have to die/seeking treatment	3	11.5
Lack of Sufficient Food	2	7.7
Child needs to accept lifelong treatment as (s)he gets older	2	7.7

* Injections, syringes, needles, cutting instruments, tattoos/scarification, nail clippers, contaminated blood from wounds of infected person, unsterilized materials in healthcare settings

§ Faithfully attending appointments, picking up medications, adhering to once-every-12-hour pill regimen, following doctor's instructions

4.8.3 Do incomplete discussions about modes of transmission contribute to self-stigmatization (of caretakers) and cognitive dissonance between caretakers' 'knowledge' and clinicians' beliefs about caretakers?

From caretakers' responses to questions on modes of transmission, we can see that all spontaneously reported sexual relations as a (general) mode of transmission and 85% of them (22 of 26) reported MTCT. A majority of caretakers (16 of 26) reported blood-borne modes of transmission such as syringes, needles, cutting instruments, blades, contact between the wounds of infected persons and uninfected persons, etc... though, again, as we saw with the

adults, this knowledge is not attributed to official sources of HIV information. All of the pediatricians and nurses working in the Day Hospital reported that they believe that MTCT is the primary mode of transmission for their pediatric patients while all also reported the existence of blood-borne routes of transmission within formal and informal healthcare (traditional healers). In terms of how caretakers believe that the patient in their care was infected, we see that 58% report through MTCT (15 of 26) while an additional 19% (5 of 26) report 'through the mother or father'. Analyzing the responses of those who report the latter, we do not find any hint of suspicions of sexual abuse by the patients' fathers, but rather a general misconception that HIV can be transmitted from father to fetus through conception, sexual relations with the mother during pregnancy or perhaps through casual contact later in life. Again, as with the adult patients, we find a disconnect between the modes of transmission reported by clinicians and the modes which are communicated to patients. We also continue to find the majority of caretakers reporting that the possible mode of transmission for the child in their care had never been discussed with them by clinicians. This becomes particularly important with these pediatric patients as the biological mothers of 19% (5 of 26) of the patients interviewed report that they do not have HIV themselves. For an additional 19%, the mother's serostatus during pregnancy (and the possibility of MTCT) is ambiguous as will be illustrated with examples below.

[modes of transmission] *"...through unprotected sexual relations, unsterilized syringes...that kind of thing. Maybe from blades, cutting instruments that another person already used. I think that's about it."* [in relation to how mother believes her own child became infected] *"...well, she [the patient] was tested because, I, her mother, didn't receive treatment during pregnancy. At that time [during pregnancy], I did take the test, there at the testing center...I went and took the [HIV] test, but it didn't show any disease"* [Interviewer: the HIV test was negative?] *"Yes. It was negative. But then I gave birth to my baby and 3 months later she began to get really sick, high fevers at night, that kind of thing...I always brought her to the hospital and they'd say that it would go away, it would go away, they're just fevers. After a while, I requested that they do exams [blood tests], but they said they couldn't do them because she was still a little baby and we had to wait a while...The time came for her to take the [HIV] test. She took it. It came out positive. From there she began treatment right away."* [Interviewer: So how do you believe she became infected then?] *"Through me, right? Maybe I was... maybe it was me who was infected but it didn't show up in the [HIV test] results..."* [Interviewer: You believe that your child was

infected by you?] ***“Yes...because, you see, I didn’t do the treatment during pregnancy. I know lots of kids who have seropositive mothers [who do treatment] and the babies don’t have HIV...so I think she got it from me, because I didn’t do the treatment.”*** [in relation to clinician’s beliefs about how child infected] ***“I’ve always heard, about children, you know, that it’s always from a lack of treatment during pregnancy”*** [Interviewer: Have you been told any particular belief specifically for your own daughter?] ***“No.”*** [31-year-old mother of 5-year-old patient, respondent #674, on ART for 4 years]

In this mother’s narrative (#674), we can see that she was tested for HIV during pregnancy and the test was negative. However, though the mother identifies blood-borne modes of transmission earlier in the interview and acknowledges that she, herself, did not have HIV during pregnancy, never does she hint that her baby could have been infected in any way other than MTCT. Though she says that it was never explained to her how her own child could have become infected, she says that she has always ‘heard’ that when children are infected, it’s because their mothers were not on ART during pregnancy. It is rather vexing that this mother continues to effectively blame herself for not avoiding MTCT (by enrolling in treatment for a disease she did not have) when there is a very real possibility that her daughter could have been infected horizontally. It is important to note here that, though no specific explanation was ever given to this mother about the source of her child’s infection, she is quite aware of the official message about pediatric HIV that is conveyed in Mozambique which is that all pediatric infection is the result of MTCT despite evidence to the contrary. For example, Mozambique’s 2009 DHS, which included concomitant HIV testing of both children and their mothers, showed that 31% of infected children (aged 0-11) were born to uninfected mothers. This would be a lower bound estimate of horizontal transmission in children as no linking of infections between infected mothers and children was carried out.

[In regards to question about how people become infected with HIV] *“That I don’t know.”* [Interviewer: **No one ever explained to you how people can become infected with HIV?**] ***“Well- they explain but I can’t say if it’s the truth”*** [Interviewer: That’s okay. Tell me how you believe that people become infected] ***“They say it can be from the traditional healers, through sexual relations....various routes to transmit this virus.”*** [how mother believes patient became infected] *“This is what I really don’t know.”* [Interviewer **No one ever explained how your child may have become infected?**] ***“No”*** [Interviewer: **But what do you think it might have been? Any ideas?**] ***“I don’t know”*** [clinicians beliefs about how patient infected] *“I don’t know”* [Interviewer: **No one ever**

spoke to you about this...?] **“No. *Nothing*”** [{uninfected} 47-year-old mother of 7-year-old patient, respondent #034, on ART for 2.5 years]

The first point that begs our attention in the narrative above (#034) is this mother’s wariness to speak of modes of transmission in a general sense. She seems distrustful of what she has heard and learned and even when she mentions some modes of transmission, she finishes with the rather vague ‘various routes’. She also claims to have no idea of how her child may have become infected nor how clinicians believe her child may have become infected. Let us put this into context to try to make sense of her responses: This mother and her husband do not have HIV, nor do their other four children. The patient in question is the only person in the household with HIV. Interestingly, this mother reported TV, radio and the hospital as sources of information about HIV (earlier in the interview) and stated that all of these sources of information are reliable. However, when the topic turns to routes of transmission (which she certainly would have seen or heard on TV, on the radio or in the hospital) she seems loath to discuss the topic. This is not particularly surprising considering that the patient is the only member of the household with HIV, possibly making this a sensitive topic, however, what is perplexing is that even in a situation such as this one where the patient most certainly was not infected through MTCT, no clinician has ever explained to this mother how her child may have become infected. Considering that she has four more children (not to mention herself) to protect from infection, one would have hoped that modes of horizontal transmission would have been thoroughly explained to this mother when her child was diagnosed with HIV. An analysis of Mozambique’s 2009 DHS data carried out by Devon Brewer shows that people who reported knowledge of blood-borne transmission of HIV (via infected blood or sharing razor blades or injection needles) were not only less likely to be infected themselves, but that mothers who identified these risks were also less likely to have HIV-infected children, making this topic more than academic.³⁷

[in relation to how mother believes her own child became infected] **“I really don’t know because...he’s the only one [in the family who has HIV]”** [regarding clinicians beliefs about how patient infected] **“He got it...well....talking about this, my heart pounds in my chest like this [beats on chest to demonstrate]. When it’s a child, generally speaking, it’s from the parents, but in my case, it’s not that so I don’t know what to say.”** [Interviewer: So, they don’t know how he got it?] **“They don’t know”** [Interviewer: And the whole family was tested?] **“Yes, yes, yes. We’re all negative”** [Interviewer: And no one here has ever explained how he could

have become infected?] “No. Nothing.” [{uninfected} 44-year-old mother of 9-year-old patient, respondent #690, on ART for 3 years]

Again, we see that this mother of five has one infected child while she and her husband (the patient's father) are also uninfected. Again we find that this mother reports that the possible mode of transmission in her child's case has never been explained to her and, indeed, she becomes quite emotional just speaking of the subject of how her child may have been infected. The only mode of transmission for children that she is able to identify is MTCT, leaving her with anxiety and confusion as to how her own child may have become infected.

[in relation to how mother believes her own child became infected]
“When I went to take the [HIV] test, nothing showed up. While I was pregnant, I had blood tests done and it was negative again. Suddenly, when I was breastfeeding her [the patient], when she was about a year-and-a-half old, I came here to the hospital with swollen breasts and they operated. Afterwards, I got...I got...from there, after they operated, I came again and they did the [HIV] test again and it was positive but it was only a year later that I began treatment.” [Interviewer: So how do you believe that your child became infected with HIV?]
“Well, that's what I don't know. I'm now positive too, but her [the patient's] father, my husband, isn't.” [clinicians beliefs] **“I don't know. I don't know.”** [25-year-old mother of 6-year-old patient, respondent #938, on ART for 1 year]

This particular response is especially disturbing as this mother of two young children tested negative for HIV both before and during her pregnancy with the patient (her second child is four years old, and uninfected; it was during that pregnancy that she began ART). It was only after she underwent a surgical procedure that she tested positive for HIV and close to 4 years later that the patient tested positive for HIV after presenting with opportunistic infections. Following this sequence of events, we may speculate that this mother could have been infected nosocomially, especially considering that her husband is uninfected, and, if she continued breastfeeding after the surgical procedure, could have infected her first child (the patient) at that time. Again, no clinician has ever discussed how this mother's older child may have been infected and she remains perplexed on the issue. She does not explicitly identify the surgery as a possible source of the HIV infection (either her own or her child's), however, as she spontaneously mentions it as having preceded her own positive test, we could surmise that she may harbor suspicions. This mother also identified the hospital and health lectures as the most reliable sources of information while not

mentioning any ‘person-to-person’ sources of information whatsoever. This further highlights the double-edged sword of trust in the formal healthcare system: on the one hand, this trust facilitates seeking and adhering to ART, but on the other hand, this places a particularly heavy burden on the healthcare system to communicate effectively and thoroughly about HIV, including communicating accurate and complete information on modes of possible transmission.

[in relation to how mother believes her own child became infected]
“Through his mother, through his father. Through me...his father had HIV as well...his father got sick, died here in the hospital, and after that the child also got sick. Before my husband died, I also wasn’t feeling well and the child was sick. They said we had HIV...just before his father died...” [in relation to clinician’s beliefs about how child infected] *“I don’t know that either. They never talk about that”* [42-year-old mother of 12-year-old patient, respondent #202, on ART for 2.5 years]

[in relation to how mother believes her own child became infected]
“I can say through blood because when I was pregnant, I took the test and they told me I was [HIV] positive, so, for me, when it came out that she had HIV as well...for me it was from the mother’s blood...my blood. [in relation to clinician’s beliefs about how child infected] *[long pause] I have to say that the doctors...they say it can’t be through other blood [not the mother’s], you know?* [Interviewer: But for your child...?] *“Through blood. Because she is still a child, she’s not a person who...she doesn’t know things about life, about this world, you know? I’ll put it like that [speaking of sex]. So, I think the doctors must believe that she got it from the mother’s blood...my blood. I don’t know.”* [43-year-old mother of 7-year-old patient, respondent #450, on ART for 1 month]

In both of the above narratives, the mothers are HIV positive. However, the first mother (respondent #202) notes that both she and her child were sick and diagnosed with HIV when the child’s father was in the hospital, dying of AIDS. The child was 9.5 years old at that time. This mother attributes her child’s infection to herself and/or the child’s father (again, she makes no reference to any suspicions of sexual abuse by the child’s father but rather seems to believe that perinatal transmission can come from an infected father). The second mother (respondent #450) did, indeed, test positive for HIV during pregnancy and, though she refers to transmission from her own blood infecting the patient, it would seem that she is referring to MTCT (and not horizontal transmission through blood exposures). This child first became sick with opportunistic

infections at 7 years old. While it is conceivable that both of these children were infected through MTCT and it is understandable that the mothers, being HIV positive themselves by the time of the child's diagnosis, would attribute the infection to MTCT, the notable point here is that the issue of how their children may have become infected was never discussed with them by clinicians.

Clinicians working with pediatric patients would be aware, both from their own experience with HIV infected children, as well as through their medical training, that long-term survival, and particularly symptom-free survival, of perinatally-infected children in the absence of ART is extremely low. For example, a paper based on the French Pediatric Cohort looked at 348 HIV-1 infected children born before January 1, 1994, and showed that only 2% of the perinatally infected children were classified as long term non-progressors (LTNPs), defined in this case as not showing signs of clinical nor immunological progression by age 10.³⁸ Another important study of perinatally- and neonatal transfusion-infected children in Los Angeles found that the average symptom-free period from birth to disease progression (symptomatic infection) was considerably shorter for perinatally-infected children (6.4 months) versus neonatal transfusion-infected children (17.8 months).³⁹ Differences in survival between the two groups in this study were also quite dramatic with 75% of perinatally-infected children dying by 44 months of age while 75% of transfusion-infected children survived until 71 months.⁴⁰ Studies of known nosocomial outbreaks of HIV in children in Romania and Russia have also found strong evidence of child-to-mother transmission of HIV through breastfeeding^{41,42}. In cases (such as respondent #202) where the child only exhibits symptomatic infection and tests positive for HIV at an advanced age (7 years old in this example) and the mother is also diagnosed at that time, it is not impossible that this child is an LTNP and was, indeed, infected through MTCT. However, clinicians should have considerable doubts about this scenario. At the very least, the possibility that the child or mother was infected nosocomially and then transmitted HIV to the other during breastfeeding should be considered.

In light of the extremely low probability of perinatally-infected children surviving to 7-11 years of age, symptom-free no less, we should be very concerned about Mozambique's 2009 DHS data which show that 7.9% of 7-11-year-olds and 8.9% of 9-11-year-olds tested for HIV during the survey were found to be seropositive. These children's mothers, who were also tested during the DHS, were found to be seropositive themselves so that these children are often excluded from discussions of possible nosocomial transmission as children whose mothers are also HIV-positive at the time of the DHS test are assumed to have been infected

vertically. The possibility that these children were infected horizontally (which could include transmission through injections, transfusions, circumcision, scarification, etc...) and could have passed HIV on to their mothers through breastfeeding is rarely spoken of in academic and policy circles and would seem to be completely excluded from communications within the Mozambican health sector. This lack of communication about horizontal transmission in children, whether between clinicians and mothers or in public health campaigns, perpetuates the social and political construction of mothers as negligent when their children are infected with HIV, as discussed briefly in Chapter 1. Only one caretaker in this study attributed her child's infection to blood-borne transmission, yet it is telling that she does not believe that clinicians attribute her child's infection to blood-borne routes, despite the fact that she herself is not infected:

[in relation to how mother believes her own child became infected]
"through 'cutting', blood." [Interviewer: during childbirth?] *"No. It's only during childbirth when the mother is infected"* [in relation to clinician's beliefs about how child infected] *"from lots of things...maybe they think that the mother...that I, have [HIV], or other family members at home...I don't know."* [{uninfected} 32-year-old mother of 7-year-old patient, respondent #013, on ART for 14 months]

Though this mother, herself, attributes her child's infection to a blood-borne route, the topic does not seem to have been discussed with her by clinicians as, when asked how the child's clinicians believe that he was infected, she guesses that they might think that she [the patient's mother] is infected (MTCT) but finishes her response with 'I don't know'. This situation raises two red flags: 1) an HIV-negative mother with an HIV-positive child and, 2) a child presenting with HIV at a relatively advanced age (6 years old at first symptoms).

Though MTCT of HIV is a real and urgent problem for which we should continue to expand pre-natal HIV testing and treatment for all infected women²⁴, it is just one more area of HIV prevention in Mozambique that suffers from the distorting effects of partial information. The probability of transmission of MTCT in Africa in the complete absence of ART ranges from 25-35%⁴³, yet here we find mothers who not only blame themselves for not treating their HIV infection during pregnancy to avoid MTCT (believing that transmission is 100%

²⁴ According to UNICEF's 2010 Country Report, by September 2010, 50% of HIV-infected women in Mozambique received ART for PMTCT and sites offering this service in Mozambique increased from 388 in 2007 to 903 by September 2010.

in the absence of treatment), but mothers who themselves were not infected during pregnancy and who believe that their children were infected with HIV because they (the mothers) did not go through a treatment regimen *for a disease that they did not have*, as in the further example below:

[modes of transmission] ***“they say that the origin [of HIV] is from sexual relations. But kids...how...how is it that they have it? This here... I just don’t know...if it comes from some other place...because there are kids who have [HIV], women who are 12, 17 or 50 years old have it, but women who have never had sex”*** [in relation to how mother believes her own child became infected] ***“...the child was infected with HIV/AIDS because of a lack of... how is it... eh...medical care. The mother didn’t do the treatment during pregnancy.”*** [in response to question about how clinicians think baby was infected] ***“From the mother...from me”*** [{uninfected} 28-year-old mother of 9-year-old patient, respondent #163, on ART for 5 years]

In this narrative, we can see an example of another interesting facet of many of these caretakers', and specifically mothers', responses. Although they themselves in these examples are the mothers of the patients, when asked about their or their clinicians' beliefs about how their child may have become infected with HIV, 10 out of 24 biological mothers interviewed invariably refer to themselves in the third person, as in: *“the mother didn’t do the treatment”* (respondent #163); *“it certainly can only have been transmission through his parents...”* (respondent #525); *“through her mother...because I’m her mother and I know she got it from her mother”* (respondent #676); *“because the mother was contaminated [infected] and, her being pregnant, the child also became infected during childbirth”* (respondent #070); *“from her mother...I guess from her mother...me”* (respondent #202). Social psychologists have long been interested in the so-called ‘self-conscious emotions’ of pride and shame and how they manifest in speech. Speaking of oneself in the third person is considered a grammatical indicator of one of these emotions, though it is probably safe to assume that, in the narratives being discussed here, pride (in the action being described), is most likely not a factor. Crozier (1998) explains it this way: “shame involves taking an ‘other’ perspective on the self [...] it is experienced when the individual recognises that his or her action gives rise to a particular kind of interpretation by others even if he or she does not believe that interpretation to be justified”⁴⁴ Rochat (2003) describes how “[t]he self is now recognized not only from a first person perspective, but also from a third person’s[...] The public outlook on the self is simulated for further evaluation of how one is perceived and valued by others. The result of this evaluation, more often than not is either a devaluation or a delusion, linked to so-called “self-conscious” emotions or attitudes such as

pride or shame.”⁴⁵ The caretakers interviewed in this study only refer to themselves in the third person when the mode of transmission of HIV to their child is discussed and, tellingly, not in response to any other questions. This indicates that they feel shame in articulating the idea that they, themselves, have transmitted HIV to their children, whether they are expressing their own belief or their ideas of how clinicians believe their child was infected. The issue of shame and how HIV prevention messages produce or propagate this shame, as well as the potential effects on ART enrollment and adherence for children, will be discussed further in the following section.

4.8.4 How are shame and fear propagated by prevention messages and what effect does this have on caretakers' experiences with ART?

Discussing shame and fear in the context of pediatric ART patients necessarily includes some elements that have already been discussed in the section on adult patients. This is because the caretakers of these pediatric patients are, particularly for younger children, responsible for seeking medical care and making sure that their children adhere to the prescribed appointment and medication regimen. Issues of discrimination against the children themselves do, of course, exist. In Mozambique's 2009 DHS, for example, we find that close to 7% of Maputo City residents believe that HIV-infected children should be separated from other children to avoid transmission. However, it would seem from responses here that caretakers of very young children with HIV do not, in fact, explain to the child exactly why (s)he is taking medications, and, indeed, many report that administering medications is sometimes trying as the children tend to argue things like: “I'm not sick, but you always make me take medicine” (respondent #690). This withholding of at least the name of the illness in question serves a protective purpose for the children themselves so that they do not talk about having HIV/AIDS with other children (or their relatives) partially shielding them from possible discrimination. Presumably, this dynamic would be quite different for pre-adolescents and adolescents, however this older age group which certainly merits study, is outside of the scope of this particular research.

Here we will examine issues of shame as they apply to the caretakers, and especially mothers, of HIV-infected children. Unlike what we have seen with the adult ART patients, the caretakers of pediatric patients did not identify shame to be seen going to the health center (by neighbors, acquaintances, etc...) as a challenge to ART adherence. Though it seems unlikely, this could be because caretakers of HIV-infected children do not feel shame to have their neighbors

know about their children's HIV infections. It would seem more realistic, however, that this could be directly linked to the fact that these caretakers were interviewed during the ongoing decentralization of pediatric patients and many of them, as mentioned earlier, travel from other, sometimes distant, neighborhoods and even from the neighboring city of Matola, to get to the Day Hospital (as seen in Map 2 at the beginning of this section). Very few of the caretakers interviewed live in the immediate vicinity of the Central Hospital. The Central Hospital is also a large and sprawling compound and several entrances (which pass through general pediatrics, for example) will take one to the Day Hospital. This combination of factors makes it unlikely that caretakers who do not live in the immediate vicinity of the hospital would be observed by neighbors or acquaintances taking their children to appointments at the Day Hospital. One pediatrician, in fact, questions the idea that decentralization was meant to diminish discrimination as she believes, from her experience, that caretakers bringing children to the Day Hospital have both more anonymity (being in the Central Hospital which sees thousands of patients for varying ailments from all over the city and province) as well as more specialized attention from physicians and, in particular, pediatricians (respondent #410).

From caretakers' responses in these interviews (as well as clinicians narratives), we see that the shame and fear that they express is more connected to disclosure of their HIV status to their husbands or partners (the fathers of the infected children) as well as disclosure to family members. Previous studies have focused on issues of disclosure for pregnant women or new mothers, often providing valuable insight into the barriers to disclosure (such as fear of domestic violence, abandonment and accusations of infidelity) these women may face.^{46,47} However, these studies stop short of examining any possible upstream causes of fear of these types of discriminatory events.

Responses from several women interviewed here demonstrated that the fear of disclosure is often justified as in the following example:

*"it was scary...because you never know, for all that you're faithful...I was living with [the patient's] father, but after he found out that I had gotten HIV, he preferred to distance himself from me. **Because I took the test again [after the patient tested positive] and, obviously, I opened up, told him that I'm like this [HIV positive]. So he went and did the test and he was negative. So he began to distance himself from that point on. There was nothing to be done, right?"** [31-year-old mother of 5-year-old patient, respondent #674, on ART for 4 years]*

This young mother was not, in fact, HIV-positive during pregnancy, however, when her child became sick and tested positive for HIV at 1 year old, the mother also took the test again and was found to be positive. She is unsure of where she became infected as she had only been with her partner (the patient's father) who was uninfected. However, she gives an implicit nod to the common and highly-publicized belief that adults are infected through (high risk) sex and infidelity when she says that 'you never know, for all that you're faithful...'. Her narrative shows that the fear of disclosure is not unjustified; upon disclosure to her uninfected partner he did, indeed, leave her and their child.

Another mother (respondent #930) recounts how she had to travel for work the month before our interview. The father of her 7-year-old son [the patient] is no longer alive, and the patient stayed with his paternal grandmother and other extended family members. Though the grandmother was aware of the patient's condition and his medication schedule, the other extended family members were not. The grandmother reportedly did not want to administer the medications in front of the other family members who might suspect that the child had HIV. The patient chimed-in during the interview, telling his mother: "I wasn't taking them [the medications] when you went away. I don't know how". His mother reports that he became very ill after approximately two weeks off of his medications and was hospitalized just before she returned to Maputo.

This fear of disclosure (whether it relates to the child's or the parent's serostatus) presents special challenges for the mothers of seropositive children. As we can see in *Table 12*, 42% (11 of 26) of caretakers reported that the greatest challenge to ART adherence (in regards to the child's adherence) is what I have characterized as "dedication to the regimen". Caring for any young child is already a challenge, particularly in a country such as Mozambique which has no governmental social safety net to assist these parents (though at times they may receive assistance from NGOs working in partnership with health facilities). Adding the additional responsibilities of caring for a child with HIV who must be given medications every twelve hours (meaning, they also must eat well every twelve hours), attend frequent medical check-ups and pick up medication refills, not to mention caring for the child should (s)he fall ill, highlights the importance of social and familial support. Many caretakers spoke of the difficulty and sacrifice inherent in keeping these children on ART:

"...I worked as a housekeeper, but afterwards it became difficult because he [the patient] had to go to appointments all the time...so I gave up working to take care of him. I gave up many things; there was just no

way...I needed to take care of him." [36-year-old mother of 9-year-old patient, respondent #177, on ART for 6 years]

"[the challenge is...] the child grows up, but you can't let her disappear...you have to take her aside and be firm about the hours that she takes the pills...take care of her constantly because she's still a child and you're the mother" [39-year-old mother of 6-year-old patient, respondent #348, on ART for 4 years]

"[the challenge is...] to comply with the hours [to take the pills], comply with the check-ups, consultations, analyses...and also to love the child, not punish the child for being sick" [27-year-old mother of 4-year-old patient, respondent #516, on ART for 3 years]

"The difficult part is in eating well...the child has to eat well to take the medications like adults have to. Eh! It's difficult. When you don't do anything [don't work] and there's no one to help you and this disease is always there...always there...It's difficult. It's really difficult." [47-year-old mother of 7-year-old patient, respondent #450, on ART for 1 month]

Nine of the caretakers interviewed here are single and six are widowed, meaning that close to 58% of the interviewees are without a partner to assist with the child's care or provide income or other tangible support. 65% of interviewees have no formal occupation and report being 'housewives'. Several of the widows and single mothers live with extended family. As we have seen with the widowed mother who had to leave her young, infected child in the care of his grandmother while she travelled for work, issues of disclosure and fears of stigma enter into the child's care in a direct and important way. Crucial social and logistical support from family and friends butts up against a certain level of guardedness on the part of caretakers to reveal the child's serostatus, even to other family members. As the child himself has obviously done nothing 'wrong' to be stigmatized, this would lead us to believe that the perceived stigma is handed down, in a sense, from the shame and stigma surrounding adult infection. As MTCT is seen as the almost-exclusive mode of transmission of HIV to children, we can imagine that the issues of stigma that arise for women affect their own disclosure of their serostatus and, by extension, that of their child as well. Recall in the section on adult patients, the mother (respondent #100) and the clinician telling a mother's story (respondent #808); they both spoke of the mothers allowing their infants to die rather than admit their serostatus to their partners and obtain treatment themselves or for their babies. One pediatrician sums up this fear of disclosure thusly:

“...I think adults are often bad at heart. If they already have [HIV], it’s like they want to give it to someone else. We have lots of seropositive mothers that, when they get to us, say: ‘Don’t tell my husband that I’m seropositive and that my child is on ART’, so you can tell that this mother, at home, has a relationship with her husband where she pretends like nothing is going on. And from there, it gets more complicated. We have a lot of mothers here where we ask ‘Why didn’t you give the [antiretroviral] syrup to your child?’ and her: ‘because his father was always with me and he can’t know that our child is on ART’. Now, working with mothers who actually care about their kids- that’s different...” [physician, respondent #410. Working with HIV patients for 6 years]

This physician recounts what seems to be a common theme of adults hiding their (and their child’s) serostatus from their partner for fear of judgment and censure, however, the physician explicitly attributes the patient’s non-disclosure to the patient’s being ‘bad at heart’ (wanting to pass HIV on to her partner) and her failure to give her child his medications (due to the issue of non-disclosure to the child’s father) as ‘not caring’ about her child. Another clinician tells a similar story of fears of disclosure at home interfering with the administration of the child’s medications, though with a markedly different tone:

“I think it’s difficult for them [to administer the medications correctly]. Or the child’s father doesn’t know or someone else in the home can’t know, so I think there are huge problems at the household level to administer these medications to the child.” [physician respondent #704. Working with HIV patients for 4 years]

As Hejoaka (2009) succinctly describes in her study of mothers of HIV-positive children in Burkina Faso: “HIV/AIDS-related stigma adds an additional layer to the burden of care, compelling mothers to deal with tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support”.⁴⁸ As long as receiving social support hinges on disclosure of the child’s serostatus (and, by implication, the perception of the mother’s serostatus), then tracing this stigma, perceived or real, to its source will continue to be an area that requires urgent attention. We can see, both from the adult patient accounts as well as the caretakers of pediatric patients, that mothers are doubly stigmatized when their children are infected with HIV as it is presumed that: 1) they acquired HIV sexually themselves, possibly through promiscuity and unfaithfulness and, 2) they passed HIV to their child(ren) through negligence; through not having done ART to prevent transmission to

their child(ren). These two presumptions are also intimately connected, as we have seen, in that pregnant women who are found to be HIV-positive may not enroll in ART to prevent MTCT for fear of involuntarily disclosing their own serostatus to their partner (by being 'caught' either taking the medications or having them in the home). Both of these messages are very apparent, not only in the patients' and caretakers' accounts, but also in the clinicians' narratives; both messages also precisely echo the thrust of HIV prevention messages that give the impression that all adult transmission is sexual (and due to 'risky' sexual behavior) and all transmission to children is via MTCT.

4.8.5 Do caretakers know that ART functions as prevention and how would that knowledge affect their and the child's experiences with ART?

As we are speaking of pediatric patients, the knowledge (or lack thereof) on the part of their caretakers of ART as a tool for prevention of sexual transmission of HIV may seem irrelevant. However, we must keep in mind two things: 1) the mechanism behind ART as prevention of sexual transmission is the same as the mechanism behind prevention of MTCT which can give us an idea of the reasoning carried out by caretakers who are aware of ART for prevention of MTCT and; 2) these children will eventually be told what disease that they have been treating for all these years and their caretakers will be in a unique position to provide them with information about their disease and on how they can live long and healthy lives while also protecting their future partners and children from infection.

As clinicians' beliefs regarding ART as prevention have already been discussed under the section on adult patients, here we will focus mainly on the caretakers' responses.

Table 13. Beliefs About the Effect of ART on Sexual Transmission of HIV, Caretakers.

	ART Decreases Transmission	ART Increases Transmission	ART No Effect on Transmission	Don't Know
Caretakers of Pediatric Patients	14 (53.8%)	4 (15.4%)	6 (23.1%)	7.7%(%)
Clinicians	4 (28.6%)	1 (7.1%)	7 (50%)	2 (14.3%)

As we may have expected, knowing that the mechanisms behind PMTCT and ART as prevention of sexual transmission are virtually the same, a greater portion of the caretakers interviewed correctly believe that ART will decrease the probability of sexual transmission of HIV (53.8%) than what we saw for the adult patients (45.5%). Fewer caretakers incorrectly believe that ART increases the probability of transmission (15.4%) versus adult patients (22.7%) and a larger proportion of caretakers believe that ART has no effect on sexual transmission (23.1%) versus the adult patients (13.6%). Some caretakers drew an explicit link between PMTCT and the probability of sexual transmission of HIV as in the following example:

“It’s like this: When someone’s sick, they have HIV/AIDS, it doesn’t mean that...well, [saying they couldn’t have sex without a condom] it would be like saying that a person with HIV/AIDS can’t have children. But when a person is adhering to the medications, maybe they get to a phase where they want to have a baby, they talk to the people who are providing them with treatment, and they can have a child. And that child can be born without any problems [HIV]. I’m completely sure, because of that, that it’s the same idea. The chance [of sexual transmission] is less” [43-year-old mother of 7-year-old patient, respondent #450, on ART for 1 month]

Others who reported that the probability of transmission is lower added caveats similar to those we saw in the adult patient interviews, mentioning that the child (when (s)he is an adult) will still always need to use condoms, such as in this example:

“The risk [to transmit] is less, but as he’s seropositive, he will always have to use condoms” [35-year-old mother of 8-year-old patient, respondent #677, on ART for 4 years]

While still others, whether they believed the risk of transmission to be greater or the same, repeated, almost verbatim, the thrust of HIV prevention messages directed at adults as in the following example:

“...she has to take antiretrovirals...and...use condoms, avoid going out, sleeping with people, smoking, drinking...” [Interviewer: but taking the antiretrovirals faithfully, if she has sex without a condom...?] *“She’ll pass HIV to the other person just the same.”* [39-year-old mother of 6-year-old patient, respondent #348, on ART for 4 years]

Overall, we see, again, that the reasoning behind the correct belief that ART reduces the probability of sexual transmission is well-grounded, this time in frequent analogies to PMTCT. Interestingly, none of the caretakers mentioned the metaphor that was common among the adult patients of ARVs 'making the bug sleep'. It would seem that this imagery is either more commonly presented to adult patients to explain the effect of ART on their own bodies, or that the imagery of prevention of MTCT is simply stronger or more visceral for caretakers of pediatric patients. Again, it is worth noting that, of the six physicians interviewed at the Day Hospital, only two reported that ART decreases the probability of sexual transmission of HIV. Apart from the importance of caretakers being given accurate information that they will eventually pass on to the infected children in their care, we must of course, remember that many of these caretakers are adult patients themselves. As we saw with respondent #674, HIV-positive mothers in particular, run the risk of abandonment by their husbands if they disclose their serostatus. This abandonment not only affects the mother, but also the couple's child or children. Were these women and the general public to have both an alternative narrative for how they may have become infected (as discussed in the section on adults) as well as medical advice as to the effects of ARVs on sexual transmission of HIV, perhaps abandonment would gradually become less of an issue, making disclosure less of a concern. As we have seen that fears of disclosure can directly affect the administration of ARVs to infected children, we should not underestimate the downstream effects of HIV prevention messages on caretakers and, ultimately, the experiences of children on ART.

4.9 Conclusions

The primary objective of this fieldwork was to explore the impact of HIV prevention messages on the experiences of people living with HIV or caring for children living with HIV. This impact has been framed as being mediated by two mechanisms: 1) creation or exacerbation of stigmatizing beliefs and; 2) accordance or disconnect between patients (or caretakers of pediatric patients) and clinicians representing the medical establishment.

4.9.1 *Adult Patients*

Through the narratives of the adult patients and their clinicians we can see that, for adults with HIV, 'delivering oneself over' to the official health establishment is repeatedly mentioned as an important step to both being tested for HIV and

ultimately enrolling in and adhering to ART. As the HIV information that these patients receive from unofficial sources (such as ‘on the street’ or from family and friends) sometimes contradicts official health messages, the patients must then accept the official messages or live with a fairly high level of cognitive dissonance. This dissonance may be a cause for people to either not present for testing or a contributor to eventual loss to follow-up for some non-adherent patients. This dynamic of ‘delivering oneself over’ to the health establishment also places a particularly high burden or responsibility on clinicians to be sure that they communicate openly with patients about the scientific facts of HIV. Many of the patients’ scientifically correct beliefs about HIV (such as those concerning blood-borne modes of transmission and the efficacy of ART as prevention of sexual transmission) are based on information they report having received from unofficial sources which they overwhelmingly identified as unreliable and not from official sources which they identified as more reliable. In contrast, clinicians, though they all report awareness of blood-borne modes of transmission, clearly state that they do not discuss these modes of transmission with patients. The clinicians also do not report having received information on the preventative benefits of ART during their medical training and very few (far fewer than the patients) report knowledge of this benefit. Those that are aware of the benefit stated that they do not discuss it with patients for fear of moral hazard or risk compensation behaviors (i.e. decreasing condom usage or increased ‘promiscuity’). There is compelling qualitative evidence from these interviews that consideration of the impact of HIV prevention messages (that historically and currently focus on sexual behavior) on PLWH and clinicians is needed if policymakers truly wish to implement combination prevention strategies. This will be an important prerequisite to achieving further scale-up of ART with early testing and treatment as well as optimal adherence. Researchers and policymakers should explicitly concern themselves with the possible stigmatizing effects of current sexual behavior prevention messages as well as with the scientific accuracy of prevention messages in general.

4.9.2 Caretakers of Pediatric Patients

Mozambique also urgently needs to address the issue of babies and children with HIV born to seronegative mothers or presenting later in childhood with first symptoms: both strong indicators of much higher than estimated levels of horizontal transmission. However, whether or not the mother of an HIV-positive child is seropositive herself, clinicians should be trained to discuss all modes of transmission with mothers for several reasons: 1) to avoid the pitfall of

creating or exacerbating stigma and fear of disclosure (related to adult sexual behavior prevention messages) which has been shown to impact not only the mothers' own treatment seeking behavior and adherence, but also that of their children and; 2) to assure that mothers have all the facts at their disposal to protect their other children from possible horizontal transmission. Despite strong evidence of high levels of horizontal transmission in babies and children in Mozambique, none of the caretakers interviewed reported having received explanations from clinicians of how their own child may have become infected so that we saw several mothers who are not (or were not) seropositive blaming themselves for their child's HIV infection, believing that because they did not take antiretrovirals to prevent MTCT, they themselves had infected their children. This kind of self-stigmatization has observable consequences for voluntary disclosure to partners and family members and has been shown to not only isolate mothers of seropositive children, but also to lead to negative effects on adherence for the children themselves (for example, when the infected child's mother must leave the child with relatives, all of whom may not be privy to her/his serostatus and treatment needs).

4.9.3 *Clinicians*

While the discussions here regarding the disconnects found between patients' and caretakers' (often correct) knowledge of topics related to HIV that go undiscussed and clinicians' own knowledge (or what clinicians discuss with patients), may seem to vilify clinicians, that was not at all the purpose. The social construction of HIV in Mozambique is powerful and manifests itself in many ways. Professionals, such as clinicians, are not immune to these social constructions and, indeed, are bound within the same framework of partial information as patients. It could even be said that clinicians may be more tightly bound than patients as they are trained in an atmosphere laden with implicit political and social priorities that are frequently out of step with the scientific and, in this case, clinical reality as discussed in Chapter 1. They are taught, for example, that UNAIDS estimates that blood-borne transmission accounts for less than 2% of transmission in sub-Saharan African nations, are hard facts. They are indoctrinated that 95% of transmission of HIV in sub-Saharan Africa is through unprotected ('high risk') sex and that MTCT is the almost-exclusive mode of transmission of HIV for infected children.

Though the Mozambican Ministry of Health, in 2001, officially acknowledged the preventative benefits of ART and claimed a dedication to their usage in this

manner (as seen in the quote at the beginning of this chapter), this knowledge is not imparted to clinicians, whether they be medical technicians, nurses or physicians. While patients may be free to muse about possible ‘truths’ in regards to HIV, clinicians carry a heavy burden of responsibility and are not free to express their opinions (however well-reasoned) to patients, particularly when those opinions contradict the official messages concerning HIV in Mozambique. Indeed, several clinicians at both health facilities expressed their own internal struggles to harmonize the ‘conventional wisdom’ on HIV with their own daily experiences with patients that, at times, seem to repudiate what they have been taught to believe and to impart to patients. Recall, for example, nurse respondent #106 who expressed doubts about how she has always been told that HIV transmission happens primarily through sexual relations, but due to her own experience with so many discordant couples, she feels that there is something amiss with the official message. Others express a general sort of disquiet with the way that prevention campaigns are carried out and with the messages imparted as in the following example:

*“Now that I’m working directly with patients, I really see that, if we had done something MORE, who knows if we would have fewer infected people, you know? But **I think that these campaigns really... they need to change something in their prevention strategy, their information, for people to be able to trust a little more and for us to really be able to decrease the number of new cases.**”*
[physician respondent #306. Working with HIV patients for 4 years]

While one physician, in her analysis of Mozambique’s HIV situation, questions not only the thrust of prevention campaigns, but also the possible intentions or ulterior motives of the ‘international development community’ in allowing HIV to rage out of control in Africa for decades, pushing what she sees as toothless prevention campaigns, while lamenting the fact that a cure remains elusive. Though we may not agree with this physician’s musings on the possible ulterior motives behind the formulation of sexual-behavior based prevention policies (which she, herself, states have no basis in scientific fact but are, rather, her ‘gut’ feeling), it is nonetheless a strong signal that some clinicians in Mozambique feel that largely internationally-imposed policies stressing sexual behavior are disconnected from the clinical and social reality found in Mozambique, while many scientifically-sound, clinical interventions (such as a cure) remain out-of-reach:

*“**HIV looks a lot like a cold war to me.** We still haven’t gotten HIV under control. It’s a huge issue with huge amounts of money, many people, and*

involves many areas...The people who die the most are the underprivileged, and that's us: Africans...And we die because we're the poorest... We know that the world is overcrowded...we already had the 1st and 2nd World Wars and many people died. We can't have a third, we can only have this kind of thing. So, when I forget medicine, lots of times, I have this opinion. Even if the virus [HIV] wasn't 'manufactured', it's a form of cold war...so many people dead from this and what do we do? Prevention campaigns! Ahhhhhh- prevention campaigns! But there's still no cure. We're so developed in all areas. Is it really possible that a cure doesn't exist? Could it be? ...I think that the time has already come for us to have a definitive treatment [cure]. A lot of us have died, but we still don't have a cure."

It is my hope that readers will recognize that most criticism embodied in this study is a criticism of upstream policies concerning HIV rather than a criticism of the mainly well-meaning and hard-working clinicians who see patients every day. Indeed, both adult patients and caretakers of infected children who were interviewed largely report that their clinicians frequently treat them well and with kindness, attempting to understand and help with issues that arise during treatment.

4.9.4 Decentralization

While decentralization was discussed here through the lens of logistical issues, it also undeniably impacts and is impacted by the social construction of HIV. Decentralization of HIV services has the potential to be a double-edged sword in that it undeniably improves potential access to ART, particularly in urban areas with numerous health centers that can now offer ART. However, as long as the issues of creation and exacerbation of stigma through official HIV prevention messages (and, by extension, the medical establishment) are not addressed, we run the risk of training an increasingly large cadre of clinicians (mainly medical technicians) in a way that will continue to enhance stigma. If we couple these stigmatizing messages with proximity to patients' homes and an increased risk of involuntary disclosure of patients' HIV status to neighbors and acquaintances, we chance offsetting some of the benefits of more proximate ART availability with the possible pitfall of increased negative social consequences for patients on ART.

Notes

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- ² Conselho Nacional de Combate ao HIV/SIDA (CNCS), *Relatório Anual de Progresso de Actividades de Combate ao HIV e SIDA – 2009*, Moçambique (2010).
- ³ Mozambican Ministry of Health (MISAU), *Relatório de prestação de Contas de Maputo Cidade* (2007).
- ⁴ *ibid*
- ⁵ The Global Fund “Grant performance report: Mozambique (MOZ-911-G10-H)” Available from www.theglobalfund.org/grantDocuments/MOZ-911-G10-H_GPR_0_en.pdf (2011).
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- ⁷ CNCS, *Relatório Anual*
- ⁸ Mills, Nachega, Buchan, et al. Adherence to antiretroviral therapy in sub-Saharan Africa and North America. *JAMA: The Journal of the American Medical Association* 296/6 (2006).
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- ¹³ Pearson, Micek and Pfeiffer et al., “One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans,” *AIDS Behavior* 13 (2009).
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¹⁶ Schneider, Kaplan, Grenfield and Wilson, "Better Physician-Patient Relationships Are Associated with Higher Reported Adherence to Antiretroviral Therapy in Patients with HIV Infection," *Journal of General Internal Medicine* 19/ 11 (2004).

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¹⁸ Ministério de Saúde Direcção de Recursos Humanos (DRH) "Relatório Anual 2010," Maputo: República de Moçambique, XXVI CCS (2011).

¹⁹ Mozambican Ministry of Health, "National ART Database", http://www.misau.gov.mz/pt/hiv_sida/programa_de_tratamento_antiretroviral_tarv/dados_tarv_nacionais (last accessed October 21 2011).

²⁰ *Ibid*

²¹ Guttman, Boccher and Salmon. "Credibility of information from official sources on HIV/AIDS transmission". *Public Health Rep.* 113 (1998).

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²⁴ Pearson, Micek and Pfeiffer et al., "One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans," *AIDS Behavior* 13 (2009).

²⁵ Ware, Idoko and Kaaya et al., "Explaining adherence success in sub-Saharan Africa: An ethnographic study," *PLoS Med* 6 /1 (2009).

²⁶ Nachega, Stein and Lehman et al., "Adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa," *AIDS Res Hum Retroviruses* 20/10 (2004).

²⁷ see for example: Ware, Idoko and Kaaya et al., "Explaining adherence success in sub-Saharan Africa: An ethnographic study," *PLoS Med* 6 /1 (2009).

²⁸ Demographic and Health Surveys, Mozambique, 2009 (<http://measuredhs.com/Data/>)

²⁹ *Ibid*

³⁰ see for example: Birbeck, Chomba, Kvalsund, et al. "Antiretroviral adherence in rural Zambia: The first year of treatment availability". *The American Journal of Tropical Medicine and Hygiene* 80/4 (2009).

- ³¹ see for example: Pearson, Micek, Pfeiffer et al. "One year after ART initiation: Psychosocial factors associated with stigma among HIV-positive Mozambicans". *AIDS and Behavior* 13/6 (2009).
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- ⁴¹ Visco-Comandini, Ubaldo, Longo et al. "Possible child-to-mother transmission of HIV by breastfeeding". *The Journal of the American Medical Association* 294/18 (2005).
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- ⁴⁴ Crozier. "Self-consciousness in shame: The role of the 'other'." *Journal for the Theory of Social Behaviour* 28/3 (1998) p 273-274.

⁴⁵ Philippe Rochat. "Five levels of self-awareness as they unfold early in life." *Consciousness and Cognition* 12/4/12 (2003) p 722.

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CONCLUSION

It was my hope, with this doctoral dissertation, to explore the socio-political economy of antiretroviral treatment (ART) as an HIV prevention strategy in sub-Saharan Africa (SSA) and, specifically, in Mozambique. As decentralization plays such a large role in efforts to scale-up HIV services (including treatment), some of the potential ‘human’ consequences of bringing treatment for a stigmatized illness closer to patients’ homes has been briefly explored as well within the case study.

We began with a look at the social construction of HIV in SSA as a ‘sexually transmitted disease’ despite the biological fact that it is, instead, a sexually *transmissible* infection with very low transmission efficiency through heterosexual sex of only 1 in 1000¹. This inordinate focus on sexual transmission in SSA to the exclusion of other routes of transmission (i.e.: blood-borne transmission in formal and informal healthcare settings and even during cosmetic procedures) in the face of evidence that sexual transmission is less important than previously believed, not only allows new infections to continue to occur in areas that do not receive attention, but also has both fed and been fed by a political and social climate that blames individuals for their infection.

The political discourse surrounding HIV relies heavily on this sexual ‘causal story’^{2,3} so that phenomena such as target groups and risk groups in HIV policy are consistently determined by perceived sexual behavior (‘lifestyle risks’) rather than any acknowledgement of environmental (or institutional level) risks. These target and risk groups are more than theoretical constructions; they determine both the recipients of beneficial or punitive policies and, perhaps more importantly, the rationales that are deployed to justify said policies. Domestic and global HIV policies that remain rooted in a rights- or justice-based discourse (such as with commitments to the ephemeral ‘universal access to HIV prevention’) ignore instrumental logic for implementing effective HIV policy, allowing politicians and society as a whole to continue to frame the issue of providing universal ART, for example, as an altruistic service of a government (or international

donor) that is attempting to mitigate a problem caused by the irresponsible and self-destructive behavior of individuals⁴.

This constructed dichotomy, therefore, has created a world where those infected with HIV are often ‘monsterized’ and the remaining population is taught that they must always be vigilant and ‘protect themselves’ from these virtual monsters. This socio-political construction assists us in the critical analysis of HIV policy, such as the discussion in Chapter 1 of the political minefield of post-exposure prophylaxis (PrEP: things like vaginal gels for uninfected women to avoid contracting HIV) versus ART for infected persons. Practical issues such as the financial, logistical and human resource constraints that are being tackled to attempt to provide ART to the 10-15% of the adult population that is infected with HIV and what these constraints would mean in terms of attempting to provide these same medications to the 85-90% of the population that is uninfected are not on the table for serious policy discussion. The issue is consistently framed as one of providing disempowered potential ‘victims’ with a way of protecting themselves from the infected population living with HIV and an honest discussion of the feasibility of the PrEP approach is not politically viable as it would pit the interests and ‘rights’ of the monsterized group against those of the ‘victims’.

Chapter 2 then explored, in depth, the most efficacious form of HIV prevention currently in existence: ART for infected persons. As proven beyond a doubt by the HTPN 052 trials, the first randomized clinical trial to test the efficacy of ART as prevention, early ART is 96% effective in preventing sexual transmission of HIV to an uninfected partner⁵. This compares to the 80-90% efficacy of condoms for HIV prevention^{6,7}. However, though ART is the most efficacious intervention, it was my hope to also demonstrate that, even with the logistical barriers to large-scale ART provision, the all-important coverage and usage factor cannot be ignored. ART is more efficacious than condoms for HIV prevention, but as we have seen only slow growth of condom usage over the preceding three decades in Mozambique, ART, which is being rolled-out at an astonishing pace, may already be preventing more new infections in Mozambique than those that are being prevented by condoms due to this difference in coverage. Condoms are a barrier method of HIV prevention, meaning that they will also prevent pregnancy. A method of HIV prevention that precludes having children (for ei-

ther the infected or uninfected partner) is a population-level dead-end. It must also be acknowledged that there are perverse consequences in terms of trust between partners of the concerted (and successful) effort over the last 30 years to link condoms to HIV prevention. This has caused many Mozambicans who do not use condoms to report that they avoid their usage because they are married and/or trust their partners⁸. Suggesting condom usage in a monogamous relationship has become akin to either showing your distrust in your partner or your own untrustworthiness.

For these reasons, I have encouraged what I call a ‘focus on the positives’; that is, HIV policy that focuses on the relatively smaller HIV-infected population, rather than the uninfected population. However, to do so, a dramatic paradigmatic shift would be necessary, particularly in terms of earmarked funding from the US government’s PEPFAR program which provides the bulk of HIV-specific funding in Mozambique and much of the developing world.

The rules surrounding PEPFAR funding remain strict in their determination of what ‘counts’ as HIV prevention (abstinence/‘be faithful’ programs, male circumcision, and targeting of multiple and concurrent partnerships)⁹. This means that the most efficacious prevention intervention known to humankind (ART for infected persons) may not be considered as prevention under PEPFAR rules and so may not receive prevention-specific funding. While 35% of FY 2010 PEPFAR funds in Mozambique were channeled towards treatment and care, this fell far short of the PEPFAR rule that 50% of total funds must go towards treatment and care¹⁰. Rather than simply being a matter of financial allocation, these types of issues show the ongoing dichotomy and political trap discussed earlier where governments and institutions must seem to care more about protecting potential ‘victims’ of the HIV epidemic than the ‘monsterized’ infected persons.

Though ART as HIV prevention will function with or without official acknowledgement, it will be important to reconsider the artificial boundary drawn between prevention and treatment that perpetuates the negative social construction of those living with HIV. The allocation of resources is an explicit manifestation of government and international donor priorities as well as the ‘philosophy’ underlying those priorities. Were ART to be officially considered a

prevention strategy, this would help to ‘de-monsterize’ and empower those living with HIV, showing that ‘the positives’ have the power to turn around the HIV epidemic through a behavior (adhering to ART) that is also in their own, personal, health-seeking interests. Though the fear of moral hazard manifests whenever discussions of ART as prevention are broached, there is very little (and often contradictory) evidence that patients on ART would compensate for the preventative effects of ART by becoming more promiscuous or decreasing condom usage. Indeed, the qualitative evidence from the interviews conducted with patients and clinicians during the fieldwork portion of this study (Chapter 4) shows a quite different scenario; one where patients express a nuanced understanding that ART as prevention would never be 100% certain (and condoms should still be used) but also the patients’ sense of pride and self-worth to know that adhering to ART could help one’s partner remain uninfected.

Though a paradigmatic shift to ‘focus on the positives’ would greatly facilitate ART scale-up (and therefore the utilization of ART as prevention), the issue of human resource constraints cannot be ignored and is the topic of Chapter 3. Mozambique’s human resources for health (HRH) are considered to be in a state of ‘critical shortage’ by the WHO¹¹. Though human resource projections through 2015 call for massive increases in clinical personnel (and some categories such as technicians, both medical and laboratory are set to exceed official goals)¹², entrenched issues of public to private brain drain and a general lack of incentives for public sector health workers must be addressed systematically. In particular, the physician cadre remains undervalued in the public sector and highly-coveted in the private, donor-funded sector. Though Mozambique attempted, in 2000, to address this issue with the non-binding ‘Kaya Kwanga Commitment’¹³, a code of conduct that was signed by virtually all the major international organizations working in Mozambique’s health sector, strong financial incentives continue to pull clinicians (and particularly, physicians) into the private sector¹⁴. Mozambique must make a concerted effort to truly implement regulations and incentive programs to avoid this internal brain drain, following through on governmental promises to increase human resource expenditures as a percentage of health spending (rather than decreasing them as we have seen in recent years)¹⁵.

Though the strategy of ‘task shifting’ which delegates clinical responsibilities from higher to lower cadres of staff (for example, from physicians to medical

technicians)¹⁶ has allowed for the crucial decentralization and expansion of HIV services (including ART provision), it cannot be considered a panacea to Mozambique's critical health worker shortage. Mozambique risks training an increasing horde of medical technicians (those to whom the responsibility of initiation and follow-up of ART has been delegated since 2006) who are steeped in the negative social construction of HIV-positive persons as discussed in Chapter 1. As, with the process of decentralization, patients are treated for HIV closer and closer to their homes, we must consider more closely the 'human' side of the human resource issue to be sure that we are not simply bringing stigma and censure closer to patients' neighborhoods.

Chapter 4 then is a culmination of the previous chapters that attempts to examine the practical effect of the social construction of HIV in Mozambique on persons living with HIV and seeking treatment. By carrying out the fieldwork portion of the dissertation in the capital, Maputo, I have attempted to minimize the logistical and human resource constraints that are more severe in peri-urban and rural areas and instead focus on the more intangible aspects of patients' experiences with ART. Through a number of semi-structured, qualitative interviews with adult patients, caretakers of pediatric patients and clinicians (physicians, nurses and medical technicians) in two medical facilities, the case study uses a mediation model to explore the effect of HIV prevention messages (focused on sexual behavior and mother-to-child transmission) on patients' experiences with and adherence to ART. The mediating factors identified are creation or exacerbation of stigmatizing beliefs and the trust or disconnect between patients and the medical establishment created by these aforementioned HIV prevention messages.

Through an examination of patients' knowledge and beliefs about HIV, their sources of information and, importantly, which sources of information they believe are credible, we find that many patients (and caretakers of pediatric patients) indeed have received correct information about HIV (for example, concerning blood-borne transmission and the efficacy of ART as prevention), but that they have received this information from sources which they identify as unreliable and not, crucially, from official sources of information (i.e. health workers, TV and radio) which they largely consider reliable. In fact, though the clinicians interviewed were aware of issues of blood-borne transmission, for example, we find a

severe disconnect between their knowledge and the knowledge that they impart to patients, with an unwillingness to discuss non-sexual (or non-MTCT) modes of transmission with patients. We find that communications with patients (whether directly through patient-clinician interactions or indirectly through public health campaigns) remain ensconced in the ideologically-tinged information base of the sexual behavior (and, to some extent, the MTCT) paradigmatic causal story of the HIV epidemic. Though some patients and clinicians expressed doubts about the accuracy of this paradigm based on their own experiences, the dominance of this paradigm is paramount and seems to be creating considerable cognitive dissonance for patients who must disregard the (correct) information they sometimes receive from unofficial sources in order to ‘deliver themselves’ over to the medical establishment with its life-saving potential. Not incidentally, we also find clinicians who seem to be experiencing a certain level of disconnect between the official HIV causal story that they have been taught (both in and out of their medical studies) and what they see in their day-to-day experience.

This continued focus on sexual transmission in HIV prevention campaigns seems to be feeding into perceived stigma among ART patients so that they repeatedly and consistently expressed shame in their seropositivity (or in the belief that they infected their child, in the case of the mothers of pediatric patients interviewed). This seems to lead to issues surrounding disclosure, both voluntary disclosure to partners and family members as well as involuntary disclosure (for example, by being seen going to the health center regularly or taking medications). As numerous studies have demonstrated the importance of disclosure to ART initiation and adherence^{17,18,19}, these issues of stigma being created by our very own HIV prevention messages and communications between patients and clinicians can no longer be ignored. Patients’ stories of how their fear and shame of disclosing their serostatus concretely impacted their experiences with ART ranged from young mothers who forwent treatment during pregnancy allowing their newborn infants to die of AIDS rather than admit their serostatus, to a young child who was admitted to the hospital with an AIDS-defining illness after his grandmother (with whom he was left while his mother traveled) failed to give him his ARVs for fear that other family members in her household would guess that the child was infected with HIV. We saw uninfected mothers whose children are on ART who blame themselves for their child’s infection, believing that it must have been their own failure to undergo treatment – *for a disease that they did*

not have – that was responsible for their child's infection. We heard the bewilderment of numerous patients when asked how they may have become infected (with some positing through bogus routes of transmission such as 'food') and, more significantly, their confessions that no clinician had ever discussed the possible mode of transmission with them. These patients, however, almost invariably believe that those around them (including their clinicians) think that they were infected through sexual relations and many, without prompting, preemptively mentioned the fact that they are faithful to their partners and/or have only ever been with one (sometimes uninfected) partner, revealing that they are quite aware that they are, indeed, being judged by both clinicians and society as sexually deviant (promiscuous and/or unfaithful) because they are infected with HIV.

If, indeed, we are to take full advantage of the preventative externalities of ART as HIV prevention, we cannot underestimate the importance of pro-active treatment-seeking behaviors. Early treatment is crucial (as discussed in Chapter 2) and adherence must be optimal. In light of this, the many stories of patients who delayed being tested for HIV due to the very real fear of social and personal consequences (such as being thrown out of their home by a husband who would assume they were unfaithful) or delay enrollment in treatment to avoid voluntary or involuntary disclosure, can no longer be ignored. We must take a critical look at how the social construction of HIV in Mozambique and globally affects 'the positives' so that we may understand how we, as a global society, can bring these HIV-infected persons into the prevention fold, empowering them and utilizing their potential to curb the HIV epidemic in the most efficacious and promising way available to us: through the explicit use of ART as HIV prevention.

Notes

- ¹ Ronald H. Gray, Maria J. Wawer, Ron Brookmeyer, et al., "Probability of HIV-1 transmission per coital act in monogamous, heterosexual, HIV-1-discordant couples in Rakai, Uganda," *The Lancet* 357/9263/4/14 (2001).
- ² Deborah Stone, "Causal Stories and the Formation of Policy Agendas," *Political Science Quarterly*, 104/2 (1989).
- ³ Moritz Hunsmann, "Political determinants of variable aetiology resonance: Explaining the African AIDS epidemics", *International Journal of STD & AIDS* 20/12 (2009).
- ⁴ Discussion of justice-based vs. instrumental-based policy rationale based on: Anne Schneider and Helen Ingram, "Social Construction of Target Populations: Implications for Politics and Policy," *The American Political Science Review*, 87/2 (1993): 334.
- ⁵ Cohen, Myron S. "HTPN 052," Paper presented at 6th IAS Conferenc, Rome, Italy (2011).
- ⁶ Weller, S., and K. Davis "Condom effectiveness in reducing heterosexual HIV transmission," *Cochrane Database Syst Rev*, 1 (2002).
- ⁷ Pinkerton, Steven D., and Paul R. Abramson "Effectiveness of condoms in preventing HIV transmission" *Social Science & Medicine* 44/9/5 (1997).
- ⁸ Demographic and Health Surveys, Mozambique. Available from <http://www.measuredhs.org> (2009).
- ⁹ The Kaiser Family Foundation "Reauthorization of PEPFAR, the United States leadership against HIV/AIDS, Tuberculosis and Malaria act: A side-by-side comparison to current law," Menlo Park, CA. (2008).
- ¹⁰ The U.S. Presiden'ts Emergency Plan for AIDS Relief "The United States Government Global Health Initiative," Available from <http://www.pepfar.gov/documents/organization/136504.pdf> (2009).
- ¹¹ World Health Organization "The World Health Report 2006 - Working together for health," Available from <http://www.who.int/whr/2006/en/index.html> (2006).
- ¹² Ministério de Saúde Direcção de Recursos Humanos (DRH) "Relatório Anual 2010," Maputo: República de Moçambique, XXVI CCS (2011).
- ¹³ Ministry of Health, Mozambique "The Kaya Kwanga Commitment: A code of conduct to guide the partnership for health development in Mozambique," Available from http://www.misau.gov.mz/pt/media/files/codigo_de_conduta (2000)

¹⁴ Pfeiffer, James, Wendy Johnson, Meredith Fort, Aaron Shakow, Amy Hagopian, Steve Gloyd, and Kenneth Gimbel-Sherr “Strengthening health systems in poor countries: A code of conduct for nongovernmental organizations,” *Am J Public Health* 98/12 (2008).

¹⁵ Ministério de Saúde Direcção de Recursos Humanos (DRH) “Relatório Anual 2010,” Maputo: República de Moçambique, XXVI CCS (2011).

¹⁶ Zachariah, R., N. Ford, M. Philips, S. Lynch, M. Massaquoi, V. Janssens, and A. D. Harries “Task shifting in HIV/AIDS: Opportunities, challenges and proposed actions for sub-Saharan Africa,” *Transactions of the Royal Society of Tropical Medicine and Hygiene* 103/6: 549 (2009).

¹⁷ Pearson, Micek and Pfeiffer et al., “One Year After ART Initiation: Psychosocial Factors Associated with Stigma Among HIV-Positive Mozambicans,” *AIDS Behavior* 13 (2009).

¹⁸ Nachega, Stein, Lehman et al., “Adherence to Antiretroviral Therapy in HIV-Infected Adults in Soweto, South Africa,” *AIDS Research And Human Retroviruses* 20/10 (2004).

¹⁹ Ware, Idoko and Kaaya et al., “Explaining adherence success in sub-Saharan Africa: An ethnographic study,” *PLoS Med* 6 /1 (2009).

APPENDICES

Appendix 1

Appendix 1, Table 1. Reasons for condom usage, Mozambique 2009

	15-19	20-24	25-29	30-34
Total # of respondents who have ever had sexual intercourse	1225	1616	1539	1295
Number who used condom at last intercourse	399	383	226	134
<i>% who used condom at last intercourse</i>	32.6	23.7	14.7	10.3
Number who used condom to prevent STI	350	288	159	92
<i>% to prevent STI</i>	87.7	75.2	70.4	68.7
Number who used condom because 'Don't trust partner'	19	23	16	14
<i>% because 'don't trust partner'</i>	4.8	6.0	7.1	10.4
Number who used condom due to messages advising use	8	13	6	1
<i>% due to messages</i>	2.0	3.4	2.7	0.7
Number who used condom to prevent pregnancy	265	257	132	77
<i>% to prevent pregnancy</i>	66.4	67.1	58.4	57.5
Number who used condom for 'Other' reasons	10	14	20	8
<i>% for 'other' reasons</i>	2.5	3.7	8.8	6.0
Number who used condom to prevent STI AND to prevent pregnancy	232	188	94	49
<i>% Overlap- STI/Pregnancy</i>	58.1	49.1	41.6	36.6
Number who used condom to prevent STI and due to messages	2	5	3	0
<i>% Overlap- prevent STI/ messages</i>	0.5	1.3	1.3	0.0

Source: Demographic and Health Surveys, Mozambique 2009

Appendix 1, Table 2. Reasons for not using condoms, Mozambique 2009

	15-19	20-24	25-29	30-34
Total # of respondents who have ever had sexual intercourse	1225	1616	1539	1295
Number who did not use condom at last intercourse	826	1233	1312	1161
<i>% who did not use condom at last intercourse</i>	67.4	76.3	85.3	89.7
Number who did not use condom because no condom available	246	196	175	146
<i>% because no condom available</i>	29.8	15.9	13.3	12.6
Number who did not use condom because partner refused	110	114	116	90
<i>% because partner refused</i>	13.3	9.2	8.8	7.8
Number who did not use condom because they use other contraceptive	13	10	17	11
<i>% because use other contraceptive</i>	1.6	0.8	1.3	0.9
Number who did not use condom because condom reduces sexual pleasure	90	93	79	55
<i>% because reduces pleasure</i>	10.9	7.5	6.0	4.7
Number who did not use condom because they 'trust partner'	183	372	368	386
<i>% because 'trust partner'</i>	22.2	30.2	28.0	33.2
Number who did not use condom because "I'm married"	230	530	689	626
<i>% because 'I'm married'</i>	27.8	43.0	52.5	53.9
Number who did not use condom because "I'm faithful"	67	148	153	161
<i>% because "I'm faithful"</i>	8.1	12.0	11.7	13.9
Number who did not use condom for other reasons	62	88	79	62
<i>% for other reasons</i>	7.5	7.1	6.0	5.3
Number who did not use condom because 'trust partner'/married	35	115	133	154
<i>% Overlap 'trust partner'/married</i>	4.2	9.3	10.1	13.3

Source: Demographic and Health Surveys, Mozambique 2009

Appendix 2

Appendix 2, Table 1. Adult Study Patient Characteristics.

	N	%
Adult Study Patients	22	
Sex		
Male	5	22.7
Female	17	77.3
Age, years		
(Median Age= 35.5)		
25-30	8	36.4
31-35	3	13.6
36-40	8	36.4
> 41	3	13.6
Months on ART		
(Median = 38)		
6-12	7	31.8
13-24	6	27.3
25-36	5	22.7
37-48	1	4.5
49-60	2	9.1
61-72	0	0
73-84	1	4.5
Transferred to Current Medical Facility During Decentralization		
Yes	6	27.3
No (began treatment at current facility)	16	72.7
Language Spoken in Home		
Changana	15	68.2
Portuguese (exclusively)	4	18.2
Ronga	3	13.6
Years of Schooling		
(Median = 8.5)		
1-5	4	18.2

6-9	9	40.9
10-12	9	40.9
Civil Status		
Single/Never Married	5	22.7
Married/Cohabiting	9	41.0
Divorced/Separated	5	22.7
Widowed	3	13.6
Profession		
Student	3	13.6
Sales/Commerce/Services	4	18.2
Domestic Employee	1	4.5
Farming	1	4.5
Professional	2	9.1
No formal occupation	11	50.0
Religion		
Protestant/Zion/Pentecostal	18	81.8
Catholic	2	9.1
Muslim	2	9.1

Appendix 2, Table 2. Caretaker and Pediatric Patient Characteristics.

	<i>N</i>	%
Caretakers of Pediatric	26	
Patients		
Sex Patient		
Male	14	53.8
Female	12	46.2
Sex Caretaker		
Male	0	0
Female	26	100
Patient Age, years		
(Median Age= 7)		
0-2	0	0
3-4	3	11.5
5-6	7	26.9
7-8	9	34.6
9-10	6	23.1

11-12	1	3.8
Caretaker Age, years		
(Median Age= 34)		
25-30	10	38.5
31-35	6	23.1
36-40	4	15.4
41-45	5	19.2
<46	1	3.8
Months on ART		
(Median = 48)		
1-12	3	11.5
13-24	2	7.7
25-36	5	19.2
37-48	4	15.4
49-60	7	26.9
61-72	1	3.8
73-84	2	7.7
85-96	2	7.7
Language Spoken in Home		
Changana	12	46.2
Portuguese (exclusively)	9	34.6
Ronga	4	15.4
'Manhambane'	1	3.8
Years of Schooling of Caretaker		
(Median = 6.5)		
1-5	11	42.3
6-9	4	15.4
10-12	3	11.5
>13		
Civil Status of Caretaker		
Single/Never Married	9	34.6
Married/Cohabiting	10	38.5
Divorced/Separated	1	3.8
Widowed	6	23.1
Profession of Caretaker		
Student	1	3.8
Sales/Commerce/Services	5	19.2
Professional	3	11.5
No formal occupation	17	65.4

Religion of Caretaker

Protestant/Evangelical	17	65.4
Catholic	6	23.1
Other	1	3.8
None	2	7.7

Appendix 2, Table 3. Clinical Provider Characteristics.

	<i>N</i>	%
Clinicians Interviewed	14	
Sex		
Male	0	0
Female	14	100
Profession		
Physician	7	50.0
Nurse	5	35.7
Medical Technician	2	14.3
Years working with HIV+ Patients		
(Median = 4)	8	57.1
1-4	4	28.6
5-8	2	14.3
9-11		
Language Spoken in Home		
Portuguese (exclusively)	8	57.1
Changana and Chope	3	21.4
Ronga	1	7.1
Other	2	14.3
Religion		
Catholic	6	42.9
Muslim	3	21.4
Christian (non-denominational)	3	21.4
Protestant/Evangelical	1	7.1
None	1	7.1



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Conclusion

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