





This is to certify that the dissertation entitled

# PEPFAR, POLITICS, AND PATIENTS / ANTIRETROVIRAL TREATMENT IN TANZANIA

presented by

Marita Eibl

has been accepted towards fulfillment of the requirements for the

Ph.D	degree in	Anthropology
	Cinne.	Jerusin
	Major Pro	fessor's Stonature
	8	09/10
		/ / Date

MSU is an Affirmative Action/Equal Opportunity Employer

DATE DUE	DATE DUE	DATE DUE
· <u></u>		·
· · · -		

PLACE IN RETURN BOX to remove this checkout from your record. TO AVOID FINES return on or before date due. MAY BE RECALLED with earlier due date if requested.

# PEPFAR, POLITICS, AND PATIENTS / ANTIRETROVIRAL TREATMENT IN TANZANIA

By

Marita Eibl

## A DISSERTATION

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

# DOCTOR OF PHILOSOPHY

Anthropology

### ABSTRACT

### PEPFAR, POLITICS, AND PATIENTS / ANTIRETROVIRAL TREATMENT IN TANZANIA

By

#### Marita Eibl

In my dissertation, I draw on research carried out in Dar es Salaam, Tanzania, in 2004 and 2007 to examine the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) programming of antiretrovirals, or ARVs, and women's access to those medicines. Using a global health diplomacy approach, which recognizes that international health initiatives address not only global health issues, but foreign policy objectives, I focus on the procedures used to scale-up ARVs and the programming used to distribute them within Tanzania. I examine PEPFAR's reliance on target numbers of participants as a measure of program success, and its adoption of the policy of regionalization in association with Tanzania's government and the U.S.-contracted treatment partners. The new regionalization policy, introduced in 2006, assigned specific U.S. ARV contractors to work in specific regions of the country, rather than in locales of their choice as in the past. I examine the effects of these policies and practices on the clinics that organize ARV treatment and the experiences of women who receive ARVs at the clinics. The dissertation illustrates how program policies affect and shape PEPFAR's response to the HIV/AIDS pandemic as well as its aim to meet its own programmatic goals.

Copyright by MARITA EIBL 2010 To Mom and Dad, for all of your love, faith, and support.

### Acknowledgements

My committee provided incredible amounts of guidance and support throughout graduate school, the research project, and the writing process. My chair, Dr. Anne Ferguson, has from day one been a great mentor and a fantastic guide through my anthropology studies and the maze of graduate school. I deeply appreciate all of the time and effort she dedicated to me through panicked office drop-ins, emails, and many, many drafts. Throughout it all, she has provided feedback and direction with endless patience. Dr. Bill Derman always encouraged me to find more interesting questions. Dr. Linda Hunt pushed me to defend my ideas, making my writing clearer and stronger. Dr. Gretchen Birbeck provided the ever-important insights from outside anthropology-in public health and epidemiology—and she helped me to write for an audience outside my discipline. Dr. Carolyn Nordstrom inspired my love for anthropology since the first day of my freshman year of college. Her inspiration and endless supply of napkins have meant the world to me as she stayed with me through graduate school. A special thank you to Dr. Kristin Peterson, who provided foresight into the direction of medical anthropology and HIV/AIDS research.

My time in graduate school was funded by a Michigan State University (MSU) Distinguished Fellowship, Foreign Language and Area Studies Fellowships, and the Ford Foundation Minority Fellowship for Immersion in African Studies, funded through the MSU African Studies Center. I am also grateful to the MSU International Studies and Programs offices that hired me throughout my time in graduate school: the African Studies Center, the Center for Gender in Global Context, and the Center for Advanced Study of International Development.

v

The dissertation research itself was funded by the Fulbright-Hays Doctoral Dissertation Research Abroad Fellowship.

My research in Washington, D.C., and Tanzania was aided by many individuals. It is because of their efforts that I was able to conduct and complete my research. I want to specifically thank Ms. Mary Ash; Dr. Ramaiya Kaushik; Mama Kashasha; Sister Hellen; the staff of Pastoral Activities and Services for People with AIDS Dar Es Salaam Archdiocese; the staff of Shree Hindu Mandal Hospital; the U.S. government; and the Tanzanian government. I am also grateful to Dr. Benedict Mongula of the University of Dar es Salaam for his guidance. A special thank you to Diana and Diamond Carvalho for all of their help. I also benefited greatly from the patience of my driver Omari, who helped me locate many offices in Dar es Salaam. I would also like to acknowledge the efforts of Mr. Bwijo Bwijo and all of his contributions to my dissertation.

The dissertation would not have been written if not for the steady caffeine supply of Espresso Royale Café. It also would not have been written if not for the friends who pushed me and pulled me out of the café as needed: James Bielo; Heidi Connealy; Andrea Freidus; Breanne Grace; Joshua Grace; Amy Jamison; Nidal Karim; Christine LaBond; Ty Lawson; Kate Patch; Maria Raviele; Karin Rebnegger; Christian Reed; Marisa Rinkus; Fredy Rodriguez; and Michael Walker. I would also like to acknowledge the efforts of Ms. Terri Bailey in helping me edit my work. A big thank you to Dr. Merritt Sargent for feeding me so well during graduate school.

Finally, I would like to acknowledge the perpetual support of my parents, John and Nora, my siblings, Sarah, Anthony, Teresa, and Rachel, and my grandmother, Marietta (Marita) Collins.

# **Table of Contents**

List of Tables	ix
List of Figures	x
Key Abbreviations	xi
Introduction: HIV/AIDS and ARVs	1
Antiretrovirals and Subira	1
HIV/AIDS and ARVs	1
A Clinical View of Antiretrovirals	5
Realities of Global ARV Treatment	8
Critical Medical Anthropology and Health Policy	9
The Anthropology of Policy	11
Global Health Diplomacy and the President's Emergency Plan for AIDS Relie	ef
(PEPFAR)	14
Organization of Dissertation	18
Chapter 1: Health Services and Policy in Tanzania	22
Colonial Control	22
Independence and Health	30
Neoliberalism, Structural Adjustment, and Health	34
HIV/AIDS, ARVs, and PEPFAR in Tanzania	39
How PEPFAR Defines Success	41
Charter 2: Project Organization and Participanta	11
Chapter 2: Project Organization and Participants	44
Project Setting	44
Organization of PEPFAK.	40
PEPFAR Participants	40
Research Questions	54
Methodology	
Methods	/ ۲
Politics, Sensitivity, and Unahenges to Research	04
Learning About PEPFAR	07
Chapter 3: "How Numbers Are Reached Is Also Important!" PEPFAR and Targets	69
Global Health Diplomacy	69
Creating a Numerical Success Story	73
How PEPFAR Activities are Funded—The Country Operational Plan (COP)	75
How the Non-Political Becomes Political	78
The Power of Numbers	89

Chapter 4: Regionalization: The Pros and Cons of a New Policy	91
A Story of Hope	92
Regionalization as Policy	93
The Benefits of Regionalization	101
Moving Challenges	
Treatment Partner Perspectives on Regionalization	
Treatment Partner Benefits: Imagined Patients and Tangible Funding	111
Regionalization: A Larger View	115
Chapter 5: Clinics: Working Between Paper and Reality	117
Differences in Policy Interpretation	118
A Tale of Two Clinics Building ARV Programs	
Determining ARV Treatment in Tanzania	
The Pros and Cons of PEPFAR Graduation	141
More Paperwork	149
Between Paper and Reality	154
Chapter 6: Women as Numbers: Dignity Seekers	
HIV/AIDS and the Women of Tanzania	
Number-Seeking/Dignity-Seeking	
After Testing Positive	
Needing Treatment	
Finding Treatment and Deciding Where to Go	
The Selective Appearances of PEPFAR	180
Chapter 7: Concluding Thoughts	
Varving Viewpoints on AIDS and ARVs	
PEPFAR Continued	
Policy Recommendations	
Insights and Acknowledgments	
Continued Work	
Concluding Thoughts: PEPFAR and Global Health Diplomacy	199
Appendix A: Care and Treatment Patient Card—CTC-2	202
Appendix B: Care and Treatment Patient Record Card—CTC-2	204
References	211

# List of Tables

Table 1:	Interviewed Government Officials, Treatment Partner Personnel, and Clinic Staff	60
Table 2:	Interviewed Women Patients	62
Table 3:	Indicator and Target Table	77
Table 4:	Treatment Partner Regional Assignment Information	100
Table 5:	HIV Prevalence Rate among Women in Tanzania	162
Table 6:	Interviewed Women Patients by Clinic	164
Table 7:	Where Women Interviewed Tested	170

# List of Figures

Figure I:	Fiscal Year 2007 Overall Treatment Results Showing Number of Individuals Reached by Treatment
Figure II:	Tanzania: Regionalization Facilitates Treatment Scale-Up92
Figure III:	Administrative Regions of Tanzania99
Figure IV:	PASADA Services Mural124
Figure V:	May God Bless You with Good Health/Mungu Akujalie na Afya Njema128
Figure VI:	Care and Treatment Patient Card—CTC-1, Page 1202
Figure VII:	Care and Treatment Patient Card—CTC-1, Page 1203
Figure VIII:	Care and Treatment Patient Record Card-CTC-2, Page 1204
Figure IX:	Care and Treatment Patient Record Card-CTC-2, Page 2
Figure X:	Care and Treatment Patient Record Card-CTC-2, Page 3, Section 1206
Figure XI:	Care and Treatment Patient Record Card-CTC-2, Page 3, Section 2207
Figure XII:	Care and Treatment Patient Record Card-CTC-2, Page 4, Section 1208
Figure XIII:	Care and Treatment Patient Record Card-CTC-2, Page 4, Section 2209
Figure XIV:	Care and Treatment Patient Record Card-CTC-2, Page 4, Section 3210

### Key to Abbreviations

ARV: Antiretroviral (ARV)

CDC: Centers for Disease Control and Prevention

- Columbia-ICAP: Columbia University's International Center for AIDS Care and Treatment Programs, Mailman School of Public Health
- CTC: Care and Treatment Clinic
- DoD: Department of Defense
- EDM: Electronic Drug Monitoring
- EGPAF: Elizabeth Glaser Pediatric AIDS Foundation
- FHI: Family Health International
- Harvard-MDH: Harvard University/Muhimbili University of Health Sciences/Dar es Salaam City Council
- IMF: International Monetary Fund
- IOM: Institute of Medicine
- MSD: Medical Stores Department
- NGO: Nongovernmental Organization
- NNR-TI: Non-Nucleoside Reverse Transcriptase Inhibitor
- NRTI: Nucleoside Reverse Transcriptase Inhibitor
- OGAC: Office of the Global Aids Coordinator
- PASADA: Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese
- PEPFAR: President's Emergency Plan for AIDS Relief
- PHC: Primary Health Care
- PMTCT: Prevention of Mother-to-Child Transmission
- **PSAP:** Priority Social Action Programme

SAP: Structural Adjustment Program

- SCMS: Supply Chain Management System
- TACAIDS: Tanzania Commission for AIDS
- TB: Tuberculosis
- USAID: U.S. Agency for International Development
- WHO: World Health Organization

### Introduction HIV/AIDS and ARVs

### Antiretrovirals and Subira

In late October 2007, Subira Kisembo,<sup>1</sup> a forty-year-old Tanzanian woman living in Dar es Salaam, made the trek to an antiretroviral (ARV) clinic. Wearing a smart blackand-white suit, Subira came to refill her prescription for ARVs. Subira chose this particular ARV clinic after receiving the test results that showed she was HIV-positive earlier the same year. At the same clinic she received ARV counseling and joined an adherence group, where she learned about ARV treatment along with other individuals who had just begun their treatments. Subira is also able to see a doctor, which was particularly important to her because when she first started ARVs, she suffered from persistent itching, a common side effect of ARV treatment. At the clinic, she is personally handed her ARVs by a pharmacist every two months when she comes in for a refill.

In order for Subira to receive her ARVs, she not only accesses the clinic that refills her prescription and its staff. She also accesses the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), a global treatment program that makes these medicines available throughout Tanzania. My dissertation study is an examination of the processes and people that make Subira's treatment possible, as well as a look at how women like Subira choose an ARV clinic to attend.

#### HIV/AIDS and ARVs

The Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome, or HIV/AIDS, is one of the most destructive pandemics of the modern era. The disease has

<sup>&</sup>lt;sup>1</sup> All proper names have been changed to protect each individual's privacy.

proved devastating on global, community, and individual levels. It contributes to the spread of other life-threatening illnesses, such as tuberculosis (TB), malaria, and sexually transmitted infections. Since the early 1980s, when AIDS was first recognized and categorized, over 25 million deaths have been attributed to it (Hardon et al. 2006:23). As of 2007, the United Nations estimated that over thirty-three million individuals were living with HIV/AIDS (UNAIDS 2007:3). The numbers of infections and deaths attributed to the AIDS epidemic continue to be alarming and large. AIDS attacks an individual's immune system, making it difficult to fight off other opportunistic infections, too often killing the productive members of society needed to build communities (Nattrass 2004:183).

It was not until 1996, at the International AIDS conference in Canada, that scientists announced one of the biggest breakthroughs in AIDS treatment research—the creation of ARVs (Altman 2006). Scientists reported success by combining different types of ARVs into a single regimen—a "cocktail" of ARVs (Epstein 2007:264). ARVs are not a cure, but can decrease the symptoms of AIDS and an individual's viral load, thereby improving quality and length of life and reducing the risk of transmitting HIV (Nattrass 2004). In addition to the decrease in the symptoms of the disease, ARVs are responsible for the "Lazarus Effect," a rapid and dramatic improvement in the physical appearance of patients who take the medicines (Farmer 1999:264). Overall, ARVs have changed what it means to have HIV/AIDS—a disease that was once a death sentence is now a chronic disease that can be managed by medications: "Before antiretroviral drugs became available in Africa, the period from the inception of AIDS to death averaged some nine or ten months, although with much variation..." (Iliffe 2006:83).

Their impacts, however, were initially limited to those who could afford the pharmaceuticals. A year's worth of ARVs could cost up to \$15,000 in the United States (Garrett 2004), well above a yearly salary in the developing world. Sub-Saharan Africa, though, has been the epicenter of the pandemic. Overall, the region accounts for over two-thirds of the total individuals infected with HIV/AIDS (UNAIDS 2007). It is also the only region in the world where the number of women living with HIV/AIDS is greater than the number of men living with the disease (UNAIDS 2007:15).

Yet ARVs remained out of reach for the many in this region who needed them, due in part to their high cost. Africa represents only 1 percent of world drug sales (Petchesky 2003:79). When ARVs first became available in resource-poor settings through private foundations and organizations, they were a limited commodity, scarce in comparison to the number of individuals in need. ARVs highlighted not only global inequalities in accessing health care, but local ones as well. On an international level, only individuals who could afford to pay for ARVs could access them. Access was delineated along lines of the developed and the developing worlds, despite the fact that a greater need was located in the developing world. Locally, those who could not afford the medications had to rely on luck that a nearby charitable organization could access to medicines.

In the early 2000s, a system that centered on individual access began to change with the start of global treatment programs. In 2002, the Global Fund to Fight AIDS, Tuberculosis, and Malaria (Global Fund) was initiated, with the goal of creating publicprivate partnerships to increase resources to prevent and treat its targeted diseases. The

following year, the World Health Organization's (WHO) 3x5 Program began with the aim of treating three million HIV/AIDS patients by 2005. In 2003, President Bush announced the creation of PEPFAR, the main focus of this dissertation. These organizations—the Global Fund, the WHO's 3x5 Program, and PEPFAR—all started at the same point, with a goal of making ARV therapies more readily available in lowresource settings. These agencies began a process of changing the system, from one that relied solely on individuals negotiating personal networks to access limited goods to one that centered on a wider-reaching distribution of ARVs.

In 2007, when I conducted the research for this dissertation, the first authorization of PEPFAR was coming to an end and many individuals in Washington, D.C., and the United Republic of Tanzania (Tanzania), a PEPFAR focus country, were beginning to discuss the final tallies for the treatment program. At the end of the first authorization, fiscal year 2008, over two million—to be exact, 2,007,800 men, women, and children—had received ARVs in PEPFAR's fifteen focus countries (PEPFAR 2009a:8). Tanzania's treatment number was 144,100 at the end of fiscal year 2008 (PEPFAR 2009a:46). These numbers, however, do not indicate how many of the 2,007,800 individuals who received ARV treatment in the fifteen focus countries—or of the 144,100 ARV patients in Tanzania—are still receiving and adhering to treatment. This dissertation explores PEPFAR's treatment policies in Tanzania, how treatment is tallied, and how individuals decide to receive treatment. In this introduction, I discuss ARVs and their place in the fight against HIV/AIDS, as well as in medical anthropology and health policy. I close the section with the organization of the dissertation.

## A Clinical View of Antiretrovirals

HIV belongs to a class of viruses called retroviruses; once retroviruses attack host cells, they use a process called reverse transcription to take viral RNA and produce viral DNA within those cells (Mboup et al. 2006). While there are many types of ARVs, the three most common are nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNR-TIs), and protease inhibitors (Hardon et al. 2006:24). NRTIs disrupt the transcription of viral RNA into DNA (United Republic of Tanzania 2005:89). NNR-TIs also disrupt the transcription of viral RNA into DNA by binding to the enzyme that translates RNA into DNA (United Republic of Tanzania 2005:89). Finally, protease inhibitors stop production of mature human immunodeficiency viruses that would infect other cells (United Republic of Tanzania 2005:89).

ARVs, though, are not automatically given to each person who tests positive for HIV. The WHO has put forth recommendations on ARV therapies. The WHO has identified and named the following four clinical stages of HIV/AIDS:

- Clinical Stage 1 defines an HIV-positive person who remains asymptomatic but may also experience persistent generalized swollen lymph nodes (WHO 2005:5).
- Clinical Stage 2 patients may experience an unexplained weight loss of up to 10 percent of their body weight, recurrent respiratory infections, fungal fingernail infections, and herpes zoster (WHO 2005:5).
- Clinical Stage 3 is the stage where clinicians can make a diagnosis of HIV/AIDS based on clinical signs. Individuals may have unexplained weight loss of more than 10 percent of their body weight, unexplained chronic diarrhea for more than a month, unexplained chronic fever, a diagnosis of pulmonary tuberculosis in the last two years, and severe presumed bacterial infections (WHO 2005:5).
- Clinical Stage 4 is characterized by events such as HIV wasting syndrome, recurrent severe or radiological bacterial pneumonia, chronic orolabial, genital, or anorectal Herpes simplex infection, extrapulmonary tuberculosis, and Karposi's

sarcoma. Any individual who presents a CD4 count less than 200 cells/mm3 is considered at Clinical Stage 4<sup>2</sup> (National Care and Treatment CTC-2 Form).

According to the WHO, clinicians need to determine the staging of an

individual's HIV/AIDS infection to determine if he or she can begin treatment. There are

three classes of patients with HIV/AIDS who should be placed on ARVs:

- 1. All who are in WHO stage 4 clinical criteria, regardless of CD4+ cell count.
- 2. Those in WHO Stage 3 and CD4+ cell < 350/mm3 as an indicator of their progression to AIDS.
- 3. All who have a CD4+ count < 200 cells/mm3, regardless of symptoms (United Republic of Tanzania 2005:90).<sup>3</sup>

In addition to meeting the clinical guidelines for ARV treatment, individual

treatment success is dependent on treatment adherence:

Studies of drug adherence in the developed world have suggested that higher levels of drug adherence are associated with improved virologic and clinical outcomes and that rates > 95 percent are needed to maximize the benefits of  $ART^4$  (United Republic of Tanzania 2005:97).

According to the WHO, 95 percent adherence means that if a patient is taking ARVs

twice a day, missing no more than three doses a month (Hardon et al. 2006: 264). If

individuals do not adhere to treatment regimens, treatment failure may occur or the virus

may become drug-resistant, greatly increasing the cost of care (Hardon et al. 2006:178).

Because a high level of adherence is necessary for success, ARV therapies require not

<sup>&</sup>lt;sup>2</sup> According to the WHO, "CD4+ T-cells are also known as helper T-cells and act as [sic] an co-ordinator of the immune response, unfortunately, CD4+ T-cells are also the main targets of HIV. HIV destroys infected CD4+ T-cells and leading to an overall weakening of the immune system... Lower numbers of circulating CD4+ T-cells indicates a weakening of the immune system and advancement in the progression of HIV disease. The CD4+ T-cell count can also be indicative of the success or failure of anti-retroviral therapy" (WHO 2009).

<sup>&</sup>lt;sup>3</sup> In 2007, the U.S. government recommended that patients begin ARV treatment if they had a CD4 count below 350 cells/mm3, but the "data supporting this recommendation are stronger" if the patient had a CD4 count below 200 cells/mm3 (Panel on Antiretroviral Guidelines for Adults and Adolescents 2007:i). In 2009, U.S. government recommendations include starting patients on ARV treatment with CD4 counts below 350 cells/mm3 (Panel on Antiretroviral Guidelines for Adults and Adolescents 2009:22). In 2009, the World Health Organization also recommended that all patients start ARV treatment if they have a CD4 count below 350 cells/mm3, regardless of clinical symptoms (WHO 2009:10).

<sup>&</sup>lt;sup>4</sup> ART is an acronym for Antiretroviral Therapy/Treatment.

only a steady supply of medicines, but also individual commitment to maintain treatment.

The government of Tanzania, which follows WHO clinical standards, recommends that

potential patients be assessed beyond clinical eligibility for ARVs:

Beyond clinical eligibility, it is important that the patient's willingness, readiness, and ability to be on ART adherently be assessed and addressed. Psychosocial considerations (not exclusion criteria) therefore need to be evaluated before initiation of therapy during several (three to six) pre-treatment visits:

- Demonstrated reliability, i.e. has attended three or more scheduled visits to an HIV clinic;
- No active alcohol or other substance abuse that could affect adherence;
- No untreated active depression;
- Disclosure: It is strongly recommended that clients have disclosed their HIV status to at least one friend or family member who will become the adherence assistant and, if possible, should join support groups;
- Insight: Clients need to have accepted their HIV-positive status and have insight into the consequences of HIV infection, the role of ART, and the very real need to adhere strictly before commencing therapy;
- Able to attend the CTC<sup>5</sup> on a regular basis (transport may need to be arranged for patients in rural areas or for those remote from the treatment site) or have access to services able to maintain the treatment chain (United Republic of Tanzania 2005:90).

Furthermore, research on patient adherence has not shown one "gold standard by

which it can be quantified" (Hardon et al. 2006:265). Studies have included testing

different methods, "pill counting, electronic drug monitoring (EDM), pharmacy refill

records, biochemical markers, and other self-reporting techniques, such as visual

<sup>&</sup>lt;sup>5</sup> Care and Treatment Clinic.

analogue and recall methods" (Hardon et al. 2006:265). Although adherence is a key determinate for success, it has proven elusive to quantify, categorize, and standardize among patient receiving ARV treatment.

### **Realities of Global ARV Treatment**

In her book on health services in Africa, Turshen observes, "Health is political" (1999:114). While global initiatives are linking individuals with much-needed medications, the success of a program like PEPFAR is not solely based on the success of individual treatment regimens. The governments, treatment organizations, and clinics that make ARV treatment possible, as well as the patients choosing to access treatment, all have varying goals within the larger objective of making ARV treatment available to those who need it.

This dissertation explores the ways in which PEPFAR policy makes ARVs available within one of its focus countries, Tanzania. It examines the viewpoints of the individuals who work within the governments and organizations that make it possible in addition to the viewpoints of ARV patients from the largest population living with HIV/AIDS in Sub-Saharan Africa—women. While the U.S. government, the funder and policy planner for PEPFAR, has created a program that addresses a global health need, it is also a program that addresses U.S. foreign interests. Within this framework, treatment partner personnel work to maintain funding from the U.S. as well as to maintain organizational priorities on the ground in Tanzania. Every day, clinicians have to meet the demands placed on them by donors as well as meet the demands of individual patients in need of ARVs. Women patients in Dar es Salaam, the city where I conducted my

research, have a choice in the clinic they want to attend—how do they decide where to receive ARVs?

In an era where medicines are now available to transform HIV/AIDS to a chronic condition, politics and policy matters take on life-and-death importance for those in need of the medications. My research is situated within medical anthropology and the anthropologies of policy and development. It addresses a "political anthropology of health" by focusing on the politics of medicine, public health, and the individuals affected (Fassin 1996 in Fainzang 2007:97). By examining how policy is actualized in everyday life, this dissertation addresses the issues faced in a global epidemic, considering the planning objectives, organizational protocols, funding plans, and patient priorities needed to develop a successful treatment program.

#### Critical Medical Anthropology and Health Policy

The realization that health is political and affected by the political is not a novel concept within medical anthropology. Much work in medical anthropology focuses on how power inequalities produce, explain, and mediate differences in health and illness. In their book *Medical Anthropology and the World System*, Baer, Singer, and Susser state that power asymmetries are the "primary determinants of health and health care" (2003:4). Because power inequalities are not static, how illness, health, and health care are constructed is dependent on time and place. Morsy (1996) argues that issues of power, control, and resistance, and definitions of health, sickness, and healing are only illuminated by recognizing particular historical contexts. This type of approach, through critical medical anthropology, focuses on how political and economic structures influence actions and constrain options. The paradigm of critical medical anthropology has

specifically explored the interactions between power inequalities and their effects on health and the availability of health services within particular political-economic contexts (Farmer 1999, 1992; Lock and Scheper-Hughes 1996; Scheper-Hughes 1992; Scheper-Hughes and Lock 1987).

Central to the discussion of health and the availability of health services, or lack thereof, is the deployment of health policy. Health policy defines what treatment should be available, who should make treatment available, to whom it should be available, and on what terms. Health became a matter to be resolved through policy during the eighteenth and nineteenth centuries (Foucault 1990:166). Illness and health demographics became objects of study that generated policy. The distribution of "health" to a specific group could be directed through the formation of policy (Foucault 1990:168). Singer and Castro write, "Since the nineteenth century, one of the defining features of the 'modern' state (at the national, regional, and local levels) has been the implementation of policies ... to protect and promote ... health" (Singer and Castro 2004:xi). Li writes that this type of power is situated within what Foucault "termed 'government.' Defined succinctly as the 'conduct of conduct' ... Its purpose is to secure the 'welfare of the population, the improvement of its condition, the increase of its wealth, longevity, health, etc." (Li 2007:5). Health care policy is not produced solely by governments; international organizations, nongovernmental organizations (NGOs), and health care providers all play a part.

Mosse also writes that policy is not simply controlled from the top down and studying it as such neglects "the complexity of policy as institutional practice, from the social life of projects, organizations, and professionals, from the perspectives of actors

themselves and from the diversity of interests behind policy models" (Mosse 2005:6). Examination of policy from the perspectives of the multiple actors involved recognizes the power of individuals and groups to adjust, reinterpret, and realize policy in terms of their own priorities and interests.

#### The Anthropology of Policy

#### Policy as Political Tool

"Policy denotes 'the principles that govern action directed towards given ends" (Shore and Wright 1997:5). In other words, policies are plans of action to achieve specific goals. Policies can affect and effect actions from groups and individuals, codify behavior, and create relationships among multiple groups and individuals so as to reach objectives. Shore and Wright state that an instrumentalist view sees policy as controlling action, work, and relationships from the top down, as a political technology. They use Foucault's notion of governmentality, "a type of power which both acts on and through the agency and subjectivity of individuals..." (Shore and Wright 1997:6, original emphasis), to describe how policies function as political technologies (Shore and Wright 1997; Wedel et al. 2005:34–35). The technical, rational, efficient approaches used by policymakers and planners assume that policy will be implemented by individuals and groups as planned. Moreover, the policy's targeted population will respond as planned. In the instrumentalist approach, policies are enacted, implemented, and followed through as planned. Individuals take on the roles assigned and even the subjectivities shaped by planners.

Farmer's work on structural violence is seminal in elucidating the effects of macro-level political decisions on the health of individuals, as well as the availability of

health services to those individuals (Farmer 1999, 1992). In one of the first ethnographies on HIV/AIDS, Farmer (1992) traces foreign political decisions made by the U.S. regarding Haiti to the individual lives of U.S. and Haitian citizens. Because scientists had not yet pinpointed the transmission routes of HIV/AIDS in the early 1980s, panic and uncertainty surrounded those living with the disease. In 1983, the U.S. Centers for Disease Control and Prevention (CDC) classified Haitians as a risk group for AIDS (Farmer 1992:211). The U.S. government placed some Haitians in detention camps in the early 1980s and the Food and Drug Administration stopped Haitians from donating blood in 1990 (Farmer 1992:209, 218). The results of discriminatory policies and practices for Haitians working in the U.S. were distressing and demoralizing-many hid their ethnicity, and others suffered socially and economically as people refused to even shake their hands. Moreover, Farmer notes that the policy resulted in the loss of tens of thousands of jobs related to tourism in Haiti (1992:213, 215–216). In an accounting of the impacts of policy, he moves his ethnography back and forth between two countries, illustrating the effects within the U.S. and Haiti. U.S.-based decisions had immediate consequences for individuals' lives and livelihoods elsewhere. Farmer's (1992) examination of policy looks at its generation and its immediate effects on the most vulnerable populations in the U.S. and in Haiti. He is concerned with how a broad political economy approach reveals the constrained health care choices available to individuals in resource-poor settings (Farmer 1999), illustrating how policy, as a political tool, shapes the subjectivities of individuals within a targeted population. The policy, while initiated by the U.S. government, affected not just how Haitians were categorized politically, but also how they were treated socially and economically.

Farmer's (1992) analysis illustrates not only an instrumentalist perspective on policy as a political tool, but also what happens as a consequence of policy. Policy is enacted from above through the work of government officials or health care providers to targeted populations. Stone describes policy planning as a production line, where policy is created through a set of stages, and then implemented as part of the sequence (Stone 1988:8). From this perspective, policy can shape the subjectivities of its targeted populations in ways that maintain certain power relationships. Yet, people do not always act or adopt subjectivities as planned, making the instrumentalist approach too simple to explain how and why there are deviations from policy implementation. The instrumentalist approach provides certain insights into how policy is actualized, but an examination of the social life of policy is needed to provide a more complete picture.

#### The Social Life of Policy

Shore and Wright's work on the anthropology of policy also recognizes that policies are not static events, but rather social ones (1997:7). While policies can function as political technologies, the resulting actions effected from different groups and individuals often are not those planned, as illustrated by Farmer (1992). Rather, policies have a "social life" through the actions of those they include and those they affect, as each has its own objectives and priorities (Mosse 2005:6). The "social life" of a policy varies from the official version because the people involved in implementing it ignore, resist, misinterpret, and reinterpret it (Mosse 2005:16). The top-down political aims and outcomes of a policy may be thwarted through unexpected consequences as it is implemented by organizations, individuals, and targeted populations with their own agendas. The anticipated subjectivities may not be adopted as a policy is enacted. Long writes that the "... people on the receiving end of policies, or those responsible for managing implementation, reduce or limit their perceptions of reality and its problems to those defined by the intervening agency as constituting the 'project' or 'programme'" (Long 2001:32). These translations by groups and individuals give rise to the social life of a policy, revealing how it is implemented on a daily basis by focusing on the individuals responsible for implementation and the population targeted by policy. Exploring the complex social lives of policy illuminates not whether or not the policy operates, but how it operates (Mosse 2005:8).

Examinations of policy and practice also reveal how narratives of success are produced. Mosse states: "What is usually more urgent and more practical is control over the *interpretation* of events" (2005:8, original emphasis). Examining the processes of implementation within a program like PEPFAR provides insight into how events are interpreted and how the official version is translated. The interpretation of how well a policy works is the determination of its success, which may influence its termination or continuation. Mosse describes this process as paradoxical—project personnel work outside of official policy, but also work to sustain the policy because it is in their interest to do so (2005:10). In this dissertation, I examine the types of power relations a global treatment program for HIV/AIDS creates among government officials, contracted organizations, local clinic staff, and the patients in need of treatment.

## Global Health Diplomacy and the President's Emergency Plan for AIDS Relief

Global health diplomacy is an emergent field that examines the intersection between global health and foreign policy issues. According to Novotny and colleagues, "Global health diplomacy may be thought of as a political activity that meets the dual

goals of improving health while maintaining and strengthening international relations." Novotny and his colleagues continue, "...the term 'global health diplomacy' aims to capture the multi-level and multi-actor negotiation processes that shape the global policy environment for health" (Novotny et al. 2009:41). As a theoretical framework, global health diplomacy analyzes how health and foreign policy affect one another by examining how different actors negotiate policy.

Global health diplomacy recognizes that health policies, like PEPFAR, have two stated official goals—the betterment of global health and international relationships. By examining how the policy operates on the ground, how it is translated and implemented by different actors, it is possible to see how those two objectives are achieved. In the next sections, I describe PEPFAR as a health policy and as a foreign policy and then discuss PEPFAR's start in Tanzania.

## **PEPFAR as Health Policy**

During his January 28, 2003, State of the Union Address, U.S. President George W. Bush spoke directly about the HIV/AIDS pandemic and a new action to be taken by

the United States:

Because the AIDS diagnosis is considered a death sentence, many do not seek treatment. Almost all who do are turned away. A doctor in rural South Africa describes his frustration. He says, "We have no medicines. Many hospitals tell people, you've got AIDS, we can't help you. Go home and die." In an age of miraculous medicines, no person should have to hear those words.

AIDS can be prevented. Anti-retroviral drugs can extend life for many years. And the cost of those drugs has dropped from \$12,000 a year to under \$300 a year—which places a tremendous possibility within our grasp. Ladies and gentlemen, seldom has history offered a greater opportunity to do so much for so many (Bush 2003).

From the previous paragraphs, PEPFAR was born.<sup>6</sup> PEPFAR's uniqueness stems from the largesse of its numbers. Its targets from 2004 to 2008 were ambitious: two million on treatment, the prevention of seven million infections, and the care of millions—later set as ten million people—infected and affected by HIV/AIDS by the end of its five-year authorization. These targets are abbreviated as the 2-7-10 goals and mirror the areas of PEPFAR interventions—treatment, prevention, and care, respectively. Of these areas, treatment was earmarked to receive the largest amount of funding, at 55 percent (U.S. Congress 2003:36). The Administration selected fifteen PEPFAR focus countries,<sup>7</sup> which account for approximately half of the world's HIV/AIDS infections (PEPFAR 2005:11). The money pledged to PEPFAR—\$15 billion over five years—is the largest amount put forth to fight a single disease, let alone by a single nation.

As a policy, it would have a direct effect on global health, a field that "focuses on health issues that transcend the territorial boundaries of states" (Janes and Corbett 2009:168). As a global treatment initiative, PEPFAR, and therefore the U.S., would have financial and programmatic influence in the distribution and clinical management of ARV treatment throughout the world. While I interrogate the use of ARVs and ARV policy as political technology throughout the dissertation, it is important to recognize and remember that ARVs are life-saving medicines—the only medicines clinically proven to treat individuals living with HIV/AIDS—that were not readily available throughout the world in the early 2000s. While the U.S. has had global influence with the introduction

<sup>&</sup>lt;sup>6</sup> The U.S. Congress passed the United States Leadership against HIV/AIDS, Tuberculosis, and Malaria Act of 2003 on May 27, 2003, which created the U.S. Global AIDS Initiative of which PEPFAR is the five-year Global HIV/AIDS Strategy.

<sup>&</sup>lt;sup>7</sup> Botswana, Côte d'Ivoire, Ethiopia, Guyana, Haiti, Kenya, Mozambique, Namibia, Nigeria, Rwanda, South Africa, Tanzania, Uganda, Vietnam, and Zambia.

and clinical management of ARV treatment, the increase in availability of these medications represents the difference between life and death for many individuals.

## **PEPFAR as Foreign Policy**

In the first authorization, the Bush administration linked PEPFAR to its foreign policy. HIV/AIDS was identified as a public health threat in the 2002 *National Security Strategy Report* (Bush 2002). As a global treatment program for HIV/AIDS housed within the U.S. Department of State, PEPFAR continues to highlight the intersection of improving health with international relations. Unlike the next largest global treatment program, the Global Fund, PEPFAR is a one-country initiative. While PEPFAR has explicit programmatic goals, which I will discuss later in the dissertation, it also embodies foreign policy priorities.

The 2006 Council on Foreign Relations report, *More than Humanitarianism: A* Strategic U.S. Approach Toward Africa, reinforces this view of PEPFAR as a foreign policy initiative:

 $OGAC^8$  will also need a strong diplomatic team to leverage higher commitments from other donors, manage relations with host governments, and integrate policy initiatives with the Global Fund, UNAIDS, and others. Likewise, the Department of State will need to create professional incentives and the structure necessary to mainstream global health within U.S. foreign policy ... (Council on Foreign Relations 2006:76).

The council's report on PEPFAR's future drew specific attention to its role within foreign diplomacy. Notice that the council does not discuss the increase of medical expertise or personnel, but rather the need for "a strong diplomatic team." Furthermore, the council writes about building foreign relations so as to build the role of the U.S. within global health.

<sup>&</sup>lt;sup>8</sup> OGAC, or the Office of the Global AIDS Coordinator, is the office that houses PEPFAR.

In 2006, Secretary of State Condoleezza Rice's speech at Georgetown University outlined the adoption of "transformational diplomacy" as U.S. foreign policy:

So, I would define the objective of transformational diplomacy this way: to work with our many partners around the world, to build and sustain democratic, well-governed states that will respond to the needs of their people and conduct themselves responsibly in the international system ... In doing things with people, not for them; we seek to use America's diplomatic power to help foreign citizens better their own lives and to build their own nations and to transform their own futures.

In this speech, Secretary Rice announced that the Department of State, where PEPFAR is housed, would adopt transformational diplomacy. In its 2007 report to Congress, PEPFAR echoed Secretary Rice's comments, "The President's Emergency Plan for AIDS Relief is a key example of effective foreign assistance and transformational diplomacy in action" (PEPFAR 2007a:107). PEPFAR's location within the Department of State specifically links transformational diplomacy with the global health objectives of the program. PEPFAR's role as a foreign policy initiative cannot be overlooked as it is linked with U.S. foreign policy goals of reducing potential threats to the U.S. caused by the increasing rates of HIV/AIDS abroad.

# **Organization of Dissertation**

This dissertation<sup>9</sup> examines PEPFAR as a health policy with an official, top-down way of implementing ARV treatment in Tanzania; and as a policy with a social life that reflects the varied interests of its implementers—governments, treatment partners, local health clinics, and women receiving treatment.

In Chapter 1, I place PEPFAR and ARVs within a Tanzanian history of biomedical health services. I argue that the tension between addressing global health and foreign policy by the U.S. shapes policy for all of PEPFAR's participants in Tanzania.

<sup>&</sup>lt;sup>9</sup> My dissertation research was funded by the Fulbright-Hays Doctoral Dissertation Research Award.

I discuss the project conception, organization, and methods I used for this study in Chapter 2. I explain the administration of PEPFAR in Washington, D.C., and in Tanzania. I also look at how ARVs are made available throughout Tanzania. Finally, I introduce the agencies and organizations involved in making ARV treatment possible in Tanzania and discuss the methods—archival work, participant observation, and interviews—I used for the research for each group: government officials, treatment partner personnel, local clinic staff, and women patients receiving ARVs.

In Chapter 3, I examine the process by which PEPFAR funding requests are implemented. The PEPFAR-funded treatment partners working in Tanzania<sup>10</sup>—Harvard University School of Public Health-Muhimbili University of Health Sciences-Dar es Salaam City Council; Columbia University's International Center for AIDS Care and Treatment Programs; Elizabeth Glaser Pediatric AIDS Foundation; AIDSRelief; Family Health International; and the U.S. Department of Defense—all rely on reporting the numbers of people treated as a basis for funding. As a group, the treatment partners have an interest in continued PEPFAR funding, as it supports their organizations financially. Increasing numbers also allow for the possibility of increased funding. Numbers are therefore of primary importance in their reports to PEPFAR. Yet, a closer examination reveals that these numbers focus on individuals who have been placed on treatment; they do not indicate how many people have adhered to, or remained on, treatment. While numbers increase, they do not necessarily mean increased positive treatment outcomes for individuals. Without being able to keep track of treatment outcomes, it is unclear what the real impacts of PEPFAR's numbers are.

<sup>&</sup>lt;sup>10</sup> The Clinton Foundation is a treatment partner in Tanzania, but is not funded by PEPFAR.

Chapter 4 discusses the impacts of regionalization on the PEPFAR program, a policy that assigns one treatment partner to an administrative region to the exclusion of other treatment partners. In Tanzania, regionalization recalls the idea of Ujamaa, the socialist policy advanced by Tanzania's first president, Julius Nyerere, who called for equitable distribution of health services throughout the country. Regionalization has resulted in greater U.S. presence throughout Tanzania, but the policy also resulted in treatment partners adjusting their work and organization's objectives to match those of PEPFAR. Due to the high amount of PEPFAR funding available to treatment partners, all of them moved to their assigned regions and continued the work of placing more individuals on medicines.

The local clinics that actually deliver treatment to individuals are also subject to the pressures of targets placed on them by PEPFAR through the treatment partners. In Chapter 5, I examine how local clinics deal with this pressure and impose their own work standards as well to ensure that each patient receives the best care the clinic can give. While donor pressures are exerted on clinics to turn in high numbers, the clinics do not necessarily ascribe to the PEPFAR focus on numbers. Local staff focuses on individual patients rather than target numbers.

In Chapter 6, I look at women patients who are receiving ARVs at clinics. Specifically, I examine what they are looking for in a treatment clinic. Women say they want a clinic that does not treat them like a number. They seek out places with "good services." They look for places that reaffirm their humanity and leave clinics that treat them poorly. While PEPFAR counts patients as numbers toward its targets, patients have not adopted that subjectivity about themselves. While PEPFAR may count a clinic as

successful because it has many patients, patients come to clinics where they have time to talk with clinicians and feel cared for by staff.

In the final chapter, I review my evaluations of PEPFAR's programming and discuss the different roles and opinions put forth by government officials, treatment partners, local staff, and women patients involved in ARV treatment in Tanzania. I discuss how PEPFAR interacts with U.S. foreign policy and put forth suggestions for PEPFAR's ARV policies and programming. I conclude Chapter 7 with ideas for future research, as well as future considerations for ARV programming.

In this dissertation I argue that, although government officials, treatment partners, and local clinics all have varying interests and priorities regarding PEPFAR policy, they do work to maintain the official policy of successfully producing treatment numbers because it ensures their own continued survival. How treatment partners and local clinics structure treatment programs for women living with HIV/AIDS affects patients' decisions to attend one clinic over another. Examining policy and its social life is integral to the understanding of how development is planned, implemented, and practiced.
## **Chapter 1** Health Services and Policy in Tanzania

In this chapter, I explore the history of biomedical health services in Tanzania and how health policy takes on a social life through the interests of the people who implement it and the people it affects. I argue that, while the interests of implementers may not exactly match PEPFAR's goal-oriented narrative of success, they all work to promote PEPFAR as a successful program because it also benefits them. In the next section, I explore a history of health policies in Tanzania, their political connections, and their effects within three periods in Tanzania—colonialism, Ujamaa, and structural adjustment.

# **Colonial Control**

## Under German Control

The region, which is now modern-day, mainland Tanzania, was already a pluralistic medical society in the late 1800s, including Muslim, diviner, herbalist, and witchcraft traditions (Turshen 1984). Christian missionaries in East Africa introduced European medicine during the first half of the nineteenth century, before colonization. While Europeans had been traveling and settling in East Africa throughout the nineteenth century, the German government gave legal permission and protection to the German Society for Colonization to officially mark Germany's colonial involvement in East Africa in 1885. During the same time period the area, in what is now mainland Tanzania, experienced ecological and health catastrophes. Smallpox prevalence was on the rise (Kjekshus 1996:132). Sand fleas, or jiggers, contributed to the loss of mobility and of lives in the 1890s (Kjekshus 1996:135–136). The rinderpest epidemic of the 1890s killed 95 percent of the cattle (Kjekshus 1996:130). The loss of cattle also led to famine and raiding within the region (Kjekshus 1996:132; Koponen 1988:130). Famine, disease, and

cattle deaths changed the economies and social relationships of East Africa. Furthermore, endemic diseases such as malaria and sleeping sickness continued to infect the population. By 1886, it is no surprise that the German and British colonizers believed that "Africans were held fast in the bondage of chronic disease, went in constant fear of attack and enslavement by neighbor or stranger, and were dominated in thought and deed by witchcraft, whilst eking out a marginal subsistence from cultivation at the mercy of alternate flood and drought" (Clyde 1962:1). While this is a description of the region at the time of European colonization, and not indicative of pre-colonial history as a whole, it illustrates the mindset of the colonizers. The "Africans" were the Other—hindered by disease, witchcraft, and ecological disasters. In comparison, the Europeans saw themselves as a civilizing, logical, constructive force; thereby justifying their presence and political control of the area.

In 1888, the Germans created the first state-sponsored medical service in East Africa by hiring two doctors for its colonial mission (Iliffe 1998:28). The colonial state termed the newly acquired territory German East Africa. Treaties Germany signed with Great Britain and the Sultan of Zanzibar by 1890 delineated its borders, consisting of present day Burundi, Rwanda, and mainland Tanzania. One year after the borders were defined and a civilian governor was appointed, the Germans created a Department of Health. While there were meager health services available, mainly for the benefit of the Germans, the most immediate problem for these colonizers was the pacification of the local population. Turshen posits that the military nature of the German invasion was reflected in the health system: "it was logical to build military hospitals in fortified towns where the wounded could be treated" (1984:133). The result of concentrating on

maintaining force and subduing the local population was a narrowly focused health system. The German colonizers did not design health services for the well-being of Europeans or African populations; the focus was on maintaining territorial control. Eventually health services became available to the general European population, but again health was focused on keeping not only a European presence in the colony, but also on Europeans maintaining political control (Turshen 1984:140).

Indigenous uprisings had occurred since the 1880s and continued into the next century, when they culminated in the largest revolt in Tanzanian history. The German colonial governor sought to address economic problems and labor questions through promotion of cash cropping. In the Southern Highlands, Africans were forced to plant cotton, sisal, rubber, and coffee, which lead to the uprising in 1905 against colonialism and the imposition of forced cultivation called the Maji<sup>11</sup> Maji Rebellion. Chiefs from over one hundred ethnic groups encouraged solidarity by passing holy water among themselves (Berg-Schlosser and Siegler 1990:67). By the time the rebellion was quieted in 1907, an estimated 70,000 Africans had died.

The Germans admitted that the "social conditions of the African could not be overlooked ... [and the German government] had overlooked African discontent, and therefore ... planned for medical stations throughout the country as a result of the revolt" (Beck 1977:11, 13). At this point, the German government adopted the idea of providing a social service to subjects for political control, although it was still aligned with military objectives. After the Maji Maji Rebellion, the German government adopted two stances toward medicine for the African population. First, medicine could be a tool of pacification, and second, it could be a prerequisite for economic development. As the

<sup>&</sup>lt;sup>11</sup> Kiswahili: water.

latter, a case raised by Packard (1997), the development of a colonial medical system needed to address not only the pressing needs of the African labor pool, but also the Europeans' health needs in the tropical climate.

At the start of World War I in 1914, the Germans had built twelve hospitals; the largest, in Tabora, had seventy-five beds, and their military included sixty-three physicians (Turshen 1984:140). German East Africa was a battleground for the Germans and the British during the First World War. Yet the most devastating loss of life, between the years of 1918 and 1920, was from the Spanish influenza that struck the area. Estimates place the loss of lives between 50,000 (Beck 1977:40) and 80,000 (Iliffe 1979). In the aftermath of World War I, European powers divided up German East Africa. The League of Nations gave Rwanda and Burundi to the Belgians and gave the remaining area, present-day mainland Tanzania, to the British as a mandate in 1918. In 1922, the newly named Tanganyikan Territory officially became a part of the British Empire. The British Invasion

By the end of World War I, Packard writes that the British stance on health services changed. While, like the German colonizers, they viewed health as technical interventions related to their own economic interests and prioritized the health of Europeans, the British began to include more local populations in the provision of health services (Packard 1997:94). In the first two years after World War I, during most of the influenza outbreak, the British did little to begin implementing their own health system. The meager health system left by the Germans had deteriorated over the years due to war, famine, and flu. The British used what was left of the remaining German system until 1920 when their first governor came to office. Of immediate concern to the new British

power was the implementation of a system of indirect rule (for more information, see Iliffe 1979; Mamdani 1996), a British administration system that used African officials, termed chiefs, to represent the British government in governing "tribes." The British eventually built a more diversified health service system that reached more of the African population than did the German system, indicating their intention to rule for a long period of time (Turshen 1984:133).

British reports displayed or revealed the connection of health to political control. In 1921, the East Africa Commission found that less than 4 percent of the population was "within the sphere of medical influence" (Beck 1977:45). The report continued:

...economically, I take it, every native life, on an average, is worth to the state £20 per annum for twenty years. Say you lose one hundred lives every year for five years from preventable disease. Then the capital machinery of state is damaged, according to my calculation ... to the tune of £200,000. This is a dead loss of capital—just the same as if your invested funds had depreciated to that extent ... (TNA 1921, quoted in Beck 1977:45).

From the earliest years of their rule, the British connected health directly to economic development. Like the German government, the British government expected economic self-sufficiency from its colonies. Health was not just a tool for population pacification, but an investment in the economic prosperity of the colony. Despite these realizations, the money invested in health care was not significant, only about £180,000 a year from 1921 to 1938 (Turshen 1984:141). In 1921, each medical officer in Mwanza was responsible for the care of 750,000 Africans (Beck 1977:43). Despite the evidence that economic growth was linked with a healthy population, the British still did not invest heavily in health services for the African population.

Yet, the British also rejected the notion of charging fees for services. The chief medical officer for Tanganyika felt that the African population expected health services in return for the imposition of taxes (Beck 1981:130). Africans could link the obligation of state taxes with the expectation of certain rights, specifically health care. While linking medical services to economic development, the British tied health services to a (nonnegotiated) social contract with the colonized that was already in place with British citizens. Colonized subjects could receive state medical care on the basis of being a subject of the state. At this point, the state provided few, but free, health services.

One of the most significant developments of this inclusion of the African population was the creation of the rural dispensary system in 1926. It was the first attempt by the British to provide services to the African population in rural areas, where most people lived (Turshen 1984:141). By 1930, there were 288 tribal dressers individuals with basic medical training and Africans trained for a few months in first aid and minor medical ailments—treating, at their peak, only a few hundred thousand cases a year (Beck 1981:17).

Ideally, the dispensaries were the first point of contact for Africans in a national referral system. From the dispensaries, patients could go to the district hospitals, run by the district medical officers, and the provincial hospitals before reaching the specialized services available in Dar es Salaam. Communication among the different levels proved difficult, so the system did not work as planned (Turshen 1984:142). Like the rest of the colonial administrative system, the British established a Ministry of Health, which functioned under the direction of a chief medical officer in Dar es Salaam. Under him were principal medical officers, the principal matron, and a chief health inspector. Outside of the city, there were provincial medical officers and district medical officers located at each district hospital who also oversaw local dispensaries.

In addition to the system of government services, private health care developed in urban, industrial areas. The 1924 East African Commission that had found so few Africans within the medical sphere, also recommended medical examinations for contract laborers (Beck 1977:46). By delivering care at the sites of production, companies could monitor and treat employees. Industrial health services, like those of colonial governments, focused on curative care in order to maintain the labor force. Seventy-two percent of private physicians were located in the five urban centers of the mainland: Dar es Salaam, Tanga, Arusha, Moshi, and Mwanza (Turshen 1984:143). Sisal plants, mines, and factories provided about 3.5 percent of all health services by the end of the colonial period (Turshen 1984:143).

## Post-World War II

After the Second World War, England needed African resources in the wake of war for its own economic growth, and the English Colonial Office argued that spending money in the colonies on health, education, labor department, and basic services would increase productivity (Cooper 1997:67). In theory, increased productivity would justify paying for social services and, according to Cooper (1997), reinvigorate the idea of Empire within European populations and colonies. While it was not novel to link health with economic development, Packard points out that in the 1940s, the connection was again emphasized: "[t]he conceptual linking of health with economic and political development made health programs interchangeable in the development puzzle" (Packard 1997:107).

What is new about post-World War II thinking about the role of state and health is that the concept of development was formally introduced. Development, in this instance,

was economic and social planning by the state. In the colonial situation, however, the state was not local, but intervening from afar, essentially an international imposition. In the post-war era, development was modernization before modernization theory was an academic theory (Cooper 1997). Modernization is a development theory based upon the idea that all underdeveloped countries can follow the same trajectory the West followed in becoming developed nations. Modernization theory, according to Lewis, aims to move people from a traditional way of life to industrialized wage labor (Lewis, paraphrased in Cooper 1997:82).<sup>12</sup> Modernization theory formalized the increasing intersections of state sovereignties with private, industrial ones that viewed health services as an input with economic development as the goal.

By the early 1950s, however, Great Britain began to doubt the economic contributions of the colonies as compared to inputs and realized that it "... could in most cases get little more economically out of a colonial rule than out of a cooperative postcolonial relationship..." (Cooper 1997:79). Whereas health had been considered a prerequisite to economic development, it, along with the colony, was costing the state too much to prove a profitable investment. This realization, along with the growing nationalist movement through the Tanganyika African Association—later the Tanganyika African National Union—led to independence in 1961<sup>13</sup> rather than an invigorated colonialism (Cooper 1997; see Iliffe 1979 for more information).

<sup>&</sup>lt;sup>12</sup> Pieterse (2001) emphasizes, like Escobar (1995), that the rise of modernization was tied to the rise of Western hegemony in world affairs.

<sup>&</sup>lt;sup>13</sup> Tanganyika was declared independent December 9, 1961. Tanganyika and Zanzibar were united as Tanzania on April 26, 1964.

## Independence and Health

The new country's first president, Julius Nyerere, declared that poverty, disease, and ignorance were the enemies of development and vowed to fight them. Although Nyerere's development plan, which was called Ujamaa, ultimately failed, it embodied the president's belief that the state was responsible for providing health care to its citizens (Turshen 1984). Once dictated by a foreign colonizer, development was now the responsibility of the new government. While citizens' expectations of free medical care were inherited from the colonial period, the new government would also draw legitimacy to rule from attempting to provide health care to citizens (Masquelier 2001). Whereas the British government had used development, in the form of social services, to strengthen colonialism; the new government was providing health services, to the exclusion of other NGOs and religious groups to assure its own sovereignty. NGOs and religious hospitals that provided health services became the property of the state (Iliffe 1998; Turshen 1999) and the state became the sole provider of health care.

## The Arusha Declaration, Ujamaa, and Health Services

At independence, the Tanzanian government's main priority was to make more resources, such as health care, available to the rural areas, where most citizens lived. After the Zanzibar Revolution, Tanganyika and Zanzibar united in 1964 and the new country was named Tanzania. The plan for the new country's political, economic, and health care development was written in the Arusha Declaration of 1967. Politically, the country would adopt Ujamaa<sup>14</sup> as a brand of African socialism that emphasized economic self-reliance for the country and for its citizens. On matters of health, the Arusha Declaration states: "To see that the Government mobilizes all the resources of this country

<sup>&</sup>lt;sup>14</sup> Kiswahili: communityhood.

towards the elimination of poverty, ignorance, and disease" (Nyerere 1967). During this time, the Tanzanian government publicly announced that health services were its responsibility and made health services free to its citizens. The Tanzanian government also denied government doctors the opportunity to practice privately for profit.

As of 1970, though, there were only one hundred and twenty-three registered Tanzanian doctors on the mainland (Iliffe 1998:22). Perhaps because of the state's promise to provide health care and the lack of doctors, President Nyerere expanded the training of medical assistants and health center workers. Auxiliary medical workers had been suggested in 1961 by a team of British medical planners, but the idea gathered steam during a Tanzanian delegation visit to China in 1967 (Iliffe 1998:201–202). The Tanzanians were took notes on the different grades of university doctor, medical school graduate, and barefoot doctor. The first five-year plan issued after the Arusha Declaration in 1969 called on the central government to train medical assistants, rural medical aids, and village health workers while also taking control of the existing rural health centers and building eighty new ones (Iliffe 1998:202–203). The emphasis put on rural health care workers and facilities by the state demonstrated that, not only were health services the right of every citizen, but there should also be an equitable distribution of services throughout Tanzania.

The number of these rural health centers rose between 1971 and 1973. They were concentrated in newly created Ujamaa villages so as to increase their effectiveness (Iliffe 1998:203). In order to encourage the idea of self-reliance and increase agricultural output, the state created Ujamaa villages in rural areas beginning in 1968. The idea behind the villages was to take dispersed rural populations and bring them together so that the

government's building of infrastructure and providing of social services would be made more efficient. The planning, decision making, organization, and evaluation of the villages were undertaken by government officials, not the villages themselves (Boesen 1977:150). Yet, as the government tried to focus on the rural areas, Tanzania was undergoing a rapid urbanization process in the 1970s. At almost 11.5 percent a year, it was the third fastest urbanization rate in the world (Iliffe 1998:207; Obrist 2006:77). Even the money for health care services had difficulty leaving urban areas. Although Dar es Salaam accounted for 1 percent of the total population in 1961, it received 20 percent of the health budget (Turshen 1984:193). The costs for upkeep of urban medical facilities continued to grow, even after the construction of hospitals was completed.<sup>15</sup> The funds used to maintain urban care drained government resources from other areas of health services and—most significantly, where over 90 percent of Tanzanians were living rural areas (Omari 1974:8).

During the 1970s, 70 percent of aid for health services came from abroad (Iliffe 1998:205). Self-reliance would not be possible for years. As Gottlieb writes, the Tanzanian state was beginning to realize the limits of its own sovereignty on an international stage:

[although the] Government favoured diverting these capital funds into rural health centres, there was no assurance that the same [international funding] sources would be forthcoming, especially since the kind of staff needed to man a rural health center could not readily be recruited abroad. And along with the hospitals was attached the promise of senior staffing which would bring to Tanzania critical skills that money could hardly buy... (*The Standard*, April 7, 1972).

<sup>&</sup>lt;sup>15</sup> For example, Muhimbili Hospital in Dar es Salaam was built in 1960 for a cost of £918,000 (Turshen 1984:194). Ten years later, the cost of upkeep was £330,000 alone for Muhimbili for one year (Turshen 1984:194). In 1972, Professor Malcolm Segall lamented that, "These hospitals ... are an example of 'overdevelopment' in Tanzania. They drain resources away from the health care of the mass of the population" (1972).

As Tanzania pushed forth an ideology of equitable distribution of health services, village health care centers, and training of village health care workers, it "pre-empted" parts of the WHO's Primary Health Care (PHC) program (Iliffe 1998:206). The WHO is a creation of the Bretton Woods meetings after World War II. It shaped a new globalized professional discourse on health, which focused on staffing by biomedical doctors (O'Manique 2004:50). Early in its existence, the WHO focused on technical and normative functions (Whyte et al. 2002:149), but by the 1970s it switched its focus to PHC. This was a health care approach that centered on preventative medicine, community participation, and appropriate technology (Lane and Rubinstein 1996:418). This approach was officially announced by the WHO at Alma Ata in 1978 with the "Health for All by 2000" plan (O'Manique 2004:51). Foley (2001:4) highlights three significant points about the Alma Ata announcement. First, the WHO critiqued poverty and the global maldistribution of resources. Second, PHC articulated equity, empowerment, and collective decision making. Third, the WHO stated that health care is a fundamental right and it is the responsibility of governments to provide it. The "Health for All by 2000" was a plan that sought to implement these ideas and plans globally.

As part of the "Health for All by 2000" plan, the WHO launched an Essential Drugs Program, developing a list of priority pharmaceuticals—"essential drugs are those that satisfy the health care needs of the majority of the population; they should therefore be available at all times in adequate amounts and in the appropriate dosage forms, and at a price that individuals and the community can afford" (WHO 2001). The goal of the Essential Drugs Program was to reduce the global maldistribution of resources, increase equity, and empower the state to be able to purchase essential medications at reduced

costs. The program was based on Kenyan and Tanzanian models (Whyte et al. 2002:151). What is particularly significant about the establishment of an essential drugs list is the WHO's announcement about the availability of and access to medications as an integral part of health care access. Like the Tanzanian government, the WHO worked and planned to make health care, specifically the distribution of medications, available to all citizens through their governments.

Since its inception, the Tanzanian government had worked to build a comprehensive health infrastructure. By 1983, 93 percent of the Tanzanian population lived within ten kilometers of a health facility (Iliffe 1998:205). Unfortunately, due to limited funding many health centers were of poor quality and not stocked with any medicines, and transport breakdowns led to drug shortages (Iliffe 1998:206). The state had worked to bring health facilities to each citizen, but lack of funds, transport, and medicines led to declining health centers and economically frustrated staff. Of most significance, though, was the fact that state had put a health infrastructure in place to reach over 90 percent of its citizens. While it was an imperfect system that suffered from a lack of funds, it did demonstrate the state's commitment to providing health services to every citizen. It also put forth the idea that access to health services was the right of every citizen.

#### Neoliberalism, Structural Adjustment, and Health

#### Neoliberalism and Structural Adjustment

Ujamaa did not improve agricultural productivity and subsequently the villages failed (Boesen 1977; Hyden 1980). With the failure of Ujamaa, Tanzania's socialist policy was not succeeding and the state was increasingly short of funds. During this same period oil prices rose, as did the cost of loans for many Third World nations—leading to a combination of national and international concerns about the growing numbers of defaulting nations. While many governments were struggling with loans, international economic policies and state responsibilities were also coming under international scrutiny through the International Monetary Fund (IMF) and the World Bank.

The responses of the IMF and the World Bank came under the banner of neoliberalism, which is, "a theory of political economic practices," ... and policies that seek 'to bring all human action into the domain of the market'" (Harvey 2005, quoted in Hoffman et al. 2006:9). Neoliberalism is a political-economic framework that organizes the relationship between the state and the market in order to privilege the market. The implementation of neoliberal programs in codified policies emerged at a specific historical moment when the international concern over the approaching financial emergencies of Third World states led to direct interventions by the IMF and the World Bank. The World Bank's 1981 report, Accelerated Development in Sub-Saharan Africa: An Agenda for Action, criticizes African postcolonial governments' lack of efficiency and organization, as well as the large size of governments (Scott 1995:72). Just as the U.S. was advocating the restraint of the state through neoliberal policies, Third World nations providing social services were deemed "bloated" by the World Bank and the IMF (Rist 1997:171). Essentially, the services that many political parties had promised during nationalist campaigns and drew legitimacy from as ruling parties became the services deemed as extraneous by extra-state institutions. In order to rescue economies facing loan debts, the IMF and World Bank offered loans, but under the condition that states also adopt structural adjustment programs (SAPs) to receive the money.

SAPs imposed neoliberal policies on African economies in three ways. First, privatization reduced the state's role in many sectors, including the provision of social services (Gershman and Irwin 2000:23). Second, liberalization enhanced economic efficiency by allowing prices to be determined by the market without interference or protection from the state (Gershman and Irwin 2000:23). Third, deregulation lifted state barriers to trade and investment (Gershman and Irwin 2000:23). In 1980, Kenya was the first African country to agree to SAPs. Between 1980 and 1988, thirty-three African countries had accepted SAPs as part of their loan agreements with the IMF and the World Bank (Deng and Oshikaya 1991:21).

Tanzania initially resisted borrowing from the IMF to avoid the structural adjustment conditions. President Nyerere created the National Economic Survival Programme, which did revive exports, as an alternative to SAPs (Campbell and Stein 1991:8). The U.S., however, continued to pressure Tanzania to accept SAPs, even though the U.S. did not directly own Tanzania's debt (Campbell 1992). By 1986, though, while Tanzania was in the midst of petrol shortages, reductions in transportation services, fears of cholera, and reports of plague, some of the Tanzanian cabinet members met with the IMF to discuss loans (Campbell and Stein 1991:16–17). With the timely retirement of President Nyerere, Tanzania's second president, Ali Hassan Mwinyi, signed an agreement with the IMF and consented to structural adjustment programs in order to receive aid. This was a turning point for the state. International financial institutions deemed the National Economic Survival Programme inadequate. Through SAPs, international financial institutions critiqued and reconstructed state sovereignty. The

Tanzanian government never formally told its population about the agreement (Campbell and Stein 1991:17).

Tanzanian citizens found themselves governed not only by the Tanzanian state, but by international financial institutions (Hindress 2002). As the state was required to roll back services, individual interactions with state services were no longer the rights of Tanzanian citizens, but the privilege of those individuals who could afford them.

#### Health Services in a Time of Neoliberalism

The WHO had advocated the state's responsibility for providing health care at Alma Ata in 1978. SAPs, though, were actively restructuring African states to reduce their size and responsibilities. The health sector was no exception to these cutbacks and, as a result, the WHO's role in international health was undermined and eventually eclipsed by pro-industry policies of the World Bank during the 1980s and 1990s (O'Manique 2004; Turshen 1999). In 1993, the World Bank cemented its new role in health with the report, *Investing in Health*, which promoted cost-effective health services that had high effectiveness in reducing disease burdens (Janes 2004:385). It also called for reduced spending on tertiary and specialized care and supported specific infectious disease packages (O'Manique 2004:53). Overall, the World Bank's policy supported disease-specific interventions instead of investing in health care system infrastructure. The World Bank's control of economics led to a control of world health policy, at the expense of the WHO.

President Nyerere had considered the provision of health services as the responsibility of the state. The ability to provide social services, like health care, which had been the benchmark of state sovereignty as established by colonial rule and the

promise of nationalist campaigns, was curtailed by lack of funds during Ujamaa and during structural adjustment. The state did not disappear, although its sphere of sovereignty shrunk. While the colonial state and Ujamaa considered health care a prerequisite for development, neoliberalism conceived of health services as contingent upon economic development. The World Bank reasoned that most individuals were not only willing to pay for, but could contribute money toward, the cost of health care (Foley 2001:4). Richer patients could then help subsidize the government care of poorer patients. To that end, SAPs included the introduction of user fees for medications, care, and services. By establishing user fees, SAP logic concludes that clinics will be free of unnecessary patients because they will think twice about going to a clinic that charges. The result in Tanzania was that individuals did think twice about going and there was a decline in clinic attendance. User fees discouraged clinic attendance in general, but most adversely affect those most in need of clinic services—the poor and sick. Specifically, "Women and children, who consume the most healthcare, are especially vulnerable to price barriers" (Turshen 1999:48, see also Rusimbi 2003). Individuals staved away from clinics because of user fees while decreased state funding adversely affected the care provided in state facilities. SAPs also affected pharmaceutical supply. Devaluing the Tanzanian shilling in 1986 caused the price of medications to increase 300 to 400 percent, making it difficult for both the individual and the state to obtain them (Turshen 1999:98).

In the late 1980s and 1990s, the international community and state governments began to enact poverty reduction initiatives to lessen the negative effects of neoliberalism and SAPs. The combination of "IMF-style austerity with 'humanitarian'" concerns is

called "adjustment with a human face" (Rist 1997:173). The World Bank also issued another report in 1989 on Sub-Saharan Africa as a response to its 1981 report, *Sub-Saharan Africa: From Crisis to Sustainable Growth*. The report "discusses the need to protect the most vulnerable members of society from the effects of structural adjustment programs..." (Scott 1995:74). At a state level, Tanzania adopted the Priority Social Action Programme (PSAP) in 1989 to help allay the negative effects of neoliberalism. PSAP was supposed to reverse the cuts in social services by increasing social service resources, restructure delivery systems, and improve management through community participation (Tripp 1991:206). While the state, here, took initiative to address the negative results of neoliberalism, its sovereignty was still restrained and reconstructed as market-based by the neoliberal structural adjustment policies.

Overall, the history of health policies in Tanzania indicates that the provisioning and availability of biomedical health services has been linked to the political and economic situation of the time. Health policy was used as a tool of both colonizing and independent governments in Tanzania as a way to advance political, economic, and development interests. Just as cuts were being made to health services in Tanzania, the HIV/AIDS epidemic was growing within the country. In the next section, I examine the history of HIV/AIDS in Tanzania.

## HIV/AIDS, ARVs, and PEPFAR in Tanzania

In Tanzania, the first cases of HIV/AIDS were reported in 1983. By 1986, all regions on the mainland had reported cases (PASADA 2006:1). Within three years, the Tanzanian government began the formation of the Tanzanian National AIDS Control Programme (National Programme) under the Ministry of Health. The third president of

Tanzania, Benjamin Mkapa, declared HIV/AIDS a national disaster in 1999 (United Republic of Tanzania with the William J. Clinton Foundation 2003:17). President Mkapa established the Tanzania Commission for AIDS (TACAIDS) in 2001 in the prime minister's office, so that it could coordinate efforts across ministries (PASADA 2006:4– 5). By 2003, HIV/AIDS prevalence in Tanzania had increased to approximately 7 percent (TACAIDS et al. 2005:67). Although the first ARV drugs were announced in 1996, due to the cost of the medications, the government's plan of addressing HIV/AIDS focused on "patient care and impact mitigation, along with ongoing prevention campaigns" (United Republic of Tanzania 2003:15).

Despite the heightened awareness of the epidemic, the cost of ARVs, like most pharmaceuticals, put them out of reach of the Tanzanian state. By 1997, though, a few individuals, mainly in Dar es Salaam, purchased ARVs. The medical director of an urban Tanzanian hospital remembers that when he wrote his first prescription for ARVs, the cost was TShs 1.2 million per month.<sup>16</sup> The William Jefferson Clinton Foundation (Clinton Foundation) estimates that 1,500–2,000 people purchased ARVs this way (United Republic of Tanzania 2003:16). A few more individuals were able to receive free or low-cost ARV medications from NGOs that bought them on the international market. In 2003, the same year PEPFAR was announced, President Mkapa invited the Clinton Foundation to help in the formation of a National Care and Treatment Plan. Dr. Joseph Temba, the retired Global Fund Coordinator and former Director of Policy and Planning for TACAIDS, remembers:

Up until 2002 and part of 2003, the government did not have the policy of providing ARVs to patients. It was thought to be too expensive. AIDS patients were literally left to die. Thank God in 2003, following

<sup>&</sup>lt;sup>16</sup> In 1997, the value of the Tanzanian shilling was TSh 597.27:US\$1 (CIA 1997).

consultations between Presidents Clinton and Mkapa of Tanzania, a mission from Clinton HIV/AIDS Foundation came to Tanzania and assisted us in developing the National Care and Treatment Plan for ARVs to AIDS patients....

The Clinton Foundation assessed the health care system and wrote a national plan for ARV distribution, in partnership with the government of Tanzania, estimating that over 400,000 Tanzanians would need treatment. The goal of the Tanzanian government was to put all Tanzanians in need of ARVs on the medications.

When Tanzania was selected by the U.S. government as a focus country for PEPFAR, the National Care and Treatment Plan became the plan that PEPFAR supported, according to the Global Fund HIV/TB coordinator at the National Programme: "With PEPFAR...the plan was for the Clinton Foundation plan to be funded wherever it could—they are 'chipping in' to that original plan." PEPFAR brings together two sovereign state powers—Tanzania, more specifically the National Programme, and the U.S. government. The goals of both the National Programme and PEPFAR are to provide ARV therapy to Tanzanians living with HIV/AIDS. The immediate goals create a targeted population for the program. As of October 2004, ARVs became available under the banner of the Tanzanian government's plan, with PEPFAR funding.

## How PEPFAR Defines Success

PEPFAR's official narrative of success during 2004–2008 was reaching its numerical goals. The 2007 Institute of Medicine (IOM) Report, *PEPFAR Implementation: Progress and Promise*, states these targets are the standard by which PEPFAR measured its own success:

Ultimately the "success" of PEPFAR will be judged by whether it has achieved its targets of effectively supporting the prevention of 7 million HIV infections, treatment for 2 million people with HIV/AIDS with ART, and care for 10 million people living with and affected by HIV/AIDS, as well as its longer-term goal of achieving sustainable gains against the HIV/AIDS epidemics in the focus countries (Sepúlveda et al. 2007:27).

The numbers provide a quantifiable measurement through which the program can manage success and monitor its progress. The Tanzanian portion of the PEPFAR treatment goal was placing 150,000 people on treatment (PEPFAR 2005:41); the goal was to be reached through the work of U.S. and Tanzanian government officials, U.S.contracted treatment partners, and local clinic staff.

## Global Health and Foreign Policy through a Development Policy Lens

From a global health perspective, the figures represent the number of individuals receiving HIV/AIDS treatment. In Chapter 2, I explain my methodologies and project conception as well as introduce the study's participants. In Chapter 3, I discuss the counting and reporting of treatment numbers in more detail. The numbers are a public accounting of the progress of PEPFAR in Tanzania. As PEPFAR meets its numerical goals, it promotes U.S. foreign policy and relations. The PEPFAR country support team leader for Tanzania pointed out that "Tanzanian views of the U.S. have improved greatly since PEPFAR…" Reaching targets is part of the public accounting of transformational diplomacy that showcases U.S. work in the arena of global health.

In order to accomplish this goal, PEPFAR policy is set up to ensure that numbers are of primary importance. In order to reach its ambitious goals, PEPFAR programs accept as many patients as possible, positively addressing the increasing need for ARVs throughout the world as a way to stem the devastating impacts of HIV/AIDS. Yet, development critics also point to the expansion of U.S. power through the deployment of such a large public health program for HIV/AIDS. In his influential book about development in Lesotho, *The Anti-Politics Machine*, Ferguson notes that the development

apparatus depoliticizes issues by presenting problems as technical and submitting technical solutions to address them (1994:256). Although problems and solutions appear technical, or politically neutral, he argues that development "is a machine for reinforcing and expanding the exercise of bureaucratic state power" (Ferguson 1994:255). Nguyen also cautions that PEPFAR "shares a common set of technologies of government that shape national policies, target specific populations and direct the way they conduct their lives" (Nguyen 2009:204). Moreover, he argues that PEPFAR has tapped into a new form of colonialism, with treatment partners and local clinics carefully surveilling individuals: "Today it is PEPFAR subcontractors … who inadvertently or not find themselves performing functions similar to their colonial predecessors as they carry out HIV screening, counseling and treatment" (Nguyen 2009:206). In its quest for numbers, is PEPFAR policy addressing global health needs, building a large U.S. bureaucracy, or creating something else entirely?

## Chapter 2 Project Organization and Participants

In this chapter, I describe the methodology I used in this study to compare and contrast the viewpoints of the participants who make ARVs available and those who receive ARVs as treatment. I discuss the project setting, research questions, how PEPFAR is organized and its participants, methodologies, methods, and my positionality in the field.

#### **Project Setting**

Dar es Salaam, Tanzania, is an ideal place to study PEPFAR's ARV programming. Tanzania's position as one of the PEPFAR focus countries in Africa guaranteed that ARVs would arrive in the country. As the commercial capital and largest city, Dar es Salaam has a population of almost four million (Kagashe 2010), compared to the country's population of almost forty million in 2007 (United Nations Population Fund 2007:90). Dar es Salaam is also where the U.S. Embassy and PEPFAR offices are located. Using Dar es Salaam as a research site provided the opportunity to examine the programming of the U.S. treatment partners since all of them have offices in the city. Furthermore, because the HIV/AIDS prevalence rate in Dar es Salaam in 2007 was 8.9 percent, there was also a great need for ARV treatment in the city (TACAIDS et al. 2008:34).

When I arrived in January 2007 to conduct my dissertation research for twelve months, PEPFAR had been in Tanzania for over two years. In Tanzania, though, PEPFAR had undergone a major policy change in 2006. The government officials, treatment partners, and clinic staff could not discuss PEPFAR without mentioning the policy change of regionalization, which is the term for the process of assigning one

treatment partner to an administrative region in Tanzania to the exclusion of the other PEPFAR treatment partners. The treatment partner becomes solely responsible for the ARV rollout and scale-up in their region or regions, regardless of the number of hospitals, clinics, or pharmacies. Regionalization is discussed in more detail in Chapter 4.

By arriving in Tanzania just after the new policy was instituted, I had the unique opportunity to study how policy affected those trying to run ARV programming in the country. The policy of regionalization provided an opportunity for those involved to reflect on their roles and actions within PEPFAR as they changed and shifted. It was also a time of flux for ARV distribution. Although regionalization has become the primary treatment policy for PEPFAR-Tanzania, it was still an ongoing process during my research period. While treatment partners had "officially" moved into their respective regions, not all of them had become the treatment partner for every care and treatment clinic (CTC) within that region. What links these two types of CTCs-those directly funded by PEPFAR and those that are not-is the Tanzania Medical Stores Department distribution system, backed by PEPFAR's Supply Chain Management System (SCMS, discussed later in the chapter), and the Tanzanian government's standardized protocols concerning ARV distribution, which are discussed in greater detail in Chapter 5. Dar es Salaam was the only place in the country where I could access the individuals and organizations involved in ARV programming-U.S. and Tanzanian government officials, the treatment partner organizations, as well as some of the clinics that distributed treatment.

Because of the effects and concerns of regionalization, I focused my dissertation research to examine how this policy change affected those who implemented and

received ARV treatment in Tanzania—the U.S. and Tanzanian governments, the PEPFAR treatment partners, the local clinics, and the women patients, who represent the most affected and infected group living with HIV/AIDS in Sub-Saharan Africa.

## **PEPFAR's Organization**

# The Administration of PEPFAR

PEPFAR is administered from the U.S. Department of State, through the Office of the Global AIDS Coordinator (OGAC). OGAC's head is appointed by the president, confirmed by the Senate, and reports to the secretary of state. The first head was Ambassador Randall Tobias, who was succeeded in 2006 by Ambassador Mark R. Dybal. The head of OGAC is responsible for the oversight of all U.S. HIV/AIDS activities, including PEPFAR, and contributions of other U.S. government agencies to PEPFAR.<sup>17</sup> Within OGAC is a Tanzania team, led in 2007 by a core team leader. The core team leader's in-country counterpart is Ann Collins, the country coordinator for Tanzania, who works for the ambassador and the deputy chief of mission at the U.S. Embassy in Tanzania. The country coordinator's role, according to Collins, is "to work with daily activities of PEPFAR, liaising with government and donors on issues, and engaging with national policy."

# How the ARVs Arrive in Tanzania

Tanzania's ARV supply is purchased by PEPFAR, the Global Fund, and the government of Tanzania. PEPFAR, which was initially limited to buying first-line adult

<sup>&</sup>lt;sup>17</sup> Other U.S. government agencies contributing to PEPFAR include the Department of Health and Human Services, including the Health Resources and Services Administration, the Department of Defense, the Department of Commerce, the Department of Labor, the U.S. Agency for International Development, and the Peace Corps.

alternative therapies, second-line adult therapy, and second-line pediatric therapies because of its contract with the Tanzanian government, can now also purchase generic first-line formulations.<sup>18</sup> As of 2007, there are twenty-nine ARV formulations purchased for Tanzania. All ARV medications are shipped to the Medical Stores Department (MSD), a Tanzanian parastatal company. MSD has eight zonal warehouses throughout the country which facilitate the distribution of ARVs to each CTC in Tanzania.

In order to smooth the progress of the purchasing and distribution of ARVs within its focus countries, PEPFAR established and then contracted with the SCMS. SCMS is a U.S. government contractor centrally funded by the U.S. Agency for International Development (USAID)<sup>19</sup> for HIV-related commodities throughout the world. Created in 2005, SCMS is made up of sixteen organizations<sup>20</sup> that 1) purchase HIV-related commodities on the world market, including ARVs; 2) build a supply chain infrastructure using existing systems in-country; and 3) foster cooperation of stakeholders within an ARV infrastructure (SCMS 2007).

Because PEPFAR purchases such large amounts of ARVs, SCMS is able to negotiate lower prices by buying in bulk, according to my interview with SCMS personnel. In Tanzania, SCMS is trying to implement a "pull" system, where CTCs

<sup>&</sup>lt;sup>18</sup> According to the World Health Organization, "First-line ART [antiretroviral therapy] is the initial regimen prescribed for a patient who fulfils national clinical and laboratory criteria to start ART. Current WHO treatment guidelines for first-line ART recommend that two classes of drugs for initial treatment, two nucleoside/nucleotide reverse transcriptase inhibitors (NRTI) and one non nucleoside reverse transcriptase inhibitors (NRTI) and one non nucleoside reverse transcriptase inhibitors (NRTI), should be the preferred approach... Second-line ART is the next regimen used in sequence immediately after first-line therapy has failed (clinically, and/or immunologically and/or virologically). Current WHO treatment guidelines recommend that the protease inhibitor (PI) class should be reserved for second-line ART and that ritonavir-boosted protease inhibitors (bPIs) are preferred, supported by two agents from the NRTI class" (WHO 2008:14).

<sup>&</sup>lt;sup>19</sup> The ceiling for the contract is \$7 billion (Nguyen 2007).

<sup>&</sup>lt;sup>20</sup> The sixteen organizations that comprise SCMS: Affordable Medicines for Africa; AMFA Foundation; Booz Allen Hamilton; Crown Agents USA, Inc.; The Fuel Logistics Group; IDA Solutions; John Snow International Research and Training Institute, Inc.; Management Sciences for Health; The Manoff Group; MAP International; North-West University; Northrop Grumman; PATH; UPS Supply Chain Solutions; Voxiva; 3i Infotech.

request the ARVs they need from MSD (versus a push system, where a set amount of ARVs are delivered on a regular basis to a clinic by MSD). Working with MSD and the CTCs in Tanzania, SCMS is implementing the Integrated Logistics System, where clinics forecast their ARV needs and send monthly requests using one paper form, according to SCMS personnel. Because all ARVs—no matter whether PEPFAR, the Global Fund, or the Tanzanian government purchases them—pass through a system that has been redesigned by a PEPFAR partner, PEPFAR has a hand in the delivery of all ARVs in the country and, therefore, in the care of all individuals receiving ARVs in Tanzania. Even clinics that are not directly funded by a PEPFAR partner, like Shree Hindu Mandal Hospital (Hindu Mandal) in Dar es Salaam, one of my research sites (discussed below), are a part of the delivery system created and built by PEPFAR. According to SCMS staff in Tanzania, SCMS took over ARV procurement and delivery from the USAID-funded DELIVER project in March 2007.

## **PEPFAR Participants**

## U.S. and Tanzanian Government Officials

The government agents I interviewed were a purposeful sample—I selected them based on the positions they held and their relationship to PEPFAR or their knowledge of ARVs within Tanzania in order to generate the most information about PEPFAR and ARVs (Patton 2002:230). I interviewed nineteen government officials in Washington, D.C., and Tanzania, making appointments with them or their offices, and meeting at a place of their choosing—offices, restaurants, wherever they would feel the most comfortable speaking with me. For U.S. government officials, I focused on individuals, like country directors, who worked for or with PEPFAR and U.S. government

organizations, such as USAID and the CDC. In seeking out Tanzanian government officials, I concentrated on individuals who worked for the National Programme and TACAIDS. The National Programme was created in 1983 as an office under the Ministry of Health and Social Welfare (United Republic of Tanzania in collaboration with the William J. Clinton Foundation 2003:15). The National Programme works mainly in HIV/AIDS policy—focusing on HIV/AIDS prevention, treatment, and care programs by addressing HIV/AIDS as a health problem. The third president of Tanzania, Benjamin Mkapa, declared HIV/AIDS a "National Emergency" in 1999 (United Republic of Tanzania in collaboration with the William J. Clinton Foundation 2003). He established TACAIDS in 2001 and placed it in the prime minister's office, so that it could coordinate across ministries (PASADA 2006:4–5). The responsibility of TACAIDS is to take a broader view of HIV/AIDS and its impacts, coordinating responses among ministries with the authority of the prime minister.

#### **PEPFAR Treatment Partners**

There are seven treatment partners in Tanzania—Harvard University School of Public Health's collaboration with Muhimbili University of Health Sciences and the Dar es Salaam City Council (Harvard-MDH); Columbia University's International Center for AIDS Care and Treatment Programs at the Mailman School of Public Health (Columbia-ICAP); Elizabeth Glaser Pediatric AIDS Foundation (EGPAF); AIDSRelief; Family Health International (FHI); the Department of Defense (DoD); and the Clinton Foundation. PEPFAR funding provides the treatment partners with technical assistance, trained personnel, salaries for personnel, medical equipment, laboratory supplies, furniture, and small budgets for opportunistic infection medicines. The treatment partners in Tanzania are funded through different mechanisms. PEPFAR initially funded ARV treatment partners through the CDC. The partners who receive this funding, Harvard-MDH, Columbia-ICAP, EGPAF, and AIDSRelief, are termed Track 1.0 and represent the first treatment partners in-country. Because the money is allocated within the U.S. to the CDC, it is called central funding. Treatment partners who are funded by USAID incountry PEPFAR funds, like FHI, are labeled Track 1.5 partners. This funding is referred to as in-country. The DoD funds its own partners separately; they are sometimes referred to as Track 2.0. The Clinton Foundation is a not a PEPFAR partner, as it does not have a contract with PEPFAR, but it does provide care and treatment in collaboration with PEPFAR in Tanzania.

## Harvard University, Muhimbili University of Health Sciences, and the Dar es Salaam City Council

The Harvard-MDH office is a large building located not far from Muhimbili, the national hospital in Dar es Salaam. Harvard University's long-term relationship with Tanzania is based on trials conducted on vitamins and nutritional support for the last fifteen years. The new assistant country director commented to me in an interview that the longstanding collaborative relationship Harvard has with Muhimbili University of Health Sciences made it ideal to work with Muhimbili again, as well as with the Dar es Salaam City Council for ARV treatment, creating the Harvard-MDH treatment partner. He summarized Harvard's mission as advancing sciences, improving patients' lives, and improving Harvard's training capacity by broadening the training scope.

# Columbia University's International Center for AIDS Care and Treatment Programs at the Mailman School of Public Health

The Columbia-ICAP office in Dar es Salaam is located almost midway between the U.S. Embassy and the city center. Its lobby is bright yellow, and numerous brochures are offered there explaining Columbia-ICAP's work and successes worldwide. Before being invited by the CDC to join PEPFAR in 2003, Columbia University had been involved primarily with mother-to-child transmission activities. In an interview with me, the director of programs and technical activities described Columbia-ICAP's model of care as a "family-centered approach," which includes prevention of mother-to-child transmission (PMTCT), care and treatment for mother, child, and the mother's partner, as well as early infant diagnosis.

## The Elizabeth Glaser Pediatric AIDS Foundation

As its title indicates, EGPAF's focus is pediatric AIDS. EGPAF had just taken over the office previously occupied by FHI within the city of Dar es Salaam in 2007. Upon entering the office, one comes face-to-face with a large poster of Elizabeth Glaser, the organization's namesake, and her daughter Ariel. The technical director of EGPAF took up his post in February 2005. He told me that EGPAF had indirectly supported PMTCT projects in Tanzania before PEPFAR through grants. It was not until 2004, after the award of PEPFAR funding, that EGPAF opened its own offices in the country. *AIDSRelief* 

AIDSRelief is the only consortium treatment partner. It is comprised of the lead organization, Catholic Relief Services; as well as Interchurch Medical Assistance for medical personnel; the University of Maryland's Institute of Human Virology as the clinical lead organization; and Constella, which does strategic information, monitoring, and evaluation. AIDSRelief was taken as a Track 1.0 partner by PEPFAR as it was on the ground in Tanzania before PEPFAR arrived. The AIDSRelief model is one where clinics are mentored by AIDSRelief with technical and material support. The overall goal of

AIDSRelief, the senior ART program manager told me in an interview, is to develop a faith-based network of clinics.

#### Family Health International

FHI started in Tanzania in May 2004 in the areas of home-based care and strategic planning, after working as a consultant to USAID (FHI n.d.:19). It successfully bid on a USAID PEPFAR grant in 2004. Dr. Ryker Henning, FHI's country director, is also a history keeper of ARVs in Tanzania. He has been in and out of Tanzania since 1974, where he started as a mission hospital director, then moved on to the national hospital at Muhimbili, before working for the WHO. He states that FHI's mission is to stimulate better health. Its model of care is to meet the comprehensive needs of their patients through continuous services. According to Dr. Henning, the goal is not just to work with the Tanzanian government, but to work through it to provide a health infrastructure in Tanzania.

## Department of Defense

The U.S. Army entered the Southern Highlands of Tanzania in 2000 to work on HIV/AIDS. European stakeholders and Munich University were already there doing transactional sex studies. The U.S. Army, though, came because of a vaccine trial for HIV. The Southern Highlands was a testing site for a National Institute of Health vaccine. When PEPFAR was announced, the people working on the vaccine petitioned to be a treatment partner. The Army had good relations with the Tanzanian Ministry of Health and had an invitation of partnership from a referral hospital. Daniel Johnson was the country team leader for the DoD program from 2004 until January 2006. After January 2006, he was medical director for treatment and research until he left the country in 2007.

He worked from a philosophy that parallels the history of the Army's work in Tanzania treatment and research should be tied together.

## Clinton Foundation

The Clinton Foundation is not a PEPFAR partner, but a care and treatment partner within the country of Tanzania. This means that PEPFAR does not contract with the Clinton Foundation, but the Clinton Foundation works with the government of Tanzania. Tanzania was the first country to request the services of the Clinton Foundation for the development of a national treatment rollout plan, which was adopted in August of 2004. Because early rollout of ARV treatment was still urban-based and focused on adults, Clinton focused on rural and pediatric access, specifically with a pilot program in Lindi. Dr. Radhi Simba, who in 2003 worked with the CDC in Tanzania just before PEPFAR announced it was coming there, became the Clinton Foundation country director in October 2005, after his term as deputy director. Now Dr. Simba is able to stand apart from his counterparts at other organizations because the Clinton Foundation is not accountable to the same PEPFAR requirements.

## <u>Clinics</u>

The two ARV clinics I studied (and learned from) are Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese (PASADA), based on my predissertation research, and Hindu Mandal, a private hospital located in downtown Dar es Salaam (more on the two clinics in Chapter 5). Both are well-respected ARV clinics in the city, as both were pioneer clinics distributing ARVs in Dar es Salaam in 1996 and 1997. As with the director of PASADA, the medical director of Hindu Mandal is wellrespected by his colleagues in Tanzania and in the United States. Like PASADA, Hindu

Mandal enjoys a good reputation in the city for AIDS care. The main difference between the two is that PASADA receives direct PEPFAR funding for its ARV program and Hindu Mandal does not receive direct ARV support, but may receive it in the future.<sup>21</sup> Currently, Hindu Mandal receives funding for its ARV programs from a variety of sources that include the Global Fund and FHI. It does receive ARVs from the MSD system, which receives funding support from PEPFAR through SCMS. The distinction in funding source allows for comparisons to be drawn from the experiences of two clinics that began ARV programs around the same time and followed a national, standardized ARV protocol, but have taken different funding paths.

## Women Patients

Women are disproportionately infected with HIV/AIDS in Sub-Saharan Africa and are being targeted for treatment programs by international donors (AfricaFocus 2005; Baylies 2000). In Tanzania, women comprise 69 percent of all HIV/AIDS cases (United Republic of Tanzania Office of the Prime Minister 2003). PEPFAR reports that more women than men are receiving treatment in the focus countries. Approximately 62 percent of recipients are women (PEPFAR 2008:47). As the largest population living with HIV/AIDS in Sub-Saharan Africa, women patients are a critical group for PEPFAR ARV treatment programming.

## **Research Questions**

In order to examine PEPFAR, I had to identify where and how PEPFAR policy works and follow it as it moved from governmental offices to the local clinics where ARVs were prescribed. My goal was to capture information that could not be found in

<sup>&</sup>lt;sup>21</sup> The PEPFAR CTC for the Dar es Salaam region, where Hindu Mandal is located, said that the clinic is slated to be a part of PEPFAR.

technical documents or reports to Congress, which focus on numbers as end results. Instead, I wanted to be able to collect information that reflected the subjectivities, or the ways in which participants thought about themselves and their work in relation to PEPFAR. In knowing how policy works in everyday life, how government officials, treatment partner personnel, clinicians, and patients champion the PEPFAR policies, call for improvement, or provide specific suggestions for improvement, I would be able to provide information on how those policies help or hinder the goals PEPFAR planners set forth for it. Because of the multiple places in which PEPFAR policy exists—the U.S., Tanzania, government agencies, treatment partner offices, and clinics—and the various people involved—government officials, doctors, public health workers, nurses, and patients—the study required not only a multi-sited ethnography, but a multi-voiced one as well.

Shore and Wright's work on the anthropology of policy posits that policies are not static events; policies can affect and effect actions from groups and individuals, codify behavior, and create relationships between multiple groups and individuals (Shore and Wright 1997:7). Policies have a cultural life through the actions of those they include and those they affect.

Therefore, to study comprehensively the anthropology of a policy requires the inclusion of the multiple actors involved in its creation, implementation, and daily execution. To do so for PEPFAR policy requires ethnographic examination of U.S. and Tanzanian government officials, treatment partner organizations, Tanzanian clinical staff, and women receiving ARVs. I developed my research questions for the project to

examine PEPFAR policy and the agencies, organizations, and individuals involved in ARV programming:

- What do government officials, treatment partners, and clinic workers think about PEPFAR treatment policies?
- How does each group view its own participation in the distribution of ARVs within PEPFAR?
- How do PEPFAR policy and changes to it affect ARV programming?
- How do women receiving ARVs choose a clinic to attend?

## Methodology

Because of the numerous actors involved who come from varied backgrounds of government, development, public health, and HIV/AIDS experiences, the study needed to incorporate the multiple perspectives of those involved with PEPFAR. In his edited volume, *Battlefields of Knowledge: The Interlocking of Theory and Practice in Social Research and Development*, Norman Long develops an actor-oriented approach specifically designed to recognize "... the 'multiple realities' and diverse social practices of various actors ... to get to grips with these different and often incompatible social worlds" (Long 1992:5). By recognizing the "multiple realities" present within the PEPFAR rollout of ARVs, I did not have to view the program from one perspective. Rather, using multi-sited and actor-oriented perspectives, I was able to examine, observe, and analyze PEPFAR as each group of participants viewed it. From this approach, I could study how each group thought of its role in PEPFAR, which of the other groups it interacted with, and how individuals viewed the program as a whole.

Long posits that an actor-oriented approach places individual agency front and center in comparison to structural approaches, taking into account the intersection of individuals' life-worlds (1992). My goal is to privilege the social actors as they view

themselves in the chain of treatment distribution, whether they are agents of the state (U.S. or Tanzania), treatment organizations, clinic groups, or individual patients, and to view them as they interact with PEPFAR policy. In order to "study through" PEPFAR policy, as advocated by Shore and Wright, one must trace policy connections "between different organizational and everyday worlds, even where actors in different sites do not know each other..." (1997:14).

Methodologically, Long argues that, in order to assess the multiple realities present in social life, the "interest in culture must be grounded in the detailed study of everyday life, in which actors seek to grapple cognitively, emotionally and organisationally with the problematic situations they face" (2001:51).

## **Methods**

In order to apply this methodological approach to my questions, I had to include the spaces where actors interact with PEPFAR: program documents, government agencies, treatment partner offices, and clinical settings. I gathered written documents, observed the daily workings of ARV programming in Dar es Salaam, and conducted semi-structured interviews (Patton 2002:4).

## Document Review

The management of the modern office is based upon written documents ('the files'), which are preserved in their original or draught form. There is, therefore, a staff of subaltern officials and scribes of all sorts (Weber 1946:197).

In order to understand PEPFAR policy, I examined official records and reports written by PEPFAR officials defining how treatment funding, protocol, and reporting are to be conducted within the PEPFAR program. The space where policy originates can be located in multiple places. The first of the two primary places is Washington, D.C., where
the headquarters of PEPFAR, in OGAC, and the overall strategic force of the program is located. The second place is the U.S. PEPFAR headquarters in Dar es Salaam, which is the in-country office and another place where PEPFAR policy for Tanzania is manufactured.

Each year, OGAC submits a PEPFAR annual report to Congress.<sup>22</sup> These annual reports are made available to the public online and hard copy, by request. The reports detail the successes of the three PEPFAR interventions of prevention, treatment, and care within the fifteen focus countries, including the numbers of individuals participating in the three programs, as well as how focus countries are progressing toward their targets.

Also available to the public, at cost, is an evaluation of PEPFAR by the IOM entitled *PEPFAR Implementation: Progress and Promise* (Sepúlveda et al. 2007). The IOM is part of the National Academy of Sciences, which "was created by the federal government to be an adviser on scientific and technological matters. However, the Academy and its associated organizations (e.g., the Institute of Medicine) are private, non-governmental organizations and do not receive direct federal appropriations for their work. Studies undertaken for the government by the Academy complex usually are funded out of appropriations made available to federal agencies. Most of the studies carried out by the Academy complex are at the request of government agencies" (Sepúlveda et al. 2007). The "task of the IOM committee is to examine a variety of measures of program success than can be ascertained at different points across the implementation timeline" (Sepúlveda et al. 2007). The IOM submitted this report to

<sup>&</sup>lt;sup>22</sup> Engendering Bold Leadership: The President's Emergency Plan for AIDS Relief (2005); Action Today, A Foundation for Tomorrow: The President's Emergency Plan for AIDS Relief (2006); The Power of Partnerships: The President's Emergency Plan for AIDS Relief (2007a); The Power of Partnerships: The President's Emergency Plan for AIDS Relief (2008); and Celebrating Life: The President's Emergency Plan for AIDS Relief (2009a).

Congress as an evaluation of the PEPFAR program. Finally, I used and analyzed reports and documents that I collected during the course of my research that are not freely available to the public.

#### Participant Observation

PASADA and Hindu Mandal allowed me to carry out participant observation. Participant observation is one of the hallmarks of qualitative research, with the idea being that one learns by seeing and doing (Bernard 2002:327). At Hindu Mandal, I observed counseling sessions as patients were taught about and then expected to demonstrate knowledge of ARVs. The ARV counselors allowed me to help fill out attendance forms and ARV registers. Because I was allowed to observe, ask questions, and in some cases actively participate, I became familiar with the clinical routines of placing individuals on ARVs. Both clinics familiarized me with the vast paperwork required of an ARV clinic by the U.S. and Tanzanian governments.

#### Interviews

### Government Officials

I used a semi-structured interview format because I wanted each individual to be able to speak about his or her work for, opinions of, and ideas about PEPFAR, treatment, and regionalization (Bernard 2002:205). Questions allowed interviewees to create their own narratives about their work, its successes, and the challenges they have faced in distributing ARVs. The interviews had two goals. I wanted to learn the administrative structure of PEPFAR and how individuals fit into it. I also wanted to understand the actor perspective of those working within PEPFAR (Long 1992:4). Selecting the interview topics and allowing the respondents to speak as they wanted on each topic permitted them to highlight what they felt were the most pressing issues about this program. Giving

interviewees the freedom to discuss their work was a way in which to explore how they constructed their views regarding PEPFAR. These interviews were conducted in English.

My goal was to interview staff members at each partner organization who worked with treatment. Those meeting these criteria included country directors, medical doctors, program directors, and treatment advisors who worked for each treatment partner. I met ten individuals through a variety

# Table 1: Interviewed Government Officials, Treatment Partner Personnel, and Clinic Staff<sup>23</sup>

Government Officials	
U.S. government officials and workers in Washington, D.C. – Includes core team leaders, senior technical advisors, senior public diplomacy and communications advisor, and employees of Supply Chain Management Systems	6
U.S. government officials and workers in Dar es Salaam, Tanzania – Includes country directors, U.S. government agency workers, and employees of Supply Chain Management Systems	7
Government of Tanzania officials and workers in Dar es Salaam, Tanzania – Includes officials from the National AIDS Control Programme, Tanzania Commission for AIDS, and Medical Stores Department	5
<b>Treatment Partner Personnel:</b> Includes country directors, technical directors, treatment program managers, physicians, etc.	10
<b>Clinic Staff:</b> Includes physicians, executive directors, nurses, counselors, pharmacists, financial managers, etc.	20

of means. Some resulted from an opportunistic meeting where they offered to be interviewed for my project (Patton 2002:240). Most, though, I interviewed by means of snowball sampling, whereby others referred them to me as a good source of information (Patton 2002:237–238, 240). As there are a limited number of treatment partners, many of the staff are familiar with their colleagues at other organizations. I was able to meet with individuals from each of the treatment partners. At some treatment agencies, I spoke with an individual multiple times. At others, I was able to conduct interviews with more than one staff member.

<sup>&</sup>lt;sup>23</sup> In order to protect the privacy of the individuals I interviewed, examples of professional titles are given for each group.

Like the government interviews, treatment partner interviews were carried out at a place of the individual's choosing, with the promise of confidentiality to those who requested it, and in English. The interviews were semi-structured so as to allow the participant to frame his or her own viewpoints of PEPFAR and ARVs. While the interviews covered the same goals of understanding the larger structure of PEPFAR and the place of his or her work within it, they also inquired into how PEPFAR policy was implemented and the daily tasks required to make the program work.

#### Clinic Staff

I also conducted twenty semi-structured interviews with staff members—ARV nurses, counselors, physicians, pharmacists, and finance personnel—of PASADA and Hindu Mandal, in English and Swahili. The interviews at PASADA were similar to other semi-structured interviews—placing the individual's work within the larger PEPFAR structure. The Hindu Mandal staff placed more weight on the daily responsibilities of running an ARV clinic. Casual conversations with staff members—ARV nurses, counselors, physicians, and pharmacists—were common on slow work days. Both PASADA and Hindu Mandal staff allowed me to ask numerous questions.

#### Women Patients

In order to gather viewpoints from this pivotal group about choosing and receiving ARV treatments, I used a semi-structured approach to interview twenty-two women receiving ARVs at the clinics. I asked them to recount their experiences from the time of their testing positive to their decision to come to a particular clinic to receive ARVs. The women varied in age and length of time receiving ARVs. The interviews covered their experiences, opinions, and ideas about the ARV clinic.

Table 2:	interviewed	Women	Patients
----------	-------------	-------	----------

Age (Range 25–63; Mean 38.8)	
25–34	7
35-44	9
45–54	5
55-64	1
ARV Start Year	
2003	3
2004	0
2005	9
2006	8
2007	2
Education Level <sup>24</sup>	
None	3
Finished Some Primary School	1
Finished Primary School	9
Some Secondary School	4
Finished Secondary School	3
Certificate of Social Work	1
Nursing Assistant Degree	1
Marital Status	
Single	5
Has a boyfriend	4
Engaged	1
Married	6
Divorced	3
Widowed	3
Children	
None	1
1–3	18
4+	3

At PASADA, when I inquired about patient interviews, the medical director and executive director put me in touch with a research assistant—a woman who was part of PASADA's pilot ARV program in 2003. PASADA's medical director requested that I provide bus fare for the women patients who I interviewed. My research assistant helped identify women patients for me to interview. At Hindu Mandal I, as well as the clinic nurses, chose women waiting in line for ARVs. Obviously, there are inherent power relations involved when

patient interviews are conducted at clinics, where clinic staff are present. Conducting the patient interviews at clinics, however, allowed for confidentiality that could not necessarily be obtained if I were to meet with individuals in community contexts. Most importantly, my research assistant or a staff member could assure the women of my status as a doctoral student researcher. Due to the sensitive nature of my questioning, these introductions gave me entrée into the lives of these patients.

By conducting interviews at the clinics, the patients did not have to worry about having their status "outed" outside of the clinic. In Tanzania, many women living with

<sup>&</sup>lt;sup>24</sup> In Tanzania, primary school consists of seven years—Standard 1 through Standard 7. Secondary school is four years—Form 1 through Form 4 (United Republic of Tanzania 2010).

HIV/AIDS fear the stigma associated with it. By not being interviewed in their own homes and neighborhoods, these women were able to avoid questions by neighbors and friends and, therefore, protect their identities. Women did not have to worry about finding extra time during the day to speak with me—they were already at the clinic.

I conducted a focus group of sixteen women receiving ARVs at PASADA. The women were selected through recommendations from the medical director as well as my research assistant at PASADA. Because some women patients had given similar responses to questions in individual interviews, the focus group provided an opportunity for peers to help me interpret those responses-to check if I was understanding them the same way they understood them (Patton 2002:386). The focus group, therefore, reflects the thoughts and opinions of women who have found a CTC they are committed to returning to every month. While it does not mean they have no complaints or suggestions, these women have finished the search for a clinic and are able to consider the thought processes that went into deciding to take up ARV treatment and finding a clinic. The goals of the focus group were (1) to help clarify answers I had heard repeatedly in individual interviews and (2) to give women an opportunity to speak openly about women without referring to themselves directly. The group atmosphere allowed for women to bring up social knowledge about these subjects without necessarily revealing personal information (Patton 2002:388–389). The interviews and the focus group were conducted mostly in Kiswahili, but some were a mix of Kiswahili and English. **Analysis** 

After reading through the documents I collected, I coded them for information as it related to the PEPFAR program; treatment intervention; treatment interventions

specific to Tanzania; and person opinions on accomplishments and lessons learned about PEPFAR in Tanzania. I typed my fieldnotes from my work with PASADA and Hindu Mandal and coded them for interactions and conversations regarding the paperwork required for ARV from donors and governments, casual comments on ARVs, and conversations on ARV programming and counseling. Finally, I typed my notes from my interviews and grouped the interviews into categories—government officials, treatment partner personnel, clinic staff, and women patients—read, and coded them for the themes that presented themselves in each category. From there, I shaped chapters around each category and the issues each group raised in their interviews.

#### Politics, Sensitivity, and Challenges to Research

"See, I don't even know if I am allowed to talk with you. This is a political program" (U.S. government employee discussing PEPFAR during one of my interviews).

Health is political (Turshen 1999). Talk of PEPFAR, ARVs, and HIV/AIDS cannot be removed from larger discussions of not only politics, but money and stigma. The announcement of PEPFAR, which came during a presidential State of the Union address, ties it to the politics of the United States. PEPFAR, itself, runs out of the State Department in Washington, D.C., and has to submit yearly reports to Congress. The funding for ARVs relies on continued good relationships with the U.S. government, as well as performance-based results. Finally, the subject of HIV/AIDS, a disease that often makes the most intimate details of an individual's personal life public, is also associated with the threat of stigma. Individuals living with HIV/AIDS often choose not to tell family or friends about their status to avoid the stigma associated with the disease. These subjects were at the forefront of this study and, therefore, weighed heavily on the minds of all involved.

Because this is a multi-sited study, my positionality shifted with the sites. The challenges at each point of study were different, but the concern of confidentiality remained constant throughout the process. Early in my research, I was told by one interviewee that obtaining some information about PEPFAR would be difficult because OGAC had strict communication rules for its employees and contractors. The interviewee described them to me as:

- Do not talk about contracts.
- Do not discuss anything undesirable.
- Information given in an interview should [only] be used as technical information.
- Do not say anything that could be used to fire someone.

These rules were designed to protect the image of one of the most well-funded health service programs in the world, as well as one of the best public relations programs of the Bush administration. This was reinforced at various points by U.S. government agencies. My interviews with the core team leader for Tanzania and the senior technical advisor for care and treatment were conducted in the OGAC office along with a senior public diplomacy and communications advisor, who was an ever-present chaperone. She was careful to reword some answers given by my interviewees about PEPFAR, treatment, and PEPFAR in Tanzania. As I noted in my field notes:

PEPFAR's presence in Tanzania is substantial as PEPFAR accounts for approximately 80 percent of care in Tanzania; it provides an enormous amount of funds for the country that any one group or the Tanzanian government would have difficulty replacing if PEPFAR left. After inquiring about the chances for sustainability if PEPFAR was not reauthorized after its five-year run, the senior technical advisor gave the realistic answer that the Tanzanian government "would never be able to pay [for what PEPFAR pays for now]." Immediately, the senior public diplomacy and communications advisor jumped in to "soften" the advisor's answer, stating, "PEPFAR works with the Global Fund and we should look to sustainability as not dependence on PEPFAR solely. The U.S. government will not fade away."

The challenge posed by the informal OGAC rules and the presence of the senior public diplomacy and communications advisor highlighted a recurring tension in PEPFAR research. Although there is the overall appearance of openness and transparency, the information made public is controlled. The concerns of the U.S. Embassy were that multiple answers or, worse, disagreements would become public. Rather, a unified answer from the public affairs office was deemed most appropriate. This unified answer was put forward, not necessarily, I believe, to place obstacles to my research, but to ensure that the program was presented in its best light. The goal of my project, though, was not a "gotcha" newspaper article, but rather an attempt to understand how policies on paper became daily practices. Many individuals agreed to participate when granted confidentiality.

Challenges were not limited to the staff of U.S. government agencies. Staff members of treatment partner organizations were concerned with not sounding "harsh" about the U.S. government. Most often, confidentiality was requested when a participant thought he or she had made a critical judgment about the U.S. government or PEPFAR. Clinic workers and women patients ran the gamut of selecting total openness to total confidentiality. Many women patients, though, were quick to ask if I would publish in local papers before consenting one way or the other.

As part of my university's institutional review board procedures, I explained my project to every participant. Each participant read, had read to her, or received a verbal explanation of the informed consent form in the language in which he or she agreed to be interviewed. In turn I received signed, marked, and oral consents from the participants.

Due to the sensitivity of the questions, I tried to actively address the concerns of all of my participants. While notes were taken during each interview, only one individual would consent to being tape-recorded during my research—all of the rest refused.

Confidentiality was offered to each participant and promised to those who requested it. In order to protect the privacy of those who participated in my research project, all of the names of individuals have been changed. Participants could refuse to answer any question at any time. As a researcher, I accept that the answers they gave represented the viewpoint they wanted to portray. Although all of the answers may not represent an objective "Truth," they revealed the subjectivities of the participants, which was always the goal of this project.

### Learning about PEPFAR

This chapter identified the administrative organization of PEPFAR and the organizations and individuals who are participants in the process of distributing ARVs in Tanzania, as well as the women who are accessing ARV treatment in Dar es Salaam. The following chapters explore further the processes of how ARVs are distributed and accessed within the PEPFAR program by examining the viewpoints of those involved in ARV distribution. To complete the picture, I also examine the processes of access through the viewpoints of women who found and are obtaining ARV treatment.

Because Tanzania had just undergone the policy change initiating regionalization among its treatment partners, the relationships among all of these parties have changed. What has remained consistent, though, is PEPFAR's emphasis on using numerical targets as evidence of success and as a basis for treatment partner funding. In the next chapter, I

discuss how PEPFAR's processes of obtaining and reporting numbers—what counts and what does not count in tabulating targets and funding—affects ARV treatment.

لنغاد

# Chapter 3 "How Numbers Are Reached Is Also Important!":<sup>25</sup> PEPFAR and Targets Global Health Diplomacy

PEPFAR is a program that highlights the increasingly overlapping interests of global health and U.S. foreign policy. Anthropologist Adams and colleagues term this intersection of global health and foreign policy as "global health diplomacy ... an emerging field that addresses the dual goals of improving global health and bettering international relations (Adams et al. 2008:316). While the intersection of health and foreign policy is not a novel concept, "experts have an easier time agreeing that health has grown in foreign policy importance over the last ten years" (Fidler 2005:7).

The global epidemic of HIV/AIDS has become a primary example in which the interests of global health and foreign policy meet. The IOM defines global health as "health problems, issues, and concerns that transcend national boundaries, may be influenced by circumstances or experiences in other countries, and are best addressed by cooperative actions and solutions" (Board on International Health, Institute of Medicine. 1997:2). As a modern pandemic, HIV/AIDS is the defining example of a health problem that has crossed national borders and refused to be contained by the work of medical professionals alone.

Because HIV/AIDS has never been just a matter of health, its effects have consequences for other areas, like foreign policy. Foreign policy aims to promote the interests of a country, which HIV/AIDS has the potential to threaten. A 1997 report by the IOM argues that, "The United States has the critical elements for a rational, enlightened, and effective foreign policy in health, and the safety of America and its

<sup>&</sup>lt;sup>25</sup> From my interview with a Tanzanian doctor.

future economic strength depends on its realization" (Board on International Health, Institute of Medicine 1997:46). Moreover, in former President Bush's *National Security Strategy of the United States* (2002), the administration stated that public health threats such as HIV/AIDS are also security threats (Bush 2002). More specifically, the *Security Strategy* notes that the public health threats of HIV/AIDS may negatively affect international trade: "Beyond market access, the most important area where *trade* intersects with poverty is in public health" (Bush 2002, emphasis added). Furthermore, "The scale of the public health crisis in poor countries is enormous. In countries afflicted by epidemics and pandemics of HIV/AIDS, malaria, and tuberculosis, *growth and development* will be threatened until these scourges can be contained" (Bush 2002, emphasis added). HIV/AIDS has the potential to affect U.S. interests as it is a security threat, making HIV/AIDS a matter of foreign policy.

Housed in the Department of State, not under the Department of Health and Human Resources or under USAID, PEPFAR works as a facet of U.S. foreign policy. It aims to reduce the security threat posed by HIV/AIDS and promote U.S. goodwill by addressing a health concern that threatens the lives of millions of people. PEPFAR has been labeled a "jewel" in U.S. foreign policy (Paul 2009) because its HIV/AIDS programs and their results are public and publicly touted. The results of PEPFAR are its stated programmatic targets, which are part of a unified U.S. strategy that emphasizes "evidence-based interventions, accountability, and performance toward goals" (PEPFAR 2005:12). Nguyen posits, "Evidence is a lubricant for keeping resources flowing from programme funders, who must prove to their constituents that their money is being used to achieve stated ends" (2009:209). With PEPFAR, evidence of success is not just a show of achievement by the program, but also a means to assert U.S. goodwill in the world.

PEPFAR achieves its foreign policy objectives through its "culture of accountability [which] bodes well not only for sustainable HIV/AIDS programs, but also for an ever-expanding sphere of transparency and accountability that represents transformational U.S. diplomacy, as Secretary [of State, Condoleezza] Rice has described it, in action" (PEPFAR 2007a:25). Transparency and accountability demand that PEPFAR's work take place on a public stage, which works to the advantage of the United States by publicizing its work on HIV/AIDS. As Nguyen points out, "It [PEPFAR] has been a central piece of American foreign policy, having been called the 'most positive foreign policy engagement of the Bush administration' (!) and touted by former U.S. Secretary of State Condoleezza Rice as 'American transformational diplomacy at work'" (Nguyen 2009:202). In order for American transformational diplomacy, and its culture of transparency and accountability, to work and for PEPFAR to remain "the brightest example of humanitarianism in Mr. Bush's record" (Nguyen 2009:203), PEPFAR has to demonstrate success.

The importance of meeting targets, or providing evidence, cannot be overstated this keeps the funding coming and, therefore, the program running. Consequently, while PEPFAR's work in the fight against HIV/AIDS directly addresses issues of global health, the public record of its activities promotes U.S. foreign policy and goodwill throughout the world. The primary way PEPFAR demonstrates its work is through the reporting of programmatic targets, which are described in more detail later in this chapter.

In this chapter, I explain how PEPFAR funding and reporting mechanisms

structure treatment programming-thereby shaping how PEPFAR policy is implemented,

treatment is delivered, and success is reported. I also discuss how the funding and

reporting mechanisms obscure other aspects of ARV programming, mainly treatment

adherence. The dissertation data will show how treatment partners and patients view

ARV programming. I argue that programmatic targets are used to promote PEPFAR's

achievement on a global scale while overlooking treatment outcomes.

#### **PEPFAR's Goals**

PEPFAR's definition of programmatic success is based on reaching its goals. In February 2004, PEPFAR published the comprehensive five-year global HIV/AIDS strategy, which stated how its accomplishments were to be measured:

To measure the "2-7-10" goals of President Bush's emergency plan, surveillance and program reporting systems will need to indicate (1) the *total number* of clients reached with ART (including through PMTCT initiatives); (2) the *total number* of clients receiving care and support services, including TB/HIV clinical care and palliative care through homeor community-based programs; and (3) the *total number* of orphans and vulnerable children reached with care and support. (PEPFAR 2004:76, emphasis added).

This statement makes clear that numbers will be the primary measure of PEPFAR's success. Moreover, "Accountability for results is a cornerstone of the President's Emergency Plan for AIDS Relief (PEPFAR) and serves as the basis for program and policy development, implementation, and improvement" (PEPFAR 2005:99). Since accountability is the determinate of success, the administrative system is built to monitor and report the numbers so that the program's progress can be determined.

This reliance on numbers is reflected most clearly in PEPFAR's reporting system.

At the most basic level, CTC recording and reporting is critical to help forecast the

services required by people living with HIV/AIDS since CTCs work directly with patients. The Tanzanian government captures information through its own required clinic reporting (discussed in greater detail in Chapter 5). With accountability a high priority according to Washington, D.C.-based PEPFAR officials, reporting is a significant, daily practice of PEPFAR participants. PEPFAR treatment partners require monthly financial reports from their CTCs.<sup>26</sup> Programmatic and technical reports from the treatment centers are sent to the treatment partners on a quarterly basis. According to one treatment partner's country director, the amount of reporting required for PEPFAR is "a lot, a lot, a lot." Reporting for PEPFAR requires a combination of monthly financial reports, quarterly reports on PEPFAR programs, a Semi-Annual Program Results (SAPR), and an Annual Program Results (APR) report, as well as an annual request for funding called the Country Operational Plan (COP).<sup>27</sup>

#### Creating a Numerical Success Story

As a development program, PEPFAR is a multi-country initiative aiming to reach millions of people. Its funding structure lays bare its priorities in determining not only how money is spent, but also how success for the program is measured across its fifteen focus countries. Li writes in *The Will to Improve* that development programs problematize a situation and then "render technical" a solution (2007:7). She defines "rendering technical" as a set of practices concerned with defining the boundaries of the problem, making visible those boundaries, collecting information about what is included

<sup>&</sup>lt;sup>26</sup> Treatment partners are allowed to capture whatever data they choose from their CTCs, however, most follow a similar pattern of monthly and quarterly reports.

<sup>&</sup>lt;sup>27</sup> Focus countries report every six months to the Office of the Global AIDS Coordinator (OGAC) and complete a full COP. Cambodia, India, and Malawi, while not focus countries, submit a report to OGAC annually and a full COP for fiscal year 2008. Non-focus countries, such as Angola, China, Democratic Republic of the Congo, Dominican Republic, Ghana, Indonesia, Lesotho, Russia, Sudan, Swaziland, Thailand, Ukraine, and Zimbabwe, that receive PEPFAR funds also submit a report annually to OGAC as well as a mini-COP" (PEPFAR 2007c).

within those boundaries, and then mobilizing a prescribed solution" (Li 2007:7). PEPFAR policy problematizes the need for ARVs as one of availability. The problem has been rendered technical by defining it solely as one that can be solved by providing ARVs and then identifying the number of people placed on treatment.

Numbers reinforce PEPFAR programming as a technical solution to the problem of HIV/AIDS treatment because of their appearance of objectivity. Rose writes in his book, *Powers of Freedom*, that numbers are a "part of the techniques of objectivity that establish what it is for a decision to be 'disinterested'" (Rose 1999:199). Numbers provide a veneer of objectivity—program outcomes are not defined subjectively, but rather with concrete evidence. Rose posits that the use of numbers alone technicalizes a decision—numbers depoliticize by their existence. He continues on to argue that the use of numbers produces objectivity, by making invisible the complex judgments, decisions, and arrangements that give rise to a certain measurement (Rose 1999:208). In health programs, those measurements are targets. Targets "become a vital means for 'knowing' about the health status, and effectiveness of specific programmes on target populations…" (Coutinho et al. 2000:657).

The initial goal for PEPFAR was to have 150,000 individuals in Tanzania on treatment by the end of fiscal year 2008.<sup>28</sup> The goal of 150,000 is part of the overall 2-7-10 goal of placing two million on treatment. As PEPFAR officials in Tanzania continue to submit COPs and reports that highlight the number of individuals on treatment in a given year, they compare it to the overall goal of 150,000. Programmatic progress is measured by how close PEPFAR-Tanzania has advanced toward its five-year goal of

<sup>&</sup>lt;sup>28</sup> Final tabulations for the first five-year authorization of PEPFAR were taken at the end of fiscal year 2009.

150,000. The numbers are used to mark the success in scope and convey the effectiveness of the program—the higher the numbers, the more effective the program. They provide PEPFAR with immediate evidence of accomplishment.

#### How PEPFAR Activities are Funded—The Country Operational Plan (COP)

This reliance on numbers is reflected most clearly in PEPFAR's reporting system. At the most basic level, CTC recording and reporting is critical to help forecast the services required by people living with HIV/AIDS, the ARVs needed to be purchased, and the personnel required to be trained. The Tanzanian government captures information through its own required CTC reporting. With accountability a high priority for PEPFAR, reporting is a significant, daily practice of participants.

The COP is an annual occurrence that runs from June to August. During the writing of the COP, the treatment partners put together an application for annual program activities and funding for PEPFAR-funded activities. Once all applications are submitted, the in-country PEPFAR team has to compile them to create the one COP for all PEPFAR-funded activities in Tanzania. The Tanzania COP is then sent to OGAC in September, where it is combined with all other PEPFAR COPs and goes to Congress. Treatment partners usually learn before the December Congressional recess and definitely by January if their requests will be funded, according to the country director of one treatment partner. The money usually arrives in the country just as the treatment partners have to ready themselves for the next COP application.<sup>29</sup>

<sup>&</sup>lt;sup>29</sup>The U.S. fiscal year runs from October 1–September 30. Because money does not reach the field on the first day of the fiscal year, treatment partners are given extra time to spend the money. For example, if fiscal year 2007 funds arrive in June of 2007, partners have until September 2008 to spend the money (PEPFAR Fiscal Year 2007 Application for Program Activities). The final tallies for PEPFAR will be taken in September 2009, once all of fiscal year 2008 funding has been spent.

For each PEPFAR activity, a separate application needs to be completed by a treatment partner. The 2007 Fiscal Year<sup>30</sup> Application for Program Activities, to be filled out by treatment partners for programs like ARV provision, is divided into three sections. The first section focuses on partner information and an activity narrative. Partners must list the sub-partners for their particular activity, the target populations reached within seven categories,<sup>31</sup> as well as the geographic area for the activity. PEPFAR gives treatment partners a 7,000-character (not word) limit to describe the activity they want funded. Millions of dollars are allocated on the 7,000-character limit.

In an interview with me, a Track 1.0 treatment partner's assistant country director described the COP process:

The CDC [Centers for Disease Control and Prevention] asks for draft narratives. Then the CDC-USG [United States Government] team asks questions [about our application] and we have to defend it, like a dissertation defense. On July 31<sup>st</sup> we had our defense and were given one week to make revisions. It is enough time to make those revisions. From our clinical working group, we sent seven people to meet with the CDC, USAID, and DoD. We have to answer for targets, fluffy narratives. The meetings are for more elaboration than the 7,500-character limit allows.

In the second section of this application, there is a list of forty-one indicators, of

which eight are further broken down by gender and another three are further separated by

gender and age. The list of forty-one represents the indicators of progress across the three

<sup>&</sup>lt;sup>30</sup> My research was conducted during fiscal year 2007. The "COP FY 2008 Template" also allowed approximately 7,500 characters for narrative. Instead of the four target indicator columns, the template asks for targets to be provided for fiscal year 2008 and fiscal year 2009 for each activity. It also includes an eleven-point checklist for "Areas of Emphasis." There is a checklist for targeted populations, which includes three main headings: "General Population," "Most at Risk Populations," and "Other." Applicants are to list the category of workers supported with salaries, training, and interventions by PEPFAR. Finally, applicants are to list the districts in which they work.

<sup>&</sup>lt;sup>31</sup> The seven categories are the general population, people affected by HIV/AIDS, special populations, community, host country government workers, health care providers, and group/organizations (PEPFAR FY 2007 Application for Program Activities).

main interventions of PEPFAR: prevention, care, and treatment. Next to the list of indicators are four columns:

Table 3: Indica	ator and 1	<b>Farget Table</b>
-----------------	------------	---------------------

	Target Flat Funding	Target +25% Funding	Target +50% Funding	Target +% Funding
Indicator #1				
Indicator #2				

The first column, "Flat Funding," refers to the PEPFAR funding received in the previous fiscal year. The percentage increases in the remaining columns refer to increases over the flat funding. Treatment partners can fill in their own percentage in these columns. The directions for this section read: "Please enter the indicator targets for the activity for which your organization is funded given the four scenarios" (PEPFAR FY 2007 Application for Program Activities). Each "Target" column provides a scenario of results based on different amounts of funding. In order to apply for funding, each partner must list what pre-decided indicators it will address and then how many individuals, or numbers, it will reach or affect based solely on funding.<sup>32</sup> The numbers report on how many people the treatment partner can place or has placed on ARV treatment—not how many people the treatment partner has kept on treatment.

Overall, the entire application focuses on the estimation of targets—of people enrolled in a specific program based on the amount of money given to fund it. The COP is the embodiment of the accountability and performance-based indicators articulated in PEPFAR policy documents. The form not only focuses on the numbers concerned with funding scenarios, but also looks at the numbers that can be aggregated to determine if PEPFAR can, will, and is on track to meet its 2-7-10 goals.

<sup>&</sup>lt;sup>32</sup> There is a third section, which focuses on the targets for secondary activities, defined as "activities conducted in pursuit of those targets for which your organization has primary responsibility" (PEPFAR FY 2007 Application for Program Activities). The same forty-one indicators are listed, but the only column listed is one for "Target Flat Funding" (original emphasis).

In "Numerical Narratives and Documentary Practices," Coutinho and colleagues argue that numbers, or estimated targets, become "statements of facts" at the level of government agencies that are removed from the on-the-ground context from which they arise (Coutinho et al. 2000:657). In describing the processes that record numbers and targets for public health programs in India, the authors posit that the use of numbers makes reporting at once "universal and uniform" for review by removing the local contexts (Coutinho et al. 2000:657). The PEPFAR Country Operational Plans funding report and request tells a story that ties increased funding to increased treatment without accounting for local realities or favorable or unfavorable treatment outcomes. Counting all of the acts of distribution as successes suggests to those who read PEPFAR's reports that all individuals who receive treatment are experiencing favorable treatment outcomes and continuing with treatment. Those numbers implicitly equate that distribution with treatment success.

While the numerical focus of success does allow for high accountability of U.S. funds, it also permits a narrow accounting of outcomes. As ARV availability continues to increase because of PEPFAR, pressure from PEPFAR will increase on those programs that deliver ARVs to demonstrate signs of success through increased numbers of patients. As targets become the primary focus for accounting for program success, questions of quality related to those who provide treatment programs and those who receive medications are obscured from view. In fact, the pressure to increase numbers may decrease the quality of care.

#### How the Non-Political Becomes Political

Ferguson, in *The Anti-Politics Machine* also argues that the development apparatus depoliticizes issues by reducing them to technical problems to be solved by

technical solutions (1994:256). Development programs become apolitical and atemporal because these technical solutions do not generally address specific political, economic, or social realities. Rather, the focus on the technical and scientific is privileged by planners over local contexts, which can then be ignored. In regards to international health programs, targets, for example, create the illusion of "a single kind of biological and cultural human population that encounters a specific technological intervention in a singular manner" (Coutinho et al. 2000:657). This technical approach depoliticizes ARV treatment.

For a large, international treatment program, the singular focus on numerical targets allows for quick understanding about the reach of the program. Charts and maps throughout the five annual reports to Congress (PEPFAR 2005, 2006, 2007a, 2008, 2009a), provide reference for PEPFAR planners about where targets are being reached and what countries are not on track to reach their PEPFAR goals. Numbers allow for planners to efficiently monitor an international initiative. Yet, more complex issues, like those of how treatment partners will provide treatment within a country, treatment adherence and dropout rates, and how PEPFAR should be implemented as part of a health service system cannot be streamlined into the required charts and maps.

Numbers appear objective, technical, and not influenced by subjective reasoning, hence, they have political influence. The rest of this chapter examines what is made invisible in PEPFAR's focus by considering how counting is encountered and experienced in Tanzania, and how it excludes certain aspects of ARV treatment, changes the way ARV treatment operates, and structures treatment outcomes.

#### Programming and Competing for Numbers

Targets are tied to funding, as President Bush made clear when announcing the funding for PEPFAR with specific goals. At OGAC in Washington, D.C., the core team leader for Tanzania noted that "a lot of funding is based on performance." Numbers are the tangible proof of treatment partners' performance. For the treatment partners, meeting the numbers set by PEPFAR ensures continued funding. Numbers provide an immediate measure of the care given by treatment partners that masks two interdependent realities— competition and quality of care.

In Tanzania, when rollout of PEPFAR drugs and the national ARV rollout program began in October 2004, treatment partners followed a primarily facility-based model. As soon as PEPFAR set the targets, there was immediate pressure to meet them. Those pressures fell most quickly to the in-country treatment partners. Track 1.0 applications for PEPFAR, filed by U.S. agencies already in Tanzania, included promises to deliver numbers, according to the country director of a treatment partner. Once selected for PEPFAR, it was logical for the treatment partners to stay in the areas in which they already worked and in facilities where they already had agreements.

While many organizations had projects, programs, and relationships in multiple places in Tanzania, not all places in Tanzania had agreements with organizations. Therefore, not all areas in Tanzania had access to ARV treatment (discussed in more depth in Chapter 4).

In the initial stages of PEPFAR, three of the four Track 1.0 partners—Harvard-MDH, Columbia-ICAP, and EGPAF—could all be found at Muhimbili National Hospital in Dar es Salaam. Dar es Salaam has one of the highest rates of HIV prevalence in the country at 8.9 percent (TACAIDS et al. 2008:34); it is a place where many individuals

are in need of ARV therapies. In a numbers-based system, however, these organizations were competing for the same patients because they were located at the same facility in the same city. Immediately, problems for the PEPFAR program revolved around its own structure—success built on numbers promotes competition among the treatment partners. Focusing on building patient numbers for funding purposes, rather than concentrating on programmatic elements, like quality of care or treatment adherence, as treatment partner personnel discuss in Chapter 4, took precedence within a target-based system.

The head of PEPFAR in Tanzania, Ann Collins, also expressed a foreign policyrelated concern over how U.S. efficiency was represented by this grouping of treatment partners: "...what does it say about us and effective use of resources, effectiveness, transfer costs?" In addition to the competition among treatment partners, an overview of PEPFAR quickly reveals, as Ms. Collins pointed out, that most resources were being used in only one part of one city in the entire country. This left many areas of Tanzania completely without ARV treatment. As the annual reports to Congress show country totals, not regional totals, the presentation of country numbers does not indicate how treatment is made available or distributed throughout the country, let alone where treatment programs are available.

#### Treatment Adherence and Patient Retention

In "Numerical Narratives and Documentary Practices," Coutinho and colleagues define numerical narratives, a type of documentary practice, as "...texts that use numbers to speak about a particular interaction between health services and target communities ... The numerical narrative is structured as a 'statement of fact' which is at once universal and uniform in a manner that it is removed from the micro-level context within which it

arises" (Coutinho et al. 2000:657). Within the narrative, numbers are the only facts needed to document how a certain health program is working or progressing with its targeted group of individuals, communities, or states. The numbers alone are capable of reviewing and making public the state of a health intervention.

In her article on an international public health intervention in India, Das explores how a numerical narrative can provide a record of a successful public health intervention while disregarding how records are created. Her work illustrates how the numerical narratives for a vaccine program "count *the number of doses of various antigens distributed and not the number of children immunized*" (Das 1999:109, original emphasis). In other words, the records focus on the numbers of medicines distributed rather than the children helped by the vaccinations. She writes, "It is part of the politics of numbers that only certain kinds of information are provided in discussions of ... success..." (Das 1999:110).

In PEPFAR, the public records, given in annual reports to the U.S. Congress, focus on the number of individuals who have received ARV in a fiscal year, not the outcome of that treatment. Adherence, however, is a key factor in the favorable outcome of ARV treatment. In order for ARVs to be effective, a patient needs to adhere to a treatment regimen at a level of 95 percent or higher (Spire et al. 2002). Otherwise, an individual faces treatment failure and increased viral resistance, leading to more harrowing symptoms of HIV/AIDS. Widespread viral resistance also escalates with high numbers of treatment failures. Therefore, adherence is the most important factor to consider in evaluating the outcomes of a program rather than simple enrollment in it. Yet, "PEPFAR does not routinely report on adherence as part of its ongoing program

monitoring" (Sepúlveda et al. 2007:150). The numbers that PEPFAR reports do not measure the successful outcomes of ARV treatment. In fact, the numbers only include those who received medicines.

Table 11: Treatment: <sup>1</sup> FY2007 Overall Results					
County	Number of individuals receiving upstream system strengthening support for treatment <sup>2</sup>	Number of individuals receiving downstream system site-specific support for treatment <sup>3</sup>	Total number of individuals reached	Planned Funding <sup>4,5</sup> FY 2007 in USD millions	Planned Funding <sup>4.5</sup> FY 2004-07 in USD millions
Botswana <sup>6</sup>	90,500	0	90,500	\$25.5	\$61.0
Côte d'Ivoire	11,100	34,900	46,000	\$32.9	\$79.1
Ethiopia	0	81,800	81,800	\$112.1	\$219.8
Guyana	0	2,100	2,100	\$10.6	\$24.6
Haiti	0	12,900	12,900	\$34.1	\$84.9
Kenya	11,500	154,900	166,400	\$167.1	\$348.1
Mozambique	34,000	44,200	78,200	<b>\$</b> 62.0	\$118.8
Namibia	4,000	39,700	43,700	\$28.8	\$62.2
Nigeria	20,300	106,100	126,400	\$138.9	\$301.6
Rwanda	19,600	24,800	44,400	\$42.2	\$100.0
South Africa	124,300	204,700	329,000	\$184.7	\$377.2
Tanzania	13,300	83,400	96,700	<b>\$</b> 91.3	\$223.0
Uganda	22,500	83,500	106,000	\$92.1	\$233.4
Vietnam	2,700	9,000	11,700	\$21.1	\$41.3
Zambia	0	122,700	122,700	\$83.5	\$234.5
All Countries	353,800	1,004,700	1,358,500	\$1,127.1	\$2,508.8
Total Funding Including Additional Attributions: <sup>7</sup>			1337.6	\$3,095.5	

Note:

Numbers may be adjusted as attribution criteria and reporting systems are refined.

Upstream and downstream numbers above 100 are rounded to the nearest 100 and then added to get totals.

#### Footnotes:

<sup>1</sup> Treatment includes the provision of antiretroviral drugs and clinical monitoring of ART among those with advanced HIV infection.

<sup>2</sup> Number of individuals reached through upstream systems strengthening includes those supported through contributions to national, regional, and local activities, such as training, laboratory support, monitoring and evaluation, logistics and distribution systems, protocol and curriculum development.

<sup>3</sup> Number of individuals reached through downstream site-specific support includes those receiving services at USG-funded service delivery sites.

<sup>4</sup> All funding figures are in millions of US dollars and reflect regularly-updated planned program funding.

<sup>5</sup> Some or all of the individuals reached by PEPFAR may also be supported by other funding sources, such as host governments and other international governments. This amount varies by country.

<sup>6</sup> Botswana results are attributed to the National HIV Program. Beginning FY2005, USG downstream contributions in Botswana are embedded in the upstream numbers, following a consensus reached between the USG and the government of Botswana to report single upstream figures for each relevant indicator. This decision mostly affected reporting in the areas of care and treatment.

<sup>7</sup> Total funding for each prevention, treatment and care programmatic area includes attribution of field and central dollars from the following categories: central procurements, supply chain, technical leadership and support, New Partners Initiative, strategic information, management and staffing, policy analysis, and systems strengthening activities. These attributions are made at the aggregate level and then added to the programmatic funding levels to get the total amount of support for each programmatic area.

# Figure I: Fiscal Year 2007 Overall Treatment Results Showing Number of Individuals Reached by Treatment<sup>33</sup>

<sup>&</sup>lt;sup>33</sup> "Number of individuals reached through upstream systems strengthening includes those supported through contributions to national, regional and local activities such as training, laboratory support,

The chart refers to the numbers of individuals receiving medicines. The "Total number of individuals reached" is contrasted with the planned funding for fiscal year 2007, as well as funding for fiscal years 2004–2007. Like Das's vaccine study, PEPFAR is focused on treatment distribution, not on treatment outcome. The report does not indicate if the treatment outcomes were favorable or not. The numbers do not indicate if PEPFAR was able to retain the individuals receiving care. The executive director of PASADA speaks directly to issues of adherence:

Muhimbili [the national hospital] is above its targets, but their patients are at PASADA. Initially, under the pilot program, PASADA had directed some patients to get drugs at Muhimbili because of our limited funds, but they're back at PASADA because they can't see a doctor at Muhimbili."

Treatment adherence is difficult to monitor because tracking individual patients is a difficult task. Patients are mobile and, without electronic record-keeping, it is difficult to monitor adherence if they choose to leave facilities. At Hindu Mandal, within a twenty-two-month period, the staff accounted for two people transferring out of the clinic and forty-four people transferring into the clinic for ARV treatments from other clinics. Unless a patient presented a patient card from another clinic, clinic staff do not have a way to investigate the ARV history of an individual. Therefore, if Patient A receives medicines from Muhimbili for six months, but then decides to go elsewhere, she can be counted twice in the records. Moreover, if Patient B receives medicines from Muhimbili

monitoring and evaluation, logistics and distribution systems, protocol and curriculum development" (PEPFAR 2008:42). "Number of individuals reached through downstream site-specific support includes those receiving services at USG-funded service delivery sites" (PEPFAR 2008:42). Because of the difference in numbers, attribution is a problem for PEPFAR. For example, in its first year, PEPFAR indicated in its annual report to Congress, *Engendering Bold Leadership: The President's Emergency Plan* for AIDS Relief (2005), that it had reached 113 percent of its first-year treatment goal for Botswana— 32,900 (PEPFAR 2005: 36). According to the operations manager of the treatment program in Botswana, Segolame Ramothwa, the numbers put out by PEPFAR are "a gross misrepresentation of the facts" (Ramothwa quoted in Timberg 2005:1). Government officials from Botswana claimed no PEPFAR money had arrived in the country yet (Timberg 2005:1). It was later characterized by the deputy permanent secretary of health services in Botswana as a mistake in counting by PEPFAR (Timberg 2005:1).

monthly but does not take them, he is still counted even though his situation represents a treatment failure.

Treatment dropouts are also difficult to monitor. One country director explained to me that, "Dropout, according to [the Tanzanian National AIDS Control Programme] definition, is loss to follow-up. If one misses three consecutive visits, he or she is lost to follow-up. Now we have to match the data to definition and exclude deaths, transfers, and moves to new areas." Patients may leave one clinic to receive treatment at another, meaning the possibility for double counting exists until they report their switch or are declared "lost to follow-up." Larger studies reveal much higher attrition rates. A study on the retention of HIV/AIDS treatment program patients in Sub-Saharan Africa "showed that on average nearly 40 percent of patients were no longer on treatment after two years. Some programmes lost almost half of their patients within two years" (Navario 2009:184).

Furthermore, dropout due to death may also be of greater concern in low-income countries than developed countries (Braitstein, et al. 2006). A 2006 *Lancet* study showed that patients in low-income countries beginning ARV treatment had lower CD4 counts than patients beginning treatment in high-income countries (Braitstein, et al. 2006:817). A low CD4 count indicates that a patient is becoming sicker and is a count used by clinicians to determine ARV eligibility. In the first year of treatment, mortality was higher among patients in low-income countries than high-income countries (Braitstein, et al. 2006:817).

Clinic and treatment partner personnel told me their estimates for their organization's or clinic's dropout rates. Their answers varied: "not many;" "5 percent;"

and "10 percent." All of them were able to guess a number or percentage of patients who had dropped out. The acting head of care and treatment for the National Programme estimates that the national dropout rate is 15 percent and adds, "...no one has really studied it." Without knowing patient retention rates or why patients are dropping out, there is no way to begin to determine how successful treatment outcomes are, let alone which programs are retaining the most patients and which programs need more assistance in keeping patients on treatment. Because it is not information that PEPFAR captures, adherence and dropout counts are not part of the numerical narrative that reports its status.

#### The Emergency Plan

An emergency, or humanitarian crisis, as defined by Redfield based on his work with Médecins Sans Frontières (MSF), is a "...state of rupture that invites response" (Redfield 2005:328). That state of rupture or emergency becomes a point of entry for intervention, by the state and by groups outside of the state (Pandolfi 2003; Redfield 2005). Inherent in an emergency, or crisis, is that urgent action is required. Because of the implication that speed in action is necessary, a crisis is "framed in terms of exception and emergency rather than universality and duration" (Nguyen 2007:8).

The word "emergency" in the acronym PEPFAR provided both a reason to intercede (the HIV/AIDS crisis!) and as a reason to scale up quickly (get two million people on ARVs by 2009!). The speed of ARV scale-up within Tanzania is tied to meeting PEPFAR's targets. As an intervention, ARVs most simply save the lives of individuals who would die without them. They keep parents alive to raise children, keep productive members economically active, and provide an example of hope to those who

saw HIV/AIDS as a death sentence. It follows then that the more individuals placed on ARVs, the more lives saved; the faster individuals are placed on ARVs, the faster individuals are saved. The IOM submitted to Congress, as required of the original 2003 U.S. Congressional Act that authorized PEPFAR, an evaluation of the program in 2007. The report, *PEPFAR Implementation: Progress and Promise*, is an evaluation of the first three years of the program. The IOM states, "In keeping with global consensus, congressional mandate, and expert opinion, OGAC characterized its strategy as an 'emergency plan' and has implemented PEPFAR accordingly" (Sepúlveda et al. 2007:246).

As head of PEPAR in Tanzania, Ann Collins recounted its history to me in her office within the U.S. Embassy. She noted that from the beginning the "demands for results [have been] apparent." Scaling up the PEPFAR program has been difficult because the targets are ambitious. Her colleague, another PEPFAR official, who has worked for over three years on HIV/AIDS for the U.S. within Tanzania agreed with her and notes:

There are a lot of frustrations ... We're working with the Tanzanians who work at a different pace, with other donors who work at a different pace. We say, 'There is an emergency and let's move.'... The scale-up is enormous and is happening over a small time.

The language used by Ms. Collins and her colleague indicate that the targets are tied to an emergency situation that demands quick action. The previous statement also alluded to the fact that the other organizations working with PEPFAR are not adopting the "emergency" mindset of PEPFAR. The consensus among the treatment partners is, in fact, different than that of the PEPFAR officials. The treatment partners agreed that the frenetic pace of scaling up to meet emergency-driven targets may affect the quality of

ARV programming that they are able to provide to patients. The technical director of

EGPAF stated:

The fact is there is a lot of focus on numbers—often sides of quality are not emphasized—they might be lost. Not focusing on quality aspects because we are not reporting on it. If you achieve 20,000, you get 20,000 [on treatment]; not a perfected system with 10,000 [on treatment]. You get focused on numbers, not on a program's capacity to maintain, expand.

The new assistant country director of a treatment partner echoed the technical director:

PEPFAR wants numbers... Targets are set in Washington, D.C., without in-country consultations. In order to meet targets, we have to scale up quickly ... Quality is in jeopardy while we are trying to scale up ... The word PEPFAR has to change, it has to drop 'emergency' ... So, my recommendation is to move away from the 'emergency' in PEPFAR. Now, malaria, tuberculosis, and reproductive health are separate systems from the CTCs. [PEPFAR] should move to being a more comprehensive system—to include malaria, tuberculosis, and reproductive health.

What the treatment partners are emphasizing in their concerns about the speed of

scale-up is the paradox of treating HIV/AIDS as a humanitarian emergency. The intrinsic paradox of PEPFAR's ARV distribution is that, while HIV/AIDS is a humanitarian emergency necessitating action, ARVs are not a temporary solution. In order to be successful, ARV treatment requires a lifetime commitment by individuals and a constant and consistent supply by PEPFAR. So, although Nguyen (2007) notes that humanitarian interventions are framed by the language of emergency, PEPFAR cannot solely address HIV/AIDS as a temporary emergency. The result of focusing on targets is a short-sighted view of sustainability, which is always a consideration in lifelong treatment regimens.

One treatment partner's staff doctor discusses sustainability as a matter of focus. According to him, the speed of the scale-up has not allowed the treatment partners to focus on programming. He told me:

I wanted to grow slowly and train people. Talk about numbers is not about quality. Numbers are not the answers ... Quality of care is sustainable, [it

includes] adequate paraprofessionals, checking on follow-up, tracking, keeping people on treatment, adjusting treatment rationally, attentiveness to laboratory.

The IOM's primary recommendation from its 2007 report reiterates one of the prime concerns and suggestions that the treatment partners wanted to see PEPFAR address as it continues: "PEPFAR should transition from a focus on emergency relief to an emphasis on the long-term strategic planning and capacity building necessary for sustainability" (Sepúlveda et al. 2007:1). ARV treatment cannot prevent death through distributing only pills. ARVs require an infrastructure to support their distribution. If targets focus only on the numbers of individuals who receive medication, and speed is required to meet those numbers, the time to adequately train staff and provide patient follow-up, which will anchor the distribution system, will be neglected.

#### The Power of Numbers

The article on ARVs by Gruskin and colleagues calls attention to the assumption "... that programmes can be determined to be successful simply because they result in more individuals being put on ART," cautioning that numerical targets must exist but must not push out other factors required of an ARV program (Gruskin et al. 2007:S16). While numbers can be used to demonstrate fact, objectivity, and precision, they also have political, subjective, and imprecise implications for those involved in the processes of distributing and accessing these medications. PEPFAR's decisions affect how treatment partners' programs are shaped, the daily work of ARV distribution, and the care available to those looking for ARVs in Tanzania. While numbers are efficient in providing evidence of programmatic success, they are just as efficient in obscuring issues generated by a program. While the foreign policy aspect of PEPFAR is built around the idea that success is numbers, the global health issues put forth by treatment—programming, adherence and retention, and health service infrastructure—challenge that idea.

PEPFAR needs to generate a numerical success story in order to fulfill U.S. foreign policy demands on the program, as well as to continue funding to ensure that health services continue for the thousands of people relying on it for treatment. This process demands a high level of accountability regarding the output of treatment and swift scale-up that does not have to report on adherence or how speed may affect the quality of care. The overall result is that within the field of global health diplomacy, the foreign policy aspects of PEPFAR outrank the global health demands of HIV/AIDS. In the next chapter I look more closely at the treatment partners within Tanzania. In particular, I look at how the treatment partners have negotiated a significant change in PEPFAR policy regarding the distribution of ARVs and how that has affected their daily operations as well as their organizational objectives.

### Chapter 4 Regionalization: The Pros and Cons of a New Policy

In his book, A Plague of Paradoxes: AIDS, Culture and Demography in Tanzania,

Setel writes that the "mosaic" of knowledge about the AIDS epidemic "represents the diversity of the epidemic itself" (1999:21). Because the global pandemic is not a uniform event, it would follow that treatment programming will not be uniform either. The global distribution of ARVs is a relatively new undertaking, and the best practices, processes, and programs are not yet known. As a fifteen-country initiative, PEPFAR works in collaboration with fifteen national governments and fifteen national strategies (PEPFAR 2005:14). In addition to government HIV/AIDS strategies, PEPFAR planners, treatment partner personnel, and clinic staffs are working to find which types of programming will be the most successful where they work. As policies are developed and implemented in an effort to improve treatment programming, they affect the lives of individual beneficiaries, but also shape the work of the organizations and clinics that receive funding from the program.

In 2007, the government of Tanzania, in collaboration with PEPFAR, implemented a new policy regarding the distribution and availability of ARVs throughout the country. As a national policy, it was not implemented throughout all PEPFAR focus countries. It is an effort by PEPFAR-Tanzania to improve ARV programming. This chapter is about the effects on the group most affected by the policy—treatment partners. This policy, termed regionalization, assigns one treatment partner to an administrative region in Tanzania to the exclusion of other treatment partners. After discussing how the idea of regionalization came about, the reasons for its implementation, as well as background on the policy, I explore the benefits and drawbacks of the policy before moving on to treatment partner perspectives on the policy. The policy increases the

availability of ARVs throughout Tanzania, aiding in meeting individuals' need for ARVs

and in reaching of PEPFAR's numerical goals, thereby addressing both global health and

foreign policy aspects of the program. Yet, the policy's timing and organization of

treatment partners created some challenges for ARV programming in the country.

## A Story of Hope

On PEPFAR's Web site and within its publications, there are "Stories of Hope."

These "show the impact America's commitment is having on men, women, and children

around the world" (PEPFAR 2009b) by highlighting the progress and successes of the

program. In April 2007, the following was released as a "Story of Hope" by PEPFAR:

In March 2003, the Tanzanian Ministry of Health developed the National Care and Treatment Plan for HIV/AIDS for 2003–2008, setting forth ambitious goals for providing antiretroviral treatment (ART). The U.S. Government, through PEPFAR, is working in partnership with the government of Tanzania to meet these goals.

A new approach, known as "regionalization," was developed in conjunction with the National AIDS Control Program and redistributes partners with the goal of ensuring that only one partner operates within any given region, reducing duplication of efforts. Regionalization gives each partner sole, region-wide responsibility for providing antiretroviral treatment in all hospitals and clinics—whether public, private, or faith-based. The regionalization model is being implemented throughout Tanzania.

Challenges remain, and the physical re-orientation of partners to new areas will need to be carefully managed. Ultimately, it is hoped that the regionalization of antiretroviral treatment services under the National Care and Treatment Plan will lead to a more effective and better coordinated response (PEPFAR 2007b).

#### Figure II: Tanzania: Regionalization Facilitates Treatment Scale-Up

Regionalization is the name of the policy that assigns a treatment partner to an

administrative region in Tanzania to the exclusion of the other PEPFAR treatment

partners. The treatment partner becomes solely responsible for ARV rollout and scale-up

in their region or regions, regardless of the number of hospitals, clinics, or pharmacies

there are in these areas. The "Story of Hope" promotes the idea that PEPFAR "developed

in conjunction with" the National Programme the policy of regionalization. The reason

stated for regionalization in the "Story of Hope" was to ensure that efforts were not being duplicated in the same area. More simply, the goal of regionalization, for planners, was to have a more efficient ARV distribution system in Tanzania. Much like the numbers published by PEPFAR, this account of regionalization reveals little of how the plan came about and how it was institutionalized, glossing over the challenges while focusing on the effectiveness of the new policy.

In September 2006, the PEPFAR treatment partners in Tanzania became regionalized treatment partners. Regionalization was a particularly stressful process because it resulted in an immediate relocation of treatment partners throughout the country in the midst of a PEPFAR funding cycle. Every treatment partner was affected by this policy change. Some were affected advantageously, others adversely. While the aim of regionalization, as stated in the "Story of Hope," is to scale up treatment more efficiently, the policy has drawbacks. The overall result is a working environment within which treatment partners navigate advantages and try to minimize the effects of the disadvantages.

#### **Regionalization** as **Policy**

#### A Brief History of Regionalization

The PEPFAR regionalization policy is inspired by a mid-1990s development model promoted by the World Bank called Sector Wide Approaches, or SWAps, that encouraged state ownership of and greater cooperation on sector development (Hill 2002:1729; Walt et al. 1999:280). Although SWAps can be applied to any area of development, they were most often instituted in the heath sector of a country. The rationale behind SWAps, in the health context, is that an improved health system would
result in improved health for individuals (Hill 2002:1725; Hutton and Tanner 2004:893). In other words, a more efficient system of funding will result in a more efficient health care system and will, ideally, result in more efficient care of the individual. So, instead of concentrating on individual project-based initiatives, development organizations, in partnership with government ministries, coordinate a "collaborative program of work that includes the development of sectoral policies and strategies, institutional reform, and capacity building" (Hill 2002:1728). Through collaboration, governments and development agencies would avoid duplicate, uneven, and unsupervised services.

The terms of SWAps, however, are specific to each context and country that use them (Hill 2002:1727; Sundewall and Sahlin-Andersson 2006). Although the premise is to reduce confusion between state and development organizations, SWAps may result in confusion. In Sundewall and Sahlin-Andersson's study, most government and development officials believed that a SWAp would fund the government's sector plan. Others interviewed, however, thought that a SWAp meant that all the activities conducted within a sector would be part of the government's overall plan (Sundewall and Sahlin-Andersson 2006:284). At the heart of this confusion lies the relationship between development partners and governments. Is coordinating activities together more efficient? Does coordination result in improved services?

Tanzania adopted a SWAp in 1998 in its own health sector with a variety of options for development partners (Wangwe and Madete 2001:4). One option was for donors to contribute to basket funding through the Health Sector Reforms Basket Funds; donors could also fund projects in line with the government's Plan of Action for health sector reforms. A second option was for donors to fund activities outside of the basket or

government requests. Finally, donors could opt for a mix of these options (Wangwe and Madete 2001:5). As noted by Wangwe and Madete, however, as donors mix funding options, the coordinated plan may become ineffectual (2001:5). In this way, development agencies never completely surrender organizational objectives to the host country. The PEPFAR shift from a facility-based to a national strategy-based approach shows obvious connections to the SWAp model.

### The Roots of Regionalization in Tanzania

Tanzania is a partner country with Clinton HIV/AIDS Initiative within the William J. Clinton Foundation (Clinton Foundation). The Clinton Foundation is not a PEPFAR partner. According to a Clinton Foundation employee, "... the Clinton Foundation ... is an implementing partner who has been regionalized by the [Tanzanian] government. We support CTCs [care and treatment clinics] in Mtwara and Lindi [administrative regions in southern Tanzania]." The Clinton Foundation offices are located in the city center of Dar es Salaam, where I met Dr. Radhi Simba, the country director. Dr. Simba is a Tanzanian man with a genial smile. When we met, he spoke about regionalization as an individual well-versed in both the theory and the practice of the program. As the country director for the Clinton Foundation since October 2005, Dr. Simba directed and guided all of the Foundation's Tanzanian activities and supported the Ministry of Health in technical, managerial, and financial matters regarding care and treatment. For the most part, according to Dr. Simba, he collaborated in technical and managerial work with the National Programme. He also emphasized that the Clinton Foundation is not a PEPFAR partner, but a care and treatment partner in southwestern

Tanzania. Before his work at the Clinton Foundation, Dr. Simba was with the CDC in Tanzania as deputy director when PEPFAR began.

Difficulties in ARV distribution in Tanzania became evident during planning in November 2003, according to Dr. Simba, and continued as PEPFAR was implemented in 2004. The Track 1.0 partners for treatment were funded through the CDC and selected based on the number of patients they pledged to reach. Three of the four Track 1.0 treatment partners—Harvard-MDH, Columbia-ICAP, and EGPAF—were based at Muhimbili Hospital in Dar es Salaam. They were competing for the same numbers of patients, in the same city, in the same hospital. Dr. Simba, had to coordinate the division of patient numbers:

They [the treatment partners] were fighting ... I had to do something to allocate patients, to give money out and see results ... It was a coordination nightmare ... I asked CDC headquarters in the first year to move partners. They did not agree because they thought the partners already had spent money, time, and invested in personnel and would not want to move and eventually complain to Congress."

From Dr. Simba's standpoint, regionalization was an opportunity to separate the care and treatment partners so as to reduce crowding of PEPFAR contractors.

Dr. Ryker Henning, the country director of FHI, was also a proponent of regionalization. Dr. Henning has lived and worked in Tanzania as a doctor, medical school professor, WHO official, and FHI country director since 1974. Together with Dr. Simba and the head of the National Programme, Dr. Henning says that they developed the idea of regionalization through discussions in 2005. Dr. Henning believes regionalization "was a better way of working," specifically for Tanzanian government health officials. Instead of working with two or three competing partners in the same region, a Tanzanian government official would only have to work with one treatment partner after regionalization. Regionalization, Dr. Henning said to me in an interview, allows "national authorities to work more effectively and efficiently" because the number of treatment partners in a region is reduced to one. Not only would regionalization reduce coordination confusion, it could also reduce the confusion concerning how many organizations were working in a given region.

The head of PEPFAR noted in her interview with me that an overview of PEPFAR pre-regionalization quickly reveals that most resources were being used in only one part, one city, of the entire country. This left many parts of Tanzania completely without ARV treatment. As a result of PEPFAR's structure, Tanzania initially had difficulty in demonstrating that it could reach its PEPFAR goal of 150,000. PEPFAR's third annual report to Congress illustrates Tanzania's progression to meeting its target. Within the first year, PEPFAR-Tanzania had only reached 1 percent of its total goal. By the second year, it had progressed to just 9.8 percent (PEPFAR 2007a:62). A scale-up of ARV services was needed in order to meet the goal of 150,000. Moreover, the new regionalization policy could address the inefficient spread of PEPFAR resources in the country and reach new patients.

# Implementing Regionalization in Tanzania

Dr. Simba said to me that after another year of conversation with individuals working at USAID, along with Dr. Henning, they agreed to ask the CDC again to reallocate the partners to different regions of the country. This time the CDC agreed, and Dr. Henning remembers that USAID was receptive to the idea and helped promote it within the U.S. government team in Tanzania. In addition to U.S. support, the idea needed Tanzanian government support. On September 25, 2005, the permanent secretary

of the Ministry of Health sent a letter to the country director of the CDC informing him officially of the regions where the treatment partners would be relocated in 2006. At the time, the U.S. treatment partners were working with over thirty facilities in Tanzania (PEPFAR 2006:48). According to the U.S. country support team leader for Tanzania, "The number of service outlets providing ARV therapy was 366 as of September 2008"—an increase of over 1000 percent.

Most treatment partners had to reduce the number of regions they were working in, while increasing the number of CTCs within the regions they supported. During regionalization, the pressure to maintain and exceed numerical targets still remained. The possibilities of achieving targets, of course, changed as treatment partners moved to regions with different prevalence rates.<sup>34</sup> The new policy assigned Harvard-MDH the Dar es Salaam region, a high-prevalence region<sup>35</sup> at 10.9 percent, the only area it had been working in pre-regionalization (TACAIDS et al. 2005:76). After regionalization, Columbia-ICAP, discussed in-depth later in this chapter, was placed in charge of four regions, of which only one is high prevalence. Before the policy, it was working in five regions, three of which were high prevalence. Of its CTCs in five regions, EGPAF maintained only two high prevalence regions-Tabora region at 7.2 percent and Kilimanjaro at 7.3 percent—out of the four regions they were assigned (TACAIDS et al. 2005:76). AIDSRelief had facilities in six regions throughout Tanzania, and regionalization reduced their numbers to four, with Mwanza having the highest prevalence at 7.2 percent (TACAIDS et al. 2005:76). The DoD did not lose any of its

<sup>&</sup>lt;sup>34</sup> Prevalence information in this paragraph is taken from the 2003–2004 Tanzania HIV/AIDS Indicator Survey (TACAIDS et al. 2005) in order to capture prevalence information before regionalization was implemented.

<sup>&</sup>lt;sup>35</sup> High-prevalence regions are defined here as regions with higher prevalence than the then national average of 7 percent (TACAIDS et al. 2005:90).



Figure III: Administrative Regions of Tanzania<sup>36</sup> (TACAIDS et al. 2005:xiv)

three regions—Mbeya, Ruvuma, and Rukwa—or gain any either. One of those regions, Mbeya, was a high-prevalence region at 13.5 percent (TACAIDS et al. 2005:76). The Clinton Foundation committed to two regions: Mtwara, a high-prevalence region at 7.4 percent, and Lindi (TACAIDS et al. 2005:76); the Tanzanian government and PEPFAR did not assign a PEPFAR partner to those regions. The only treatment partner to gain a

<sup>&</sup>lt;sup>36</sup> Treatment partner information from Ministry of Health letter 2005 and interviews.

Treatment Partner	Assigned Regions <sup>37</sup>	HIV/AIDS Prevalence in Assigned Regions <sup>38</sup>	Population in Assigned Regions <sup>39</sup>	Pre- Regionalizati on Regions <sup>40</sup>
AIDSRelief	Manyara Mara Mwanza Tanga	2.00% 3.50% 7.20% 5.70%	999,729 1,432,476 2,665,956 1,742,413	Arusha Dodoma Mara Mwanza Ruvuma
Columbia University's International Center for AIDS Care and Treatment Programs	Kagera Kigoma Pwani Zanzibar Ocean Road Cancer Institute (Dar es Salaam)	3.70% 2.00% 7.30% Zanzibar was excluded from 2003–2004 Tanzanian HIV/AIDS Indicator Survey	1,957,921 1,240,939 848,316 1,003,794	Dar es Salaam Kagera Kilimanjaro <b>Mwanza</b> Zanzibar
Department of Defense	Mbeya Rukwa Ruvuma	13.50% 6.00% 6.80%	2,235,271 1,218,977 1,222,242	Mbeya Rukwa Ruvuma
Elizabeth Glaser Pediatric AIDS Foundation	Arusha Kilimanjaro Shinyanga Tabora	5.30% 7.30% 6.50% 7.20%	1,292,973 1,381,149 2,805,580 1,717,908	Dar es Salaam Dodoma Kilimanjaro Morogoro Tabora
Family Health International	Dodoma Iringa Morogoro Singida	4.90% 13.40% 5.40% 3.20%	1,698,996 1,495,333 1,759,809 1,090,758	Arusha Dar es Salaam Iringa
Muhimbili–Dar es Salaam City Council– Harvard University	Dar es Salaam	10.90%	2,497,940	Dar es Salaam
Clinton Foundation	Mtwara Lindi	7.40% 3.60%	1,128,523 848,562	Mtwara Lindi

Table 4: Treatment Partner Regional Assignment Information

 <sup>&</sup>lt;sup>37</sup> Information from United Republic of Tanzania Ministry of Health letter 2005 and interviews.
<sup>38</sup> Prevalence information in this paragraph is taken from the 2003–2004 Tanzania HIV/AIDS Indicator Survey (TACAIDS et al. 2005) in order to capture prevalence information before regionalization was implemented.

<sup>&</sup>lt;sup>39</sup> Population information taken from the 2002 Tanzania Population and Housing Census (Republic of Tanzania 2003). <sup>40</sup> Information from United Republic of Tanzania Ministry of Health letter 2005.

region was FHI, which went from a presence in three regions to four regions total, of which one region, Iringa, was a high-prevalence region at 13.4 percent (TACAIDS et al. 2005:76).

#### The Benefits of Regionalization

Most immediately, regionalization addressed the issues of ARV service duplication and ARV service neglect. The Tanzanian government, with PEPFAR, assigned the administrative regions of Kigoma, Manyara, Pemba (located within the Zanzibar islands), Pwani, Shinyanga, Singida, and Tanga (Ministry of Health letter 2005) a treatment partner where there was not one working pre-regionalization. The technical director of one treatment partner said to me that the treatment partners had to shift their mindsets away from a facility-based model: "You can't justify staying in one hospital [when] you're responsible for the whole region." As treatment partners responsible for providing ARVs to an entire region, each essentially enjoys an ARV service monopoly in which to expand to meet the PEPFAR treatment targets. While implementation of regionalization began in mid-2006, by the end of fiscal year 2006 Tanzania reported higher patient numbers. The number of U.S. government-reported sites providing treatment increased to sixty-seven during 2006 (PEPFAR 2007a:68), up from sixteen in 2004 (PEPFAR 2005:37) and thirty-three in 2005 (PEPFAR 2006:48). Moreover, PEPFAR reported that the number of individuals reached by ARV treatment in Tanzania was at 44,300 by the end of 2006, over 29.5 percent of the total five-year goal for PEPFAR-Tanzania (PEPFAR 2007a:60).

For PEPFAR purposes, the scale-up provoked by regionalization was a success in terms of numerical goals. Even if all the individuals counted as starting treatment did not

have favorable outcomes, the numbers do indicate a greater availability of ARVs throughout Tanzania. So regionalization addressed duplication and ARV availability, as well as dispelled the notion that the U.S. was only funding certain regions within Tanzania, while others remained without treatment access. By the end of 2007, when 64 percent of the PEPFAR goal was reached at 96,700 (PEPFAR 2008:42, 64), the head of PEPFAR in Tanzania was projecting reaching a new country goal of 200,000 instead of the original 150,000.<sup>41</sup> In 2008, PEPFAR-Tanzania reported 144,100 individuals on treatment (PEPFAR 2009a:48).

The treatment partners themselves also state that they saw the logic of regionalization. They recognized the benefits accruing to the Tanzanian government officials from streamlining who they would need to speak with in their region about ARV treatment concerns. A former member of the DoD team argued that regionalization "makes excellent sense. It's crazy for the [Tanzanian] regional [medical] officer to deal with a half a dozen organizations ... without it, the total number of partners is a direct correlation to the chaos." Like his counterparts, he mentioned the crowding of organizations within a region as an obstacle to an efficient system of treatment. The result, according to the DoD employee, was that regionalization makes the program more accountable to its Tanzanian counterparts. If there are too many contractors, the [Tanzanian] regional medical officer will be less efficient, no matter how dedicated. The DoD employee's answer illustrates how U.S. inefficiency contributed to Tanzanian inefficiency. Simplifying the U.S. program resulted in Tanzanian government officials accomplishing their work more efficiently.

<sup>&</sup>lt;sup>41</sup> The PEPFAR goal of 150,000 was never officially changed.

Regionalization was not without its drawbacks. As one treatment partner program director noted, "[Regionalization] is a great idea, but the way in which it was done was not good." She went on to explain that regionalization was not done well because it was implemented in the midst of a funding cycle and she would have preferred being regionalized from "day one." The next section explores some of the challenges that regionalization created, primarily for the treatment partners.

#### Moving Challenges

Regionalization expanded the distribution of ARVs throughout Tanzania. It was now possible for every person living with HIV/AIDS in Tanzania to obtain treatment, regardless of location. Yet, regionalization presented its own challenges as treatment was expanded throughout Tanzania. There were no standardized care packages or instructions for the treatment partners to follow. Even though there are standardized treatment protocols within the country, each partner could provide care and treatment in its own way. The assistant country director of MDH said to me in an interview, "Regarding CTC ... we all follow the national guidelines, but we [the treatment partners] all have different modalities, strengths, and cultures. Treatment initiation is standard ... The basic package is similar, same reporting mechanisms, but styles differ—some are more expensive and some are less expensive." Pre-regionalization, partners could pick facilities that would complement the type of care it would provide.

Even before PEPFAR, the partners had built partner-specific programs, such as Harvard's nutritional trials, Columbia University's work on early infant diagnosis, EGPAF's focus on mother-to-child transmission, and AIDSRelief's intensive mentoring. With regionalization, partners lost their hand-picked facilities and the continued

opportunity to select only the facilities in which they wanted to work. While this resulted in greater availability, it also meant a change of working relationships on the ground as treatment partners left facilities they had worked in for years. In addition, local staffs had to build new relationships with new treatment partners. Treatment partners also had to expand their repertoire of care as they came into contact with other service programs during the transition to regionalization.

So while regionalization has created more ARV availability in Tanzania, it also resulted in losses of experience and expertise in certain regions. One treatment partner's technical director remarked:

The whole concept of regionalization was for a partner to provide a more comprehensive package right from prevention, treatment, home-based care, all those things. That was the whole concept of regionalized partners. All partners cannot provide, [so] there are delays in moving out until a new partner gets expertise or finds another partner that can do it [such as a subcontractor].

What the technical director is pointing to is that although each partner was equipped and funded to be a care and treatment partner, they were not all prepared or funded to take on other programs surrounding care and treatment programs. While all partners follow the national care and treatment guidelines, not all partners are funded for exactly the same activities surrounding their ARV programs. Partners had enjoyed the freedom to not only select facilities, but also to create their own specific programs.

While partner-specific strengths were originally points of achievement, during regionalization they became areas of confusion, because PEPFAR had not formulated a standard package that all partners would provide post-regionalization. PMTCT is an example of a PEPFAR-related activity that all treatment partners had to take on after regionalization. As noted by a senior ART manager at a treatment partner, when a

treatment partner takes over a new program, like PMTCT, it does not mean that it has run the program before successfully or that it is the best at it.

The program pharmacist for the National Programme and the then acting head of the Care and Treatment Unit in Dar es Salaam said, "We [the National Programme] didn't have a list of what they [the treatment partners] should do ... there was no kind of uniformity of partner support." Although the policy of regionalization aimed to clarify for national health authorities the ARV services provided within a region, the policy also created confusion for the National Programme, as it was unsure of what the treatment partners should do.

With treatment partners now fully responsible for their regions, they had to subcontract with other partners to ensure some services were not disrupted. Some partners had been funded for PMTCT programs that relied on technical and financial input from a partner such as EGPAF. As a result, EGPAF was running PMTCT programs in seven regions at one point,<sup>42</sup> while it became the head of care and treatment in four regions. The subcontracting necessary to keep certain programs afloat after regionalization show treatment partner commitments to the populations within a region to keep programs constant and acquire the expertise needed to keep them going. Subcontracting, however, placed EGPAF in two more regions than it was originally. The worries about service duplication were not completely eased by regionalization multiple PEPFAR partners were still working in many regions as subcontractors.

Regionalization, however, did create a clear line of communication, designating which organization was in charge of care and treatment services. As of 2007, PEPFAR

<sup>&</sup>lt;sup>42</sup> Subcontracting is left to the discretion of the care and treatment partner in the region. The partner may decide to take over certain activities or may continue subcontracting certain activities.

planned to regionalize, or assign to the treatment partners, PMTCT services as well as orphan and vulnerable children care—helping to clarify more treatment partner responsibilities.

# **Treatment Partner Perspectives on Regionalization**

## Treatment Partners at Work

In a program where success is judged by numbers, the loss of potential ARV patients is a cause for concern. Partners say that not meeting targets can lead to a souring relationship with PEPFAR which, most believe, may lead to a loss of funding. As regionalization moved partners out of certain places and into others, they faced different prevalence rates and different sets of infrastructure. One U.S. government official referring to MDH and regionalization, simply remarked, "Harvard did not lose at all." Harvard-MDH, considered a "winner" of regionalization by other partners, retained Dar es Salaam, in which they were already working. The popularity of Dar es Salaam as a treatment site was demonstrated by the large numbers of treatment partners working there in 2004. Most significantly, according to the assistant country director, MDH only had to take over existing care and treatment sites in the region, rather than move out of or build new ones: "Harvard is in a better position [in Tanzania]—[it] only had to take over facilities, it did not have to move out." Harvard-MDH was set to increase the facilities it took over and its patient numbers in the Dar es Salaam region.

While Harvard-MDH benefited, there is informal consensus among many of the treatment partners that Columbia-ICAP lost the largest patient numbers in Tanzania. Of the four care and treatment sites they held pre-regionalization, two were high profile— Muhimbili National Hospital in Dar es Salaam and Sekou Toure Regional Hospital in

Mwanza—in that they provided almost 5,000 people with ARVs. Overall, Columbia-ICAP lost 60–70 percent of its patient numbers during regionalization, according to the director of programs and technical activities. Columbia-ICAP originally worked in five regions, including three regions where HIV/AIDS prevalence was higher than the national average—Dar es Salaam, Kilimanjaro, and Mwanza. After regionalization, Columbia-ICAP was placed in charge of four regions, of which Pwani Region has the highest prevalence at 7.3 percent (TACAIDS et al. 2005:76). According to the director of implementation and site support, Columbia-ICAP was thrown into remote, rural areas, virgin land without standing care and treatment sites, an ordeal that was initially "painful." He also went on to say, "...you invest quite a lot and then you have to move and can't take everything with you. It was major change for the partners." The new regions' lower prevalence numbers and more poorly equipped, or nonexistent, CTCs meant that the previously high patient numbers were replaced with lower numbers and Columbia-ICAP's standing as the second leading treatment partner in numbers was lost. In early fall of 2007, Columbia-ICAP had over 10,000 individuals on ARVs, up from over 6,300 at the end of 2006.

# **Changing Priorities**

AIDSRelief, another treatment partner, illustrates organizational transformation caused by regionalization. AIDSRelief, a nine-country initiative, is the only consortium partner in Tanzania. It consists of the lead organization (Catholic Relief Services), the Institute of Human Virology at the University of Maryland, Constella Futures, and Interchurch Medical Assistance. The AIDSRelief vision for their work in Tanzania was to create a faith-based network of hospitals. Using their inroads to organizations,

AIDSRelief set out to work with existing hospitals. Pre-regionalization, AIDSRelief was working with eight facilities in six different regions in Tanzania. Of the eight facilities, PASADA was slated by AIDSRelief to be a center of excellence within the faith-based network.

According to the senior ART program manager, the plan was to have staff from AIDSRelief's other care and treatment sites visit PASADA to exchange ideas and learn from one another. By selecting eight clinics for a private network, AIDSRelief could create its own funding network and administrative procedure. Furthermore, the AIDSRelief model of involvement allowed them to provide an intensive mentoring relationship—providing technical and material support to a CTC and its staff—with each of their facilities.

With regionalization, however, AIDSRelief was no longer the sole decision maker in running its CTCs. Now, instead of a private, faith-based network, AIDSRelief is part of a country-wide system. As one AIDSRelief official recalled the transition, the learning curve was steep: "Now that we [are] in charge of government hospitals, we needed to learn how to sign agreements with them, how to open [Tanzanian] bank accounts." No longer a private network, regionalization had made AIDSRelief a part of the state's health service network. AIDRelief's role includes taking on obligations that were not part of their original plans in Tanzania and completely changing their overall vision. Regionalization separated the existing faith-based network.

While having to give up its original vision, AIDSRelief also had to create partnerships with staffs that did not necessarily ascribe to its faith-based priority. In both work and staff, AIDSRelief is becoming a more secularized, governmental treatment partner. The intensive mentoring model AIDSRelief was able to use with its eight facilities became more difficult to maintain as the four regions they inherited already had thirty-four facilities that would need their attention before they could work on expanding the number of sites. A program manager for AIDSRelief said that the effects of regionalization did result in a mentoring change: "We still do on-site trainings, but not as intensively, not enough time or resources, even with more money—we have too many facilities." Not only were their patient numbers increasing, but their facility numbers were as well. In the first year of regionalization, AIDSRelief officials told PEPFAR that it could take on sixteen CTCs, according to an AIDSRelief program manager. In the following year, AIDSRelief took on a total of thirty-four care and treatment sites with plans to continue scaling up.

#### Graduation

Along with regionalization, PEPFAR also implemented a policy of graduation. Graduation occurs when an individual CTC no longer receives support for its ARV program from a treatment partner. Rather, it receives ARV program funding from PEPFAR via a USAID funding mechanism—the ARV program is only funded by USAID. As noted by the PEPFAR media outreach coordinator, graduation "cuts out the middle man." She also went on to say that graduation reflects two things about a CTC: "[Graduation] means an organization can meet the financial reporting standards of USAID ... [and has] sustainability—meaning, [the clinic can] ... carry out and reach objectives." Graduation requires that a CTC fulfill the reporting requirements of USAID, which include monthly, quarterly, and annual reports, as well as audits and the Country Operational Plan (COP). Treatment partners are responsible for submitting these reports to PEPFAR for each of the clinics they support. Once a clinic graduates, these responsibilities fall directly on the staff of the clinic. Furthermore, PEPFAR also views graduation as a step toward the sustainability of the program. The PEPFAR country team support leader for Tanzania says that graduation "...is a part of sustainability..." As more clinics are graduated, USAID can directly fund the clinics—without a treatment partner.

During the year regionalization was implemented, two clinics graduated, Selian Lutheran Hospital in Arusha region and PASADA in the Dar es Salaam region.<sup>43</sup> From PEPFAR's point of view, Selian and PASADA do "a great job." Essentially, if a clinic is doing great care and treatment work, they could acquire some administrative staff in order to graduate and "just go about business," according to a PEPFAR official. Ms. Collins, the head of PEPFAR, expressed that "there was concern that they [Selian and PASADA] weren't ready, but [there was an] opportunity cost." In other words, if AIDSRelief was focusing on PASADA, which is already doing a "great job," would its energies be better spent on a CTC that was not doing a great job? Even if the clinics were not completely ready, this process would force them to "mature" quickly.

Before regionalization, both Selian and PASADA received support from AIDSRelief. The senior ART program manager at AIDSRelief says that PEPFAR informed AIDSRelief about Selian and PASADA's graduations. While he said that AIDSRelief had planned to make PASADA a "center of excellence" within its faithbased network for other clinics to learn from, he still thought "PASADA had things to work on ... PASADA thought they had things to work on. The U.S. government was confident that [PASADA] could do it..." Moreover, an AIDSRelief program officer agrees, saying, "AIDSRelief is under the impression that their two highest profile

<sup>&</sup>lt;sup>43</sup> More on PASADA's account of graduation in Chapter 6.

organizations were graduated, but no other partners had to graduate anyone. They were clinically ready, but not financially ready. AIDSRelief can barely keep up with U.S. government demands; how can PASADA when they never had the experience?" From AIDSRelief employees' perspective, PASADA would have been a center of excellence, but with the support of a treatment partner. Although AIDSRelief still supports some administrative and other aspects of PASADA's activities, their fourteen-year relationship is changing—AIDSRelief now has the opportunity to hire away PASADA's staff. In 2007, AIDSRelief hired away PASADA's medical director. In the realm of ARV services, AIDSRelief and PASADA are now separate entities and, in some ways, competitors, as evidenced by the hiring away of staff.

While regionalization does give treatment partners region-based monopolies, PEPFAR, through graduation, can take away specific CTCs. Like any graduation, it is a bittersweet process. Selian and PASADA were successful clinics under a treatment partner—successful enough to be noticed by PEPFAR. Now they have become successful clinics under USAID instead (clinic perspectives on graduation discussed in Chapter 5). AIDSRelief can no longer report the ARV programs' successes or count the patient numbers as their own despite years of funding. Furthermore, EGPAF and MDH, the new treatment partners for Arusha and Dar es Salaam regions, respectively, cannot count the patient numbers at two clinics within their regions either; and Selian and PASADA are subject to their own PEPFAR numerical targets.

### **Treatment Partner Benefits: Imagined Patients and Tangible Funding**

While the policy of regionalization assigned treatment partners to regional monopolies in which to expand their programs, the treatment partners are also subject to

the objectives of PEPFAR. The result for the treatment partners is a continually changing playing field. Even though the pressure to reach numerical targets set by PEPFAR remains constant, the locations in which treatment partners work became subject to change in the midst of funding due to regionalization. Despite these ever-changing work conditions, none of the treatment partners have halted their affiliation with PEPFAR or left Tanzania. As treatment partner personnel—country directors, program officers, technical managers, and physicians—discuss the reasons for staying with a demanding donor, they draw answers from what is working well in PEPFAR. They also can speak directly to what they value about their own work within PEPFAR. For this particular group of individuals, the meaning of their work comes from two primary sources—imagined patients and tangible benefits.

Treatment partner offices are headquartered in Dar es Salaam. While country directors, treatment technical advisors, and directors of ARV services work, plan, and budget for HIV/AIDS treatment on a daily basis, they do not usually see, treat, or interact with patients. Nonetheless, these employees view their work as having a real effect on the daily lives of people they do not know and might never meet. They recognize that ARV treatment is made possible through their work with PEPFAR—and is positively affecting many lives.

The Harvard-MDH assistant country director remarked that their contract and work with PEPFAR is important:

Most of the agencies like Columbia, Harvard, Johns Hopkins apply to be part of PEPFAR—why? Because they are accountable to give services in Third World, where help is needed. They have an obligation to serve people beyond training ... [it is] a noble thing to be involved in because we are saving lives. In a later interview, he again noted that "We are saving lives, and loving what we do. People are going back to work, teachers are not dying. We are doing something good." In this way, treatment partner personnel imagine patients. While there is no doubt that PEPFAR is affecting the daily lives of Tanzanians and individual patients are benefiting from ARV treatment, the treatment partners have to imagine the patients who benefit.

The director of implementation and site support at Columbia-ICAP, which was notably rearranged by regionalization, speaks to the initial loss of programs, infrastructure, and patients: "We always say we got a raw deal because of regionalization because transport, infrastructure, and security are all major problems in our new areas. But, we are brave enough to take services to the people; we have passion!" In his statement, he focuses on the fact that Columbia-ICAP makes services available to people who need them. He, like the Harvard-MDH assistant director, does not treat individual patients, but he can imagine the impact of Columbia-ICAP's work on their lives.

While treatment partner employees can discuss the nobleness of their cause and purpose as reason to work through the ever-changing realities associated with PEPFAR, they also discuss the tangible benefits of working with PEPFAR. The most basic, concrete benefit of working as a treatment partner for PEPFAR is the funding, according to treatment partner country directors and ARV program managers. Treatment partner personnel, though, discuss money for their current programs and programs they would like to initiate as reasons to stay with PEPFAR. Treatment officials at AIDSRelief were open about the possibilities PEPFAR funding creates for their programs. One treatment partner program manager said that a reason to stay with PEPFAR was, "... lots of money, amazing amounts of money. You can launch initiatives that you want [to try]. You can

really do what you want and follow promising practices because we don't know what the best practices are yet." A colleague at AIDSRelief concurs, "There's a huge amount of funding for any type of programming. If it has to do with HIV/AIDS and you can sell it..., you can do it. You can try out different things and find out what models are working and which are not." For these two colleagues, funding is a concrete benefit that allows programming—new and creative programming—to be funded, which in turn helps individuals. The tangible benefits of money and its effects on imagined patients are combined to find meaning in an instance where efficient plans do not always result in efficient outcomes.

Treatment partner personnel also recognize the tangible benefits that apply solely to their organization. As PEPFAR provides 80 percent of ARV treatment in Tanzania, leaving it or working outside of it would create more work for the organization itself, according to the director of technical activities for one treatment partner:

Now, of course, you could go to Global Fund or DFID [United Kingdom Department for International Development] or the European Union, and get money and work outside of regions assigned by U.S. and the government of Tanzania, but it means more work for you...When you have Tabora [region], you have the whole region [with PEPFAR]....

PEPFAR guarantees a set, funded region in which to work. Working outside of a program that funds 80 percent of ARV distribution would result in more work for treatment partners to find places and facilities that need funding.

Furthermore, as MDH's assistant country director was able to speak eloquently about finding meaning for MDH's work in saving lives, he was also able to point out the pragmatic benefits that PEPFAR provides for MDH: PEPFAR "opens up a larger avenue to bring in students and faculty. It broadens their scope of international health and [helps them] get experience ... [This work] improves teaching back home and people learn how to work without the high-tech equipment available at home." In addition to the funding that keeps the organization working, individuals can also advance their personal careers by working in an international setting and learning a new skill set regarding HIV/AIDS care and treatment. Furthermore, individuals with international experience and the background and know-how to work with international donors are those who will keep trying new programs and following "promising practices" until "best practices" are discovered. Just as the imagined patients provide meaning and logic to continue on with PEPFAR, so do more tangible benefits for the treatment partners.

# **Regionalization:** A Larger View

France has also adopted a regionalization approach for its ARV hospitals (Nguyen 2009:205). Nguyen has termed this "therapeutic re-colonization": "Parisian hospitals were attributed therapeutic territories corresponding to former French colonies" (2009:205). He continues:

The 'scramble for Africa', and the colonial regime it installed to rule over territories and the peoples they contained, resulted in arbitrary borders and ethnic cleavages that persist to this day with at times tragic consequences. HIV programmes do not create new borders, but they reflect a geopolitical logic in deciding who gets to intervene where, and they also produce arbitrary social borders. Mass HIV treatment programmes cleave those who benefit from those who do not (Nguyen 2009:206).

Nguyen (2009) argues that the treatment partners hold a sovereign power over those in their assigned regions as they have power over individuals' lives and deaths. Yet, recolonization is a problematic term to describe the Tanzanian regionalization policy.

As noted by Drs. Simba and Henning, regionalization was promoted by Tanzanians and the Tanzanian government, as well as PEPFAR, making it a requested rollout of treatment from within the country itself, not simply an imposed condition. As noted in Chapter 1, President Nyerere championed the idea of health service availability for every Tanzanian. By 1983 over 90 percent of the population lived within ten kilometers of a health facility (Iliffe 1998:205). Moreover, the Arusha Declaration called for the new government not to isolate health care facilities in urban areas, but to ensure that rural regions also had access to them (Iliffe 1998:202). In this regard, regionalization may be said to reflect a return to the ideals of the Arusha Declaration.

Furthermore, whereas the history of colonialism is one fraught with cleavages and tragic consequences, lives are saved by PEPFAR's provisioning of ARVs. PEPFAR because of the system's numerical targets—is trying to actively place patients who need treatment on ARVs. Because treatment partners need numbers to guarantee continued funding, they aim to reach as many potential patients as possible. Ideally, a treatment partner, within its region, will reach every individual in need of ARVs—there will not be a need to triage patients or create divisions between those who receive ARVs and those who do not. Regionalization uses the geopolitical boundaries within Tanzania to improve the availability of treatment throughout the country—thereby helping stem the effects of the HIV/AIDS epidemic while improving political relationships with the government of Tanzania.

In the next chapter, I look at two CTCs in Dar es Salaam. Clinics distributing ARVs are where the conditions placed on them by international donors and the national requirements become daily practices. They are also the spaces in which patients first encounter ARVs and treatment programming. I will discuss how clinic staffs manage the policies that come from PEPFAR and the Tanzanian government in caring for individual patients.

# Chapter 5 Clinics: Working Between Paper and Reality

A clinic is the space where international initiatives, state authority, and local realities meet. In the provisioning of ARVs, clinics are the spaces where the discussions, planning, and forecasting associated with ARVs result in pills handed to patients. They are also the spaces where patients have interactions not only with the clinic staff, but also with the state and PEPFAR via the clinical staff. Previous chapters have focused on the politics of ARV rollout, or the distribution of treatment, as well as the plans associated with success and the power given to and generated by numerical targets within PEPFAR. The focus of these plans and the numbers they generate has been on the distribution of ARVs. These chapters have examined how these official channels of power are reified by paperwork and numerical targets. CTCs, or the clinics that distribute ARVs, are the final link in the institutional chain that rolls out medications. While they are subject to the demands of their donors, clinics are the spaces where donor plans are actualized by doctors, nurses, and counselors. It is the clinic staff who "produce policy daily" through their work (Booth 2004:20).

While CTCs are the last stop in distribution, they are also the first point of ARV access. The numbers so often cited in PEPFAR reports become patients at the clinics. The concerns and problems associated with access to ARVs become realities for the staff of CTCs to address in their everyday work. As the executive director of one CTC in Dar es Salaam said to me, "When you are completely donor dependent, you have to watch your mouth ... because if funds are cut, it is services to the poor that are cut." Clinic staff is subject to the demands of their donors, PEPFAR or otherwise, which means they are required to keep the records demanded of them. On the other hand, clinics must deal with

the concerns of patients who are beginning a lifelong treatment process, which requires counseling and building trust with individuals. In trying to accomplish both tasks, clinic staff works between donor paper requirements and the reality of placing numerous individuals on ARV treatment. Every day, clinic staff throughout Tanzania counsels individuals as each is diagnosed as HIV-positive, undergoes ARV counseling, and decides to begin ARV treatment. While these actions are recorded and quantified in the clinic itself, these are actions that take place because of the work of individuals.

#### **Differences in Policy Interpretation**

As staff find themselves as the last point of distribution from a policy perspective and the first point of access from a patient perspective, staff link individuals to donors. Yet, as they carry out the work of donors, in this case an international, governmental initiative, there can be differences in interpretations of policy between donor plans and staff. Nguyen et al. (2007), Nguyen (2005), and Booth (2004) compare how clinic staff interpretations of policy differ from donor interpretations of policy. When ARVs first became available in resource-poor settings through private foundations and organizations, they were a limited commodity, scarce in comparison to the number of individuals in need before the advent of global treatment programs. The scarcity of these medications created a particular system of distribution when they did become available in the late 1990s. Nguyen's work with West African People Living with HIV/AIDS (PLWHA) groups in the late 1990s illustrates how individuals negotiated their own social networks to access ARVs (2005). Those groups able to access ARVs began to function as "social triage" centers, determining who could and could not have access to the medications (Nguyen 2005:132). Because the groups selected who would receive these limited

commodities, it was up to the individual to tell the "right story" to them in order to access ARVs (Nguyen 2005:133). According to Nguyen and colleagues (Nguyen et al. 2007), the donors who supplied the medicines expected the most vulnerable members of society to benefit from their donations. Instead, the PLWHA groups began to use their triage system not to focus on individuals, but on the group. Individuals whose good health would most likely translate into better access to or more resources for the group as a whole were selected first (Nguyen et al. 2007:S33). The authors note that charismatic individuals who could publicize the work of the group, or individuals whose jobs, such as customs officers, could facilitate the importation of medicine, were chosen by the group (Nguyen et al. 2007:S33). Through this system, the group identified and selected persons who would also be positive advertisements for ARVs (Nguyen et al. 2007:S32). In other words, the groups selected individuals who they thought would be good adherents to the daily regimens of treatment. The PLWHA groups created a system of social triage with the goal of trying to ensure the continued flow of ARVs.

Booth's study of Kenyan clinics examines an AIDS-control program that specifically addressed women. While, according to Booth, the project intended to provide the same services to any woman who came to the clinic, the project planners failed to take into account women's social and economic power within the community (Booth 2004:122). The result was "that quite consciously the nurses were *selectively* accepting and rejecting aspects of the AIDS-control project that the Kenyan state, the WHO's Global Programme on AIDS, and a team of foreign medical researchers had together imposed on their clinics" (Booth 2004:4–5, original emphasis). The clinic staff, she argues, while grateful for the funding (2004:5), adapted and reinterpreted the AIDS-

control project based on local knowledge and customs. What Booth (2004) illustrates is that donor demands, while important, are not carried out uniformly from policy planner to clinic staff. The result is that the official work of the project continues, while an informal system—how staff runs programs and works with patients—forms and operates within it. Nguyen and colleagues suggest that PLWHA groups privilege the interests of their groups over donors' expectations (Nguyen et al. 2007; Nguyen 2005), and Booth argues that the differential treatment patients receive at the hands of the Kenyan nurses results in some women patients not receiving certain types of care (2004).

Both accounts describe programs in which the informal system—the interpretation of policy by local staff—differs from donors' intentions. For PEPFAR in Tanzania, the aim of the donors and the local staff do not necessarily differ, but while PEPFAR planners view HIV/AIDS from a countrywide perspective, the local clinic staff views it through the needs of individuals. While PEPFAR aims to reach every patient it can, the clinic staff is aiming to make sure quality care is available for every individual who comes to the clinic.

In this chapter, I examine how clinic staff not only works to fulfill the policy and paperwork expectations of the Tanzanian state, PEPFAR, and others who fund their ARV programs, but also how they assert themselves as professionals who shape the type of care and treatment they provide at their clinic. I examine the ARV programs of two CTCs in Dar es Salaam. PASADA is a faith-based clinic that was a part of PEPFAR from PEPFAR's inception in Tanzania and has followed a path of PEPFAR-defined success. Hindu Mandal is a private hospital that is affected by PEPFAR's work within the country, but has yet to receive PEPFAR funding specifically for its ARV program. It distributes

ARVs as part of the National Programme and runs an ARV program for those in financial need funded by the Global Fund. It is slated, according to the PEPFAR regional treatment partner, to become an official part of PEPFAR within the next three years. I look at how these two organizations have created their ARV programs. I examine how national guidelines and standards of care are employed by the staff of the clinics and shape their workday; how policy changes affect the work of clinical staff; and how clinical staffs view their work in relation to international and state plans for ARV programs and based on their relationships with patients.

# A Tale of Two Clinics Building ARV Programs

#### Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese

PASADA is a social service agency under the Roman Catholic Church in Dar es Salaam (PASADA 2006:7). It began in August 1992 in Kariakoo, a commercial area of Dar es Salaam, under the direction of the archbishop as a selfsupport group to address the needs of those living with HIV/AIDS, as well as orphans and vulnerable children (PASADA 2006:7). Its mission statement outlines the agency's duties as well as the spirit of its work:

Responding to the call of faith, PASADA strives to provide and maintain quality caring and compassionate services and support to people affected by HIV and AIDS in the Archdiocese of Dar es Salaam, with particular attention to the poorest and most needy, through a holistic approach and with special emphasis on the values of justice and solidarity (PASADA n.d.).

In 1994, PASADA was able to open a dispensary in the Dar es Salaam district of Temeke and provide free medical services and pediatric care to individuals living with HIV/AIDS (PASADA 2006:10). The clinic located at PASADA's headquarters in Temeke also has the name Upendano. Eventually PASADA also moved its orphans and vulnerable children offices to Temeke and from this point forward PASADA, through a variety of donors, was able to continually add to the medical services it provided. Through a collection of Italian donors, PASADA was able to run "AIDS Free Newborn," a program that ran from 2002 through 2005 that aimed to reduce mother-to-child transmission of HIV/AIDS by 40 percent, improve medical care and data collection, provide health education and HIV prevention, and support families affected by HIV/AIDS (PASADA 2006:10–11). Through this program, PASADA was able to establish its own PMTCT program. In 2003, PASADA began a Tuberculosis (TB) Diagnostic and Treatment Centre. This program grew community-wide as it spread to the other diocesan dispensaries within Dar es Salaam. As the TB program expanded, PASADA worked to combine it with its HIV/AIDS program. PASADA had started voluntary testing and counseling (VCT) and home-based care services throughout the diocesan dispensaries (PASADA 2006:11).

In 2003, PASADA took active steps to build a more comprehensive HIV/AIDS management clinic (Urdeneta 2004:1). It successfully applied for a Rapid Funding Envelope<sup>44</sup> one-year grant, which allowed PASADA to improve its information and management collection; provide more training to staff on how to assist people living with HIV/AIDS; establish a network between PASADA staff and social welfare professionals to help abused children; open a vocational training program for orphans and vulnerable

<sup>&</sup>lt;sup>44</sup> "The Rapid Funding Envelope for HIV/AIDS (RFE) is an innovative partnership between the Tanzania Commission for AIDS (TACAIDS), the Zanzibar AIDS Commission (ZAC), nine bilateral donors, and one private foundation. Established in 2002, the RFE's purpose is to enable civil society institutions in Tanzania to participate fully in the national multi-sectoral response to the AIDS epidemic. To do so, the RFE provides grants to Tanzanian non-profit civil society organisations, academic institutions, and civil society partnerships for essential, short-term projects aligned with the National Policy on HIV/AIDS and the National Multi-Sectoral Strategic Framework" (Rapid Funding Envelope 2009). The donors have included the Bernard van Leer Foundation, Canadian International Development Agency, Irish Aid, Swiss Agency for Development and Cooperation, Embassy of Finland, Royal Netherlands Embassy, Royal Danish Embassy, Royal Norwegian Embassy, United Kingdom's Department for International Development, and United States Agency for International Development.

children; and purchase new clinic equipment and HIV testing kits (Urdaneta 2004:2). In 2003, PASADA began a pilot program for ARV treatment using private funds. Thenmedical director Brigid Corrigan stated in 2004 that the program was the result of both wanting to take action against AIDS and preparing the clinic to join PEPFAR under the treatment partner AIDSRelief. USAID funds the ARV program at PASADA, but a group of approximately fourteen other donors—including the Stephen Lewis Foundation, Comic Relief UK, Elton John AIDS Foundation, and the Canadian Institute of Cultural Affairs, according to PASADA's executive director Sarah Pell—helps fund PASADA's other activities. Ms. Pell also said that in 2007 PASADA had a staff of nearly 140 individuals.

From where the minibus would drop me off, I could only see the church to which PASADA is attached, a yellow building at an intersection. PASADA's offices are deceptively large, in comparison to what I could see from the street. After entering the gate surrounding the church, I would walk down a sandy path until, on any given day, I could see patients waiting outside the records office to make an appointment to see the doctor. PASADA's offices are constructed as an open square with a large courtyard in the center. Three of the four sides of the square have two stories, while the fourth side is one story. Within the offices, there are room air conditioners that help the people, their equipment, their computers, and their medicines stay cool. Because of this setup, if it rains, patients and staff (and anthropologists) must run under covered walkways as they move from office to office. The outside walls of the buildings that face the center courtyard are covered in colorful murals and large painted boards explaining the services PASADA offers, as well as offering information about ARVs. Also on these outside walls



Figure IV: PASADA Services Mural

are small, white, plastic-like plaques that identify donors and governments that have funded construction at the offices, such as, "PASADA is grateful for the generosity of the people of the United States of America through USAID for the expansion of the buildings of the Upendano Centre." Behind this square office setup, there are metal containers that contain more offices, for the ever-expanding PASADA.

The most obvious detail of PASADA's office setup is its exposure. Rain can fall within it, the sun shines down upon it, and people are offered little shelter from the

elements until they are inside an office. That physical exposure also translates into exposure for patients. Patients are exposed in that while waiting to make an appointment, waiting for the doctor, waiting for the pharmacist, everyone at the clinic can see them. The triage nurse noted, "Most of the people who can't buy drugs come here. The rich don't want to be exposed, to be seen. There is no privacy here...." The executive director echoed the triage nurse's sentiments in a separate interview. There is a quiet admission of each individual's health status by their continuing to come to PASADA. PASADA's title makes obvious the target population of its activities, even though it does not turn away anyone in need of help.

Because of the stigma still associated with HIV/AIDS in Dar es Salaam and in Tanzania, the staff is particularly sensitive to PASADA's mission and tries to fulfill it. Every staff member I spoke with stated the mission is "working with the poorest of the poor." A financial manager told me that the mission is the first thing one must learn when working at the clinic—regardless of whether one works directly with the patients or not. Overall, PASADA staff felt they are particularly sensitive to the needs and vulnerabilities of their patients.

The other often-mentioned sentiment at PASADA was concern over the increasing number of patients. The triage nurse, the executive director, the pharmacist, and the counseling director all stated a concern about the growing number of patients. Comments from them included, "…Too many people are coming … We can't afford to receive all clients … The number of clients is increasing daily." The tension between numbers and quality is a daily concern for PASADA staff.

The executive director of PASADA is a British woman named Sarah Pell who has worked in Africa since 1990 and came to Tanzania in 2003 when she took her current position. As executive director, Ms. Pell said she is responsible for strategic planning, the execution of those plans, relations with donors, government bodies, and other organizations, as well as all legal issues. She is an expressive woman who talks with her hands. While it is obvious she has enthusiasm and passion for her work at PASADA, Ms. Pell also experiences deep stress and frustration because of her work. She explained to me PASADA's mission:

PASADA provides holistic services for the poor and most needy. We provide quality services. Just because people are poor does not mean they do not deserve quality services. We are compassionate. Because of our work, we need to be more professional, need trained people who work with people in vulnerable situations, need *people who will not [forget] faces* (emphasis added).

For Ms. Pell, remembering faces, stories, and people means that patients cannot simply

be numbers factored in reports. In one of our discussions, Ms. Pell described how she

views PASADA's work in comparison to the national hospital:

PASADA will not compromise quality for numbers, as monitoring is important. Muhimbili [the national hospital in Dar es Salaam] is above their targets, but [Muhimbili's] patients are at PASADA. Initially, under [PASADA's] pilot program, PASADA had directed some patients to get drugs at Muhimbili because of our limited funds, but they're back at PASADA because they can't see a doctor at Muhimbili.

The triage nurse repeated Ms. Pell's comparison of PASADA to Muhimbili, pointing out

that PASADA offers free medicines for opportunistic infections, whereas government

hospitals like Muhimbili do not. As the number of patients continues to increase, Ms. Pell

is determined to maintain the quality of services and the compassionate workers required

for PASADA to remain true to its mission. As of the end of October, Ms. Pell said that

PASADA's Upendano Clinic had 2,481 individuals on ARVs. According to PASADA's

medical director, Dr. Harry Akida, PASADA now places ten to fifteen individuals a day on ARV treatment, which is a significant change from its pilot program, which only had twenty-two individuals in 2003–2004.

#### Shree Hindu Mandal Hospital

Hindu Mandal is a nonprofit organization with four main institutions in Dar es Salaam—a nursery school, a primary school, secondary school, and a hospital. The organization was started by the Hindu community in Dar es Salaam in June 1919 with the purpose of "serving Tanzanians of all religions, races, and colour" (Shree Hindu Mandal 2008). In the 1930s the organization added a dispensary that developed into Hindu Mandal in 1953 (Paydos 2006:1). Hindu Mandal is now a private hospital with sixty-five beds located in the heart of Dar es Salaam's city center.

The hospital is located not too far from "Posta," the main city center stop for minibuses and buses. In the morning, packed minibuses unload their passengers onto the streets of downtown Dar es Salaam. In the afternoon, those same passengers mob the same buses, rushing open doors and climbing through windows to get a place to sit or stand as they rush to get home. The rush hour flows of traffic marked my days at Hindu Mandal. Unlike the sandy path used to get to PASADA, I followed cracked pavement from Posta to get to Hindu Mandal, which is slowly expanding to take over an entire city block. During the early part of my fieldwork, I would walk in the main doors of the hospital, past the hospital pharmacy, casualty (emergency room), and up the stairs to get to the second floor, where the HIV/AIDS clinic was located. Staff members in blue, white, or orange uniforms were always circulating among the floors of the hospital. At the top of the stairs, a sign is posted, "May God Bless You with Good Health/Mungu

Akujalie na Afya Njema." From that sign, I would turn left and enter one of the two examination rooms that had been converted to the AIDS clinic, which opened on weekdays at 8:00 a.m. and closed at 3:30 p.m. On Saturdays, it closed early in the



Figure V: May God Bless You with Good Health/Mungu Akujalie na Afya Njema

afternoon, and on Sunday it closed completely. The rooms were at opposite ends of a small hallway, with a waiting room between them. One room was used for ARV storage and the other room is where VCT and ARV counseling took place. When there was a line of patients, the ARV room was also used for counseling. Both rooms were cramped spaces, but they were temporary as a new office was being built for the HIV/AIDS clinic.

Halfway through the year, the staff moved into the new office as it was being completed. Once the office itself was completed, its walls were painted cream and yellow. The new clinic had its own waiting room, two testing and counseling rooms, an ARV storage room, a small laboratory where HIV tests could be completed, and a nurses' station. Because of the construction, one could only enter the new office from the street—meaning patients had to walk into the hospital's main entrance, ask for their folders, and then walk back outside and around the corner to enter the clinic. The cover of Hindu Mandal's buildings provide what the open air atmosphere of PASADA cannot—privacy. Individuals walking by the hospital cannot easily peek in to see who is waiting at the HIV/AIDS clinic. The walls that separate clinics and waiting rooms at the hospital create spaces within which individuals are free from the eyes of others waiting at the hospital. Furthermore, because Hindu Mandal is a hospital, individuals could be there for a variety of reasons—going there did not immediately identify one as living with HIV/AIDS.

Dr. Viruj Narottam, consulting physician and assistant medical director of Hindu Mandal, oversaw the HIV/AIDS clinic. He is a respected physician in multiple arenas in HIV/AIDS care and management, in general practice, and in diabetes research. I had first heard his name in Washington, D.C., when I asked for individuals who were managing well-run AIDS treatment clinics. When I first met him at Hindu Mandal I was one of many individuals waiting on benches outside of his office. His office is unique in that above his door is an electronic number counter. When a patient receives a number, she knows where she falls in line because above the doctor's door is the number he is now treating. Hospital attendance decreases when Dr. Narottam is not there—hospital employees joke that the hospital should shut down when he takes annual leave. Dr. Narottam is a direct man who both speaks and walks quickly. He is recognizable by his
own uniform—button-down short-sleeve shirt with a tie. He has been at Hindu Mandal since 1982.

According to Dr. Narottam, Hindu Mandal was one of the first organizations in Dar es Salaam to begin providing ARVs in the late 1990s. At that time, though, all prescriptions had to be purchased and the cost was too high for the many who needed them. In the early 2000s, Hindu Mandal was working to create a "Centre of Excellence" for the management of HIV/AIDS (Paydos 2006:2). In 2003, the same year PASADA applied, Hindu Mandal also applied for its first Rapid Funding Envelope grant. It used the money to triple its number of VCT staff, link VCT to the prenatal, maternal, and child clinics within the hospital, and purchase laboratory equipment, including Tanzania's first viral load machine, which monitors the level of HIV in the blood (Urdaneta 2004:2). In 2005, Hindu Mandal successfully applied for another Rapid Envelope Fund grant, which the hospital used to expand the laboratory facility within the hospital and purchase equipment to diagnose opportunistic infections (Paydos 2006:2). Hindu Mandal is also using the funds to build a resource center to continue training staff on caring for those with HIV/AIDS (Paydos 2006:2). Between Rapid Funding Envelope grants, the hospital received a Global Fund Round Three grant to work with networks of people living with HIV/AIDS, to identify those who have tested positive and need care and treatment but cannot afford it (Paydos 2006:2). The five-year grant provides funding for HIV- and TBrelated care—VCT; directly observed therapy, short course; opportunistic infection treatments; home-based care; and psycho-social support (Global Fund to Fight AIDS, Tuberculosis and Malaria 2003:4). As a CTC since July 2005, Hindu Mandal also distributes free ARVs from the Tanzanian government. In addition to the Global Fund,

Hindu Mandal also receives funding from other sources, including FHI and PharmAccess, a Dutch NGO, for its HIV/AIDS program.

Underneath this system of funding is the reality that, although PEPFAR does not fund Hindu Mandal's ARV program directly,<sup>45</sup> it does impact it. Supply Chain Management Systems (SCMS), the PEPFAR-created and -funded organization, has been contracted by the U.S. government to create an infrastructure to support the National Programme's free ARV program. This requires SCMS to build ARV reporting and forecasting tools for the entire country, for all CTCs. Although there is no direct funding, PEPFAR's decisions on how ARVs are directed to CTCs do affect Hindu Mandal's dayto-day paperwork. Every CTC, regardless of funding, must fill out and submit to the National Programme identical paperwork, reporting the types of ARV prescribed. Personnel from SCMS in Washington, D.C., and in Dar es Salaam told me that the organization is helping the National Programme with document management, including building ARV reporting and forecasting tools.

ARVs are available to three different types of patients under Hindu Mandal's funding system: One, patients or their employers paying the entire cost of care, including consultation, laboratory fees, as well as medicines for opportunistic infections. Two, patients who access the free ARVs from the Tanzanian government, but pay for all other services. Three, patients who qualified for Global Fund support and receive all services free of costs. By the end of 2007, Hindu Mandal had nearly one thousand individuals on ARVs, of which approximately three hundred were Global Fund patients.

<sup>&</sup>lt;sup>45</sup> Shree Hindu Mandal Hospital was a PEPFAR sub-partner under a PEPFAR prime partner, Deloitte Touche Tohmatsu during fiscal year 2004. A sub-partner is an "entity to which a prime partner allocates funding"; a prime partner is an entity which received funding directly from, and has a direct contractual relationship (contract, cooperative agreement, grant, etc.) with, the USG Agency" (PEPFAR 2005).

As a whole, the hospital attracted a slightly wealthier patient population than PASADA, as there was a TSh 2000<sup>46</sup> hospital fee before an individual saw a doctor or nurse. The patients who are a part of Hindu Mandal's HIV/AIDS program, however, came from a wide range of economic backgrounds. This was due in part to the different ways in which patients could access HIV/AIDS care.

One Hindu Mandal patient who was also enrolled in the Global Fund program, Radhi Didas, was actually directed to Hindu Mandal from PASADA. As she recalls:

I heard about Hindu Mandal from PASADA ... When I was at PASADA [one day], they announced that the first twenty people would be taken for CD4 counts that day. The others would have to wait. Then they announced that Hindu Mandal would test for CD4 and they announced that Hindu Mandal had the Global Fund program.

While Hindu Mandal is not formally a CTC supported by PEPFAR, PASADA staff does feel comfortable sending patients to Hindu Mandal because the Global Fund support ensures that people will not have to pay anything for care and treatment, just as they would not if they attended PASADA.

In order to be enrolled in the Global Fund program, the ARV nurse counselors told me, patients had to be referred by an HIV/AIDS testing center, a PLWHA support group, or another CTC. Global Fund eligibility at Hindu Mandal was determined by a fourperson hospital board consisting of at least two doctors. The three-page exemption form found in Global Fund patient files included the following information about the patient: her employment; if she has received treatment elsewhere; how much income she makes; what property she possesses, including if she owns a radio, bicycle, refrigerator, television, or house; how long she has lived in her residence; how many meals per day

<sup>&</sup>lt;sup>46</sup> In 2007, the value of the Tanzanian shilling was TSh 1255: US\$1 (CIA 2009). The gross national income per capita of Tanzania in 2007 was US\$366. Hindu Mandal's fee increased to TSh 3000 by mid-2007.

she eats; a ranking of her food security; and if an exemption should be recommended and authorized. Once the board approves an individual, the individual is enrolled in the program.

Although Hindu Mandal is not currently a PEPFAR-supported CTC, the assistant country director for Harvard-MDH, the treatment partner for the Dar es Salaam region, says that they are working to incorporate other CTCs in the Dar es Salaam region, about four at a time. According to their assistant country director, Harvard-MDH has talked with Hindu Mandal and it "will be the partner for Hindu Mandal." When asked if Harvard-MDH will become the partner for Hindu Mandal, Dr. Narottam answers, "Ask them."

Although PASADA and Hindu Mandal have built different ARV programs, their staff is facing the same international and national standards of care, the same day-to-day paperwork, and the same concerns about keeping patients on ARV regimens. The rest of this chapter explores the similar and contrasting worldviews and work views of the staff that make ARVs a reality for thousands of people living with HIV/AIDS.

# Determining ARV Treatment in Tanzania

Once an individual tests positive for HIV, the individual enters the National Programme, which tracks and monitors HIV-positive patients, whether or not they are on ARVs. Tanzanian clinics follow the WHO Clinical Staging of HIV Infection for Adults and Adolescents in determining the staging of an individual's HIV/AIDS infection, which in turn determines if a clinician recommends that an individual begins ARV treatment. The status of a patient's infection is tracked clinically by staff. As not all patients are immediate candidates for treatment, these determinations take place at the clinic. According to National Programme standards, there are three groups of people who are candidates for ARV treatment. These standards are based on two factors, the staging<sup>47</sup> of the illness and an individual's CD4 count.<sup>48</sup> According to the WHO, clinical staging ranges from Clinical Stage 1, when an individual is asymptomatic, to Clinical Stage 4, when a patient is quite ill. A CD4 count measures the response of the T-cells in the immune system. A healthy adult has a CD4 count between 500mm3 and 1500mm3 (Gallant and Hoffman 2009). In general, there are three classes of individuals who are clinically eligible to begin treatment:

- All who are in WHO stage 4 clinical criteria, regardless of CD4+ cell count
- Those in WHO Stage 3 and CD4+ cell < 350/mm3 as an indicator of their progression to AIDS</li>
- All who have a CD4+ count < 200cells/mm3, regardless of symptoms (United Republic of Tanzania 2005:90)<sup>49</sup>

According to the Tanzanian government standards, once a clinician determines an

individual's eligibility for ARVs and the patient agrees to initiate therapy, the patient must

<sup>&</sup>lt;sup>47</sup> The clinical stages of HIV/AIDS range from Clinical Stage 1 to Clinical Stage 4, which is the most serious. Clinical Stage 1 is being asymptomatic. Clinical Stage 4 is characterized by events such as HIV wasting syndrome, Pneumocystis pneumonia, recurrent severe or radiological bacterial pneumonia, chronic orolabial, genital, or anorectal Herpes simplex infection, Candidiasis of the oesophagus, Extrapulmonary tuberculosis, Karposi's sarcoma, CNS taxoplasmosis, HIV encephalopathy, etc. Any individual who presents a CD4 count < 200 cells/mm3 is considered at Clinical Stage 4. (National Care and Treatment Program CTC-2).

<sup>&</sup>lt;sup>48</sup> According to the WHO, "CD4+ T-cells are also known as helper T-cells and act as [sic] an co-ordinator of the immune response, unfortunately, CD4+ T-cells are also the main targets of HIV. HIV destroys infected CD4+ T-cells and leading to an overall weakening of the immune system ... Lower numbers of circulating CD4+ T-cells indicates a weakening of the immune system and advancement in the progression of HIV disease. The CD4+ T-cell count can also be indicative of the success or failure of anti-retroviral therapy (ARV)" (WHO 2010).

<sup>&</sup>lt;sup>49</sup> In 2007, the U.S. government recommended that patients begin ARV treatment if they had a CD4 count < 350 cells/mm3, but the "data supporting this recommendation are stronger" if the patient had a CD4 count < 200 cells/mm3 (Panel on Antiretroviral Guidelines for Adults and Adolescents 2007:i). In 2009, U.S. government recommendations include starting patients on ARV treatment with CD4 counts < 350 cells/mm3 (Panel on Antiretroviral Guidelines for Adults and Adolescents 2009:22). In 2009, the World Health Organization also recommended that all patients start ARV treatment if they have a CD4 count < 350 cells/mm3, regardless of clinical symptoms (WHO 2009:10).</p>

meet with a counselor "to discuss about adherence, medication dosing, and adverse event management" (United Republic of Tanzania 2005:9). The counselor at any CTC is then the gatekeeper of ARV treatment. The counselor has to be satisfied that patients are ready to begin treatment in order to refer them back to the physician so that ARVs can be prescribed. It is the counselor's responsibility to prepare patients for the responsibilities of ARV therapy, ensure that patients understand dosing and what to do if side effects develop. Once a patient is deemed "ready" by the counselor, he or she is sent back to the clinician for an ARV prescription. The practice of ARV counseling, the first concrete step toward placing an individual on treatment after a clinical diagnosis, is interpreted by staff at PASADA and Hindu Mandal in both similar and contrasting ways, which are discussed later in the chapter.

### National Care and Treatment Programme Forms

Clinicians use National Programme forms to keep track of other medications a patient may be taking, as well as tracking ARV counseling sessions. The National Programme follows patient care through a series of forms: CTC-1,<sup>50</sup> CTC-2,<sup>51</sup> and the CTC-3 (CTC refers to care and treatment clinic). All three forms are marked by the Tanzania National Coat of Arms and its motto: "Uhuru na Umoja."<sup>52</sup> Because there are no other seals or logos on any of the CTC forms, they are all distinctly Tanzanian government forms.

The CTC-1 card is titled "Kadi ya Utambulisho"<sup>53</sup> and is the identification card kept in each patient's possession. It is a tri-fold card that has the national coat of arms and

<sup>&</sup>lt;sup>50</sup> See attached Appendix A.

<sup>&</sup>lt;sup>51</sup> See attached Appendix B.

<sup>&</sup>lt;sup>52</sup> Freedom and Unity.

<sup>&</sup>lt;sup>53</sup> Identification Card.

"Jumhuri ya Muungano wa Tanzania/Wizara ya Afya na Ustawi wa Jamii"<sup>54</sup> on the cover. The patient is to show the card at each visit to the CTC. Also on the cover is the name of the CTC and its phone number. Finally, there is the patient number, standardized in a nationally recognized eight-digit format. The first four digits indicate the facility where a patient first received a card. The first two digits identify the region, the third number represents the district, and the last number indicates the CTC. Collectively they identify a particular CTC (United Republic of Tanzania n.d.:4). The last four digits are sequential numbers that identify the patient within that clinic. For example, within the number 01234567, 0123 identifies a particular clinic and is shared by all of the patients at that clinic. The last four digits, 4567, signify that a particular patient is the 4,567<sup>th</sup> patient to be enrolled in the National Programme at a CTC. Ideally, even if a patient switches CTCs, she is supposed to take her patient card with her; she retains her patient number regardless of which CTC provides her treatment.

On the card, there is a seven-column table that can be filled out by CTC staff. The first column is for the date, the second indicates what drugs were prescribed to a patient, the third column is for how many days the medicines are for, and the fourth column is a space for CD4 counts. The fifth column is for the clinic to write its facility card number to indicate where medicines were picked up, the sixth is for a clinician or pharmacist to write her name so as to show who dispensed medicine, and the final column gives the patient a date to return to the clinic. There is also another table underneath the primary table for clinicians to make notes regarding a patient's care.

On the back flap of the CTC-1 card is a table for patient information, including name, phone number, sex, and the date ARV therapy started. There is also room for a

<sup>&</sup>lt;sup>54</sup> The United Republic of Tanzania/Ministry of Health and Social Welfare.

patient's region, district, and city district or village. The CTC-1 card has space for a city district's official chairperson, government minister, and the leader of a town or village to be listed. Finally, if a patient has a person who assists them in taking their medicine, a "Treatment Supporter," that person's name and phone number are also written on the CTC-1 card.

The CTC-2 form is the "Patient Record Form" kept at the CTC. It is a record that includes the socio-demographic information also on the CTC-1, the patient number, as well as how a patient was referred to the clinic. It is a two-sided document. The first side is the patient's clinical record post-HIV diagnosis. It keeps a record of appointments, weight, hospitalizations, pregnancies, cases of TB, CD4 counts, blood work, laboratory results, and nutritional support.<sup>55</sup> It also keeps track of medications for opportunistic infections as well as ARVs. AIDS-defining events are recorded here. Specific codes for starting, stopping, and changing ARV therapies, as well as codes for certain combinations of ARV therapies, are recorded here. The back side of the CTC-2 form lists the codes—for the staging of HIV/AIDS symptoms, for combinations of ARVs, for side effects, as well as for starting, stopping, and changing ARV therapies.

Finally, the CTC-3 is a book of triplicate forms kept at the facility. Of the three carbon copies, one copy stays at the facility. The other two copies are sent to the district medical officer and the National Programme. At Hindu Mandal, I helped the ARV nurse counselors fill out the CTC-3 forms. Usually we did this at the end of the day or, if a day had been particularly busy, the following morning. The nurse counselors would work their way through the CTC-2 records from the day and I would record the information

<sup>&</sup>lt;sup>55</sup> "Nutritional support is a broad term that may encompass a range of services, including nutritional supplements, food, and nutritional counseling" (United Republic of Tanzania n.d.a:23–24).

they told me on the CTC-3 form. The CTC-3 form calls for the date, whether the patient was new or continuing, a patient number, date of birth, sex, pregnancy status, weight, TB status, CD4 counts, if nutritional support was provided, if the patient was on particular opportunistic infection medicines, and then the codes for the patients ARV therapies and if that therapy indicates a start, stop, or change in therapy. The Hindu Mandal nurses used the time filling out CTC-3 forms to make sure that the CTC-2 forms, normally filled out by the doctors, were legible and to double check that the doctor had filled out the correct columns. One doctor was particularly notorious for writing across columns information that was not needed on the forms. The nurses would double check other forms in a patient's file to ensure that the CTC-2 and the CTC-3 were filled out correctly.

The CTC forms maintain a daily record of a clinic's activities and are the primary documents that clinic staff and patients come in contact with daily, a point further addressed in Chapter 6. Every CTC in Tanzania fills out these forms for patients—they are the record for the National Programme. At the National Programme headquarters, I saw piles and piles of CTC-3 form copies, their information entered into computers by National Programme staff.

### **ARV Counseling Sessions Overview**

Although National Programme guidelines do not specify how many times a counselor must meet with a patient, it encourages "multiple encounters" (United Republic of Tanzania 2005:63). At both PASADA and Hindu Mandal, three visits to a counselor before initiating treatment was average—although some patients had as few as two visits and others required more than three sessions. ARV counseling at both clinics covered the same ground, including adherence, timing, protection, nutrition, and treatment support.

Most importantly, adherence is emphasized by the counselors. Adherence is "missing less than three doses in a month" (United Republic of Tanzania 2005:63). PASADA conducts group ARV counseling "refresher sessions" at other CTCs. I accompanied PASADA's triage nurse to one of those sessions. She has worked at PASADA for over two years. As she discussed adherence during the group session, she described how the medicines work. ARVs, she said, do not kill HIV/AIDS. Rather, the medicines keep the virus sleeping in the body. By missing a dose, the virus may wake up. At Hindu Mandal, the counselors use a sheet, "The effect of missed doses," to illustrate for patients how missing doses affects their viral loads. The sheet shows how the level of ARVs in the body rise and fall as a patient takes her doses during the day. When doses are taken on time, HIV replication is minimized. When a patient misses a dose, as illustrated, HIV replication increases and ARV-resistant HIV appears.

Furthermore, part of the National Programme guidelines for the ARV counseling process includes finding a "treatment supporter." A treatment supporter is an individual who knows about a patient's HIV/AIDS status and is able to offer encouragement and reminders to keep that individual on her treatment regimen. According to the director of counseling at PASADA and the counselors at Hindu Mandal, individuals who undertake ARV counseling are encouraged to select treatment supporters and bring them to the second and third sessions of ARV counseling.

In addition to emphasizing adherence, counselors also emphasize the timing of the medications. The counselors at PASADA and Hindu Mandal work to have patients understand the importance of timing. In general, counselors at both clinics had patients review their daily schedule so they could discuss what would be a convenient time to take

ARVs. Most ARV combinations are taken twice a day—once in the morning, once at night. The counselors often recommend that a patient pick one time—7:00 or 8:00. Whether it was 7:00 am or 7:00 pm, 8:00 am or 8:00 pm, the patient would know that she should take her ARVs. By discussing a patient's schedule as well as timing, counselors could illustrate how ARV adherence would fit into her schedule.

ARV counseling also included a discussion about "protection." At PASADA and Hindu Mandal, this discussion was approached from a self-protection standpoint. Instead of discussing how the patient should protect others from HIV infection, the counselors spoke with patients about the threat of "maambukizo mapya."<sup>56</sup> One of the counselors at Hindu Mandal explained to a patient undergoing ARV counseling that protecting oneself during sex was important, even if he was taking the medicine, because a re-infection could cause his CD4 count to drop. As stated by one of the other Hindu Mandal counselors to me, "… the medicine does not protect against re-infection." Female patients I interviewed at PASADA stated that they learned about re-infection and its consequences during their ARV counseling sessions.

Counselors also cover the importance of good nutrition during ARV counseling. Each day at Hindu Mandal, the counselors spend ARV counseling time on nutrition, discussing the importance of making good decisions or how to "eat healthy." The counselors focused on encouraging patients to incorporate more vegetables, fruit, fish, and rice into their diets instead of chipsi mayai [a local dish that consists of french fries and eggs fried together] and soda. PASADA staff also encouraged patients to make the same healthy decisions regarding food choices. PASADA staff, however, also had to consider that some of their patients do not have the means to buy food at all. A former

<sup>&</sup>lt;sup>56</sup> Kiswahili: New or re-infections.

medical director at PASADA said to me that good nutrition is a "big problem" for those on ARVs, but sometimes there is not even "enough food." Because their patient base is, in general, poorer than Hindu Mandal, PASADA's program does try to incorporate some nutritional support for their patients. The head of the PMTCT program at PASADA is able to help about fifty "very poor mothers" with monthly support of two kilos of flour, rice, beans, and a small amount of fat." She also admitted to me that there are more people who need food support. She lamented that, "People think PASADA has everything, food, clothes, money, but it doesn't and cannot do everything." While nutrition is emphasized throughout ARV counseling, the clinical staff at both CTCs are aware of the difficulties faced by some patients in not only making health choices, but having enough to eat.

# The Pros and Cons of PEPFAR Graduation

In 2006 when the policy of regionalization was implemented in Tanzania, PASADA was one of two CTCs that were "graduated" by the U.S. government. Within this context, graduation means PASADA now receives funding directly from PEPFAR, via a USAID funding mechanism, instead of through a PEPFAR treatment partner. According to my interview with the PEPFAR media outreach coordinator, graduation means that an organization can meet the USAID financial reporting standards and has the ability to carry out and reach their objectives. PASADA is now directly under PEPFAR instead of being a sub-partner under the treatment partner AIDSRelief. It now has its own targets to reach and its numbers are no longer counted by AIDSRelief. As CTCs are able to manage their own money and reporting, they rely less on the technical support of the treatment partners. PASADA is an example of how PEPFAR envisions its future. In an interview with the head of country support team lead for Tanzania, Zambia, and Ghana, who is based in Washington, D.C., she said that PEPFAR aims to graduate as many CTCs as possible.

The head of PEPFAR in Tanzania, Ann Collins, says that graduation is the mark that an organization is doing well:

There are organizations that are doing a great job. If they could "buy" or engage a CPA, they could just go on about business. Selian and PASADA are strong organizations that could go at it on their own. There was a concern that they weren't ready, but there was an opportunity cost at the expense of places providing "scary care."

From the viewpoint of PEPFAR, organizations that are providing good care and services need only to acquire an accountant so as to continue their work. Once a CTC is up and running well, a treatment partner does not need to stay and mentor it. The opportunity cost of treatment partners spending time and energy at a clinic that is running well is a loss to CTCs that are not doing well. A treatment partner can move its time and energy to another CTC that may be providing less than ideal care, or "scary care."

The benefit to PEPFAR to graduate clinics goes beyond freeing up time for their treatment partners. As noted by a treatment partner official, by graduating the CTCs that are doing exceptionally well, those clinics become "model organizations for the U.S. government." The U.S. government can claim them as success stories for the U.S. without having to mention a treatment partner. Every graduation is a success story for PEPFAR.

PASADA uses the term "graduated" to point out that graduation was an imposed change and surprise for the clinic staff and its treatment partner, AIDSRelief. Members of PASADA's and AIDSRelief's staff told me in interviews that they were informed of PASADA's graduation by the U.S. government. According to Ms. Pell, "PASADA was never consulted about its change in status before [graduation was initiated]." The senior ART program manager at AIDSRelief said of the process, "We [AIDSRelief] thought PASADA had things to work on. PASADA thought they had things to work on, but the U.S. government was confident that PASADA could do it. But they didn't have research to back it up." Decisions regarding graduation are left completely to the discretion of PEPFAR—treatment partners and CTCs do not have to be consulted by PEPFAR.

Because of the surprise graduation, PASADA's staff found itself placed in new territory. For the staff, there are both negative and positive consequences to graduation. The negative consequences, in general, stem from being granted a new status without their consent or input in the decision. Ms. Pell told me that having a treatment partner was like having a partner who shared technical support. Furthermore, she said that AIDSRelief "linked PASADA to a faith-based network. Leaving takes PASADA out of that network—it reduces the network." After working with PASADA for fourteen years, AIDSRelief was no longer supporting PASADA's ARV program.

The loss of AIDSRelief as a treatment partner changed not only PASADA staff's idea of how it fit into a network of care, but also their everyday responsibilities. The most significant change is the accounting system. Now that it is a direct partner under USAID, PASADA's finance department has seen the largest increase in its workload. As a former PASADA medical director put it, "... with more money, there is more trouble ... The finance department is now running around."

PASADA's finance department staff agrees. Whereas before graduation AIDSRelief was responsible for the opening of bank accounts and accounting in general, now PASADA is responsible. Meeting the accountability standards of USAID is a

difficult task. As an example, Ms. Pell recalls how under AIDSRelief PASADA was audited. Thirty-five issues were raised after the audit. After meeting with the U.S. government, the list shrunk to twelve. The main problem was not that PASADA had misused funds, but that street vendors did not provide receipts or take checks. A treatment partner used to be able to help negotiate those issues.

Nena Reem, a staff member of the finance department, told me in an interview that the first thing PASADA had to do was open a bank account for PEPFAR funding. Before graduation, PASADA used to complete reports on a quarterly basis. In a postgraduation world, PASADA has to complete monthly reports, of which Ms. Reem said, "... [there are] so many forms for one month, forms that were not needed before." Accounting includes organizing internal requests for monthly funding by the 15<sup>th</sup> of each month. By the 26<sup>th</sup> of each month, all the money spent by each department has to be accounted for by the finance department. By the 5<sup>th</sup> of the month, internal reports are complete, and five days later the external report is complete. Moreover, PASADA staff now has to forecast its work plan, medical department plans, and pharmacy needs every three months, according to Ms. Reem. The result, according to Ms. Pell, executive director of PASADA, is that the current reporting has too many forms: "There is a focus on forms, rather than listening. Seventy percent of our time is spent on forms. We need faster process or less forms."

There is an up-side to graduating. Ms. Reem admits that, while graduation means more scrutiny, it might be better for PASADA to be closer to the source of funding. Graduation has raised the profile of the institution in certain ways. The research advocacy officer, Elimu Nikusubila, said in an interview that graduation "is a credit to the

institution, that PASADA is growing, and what we are doing is appreciated. We are a model for other organizations. Other organizations want to write joint proposals with PASADA now." Graduation is a public acknowledgement by PEPFAR that an organization is doing a good job. That acknowledgement brings more attention from other organizations that are looking for steady sources of funding. Graduation is an implicit stamp of approval.

### Creating Community

PASADA staff takes pride in the work they are doing. In fact, they can now assert their own expertise in ARV treatment. The staff is able to shape their work days and ideas about what is important to the patients. They have control and ownership over the work and direction of the organization. While the increasing number of patients and paperwork has burdened the staff as a whole, people work to maintain the quality of the services. Overall, PASADA's goal is building a sense of community among its own staff and its patients.

## The Staff

In organizing the workday, PASADA instituted an appointment system. While it still sees from one hundred and fifty to two hundred patients every day, the new system allows for a greater variety of patients according to medical director and doctor, Harry Akida:

People used to come at 4:00 am and sleep outside and they stayed until late. We used to give numbers out and after they ran out, we took no more patients for the day. People outside used to scream. We would see the same people because they were the ones who could come early. The very sick could never come at 5:00 am. We used to put three new people on ARVs a day; now we put fifteen to twenty a day on ARVs.... Dr. Akida felt that the overall benefit of the new appointment system is that fewer patients will "be lost." With the new system, doctors can track patients more closely and the appointment system makes clear to the patient what day she should return to the clinic and to the doctor what day to expect the patient. Instead of the doctor saying "return in two weeks" to the patient, and then maybe the patient forgets what day to return and the doctor may not have the laboratory results, each participant has clear expectations. Through an appointment system, PASADA's staff is able to exert some control over their workload, as they take emergencies. As Dr. Akida says, they also see a greater range of their own patients more often.

Every Thursday morning the staff holds a clinical meeting. These meetings are not only for the medical directors, attendants, and physicians, but for the whole staff. As a group of almost thirty, they gather to discuss a clinical matter, such as the side effects of ARVs. There is a classroom-like feel to the meetings, as one of the physicians stands at the front of the room to write down words and ideas. In the meeting discussing the side effects of ARVs, defined as "discomfort following the initiation of ART," symptoms were outlined by the physician and the staff. The group discussed a range of symptoms considered side effects of ARVs, like headaches, gastrointestinal upset, changes in body shape, and dizziness. In addition, there was discussion about what could be done at home to relieve symptoms and when a patient should seek medical attention. As a result of these meetings, the staff current on ARV information. If staff members notice symptoms among the patients or have concerns or comments to make, they can do so at these meetings.

Counselors are also given special consideration as they work daily with individuals—adults and children—who are learning to accept their new status of living with HIV/AIDS and adapting to changes in their everyday lives by starting a treatment regimen. PASADA counselors, through non-PEPFAR funding, have continual training, but also supportive group therapy sessions, which include "motivation" days for them. Motivation days, according to PASADA's director of counseling, function to stave off burnout for the counselors and include break times and picnics. PASADA is also working to make patients counselors. Patients can choose to complete a three-week workshop and one hundred hours of training to become a certified PASADA volunteer counselor. These training and group therapy sessions ensure that the counselors keep their training current and receive breaks. The volunteer counselor program also creates a new community that ties some patients more closely to the work of the CTC.

### The Patients

Establishing a community for the patients is a priority at PASADA. When I asked Ms. Pell about treatment supporters and if promoting the idea was harmful to individuals and their privacy, she disagreed. In separate interviews, she and the PASADA director of counseling, Karima Zada, told me that PASADA does discuss with patients the advantages and disadvantages of disclosing their status, and that disclosing is not for everyone. While stigma and discrimination due to HIV/AIDS are real issues, isolation is also an issue for patients. Ms. Pell offered a story about a patient at PASADA as an example of the effects of stigma:

... In 2003, a woman who had tested positive for HIV/AIDS came to PASADA for the end-of-month meetings for those newly tested .... She was well-educated and she shared her own story. When she went to tell her husband [initially brought up the subject of HIV/AIDS], he exploded and

said he didn't want to hear about HIV/AIDS and he would kill his family if they were positive. She didn't tell him about her status. In the meantime—there has been seven years between her initial positive test and her test at PASADA—they had another child. I feel that the woman must have felt so lonely, so isolated....

Dealing with loneliness and feelings of isolation in the lives of patients factors into care at PASADA. The director of counseling, Karima Zada, has been with PASADA for ten years. She says that counseling is "essential" in ARV preparation. She views her work as readying patients for ARV therapy no matter how long it takes, three weeks or two months. As more and more patients are slated to begin ARV treatment, PASADA has begun adherence counseling sessions in small groups. Because of the large numbers of patients PASADA continues to take on, Ms. Zada told me that these first meetings are now taking place with small groups of newly diagnosed patients. This practice creates small communities of patients, as well as promoting the idea that one is not alone in coming to PASADA. As patients learn about ARVs and see others undergoing the same experiences, they will not feel that they are isolated, but rather that others share their experiences.

When the adherence counseling has ended, PASADA continues counseling for patients who need it. According to Ms. Zada, "Emotional issues arise after ART is initiated; there can be change of body shape.... [There is] supportive group therapy [where people can learn] how to live positively." In this way, the sense of community among patients continues. As patients meet one another and share stories and experiences, they are not just creating bonds but also a type of treatment support network. A woman patient, a widow who had begun ARVs in 2003 as part of PASADA's pilot program, explained to me in an interview how PASADA's treatment community provides support to patients. She said that if an individual misses meetings, other patients and staff

will notice and make efforts to contact the individual to find out why she is no longer coming to the clinic. Through these small communities, patients are able to be group "treatment supporters."

The numerical targets are a large focus of the work for PEPFAR policy as a whole-meaning that the U.S. government offices as well as the treatment partner offices concern themselves with meeting and reaching the goals. At the clinic level, the executive director of a graduated CTC, while not unconcerned with targets, can say that those targets are not always met at PASADA. The confidence PASADA has in its approach is evidenced by Ms. Pell's take on the target system that PEPFAR runs: "[Our] program is going, but the targets are not reached—targets set by the U.S. government ... Repercussions from not reaching targets? So far, none ... PASADA is in its third year of funding from PEPFAR. We think it's because they know what we're doing [activitywise]." PASADA is unique in that as a new "graduate" it is taking on the role of a treatment partner like Harvard-MDH, Columbia-ICAP, EGPAF, and its former partner, AIDSRelief. As it progresses in its new role, it is possible it will become just as focused on targets as its treatment partner colleagues. In the meantime, though, the staff will continue its effort to maintain the quality of its services even as the quantity of its patients increases.

### More Paperwork

### National Programme Paperwork

Because Hindu Mandal is a private hospital, its CTC is one part of a multidepartmental organization. The everyday operations of the CTC were headed by two nurse counselors, Mama Mmile and Mama Nandi. Mama Mmile had been with Hindu

Mandal since 1997. Mama Nandi began her work at Hindu Mandal in 1982 and then starting working in the HIV/AIDS clinic in 2005. Together with the pharmacists, laboratory technicians, and physicians at Hindu Mandal, these two women organized and managed the ARV program at the hospital.

While the nurses were not responsible for managing the finances of hospital donors, they were responsible for CTC reports. They double checked and filled out patients' CTC-1 cards and the clinic's CTC-2 and CTC-3 records. They were also in charge of completing government reports for Hindu Mandal.

#### Hindu Mandal

The CTC at Hindu Mandal is open six days a week, 8:00 am-4:00 pm Monday through Friday, and 8:00 am-12:00 noon on Saturday. On a typical morning, the nurses arrived before 8:00 am and changed into their white uniforms, set up the scale to weigh patients and the blood pressure equipment, and set out information brochures about HIV/AIDS, prevention, treatment, and nutrition in the waiting area. Once the day started, their work consisted of a mix of voluntary counseling and testing sessions with individuals who wanted to be tested for HIV/AIDS; ARV counseling sessions for those individuals who are deemed clinically ready to begin ARV treatment; refilling ARV prescriptions; and filling out attendance and ARV attendance registers as well as CTC forms. They did this during every work day with only one tea break.

As stated earlier, one of the main differences between Hindu Mandal and PASADA is that the hospital offers more privacy to its patients. The waiting area for the care and treatment is not outside on the street, it is sheltered from the eyes of passersby. While PASADA emphasizes community, Hindu Mandal emphasizes confidentiality.

Patients at Hindu Mandal do not attend support groups together and there are no monthly meetings for the newly diagnosed. ARV counseling sessions do not take place in groups; they take place on an individual basis, although not always alone, as treatment supporters are encouraged to attend as well. The counselors also give patients brochures to go home and "study" as they undergo ARV counseling. The result is that at Hindu Mandal, personal relationships instead of group ones are forged. Mama Mmile and Mama Nandi work to create personal relationships with each patient, to remember every story, so as to build a relationship of trust. They explained to me that adherence counseling is important, but if people feel bad, they will not return. One day after a pharmacist had reprimanded a patient for not coming on time to refill his prescription, Mama Mmile explained to me further about how they counsel patients:

You have to be cool when talking to patients. Even Mama Nandi shows tough love ... If you tell someone he is HIV-positive, you have to listen. If someone yells [at the patient], 'Why didn't you come on the right date?,' there could be no money for bus fare or the patient is late. You have to use polite language and remind them about what will happen with a missed dose.

Her point is simply that patients have to feel comfortable enough with the counselors to trust them. Patients will not return to a clinic where they do not trust or are not comfortable with the clinic staff. She considers herself "calm," meaning she always uses polite language, in comparison to Mama Nandi, who shows "tough love," meaning she used stronger language, in counseling patients and in reminding them to follow their dosing schedule. Even Mama Nandi limited using harsh language with patients; she told me, "… you don't want to yell at patients, since that might be seen as stigmatizing." As patients find a counselor they are comfortable with, they will seek out that counselor at Hindu Mandal.

Disclosure is also encouraged at Hindu Mandal. The counselors feel that disclosure is tied to adherence. According to Mama Mmile and Mama Nandi, patients will not be able to adhere unless they can disclose. If patients have to hide their ARVs, they may miss doses. The counselors believe that if someone discloses, she will be able to take her medicines openly and without feeling stigmatized. In order to encourage disclosure at Hindu Mandal, like PASADA and as recommended by the National Programme's clinical standards, the counselors have those patients receiving ARV counseling bring a treatment supporter to the sessions. By having patients bring in treatment supporters, the counselors can educate both the patient about ARVs and the supporter about the type of support a patient may need.

Tied in with the daily work of counseling HIV/AIDS patients is the work of building those patient relationships. For Mama Mmile and Mama Nandi, this requires not only choosing their own words carefully and providing an atmosphere of trust, but also remembering patients and their histories. Because of the sensitive nature of these topics—sexual histories, admitting infidelities, and discussing loved ones who have died—remembering these details are part of the work of counselors. A man came in to Hindu Mandal to be tested. After his counseling session, Mama Mmile knew that he had buried two wives who had most likely died of HIV/AIDS. Even though he was pretty sure he was infected, he married his housegirl<sup>57</sup> without informing her about his wives' deaths or his own health status, and together they now had a two-year-old son. Within minutes, this man shared more of his personal history with a counselor at Hindu Mandal than he had shared with his own wife—the causes of deaths for his first two wives, his fears about his own health, and the risk he put his family at for contracting HIV/AIDS.

<sup>&</sup>lt;sup>57</sup> A housegirl is a teenage girl or woman hired to work as a housekeeper.

Mama Mmile was also counseling a couple where the husband was infected with HIV/AIDS and his wife was not. The man, a prominent Christian businessman in the city, was personally embarrassed by his status to the point that he had his records kept at the hospital under a fake Muslim name. Each time he returned to Hindu Mandal, he used his fake name. As his confidentiality was kept by the staff, he continued to return to the hospital.

As Mama Mmile and Mama Nandi get to know and counsel the patients who attend the hospital, they keep their secrets as well. Even though Mama Mmile was upset that the first gentleman married again knowing he was most likely HIV-positive, and Mama Nandi was worried over the fate of his third wife and child, they were at a loss as they could not betray his trust. Mama Mmile was personally upset with the behavior of the Christian businessman, but she could only counsel him to rethink his decisions. Of the frustrations faced by the counselors, Mama Mmile says, "You will burn out if you can't share with fellow workers." Sharing her stories with Mama Nandi helps her to deal and cope with the stories and daily struggles of those learning to live with HIV/AIDS.

# Pride in Work

While Mama Mmile and Mama Nandi may not have control over hospital funding or all of their patients' decisions, they do exercise control over the work that they do. They take a great deal of pride in their work at Hindu Mandal and have high expectations of themselves and their colleagues. When the pharmacist makes patients wait for their ARVs, Mama Nandi said to me that his behavior affects the patients' mindset: "This is not good, patients feel he is stigmatizing them ... they need medicines." When the laboratory technician who completes the blood work for HIV/AIDS tests leaves the

hospital without telling the counselors, Mama Nandi lamented, "I'm always ashamed to tell a patient to return at a certain time and then we are not ready [with the results] ... they will say the counselors are liars." The counselors made sure that their colleagues knew when they were disappointed in their behavior. The pride that the counselors felt in their work is not just indicative of their personal work ethic, but also of the type of service they want to provide for individuals. They see their actions and decisions as affecting those of their patients. They take pride in the work they do because they want patients to come back, to adhere to treatment, and to trust the hospital. Most importantly, they want every patient to feel that way about her ARV program.

By counting and recording the numbers of patients a CTC has, the staff keeps that system running and the donors satisfied. As the clinics comply with the demands of donors, the reports can keep the ARVs coming to the clinic. The assumption made by donors, then, is that ARVs will keep the patients, and therefore the numbers, coming to the clinic. In the next chapter, I discuss how donor demands, focused on numbers, are not the same as the demands of patient needs, and how patients choose an ARV program, as well as what they feel is important to keeping an individual on ARV treatment.

### **Between Paper and Reality**

In the everyday routines of care and treatment centers in Tanzania, the staff works to fulfill the needs of two systems—the paper requirements of PEPFAR and the government of Tanzania and the needs of the patients who come to the clinic. The paperwork, the CTC forms, the auditing reports, and the number counts of patients are standard—a daily, monthly, and quarterly routine. While these reports can ensure that funding continues, although not always, as in the case of the Global Fund, they do not ensure that a program provides successful treatment.

# When Funding Fails

While the National Programme is able to provide ARVs free of cost to all Hindu Mandal patients, only those enrolled in the Global Fund program receive all of their care free of charge from the hospital. Because of this program, almost three hundred individuals who could not normally afford care and ARVs at Hindu Mandal can receive it, although they can only receive the care when the Global Fund provides funding. Like PASADA, Hindu Mandal is also experiencing changes in the way its funding operates. Halfway through my fieldwork experience in Tanzania, Global Fund money stopped. For the patients, this stoppage meant an immediate stop in free medications for opportunistic infections, as well as any other medical treatment needed in addition to the ARVs themselves. Because patients accepted into the Global Fund are the individuals deemed economically vulnerable, the lack of funds is distressing. When I interviewed some women patients at Hindu Mandal, some of the Global Fund patients, like Neema Hehe, a thirty-year-old woman who has been taking ARVs since 2005, complained to me in an interview, "... We are not getting drugs for opportunistic infections. Sometimes people cannot check their CD4 count and cannot afford opportunistic infection prescriptions ... I cannot pay for the CD4 checks and the other medicines. I am scared because I cannot afford the medicine."

Mama Mmile explained to me that the Global Fund has not paid Hindu Mandal TSh 40,000,000<sup>58</sup> it needs for the program because other clinics did not send in their

<sup>&</sup>lt;sup>58</sup> In 2007, the value of the Tanzanian shilling was TSh 1255: US\$1 (CIA 2009). TSh 40,000,000 was approximately US\$31,872.00.

reports to the Global Fund. I asked Dr. Buruji Buruji, the former head of the care and treatment unit at the National Programme and now the TACAIDS Global Fund coordinator for Tanzania, about the Global Fund monies. As the Global Fund coordinator for Tanzania, he is the main liaison between the Global Fund and Tanzania, responsible for developing proposals, coordinating implementation of funds, and submitting reports to Global Fund headquarters in Geneva. According to Dr. Buruji, "[There has been a] delay with monitoring and evaluation data delays, but we're working on that now. The reports are not going out on time and some other things out of our control." Tanzania's TB/HIV Global Fund coordinator, Dr. Beatrice Mgaya, also admits that the delay of funds is due to delays in Geneva. Dr. Mgaya's job is to work at the National Programme to monitor the implementation of Global Fund Round Three grants at the Ministry of Health. According to her, "The funds do not come to a specific place, but are sent to the whole country. The delay is in Geneva ... Funds from last year have still not arrived. We are working to meet their conditions, and hope before the end of the year to receive the funds." The official responses indicate that the Global Fund funding relies on country reports submitted on time. If clinic staff submits its report on time, there is no guarantee that the money will arrive on time for them. The Global Fund requires that the money is sent to the country as a whole, not piecemeal. Delays on the part of some result in delays of funding for the entire country.

In the case of Global Fund programming, Hindu Mandal finds itself at the mercy of colleagues that also receive Global Fund monies. As with PASADA's graduation, Hindu Mandal's funding is not within their control. Donor decisions about funding take place without the input of the clinics, and therefore the patients that are affected by the

changes. Hindu Mandal, like PASADA, can only accept the changes and work with them, which in the hospital's case means waiting for the funding to return. Dr. Narottam is hopeful; "... it [the funding] should return, God willing, early next year." In the meantime, however, patients who were deemed economically vulnerable become more so as they struggle to pay for the other medicines and treatments they need or continue waiting until the funding returns.

The Global Fund situation is an example of how dependent the clinics are on donor-funded programming. Even with Tanzanian government support for the ARVs, it is not enough to support ARV programming—counseling, medicine for opportunistic infections, money for laboratory tests. Just as the nurses in Booth's (2004) account of a Kenyan clinic thought that they were lucky to be the recipient of funding, so too do the counselors at Hindu Mandal.

#### Policy Producers

It is the clinical staff who work to ensure individual patients come for treatment and keep returning. Without the staff, CTCs would function solely as pill dispensaries. It is the counseling, the type of social support, that a staff provides that affects how ARV treatment is presented, how patients are counseled and managed. The staff at PASADA and Hindu Mandal feels it is their dedication that ensures that patients feel comfortable enough to share intimate details of their lives. Due to the control that the Kenyan nurses exercised, Booth writes that it is the nurses who "produce policy daily" through their actions (2004:20). Whether it is the group support setting of PASADA or the individualized counsel of Hindu Mandal, it is the staff that makes PEPFAR policies daily practice.

PEPFAR, as a global initiative, cannot take an individual view of patients—that responsibility falls on the clinic staff. While the PWLHA groups recounted by Nguyen and colleagues (Nguyen et al. 2007; Nguyen 2005) rerouted ARVs to individuals who could contribute to the group's well-being and Kenyan nurses studied by Booth (2004) edited donors' plans to fit local social customs, the clinic staff of PASADA and Hindu Mandal worked not only to provide patients with ARVs, but to ensure that each patient received quality care. Neither staff subverted the aims of PEPFAR or the National Programme, but each staff worked to make sure patients received the best care they could at a clinic. PASADA staff's focus on creating community and Hindu Mandal's work on building personal relationships were different approaches developed by the staff, based on the needs of patients and the abilities of the facility, but still fulfilling the requirements of PEPFAR and the National Programme.

As the individuals who have the closest contact with patients, clinic workers influence how patients view ARVs and ARV programming. In the next chapter, I focus on women patients and their decisions to access treatment. Within the decision to begin an ARV regimen, women in Dar es Salaam can also choose where to access treatment. In making decisions about where to receive treatment, factors such as the compassion of clinic staff play an important role. While the compassion of clinic workers is not measurable by PEPFAR, it is an intangible that affects how many patients may choose to attend a clinic and then how many patients may choose to stay at a clinic.

## Chapter 6 Women as Numbers: Dignity Seekers

PEPFAR exists both as a health service program, making ARV programs a reality for thousands of individuals in Tanzania, and as a foreign policy program, aiming to promote U.S. interests. The health service aspect of PEPFAR functions as a large-scale development and humanitarian program. The foreign policy aspect relies on the success of health services to promote the United States around the world: PEPFAR's "culture of accountability bodes well not only for sustainable HIV/AIDS programs, but also for an ever-expanding sphere of transparency and accountability that represents transformational diplomacy in action" (PEPFAR 2008:20).

In the previous chapters, I discuss how the goal of reaching targets is central to PEPFAR's success. The policy of regionalization implemented by PEPFAR through its treatment partners in Tanzania helped increase patient numbers throughout Tanzania. PEPFAR's policy of graduating certain clinics is done so treatment partners can focus on struggling ARV clinics, thereby increasing their patient numbers clinic by clinic. The work of the PEPFAR planners, treatment partners, and clinics all contribute to the standing of PEPFAR as a successful program, even as the ever-present pressure to keep reaching targets is felt by those who help implement PEPFAR ARV treatment throughout Tanzania.

The other side of the massive, global organizational planning needed to make treatment available is the hundreds of thousands of individuals deciding to receive treatment. Because individuals are the ultimate consumers of ARV treatment, how they decide to access these medicines is an integral part of what makes a treatment program successful. A fully stocked clinic with no patients cannot successfully distribute medicines, just as clinics with patients but no medicines cannot be successful. The individuals who begin ARV treatment are the individuals who generate the numbers published in PEPFAR annual reports. As the people who "count" for PEPFAR, patients hold a unique position.

Successful treatment programs are, at their core, the amalgamation of many individual successful treatment regimens. While the provisioning of these services requires large-scale planning, they also require individual commitments from patients in order to produce successful treatment outcomes. As numerical targets increase, PEPFAR will need more and more individuals to commit to counseling, education, laboratory reports, prescription refills, and clinical visits—all parts of an ARV regimen.

Yet the emphasis on targets does not reflect the interests of individuals receiving ARVs. Patients receiving ARVs are not concerned with how their prescription might be counted by their clinic, by a treatment partner, or by the U.S. government. Patients are looking for care for themselves, not for a targeted population. In Dar es Salaam, specifically, patients in need of ARVs have many CTCs to choose from, as there are over twenty in the city alone, according to the assistant country director of a treatment partner. The city is home to PEPFAR-funded clinics and private clinics. While Harvard-MDH, the official treatment partner for Dar es Salaam, will eventually be in charge of all of the CTCs, it has not taken charge of all of them yet. Patients in Dar es Salaam do not just have the availability of ARV treatment, but also choice as to where to receive it.

In this chapter, I examine the divergence between PEPFAR's objectives and the goals of individuals, specifically women, receiving ARVs. As the largest population living with HIV/AIDS in Tanzania and Sub-Saharan Africa, women are a targeted

population for ARV programs. I outline the main foci of large-scale health programs, like PEPFAR, as well as those of women on ARV regimens. I then report on women's decision-making processes in choosing ARV treatment programs based on individual interviews, a focus group, as well as observation from the field. Specifically, I look at what women say they are looking for when they choose an ARV clinic, what they like about the clinics they attend, and what they would like to see changed at the clinics. Despite the different models of care offered by PASADA and Hindu Mandal, patients from both clinics offer similar notes of praise and ideas for improvement. Finally, I examine how patient interactions with PEPFAR ARV programming in Tanzania interact with the foreign policy aspects of PEPFAR.

# HIV/AIDS and the Women of Tanzania

Women are disproportionately infected with HIV/AIDS in Sub-Saharan Africa and are being targeted for treatment programs by international donors (AfricaFocus 2005; Baylies 2000). Worldwide, women comprise 50 percent of those living with HIV/AIDS (WHO 2008). In Sub-Saharan Africa, though, 60 percent of those living with HIV/AIDS are women. According to the *Tanzania HIV/AIDS and Malaria Indicator Survey 2007–08* (TACAIDS et al. 2008), the national average of HIV prevalence among women is 7 percent, compared to a prevalence rate of 5 percent among men (TACAIDS et al. 2008:33). Women are the largest group in need of ARVs. As of 2007, PEPFAR became the first international initiative to disaggregate data according to gender. Because of the gendered impact of HIV/AIDS in Sub-Saharan Africa, ARV need is also gendered.

In the city of Dar es Salaam, the prevalence rates for women and men are 10.2 percent and 7.3 percent, respectively, both higher than the national average of 6 percent

(TACAIDS et al. 2008:33, 34). Broken down by age groups, the HIV rate among women in Tanzania is as follows (TACAIDS et al. 2008:34):

Table 5: HIV PrevalenceRate among Women inTanzania

Age	Percentage HIV Positive	
15–19	1.3	
20–24	6.3	
25–29	7.9	
30–34	10.4	
35–39	9.5	
40-44	7.6	
45-49	6.8	

As the largest population living with HIV/AIDS in Tanzania, women are a targeted population for PEPFAR. A Senior Public Diplomacy and Communications Advisor for the Office of the Global AIDS Coordinator in Washington, D.C., proudly told me that PEPFAR is the "only international initiative to disaggregate data according to

gender." In its fifth report to Congress, *Celebrating Life: The U.S. President's Emergency Plan for AIDS Relief*, PEPFAR highlights that of, "those for whom PEPFAR provided downstream support<sup>59</sup> for treatment in the focus countries, approximately 63 percent were women..." (2009a:48). As women are a targeted population and placing them on ARV regimens is a point of accomplishment for PEPFAR, how women choose an ARV clinic is an important issue for PEPFAR as it looks to increase its numerical target reports.

I interviewed twenty-two women who were receiving ARVs at the clinics for my study, eleven at PASADA and eleven at Hindu Mandal. In the interviews, I asked them to recount their experiences and decisions from the time of their testing positive to their decision to come to a particular clinic to receive ARVs. The women varied in length of time receiving ARVs. Except for three women who began taking ARVs as a part of PASADA's pilot program in 2003 and 2004, the women I interviewed began treatment between 2005 and 2007, which covers the duration of the availability of free ARVs in Tanzania until and through my fieldwork. The interviews covered their experiences and

<sup>&</sup>lt;sup>59</sup> "Number of individuals reached through downstream site-specific support includes those receiving services at USG-funded service delivery sites" (PEPFAR 2009a:48).

opinions and ideas about the ARV clinic. At PASADA, the women were, in part, selected by my research assistant—a woman who was part of PASADA's pilot ARV program in 2003. At Hindu Mandal, I, along with the clinic nurses, helped select women who were receiving ARV treatment to be interviewed.

As a group, they ranged in age from twenty-five to sixty-three. The range in age for the women I interviewed at PASADA was twenty-six to fifty-four; at Hindu Mandal it was twenty-five to sixty-three. The overall average age for the women was 38.8 years; the average age for the women I interviewed at PASADA was 40 and at Hindu Mandal, 37.5. According to the *HIV/AIDS and Malaria Indicator Survey 2007–08*, the average HIV prevalence for Tanzanian women aged 37.5–40 years is 9.5 percent, which is the second highest prevalence age group for Tanzanian women, behind 10.4 percent at 30–34 years (TACAIDS et al. 2008:34).

Overall, nine of the women finished primary school. Three women completed their secondary education. Four women completed some secondary school whereas two women completed some primary school. Three women reported having no schooling. One woman recently graduated with a certificate in social work. The *HIV/AIDS and Malaria Indicator Survey 2007–08* report shows that over half of Tanzanian women complete primary school, but only 9.6 percent of women complete some or all of secondary school (TACAIDS et al. 2008:8). Women who complete secondary school have the lowest HIV prevalence rate at 5 percent (TACAIDS et al. 2008). Women who complete primary school have a prevalence rate of 7.3 percent (TACAIDS et al. 2008a). Eleven women reported working outside of the home, five as unemployed, four not working outside of the home, one actively looking for work, and one volunteering.

The HIV/AIDS and Malaria Indicator Survey 2007–08 report indicates that over 54 percent of Tanzanian women are married; 9.1 percent are divorced or separated; 3.2 percent are widowed; 9.8 percent are living with a boyfriend; and over 23 percent have never been married (TACAIDS et al. 2008:8). Although widowed women make up the smallest group within the range of marital statuses, widowed women make up over 25 percent of the women living with HIV/AIDS (TACAIDS et al. 2008). Married women and divorced women have a prevalence rate of 6 percent and 15 percent, respectively (TACAIDS et al. 2008). Never married

Table 6: Interviewed Women Patients by Clinic		
Age	PASADA	Hindu Mandai
25–34	3	4
35-44	5	5
45-54	3	1
55–64	0	1
ARV Start Year		
2003	3	0
2004	0	0
2005	1	8
2006	5	3.
2007	2	0
Education Level <sup>60</sup>		
None	2	1
Some Primary School	0	1
Finished Primary School	5	4
Some Secondary School	2	2
Finished Secondary School	1	2
Certificate of Social Work	1	0
Nursing Assistant Degree	0	1
Marital Status		
Single	2	3
Has a boyfriend	2	2
Engaged	1	0
Married	2	4
Divorced	2	1
Widowed	2	1
Children		
None	1	0
1–3	9	9
4+	1	2

women have an HIV prevalence rate of almost 2.5 percent (TACAIDS et al. 2008). Regarding marital status among the women I interviewed, six are married; five are living with a boyfriend; three are widowed; and eight are single, which includes divorce, separation, and never being married. Twenty-one of the women have children.

<sup>&</sup>lt;sup>60</sup> In Tanzania, primary school consists of seven years – Standard 1 through Standard 7. Secondary school is four years - Form 1 through Form 4 (United Republic of Tanzania 2010).
In addition to individual interviews, I also conducted a focus group with sixteen women on an ARV regimen at PASADA. These women were selected through recommendations from PASADA's medical director and my research assistant. This group of women included individuals who had started taking ARVs during PASADA's pilot program in 2003 and 2004, as well as women who started a treatment regimen in 2005, 2006, and 2007. The goals of the focus group were (1) to help clarify answers I had heard repeatedly in individual interviews and (2) to give women an opportunity to speak openly about women without referring to themselves directly. Because some women had given similar responses to questions in individual interviews, the focus group provided an opportunity for peers to help me interpret those answers-to check if I was understanding them the same way they did (Patton 2002:386). A second aim of the focus group was to give women a chance to speak in general about sensitive subjects-HIV/AIDS stigma, HIV/AIDS disclosure, ARVs, and how women seek care. The group atmosphere allowed women to bring up social knowledge about these subjects without necessarily revealing personal information (Patton 2002:388–389). The interviews and the focus group were conducted mostly in Kiswahili, but some were a mix of Kiswahili and English.

# Number-Seeking/Dignity-Seeking

Even though as a global health program PEPFAR aims to address the need for ARVs in Tanzania, its overall goal is different from those individuals who need ARVs. The U.S. plan for "transformational diplomacy," of which PEPFAR is a primary example (PEPFAR 2007a:9), demands "transparency and accountability" (PEPFAR 2007a:25). The public accounting of numbers by PEPFAR is an indication of not only its programmatic success, but its mark as a piece of foreign legislation. If PEPFAR's foreign

policy goal is to promote U.S. interests, then PEPFAR needs public recognition of its global health work. Janes writes that current approaches to health "advance a highly rational, universal, and efficiency-based model of health care and public health..." (2004:459). By basing funding on numerical performances and policy decisions, PEPFAR is following Janes's description. As I write in Chapter 3 on targets, the numbers count the number of people who are started on ARV pills, they do not account for the patient dropouts, whether patients opted to attend another clinic, dropped out of treatment completely, or passed away. Janes also argues that these health approaches are "driven by the view that individuals in community can be forced to become 'rational' economic actors..." (2004:467). The assumption within universal, rational, and efficiency-based health programs is that the behavior of targeted individuals will match the expectations of the planners. PEPFAR's general focus on the quantification of treatment assumes that women need just consider availability when choosing an ARV clinic.

PEPFAR's perspective of patients is that of a global epidemic. PEPFAR's annual reports to Congress do not mention or address how the individuals PEPFAR hopes to reach in its program will select clinics for treatment. Its concentration on numerical targets, performance-based funding, and quick scale-up focuses on the distribution aspects within an ARV program, not on how individuals choose to access programs. As a program, PEPFAR can only view groups of patients, not individual patients. While there is no question that the distribution of ARVs is an important accomplishment, there is a question as to how women decide to select and stay with an ARV program. How women decide to choose (or not choose) an ARV program affects PEPFAR success.

The factors that affect where women decide to receive treatment do not match the PEPFAR's numbers-driven program. One day at PASADA, the executive director, Sarah Pell, and I discussed ARV treatment and PEPFAR. During the conversation, Ms. Pell recounted discussions that had taken place when ARVs first became available. She remembered that a Tanzanian government official argued that no matter what happened after the first authorization, ARVs could buy five more years of life. Five more years meant five more years of parent time raising children. Ms. Pell reflected on that memory and then marveled at what ARVs make possible: "ARVs create more quality life with dignity, unlike chemotherapy where people get sicker when they are being treated." Her point was that individuals taking the medications can live and work and not suffer the symptoms of the disease: "ARVs create more quality life with *dignity*" (emphasis added).

To Ms. Pell, what is important is simply that at a personal level ARVs not only lessen the symptoms of the disease but can also restore dignity to individuals by allowing them to live and work as healthy individuals do. As the largest group infected with HIV/AIDS in Sub-Saharan Africa, as well as in Tanzania, more women than men are making choices about ARV treatment (United Republic of Tanzania Office of the Prime Minister 2003). As patients, particularly women, decide to undertake ARV treatment, they are not just searching for pills. As ARVs are readily available throughout Dar es Salaam, Tanzania, women have choices about the clinic where they receive free treatment. How do women decide which CTC to attend?

# After Testing Positive

The National Programme makes free ARVs available to Tanzanians in need of them. After individuals test positive for HIV, the testing site refers patients to a CTC

(United Republic of Tanzania 2005:9). The idea behind this system is that HIV-positive patients will be monitored by clinicians and put on treatment when clinically ready. Because of the increase in the number of care and treatment clinics throughout Tanzania, including Dar es Salaam, the testing site often has a CTC on site as well. As of 2007, a U.S. Supply Chain Management System member estimated, there were approximately two hundred CTCs throughout Tanzania, with over twenty-three of them located in Dar es Salaam. My interviews with individual women focused on the decisions they made after they tested positive for HIV, which led them to receive ARV treatment either at PASADA or at Hindu Mandal.

The feelings women described upon hearing their positive results ranged from acceptance, to grief, to denial: from "I agreed with the diagnosis," stated by a twenty-sixyear-old woman who began an ARV regimen in December 2005; to "I felt bad because I was thinking about how to live with the virus and I cried," from a forty-six-year-old woman who began taking ARVs in May 2006; to "After getting results, I did not believe [them]," from a fifty-four-year-old woman who began ARVs just six months before I interviewed her. Of the women who explained the emotions they felt after receiving a positive diagnosis, eight said that after counseling they began to come to terms with their health status. The counseling situations the women described were one-on-one as well as support-group situations. Once women were counseled as well as saw that other women were living with HIV/AIDS, they described accepting the test results.

Most women I spoke with described this acceptance as not immediate, but rather as taking time. Anna Luhwago began taking ARVs in 2006 at PASADA after being tested in 2004. Unofficially, she recognized she was positive after seeing that her baby was sick in 2004. She heard about PASADA from Amana, a government hospital she was attending, but not for ARV treatment. Of the hospital, Ms. Luhwago complained to me, "I didn't like to remain at [the hospital]. I didn't like how they provide service at the government hospital." After testing positive at PASADA, she said, "I knew and then I lost hope when I found out officially. But, after getting counseling, I am doing well." Unlike her experience with the government hospital, Ms. Luhwago described PASADA as providing good services because "they care about patients, quality here."

Hadiya Kazenga tested positively at PASADA in 2005. There she was told about the Global Fund monies available at Hindu Mandal, so Ms. Kazenga came to Hindu Mandal as a part of the Global Fund grant and began taking ARVs in November 2005. She told me about testing positive: "I felt very bad until I found out there were a lot of patients, then I didn't feel so bad." Of Hindu Mandal, Ms. Kazenga explains that:

I like the services. The doctors listen well and they write [a prescription]. In other places, you don't finish talking and they've already written a prescription. One day I was seriously ill, a nurse here saw me and took me to Casualty [the Emergency Room] immediately. Other places would not let that happen. If you are serious [ill], no one cares.

Of course, not all women had positive experiences where they tested. Mwamini Sinda, a patient at Hindu Mandal with the Global Fund who began taking ARVs in 2005, was tested at Magomeni, a government health centre. Ms. Sinda is an outspoken woman with a wide smile. She recounted what happened to her after receiving her results. The counselor at Magomeni inquired about to whom Ms. Sinda might disclose her status. Ms. Sinda said that she would tell her mother. The counselor replied, "No! She will die [if you tell her]." Unhappy with those "explanations," Ms. Sinda decided to leave Magomeni. Her sister-in-law brought her to Hindu Mandal, where she started ARV treatment. She says that she likes everything about Hindu Mandal except having to pay for her

opportunistic infection medicine now that the Global Fund stopped its funding.

### **Needing Treatment**

The women I interviewed tested at thirteen separate locations, with some testing

more than once:

Testing Site	Number of Women Tested	ARV Treatment Available
Pastoral Activities and Services for People with AIDS	8	Х
Dar es Salaam Archdiocese		
Shree Hindu Mandal Hospital	5	X
Amana Municipal Hospital	1	X
African Medical and Research Foundation	1	
Cardinal Rugambwa Hospital	2	
Kilimanjaro Christian Medical Centre	1	Х
Konga Dispensary	1	
Infectious Disease Centre	1	X
Lugalo Military Hospital	1	X
Marie Stopes International	1	
Magomeni Health Centre	1	Х
Muhimbili National Hospital	4	X
Seventh Day Adventist Dispensary in Temeke	1	

Table 7: Where Women Interviewed Tested (Allers et al. 2003; Interviews)

In Tanzania, hospitals, clinics, and dispensaries offer VCT for HIV/AIDS. The majority of women I interviewed individually (19/22) decided to be tested on their own, as a result of being continuously ill or after watching a husband or a child die. One woman found out she was HIV-positive after a routine prenatal test given to expectant mothers. Despite the availability of ARV treatment at VCT sites, though, women do not have to stay for treatment at the same clinic where they tested. Of the women I interviewed, thirteen chose to begin treatment at a clinic other than where they had tested positive. Of those thirteen, eight women left a clinic where treatment was available and began ARVs at another clinic. Five of them could not receive ARVs where they tested positive.

The women I spoke with who decided to leave one clinic and receive treatment at another CTC did so for varied reasons. Two were to begin treatment at PASADA, but decided to join the Global Fund grant at Hindu Mandal after hearing information about it at PASADA. One of the women tested positive at Muhumbili in 2001 before ARVs were readily available. When treatment became available, she listened to the advice of the HIV/AIDS support group she attended when the group recommended PASADA. Two other women originally bought ARVs from maduka ya dawa<sup>61</sup> until the medicines became available for free. Both women were brought to Hindu Mandal by family members.

Three women decided to try other clinics after testing positive. Mwamini Sinda did not return to Magomeni Health Centre after she tested positive because of the counseling she received there. Basma Peter's story begins in 1997 when she was experiencing stomach pains. The government hospital she visited sent her to the Infectious Disease Centre (IDC) to be tested. Ms. Peter tested positive for HIV/AIDS for the first time at the IDC in 1997. She tested positive in 1999 at Muhimbili Hospital and again in 2000 at PASADA. After testing positive at PASADA, Ms. Peter's husband placed her and himself on Chinese herbs he had purchased for two months. It was not until she arrived at Hindu Mandal for chest pain that a doctor decided she was clinically ready to begin ARV treatment in 2005. Ishara Makunga began treatment at PASADA in 2003 after testing positive at two other hospitals. The first hospital would not give her the test results until she returned with her husband. The second hospital she tested positive at was Lugalo Military Hospital. After she received the news, the same friend who escorted her to Lugalo suggested she try treatment at PASADA. Unable to receive her results at

<sup>&</sup>lt;sup>61</sup> Medicine stores, local pharmacies.

the first hospital without her husband, Ms. Makunga decided to try PASADA and then decided to begin ARV treatment there.

Testing positive at a site that also provides treatment is no guarantee that a woman will stay for treatment where she tested. As the number of CTCs continues to increase and their funding essentially relies on the numbers of individuals they can place on treatment, CTCs will need to appeal to women living with HIV/AIDS. What do women living with HIV/AIDS look for in a CTC?

# Finding Treatment and Deciding Where to Go

#### Women and HIV/AIDS Stigma

Castro and Farmer argued that the "social experience of AIDS is affected profoundly by the advent of effective therapy." Their work in Haiti suggests that effective ARV treatment made readily available reduces HIV/AIDS-related stigma (Castro and Farmer 2005). Yet, while available treatment may lessen stigma, stigma may also prevent the utilization of treatment services.

HIV/AIDS-related stigma was apparent during my predissertation research at PASADA in 2004 when I met Rose. At the time we met, Rose was twenty-four years old and lived with her mother, three sisters, and a brother. She tested positive in 2000 at a state hospital. Rose traveled to a church for help, but did not go to the church her family attends as she was afraid someone might tell her mother about her condition. Scared and contemplating suicide, she was taken by a priest to PASADA. Rose started treatment in November 2003. In addition to receiving treatment from PASADA, Rose was also giving talks to other individuals with HIV/AIDS about living with the disease. Rose created a supportive community for herself. Yet when I spoke with Rose in 2004, she was keeping

her status a secret from her family because, "For family, it is a big thing. If you get AIDS, you are going to die ... I don't see anyone to tell." Rose was keeping a significant part of her life completely separate from the people she lived with as she was trying to avoid being stigmatized by friends and family because of her health status.

Three years later, when I met with a focus group of women to discuss women, HIV/AIDS, and treatment, stigma remained a significant part of the discussion. Stigma affects how women view HIV/AIDS and how they feel others view their health status. For the purposes of treatment, though, stigma is a major factor in "inhibiting service utilization," according to the National Programme's *Clinical Guidelines* (United Republic of Tanzania 2005:15). PEPFAR's first report to Congress also notes "... the stigma of HIV, which poses a barrier to service and increasing access [to treatment]" (PEPFAR 2005:27). Moreover, stigma creates "... fear and hopelessness that can keep people from acting on vital prevention messages or seeking testing, care, and treatment" (PEPFAR 2005:44). Not only may people not show up to receive treatment, but people may not follow a treatment regimen in order to hide the medicines from family and friends.

Stigma, as defined by the women in the focus group, is separation from family. Stigma is what Galvão terms a "civil death"—although physically alive, an individual is ignored by her family as if she were dead (2002). In everyday practice, stigma results in a family viewing an individual differently, not allowing her to eat with the family, or not allowing her to live with the family. The women at PASADA told me that there is stigma surrounding HIV/AIDS because "it is a dangerous disease ... an infection from private parts," according to a woman who began taking ARVs in 2006. Moreover, the women in the focus group concluded that women experience a different type of stigma than men as a result of HIV/AIDS. One woman who began taking ARVs in 2005 explained, "... because most of women depend on men, they [the women] don't work." This comment was followed by a statement from another woman, who also began treatment in 2005, that if one tells her husband, "he will chase you away and marry another woman." Because of these ideas about gender relations, the women in the focus group agreed that, although women should disclose to their husbands or partners, they are the most difficult people to tell about HIV/AIDS. The stigma surrounding HIV/AIDS, particularly for women, highlighted the economic and social vulnerability women face in disclosing their health status—not just from society, but from their closest, most intimate relationships.

Women are aware of how society, their families, and their significant others will view their health status. Of the women I interviewed individually, fourteen had chosen not to tell some members of their families or friends about their health status.

With women wondering whether or not their relatives and friends will accept their diagnosis, that concern extends to fear of stigma from health care workers. According to the focus group, patients consider a bad staff member as a person with poor communications skill. While stigma is a factor in considering which CTC to attend, the women attest that it is not the only reason a woman may select a clinic. One woman, who began ARV therapy in 2007, stated that choosing a clinic depends on how a patient is treated: "It's also because of love. I have been at Temeke [Hospital—a government-run hospital]; they did not treat me well. Here [at PASADA] doctors treat me properly..."

treatment by staff, as provided at either PASADA or Hindu Mandal, as what they like about receiving treatment at a particular CTC.

## Good Services Defined

"Good services" was the reason most mentioned as to what they liked about attending a clinic. Given that PASADA and Hindu Mandal offer different types of programming around ARV therapies, it is striking that patients would list the same reason for attending CTCs. I asked the focus group to define what services a good clinic provides and the overall definition was that clinicians took the time to listen to patients: "Patients can tell their problems to a doctor and the doctor listens," is how one woman, who began ARV treatment that week, expressed it.

The focus group helped define what "good services" means to women patients. In discussing the details of good services, most of the women at both clinics said that the doctors and staff of the clinic cared for the patients. A woman who began ARVs in 2004 said during the focus group that how staff cares for patients is shown by how the patients are welcomed at the clinic and the rapport the staff builds with patients. Five of the patients at PASADA and nine of the patients at Hindu Mandal<sup>62</sup> mentioned that what they liked about PASADA or Hindu Mandal was how the patients are treated by the clinic's staff. Doctors and staff could show that they care by listening to the patients, a fact listed by Ms. Kazenga in her reasoning for choosing Hindu Mandal, as well as other women patients.

Ms. Raquel Philemon was the tenth person to begin ARV treatment in PASADA's pilot program in 2003. She originally had taken her mother to PASADA for malaria

<sup>&</sup>lt;sup>62</sup> Some women mentioned more than one reason as to why they attended a particular care and treatment clinic. Therefore, when added together, these reasons may total more than the number of interviewees.

treatment, but during follow-up at her home the PASADA staff urged her to come to PASADA for HIV/AIDS testing. Because they kept coming, Ms. Philemon returned to PASADA for testing and, eventually, treatment. She liked coming to PASADA for treatment because "I like that the treatment is free and the love that the staff show to us [patients] ... They observe you and your problems." Staff attention was a key factor in what she likes about PASADA.

Another PASADA patient, Ms. Fila Macha, credited visits to PASADA support groups as helping her realize that she was not the only one living with HIV/AIDS. Of PASADA she said, "PASADA is love. We receive counseling, seminars ... and hear about the challenges about HIV. We receive education ... I love PASADA." While Ms. Macha spoke well of the education and the group seminars at PASADA, which she connects to being a part of PASADA's community, she saw the group experiences as something that PASADA provides to its patients. For Ms. Macha, these services made her experiences at PASADA positive ones.

When Dalila Sadallah worked as a nursing assistant in Arusha, Tanzania, she said that she recognized some symptoms of HIV in herself and decided to test herself. She and her husband initially attended a private hospital in Arusha and bought ARVs themselves until she switched to the National Programme. She moved to Dar es Salaam and her son, an engineer who works near Hindu Mandal, decided to take her to the clinic. Ms. Sadallah said that she likes Hindu Mandal because "... the services are good. If something is wrong, I can see [the doctor]. I have his phone number, he is ready to help me at any time." Like the patients from PASADA, Ms. Sadallah and Ms. Kazenga highlight that they feel the clinic staff cares for them. While Ms. Sadallah and Ms. Kazenga spoke more about their time with individual doctors, the patients from PASADA focus more on clinic staff as a whole. Even though PASADA provides more community-focused treatment and Hindu Mandal provides a more confidential approach to treatment, the women patients still report the same ideas of what good services means at each CTC.

Yet, the overall focus for women regarding "good services" was that they feel the staff cares about the patients, that the patients are not ignored, and that they feel they can speak to the staff about their health concerns and be heard by the staff. No matter the model of care, patients will have positive experiences as long as they feel that the clinic provides "good services."

## Suggestions for Improvement

While the twenty-two women I interviewed all had and continue to have positive experiences at PASADA and Hindu Mandal, the women did have suggestions about how each CTC could improve their services. When I asked women what they did not like about the clinic they attended, their answers followed two patterns. They either spoke about what they did not currently like about the clinic or spoke about what future changes they would like to see in the clinic. Four of the patients I interviewed at PASADA spoke the most about the difficulties in transportation—cost and distance—in coming to PASADA.<sup>63</sup> They would suggest that PASADA cover at least the cost of their travel. Three PASADA patients also wanted an increase in programming at PASADA. These women listed more programming as paying school fees for orphans; more seminars on HIV/AIDS education; and building beds on-site.

<sup>&</sup>lt;sup>63</sup> In the interviews, some women mentioned more than one reason as to why they attended a particular care and treatment clinic. Therefore, when added together, these reasons may total more than the number of interviewees.

The women at Hindu Mandal felt that the fees associated with the private hospital were too expensive. Three of these complaints were centered on the loss of the Global Fund monies. One woman, Dalila Sadallah, had this viewpoint about the fees of the private hospital: "The services are good, but expensive. Others want Hindu Mandal services." Ms. Sadallah's point is that Hindu Mandal's fees were a barrier to some people in need of good services at a CTC. Three patients at Hindu Mandal were concerned with their pharmacists. All the patients, after seeing physicians and nurse counselors, must wait to receive their ARVs from two pharmacists who run between the hospital pharmacy and the clinic pharmacy. The concern about the pharmacists is that one of them delays in coming to the clinic pharmacy, making the patients wait a considerable amount of time when they come to pick up their ARVs.

The issues that the patients raise regarding cost highlight that, even though ARVs are free, treatment itself is not just ARVs. Travel costs, money for laboratory tests, and the price of medicines for opportunistic infections all add to what women must pay to keep up with ARV therapy. The women who lost free services because of the loss of the Global Fund grant cannot afford to stay current on needed laboratory tests or other medications. The increase in programs requested at PASADA are enhancements of what PASADA provides now. Because women want "more" at PASADA, their requests show how comfortable they are with PASADA's other programs. The complaints about the pharmacist at Hindu Mandal are valid—the nurse counselors often spoke to the offending pharmacist about his behavior. Yet, the women patients narrowed their complaints to one individual—they never condemned the ARV program as a whole.

### What Women Don't Want

Just as there are experiences at a CTC that encourage patients to keep returning, there are issues that patients want clinics to address. The women patients of the focus group say that when there is bad staff at a clinic, it means the patients are not listened to and not cared about. The women patients in the focus group also feel that sometimes workers have too much work to do, so they cannot listen to every client. When I asked the focus group about the impact of a bad staff member on patients, the women responded that if treated poorly a patient can run away, thereby causing the patient to die.

Overall, women chose clinics where they feel they are welcomed and listened to by the staff. They leave clinics where they have bad experiences with staff members or do not receive proper attention. They avoid AIDS-related stigma by clinic workers in making these choices. Ms. Peter, who I profiled earlier in this chapter, explained that when she was admitted to a hospital, she received medicines and was simply told what time to take them. At Hindu Mandal, though, she said, "Doctors are ready to listen and do investigations. [When] I felt bad and listless ... the doctor [ran tests] and he changed my medicine from Triomune 40 to Triomune 30."<sup>64</sup> Her brief accounting of an ARV dosing change illustrated her point that she liked the services better at Hindu Mandal because the staff not only discussed her health with her, but listened to her and answered her questions. By treating her with respect, Ms. Peter, as with many of the women I interviewed, felt that she did not have to worry about stigma at her ARV clinic. Just as the ARVs are improving their health and their quality of life, the women are looking for their clinical experience to reinforce that dignity. Ultimately, they are seeking out individualized care, a CTC that will not treat them as a number.

<sup>&</sup>lt;sup>64</sup> A different dose of the ARV, Triomune.

As PEPFAR keeps increasing its numerical targets, can women continue to expect "good services" from their clinics? During one of my individual patient interviews, I spoke with Ms. Malisa, a patient at PASADA who was diagnosed with AIDS in 2002. She described how she found PASADA: "[My friend] Raquel actually told me about [PASADA], that it was free and it is the best." She continued on to say that "doctors show love to patients ... If you don't come, the doctors and nurses come to your home, [they] will call on your cell." Ms. Malisa also noted that, "I am thinking that PASADA has so many patients [now], they may not be able to provide for everyone." Since she first starting coming to PASADA in 2002, Ms. Malisa has noticed an increasing number of patients coming for "good care." Her fear lies in wondering how many more people PASADA can continue to provide for regularly. So, as PEPFAR keeps increasing numbers, it is threatening the very thing that the women patients told me keeps them coming back to a clinic.

# The Selective Appearances of PEPFAR

# The Politics of PEPFAR and the Tanzanian State

Patients who receive ARVs in Tanzania do not see PEPFAR branding. The appearance of the Tanzanian state on the CTC-1 card highlights the lack of PEPFAR branding at the patient level. The two tangible means of connection a patient has with her ARV program are her CTC-1 card and the actual ARV medications. The CTC-1 form that is the property of the patient—the piece of paper that connects her to an ARV program—does not have the PEPFAR logo on it.<sup>65</sup> All of the CTC forms, described in Chapter 5, are stamped with the Tanzanian state's coat of arms. All of the boxes of drugs given to patients are stamped with the phrase, "Government of Tanzania."

<sup>&</sup>lt;sup>65</sup> It does not have the Global Fund logo on it either.

The Tanzanian state, through these highly visible displays, represents itself as the provider of ARVs. PEPFAR, its treatment partners, the Supply Chain Management System that ensures the delivery of ARVs throughout the country, and the Global Fund are not visible to the patient. At the end of each patient interview, I asked the women if there was anything else they wanted to say about ARV treatment, women's health, or HIV/AIDS in Tanzania. Two of the women took the opportunity to thank the Tanzanian government, one from PASADA and one from Hindu Mandal, respectively:

"I want to thank the government and other organizations for supporting the patients to get drugs. Thank God," said Mary Machira in an interview. Ms. Machira has been taking ARVs since July 2005.

"I want the government to continue buying these medicines and other people should get tested to know their status before they get sick," Radhi Didas told me in an interview.

Even within the focus group, one woman, on ARVs since 2005, took the opportunity to point out, "The government, which is providing medicines, has seen the importance of using ARVs. The government is the one who has supported us." What is significant about these women's statements is that they are about the Tanzanian government, they do not mention PEPFAR.

### Treatment and Foreign Policy

In Tanzania, the patients were not aware of the role that PEPFAR plays in the delivery of ARV care, so individual patients are not going to provide the public recognition PEPFAR needs for foreign policy success. PEPFAR needs the numbers to demonstrate its programmatic work, but it does not necessarily need the work to be recognized by the patients receiving ARVs. This is another point where the gap between the global health and foreign policy aspects is made visible, but also another place where PEPFAR and patient needs diverge. U.S. foreign policy can only reap the benefits of PEPFAR if that work is publicly recognized. Moreover, patients' ARV needs only go as far as ARV programming. PEPFAR, on the other hand, needs patient numbers, although it does not necessarily need patient support, for public recognition.

In reviewing the reauthorization of PEPFAR, Bristol notes that, "On the Senate floor, [PEPFAR] bill sponsors emphasised the programme's role in improving the USA's reputation abroad, providing a positive, humanitarian image for a country tainted by controversial decisions on foreign policy" (Bristol 2008:278). As a foreign policy initiative, PEPFAR has promoted a positive image of the United States abroad, which the bill sponsors have argued is a benefit to the United States. According to a Gallup Poll, former President Bush's last trip to Africa was marked by outpourings of gratitude: "In Tanzania, tens of thousands reportedly lined Bush's route, which was plastered with billboards expressing thanks for his support in fighting malaria and HIV/AIDS."

The friendly reception Bush has received [in Africa] likely reflects recognition of substantial humanitarian and health initiatives during his presidency, as does general approval of U.S. leadership across Africa. Median approval across twenty-six countries surveyed in Sub-Saharan Africa in 2006 and 2007 is 66 percent (Ray 2008).

The claims that PEPFAR is good for the image of the U.S., as well as the approval numbers, assume an awareness of PEPFAR's work among the populations the program support—not necessarily a public outpouring of patients receiving ARVs. PEPFAR, however, does publicize its own work. In 2007, the U.S. Embassy in Dar es Salaam employed a PEPFAR media outreach coordinator. Larry André, Chargé d'Affaires at the

U.S. Embassy in Dar es Salaam in 2009 announced:

The "One USG [U.S. government]" strategy is also essential to our outreach to the Tanzanian general public. By eliminating the impersonal bureaucratic branding of agency specific logos, the tagline "From the American People" reinforces the generosity and good will of Americans. The tagline is prominently displayed at all U.S. Embassy public events and on communication materials for both PEPFAR and non-PEPFAR initiatives. By celebrating our successes, for example through inaugural ceremonies for care and treatment clinics and laboratories, we have achieved greater recognition by Tanzanians of the support of the American people (André 2009).

Although PEPFAR branding may not be visible on boxes of ARVs, U.S. government branding is prominent through a presence at "inaugural ceremonies for care and treatment clinics," as well as other activities, which include PEPFAR's interventions in prevention and palliative care. While individual ARV patients may not be aware of PEPFAR, the U.S. government actively works to make the Tanzanian public aware of its work.

The final target of PEPFAR's foreign policy work is the global community, not the patients themselves. The "highly rational, universal, and efficiency-based model of health care and public health" (Janes 2004:459) works to meet the public accounting PEPFAR wants to demonstrate. The dignity PEPFAR patients seek in their quest for treatment does not necessarily include a public admission of their own health status, let alone the recognition of a treatment provider. Furthermore, patients, in their interactions with CTCs, appear to only recognize the treatment provider as their own government. The foreign policy aspect of PEPFAR, meant to reach out to individuals in need around the world, is not a concern for the women patients. For them, the focus is solely on the availability and the quality of the ARV health services they choose to receive. The foreign policy aspect of PEPFAR relies on non-patients being made aware of PEPFAR's work. The individual patients do not need to know what group or government provides their treatment and care because the positive impact of PEPFAR on the U.S. does not rely on their opinions, but on the global community's knowing who provides treatment and care.

# Chapter 7 Concluding Thoughts

"... When you start issuing policy prescriptions, when you start advising heads of state, you no longer have the luxury of only being judged on how you *think* your ideas will affect the world. You begin having to contend with how they actually affect the world, even when that reality contradicts all of your utopian theories" (Klein, quoted in MacFarquhar 2008:71, original emphasis).

My dissertation explores the different realities faced in providing ARV treatment by the governments, organizations, and individuals working to make it available in Tanzania. I also examine what PEPFAR's numbers tell and do not tell about ARV treatment in Tanzania. The numbers provide concrete evidence of PEPFAR's work addressing HIV/AIDS and of the program's progress in reaching its self-defined goals. The final numbers from the first authorization also publicize the success of the most wellfunded program fighting the HIV/AIDS pandemic, as well as the "ever-expanding sphere of transparency and accountability" of U.S. foreign policy (PEPFAR 2007a:25). In this chapter, I review PEPFAR's programming and discuss the different roles and opinions put forth by government officials, treatment partners, local staff, and women patients involved in ARV treatment in Tanzania. I explore how PEPFAR factors into U.S. foreign policy and recommend suggestions for PEPFAR's ARV policies and programming. I also review how policy shapes PEPFAR programming and how PEPFAR's participants—the government officials, treatment partner personnel, local clinic staff, and women patients-shape how policy is actualized in Tanzania. I conclude by discussing future research, how my dissertation connects to existing scholarships in medical anthropology and the anthropologies of development and policy, as well as future considerations for PEPFAR ARV programming.

## Varying Viewpoints on AIDS and ARVs

## Addressing the Research Questions

In this dissertation, I addressed the following four questions:

- What do government officials, treatment partners, and clinic workers think about PEPFAR treatment policies?
- How does each group view its own participation in the distribution of ARVs within PEPFAR?
- How do PEPFAR policy and changes to it affect ARV programming?
- How do women receiving ARVs choose a clinic to attend?

Because of their different positions within PEPFAR, government officials, treatment partners, clinic staff, and women patients all have different views of the epidemic. In this dissertation, I examined how these various viewpoints resulted in different programmatic approaches. The questions sought to address how the agencies, organizations, and individuals involved in PEPFAR and ARV treatment in Tanzania thought about their work with PEPFAR and in treatment programming. Because of the introduction of the regionalization policy, treatment partner personnel were reflecting on their work at a moment when it was changing. PASADA staff, also because of the policies of regionalization and graduation, was able to talk about their work while their clinic was transitioning to a new status. Finally, women patients who are currently taking ARVs were able to discuss how they selected clinics, what they liked about their clinic, and what improvements they wanted to see in it.

PEPFAR planners have a global view of the pandemic and focus on increasing the availability of ARVs worldwide. In Tanzania, this focus was put toward meeting the goal of 150,000 people on treatment. While the numbers provide proof of PEPFAR's work, they also make other aspects of the program invisible. The PEPFAR Country Operation

form ties increased funding to increased treatment numbers in Tanzania, without having to account for treatment outcomes. Treatment outcomes are the ultimate marker for whether or not ARV treatment can be considered a success. Without knowing if patients drop out of a program due to personal treatment stoppage, moving, or dying, PEPFAR's numbers reflect only the number of people who have been placed on treatment, not the number of people still on treatment or the outcomes of the treatment. The focus on placing two million people on ARVs, or 150,000 Tanzanians on ARVs, can mask the number of treatment dropouts and the creation of growing numbers of drug resistant viruses, which will pose health risks to others.

Treatment partners and clinical staff work to meet the demands of an international health initiative and to incorporate their own expertise into ARV programs. Treatment partners now have regional views of the epidemic. As noted by one program officer, treatment partners know that global treatment programs are new and they are looking for "best practices." The Tanzanian government and PEPFAR's implementation of the new regionalization policy aimed to increase efficiency among the treatment partners in Tanzania while increasing the numbers of individuals placed on ARVs. While numbers did increase, bringing Tanzania much closer to reaching its goal of 150,000, implementing it in the midst of the funding cycle did not help with efficiency. Regionalization has resulted in improved service delivery, but treatment partners lost a year and a half of infrastructure and relationship building by not implementing it from the onset. Treatment partners also view PEPFAR funding as opportunity to create new programs that will benefit the patients in their assigned regions and to find ways to test the best practices of ARV programming. The opportunity PEPFAR opens for the

treatment partners to continue to provide treatment is a primary reason for them to meet the program's targets.

The clinic staff of PASADA and Hindu Mandal, however, sees the epidemic through individual patients. The staff I worked with looks for ways to guarantee that individual patients will continue to return for treatment—friendly staff members, personal counseling sessions with patients, group counseling sessions with patients, personal phone calls. While PASADA is under pressure from PEPFAR to meet patient targets, its executive director is trying to maintain the quality of care that draws patients to the clinic. Hindu Mandal's staff works to make sure patients see the counselor they prefer upon their visits. As patients build personal relationships with the counselors, the counselors hope this will keep them returning to refill their prescriptions.

Patients, the key participants in the success of ARV treatment, experience the epidemic personally. The women I interviewed wanted face time with clinic staff at the ARV clinics they chose to attend. Because there are multiple ARV clinics in the city, patients can always select another clinic to attend if they are dissatisfied. Women patients, a targeted population for ARV treatment, are a specific group that PEPFAR counts in its reports to Congress: "PEPFAR provided downstream support<sup>66</sup> for treatment in the focus countries, approximately 63 percent were women, which is higher than the estimated percentage of women living with HIV in sub-Saharan Africa" (PEPFAR 2009a:48). Women's decisions about where to receive ARV treatment affect the success of the programs, and the women I interviewed were specifically looking for clinical staff that did not treat them as a number, but treated them with dignity—taking time to listen

<sup>&</sup>lt;sup>66</sup> "Number of individuals reached through downstream site-specific support includes those receiving services at USG-funded service delivery sites" (PEPFAR 2008:42).

to them, answering specific questions, and treating them with respect. Some of the women I spoke with discussed leaving places where the staff did not treat them with dignity, and these were the women who decided to continue treatment elsewhere. Some patients may have a poor experience at an ARV clinic and not seek out treatment elsewhere or not have the option to seek it at another care and treatment clinic. While placing individuals on treatment is important, keeping them on it is also important to the success of ARV treatment for individuals and, ultimately, any treatment program. Programmatic Tensions and Global Health Diplomacy

At the core of my dissertation is a set of tensions. The primary tension, as discussed in Chapter 1, is global health diplomacy. PEPFAR aims to address both an issue of foreign diplomacy as well as global health. As former Secretary of State Rice noted, PEPFAR is U.S. transformational diplomacy in action (PEPFAR 2007a:25). As numerical targets are set and held as the standard of success for the program by PEPFAR planners, PEPFAR as a whole can be declared successful. As accountability is required of clinics and treatment partners to generate the numbers that are reported to Congress, the foreign diplomacy benefits are not as tangible. As PEPFAR works toward accountability and concrete proof of its work—how does that accountability translate to foreign diplomacy?

In the weeks leading up to the authorization of PEPFAR II by Congress, U.S. Senate Foreign Relations Committee Republican leader Richard Lugar spoke on the floor about PEPFAR's dual nature as both a foreign policy program and a global health initiative as a reason to reauthorize the program:

The U.S. National Intelligence Council and innumerable top officials, including President Bush, have stated that the HIV/AIDS pandemic is a

threat to national and international security ... I believe that in addition to our own national security concerns, we have a humanitarian duty to take action. Five years ago, HIV was a death sentence for most individuals in the developing world who contracted the disease. Now there is hope. We should never forget that behind each number is a person—a life the United States can touch or even save ... In my judgment, the dollars spent on this program can be justified purely on the basis of the humanitarian results that we have achieved. But the value of this investment clearly extends to *our* national security and to *our* national reputation (Lugar 2008, emphasis added).

Lugar's reference to "humanitarian duty" refers to the global health need of ARV treatment—treatment saves lives. While he does say that saving lives might be reason alone to fund PEPFAR II, he also says that the U.S. is benefiting. U.S. national security will benefit from PEPFAR and "our national reputation" will improve from continued investment in the program. How increased goodwill will benefit U.S. foreign policy interests may not always be clear to the U.S. public, but Lugar's words state that PEPFAR has direct benefits to the U.S.—improving security and reputation. Yet, these benefits will only continue if PEPFAR is a successful program, and for treatment, adherence is critical to that success.

Moreover, international health programs do well with U.S. taxpayers. Levine notes that, "...energetic, visible, and effective international health endeavors ... are among the international activities most favored by U.S. taxpayers..." According to a poll conducted in 2006 by *Research!America*, health is among Americans' top priorities for development assistance (Levine 2008:45). The numerical targets and the reporting required to deliver them not only chart the program's progress, but also allow the work to be seen as energetic, visible, and certainly effective—not just internationally, but domestically as well. Hackbarth states that PEPFAR promotes U.S. interests as an example of soft power (2009:1). Soft power is defined by Nye as "the ability to get what you want through attraction rather than coercion or payments. It arises from the attractiveness of a country's culture, political ideals, and policies. When our policies are seen as legitimate in the eyes of others, our soft power is enhanced" (Nye 2004:x). Unlike hard power, which Nye associates with command and coercion (Nye 2004:8), soft power generates goodwill. Hackbarth draws on Nye and explains how soft power benefits a state:

Nye points out that the U.S. gains greatly when it promotes public goods like preventing HIV/AIDS, saying they gain "from the goods themselves, and from the way that being a major provider legitimizes and increases its soft power." Soft power and legitimacy are also increased because the United States has worked closely with international partners and African states. Most importantly, however, actions have spoken louder than words. As Nye finds, "that's why initiatives such as the Bush administration's push to increase development assistance or combat HIV/AIDS are so important" (Hackbarth 2009:8).

In short, development and humanitarian assistance—in the form of programs, such as PEPFAR—contribute to the U.S.'s soft power abroad and therefore promote U.S. interests. While PEPFAR does generate soft power for the U.S., it is also addressing a global health crisis. Because of the size of PEPFAR's funding and programming, the U.S. is not just taking "the lead on HIV/AIDS programs worldwide, it set the agenda for how to combat the disease" (Hackbarth 2009:8). In setting the agenda, the U.S. government has inserted itself in every discussion that any country's government, agency, or organization has about ARV treatment—whether or not U.S. funding is involved.

### **Policy Recommendations**

While the previous chapters have explored how individual treatment success is not PEPFAR's only aim, adherence remains the key indicator in determining the success of ARV treatment. Because treatment needs to remain a primary intervention for the second authorization of PEPFAR and millions of ARV patients were created in the first authorization, its success is an integral part of the PEPFAR program.

The first lesson is simply that treatment numbers are not indicators of success. Tanzania's policy of regionalization specifically addressed the issue of availability in the country. While regionalization accomplished a victory in making ARV treatment available throughout Tanzania—an achievement not reached in the first years of the program—the policy did not address the issue of adherence. Again, making ARV treatment a possibility for Tanzanians, regardless of where they live, is progress for a country where treatment was only a possibility for the few individuals who could afford the medications in the late 1990s. Yet, because regionalization was implemented by the Government of Tanzania and PEPFAR in the midst of a funding cycle, treatment partner personnel were trying to meet numerical targets set before regionalization to keep their funding while trying to build organizational programs and relationships in different regions of the country—in some areas where maintaining current patient numbers may not have been possible.

Ultimately, treatment requires individual adherence for success. The main consequences of not adhering to ARVs are individual treatment failure, the emergence of drug-resistant strains of HIV, and the higher cost of providing second-line treatment (Hardon et al. 2006:14). Because the consequences have the possibility to affect the global epidemic, I argue that PEPFAR's continued success in not only global health, but also foreign policy, will require more resources oriented toward ARV adherence.

The easiest way for PEPFAR to prioritize adherence is for it to build funding around adherence. Just as treatment partners discussed the link between placing a certain

number of people on treatment and funding, PEPFAR could link funding to adherence counts. Because there is no universally accepted standard of quantifying and measuring adherence (Hardon et al. 2006:265), PEPFAR, its treatment partners, and local clinics would need to develop programs, plans, and policies that might work in specific regions throughout the world. Adherence, while not as easy to count as the distribution of medications, would not only provide PEPFAR with an assessment of its own impact in the world, but might also provide insight into which ARV programs are the most effective within PEPFAR. Are clinics that specifically train staff to be compassionate and respectful retaining higher numbers of patients than clinics that do not offer such training? Are clinics that offer additional programs like transportation reimbursements, nutritional support, and group counseling sessions retaining patients at a higher level than clinics without such programs? Such counts would also give PEPFAR an idea of where treatment failures were more common and where second-line medications would most likely be needed. Instead of just projecting a new, larger target of the number of individuals to be placed on ARV treatment in the next authorization, PEPFAR planners could begin re-shaping the program during the current authorization to prioritize adherence. If reaching numerical targets primarily determined funding during the first authorization, treatment partner and clinic staff that tried adherence programs or tried new adherence programming ideas at clinics could be prioritized in funding provisioning during the third. Without privileging adherence, PEPFAR's work in global ARV treatment may impact the program's effect on foreign diplomacy. Increasing the number of virulent strains of HIV, the number of people in need of more expensive second-line treatment, or the number of treatment failures will not garner goodwill for the U.S.

## **PEPFAR** Continued

## **PEPFAR: The Final Tallies**

At the end of the first authorization 2,007,800 men, women, and children had received ARVs in PEPFAR's fifteen focus countries (PEPFAR 2009a:8).<sup>67</sup> This number exceeded PEPFAR's goal of placing two million individuals on ARV treatment in the focus countries (PEPFAR 2005:5). Tanzania's treatment numbers were 144,100, just short of the goal of 150,000 (PEPFAR 2009a:46). PEPFAR's fifth annual report to Congress boasts that Tanzania experienced a 25,527 percent increase in national ARV coverage between the first and last years of PEPFAR (PEPFAR 2009a:14). PEPFAR also stated that "PEPFAR treatment support is estimated to save 3.28 million adult years of life through September 2009" (PEPFAR 2009a:7).<sup>68</sup> The number was "based on the actual number of persons on ART<sup>69</sup> as of September 30, 2008, and projected numbers of people to be on treatment for FY2009" (PEPFAR 2009a:14). It remains unclear, though, how estimates of the number of adult years of life saved can be made without knowing how many individuals have remained on their treatment regimens. There is no doubt that

<sup>&</sup>lt;sup>67</sup> By December 2008, 10,072,100 men, women, and children received care, exceeding the goal of ten million (PEPFAR 2009a:8). Regarding prevention, PEPFAR's 2009 Annual Report notes, "PEPFAR-supported programs reached 58.3 million people with support for prevention of sexual transmission using the ABC approach (Abstain, Be faithful, correct and consistent use of Condoms). The U.S. Government (USG) has supplied more than 2.2 billion condoms worldwide from 2004 through December 20, 2008—as Dr. Peter Piot, former Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS) has said, more than all other developed countries combined. The American people have supported nearly 57 million counseling and testing encounters cumulatively through FY2008. Over the past five years, the fourteen countries that received PEPFAR support for safe blood programs have seen a decrease in the prevalence of HIV-infected units and are moving progressively closer to meeting their annual demand for safe blood" (PEPFAR 2009a:8).

<sup>&</sup>lt;sup>68</sup> PEPFAR cites the process used to determine the number of years: "Estimates were obtained using final country Spectrum files from UNAIDS and Spectrum version 3.2, incorporating modeling changes recommended by the UNAIDS/WHO Reference Group on Estimates, Modeling, and Projections in 2006, and by new data identified in the 2007 UNAIDS regional workshops on HIV estimates. Total person-years-of life added are based on the actual number of persons on ART as of September 30, 2008, and projected numbers of people to be on treatment for FY2009" (PEPFAR 2009a: 14).

<sup>&</sup>lt;sup>69</sup> ART is short for Antiretroviral Treatment.

PEPFAR has made life-saving medications increasingly available in a country where there is a great need, years have been added to lives, and lives have been prolonged. It is unclear if the number of people placed on treatment is the same as the number of successful treatments.

### <u>PEPFAR II</u>

Just as discussions were underway in Washington, D.C., and Dar es Salaam, Tanzania, about the final numbers of PEPFAR, discussions on the next authorization, PEPFAR II, were also taking place. What would the next round of goals be? Would PEPFAR be able to maintain providing treatment throughout the world?

In May 2007, President Bush announced reauthorizing PEPFAR and proposed increasing funding to \$30 billion over five years. At first glance, it appears that President Bush doubled funding for his program. A U.S. government official I interviewed in Tanzania speculated on the costs of a new program: "...There will be no focus countries in PEPFAR II, but just to maintain PEPFAR [the first authorization's programs] for another five years will cost \$27 billion so it'll really only be \$3 billion in new money, so most will remain in focus countries."

Between the first proposal put forth by President Bush and when PEPFAR II, H.R. 5501, the Tom Lantos and Henry J. Hyde United States Global Leadership Against HIV/AIDS, Tuberculosis, and Malaria Reauthorization Act of 2008 was signed into law in July 2008, some changes had been made. One of the most notable changes was the increase of funding to \$48 billion (PEPFAR 2010). For PEPFAR II, the next five-year authorization aims to transition the program from an emergency-based program to focusing on building sustainable country programs. The first PEPFAR had three main interventions: prevention, care, and treatment. The second authorization's targets are: 1) Prevention; 2) Care, Support, and Treatment; and 3) Sustainability. In the first authorization, PEPFAR was to prevent seven million infections; in the second authorization, it is to prevent twelve million new infections (PEPFAR 2010). For the first PEPFAR, ten million people were to receive care, including orphans and vulnerable children; in PEPFAR II, twelve million are to receive care, five million of them orphans and vulnerable children (PEPFAR 2010). Where the first PEPFAR called for two million people to receive ARVs, the second authorization calls for two million more people to be placed on ARV treatment, thereby doubling the number of people PEPFAR placed on treatment during the first authorization (PEPFAR 2010). Finally, PEPFAR will put money toward training and retaining health care workers, effort toward defining roles and needs in every country with more than \$5 million of PEPFAR funding, and helping countries to address larger issues of "genderbased violence, stigma, [and]... low male partner involvement" (PEPFAR 2010).

Regarding adherence, PEPFAR supports treatment adherence, but it is not a targeted goal of PEPFAR II: "Once PEPFAR initiates treatment, programs work to maximize drug adherence and retention in care. Effective measures for doing so include use of pharmacy records and targeted monitoring, with a focus on gaining the greatest utility from first-line medications" (PEPFAR n.d.). While adherence is recognized and promoted by PEPFAR, its importance does not reach the level of having its own numerical targets.

### Insights and Acknowledgements

My dissertation is informed by literature in the field of medical anthropology as well as the anthropologies of development and policy. Central to these literatures is the study of how power structures are created, maintained, and changed. Critical medical anthropology, in particular, urges inspection of how the political and the social affect health services and access to care (Farmer 1999; Farmer 1992; Lock and Scheper-Hughes 1996; Morsy 1996; Scheper-Hughes 1992; Scheper-Hughes and Lock 1987). Global health diplomacy (Fidler 2005; Novotny et al. 2009:41) maintains that examination, but also calls for studying of how health services can shape the political and the social. Global health diplomacy, I argue, can be incorporated into Fassin's "political anthropology of health," which calls for critical examination of the politics of medicine, public health, and the individuals affected (Fassin 1996 in Fainzang 2007:97). In this dissertation, I aimed to connect the individuals who make and implement policy directly with the individuals who receive medications. In medical anthropology, the examination of politics in medicine will require the study of health systems and the linking of many groups of people as health services like ARVs are increasingly influenced by and influence global policies and politics. For the United States, HIV/AIDS is not simply a disease, but a national security threat. The health services to treat AIDS address individuals, but also the political interests of the U.S. There is no doubt that PEPFAR is influenced by the politics of the U.S., but PEPFAR is also influencing how the U.S. views and uses its foreign diplomacy tools. Just as Turshen noted, "Health is political" (1999:114).

Ferguson (1994) and Li's (2007) work on the anthropology of development focuses on the power in defining a problem. Ferguson's (1994) work in Lesotho discusses the repercussions of depoliticizing issues by reducing them to technical problems, a process Li (2007) defines as "rendering technical." Their work illustrates that the complexity of a project can be masked by technical goals. As I argue, PEPFAR's focus on numerical targets masks the complexity of adherence, which is critical for ARV success, not just for PEPFAR, but for all of the individuals receiving medications.

My work also significantly draws from and contributes to the anthropology of policy. Shore and Wright's (1997) call for an anthropology of policy asks that scholars not just look at the instrumentalist, top-down effects of policy, but also to explore the social effects—how subjectivities are created by policy. Mosse states that social life of projects—the diversity of actors and their varied interests—begins to address the complexity of policy as practice (Mosse 2005:6). The anthropology of policy asks not just about the effects of policy on people, but the effects of people on policy. What my research addresses is PEPFAR as policy written and applied by the U.S. government and, just as importantly, PEPFAR as a program implemented by government officials, U.S. contractors, local clinic staff, and women patients who all have their own opinions and motivations for participation in ARV programming.

## **Continued Work**

My dissertation provided an overview of PEPFAR's ARV programming in Tanzania, as well as more questions for future research. Now that PEPFAR II has begun under a new administration, what changes will the U.S. government make for PEPFAR's ARV programming? Will adherence counts be included on Country Operational Plan

Applications for Funding? As the availability of ARVs increase throughout Tanzania, researchers will need to start tracking not just adherence, but the presence of drug-resistant viruses. The cost of fighting drug-resistant viruses will affect the cost of ARV treatment to PEPFAR. Because PEPFAR II has an intervention termed "Sustainability," the U.S. government is implying a transition from an emergency-focused program to a longer term endeavor with increased local country support. How will that future work in ARV treatment be shaped?

My work suggests that more research is needed to examine how treatment partners conduct research outside of their PEPFAR funding. If, as noted in Chapter 3, treatment personnel are able to guess at what their drop-out rates are, how are they tracking that information? What are their suggestions for "best practices?" What are their suggestions since regionalization has started? How are they using PEPFAR funding to implement those ideas? Since regionalization was implemented in 2006, the confusion and concern over regionalization experienced by treatment partner personnel in 2007 might be remembered differently. My research did not examine how clinics that lost a treatment partner only to gain a new one felt about the change—a more complete view of regionalization would examine not just how regionalization affected the treatment partners, but also the clinics who changed treatment partners.

Both clinics I worked with were changing their statuses. PASADA had just taken on a new role as a "PEPFAR-graduated clinic" and Hindu Mandal was slated to become a PEPFAR-funded clinic in the next two to three years. Continued research will show how the staff at each clinic adapted to the clinic's new role and responsibilities. Will PASADA's staff try harder to reach their PEPFAR assigned targets? Will Hindu Mandal

become a PEPFAR-funded clinic and be assigned targets of its own? How will the staff adapt to those changes?

My dissertation research focused on the women patients who attended PASADA and Hindu Mandal. Will the women I interviewed remain on their treatment? To what factors will they attribute that success after they have been on their treatment for a longer period of time? If they do not remain on treatment, to what factors will they attribute the fact that they stopped going to the clinic? My work did not examine the patients lost to follow up from these clinics, but more research may reveal the reasons why patients drop out of ARV treatment in Dar es Salaam, Tanzania. More research on what keeps women on treatment or what compels them to stop will enhance the abilities of government officials, treatment partner personnel, and clinic staff to design programs that increase the likelihood women will remain on ARV treatment.

## **Concluding Thoughts**

Policy is not just executed from the top down, but also through the social life it takes on through the multiple actors involved in its implementation (Mosse 2005:6). In the preceding chapters, I have argued that although government officials, treatment partners, and local clinics all have varying interests and priorities in regard to PEPFAR policy, they do work to maintain the official policy of successfully producing treatment numbers. PEPFAR's targets exert a top-down pressure from U.S. government officials to treatment partner personnel to local clinic staff. As designed by PEPFAR planners, the numbers are indicative of the program's success. Treatment partners and local clinics are able to ensure their own funding, and their continued work in the program, by meeting their PEPFAR goals. While the primary stress put on treatment partners and clinics by

PEPFAR is the target numbers, both groups found ways to place their marks on ARV programming. Treatment partners realized that staying with a demanding donor like PEPFAR allowed them to apply for money that let them to try out new, different programs. The goals of these programs were to find that "best practice" approaches to treatment. Staying with PEPFAR also allowed for individual career advancement. Personnel from all treatment partners discussed how working with PEPFAR gave them an opportunity to help patients—patients they did not interact with—who needed lifesaving medicines.

Clinic staff at both PASADA and Hindu Mandal prioritized staff time with patients. At PASADA, the executive director, Ms. Pell, felt that time with patients should be prioritized rather than meeting targets. Hindu Mandal's nurse counselors tried to establish relationships with patients to encourage their return to the clinic, and therefore their adherence to ARVs. As PEPFAR now directly funds PASADA and Dar es Salaam's treatment partner is planning on funding Hindu Mandal, the clinic staffs may find increased target pressure in the coming years.

Women patients, specifically, are not just concerned with the availability of ARVs, but also the care that accompanies treatment. Since patients are the critical factor in a treatment program, what brings them to clinics and keeps them there will determine the impact of a treatment program on the global health issue of HIV/AIDS.

While the foreign policy benefits may not be as tangible as PEPFAR's numerical goals, they are still ever-present within the program, just more difficult to monitor and measure. There is no doubt that PEPFAR has made life-saving medications increasingly available in a country where there is a great need, years have been added to lives, and
lives have been saved. There is doubt as to whether or not the number of people placed on treatment is the same as the number of successful treatments. Until there is a focus on treatment adherence, it appears that the foreign policy objectives outweigh the global health goals within PEPFAR.

By examining policy and its social life, I have explored how PEPFAR ARV programming is planned, implemented, and practiced, and how it affects the patients it aims to reach in Tanzania. As PEPFAR increases its targets for its second authorization, and therefore the number of individuals placed on ARV treatment, how ARV programming is administered and implemented will remain salient issues until a cure for HIV/AIDS is found.

### Appendix A: Care and Treatment Patient Card-CTC-1

# Annex 3

# **HIV Care/ART Monitoring and Evaluation Tools**



### JAMHURI YA MUUNGANO WA TANZANIA WIZARA YA AFYA NA USTAWI WA JAMII

### **CTC 1: KADI YA UTAMBULISHO**

### (ONYESHA KADI HII KATIKA KILA HUDHURIO)

Namba ya faili ya kituo	JINA LA KITUO	Simu ya kituo
Namba ya faili ya kituo	JINA LA KITUO	Simu ya kituo
Namba ya faili ya kituo	JINA LA KITUO	Simu ya kituo
Namba ya faili ya kituo	JINA LA KITUO	Simu ya kituo

Namba ya utambulisho:		Wilaya Tarafa
Jina kamili		Mtaa/Kiiiii
	, ,	Mwenyekiti wa Mtaa /Kijiji/Kitongoji
larene ya kuzaliwa	//	Mjumbe / Balozi
	siku mwezi mwaka	Mkuu wa kaya
Jinsia 🗌 Me 🗌 Ke		Jina la msaidizi wa karibu
Matibabu ya ARV tangu	1 1	Simu
	siku mwezi mwaka	Anuani ya Msaidizi wa karibu
Simu ya mgonjwa		Idadi ya kadi alizokwishapata 1 1 2 3 4 5

**Figure VI: Care and Treatment Patient Card—CTC-1, Page 1** (United Republic of Tanzania 2007:74–75)

### MAHUDHURIO

Tarehe	Dawa zilizotolewa	Jumla ya siku	CD4 count (% <6 yr)	Namba ya kituo	Jina la mtoa dawa	Tarehe ya kurudi
/						<u> </u>
						<u> </u>
						<u> </u>
//						
						<u> </u>
						I
						I
11						11

### Taarifa muhimu ya mteja (ijazwe na mganga)

/	

Figure VII: Care and Treatment Patient Card—CTC-1, Page 2 (United Republic of Tanzania 2007:74–75)

		MIN	THE UNITED I	ALTH AN	D SOC	TANZ	ANIA VELF#	RE		
			NATIONAL HIN	CARE	AND T	REATI	MENT			
	FACILITY N	AME		FACILIT	Y CODE			ISTRICT		
	UNIQUE CT	C ID NUMBE	R	HEALTH FAC	ILITY FILE	NUMBER				
NAME			(firs	st middle	ast) SE)	M	DA	<b>FE OF BIRT</b>	H	(dd/mm/yy)
AGE	YRS/M	ONTHS (circle yea	e months if age is less that r and fill in age in months)	an 1 MARI	FAL STATU	S				(see codes)
DATE OF FIR	ST HIV+ TEST		dd/mm/yy) PATIENT 1	ELEPHONE N	UMBER					
PATIENT RE OPD STI	PMTCT	(tick app INPATIE TB / DC HBC	International In	ADDRESS DIVISION/WAF ILLAGE	RD	Ź				
	REFERRAL (I R (SPECIFY)	INCLUDES V	CT) TEN CELL HEAD OF I	HOUSEHOLD						
VISIT DATE check box for first visit : trans- fer in, write TI in margin	WEIGHT (and HEIGHT/ LENGTH if <15 YRS)	WHO CLINICAL STAGE insert number	AIDS DEFINING ILLINESS, NEW SYMPTOMS, SIDE EFFECTS, HOSPITALIZED see abbreviations or write in	PREGNANT Y/N, if Y, write in EDD	FUNC- TIONAL STATUS W, A or B	TB STATUS see codes	COTRIM Y/N	DIFLUCAN Y/N	ARV STATUS see codes	ARV REASON see codes
1 1										
If meds are pic	cked up by a tr	eatment suppo	orter or other person, write t	he name of this	person in th	he same row	v following	the encount	er date	

Appendix B: Care and Treatment Patient Record Care-CTC-2

# Figure VIII: Care and Treatment Patient Record Card—CTC-2, Page 1 (United Republic of Tanzania 2007:76–77)

		//_/_/_/_/_//ERSION 0706)	2					IT I	rwise CD4 co	n <6 CD4%, othe	* for childre
		11									
OF CLINICIAN	FOLLOW UP STATUS see codes	NEXT VISIT DATE	REFERRED TO see codes, enter all that apply	NUTRITION SUPPORT NEEDED Y/N	ABNORMAL LAB RESULTS / OTHER	ALT	нв	CD4 COUNT/%	RELEVANT CO-MEDS	ARV ADHERE STATUS (if poor, reasons) see codes	ARV COMBIN. REGIMEN see codes/ No. of days dispensed
04	GHTCD	ION WEIG	FUNCT	IICAL STAGE	TART ART : CLIN	JS AT S	STATL		len	EK IN (WILLIEW)	
ert) sert)	appropriate) .Y (inse	ELIGIBLE (lick CLINICAL ONL CD4 COUNT/% TLC	<u>2</u>	(dd/mm/) (dd/mm/y (dd/mm/) (dd/mm/)	RMED HIV+ LED IN CARE LIGIBLE LE & READY ART	CONFIF ENROLI MED. EL ELIGIBI	DATE DATE DATE DATE DATE	cords)	ppropriate) pr in without re HERAPY	(POSURE (lick a) HERAPY (transfe MONOTHERAPY COMBINATION T	PRIOR ARV E NONE PRIOR PRIOR PMTCT
								NUMBER	ELEPHONE	SUPPORTER T	COMMUNITY
									DDRESS	SUPPORTER A	TREATMENT
								Ž	NFORMATIO RTER	SUPPORTER II	TREATMENT
										RGIES	DRUG ALLE
			DRM		IENT REC	PAT	2	СТО			

Figure IX: Care and Treatment Patient Record Card—CTC-2, Page 2 (United Republic of Tanzania 2007:76–77)

	noi	xy ssə	1 1601	Ы			an	sol	osib	o 'u	oitu	9V6	bud	osi	seq	uo	uoi	iteo	npΞ	1			
CTX, INH prophylaxis	care and treatment team	Follow-up appointments,	Available treatment/prophylaxis	Progression of disease	Child's blood test	prevention MTCT	Reproductive choices,	Shared confidentiality	Family/living situation	To whom disclosed (list)	Disclosure	Testing partners	Positive living	of results	Post-test counselling: implications	precautions, what is safe	Prevention: household	sex, condoms	Prevention: abstinence, safer	Basic HIV education, transmission	and the standard standa	Topic	Follow-up educa
																					comments	Date /	ition, Support a
																				1	comments	Date /	and Preparation
																					comments	Date /	on for ARV Th
																	•				comments	Date /	herapy
																					comments	Date /	

Figure X: Care and Treatment Patient Record Card—CTC-2, Page 3, Section 1 (United Republic of Tanzania 2007:76–77)

	,916,	ort sd c	oddr	าร q-อเ	noH					itor	uou	nt, n	odd	ns 'i	noite	sitin	i 'uc	ratic	edə	h pr	/ЯA			
Community support	Support groups	Home-based care - specify	Caregiver Booklet	care at home	Symptom management/palliative	How to contact clinic	ARV support group	Which doses, why missed	Treatment-supporter preparation	diary)	Adherence plan (schedule, aids, explain	What to do when travelling	What to do if one forgets dose	how to manage side effects	What can occur,	Explain dose, when to take	Care and treatment-team discussion	DATE/result	Indicate when READY for ART:	indicate visits	Adherence preparation,	Why complete adherence needed	(locally adapted)	ART - educate on essentials
													and the second second					1						

Figure XI: Care and Treatment Patient Record Card—CTC-2, Page 3, Section 2 (United Republic of Tanzania 2007:76–77)



#### Figure XII: Care and Treatment Patient Record Card– CTC-2, Page 4, Section 1 (United Republic of Tanzania 2007:76–77)

THRUSH – oral/vaginal UD Urethral Discharge ULCERS – mouth or other Weight loss Zoster If other, specify	GUD Genital Ulcer Disease Headache IRIS Immune Reconstitution Inflammatory Syndrome Jaundice KS Kaposi's Sarcoma Molluscum Nausea OC Osephageal Candidiasis PE Parotid Enlargement PID Pelvic Inflammatory Disease Pneumonia PCP PneumoCystis Pneumonia PPE Papular Pruritic Eruptions	FEVER
REFERRED TO 1=PMTCT 2=HBC 3= PLHA SUPPORT GROUP/CLUB 4=ORPHAN AND VULNERABLE CHILDREN GROUP 5=MEDICAL SPECIALITY 6=NUTRITIONAL SUPPORT 7=LEGAL 8=OTHER (SPECIFY)	G (good)= fewer than 2 missed days P (poor)= 2 or more missed days 1= TOXICITY 2= SHARE WITH OTHERS 3= FORGOT 4= FELT BETTER 5= TOO ILL 6= STIGMA 7= PHARMACY DRUG STOCK OUT 8= PATIENT LOST / RAN OUT OF PILLS 9= DELIVERY / TRAVEL PROBLEMS 10= INABILITY TO PAY 11= ALCOHOL 12= DEPRESSION 13= OTHER (SPECIFY)	ARV ADHERENCE
142=PATIENT DECISION 143=PREGNANCY 143=PREGNANCY 144=END OF PMTCT 148=STOCK OUT 149=OTHER REASON (SPECIFY) 151=RESTART ARV AFTER 3 OR MORE MONTHS NOT ON ARV	113=HEADACHE 114=FEVER 115=RASH 116=PERIPHERAL NEUROPATHY 117=HEPATITIS 118=JALINDICE 119=DEMENTIA 120=ANAEMIA 121=PANCREATITIS 122=CNS ADVERSE EVENT 123=OTHER ADVERSE EVENT 123=OTHER ADVERSE EVENT (SPECIFY) 123=OTHER ADVERSE EVENT (SPECIFY) 123=OTHER ADVERSE EVENT (SPECIFY) 131=TREATMENT FAILURE, CLINICAL 132=TREATMENT FAILURE, IMMUNOLOGICAL CHANGE OR STOP ARVS, OTHER REASON	112=DIARRHEA

.

.

**Figure XIII: Care and Treatment Patient Record Card— CTC-2, Page 4, Section 2** (United Republic of Tanzania 2007:76–77)

10	9	8	7	6	5	4	З	2	1		FAMI	FOLLO MISSA LTF=L OR 3 c STOP TO = T DEAD REST/
										NAME	LY INFORMATION	<b>DW UP STATUS</b> NPP = 1 OR 2 MISSING APPOINTMEN OST TO FOLLOW-UP (Not seen for 3 or primore missing appointments [pre-AR] pre-AR] PATIENT/PROVIDER DECISION TO = PATIENT/PROVIDER DECISION TO FRANSFER OUT; if TO, to where? = DIED = DIED ART = Patient restarts ARVs after interr
										RELATION		TS or more months sin patients] with 2 at STOP ART, ADD F STOP ART, ADD F
							r			AGE		ce last sch lempts to f tEASON C
		-								HIV STATUS + / - / unknown		eduled appointment [A ollow-up) ODE
								-		HIV CARE Y / N		.RT patients],
										UNIQUE CTC ID No.		
										HEALTH FACILITY FILE No.		



### REFERENCES

- Adams, V., T. E. Novotny, and H. Leslie. 2008. Global health diplomacy. *Medical Anthropology* 27(4):315–23.
- AfricaFocus. 2005. Africa: Year of action for AIDS treatment? *AfricaFocus Bulletin* (January 9), http://www.africafocus.org.
- Allers, C., M. Noguera, B. Chovitz, A. Diallo, C. Shaw, T. Pandit, S. Mlandula, P. Senge, G. Massuki, and M. Burke. 2003. Tanzania: Logistics system capacity and site readiness to expand PMTCT and initiate ART—Findings and recommendations of the PMTCT and ART assessment team. Arlington, VA: John Snow Inc./DELIVER, for USAID.
- Altman, L. K. 2006. Talking about AIDS, with all the world watching. *New York Times*, August 8, Health section.
- André, L. 2009. Remarks made at the PEPFAR Annual Meeting with Track One Partners, held in Dar es Salaam, Tanzania, on August 4, 2009. http://tanzania. usembassy.gov/sp\_08042009.html.
- Baer, H. A., M. Singer, and I. Susser. 2003. Part I: What is medical anthropology about? In *Medical anthropology and the world system*, Second Edition, 1–54. Westport, CT: Praeger Publishers.
- Baylies, C. 2000. Perspectives on gender and AIDS in Africa. In AIDS, sexuality, and gender in Africa: Collective strategies and struggles in Tanzania and Zambia, eds. C. Baylies and J. Bujra, with the Gender and AIDS Group, 1–24. London and New York: Routledge.
- Beck, A. 1981. Medicine, tradition, and development in Kenya and Tanzania, 1920– 1970. Waltham, MA: Crossroads Press.

\_\_\_\_. 1977. Medicine and society in Tanganyika, 1890–1930: A historical inquiry. Transactions of the American Philosophical Society 67, Part 3. Philadelphia, PA: The American Philosophical Society.

\_\_\_\_. 1970. A history of the British Medical Administration of East Africa, 1900–1950. Cambridge, MA: Harvard University Press.

- Berg-Schlosser, D. and R. Siegler. 1990. Political stability and development—A comparative analysis of Kenya, Tanzania, and Uganda. Boulder, CO: Lynne Rienner.
- Bernard, H. R. 2002. Research methods in anthropology: Qualitative and quantitative approaches, Third Edition. Walnut Creek, CA: AltaMira Press.

- Board on International Health, Institute of Medicine. 1997. America's vital interest in global health: Protecting our people, enhancing our economy, and advancing our international interests. Washington, DC: The National Academies Press.
- Boesen, J. 1977. Ujamaa, Socialism from Above. Uppsala: Scandinavian Institute of African Studies.
- Booth, K. M. 2004. Local women, global science: Fighting AIDS in Kenya. Bloomington, IN: Indiana University Press.
- Braitstein, P., M. W.G. Brinkhof, F. Dabis. M. Schechter, A. Boulle, P. Miotti, R. Wood,
  C. Laurent, E. Sprimz, C. Seylet, D. R. Bangberg, E. Balestre, J. A.C. Sterne, M.
  May, and M. Egger. 2006. Mortality of HIV-1 infected patients in the first year of
  antiretroviral therapy: comparison between low-income and high-income countries. *Lancet* 367(9513): 817-824.
- Bristol, N. 2008. U.S. Senate passes new PEPFAR bill. The Lancet 372(9635):277-78).

Bush, G. W. 2003. State of the Union. http://georgewbush-whitehouse.archives.gov/ news/releases/2003/01/20030128-19.html.

\_\_\_\_\_. 2002. National Security Strategy. http://www.nytimes.com/2002/09/20/politics /20STEXT\_FULL.html (14 September 2009).

- Campbell, Horace. 1992. External Factors on Domestic Politics in Tanzania. In *Politics* and Administration in East Africa, ed. Walter O. Oyugi, 469-501. Nairobi: Konrad Adenauer Foundation.
- Campbell, H. and H. Stein, eds. 1991. *The IMF and Tanzania*. Harare: Southern Africa Political Economic Series.
- Carmody, P. 2005. Transforming globalization and security: Africa and America post-9/11. Africa Today 52(1):97-120.
- Castro, A. and P. Farmer. 2005. Understanding and Addressing AIDS-Related Stigma: From Anthropological Theory to Clinical Practice in Haiti. *American Journal of Public Health* 53-59.
- Central Intelligence Agency. 2009. *The world factbook—Field listing: Exchange rates*. https://www.cia.gov/library/publications/the-world-factbook/fields/2076.html. \_\_\_\_\_\_. 1997. *The world factbook—1997*. http://www.umsl.edu/services/govdocs/ wofact97/country-frame.html.
- Clyde, D. F. 1962. *History of medical services of Tanganyika*. Dar es Salaam, Tanganyika: Government Press.

- Cooper, F. 1997. Modernizing bureaucrats, backward Africans, and the development concept. In *International development and the social sciences*, eds. F. Cooper and R. Packard, 64–92. Berkeley: University of California Press.
- Council on Foreign Relations. 2006. More than humanitarianism: A strategic U.S. approach toward Africa. New York: Council on Foreign Relations.
- Coutinho, L., S. Bisht, and G. Raje. 2000. Numerical narratives and documentary practices: Vaccines, targets and reports of immunisation programme. *Economic and Political Weekly* 35(8 and 9):656–66.
- D'Adesky, A. 2004. *Moving mountains: The race to treat global AIDS*. London and New York: Verso.
- Das, V. 1999. Public good, ethics, and everyday life: Beyond the boundaries of bioethics. *Daedalus* 128(4):99–133.
- DeCock, K. M., D. Mbori-Ngacha, and E. Marum. 2002. Shadow on the continent: Public health and HIV/AIDS in Africa in the 21<sup>st</sup> century. *The Lancet* 360(9326):67–72.
- Deng, L. and T. Oshikoya. 1991. Structural adjustment programs in Africa in the 1980s: An overview of the performance of restructuring economies. In *Democratization and structural adjustment in Africa in the 1990s*, eds. L. Deng, M. Kostner, and C. Young, 21-30. Madison, WI: African Studies Program, University of Wisconsin-Madison.
- Eibl, M. 2005. HIV/AIDS and antiretrovirals: Accessing treatment in Tanzania. AIDS and Anthropology Bulletin 17(2):9–10.
- Epstein, H. 2007. The invisible cure: Africa, the West, and the fight against AIDS. New York: Farrar, Straus, Giroux.
- Escobar, A. 1995. Encountering development: The making and unmaking of the Third World. Princeton, NJ: Princeton University Press.
- Fainzang, S. 2007. Medical anthropology in France: A healthy discipline. In Medical anthropology: Regional perspectives and shared concerns, eds. F. Saillant and S. Genest, 89–102. Malden, MA: Blackwell Publishing.
- Family Health International. nd. Tumaini: A message of hope. Linking Communities with Health Facilities to Care for People Living with HIV/AIDS. Durham, NC: Family Health International.
- Farmer, P. 1999. Infections and inequalities: The modern plagues. Berkeley, CA: University of California Press.

\_\_\_\_. 1992. AIDS and accusation: Haiti and the geography of blame. Berkeley, CA: University of California Press.

- Farmer, P., F. Leandre, J. Mukherjee, M. Sidonise Claude, P. Nevil, M. Smith-Fawzi, S. Koenig, A. Castro, M. Becerra, J. Sachs, M. Attaran, and J. Yong Kim. 2001. Community-based approaches to HIV treatment in resource-poor settings. *The Lancet* 358 (9279): 404–9.
- Ferguson, J. 1994. The anti-politics machine: "Development," depoliticization, and bureaucratic power in Lesotho. Minneapolis, MN: University of Minnesota Press.
- Fidler, D. P. 2005. *Health and foreign policy: A conceptual overview*. London: The Nuffield Trust.
- Foley, E. E. 2001. No money, no care: Women and health sector reform in Senegal. Urban Anthropology and Studies of Cultural Systems and World Economic Development 30(1):1-50.
- Foucault, M. 1990. *History of sexuality, volume 1: An introduction*. New York: Vintage Books.
- Gallant, J. and C. Hoffman. 2009. Johns Hopkins Poc-IT Center HIV Guide: CD4 cell count. http://www.hopkins-aids.edu/management/laboratory\_testing/cd4\_cell\_count. html?contentInstanceId=8279.
- Galvão, J. 2002. Access to antiretroviral drugs in Brazil. The Lancet 360(9348):1862-5.
- Garrett, Laurie. 2004. Bragging in Bangkok. New York Times, July 16, Opinion section.
- Gershman, J. and A. Irwin. 2000. Getting a grip on the global economy. In *Dying for* growth: Global inequality and the health of the poor, eds. J. Y. Kim, J. V. Millen, A. Irwin, and J. Gersham, 11–43. Monroe, ME: Common Courage Press.
- Global Fund to Fight AIDS, Tuberculosis and Malaria. 2003. Executive Summary of Proposal. http://portfolio.theglobalfund.org/Grant/Index/TNZ-304-G03-C?lang=en.
- Good, B. J. 1994. *Medicine, rationality, and experience: An anthropological perspective.* Cambridge, MA: Cambridge University Press.
- Gottlieb, M. 1972. The case for large hospitals. The Standard, April 7.
- Gruskin, S., L. Ferguson, and D. O. Bogecho. 2007. Beyond the numbers: Using rightsbased perspectives to enhance antiretroviral treatment scale-up. *AIDS* 21 (Supplement 5):S13–S19.
- Hackbarth, Major J. R. 2009. Soft power and smart power in Africa. *Strategic Insights* 8(1):1–19. http://www.nps.edu/Academics/centers/ccc/publications/OnlineJournal/2008/Dec/hackbarthDec08.pdf.

- Hardon, A., Sheila D., T. Gerrits, C. Hodgkin, H. Irunde, J. Kgatlwane, J. Kinsman, A. Nakiyemba, and R. Laing. 2006. From access to adherence: the challenges of antiretroviral treatment: Studies from Botswana, Tanzania, and Uganda. Geneva, Switzerland: World Health Organization Press.
- Hill, P. S. 2002. The rhetoric of sector-wide approaches for health development. *Social Science and Medicine* 54:1725–37.
- Hindress, B. 2002. Neo-liberal citizenship. Citizenship Studies 6(2):127-43.
- Hoffman, Lisa, Monica DeHart, and Stephen J. Collier. 2006. Notes on the Anthropology of Neoliberalism Anthropology News 47(6):9-10.
- Hutton, G. and M. Tanner. 2004. The sector-wide approach: a blessing for public health? Bulletin of the World Health Organization 82(12):893–4.
- Hyden, Goran. 1980. Beyond Ujamaa in Tanzania: Underdevelopment and an Uncaptured Peasantry. Berkeley: University of California Press.
- Iliffe, J. 2006. The African AIDS epidemic: A history. Oxford: James Currey Ltd. . 1998. East African doctors: A history of the modern profession. Cambridge, MA: Cambridge University Press.

\_\_\_\_\_. 1979. A modern history of Tanganyika. Cambridge, MA: Cambridge University Press.

- Janes, C. R. 2004. Going global in century XXI: Medical anthropology and the new primary health care. *Human Organization* 63(4):457–71.
- Janes, C. R. and K. K. Corbett. 2009. Anthropology and global health. *Annual Review of Anthropology* 38:167–83.
- Kagashe, B. 2010. Tanzania: Dar es Salaam to get ten more MPs. *The Citizen*. http://allafrica.com/stories/201001260495.html (21 February 2010).
- Kjekshus, H. 1996. Ecology control and economic development in East African history. Athens, OH: Ohio University Press.
- Koponen, J. 1988. People and production in late precolonial Tanzania: History and structures. Uppsala, Sweden: Scandinavian Institute of African Studies.
- Lane, Sandra D. and Robert A. Rubinstein. 1996. International Health: Problems and Programs in Anthropological Perspective. In *Medical Anthropology: Contemporary Theory and Method*, eds. T.M. Johnson and C.F. Sargent, 396-423. New York: Praeger.

- Levine, R. 2008. Health foreign policy: Bringing coherence to the global health agenda. In *The White House and the world: A global development agenda for the next U.S. president*, ed. N. Birdsall, 43–62. Washington, DC: Center for Global Development.
- Lewis, S. 2005. Global issues in women's health. Presentation at the University of Pennsylvania Summit, April 26, Philadelphia, PA.
- Li, T. M. 2007. The will to improve: Governmentality, development, and the practice of politics. Durham, NC: Duke University Press.
- Lock, M. and N. Scheper-Hughes. 1996. A critical-interpretive approach in medical anthropology: Rituals and routines of discipline and dissent. In *Medical* anthropology: contemporary theory and method, eds. C. F. Sargent and T. M. Johnson, 41-70. New York: Praeger Publishers.
- Long, N. 2001. Development sociology: Actor perspectives. London and New York: Routledge.
- Long, N. and A. Long. 1992. Introduction. In *Battlefields of knowledge: The interlocking* of theory and practice in social research and development, eds. Norman Long and Anne Long, 3-15. London and New York: Routledge.
- Lugar R. 2008. Lugar Senate floor speech highlights humanitarian duty to reauthorize PEPFAR. http://lugar.senate.gov/press/record.cfm?id=300627.
- MacFarquhar, L. 2008. Outside agitator. The New Yorker, December 8.
- Mamdani, M. 1996. Citizen and subject: Contemporary Africa and the legacy of late colonialism. Princeton, NJ: Princeton University Press.
- Masquelier, A. 2001. Behind the dispensary's prosperous façade: Imagining the state in rural Niger. *Public Culture* 13(2): 267–91.
- Mboup, S., R. Musonda, F. Mhalu, and M. Essex. 2006. HIV/AIDS. In Disease and mortality in Sub-Saharan Africa, eds. D. T. Jamison, R. G. Feachem, M. W. Makogba, E. R. Bos, F. K. Baingana, K. J. Hofman, and K. O. Rogo, 237–46. Washington, DC: The International Bank for Reconstruction and Development/World Bank.
- Morsy, S. A. 1996. Political economy in medical anthropology. In *Medical anthropology: Contemporary theory and method*, eds. C. F. Sargent and T. M. Johnson, 21–40. New York: Praeger Publishers.
- Mosse, D. 2005. *Cultivating development: An ethnography of aid policy and practice*. London and Ann Arbor, MI: Pluto Press.

- Nattrass, N. 2004. *The moral economy of AIDS in South Africa*. Cambridge, MA: Cambridge University Press.
- Navario, P. 2009. PEPFAR's biggest success is also its largest liability. *The Lancet* (374):184-85.
- Nguyen, V. K.. 2009. Government-by-exception: Enrolment and experimentality in mass HIV treatment programmes in Africa. *Social Theory and Health* 7(3):196–217.

2007. Experimentality: Massive AIDS intervention in Africa as militarytherapeutic complex. Paper presented for Experimental Systems, States, and Speculations: Anthropology at the Intersection of Life, Science, and Capitalism, April 13–14.

. 2005. Antiretroviral globalism, biopolitics, and therapeutic citizenship." In Global assemblages, technology, politics, and ethics as anthropological problems, eds. A. Ong and S. Collier, 124–44. Oxford: Blackwell.

- Nguyen, V. K, C. Y. Ako, P. Niamba, A. Sylla, and I. Tiendrébéogo. 2007. Adherence as therapeutic citizenship: Impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS* 21(Supplement 5):S31–S35.
- Novotny, T. E., I. Kickbusch, with H. Leslie and V. Adams. 2009. Global health diplomacy—A bridge to innovative collaborative action. *Global Forum Update on Research for Health* 5:41–5.
- Nye, Jr., J. S. 2004. Soft power: The means to success in world politics. New York: PublicAffairs.
- Nyerere, J. 1967. The Arusha Declaration. http://www.milestonedocuments.com/ documents/full-text/arusha-declaration.
- Obrist, B. 2006. Struggling for health in the city: An anthropological inquiry of health, vulnerability and resilience in Dar es Salaam, Tanzania. Bern, Switzerland: Peter Lang.
- O'Manique, C. 2004. *Neoliberalism and AIDS crisis in Sub-Saharan Africa*. New York: Palgrave-Macmillan.
- Omari, C. K. 1974. Tanzania's emerging rural development policy. *Africa Today* 21(3):9–14.
- Packard, R. 1997. Visions of postwar health and development and their impact on public health interventions in the developing world. In *International development and the social sciences*, eds. F. Cooper and R. Packard, 93–188. Berkeley, CA: University of California Press.

- Pandolfi, M. 2003. Contract of mutual (in)difference: Governance and the humanitarian apparatus in contemporary Albania and Kosovo. *Indiana Journal of Global Legal Studies* 10(1):369–81.
- Panel on Antiretroviral Guidelines for Adults and Adolescents. 2009. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Washington, DC: U.S. Department of Health and Human Services.

\_\_\_\_. 2007. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Washington, DC: U.S. Department of Health and Human Services.

PASADA. 2006. Holistic HIV and AIDS service provision: Building on hope—PASADA best practices. Dar es Salaam, Tanzania: Old East Graphic (T) Services.
\_\_\_\_\_. n.d. Pastoral activities and services for people with AIDS. Dar es Salaam, Tanzania: Dar es Salaam Archdiocese.

Patton, M. Q. 2002. *Qualitative research and evaluation methods*, 3<sup>rd</sup> Edition. Thousand Oaks, CA: Sage Publications, Inc.

Paul, K. 2009. The PEPFAR paradox. Newsweek. http://www.newsweek.com/id/224963.

Paydos, M. 2006. The rapid funding envelope for HIV/AIDS: Tanzania. One year later: Shree Hindu Mandal Hospital's increased capacity. http://www.rapidfunding envelope.org/pdf/SuccessStories/0106\_SHM.pdf.

PEPFAR. 2010. PEPFAR's targets from fiscal year (FY) 2010–FY 2014. http://www.pepfar.gov/about/138278.htm.

\_\_\_\_. 2009a. Celebrating life: The President's Emergency Plan for AIDS Relief. 2009 Annual Report to Congress. Washington, DC: Office of the United States Global AIDS Coordinator.

\_\_\_\_\_. 2009b. Stories of hope: Eastern Africa. http://www.pepfar.gov/pepfar/press/ 83878.htm.

2008. The power of partnerships: The President's Emergency Plan for AIDS Relief. 2008 Annual Report to Congress. Washington, DC: Office of the United States Global AIDS Coordinator.

\_\_\_\_. 2007a. The power of partnerships: The President's Emergency Plan for AIDS Relief. Third Annual Report to Congress. Washington, DC: Office of the United States Global AIDS Coordinator.

\_\_\_\_. 2007b. Stories of hope: Tanzania: Regionalization facilitates treatment scale-up. http://www.pepfar.gov/pepfar/press/83878.htm.

\_\_\_\_. 2007c. Indicators reference guide: FY 2007 reporting/FY 2008 planning. http://www.pepfar.gov/guidance/phase\_i\_indicators/index.htm.

\_\_\_\_. 2007d. FY 2007 application for program activities. Dar es Salaam, Tanzania: U.S. Mission to Tanzania PEPFAR-Tanzania Coordination Office.

\_\_\_\_\_. 2006. Action today, a foundation for tomorrow: The President's Emergency Plan for AIDS Relief. Second Annual Report to Congress. Washington, DC: Office of the United States Global AIDS Coordinator. \_\_\_\_\_. 2005. Engendering bold leadership: The President's Emergency Plan for AIDS Relief. First Annual Report to Congress. Washington, DC: Office of the United States Global AIDS Coordinator.

\_\_\_\_. 2004. The President's Emergency Plan for AIDS Relief: U.S. five-year global HIV/AIDS strategy. Washington, DC: Office of the United States Global AIDS Coordinator.

- Petchesky, R. P. 2003. Global prescriptions: Gendering health and human rights. London: Zed Books.
- Pieterse, J. N. 2001. Development theory: Deconstructions/reconstructions. London: SAGE Publications.
- Rapid Funding Envelope. 2009. *About the RFE.* http://www.rapidfundingenvelope.org/AboutRFE.htm.
- Ray, J. 2008. On Africa trip, Bush finds more receptive audiences. http://www.gallup. com/poll/104440/africa-trip-bush-finds-more-receptive-audiences.aspx.
- Redfied, P. 2005. Doctors, borders, and life in crisis. *Cultural Anthropology* 20(3):328-61.
- Richey, L. A. and S. J. Haakonsson. 2004. Access to ARV treatment: Aid, trade, and governance in Uganda. Copenhagen, Denmark: Danish Institute for International Studies, Working Paper.
- Rist, G. 1997. The history of development: From Western origins to global faith. London: Zed Books.
- Rose, N. 1999. *Powers of freedom: Reframing political thought*. Cambridge, MA: Cambridge University Press.
- Rusimbi, Mary. 2003. SAP for whom? Grassroots Perspectives. In Against Neoliberalism: GenderDemocracy and Development, eds. Chachage S.L. Chachage and Majorie Mbilinyi, 99-109. Dar es Salaam, Tanzania: E&D Limited.
- Scheper-Hughes, N. 1992. Death without weeping: The violence of everyday life in Brazil. Berkeley, CA: University of California Press.
- Scheper-Hughes, N. and M. M. Lock. 1987. The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly* 1(1):6–41.
- Scott, C. V. 1995. *Rethinking modernization and dependency theory*. Boulder, CO: Lynne Rienner.

Segall, M. 1972. The class struggle in health. *The Standard*, March 22.

- Sepúlveda, J., C. Carpenter, J. Curran, W. Holzemer, H. Smits, K. Scott, and M. Orza, eds. 2007. *PEPFAR Implementation: Progress and Promise*. Institute of Medicine of the National Academies. Washington, DC: The National Academies Press.
- Setel, P. W. 1999. A plague of paradoxes: AIDS, culture, and demography in northern Tanzania. Chicago: University of Chicago Press.
- Shore, C. and S. Wright. 1997. Policy: A new field of anthropology. In Anthropology of policy: Critical perspectives on governance and power, eds. C. Shore and S. Wright, 3-29. London and New York: Routledge.

Shree Hindu Mandal. 2008. Dar es Salaam, Tanzania. http://hindumandal.org/.

- Singer, M. and A. Castro. 2004. Anthropology and health policy: A critical perspective. In Unhealthy health policy: A critical anthropological examination, eds. A. Castro and M. Singer, xi-xx. Walnut Creek, CA: AltaMira Press.
- Spire, B., S. Duran, M. Souville, C. Leport, F. Raffi, J. Moattia, and the APROCO Cohort Study Group. 2002. Adherence to highly active antiretroviral therapies (HAART) in HIV-infected patients: from a predictive to a dynamic approach. Social Science and Medicine 54:1481–96.
- Stone, D. A. 1988. Policy paradox and political reason. London: HarperCollins.
- Sundewall, J. and K. Sahlin-Andersson. 2006. Translations of health sector SWAps—A comparative study of health sector development cooperation in Uganda, Zambia and Bangladesh. *Health Policy* 76(3):277–87.

Supply Chain Management Systems (SCMS). 2007. About us. http://scms.pfscm.org/scms.

- Tanzania Commission for AIDS, National Bureau of Statistics, and ORC Macro. 2005. *Tanzania HIV/AIDS indicator survey 2003–04*. Calverton, MD: TACAIDS, NBS, and ORC Macro.
- Tanzania Commission for AIDS (TACAIDS), Zanzibar AIDS Commission, National Bureau of Statistics, and Measure DHS, Macro International Inc. 2008. *HIV/AIDS* and malaria indicator survey 2007–08: A preliminary report. Calverton, MD: TACAIDS, ZAC, NBC, and Measure DHS.
- Timberg, C. 2005. Botswana's gains against AIDS put U.S. claims to test. *Washington Post*, 1 July. http://www.washingtonpost.com/wp-dyn/content/article/2005/06/30/ AR2005063002158.html.
- Tripp, A. M. 1991. Urban women and Tanzania's new "adjustment with a human face" approach to economic recovery. In *Democratization and structural adjustment in*

Africa in the 1990s, eds. L. Deng, M. Kostner, and C. Young, 203–10. Madison, WI: African Studies Program, University of Wisconsin–Madison.

Turshen, M. 1999. *Privatizing health services in Africa*. New Brunswick, NJ: Rutgers University Press.

\_\_\_\_\_. 1984. The Political Ecology of Disease in Tanzania. New Brunswick, NJ: Rutgers University Press.

- UNAIDS. 2007. Joint United Nations Programme on HIV/AIDS and the World Health Organization 2007 AIDS epidemic update. Geneva, Switzerland: UNAIDS.
- United Nations Population Fund. 2007. State of world population 2007: Unleashing the potential of urban growth. New York: United National Population Fund.

United Republic of Tanzania. 2010. Education. http://www.tanzania.go.tz/education.html. \_\_\_\_\_\_. 2007. Basic training course for comprehensive art counselling support. Module 2 participants manual. Dar es Salaam, Tanzania.

- \_\_\_\_. 2005. National guidelines for the clinical management of HIV and AIDS. National AIDS Control Programme (NACP), Second Edition, April 2005.
  - . 2003. 2002 Tanzania population and housing census.

www.tanzania.go.tz/sensa/nbs.htm.

- \_\_\_\_\_. n.d. National HIV/AIDS care and treatment programme. Participant training manual. HIV care and treatment patient monitoring.
- United Republic of Tanzania Ministry of Health. 2005. Site selection for USG-supported ART partners. Letter from Dr. Gilbert R. Mliga, Permanent Secretary. 26 September.

United Republic of Tanzania in collaboration with the William J. Clinton Foundation. 2003. HIV/AIDS Care and Treatment Plan 2003–2008. Business Plan 4.0.

- United Republic of Tanzania Office of the Prime Minister. 2003. National HIV/AIDS Policy of the United Republic of Tanzania.
- United States Congress. House of Representatives. 2003. United States Leadership Against HIV/AIDS, Tuberculosis, and Malaria Act of 2003. H.R. 1298. 108th Congress, 1st Session. http://frwebgate.access.gpo.gov /cgibin/getdoc.cgi?dbname=108\_cong\_bills&docid=f:h1298enr.txt.pdf (26 October 2009).
- Urdeneta, C. 2004. The rapid funding envelope for HIV/AIDS: Tanzania. A beacon of hope for Tanzanians living with AIDS. http://www.rapidfundingenvelope.org/pdf/SuccessStories/0504\_PASADA.pdf.
- Van der Geest, S. and S. R. Whyte. 1988. The context of medicines in developing countries: Studies in pharmaceutical anthropology. New York: Springer Publishing Company.

- Vaughan, M. 1991. Curing their ills: Colonial power and African illness. Stanford, CA: Stanford University Press.
- Walt, G., E Pavignani, L. Gilson, and K. Buse. 1999. Managing external resources in the health sector: Are there lesson for SWAps? *Health Policy and Planning* 14:273-84.
- Wangwe, S. M. and L. Madete. 2001. *Pooling of technical assistance in the context of sector-wide approaches*. Maastricht, The Netherlands: European Centre for Development Policy Management.
- Weber, M. 1946. From Max Weber: Essays in sociology, trans. and eds. H. H. Gerth and C. Wright Mills. Oxford and New York: Oxford University Press.
- Wedel, J. R., C. Shore, G. Feldman, and S. Lathrop. 2005. Toward an anthropology of public policy. *The Annals of the American Academy of Political and Social Science* 600:30–51.
- Whyte, S. R., S. Van Der Geest, and A. Hardon. 2002. Social lives of medicines. Cambridge, MA: Cambridge University Press.

World Health Organization. 2010. CD4+ T-cell-counting technology. http://www.who.int/diagnostics\_laboratory/faq/cd4/en/index.html.

\_\_\_\_\_. 2009. Rapid advice: Antiretroviral therapy for HIV infection in adults and adolescents. Geneva, Switzerland: World Health Organization Press.

\_\_\_\_\_. 2008. Antiretroviral therapy. http://www.who.int/hiv/topics/treatment/en/ index.html.

\_. 2005. Interim WHO clinical staging of HIV/AIDS and HIV/AIDS case definitions

for surveillance, African region. Geneva, Switzerland: World Health Organization. 2001. WHO medicines strategy: Revised procedure for updating WHO's Model List of Essential Drugs. http://apps.who.int/gb/archive/pdf files/EB109/eeb1098.pdf.