

©2014

Chaunetta Jones

ALL RIGHTS RESERVED

BETWEEN STATE AND SICKNESS:  
THE SOCIAL EXPERIENCE OF HIV/AIDS ILLNESS MANAGEMENT AND  
TREATMENT IN  
GRAHAMSTOWN, SOUTH AFRICA

By

CHAUNETTA JONES

A Dissertation submitted to the  
Graduate School-New Brunswick  
Rutgers, The State University of New Jersey  
in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

Graduate Program in Anthropology

written under the direction of

Peter J. Guarnaccia and Dorothy L. Hodgson

and approved by

---

---

---

---

New Brunswick, New Jersey

MAY 2014

ABSTRACT OF THE DISSERTATION  
BETWEEN STATE AND SICKNESS: THE SOCIAL EXPERIENCE OF HIV/AIDS  
ILLNESS MANAGEMENT AND TREATMENT IN  
GRAHAMSTOWN, SOUTH AFRICA

By Chaunetta Jones

Dissertation Directors:

Peter J. Guarnaccia

Dorothy L. Hodgson

This dissertation examines the health and antiretroviral treatment-seeking behaviors among people living with HIV/AIDS in Grahamstown, South Africa. I conducted fourteen months of ethnographic fieldwork from 2008-2009, and use the concept of illness management as a complementary framework to medical anthropological health-seeking models to trace the social experiences of disease among those infected with and affected by HIV/AIDS. My research reveals that entrenched economic inequalities and structural barriers to healthcare, largely a result of apartheid-era policies and delayed HIV/AIDS decision-making at the national level, often force people living with HIV/AIDS to choose between their economic or health security. In communities with extremely high unemployment, like Grahamstown, people living with HIV/AIDS increasingly rely on government disability grants as their sole source of income. My ethnographic findings uncovered a complex dilemma, in which people engage in a range of treatment-seeking practices, including manipulating antiretroviral

treatment adherence, to keep their CD4 counts at or below the threshold to remain eligible for a grant. Failed or modified treatment adherence may lead to the development and spread of drug resistant strains of the virus, potentially creating significant individual and public health concerns.

Further, using rich life history and illness narratives, I demonstrate how state-prescribed health care models, based largely on standardized, biomedical categories, often belie the ways in which health-seeking processes are highly fluid and nuanced within everyday lived experiences. Future state-prescribed HIV/AIDS treatment programs should remain cognizant of patient treatment and prevention strategies, and develop holistic initiatives that address both health and economic security, particularly in resource-limited communities. This research contributes to medical anthropological scholarship on inequality and health, ethnographic studies on HIV/AIDS in southern Africa, and anthropological analyses of how socio-political and economic forces shape health and treatment-seeking practices.



## **DEDICATION**

I dedicate this dissertation to my father, Chauncey Harold Jones, Jr.

You gave me the very best of who you were.

## ACKNOWLEDGEMENTS

Anyone who has completed a PhD knows that the journey is full of excitement, challenges, and self-doubt. The end feels surreal, but I know that I am here because of the support of many who believed in me and the merits of my work. My dissertation was made possible by several fellowships and grants. These include generous support from the Rutgers University Ralph Bunche Fellowship (2003-2005) and Minority Academic Careers Fellowship (2005-2009) that supported my graduate coursework and data collection. Preliminary fieldwork and language training were made possible by funding from the Mellon-Mays Undergraduate Fellowship Program (2004, 2005 and 2008), Rutgers University Department of Anthropology Bigel Research Fund (2004 and 2005), Rutgers University African Language Study Grant (2005-2006), Princeton University Urbanization and Migration Research Grant (2005), Oberlin College Alumni Research Grant (2005), and the Rutgers University Waterman Pre-Doctoral Research Award (2004 and 2005). A Fulbright-IIE Doctoral Research Fellowship supported my long-term fieldwork in Grahamstown, South Africa from 2008-2009, and a Ford Foundation Dissertation Fellowship (2010-2011) and Philanthropic Education Organization Scholar Award (2010-2011) supported the initial phase of data analysis and dissertation writing.

An article partially based on Chapter Five, titled “‘If I Take My Pills I’ll Go Hungry’: The Choice between Economic Security and HIV/AIDS Treatment in Grahamstown, South Africa,” was published in the theme issue “Anthropological Approaches to Confronting HIV/AIDS in Sub-Saharan Africa” in the *Annals of Anthropological Practice* 35(1):67-80.

This research would not have been possible without several community members in Grahamstown, including, Nola Elliot, Mama Meitjie Diko, Carla Tsampiras, Annalie “Jabu” van Niekerk, Kevin Kelly, and the Camp Siyaphumelela youth. My deepest gratitude to the research participants, who opened up their lives and shared their most intimate experiences. I am humbled by their trust in me, and am hopeful that I have satisfactorily captured their narratives in these pages.

Very special thanks to my co-advisors, Peter J. Guarnaccia and Dorothy L. Hodgson, for their patient, ongoing engagement with my work. They always challenged me to think critically and strive to take my work to the next level. I am able to confidently assert the contributions of my research because of their collective efforts to push me forward. To my other committee members, Walton Johnson, Meredith Turshen and Ida Susser, I appreciate the thoughtful questions you have asked to help me deepen the analysis and answer the “so what” questions. Thanks also go to my Oberlin College family, A.G. Miller, Brenda Grier-Miller, Pam Brooks, Caroline Jackson-Smith, Monique Burgdorf, and Maria Paz G. Esguerra, who helped lay the foundation for my scholar/activist presence.

I am also grateful to Fran Mascia-Lees for serving as a sounding board and offering encouraging words of support. I have greatly benefited from my Rutgers colleagues who have spent countless hours talking with me about my research, reviewing drafts, and offering words of support that can only come from folks who have been there and understand the complexities of being a doctoral student: Fatimah Williams Castro, M. Nell Quest, Chelsea Booth, Emily McDonald, and Jane Park. I also owe a great amount of gratitude to Amada Armenta and Marcus Redd, members of the Mellon

dissertation group, for the many rounds of collective writing. Sabrina Chase, you were the most amazing dissertation coach. I admired your ability to help me balance the intensity of the process without losing sight of the bigger picture. Thank you for believing when I didn't.

I often questioned the sanity of concurrently completing my MPH and PhD, but the mentors and friends I gained during my time at UNC-Chapel Hill have convinced me that it was one of the best choices I have ever made. To the faculty at UNC: Carol Golin, Jo Anne Earp, Kurt Ribisl, Catherine Grodensky, Claire Farel, Elizabeth French, Geni Eng, and Angela Thrasher—thank you for challenging me to think about health in new ways. I am also indebted to a group of amazing women from UNC who always kept me laughing and constantly reminded me (mostly over Gchat) that I had exactly what I needed to finish: Nakeva Redmond, Adrienne Gill, Chassidy Hanley, Cameron Hartofelis, Elizabeth Hayward-Janzen, Kathleen Amanda Houpt, Susan Kirtz, Meheret Mamo, Megan Nelson, and Brianna Norton.

To my FDA Center for Tobacco colleagues: A special thanks to Tesfa Alexander, Atanaska “Nasi” Dineva, Lucinda “Cindy” Miner, Rhonda Moore, Matthew Walker, and the Office of Health Communication and Education for welcoming me to CTP and being so generous with their support and encouragement. Thank you, Amy Henry, for bringing joy to my “double shift” days of working and writing—and for calling my bluff when I planned to leave before sunset. To the CTP ORISE Fellas: Ashley Fahle, thank you for your editing help--and the tea. I would not have made it through January without it. Shaola Abagat, you have such a positive, infectious outlook that kept me energized. Kate Cole, my union buddy, our frequent check-ins kept me encouraged.

It would have been impossible for me to complete this journey without the spiritual guidance and support from my pastors, William D. Watley and Bankole Akinbinu, Godparents, Cleophus and Deborah Atkins, church families at St. James AME and Baptist Grove, and the St. James Dance Ministry. I also appreciate the many prayers and support from G.W. and Cynthia Mingo—thank you for the care packages. Mariam Merced, in you I am always reminded of the importance of community and activism. Thank you for being such a great role model and friend.

The biggest thanks go to my family and close friends who have loaned me to graduate school for the last eleven years. Ms. Jane R. Rand, you are the most intelligent, thoughtful, and honest mentor I could have ever asked for. Thank you for being one of my biggest cheerleaders. I am humbled to be your mentee. To my sister-friends, Eva Umoh Asomugha, Debbye Atkins, Felicia Kennedy, Lilian Smit, Fatimah Williams Castro, Courtney-Savali Andrews, Patrice Howard, Janice Gaines, and Nola Elliot, you know exactly who I am and you love me all the same. I am entirely certain that I would not have finished without you in my life.

To my Nana, Carolyn Allen, Grandma, Gloria Florence, and family members, Froya Fields, Eric Allen, Tonishia McAllister, Mariah Fields, Toya McAllister, Carl McAllister, and the entire North Carolina crew: You encouraged me to keep going despite the many obstacles and challenges. You are the true definition of family. To my pup, Teddy Graham: Your bright eyes and abundant kisses gave me something to look forward to everyday—no matter how daunting the long nights of writing seemed.

To my best friend and spades partner, Gerald Mingo, I appreciate all that you have done to help me cross the finish line. You comforted me in my lowest moments of

grief and self-doubt, sponsored doggie daycare when I needed to write without guilt that I was neglecting TG, and celebrated every accomplishment with me as if it were your own. I share this moment with you. You are my blessing. Le'hoop!

Karena Allen-Fields, I am so thankful that you were destined to be my Mama. You are such a beautiful example of perseverance and joy. I have learned from you what God's grace truly looks like. I am strong, courageous, and big-hearted because of you—and I wouldn't have it any other way.

And finally, to my father, Chauncey Jones, Jr.: You punished me when I brought home A's instead of A+'s to teach me that excellence is always within reach. The end of this journey has been incredibly emotional. Every step closer to completion was a reminder that you are not here to celebrate with me. I dedicate this final A+ to you, Daddy. I know I have made you proud.

## TABLE OF CONTENTS

ABSTRACT OF THE DISSERTATION.....	ii
DEDICATION .....	iv
ACKNOWLEDGEMENTS.....	v
LIST OF ABBREVIATIONS.....	xii
LIST OF FIGURES .....	xv
INTRODUCTION .....	1
Anthropological Approaches to HIV/AIDS in Africa .....	6
Inequality and Health.....	12
Anthropological Approaches to Studying the State.....	15
Chapter Outline .....	21
CHAPTER ONE: HISTORICAL BACKGROUND: THE NATIONAL AND LOCAL LEGACY OF APARTHEID .....	25
Brief History of Apartheid .....	25
The Local Context: Grahamstown, South Africa .....	31
Formation of Racially Demarcated Communities in Grahamstown.....	32
The Rise of Resistance: The African National Congress.....	37
Post-Apartheid: Democracy, Reconstruction, and Development .....	38
Impact of Apartheid on HIV/AIDS.....	43
The Healthcare Landscape in Grahamstown .....	45
CHAPTER TWO: METHODOLOGY: APPROACHES TO COMMUNITY-BASED HIV/AIDS RESEARCH .....	47
Site Selection: Grahamstown, South Africa .....	48
Community Sites.....	49
The Grahamstown Community Center .....	50
Township Health Center .....	52
Research Questions and Data Collection Methods .....	53
Participant Observation.....	55
Informed Consent and Human Subjects Protections .....	56
Unstructured, Semi-structured, and In-depth Interviews .....	57
Data Analysis .....	62
Community Involvement .....	64
Reciprocity .....	66
Challenges in the Field: Death and Temporal Boundaries .....	67
CHAPTER THREE: HIV/AIDS POLICY AND WOMEN’S EXPERIENCES OF ILLNESS MANAGEMENT .....	70
Onset of HIV/AIDS in South Africa.....	71
Early Approaches to HIV/AIDS by the State .....	75
Transition to Democracy: The Mandela Presidency.....	76
Mbeki Presidency: June 1999-2008.....	81
Mothering in the Pre-ART Era: Nevirapine and the Effects of the Lack of Availability and Accessibility to Treatment .....	84

The Rollout of Antiretroviral Treatment and Cost of Denial .....	89
Challenges and Cultural Implications of Breastfeeding .....	93
Sexual Trauma and Illness Management .....	97
Conclusion .....	101
CHAPTER FOUR: THE HEALTH-SEEKING PROCESS: PRE-HIV, DIAGNOSIS, AND	
ANTIRETROVIRAL TREATMENT MANAGEMENT .....	103
Entering the Health-Seeking Process .....	103
Models of Health-Seeking .....	107
The State-Prescribed Health-Seeking Model .....	108
Phase I: Pre-HIV Diagnosis .....	116
Phase II: HIV Testing and Diagnosis .....	118
Prior Knowledge about HIV .....	119
Concurrent Sexual Partnerships and Condom Usage .....	126
Phase III: Readiness Process .....	128
The Next Stage of Readiness .....	130
Phase IV: Antiretroviral Treatment .....	133
Treatment Management .....	134
Conclusion .....	138
CHAPTER FIVE: “IF I TAKE MY PILLS, I’LL GO HUNGRY”: ECONOMIC INSECURITY AND	
HIV/AIDS .....	140
Inequality and Health .....	141
The Poverty Profile in South Africa .....	142
The Economic Landscape in Grahamstown .....	147
The Cost of HIV/AIDS at the Household Level .....	149
Social Security in South Africa .....	151
Medical vs. Social Disability .....	155
Accessing the Disability Grant .....	157
Choosing Economic Security or Health Security .....	159
The Implications of Failed Treatment Adherence .....	161
Subjectivity of the Biomedical Disability Model .....	166
The Role of Doctors in Awarding Disability Grants .....	166
Conclusion .....	170
CONCLUSION .....	171
BIBLIOGRAPHY .....	183



## LIST OF ABBREVIATIONS

3TC	Lamivudine
AIDS	Acquired Immune Deficiency Syndrome
ACTG	AIDS Clinical Trials Group
ALT	Alanine Amino Transferase
ANC	African National Congress
ARV	Antiretroviral
ART	Antiretroviral treatment
AZT	Zidovudine
CBO	Community-based Organization
CHBC	Community Home Based Care
CHW	Community Health Worker
CoC	Continuum of Care
D4T	Stavudine
ddI	Didanosine
DOTS	Directly Observed Therapy, short course
EDL	Essential Drugs List
EFV	Efavirenz
EPI	Expanded Program on Immunization
FDC	Fixed Dose Combination therapy
HBC	Home Based Care
HAART	Highly active antiretroviral treatment
HIV	Human Immunodeficiency Virus

INH	Isoniazid
IPT	Isoniazid Preventive Therapy
LPV	Lopinavir
M&E	Monitoring and Evaluation
MCC	Medicines Control Council
LAC	Local AIDS Council
NGO	Non-governmental Organization
NNRTI	Non-nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NVP	Nevirapine
OI	Opportunistic Infection
OVC	Orphans and Vulnerable Children
PACTG	Pediatric AIDS Clinical Trials Group
PCR	Polymerase Chain Reaction
PEP	Post-exposure Prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief (USA)
PI	Protease Inhibitors
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
RTV	Ritonavir
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TB	Tuberculosis

THP	Traditional Health Practitioners
TLC	Total Lymphocyte Count
VCT	Voluntary Counseling and Testing
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary Counseling and Testing
VL	Viral Load
WHO	World Health Organization

## LIST OF FIGURES

FIGURE 1.1 THE CAPRICIOUS NATURE OF APARTHEID RACIAL CLASSIFICATIONS .....	27
FIGURE 1.2 MAP OF SOUTH AFRICA .....	32
FIGURE 1.3 GRAHAMSTOWN DURING SEGREGATION ERA, MID-1930S.....	34
FIGURE 1.4 GRAHAMSTOWN DURING APARTHEID, MID-1980S .....	35
FIGURE 1.5 VIEW FROM TOWN: COLORED AREA AND BLACK TOWNSHIPS IN THE DISTANCE .....	36
FIGURE 1.6 RDP HOUSES IN GRAHAMSTOWN.....	39
FIGURE 1.7 CORRUGATED TIN HOMES IN GRAHAMSTOWN .....	41
FIGURE 1.8 MUD HOUSE IN GRAHAMSTOWN .....	41
FIGURE 1.9 CURRENT NEIGHBORHOOD DEMARCATIONS IN GRAHAMSTOWN .....	42
FIGURE 2.1 MALE AND FEMALE CLIENTS BY YEAR DIAGNOSED .....	55
FIGURE 2.2 BANNER FROM AIDS MEMORIAL SERVICE .....	65
FIGURE 2.3 MEAT PARCELS GIVEN TO PARTICIPANTS .....	66
FIGURE 3.1 NATIONAL HIV PREVALENCE 1990-2002 .....	73
FIGURE 3.2 HIV PREVALENCE IN AFRICA 1990-2002 .....	74
FIGURE 3.3 AIDS POLICY TIMELINE: DEMOCRATIC TRANSITION .....	77
FIGURE 3.4 AIDS POLICY TIMELINE: MANDELA PRESIDENCY.....	78
FIGURE 3.5 AIDS POLICY TIMELINE: EARLY MBEKI PRESIDENCY .....	81
FIGURE 3.6 AIDS POLICY TIMELINE: MBEKI PRESIDENCY AND ANTIRETROVIRAL TREATMENT .....	83
FIGURE 3.7 AIDS POLICY TIMELINE: ROLLOUT OF ANTIRETROVIRAL TREATMENT .....	90
FIGURE 4.1 DIAGRAM OF GRAHAMSTOWN COMMUNITY CENTER OFFICES AND TESTING AREA .....	104
FIGURE 4.2 ANTIRETROVIRAL DRUG REGIMENS FOR ADULTS .....	111
FIGURE 4.3 ADULT HIV MANAGEMENT FLOWCHART .....	112
FIGURE 4.4 HIV HEALTH-SEEKING PROCESS FLOWCHART.....	115
FIGURE 5.1 PERCENTAGE DISTRIBUTION OF SOURCE OF INCOME BY POVERTY STATUS ..	144
FIGURE 5.2 SELECTED POVERTY INDICATORS BY POVERTY STATUS .....	145
FIGURE 5.3 DISTRIBUTION OF TOTAL HOUSEHOLD EXPENDITURE BY POVERTY STATUS..	145
FIGURE 5.4 PERCENTAGE SHARE OF POVERTY BY RACIAL GROUP .....	146
FIGURE 5.5 UNEMPLOYMENT IN SOUTH AFRICA, 2008-2012.....	148
FIGURE 5.6 UNEMPLOYMENT BY SEX, 2008-2012 .....	148
FIGURE 5.7 UNEMPLOYMENT BY LEVEL OF EDUCATION, 2008-2012.....	149
FIGURE 5.8 POVERTY INDICATORS BY PROVINCE .....	149
FIGURE 5.9 TOTAL NUMBER AND GROWTH RATE OF GRANT RECIPIENTS BY GRANT TYPE.....	154
FIGURE 5.10 SELF-REPORTED USES OF THE DISABILITY GRANT AMONG PLWHA IN THE EASTERN CAPE, %.....	158

## INTRODUCTION

South Africa remains the epicenter of the HIV/AIDS pandemic. With nearly six million people living with HIV and AIDS, more than one out of every five adults (ages 15-49) is infected. The introduction of highly active antiretroviral treatment (HAART), while often contentious, was a pivotal step in allowing millions of South Africans access to life-saving medications. In this dissertation, I seek to understand what actually happens in communities *after* antiretroviral treatment has been made available (Schoepf 2004). I argue that availability and access to treatment are not always enough of an impetus for patients to begin and maintain treatment regimens. In this dissertation, I investigate how key historical, political, and economic policy decisions have created a context of entrenched and acute structural and economic inequality in South Africa. I contend that those policy decisions, specifically HIV/AIDS-related decisions at the early onset of the epidemic in South Africa, have shaped the health-seeking behaviors among people living with HIV/AIDS (PLWHA) in ways that complicate and challenge their responses to antiretroviral treatment (ART).

My examination of the negotiation of HIV/AIDS treatment and economic inequality in South Africa builds on a rich body of foundational and contemporary anthropological work on HIV/AIDS in South Africa. I draw from research grounded in medical anthropology (Susser 2009; Steinberg 2008; Schoepf 1992, 1988), the anthropology of Southern Africa (Johnson 1994), and political anthropology (Turshen 1981; Powers 2013, 2012). My work also intersects with literature in public health and gender and sexuality studies. The anthropology of southern Africa offers models with which to better understand the cultural and local context of the HIV/AIDS pandemic,

specifically in South Africa. Political anthropology promotes a consideration of the effects of economic restructuring and political change within the HIV/AIDS pandemic. Finally, medical anthropology has been instrumental in shaping the shift in HIV/AIDS research from its original focus on risk-groups and individual and cognitive models of intervention, to a discourse that critically engages the political economy of the HIV/AIDS pandemic. While these bodies of literature are not always congruent, I engage them as complementary frameworks to more fully examine the dynamics between health and economic inequality.

I engage Chrisman's (1977) health-seeking model as a main foundational framework throughout the dissertation. The concept of health-seeking is comprised of five components: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and adherence. "The health seeking model is an attempt to conceptualize people's experiences with sickness *holistically* as *natural histories of illness*, a view that has advantages for the development of theory in medical anthropology" (Chrisman 1977:351). This model is useful as a framework to explore the health-seeking behaviors among HIV-positive participants in the study because it "outlines the likely relationships of health-related behaviors and sociocultural contextual features allowing the opportunity to test propositions about the impact of daily life on these behaviors" (Chrisman 1977:352). It remains a relevant conceptualization because it accounts for the ways in which culture, people's experiences with sickness or health information, and self-perceived susceptibility to illness are part of a complex process of health-related decision making. In my study, I expand on Chrisman's components and employ the concept of health seeking to refer to the layered experiences among research

participants as they attempt to navigate the healthcare system(s) to both access formal and informal health resources alongside instrumental and tangible social and economic support. In the dissertation, I demonstrate how the process of addressing health-specific concerns becomes intricately intertwined with the dire need for economic security.

My research also draws on other critical medical anthropological concepts, including the social production of sickness (Singer and Baer 1997), health disparities and structural violence (Farmer 1999), therapy management (Janzen 1978), and social suffering (Kleinman et al. 1997). Social suffering stands as a particularly salient central theme across each chapter since “Social suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power from themselves influence responses to social problems” (Kleinman et al. 1997:ix). Additionally, I engage the concept of illness management (Mechanic 1977) as a complementary framework to the health-seeking process:

Illness management is about the social relations that are negotiated in the context of a given illness that shape the meanings, experiences and actions surrounding a specific illness. It is, furthermore, about the political-economic conditions that determine the presence and distribution of a disease in a given locality, as well as the priorities and entitlement to resources people can claim in a community, household or family concerning the treatment of a disease (Dilger 2010:7).

More specifically, my use of the term illness management throughout the dissertation describes what I characterize as the ongoing individual and community-level responses to HIV/AIDS in Grahamstown, South Africa—responses that are inclusive of a range of social and illness experiences in conjunction with health-seeking practices to address HIV/AIDS.

Grahamstown, South Africa, located in the Eastern Cape Province, offers a unique opportunity to explore the dynamics of HIV/AIDS treatment within a context of profound

socio-economic inequality. My case study of Grahamstown also illustrates the lived experience of the HIV/AIDS epidemic within a context in which inequality and health intersect in critical ways—that fall outside of the strict city/country dichotomy and manifest in what is considered a peri-urban community. Peri-urban spaces in South Africa are partly products of the former apartheid regime and are generally sites with high HIV/AIDS prevalence. They epitomize many of the new social and economic relationships spurred by the political transition from apartheid to democracy. Selecting this site enabled me to undertake a more comprehensive investigation of the epidemic that goes beyond its effects within exclusively urban or rural settings to offer an analysis of the dynamics of HIV/AIDS within a community in which the lines between urban and rural disease patterns have become blurred (Patton 1994). My aim is to demonstrate how HIV/AIDS treatment, broadly defined, becomes an inclusive community experience negotiated at the level of individual patients, by affected caregivers and family members, and among community-based organizations and healthcare practitioners in the HIV/AIDS community, forming a collective therapy managing group (Janzen 1978). Ultimately, I contribute new ways of framing how illness becomes collectively experienced, particularly in resource-limited communities, as part of a complex process of illness management.

Medical anthropologists have long been concerned with processes surrounding illness management. They have often attempted to trace the ways in which individuals and communities deal with disease (see Janzen 1978; Kleinman 1980; Baer, Singer and Susser 1997). Initial discourses around the onset of HIV/AIDS in Sub-Saharan Africa were deeply embedded within biomedical and public health arenas; they focused heavily



on individual sexual and risk behaviors (Bolton and Singer 1992). Paula Treichler (1999) notes how the epidemic became one of “signification” as persons placed in risk groups were stigmatized and highly discriminated against. The late Jonathan Mann was critical of this approach, stating that “the focus on individual risk reduction was simply too narrow, for it was unable to deal concretely with the lived social realities” (Mann 1999:3). As more anthropologists began to conduct research on HIV/AIDS in Africa, the concepts of “risk groups” and a special “African sexuality” that led to high rates of transmission were challenged. Researchers became highly critical of the ways in which culture was being used as a determinant of HIV transmission, and it became increasingly clear that the spread of the epidemic was linked to systems of inequality and poverty (Sobo 1999). During my fieldwork, it became evident that as much as my research was about treatment negotiation, it was equally about the strategies people use to cope with poverty (Stack 1974).

Increasingly, these strategies are formed and negotiated among both the *infected* and *affected*. I contend that access to treatment creates new spaces of negotiation among both the *infected* and *affected*, and raises critical questions about the ways in which clients and communities learn to collectively respond to and negotiate illness management through ART. Throughout my work, I challenge the existing dichotomy between those *infected with* versus those *affected by* HIV/AIDS. I define *infection* as the biomedical diagnosis of testing positive for HIV antibodies. Those infected with HIV are often described as “people living with HIV/AIDS” or “people living with the virus.” I define *affected* as the social context of experiencing HIV/AIDS through relationships with family and/or community members that are diagnosed as HIV-positive. While

*infection* is more easily determined, it is harder to pinpoint the degree to which one is *affected*. I argue that this distinction is largely based on a biomedical construct, is easily blurred, and often disappears within everyday experiences of living with HIV/AIDS, particularly as people often move fluidly between the two categories.

I assert that “living with the virus” is not isolated only among those who have been diagnosed as HIV-positive, but describes the inclusive community experience of both the *infected* and *affected*. Left unchallenged, this dichotomy continues to create false boundaries within communities, particularly among members of resource-limited communities who often rely on each other to meet their basic needs. Not only does this distinction continue to reinforce stigma among those that are marked as infected, it also manifests in the ways in which state interventions and the allocation of resources are unevenly developed for the infected versus the affected.

### **Anthropological Approaches to HIV/AIDS in Africa**

The emergence of HIV can be traced to the late 1970s and the first AIDS cases were officially documented in the early 1980s. Anthropological research and literature on HIV and AIDS remained limited until the mid-1980s (see Feldman and Johnson 1986, Herdt 1987, Parker 1987). The approach of anthropologists to the study of HIV/AIDS in the 1980s contributed heavily to the social epidemiology of HIV and the work of epidemiologists, public health scientists, and health policy analysts to better understand the cultural factors that shaped the spread of HIV in Africa, which largely seemed to be the result of heterosexual transmission. This research was not always altruistic, however, as “That interest of the biomedical community was based less on a concern for the fate of Africa than on a potential fear that the same pattern of heterosexual HIV transmission

might quickly hit the shores (and bedrooms) of North America and Europe” (Feldman 2008:1). Several early works, however, have shaped my own research and highlight important questions and concerns that remain relevant.

In 1986, *Medical Anthropology Quarterly* published a set of commentaries by social scientists interested in investigating HIV and AIDS. Although brief, the commentaries revealed the ways in which researchers were beginning to grapple with and develop an understanding of the meanings and larger implications of HIV/AIDS as it spread rapidly throughout the United States and other parts of the world. In 1984, many researchers in the medical community still believed that AIDS could actually “be contained, that a vaccine could be developed, that a cure could be found” (Feldman and Johnson 1986:37). Several of the articles, directly reflecting the common sentiment that AIDS was in fact restricted to the *4-Hs* (see quote), asserted that “AIDS provides unique anthropological opportunities to explore the subcultures of homosexuals, hemophiliacs, IV [heroin] drug users, and Haitian-Americans in order to determine the respective parameters of health, disease, and culture that occur for each population” (Gorman 1986a:31). Gorman (1986b) highlighted the ways in which the spread of HIV raised important questions about the relationship between health care and culture, while Friedman (1986) foreshadowed the reality that “as time goes on the numbers of AIDS patients from different risk groups will vary—for example, we anticipate an increase in the proportion of women who do not use IV drugs among AIDS patients in the United States” (1986:34).

By the mid-1990s, the limited number of book-length ethnographies published by anthropologists on HIV/AIDS (Green 1994; Feldman 1994; Mogensen 1995; Wilson

1995) established useful guideposts for the field that remain anthropologically salient. Key themes arose from the early literature that reflects the thematic progression of anthropological work on HIV/AIDS. My work draws on this early work by continuing to question the tensions between structure and agency and the role of narrative in understanding individual responses to illness. I seek to better understand how particular behaviors, specifically those deemed “risky,” could be better understood within conditions of restricted agency and structural violence.

One key text that was instrumental in raising these questions around structure and agency was *Global AIDS Policy*, an edited volume by Douglas Feldman (1994). The volume is a collection of short essays by anthropologists primarily interested in the relationships between health policy and HIV/AIDS. It provides several examples of the tensions between structure and agency, asking, for example, how anthropologists are to reconcile people’s knowledge about HIV/AIDS transmission alongside what seems to be little to no behavioral change to prevent contracting the virus. It opens up the discussion of what role anthropologists can play in interrogating agency, specifically with regard to its constraints on HIV/AIDS prevention. Other anthropologists (see Klepp, Biswalo, and Talle 1995) have contributed to the structure/agency debates by focusing specifically on increased risk factors and agency constrictions among women, specifically within resource-poor countries. This foreshadowed the developing intersections between the HIV/AIDS pandemic and the global political economy.

While Feldman’s volume is bereft of personal voices, Carter Wilson’s (1995) *Hidden in the Blood: A Personal Investigation of AIDS in the Yucatan* offers an ethnographically rich text that explored the development of discourse on AIDS and

sexuality in Mexico while the first cases of the virus were diagnosed. This research speaks directly to earlier claims within public health discourse of anthropologists' purported ability to obtain and explain a "special understanding of sexuality." Wilson's case-study directly refutes those claims, and instead argues that anthropologists did not, in fact, possess any "special" knowledge of sex and sexuality. Wilson contends that, "far from being obsessed with sex and sexuality, the anthropologists have been so negligent of the subjects that their accounts contained almost no data that could be useful in slowing the spread of the disease" (Wilson 1995:69). In addition to speaking to the role of anthropologists in the development of sex and sexuality discourse on HIV/AIDS, the text also begins to question the relationships between inequality and HIV/AIDS among the rich and the poor.

In 1995, another text marked a shift in the theoretical framework by anthropologists conducting research on HIV/AIDS. In her exposition on Tongan communities within Southern Zambia, Mogensen (1995) stressed the importance of the connection between discourse and narrative. Her research focused on the recurring theme among her participants that there was a direct relationship between HIV/AIDS and a traditional disease, kahungo, caused by some form of sexual pollution. By integrating those interpretive frameworks about HIV and AIDS existent among the Tongan themselves, Mogensen's work offers an example of how individual and collective conceptualizations and perceptions of illness shape theoretical frameworks. Mogensen contends that while AIDS researchers outside of anthropology were not primarily concerned with larger social and political economy theoretical frameworks, "the Tonga did show through [their] narratives about kahungo that they themselves were" (1995:99).

My work incorporates social and personal narratives of illness to push back against normative narratives about promiscuity and “cultural obstacles” as the root causes of disease spread and the origin of barriers to change in sexual behavior. Instead, I demonstrate how health-related decisions are made within a complex system of medical decision-making in which personal experiences are directly linked to social relations, political economy, and large-scale global policy questions.

Another important text is Edward Green’s (1994) *AIDS and STDs in Africa: Bridging the Gap between Traditional Healing and Modern Medicine*. Green, an anthropologist whose research is largely based in eastern and southern Africa, became a key player in the early literature written by anthropologists on HIV/AIDS. In this text, Green interrogates the relationship between biomedicine and traditional African healers. He provides a strong argument that collaboration between the two is necessary. Green contends, “that some sort of collaborative action program involving traditional healers is necessary if we wish to significantly impact the spread of AIDS and other STDs in Africa” (1994:3). While this is a seemingly reasonable approach, this text has become more useful for its shortcomings than for its intended insights. For example, while Green accurately asserts that many biomedically-oriented healers have only recently become scientifically trained and that they largely remain outnumbered by traditional healers, he states, “A majority of Africans vote with their feet and pocketbooks by choosing the services of the latter, even when the former are available and perhaps cheaper” (1994:43). Within the larger context of the text, this statement asserts the existence of a particular level of agency among his African research participants by suggesting that they can actively choose among several wellness options. This may be an oversimplification of

the situation, however. Green does little to complicate or tease out the effects of widespread poverty, inequality of access, and other logistical and structural barriers in shaping help-seeking practices among the poor and those most at-risk of exposure to STDs and HIV/AIDS. Yet, Farmer points out, poor blacks in South Africa were not able to access biomedical services comparable to those available to white South Africans:

That is, the inability of the poor and underserved to obtain effective treatment for acute or chronic medical conditions is recast as a reflection of cultural difference: when ill, they seek the ‘cultural fit’ of traditional healers. This conflation of structural violence and cultural difference has marred much commentary on AIDS, especially AIDS among the poor (Farmer 1997:523).

So, while Green’s text generated strong critiques of the ways in which he exaggerated the agency of the poor and romanticized the efficacy of traditional healers, it raised important questions about the relationships between biomedical systems and traditional methods of healing. It is not necessary, however, to construct the relationship in opposition or as a dichotomy between holistic or narrowly focused and fragmented approaches to healing. Rather, more might be gained from reflecting on how both approaches can be used in tandem with each other within a range of available health resources.

By the early 1990s, anthropological research on HIV/AIDS in Africa had shifted from a biomedical framework to one that included an analysis of political economic forces, specifically the effects of neoliberal policies and structural violence. In mapping the spread of HIV and AIDS in Eastern and Southern Africa, from the early “AIDS belt” countries of east Africa (i.e. Uganda, Kenya, and Tanzania) to Malawi, South Africa, and Zambia, it became evident that while contemporary prevention strategies have increased our knowledge of HIV/AIDS in Southern and South Africa, “more effective prevention strategies will need to address those underlying causes of HIV/AIDS that are rooted in inequitable gender relations, lack of employment opportunities for both men and women,

and cultural meanings surrounding forms and functions of sexual exchange” (Kalipeni et. al. 2004:67).

### **Inequality and Health**

The relationships between disease and inequality can be understood in different ways. One approach sees disease as the manifestation or embodiment of hierarchical social relationships and structural inequality. In other words, inequality becomes a form of structural violence that manifests indirectly through discourses of risk and blame, mapped directly onto the body. This conceptualization is useful because it accounts for social change in framing how inequality becomes embodied. Within this context, the concept of structural violence refers to those processes and inequalities that create dramatic differences between the “haves” and “have nots.” More specifically, it refers to the set of adverse social, economic, and political conditions under which many of the world’s impoverished are forced to live (Schoepf 2004).

One of the major ways in which inequality becomes visible is through risk, manifested by incidence and prevalence of disease among various social groups. “Risk, then, can be said to be a measure of social [structural] violence, capturing how power distributes unevenly down the social ladder” (Nguyen and Peschard 2003:457). This is reminiscent of Farmer’s (1999) notion of the AIDS pandemic’s ability to trace along “social fault lines.” Specifically, this means that those who are lower in the social strata are often “blamed for behavior over which they have little effective control and find themselves subject to interventions that medicalize social forms of suffering, even as they are excluded from collective forms of solidarity” (Nguyen and Peschard 2003:458).



The effects of structural violence manifest in various ways throughout South Africa, specifically through unequal access to resources, lack of employment, poor healthcare, and inadequate educational systems. Farmer (2004) draws on Fassin's notion that historically rooted manifestations of structural violence also become socially inscribed on bodies, and asks, "(h)ow can ethnography apprehend this embodiment of the past?" (Farmer 2004:319). This becomes a particularly important question within the context of South Africa, as many residents are managing ongoing post-apartheid political and social transitions while simultaneously negotiating how memory, historical time, and remnants of apartheid have become inscribed onto bodies (Fassin 2007). My research draws on previous studies of structural violence (Farmer 2003, 1997; Foucault 1977; Kleinman et al. 1997; Scheper-Hughes 1992) to further interrogate the role of ethnography in developing a better understanding of the relationships among historical and contemporary social and political structures, violence, and systems of power and oppression.

Medical anthropologists have contributed to this theoretical framework by delineating the boundaries of the relationships among poverty, inequality and health, beyond biological or social determinants, to link local contexts to an analysis of broader geopolitical contexts (Coburn 2000). Farmer (1997) for example, offers a critical investigation of health and inequality that goes beyond the epidemiological framework to combine critiques of social suffering (Kleinman et al. 1997) with an examination of the social forces that shorten the life spans of the poor. In effect, this posits that one perspective on the relationship between inequality and health is that "between the body and society and fleshed out by ethnographically driven approaches" (Nguyen and

Peschard 2003:454). Only through a careful consideration of inequality, however, on both the global and local level, will we be able to “account for lived reality in a way that makes sense for the social agents themselves” (Farmer 2004:319). A critical medical anthropology, then, works well alongside a political anthropology of health to offer a theoretical framework to gain a better understanding of the relationships among poverty, economic inequality, and illness (Nguyen and Peschard 2003, Subramanian 2002, Wilkinson 1997). Within the context of HIV/AIDS in South Africa, the lived reality is one in which economic inequality and structural barriers have created dire situations that force many PLWHA to choose between their economic security and health security.

While it has been argued that positive health outcomes are directly determined by how relative inequality operates within a society (Wilkinson 1997), the underlying relationships between inequality and disease continue to be poorly understood. Anthropologists have contributed to developing a better understanding of this dynamic through explorations of the ways in which hierarchy and economic power are translated into disease within broader historical and sociocultural frameworks. There remains, however, “methodological difficulty in examining the inequality/disease relationship” and separating out the effects of inequality from those induced by poverty (Clarke et al. 2002). Despite the methodological difficulty of teasing apart this relationship, my research critically examines the political economy of health and the ways in which changes in macroeconomic policies impact the health of populations, specifically the poor of South Africa (Kim et al. 2000, Navarro 2002). Within this context, it is difficult to tease apart poverty, inequality, and structural violence. All three are interconnected

and operate as a constant backdrop as participants simultaneously negotiated HIV/AIDS and economic inequality.

### **Anthropological Approaches to Studying the State**

South Africa's transition to democracy following the end of apartheid in 1994 was a significant political moment. The effects of structural violence remained prevalent, however, and continued to manifest in multiple ways, specifically through state economic policies, unequal access to health resources, and lack of employment options. The state, then, emerges as a central figure within the complex process of illness management. The nature, role, and character of the state has been thoroughly analyzed and heavily critiqued (Mitchell 2006, Das and Poole 2004, Asad 2004, Abrams 1988, Hannerz 1989, and Shils 1975). There are multiple methods for studying the state that ultimately characterize it as an ensemble of often contradictory processes and practices:

The state—or apparatus of “government”—appears to be everywhere, regulating the conditions of our lives from birth registration to death certification. Yet, the nature of the state is hard to grasp. This may seem peculiar for something so pervasive in public and private life, but it is precisely this pervasiveness, which makes it difficult to understand. There is nothing more central to political and social theory than the nature of the state, and nothing more contested (Held 1983:1).

Although a challenging exercise, the state continues to remain an important site of exploration, critique, and analysis. In this section, I highlight the theoretical frameworks drawn from anthropological approaches to studying the state that are central to my research.

Tensions have emerged between the local and central state in contemporary post-apartheid South Africa, where the process of nation (re)building has become a central tenet. The emergent relationships between the new central South African state and the new local state, is an example of how the making of the local state in post-apartheid

South Africa is consistent with the ways in which central states have retreated from redistribution and welfare provision, relegating responsibility to newly formed local states, or the private sector, including non-governmental organizations (NGOs). The way in which the central South African state has retreated from redistribution of social and economic resources in the form of land, housing, and employment opportunities represents “precisely the sort of reconfigurations of territorial state power associated with neoliberal capitalism in many different parts of the world... What renders this process particularly explosive in post-apartheid South Africa is how the spatial dimensions of race, wealth, and privilege have become reinscribed within the local state” (Hart 2002:235).

Yet, the central South African state is still responsible for managing and allocating resources, which creates tensions between the local state and the central state, ultimately exposing the limits of power within the local state to address and manage the burdens of poor health and economic inequality. Within this context, HIV/AIDS specific NGOs have emerged as dominant and prominent figures, both globally, and particularly in South Africa, where the state has either failed or remained critically delayed in providing services. This raises important questions about the responsibility of the state, the role of local organizations in facilitating the response to HIV/AIDS, and the relationship between the state and civil society.

The concept of civil society is useful to understand the scale, relationship, and movement between the “top” and “bottom,” the state and society. Civil society has been framed mostly in opposition to the state (for counter examples see Taylor 1990), and as “a kind of buffer between the low and the high, an imagined middle zone of contact or

mediation between the citizen, the family, or the community, on the one hand, and the state, on the other” (Ferguson and Gupta 2002:983). Hegel (1942), for example, offers a precursory viewpoint by contending that civil society was in fact the intermediary between society and the state, and the state both ethically and politically superior to the social institutions “on the ground” (Hegel 1942). In tracing the history of the concept of civil society (Burchell 1991; Chatterjee 1990; Comaroff and Comaroff 1999; Seligman 1992), we see that there is a specific historical employment of the “top-down” metaphor that has “allowed civil society to appear as a zone of mediation between an ‘up there’ state and an ‘on the ground’ community” (Ferguson and Gupta 2002:983). Mamdani (1996), however, chooses not to focus on the *exclusion* of particular subjects from civil society, but rather concentrates on how subject populations are *incorporated* into the realm of state, national, and colonial power.

Additionally, as globalization allows for grassroots organizations and NGOs to mobilize in new ways, often transnationally, the scales overlap in different ways, and at times, collapse upon each other (Merry 2001; Brenner 1997; Smith 1992). In South Africa, the increasing dependence on NGOs represents an “NGO-isation” of state responsibilities as local entities rely on NGOs to function when the state no longer does. The irony of this phenomenon is particularly salient in post-apartheid South Africa, where civil society was critical in bringing down apartheid, but now is expected to provide its own care.

Non-governmental and community-based organizations (NGOs and CBOs) are key stakeholders within my research because they not only serve as sites of HIV testing and treatment, but also link the local to the global as mediators of state policies within a

larger framework of HIV/AIDS health-seeking practices. The varying degrees of what NGOs look like and the functions and roles they play make it difficult to understand their significance and impact at the local and national levels. Fisher (1997) highlights the challenge inherent in understanding and analyzing NGOs:

The term NGOs has been applied to groups providing social welfare services; development support organizations; social action groups struggling for social justice and structural changes; support groups providing legal, research, or communications support; and locally based groups. Some are focused on a single issue or operate in a specific location. Others provide legal, research, or communications support to more locally based groups. The designation has been applied to groups with mass membership as well as claimed by small, opportunistic ‘brief-case’ NGOs formed by members of an urban middle class to seek funding (1997:447).

Despite the sharp increase in NGOs globally since the 1990s, these organizations are challenged to remain effective and sustain innovative initiatives—all while negotiating “complex transnational links for their material and political survival” (Englund 2006:8).

This dynamic was evident among the network of NGOs in Grahamstown, as they struggled to combat the social ills (i.e. hunger, poverty, HIV/AIDS) within the community, while concurrently competing for scarce resources:

Crucially, NGOs have multiple accountabilities—‘downward’ to their partners, beneficiaries, staff, and supporters; and ‘upward’ to their trustees, donors, and host governments. Multiple accountability presents any organization with problems, particularly the possibilities of having to ‘overaccount,’ because of multiple demands, or being able to ‘underaccount,’ because each overseeing authority assumes that another authority is taking a close look at actions and results” (Edwards and Hulme 1995:8).

This tension often trickled down to the level of the actual clients and community partners.

As the Grahamstown Community Center (GCC) became more focused on developing relationships with international agencies and funders to simply keep the doors open, they lost some of their “community-edge,” creating an image that often ran counter to their original mission. This shift is indicative of the “structural predicaments” that many

NGOs face as they attempt to reconcile external pressures from international donors, transform relationships with local governments, and manage expectations among their community-based constituents (Hodgson 2002).

NGOs have also become central to the processes of negotiating between civil society, the state, and transnational organizations like WHO and the Global Fund (Edelman 2001; Englund 2006; Robins 2006). More specifically, NGOs often assist in facilitating the practices of western development agencies that choose to circumvent national governments and work directly with civil society to develop their own programs and interventions. Ferguson and Gupta (2002) refer to the emergence of these relationships as part of “a transnational apparatus of governmentality” that can be thought of “not as challengers pressing up against the state from below but as horizontal contemporaries of the organs of the state—sometimes rivals; sometimes servants; sometimes watchdogs; sometimes parasites; but in every case operating on the same level; and in the same global space” (2002:994). This forces us to challenge the common understandings of states as operating within pre-existing spatial patterns and on particular scales without constantly engaging in an exploration of these changing relationships. New practices, including those that are a result of neoliberal policies and globalization, have created spaces that offer opportunities for new and more in-depth explorations that challenge the seemingly previous naturalization of the verticality of the state—the notion of the state as being an overarching institution that is “on top” of social institutions like the family, community, and civil society.

In considering the multiple frameworks for theorizing, locating, defining, and critiquing the state, how do these theoretical models help us to ethnographically examine

the state in relation to everyday lived experience? Methodologically, developing an ethnography of the state and “studying up” presents particular challenges (Nader 1972). My approach considered the relationship between public culture and everyday practices. “Looking at everyday practices, including practices of representation, and the representations of (state) practice in public culture helps us arrive at historically specific and ideologically constructed understanding of ‘the state’” (Gupta 2006:230). I am less concerned with whether the state actually does possess a particular superiority, but rather focused more on developing an understanding how these particular images become routinely employed and have become part of the dominant discourse on how the state is theorized.

Many scholars discuss how the particular metaphors that shape how states are imagined become important within the contemporary dynamics of the state in post-colonial Africa (Bayart et al. 1999, Bayart 1993, Mamdani 1996, Werbner and Ranger 1996, Mbembe 1992). My research is about using HIV/AIDS as a lens to link lived experience among individuals and communities on the ground to a larger network at the level of the state. As such, my study offers an example of the complex relationships that simultaneously exist both horizontally and vertically among the key stakeholders in the process of illness management. More specifically, within the context of my study where state health policies and approaches to HIV/AIDS directly shape help-seeking practices my research moves from the macro-factors that contribute to poverty to a close look at how those factors play out at the community-level and among individuals within households. A critical medical anthropology, then, works well alongside an anthropology



of the state to offer a theoretical framework to gain a better understanding of the relationships among state policy, economic inequality, and health.

This review of the literature demonstrates the ways in which HIV and AIDS become imbued with immense cultural symbolism and carry great significance within communities (Sontag 1989, Bolton and Singer 1992). However, as we continue to move out of an HIV epidemic and further into an AIDS epidemic in which people manage their chronic illness with ARVs, anthropological research remains a critical tool for furthering our understanding of how health-seeking practices in particular communities, specifically in regard to HIV/AIDS, shift to reflect changes in the socio-economic climate. South Africa is a useful case study because it provides an extreme example of the ways in which on-going structural violence becomes embedded within the social and political fiber of a society, exposing the ill effects of that violence on the health of its citizens. Only through a careful consideration of inequality, however, on both the global and local level, will we be able to “account for lived reality in a way that makes sense for the social agents themselves” (Farmer 2004:319). Within the context of HIV/AIDS, the lived reality is one in which economic inequality and structural barriers have created dire situations that force PLWHA to choose between their economic security and health security.

### **Chapter Outline**

The following research questions have driven my inquiry: (1) What factors affect people’s general conceptualizations of HIV/AIDS in Grahamstown, South Africa? (2) How do these factors shape people’s practices when choosing to begin, refuse, or modify their HIV/AIDS treatment? (3) In what ways do health policies shape the help-seeking

practices among those infected with and affected by HIV/AIDS? (4) What key barriers create challenges for people in need of HIV/AIDS treatment? And finally, (5) What implications do these barriers have on the long-term effectiveness of HIV/AIDS treatment programs and general public health within the local community and abroad?

In Chapter One, I provide a historical background of South Africa and trace how apartheid policies created systems of structural and economic inequality, both nationally and locally in Grahamstown. I describe how poor and black South Africans are affected most acutely by this legacy of entrenched inequality, creating the political and economic context that shaped participants' general conceptualizations of HIV/AIDS. In Chapter Two, I describe my research methodology and discuss the logistical and ethical challenges of conducting research on such a highly sensitive topic. This chapter highlights my deep community involvement and how that engagement helped me to cultivate intimate relationships with participants and members of the greater community.

In Chapter Three, I describe the evolution of HIV/AIDS policy in South Africa to demonstrate how failed and delayed decision-making at the state level facilitated the exponential rise in HIV incidence in the post-apartheid transition to democracy. These policies, compounded by entrenched economic inequality, had grave effects on the ground for those most vulnerable and at risk for infection, specifically poor, black women. Throughout the chapter, I discuss the experiences of female participants and explore how they reconcile these processes—where shifts in state policy have and continue to have direct implications and consequences within their individual and communal health-seeking experiences.

In Chapters Four and Five, I examine those multiple social and economic factors. In Chapter Four, I build on ethnographic accounts to describe the health-seeking process in Grahamstown. This chapter traces the process that patients, their family members, and healthcare workers navigate as they collectively negotiate antiretroviral treatment and illness management. I critique the state-prescribed model of testing to treatment and argue that the reliance on a biomedical model fails to capture the extensive social and economic factors that create barriers and challenges for people in need of ART.

In Chapter Five, I turn to the ways in which the health-seeking process is intricately tied to issues of economic security. I argue that poverty, inequality, and structural barriers directly shape the health-seeking behaviors among people living with HIV/AIDS. Throughout the chapter, I trace how specific policies around the Disability Grant system in South Africa have created unique challenges for HIV-positive patients and those affected which often force them to choose between their economic security and health security. Further, I examine the relationships among poverty, inequality, and economic security to highlight the ways in which the health-seeking process is layered with multiple forms of suffering.

In the Conclusion, I summarize how this project contributes to a better understanding of how state policy is experienced in everyday life. Further, I offer insights into the strategies people in resource-limited communities use to cope with HIV/AIDS. My research promotes a political anthropology of health that addresses the ways in which socio-political and economic forces have real impacts on health and health-seeking behaviors. Finally, I contend that medical anthropology offers a viable framework for theorizing the relationships among health, inequality, and structural

violence in ways that can aid in the development of innovative community initiatives that do not further complicate the treatment experience, but rather, offers a holistic approach to treatment, illness management, and economic security. I further discuss the implications of my findings for social and public health policy that could improve the lives of those living with HIV/AIDS.

## CHAPTER ONE

### **Historical Background: The National and Local Legacy of Apartheid**

The story of HIV/AIDS in South Africa has been marked by many pivotal moments that have shaped responses to the epidemic at both the national level and among those at the local and community levels. In this chapter I provide an overview of major historical moments to highlight the ways in which apartheid created an intricate system of structural and economic inequality both nationally and locally in Grahamstown. Additionally, I describe how that legacy of entrenched inequality persists in current-day Grahamstown and is experienced most acutely by poor, black South Africans.

#### **Brief History of Apartheid**

The current socio-political climate in South Africa has been indelibly shaped by apartheid. Apartheid, literally “apartness,” was based on an ideology of segregation and racial classification; founded on the belief that the differences between whites and non-whites, i.e. Indians, Coloreds, and Africans/blacks, were so profound that it was impossible for them to live together (Marquard 1968; Marmelstein 1987; Johnson 1994). Cooper (2002) explores the sophistication of the apartheid system; as other African governments were more focused on development, the apartheid regime maintained its commitment to delivering great wealth and control to the white minority. Critical to the success of the apartheid system was the implementation of influx controls in the form of pass laws, a strategic set of controls that not only regulated movement *into* the urban areas, but were also employed as a way to expel permanent residents from “white only” areas and forcefully relocate them to rural homelands (Platzky and Walker 1985; Giliomee and Schlemmer 1985; McLachlan 1987).

The Nationalist Party won the general elections in 1948. The three major points of the Nationalist's manifesto were white supremacy, racial segregation, and the development of a Christian National state. These goals were achieved through the implementation of strict racial segregation in the towns, restricted black urbanization, and a tightly controlled and expanded system of migrant labor. Additionally, the Nationalists initiated a drastic strengthening of security legislation and control (Platzky 1985:95).

The Nationalist party passed some of its most notorious laws shortly after assuming power. The first was the Population Registration Act 30 of 1950. This Act implemented a system of classification that divided the population of South Africa into four racial categories: white (either of Dutch or British descent), colored (often of mixed race), Indian, and black.<sup>1</sup> Blacks and coloreds were further divided into ethnic groups and blacks were subjected to the worst treatment. These classifications were strictly arbitrary, and predicated on outward appearances and the discretion of the officiating board. "Generally, a child will have the same classification as his/her parents, but for those who do not fall into any definite category, their status was determined by criteria such as descent, appearance (hair, lips, and nails), social acceptance, habits, speech and education" (McLachlin 1986:76). An article in *The Star* Newspaper reveals just how subjective and capricious these classifications were:

---

<sup>1</sup> Although the official system of apartheid has ended, the racial categories imposed during its control are still important in any examination of developments post-apartheid. The four categories are white, colored,



**Figure 1.1** The Capricious Nature of Apartheid Racial Classifications

Also in 1950, the Nationalist Party passed the Groups Areas Act 41. The basic premise of this Act was that different groups would live in defined and separated geographic spaces based upon their racial and ethnic grouping. The District Six neighborhood in Cape Town became a well-known example of the effects of this Act when it was proclaimed a white area only area in 1966, even though 90 percent of its residents were colored (McLachlan 1986). Apartheid's racial categorizations were not only successful in dividing the people of South Africa into whites and non-whites; it also destroyed families who were separated because some members were considered colored while others were classified as black.

The[se] Act[s] tried to encourage black people to think of themselves as 'colored' and 'Indian' and 'African', rather than as blacks or workers or oppressed people who had many problems in common. Those African people who saw their land taken away and

turned into townships for coloreds or Indians were understandably bitter- but many turned their anger not against the government that had made the laws, but against the people who had been directed into their former houses. In this way, the Group Areas Act worked against organizations such as the ANC,<sup>2</sup> which were trying to unite blacks to stand together against the onslaught of apartheid (Platzky 1985: 101).

By 1980, it was estimated that the total population of South Africa was approximately 29 million people. Of that 29 million, 72.7 percent (21.0 million) were African/black, 15.5 percent (4.5 million) were white, 9.0 percent (2.6 million) were colored, and 2.8 percent (0.8 million) were Indian. Only 13.7 percent of the country's land area was allocated for black South Africans, however. The remaining land was designated as "white only." The lands designated for blacks were originally known as "bantustans," and later became known as "homelands" or "black states."

The government presented bantustans as independent black nations within the borders of white South Africa. All Africans have been artificially divided by their ethnic affiliation. One-half the African population of South Africa have never set foot in these areas, which in any event comprise only 13.5 percent of the land, land which is overwhelmingly arid, nonarable, and incapable of supporting its population (Lapchick and Urdang 1984:5).

The traditional townships in which most blacks lived were deproclaimed, or closed to the black residents. Where a town was within commuting distance (up to 75 kilometers) of a bantustan, the African township was closed and the residents moved to a new rural township built in the bantustan. The implementation of the homelands signaled a pivotal point in the development of resistance against the apartheid government. This marked the development of state controls that restricted the movement of its people based not only on race, but also on gender. Men, having been forcibly removed to homelands,

---

<sup>2</sup> A group from a small African middle-class developed the South African Native National Congress in 1912. The founding members were educated in the west and were non-traditionalists. Their aim was to promote non-tribal African nationalism and inclusion of Africans into white society. The organization was renamed the African National Congress (ANC) in 1923, and continued to be a political vehicle through which coloreds, Africans, and Indians staged anti-apartheid movements. The ANC won the democratic elections in 1994, and continue to be the presiding party.



automatically migrated into the urban areas for work to support themselves and their families. This system in turn created a cyclical dynamic of migration based on systems of power, control, and surveillance that forced many men to travel to the urban areas to seek employment, often leaving women behind in the rural Bantustans (Foucault 1995; Walker 1982; Kuumba 2001).

These methods of influx control by the South African government resonate strongly with Foucauldian notions of surveillance (see Yacobi 2001). In the case of the townships within the South African context, the bantustans replaced the structural buildings of the panopticon and served as sites of surveillance, social control, and mechanisms for power.<sup>3</sup>

In consequence, a real and effective ‘incorporation’ of power was necessary, in the sense that power had to be able to gain access to the bodies of the individuals, to their acts, attitudes, and modes of everyday behavior (Foucault 1977).

The actual implementation of pass laws and the creation of townships represents the state’s ability to not only gain access to the bodies of individuals, but to impose control in such a way that it influenced and structured modes of interaction and behavior between coloreds, blacks, and Indians throughout South Africa.<sup>4</sup>

The pass laws lay at the very heart of apartheid, and were a manifestation of the ideological core of the system. From the initial stages of colonization, a form of the pass

---

<sup>3</sup> The panopticon, developed in 1787 by Jeremy Bentham, was used as an architectural model for buildings whose essence was social control such as hospitals, prisons, factories and the like. The structure of the panopticon was to hide the presence of any supervision, which produced an effect that made subjects unable to detect supervision, but induced a fear that supervision was always present, or at least readily accessible by those in control.

<sup>4</sup> Foucault’s notion of governmentality is evoked here. The bantustans represented a multi-layered process of power dynamics that lie at the intersection of how to govern oneself, how to govern others, and how to be governed; serving as apparatuses of security. See Sharma and Gupta (2006) and Ferguson and Gupta (2002) for further discussion on governmentality, power, and the state.

law existed, but men initially were the only ones required to carry passes. As more non-whites began to stream into the urban centers designated as “white only” areas, the need for influx control became of greatest importance. The whites that lived in these areas were well aware that they were the minority, and scrambled to impose restrictions that would stabilize their power. The pass law system applied to all non-whites, but it was most heavily enforced upon the black populations. The law required all blacks over the age of 16 to register with the Central Reference Bureau to secure identity documents. Known as a passbook, and later a reference book, it became the passport for the residents of all bantustans.<sup>5</sup>

For women, the restrictions of the passbooks were even more severe. Women were required to have all of the above information in their pass books, and additionally, they had to also document consent of the commissioner of their assigned homeland and consent of their parent, guardian, or husband to go to work or live in a different bantustan. Anti-apartheid writer Phyllis Ntantala vividly described how severe the pass system was experienced among black men and women:

The pass system affects every black person, male and female, young and old, in city and countryside. In South Africa today no black person may go anywhere at any time without the permission of some white official, and to have this permission, one must carry a Pass. No black person, be he a doctor, lawyer, nurse or businessman, may practice his profession unless he has a Pass; no school child may enter any institution of higher learning, write any examination under the state or provincial department, unless he has a Pass;...no black corpse may be buried, unless it has a Pass. It is the Pass System that has broken up the family life of the African people;...controls their

---

<sup>5</sup> The passbook contained sections for the following documents: Residential address; labor bureau where registered; official permit to remain in, or go to, a specific area; and any referrals or admittance to aid centers; employer’s name and address and signature for each week, as well as endorsements for leave; for students, pupils and scholars there must be a record of the name of the head of the school, university or college and a certificate of enrollment for the quarter; tax receipts; driver’s license; weapons license; identity document with sex, name, ethnic classification, photograph, and Reference Book number.

movements and regulates their lives from the cradle to the grave...Is it a wonder then that such a system and such laws have aroused anger and hatred in the hearts of their victims? (Ntantala 1976:41)

These Acts and the pass laws resulted in tremendous conflict and struggles between the white minority and the black majority over who had physical access to the cities. “The emergence of numerous new informal settlements, the estimate that a thousand additional people per day were migrating to the city, and the growing strength of squatter resistance organizations, [however], made it clear that the system of influx control was breaking down” (Watson 2002:17). From the mounting tensions between the white minority and the non-black majorities in the struggle over apartheid grew a social movement organized around ending the reign of the apartheid state. This movement cultivated resistance, and “with mass action a fighting culture develops, not as a celebration of the past but as new forms of social activity, transforming subjectivity of daily ‘ways of life’ expressed in daily meetings, decisions, discussions, and actions into a new way of life” (Gibson 2001:72).

### **The Local Context: Grahamstown, South Africa**

My field research was conducted in Grahamstown, South Africa. Grahamstown is located in the Eastern Cape Province and falls within the Makana Local Municipality. The closest major urban centers are Port Elizabeth and East London (Figure 1.2). During my fieldwork, the population of Grahamstown proper stood close to 62,000 people,<sup>6</sup> while the total population of greater Grahamstown, which is inclusive of the black communities that lie on the periphery of the city, was roughly 125,000 people. Of the total population, 78 percent are black, 12 percent are colored, 10 percent are white, and less than 1 percent are Indian. The predominant language spoken in Grahamstown is

---

<sup>6</sup> Figures used are taken from the 2001 South African Census.

isiXhosa, while most residents also speak English and/or Afrikaans. Forty-five percent of the population was between the ages of 20 and 49 years of age, while 39 percent were younger than 20 years of age. During my fieldwork, adult HIV prevalence in Grahamstown was estimated at 17 percent (Kelly and Ntalbani 2007).



**Figure 1.2** Map of South Africa

## **Formation of Racially Demarcated Communities in Grahamstown**

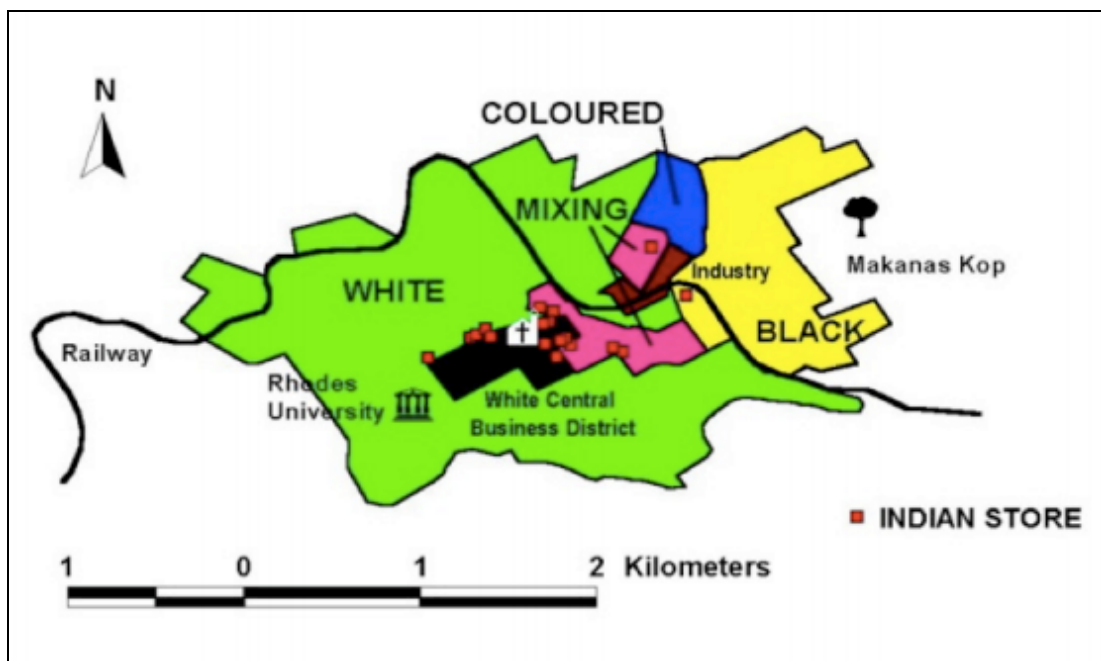
### *The Segregation Era*

Grahamstown was first established as a frontier space between European settlers and the amaXhosa in the region, and was proclaimed and named after Colonel John Graham in 1811. Over the next two decades, the area experienced a surge in English settlers following failed farming endeavors that forced them to move away from flood-prone areas like Port Elizabeth (formerly called Algoa Bay) and into neighboring towns (Irvine 2012). Grahamstown's population swelled from 400 residents in 1830 to 3,500

people by 1834. It was a dominant economic, political, and strategic colonial loci, at the time second only to Cape Town in size and importance (Irvine 2012:80) (see Figure 1.3).

Grahamstown's popularity drew amaXhosa to the town, and by the mid-1830s, there was an increase in Xhosa squatters in the area. In 1841, a separate Xhosa settlement was established, and in 1848, the Municipal Commissioners of Grahamstown officially designated the area now known as Grahamstown East (or Rhini) specifically for Africans. In 1857, those Xhosa who could afford to purchase land plots were given freehold title deeds, establishing the area currently known as "Fingo Village" (Irvine 2012:83). Other African areas were subsequently established, including Tanti in the 1870s and Xolani in the 1930s (Møller 2008:3). Formal land ownership, however, was not a viable option for most African residents, resulting in ensuing squatter settlements. The roots of the colored community in Grahamstown date back to 1829 with the establishment of the "Hottentot Village" populated by the Khoisan. Unlike some of the areas in Grahamstown East, landowning rights were not granted for this region of town. The area, expanded in 1945 and 1957, has since remained the center of the colored community in Grahamstown (Irvine 2012:83). In contrast to the black and colored communities, the Indian community in Grahamstown has always been small. Irvine characterizes the Indians who settled in Grahamstown as "'passenger Indians,' who came on the ships with those who were indentured laborers on the Natal sugar plantations" (Irvine 2012:83). Many Indians established businesses and lived within the Grahamstown Central Business District, at the time a racially mixed area (see Figure 1.3). The small size and economic standing of the Indian community made Indian residents

technically exempt from municipal regulations that forced residents to live in specific areas (Dullabah 1994).



**Figure 1.3** Grahamstown During Segregation Era, Mid 1930s

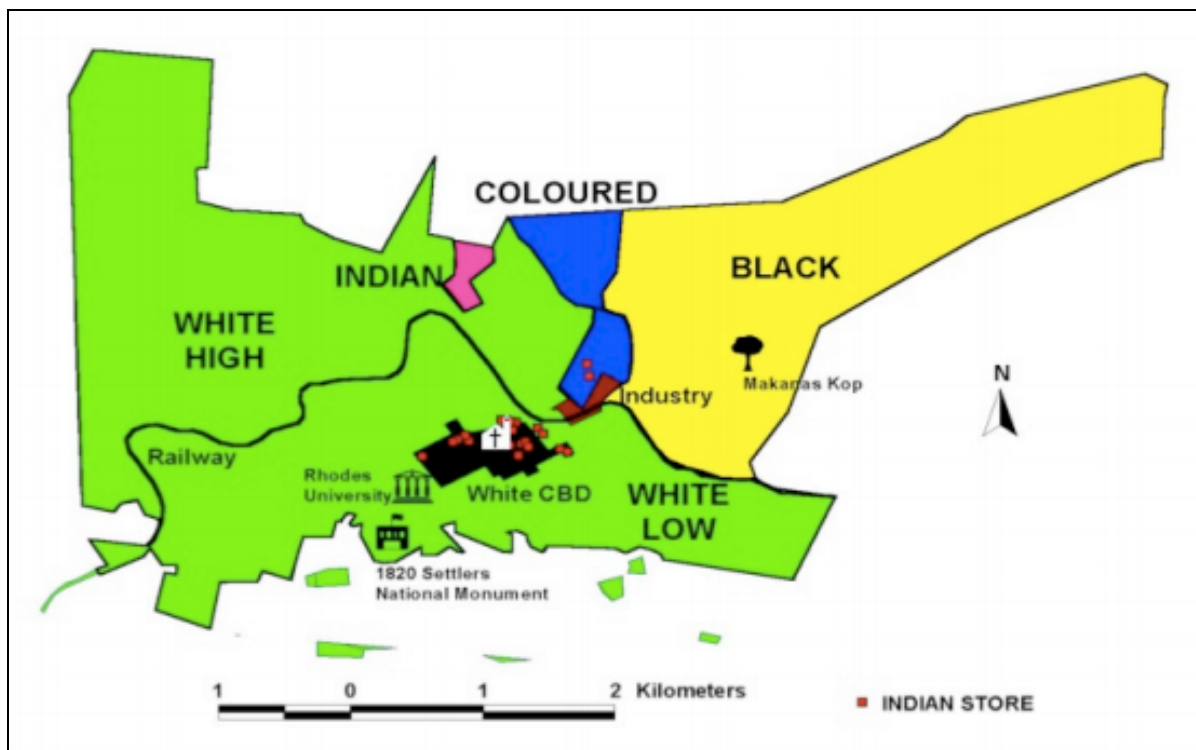
*Source: Fox 2009*

#### *The Apartheid Era*

Racially segregated communities became further entrenched during the apartheid era, but the strict legal demarcations enforced in most parts of the country were not realized in Grahamstown. When the Group Areas Act was passed in 1950, it took five years for the Grahamstown Council to submit zoning proposals to begin implementing state-prescribed apartheid demarcations in the city. By 1957, racial zoning was completed and the black population was to be moved from Grahamstown East and replaced with colored and Indian residents. This proposal was never implemented, however, and not revisited until 1970.

In 1970, the first white and colored areas were officially zoned, and the government proposed forcibly moving black residents to the Ciskei region (25 miles from

Grahamstown), and resettling those areas with colored residents. Plans to forcibly remove black residents out of Grahamstown were also never implemented, but residents living in the mixed areas were, however, removed to racially segregated parts of town. Indian residents who had previously occupied racially mixed areas were removed to Oatlands North, a new area designated under the Group Areas Act (Figure 1.4).



**Figure 1.4** Grahamstown During Apartheid, Mid 1980s

*Source: Fox 2009*

This removal was not entirely significant, however, since Indian commercial sites still remained within the CBD and further plans to move the Indian community to Port Elizabeth never materialized.<sup>7</sup> In many ways, the ensuing entrenched racial separation in Grahamstown (see Figure 1.5) is more a result of pre-apartheid demarcations that

<sup>7</sup> The proposed forced removal of Indian residents from Grahamstown to Port Elizabeth was thwarted by resistance from Black Sash members, a women's organization that actively opposed the apartheid system (see Irvine 2012:87).



perpetuated economic barriers along racial lines; less so a result of the Group Areas Act and apartheid legislation that more directly affected other regions across South Africa.



**Figure 1.5** View from Town: Colored Area and Black Townships in the Distance  
*Source: C. Jones*



### **The Rise of Resistance: The African National Congress**

The mission of the African National Congress (ANC), which became highly visible in the late 1980s, was to champion change and transformation in South Africa. These emotionally charged motives were fueled by the hope that the masses could, in fact, force a radical restructuring of the economy that would reverse the expropriation and exploitation of African labor and land (Gibson 2001:69). These aims were more concretely articulated with the adoption of the Freedom Charter in 1955. The Freedom Charter was used as a guide to establish an ANC political platform that promoted the redistribution of land and wealth, a mandate for private businesses to cooperate in promoting social wellbeing, and the responsibility of the state to meet the needs of the entire South African population. “As signatory to the Charter, the ANC was accurately seen as a black nationalist organization with a radical, socialist politics” (Peet 2002:68).

The anti-apartheid movement cultivated a participatory style of democracy that many hoped would form the foundation of post-apartheid South Africa. The translation of this radical restructuring into a pragmatic liberation theory, however, was a difficult task for the ANC. The ANC was able to exploit this ideological pitfall by “captur[ing] these narratives and celebrat[ing] the idea of ‘people’s power’ while remaining the self appointed future negotiators (Gibson: 2001:72).

Workers speaking for themselves, histories rediscovered, new forms of political elections, new cultural productions such as worker-theater and poetry were challenges to the ANC...[These actions were] slowly diverted back into ANC strategies [and] under the pressure of ‘unity’ alternative ideas became marginal. The call for ungovernability was the means to open up negotiations. The mass movement simply became its cannon fodder (Gibson 2001:74).

In 1994, the ANC was successful at reaching an historical settlement with the Nationalist Party that signaled the end of apartheid. The subsequent democratic elections were the

first to allow black South Africans the right to vote. The end of influx controls reflected the existing resistance to apartheid, and the mounting attempts by coloreds and blacks to effect change within the system. Many, united in the struggle against apartheid, saw democratically elected president Nelson Mandela and the ANC as the vehicles through which that change was going to come.

### **Post-Apartheid: Democracy, Reconstruction, and Development**

The end of apartheid created a new opportunity to create a reconstruction and development plan that focused on meeting the basic needs of the majority and more evenly distributing power. The ANC's landslide election victory was based on a platform created around its Reconstruction and Development Program (RDP), which emphasized two major aims: the alleviation of poverty and the reconstruction of the economy. These objectives were seen as interrelated: there could be no growth without development and "(p)olicies concentrated purely on promoting growth would accentuate existing inequalities and maintain mass poverty, and these would soon stifle growth" (Lodge 2003:54). The RDP was based on several principles that called for an integrated and sustainable program implemented through a people-driven process focused on ensuring peace and security for all. The RDP also promoted nation building, the linking of reconstruction with development, and the democratization of South Africa (Peet 2002:70).

Its targets included creating 2.5 million jobs in 10 years; building one million low-cost houses by the year 2000; redistributing 30 percent of arable agricultural land to black farmers within five years; and democratizing and restructuring state institutions to reflect the racial class and gender composition of society (Cheru 2001:508). The RDP

aimed to link the concepts of development and redistribution in ways that previously had never been formulated by the state. The RDP was successful at meeting some of its established goals, including connecting electricity to 1.3 million homes, providing free medical care to pregnant women and children under age six, launching of almost 500 public works projects. Under RDP many “informal” housing areas were razed and replaced with RDP homes (Figure 1.6).



**Figure 1.6** RDP Houses in Grahamstown

*Source: C. Jones*

In Grahamstown, the suspension of the Group Areas Act in 1991 led to an expansion of informal housing as the townships experienced an overflow of new residents migrating into the city. RDP-sponsored housing improvement projects were initiated throughout the formal and informal areas of Grahamstown East. Colloquially, RDP houses are called “inzwane zingaphandle,” which translates from isiXhosa to “the toes stick out”—a reference to the compact size of RDP homes. It also acknowledges

awareness among those directly affected by RDP policies, and forced to move into a RDP house, which was not always an upgrade, especially among those residents who previously had larger “informal” homes. The program ultimately fell short of its goal to build one million homes, however, and came under fire for not having a clearly defined macroeconomic policy.

In 1996, without much warning, the ANC terminated the RDP, and rearticulated their goals in the form of the Growth, Employment, and Redistribution strategy (GEAR). The GEAR strategy was marketed as the macroeconomic counterpart to the RDP, but it was clear that this strategy represented a decisive shift from socialist approaches to neoliberal policies since GEAR supported economic policies that were largely structured in favor of foreign capital. More specifically, GEAR emphasized deficit reduction, government ‘rightsizing,’ tariff reduction, privatization, and productivity-linked wage rates (Lodge 2003).

Impoverished South Africans interpreted the ANC’s shift to GEAR as an abandonment of redistribution and development principles. This sharp transition had grave effects “on the ground,” especially for black and impoverished South Africans. The failure to meet RPD goals, specifically in the area of housing, meant that the many South Africans who stood to benefit from redevelopment initiatives were forced to continue to live in substandard homes. Many residents in Grahamstown, for example, continue to live in corrugated tin or mud homes (see Figures 1.7 and 1.8), and the majority of households in Grahamstown East still rely on pit or bucket latrines, since adequate flush toilets and sewerage systems have yet to be constructed.





**Figure 1.7** Corrugated Tin Homes in Grahamstown

*Source: C. Jones*



**Figure 1.8** Mud House in Grahamstown

*Source: C. Jones*

Some black residents I met during my fieldwork reported a sense of feeling “forgotten about by the government,” and expressed frustration about their living conditions. This sentiment was particularly strong among residents whose homes were razed or relocated in preparation for a RDP house that was never built. In contrast, the steady expansion of Rhodes University has led to new, gated housing developments in the white areas of town (Grahamstown West), commonly referred to as “Town” (Figure 1.9).



**Figure 1.9** Current Neighborhood Demarcations in Grahamstown  
*Source: C. Jones*

For outside observers, the ANC’s premature abandonment of the RDP in favor of GEAR may appear as a sudden break with the past. In reality, however, the ideological downshifting dated back to the pre-election period (1990-94), when the ANC leadership made a strategic surrender on the economic front. Although political power was handed

to blacks, economic policy followed the same neoliberal restructuring that began in the mid-1980s under the National Party of FW De Klerk. This sharp transition had grave effects “on the ground,” especially for black and impoverished South Africans, and also for many colored South Africans. “The large Colored population caught in between were also waiting, of course, though given their liminal social and political position—caught halfway between white and black worlds, theirs was a cautious *watchful waiting*, in which hope for the future was seasoned with fear that things might not work out so well for them” (Scheper-Hughes 2007:184, Crapanzano 1986). The subsequent shift to focus on reconciliation and economic development, however, was not coupled with a strategic response to the growing HIV/AIDS epidemic. In Chapter Four, I detail several key HIV/AIDS policy decisions in South Africa and trace the ways in which those decisions had direct implications for the lives of those infected with and affected.

### **Impact of Apartheid on HIV/AIDS**

Separationist legislation enforced during apartheid and entrenched structural inequality facilitated the conditions that led to the widespread transmission of HIV in South Africa during the early and mid-1990s. The connection between migration and sexual health in Africa has been established by previous studies (Navarro 1974; Turshen 1977; Murray 1977, 1980, 1981; Doyal 1981; Hunt 1989; Jochelson 1999). The combination of pass laws and the Group Areas Act forced a system of migrant labor that created a steady flow of cheap black labor for African industries, farms, and mines (Turshen 1977, 1984; Doyal 1981; Moodie 1994). This migrant labor system promoted the spread of gonorrhea, syphilis, and other sexually transmitted infections (STIs) throughout South Africa (Kark 1949), and also fostered sex work in many of the urban



areas (Doyal 1981; Stichter 1985; Hunt 1989). The cessation of the pass laws following the end of apartheid allowed blacks less restricted access to the urban centers, promoting an influx of blacks into the cities. This resulted in over crowding, and many people were subsequently pushed into urban slums and informal settlements that became key sites in the struggle for legitimacy and resources (Lefebvre 1974; Harvey 1990; Gupta and Ferguson 1997; Yacobi 2001; Haferburg 2002).<sup>8</sup>

These mass movements also increased both the possibility of HIV/AIDS transmission and increased both men's and women's vulnerability to it, among other STIs (Epstein and Packard 1987). The end of apartheid facilitated a sense of mobility and "border crossing" that manifested linguistically, ethnically, racial and physically, and had a direct impact on the spread of the virus. The ending of apartheid, however, did not eliminate the systems of inequality that had become so deeply entrenched in South African society.

The dismantling of the apartheid regime has not yet brought the dismantling of the structures of oppression and inequality in South Africa, and persistent social inequality is no doubt the primary reason that HIV has spread so rapidly in sub-Saharan Africa's wealthiest nation (Farmer 2003:45).

Susser (2009) demonstrates how the shift to embrace GEAR in 1996 was interconnected with several key moments along the trajectory of approaches and responses to HIV/AIDS, both within South Africa and globally:

In 1996, the same year as structural adjustments were introduced in South Africa, newly effective, life-prolonging AIDS drugs became available in the United States and Western Europe. The possibilities for AIDS treatment massively expanded and with

---

<sup>8</sup> The end of influx controls also generated discussion among city planners and developers about how to redefine spaces like the city center of Cape Town to better reflect a more progressive and racially integrated dynamic. I argue, that spaces at the periphery, like Grahamstown, however, were not included in that larger conversation about reconfiguring space. As such, Grahamstown, and other periurban areas that fall along the outskirts of formal urban areas are still delineated along racial categorizations, retaining colored, Indian, and black "areas."



this success the gap between the options for people in rich and poor countries starkly widened. To add to the situation of global inequality, just as AIDS treatment became available, the World Trade Organization initiated a multistage process of international patent laws, known as Trade Related Aspects of Intellectual Property Rights (TRIPS) that limited, among many other things, the manufacturing and distribution of new AIDS medicines (Susser 2009:93).

On the heels of the 1994 democratic elections, the South African Government was faced with the increasingly difficult challenge to transform the country and build a “new” South African society based on ideals of equality and human rights. This historical moment also became punctuated by the increasingly grave reality that the transition to democracy was happening concurrently with the onset of HIV in South Africa, leaving the majority of those infected without recourse for care and treatment (Fourie 2006).

### **The Healthcare Landscape in Grahamstown**

Grahamstown has an established network of HIV/AIDS initiatives, including the Grahamstown Community Center, the Township Health Center, the Center for AIDS Development Research and Evaluation (CADRE), Settler’s Hospital, Rhodes University, and the African Journal of AIDS Research. The available public medical and health resources in Grahamstown include Settler’s Hospital, Fort England (Psychiatric) Hospital, and Temba Santa Tuberculosis Hospital. This nexus of key organizations facilitated a nuanced, yet contained, exploration of my research questions. Despite the quantity of medical services in Grahamstown, however, the town is not immune to the greater province-wide challenges to health and healthcare. Post-apartheid healthcare services and expenditures continue to perpetuate entrenched unequal access to health resources and care through the government’s promotion of growth in the private health sector, while local services remain largely fragmented (McIntyre et al. 2008). For many participants, specifically women, these challenges are compounded by failed and delayed

HIV/AIDS policy decisions made at the national level during the transition from apartheid to democracy (see Chapter Four). The Eastern Cape remains one of the most poverty stricken regions in the country and is consistently ranked highest among provinces with number of residents living at or below the national poverty line.

In the following chapters, I highlight the personal experiences among participants in order to describe the ways in which reliance on biomedical categories, while seemingly objective, belies and obscures the lived realities of PLWHA in Grahamstown. First, I outline my methodology and describe the ethical and methodological challenges I faced in the field. Next, I explain the state-prescribed HIV/AIDS testing to treatment process to critique the ways in which that model does not map on to the social complexities of living with HIV/AIDS. Finally, I build on the illness narratives of participants to offer an analysis of how multiple factors, including gender, and structural and economic inequality, shape the health-seeking process.

## CHAPTER TWO

### **Methodology: Approaches to Community-based HIV/AIDS Research**

My engagement with South Africa began in 2001 as an Oberlin College undergraduate student. I participated in the International Human Rights Exchange Program (IHRE), based in Cape Town, during which I enrolled in courses on identity, difference, and culture. I was challenged by a multidisciplinary team of instructors and students from the United States and South Africa to explore the cultural dynamics of identity and difference through the themes of Manichean psychology and structural violence (Bulhan 1985), race and ethnicity (Fanon 1967), and the relationships among citizenship, nationality, and space (Holston and Appadurai 1996). During the summer of 2004, I conducted exploratory dissertation research in Cape Town, South Africa and took a course on HIV/AIDS at the University of the Western Cape, also as part of IHRE. My class that summer aided me in a deeper exploration of the emergence of HIV and AIDS discourses and the ways in which conflicting constructions of the virus complicate prevention and intervention efforts (Sontag 1989).

Informal interviews I conducted in Cape Town and Grahamstown during the summer of 2005 revealed that despite the prevalence of human rights work that was being done to address HIV/AIDS (Mann 1999), the *rights* framework was not seen as the only effective model to address existing inequalities. In fact, some informants called for a paradigm shift away from the management of inequalities through broad mechanisms—like human rights—to a focus on the production of pragmatic services that more effectively protect and secure life (Farmer and Gastineau 2002, Foucault 1977). These

pragmatic services included addressing the socio-economic challenges people face on a daily basis, with an understanding of how these challenges directly impact health-seeking practices. I became most interested in the intersections among health, inequality, and structural violence, with a specific focus on the ways in which HIV/AIDS affects members of resource-poor communities. My dissertation research questions and methodology were subsequently shaped by an interest in these themes. In this chapter, I outline the research design, methodology, and data analysis approach to answer my research questions and glean a deeper understanding of the individual and community level responses to antiretroviral treatment among HIV/AIDS infected and affected participants in Grahamstown. In this chapter, I also outline my broader community engagement experiences to highlight the ways in which I gained access to and became deeply involved within the community. Lastly, through ethnographic narratives, I discuss the ethical considerations and methodological challenges I faced while conducting field research centered on such a personal and sensitive topic.

### **Site Selection: Grahamstown, South Africa**

Spatial transition following the end of apartheid became a critical issue across South Africa. While many scholars focused on South Africa's inner cities and major urban hubs, other scholars have argued that small towns in South Africa were neglected, yet provided rich opportunities to explore post-apartheid desegregation (Lemon and Clifford 2005). My preliminary research in South Africa (summers 2004 and 2005) was based in Cape Town, and despite the potentially rich data available in Cape Town, the area was saturated with HIV/AIDS researchers. Additionally, a large amount of research was also being conducted in many of the rural areas of South Africa to capture the spread

of HIV from urban centers to rural nodes. Grahamstown offered a unique opportunity to explore the dynamics of the HIV/AIDS epidemic within a context in which inequality and health intersect in critical ways—that fall outside of the strict city/country dichotomy and manifest in what is considered a peri-urban community. Selecting this site enabled me to undertake a more comprehensive investigation of the epidemic that goes beyond its effects within exclusively urban or rural settings to offer an analysis of the dynamics of HIV/AIDS within a peri-urban community in which the lines between urban and rural disease patterns have become blurred (Patton 1994), and where the entrenched effects of apartheid persist.

### **Community Sites**

Within a context in which the negotiation of illness is often a collective experience, community-based HIV/AIDS voluntary counseling and testing (VCT) centers emerge not only as sites of health information, but also as mediators between community residents and the complex dynamics of healthcare system(s), policies, and structures. These relationships became particularly important as patients tried to reconcile biomedical models of healthcare with cultural and traditional systems of healing. Both of my primary research sites, the Grahamstown Community Center (GCC), Grahamstown's first voluntary HIV/AIDS testing and counseling center, and the Township Health Center (THC) were important sites of investigation because they served as critical links between HIV/AIDS *testing* and HIV/AIDS *treatment*. Both provided windows into the dynamics of how people negotiate HIV/AIDS within their daily lives (further discussed in Chapters Four and Five). I chose these sites because they were the only two sites in Grahamstown that provided daily social support for HIV-positive clients independent of a medical

facility. I believed that conducting research at these sites, versus medical facilities, would allow me to develop an ongoing rapport with clients and staff and observe the ways in which patients attempted to garner social support among themselves and the centers' staff members. They were the most viable sites for observing and collecting data about ongoing process of illness management.

### **The Grahamstown Community Center**

The GCC was established in 1999 by a group of local volunteers as a support center for local residents infected with HIV. After a year of loose organization, the Center was formalized under the umbrella of the Anglican Church and became Grahamstown's first voluntary counseling and testing center. The core objectives of the Center are to offer:

- HIV prevention, education, and training
- Voluntary counseling and testing
- Prevention of mother to child transmission
- Resources for orphans and vulnerable children
- Rural mobile counseling and testing
- Emergency food support, and
- Legal advocacy

During my fieldwork, the GCC was staffed by Teresa (the director), Karen (the operations manager), a business manager, two VCT pre/post-test counselors, a nurse, a rural outreach coordinator, and a driver. The GCC is dedicated to improving access to HIV/AIDS services by providing support, education, and life-skills training to people living with HIV and AIDS, achieved through on-site support and community outreach

initiatives. The services ranged from workshops on aspects of living with HIV, English classes (taught by Rhodes University students), yoga, and gardening. The GCC was the only HIV/AIDS community center in the Eastern Cape Province that provided rural mobile testing. The Nikithemba (“giving hope”) Rural Outreach Program, allowed the rural outreach coordinator to travel to local farms and other rural areas to educate residents about HIV/AIDS and provide testing and counseling services.

An average of 15 clients attended the GCC on a daily basis as part of a rotational support group. After two or three months, another group of regular clients would replace the current clients. Clients were provided daily transportation to and from the Center and were given breakfast and lunch. Most clients reported coming to the Center to be in a safe and supportive environment, and the supplemental activities were an added incentive. As one client commented, “Most of us have nothing to do if we are not here. It is important that we don’t sit alone with HIV.” In addition to hosting regular, daily clients, the GCC provided services for over 1,000 people per month who were dependent on the Center for food parcels, school fees, and legal advocacy. The ideal operational model of the GCC did not always work smoothly, however, and some clients stayed for months, even years. It was challenging for Theresa to dismiss clients, as dismissals led to feelings of being “thrown away” and fear among clients about how to cope with HIV/AIDS after their tenure at the GCC was completed. Despite the GCC’s mission on paper, however, the Center struggled to offer a regular or sustained schedule of workshops and daily support services. By the end of my fieldwork, only two or three clients regularly attended the Center on a daily basis. This was partially attributed to the GCC’s lack of transportation services after the death of the Center’s long-time driver,

affectionately known as “Tatamkhulu” (grandfather). Without a mode of free transportation to and from the GCC, very few, if any, clients could afford the daily round-trip minibus taxi fare from the townships to the Center.

### **Township Health Center**

Participants were also recruited from the Township Health Center (THC) whose goals mirror those of the Grahamstown Community Center, but are achieved primarily through door-to-door outreach initiatives. The Township Health Center was established in 2005 and is located in Extension 9, a section of the black township adjacent. The creation of the THC was the result of a local pastor’s dream; a pastor who decided to open a facility with a single mission: to help HIV-positive people in need. The THC and GCC were often referred to as brother and sister organizations, but in reality, the relationship between the two had deteriorated, since funding remained highly competitive and the services they offered frequently overlapped.

Interestingly, despite the strong desire of the THC founders to create a place of solace and assistance for those infected with and affected by HIV and AIDS, the official name of the Township Health Center was changed following a protest by members of the local township community. Neighbors adjacent to the THC believed that including the word “AIDS” in the name of the center would unfairly stigmatize them based on their proximity to the THC. They were afraid that people who visited the THC would think that all of the residents in that area were HIV-positive. In response, the name was changed from Township Health *AIDS* Center to the Township Health Center. On one level, the protest and subsequent name change demonstrated just how deeply the stigma of HIV and AIDS had permeated society in both Grahamstown and throughout the



country. People were afraid that they would be deemed HIV-positive simply by association and through the proximity of their homes to the center. On another level, the name change was somewhat ironic. Since the THC was operating with limited financial resources, they were only able to alter the sign and not replace it. The word “AIDS” was painted over with a thin coat of paint, leaving an obvious void when you looked at the sign. Yet, as you walk into the building and pass the sign, the word AIDS is still visible. Symbolically, this demonstrated the ways in which local communities were attempting to grapple with the deep fear of HIV/AIDS stigmatization.

### **Research Questions and Data Collection Methods**

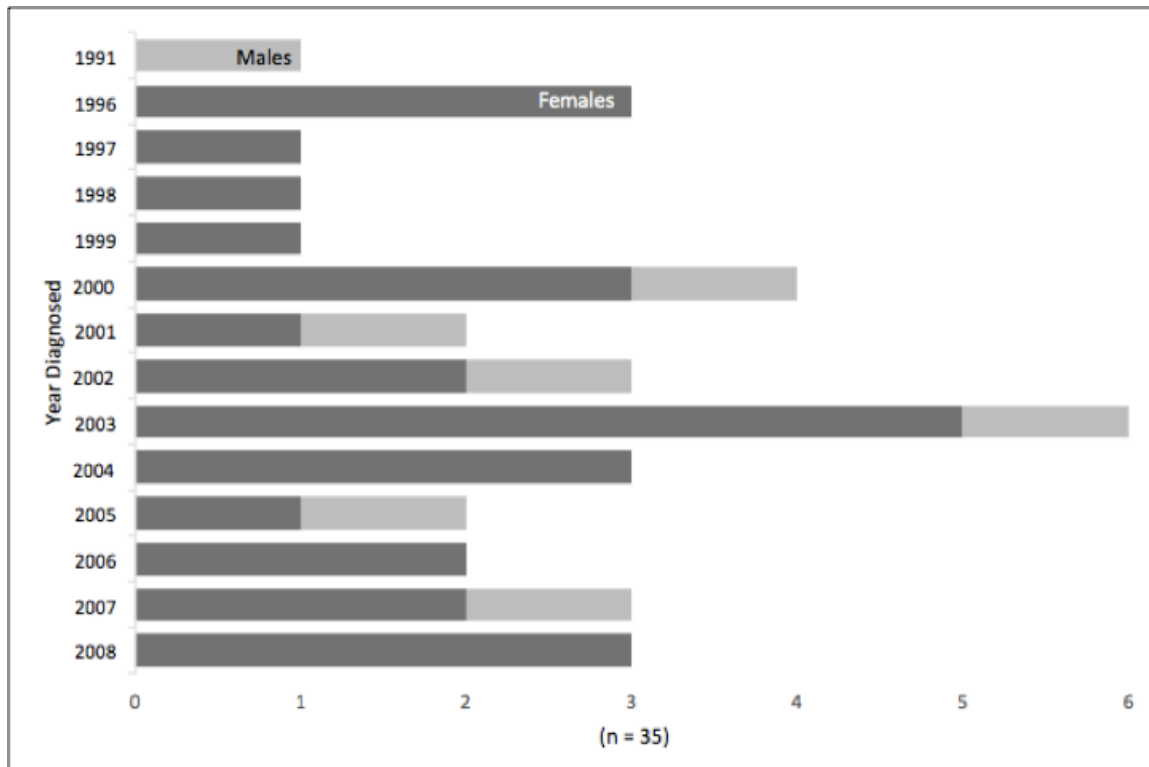
The following research questions guided my inquiry:

- Q1. What factors affect people’s general conceptualizations of HIV/AIDS in Grahamstown, South Africa?
- Q2. How do these factors shape people’s practices when choosing to begin, refuse, or modify their HIV/AIDS treatment?
- Q3. In what ways do health policies shape the health-seeking practices among those infected with and affected by HIV/AIDS?
- Q4. What barriers create challenges for people in need of HIV/AIDS treatment?
- Q5. What implications do these barriers have on the long-term effectiveness of HIV/AIDS treatment programs and the general public health within the local community and abroad?

At the broadest level, my research sample was comprised of 80 participants, including HIV-positive clients, the staff and care workers from the GCC and THC, and community members active in HIV/AIDS care and treatment efforts in Grahamstown.

From within this broad sample, I recruited 35 HIV-positive men and women to participate in the study. Participants from the GCC and THC had all openly disclosed their HIV-positive status—with the exception of one client from the THC who had selectively disclosed to only a few people, including my research assistant. This client was recruited by Mandisa and disclosed her status to me during our interview.

Participants were selected with assistance from the directors and staff at each community center and were screened based on their age, gender, time living with HIV/AIDS, and whether or not they had begun antiretroviral treatment. The goal during recruitment was to include participants with a range of health-seeking practices and life and illness histories. The final sample included 28 women and seven men (all the men were clients of the THC). Participants' ages ranged from 23-58, with the average age of GCC clients at 38 and 35 at the THC. All of the clients ( $n = 19$ ) of the GCC had given birth to children, although some had since passed away. Most clients at the THC ( $n = 16$ ) reported having children, and only three did not. The average level of education was Standard 7 (Grade 9), with only three clients reporting completing Standard 10 (Grade 12). The earliest HIV-positive diagnosis in the group was in 1991, and the most recent in July 2008 (Figure 2.1).



**Figure 2.1** Male and Female Clients by Year Diagnosed

### Participant Observation

Participant-observation remains a hallmark research method among anthropologists. It allowed me to remain an active part of the local fabric of the community, while also maintaining a critical distance for observation. The GCC and THC served as my key sites, and I also conducted observations at Local AIDS Council meetings and community HIV/AIDS-related events. I gained access to these sites through introductions from Teresa, Karen, and members of the local church I attended during my fieldwork. The core of participant observation relies on the intentional integration of the researcher into the research setting in a manner that facilitates an insider's understanding of the daily workings of the organizations. I chose to spend several days during the initial stages of research simply “hanging” out at the GCC in

order to both understand the culture of the organization and identify key areas of interest that would later shape both my semi-structured and in-depth interviews. Observational data included descriptions of the physical environment, how the clients and staff at each key site flowed through and interacted in the space, and interactions between clients and among the clients, staff, and center directors.

My observations were recorded in detailed ethnographic field notes, both written and verbally dictated. Throughout the tenure of my research in Grahamstown, my field notes served as a medium through which to record my impressions, insights, questions and concerns. These notes were an important and integral part of the ongoing analysis and constant reshaping of my project while in the field. Reviewing my field notes and maintaining observations also shaped the ways in which I felt I could contribute to my research sites, thereby creating a reciprocal relationship that involved active engagement participant-observation and community service. Initially, it was very challenging to visit the GCC several days a week and just “be there.” Yet, “being there” allowed me to ease into the community and lay a solid foundation of trust and accountability. This later proved invaluable when clients felt comfortable enough with me to share their very personal and sensitive sexual health histories and experiences.

### **Informed Consent and Human Subjects Protections**

The Rutgers University Institutional Review Board approved this project in January 2008, and throughout my fieldwork, I remained cognizant of the necessary human subjects protections. To obtain informed consent, the aims of my study were clearly explained to all prospective participants in plain language. I also made it clear that each participant could choose to not participate and rescind his or her participation in

the study at any point. Further, I ensured that participants were aware that they were able ask me questions about my research or me at any time. I initially chose not to use written consent forms because I felt that they would provide a record of involvement that might be read as reflecting an HIV-positive status, possibly exposing the participants to the stigma that is attached to being HIV-positive in South Africa. Subsequently, however, while I relied mostly on oral consent, I also provided a written consent form for participants to read that was translated into English and isiXhosa. For participants who spoke Afrikaans, they were able to read the English version of the consent form. Participants also were informed of the confidential nature of the data collected. I ensured confidentiality by using pseudonyms and securing all materials in protected computer files and locked storage cabinets at my apartment. Participants also had the option to decline to have their interviews audiotaped as part of a separate consent process, but all consented to have their interviews audio-recorded.

### **Unstructured, Semi-structured, and In-depth Interviews**

During my research, I employed a number of interviewing strategies, including unstructured, semi-structured, and in-depth interviews. Unstructured interviews were primarily conducted during impromptu conversations before and after formal meetings such as the monthly Local AIDS Council meetings. I also conducted informal interviews with staff and volunteers at the GCC, THC, faculty members at Rhodes University, and Grahamstown residents to develop an introductory understanding of HIV/AIDS in Grahamstown. Informal interviewing was most useful during the initial phase of my research because it allowed me to uncover salient topics of interest that emerged from informal conversations and observations throughout the day (Bernard 1995:209). These

interviews followed a very conversational style that was helpful in guiding future interactions. The responses given often raised questions and concerns that were later explored in subsequent semi-structured interviews.

Semi-structured interviews were conducted among key stakeholders at my research sites, including several with the staff and directors of the GCC and THC. For these interviews, I developed an interview guide that outlined the questions and concerns I planned to address pertaining to each center's history, the services it provided, operational practices, and relationships within the HIV/AIDS network in Grahamstown and the Eastern Cape Province. During the interviews participants shaped the exchange and generated new avenues to explore based on their responses. Some of the questions I asked included:

- What HIV/AIDS-related programs or initiatives do you operate?
- What is the range of services provided through these initiatives?
- With which organizations do you work most closely within Grahamstown? In other parts of the province?
- What approaches do you use to advertise your services or solicit involvement within the community?
- What are the challenges you face or have faced in trying to sustain your HIV/AIDS-related initiatives?

From these interviews, I was better able to understand the full range of treatment options available in Grahamstown and the challenges that patients and community health workers faced. Most importantly, I began to understand how people made decisions about whether to refuse or modify their ART regimens.

*Life history and illness narrative interviews*

I conducted in-depth life history interviews with each of the 35 HIV-positive research participants. During the life history interview, I was able to gather data from each participant and situate their experiences within a larger sociopolitical and economic framework. I also solicited respondents' illness narratives (Kleinman 1988), a medical anthropological tool that allowed me to better conceptualize how each participant situated HIV/AIDS within their greater life histories. During these in-depth interviews, participants had the opportunity to voice their experiences, something many expressed as a primary motivation for agreeing to be part of my study. One participant, for example, was disappointed when during the consent process I explained that her name would be changed to protect her information: "I want people to know that this is *my* story! I am proud of who I am and I want to keep my name," she declared. I ultimately chose a pseudonym for her, but the moment highlighted one aspect of why my project was seen as important among members of the community. Those infected and affected by HIV/AIDS wanted to share their experiences. Despite the stigma that surrounds HIV/AIDS, they were intentional about sharing those experiences, giving life to their circumstances, and in the process finding ways to garner emotional, and in many cases, instrumental social support.

The life history interview process was guided by each participant's communication style and personal approach to sharing their illness narrative. It was a non-invasive way to explore sensitive personal issues, and allowed each participant the freedom to guide the exchange. Some participants chose to start their narratives from the time of their HIV diagnosis, while others began at their childhood, nostalgically sharing

memories of “a better time.” Some interviews, particularly those with men, followed a more traditional interview format in which they responded to direct questions and rarely, if ever, redirected their responses to other topics or themes. In some cases, it was more challenging to structure the interview process with participants who went on long, unrelated tangents.

During each interview, I remained aware of body language and social clues to determine when it would be appropriate to ask follow-up questions or probe further. Usually, I was able to interject during natural silences in ways that did not disrupt the narrative. Some follow-up questions were met with blank stares, while other participants were very intent on controlling the flow of the interview, ignoring or refusing to respond to certain probes. Topics that I assumed would not be freely discussed, including condom use (or lack of) among HIV-positive participants, did not pose any difficulty in soliciting responses among participants. Most participants were forthcoming about their condom use behaviors— many of them having chosen not to regularly use condoms— despite their assertions and clearly understood the implications of not protecting themselves and/or their partners during intercourse. Some participants were more reserved and hesitant to openly discuss other lifestyle choices, however, including infidelity and alcohol use.

On average, each in-depth interview was 30 to 45 minutes long, and the longest was two hours. During each interview, I attempted to elicit a participant’s 1) demographic information, including age, number of children, number of people living in the household, level and source of income, and level of education, 2) illness history, including method and location of HIV testing, date of HIV diagnosis and other illnesses,



if applicable and 3) the health-seeking behaviors each participant had or was currently engaged in, including where they sought help and support, to whom they chose to disclose their status, and whether or not they had begun to use and/or adhered to antiretroviral treatment.

I completed three courses in isiXhosa (two prior to leaving for the field and one at Rhodes University during fieldwork). I felt proficient during daily, conversational exchanges, but was not fluent enough in isiXhosa to conduct in-depth interviews. The majority of participants in my study spoke isiXhosa, others spoke Afrikaans, and a few were fluent in English.<sup>9</sup> Due to the sensitive nature of my research, it was important to me that participants felt comfortable to conduct the interview in the language(s) they were most comfortable. Of the participants who were fluent in English, only one chose to respond to interview questions solely in English. Most responded exclusively in isiXhosa or Afrikaans, while some switched between isiXhosa and/or Afrikaans and English during a single interview.

To compensate for any language barriers during the interviews, I hired a research assistant, Mandisa, who is fluent in isiXhosa, Afrikaans, and English. In addition to being multi-lingual, Mandisa was a former HIV/AIDS community health worker, well versed in the medical terminology necessary to effectively translate the subject matter, and was intimately familiar with HIV/AIDS prevention and treatment initiatives in Grahamstown. During interviews, I asked questions in English, Mandisa translated them to the participant in the applicable language(s), the participant responded in whichever language they felt comfortable, and Mandisa translated the response back to English,

---

<sup>9</sup> Unstructured and semi-structured interviews with stakeholders and staff were all conducted in English. My research assistant was only present during the life history and illness narrative interviews with GCC and THC clients.

when necessary. The participant narratives and quotes used throughout the dissertation are taken from transcriptions of the English translations provided by Mandisa during the in-depth interviews. To verify the accuracy of Mandisa's translations, I hired a part-time research assistant to listen to a random sample of interviews and independently translate excerpts. His translations closely aligned with Mandisa's and helped to reinforce my confidence in the English translations used in the dissertation. There were benefits and challenges related to my decision to include Mandisa as part of the in-depth, life history interviews. Many of the participants were familiar with Mandisa through her community health work and service at the THC. I was initially concerned that those existing relationships would complicate the interview process or make participants hesitant to be candid in their responses, but her presence was welcomed and seemed to put participants at ease because of their common ground of experiences in Grahamstown. The major challenge I encountered was Mandisa asking follow-up questions during interviews without first translating her questions into English for my benefit. Most of the time, they were simple, clarifying questions. At other times, however, her probes were more extensive, and I had to request that she refrain from interjecting into the conversation. Ultimately, Mandisa's involvement with the study was essential, since her strong rapport with patients and positive reputation with community members helped to facilitate participant recruitment and receptivity to the research project.

### **Data Analysis**

I analyzed my research data with the goal of examining which factors shaped participants' health-seeking behaviors, and what barriers, if any, impacted those decisions. Qualitative data were analyzed through a series of iterative processes. Some

interviews were transcribed while I was in Grahamstown, which allowed me to identify preliminary themes and modify my interview guide for subsequent interviews. The bulk of the transcription was completed when I returned from the field. Most interviews were fully transcribed, while others were extensively indexed in the interest of time during data analysis. I first listened to all participant interviews in order to identify central themes and topics prevalent across the narratives. In the process, I created a matrix of categorical and qualitative data, detailing demographic information and other characteristics (i.e. gender, level of education, diagnosis date, and ART status). While listening, I also generated a hand-coded list of topical and interpretive codes, subsequently layering the topical codes with emergent themes. During coding, I concentrated on the key themes that emerged, with a particular focus on those responses that addressed my primary research questions. More specifically, I developed a codebook centered around participants' views about the range of treatment options available to them, the types of treatment people had sought, which organizations or service providers they used to facilitate their HIV/AIDS care or treatment, and what they saw as barriers or challenges to choosing or refusing antiretroviral treatment.

Based on the emergent themes across the interviews, I next developed participant profiles—some of which reflected specific participants, and others that were composites of several participants whose interview responses represented similar experiences across the interviews. Finally, my research was analyzed through a triangulation of statistical data, health records and information from the GCC, and the ethnographic data I collected. This approach facilitated a broad understanding of the experiences and challenges that PLWHA in Grahamstown face, revealing trends, gaps, or inconsistencies in those

experiences. A summary of the major findings of this study will be shared with all study participants.

### **Community Involvement**

One of the reasons I chose Grahamstown as my research site was because its size lent itself to close ethnographic work and the collection of very rich, nuanced data. In addition to participant observation at the Grahamstown Community and Township Health Centers, it was important to me to become deeply engaged within the community. I worked closely with several local HIV/AIDS-related organizations, including the Local AIDS Council (LAC). The LAC was established in 2006 and is comprised of members from area organizations committed to promoting HIV prevention and working collaboratively to address the needs of those infected and affected by HIV/AIDS in Grahamstown. In addition to the GCC and THC, the LAC is comprised of representatives from the Grahamstown mayor's office, Hospice (the organization responsible for palliative, end of life care), the Department of Education, Khomanani (the government sponsored HIV/AIDS awareness campaign), and the local chapter of the Treatment Action Campaign (TAC).

In addition to my ongoing work with the LAC, I also planned and executed several community events, including World AIDS Day and AIDS memorial services (Figure 2.2), Christmas and Back-to-School gift and supply giveaways, and monthly food parcel deliveries to families who depended on GCC outreach initiatives. I also helped to develop and coordinate innovative HIV/AIDS-related youth initiatives, including Camp Siyaphumelela (isiXhosa for "We are coping"), a camp for orphaned and vulnerable HIV/AIDS infected and affected youth. This level of community involvement was

instrumental in establishing my presence and authority in the field, and helping me to build rapport within the tight-knit HIV/AIDS community in Grahamstown.

Additionally, I received intellectual and institutional support from the History Department at Rhodes University under the guidance of Dr. Carla Tsampiras. A historian, Dr. Tsampiras' research focuses on political and historical aspects of HIV/AIDS in South Africa, and she was also the Chairperson of the University's Treatment Action Campaign (TAC) branch. While in the field, I served as a Teaching Assistant and guest lecturer for two of Dr. Tsampiras' courses: "Introduction to South Africa" and "History, HIV, AIDS, and South Africa."



**Figure 2.2** Banner from AIDS Memorial Service  
*Source: C. Jones*

## Reciprocity

The communal context of my field research made it imperative that I offered participants a token of appreciation in exchange for sharing their personal experiences. It was unsafe and unethical for me to offer monetary remuneration for fear of being robbed or biasing participant involvement and responses. The issue of food insecurity emerged as a dominant and recurring theme throughout my research (further addressed in Chapter Five), and guided my decision in choosing how I would display reciprocity. I considered a number of options and ultimately decided to give meat. In an environment in which hunger was prevalent, offering participants meat became an appropriate gesture. Further, meat carries great significance in South African culture—where the ability to buy meat is seen as a display of wealth and the consumption of meat, particularly at social events like braais (barbeques), creates social cohesion.



**Figure 2.3** Meat Parcels Given to Participants

*Source: C. Jones*

The irony of this gesture was not lost on my participants, many of whom were aware that I was a vegetarian. I was very deliberate when I purchased the meat and chose specific cuts of beef based on recommendations from community members. Once purchased, I blackened out the price tag on each packet to eliminate competition and comparison among participants. I stored the meat in a deep freezer at the GCC, and after each initial interview gave each participant a meat parcel. While the meat parcels most likely provided some incentive for participants to be part of the study, most had already agreed to be interviewed before knowing that they would receive anything from me.

### **Challenges in the Field: Death and Temporal Boundaries**

I confronted various methodological ethical issues while conducting fieldwork in Grahamstown. The greatest challenge I encountered was processing trauma—both the everyday heaviness of participants’ narratives of suffering and the temporal reality of death.

---

When I arrived in Grahamstown in March 2008, I was nervous and anxious about conducting fieldwork. On my third day in Grahamstown, Teresa gave me a tour of the town to highlight “some important changes that have been made since you were last here.” Our last stop on the tour was the palliative care and HIV/AIDS wards at Settler’s Hospital, which had both been remodeled since my last visit to Grahamstown. The HIV/AIDS and palliative care wards at Settler’s Hospital previously had poor reputations because both wards were dilapidated and constantly lacked basic medical supplies. Patients were required to bring their own blankets and due to staff and medication shortages, had at times been turned away from the hospital and sent to “die at home.” As

I walked in to the dimly lit foyer of the palliative care ward, I admired the renovations, but remained keenly aware of the heaviness in the air as families were saying their last goodbyes and preparing funeral arrangements.

That afternoon, I met a woman named Denise, who was a client at the GCC. I did not know her history, how old she was, or the series of events that left her spending her last days in the palliative care ward. She was suffering from an extremely severe case of thrush and was unable to speak, simply nodding or shaking her head in response to our questions and comments. At one point, she pressed her hands together in a posture of prayer, requesting that we pray with her. Teresa and I prayed with her and wished her peace in her final days. Although extremely frail, she weakly smiled and shook our hands as we departed her room.

After leaving the palliative care ward, we walked to the HIV/AIDS unit. Unlike the palliative unit, the HIV/AIDS unit is designed to care for HIV-positive patients who are experiencing complications, either from opportunistic infections or adverse responses to antiretroviral treatment. It is intended for patients who require short-term medical attention. We entered the ward through two large swinging doors and immediately were in the patient quarters. The space was filled with hospital beds lined up against the walls along the perimeter of the room. Some patients were busy chatting with each other, others were asleep, and some just seemed to be relaxing. There was no privacy, as each person could look around the room and see all of the other occupants.

Teresa introduced me to another client of the GCC who had recently been admitted to the HIV/AIDS ward. In contrast to Denise, Janet was energetic, extremely talkative, and nothing about her physical appearance alluded to illness. Days earlier, she



had been discharged from Temba, the tuberculosis (TB) hospital, and told us that she had just begun antiretroviral treatment. After spending six months at the TB hospital, Janet was looking forward to going home and being reunited with her family. She was thrilled to have finally been readied for treatment.

Within five days, both women were dead.

---

Within a week of being in Grahamstown, I experienced the first of many deaths. It was incredibly challenging to conduct fieldwork in a context in which time and temporality were so tangible, fluid, and fleeting at the same time. It meant that while my methodology needed to be organized around my previously scheduled time in the field, it also had to be flexible to account for the reality that my research participants could die during fieldwork or become too sick to remain involved with my study. None of my core study participants passed away while I was in the field, but some became too ill to complete subsequent interviews. Sadly, some have died since my return to the U.S. I chose not to attend any funerals while I was in the field as a way to buffer the experience of witnessing the deep suffering participants expressed. The deep participatory nature of my fieldwork, however, meant that it was often impossible to maintain that distance. I remain grateful for the opportunity to give voice to the deeply personal lived experiences entrusted to me by participants.

## CHAPTER THREE

### **HIV/AIDS Policy and Women's Experiences of Illness Management**

*If I were going to design an infection that was going to ravage this country, I could not do better than HIV and AIDS.*

– Salim Abdool Karim<sup>10</sup>

On the heels of the 1994 democratic elections, the South African Government was faced with the increasingly difficult challenge to transform the country and build a “new” South African society based on ideals of equality and human rights. This historical moment also became punctuated by the increasingly grave reality that the transition to democracy was happening concurrently with the onset of HIV in South Africa, leaving the majority of those infected without recourse for care and treatment (Fourie 2006). Scholars have highlighted the importance of capturing the historical and political context as a way to inform a broader understanding of the HIV/AIDS epidemic (Susser 2009, Parker 2001, Bond et al. 1997).

In this chapter, I detail the key HIV/AIDS policy decisions that were part of the backdrop to many of the personal experiences highlighted across participants' illness narratives. Women's experiences of HIV/AIDS illness management and health-seeking emerged as salient themes across my data. Their stories reflected the ways in which

---

<sup>10</sup> Quoted in Cohen 2000. Salim “Slim” Abdool Karim, former head of the HIV Prevention and Vaccine Research unit in Durban, commented that the South African government's confused response to the epidemic, confounded by high rates of STIs, widespread poverty, and a large migrant workforce provided “fertile ground” for HIV: “You couldn't ask for anything else.” The themes of poverty, population influx into urban centers, and shifting discourses on HIV/AIDS in South Africa are constant undercurrents among the narratives of HIV-positive participants that I detail in the subsequent chapters.

historico-political and biological differences among women (e.g. the ability to become pregnant) compounded their experiences of negotiating HIV/AIDS care and treatment. As Susser (2009) highlights, “With respect to every aspect of HIV, transmission, diagnosis, treatment, access to care, care-giving, reproduction, and stigma, women have particular experiences and needs different than men” (2009:33). My goal in this chapter is to trace the lived implications of those policy decisions and detail the dire and lasting consequences experienced among those women infected with and affected by HIV.

Like many ethnographic studies, my fieldwork was extensive and conducted over a protracted period of time from March 2008-May 2009. The benefit of an anthropological, ethnographic approach is that the resulting data are richly nuanced and offer in-depth insights leading to thoughtful analyses. The challenge, however, is that the contextual moment is often overtaken by more current events. In this and the following chapters, much of the ethnographic data drawn from participant interviews speaks to a period in South Africa when AIDS was still extremely stigmatized and healthcare policies were less refined than they are currently. In presenting these data, my aim is not to portray a static representation of timelines, but to highlight the enduring primacy of past events within the present-day lived experiences among study participants. As I detail throughout the dissertation, there are many insights that can be gleaned from their narratives to inform a deeper understanding of illness and antiretroviral treatment negotiation in South Africa.

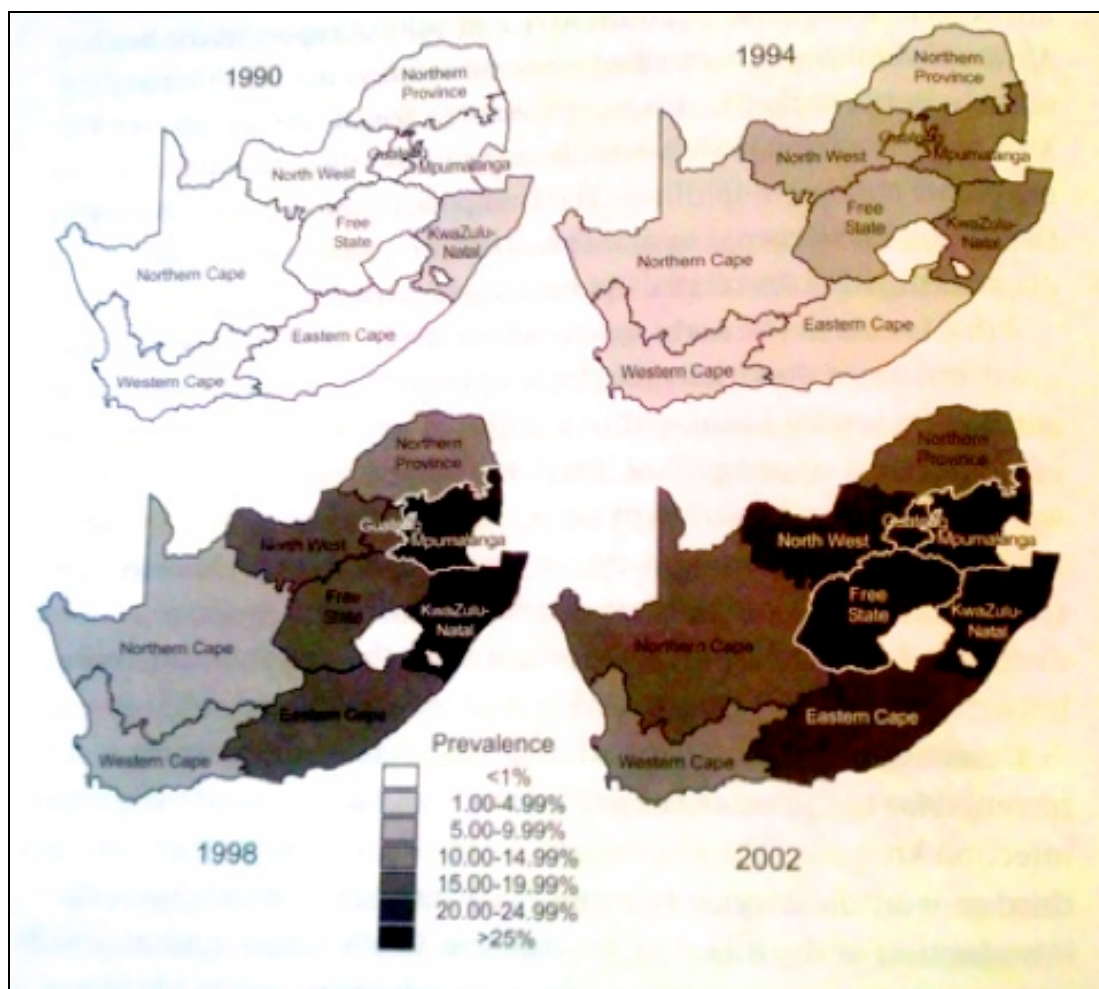
### **Onset of HIV/AIDS in South Africa**

The first AIDS cases in South Africa were reported in 1982 (Ras et al. 1983). The South African Medical Journal detailed two cases, both homosexual men,

leading to the epidemic initially being framed as a “homosexual” problem and restricted among special “at risk” populations, including hemophiliacs.<sup>11</sup> This initial framing led to a marginal response by the government in the 1980s to create a direct response to address the spread of the virus. By 1989, a rise in heterosexual cases confirmed that HIV incidence was increasing among the heterosexual population. In 1990, antenatal (prenatal) surveys were implemented in government clinics across each province as a way to gather HIV and other STI surveillance data. The first antenatal surveys in the 1990s indicated that less than one percent of women tested were HIV-positive. By 1994, HIV prevalence rates had begun to climb, but the highest national rates, in Kwa-Zulu Natal and Mpumalanga Provinces, remained below 15 percent. In 1998, there was a drastic rise in prevalence, however, and by 2002, much of the country reported HIV prevalence rates of 20 percent or greater (Figure 3.1). Figure 3.2 offers a continent-wide perspective of HIV prevalence rates over the same time period, and illustrates South Africa’s transition from low prevalence to an epicenter of the pandemic. These rate changes directly correlate with the timing of the transition from apartheid to democracy, and underscore the public health implications of the delayed state policies outlined in this chapter, particularly in the immediate post-apartheid era.

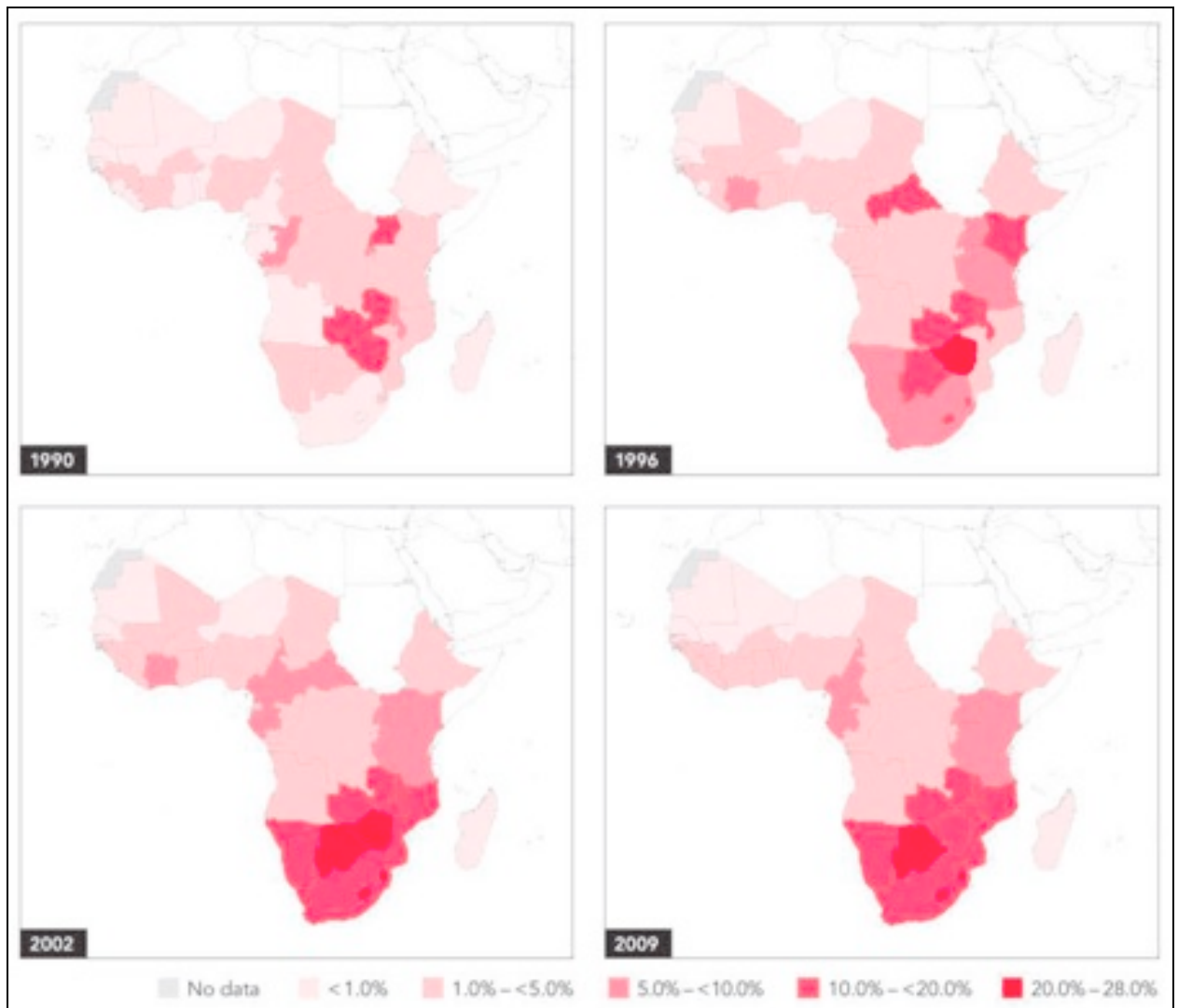
---

<sup>11</sup> This is reminiscent of the early framing of the AIDS epidemic in the United States. Following a purported trend among cases, the Centers for Disease Control and Prevention (CDC) described four AIDS risk factors: being of Haitian origin, homosexual, hemophilia, and heroin use (intravenous drug use). By the early 1980s, there were general references made about the “4H” club in the United States. The U.S. framing of HIV/AIDS, coupled with intense stigma attached to homosexuality in South Africa, were factors that influenced the slow response by the South African government to address HIV/AIDS in the 1980s.



**Figure 3.1** National HIV Prevalence 1990-2002

*Source: South African Health Department*



**Figure 3.2** HIV Prevalence in Africa 1990-2002

Source: UNAIDS

Rising prevalence rates underscored a need to shift from the previous discourse of AIDS as a homosexual issue to one inclusive of the growing awareness of the effects of HIV and AIDS among the heterosexual population. Once HIV was detected among black South Africans, however, it was deemed a potentially communicable disease and immigration officials were allowed to require HIV tests for potential immigrants and deny entry into South Africa based on HIV status

(Nattrass 2007:38). By the mid-1990s, incidence and prevalence of HIV among heterosexuals firmly planted the epidemic as predominantly driven by heterosexual transmission across the country and continent. This change in the framing of the virus, however, was not without critique:

Overall, since the measures of ‘heterosexual transmission’ do not in themselves imply the differences in cultural, economic, age, or physical power between the groups, the ‘men’ and ‘women’ incorporated indiscriminately in the term ‘heterosexual’ are in fact apples and oranges. Such confounding of categories makes it difficult to sort out the social and cultural pathways of risk and vulnerability” (Susser 2009:36).

The shift to describing the spread of the virus as heterosexually driven evoked a generalized characterization of transmission that failed to fully capture the nuances of infection and transmission. Infection and transmission were, in many ways, mediated by several differences, including gender and economic status. A generalization of those experiences often clouded the multiple and varied ways in which the epidemic affected those impacted by its spread. As I demonstrate in this chapter, while under the rubric of “homosexual transmission,” the implications of HIV/AIDS policy decisions and the transmission of the virus were often differently experienced among women.

### **Early Approaches to HIV/AIDS by the State**

The South African Government, particularly at the level of the Presidency, has been highly criticized for its approaches and missteps to addressing HIV, especially in the early stages of the epidemic. These approaches, however, were located within a larger context of what the immediate post-apartheid moment meant for South Africa politically. The conflicts that arose around HIV/AIDS were also about the struggle over voice and who had the power to speak for South Africa as it was defining itself vis-à-vis the epidemic. “Ultimately, it can be seen as an attempt on the part of the political leaders to

establish who will legitimately be accepted as civil society partners with the new state and the extent to which non-state actors can define government policy” (Schneider 2002:153). Ironically, the government’s critiques were voiced at the same time that new economic policies were being embraced. As discussed in Chapter One, the adoption of new economic platforms, like the GEAR strategy, underscored a shift to neoliberal policies that were also regarded as being anti-poor in many ways, particularly since these policies have subsequently exacerbated structural and economic inequalities and further entrenched poverty. The following sections trace government officials’ policy decisions, and document the key policies that comprise the national response to HIV and AIDS in South Africa following the end of apartheid through 2007. The policies highlighted in the chapter are not intended to be an exhaustive list of the voluminous HIV/AIDS-related decisions made by the South African government. Rather, I have two aims: 1) to highlight those policies and decisions that provide a topline understanding of how the national stance on HIV/AIDS evolved over time, and 2) to detail specific points within that trajectory that illuminate and help explain the context of the salient themes that emerged from the in-depth interviews with participants.

### **Transition to Democracy: The Mandela Presidency**

#### *Pre-Democracy: 1990-1993*

Following the first cases of AIDS in South Africa, the transition government demonstrated an initial interest in addressing HIV/AIDS. Figure 3.3 highlights some of the key policy decisions made during the pre-democratic transition.



<b>Pre-Democracy (1990-1993)</b>	
1990	Antenatal HIV surveillance surveys introduced
1991	HIV testing dropped from immigration requirements
1992	Free national AIDS helpline started
1992	MRC launches national AIDS research program
1992	NACOSA formed following meetings between ANC and Department of Health
1992	NACOSA shares comprehensive National AIDS Plan

**Figure 3.3** AIDS Policy Timeline: Democratic Transition<sup>12</sup>

In demonstrations of good intention, the government dropped HIV testing from immigration requirements in 1991, and in 1992, established a free national AIDS helpline. Also in 1992, the National AIDS Committee of South Africa (NACOSA) was formed to coordinate the country's AIDS response during the democratic transition. NACOSA developed a comprehensive AIDS plan in 1992 that was quickly adopted by the ANC in 1994 when the party assumed power.<sup>13</sup> The National AIDS Plan (NAP) was composed in collaboration with international organizations, members of South African civil society and a range of policy stakeholders. While it aligned with then-current WHO guidelines, it has been criticized for being far-reaching and idealistic with little focus on process and realistic implementation.<sup>14</sup> It would take President Mandela three years, however, to publically comment on AIDS. These early decisions during the transition to democracy seemingly reflected a prioritization of HIV/AIDS among the ANC, but this

<sup>12</sup> Timelines adapted from Nattrass 2007.

<sup>13</sup> The National AIDS Plan (NAP) was composed in collaboration with international organizations, members of South African civil society and a range of policy stakeholders. While it aligned with then-current WHO guidelines, it has been criticized for being far-reaching and idealistic with little focus on process and realistic implementation. For further discussion of the shortcomings of the NAP, see Whiteside and Sunter 2000 and Fourie and Meyer 2010.

<sup>14</sup> For further discussion of the shortcomings of the NAP, see Whiteside and Sunter 2000 and Fourie and Meyer 2010.

momentum would soon give way to a number of scandals and controversial missteps at the national level.

*Mandela Presidency: 1994-June 1999*

<b>Mandela Presidency (1994-June 1999)</b>	
1994	National AIDS Plan adopted
1997	Mandela calls for united action on AIDS
1998	HIV/AIDS education included in secondary school curriculum
July 1998	Price of AZT <sup>15</sup> is reduced in developing countries; government pilot launched to test effectiveness of AZT in Prevention of Mother to Child Transmission (PMTCT)
October 1998	Health Minister announces pilot PMTCT discontinued
January 1999	Western Cape provincial gov't defies Health Ministry and continues with PMTCT pilot

**Figure 3.4** AIDS Policy Timeline: Mandela Presidency

In 1994, during the early stages of Mandela's presidency, the National AIDS Plan was adopted. The government's initial progressive steps to implement national responses to the HIV/AIDS epidemic were drastically compromised in 1996 and again, a year later, in 1997. The *Sarafina II* controversy began in 1995 when South African playwright Mbongeni Ngema was first commissioned to produce a stage play intended to raise awareness and education about HIV/AIDS among young people in South Africa. Ngema was widely known for his anti-apartheid stage plays, most notably *Sarafina!*, which highlighted the involvement of students in the Soweto Riots during the anti-apartheid movement.<sup>16</sup> The National Department of Health granted Ngema a R14.27 million budget—a significant portion of the annual national AIDS budget—to produce the play. Payment was fast-tracked by the Health Minister in violation of the national tendering

<sup>15</sup> AZT and Nevirapine are both drugs taken to prevent mother to child transmission of HIV.

<sup>16</sup> The original *Sarafina!* was made into a filmed musical starring Whoopi Goldberg and later premiered on Broadway in 1998.

procedures, drawing criticism and official opposition in Parliament. By 1996, the play was ultimately deemed ineffective and many AIDS activists declared that the contents and key messages were unsuccessful in reaching the target population (Fourie and Meyer 2010). Disapproval of the Health Department and play were far reaching and scathing:

When the Department of Health embarks upon a R14.27 million exercise to fund a single stage production mounted by a person with an established track record of overspending on mediocrity and, in the process, sidestepping every known convention and procedure for the awarding of such a contract, one's hackles must inevitably rise (Eichbaum quoted in Fourie and Meyer 2010:94).

Fourie and Meyer (2010), drawing on work by Crewe (2000) and Cohen (2001), detail how critics of government responses to HIV/AIDS soon became viewed as enemies of the state and fostered an environment of confusion and distrust among AIDS activists and members of civil society, particularly the TAC.

Embarrassment continued for the Mandela-led government in 1997 with the Virodene scandal. Then Deputy President, Thabo Mbeki, expressed early opposition to supporting established best practices to addressing HIV/AIDS that had become widely adopted in United States and other western countries. Mbeki became a vocal AIDS dissident and refuted well-researched scientific claims about the relationship between HIV and AIDS and the efficacy of available antiretroviral treatment options. He threw his support behind two researchers from the University of Pretoria, Ziggy and Olga Visser, who “informed the Health Minister that an unofficial trial they were conducting on AIDS patients was showing that an antifreeze solution (dimethylformamide), which they called Virodene, was an effective antiviral medication” (Nattrass 2007:42). In effect, they were promoting an “African solution to AIDS,” which appealed to Mbeki’s mistrust of western science. “In its willingness to entertain the AIDS dissidents, the

South African presidency was not only aligning itself to certain scientific views, but also to a critique of the political economy of biomedical research” (Schneider 2002:152).

The Gauteng Provincial Department of Health and the University of Pretoria tested Virodene in a military hospital in Tanzania, and after a thorough review of the drug, it was discovered that the drug was no cure for AIDS. In fact, it contained an industrial solvent that was linked to both cancer and liver damage. Ironically, it was determined that this “African solution” was toxic and potentially lethal. Mbeki’s stance became a statement of the ways in which the office of the presidency felt ARV supporters had bought into the pharmaceutical industry’s rhetoric, which the South African government felt was reflective of “anti-poor and elitist” policies—ideals that ran counter to the platform of the ANC in the era directly following the end of apartheid (Schneider 2002). Although Mandela called for united action on AIDS and mandated a government pilot to test the effectiveness of AZT (later discontinued) towards the end of his presidency (see Figure 3.4), he was largely criticized for policy decisions (or lack thereof) during his tenure:

He more than anyone else could through his enormous stature have reached into the minds and behaviors of people...A message from this man of saint-like, in some ways almost god-like, stature would have been effective. He didn’t do it. In 199 ways he was our country’s savior. In the 200<sup>th</sup> way, he was not (Cameron 2007).

During his presidency, Mandela largely failed to offer a clear and comprehensive response to HIV/AIDS, but would later go on to become a global icon and champion of HIV/AIDS awareness.<sup>17</sup>

---

<sup>17</sup> In 2002, Mandela started the 46664 (four, double six, six four—named after his inmate number and year of imprisonment on Robben Island) to raise global awareness about HIV/AIDS prevention. Mandela highlighted the personal impact of the epidemic when in 2005, he shared that his son had died from an AIDS-related illness. The public declaration was widely applauded—and for some, helped to refashion Mandela’s image with regard to HIV/AIDS. The organization has since expanded to focus on a range of humanitarian issues.

### **Mbeki Presidency: June 1999-2008**

Upon assuming office in June 1999, President Mbeki maintained his disapproval and criticism of western-based approaches; reminiscent of his early AIDS dissidence while deputy president. Under Mbeki, the post-apartheid era became layered with many intricate processes of remaking and rebranding South Africa, both nationally and internationally. The government's desire to prioritize its goal for global positioning over addressing the concurrent rapid spread of the HIV/AIDS pandemic was made clear when, "the government initially rejected millions of dollars for treatment, while simultaneously accepting millions in business investment" (Susser 2009:104). Mbeki's presidency also promoted a shift towards a more nationalist and traditionalist stance that embraced an approach to finding "African" solutions to the issues of HIV and AIDS (like Virodene).

<b>Early Mbeki Presidency (June 1999-2000)</b>	
1999-2000	Western Cape continues PMTCT pilot
October 28, 1999	Mbeki says that AZT is toxic
January 2000	SANAC is created, no medical or TAC representation
March 14, 2000	Mbeki refuses to declare a national emergency
March 30, 2000	Health Minister prohibits Nevirapine from being offered in public hospitals until she sees more research
May 2000	Gov't publishes Strategic Plan for managing HIV/AIDS and STDs
May 6, 2000	First Presidential AIDS Advisory Panel meeting
July 2000	Health Minister rejects offer by pharmaceutical company to provide Nevirapine free of charge to government MTCT programs
July 9, 2000	Mbeki speaks at the International AIDS conference, says poverty, not AIDS is the world's biggest killer
September 21, 2000	Mbeki tells parliament that gov't policy will be based on the idea that HIV causes AIDS, but posits that "a virus cannot cause a syndrome",

	warns members about taking ARVs
October 15, 2000	Mbeki withdraws from the public debate on HIV
October 24, 2000	Department of Health releases recommendations for treatment of AIDS, acknowledges that HIV causes AIDS
Late 2000	Western Cape Province works with MSF to start pilot HAART project in Khayelitsha (township near Cape Town)

**Figure 3.5** AIDS Policy Timeline: Early Mbeki Presidency

Mbeki aimed to shed South Africa's apartheid legacy by dispelling long-held perceptions and representations of South Africa and other African countries as sexually promiscuous and deviant. "Rather than combat this stereotype with effective HIV policies, he chose to undercut the policies and simply use the negative representation as a reason to avoid addressing the problem of AIDS at all" (Susser 2009:98). This approach resulted in a series of controversial decisions at the national level that produced an "epidemic of disputes" (Fassin 2007). The first phase of Mbeki's presidency was characterized by financial scandals, disagreements over the relationship between HIV and AIDS, the efficacy of antiretrovirals (ARVs), and an ongoing battle between the state and civil society over access to ARVs, initially for the prevention of mother to child transmission, and later for all PLWHA.

As outlined in Figure 3.5, Mbeki was initially highly resistant to progressive AIDS policies. In 1999, he renounced the efficacy of AZT, and despite the clear exponential rise of HIV/AIDS prevalence in South Africa (see Figure 3.1), refused to declare the health crisis a national emergency and rejected international aid. By mid-2000, the government also disallowed nevirapine, proven effective at preventing the transmission of HIV from mother to child, to be offered in government PMTCT

programs. By late-2000, however, Mbeki had mostly withdrawn from speaking publically about HIV/AIDS, and the Department of Health shifted its stance to acknowledge that HIV did in fact cause AIDS.

This shift by the Department of Health did not indicate a full reversal of approaches to HIV/AIDS policy by the government, however. Figure 3.6 highlights the sustained series of obstructionist policies that continued to impede the rollout of HAART. Despite the argument by the Health Department that antiretrovirals were still not affordable, the increasing need to better address patient care led some provincial health departments to defy national guidelines and initiate PMTCT programs. The then Finance Minister rebuffed those prevention and treatment efforts, claiming that money spent on ARVs was a waste of limited financial resources. By fall 2003, however, after mounting pressure from NGOs and court battles between the Department of Health and the TAC, the Cabinet mandated the government to provide ART in the public sector.

<b>The Fight for Antiretroviral Treatment (2001-2003)</b>	
April 2001	The Medical Controls Council (MCC) registers Nevirapine for PMTCT
April 19, 2001	Gov't announces ARVs are still unaffordable, expresses ongoing concerns about ARV safety
February 2002	Kwa-Zulu Natal and Guateng provinces defy national guidelines and roll out MTCT programs
March 2003	Finance Minister says spending government money on ARVs is a waste of limited resources
April 4, 2002	Constitutional Court instructs gov't to provide Nevirapine in the public health sector
April 17, 2002	Cabinet releases statement that ARVs can be beneficial if administered in according to international guidelines
April 24, 2002	Mbeki says on TV that he rejects calls for ARVs because they not yet proven to be safe
May 2003	Health care workers submit petition to Health Minister, declare patients dying due to staff shortages and inadequate training to cope with the

	epidemic
June 2002	Health Minister stalls US\$72 million Global Fund grant
August 2003	Gov't finally approves Global Fund grant to KZN
August 8, 2003	Cabinet commits gov't to providing ARVs in the public sector, promises detailed plan by end of September 2003
November 2003	Gov't publishes Operational Plan on Comprehensive HIV and AIDS Care

**Figure 3.6** AIDS Policy Timeline: Mbeki Presidency and Antiretroviral Treatment

### **Mothering in the Pre-ART Era: Nevirapine and the Effects of the Lack of Availability and Accessibility to Treatment**

One major debate was whether the drug Nevirapine should have been made available to pregnant HIV-positive women as a way to prevent mother-to-child transmission. Nevirapine is an antiviral medication that was proven to greatly reduce the transmission of HIV from mother to child. Government policy, however, stipulated that this treatment was not to be made available in public health facilities, even when offered free of charge by pharmaceutical company Boehringer Ingelheim. This decision led some physicians who worked in public clinics to defy the government ban on nevirapine and supply it to their female patients for PMTCT. Some even purchased the medications out of their own pockets. One physician in Grahamstown was among those doctors and recalled how he paid for the treatment himself, based on what he felt was “an obligation to my patients.” The refusal to treat HIV-positive pregnant women or make PMTCT medications available sparked an intense debate among the South African government, treatment advocacy organizations, western scientists, and public health workers. While the disputes dragged on, however, the absence of antiretroviral treatment had grave



effects on the ground for many families. Women who were HIV-positive and pregnant had little choice but to give birth to HIV-positive children.

During the course of my fieldwork, the women I interviewed told me several stories about their experiences living with HIV and AIDS, the ways in which their families have been affected by the virus, and how ARVs have (or have not) figured prominently in their health-seeking processes. Many of the stories were wrought with vivid examples of women who had been faithful to their partners, and yet still contracted HIV. Others, who did not “know about HIV at that time,” did not use condoms during sexual intercourse. Few stories were more difficult to listen to than the stories of women who had contracted HIV and, unknowingly, transmitted the virus to their unborn and newborn children during childbirth or through breastfeeding.

These women intimately straddled the line between infected and affected. After testing positive for HIV, they became aware of their own status as infected, and also had to cope with knowing that their babies would be acutely affected, and in many cases, also infected themselves. The health-seeking process became even more complex for these women. In addition to learning to navigate the healthcare system and manage severe economic insecurity (further discussed in Chapters Four and Five), they also had to deal with an extra layer of social suffering—as some of them literally mothered their children to death. The lack of availability of nevirapine was confounded by limited knowledge and inconsistent information about the virus. In the mid-1990s, doctors and nurses still struggled to find the language to explain the illness and its implications for both women and their un/newborn children. These challenges were evident in Lindiwe’s narrative (36-year-old widowed mother of three, ages 15, 12, and 4):

---

Lindiwe: I found out I was HIV positive after I had my second child. That was in 1996.

*CJ: How did you find out?*

N: After I have delivered the baby, they have tested my blood. In 1996, I have fallen pregnant. While I was pregnant they tested my blood, but they didn't know what HIV was at that time at the hospital, so all they have told me is that I have "dirty blood." And then they give me B-co, Cozole, and folic acid. I am still using that since 1996.

*CJ: And the child, and the second child?*

N: Because there was no Nevirapine that time, my second boy was born and he is infected with HIV. He is living, too, with the virus, but with this child, the youngest one, there was Nevirapine, so this one is negative.

*CJ: So when they told you had "dirty blood" they didn't call it HIV?*

N: No, they just said "dirty blood." They didn't name it. They just say, we are going to give you two needles for your "dirty blood." I don't know what they actually gave me. Then I went to the clinic and they named it for the first time and said, "Sisi, this is HIV."

*CJ: What made you go to the clinic in the first place?*

N: My husband was in the clinic. That's why I went in the first place. I didn't even know that there was a sickness called HIV at that time. But based on the actions of my husband, he didn't just have one woman, he left me here and went with many, so I went to the clinic at that time because he was not being faithful. When I went to the clinic, they gave me a form and asked me if I wanted to test. I said yes.

*CJ: Did your husband know that the second child is HIV positive?*

N: My husband did know that the second child is HIV positive. He was very supportive when we went to the clinics and everything before he died from AIDS. He died earlier this year in February, the 3<sup>rd</sup> of February. I started to explain HIV to my son when he switched over to ARVs this year when he turned 11. So now he knows that he is HIV positive and he is eating his pills every day. When I told him he was HIV positive, he didn't react any kind of way. He takes 3TC...and I can't remember the name of the other ones. I would like to take the ARVs, too, but they only judge you based on your CD4 count, so they say I'm too strong.

---

Lindiwe's narrative illustrates many of the complex elements that factor into her current illness experiences. Her story is indicative of the "early testers" in my study, for whom HIV was unknown and prevention and transmission initiatives were limited. She explicitly discusses that while she was given prophylactic treatment for opportunistic infections, she emphasizes that there was "no nevirapine [at] that time." Among the women who transmitted HIV to their children during or after childbirth, only two of them had children who survived. Ironically, both women were classified as being "too strong" or not yet medically eligible for ART, but their infected children were taking ARVs.

Nelisa's story highlights the other spectrum of experiences among mothers in my study: an experience of mother to child transmission that ultimately led to the death of her child in the absence of nevirapine:

---

Nelisa: I'm 30 years old. I have one child and she's a girl who's 10 years old. She stays with me. I don't work.

*CJ: Have you worked before?*

N: Yes, I did at Extension 4 (area in the black township). I did domestic work.

After a series of introductory questions and exchanges, Nelisa began to share her life history:

N: I grew up very well. I didn't experience any problems. My situation changed when I was diagnosed positive. Well, even then, I only knew about my status when I gave birth to my young one and then later when my boyfriend got sick. At home they didn't know until recently when I lost my young one as I kept it to myself. I didn't experience any problems with the first child but with the second one there were a lot of health problems. I gave birth to the second child whom I lost in 2001. I mean the one who passed away. The first child was born in 1998. I only knew after giving birth to the second one as he often was sick and I had to take him to the Hospital.

*CJ: Why did they decide to test you in 2001?*

N: As I repeatedly took the child to the hospital, they gave him a brownish medicine that made his eyes turn upwards as if he was to die instantly after taking it. He would vomit after taking it. They asked to run a TB test for the child and results were positive. Then they asked that I also test and I agreed. I felt nothing at that time, not at all sick. There were no rapid test results then, so I had to wait in the hospital for the blood results, which took about two to three weeks until I was told.

*CJ: When your results came back, what did they say?*

N: They started with counseling me first, trying to help me deal with the results as I was also stressed with the child's situation. Then they told me and I also tried to accept it. They told me that I'm HIV positive.

*CJ: What about the baby? Do you think that the baby only had TB or was he also HIV positive?*

N: Well, from what I used to see at the clinic when looking at the posters on the wall, where you'd see a person's tongue with white color, my child also had a white tongue with a very bad smell, which made me take him to the clinic. When they couldn't find his temperature at the clinic, they quickly called an ambulance to take him to the hospital. From seeing his condition I compared him to being HIV positive.

*CJ: Did you tell your family then, or was there anyone to support you?*

N: There was no one from the family. The only person I was staying with was my boyfriend. He was the only one who knew that the child had TB. At the hospital, I was told to wait until the next day for the doctor as it was at night. When I woke up, I realized that everyone was bathing their children so I looked at mine and noticed that something was not right as he was not breathing but his eyes were not closed and he still felt warm when I touched him, but there was no movement. It's as if he had died not long ago in the same night. I quickly ran to inform the nurse and she said yes, the baby has passed away. I was told to go home. So, I went home to tell my aunt but didn't tell her what actually took place. They made arrangements for the baby to be buried. He was a little boy. He was five months when he passed away. I still remember. It was on the 20<sup>th</sup> of December. My family now knows my status but what they don't know is my child's status and I don't want them to know.

As Nelisa began to cry, I reached across the table and squeezed her hand. I paused the interview for a few moments until she was ready to continue.

---

Nelisa's narrative highlights several key themes. First, there is a direct alignment with the timing of her HIV diagnosis and the then ongoing debate about accessibility to nevirapine, underscoring the real life implications of those delayed policy decisions.

Secondly, Nelisa's experience is also characteristic of testing experiences in the late 1990s and early 2000s, where patients often had to wait several weeks or up to a month for HIV test results. The social context of Nelisa's narrative is also evident. Her decision not to disclose the HIV status of her deceased baby reflects a climate in South Africa in which there was intense stigma and shame related to HIV infection. Stigma still persists, but the socialization of HIV/AIDS has helped to lessen HIV/AIDS stigma. Nelisa's description of her baby's symptoms also illustrates a growing awareness and knowledge about HIV that was emerging in the late 1990s and early 2000s.

### **The Rollout of Antiretroviral Treatment and Cost of Denial**

The lack of nevirapine did not go unchallenged. The growing prevalence rate of HIV reflected in antenatal surveillance data (see Figure 3.1), made it increasingly challenging for the government to continue to block access to treatment. The TAC launched a series of legal proceedings in an attempt to force the government to begin providing ARVs. Despite judicial rulings directing the Health Ministry to provide access to ART, the government remained slow to respond. The process became bogged down in repeated efforts to block PMTCT programs. In an attempt to deconstruct the numerous amounts of paperwork that accompanied the government's repeated efforts to obstruct and appeal the roll-out of PMTCT programs, Mark Heywood explains:

Although intimidating in volume, once deconstructed, it was clear that the government papers were full of deception and contradiction. Health Department officials sought to undermine established science and scientific institutions. There seemed to be very little of a sense of urgency to come to the assistance of pregnant women with HIV or to resolve the dilemmas expressed by hundreds of doctors in the TAC papers about not being able to treat women properly (Heywood 2003:298).

Only after exhausting all possible legal options did the South African Government shift their policy on PMTCT and begin to make HIV treatment available for pregnant

women. In April 2002, the Constitutional Court instructed the government to provide Nevirapine in the public health sector, but not before an untold number of women, children, and families were infected, affected or died because of the delay. It would take over a year more of contentious debates before the government finally committed to providing HAART in the public sector. In January 2004, HAART rollout was initiated (unevenly) across all nine provinces, marking at least a public shift in the government's HIV/AIDS position (Figure 3.7).

<b>Rollout of Antiretroviral Treatment (2004-2007)</b>	
January 2004	HAART rollout is initiated (unevenly) in all provinces
February 2004	Mbeki move rollout target forward one year in State of the Nation speech
March 2004	Procurement timetable indicates it will take until at least July 2004 to obtain ARVs
July 2004	MCC causes confusion over guidelines for Nevirapine
September 2004	Department of Health releases ARV treatment guidelines
December 2004	Pressured by TAC, court reveals no rollout timetable adopted by Cabinet or Department of Health
February 2005	Mbeki boasts during State of the Nation speech that South Africa has one of the best “comprehensive” AIDS programs, despite targets not being met
March 2005	ARV drugs finally procured
End 2005	HAART Rollout begins in all provinces by year end
September 2006	Deputy President (Zuma) made responsible for coordinating AIDS policy
April 2007	National Strategic Plan for 2007-2011 is signed

**Figure 3.7** AIDS Policy Timeline: Rollout of Antiretroviral Treatment

The rollout process was still impeded by poorly planned procurement timelines, however, and antiretroviral medications were not readily available in all provinces until the end of 2005.

For many, former President Thabo Mbeki's stance has been classified as denialist (Cameron 2005). In this context, denialism is based on belief that "the scientific canon on AIDS has been irredeemably corrupted by the pharmaceutical industry and that ARVs cause more harm than good. AIDS denialists present themselves as heroic 'dissidents' daring to question an 'AIDS establishment'" (Nattrass 2007:2). One particularly destructive aspect of this new theory was the claim that available medications were toxic, possibly an intentional poisoning of the African population on the part of the Western medical establishment, and, therefore, should not be distributed in South Africa (Susser 2009:97). Along with Mbeki, among the most famous AIDS denialists were scientists Peter Duesberg and Matthais Rath, founder of the Rath Health Foundation:

For the most part, active AIDS denialists are a collection of minor academics, alternative therapists and somewhat paranoid and grandiose eccentrics. If it had not been for their championing by Mbeki, a State President who preside[d] over the largest number of HIV-positive people in any country on Earth, they would have been consigned to obscurity long ago" (Nattrass 2007:2).

One of the core beliefs of denialists is that HIV does not cause AIDS. More specifically, they do not think that HIV is unequivocally linked to AIDS and argue that it may be harmless. AIDS denialists posited that ARVs actually were to blame for AIDS deaths in South Africa, and those death rates did not accurately indicate that AIDS was actually a problem. "Essentially, AIDS denialists argue that AIDS death statistics are a figment of the imagination of demographic modelers and that any rise in recorded deaths is a product either of improved collection of death statistics or of poverty" (Nattrass 2007:94). The initial denialist stance of Thabo Mbeki has been extensively examined (see Fourie and Meyer 2010), but there is no conclusive agreement about the utility of Mbeki's approach to impede access to life-saving medications aside from his initial strongly held personal conviction about ARVs.

One additional explanation that has been suggested may hinge on the economic implications of offering ARVs nationwide since the cost of antiretroviral drugs was a recurring theme throughout the evolving debate on ART. “One possible explanation was that the government feared that MTCTP would open the floodgates to demands to provide expensive, long-term highly active antiretroviral therapy (HAART) for AIDS-sick people” (Nattrass 2007:4). The standard PMTCT concept focuses primarily on preventing transmission of the virus from mother to child, but often fails to address support and treatment for the mother, who may have found out that she was positive during prenatal testing. In March 2003, the Finance Minister lamented that spending government money on ARVs was a waste of limited government resources. Before his death, presidential spokesman Parks Mankahlana infamously declared that it was cheaper to withhold PMTCT than it would be for the government to manage the number of surviving orphans:

A country like ours has to deal with that. That mother is going to die, and that HIV-negative child will be an orphan. That child must be brought up. Who’s going to bring that child up? It’s the state, the state. That’s resources, you see?” (quoted in Cohen 2000).<sup>18</sup>

Nattrass presents a counter to this argument, however, and posits that the potential economic deterrents put forth by the government were not well founded. She contends

---

<sup>18</sup> Parks Mankahlana served as the presidential spokesperson for both Mandela and Mbeki. He publically criticized the premise that HIV causes AIDS, but after his comments on PMTCT and orphans were widely rebuked, he denied having given the interview in which the comments were recorded. While never publically confirmed, it is widely believed that Mankahlana died from an AIDS-related illness in October 2000. Following his death, the TAC called on the South African government to “tell the truth” about Mankahlana’s death. Three years later, Mbeki tells the *Washington Post* “Personally, I don’t know anyone who has died of AIDS. I really, honestly don’t.” – further perpetuating a denialist stance. (For Mbeki’s interview, see <http://news.bbc.co.uk/2/hi/africa/3143850.stm>.)



that support for economic considerations as the underlying factors to delaying rollout of ART were actually based on a shortsighted vision among government officials:

It takes for granted that providing large-scale access to ARVs was impossible within the existing resource envelope when using ARVs for prevention and treatment would have saved costs elsewhere in the health sector (fewer resources would be needed to treat HIV-related opportunistic infections)...It also fails to consider that human resources could have been employed more efficiently through better management of the health system, and that drug prices could have been reduced through negotiations with pharmaceutical companies (Nattrass 2007:82).<sup>19</sup>

Fourie and Meyer (2010) also highlight a broader framework for contextualizing Mbeki's early stance:

Again, this underscores the deepening willingness on the part of very senior government officials to insist on monopolizing the right to define the AIDS policy problem itself, discounting any position that countered their AIDS orthodoxy (2010:97).

Decision-making about HIV/AIDS at the national level was layered with competing interests and priorities. In the midst of the struggle for HAART, the epidemic rose precipitously, and South Africa ranked first in HIV/AIDS prevalence across the globe, damaging the ANC's reputation both locally and internationally. As the debate dragged on at the national level about granting permission to administer Nevirapine, the real life costs continued to manifest.

### **Challenges and Cultural Implications of Breastfeeding**

Early antiretroviral treatment programs were not run in conjunction with PMTCT programs, leaving HIV-positive mothers with the task of navigating both the ART and PMTCT systems simultaneously. In 2000, the World Health Organization issued policy guidelines that have been used as the tenets for developing and implementing PMTCT

---

<sup>19</sup> See Nattrass 2004 for a more extensive discussion of the social and economic implications of the pandemic from an ethical perspective. Nattrass and Geffen 2005 also offer further discussions on the cost-effectiveness of HAART.

programs and informing mothers about breastfeeding. The World Health Organization (WHO) guidelines advise that exclusive breastfeeding is recommended for HIV-infected women for the first six months of life unless replacement feeding is acceptable, feasible, affordable, sustainable and safe for them and their infants before that time. These guidelines stipulate that exclusive breastfeeding works best, or total replacement feeding (using formula). This guidance, however, was sometimes challenging to implement in a context where infected mothers who had not disclosed to their families were afraid to use formula and possibly raise questions about why they were not nursing their infants, particularly when cultural norms often dictated nursing practices. One participant, Sasha, recounted how a lack of knowledge about HIV/AIDS, cultural norms around breastfeeding, and gender expectations impacted her life:

---

Sasha: After I went to school I had the responsibility to look after the kids on the farm. I was responsible for girl things because I had to take care of supper in the night. And in weekends, we had land that we were planting so we had to work on the weekends. That was the farm life. Then we moved to Grahamstown we didn't have our own property, we were like paying rent for the land. We were living off of selling fruit on the streets on Grahamstown. As time went on, I got a boyfriend, and that boyfriend has never told me that he was HIV positive. And then I fell pregnant in 1997, and when you get pregnant you have to go to the clinic. So I went to the clinic and they took samples and all the other ladies' results came back but mine was delayed. It was not coming fast enough.

*CJ: Did they tell you that they were going to do an HIV test?*

S: No, they never said anything. The results took so long that it was time for me to give birth. And I didn't give a normal birth I had a cesarean. When I woke up, they were feeding the baby with instant milk. The nurses didn't wake me to breast-feed; they gave the baby a bottle. The next day the sister (nurse) came to me and said that I must take light food to heal after her surgery. They still had not given me any results. After I was discharged my child had gotten sick and I was already breastfeeding.

*CJ: Did they tell you not to breastfeed?*

S: Nope! I took him to the clinic and they sent us to the hospital. When I got to the hospital they took some blood from the child and me. They gave us another day that we must come back to fetch the results.

*CJ: How long did it take for you to get the results?*

S: I can't remember how long it had taken, but I went back and got the results and they told me that I am HIV-positive and I'm not supposed to breastfeed the child. But the child was already used to breastfeeding. The child was not supposed to breastfeed because I am HIV-positive. They told me to put some peri-peri (hot sauce) on my breast to make the baby not want to breastfeed anymore and they were going to give the baby some medicine to clean out the milk from its system.

*CJ: What were the results of the baby? Did they give you the test results of the baby too?*

S: ...and the child was already HIV-positive, too. My child have ignored all the things. Peri-peri (hot sauce) and aloe wasn't doing anything. He didn't like the bottle, he preferred breastfeeding.

*CJ: Were you scared that he was going to become sicker when you continued breastfeeding?*

S: My mom was very fond of children and said 'No, let the child drink.' Then the child was admitted to the hospital. The nurses were trying to feed him with a bottle, but he kept refusing the bottle. He didn't even want to take food anymore. Only taking one teaspoon. I got sick too and was admitted Temba [Hospital] for TB treatment.

*CJ: When they took your blood, did they explain to you what HIV is, or did you already know?*

S: No they never told me, they just told me that Sisi you are sick and have HIV, but they never explained to me what this was all about—so it was very early still at the hospital. They eventually transferred me to SANTA hospital. When I had just arrived at SANTA, I got a phone call saying that my child had just passed away at Settler's hospital. That was in 1998 that my baby have died.

She began to cry and her voice trailed off. I asked her to share her son's name with me because I didn't want him to remain nameless in my field notes. She quietly spelled out his name for me, and we continued:

*CJ: Did you get to go back to the hospital to go see your baby?*

S: I asked for some time off from the hospital so that I could be part of the organizing for the funeral, and after that, I went back to the hospital.

---

Despite evidence of the effectiveness of nevirapine in preventing mother to child transmission, women who relied on the public health care system prior to the early 2000s were still not able to receive the proper services and information. Sasha's experience illuminates some of the sensitive issues related to PMTCT and breastfeeding during this era and the ways in which women had to weigh the costs and benefits of replacement feeding in lieu of breastfeeding, against what they felt was best for the baby overall. These previous policies also raise questions about what was privileged in this complex dynamic: should the benefits established through breastfeeding trump the possibility or actual transmission of HIV to the infant? The issue of preventing the transmission of HIV from mother to child becomes even more complicated by the cultural implications associated with breastfeeding. Past breastfeeding guidelines failed to take into account the local climate in which the initiatives were proposed. Often, those policies were limited or unable to account for what how health guidelines are adopted not just medically but also socially.

The gendered experiences of illness management remain critical issues both locally in Grahamstown and more broadly across South Africa. I do want to note that experiences of child and partner loss were not exclusive to the female research participants. One male participant discussed losing his girlfriend and son to AIDS-related causes, but declined to elaborate on how that experience impacted his life history. His reaction was in line with the consistent tone among most of the men I interviewed—there were few emotions expressed, and unlike the women, the men in the study generally declined to respond to probes about the death of a partner or loss of a child.

When the political moment evolved at the national level and antiretroviral treatment and PMTCT programs became more widely available, the related and consequential experiences of suffering have been left out of the current narrative of HIV/AIDS in South Africa. As treatment programs continue to evolve and improve, patients increasingly have access to life saving care. These advancements are hugely important, but often overshadow the persistent layer of social suffering among women who lost or infected their children in previous eras. It is important to highlight that the occurrences of child loss and MTCT-related challenges had not happened that long before I collected these narratives. Some participants had lost children as recently as 2005, while the rollout of ART remained stunted at the national level. Participants were still trying to reconcile the historical decision-making process at the national level within their personal, ongoing processes of illness management.

### **Sexual Trauma and Illness Management**

Previous research has demonstrated the ways in which gender lies along one of the major fault lines of vulnerability and susceptibility to HIV (Bond et al. 1997, Schoepf 1992). Craddock (2004) contends that “clearly, coerced sex in any situation is an indication of larger structural inequities mapped onto gender subordination, and these both need to be addressed for effective intervention in AIDS” (2004:86). Sexual trauma was another theme among participants’ narratives that contributed to the complex illness management process. I closed out my interview with Nelisa in the same way that I closed out every interview: asking if the participant had any questions for me. Because the previous portion of our interview had been so emotionally taxing with the details of the death of her son, I was ready to close out the day and have a chance to process what

she had told me about her life. Most often, participants said that they did not have any questions for me and instead were happy to get their meat parcels and leave the room.

Nelisa, however, paused after my question for several moments before responding:

---

Nelisa: Eh! Sisi, if you were to get into my heart, you may think that I'm happy as you see me but there are a lot of terrible things that are happening to me. My daughter is giving me heartache because she has been raped and up to now we've not known who did it. [She begins to sob loudly.] Her case is on and off. When she starts to heal the police will re-open the case and it doesn't end and she doesn't get all the pieces together so every time they have to re-open the case. It hurts because it's like she has to tell the story over, and I don't know whether they are doing it intentionally to inflict pain on me.

*CJ: When did this take place?*

N: I can't remember well but I think in 2006, she was still about seven years then.

*CJ: How did you find out? Did your daughter tell you?*

N: One day, I went to go and receive her grant money and then I went to prayer service and when I got back she was lying down and I told her to go and urinate and so she did. My boyfriend was awake and asked me if I had noticed her panty and I asked how is it? It didn't seem to be something fresh, it's just a small blood stain like it's blood that has come into contact with water, it's not that visible and doesn't look like it's something fresh that's taken place lately. It looks like it happened at noon. It's then that I reported to my mom and my mom and sister took her to the hospital. It came out that she was raped and she was admitted for about a week or so at the hospital.

*CJ: Has she told you what happened?*

N: No, she doesn't want to talk even now she only cries when asked even in front of the police in my absence. Some of the kids in the neighborhood say that it could have been one of the other kids with like a stick or something, but the police don't agree with that saying based on the exam it can't be kids who have done that.

At this point in the interview, I was at a loss for how to respond. Nelisa had shared so many heavy life experiences in one 40-minute interview. As she continued to weep, I remember feeling so emotionally overwhelmed in the moment. I finally responded:

*CJ: The good thing is that she has her mom to love her, hug her, you know she has somebody to be there for her even if she doesn't want talk about it. Everyday, you tell*

*her that she is beautiful and you love her and that no matter what she's always going to be important.*

N: Now that this has happened to her, it has happened to me, too. We are both vulnerable, I am scattered. I'm doing the best I can, even there at the GCC they used to bring her things but she refuses to talk. Even at home as we are together I sometimes bring her some thing even if it's bread, I will bring it to her. The only thing is that she doesn't want to open up. I don't want to add anything like talking more on this issue.

Mandisa injected and asked:

*M: When you arrived at the flat where was ubhuti (the boyfriend)?*

N: He had already been there at that time.

*M: So, when you arrived they both were there. Didn't they suspect ubhuti?*

N: I had told them to go ahead and question him, but the police never came here. Cha, can you cut this off?

Nelisa motioned to the voice recorder and asked if I could stop recording our discussion.

I obliged, and after the recording was over, she said that she was suspicious of her boyfriend, but was afraid of him. When Mandisa and I encouraged her to share her thoughts with the police on the case, she silently shook her head and asked if we could end the interview. She signed for her meat parcel and left the room.

---

Sexual trauma was reported by other participants as well, and, as Sasha demonstrated, one of many layered social experiences that highlight the complex intersections between sexual trauma, gendered vulnerability, health, and economic security:

Sasha: After I got tested, the same day, I've gone straight and told my mom and my sister.

*CJ: And then?*

S: After I told I my mom, my mom went and told the whole world out there. She has gone into the location to tell everyone that I am HIV positive.

She starts to cry and I hand her some tissues. She continues:

S: My mom has an alcohol problem, and when she's drunk she will swear at me and say that I am HIV, and it's not depression or anything, but it's like she's showing off when she's drunk.

*CJ: Is your sister supportive though?*

S: My brother and my sister, at least they care for me. They don't let me feel so bad.

*CJ: What helps you to cope with your diagnosis?*

S: It's the support of the THC that helps me. And the grant that I get for my son, the child support grant that is R250 a month.

*CJ: The money that you get for the grant from your son, is it enough for you to buy food and get everything you need, or do your sister and brother help?*

S: No, it's not enough for everything that we need. It can't do everything, so my sister is covering the rest that I need.

*CJ: Does she work?*

S: No, she's on a grant, too.

*CJ: What kind of grant?*

S: She gets R940, well R1000 now every month.

*CJ: Is the grant for HIV or is it for something else?*

Her voice drops and she said, "She was raped and they traumatized her, so she is getting a disability grant."

---

Sasha and her sister are supporting a household of five people with R1250 (\$155) per month. This interview shows how dependent families are on government support. The range of trauma, from HIV-related stigma to rape is present, and the importance of social security grants—from the disability to childcare grant, is evident. Sasha is very clear that this is not money enough to live off of, and ironically, experiences of trauma, unfortunately, have become the avenues through which she and her sister are able to



access economic support. The interview ended with her quietly leaving the room. I couldn't tell if her story, or talking about her sister's rape and trauma caused a shift in her mood, but perhaps the combination of both realities weighed on her as she walked away quietly and with, as I noted in my field notes, "sadness behind her eyes." Sasha's narrative illustrates the multiple layers of social suffering and economic inequality experienced among participants, particularly the women in the study. Both she and her sister illustrate lived experiences directly shaped by historical and political decisions, experiences that leave them firmly along the social fault lines of vulnerability and risk.

### **Conclusion**

The key political decisions highlighted in this chapter are only a handful of the government's multiple and nuanced responses (as noted in the timeline tables) to the HIV/AIDS epidemic over a decades long battle to develop a comprehensive national AIDS strategy. The shift from silence to the adoption of a treatment system heavily based on scientific standards and biomedical markers demonstrates drastic (albeit slow) change at the national level. The effects of these shifts also include layered, and personal lived experiences among those who were affected by and infected with HIV/AIDS- people whose lives literally depended on the government for access to ART. My work gives voice to those women affected by those policies to highlight the ways in which these issues are an indelible part of their health-seeking processes. The narratives presented also speak to the importance and necessity of community-based support programs like those offered by the GCC and THC. In addition to mediating the testing to treatment process, these sites offer a communal space to not only talk about negotiating treatment and what it means to live with HIV and AIDS, but also to how manage loss and

personal voids alongside concurrent health-seeking challenges. In the next chapter, I expand on the concurrent challenges participants faced and describe the ways in which they attempted to navigate the health-seeking process.

## CHAPTER FOUR

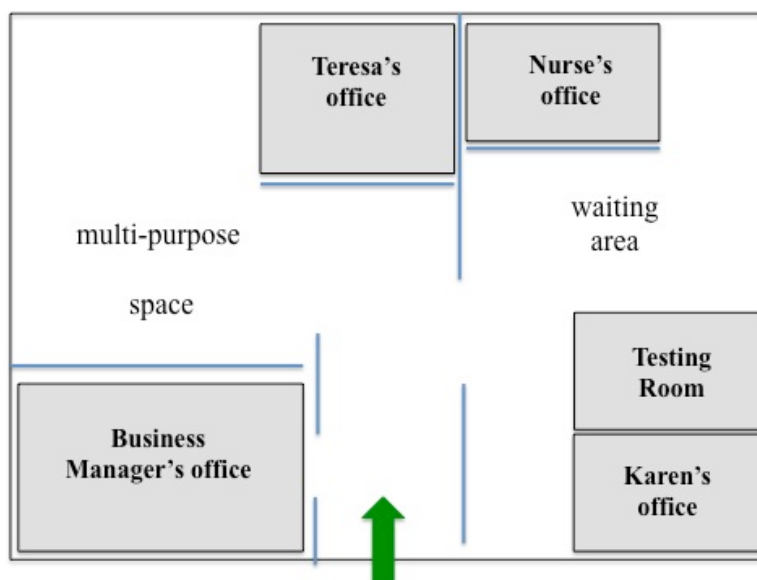
### **The Health-seeking Process: Pre-HIV, Diagnosis, and Antiretroviral Treatment Management**

#### **Entering the Health-seeking Process**

I arrived to the GCC one afternoon in early April 2008 for a meeting with Teresa. This was the first time we would see each other in person since my last visit to Grahamstown three years earlier. During my previous trip, I was still in the process of refining my dissertation topic, and had been introduced to Teresa and alerted to the work done at the GCC by a professor at neighboring Rhodes University. In the interim, from 2005 to 2008, Teresa and I had occasionally remained in contact by phone and email, and she kept me abreast of the general news at the GCC. Also during that time, I had decided to conduct my long-term field research in Grahamstown, with the GCC serving as my primary research site. Like most buildings in Grahamstown, the door of the GCC is guarded with metal bars that can only be opened using a switch inside the center or by keying in a security code on the alarm pad that sits to the right of the door. After being let into the building by one of the HIV test counselors, Teresa welcomed me into her office, a dimly lit room with a wall of plexi-glass windows that opened up to the multipurpose room on the other side.

After we exchanged pleasantries, Teresa got right down to business and I could tell that she was very used to having these types of “tell me about the GCC” meetings with visitors. Years earlier, we had had a similar conversation, but this time, I had a more refined purpose for our meeting since I was set to begin 14 months of fieldwork at the GCC. “So, what would you like to know?” she asked. I rattled off my list of

prepared questions about the GCC's mission, background, and community involvement. I also asked about the testing process since the GCC is one of the only voluntary testing and counseling centers in Grahamstown. Teresa was able to quickly answer my more general questions, but found it difficult to fully walk me through the HIV testing process at the GCC. It was really important to me to capture the essence of the testing experience, since I knew that much of my research hinged on research participants' health-seeking processes, which required them to directly engage centers like the GCC for both testing and support services. After more probing, Teresa finally said, "To be honest with you, I'm really not sure exactly what happens over there (referring to the HIV testing side of the center)" (see Figure 4.1).



**Figure 4.1** Diagram of Grahamstown Community Center Offices and Testing Area  
*Source: C. Jones*

She suggested that I set up a meeting with one of the HIV test counselors to get a more detailed overview of the process. I decided that the best way to understand the process was to experience it firsthand and without much thought, elected to take an HIV test at the GCC that afternoon. Teresa seemed a bit surprised by my decision and asked,

“Are you sure?!” “Yes,” I responded. “It’s probably the best way for me to see for myself what testing is like here.” “Ok, let me walk you over to the testing room,” she said. The testing room was across the hall from Teresa’s office and was manned by one of the two HIV counselors.

The testing room should more specifically be called the pre/post-testing room, since the actual HIV test is conducted in the Nurse’s office. The room was somewhat small, with only enough space for a desk and two chairs—one for the counselor and one for the person being tested. Unlike the testing waiting room that was plastered with posters and banners imploring visitors to “condomize” and “know your status,” the counseling room was sterile and the walls completely bare. Pumla, the HIV test counselor, ushered me into the room with a warm smile and a hearty handshake. “Molo Sisi. You are welcome to come in,” she said. Once in the room, Pumla proceeded with the pretest counseling process and began to ask me a series of scripted questions. The first set focused on general information like my age and sex. The next set of questions was much more personal: “How many sexual partners have you had? Have you ever had a sexually transmitted infection? Have you been sexually assaulted?” I responded honestly to all of the sexual history questions. At this point in the process, the tone of the session changed. A lot was potentially at stake in this encounter. This was my first official visit to the GCC as a visiting researcher and the start of my fieldwork. The implications of the test results could significantly shape the trajectory of my time in the field. I could tell that Pumla was nervous. I wondered, despite how quickly and seemingly comfortable I was in answering her questions, if she could tell that I had become more nervous, too.

At the conclusion of the pre-test counseling session, I was taken into the nurse's office, where the actual HIV test was administered. To get to the nurse's office, I had to walk through the waiting room. There was no one in the waiting room that day, but I noted how the layout of the testing area at the GCC did little to support confidentiality. If other clients had been in the waiting room, they not only would have seen me go into the nurse's office, but also could have seen how long I stayed in her office, since clients with a positive HIV test may have longer sessions with the nurse.

When I walked into the nurse's office, I noticed patient files stacked on bookcases along the wall, boxes of alcohol swabs on the desk, and the actual testing mechanism sitting squarely in front of the nurse. As I sat across from her, she smiled and asked, "Are you ready, Sisi?" "Yes, sister," I responded. I again tried to mask my anxiety by firing off a series of questions about her experience as a nurse and the challenges of delivering HIV test results. I was hoping she would be as talkative as Pumla, and while certainly friendly, it was clear that she preferred to focus on the test and not on holding a conversation with me. I carefully watched as she methodically but gently pricked my left index finger and dabbed it with the rapid test strip to collect the blood sample. She then inserted the test strip into the testing mechanism and informed me that I had to wait three minutes for the results. While I waited, she explained that if she recorded my test result with a red pen, it meant that I was HIV-positive. If she wrote with a black pen, the test result was negative.

In retrospect, I believe getting tested at the GCC added value to my fieldwork experience. On one level, I no longer had to rely on charts and graphs to understand the process of HIV testing at a VCT site in Grahamstown. The personal experience added to

my ability to relate to my research participants' narrative descriptions of their testing experiences. Additionally, I think that choosing to be tested helped to humanize my relationships with the GCC staff and clients because it showed them that I was willing to be vulnerable in their space. In turn, as participants shared very personal details about their illness experiences, I hoped that my initial and ongoing commitment to be vulnerable with them helped to strengthen the trust and rapport between us.

### **Models of Health-seeking**

Medical anthropologists have remained engaged in tracing the ways in which individuals and communities respond to and manage disease (Chrisman 1977; Janzen 1978; Kleinman 1980; Baer, Singer and Susser 1997). Scholars have proposed several health-seeking models that attempt to explain the ways in which individuals seek help for illnesses (Chrisman 1977). In this chapter, I build on previous work among anthropologists (Stoner 1985, Young 1982, Kleinman 1978) to examine how individuals navigate health systems and evoke various models to inform their health-seeking practices. These models are influenced by multiple elements and are widely shaped by sociocultural factors and individuals' experiences with and conceptualizations of illness. Chrisman's (1977) model of the health-seeking process continues to be a foundational framework for examining how people holistically conceptualize their experiences with sickness through five interrelated processes: symptom definition, illness-related shifts in role behavior, lay consultation and referral, treatment actions, and adherence.

Other models also incorporate a broader understanding of the sociocultural influences on individual reactions to distress. Mechanic (1968) acknowledged the roles that cultural and social conditioning play in patterns of *illness behavior*, a notion shaped

by four factors that include: the way the individual perceives and interprets symptoms, how the individual seeks help or notifies others, how symptoms are communicated between the individual and others, and how the individual reacts to treatment (Tseng and Streltzer 2001). These models are useful frameworks to understand health-seeking behaviors, which I define as the processes through which individuals, often in consultation with referent others (e.g., family members, community leaders, etc.), make and act on decisions about their health and wellbeing. I also use the term health-seeking to refer to the layered experience of accessing formal and informal resources for both health-specific and socioeconomic concerns. My aim in this chapter is to describe the state-prescribed health-seeking management model and examine the ways in which participants' enter and move through that process—with varying degrees of success. Additionally, I highlight the ways in which these processes are complicated by multiple, layered social experiences that lead to challenges that impede or altogether stop the health-seeking process for some participants.

### **The State-Prescribed Health-Seeking Model**

The National 2000-2005 Strategic Plan in South Africa initiated the adoption of public sector ART protocols.<sup>20</sup> These protocols relied on the WHO guidelines, also called “staging,” to determine the severity of a patient’s HIV status. Stage I means that a patient is asymptomatic. At Stage II, a patient may exhibit minor symptoms like recurring respiratory infections. Chronic diarrhea, bacterial infections and pulmonary TB characterize Stage III. At Stage IV, an individual is clinically diagnosed as an AIDS patient, sometimes characterized by thrush or Kaposi’s sarcoma. In addition to the WHO

---

<sup>20</sup> Guidelines synthesized from the full 2004 National Antiretroviral Treatment Guidelines, which can be found at: <http://southafrica.usembassy.gov/media/2004-doh-art-guidelines.pdf>.



staging guidelines, medical and psycho-social factors are considered to determine patient readiness for ART. During my time in the field, medical personnel used the following criteria to determine patient selection for ART readiness:

- **Medical criteria:**

CD4 count  $<200$  cells/mm<sup>3</sup> irrespective of WHO stage<sup>21</sup>

**OR**

WHO Stage IV disease irrespective of CD4 count

**AND**

Patient expresses willingness and readiness to take ART adherently

- **Psycho-social considerations:**

Demonstrated reliability, i.e. patient has attended three or more scheduled visits to an HIV clinic.

No active alcohol or other substance abuse.

No untreated active depression.

Disclosure: It is strongly recommended that patients have disclosed their HIV status to at least one friend or family member OR have joined a support group.

Insight: Patients need to have accepted their HIV-positive status. They need to have insight into the consequences of HIV infection and the role of ART before commencing therapy.

Patients should be able to attend the antiretroviral center on a regular basis or have access to services that are able to maintain the treatment chain.

Transport may need to be arranged for patients in rural areas or for those far away from the treatment site.<sup>22</sup>

---

<sup>21</sup> CD4 cells are a type of white blood cell that help to fight infection. A CD4 count is the amount of CD4 cells per microliter of blood, and is used to gauge the body's defenses against infection. A healthy person's CD4 count can range from 500 to 1,000 cells/microliter.

<sup>22</sup>The guidelines stipulate that the psycho-social criteria are not exclusion criteria, but rather that the final decision to treat a patient with ART will be made by a multi-

The medical criterion for HIV staging and treatment outlined here and throughout the dissertation are applicable to the time I was conducting fieldwork. It is important to note that these guidelines have since been revised. For example, a CD4 count of 350 instead of 200 is currently the marker to begin ART. Further discussion of these changes and the current landscape of HIV/AIDS treatment and care are presented in the concluding chapter of the dissertation.

In South Africa, there are only two tiers of antiretroviral treatment available in the public health sector. Figure 4.2 lists the medications, associated monitoring tests, and the frequency at which those tests are conducted. Treatment naïve, or newly initiated patients, are put on the first tier of treatment. Women without a reliable form of contraception are put on regimen “1b” and Efavirenz (EFV) is replaced with nevirapine as a prophylaxis for mother to child transmission. Patients who have demonstrated treatment adherence but continue to have adverse reactions to regimen 1 medications may be changed to “second-line” medications. The availability of only two tiers of treatment in the public sector is a critical point to illuminate. If a patient on first line medications fails to properly adhere to their treatment regimen, they may potentially develop medication resistance, leaving only one “line” of drugs available to them. Continued poor adherence while on second line medications can result in a patient being denied further access to antiretroviral treatment.

---

disciplinary team at the treatment facility responsible for initiating treatment. The guidelines also stipulate that the patient and/or caregiver must be involved in this decision.

Regimen	Drugs	Monitoring Tests <sup>23</sup>	Frequency <sup>24</sup>
1a	Stavudine (d4T) Lamivudine (3TC) Efavirenz (EFV)	<ul style="list-style-type: none"> <li>• CD4</li> <li>• VL<sup>25</sup></li> <li>• ALT</li> </ul>	<ul style="list-style-type: none"> <li>• Staging, then every 6 months</li> <li>• Baseline, then every 6 months</li> <li>• When symptomatic</li> </ul>
1b	Stavudine (d4T) Lamivudine (3TC) Nevirapine (NVP)	<ul style="list-style-type: none"> <li>• CD4</li> <li>• VL</li> <li>• ALT</li> </ul>	<ul style="list-style-type: none"> <li>• Staging, then every 6 months</li> <li>• Baseline, then every 6 months</li> <li>• Baseline, week 2, 4 and 8, then every 6 months</li> </ul>
2	Zidovudine (AZT) Didanosine (ddI) Lopinavir/ritonavir (LPV/r)	<ul style="list-style-type: none"> <li>• CD4</li> <li>• FBC</li> <li>• Fasting cholesterol and triglycerides</li> <li>• Fasting glucose</li> </ul>	<ul style="list-style-type: none"> <li>• Staging, then every 6 months</li> <li>• Baseline, then monthly for 3 months, then every 6 months</li> <li>• Baseline, at 6 months, then every 12 months</li> <li>• Baseline and 12 months</li> </ul>

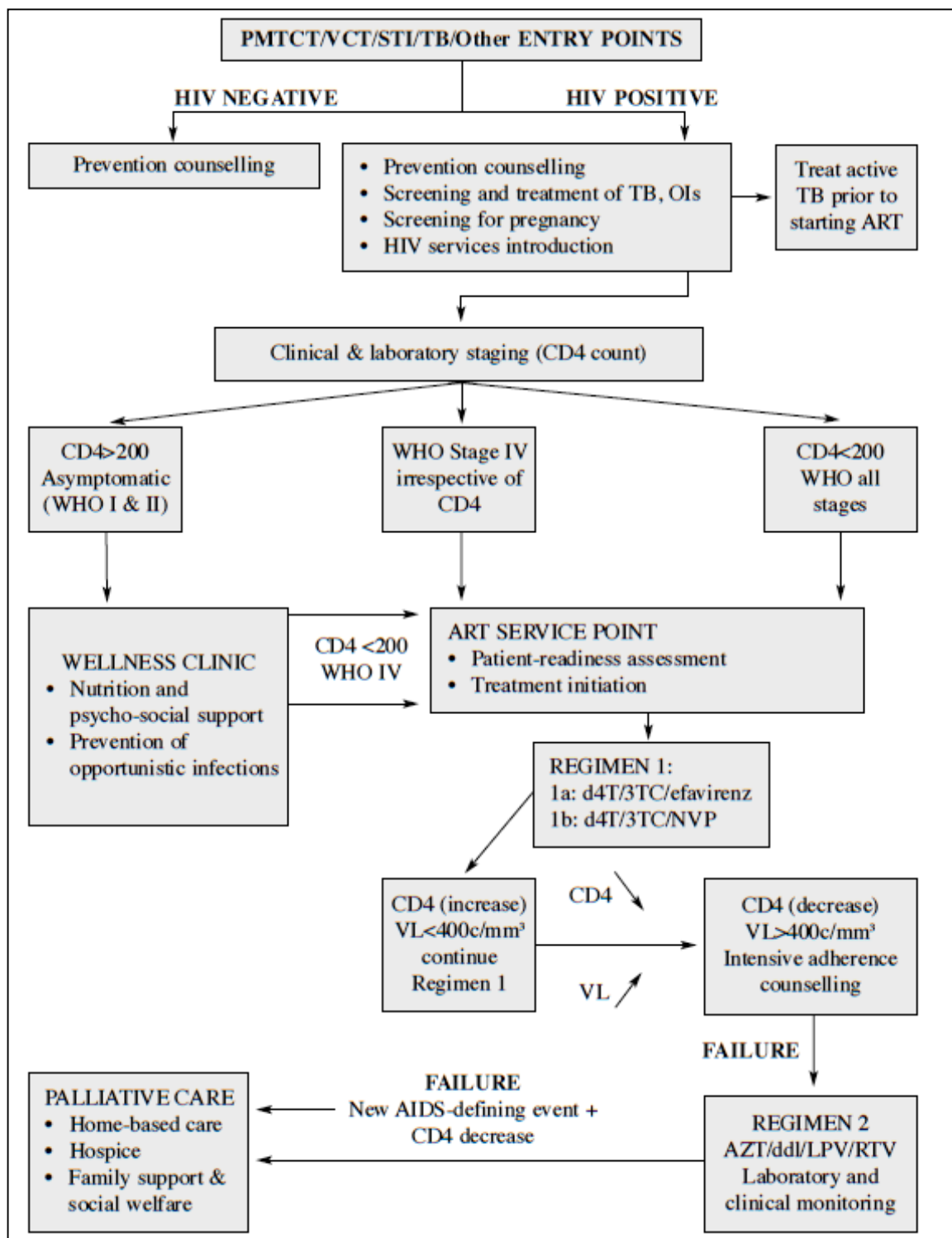
**Figure 4.2** Antiretroviral Drug Regimens for Adults

Source: SA Department of Health (2004)

<sup>23</sup> CD4 = CD4 count; VL = Viral Load; ALT = Alanine Aminotransferase Levels (key marker of liver function); FBC = Full Blood Count

<sup>24</sup> Staging = Initial testing for all patients when being referred for ART Baseline = Testing for ART eligible patients, at initiation of ART

<sup>25</sup> There is generally an inverse relationship between viral load and CD4 count. Typically, the higher a person's viral load (the level of HIV in the blood), the lower their CD4 count.



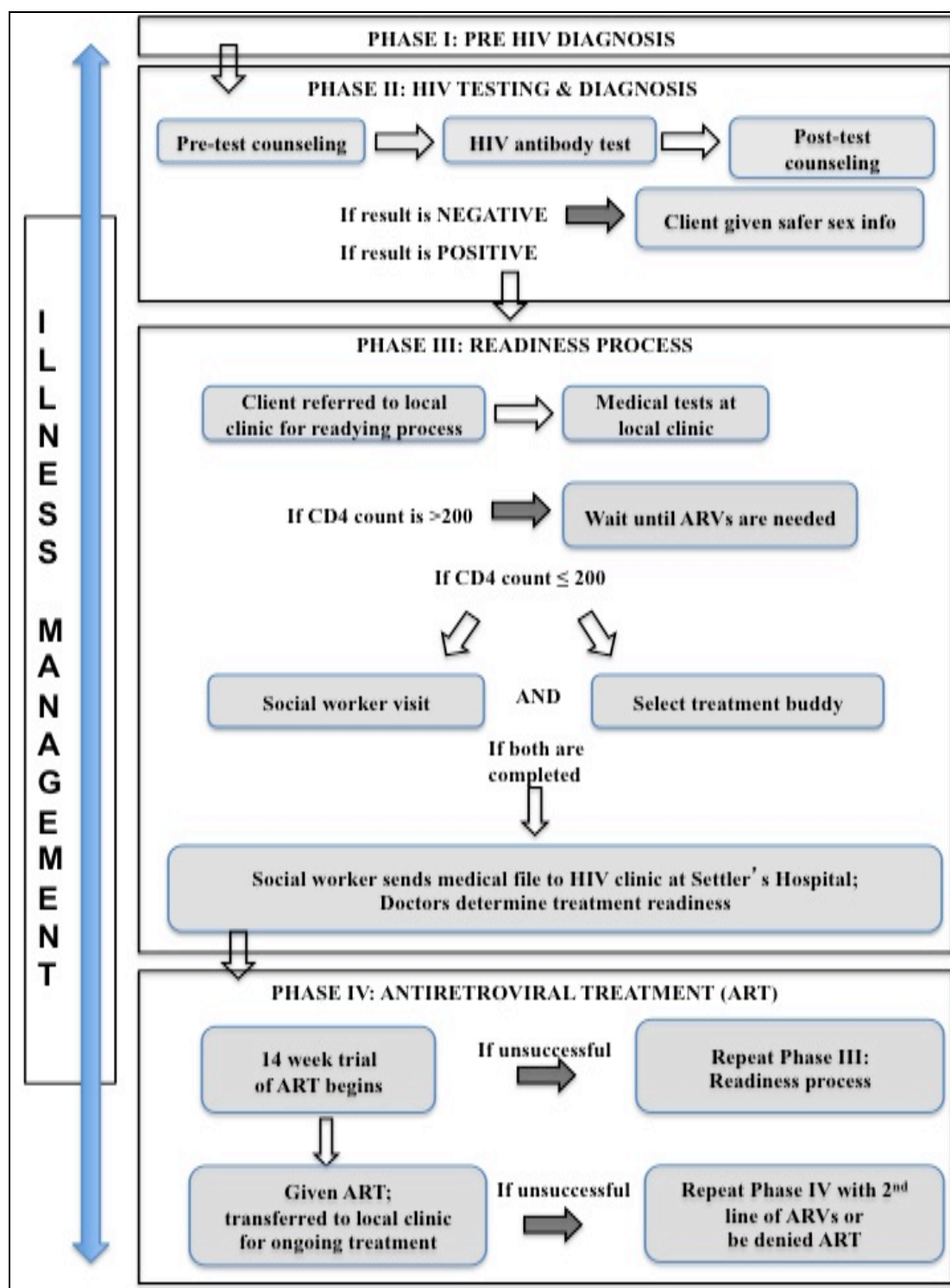
**Figure 4.3** Adult HIV Management Flowchart  
 Source: South Africa National Department of Health

Finally, the guidelines also included a state-prescribed HIV management flowchart (Figure 4.3), to instruct medical practitioners and patients through the testing to treatment process. The flowchart begins with entry points for testing: PMTCT/VCT/STI/TB/Other. Pregnant women are tested for HIV when they visit public clinics for prenatal care as a way to prevent mother to child transmission. Voluntary counseling and testing (VCT) sites—like the GCC, hospitals, and local clinics, are other entry points widely used among my research participants. The chart details the subsequent state-prescribed HIV management steps from testing to treatment. The steps are extensive and include many biomedical markers (CD4 count, comorbid conditions, opportunistic infections) that determine the ways in which patients are moved through the process.

I initially used the South African Department of Health flowchart to map participants' narratives about health-seeking, but realized that the flowchart was leaving out some pertinent aspects of their experiences. Many participants spoke in depth about their lives before their HIV testing experience, highlighting the ways in which pre-diagnosis factors greatly impacted their impetus for and experiences with HIV testing. Additionally, participants described the ways in which illness management was a recurring theme throughout their lives, often before being diagnosed with HIV.

Building from these insights, I created a revised flowchart, the HIV Health-seeking Process Flowchart (Figure 4.4) that more closely reflects these additional elements and the ways in which the health-seeking process was described among participants. I have broken the chart into four phases: Pre-HIV Diagnosis, HIV Testing and Diagnosis, the Readiness Process, and ART. The open arrows reflect flow from one

phase to the next, while the solid arrows show the general stop points for participants, with an understanding that each person's experience is unique and often maps onto this process incongruently. The left side of the HIV Health-seeking Process Flowchart demonstrates how illness management is a concurrent element across phases. I attempted to simplify the HIV management process, but both flowcharts remain dense and the steps included are extensive. In the optimal scenario, participants move from pre-HIV diagnosis to testing to treatment seamlessly, but this was not the case for any of the 35 HIV-positive participants in the study. Not one of them had a linear experience through the testing to treatment process.



**Figure 4.4** HIV Health Seeking Process Flowchart

Source: C. Jones

### **Phase I: Pre-HIV Diagnosis**

The social and economic context in which participants engaged the health-seeking process became a consistent theme across participants' illness narratives. In this section, following the first phase outlined in the HIV Health-seeking Process Flowchart: *Phase I: Pre-HIV Diagnosis*, I describe the motivations for testing among participants, and highlight what their lives were like leading up to their HIV tests and HIV positive diagnoses. During my in-depth interviews, I questioned why people initially chose to test for HIV. I wanted to investigate the reasons why individuals who were not in need of emergency care or prenatal services would come to the GCC or other sites to voluntarily initiate an HIV test, particularly considering the immense stigma attached to an HIV-positive diagnosis. For some, the decision to take an HIV test was made over time after many years of dormant symptoms in the midst of suspicions, and for others, it was a more immediate decision.

Most broadly, while the specific details of each participant's story were unique, the general impetus for testing fell into three main areas: the onset of physical symptoms, learning that a current or past sexual partner was HIV positive, or entering into prenatal care. Additionally, for those who consented to be tested, unlike participants who were tested during pregnancy without their knowledge or informed consent, the decision was often shaped by the level of social support, the perceived emotional, economic and social implications of a positive HIV diagnosis for individuals and their families, and knowledge of HIV/AIDS—where those who were fearful of dying or “wasting away” often delayed testing. Individuals who had higher levels of social and emotional support from family members were more apt to readily test for HIV and disclose their status to



family members and friends. Other participants, particularly those who were tested earlier in the epidemic or who had less knowledge about HIV/AIDS, often delayed testing. These two social aspects were evident in Xolisma's narrative, as she described the factors that shaped her pre-HIV diagnosis experiences and decisions about testing and disclosure:

---

Xolisma: I'm born here in Grahamstown on V Street. I grew up with a single parent. Just with my mom. We were always struggling, but I went to school until 10<sup>th</sup> grade, [she laughs as she is talking and I note in my journal that she seems almost embarrassed by what she is saying and her laughter is a nervous laughter] because I left school and got involved with the people who are putting up the housing and building the roads. They were building the N2 highway. So in 1996, that is where I pick it up, because I started dating those guys there.

*CJ: What led you to get tested in 1996?*

X: In '96 I used to do a washing job and these people fired me so unexpected and they didn't have to do it that way. So then I started to get headaches and I thought it was because I was stressing about being fired. So, I went to the clinic and the clinic have checked me out and found out that I do not have depression. I was not 'stressing.' And they take blood samples to test me at Settler's Hospital.

*CJ: How long did you have to wait to get your results?*

X: Three months.

*CJ: Three months?! (I ask incredulously)*

X: Yes, it took a long time.

*CJ: So, did you know about HIV?*

X: Yes, I did know about HIV at that time. The only thing that was bothering me was that I have known that you would die from it and I was afraid of looking spooky.

I wasn't sure what she meant and probed further for her to explain:

X: Like spooky, you know. Like creepy like a zombie or a skeleton.

*CJ: Oh, like wasting away?*

X: Yes. So, in 1996 I was diagnosed positive. Then I left it like that, and in 2003 I started to tell my family.

Mandisa whispered to me: “Oh, she have taken long”—within earshot of Xolisma.

*CJ: Why did you choose to wait so long to tell your family from 1996 to 2003?*

X: Because my mom have a problem with alcohol and she likes to swear at me, so I thought, if I tell her now, she’s going to swear at me and tell everybody.

Mandisa interjected and asked:

*M: Around 1996, I know that no one wanted to talk about HIV/AIDS. Was it only your personal shame, or did you have that stigma that you didn’t want everyone to know?*

X: The reality that I was facing was that I didn’t want to talk about it at home because I know my mom and I know my mom was going to get drunk and tell everybody.

---

Elements of Xolisma’s narrative were typical among participants who had been diagnosed earlier in the epidemic: the wait time to get results were extensive, sometimes up to three months; the decision to test was often moderated by fears of wasting away and death before antiretroviral treatment was available; and disclosure was often complicated by intense stigma and lack of familial and social support.

## **Phase II: HIV Testing and Diagnosis**

In *Phase II: HIV Testing and Diagnosis*, individuals enter into the formal HIV testing process. As outlined in the HIV Health-seeking Process Flowchart, the first step in this process is the pretest session, in which individuals seeking an HIV test are advised by an HIV test counselor in a private session. During the session, the counselor asks questions about previous sexual practices, level of knowledge about HIV/AIDS and other sexually transmitted infections, and generally prepares the client for what to expect in the other stages of the HIV testing process. Next, clients are presented to a nurse who is trained to administer the HIV test. At VCT sites, this is often done through a finger prick

in which a small sample of blood is collected onto the testing device. At other medical facilities, however, like hospitals, it is possible that clients have their blood drawn for testing. Most participants had tested at one of the public sites in Grahamstown, but some of them had received their test results at facilities in neighboring areas or other towns. Patients who have medical insurance, however, can choose to be tested by a private doctor. During the finger prick method, the results are almost immediate (three minutes) and the client waits in the office with the nurse while the testing device processes the blood sample. Testing via blood draw, however, may require the participant to return to the testing site several days later for their test results. Testing experiences varied among my participants, as patients diagnosed before the introduction of rapid HIV testing methods, like Xolisma, had to wait weeks or even months for their test results.

Once the test device reports the client's HIV status, the nurse shares the information with the client and then transfers them back to the original staff member for post-test counseling. During the post-test counseling session, HIV negative clients are given safer sex information and encouraged to remain HIV negative. Those who test HIV positive are counseled around the meaning of their HIV positive diagnosis (i.e., ARV treatment, need to practice safer sex behaviors, availability of social support services, etc.).

### **Prior Knowledge about HIV**

Prior knowledge about HIV/AIDS and the onset of HIV-related symptoms often worked in tandem to influence why participants chose to get tested for HIV. The level of awareness and actual knowledge about modes of transmission were not necessarily congruent. Over the course of my fieldwork, it became clearer that this knowledge often

was anecdotal or incomplete. Participants stated, for example, that they saw advertisements about HIV/AIDS on television, but were not always keenly aware of the direct implications of the virus in relation to their personal lives and sexual behaviors. This schism between knowledge and behavior was especially challenging for me to reconcile when I met Bernice.

Bernice was a 27-year-old HIV counselor at the THC. She was employed at one of the grocery stores in town, and had completed the Standard 8 (Grade 10). She had a two-year-old daughter and lived in the colored area of Grahamstown. When I sat down for the interview across the table from Bernice, I wondered why my research assistant had suggested that I invite her to participate in an interview. I assumed Mandisa thought that it was important for me to gain the perspective of a community healthcare worker, to more fully understand healthcare workers' roles in the health-seeking and illness management processes. Naively, I asked Bernice what she wanted to share with me about her experience, expecting her to engage me in a conversation about her role and the challenges of being a healthcare worker. Instead, in an almost whisper, she said, "I'm not going to lie, I'm still feeling a little sore inside, but I feel like if I talk to you, I'll feel better. So, it's a must that I talk to you. What I really want to talk about is the sickness, the HIV that is inside." A bit confused, I gently encouraged her to continue. She proceeded to tell me how she had recently been diagnosed with HIV after taking an HIV test at the GCC. My follow-up question was steaming with judgment: *Were you already a caregiver here? So you knew a lot about HIV already?* "Yes, I was a caregiver here. I started working here in 2005." Trying to recover in the interview, I asked her what prompted her to get tested. "I went to test because of my new boyfriend. I didn't have

symptoms. I knew that the old boyfriend was sick, but I didn't take notice, but then I went and I was HIV positive." In my field notes, I wrote:

*It was clear that I was judging her and basically saying: You have been an HIV/AIDS caregiver. You of all people should know how to project yourself. How did you end up in this situation? I could hear the tinge of "You brought this on yourself" in my voice. Somehow I felt that with her many years of training and having served specifically as an HIV/AIDS community health worker, how could she be in this position? I don't think she recognized it because she continued to be open and forthcoming as she recounted her illness experience, but I was extremely disappointed in myself for not being able to mask my reaction and recover more quickly.*

Both had chosen to delay disclosing her HIV status to most of her family and friends. Her decision seemed to be guided more by a need to personally cope with her diagnosis before sharing it with others, as she had been diagnosed only four months prior to our interview. For Bernice, an HIV positive diagnosis conflicted with her position as a THC counselor in that she felt her personal sexual practices ran counter to the guidance she gave the clients at the THC about sexual wellness and HIV prevention.

Sandisiwe also offered an example of the slippage among participants between knowledge and practice. During our interview, she offered vague descriptions of her understanding of the symptoms associated with HIV and AIDS, but was insistent that she was knowledgeable and very aware of HIV: "Yes, but I've known a lot about HIV before my diagnosis." *Do you remember what you knew about it?* "I've known that if one person has a cut and the other person has a cut, then you can get HIV like that. And I know that if you have sex you can get it that way, too." When probed about his prior knowledge about HIV and AIDS, Thando, however, helped to characterize what the experience was like "in the early days:" "In 1991, there wasn't a lot of information available about HIV. There was awareness but it wasn't like it is now. It was not overlapping like it is now."

Tuberculosis (TB) often was characterized as a gateway for HIV testing. A common saying among many participants was that “TB and HIV go hand in hand,” and TB was the most common comorbid condition. All of my participants, except for Bernice, had been previously diagnosed with TB. For Thobeka, her TB diagnosis was the predominant impetus for her to get tested for HIV.

Thobeka was a 39 year-old mother of two daughters, ages one and 14. She was born on a farm outside of Grahamstown and had completed Standard 7 (Grade 9). At the time of our interview she described herself as “single,” but made a point to tell me that her boyfriend had passed away in 1996. The moment was further punctuated when she insisted that I write his name down, checking that I had spelled it correctly. Later, as she told her story, I understood that his death was a defining life moment for her and shaped her pre-diagnosis illness experience. At the time of our interview, Thobeka lived with only her 1-year-old daughter and was unemployed. She moved away from Grahamstown when she was younger, but returned in 2002 when she “became blind since I’m stressed.” This was her chosen entry point into her life story:

---

Thobeka: After my boyfriend have passed away, I started to think and stress too much and that is what caused my blindness.

*CJ: When did you lose your eyesight?*

N: 2004.

*CJ: Did you go see a doctor?*

N: Yes.

*CJ: What did they say?*

N: The doctor said it’s because I’m thinking too much and it’s causing to put pressure down on my veins...In 2005, or 2006 I got transferred to a doctor in PE (Port

Elizabeth) and they made an operation on my eyes. And they referred me to Social Development so that I can get help and get a grant. I was thinking it was going to help, but the operation didn't help.

She continued,

N: Last year, I got sick in September. I did get sick, but I didn't take steps in time. I didn't go. So now, I started to go to doctors this year in January. So I didn't know where to go because I was just coughing and I was always feeling cold...so I asked the people, can you please take me for an X-ray at Settler's and the result came from the X-ray that I have TB. I started TB treatment in April. So between January and April I had no TB treatment.

*CJ: What happened next?*

N: After they tested me for TB, I volunteered that they must test me for HIV and they did the finger prick and they told me, "Sisi, you are HIV."

*CJ: Why did you volunteer to take the HIV test?*

N: In 2005 or 2006 I got involved with another boyfriend who lived on a farm. So I did not condomize because I was not educated about HIV and AIDS that time. I didn't have a big body, but after I got involved with this guy I could tell that I was losing weight and so I started to get concerned.

*CJ: What was your reaction when they told you?*

N: I didn't have a shock but I was more concerned about my child and my parents. [She began to cry.] Because I was a mother and a father of this child, I was more concerned about her.

We pause the interview for Mandisa to go get some tissues. While we waited for

Mandisa to return, Thobeka continued to cry. I looked up at her and we locked eyes. I

was really at a lost for what to say. I silently wondered how long it is going to take for

Mandisa to come back with tissues.

---

For others, the decision to get tested came after hearing from family members or friends about their partners' status. Thando, for example, recalled that his girlfriend at the time of his diagnosis was already HIV positive, but "tried to hide it." As he explained, "I met her in 1991 in Grahamstown. We were not dating while I worked in the mines (from

1987-1990). When we started dating, she knew she was HIV positive but she didn't tell me." When I asked him if they ever discussed their HIV status, he said, "Sometimes she and her sister would argue because her sister one day said, "why don't you tell the other child that you are sick, that you are HIV positive, and that you infected him?" So, I asked her about that when we were alone and she got so angry so I left it alone and didn't push the issue. He eventually overheard his girlfriend and her sister argue about her non-disclosure at a later time and it prompted him to get tested.

Yolandi was also prompted to get tested based on interactions with her partner. Yolandi has three children, three boys ages 23 and 16 (twins). She listed her relationship status as "single." When I asked her about how many people she shared a household with, she reported that she was living with her boyfriend and her kids until her boyfriend passed away earlier that year in August. I duly noted her response. Later, however, when reviewing my field notes and in listening to her interview again, I was struck by my lack of reaction to her telling me that she had just lost her boyfriend only months earlier. I cannot say if my lack of a more appropriate response was because I was focused on the interview guide, or if it was because of the very matter-of-fact way in which she shared that information, with very little emotional emphasis.

In 2003, the boyfriend that I was living with, the one that has just passed away was always staring at me. And I was always asking him, why are you always staring at me, is there something you want to tell me? Why must you always stare and he would always respond 'I love you a lot.' And I would leave it alone. We were relaxing, me and this boyfriend, and I was undressing myself getting ready for bed but I could notice that my body was full of pimples, but he was drinking and I think that gave him guts that night and he said, 'You must go to the clinic to check yourself because I am HIV positive.' And I was drunk that night and so when the children came home, I said, you can take that bed, you can have that bag...because I am going to die because I am also HIV. That was in 2003. And then the next day, I remembered the night before and I was considering everything this guy was saying and I started to make my mind up and I said, let me go to the clinic.



Later in our interview, I asked her to speak more about her impetus for getting tested: *So, when you went to actually get tested, other than the pimples, did you have any inkling that something was wrong?* Yolandi responded, “I have never thought this guy could be HIV positive because he was healthy. He never looked sick, so you could never compare him to that. He was normal.” She went on to tell me about her actual testing experience at what she called “the colored clinic”—Middle Terrace Clinic in the colored area of Grahamstown. “They told me I was HIV...When they told me, I just accepted it. No matter, it’s in my blood now.”

Some participants, like Nandi, shared that they were tested for HIV without their knowledge: “So, I fall pregnant and if you are pregnant, you have to go to the clinic and they do the pap smear and they do samples from my....and it was a delay on my results and it didn’t come up. All the other ladies I was in the clinic with got their results but my results were not coming fast enough.” *Did you know they were doing an HIV test?* “No, they didn’t say anything.”

---

These narratives revealed that there were multiple ways to enter into the HIV testing process. For most participants, the decision was influenced by the onset of symptoms—that ranged from “feeling cold” to more visible symptoms like thrush. Women, like Nandi and the many women discussed in the previous chapter, entered the process through PMTCT programs, and underwent mandatory prenatal HIV testing. The third major reason people got tested was based on the suspected or confirmed HIV positive status of their partner. These decisions were often mediated by prior knowledge of HIV/AIDS.

### Concurrent Sexual Partnerships and Condom Usage

One of the recurrent themes, while at times not always explicit, was partner concurrency—defined as a person having sexual relationships with more than one person overlapping during the same time span. The discussion about concurrent partnerships often was had in tandem with conversations about condom use behaviors. The issue of partner concurrency was generally treated differently among female participants than among the male research participants. Male participants were slow to admit concurrent sexual partners, and often only admitted to or shared details about partner concurrency within the context of sharing their illness narratives. They were reluctant to discuss having concurrent partners when asked directly. Men were, however, aside from two female participants, the only respondents that reported having concurrent sexual partners. Thando, for example, recounted during his illness narrative a common experience among men of his generation who had worked in the mines before HIV/AIDS became prevalent in South Africa: “I used to work in the mines from 1987 to 1990 in Jo’burg. Then I worked at the docks loading things off and on from 1993-1995 in Port Elizabeth (Eastern Cape, 1.5 hours southwest from Grahamstown).” I asked him what the experience was like in the mines: “I was washing off all the pipes. I was doing maintenance.”

I probed further: *Was it difficult to be away from your family? If you had to describe what mining life was like in Johannesburg, how would you describe it?* He went on to describe the dangers of the mine until I explicitly asked him about multiple sexual partners: *Often, you read about how men were separated from their families and how some men had local families close to the mines. What do you think about that?* He responded, “Yes, it did happen that this man does have a family and also have a

girlfriend, but at that time, there was no HIV then at that time. It was STIs, things that we could cure. Drops, infections that...all those things that we could cure. But there was no HIV.” He then admits, “Or maybe we just didn’t know yet, because... I agree that it was probably starting then.” During our conversation, Thando also talked about his condom use behaviors: “In the past we didn’t need to worry about condoms.” *And since then, have you used condoms always?* He laughed nervously and shot a quick glance to Mandisa, who nodded her head as if to encourage him to answer the question: “Sometimes I do use it and sometimes I forget that I have to wear a condom.” While male participants mainly reported concurrent partnerships, poor condom use practices were a shared narrative among both men and women. Xolisma’s narrative earlier in the chapter left off with the factors that shaped her pre-HIV diagnosis experience, impetus to be tested, and decision to wait seven years to disclose her status. Later in our conversation, I asked explicitly about her current condom use practices:

---

*CJ: By 2003, people knew more about HIV. There was less confusion about what it was. So between 1996 to 2003, did you change your behavior, did you use condoms, since you chose not to tell anyone during that time?*

X: Ok, I did get involved with another relationship after I was diagnosed HIV positive, but I did tell the boyfriend straight, ‘Bhuti, whatever we are going to do we have to use a condom because I am HIV positive.’ I was telling him to see how he’s going to react when he heard that I’m HIV positive. And then he agreed. After I ask him to use a condom, we have used it for a very short period. And he just let go on the condom and we stopped condomizing. We just go through without the condom. Now I was sensing that he was HIV positive, too, because why should you just stop using the condom when I have told you that I am HIV positive?

*CJ: Ok, did he ever go to test?*

X: And then I have fallen pregnant, ne, and after the baby he have gone to get tested and he was found out HIV positive.

*CJ: So that’s the father of your 12 year old?*

X: No, it's the father of the six year old. The 17 and the 12-year-old's father have passed away.

*CJ: So you dated him for a while?*

X: Yes.

*CJ: Do you know why the father of the other two passed away?*

X: [She laughs and responds flippantly] Obviously, he passed away because of HIV/AIDS.

*CJ: Do you think you contracted it from him, or are you sure?*

X: Yes, I contracted it from him. He have passed away in 2004.

---

One historical factor that retarded the prevention of HIV/AIDS in South Africa, and in many other parts of the world, was the notion of women as “vectors” of disease or “core transmitters”—the idea that women, serving as sex-workers/prostitutes, or through sexual-economic exchanges, were the main transmitters of the virus. This was not a common narrative among the female participants in my study, however. In fact, the notion that promiscuity by women was the primary way to contract the virus failed as a dominant discourse within my findings. More commonly, female research participants, like Xolisma remained faithful to a single partner, and in turn, became disarmed, and believed that their fidelity would secure their protection against contracting HIV/AIDS or other STIs. Sadly, this was not the case for most of the women in the study.

### **Phase III: Readiness Process**

Once a client tests positive at the GCC, they are referred to their local clinic by the nurse to begin the *readying process*. Readiness refers to the predetermined steps that must be taken and satisfied before a client is given ARVs. More specifically, it describes the set of medical procedures and lifestyle checks that are performed by healthcare

workers and doctors to determine if a patient will be given ARVs. The readiness process begins with an initial medical “work-up,” and if a patient has a CD4 count of 200 or below, it continues with a home visit by a social worker and the selection by the patient of a treatment buddy. Readyng is a critical step in the treatment-seeking process for HIV-positive patients, yet as I more fully describe the process, it became evident that it is neither linear nor consistent across patient experiences. One local HIV/AIDS nurse, Linda, described her approach to the readiness process:

Once a client tests positive in my office, I refer them to the nearest clinic for further management. Before they leave here, though, I take them step by step. I want them to be ready to know what those people [at the clinic] are going to do to them. I want them to be ready. I don’t want to scare them by saying all sorts of dumb things.

At the clinic, you need to look at the client’s clinical picture first.

We start by doing the ARV work-up, the baseline. We take blood and if it’s a male we draw blood to find out the full blood count, we test for hepatitis B, measure the CD4 count, and take the viral load. Then we conduct a liver function test, rapid plasma test, and test for the main STIs, gonorrhea and syphilis. And for women, we do all of that plus a pap smear and test for other STIs because there’s trich (trichomoniasis) and vaginitis.

Then we do chest x-rays and a sputum test for TB. We also do an abdominal scan for TB because it may not be pulmonary TB. TB can be anywhere in the body. Initially TB doesn’t have to start in the lungs, it can start in the spleen, the liver, the vertebrae, the nodules, wherever. All of those places. And then we fill in the baseline forms and note if there’s any previous history of HIV, if the person a defaulter, if they are starting on the first line regiment, the second line regiment; then we get a supporter.

We do the lab tests one week and then they come back and we do the tests for the STIs and OIs [opportunistic infections]. It takes the results of the CD4 count about two to three days to come back. Depending on your CD4 count, if it’s below 200, we start you on prophylaxis, on Co-trimaxazole. We call it Cozole. It’s a broad spectrum antibiotic covering the body against all of the OIs, which means that it’s not a narrow spectrum antibiotic. This one is a whole body antibiotic and fights bacteria in the whole body. We also give clients folic and ferrez, the multivitamins and iron supplement. If there is something going on, I immediately put them on prophylaxis, even if the CD4 count is 400. It’s so important to do a disease staging.

Nurse Linda's account of being *readied* demonstrated not only how lengthy the process is, but also detailed how the process involves multiple, concurrent processes.

A client has to learn how to come to terms with their HIV diagnosis while they simultaneously are ushered into a complex system of healthcare and illness management. Some participants described being overwhelmed by having to learn all of the new “language,” including what CD4 count means, the importance of the viral load, and the basics of how the virus affected their body. This was particularly evident among patients who had already started ARVs. There were only a two or three who proudly declared that they knew the names of all of their medications. The majority, however, did not, and some seemed almost embarrassed when they could not tell me which ARVs they were on. They instead referred to their pills as “the white ones” or “the big ones.” For clients whose CD4 count is above 200, they are given prophylaxes, multivitamins, and monitored until they present with an opportunistic infection or their CD4 count drops low enough to need ARVs. This stage becomes fairly contentious, however, as patients who are “not sick enough” have no choice but to wait until they meet the government benchmark to receive treatment, or a doctor decides to put them on ARVs at an earlier stage. Later, I specifically discuss doctors and nurses, and the ways in which their responsibilities and roles became reconfigured and negotiated during this process.

### **The Next Stage of Readiness**

Patients who initially had CD4 counts of 200 or below continued on in the process. As the chart depicts, the next steps are a visit by a social worker and the selection of a treatment buddy. Pumla, the GCC counselor who assisted me with my HIV test, described the purpose of the social worker visit:

The social worker is supposed to come to your house to check on things. The purpose of the social worker coming to your house is so that they can get a local context of your lifestyle. They are looking to see if your home environment is good enough for you to start ARVs. Unfortunately, there are not enough social workers, so sometimes people have to wait for the visit. Also, some people are rejected from ARVs because of the social worker. Some social workers accept hearsay from neighbors or other people about that person without actually seeing from themselves. And sometimes, if you live near a shabeen (a township bar) or something like this, they will say that you cannot support a healthy lifestyle and deny you.

The social worker becomes an integral part of the treatment readiness process, and in some situations, has the authority to block the ability of a patient to begin ARVs. As such, decisions about access to antiretroviral treatment are sometimes made not based on medical work-ups, a patient's CD4 count, or other biomedical indicators. Rather, they are based on subjective interpretations about social behaviors and lifestyle choices. As Pumla noted, however, there is a shortage of social workers in Grahamstown, which leaves a backlog of patients who are waiting for treatment. I am not certain why there is a shortage of social workers, but I surmise that a lack of funding for more positions plays a key role. This is an important point, particularly since officials at the HIV/AIDS clinic at Settler's Hospital maintained that there was no list of patients waiting for treatment. Those claims, however, perhaps failed to account for clients who had yet to make it to that stage of the process and were awaiting clearance from a social worker. Additionally, a public visit by a social worker potentially raises important questions about confidentiality. With so few social workers, many residents were aware of what a visit by a social worker signaled, inadvertently disclosing a patient's status.

The selection of a treatment buddy is also a necessary step in being readied to begin ARV treatment. The role of the treatment buddy is to hold patients accountable to adhering to their ARVs. Most commonly, participants chose their significant other or a parent to serve as their treatment buddy. The role of the treatment buddy also serves dual

needs. In the initial work-up stages, treatment buddies are required to accompany patients during their doctor's visits so that they also can learn about their responsibilities and how to properly monitor and encourage treatment adherence. For Nurse Linda, the secondary role of the treatment buddy is, "for me to make sure that you are sticking to your regimen, you have someone to say after breakfast, 'Hey did you take your medication?'" Other healthcare workers expressed similar sentiments, and as one doctor put it: "The treatment buddies are there to protect me." Requiring clients to have a treatment buddy, however, raises important financial concerns and becomes one of many economic negotiations patients make in the help-seeking process. For example, ARVs are free at the point of service, but treatment is not without cost. So, while ART is technically free, the readiness treatment maintenance processes can create a financial burden for participants.

Not only does the requirement of a treatment body force disclosure, but it also creates a space for the development of new types of relationships among clients and their family members as they collectively negotiate treatment management. This new dynamic became particularly poignant among patients who rely on their teenage children to serve as their treatment buddy. Youth have to learn how to negotiate what it means to live with and care for a chronically ill parent. This in turn changes the experiences of affected youth. This dynamic becomes particularly challenging when teens and young adults often are tasked to assume the role of treatment buddy for their parents—holding them accountable to monitor their parent's healthcare regiment and enforce strict adherence to antiretroviral treatment. In their new roles as caregivers, youth become directly implicated in the complex, high stakes process of illness management and decisions that



ultimately contribute to the life or death of a parent. Quite often, the burden to maintain an ARV regiment falls on those who are designated as supporters and are not biomedically marked as being HIV-positive. This highlights the communal and collective nature of the illness management process that is not easily captured by the state prescribed model or the revised model that I have presented at the opening of the chapter.

#### **Phase IV: Antiretroviral Treatment**

Once a patient has been tested, completed a medical work-up, been screened by a social worker, and selected a treatment buddy, the patient's entire medical file is prepared by the social worker and presented to the HIV/AIDS clinic at Settler's Hospital. Settler's Hospital is the first site where all patients begin ART. After the file is reviewed, the patient is given a date to come to the clinic at Settler's. Now that the readiness process has been completed, the patient is ready to begin training on how to properly take antiretroviral treatment. This portion of the process is 14 weeks, and it is at this point that patients actually begin to receive ARVs. At the first appointment, patients are given complete physicals (again), including chest x-rays and all of the exams that were performed at the beginning of the readying process. During this visit, clients must come with their treatment buddy and both patient and supporter are given a thorough explanation about ARVs, counseling, and finally, actually given medication. The subsequent visits occur at weeks two, six, 10, and 14, respectively. During those appointments, vitals are taken and pills are counted to ensure proper adherence. Taken together, the doctors believe that pill counts and consistently taking vitals are an adequate method of gauging treatment adherence, evidenced by a decreased viral load and/or an increase in CD4 count. According to one of the doctors from the HIV/AIDS clinic:

If someone is having trouble with the adherence, it's usually pretty obvious what the problem is. It's either poor understanding or comprehension of treatment, alcohol or lifestyle issues, things like that. So, if that's the case, they go through the process of counseling all over again, but we don't declare that person a defaulter yet. It depends on the circumstances. Some people are given multiple chances, but we let them know when they have come up against their last time.

The matter of fact tone of the doctor, however, belies the fact that the timing of this process can medically mean something different altogether. Thinking back to the second woman I met at the hospital when I arrived to Grahamstown, I considered the ways in which the readying process fails patients like Janet. After completing all of the necessary stages, Janet finally began taking ARVs. I will never forget how happy she was to be on treatment, only to die a few days later. It was too late for Janet. For patients who wait too long, their immune systems will no longer respond quickly enough for treatment to be effective. Yet, there are few ways to be fast-tracked in this process and immediately be given ARVs. This is one of the barriers to care that patients, community organizations and healthcare practitioners have to negotiate as part of the help-seeking process.

### **Treatment Management**

After a client successfully completes the 14-week program at Settler's Hospital, they are transferred to their local clinic to begin their treatment management. From this point, they return to the clinic once a month for check-ups and to retrieve another 30-day supply of ARVs. If a client fails to return each month as scheduled, they are in danger of defaulting. Once defaulted, the readiness process starts all over again—but only for those clients who the clinical or hospital staff feels are good candidates for ARVs. For Unathi, this became a reality when she twice defaulted on ART. During our interview, she passed her medical passport to me. The passport is striking because it is reminiscent of the passbooks residents were required to have during apartheid (see Chapter One). Now,

passports are used to document a person's medical history. Ironically, people often carry their medical passports similarly to how they like they previously carried their passbooks. I was surprised when several of participants pulled out their medical passports during the interview. When I asked certain questions, they would pull it out as a quick reference to check the results of their medical tests and previous CD4 counts. The passport is also where doctors notate when a patient has been readied for ARVs and whether or not they recommend that patient for a disability grant (discussed in Chapter Five). Where as the passbooks were used to grant access to certain restricted parts of the country, medical passports are now used to gain access to health services and financial resources. Unathi's passport read: "2006; default; transferred back to the B-co and Cozole, but before we put you back on the ARVs, must take your CD4 count." The details of Unathi's experience are specific to her personal situation, but many other participants talked about the challenges of navigating the health-seeking process. The process has so many steps and at each step the potential for clients to fall out of the system often intensifies. This process not only becomes challenging for individual patients and their affected family members, but also becomes a complicated negotiation for doctor and nurses.

The introduction of antiretroviral treatment has created new spaces for doctors and healthcare practitioners that force them also to make difficult decisions about the care and treatment in relation to their HIV and AIDS patients. While government guidelines about who qualifies for treatment are fairly rigid and straightforward, those standards fail to account for the ways in which doctors have to interpret those policies in the everyday experience, in much of the same way that patients learn to reinterpret health policies to fit the circumstances of their lives. As a result, the longstanding dichotomy between patient

autonomy and medical power fails to capture the assumptions made about medical authority.

Similarly as their patients, physicians confronted with HIV also struggle with its hidden presence, its dual meaning of being both potentially deadly and yet an undefined ‘opponent.’ The ambiguity of HIV places the patient in an unclear position in regard to his/her main attribute within the health care setting, i.e. in regard to sickness. The patient is ‘sick and yet his is not,’ a situation that questions the ‘strategy’ of the physician (Kopp 2002:18).

Within the context of the HIV/AIDS epidemic the introduction of ARVs have now empowered physicians to be able to do *something*, instead of simply sending patients home to die. They now are able to assert themselves in very powerful ways because they are in control of the prescribing process. This process, however, is not without complications, and a fair share of subjective approaches (further discussed in Chapter Five). As I tried to capture the health-seeking process during the in-depth interviews, participants continued to reframe the conversation and underscore the importance of the multiple social and economic challenges in shaping their health-seeking behaviors.

I met Ziyanda when I was about halfway through my fieldwork. She was a client of the THC and was introduced to me by my research assistant, Mandisa. Ziyanda was 47 years old and from a small farm about five hours west of Grahamstown. She had one child, who she proudly proclaimed had gone to the bush when he was 20, signaling that he was a “bhuti” or man and no longer viewed as a boy among men. She had never been married but described herself as being in a relationship. She shared a household with six other relatives, including her mother, sister, two nieces, and two grandnieces. Her son, then age 27, lived in a neighboring town with her brother. Ziyanda had never been employed and had completed Standard 5 (Grade 7). I noted that she was extremely

expressive in her responses throughout our interview as she told me about her pre-HIV diagnosis and treatment experience:

---

Ziyanda: I grow up and live my normal life but I start to get sick last year in September 2007. They have diagnosed me at a very terrible time. At the time that I went to the clinic I found out that the same day that my sister has died, so I was going to the clinic with this child and found out that the mother of this child has died, so it was a very bad time for me.

Ziyanda became visibly upset as she continued to talk about the challenges she faced:

*CJ: When you started to feel sick? What symptoms did you have?*

P: The symptoms that I was noticing, was that I was having a terrible headache and I had this constant cough, and everywhere I was going, I felt like I was picking up everything, and I had this funny sound in my neck. I then went to Joza clinic and they did the finger prick blood draw on me. I got my results the same day. The first time they take the first test and there was no reading, and I was so happy. So they said, 'Wait, it may not be true,' so they took another test and then it moved (the line on the HIV testing device) down and said it was positive.

*CJ: Did you know what HIV was when you went to get tested?*

P: I never thought about HIV and that I could be HIV positive. I was feeling cold like I was going to catch fever and I thought that it was because the season was changing from summer to autumn, so I thought that was what it was. I never thought it was HIV.

*CJ: How did you feel when you got the results?*

P: It was a very terrible day for me. I couldn't burst out in tears because I had this child and I had to be strong because the mother of this child was dying, so I couldn't burst out in tears, but I wanted to burst out in tears. [She began to cry and I passed her a handful of tissues.] My concern was more about my mom and my child. My thought was like, my mom was going to pass away before me, but my thought was like, what if I pass away before my mom, then who will take care of my mom and my child? But now I am feeling much stronger than I was at that time.

*CJ: Did the nurse explain what HIV was to you?*

She continued to cry and paused before responding:

P: What upset me was the situation that I was living in. We didn't even have our own house at that time and it was already a struggle that my sister has passed and now we must go and ask for some place that we can bury her, and me, I was very thin and sick

and thinking that I could die at anytime. So that is the situation that I was in at that time and it made me feel more bad about things.

*CJ: [softly] Ok, ok, Sisi.*

---

Several key themes were present in Ziyanda's narrative. First, her life experience aligns with the indicators for vulnerability and risk among women as discussed in the previous chapter. She illustrates the ways in which social suffering has become a background for her illness experience. I never learned why her sister died, but the emotional reaction she had while talking about it clearly contributed to her layered experiences of suffering. This was a recurrent theme among participants' narratives—the burden of death of loved ones, often from AIDS-related illness. When I asked Ziyanda about HIV, she paused and responded by discussing her living situation. Like Ziyanda, many participants alluded to the primacy of the economic context of their lives. The fact that she and her family had to ask for help to bury her sister added to her burden, and made her feel “more bad about things”—underscoring how HIV was not necessarily the dominant factor that guided participants' illness narratives about HIV testing and diagnosis.

## **Conclusion**

The models outlined in this chapter are largely based on standardized, biomedical categories that often belie the ways in which the health-seeking process is highly subjective within everyday lived experiences. I argue that the health policies that shape these processes, while perhaps appearing streamlined in theory, in fact have created an extremely circuitous system that is difficult to navigate in practice. Throughout my study, it became clear that multiple stakeholders, who were all intertwined within this process in

specific ways, simultaneously negotiated the treatment-seeking process. In many ways, while availability of ARVs remains important, the central issue became less about availability and more about the ways in which patients learned to navigate the health systems. Figure 4.4 was an attempt to streamline and present a more simplified visual of the health-seeking process, while also acknowledging how illness management is mapped onto the process as a constant, ongoing set of factors. What both graphs fail to capture, however, are the social and economic factors that layered onto the process and also complicate the ways in which patients navigate through the healthcare system(s). In the next chapter, I highlight the antiretroviral treatment experiences among my participants, and critique the ways in which illness management is a multi-layered experience that is directly shaped by economic inequality.

## CHAPTER FIVE

### **“If I Take My Pills, I’ll Go Hungry”: Economic Insecurity And HIV/AIDS**

Toward the end of my fieldwork, my research assistant introduced me to a man named Temba. “I think this bhuti (man) would be a nice addition to your research,” she commented. We agreed to meet at her house the following day and I looked forward to having the perspective of another man to include in my mostly female participant pool. The next day, I arrived at her house and the three of us settled in for the interview. I was immediately struck by how gaunt he appeared. I was even more surprised to hear that he was only thirty-four years old. In my field journal, I noted, “Wow, he looks so rough and worn for 34 years old. I would have thought he was closer to 45 or 46.” As our conversation progressed, Temba shared his history and eventually began to recount how he found out that he was HIV-positive. His story was punctuated by a series of events, including a promising sports career as a youth, dropping out of school in the 11th grade to care for his newborn child, and later, coming to terms with being HIV-positive while battling recurring bouts of tuberculosis. About 30 minutes into the interview, however, Temba’s comments crystallized the complexity of the lived experience among my participants.

---

My girlfriend came to live with my family and me because she had nowhere else to go, and she was the mother to my child. While I would go out to look for a job, my mind started to wonder about this girl and I found that this she was cheating on me. She had found a “sugar daddy” and was spending the time with him. We broke up and had a big fight, but eventually I came to forgive her. After I have forgiven her, things were ok.



I interrupted to ask, “Were you faithful to her, or were you also cheating?” He initially refused to answer, but eventually admitted that he was also “sleeping around.” Temba continued:

My girlfriend starting going to visit her sister’s house in Extension 4. Whenever she would come back, she would always come with something nice...some food or something nice. Now, the way that I have found out that she was cheating for the second time, she brought home some cookies, but the paper bag that she has put the cookies in had a disgusting smell. By knowing the standards of living of her sister, I could judge from there. This is not coming from that house. I could smell that this is coming from poor people. People who are suffering. Even the lunchbox the cookies were in smelled like it was from somebody who is struggling. I’m not trying to make a joke, but you can even smell poverty. If there’s poverty in that area, you don’t see it only out of living it, but you can even smell it. *You can even sense and smell poverty.*

The complex, lived experience of illness and poverty became profoundly clear during my interview with Temba. It also underscored that, as much as my research was about treatment negotiation, it was equally about the strategies people use to cope with poverty within the larger process of illness management.

### **Inequality and Health**

As discussed earlier, the effects of structural violence manifest in various ways throughout South Africa, specifically in the form of unequal access to resources, lack of employment, poor healthcare, and inadequate educational systems. As the prevalence of HIV/AIDS in South Africa continued to rise, it became apparent that the spread of the epidemic was linked to systems of inequality and poverty (Sobo 1999). HIV/AIDS has become a link within a chain of tragedies that are couched within a larger context of poverty and economic inequality. Specifically, “their sicknesses may be thought of as a result of ‘structural violence,’ because it is neither nature nor pure individual will that is at fault, but rather historically given (and often economically driven) processes and forces that conspire to constrain individual agency” (Farmer 1996:23). Here, emphasis is aptly

placed on the notions of *process* and *agency*, and “by social processes, we mean the economic, political, and cultural forces that can be shown to shape the dynamics of HIV transmission” (Farmer 1996:23). Participants’ narratives revealed that living in a context of extreme inequality and poverty deepened their experiences of social suffering (Kleinman et al. 1997). In this chapter, I describe the economic landscape of South Africa and Grahamstown to examine how economic inequality became intricately connected to their health-seeking practices. I argue that the larger economic context shaped participants’ illness management practices and often forced them to make difficult choices about their health and economic security.

### **The Poverty Profile in South Africa**

From September 2008 to August 2009,<sup>26</sup> the first Living Conditions Survey (LCS) was conducted by Statistics South Africa (Stat SA). The survey was designed to measure poverty in South Africa and “properly direct and align all government departments in a concerted effort to achieve the desired victory against poverty in South Africa” (Stat SA 2012a:3). There are several ways to define the poverty line in South Africa (March 2009 figures). First, the food poverty line (R305 per person per month),<sup>27</sup> refers to the amount of money an individual will need to consume the required energy intake. The lower-bound poverty line (R416 per person per month) is the food poverty line plus non-food consumption. The upper-bound poverty line (R577 per person per month) is inclusive of

---

<sup>26</sup> I use data from this survey throughout the chapter because the data collection period most closely aligned with my tenure in the field. Two other surveys were conducted prior to the 2008/2009 LCS, the Income Expenditure Survey (IES) 2005/2006 and IES 2000. These surveys were not designed to capture the same poverty indicators as the LCS, however, and therefore, there is limited data to provide a time series of the same poverty measures.

<sup>27</sup> \$1 = R8 (as of 2009)

the food poverty line and expenditures for non-essential non-food items.<sup>28</sup> The upper-bound poverty line (R577, \$75) is used as the dividing line to delineate the poor from the non-poor. According to the LCS results, there were 48.9 million people and 12.6 million households in South Africa during the survey period. Of those, 25.6 million people and 4.8 million households were living below the upper-bound poverty line. Other poverty indicators included the number of households connected to a main electricity supply, households with piped water, and a source of income. Figure 5.1 shows the distribution of the population with a source of income, categorized by main income source and poverty status (based on the upper-bound poverty line).

---

<sup>28</sup> For a more detailed explanation of how these national poverty lines are determined, see *Measuring Poverty in South Africa: Methodological Report on the Development of the Poverty Lines for Statistical Reporting*, found at: <http://www.statssa.gov.za/publications/statsdownload.asp?ppn=D0300&SCH=5462>

Sources of Income	Poor (%)	Non-poor (%)	Total (%)
Salaries and wages	35,7	64,5	52,9
Net profit from business	4,7	8,4	6,9
Income from subsistence farming	-	0,1	0,1
Income from letting of fixed property	0,3	0,4	0,3
Royalties	-	-	0,0
Interest received	-	0,6	0,4
Dividends on shares	0,1	0,2	0,1
Regular receipts from pensions	0,9	4,0	2,8
Social welfare grants	47,5	13,6	27,3
Alimony, maintenance and similar allowances	3,3	2,3	2,7
Regular allowances received from non-household members	3,5	2,2	2,7
Other income	0,6	0,8	0,7
Unspecified	3,3	2,8	3,0
Total	100,0	100,0	100,0

A dash indicates that the proportion is less than 0.1%

**Figure 5.1** Percentage Distribution of Source of Income by Poverty Status

Source: Stat SA 2012a

Figure 5.1 also indicates that of those who reported an income, salaries and wages were the main source of income. This was true across both the poor and non-poor. Among those in the population with no source of income, however, social welfare grants were reported as the main source of income. This percentage was especially high among those living below the upper-bound poverty line, with 47.5 percent of poor residents reporting social grants as their source of income. Figure 5.2 illustrates a similar trend across a number of selected poverty indicators. The proportion of survey respondents who had an RDP house (15.4 percent) was higher among the poor than the non-poor, and 70.6 percent of poor residents had at least one household member receiving a social grant.

Indicator	Poor	Non-poor	Total
Proportion of households who had an RDP house	15,4%	9,0%	11,4%
Proportion of households where at least one member is receiving a social grant	70,6%	24,7%	42,2%
Proportion of the population whose main source of income was social grants	54,7%	17,9%	28,1%
Average annual household expenditure in-kind (including educational grants)	R758	R10 040	R7 209
Average annual household income excluding in-kind	R30 526	R126 908	R90 274
Average annual household income excluding social grants	R21 452	R123 151	R84 497
Average annual household income including in-kind income	R30 727	R130 627	R92 656

**Figure 5.2** Selected Poverty Indicators by Poverty Status

Source: Stat SA 2012a

Main Expenditure Groups	Poor (%)	Non-Poor (%)	Total (%)
Food and non-alcoholic beverages	42,3	16,1	19,3
Alcoholic beverages and tobacco	1,0	1,0	1,0
Clothing and footwear	7,4	4,5	4,8
Housing	15,2	26,3	24,9
Furniture, furnishings and other equipment	6,6	5,2	5,4
Health	1,7	1,3	1,3
Transport	8,3	16,2	15,3
Communication	3,0	3,4	3,4
Recreation and culture	2,1	4,6	4,3
Education	1,0	3,0	2,8
Restaurants and hotels	1,5	2,5	2,4
Miscellaneous goods and services	9,9	15,6	14,9
Unclassified items	0,1	0,3	0,3
All expenditure groups	100,0	100,0	100,0

**Figure 5.3** Distribution of Total Household Expenditure by Poverty Status

Source: Stat SA 2012a

Figure 5.3 illustrates the household expenditures according to poverty status. It highlights the considerable differences in spending patterns between the poor and non-poor, with the highest disparities between expenditures coming from food and housing. Poor households spend almost half of their income on food and non-alcoholic beverages (42.3 percent) with the next largest amount being spent on housing (15.2 percent). Figure 5.4 shows that these disparities exist not only according to poverty level, but are also experienced unevenly by racial group.

Population group	Food poverty line (R305) (%)	Lower-bound poverty line (R416) (%)	Upper-bound poverty line (R577) (%)	RSA (%)
Black African	96,4	95,2	93,8	79,3
Coloured	3,3	4,5	5,7	9,0
Indian/Asian	0,0	0,1	0,4	2,6
White	0,2	0,2	0,2	9,2
<b>RSA</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>	<b>100,0</b>

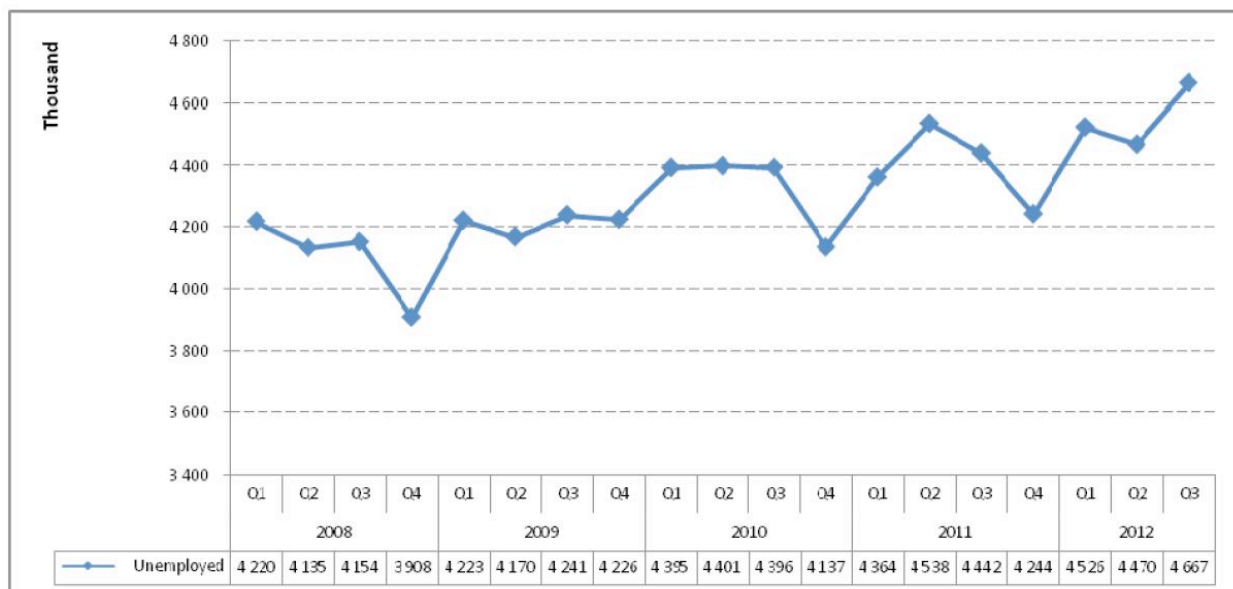
**Figure 5.4** Percentage Share of Poverty by Racial Group

*Source: Stat SA 2012a*

Of those who were living below the upper-bound poverty line, the overwhelming majority were black South Africans (96.4 percent). This reinforces my earlier argument that the economic policy shifts had grave effects in the community and were felt most severely among poor, black South Africans. Although statistics can never illustrate the full context of a population, these figures help to illuminate the poverty profile in South Africa and demonstrate how extreme economic inequalities can lead a participant like Temba to declare that “you can even smell poverty.”

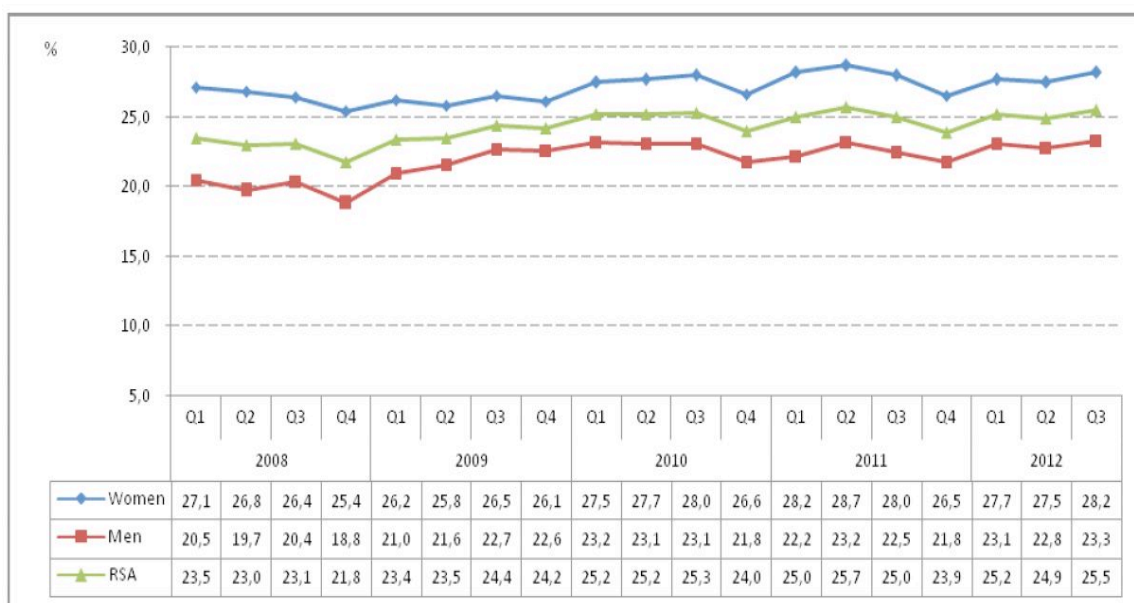
### **The Economic Landscape in Grahamstown**

At the end of 2008, there were approximately 3.9 million people unemployed in South Africa (Figure 5.5). By early 2009, the number of unemployed residents climbed rapidly, most likely the result of the global economic and financial crisis. The national unemployment rate among black South Africans was 25.9 percent, with rates even higher in the townships (Statistics South Africa 2009). In Grahamstown, rates were estimated at almost three times the national rate, with unemployment reported as high as 70 percent among black residents (Kelly and Ntlabati 2007). The unemployment rates among women remained higher than those of men and consistently exceeded the national average (Figure 5.6), underscoring the vulnerability and uneven experience of economic inequality. Level of education is also linked with unemployment rates, with lower rates of unemployment associated with higher levels of education (Figure 5.7). In 2008, approximately 64 percent of the total number of unemployed residents had less than a 12th grade level of education, in comparison to approximately five percent of the population with a tertiary level of education. These three major variables cut across the demographic profile of participants in my study; the majority of whom are women, black, and had not completed Standard 10 (Grade 12). The LCS did not measure variables at the city level, but provincial data (Figure 5.8) illustrate where the Eastern Cape Province, in which Grahamstown is located, falls within the national poverty landscape. Using the food poverty line as an indicator, the Eastern Cape ranked as the second poorest province.



**Figure 5.5** Unemployment in South Africa, 2008-2012

Source: Stat SA 2012b



**Figure 5.6** Unemployment by Sex, 2008-2012

Source: Stat SA 2012b





**Figure 5.7** Unemployment by Level of Education, 2008-2012

Source: Stat SA 2012b

Province	Food poverty line (R305)			Lower-bound poverty line (R416)			Upper-bound poverty line (R577)		
	P <sub>0</sub>	P <sub>1</sub>	P <sub>2</sub>	P <sub>0</sub>	P <sub>1</sub>	P <sub>2</sub>	P <sub>0</sub>	P <sub>1</sub>	P <sub>2</sub>
Limpopo	48,5	16,6	7,8	62,1	26,9	14,4	74,3	38,8	23,6
Eastern Cape	35,7	11,8	5,3	51,0	20,4	10,4	66,1	31,1	18,0
Mpumalanga	32,1	10,9	5,1	47,6	18,7	9,7	62,5	29,1	16,7
KwaZulu-Natal	33,0	10,7	4,8	46,1	18,5	9,5	60,2	28,2	16,3
Northern Cape	26,0	7,9	3,3	42,6	14,8	7,1	58,2	24,9	13,4
Free State	24,6	7,1	2,9	42,0	14,1	6,5	57,8	24,3	12,8
North West	26,3	8,8	4,1	42,0	15,6	7,9	56,9	25,1	14,0
Western Cape	9,0	2,2	1,0	17,8	5,5	2,4	30,6	10,8	5,2
Gauteng	10,1	2,6	1,0	18,1	5,7	2,5	29,0	10,7	5,3
RSA	26,3	8,5	3,8	38,9	15,0	7,5	52,3	23,6	13,3

**Figure 5.8** Poverty Indicators by Province

Source: Stat SA 2012a

### The Cost of HIV/AIDS at the Household Level

In addition to the emotional, physical, and psychological effects of HIV as described in the previous chapters, the financial costs are significant both for individual

patients and at the household level. Families affected by HIV/AIDS incur higher healthcare expenses and increased transportation costs to get to medical appointments. They experience loss of income, high levels of debt and borrowing, and shoulder the burden of the many general costs associated with daily caretaking (Kelly and Ntlabati 2007). The range of activities required to care for sick family members is vast and includes a combination of any or all of the following: buying and cooking foods for special diets, monitoring and facilitating medication adherence, washing clothes, collecting water, dressing the person, carrying them to the bed or toilet, and providing them with company to keep them motivated and encouraged. Despite the extra demands made by HIV/AIDS on affected households, “the health of many people sick with AIDS, and their communities, is compromised by lack of sufficient and clean water for sanitation, washing, drinking and caring” (Kelly and Ntlabati 2007:3).

Most of these activities involve some sort of financial contribution by the caretaker, along with increased usage of electricity, water, and food. These costs often are overlooked in the discussion of HIV/AIDS care, but become important when analyzing why social grants have become such a central part of the discussion around health and illness management. This burden becomes even more complicated when situated within the current state of municipal services in South Africa broadly, and Grahamstown, specifically. The state has expended no concentrated effort to create a basic infrastructure that would help relieve this burden. Instead, within the national strategy for service provision, marketization of services has become the acceptable norm. “Marketization of urban services refers to a broad movement that insists that water and

urban services are most efficiently used when they are regarded as economic goods or commodities, not as entitlements” (Kelly and Ntlabati 2007:3).

Most families represented in my study were in arrears for water payments, will likely never be able to pay their debt, and as a result, have had to learn how to manage their needs based on a restricted or nonexistent water supply. Additionally, the lack of reliable electricity, which is prepaid and usually too expensive to maintain on a regular basis, also posed significant challenges to HIV-affected households. The absence of electricity limited the ability to cook, boil water for sanitation purposes, and heat the home. As a result, many township residents relied on paraffin as a heating and cooking source. While it is cheaper and often more accessible than electricity, paraffin is not considered safe for those with compromised immune systems or respiratory conditions because of the fumes produced when burned indoors.

### **Social Security in South Africa**

During my time in the field, the most recent national community survey reported that 11.2 million people were shown to receive some kind of state-funded social grant (Statistics South Africa 2007). The South Africa Social Security Agency (SASSA) is responsible for managing, administering, and distributing all of the country’s social assistance grants. These grants include support for war veterans, senior citizens, foster children, child support, and those deemed disabled. The social assistance system in South Africa does not provide support for those who are unemployed. While the

majority of respondents received child support grants and old-age pensions,<sup>29</sup> 1.2 million people (23 percent of the population) reported that they were awarded a disability grant.

The disability grant system, established by the Social Assistance Act of 1992, and subsequently updated in 2004 and 2008, was designed to provide monetary support for those deemed unable to work as a result of disability (Seekings 2002). The SASSA defines disability as “a physical or mental handicap which has lasted for six months or more, or is expected to last at least six months, which prevents the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities.” To qualify for a disability grant (DG), applicants must pass “means tests” and satisfy several conditions including that they:

- Be a South African citizen, permanent resident or refugee currently residing in country
- Female applicants must be between 18 and 59 years old; male applicants 18 to 60 years old<sup>30</sup>
- Submit a medical assessment report no older than three months at the date of application confirming their disability
- Cannot be cared for in a state institution
- Cannot be in receipt of another social grant
- Meet the income means test<sup>31</sup>

---

<sup>29</sup> Several participants in this study depended on the redistribution of grant money from their parents or older relatives, underscoring the communal dependency on grants in multi-person households. For a discussion of the social security system and prevalence and redistribution of the old-age pension grant, see Case and Deaton 1998, Duflo 2003, and Seekings 2002.

<sup>30</sup> There is no explanation given for this age difference.

<sup>31</sup> For the old age, veteran, and disability grants, applicants must make less than R29,112/year if single and R58,224, if married (approx. \$4,200; \$8,300). The threshold for the child support grant is slightly lower at R28,800 if single, and R57,600, if married (approx. \$4,100; \$8,230).

Although the 1994 and 2004 Social Assistance Acts clearly outline the terms by which a person can apply and be awarded a disability grant, there was no specific mention of HIV/AIDS. As such, there was no guidance until 2008 on how to apply the grant requirements to applicants with HIV/AIDS.<sup>32</sup> It is difficult, therefore, to surmise how many HIV-positive people were accessing the grant. During my tenure in the field, the number of disability grants issued had reached a peak, more than doubling since 2000 and reaching 1.4 million recipients in 2008 (de Paoli 2012) (Figure 5.9). It has been argued that this sharp rise can be attributed to an increase in AIDS patients gaining access to disability grants in the initial absence and subsequent roll out of ART (see Natrass 2006). Despite not being designed to target those affected by HIV, the disability grant likely made a greater contribution to affected households, particularly the sick person's socioeconomic status, than the smaller child support grant (Knight et al. 2013:136). HIV/AIDS, then, has become one pathway to access the disability grant, and in effect, the opportunity for economic security.

---

<sup>32</sup> At the end of 2008, the Act's language was updated to explicitly include AIDS-specific guidance for grant eligibility. I was still in the field when this happened, but those changes were not uniformly implemented before I left in May 2009. My references to social security and the grants system throughout the chapter are based on the system as it was when I entered in the field in early 2008.

Years	Older Persons Grant	War Veterans Grant	Disability Grant	Foster Child Grant	Care Dependency Grant	Child Support Grant	Total	Growth rate
1996/7	1,637,934	13,473	711,629	42,999	2,707	-	2,408,742	-
1997/8	1,697,725	10,525	660,528	43,520	8,172	-	2,420,470	0.5 %
1998/9	1,812,695	9,197	633,778	46,496	16,835	21,997	2,540,998	5%
1999/00	1,848,726	7,908	607,537	49,843	22,789	150,366	2,687,169	5.8%
2000/01	1,900,406	5,617	655,822	66,967	33,574	1,111,612	3,773,998	40.4%
2001/02	1,903,042	5,336	694,232	67,817	34,978	1,277,396	3,982,801	5.5%
2002/03	1,943,348	4,638	840,424	83,574	42,355	1,998,936	4,913,275	23.4%
2003/04	2,050,572	3,996	1,228,231	120,571	76,494	2,996,723	6,476,587	31.8%
2004/05	2,124,984	2,963	1,293,280	195,454	86,917	4,165,545	7,869,143	21.5%
2005/06	2,146,344	2,817	1,315,143	317,434	90,112	7,075,266	10,947,116	39.1%
2006/07	2,195,018	2,340	1,422,808	400,503	98,631	7,863,841	11,983,141	9.5%
2007/08	2,229,550	1,924	1,408,456	454,199	102,292	8,189,975	12,386,396	3.4%
2008/09	2,390,543	1,500	1,286,883	474,759	107,065	8,765,354	13,026,104	5.2%
2009/10	2,547,657	1216	1,264,477	510,760	110,731	9,562,667	13,997,508	7.5%
2010/11	2,618,960	1104	1,224,990	511,053	110,512	9,960,661	14,427,280	3.1%

**Figure 5.9** Total Number and Growth Rate of Grant Recipients by Grant Type

Source: SASSA 2010

Prior to starting my long-term fieldwork in Grahamstown, I had a phone conversation with Teresa, the Director of the GCC, to update her on my travel and research plans. I was not due to arrive in Grahamstown for several more months, but made a point to keep in touch with her in the interim. During our conversation, I walked through my proposed research design and asked for her input on the project. She told me, “Well, I think your interest in women and HIV/AIDS is appropriate, but there’s also this new thing that’s happening that has us pretty concerned. Now, a lot of our clients are starting to not take their treatment because they want to access the disability grant.” At the time, I did not know what the disability grant was. Teresa explained that it is a government subsidy available to PLWHA who are too sick to work. Teresa’s comments

were intriguing and led me to question and ultimately shape my research to explore what happens in communities when availability and access to antiretroviral treatment no longer are the only major barriers to care.

I returned to Grahamstown in the spring of 2008 expecting to see a clear trend of treatment refusal, but instead, it became evident that community members were attempting to grapple with what it means to transition from managing a fatal disease to managing a chronic illness through the use of antiretroviral treatment. Antiretroviral treatment refusal was not a dominant theme among participants' narratives. It was only one component of a layered experience of illness management that was shaped by a range of treatment responses, mediated by multiple factors.

### **Medical vs. Social Disability**

Within the context of HIV/AIDS, the issue of disability is complex. It becomes difficult to tease out which elements are individual, which are externally perpetuated by environmental, socioeconomic, or political factors—or a combination thereof. This challenge has broadened the discussion about the definition and experience of disability in the South African context, and raises important questions about how shifting ideas about disability both directly and indirectly shape perceptions of HIV/AIDS and its effects on the health-seeking practices among both those infected with and affected by the virus.

There have been marked shifts in the ideas and concepts that framed early Disability Studies discourses. The WHO, for example, promoted an understanding of disability based on the idea of individual limitation – an injury or illness that prevented a person from performing everyday activities and relied heavily on a framework of

medicine and rehabilitation. The then-dominant model “within social science and medicine was to assume that the social disadvantage experienced by disabled people was an individual problem caused by impairment. If the problem was an individual one, then the most appropriate social response was either to correct the impairment or to help the person ‘come to terms’ with their assumed disadvantage, by negotiating different (less valued) social roles” (Priestley 2006:21). This medical model of disability is founded on the notion that disability is “something that simply ‘happens,’ by chance, to individuals,” and is explained by bodily differences (Watermeyer and Swartz 2006:3).

Social model theorists (see Oliver 1990), however, began to challenge the biomedical model of disability to instead “emphasize that disability is a form of social inequality or disadvantage resulting from oppressive social structures and processes, rather than from individual difference or biology” (Priestley 2006:19). Additionally, social model supporters contend that “disability is not random or natural, but a social accomplishment-disability is created by a disablist society, through the perpetuation of barriers to the participation of persons with impairments” (Watermeyer and Swartz 2006:3). Disability, then, has come to be understood as “a social problem caused by social processes” (Priestley 2006:21).

Over the years, there have been mixed responses about the inclusion of PLWHA into the social grants system. Most advocates see disability grants as absolute necessities for low-income PLWHA since there is no institutional form of regular social assistance for unemployed, low-income persons. Critics of PLWHA who access the grant argue that neither HIV nor AIDS are disabilities and the inclusion of PLWHA in the disability grant structure is a way of privileging HIV/AIDS over other chronic illness.



In their 2007 Grahamstown study on the effect of HIV-related illness on households, Kelly and Ntlabati noted that 73 percent of the survey respondents reported that their main source of household income was one or more government grants. Among participants in my study, it was clear that the majority of households were dependent on a combination of social grants, often a mixture of child support grants, old age pensions and the disability grant. These grants were often used to cover individual household expenses in addition to the costs of other households that were unable to meet their basic needs without assistance from extended family. In Grahamstown's township communities, the physical proximity of extended family homes facilitated this process. Unlike family members in other parts of the country, local extended family members have physical access to breadwinners and are keenly aware of grant dispersal dates. This again reinforces the ways in which the negotiation of treatment becomes a communal experience. It also highlights the varied ways in which HIV complicates daily living experiences in ways that directly affect both the infected and the uninfected.

### **Accessing the Disability Grant**

Permanent disability grants, like the one that Sasha's sister was receiving, are renewable every five years. To be eligible for a disability grant, an AIDS patient was required to have a CD4 count of 200 or less. Following a doctor's diagnosis of a physical or mental disability, patients were eligible to apply for the grant, distributed as a monthly stipend of R1000 (approximately \$150).<sup>33</sup> Temporary, 6- or 12-month grants are intended to act as a bridge until the recipient's health improves through adherence to ART and s/he

---

<sup>33</sup> The amount of the disability grant increased from R940 to R1000 while I was in field. I use R1000 in the general mention of the grant, and specify R940 during the narratives where participants' grants had not yet reflected this increase.

is able to find employment. The high unemployment rate in Grahamstown, however, means that for most residents, employment is extremely difficult to secure, regardless of health status. Among study participants, almost all of them spoke about the disability grant as a means to alleviate poverty. All but two participants were either currently being supported by a disability grant, had been awarded a grant in the past, or had an application pending. In their study on the DG among PLWHA in the Eastern Cape, Phaswana-Mafuya et al. (2008) found that money from the DG was mostly spent on buying food, paying for funeral policies, buying clothes, and paying for school fees (Figure 5.10).

What was the item the grant was spent on?	First	Second	Most
1. Pay municipality bill (water, electricity, rates, taxes)	3.1	2.6	3.9
2. Buy clothes	22.6	22.6	13.8
3. Buy food	63.2	18.1	48.3
4. Pay for funeral policy scheme debt	7.7	27.2	19.0
5. School fees	2.3	22.0	11.2
6. Pay accommodation or rent	0.8	3.9	0.4
7. Sent money to child or someone else outside household	0.4	0.4	0.0
8. Leisure activities (alcohol, gambling)	0.0	0.0	0.0
9. Other	1.5	2.2	1.7
10. Do not know	1.5	2.2	1.7

**Figure 5.10** Self-Reported Uses of the DG among PLWHA in the Eastern Cape, %  
Source: *Phaswana-Mafuya et al. 2008*

In the context of extreme poverty and economic inequality, the disability grant system highlights the difficulty in translating suffering into biomedical categories that often conflate the complexity of the experiences of illness and the meanings attached to those experiences (Kleinman 1988). The grant system, then, is not inclusive of various forms of social disability. Within a context where widespread unemployment and

inequality are prevalent, the concept of disability and HIV/AIDS intersect in critical ways that shape health-seeking practices among participants.

### **Choosing Economic Security or Health Security**

#### *Sibongile's Journey*

Sibongile's journey with HIV/AIDS began before she was tested for the virus. She was caring for a friend who had tested positive, and she noticed some of her own symptoms mirrored the experiences of her friend. In 2000, she started to get sick and experienced terrible pains in her legs, side, back, and ribs that resulted in a three-week stay at one of the local clinics. It was during her stay in the clinic that a nurse suggested she consent to an HIV test. Sibongile obliged. After waiting for three weeks, she received her test results. While it was a shock, she recalls that she "had it in her head" that she might be HIV positive because of the symptoms exhibited by those around her who already had tested positive. At that time, Sibongile's CD4 count was 236 (the range for a healthy CD4 count is 500 to 1,000) and she was recommended for ART.

The doctor at the local hospital prescribed a cocktail of multivitamins and Cozole. Eventually she was put on what she called a "compound," referring to a twice-daily fixed dose combination of d4T (Stavudine), 3TC (Lamivudine), and EFV (Efavirenz). Sibongile was also recommended for a disability grant, as her doctor felt she was "too sick to work." The disability grant provided Sibongile and her family with a stable form of income that she used to buy food and meet other basic needs. As part of the process of collecting her illness narrative, I asked if any of the medications made her sick. She replied, "at one point the Cozole was taken away, but once my doctors realized that it was helping to relieve my headaches, they returned it to my treatment." I followed up by

asking her if it was difficult to take her ARVs. With a bit of blushing and nervous laughter, she finally responded and stated, “I only take my treatment when I don’t feel alright.” Her response drew the immediate disapproval of my research assistant who blurted out, “I don’t think that’s okay. You are cheating wena!” I immediately intervened, afraid that Sibongile would not continue to share with me her decision to modify her treatment regimen. As she proceeded to share why she modified her adherence to ART, Sibongile made clear that her primary objective was to manipulate her CD4 count so it would stay low enough for her to remain eligible for the disability grant.

Much of the literature examining the relationship between the disability grant and ART has questioned whether receiving the disability grant generates adverse responses and disincentives to treatment adherence among patients (Hardy and Richter 2006, Leclerc-Madlala 2006, Phaswana-Mafuya et al. 2008, Venkataramani et al. 2010). As Theresa described in the opening of the chapter, there was growing concern that patients who were eligible to receive the disability grant would discontinue use or refuse antiretroviral treatment to maintain the grant. The literature, however, has not found overwhelming support of AIDS patients actually refusing treatment as a trade-off for the disability grant. The same findings held true in my study, as no participants reported directly *refusing* treatment specifically for the disability grant. The data from my study, however, do reveal a complex negotiation of treatment practices, among which treatment *modification*, as highlighted in Sibongile’s narrative, was reported. Some PLWHA who relied on social assistance grants began to modify their adherence to ART because improved health would render them ineligible for the grant, leaving them unable to meet their basic needs. The manipulation of this system has created adverse and unanticipated

responses to treatment as many patients are tempted to compromise their health, secured through adherence to ART, in order to meet their basic needs through the grant's financial assistance.

### **The Implications of Failed Treatment Adherence**

To be successful, ART requires an adherence rate close to 85 percent, which is markedly higher than that required for the proper management of other chronic illness. Poor adherence to ART will lead to the development of drug-resistant strains of the virus among those receiving treatment. Therefore, the manipulation of ART becomes a major health concern. The possible spread of drug resistant strains of HIV through new infections or re-infection poses a grave population threat with the potential to undermine decades of local and global public health and prevention efforts. This is particularly crucial for countries like South Africa, where tertiary and quaternary lines of ARV cocktails are not readily available or accessible by those dependent on state-funded ARV treatment programs.

Sibongile admitted feeling fearful about being honest with her doctors about the ways in which she actually uses her ARVs and the way that she fits treatment into her day-to-day life. Much of her fear of disclosing her actual treatment practices stems from the stigma of “defaulting,” (failing treatment) particularly because there are few second-line drugs available to patients who default. Additionally, because her only source of income-the disability grant-hinges on her medically “sick” status, admitting treatment modification could have significant and devastating effects on her economic security if her grant is revoked. At the time of our interview, Sibongile was able to maintain the range of CD4 count she desired, although only time will tell if her treatment modification

will be effective in the long-term. There are greater implications for patients like Sibongile. The longer she goes without full adherence to ART, the greater the likelihood that a drug resistant strain of HIV will develop. Unfortunately, Sibongile may not know if she has developed drug resistance until she is faced with an opportunistic infection or the onset of more severe and possibly untreatable symptoms. This outcome is not just an individual issue but it resonates on the level of population health and efficacy of government treatment and the state's ability to address the public health needs of its citizens.

Treatment modification was not the sole or dominant narrative, however, and was just one of many adherence and illness management practices employed among participants. The range of responses included full adherence to ART, treatment modification, refusal or hesitation to begin ART, and one participant who had twice defaulted on her treatment. Phindile, for example, felt that she was not willing to cope with the responsibility of lifelong adherence to ART because medication would, “complicate my life.”

---

Phindile: I have not started taking ARVs. My last CD4 count was in April (2008) and it was 450. I buy the multivitamin pills, and they have given me Cozole, folic acid, and B-co. I don't take it everyday. Sometimes I'm naughty and sometimes I don't take it because I don't want to depend on the pills. I don't take it because I don't want to depend on them.

*CJ: Do you want to start the ARVs?*

N: I've never asked them for the ARVs at the clinic. No, Sisi, I do not want the ARVs. I don't think I'll cope with the responsibility that comes with ARVs. And it makes you out of shape and I want to keep my shape. It's going to give you big boobs and a big stomach. It's just going to change your body. So, no, I don't want ARVs. My health, I'm a healthy person. I don't think the vitamins are helping me, I think it's just because I'm a healthy person.

---

Unathi also expressed a disinterest in the responsibility that comes with ART adherence, but only after defaulting twice on her treatment. Unathi had been receiving a disability grant since April 2003, although she admitted that she was unsure about why she was still receiving it:

Unathi: The last CD4 she remembers taking was in 2007 and it was 337. I think my CD4 was so high because of the ARVs. I started ARVs in 2004 and they gave me the 3TC, D4T and EFV. And then I defaulted. I defaulted twice because I had to transport my mom when she had to go to PE (Port Elizabeth). So I defaulted and they took it away

*CJ: Why do you think that made you default? You couldn't take the pills with you?*

N: The due date that I must go and fetch another round of pills sometimes fell at the same time I was supposed to go and transport my mom, so I couldn't go and pick it up. When I defaulted the first time, I was already referred down to the clinic. They give me ARVs again after the first time and the second time, they said "no" and they took it away from me. The first time was in 2006. Then I go back to the clinic because I was having a headache, and in the passport, they see that I was supposed to be taking the ARVs and they have written in there that I have defaulted. In my passport, they wrote the word "Defaulted." And then they have transferred me back to the medications I had before and then they had to take another CD4 count and said that I have to start all the way from the beginning again. So they started me again on the folic acid and Cozole. And then they give me the ARVs again, and because I have to pick up my medication every month, it was in the same year, that I missed 2-3 months in the same year in 2006. It was for the same thing, because I had to transport my mother.

*CJ: So they didn't give you ARVs again?*

N: Until now they didn't give me ARVs again. I'm still on the folic acid and I don't want to involve myself with the ARVs again because there is too much talking and too much arguing with them. You have to take responsibilities when you have ARVs and if you're not following what they tell you, you're always going to be like talking and have to have an explanation for why this happened and why that happened and all those things. So, I can't cope with that. And already, it was messing up my body because I was always a slender girl and it was making me have a big body and a funny tummy, so without ARVs, I am quite pleased with myself now.

When I asked what her thoughts were about managing HIV with ARVs, she stated:

N: Today, I went to the clinic and they said they want me to come and take some blood samples because they want me to go back to the ARVs, but I'm not interested.

On the other side I like to be jol'ing (hanging out) on the weekends and this medication does not mix with the booze, and I'm afraid that I'm going to make a mistake with the medication and the booze, so I'd rather just make my body use the folic and whatnot and stay away from the ARVs.

While HIV is one way to access the disability grant, I am not suggesting that patients are only interested in the grant itself. Participants made it clear that they wanted access to both ARVs *and* a form of economic stability, either through gainful, regular employment or through social assistance programs like the disability grant.

One afternoon at the Grahamstown Community Center, I interviewed Sipho, a 46-year old man diagnosed with HIV in 2002. For Sipho, having “one without the other” was not a practical option.

---

*CJ: So have you started ARV treatment?*

Sipho: They first put me on a multivitamin and Cozole

*CJ: Did you start ARVs?*

S: No.

*CJ: What is your recent CD4 count?*

S: (pulls out his medical “passport” book detailing his health history) In 2004 it was 532. In 2005 it was 427. Last year in September 2008 my CD4 count was 155.

*CJ: Do you feel like you need ARVs now? Do you feel healthy? Do you feel strong?*

S: I am experiencing shortness of breath. Something new that I've got since the CD4 count has come down. I'm thinking that if I can have these ARVs they can bring a big difference but... (after a long pause)...It's ok to not have the ARVs. I do feel that the treatment of the ARVs will bring a difference, but with treatment you have to take it with food. If I don't have any income, am I still going to take my ARVs? ARVs are strong and you need to take them with food. This is my concern. Although I do feel that there will be a difference with ARVs.

---



Although he was diagnosed in 2002, Sipho did not become eligible for ART until 2008, when his CD4 count fell below 200. He is currently unemployed and describes himself as “lazy,” a colloquial way of referring to being tired and possibly weak or sick. His lack of energy, however, has created a conflict within his household, as his sister has begun to withhold food from him when he does not complete his household chores. Without income or other means to regularly access food, Sipho is at the mercy of his sister. His sister is the sole provider in a household of five, and according to Sipho, “punishes” him by refusing to share the limited household resources, specifically food, with him. Although he is eligible for treatment, Sipho is faced with a dilemma. While he admits that taking ARVs will improve his health, he’s uncertain about his ability to manage the potency of the drugs on an empty stomach. In a context where food is precarious and a healthy diet is an important component of successful treatment, Sipho is reluctant to begin ART because he does not have access to food security. Additionally, he knows that applying for a disability grant could be a means for him to access food security, but he also was keenly aware that it was only a temporary measure that may be terminated with improved health.

While participants’ responses to treatment are different, the common theme throughout their narratives is the constant factor of economic insecurity in their decision-making processes. As is the case for Sibongile, in the absence of other means to alleviate poverty, for many residents, the disability grant is seen as a way to achieve economic security. The grant system’s reliance on biomedical categories to define disability, like the measure of a patient’s CD4 count, however, presents some challenges.

### **Subjectivity of the Biomedical Disability Model**

There is difficulty in standardizing a system based around a fluid state of being. While patients who have been clinically diagnosed as having AIDS are never relabeled simply HIV-positive, proper adherence to ART will most usually result in a higher CD4 count, sometimes higher than those who have not yet been diagnosed as having AIDS. Other studies (Venkataramani et al. 2009) have discussed other inconsistencies in the grant system, demonstrating how among some clients, the disability grant did not appear to be directly linked to the health outcomes. Some individuals continued to receive their grants even after securing employment. Others, ironically, started to receive the grant only after they had begun working. Decisions to award disability grants, specifically to PLWHA, are not always based on a standardized system and vary from one province to another. Some grants are given based on an assessment of activity limitation, or more commonly, “being too sick to work.” Other grants are awarded based solely on a patient’s CD4 count, and still others are anecdotally reported to be awarded based on a wide range of practices among doctors, state employees who process the grant applications, and patients modifying health data.

### **The Role of Doctors in Awarding Disability Grants**

Doctors play a critical role in the disability grant process. They are usually the ones who assess “disability” among HIV-positive patients and determine who should be recommended for a grant. This responsibility places physicians in challenging situations, since they have to make subjective observations about the extent to which a patient is “too sick to work.” This challenge extends beyond simply making decisions about who should get the grant. It also encompasses decoding who should receive ART. During the

initial work-up after a positive HIV test, most patients are given the opportunity to access ART. After clients default on treatment, however, the medical staff reserves the right to deny subsequent treatment. During my meeting with Dr. Williams from Settler's Hospital, she shared that the decision to declare someone a defaulter is made collectively among a committee of physicians and that it is not always based on one set of criteria, but takes into account the range of factors that facilitated poor treatment adherence. The lack of standing guidelines for the disability grant means that physicians hold immense power in the decision-making process, both in the awarding and termination processes. Doctors, in communities like Grahamstown, where social and communal ties closely overlap, are forced to balance biomedical criteria with an understanding of a patient's employment or socioeconomic status. This creates challenges when attempting to assess a patient's need for a disability grant:

The question an assessment has to answer is individual and categorical: 'Does this person qualify for a grant or not?' This flies in the face of arguments which correctly point out that there is no neat distinction between the 'disabled' and the 'nondisabled,' and also that disability is contextual and fluctuating according to social and environmental conditions. Ideally, therefore, disablement should be seen not as a static condition inherent to a person, but as a contextually dependent process in which impairment, functioning and the environment interact and change in potentially unpredictable directions over time" (Swartz and Schneider 2006).

The line between traditional "disability" becomes blurred within the context of post apartheid South Africa, where a large portion of the greater society is struggling to overcome grave inequalities and extremely high rates of unemployment and poverty. Recent studies (see de Paoli 2010) have noted inconsistencies among doctors and their grant assessment procedures. "The rationale for prescribing grants differed between doctors, which reinforced the participants' belief that the decisions regarding disability grant eligibility and duration were ad hoc and inconsistent. For example, some employed

patients with high CD4 counts were still receiving disability grants, when some unemployed patients with low CD4 counts were unable to receive the grant” (de Paoli 2010:18).

Despite the clear mandate for full or close to perfect adherence given to patients at the uptake of ART, participants described a range of practices that demonstrate how full adherence is often an evolving process. Anele, “used to forget before, but now that I’m used to I am used to it, I go and collect it myself. Nobody has to remind me to take it.” I asked her if she takes her medication everyday: “I am really dependent on it because it is the ARVs that make me this person so I take it everyday. I take them with me everywhere. Even if I’m going to a party, I’m going to take my pills with me, just like my cell phone.” She had difficulty recalling which ARVs she was taking and pulled out her pill bottles so that I could read and record the labels. In the process of examining Anele’s medications, I dropped one of her pill bottles and some of the pills fell out onto the table. Anele and Mandisa reacted immediately, jumped out of their chairs and started to grab at the pills. Their reaction and Anele’s subsequent irritation after all the pills were back in the bottle surprised me. Anele reminded me that it was important that we were sure to pick up all the pills because “they count them and they all have to be accounted for. They don’t just take your word for it when you go back to the clinic. You have to take the empty packets with you and they count too because they have to be finished that day, the morning of the day you go back. So you take them all.” In some ways, the model of using pill counts as a way to measure adherence reinforces the biomedical model on which the ART system was designed. My accident with Anele’s pills, however, highlights the challenges with that model, as accidents happen and people

have less than accurate ways of accounting for the number of pills in each monthly disbursement.

Relying on pill counts to measure ARV adherence presents unique challenges since patients engage in different practices around how they store and segment their medications. Some patients, for example, may pocket the number of pills they need for the day in an effort to eliminate the need to pull out pill bottles in public, reducing the chance of people knowing that they are on medication and deflecting the potential to be stigmatized. However, it is difficult to differentiate those patients, who may accidentally lose a pill from those who may be more deliberate in their treatment modification or non-adherence. De Paoli et al. (2012) highlight what they refer to as “circumstantial” non-adherence, characterized by doctors in their study who report seeing patients in their clinics flushing tablets down the toilet or dumping them on the grounds of the clinic. The range of these practices surrounding adherence to ART, as I examine throughout this chapter, is mediated by multiple factors that do not always reconcile with quantitative models and biomedical markers for gauging adherence.

Many HIV-positive clients who are awarded a disability grant are awarded temporary grants based on the notion that those who have reached the point of “disability” have been clinically diagnosed with AIDS and will soon begin ART. This process creates misunderstandings about the reapplication process, the termination criteria, and sets up logistical barriers regarding the application process. Although the SASAA provides streamlined information about eligibility and grant termination policies, in practice, these policies are constantly in flux and often reinterpreted by provincial and local authorities. Additionally, patients circulate their own understanding of how the

disability grant system works, sometimes increasing the collective confusion. I argue that the modification of treatment is one way to exert control in an otherwise imbalanced life situation, but as the narratives reveal, it is a decision shaped by multiple factors that are difficult to isolate.

## **Conclusion**

The complex dilemma between disability grants and the refusal, modification, or defaulting of HIV/AIDS treatment is continually evolving in South Africa, highlighting the timeliness of this research project as an important contribution to current research on HIV/AIDS within South Africa. This chapter explores the tensions and conflicts that arise when the physical effects of the virus are managed through the introduction of antiretroviral treatment, but the concurrent economic effects of the virus remain inadequately addressed. While the “roll-out” of ARVs in South Africa continues to happen, albeit slowly in many parts of the country, the speed and scale of the government’s response to ART “reflects a set of judgments about what scale of intervention is appropriate” (Nattrass 2004:180). Notwithstanding the speed and availability of treatment, more attention must be made to the concurrent and overlapping health and economic issues. ARVs, when taken properly, have the potential to address the biomedical ills among PLWHA. However, states also must treat the social ills and alleviate barriers to economic security that impacts the health-seeking practices of PLWHA seeking treatment. Treatment should not be privileged over other social objectives, particularly the alleviation of poverty and food insecurity, better service delivery, and the creation of employment opportunities.

## CONCLUSION

This dissertation examines the health and antiretroviral treatment-seeking behaviors among people living with HIV/AIDS in Grahamstown, South Africa. My study was guided by five central research questions: (1) What factors affect people's general conceptualizations of HIV/AIDS in Grahamstown, South Africa? (2) How do these factors shape people's practices when choosing to begin, refuse, or modify their HIV/AIDS treatment? (3) In what ways do health policies shape the help-seeking practices of those infected with and affected by HIV/AIDS? (4) What key barriers create challenges for people in need of HIV/AIDS treatment? And finally, (5) What implications do these barriers have on the long-term effectiveness of HIV/AIDS treatment programs and general public health within the local and global community?

At the core of my inquiry was a desire to better understand what actually happens in communities after antiretroviral treatment has been made available. I arrived to the field in March 2008 to question why some PLWHA were reportedly refusing antiretroviral treatment. Over the course of 14 months, I developed deeply personal bonds with several community members in Grahamstown, including many PLWHA who were actively engaged in the process of negotiating their HIV/AIDS care and treatment. As I demonstrate in the previous chapters, availability and access to antiretroviral treatment were not always enough of an impetus for HIV-positive patients to initiate or sustain treatment. My aim throughout the dissertation has been to critically examine the relationships among poverty, inequality, and health to link local, lived experiences to a larger analysis of state approaches to care.

The data presented in the preceding chapters offer several snapshots of various contextual moments in South Africa and within the lives of research participants. One inherent challenge to the time-intensive nature of fieldwork, however, is that these contextual moments are often overtaken by more current events. The evolution of HIV/AIDS treatment policies in South Africa since my time in field exemplifies this challenge. Many of the descriptions throughout the dissertation reflect a time in South Africa that predates the rollout of ART and when HIV/AIDS was highly stigmatized, arguably much more deeply than in the present day. I remain keenly aware of the need to tease out these historical snapshots to avoid generalizations about post-rollout that do not align with the current climate of HIV/AIDS treatment in South Africa. As I detail throughout the dissertation, however, there are many insights that can be gleaned from the included narratives to inform a deeper understanding of illness and antiretroviral treatment negotiation that are applicable to present-day South Africa.

### **Current Landscape of HIV/AIDS Treatment in South Africa**

Since 2008/2009, there have been several advancements in antiretroviral treatment in South Africa. Previous medical eligibility criteria for ART was based on a patient having a CD4 count of 200 cells/mm<sup>3</sup> irrespective of the WHO disease stage, or classified as WHO Stage IV, characterized by various illnesses like thrush or Kaposi's sarcoma. Current medical eligibility criteria, as of March 2013, stipulate that patients with CD4 counts of 350 cells/mm<sup>3</sup> or less may be permitted to begin ART.<sup>34</sup> The previous medical marker of 200 cells/mm<sup>3</sup> generally meant that patients had to wait until

---

<sup>34</sup> Current guidelines synthesized from the 2013 Revised Antiretroviral Treatment Guidelines, which can be found at: <http://www.sahivsoc.org/upload/documents/FDC%20Overview.pdf>.



they were significantly ill and their immune systems were considerably compromised before they were granted access to antiretroviral treatment. A healthy CD4 count can range from 500 cells/mm<sup>3</sup> to 1,000 cells/mm<sup>3</sup>. A CD4 count of 350 cells/mm<sup>3</sup> means that patients are generally more physically viable, a departure from the era of “wasting away” or waiting until a patient was gravely ill before treatment commenced, as was the case under previous treatment guidelines.

Current guidelines also depart from the triple combination drug regimens that were in use during my time in the field (see Figure 4.2). As of April 2013, Fixed Dose Combination (FDC) therapy is the standard. The FDC ARV that is available is a one pill ARV which contains three drugs: Tenofovir, Emtricitabine, and Efavirenz. The implementation of these changes is currently being phased throughout the country according to priority groups. New patients (including adults, adolescents, and pregnant women) eligible to start ART are in the first priority group, followed by all pregnant women needing triple therapy and breastfeeding mothers currently stable on a FDC-compatible regimen (priority group two). Priority groups three through seven vary according to comorbid conditions (e.g. TB, hypertension, diabetes mellitus, etc.), level of viral suppression on current first line regimens, and desire among patients to be switched to a FDC.

There are several additional key changes in the 2013 treatment guidelines. First, pre-ART literacy sessions for ART eligible patients are being phased out. This stage, the first step of Phase IV (see Figure 4.4), previously required a patient to complete a 14-week ART initiation process. In place of this separate, protracted procedure, current guidelines call for the introduction of concurrent adherence literacy as a way to

strengthen treatment adherence support. It is also now mandatory that patients be started on treatment within seven days after being deemed eligible for ART—a significant difference from the context that existed during my fieldwork, where some patients had to wait weeks and sometimes months for treatment to commence. Treatment programs have also begun to increase support for patients with comorbid conditions, and early treatment is now offered as a way to prevent HIV transmission between discordant sexual partners (where one partner is HIV-positive and the other is not infected). The advancements in comprehensive HIV/AIDS policies in South Africa reflect a strong commitment by the government to better address and meet the treatment and care needs of the millions of South Africans infected with HIV.

### **Key Findings and Contributions**

After decades of research by scholars, the body of literature on HIV/AIDS is vast. My research closely aligns with previously conducted anthropological studies on HIV/AIDS in South Africa that investigate the ways in which poverty, gender, and layered experiences of culture shape health-seeking practices (Schoepf 2004; Steinberg 2008; Susser 2009; Powers 2012). In the dissertation, I also trace the ways in which participants' lives have become shaped by a biopolitical lens and key political moments have shaped both their social and biological subjectivities (Rabinow and Rose 2006; Rose 2007). This builds on previous work by scholars who have interrogated the ways in which biopolitical lived experiences have emerged out of health crises (Petryna 2002; Biehl 2007; Nguyen 2010).

More specifically, my work contributes a deeper exploration of what actually happens in communities after ART has been made available. I contend that while there is

a broad understanding of HIV/AIDS in South Africa, systematic, ethnographic studies of disability grants and poverty are limited. Participants' illness and history narratives revealed complex practices of illness management in which an HIV diagnosis was not always the primary issue in their lives, but rather one of many links within a chain of tragedies that were couched within a larger context of poverty and deeply entrenched economic disparities. It became evident that as much as my research was about treatment negotiation, it was equally about the strategies people use to cope with poverty (Stack 1974).

Within that context, health-seeking practices have evolved to include a range of treatment-seeking strategies. In response to my broad research question about why some patients were reportedly refusing ART, what I uncovered was a complex dilemma in which HIV-positive patients were often forced to navigate circuitous healthcare systems while concurrently managing the effects of acute economic inequality. Patients had begun to see treatment modification, the practice of choosing not to fully adhere to antiretroviral treatment in order to manipulate their health status and remain eligible for government subsidies, as a viable, common sense approach to health-seeking.

The applied, practical implications of this treatment-seeking strategy, however, have the potential to undermine the advances of HIV/AIDS treatment research that stipulates that full adherence to ART is the only way to ensure its effectiveness to extend a patient's life. Failed or modified treatment adherence may lead to the development and spread of drug resistant strains of the virus, potentially creating significant individual and public health concerns. The implementation of a one pill FDC therapy versus a triple-therapy cocktail, however, means that going forward, patients may be limited in their

ability to modify treatment in order to manipulate their CD4 counts. As these new policies are being rolled-out across the country, it will be of interest to monitor how the current treatment climate will shape and impact treatment-seeking strategies in the future.

I also found that these treatment-seeking strategies were increasingly negotiated among both the infected and affected. In Grahamstown, the illness management process became an inclusive, communal experience as patients relied on social relationships drawn from a broad network of multiple stakeholders, including family members, healthcare practitioners, and HIV/AIDS-related community-based organizations. This dynamic of illness negotiation has led to the creation of new relationships among patients, their families, and healthcare practitioners, many of who have assumed new roles as caregivers and supporters in the treatment-seeking process. While their voices are not explicitly included in the narratives presented in the dissertation, affected family members and caregivers are drawn into these processes of treatment in ways that clearly demonstrate how illness is socially experienced. It remains challenging, then, to continue talking about “infected” and “affected” individuals as if they constitute distinct, non-overlapping categories. In actuality, their experiences become intricately intertwined. “Treatment” in the context of this study, then, is focused widely on the many ways in which treating illness also means treating the social body and directly addressing those everyday challenges people experience as part of the health-seeking process. Moving forward, I suggest that state governments rethink the concept of *treatment* to frame it more broadly in ways that acknowledge the layered and collective experiences of illness management.

My study also contributes an analysis of the dynamics of HIV/AIDS in peri-urban centers, like Grahamstown, that are affected by high HIV/AIDS prevalence rates and where spatial remnants of apartheid persist. Peri-urban spaces not only fall outside the strict city/country dichotomy, but the lines between urban and rural disease patterns have become blurred (Patton 1994). This critical analysis will increase our understandings of the nuanced dynamics of HIV/AIDS transmission in South Africa, reflecting a more comprehensive investigation of the epidemic, and not just its effects within extremely urban or rural settings.

The salient finding of treatment modification goes beyond the ethnographic contributions to understanding treatment-seeking practices, and offers an example of how the ongoing process of illness management is linked to macro level debates about health and state responses to HIV/AIDS treatment in South Africa. The legacy of apartheid, which persists as an undercurrent throughout present-day South Africa, manifests in the form of socioeconomic inequality, uneven access to resources, and deeply entrenched poverty. National discourses and the ways in which HIV/AIDS has been addressed at the level of the state have directly impacted the conceptualizations of HIV/AIDS among those infected and affected. Generally, Grahamstown residents have taken their cues about sexual wellness and HIV/AIDS from the ways in which these issues have been framed and promoted by state leaders. Despite the advancements in treatment initiatives as outlined above, historical, political, and economic policy decisions made during the early onset of the epidemic in South Africa, specifically those related to HIV/AIDS care and treatment, continue to shape health-seeking practices and experiences of illness among PLWHA. For some, like the many female participants affected by delayed

PMTCT programs, the effects of those policies persist as people continue to grieve and manage the multiple, layered experiences of social suffering.

My work aims to go beyond biological or social determinants and delineates the boundaries of the relationships between poverty, inequality, and health to link local context to an analysis of broader geopolitical contexts (Coburn 2000). The South African government's retreat from a platform of redistribution and reconstruction, which was largely focused on service delivery through people-driven processes, to embrace macroeconomic policies, represented a decisive shift from socialist approaches to neoliberal policies. The adoption of new economic platforms, like the GEAR strategy, underscored a shift to neoliberal policies that were also regarded as being anti-poor in many ways, particularly since these policies have subsequently exacerbated structural and economic inequalities and further entrenched poverty.

The disability grant is one ultimate example of the neoliberal form, in which the state fails to provide an umbrella of support and care, but rather, those in need must negotiate their care within a healthcare model driven by broad, monetary top-down approaches. The introduction of ARVs in South Africa opened up new spaces in which patients, who previously were left without recourse to medically manage the progression of HIV, were able to have access to life extending treatment. The introduction of treatment also created new opportunities for patients to push the boundaries of the state-prescribed system to explore the ways in which their HIV status could be used for economic stability. Within this context, the economic value of HIV/AIDS emerged, as being HIV-positive opened up access to material resources, despite the potentially significant trade-offs to individual and public health.

The relationships between economic inequality and antiretroviral treatment reveal that political economy matters and becomes central to my critique of responses by the state to HIV/AIDS treatment. Historical changes in the form and nature of the state are reflected in the policies related to the monitoring and treatment of patients and the general economic support and welfare of its citizens. The broad lack of attention to economic support and welfare by the state underscores the importance of examining how the effects of state approaches to care are experienced among both the infected and affected. Experiences of suffering go beyond the social and relational context of illness and demonstrate the ways in which difficult, communal choices between health, food, and economic security are experienced collectively and broadly among “the have nots,” and are largely driven by political economic structures. Despite the temporal context of my fieldwork, the complex dilemma between disability subsidies and refusal or modification of HIV/AIDS treatment persists as a major concern, underscoring the relevance and contribution of my findings to current research on HIV/AIDS in South Africa.

The ways in which the central South African state has retreated from redistribution has also created tensions between the local and central state in contemporary post-apartheid South Africa (Hart 2002). The responsibility for welfare provision has been relegated to newly formed local states, including non-governmental and community-based organizations. NGOs and CBOs have emerged as key partners in the HIV health-seeking process. Many have become mediators through which patients determine their HIV status, seek ART and other forms of therapy, and learn how to fold HIV/AIDS into their lives, some more successfully than others. Yet, the central South

African state is still responsible for managing and allocating resources, ultimately exposing the limits of power within the local state to address and manage the burdens of poor health and economic inequality. As global financial resources are diverted to address health concerns other than HIV/AIDS, HIV-related organizations are increasingly forced to compete for scarce resources. Organizations like the Grahamstown Community Center are finding it increasingly challenging to balance these “structural predicaments” and reconcile their community service commitments with the need to focus on funding applications and securing partnerships with international donors (Hodgson 2002). These challenges leave unanswered critical questions about the responsibility of the state and the role of local organizations in facilitating the response to HIV/AIDS, particularly as South Africa has transitioned from managing HIV as a fatal disease to chronic illness management, which requires long-term and ongoing economic resources for care and treatment.

In addition to the theoretical contributions, my findings offer insights that have applied, policy implications that can inform future state approaches to treatment and care. I offer a critique of the state-prescribed HIV management model that, although a more enhanced and progressive model than previous approaches by the South African government, continues to rely heavily on biomedical markers of disease. This approach persists in failing to capture the complex, communal experiences of illness that characterize the full context of participants’ lives. The implications of using standardized, biomedical frameworks to gauge the effectiveness of government treatment programs can lead to a skewed perspective on their effectiveness. Program targets and objectives may be met in terms of the number of people in need receiving treatment, but



the programs are incongruent with local treatment-seeking and illness management practices. Additionally, the biomedical model presumes that individuals are generic and interchangeable, yet what my research demonstrates is that this is not true. Rather, economic status, social relations, and where you live matter significantly to how people move through the health-seeking process.

I am not implying that standardized, biomedical criteria are not important indicators for treatment and care, but recommend that approaches should not only be top-down, but rather, developed as part of a multi-level approach that reflects a nuanced understanding of the individual and collective aspects of illness management. Instead of relying on draconian measures to withdraw treatment or economic support from patients who meet challenges in the treatment-seeking process, one recommendation for how this model could be amended would be to reframe the system towards a focus on positive reinforcement in which treatment adherence would be incentivized. The implementation of a model like this, however, would require a major shift by the state to again focus on the alleviation of poverty and local service delivery—a platform that runs counter to the current macroeconomic policy landscape in South Africa.

South Africa remains a useful case study because it provides an extreme example of the ways in which structural violence becomes embedded within the social and political fiber of a society, exposing the ill effects of that violence on the health of its citizens. Only through a careful consideration of inequality, however, on both the global and local level, will we be able to “account for lived reality in a way that makes sense for the social agents themselves” (Farmer 2004:319). Ultimately my research contributes insight into the multiple decisional factors that shape treatment seeking behaviors and

richly illustrates the ways in which communities collectively cope with illness while managing multiple forms of inequality.

## BIBLIOGRAPHY

Abrams, Philip

1988 Notes on the Difficulty of Studying the State. *In* *The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 112-130. Malden, MA: Blackwell Publishing.

Althusser, Louis

2006[1971] Ideology and Ideological State Apparatuses (Notes towards an Investigation). *In* *The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 86-111. Malden, MA: Blackwell Publishers.

Anderson, Benedict

1991 *Imagined Communities: Reflections on the Origins and Spread of Nationalism*. London: Verso.

Appadurai, Arjun

1996 *Modernity at Large: Cultural Dimensions of Globalization*. Minneapolis: University of Minnesota Press.

Aretxaga, Begona

2003 Maddening States. *Annual Review of Anthropology* 32:392-410.

2000 Playing Terrorist: Ghastly Plots and the Ghostly State. *Journal of Spanish Cultural Studies* 1:43-58.

Asad, Talal

2004 Where are the Margins of the State? *In* *Anthropology in the Margins of the State*. Veena Das and Deborah Poole, eds. Pp. 279-288. Santa Fe: School of American Research Press.

Avineri, Shlomo

1972 *Hegel's Theory of the Modern State*. Cambridge: Cambridge University Press.

Baer Hans A., Merrill Singer, and Ida Susser

1997 *Medical Anthropology and the World System*. Westport, CT: Praeger.

Barnett, H.G.

1948 On Science and Human Rights. *American Anthropologist* 50:352-5.

Basch, Linda, Nina Glick Schiller, and Cristina S. Blanc

1993 *Nations Unbound: Transnational Projects, Postcolonial Predicaments, and Deterritorialized Nation-states*. Langhorne, PA: Gordon and Breach.

Bayart, Jean-Francois

1993[1989] *The State in Africa: The Politics of the Belly*. New York: Longman.

- Bayart, Jean-François, Stephen Ellis, and Beatrice Hibou, eds.  
1999 *The Criminalization of the State in Africa*. Bloomington: Indiana University Press.
- Biehl, João  
2007 *Will to Live: AIDS Therapies and the Politics of Survival*. Princeton: Princeton University Press.
- Bhattacharjee, Anannya  
2006[1997] *The Public/Private Mirage: Mapping Homes and Undomesticating Violence Work in the South Asian Immigrant Community*. In *The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 337-355. Malden, MA: Blackwell Publishers.
- Bernard, H. Russell  
1995 *Research Methods in Anthropology: Qualitative and Quantitative Methods*, Third Edition. Thousand Oaks, CA: Sage Publications.
- Bolton, R. and M. Singer, eds.  
1992 *Rethinking AIDS Prevention: Cultural Approaches*. Philadelphia: Gordon and Breach.
- Bond, George C., Kreniske, John, Susser, Ida, and Joan Vincent  
1997 *AIDS in Africa and the Caribbean*. Westview Press.
- Bosniak, Linda  
2003 *Citizenship*. In *Oxford Handbook of Legal Studies*. Peter Crane and Mark Tushnet, eds. Oxford University Press.
- Bourdieu, Pierre  
2000 *Pascalian Meditations*. Stanford: Stanford University Press.
- Bourgois, Phillippe and Nancy Scheper-Hughes  
2003 *Violence in War and Peace*. Malden, MA: Blackwell.
- Bourgois, Phillippe and Nancy Scheper-Hughes.  
2003 *Violence in War and Peace*. Malden, MA: Blackwell.
- Brenner, Neil  
1997 *Global, Fragmented, Hierarchical: Henri Lefebvre's Geographies of Globalization*. *Public Culture* 10(1):135-167.
- Bulhan, Hussein Abdilahi  
1985 *Frantz Fanon and the Psychology of Oppression*. New York: Plenum Press.

Burchell, Graham

1991 Peculiar Interests: Civil Society and Governing 'The System of Natural Liberty'.  
*In* The Foucault Effect: Studies in Governmentality. Graham Burchell, Colin  
 Gordin, and Peter Miller, eds. Pp. 119-150. Chicago: University of Chicago Press.

Cameron, Edwin

2007 Witness to AIDS. New York: Palgrave Macmillan.

Carnoy, Martin

1984 The State and Political Theory. Princeton: Princeton University Press.

Chase, Sabrina

2011 Surviving HIV/AIDS in the Inner City: How Resourceful Latinas Beat the Odds.  
 New Brunswick, NJ: Rutgers University Press.

Chatterjee, Partha

1990 A Response to Taylor's 'Modes of Civil Society'. *Public Culture* 3(1):119-132.

Cheru, Fantu

2001 Overcoming Apartheid's Legacy: The Ascendancy of Neo-liberalism in South  
 Africa's Anti-poverty Strategy. *Third World Quarterly* 22(4):505-527.

Chrisman, Noel J.

1977 The Health Seeking Process: An Approach to the Natural History of Illness.  
*Culture, Medicine, and Psychiatry* 1(4):351-377.

Clarke, Phillip with U.G. Gerdtham, M. Johannesson, K. Bingenfors, and L. Smith

2002 On the Measurement of Relative and Absolute Income-Related Health  
 Inequality. *Social Science and Medicine* 55:1923-28.

Clarke, Phillip with U.G. Gerdtham Chatterjee, Partha

1990 A Response to Taylor's 'Modes of Civil Society'. *Public Culture* 3(1):119-132.

Coburn, David

2000 Income Inequality, Social Cohesion and the Health Status of Populations: The  
 Role of Neoliberalism. *Social Science and Medicine* 51:135-46.

Cohen, S.

2001 States of Denial: Knowing about Atrocities and Suffering. Oxford: Blackwell.

Comaroff, John

1998 Reflections on the Colonial State, in South Africa and Elsewhere: Factions,  
 Fragments, Facts, and Fictions. *Social Identities* 4(3):321-361.

Comaroff John and Jean Comaroff, eds.

1999 Civil Society and the Political Imagination in Africa. Chicago: University of  
 Chicago Press.

- Cooper, Frederick  
2002 *Africa Since 1940: The Past of the Present*. Cambridge: Cambridge University Press.
- Coutin, Susan Bibler  
2006[2003] Cultural Logics of Belonging and Movement: Transnationalism, Naturalization, and US Immigration Politics. *In The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 310-336. Malden, MA: Blackwell Publishers.
- Craddock, Susan  
2004 Beyond Epidemiology: Understanding the Issues in Social Terms, Introduction. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 83-88. Malden, MA: Blackwell Publishing.
- Crapanzano, Vincent  
1986 *Waiting: The Whites of South Africa*. New York: Vintage Books.
- Crewe, Mary  
2000 How Do We Make Sense of President Mbeki? *AIDS Analysis Africa*, 11(1).  
  
1992 *AIDS in South Africa-the Myth and the Reality*. London: Penguin.
- Das, Veena and Deborah Poole  
2004 *Anthropology in the Margins of the State*. Santa Fe: School of American Research Press.
- de Paoli, Marina Manuela, Arne Backer Grønningsæter, and Elizabeth Mills  
2010 HIV/AIDS, the Disability Grant and ARV adherence: Summary Report. Fafo 2010:28.
- Dilger, Hansjorg  
2010 Morality, Hope and Grief: Towards an Ethnographic Perspective in HIV/AIDS Research. *In Morality, Hope and Grief: Anthropologies of AIDS in Africa*. Hansjorg Dilger and Ute Luig, eds. Pp. 1-20. Oxford: Berghahn Books.
- Doyal, Lesley, and Immogen Pennell  
1981 *The Political Economy of Health*. Boston: South End Press.
- Dullabh, Neela  
1994 An Examination of the Factors Influencing the Spatial Distribution of the Indian Communities in Grahamstown, King William's Town, Queenstown and Uitenhage from 1880 to 1991. Grahamstown: Rhodes University. (Masters' Dissertation).

- Edelman, Marc  
2001 Social Movements: Changing Paradigms and Forms of Politics. *Annual Review of Anthropology* 30:285-317.
- Edwards, Michael, and David Hulme, eds.  
1995 *NGO Performance and Accountability: Beyond the Magic Bullet*. London: Earthscan.
- Engels, Friedrich  
[1972] *The Origin of the Family, Private Property, and the State*. New York: Pathfinder Press.
- Englund, Harri  
2006 *Prisoners of Freedom: Human Rights and the African Poor*. Berkeley: University of California Press.
- Evans-Pritchard, E.E.  
1940 *The Nuer*. Oxford: Clarendon Press
- Epstein, Paul, and Randall Packard  
1987 Ecology and Immunity. *Science for the People* Jan/Feb:10-17.
- Fanon, Franz  
1967 *Black Skin, White Mask*. London: Penguin.
- Farmer, Paul  
2004 An Anthropology of Structural Violence. *Current Anthropology* 45(3):305-325.  
2003 *Pathologies of Power*. Berkeley: University of California Press.  
2002 Rethinking Health and Human Rights: Time for a Paradigm Shift. *Journal of Law, Medicine and Ethics*, Winter.  
1999 *Infections and Inequalities: The Modern Plaque*. Berkeley, CA: University of California Press.  
1997 AIDS and Anthropologists: Ten Years Later. *Medical Anthropology Quarterly* 11(4):516-525.  
1997b On Suffering and Structural Violence: A View from Below. *In Social Suffering*. Arthur Kleinman, Veena Das, Margaret Lock, eds. Pp. 261-84. Berkeley, CA: University of California Press.  
1996 *Women, Poverty and AIDS: Sex, Drugs, and Structural Violence*. Monroe, ME: Common Courage Press.

Farmer, Paul and Nicole Gastineau

2002 Rethinking Health and Human Rights: Time for a Paradigm Shift. *Journal of Law, Medicine and Ethics*. Winter.

Fassin, Dider

2007 *When Bodies Remember: Experiences and Politics of AIDS in South Africa*. Berkeley: University of California Press.

Feldman, Douglas, ed.

2008 *AIDS, Culture and Africa*. Gainesville, FL: The University of Florida Press.

1994 *Global AIDS Policy*. Westport, CT: Bergin and Garvey.

Feldman, Douglas and Thomas Johnson, eds.

1986 *The Social Dimensions of AIDS: Method and Theory*. New York: Praeger.

Ferguson, James and Akhil Gupta

2002 Spatializing States: Toward an Ethnography of Neoliberal Governmentality. *American Ethnologist* 29(4):981-1002.

Fisher, William F.

1997 "Doing Good? The Politics and Antipolitics of NGO Practices." *Annual Review of Anthropology* 26:439-64.

Foucault, Michel

2006[1991] *Governmentality*. In *The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 131-143. Malden, MA: Blackwell Publishers.

1995[1977] *Discipline and Punish: The Birth of the Prison*. Alan Sheridan, trans. New York: Vintage Books.

1977 *Truth and Power*. In *Reading for a History of Anthropological Theory*. Paul Erickson and Liam Murphy, eds. Pp 525-526. New York: Broadview Press.

Fourie, Pieter

2006 *The Political Management of HIV / AIDS in South Africa : One Burden Too Many?* New York, New York: Palgrave Macmillan.

Fourie, Pieter and Melissa Meyer

2010 *The Politics of AIDS and Denialism: South Africa's Failure to Respond*. Surrey, England: Ashgate Publishing Limited.

Fox, Roddy

2009 *Development of Grahamstown: A Field Excursion Guide*.



- Friedman, Samuel  
1986 Thoughts about Social Science and AIDS. *Medical Anthropology Quarterly* 17(2):34-35.
- Galtung, Johan  
1969 Violence, Peace, and Peace Research. *Journal of Peace Research* 6:167-91.
- Ghosh, Jayati and Ezekiel Kallipeni  
2004 Rising Tide of AIDS Orphans in Southern Africa. *In HIV and AIDS in Africa: Beyond Epidemiology*. Ezekiel Kallipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp 304-315. Malden, MA: Blackwell.
- Gibson, Nigel  
2001 Transition from Apartheid. *Journal of Asian and African Studies* 36(1):65-85.
- Giliomee, Hermann and Lawrence Schlemmer, eds.  
1985 *Up Against the Fences: Poverty, Passes and Privilege in South Africa*. New York: St. Martin's Press.
- Gorman, Michael  
1896a Introduction. *Medical Anthropology Quarterly* 17(2):31-32.  
  
1986b The AIDS Epidemic in San Francisco: Epidemiological and Anthropological Perspectives. *In Anthropology and Epidemiology*. Craig James, Ron Stall, and Sandra Gifford, eds. Pp 157-172. Dordrecht: D. Reidel.
- Gramsci, Antonio  
2006[1971] State and Civil Society. *In The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 71-85. Malden, MA: Blackwell Publishers.
- Green, Edward  
1994 *AIDS and STDs in Africa: Bridging the Gap between Traditional Healers and Modern Medicine*. Boulder, CO: Westview Press.
- Guest, Emma  
2004 A Child-headed Household Story. *In HIV and AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp 316-322. Malden, MA: Blackwell.
- Gupta, Akhil  
2006[1995] Blurred Boundaries: The Discourse of Corruption, the Culture of Politics, and the Imagined State. *In The Anthropology of the State: A Reader*. Aradhana Sharma and Akhil Gupta, eds. Pp. 211-242. Malden, MA: Blackwell Publishers.

- Gupta, Akhil and Aradhana Sharma  
2006 Globalization and Postcolonial States. *Current Anthropology* 47(2):277-307.
- Gupta, Akhil and James Ferguson  
2002 Beyond 'Culture': Space, Identity, and the Politics of Difference. In *The Anthropology of Globalization*. Jonathan Xavier Inda and Renato Rosaldo, eds. Pp. 65-80. Oxford: Blackwell.
- Gupta, Akhil and James Ferguson  
1997 Beyond "Culture": Space, Identity, and the Politics of Difference. In *The Anthropology of Globalization: A Reader*. Jonathan Xavier Inda and Renato Rosaldo, eds. Oxford: Blackwell Publishing.
- Haferburg, Christoph  
2002 The Informal Settlement Phola Park in the Context of Cape Town's Plan for Socio-Spatial Integration. *Urban Forum* 13(2).
- Hannerz, Ulf  
1989 Notes on the Global Ecumene. *Public Culture* 1(2):66-75.
- Hardy, Chloe and Marlise Richter  
2006 Disability Grants or Antiretrovirals?: A Quandry for People with HIV/AIDS in South Africa. *African Journal of AIDS Research* 5(1):85-96.
- Hart, Gillian  
2002 Accumulating Tensions: Remaking the Local State. In *Disabling Globalization: Places of Power in Post-Apartheid South Africa*. Pp. 235-289. University of California Press: Berkeley.
- Harvey, David  
2005 *A Brief History of Neoliberalism*, Oxford, Oxford University Press.
- 1990 *The Condition of Postmodernity: An Enquiry into the Origins of Cultural Change*. Cambridge, MA: Blackwell.
- Hegel, Georg Wilhelm Friedrich  
1942 [1821] *Philosophy of Right*. Thomas Malcolm Knox, trans. Oxford: Clarendon Press.
- Held, David, ed.  
1983 *States and Societies*. Oxford: Martin Robertson.
- Herd, Gilbert  
1987 AIDS and Anthropology. *Anthropology Today* 3(2):1-3.

Heywood, Mark.

2003. Preventing Mother-to-Child HIV Transmission in South Africa: Background, Strategies, and Outcomes of the Treatment Action Campaign Case against the Minister of Health. *South African Journal of Human Rights* 19:278-315.

Holleman, H. & Paterson, L. (eds).

1997 *Graham's Town: The Untold Story. A social history and self-guided tour.* Grahamstown: Black Sash.

Holston, James and Arjun Appadurai

1996 Cities and Citizenship. *Public Culture* 8:187-204.

Hunt, Charles W.

1989 Migrant Labor and Sexually Transmitted Disease: AIDS in Africa. *Journal of Health and Social Behavior* 21(1):157-173. International Defense and Aid Fund for Southern Africa

1982 *Apartheid: The Facts.* Cambridge, MA: A. G. Bishop and Sons.

Irvine, Philippa Margaret

2012 Post-apartheid Racial Integration in Grahamstown: A Time-geographical Perspective.

Janzen, John

1978 *The Quest for Therapy: Medical Pluralism in Lower Zaire.* Berkeley: University of California Press.

Jochelson, Karen

1999 Sexually Transmitted Disease in Nineteenth- and Twentieth-Century South Africa. *In* *Histories of Sexually Transmitted Diseases and HIV/AIDS in Sub-Saharan Africa.* Peter W. Setel, Milton Lewis, and Maryinez Lyons, eds. Pp 1-16. London: Greenwood Press.

Johannesson, M., K. Bingefors, and L. Smith

2002 On the Measurement of Relative and Absolute Income-Related Health Inequality. *Social Science and Medicine* 55:1923-28.

Johnson, Walton R.

1994 *Dismantling Apartheid: A South African Town in Transition.* Ithaca: Cornell University Press.

Joseph, Gilbert and Daniel Nugent, eds.

1994 *Everyday Forms of State Formation: Revolution and the Negotiation of Rule in Modern Mexico.* Durham, NC: Duke University Press.

- Kalipeni, Ezekiel, Susan Craddock, and Jayati Ghosh  
 2004 Mapping the AIDS Pandemic in Eastern and Southern Africa: A Critical Overview. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 58-69. Malden, MA: Blackwell Publishing.
- Kark, S.L.  
 1949 The Social Pathology of Syphilis in Africans. *South African Medical Journal* 23:77-84.
- Kaufman, Sharon  
 1988 Toward a Phenomenology of Boundaries in Medicine: Chronic Illness Experience in the Case of Stroke. *Medical Anthropology Quarterly* 2(4):338-354.
- Kelly, Kevin and Pumla Ntlati  
 2007 Marketisation of Municipal Services, Daily Life and HIV in South Africa. David A. McDonald and Greg Ruiters, eds. Canada: Logo Printers
- Kim, Jim Yong with Joyce Millen, John Gershman and Alec Irwin  
 2000 Dying for Growth: Global Inequality and the Health of the Poor. Monroe, ME: Common Courage.
- Kleinman, Arthur, Veena Das, and Margaret Lock, eds.  
 1997 Social Suffering. Berkeley: University of California Press.
- Kleinman, Arthur  
 1988 The Illness Narratives: Suffering, Healing and the Human Condition. New York: Basic Books.
- 1980 Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine and Psychiatry. Berkeley: University of California Press.
- 1978 Concepts and a Model for the Comparison of Medical Systems as Cultural Systems. *Social Science and Medicine* 12B: 85-93.
- Klepp, Knut-Inge, Paul Biswalo, and Aud Talle, eds.  
 1995 Young People at Risk: Fighting AIDS in Northern Tanzania. Oslo: Scandinavian University Press.
- Knutilla, Murray and Wendee Kubik  
 2000 State Theories: Classical, Global and Feminist Perspectives. New York: Zed Books.

- Kopp, Christine  
2002 *The New Era of AIDS: HIV and Medicine in Times of Transition*. Boston: Kluwer Academic Publishers.
- Kuumba, Bahati  
2001 *Gender and Social Movements*. Walnut Creek, CA: AltaMira Press.
- Kymlicka, Will  
1999 Citizenship in An Era of Globalization. *In Democracy's Edges*. Ian Shapiro and Casiano Hacker-Cordon, eds. Cambridge U. Press.
- Lapchick, Richard, and Stephanie Urdang  
1984 *Oppression and Resistance*. Westport, CT: Greenwood Press.
- Latour, Bruno  
1993 *We Have Never Been Modern*. Catherine Porter, transl. Cambridge, MA: Harvard University Press.
- Leach, E.R.  
1964 *Political Systems of Highland Burma*. Boston: Beacon Press.
- Leclerc-Madlala, Suzanne  
2006 'We Will Eat When I Get the Grant': Negotiating AIDS, Poverty and Antiretroviral Treatment in South Africa. *African Journal of AIDS Research* 5(3):249-256.
- Lefebvre, Henri  
1974 *The Production of Space*. Paris: Anthropos.
- Lemon, A. & Clifford, D.  
2005 Post-Apartheid Transition in a Small South African Town: Interracial Property Transfer in Margate, KwaZulu-Natal. *Urban Studies*. 42(1): 7-30.
- Lenin, V.I.  
1965 *The State and Revolution*. Peking: Foreign Languages.
- Lodge, Tom  
2003 *Politics in South Africa: From Mandela to Mbeki*. Bloomington: Indiana University Press.
- Lutz, Catherine  
2002 Making War at Home in the United States: Militarization and the Current Crises. *American Anthropologist* 104(3):723-735.
- Malkki, Liisa  
1995 *Purity and Exile: Violence, Memory, and National Cosmology among Hutu*

Refugees in Tanzania. Chicago: University of Chicago Press.

Mamdani, Mahmood

1996 *Citizen and Subject: Contemporary Africa and the Legacy of Late Colonialism*. Princeton: Princeton University Press.

Mann, Jonathan with S. Gruskin and M. Grodin, eds.

1999 *Health and Human Rights: A Reader*. London: Routledge.

Mann, Jonathan

1999 Human Rights and AIDS: The Future of the Pandemic. *In* *AIDS Education: Interventions in Multicultural Societies*. Inon Schenkek, Galia Sabar-Friedman and Francisco Sy, eds. Pp. 107. New York: Plenum Press.

Marmelstein, David, ed.

1987 *The Anti-Apartheid Reader: The Struggle against White Racist Rule in South Africa*. New York: Grove Press.

1975 Critique of Hegel's Doctrine of the State (1843). *In* *Early Writings*. Pp. 57-198. New York: Random House.

Marquard, Leo

1968 *The Story of South Africa*. London: Faber and Faber.

Mbembe, Achille

1992 The Banality of Power and the Aesthetics of Vulgarly in the Postcolony. *Public Culture* 4(2):1-30.

McIntyre, Diane, Bertha Garshong, Gemini Mtei, Filip Meheus, and Michael Thiede

2008 Beyond Fragmentation and Towards Universal Coverage: Insights from Ghana, South Africa and the United Republic of Tanzania. *Bulletin of the World Health Organization* 2008;86:871-876.

McLachlan, Fiona

1987 The Apartheid Law in Brief. *In* *The Anti-Apartheid Reader*. David Marmelstein, ed. New York: Grove Press.

Mechanic, David

1977 Illness Behavior, Social Adaptation, and the Management of Illness. *Journal of Nervous and Mental Disease* 165:78-87.

1968 *Medical Sociology: A Selective View*. Ann Arbor: University of Michigan Press.

Merry, Sally Engle

2006 *Human Rights and Gender Violence: Translating International Law into Local*

Justice. Chicago: University of Chicago Press.

2001 Spatial Governmentality and the New Urban Social Order: Controlling Gender Violence Through Law. *American Anthropologist* 103(1):16-29.

Mkhize, Sibongile

2009 The Difference in Pain: Infected and Affected. *In* AIDS, Sex, and Culture: Global Politics and Survival in Southern Africa. Ida Susser. Pp 107-117. Oxford: Wiley Blackwell.

Mitchell, Timothy

2006 Society, Economy, and the State Effect. *In* The Anthropology of the State: A Reader. Aradhana Sharma and Akhil Gupta, eds. Pp. 169-186. Malden, MA: Blackwell Publishers.

1991 The Limits of the State: Beyond Statist Approaches and their Critics. *Political Science Review* 85(1):77-96.

Mogensen, Hanne Overgaard

1995 AIDS is a Kind of Kahungo that Kills. Oslo: Scandanavian University Press.

Møller, Valerie

2008 Living in Rhini: A 2007 Update on the 1999 Social Indicators Report. Research Report Series No. 14. Grahamstown: Institute of Social and Economic Research (ISER), Rhodes University.

Moodie, T. Dunbar, with Vivienne Ndatshe

1994 Going for Gold: Men, Mines and Migration. Berkeley: University of California Press.

Murray, Colin

1977 High Bridewealth, Migrant Labour and the Position of Women in Lesotho. *Journal of African Law* 21 (1): 79-96.

Nader, Laura

1972 Up the Anthropologist-Perspectives Gained from Studying Up. *In* Reinventing Anthropology. Dell Hymes, ed. Pp. 284-311. New York: Pantheon Books.

Nattrass, Nicoli

2004 The Moral Economy of AIDS in South Africa. Cambridge, UK: Cambridge University Press.

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

Nattrass, Nicola and Nathan Geffen

- 2005 The impact of reduced drug prices on the cost-effectiveness of HAART in South Africa. *African Journal of AIDS Research*. (4):65–67.
- Navarro, Vincente  
 2002 *The Political Economy of Social Inequalities: Consequences for Health and Quality of Life*. Amityville, NY: Baywood.
- 1974 The Underdevelopment of Health or the Health of Underdevelopment. *Politics and Society* Winter:267-293.
- Nguyen, Vinh-Kim  
 2010 *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS*. Durham, NC: Duke University Press.
- Nguyen, Vinh-Kim and Karine Peschard  
 2003 Anthropology, Inequality and Disease: A Review. *Annual Review of Anthropology* 32:447-74.
- Nichter, Mark and Margaret Lock, eds.  
 2002. *New Horizons in Medical Anthropology: Essays in Honour of Charles Leslie*. London: Routledge.
- Ntantala, Phyllis  
 1976 *An African Tragedy: The Black Woman Under Apartheid*. Detroit: Agascha Productions.
- Nugent, David  
 2004 Governing States. *In A Companion to the Anthropology of Politics*. David Nugent and Joan Vincent, eds. Pp. 198-215. Oxford: Blackwell.
- 2002 Modernity at the Edge of Empire. *In The Anthropology of Politics*. Joan Vincent, ed. Pp. 313-324. Malden, MA. Blackwell Publishing.
- 1994 Building the State, Making the Nation: The Bases and Limits of State Centralization in 'Modern' Peru. *American Anthropologist* 96(2):333-369.
- Obbo, Christine  
 1999 *Social Science Research: Understanding and Action*.
- Oliver, Michael  
 1990 *The Politics of Disablement: A Sociological Approach*. Palgrave Macmillan.
- Omi, Michael and Howard Winant  
 1986 *Racial Formation in the United States*. New York: Routledge and Kegan Paul.
- Ong, Aihwa



- 2004 Citizenship. In *A Companion to the Anthropology of Politics*, David Nugent and Joan Vincent, eds. Pp. 55-68. Oxford: Blackwell.
- 1998 Flexible Citizenship Among Chinese Cosmopolitans. *In Cosmopolitics: Thinking and feeling Beyond the Nation*. Pp. 134-42, 146-62. Pheng Cheah and Bruce Robbins, eds. Minnesota.
- Parker, Richard  
2001 Sexuality Culture and Power in HIV/AIDS Research. *Annual Review of Anthropology* 30:163-199.
- Parker, Richard, Regina Barbosa, and Peter Aggleton, eds.  
2000 Framing the Sexual Subject. Pp. 110-115. Berkeley: University of California Press.
- Parker, Richard  
1987 Acquired Immunodeficiency Syndrome in Urban Brazil. *Medical Anthropology Quarterly* 1(2):155-175.
- Patton, Cindy  
1994 Last Served: Gendering the HIV Pandemic. London: Taylor and Francis.
- Peet, Richard  
2002 Ideology, Discourse, and the Geography of Hegemony: From Socialist to Neoliberal Development in Postapartheid South Africa. *Antipode* 34(1):54-84.
- Petryna, Adriana  
2002 Life Exposed: Biological Citizens after Chernobyl. Princeton, NJ: Princeton University Press.
- Phaswana-Mafuya, Nancy, Karl Peltzer, and George Petros  
2009 Disability grant for people living with HIV/AIDS in the Eastern Cape of South Africa. *Social Work Health Care Journal*. 48(5):533-550.
- Phillip, Oliver  
2004 The Invisible Presence of Homosexuality: Implications for HIV/AIDS and Rights in Southern Africa. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 83-88. Malden, MA: Blackwell Publishing.
- Phillips, Howard  
2001 AIDS in the Context of South Africa's Epidemic History: Preliminary Historical Thoughts." *South African Historical Journal* 45:11-26.
- Platzky, Laurine and Cherryl Walker  
1985 The Surplus People: Forced Removals in South Africa. Johannesburg:

Ravan Press.

Powers, Theodore

2013 Institutions, Power and Para-State Political Alliances: A Critical Reassessment of HIV/AIDS Politics in South Africa, 1999-2008. *Journal of Modern African Studies* 51(4): 605-626.

2012 Institutionalizing Dissent: HIV/AIDS, the Post-Apartheid State, and the Limits of Transnational Governance in South Africa. *Journal of Southern African Studies* 38(3): 531-549.

Priestly, Mark

2006 Developing Disability Studies Programs: The International Context. *In* Disability and Social Change. Watermeyer, Brian, Leslie Swartz, Theresa Lorenzo, Marguerite Schneider, and Mark Priestly, eds. Cape Town, South Africa: HSRC Press.

Rabinow, Paul and Nikolas Rose

2006 Biopower Today. *BioSocieties* 1:195–217.

Ras, G.J., Simson, I.W., Anderson, R., Prozesky, O.W. and Hamersma, T.

1983 Acquired Immunodeficiency Syndrome: A Report of 2 South African Cases. *South African Medical Journal*, 64.

Renteln, Alison Dundes

1988 Relativism and the Search for Human Rights. *American Anthropologist* 90:64.

Robins, Steven

2006 From “Rights” to “Ritual”: AIDS Activism in South Africa. *American Anthropologist* 108(2):3120323.

Rose, Nikolas

2006 *The Politics of Life Itself: Biomedicine, Power and Subjectivity in the Twenty-first Century*. Princeton, NJ: Princeton University Press.

Rosenberg, Charles

1992 *Explaining Epidemics and Other Studies in the History of Medicine*. New York: Cambridge University Press.

Ross, Fiona C.

2003 *Bearing Witness: Women and the Truth and Reconciliation Commission in South Africa*. London: Pluto Press.

Scheper-Hughes, Nancy

2007 Violence and the Politics of Remorse: Lessons from South Africa. *In* Subjectivity: Ethnographic Investigations. Joao Biehl, Byron Good, and Arthur

Kleinman, eds. Pp 179-233. Berkeley: University of California Press.

2000 The Global Traffic in Human Organs. *Current Anthropology* 41(2):191-224.

1992 *Death Without Weeping: The Violence of Everyday Life in Brazil*. Berkeley: University of California Press.

Schneider, Helen

2002 On the Fault-Line: The Politics of AIDS Policy in Contemporary South Africa. *African Studies*, 61(1): 145-167.

Schoepf, Brooke Grundfest

2004 AIDS, History, and Struggles over Meaning. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 15-28. Malden, MA: Blackwell Publishing.

2004b AIDS in Africa: Structure, Agency, and Risk. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 121-132. Malden, MA: Blackwell Publishing.

1992 Women at Risk: Case Studies from Zaire. *In The Time of AIDS: Social Analysis, Theory and Method*. G. Herdt and S. Lindenbaum, eds. Pp. 259-286. Newbury Park, CA: Sage Publications Inc.

1988 Women, AIDS, and Economic Crisis in Central Africa. *Canadian Journal of African Studies* 22(3):625-644.

Scott, James

1998 *Seeing Like a State*. New Haven: Yale University Press.

Seligman, Adam

1992 *The Idea of Civil Society*. Princeton: Princeton University Press.

Setel, Philip W.

1999 Comparative Histories of Sexually Transmitted Diseases and HIV/AIDS in Africa: An Introduction. *In Histories of Sexually Transmitted Diseases and HIV/AIDS in Sub-Saharan Africa*. Peter W. Setel, Milton Lewis, and Maryinez Lyons, eds. Pp 1-16. London: Greenwood Press.

Sharma, Aradhana and Akhil Gupta, eds.

2006 *The Anthropology of the State: A Reader*. Malden, MA: Blackwell Publishing.

Shils, Edward

1975 *Center and Periphery: Essays in Macrosociology*. Chicago: University of Chicago Press.

Shklar, Judith

1991 *American Citizenship: The Quest for Inclusion*. Cambridge, MA: Harvard University Press.

Smith, Neil

1992 *Contours of a Spatialized Politics: Homeless Vehicles and the Production of Geographical Scale*. *Social Text* 33:54-81.

Sobo, Elisa

1999 "Cultural Models and HIV/AIDS: New Anthropological Views (editorial)." In *Anthropology of Medicine* 6(1):5-12.

Sontag, Susan

1989 *AIDS and Its Metaphors*. New York: Farrar, Strauss, and Giroux.

Spencer, Jonathan

2007 *Anthropology, Politics, and the State: Democracy and Violence in South Asia*. Cambridge: Cambridge University Press.

Stack Carol

1974 *All Our Kin: Strategies for Survival in a Black Community*. New York: Harper and Row.

Statistics South Africa (Stat SA).

2012a *Living Conditions Survey: Poverty Profile on South Africa*.

<http://www.statssa.gov.za/publications/Report-03-10-03/Report-03-10-032009.pdf>

2012b *Quarterly Labor Force Survey*.

<http://www.statssa.gov.za/publications2/P0211/P02113rdQuarter2012.pdf>

2007 *Community Survey (Revised Version)*. Statistical Release P0301.

Steinberg, Jonny

2008 *Three-Letter Plague*. Cape Town: Jonathan Ball Publishers.

Steward, Julian

1948 *Comments on the Statement on Human Rights*. *American Anthropologist* 50: 351-2.

Stichter, Sharon

1985 *Migrant Laborers*. New York: Cambridge University Press.

Stoler, Ann Laura

2004 *Affective States*. In *A Companion to the Anthropology of Politics*. David Nugent and Joan Vincent, eds. Pp. 4-20. Oxford: Blackwell.

- Stoner, Bradley, P.  
1985 Formal Modeling of Health Care Decisions: Some Applications and Limitations. *Medical Anthropology Quarterly* 16(2): 41-46.
- Strathern, Marilyn  
1995 *The Relation: Issues in Complexity and Scale*. Cambridge: Prickly Pear Press.
- Subramanian, S.V.  
2002 The Macroeconomic Determinant of Health. *Annual Review of Public Health* 23:287-302.
- Susser, Ida  
2009 *AIDS, Sex, and Culture: Global Politics and Survival in Southern Africa*. West Sussex: John Wiley & Sons.
- Susser, Ida and Zena Stein  
2004 Culture, Sexuality, and Women's Agency in the Prevention of HIV/AIDS in Southern Africa. *In HIV & AIDS in Africa: Beyond Epidemiology*. Ezekiel Kalipeni, Susan Craddock, Joseph Oppong, and Jayati Ghosh, eds. Pp. 133-143. Malden, MA: Blackwell Publishing.
- Susser, Ida and Zena Stein  
2000 Culture, Sexuality, and Women's Agency in the Prevention of HIV/AIDS in Southern Africa. *American Journal of Public Health* 90(7):1042-1048.
- Taylor, Charles  
1990 Modes of Civil Society. *Public Culture* 3(1): 95-118.
- Treichler, Paula  
1999 *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham, NC: Duke University Press.
- Tseng, Wen-Shing and Jon Streltzer  
2008 *Cultural competence in Health Care: A Guide for Professionals*. Springer Science: New York.
- Turshen, Meredith  
1984 *The Political Ecology of Disease in Tanzania*. New Brunswick, NJ: Rutgers University Press.
- 1977 The Impact of Colonialism on Health and Health Services in Tanzania. *International Journal of Health Services* 7:7-35.
- Venkataramani, Atheendar, Brenden Maughan-Brown, Nicoli Nattrass, and Jennifer Ruger

- 2009 Disability Grants and Individual and Household Welfare among HAART Patients in South Africa. Centre for Social Science Research Working Paper No. 240. February.
- Wagstaff, Adam  
2002 Poverty and Health Sector Inequalities. *Bull. WHO* 80(2):97-105.
- Walker, Cherryl  
1982 Women and Resistance in South Africa. London: Onyx Press.
- Walker, R.B.J., and Saul H. Mendlovitz  
1990 Interrogating State Sovereignty. *In* Contending Sovereignities: Redefining Political Community. R. B. J. Walker and S. H. Mendlovitz, eds. Boulder, Co: Lynne Rienner.
- Wallerstein, Immanuel  
1974 The Modern World System I: Capitalist Agriculture and the Origins of the European World Economy in the Sixteenth Century. New York: Academic Press.
- Washburn, Wilcomb E.  
1987 Cultural Relativism, Human Rights and the AAA. *American Anthropologist* 89: 939-43.
- Wasserman, Stanley and Katherine Faust  
1994 Social Network Analysis: Methods and Application. Cambridge: Cambridge University Press.
- Watermeyer, Brian, and Leslie Swartz  
2006 Introduction and Overview. *In* Disability and Social Change. Watermeyer, Brian, Leslie Swartz, Theresa Lorenzo, Marguerite Schneider, and Mark Priestly, eds. Cape Town, South Africa: HSRC Press.
- Watson, Vanessa  
2002 Change and Continuity in Spatial Planning: Metropolitan Planning in Cape Town under Political Transition. London: Routledge.
- Weeks, Jeffrey  
1989 Sex, Politics, and Society; The Regulation of Sexuality since 1800. Harlow: Longman.
- Werbner, Richard and Terence Ranger, eds.  
1996 Postcolonial Identities in Africa. Atlantic Highlands, NJ: Zed Books.
- Whiteside, A. and Sunter, C.  
2000 AIDS: The Challenge for South Africa. Cape Town: Human and Rousseau/Tafelberg.

Wilkinson, Richard

1997 *Unhealthy Societies: The Affliction of Inequality*. New York:  
Routledge

Wilson, Carter

1995 *Hidden in the Blood: A Personal Investigation of AIDS in the Yucatan*. New  
York: Columbia University Press.

Wilson, Richard Ashby, ed.

1997 *Human Rights, Culture and Context: Anthropological Perspectives*. London:  
Pluto Press.

Yacobi, Haim

2001 *From Urban Panopticism to Spatial Protest: Housing Policy, Segregation  
and Social Exclusion of the Palestinian Community in the City of Lydda-Lod*.  
Paper presented at a Lincoln Institute course titled, *International Seminar on  
Segregation in the City*, July 26-28.

Ziegler, Phillip

1982 *Black Death*. Harmondsworth: Penguin.