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THE EFFECTS OF ANTIRETROVIRAL ACCESS ON THE CREATION AND MAINTENENCE OF HIV-SEROPOSITIVE IDENTITY

by

KYLE P. PEPLINSKI

Under the Direction of Cassandra White, PhD.

ABSTRACT

The study of identity based on the presence of disease has traditionally focused on landmark events, such as diagnosis or the introduction of treatment options. These events have been shown to significantly alter so-called "illness identities." The project was undertaken in Atlanta, GA, which has a relatively high rate of HIV infection and a large number of HIV-related services and support mechanisms. This study contextualizes illness identities within a larger socio-political and economic paradigm, recognizing that individuals use multiple identities to inform their interactions and decisions, specifically those regarding the beginning and continuation of antiretroviral (ARV) treatment. In addition, structural barriers which limit one's access to ARV treatment are considered within a context of social and economic marginalization and inequitable power relationships within a post-industrial Western society.

INDEX WORDS: HIV/AIDS, Identity, Structural violence, Antiretroviral therapy

THE EFFECTS OF ANTIRETROVIRAL THERAPY ON THE CREATION AND MAINENENCE OF HIV-SEROPOSITIVE IDENTITY

by

KYLE P. PEPLINSKI

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

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Chapter 1
"Long-term chemotherapy:" Introduction and the Access Landscape Today.

The global HIV/AIDS pandemic has affected nearly 40 million people worldwide, with over 1.2 million of those cases being reported in the United States (WHO 2008). While these statistics illustrate an enormous public health challenge, they also imply a larger political, social, and economic tragedy. In the last 10 years, effective medications, known as antiretrovirals (ARV) or antiretroviral treatment (ART), have been developed to extend and improve the quality of life of people living with HIV/AIDS. These medications are effective in maintaining high CD4 white blood cell counts and reducing viral loads, in many cases to undetectable levels, which are important signifiers in HIV healthcare. However, they are often prohibitively expensive to the individual. Providing these pharmaceuticals to those who need them has been a major challenge and focus for global, national, and local stakeholders throughout the world. Although public health authorities are almost exclusively concerned with the healthcare benefits of adherent use of ART, anthropologists have long considered the social and economic ramifications of ART use. An important component to this line of questioning is how access to and utilization of ART affects identity for HIV-positive individuals.

The United States has seen a tremendous effort to provide for and support treatment options for people living with HIV/AIDS, both through governmental and private channels. Private insurance and a multitude of non-profit organizations have been providing access to ART since 1996, and to ART's predecessors since 1987. The United States government has provided access, through Medicaid and Medicare, since 1990 and has developed numerous other programs to subsidize ART since then. However,

although there are numerous routes through which to garner access in the United States, many people living with HIV are not utilizing it. Why these people "choose" to forgo treatment has many explanations and outcomes. It has been shown that adherent use of ART can beneficially impact quality of life measurements (Mannheimer et al. 2005). This result, then, begs the question, if access to ART is provided for to a significant majority of people living with HIV in the United States, why are utilization rates not universal among the United States population? Of course, the answer to this question is multi-faceted and, in many cases, ambiguous. There are both personal and structural limitations affecting who utilizes ART and when they do so. Although the United States has attempted to remedy the structural barriers to ART access, underlying issues of poverty, education, and class, gender, and race inequality exist as general impediments to healthcare access, and HIV-related healthcare is no exception. Identifying these structural limitations is a major responsibility of critical social science and a first step in alleviating the inequalities they create.

While these structural barriers have, to some extent, more recently received the attention of anthropologists and other social scientists, especially in a U.S. context, personal factors affecting the utilization of ART have long been, and continue to be, a focus of the field. Parker and Aggleton note, in the context of anthropological research on HIV/AIDS, that, "much work has tended to focus on stereotyping rather than on the structural conditions that produce exclusion from social and economic life" (Parker and Aggleton 2003: 15). For the purpose of this paper, I am defining personal traits as psychological and emotional states or values that, in one way or another, affect the decision making process of an individual. It should be noted that these are not absolute

categories and certain characteristics, most notably stigma, fall in a grey area somewhere between what is emotional/psychological and what is structural. In illustrating this point, Scheper-Hughes and Lock (1987) note that, "Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication-the language of the organs-through which nature, society, and culture speak simultaneously" (Scheper-Hughes and Lock 1987: 31). The undeniable link between mind/body, cultural/biomedical, and personal/structural must be taken into account with any holistic study of illness and health. These categories are not meant to be dichotomous, but continuums of experience and effect on any individual or collective. It should also be noted that there were several early studies which focused on the risk of acquiring HIV/AIDS through the structural prisms of economic, social, and gender inequality (Schoepf 1995; Singer et al. 1990). This study is an effort to weave the personal and structural factors affecting access to HIV treatment and the subsequent effects of that treatment on identity creation into a coherent statement on the challenges confronting people living with HIV/AIDS today.

To this end, my research has been heavily influenced by the theoretical paradigm introduced by Michel Foucault (1973) in *The Birth of the Clinic: An Archeology of Medical Perception*. In this work, Foucault examines the roles of the "doctor," patient, and healthcare system on the medical experience. He develops the clinical gaze as an explanatory tool for the hegemonic control of biomedicine over the clinical experience. The clinical gaze, as Foucault posits, is an epicenter of knowledge and authority which only a "doctor," someone who has been trained in biomedicine, can possess. This knowledge base allows the healthcare professional to interpret symptoms, signs of illness, into meaningful and culturally salient entities. The "doctor" becomes a translator of

biology and the patient is, in effect, told how to respond to and understand his illness. The concept of the clinical gaze has been extremely influential to the field of medical anthropology, and others have extended the gaze to include social settings, which I will expand upon in chapter 3. However, in Foucault's conception of the gaze, medical authority and knowledge was tied to not only physical manifestations of disease, symptoms, but also to specialized training in medicine. There are, however, several critiques of this understanding.

First, especially in the case of HIV, there are long periods of time when no physical symptoms are manifest but the diagnosis has already been made. Although the act of diagnosis falls within Foucault's original paradigm, where HIV antibodies constitute the visible "symptoms" which are interpreted and related to the patient, the incubatory stage of HIV has few, if any, visible symptoms to record, "visualize," and relate. However, during this time a person living with HIV continues to have a relationship with his illness and their behaviors, outlooks, and identity continue to be tied to that relationship. The gaze, thusly, reconstitutes itself and the patient becomes the "owner" of the gaze. Second, with the assistance of modern technology, which Foucault could not have anticipated, medical knowledge has been democratized, namely through the internet. The "doctor" is no longer the sole holder of information, including anticipated symptoms, treatment options, etiology, and lifespan of the pathogen. Patients are, often, more able to access and interpret for themselves this information and make judgments independently from their healthcare provider.

This theoretical paradigm has methodological consequences for data collection and interpretation. Methodologically, I have drawn from the work of Arthur Kleinman

and collected illness narratives from my research participants. These narratives serve as tools for the recollection of past experiences and identification of issues and barriers each participant faced/faces in his struggle with developing a normative lifeway. Illness narrative approaches to collecting data from people living with HIV have long been a staple for anthropological researchers. For this study, the recollection of past feelings, events, successes, and failures especially centered around treatment, offer the raw material needed to assess the efficacy of ARV treatment and identify the barriers of/to such treatment. Participant observation in HIV/AIDS-related educational forums provided another source of information on the issues faced by people living with HIV/AIDS today. Including both one-on-one interviews and attendance at group events allow for a more holistic perspective and comparing data from each site is an interesting endeavor in concluding whether my participants are more forthcoming individually or in group settings. Either way, including both sites underscores and takes into account that people act and respond differently in divergent settings. Thus, my methodology is an attempt to include a holistic and encompassing perspective in this research.

Developing a coherent and sound understanding of any illness, from a biological, political, social, and economic perspective, is a monumental challenge. However, the myriad complications that HIV/AIDS presents because of its lack of predictability, sexual transmissibility, stigmatizing effects, and the social and political instability it leaves in its wake only further contribute to those challenges. Anthropological theory and methods offer a unique opportunity to understand how and why the biological and clinical manifestations of HIV/AIDS lead to social, political, and economic inequality, specifically regarding access to and utilization of ARV treatment. Furthermore, the

effects of that treatment on the perceptions and understandings of those living with the illness have the ability to offer insight into more than simply the biomedical benefit of ART. A cost/benefit analysis of ART, from a psychological, biological, social, cultural, economic, and personal standpoint has the potential to validate or invalidate the continued funding of ARV treatment for those in need, by governmental and private entities. It is my hope that through this research it will be shown that ART has more than physical benefits and those benefits may include reducing HIV/AIDS-related stigma, using the mind/body connection to incite increased levels of healing and health than ART may alone, and allowing people to return to normative lifeways, which has the potential to increase economic productivity and contribute to the success of future generations. While these may be lofty goals, these idealistic macro-level benefits have substantive and concrete implications on the "ground." It is these "real world" applications which will be highlighted throughout the following pages because, it is my belief that real change and progress begin at the level of the individual.

Chapter 2
"Most people have a 1987 view of AIDS and this is 2008:" Background.

The HIV/AIDS epidemic has transformed from a sub-population specific virus to "perhaps the greatest challenge of our age and our generation" (Kofi Annan 10/10/05) in the short span of 25 years: from first being recognized as Gay-Related Immunodeficiency Syndrome (GRIDS) in 1981 to now more than 40 million people living with HIV/AIDS in the world and 3.1 million people dying from the illness every year. The mechanisms behind the enormous growth in prevalence and mortality of this fatal virus cannot be easily or succinctly summarized and has attracted the best minds in public health, health policy, humanitarian aid, and government. However, both the specific etiology and epidemiology of HIV/AIDS play large roles in creating the problems faced by the global public health community and help explain the astonishingly rapid pace at which HIV/AIDS has become the major global health challenge of the 21st century.

The first recorded cases of what we now know as AIDS were documented in New York City in 1981 because of the onset of rare "opportunistic diseases" which generally attack immuno-depressed individuals. Because of the confines of these rare cancers and strains of pneumonia to gay men and because there was no actual evidence of anything except immuno-suppression, the cause and transmission of AIDS was obscured. It was not until a year later, when these symptoms were also being reported in hemophiliacs and a few women, that the CDC and others identified sexual and blood transmission as possible mechanisms. Furthermore, it was not until 1983 that the retrovirus which causes AIDS was isolated and researchers could begin studying it. Meanwhile, AIDS had

appeared on every inhabited continent, in over 51 countries. By 1985 AIDS had truly become a worldwide pandemic spreading rapidly and with no effective treatments available. The first drug approved to combat the effects of AIDS was azidothymidine (AZT), in 1987, but at $10,000 per patient a year it was prohibitively expensive and not widely available. It was also in 1987 that a general consensus emerged that the virus, HIV, actually led to the syndrome, AIDS. In 1993 the CDC expanded its definition of what constitutes a case of AIDS and the caseload in the United States spiked 111% in one year (Castro et al. 1992). In the years following the expanded definition of AIDS by the CDC, many epidemiological reference points shifted leading researchers to a much clearer picture of the actual state of the epidemic, especially in the United States. In 1995, with the new CDC definition, AIDS and AIDS-related sicknesses became the leading cause of death for 25-44 year olds and in 1996, for the first time, the number of cases among African-Americans exceeded that of white Americans (Castro et al. 1992).

This drastic shift in the demography of groups affected by HIV/AIDS most likely brought the surveillance community closer to understanding the actual representation of HIV/AIDS in the United States and opened a window for public health prevention and treatment efforts to expand from targeting traditionally "at-risk" populations into a much broader audience. This transformation was significant in targeting African-Americans, Hispanics, and women, especially as the risks associated with heterosexual sex were becoming more apparent. Today the sub-population with the highest rates of infection in the United States is African-American women and cases among women, in general, have tripled since 1986. Of women affected by HIV/AIDS in the United States, nearly 70% of them contracted the virus through heterosexual intercourse (NIH 2008).

However, 1996 also marked a turning point for the fight against HIV/AIDS with the introduction of the first Protease inhibitor medications, which were shown to significantly extend the lives of people living with HIV/AIDS. The United States saw a 23% decline in AIDS-related deaths in that year and a 42% decline the following year. With the new medications entering the market, people with access to those medications were living longer and substantially altering the mortality landscape in the developed world. But still, the United States has vast inequalities with regards to who is becoming HIV positive. Just a few years later, in 1999, statistics showed that over 95% of the worldwide caseload of HIV/AIDS resided in developing countries and 95% of AIDS-related deaths also occurred in the developing world. These data promptly altered the scope and direction of the greater public health community to focus on HIV/AIDS as a global concern, prompting the United Nations, in 2000, to declare the fight against HIV/AIDS "…an international security issue because it threatens social, economic, and political structures worldwide" (amfAR 2002). It was not until quite recently that the suite of issues that accompany the devastation of HIV/AIDS was realized; 15 million children have been orphaned and countries, such as Lesotho, Botswana, and Swaziland dealing with nearly 40% of the population infected. In sub-Saharan Africa, 75% of cases in people aged 15-24 are women (UNAIDS 2006). These statistics help define the global issues faced when dealing with the current state of HIV/AIDS.

Etiologically, HIV is in a family of viruses known as retroviruses. Human Immunodeficiency Virus creates a response in the body's immune system when it enters the body. White blood cells are produced to fight off the infection and the virus attaches to the attacking white blood cells and uses them to replicate. This is the first stage where

infected individuals feel general flu-like symptoms because of the creation of antibodies to fight off the invading virus. Once the virus has attached itself to enough white blood cells those symptoms disappear because the "foreignness" of the virus has disappeared. The infected individual then enters an asymptomatic "incubation" period, which can last from just a couple a months to over 10 years where the patients' CD4 cell count stays at or above 500 cells/mm^2. Once a patient's CD4 cell numbers reach 499 cells/mm^2 they have reached stage 2, where most physicians recommend beginning treatment with antiretroviral medications to ward off possible "opportunistic infections" which attack because of the immuno-suppressed condition. Treatment is usually not recommended before this because of the possibility of developing a drug resistant form of the HIV virus, which would seriously disrupt future options for treatment (Blankson 2005). The CDC issued a statement to this effect in 2001 (amfAR 2002).

At this point HIV medications can extend the life and quality of life of a patient. Currently it is unknown how long ART can effectively keep CD4 cell counts high and viral load counts low because of its relatively recent development. However, many people who began ARV treatment in the mid-1990's are still responding to treatment and treatment efficacy is highly variable between individuals. Furthermore, the relatively fast development of new classes and types of ART have created innumerable combinations of treatment options. These multiple combinations allow for treatment options if initially prescribed combinations are not effective or become ineffective. Eventually, however, the CD4 cell count will begin to decline leading to increasingly more severe immuno-suppression. A suite of illnesses accompany stage 2 HIV status including candidiasis, bacillary angiomatosis, and pelvic inflammatory disease (PID) (Moss et al. 1988). Stage

3 begins when CD4 cell counts fall below 200 cells/mm^2. At this point a patient is diagnosed with AIDS, regardless of the presence of additional infections or not. Furthermore, it only takes one CD4 count below that level to be diagnosed with AIDS, rather than requiring two or more. For this reason, the reported AIDS cases in the United States may be slightly skewed, including HIV patients with CD4 counts above 200 cells/mm^2 if they have ever had a count below that. It has been shown by Hoover et al. (1992) that CD4 cell counts can fluctuate, by an average of 44 cells/mm^2 due to diurnal variation. However, at this point, especially in patients with CD4 cell counts consistently below 200 cells/mm^2, an opportunistic disease will eventually set in and the patient's immune system will not be able to combat it. This degenerative nature of HIV/AIDS is one of the most distressful aspects of it. Similarly, the unknown and highly variable incubation period make living with HIV a constant guessing game about when, not if, your CD4 cell count will begin to decline (Centers for Disease Control 1992).

In addition to the biological realities of HIV/AIDS transmission, there have always been political and economic determinants hastening the spread of the disease, which have particular relevance for sub-Saharan Africa, with 55% of the world's HIV/AIDS cases. On a much smaller scale, the United States is grappling with the inequalities that are becoming apparent through continued surveillance. While, until recently, there was a trend of a declining number of new cases in the United States, African-Americans and Hispanics are an increasingly large proportion of those cases, and the progressive rate of women, especially young women, acquiring the virus is alarming. There is, however, hope, with the creation and availability of drugs, agreements with pharmaceutical companies to offer reduced pricing, and the attention of less severely

affected nations and the United Nations on programs and monetary resources to combat the pandemic.

In the midst of these biological, etiological, and epidemiological discoveries, the social science community has been actively involved in contributing to cultural understandings of HIV risk, coping mechanisms, and more recently, structural constraints facing the effective utilization of testing and treatment options. Early anthropological accounts of HIV/AIDS struggled with the inherent complexity and stigmatizing effect of the illness. Understandably, much of the research was focused on the cultural and social stigma facing people living with HIV/AIDS and the testing process. Glick-Schiller argued in 1992, and others had earlier, that groups termed "at-risk" by the public health community were done so in order to "exoticize" already socially marginalized groups and maintain a sense of impenetrability to HIV among the general population (Glick-Schiller 1992). Multi-faceted stigma would then be applied to traditionally "at-risk" populations. For example, "gay" and "HIV-positive" came to be equated with each other in the public imagination.

Another vein of early research focused on the adaptive tasks of people living with HIV. The methods which informed these studies drew extensively on the work of Arthur Kleinman and instituted an explanatory model and illness narrative approach to understanding the illness. From the very beginning of the epidemic, social science researchers were interested in listening to how people felt, which included resistance to hegemonic conceptions of risk and infection (Whittaker 1992), dealing with the knowledge of a curtailed life span, and maintaining both physical and mental health (Siegel and Krauss 1991). As McCombie (1986) points out while discussing the impact

of the introduction of testing options in America, "In some health jurisdictions that have embraced the test, it is viewed as a powerful counseling tool and device for behavior modification. However, the actual behavioral outcome that results from being told that one is positive or negative has not been documented" (McCombie 1986: 458). This point illustrates the assumptions and causal weight which was, most assuredly, placed on the introduction of HIV testing instruments.

Likewise, Glick-Schiller (1992) argues that public health authorities incorrectly assumed a static and bounded cultural understanding of traditional "at-risk" groups. Gay and bisexual men, Haitians, and intravenous drug users (IVDU) were, simply, at risk, regardless of the behaviors they engaged in or the context in which they found themselves (Glick-Schiller 1992). These groups, she goes on to argue, are not distinct and bounded, but dynamic and fluid, moving between each other, informing each other, and sharing members with one another. Furthermore, not all men who have sex with men (MSM), Haitians, or IVDU engage in behaviors deemed at risk. Richard Parker (1987) also confronts this issue by concluding that the two prominent models of transmission in the 1980's, heterosexual and homosexual/bisexual, "may well have limited our understandings of the disease itself, distorted our perception of its transmission, and, perhaps most important, partially obscured its potentially more serious consequences at home and abroad" (Parker 1987: 156). These two models of transmission were tied to perceived regional variations in transmission with predominantly homosexual/bisexual transmission being observed in developed nations and predominately heterosexual transmission in Africa, Latin America, and Asia (Parker 1987). This paradigm helped to concretize the stereotypes of "at-risk" populations and, as Sontag contends in her essay

"AIDS and Its Metaphors" (1988), all members of these traditional "at-risk" groups came to be conceptualized as HIV positive, whether or not they showed symptoms, engaged in "risky" behavior, or exhibited any of the "classic" signs of infection with HIV.

Certainly, the inclusion of MSM in early "at-risk" group categorizations made epidemiological sense at the time, but the usefulness of such categorizations needs to be questioned. The prevailing paradigm, which necessarily associates unassociated characteristics with HIV transmission, such as sexuality identity, country of origin, or medical condition, needs to be questioned. A paradigm which focuses on behaviors, and the underlying causes of those behaviors, should take its place. Behaviors, such as unprotected sex, needle sharing, and receiving unscreened blood transfusions are the causes of HIV transmission, not sexual orientation or birth place or drug use. As Marshall and Bennett contend, "Although the 'risk group' idea is useful, in reality all people are at relative risk as a result of particular behaviors – their own or others'" (Marshall and Bennett 1990: 4). And while these routes of transmission are the target of most interventions today, early public health strategies had already ingrained powerful associations between the "at-risk" groups and ubiquitous HIV infection. So ubiquitous are these connections that even the members of those "at-risk" groups are not surprised when they are diagnosed, and as Gary, one of my informants, told me, it "made sense" that he was HIV-positive. This consent and unquestioning compliance among marginalized populations truly illustrates the hegemonic power that public health authorities have in the conceptualization of epidemic disease. Glick Schiller expands on this concept as "the means by which subordinated populations participate in cultural constructions that contribute to their continuing subordination" (Glick Schiller 1992:

248). It is clear that my participants continue to be influenced by this public health hegemony

As the biomedical picture of HIV and AIDS progressed, transmission mechanisms became clearer, testing procedures advanced, treatment options expanded, and the demographic and epidemiologic diversity of the epidemic grew, public health officials, and, in turn, the general population could no longer generalize and stereotype who became infected and why. Social scientists began attempting to explain the growing inequality of infection, as increasing numbers of people of color, the poor, and the socially marginalized were being diagnosed. The structural constraints of poverty, education, language, and access to testing and treatment began to become elucidated and public policy soon followed.

Legislation, such as the Ryan White Act, was passed in 1990, guaranteeing access to treatment for all minors and providing supplemental coverage for people whose needs were not being met by Medicaid or private insurance (Dept. of Health and Human Services, HIV/AIDS Bureau 2008). Along with access to treatment and testing services, the confluence of sex, drugs, poverty, and HIV was becoming increasingly clear. Gorman et al. (1997) was one of the first studies to document the deadly combination of crystal meth and HIV infection and the resurgence of HIV infection among traditional "at-risk" groups, especially MSM. They contend that, "Gay and bisexual men are of particular concern because of their multiple risk factors for HIV infection and transmission" (Gorman et al. 1997: 507). While drug use alone can not be termed a structural limitation, in and of itself, Gorman et al. suggest that higher levels of drug usage exist among lower socio-economic status (SES) and homeless MSM. While the

causal mechanisms between low SES and drug use are unclear, it has been posited that mental illness, such as depression, can influence both factors and that a cyclical relationship exists between low SES and drug use, with each contributing to dependence on the other (Gorman et al 1997: 509).

Likewise, Singer and Clair (2003) point to the syndemic nature of HIV/AIDS, especially in urban inner-city environments where poverty, drug use, HIV, and a host of other illnesses coalesce at the individual and population levels and have direct biomedical, social, economic, and political consequences. They contend that, "Ultimately social factors, like poverty, stigmatization, racism, sexism, ostracism, and structural violence may be of far greater importance than the nature of pathogens or the bodily systems they infect" (Singer and Clair 2003: 428). According to Singer and Clair, the recognition of the syndemic possibilities of the HIV/AIDS pandemic have largely been recognized in the last 10 years and have forced a change in the focus of research to the biocultural and structural assessments of the illness and the ways in which HIV/AIDS interacts with other diseases, cultural models and classifications of illness, and social and economic marginalization (Singer and Clair 2003). This assessment calls for the study of HIV/AIDS from a holistic structural, political, economic, social, and historical perspective.

The study of these structural limitations, which tend to interact with and exacerbate each other, perhaps offers the most concrete and coherent possibility of benefit to the HIV community. While U.S. policy has, in many ways, been progressive, both domestically and internationally, a greater understanding of the logistical, financial, and cultural constraints people face is necessary in order to develop increasingly

efficacious and beneficial testing, prevention, and treatment programs. The United States has funded HIV treatment since the early 1990's through multiple means, including Medicare, Medicaid, the AIDS Drug Assistance Program (ADAP), and by subsidizing individual local and state programs. However, the effectiveness of these programs, especially to socially and economically marginalized populations, needs to be evaluated. Similarly, there remains a substantial population who are unable to access these assistance programs. Many of these people simply fall through the cracks of government bureaucracy; the self-employed who cannot afford private health insurance, those unable or unwilling to negotiate the confusing government red tape, and those who have private insurance but cannot afford increasingly high prescription co-pays.

The marginalization of traditionally "at-risk" populations is not confined to the shaping of the public imagination and public health response. Economic factors that shape whether or how someone accesses healthcare, specifically ART, also play a part in how marginalized populations are further subordinated. The epidemic of runaway gay youth, such as Jake, one of my informants, as evidenced by the numerous support agencies devoted to this particular topic, creates a precarious situation of economic instability and, in many cases, the loss of sexual agency. Many homeless gay youth turn to commercial sex work and drug use as means to economic and emotional support and stability. In a study conducted in 1993-1994, Clatts and Davis (1999) found that nearly 35% of their sample of homeless youth in New York City identified as gay or bisexual, a number they contend is probably under-representative of the actual prevalence of homeless gay youth (Clatts and Davis 1999). They also note that prostitution and illegal drug use are staples of both income and recreation for many homeless youth. Multiple-

partner unprotected sex was significantly associated with being gay or bisexual ($p<.001$) in their population and the ramifications for HIV infection risk are clear (Clatts and Davis 1999). In this example a disproportionate number of homeless youth identify as gay or bisexual and that identification makes them more likely to engage in behaviors deemed "high risk" by public health authorities. It is clear that the structural limitations of discrimination and social marginalization and the possibilities for action, based on personal agency, are intertwined and shape the situations available to homeless gay youth in tandem; economic marginalization and a decrease in sexual agency.

Another area where the line between what is structural and what is agential is blurred is the decision to forgo public funding, namely Ryan White based programs, even when exclusive use of private insurance represents a financial hardship for the person living with HIV/AIDS. While burdensome prescription co-pays could be offset by federal assistance programs, these programs are often conceptualized as the easy way out or available to people who do not see themselves as the "type" of person to utilize government assistance programs. Welfare recipients carry with them a certain stigma and the aversion to accepting Ryan White based funding could be viewed as an attempt to reduce the stigma already felt by people living with HIV/AIDS (Bullock 1999). As such, people with private insurance have a choice, mediated by personal agency, to accept or forgo such funding, if they qualify for it. However, this choice must be contextualized within the economic realities of each person and the structural constraints imposed by such limitations. It is, therefore, a choice based on a synergy of factors, including personal agency and structural limitations, which inform such decisions.

Obviously, more needs to be done on the domestic front to develop new innovative programs with greater depth and scope, in terms of whom they provide for and the services they provide. One positive change, occurring as we speak and continuing over the next few years, is the conversion to generic drugs in the U.S. This process greatly reduces the cost, not only to the consumer, but to insurance companies and the government who are buying drugs from the pharmaceutical companies. These positive changes offer the opportunity to innovate in the future, as long as the supporting research and political will are present.

Chapter 3
"A second coming out:" The Clinical and Reflexive Gaze.

The theoretical perspectives which inform this research emanate from Michel Foucault's discussion of biomedicine and the clinical gaze and from Arthur Kleinman's concepts of the explanatory model and the illness narrative. These two independent, yet compatible bodies of work are well suited to developing an understanding of how people living with HIV/AIDS define their relationship with the illness and negotiate the obstacles, both structural and personal, which stand in the way of reclaiming "normal" lifeways. Although Foucault's clinical gaze (Foucault 1973), both a producer and by-product of hegemonic biomedical control, continues to impact the clinical experience, the biological realities of HIV and the technological advances of post-industrial society have lead to a re-structuring of the power relationships which formerly directed the clinical experience. Kleinman (1988), taking account of this phenomenon, has called for clinicians to take seriously the explanations and accounts of causation that their patients offer, in effect to elicit illness narratives from their patients. This power shift has not left healthcare providers without authority, but has chipped away at the hegemonic control of biomedicine and traditional clinical teaching. Homeopathic, complementary, and new-age therapies are becoming increasingly popular and legitimate as patients seek out their own explanations of causation and illness. Healthcare providers and insurance companies are forced to add legitimacy to these treatments in order to maintain their own hegemony over an increasingly non-Western healthcare sector. Kleinman, then, expounds, although not explicitly, on the reversal of Foucault's clinical gaze by addressing the innate possibility for patient agency within the clinical setting. By

encouraging the patient to talk about their illness one is also encouraging them to consciously think about and develop notions and authoritative knowledge about their illness.

In *The Birth of the Clinic: An Archeology of Medical Perception*, Michel Foucault (1973) develops the idea of the clinical gaze, which he posits is both a literal and metaphorical gaze which conveys meaning from the patient, or more accurately the patient's symptoms, to the doctor. The doctor can then assess the symptoms using his exclusive knowledge in biomedicine to treat the patient. As Foucault understands it, the clinical gaze is possessed solely by those who have undergone biomedical training and are educated in the clinical and environmental causes of disease. It is intentionally obscured from the patient through the specific educational requirements of biomedicine that are relegated to exclusive institutions inaccessible to the lay population, the standardization and institutionalization of biomedicine, such as board certification, and the development of a particular "language" to identify disease, symptoms, and treatment. In fact, Foucault argues that the patient becomes the disease in eyes of the medical professional, saying, "The patient is the rediscovered portrait of the disease; he is the disease itself, with shadow and relief, modulations, nuances, depth; and when describing the disease the doctor must strive to restore this living density…" (Foucault 1973: 15). With the doctor conceptualizing the patient as simply an embodiment of disease, the patient loses agency and the ability to contribute to the diagnosis and treatment process and become an active participant in his/her own lived experience. Foucault argues, however, that this disassociation of the patient from his/her disease is a side effect of the hospital and clinical teaching paradigms.

These two spaces force doctors to concentrate on disease by the nature of their purpose, which is to instruct students about disease and have the "[tendency] to prefer those cases that have a high instructive value" (Foucault 1973: 59). An important distinction here is that between patients and cases. When doctors assess cases they are, often, addressing the social and historical causations of disease and treating the whole person, namely treating illness. Hospitals are a space devoted to treating illness, not disease, and although this medical distinction had not been made yet at the time of Foucault's writing, he understood the difference in the context of how spaces were used, namely the hospital versus the clinic. Although it seems that Foucault is often implying the greater existence of patient agency in the hospital, this point is never explicitly stated. He does say, however, that "in the hospital, the patient is the *subject* of his disease, that is, he is a *case*; in the clinic, where one is dealing only with *examples*, the patient is the accident of his disease, the transitory object that it happens to have seized up" (Foucault 1973: 59, emphasis in original). Here, Foucault is concretizing the difference between hospital and clinic, disease and illness, and patient and case.

All of these factors are informed by the clinical gaze, which is always in operation in both hospitals and clinics. As Foucault describes it, the clinical gaze is a conduit of both information and meaning. The diseases, which are signified to the doctor by their symptom manifestations, have both biomedical and cultural significance to the doctor and patient. As Stein (1986) contends those significances and meanings are then interpreted by the biomedical professional to fit within their own worldview and cultural understandings.

Foucault saw the clinical gaze as both hiding and illuminating "truth" at the same time. This seemingly paradoxical statement is reconciled because in Foucault's work truth is not just one fixed reality, but an ever expanding field of perception and knowledge. Therefore, the gaze is superimposed on top of truth because it acts as a conduit between what one sees, what one knows, and how one speaks. In relating this concept to medicine, Foucault wrote of the difference between symptoms, signs, and disease. Symptoms and signs are tools used to relate the perception of disease to the doctor. Because one cannot actually see disease, one must rely on the physical/perceptual manifestations of disease in order to ascertain the effects on the body and mind. Because symptoms and signs are directly observed, they are what add to medical knowledge, not disease itself (Foucault 1973: 5). Therefore, because what a doctor observes is translated into knowledge, disease becomes the object of the gaze and the patient becomes nothing more than a positive support mechanism for disease. The doctor's role has thus been cemented as biologically centered, rather than socially centered.

Furthermore, the clinical gaze is confounded by the use of language to convey meaning and knowledge in a clinical setting. How one talks about medical phenomena in turn creates those phenomena. More specifically Foucault writes, "There is disease only in the element of the visible and therefore statable" (Foucault 1973: 95). Disease becomes the interpretation and perception of symptoms which are seen by the doctor, related by the patient, and taught to the medical student. Symptoms become bound to disease and are therefore signified by it; however, the purpose of assessing symptoms is to signify disease. Symptoms become both signifier and signified which lends them a

certain particularism which disease is lacking. They are perceived as limited in number and scope and vary only in time, intensity, and combination (Foucault 1973: 101). Once these relatively few symptoms are identified and understood, they add a transparency to disease and the patient becomes subordinate to the pathological facts he embodies which the gaze can observe and verbalize.

The authoritative knowledge which the clinical gaze conveys has been reinterpreted to include not only the biomedical knowledge of the healthcare professional, but also a patients own understandings of illness and physical manifestations of disease as a social marker as authoritative knowledge bases. Asha Persson (2005) writes of how the clinical gaze becomes the social gaze when HIV infection becomes visible due to the introduction of ART and its related side effects. ART can often cause a condition called lipodystrophy in which fat deposits in the body are reconstituted to cause visible fat deposits in the belly and back of the neck and the loss of fat in the arms, legs, and buttocks. This condition has become a marker of HIV status among the population she studied in central Sydney and its presence imparts information and meaning from the individual to the larger community. Thus, the same signs and symptoms that Foucault articulated as informing the medical professional are now informing the general populace within the context of the post-industrial Western world where information about ART and its side effects are easily accessed and widespread. In my research I have found what I have called the reflexive gaze, in which the patient must make sense of their own disease. This process is central to the creation of an identity, or identities, corresponding to their illness. Foucault's framework of only being able to "observe" the physical is problematized when applied to a disease like HIV where there are few, if any, physical

manifestations through much of its trajectory. The event of diagnosis, along with subsequent events, which may or may not be perceived as directly related to serostatus, all contribute as outcome variables to the eventual creation of a grouping of identities used to interact both with the disease and within social settings. As discussed in more detail in the literature review section, many people have studied how individuals cope with HIV and explain their own illness experiences. However, to my knowledge, no one has characterized these self-reflexive processes using a Foucauldian paradigm. Conceptualizing how a person understands their own illness as an informative and meaningful transfer, or transition, of knowledge through the use of a reflexive gaze continues to be of importance to the fields of medicine and social science.

In addition to the clinical gaze, Foucault espoused a theory of truth in relation to illness which, in his view, allowed him to systematically and objectively analyze historical documentation. When Foucault wrote about truth he did not mean "Truth," but increasingly complex layers of perception. "For Foucault, fields such as psychiatry and biomedicine are best understood as 'cultural systems' that offer different claims to truth. The evidence they amass, and the understandings they promote are not 'facts' or 'truths' in any simple sense, but social products linked to the power of the profession" (Parker and Aggleton 2003: 17). The method he utilized, what he called "archeology," was an attempt to ascertain truth not through discourse, which would only complicate the already muddled conversation, but through systematic analysis (Dreyfus and Rabinow 1982: 14). This archeology was meant to add to the discourse by analyzing the innate dialogue which naturally emanates from all social institutions (Dreyfus and Rabinow 1982: xxiv). He is then able to treat discourse as an object of analysis and transcend the existing

debates about the "truth" of the discourse.

The Birth of the Clinic was Foucault's most explicit example of structuralism because of his analysis of social institutions, such as the clinic, as "autonomous systems of discourse" (Dreyfus and Rabinow 1982: xxiv). He also refers to discourse, which he is attempting to study, as a system governed by strict and replicable rules (Dreyfus and Rabinow 1982: xxiv). He showed that medicine is actualized and made real only through perception and that how doctors used that perception to diagnose and understand disease was arbitrary and subject to the idealization of biomedicine in Western intellectual tradition. Society had become medicalized, and thus enslaved to the limits of categorical accounting of patients and disease. Innumerable iterations of cases and great diversity in experience became hallmark traits of the clinic (both clinical medicine and medical education) (Foucault 1973: 101). The new truth of medical perception became institutionalized in collective consciousness. That is to say that a dominant medical "knowledge" permeated society. This knowledge was controlled and amended by clinical medicine and was given the power of a social fact by those who adhered to the theory of biomedicine. It is this collective consciousness which Paul Farmer (1999) refers to as cultural models (Farmer 1999: 166). Although these concepts might not be perfect synonyms, they both are meant to describe how population level understandings of disease and illness function and biomedicine, in a U.S. context, contributes to the creation of these cultural models.

Foucault's idea about collective consciousness has thus been interpreted to mean how a population or community constructs and renegotiates notions about what disease is, how to treat it, and how to behave toward it. The cultural models serve as a "baseline"

understanding for how a disease is viewed in the context of a particular culture. A cultural model of disease becomes truth, albeit dynamic and constantly updated, through a population's local experiences which inform their developing notions about who gets it and how they get it (Farmer 1999: 168).

While Foucault was writing about illness from a decidedly structural and systemic perspective, his concepts are echoed from a more psychological and personal perspective through the work of Arthur Kleinman. Although Kleinman's work is often conceptualized from a methodological standpoint, as I have also largely done, he makes key theoretical insights to the study of illness identity. Kleinman recommends important advancements in the practice of clinical biomedicine with the development of the explanatory model (EM) and the use of illness narratives to address the patient's concerns and assist in the physician's diagnosis of illness. These methods, then, have the effect of increasing patient agency within a clinical context and reducing any confusion that may exist between the physician and patient. By including the patient's perspective in the overall diagnosis schema, it is hoped that interpersonal, cultural, and linguistic differences can be reconciled. Supporting this increase in agency is an important step in the collection of illness narratives and can greatly alter the ways in which a person interacts with their own illness. This point is especially important to this study because increased patient agency is also a key factor to determining access to ART within a context of a sophisticated and often confusing health care system.

The concept of illness narratives not only necessitates the inclusion of the patient's perspective in diagnosis and treatment schemas, but alters the direction of authoritative knowledge and chips away at the hegemonic control of biomedicine.

Kleinman develops a paradigm in which a patient's relationship with and understandings of their illness are important tools used by both the healthcare provider and patient, himself. While Kleinman focuses on the outcomes of this patient-illness relationship for the healthcare provider, the act of developing this relationship is an important component to how and what the patient feels is important to relate to the healthcare provider. The analysis of this process, from an anthropological perspective, is, thus, a key element to a holistic understanding of illness and lived experience, from the patient's point of view. It is this process through which the reflexive gaze can be understood as a conduit of meaning between the illness and the patient. From the moment of diagnosis, or even earlier is some cases, a patient must make sense of his illness through the lens of personal experience and standing cultural models. While these cultural models of illness may inform the general population, and to some extent, the patient himself in assigning meaning to a particular illness, the lived experience of illness, diagnosis, symptom awareness, clinical experience, and treatment efficacy, play a large role in how one deals with, assigns meaning to, and develops understandings about what is occurring within their body and the eventual outcome of their experience. These two conduits of meaning, the social gaze and the reflexive gaze, create reference points for interpretation of the illness experience.

To a large extent, especially in the case of HIV/AIDS, stigma has played an historically important role in the development of understanding the illness, both among the general population and individual people living with HIV/AIDS. While Goffman's classic definition of stigma as a discrediting characteristic (Goffman 1963) applies, generally, to HIV/AIDS, much more specific and timely work has been done in response

to the HIV/AIDS epidemic. Richard Parker and Peter Aggleton offer a conceptual framework for understanding HIV/AIDS-related stigma as a "reproduction of social difference" (Parker and Aggleton 2003: 13). They argue that stigma can be read as reproductions of gender, race, class, and sexual inequalities. An important concept that Parker and Aggleton have contended, and that I am reasserting here, is that previous work done on HIV/AIDS-related stigma, "has encouraged highly individualized analyses in which words come to characterize people in relatively unmediated fashion" (Parker and Aggleton 2003: 14). This "personalistic" analysis of stigma has imposed not only the identification of stigmatized on people living with HIV/AIDS, but also imposed the value and type of relationships, which stigma is understood to devalue. The imposition of value by the researcher, as well as, in many cases, internalized judgment, has significant outcomes on data collection. Although it has long been a mantra of anthropological fieldwork to be cognizant of the researcher's influence on the study population, this realization is often more difficult to put into practice than it is to enunciate.

There is a large body of literature on stigma, HIV/AIDS-related stigma included, which frames the concept as a means of social control. Stigma acts as a mechanism to "otherize" those possessing the stigmatizing trait. By forcing those with the trait, in this case people living with HIV/AIDS, out of the mainstream, social and economic marginalization of that population is maintained. This process is cyclical in nature, with the subjugation of trait-carrying populations as a result of and resulting from possessing the characteristic. The stigmatized group is unable to access the appropriate support mechanisms and, in the case of infectious disease, the implication is the relegation of the illness to subjugated and stigmatized groups. In the case of the HIV/AIDS epidemic in

the United States, traditionally stigmatized groups, such as MSM, IVDU, and certain immigrant groups who exhibited high rates of infection from the beginning of the epidemic, were further marginalized in an attempt by the general population and, as some would argue (Glick-Schiller 1992), public health officials to create a belief of impenetrability to HIV/AIDS among non-marginalized, or socially elite, groups. Parker and Aggleton argue that to distance ourselves from such a view we must consider:

> [A] new emphasis on stigmatization as a process linked to competition for power and the legitimization of social hierarchy and inequality, highlight[ing] what is often at stake in challenging HIV and AIDS-related stigmatization and discrimination. It encourages a move beyond the kinds of psychological models and approaches that have tended to dominate much of the work carried out in this field to date – models which all too frequently see stigma as a thing which individuals impose on others. It gives a new emphasis to the broader social, cultural, political, and economic forces that structure stigma, stigmatization, and discrimination as social processes inherently linked to the production and reproduction of structural inequalities (Parker and Aggleton 2003: 18-19).

Viewing stigma as not just a psychological or emotional barrier to social equality, but as a process and mechanism for political, social, and economic control and subjugation is an integral component to the Parker and Aggleton framework. Overcoming that subjugation by addressing the structural forces reproducing inequality is a necessary step in, not only reducing HIV/AIDS-related stigma, but also in increasing the benefit of HIV/AIDS testing, treatment, and support entities.

What Parker and Aggleton are proposing is an emphasis on the structural constraints, or structural violence, which breed inequality and stigma. Paul Farmer has been a leading voice in anthropology, public health, and clinical medicine calling for the concentration of academia and resources on the alleviation of the root causes of inequality. He, and others, have called for the development of critical medical anthropology, "the application of political economy and world systems theory to the

domains of sickness and health care" (Scheper-Hughes and Lock 1986: 137). A critical approach to the field takes the culturally deterministic and culturally bound notions of health and illness and puts them in political, economic, and historical perspective. This study is an attempt to continue that tradition and develop a holistic picture of the state of access to ART in the United States today. While Farmer, as a physician/anthropologist, has always begun from a different set of assumptions than the traditional anthropologist, he has continued to assert the benefit and importance of anthropological research to the study of illness. In his *Pathologies of Power: Health, Human Rights, and the New War on the Poor* he makes an eloquent plea for the reinstatement of the concept of "bearing witness." He contends that the socially and economically marginalized are conditioned into silence by the weight of structural violence; it is not that they are unable to speak for themselves or could not make sense out of their plight, but "members of any subjugated group do not expect to be received warmly even when they are sick or tired or wounded" (Farmer 2005: 25). As anthropologists, we bear witness to this suffering and attempt to relay it to a wider audience - to expose the injustice and inequality in the world. But again, Farmer is wary of this anthropological convention, saying, "to be honest, writing of the plight of the oppressed is not a particularly effective way of assisting them" (Farmer 2005: 26).

A praxis approach to anthropological research development is needed in order to, not only document, but alleviate the suffering and inequality we, as anthropologists, contend with in our research. This is an important point from both a theoretical and methodological perspective. Praxis anthropology is an attempt, not only to develop and test theoretical possibilities, but also to ensure that social justice is maintained or

promoted (Kozaitis 2000). In the case of HIV/AIDS in the United States, vast inequalities exist, not only in who is becoming infected, but who is receiving optimal healthcare and treatment. When put into political-economic perspective, many of these inequalities can be attributed to structural violence. Although structural determinants of increased risk for infection is extremely difficult to prove, it is no accident that people of color, the poor, and socially marginalized have the highest rates of infection in America, and throughout the world. The intricate webs of poverty, drug use, intravenous and other, and lack of access to healthcare education, testing, and treatment spin a morbid and disturbing tale of HIV infection with little possibility of management. The praxis anthropologist has an obligation, not only to expose these inequalities, but also to use the data and conclusions from their research to the benefit of the community they are working in. While the explicit implications of this research will be discussed in depth in the conclusion, it should be noted now, as a theoretical point, that I am employing both a critical and praxis medical anthropological paradigm. From the cerebral ruminations of Foucault to the methodological applicability of the work of Kleinman, Farmer, and Kozaitis, the theoretical underpinnings supporting this research are focused on the effects of inequality and subjugation on the creation of illness-related identities, specifically, in regards to HIV/AIDS and access to ARV treatment.

Chapter 4
"HIV isn't a gay thing but if you were straight this wouldn't have happened:" Literature Review:

According to the National HIV Prevention Conference (2005) an estimated 1.1 million people were living with HIV/AIDS in the United States in 2003 and over half a million people have died of AIDS since the beginning of the epidemic. While funding within the United States for providing antiretroviral access could be considered an exemplar for other countries, there are still strikingly disconcerting epidemiological trends which are woefully under-nuanced in the literature. There are only two main routes to reliable and cost-effective access in the U.S.: private insurance and government subsidies such as Medicare and Medicaid. In addition to these more dependable frameworks there are also multiple non-profit and philanthropic organizations which distribute either antiretrovirals directly or finance private health insurance for those who can not afford it. At the head of these groups is a government organization, the AIDS Drug Assistance Program (ADAP). However, there are multiple issues restricting the availability of these resources, including limited funding, perceptions of stigma and discrimination, and logistical limitations of geography and access. Thus, access to antiretrovirals is still an important and contested issue in the United States with multiple layers of inequality. Unpacking and understanding how access to antiretrovirals informs a person's understandings of their seropositive status can be an important component to asserting the significance of continued and increased funding to government and non-profit organizations providing free or subsidized antiretroviral access or insurance coverage to those who would otherwise not have such access.

Even though these large and daunting issues continue to surround the American epidemic, anthropologists, public health officials, the media, and the popular imagination have turned their rather considerable attention to the pandemic facing the developing world in recent years. Anthropological attention to HIV/AIDS research began in the first years after the "latest and most deadly venereal scourge" (Kleinman 1988; 84) was discovered and isolated and by 1988 an already large and quickly growing body of literature had been amassed. This new literature focused mainly on domestic concerns, and as epidemiologic studies began to surface, on specific sub-group populations. These sub-groups, termed "at-risk" populations, tended to include what was then termed gay and bisexual men, intravenous drug users (IVDU), and recent immigrant groups, especially from Haiti.

These studies, of which I have selected a small sample to discuss in more depth, tended to focus on coping mechanisms and the lived experience associated with a positive serostatus diagnosis. In "Living with HIV Infection: Adaptive Tasks of Seropositive Gay Men," Siegel and Krauss (1991) identify three challenges that confront people living with HIV: "dealing with the possibility of a curtailed life span, dealing with reactions to a stigmatizing illness, and developing strategies for maintaining physical and emotional health" (Siegel and Krauss 1991; 17). By 1991, when this article was published, the first generation of antiretroviral (ARV) medication was widely available in the developed world which had allowed HIV to be reconceptualized as a chronic illness (Chaison 1990; Coates 1990; Cotton 1989; Mayer 1989; Piot 1987; Redfield and Burke 1988). Although the proper use of ARV therapy can extend the lives of people living with HIV/AIDS, the disease still has an unpredictable trajectory and this uncertainty can

cause patients to discontinue investing in their future and attempt to complete life goals urgently (Siegel and Krauss 1991; 21). This, and other studies, set an important precedent for using unstructured interviews and an illness narrative approach to the study of HIV.

In a more recent attempt to discuss life trajectory and changing perceptions of quality of life, Bloom, in his article, "'New Beginnings': A Case Study in Gay Men's Changing Perceptions of Quality of Life during the Course of HIV Infection," illness narratives were elicited, leading to life history accounts and how HIV related to the overall "psychocultural expression of the self" (Bloom 2001: 41). Bloom arranges the results of these life histories into thematic groupings, including survival, reciprocity, appreciation, and average life. He contends that the theme of survival is, by far, the most numerous which is characterized by overcoming obstacles and hardships. These themes must then be understood within the context of the personal, situational, social, and historical (Bloom 2001: 48). Again, adding this context to what people say and how they act is a crucial component to understanding HIV/AIDS and personal and social responses to it. While Bloom includes a discussion of cultural values, and how they shape the life histories of his research participants, as the context for understanding his thematic arrangements, the structural forces which shape(d) the narratives of his participants are ignored. He offers lip service to power relationships and their effects on understandings of illness but the concrete mechanisms of social and economic marginalization are not discussed. This article adds to the large literature which, "has been on the perceptions of individuals and the consequences [of] (*sic*) these perceptions for social interactions. Much work has tended to focus on stereotyping rather than on the structural conditions

that produce exclusion from social and economic life" (Parker and Aggleton 2003: 15).

Stigma has long been conceptualized as both a structural and psychological impediment to prevention and treatment efforts for HIV/AIDS. McCombie offers an early example of how the introduction of the 'AIDS' test worked to both misrepresent who is at risk for acquiring HIV/AIDS and function as an unwarranted measure to reduce transmission. McCombie shows, through data collected through participant-observation, that public health and healthcare workers further reinforced stigma targeted at traditional "at-risk" populations by assuming their risk behaviors were more likely to result in infection than their "less at-risk" counterparts. Furthermore, because McCombie contends that the 'AIDS' test was conceptualized as a "magic bullet" to interrupt transmission of HIV, it was seen as a behavior modification tool. Similarly, Glick-Schiller (1992) argues that public health has assumed the behavioral outcomes of HIV testing and treatment among traditionally "at-risk" populations and those assumptions come with little research to support their claims. In fact, McCombie writes, "the actual behavioral outcome that results from being told that one is positive or negative has not been documented" (McCombie 1986: 458). While these issues have been better studied in the years following McCombie's article, her point illuminates the general need for more qualitative and contextual research on the socio-cultural effects of testing and treatment on individual and collective behavioral outcomes.

Another article, with particular relevance to my own study is "Living with HIV: Resistance by Positive People." In this article (1992), Andrea Whittaker attempts to show that activism by people living with HIV/AIDS is a form of resistance to the hegemonic discourse surrounding the illness. She posits that HIV activists have

developed several strategies through which they redefine their relationship with their illness in a positive manner, rather than utilizing popular ideas about HIV, which tend to construct it in a negative light. These strategies include "the inversion of AIDS metaphors; the redefining of being HIV antibody positive as a stage in a disease process, not a terminal condition; and an active engagement with their condition" (Whittaker 1992; 385). These strategies were developed to give a voice and agency to the most important stakeholders in the game, those living with HIV/AIDS. Whittaker elicits explanatory models from her subjects in order to understand how they think about and react to their illness, which was an important methodological breakthrough for the early 1990's. While I believe that Whittaker was influenced by the *en vogue* notion of resistance that was so pervasive at the time, her work using qualitative methods in order to attempt to understand the patient's relationship with their illness added to the growing literature of qualitative HIV research at the time and is worthy of note.

As time progressed, the reliance of the public health community on "culture" as an explanatory mechanism began to be called into question by the anthropological community. Glick-Schiller (1992) offers an important and timely discussion and critique of the ways in which the concept of culture can be misinterpreted by the public health sector when defining "at-risk" groups in terms of acquiring HIV. She argues that public health officials often take a rather simplistic view of culture, assuming that each "at-risk" population has distinct and bound cultural practices unique to its members. Thus, the implicit assertion is that these groups never overlap or mix and that cultural behaviors are universal for a given "at-risk" population. While these assumptions may make epidemiological studies easier by grouping individuals using demographic and lifestyle

information, they do not capture the subtle and complex ways that "culture" can be dynamic, overlapping, and fluid between and within populations.

One of the most important points Glick-Schiller mentions is the need to address issues of structural violence. She contends that although a public health focus on culture as an explanatory technique is beneficial in principle, the definition of the concept is applied only simplistically, with often detrimental consequences. On the other hand, an anthropological conception of culture is much more nuanced, focusing on the collective behaviors of groups of individuals rather than generalizations about populations. This subtle distinction has profound implications. While Glick-Schiller does not use the term "structural violence," she is referencing a need to assess the structural reasons which lead to risky behavior (Farmer 1999). Issues of poverty, racism, classism, and power lead, both directly and indirectly, to what are now termed "risky" behaviors. Paul Farmer was one of the first anthropologists to articulate the extreme influence these factors can have on individual and population level behaviors in relation to health and illness (Farmer 1999). While the anthropologist is most interested in the collective and the epidemiologist on the population level, these two perspectives can, and should, inform each other. These forces of power, racism, and poverty manifest themselves, in similar and different ways, at both levels. Another of Glick-Schiller's main arguments is to point out the hegemonic constructions of AIDS "risk groups." She contends, and I believe accurately, that risk groups, which can have some basis in biological and epidemiological reality, are essentially a way to define those with HIV/AIDS as the "other." Again, to the public health community, those who are members of "risk" group populations are at risk because of their race, gender, or lifestyle, and not because of the behaviors in which they

engage. Much like Glick-Schiller's critique, more recent anthropological articles have engaged the public health community in debates over a myriad of issues including the development of culturally appropriate prevention and treatment programs (Smith 2003; Abadia-Barrero and Castro 2006) and unmasking the false dichotomy between prevention and treatment in public health (Onjoro Meassick 2007).

Another important issue beginning to crystallize in the ever-changing environment of HIV/AIDS is that of adherence to ART if access is garnered. Mannheimer et al. (2005) used a quantitative measure of quality of life among a study population beginning an ART regime. They showed that 12 months into the regime subjects reporting 100% adherence to the ART had significantly higher quality of life scores than they did coming into the program or than subjects reporting lesser adherence. While Mannheimer et al. (2005) are using quantitative analysis, there is an implicit argument being made that adherence is an important component to both the physical and mental health of patients. One of the contentions of my research is that the type of research Mannheimer et al. undertake should be followed up with qualitative research, adding context and depth to the data. In addition to quality of life scores the level of adherence can affect the likelihood of transmission, with subjects with high adherence having lower viral loads, and the development of drug-resistance. These issues are extremely important when dealing with marginalized populations where access may be sporadically available or structural limitations support "risky" behavior, such as sex without a condom, needle-sharing, or other illegal drug use. Although the causal mechanisms between poverty and such "risky" behaviors are not clear there continues to be evidence which suggests that poverty, drug use, and "unsafe" sexual practices are

correlated. Gorman et al. states that, "A number of studies suggest that among gay and bisexual men participation in unsafe sexual activities occurs in the context of drug use, which may have a dis-inhibiting effect" (Gorman et al. 1997: 508). Furthermore, CDC statistics show that a large and increasing number of new HIV cases are among the urban and rural poor (Centers for Disease Control 2008).

The theme of drug use, especially methamphetamine use (meth, crystal, etc) was common in both my interviews and participant observation. One event I attended was the screening of a documentary about meth use in the gay community. While not specifically relating to HIV/AIDS, it was telling that nearly 90% of those meth addicts included in the documentary were HIV positive. However, the risks associated with meth use and other drug use, especially intravenous drug use, are quite different. While meth can be boiled down into a liquid and injected it is most often kept in its solid form and smoked through a pipe. As Gorman et al. points out meth use may trigger unsafe sexual practices, namely sex without a condom, while IVDU and needle sharing presents an inherent risk of injecting the HIV virus directly into one's bloodstream. Although there have been no studies, to my knowledge, which conclusively link poverty, drug use, and HIV risk, a recent government-funded study showed that meth users are three times more likely to test positive for HIV antibodies than non-meth users (amfAR 2005). Furthermore, a critical reading of the available literature would suggest that these three issues are related through structural connections. In fact, Smith asks,

> Even when one can assume adequate knowledge, can one assume that people have the capacity to act on that knowledge? For example, one may simply ask whether people have access to condoms. However, a more sophisticated and theoretical manner of asking this question requires attention to issues of how sexual relations and condom use are negotiated within contexts of poverty, age and gender inequality, and other configurations of power that influence people's priorities and constrain their choices (Smith 2003: 344).

Thus, it is not the behavior of unsafe sex or drug use which may be understood as a structural constraint to HIV/AIDS prevention, but the power relationships and marginalization that shapes those decisions and behaviors which can be conceptualized as structural constraints. When I write of these behaviors as structural limitations to HIV prevention and treatment, I mean not only the actual behaviors but also the power relationships that are at the root of these behaviors.

Bourgois, in his book *In Search of Respect: Selling Crack in El Barrio*, offers a pertinent example of the cyclical nature of poverty and drug dependence. He posits that it is social marginalization which leads to poverty and, in turn, drug use, saying "substance abuse in the inner city is merely a symptom – and a vivid symbol – of deeper dynamics of social marginalization and alienation" (Bourgois 2003: 2). This offers one of the most compelling cases in the literature for the relationship between poverty and drug use, the structural and behavioral. While drug use and "unsafe" sexual practices may not be directly related to the structural factors of poverty, economic marginalization, lack of education, and language barriers, they are, no doubt, closely related to these issues in a recurring and substantial way. Likewise, Bourgois' work may be read as understanding poverty as a predisposition for substance abuse. This is not to say that these two outcomes of economic marginalization are mutually exclusive, but that the positive correlations between the two are undeniable.

Furthermore, Singer (1996), and many others, have related the connections between drug use and HIV infection. It is Singer, however, who most notably addresses the syndemic nature of, what he calls SAVA (substance abuse, violence, and AIDS). He contends that they are "not wholly separable phenomena," (Singer 1996: 99) but that they are interdependent and fuel one another. While Singer is addressing the issues faced by IVDU, generally, the extension to meth and other non-injecting drug users is clear, and in fact, in later articles (2003) he addresses the use of "mind-altering substances" (Singer and Clair 2003: 431) instead of injection drugs, specifically. In one study he found that 25% of IVDU he surveyed were infected with HIV and that poverty and homelessness was a significant predictor of disease burden and morbidity (Singer and Clair 2003). These data show the impossibility of separating the social and biological and the structural and personal components of illness risk and stresses the importance of biocultural and syndemic analysis.

Finally, Niehaus (1990) in her chapter in *Culture and AIDS* (Feldman 1990) takes an interesting look at the differences between people living with AIDS from the "professional" class and working class. She contends that although the professional class generally has employer funded group health insurance which covers extended hospital stays, home healthcare, and expensive medications, those economic securities only mask the continued insecurity associated with the psychological and social costs of living with HIV/AIDS. According to Niehaus, people without insurance or with poor quality insurance tend to rely on government and community-based support mechanisms, perhaps for obvious reasons. The professional class, however, "relies primarily upon informal supports and on privately funded care" (Niehaus 1990: 189). These informal

supports generally include family and friends and may be relied upon to ensure privacy to the individual and family from a stigmatizing illness among a social class where innuendo and association with "gayness" and HIV/AIDS may result in adverse social standing. As Niehaus states, "Families will be there so long as their own 'name' is not compromised, and so long as the privacy of personal family affairs is respected by the PWA and his friends" (Niehaus 1990: 192). This article relates well to my research where most of my informants did have private employer based insurance and many thought about the effects of disclosure on their families and friends as a function of maintaining informal support networks.

My research is an attempt to add to the literature in several ways. First, I think it extremely important to continue to stress the magnitude and severity of the HIV epidemic in the developed world, particularly the United States. While much of the public health and anthropological attention has been shifted to the developing world, especially sub-Saharan Africa, the rapid and far-reaching changes that are occurring in the United States are begging for the analysis of social science. As Mannheimer et al. suggest as recently as 2005, "The relationship between QoL (quality of life) and adherence has not been well studied" (Mannheimer et al. 2005; 11). And while amazing biomedical research associated with HIV/AIDS is taking place in the universities and research labs around this country, we are left to wonder what the effects of those medical breakthroughs are to the populations who utilize them most. A more comprehensive understanding of ART and access to it on the social, psychological, and cultural milieu they serve should not be an afterthought, but a purpose of the field of medical anthropology. Second, I believe the theoretical implications of my research are a novel and interesting approach to the study

of HIV infection. While Foucault (1973) argues that only the physician has the authoritative knowledge to understand disease, and therefore a clinical gaze, I have suggested that the patient also has a certain authoritative knowledge which allows him to understand his illness in ways that make sense to him, and perhaps more sense than what a physician tells him, a reflexive gaze. Thus, the patient creates a relationship with the illness which changes and undergoes revision constantly, but is always interpreted from the patient's perspective. This reflexive gaze certainly mediates and shapes the explanatory model and the ways that illness is relayed and talked about. Third, I believe that the use of an explanatory model and illness narrative technique is the best way to elicit responses from subjects regarding illness. While many studies have utilized these methods before, I hope to reiterate the efficacy and usefulness of such methods. I, thusly, see my own research as contributing to the greater body of knowledge through applied, methodological, and theoretical avenues.

Chapter 5
"I never talked about it:" Methodology:

Methods Used:

For this research project I conducted seven semi-structured interviews with self-described people living with HIV/AIDS. All of my participants were gay men between the ages of 22 and 45. Generally, the socioeconomic status of my participants was between middle and upper-middle class, although one of my participants would be classified as lower-middle class. Each interview lasted between 45 minutes and two hours with in-depth probing focusing on each participant's interests and experiences. All but one interview took place at a local coffee shop in Midtown Atlanta; the one exception was a phone interview. Interviews were conducted between July 2007 and March 2008. I also attended three community educational forums sponsored by a local community based organization and free testing clinic between July 2007 and December 2007. These forums focused on gay men's health and HIV prevention and treatment options, specifically. I spoke with two members of that organization, a full time staff member and a volunteer, informally at these events.

In addition, I have conducted countless informal conversations over the past several years, both with people living with HIV/AIDS and other members of the Atlanta gay community, about how they conceptualize and understand HIV/AIDS, medically and socially. This participant observation has certainly shaped and focused this research and my own understanding of HIV/AIDS in the American context. I have been involved with a local community based non-profit organization which deals with prevention, testing, and treatment of HIV/AIDS for the last several years as a volunteer and fund-raiser. Again, although no data from this work is explicitly included in this thesis, my work with

this organization has helped me define and implement this research project and identify the research needs in this area. Although I have worked with this organization for some time I was barred from any support group meetings and from directly approaching clients of the organization as interview participants because of concerns about the confidentiality of the participants.

I chose to conduct semi-structured interviews at set times and places with my participants. This method adds a level of formality to the interviews, which I have consciously included because I do not know most of my participants personally and have little opportunity to interact, in a participant-observer context, with an "HIV-positive community." Because of these limitations I have recruited participants through mutual acquaintances using a snowball mechanism. Therefore, I am using the formality of the interviews to develop a level of trust and rapport with my subjects. I believe the interviews achieve this end by imparting a certain level of academic credibility and legitimacy to the participants. In terms of the interview schedule (Appendix A), I created a set of 15 questions which I initially thought would get my participants talking about the issues of interest to this project. Those questions went through a slight revision during the Institutional Review Board (IRB) process and were then put into practice. I used my first several interviews as a pre-test stage (although the data collected is included in this final thesis), after which I revised the questions again. I cut several questions which I came to think of as irrelevant, including questions about the eventual discovery of a cure for HIV/AIDS. I also added questions about the daily tasks and obstacles associated with the complex antiretroviral (ARV) cocktail and the influence of that on adherence to ARV treatment.

Theoretical Basis of Research Design:

My research methodology was designed to reconstruct issues surrounding living with HIV. However, this very simple statement has many layers and caveats embedded within it. To begin with, one research methodology is not appropriate for each situation encountered. The experience of living with HIV is not static, but a dynamic and constantly changing process. I have come to understand that the evolution of experience can be based on life events associated with being HIV positive, such as diagnosis, the introduction of treatment, and issues surrounding disclosure, as was initially expected. However, life events not directly associated with one's HIV status can also have a profound effect on the way one deals with their serostatus. Issues such as drug use, sexual activity, and family acceptance can directly impact not only how one creates an identity, or identities, surrounding HIV status, but also more tangible issues, such as treatment seeking behavior.

To this day there continue to be debates within social science about the validity and analytic usefulness of the study of identity. Brubaker and Cooper (2000) argue that "by stipulating that identities are constructed, fluid, and multiple – leaves us without a rationale for talking about 'identities' at all…" (Brubaker and Cooper 2001: 1). However, much of the work done on HIV-related identity construction has tended to conceptualize identity as a "thing;" for example, racial identity, sexual identity, or gender identity. The questions being asked are how does HIV interact with these previously constituted and traditionally recognized normative social/biological identities. The issues of identity creation based specifically on serostatus have received negligible attention in the literature. This is a conceptual, theoretical, and methodological point.

Methodologically, how one approaches the study of identity must be altered to not impose or constrict the natural fluidity and plasticity of identity creation and, what I have called maintenance, referring to the constant revision and updating of how one defines himself. In order to do this I have employed a hybrid technique of Arthur Kleinman's idea of focusing on the explanatory model (1988). Kleinman espouses a methodology which allows for the definitions of sickness, illness, and suffering to come directly from the patient to the health care professional. This allows the patient to define their own relationship with their illness. This was, and is, a novel approach to how illness is conceptualized and treated, in a biomedical sense. While Kleinman did not deal specifically with how those explanatory models were interpreted to signify identity, he did elucidate how and why they could assist in the diagnosis and interpretation of the health care professional. Therefore, I have modified the explanatory model paradigm to be more useful in assessing the more intangible concept of identity.

Kleinman's concept of allowing the explanation of illness to come directly from the patient who embodies that illness is an important cornerstone in assessing identity also. This methodology allows for a more organic and holistic interpretation without imposing a researcher's preconceived notions onto the patient. Through the use of explanatory models coming directly from the participant, the participant can then enunciate what and how they are feeling about their illness. This information will then have to be interpreted by the researcher, which may or may not represent the emic perspective. However, I believe the most organic way of defining identity is allowing it to come directly from the participant. However, when attempting to assess past feelings and perceptions of illness, the participant's memory of those emotions is subject to

revision. While this revisionary technique is a perfectly valid form of identity analysis, the actual nature of events, feelings, and perceptions can never truly be determined. Because of this limitation, using the current state of the patient, and their revised memories, to assess their past and future illness trajectories is an important process.

All of these issues, revisions, and additions are an attempt to collect more coherent and accurate illness narratives. Illness narratives, as enunciated by Arthur Kleinman, are an attempt to reconstruct memories, events, or feelings to "give coherence to the distinctive events and long-term course of suffering" (Kleinman 1988; 49). Much like Foucault (1973), Kleinman focuses on the physical, psychological, or, in many ways, tangible aspects of disease and suffering. However, Kleinman's paradigm takes into account the cultural significance of disease to the patient, as well. When speaking of a homosexual patient suffering from chronic pain in the late 1980's, Kleinman says, "AIDS holds powerful cultural meanings in Western society, and its social construction as the latest and most deadly venereal scourge, as a modern plague, is something we have all read about in the newspapers and magazines and seen on television" (Kleinman 1988; 84). From a clinical perspective these insights may be irrelevant, but increasingly, the biomedical community is realizing the importance of social, cultural, and even personal beliefs of illness on the health outcome for patients. Thus, a study designed to collect and interpret these beliefs has the potential to inform the medical and public health communities and influence the ways in which people living with HIV/AIDS are consulted about their serostatus and the associated logistics and treatments.

However, many previous studies have documented illness narratives from people living with HIV/AIDS (Bloom 2001; Gorman et al; 1997; Siegel and Krauss 1991;

Whittaker 1992). All of these studies conceptualize HIV infection from particular agendas, as would be expected. Different "at-risk" populations are singled out and macro-level theories are applied to the analysis of the illness narratives. Of course, my particular study is the same, looking at specific sub-groups and utilizing particular bodies of theory. The successful use of illness narrative and explanatory model approaches in these and other studies legitimizes the continued use of such models in further research on living with HIV/AIDS. My research can then continue to support such methods for the study of chronic and infectious disease. That is not to say that these methods do not have disadvantages. As I have already pointed out, the recollection bias associated with the reconstruction of past feelings and events necessarily distinguishes what people remember from what "actually" happened. However, what people remember is also an important component to assessing and interpreting how people have reconstructed their current frame of mind, or identities. It is, in fact, remembered experience which continues to inform how people act and react to current situations, both situationally and relationally (Evans-Pritchard 1940; Kondo 1990) - situationally, in the sense that people react to different situations and identify themselves in opposition to other, what are conceptualized as outside, people or groups (Evans-Pritchard 1940) and relationally, in the sense that concepts of identity vary depending on whom a person is interacting with (Kondo 1990).

An added layer in my study to the collection of illness narratives is the component of if/how access to treatment alters the ways in which identities formed around illness would otherwise be created and maintained. This point can be both intertwined and separated in the collection of illness narratives. In my interview schedule I have included

several questions that ask about treatment specifically and whether that treatment altered the subject's outlook on their illness. Important to this line of questioning is also the added dimension of adherence to treatment; why adherence is maintained or discontinued; what is the level of compliance with a health care professional's recommendations; and whether exclusive or complementary alternative therapies are used. Beginning and stopping treatment for HIV can produce many complications and outcomes. From a biomedical standpoint, sporadic adherence can lead to the development of drug-resistant strains of the HIV virus, which can then be passed on to other individuals (Blankson 2005). It can also complicate future treatment if the virus no longer responds to previously prescribed medications. However, from a social and personal perspective, sporadic adherence can seem like the best option for the person living with HIV/AIDS. A subject may discontinue treatment if symptoms go away, their T-cell count returns to "acceptable" levels (500 cells/mm^2) (amfAR 2006), or they no longer feel like treatment is helping or necessary. I would call these more personal factors which have received a great deal of attention in the literature (Bloom 2001; Gorman et al. 1997; Smith 2003), but in my own research I have identified several structural factors which also can affect optimum adherence to treatment. These factors include both the financial aspects and, more likely, time constraints associated with filling prescriptions and scheduling doctor's appointments, illegal drug use which affects priority decision-making, and the stigma of treatment seeking behavior, which often necessitates serostatus disclosure to family, employers, and insurance companies.

These structural constraints to both treatment and adherence have methodological repercussions in terms of research and interview design. The research design must be

able to focus on the structural mechanisms at work. This is why, in addition to interviews with people living with HIV/AIDS, I have also included a participant-observation component, attending community-based discussion groups targeted at HIV awareness, mostly in the gay community. These discussion groups can offer a more concrete explanation of the actual process and options for acquiring ARV treatment in the area. Some of these organizations actually have funding to provide the treatment themselves. The issues associated with HIV testing are similarly important. The differences between anonymous and confidential testing and the repercussions for insurance coverage can have profound effects on newly diagnosed people, where any positive test result from a confidential test is legally required to be forwarded to state and federal departments of health and the diagnosis being noted as a pre-existing condition when applying for insurance coverage, whereas an anonymous test result cannot be shared with any outside agencies. In terms of interview design, a more concrete and tangible structure needs to be employed. In the literature, illness narratives often focus solely on perceptions and feeling about illness, but not on how the climate within which one lives effects those perceptions and feelings. Understanding that treatment seeking and adherence behaviors are influenced by both personal and structural forces can better inform a more holistic and complex view of the nature of living with HIV.

There are, of course, a myriad of ethical issues which surround and encompass research on both personal and structural issues associated with living with HIV/AIDS. The collection of illness narratives from people living with HIV/AIDS can be a difficult process for the participant and the researcher. Creating a frank, yet sensitive interview schedule is a large component of conducting ethically sound research, especially when

discussing the trajectory of a "chronic" yet eventually fatal disease, such as AIDS. Great care was taken on my part to word questions in ways that are hopeful and continuous. However I found that most of my interview participants were very open to talking about their serostatus and well-adjusted, in terms of coping with and understanding the biomedical, social, and personal ramifications of living with HIV. It made it easier that my study was designed to look at the past and present, and future plans or expectations are only marginally discussed. Of course, many subjects want to talk about how they expect to be or act in the future and those conversations do find their way into the interviews; however those feelings are not the main focus of my research.

I have also collected a list of local HIV/AIDS counseling and support groups for dissemination to participants, should they have requested or appeared to need them. However, I have found that most of my participants have an extensive knowledge of what local resources are available to them, even to a greater extent than I do. Another important aspect to ethically sound research is the benefit of the community to which one is researching. In the long-term this study lays the groundwork for a longer more in-depth study which should have concrete beneficial application. The methodologies employed in this study are, thus, designed to maximize theoretical and applied outcomes, as well as add relevant and novel information to the appropriate literature.

Chapter 6
"More difficult than having a crack baby:" Living with HIV.

Results:

As I was initially conceiving of and developing my research questions and methodology, I conceptualized "identity" as an important component to how people live with and manage HIV/AIDS. Furthermore, I hypothesized that "access" to ART had something to do with how those identities were developed and maintained. While my research has supported this initial conception, to some extent, what I have realized is that whether a person has access at all and how they access ART has far more consequences than the development of an HIV-related identity. Whether and how people access ART has consequences for the development of drug resistant HIV, "opportunistic" infections, transmission schemas, disclosure possibilities, and social and economic marginalization. These issues struck me as, somehow, more pertinent than an ephemeral notion of "HIV identity." Likewise it was these issues that my informants wanted to talk about. As the following pages will illustrate, my informants cited structural impediments to ART access as major barriers to adherence. It is these external agents which predominately shape the access landscape, at least for my participants.

Structural and agentive factors contribute to how people living with HIV/AIDS create and renegotiate identities based on their condition. By condition, I mean both their illness, as well as their economic, personal, psychological, social, and historical viewpoint. While each of my informants cited different factors and emphasized different sources of influence in how they conceived of their condition, there are definite themes which have emerged that link the individual experiences of my informants. Some of

those themes include the perceived connection between sexual orientation and HIV infection, the trust placed in biomedical treatment, the influence of structural factors on the availability of testing and treatment options, and lack of disclosure to the immediate family. Obviously, these themes are not ubiquitous, but each informant echoed at least two of these themes, to varying degrees. I will offer three case studies to illustrate these themes.

Gary:

Gary is a 30 year old pharmacy manager who was diagnosed with HIV in 2002 at the age of 24. However, he and his physician have estimated that he was initially infected one year previous to the diagnosis after he suffered a year with reoccurring and misdiagnosed tonsillitis, leading to three separate hospital stays. After his diagnosis his long-term tonsillitis was attributed to immuno-suppression, caused by his low CD4 cell count and HIV infection. He is currently on an ART combination which is part of a clinical trial by a large pharmaceutical company testing a new class of ART which is designed to inhibit the integration and bonding of the HIV virus to the white blood cells it attacks. He initially became involved in the trial because his primary care physician is also the primary investigator for the trial and for the AIDS Research Consortium of Atlanta (ARCA). As a pharmacy manager, Gary had insight, not only to his own condition, but also to the larger pharmaceutical industry and the patients he serves.

Gary articulated all of the prominent themes I have identified. During our interview he told me that it "made sense" to him that he would eventually contract HIV because he is gay. He explained that growing up in rural Appalachia, what he saw about HIV was "mediated through T.V." and linked being gay with certain HIV infection. It is

because of this upbringing that he has not disclosed his sexual orientation, nor his HIV status to his immediate family. As he contends, if he is "not dying, they don't need to know." He noted that his compliance to ART is good and that he "never took a vacation from meds," but that he "can see non-compliance" in the patients he serves. When I asked Gary if he had ever experienced HIV-related stigma he responded by pointing out that he has never faced discrimination in the workplace and most of the stigma he felt was in dating. He said that he tends to "serosort," or seek out other HIV-positive partners, and he outlined a paradigm based on age for how people respond to his status disclosure. He mentioned that older men tend to understand and empathize with him because they lived through the beginning of the AIDS epidemic and experienced extremely high rates of infection among their friends and community. Men in the middle of the age spectrum Gary characterized as scared of and avoiding people living with HIV/AIDS, at least sexually. These were members of a generation conditioned into fear of HIV by the previous generation and also the first to effectively prevent infection because of expanding knowledge about transmission. And finally Gary characterized the youngest tier as naïve and reckless; those who were not born yet or are too young to remember the early epidemic and have grown up in an age where AIDS did not mean a quick and certain death for most.

Gary pointed to his work as a pharmacy manager in shaping how he thought and felt about HIV, in general. He clearly understood what impediments people living with HIV/AIDS faced when dealing with the healthcare sector; physicians, insurance companies, and pharmaceutical companies. He suggested the increase in generic pharmaceuticals, whose availability is rapidly growing, is one of the most important and

meaningful changes to positively effect people living with HIV/AIDS. However, many of the people he sees in his pharmacy are wary of generic drugs and, to some extent, unwilling to switch over to them. Furthermore, rising prescription co-pays often stretch thin the financial capacities of ARV consumers. These structural limitations were central to how Gary conceptualized living with HIV and he saw his work as a pharmacy manager as an opportunity to alleviate some of those limitations by ensuring proper drugs were in stock, catching mistakes in physician prescriptions, and working with his customers to understand their insurance policy or the opportunities for government assistance. From a more personal perspective, Gary characterized living with HIV as "more difficult than having a crack baby." From his standpoint, HIV is an entity, separate from himself, which exists inside him and, to some extent, functions independently from him. It is a condition that requires constant attention and affects all facets of his life, regardless of the efficacy of ART. Although ART can limit the physical manifestations of HIV, its specter is ever-present in Gary's social and medical life. He trusts his doctor to make beneficial decisions about his health for him and believes in the ability of biomedicine to maintain control over his "crack baby."

Gary personified all four prevalent themes I identified and my interview with him largely convinced me that the structural factors affecting access to ART continue to be of great concern to people living with HIV/AIDS, even in the United States. While these structural constraints are mediated by existing power relationships and often disproportionately affect the socially and economically marginalized, including gay men, there is also a certain level of personal control, or agency, which may or may not be mediated by and mediate these constraints. Gary would characterize his experiences with

HIV as relatively "lucky," as would most of my informants. He has been afforded a level of personal agency which allows him to choose to utilize condoms, select his sexual partners, receive ART and use it adherently. He can schedule doctor's visits, continue to work, which provides him with high-quality private insurance coverage, and participate in medical trials. His level of cultural capital and personal agency disassociate him from many of the structural constraints he identified and which he sees in his pharmacy customers. However, not all of my informants shared this relatively elite status.

Tyrone:

Tyrone is 22 and has been living with HIV since 2006. He was diagnosed when he was 20 years old after an extended hospital stay for a bacterial infection. He is a college student and does not have private insurance, but has been utilizing ART for almost two years through ADAP and state funded healthcare for people with low-incomes. His current ART regimen consists of one combination pill a day, which includes three different ARV's.

Tyrone also articulated all four of the prominent themes. He characterized his condition as an "emotional burden," not only for himself but for the people to whom he disclosed his status. This is one reason why he has not told his immediate family of his status and has had a difficult time telling his closest friends, whose reactions tended to be more emotional than his own. He was also concerned about the reaction of his family, both to his serostatus and also to his sexual orientation. He characterized his family as "one of those kinds of families" who would think "HIV isn't a gay thing, but if you were straight this wouldn't have happened" and conceptualized disclosing his status to his family as "a second coming out." Much like Gary, Tyrone had internalized a correlation

between being gay and becoming infected with HIV. After his initial diagnosis Tyrone described a period where he attempted to "re-normalize" and undo the damage that the diagnosis and extended hospital stay had caused in his life, both emotionally and logistically. As a result of the length of the hospital stay Tyrone lost his house, his family, his friends, and his health because he was unable to work while in the hospital and unwilling to disclose his status to friends and family which caused a decrease in the level of intimacy and trust with those closest to him. After his diagnosis he attempted an "adjustment to a more stable life." Tyrone found comfort in a traditionally black church, where he eventually entered into the leadership, and said about his status that "it enhanced it [his faith]." He has disclosed his status and sexual orientation to the leadership of his church, which, he says, has a large HIV-positive congregation.

However, Tyrone also saw structural issues as central to how people think about and perceive HIV/AIDS today. He acknowledged that his own circumstance, receiving ART through government assistance, had led to his inconsistent adherence. He also saw a lack of proper and relevant education as a key impediment to the fight against HIV/AIDS, specifically through the work that his church engages in, which involves regular support of local HIV-related prevention and treatment organizations and plans to institute its own free testing clinic. In his own experiences he has seen little to dissuade common misconceptions about HIV/AIDS, saying "most people have a 1987 view of AIDS and this is 2008." He also gave an example of this when speaking about how people need to put "information in context" and understand that while a low viral load count may reduce the chances of passing HIV to a partner, an undetectable viral load does not mean that you cannot transmit the virus, as he contends many people believe.

In Tyrone's case, HIV was certainly mediated and understood through his views and beliefs about being gay, but also by the lifestyle that he sees going along with that identity. His discussion of the need to "re-normalize" and an "adjustment to a more stable life" were clearly within the context of being young, gay, and participating in the activities that he understood that to entail, namely binge drinking and being sexually promiscuous, relative categories he did not define in our interview. From a personal agency standpoint he did, and does, have the ability to make decisions regarding whom he engages in sex with and whether or not to use a condom. However, after his diagnosis, his ability to access the appropriate healthcare in a timely manner, on his terms, has been severely curtailed because of his lack of insurance and reliance on government funded programs. He does not have the ability to alter the regimen he is on and his options, if that regimen were to become ineffective, are significantly reduced compared to someone with private insurance. His level of agency within the healthcare sector is, thus, greatly reduced. Tyrone's reflexive relationship with HIV was characterized by the "emotional burden" it placed, not only on him, but the perceived burden on his friends and family to whom he disclosed his status. The issue of disclosure was central to him and the responses and reactions of those close to him were of utmost importance to him when making decisions about who to disclose his status to, and when. Tyrone felt that his power and agency came from being able to disclose or not disclose his status to whom he chose when he chose to do so.

Jake:

Jake is a 37 year old man who has been living with HIV for approximately 15 years. He thinks he contracted HIV while engaging in unsafe sex while under the

influence of methamphetamines. In fact, Jake is a recovering meth addict, a common correlate with HIV infection, especially among gay men. He has never taken ART, with the exception of a one week trial in 1996 when, he says "they were putting everyone on the new drugs." Jake has consistently sought alternative treatments and is currently utilizing herbal teas, meditation, and yoga as his treatment schema. When asked if he would ever consider using ART if his health worsened or his CD4 cell count began to decline he emphatically replied that he would, but that that situation had not yet presented itself. The personal agency needed to make such a decision implies the ability to research and access alternative therapies, independent of a healthcare provider's recommendations, and also work outside of the dominant insurance paradigm which shapes much of the healthcare access landscape in the United States today.

Jake's experiences offer an interesting example of the hard to define, yet ever present link between meth use and increased risk for HIV infection. As discussed previously, meth itself generally does not present an inherent risk, but the effects of meth, which is known to reduce inhibitions and increase sexual pleasure, often cause an inability to make decisions and increase the desire for sex. Furthermore, meth is extremely addictive, often after only one or a few uses. Jake expounded upon these phenomena in our interview, and he felt lucky, in many ways, that HIV was the only consequence of his years of drug use. Jake fell into meth use to cope with a bad family situation and his eventual final resort, which was to run away as a teenager. Again, the epidemic of homeless gay youth, fleeing abusive or un-accepting family situations is, most certainly, partially responsible for the growing rate of incidence of HIV among young gay men in recent years.

From a personal perspective, Jake understood his diagnosis and subsequent events as a "wake up call" to, again, stabilize his life and exit the lifestyle he associated with young gay men, namely binge drinking, drug use, and promiscuous sex. While Jake never entered the dominant healthcare paradigm after diagnosis, he conceptualized his HIV infection as a spiritual awakening to take care of his body, which, for him, involved exploring alternative therapies. This divergence from the dominant paradigm suggests, in Jake's case, high levels of personal agency and the ability to seek out and pay for alternative therapies not covered by insurance plans. Jake's story embodies the fewest of the prominent themes I have outlined, as he has disclosed his status to his family and does not utilize ART, even though he does not necessarily distrust biomedicine. He was, however, unable to escape the power structures which mediated his meth use and also had internalized the hegemonic constructions of HIV/AIDS as ubiquitous among gay men. Jake's case is best characterized as one of hope, leading to the recovery of a meth addict and finding an emotional and personal center in health and life.

I have selected these individual case studies, because they, in many ways, clearly illustrate the broader themes I have found in my research. In addition to these three cases, I conducted four other interviews with gay men living with HIV in the Atlanta area. Curtis, who is approximately 50 years old, was diagnosed in 1982 and began taking AZT in 1989 and ART in 1996. He currently takes two ARVs and an additional 12 medications a day. These additional medications are all related to the side effects of ART, although he is the only one of my informants to report such high morbidity associated with pharmaceutical side effects. He characterized ART as "long-term chemotherapy" as he made associations between the treatment of HIV/AIDS and cancer.

Curtis is also involved in AIDS activism within the faith-based and activist communities. He serves on the board of a local HIV/AIDS treatment and testing center and is the national AIDS liaison for the Episcopal Church. Curtis trusts the efficacy of biomedicine and his doctor's recommendations to treat HIV and noted that he has a degree in biology when he explained that he conceptualized HIV/AIDS from a clinical and biomedical perspective. He was my only informant who attributed his serostatus to behaviors, not identity, saying it is contracted through an "activity, not who you were." This is perhaps because he was diagnosed before much was known about the transmission of HIV and, therefore, cannot be held "accountable" for his status. My other informants were all diagnosed after transmission routes were firmly established and, perhaps, blame gay identity with infection as an attempt to justify their involvement in known "risky" activities; activities that they understand as a part of being gay.

Mark is a 33 year old gay man who was diagnosed with HIV in 1994. Along with Curtis he was the only one of my informants to be tested regularly before his diagnosis. He also attributed his serostatus with gay identity, saying that he expected it and, therefore, "never really freaked out…about it." After researching internalists who specialized in HIV medicine he went through a short period of trial and error with medications before settling on his current combination of 3 ARVs. He did not begin treatment until 2000 at his doctor's recommendation. He has not disclosed his status to his immediate family except for his sister saying that his "mom had a tough life," and it was not necessary to do so. Once again, Mark exemplifies the themes of trust in biomedicine, not questioning the authoritative knowledge of the healthcare professional, and being influenced by the public health hegemony which associates being gay with

eventual HIV infection. An interesting caveat to the theme of placing trust in the healthcare professional is that five of my seven informants did not research treatment options and are currently taking a doctor's recommended regimen. However, they all spent considerable time researching doctors. The personal agency being activated is at a different level than I had anticipated. These informants have the ability to choose a doctor within the, often, broad scope of their insurance coverage and HMO plan. While they do not activate their agency to work outside of the healthcare system or research ART independently of their doctor, they have already done enough, in their minds, to ensure their continued health by placing themselves in the care of a doctor they have hand selected and, in many cases, spent considerable time finding. Tyrone was my only informant who was barred from this process because of the structural impediment of lack of insurance coverage. He has no options in his treatment schema which is prescribed to him through a state funded health program.

Brian is approximately 45 years old and was diagnosed with HIV in 1995. He thinks he contracted HIV while engaging in oral sex with an anonymous partner. Although he cites this "risky" behavior as the reason why he contracted HIV he still anticipated such a diagnosis because of his sexuality, saying "living through the early epidemic everyone who got it was gay and we didn't know why, I was surprised it took me so long." Although the transmission routes became more clear by the time Brian was diagnosed, he was unaware of the risks associated with oral sex. Again, Brian's conception of risk was mediated through behaviors he associates with being gay, but these behaviors are merely a side effect of a lifestyle shaped by hegemonic constructions of what it means to be gay in the United States. These constructions are largely meant to

"exoticize" the gay population and have had the effect of keeping relevant prevention education cloistered because many of the behaviors associated with gay men are deemed taboo by the public imagination; behaviors such as anal intercourse and oral sex. A discourse surrounding such behaviors, especially oral sex, is only recently being developed in prevention programs and is largely limited to self-selected participants, in my experience. These behaviors have, thus, becoming inseparable from gay identity and attribution of risk is tied to both, behavior and identity. When I say that my informants "blamed" their sexual orientation for their HIV infection, it is impossible to separate that from the behaviors which that identity entails. However, it is important to note that those are often stereotypic behaviors that have been ingrained into the public imagination through hegemonic discourse and may or may not be attributable to actual causation of infection. It is, therefore, the identity construction, not individual behaviors, that many of my informants understand as being responsible for their infection, which is not necessarily related to particular behaviors.

Jay is 25 years old and was diagnosed with HIV in 2005. He is currently utilizing ART through employer provided insurance. He is concerned, however, that his insurance may soon be revoked because he is a part-time employee and apprehensive about the state of the economy and the company's willingness to continue offering insurance coverage to part-time employees. He was only marginally aware of state provided assistance programs for accessing ART and skeptical of their efficacy and availability and seemed unwilling to look into such a possibility further. Jay has clearly conceptualized his condition as a chronic illness and said, it "hasn't impacted me hardly at all." He lauded the "wonders of the drugs" and said he only felt "very minor" stigma

attached to being HIV-positive.

In addition to the formal interviews there are several important findings which emanated from the participant-observation component of my research. Patrick, the full time employee of the community-based organization, suggested that the gay population in Atlanta has an overwhelmingly accurate biomedical model of HIV transmission, but that there were still high levels of confusion about certain "higher risk" behaviors that are not common in the discourse of HIV prevention. Most people know that unprotected anal intercourse and the introduction of bodily fluids, such as semen, to abrasions is deemed extremely high risk, most people do not know what risk is associated with unprotected oral sex or other behaviors not frequently discussed because of possible taboos on such behavior. What Patrick was trying to demonstrate to me was that most people know the extremes of risk, basically what is and is not "risky." However, the level of knowledge begins to decrease when behaviors which fall in the center of the risk continuum are assessed by individuals. In the rationalization and justification stage of deciding whether or not to engage in a behavior people draw on past experiences and knowledge to inform their decisions. When people have never been told that brushing your teeth before engaging in oral sex can increase your likelihood of contracting HIV (an example of prevention information which was relayed to me during an educational forum), for example, they have no frame of reference with which to evaluate those behaviors. Addressing these issues and reducing the stigma attached to "taboo" behaviors in order to tackle them with a broad audience are key components to developing more accurate and useful educational prevention programs. This is one example of how the prevailing prevention education contributes, or does not contribute,

to understandings of HIV transmission for the general public. These educational forums often consist entirely of self-selected participants who seek out the educational opportunity, and are not known or available to those at highest risk. This same level of information is, generally, not accessible to the lay population and illustrates, once again, that proper education is lacking in the majority of HIV-related discourses.

I have characterized my findings as a confluence of personal agency and structural impediments to healthcare access. However, the specter of stigma and discrimination cannot remain absent from any discussion of HIV/AIDS and because of that I had considerable difficulty in recruiting research participants. I contacted, through personal acquaintances, over 20 possible research participants, as well as contacting five HIV/AIDS-related support agencies. Of those contacted, only seven were willing to participate in this research and none of the agencies were supportive of assisting my research. Using my recruitment contacts as sources of information, because I did not actually speak to many of the people who refused to be interviewed, many of those who refused did so because they were either still dealing with the emotional upheaval of being newly diagnosed and had not disclosed their status to many people or they did not think they possessed adequate knowledge to participate in an interview about HIV. Both of these findings are interesting and support the claim that there continues to be considerable stigma and discrimination pertaining to HIV/AIDS.

Many of my recruitment contacts conveyed responses from possible informants who refused to participate about their unease talking about living with HIV/AIDS. Most of these people were newly diagnosed and had not disclosed their status to many people. Even after I had assured my recruitment contacts that all information was confidential

and academically sanctioned, their trepidations were not alleviated. While this discomfort with speaking about their condition could be caused by a multitude of factors, and vary between individuals, there is no doubt that personal feelings of judgment and stigma are factors in making these decisions. It is clear that personal feelings of stigma influence who people living with HIV/AIDS are willing to openly talk to about their condition. It may be for this reason that my informants did not describe feeling high levels of stigma but, it would seem, many of those who chose not to talk with me did. This may be a result of a selection bias.

Furthermore, according to my recruitment contacts, many people who refused participation did so because they did not feel they had adequate knowledge of HIV/AIDS, from a biological and pharmaceutical perspective, to complete an interview regarding the subject. Again, I attempted to clarify my position by indicating that no formal knowledge of HIV/AIDS, its treatment, or transmission was necessary to participate in the study. Even after such a clarification, none of the prospective informants reevaluated their refusal to participate. Clearly, these possible participants anticipated what information I was seeking and withdrew themselves from considering involvement if they did not feel they possessed such information. This phenomenon also represents a methodological bias, with the informants responding to the investigator in the ways they expect or assume are appropriate or correct, or in this case not participating in the research at all. However, there may be additional underlying assessments by the prospective informants of judgment from the investigator. They may assume a negative judgment from the investigator because they do not possess high levels of knowledge about their condition and are attempting to avoid such a judgment.

This assessment can lead us to two intertwined conclusions. First, the prospective informants who refuse to participate because they lack adequate knowledge of their condition are anticipating negative judgment and have been habituated to the expectation of stigma based on their illness. This expectation of judgment and stigma indicates that a pervasive stigma still exists regarding HIV/AIDS and those living with the illness are careful to avoid such stigma. Secondly, a reflexive gaze paradigm may offer interesting explanations to why these people do not feel they possess adequate knowledge about their illness. This paradigm would suggest that understandings of one's illness are constantly updated and, especially in post-industrial Western society, biomedical and pharmaceutical knowledge is a key component to those understandings.

Analysis:

Access to ART is only one aspect in the larger picture of living with HIV/AIDS. There is always present a personal relationship with the illness that shapes how people living with HIV/AIDS act and react to people, information, and the "outside" world. This reflexive gaze conveys meaning, bi-directionally, between the person and his or her illness. This is to say that the illness informs the person and the person informs the illness, through adherent use of ART and through the effects of a strong and ever present mind/body connection. A person's actions and feeling regarding their illness can have profound effects on the quality of life and outcome of that illness. Thus, the mental health of a patient has implications for the biomedical trajectory of the illness. It is for this reason that understanding how a person living with HIV/AIDS experiences and deals with their illness, from a personal and social perspective, is an important component to better treating HIV/AIDS from a holistic and patient-centered perspective. This is not to

say that personal agency and structural limitations should be viewed as dichotomous, but complementary, intersecting and fueling each other. First, I will outline the structural limitations to ART access my participants have articulated. I will then contextualize those data within a larger socio-political and economic landscape. Secondly, I will analyze how personal decisions to utilize ART effect the creation and maintenance of an HIV-related identity by using the personal illness narratives of my participants.

Of my informants, most of whom were currently utilizing ART did so through private insurance. One of my informants garnered access through ADAP and a state provided health care program, which was free of charge to him. However, the structural limitations associated with utilizing government funded health care were numerous and after his diagnosis he was unable to receive a follow-up doctor's visit for four months. He commented on the confusing and burdensome bureaucratic "red tape" which contributed to his sporadic adherence to ART, even though his "cocktail" was the easiest to maintain, with only one combination pill a day. The rest of my informants reported optimal or near optimal adherence with more intricate and encumbering ART regimens, with one of my informants, Curtis, taking a total of 14 medications a day, two ARVs and 12 meds related to the side effects associated with those ARVs. All of those informants received ARVs through private insurance.

It is clear that adherence is a critical issue to the proper and optimal treatment of HIV and how one gains access to treatment can have profound effects on its adherent use. Less than optimal adherence has the potential to increase the likelihood of developing drug-resistant HIV, which can not only be transmitted to others, but also complicate future treatment options. However, the relatively fast rate of development of new drugs

and new classes of drugs helps curb this issue, especially in the United States where most drugs are available to the average consumer. In fact, Gary, age 30, characterized his experience with starting an ART regimen as trial and error, with different drug options and combinations being tested, under his physician's supervision, to determine their efficacy, at the individual level. While this luxury is not shared throughout most of the world, especially in many developing countries, the decisions to begin and maintain ARV treatment are multitudinous and often confusing. Five of my informants began ART immediately or soon after being diagnosed based on the recommendations of their physicians. Curtis began taking AZT in 1989 and has had no interruption in his treatment since then. However, the CDC and WHO generally recommend not beginning an ART regimen until CD4 cell counts fall below 500 cells/mm^2 (amFAR 2005).

This contradiction is, at least, partially explained by the time of diagnosis. Five of my seven informants, Gary and Tyrone included, were not routinely tested for HIV and received their diagnoses due to the onset of opportunistic infections which led to extended hospital stays in both cases. In Gary's case he was diagnosed with tonsillitis and hospitalized three times over the course of a year before he was eventually diagnosed with HIV and his ongoing illness attributed to immuno-suppression. When he was diagnosed in January 2002 his T-cell count was 176 cells/mm^2. Likewise, Tyrone was hospitalized in August 2006 because of the onset of a bacterial infection. He explained that after being initially treated for the infection, the ER doctor explained that they were going to test him for HIV because of the severity of the infection and the possibility of immuno-suppression. It was not until several days later that he received the results, during which time he had "prepared" for the possibility of a positive diagnosis. At this

time his T-cell count was around 300 cells/mm^2. Four months later when he had his first follow-up visit and ARV's were prescribed his T-cell count had fallen to around 180 cells/mm^2.

An important and interesting question to be considered is why neither of these people, both of whom saw a correlation between being gay and HIV infection, got tested regularly. Both were diagnosed in the early to mid 2000's and lived in Atlanta at the time of diagnosis. Free testing centers were numerous at that time in the Atlanta area, as were pubic education campaigns, especially targeting gay men. In fact, the CDC estimates that nearly 25% of the approximately 1.1 million people living with HIV/AIDS in the United States are undiagnosed (Centers for Disease Control 2008). Again, structural barriers, mediated and reinforced by existing power relationships, offer a convincing explanation. Gary spoke of not only his personal struggle with finding a primary care physician, but also, as a pharmacy manager, his experiences with physicians who were homophobic and who often prescribed inappropriate combinations of ARV's for their gay patients. From Gary's perspective these "mistakes" were probably not intentional, but, most likely, stemmed from underlying, or perhaps, unconscious systematic discrimination against gay men. These vignettes offer case examples supporting the large literature showing that access to testing and treatment options does not equate to the utilization of those resources (Abadia-Berrero and Castro 2005; McCombie 1986; Smith 2003). While this disjuncture is often conceptualized through a lens of stigma and discrimination, it is important to keep in mind the confluence of structural factors in addition to simple access which restrain the choices and priorities of the socially and economically marginalized.

One of the most serious emerging and least talked about structural issues is the phenomenon of rising prescription co-pays. One of my informants, Gary, who is a pharmacy manager, spoke of the vast inequality which characterizes such co-pays. People living with HIV who access ART through Medicare or Medicaid often have prescription co-pays as low as 50 cents per prescription, while many people with private insurance can have co-pays up to $100 per prescription, depending on the type and quality of insurance coverage. Gary spoke of an overriding ethic among the patients he serves of "trying not to go on Ryan White," even if they face serious financial hardship due to paying $200-$300 a month, out of pocket, for their prescriptions. Even though Ryan White based funding, such as ADAP and other local and state assistance programs, may be available to them, they often conceptualize their enrollment in the programs offered through Ryan White as taking a spot from someone who really needs it. While this characterization may not be entirely accurate, from a funding standpoint, there is considerable apprehension among those with private insurance towards enlisting in Ryan White based programs. Similarly Niehaus (1990) writes of the Gay Men's Health Crisis, a community-based non-profit, "While the professionals with AIDS certainly aknowledge the value of such services for others, and on occasion would themselves serve as volunteers in these organizations, they often felt that they themselves has no need for the mutual assistance group services" (Niehaus 1990: 189). In Atlanta, there is very little community-based and local education about who is, or should be, utilizing such programs and assistance. This is a major area for social science research to target and help alleviate as the inequalities associated with differential prescription co-pays increases.

The structural limitations associated with access to ART - rising prescription co-pays, access to and knowledge of education and testing services, different routes of access, be it private insurance or government funded programs, and systematic discrimination by the healthcare sector - are all byproducts of a larger ailment which is pervasive in healthcare in the United States. Inequity of access is a complex and multi-faceted issue which extends far beyond the reaches of the simple ability to pay for healthcare. Although endemic poverty plays a large role in this inequity, the power structures which control, shape, and influence America's healthcare system replicate that inequity on many levels. In particular, gay men have long been segregated within the healthcare sector to primary care physicians who "specialize" in gay men's health, from donating blood (Owings 2007), and have been labeled "at-risk" for contracting HIV. In fact, the CDC continues to classify all sex between men as "high risk," but "high risk" heterosexual sex only constitutes unprotected sex with a partner known to have been exposed to the HIV virus (Centers for Disease Control 2008b). Of course, this definition seems quite outdated when heterosexual intercourse accounts for over 30% of new cases in 2006, nationally (Centers for Disease Control 2008b). This type of marginalization continues to stem from early characterizations of HIV/AIDS as a "gay plague," and my informants continue to internalize this hegemonic construction even after the statistical evidence and concerned public interest groups have debunked such notions.

As the epidemic in the United States continues to grow and diversify, related support agencies are making systematic changes in policy and direction in order to keep up. Over the last several years I have worked with a non-profit community-based HIV/AIDS-related testing and support agency which is doing just that. The growth in

staff and resources devoted to outreach to African Americans, Latinos, non-native English speakers in general, and non-injecting drug users (especially methamphetamine users) has been considerable. Because of the relatively progressive policy in the United States for supplying ART to people living with HIV/AIDS, the need for organizations such as this to provide them is greatly reduced. Much of the work now is devoted to helping newly diagnosed people access available resources from both government and private sources. The organization with which I work employs 40 full-time case managers for this purpose, and is the largest of its kind in the Atlanta area.

Even as the epidemic continues to diversify, gay men, especially young gay men, continue to be a locus of infection and target for intervention strategies. My informant, Gary, commented when talking about how his HIV status has affected his dating life that younger gay men are naïve about the consequences and severity of becoming infected. In a more nihilistic view, my informant, Curtis, said, "anyone 25 and below has no excuse for getting infected, especially if they are middle class and gay. The information is out there." What is interesting about Curtis' comment is the explicit notion that class has something to do with prevention and education awareness. While Curtis is essentially blaming the "victim" if they are middle class and gay, he does not see his own serostatus as preventable, because he is over 25 and told me he was diagnosed in 1982, before the mechanisms of HIV transmission were know. However, there is an implicit understanding that structural limitations play a role in who is targeted for prevention efforts and who has the cultural capital to act on that knowledge.

These findings and case studies, in particular, offer evidence of the extreme influence of structural impediments, personal agency, and a reflexive gaze on how my

study population thinks about and deals with living with HIV/AIDS. The structural factors which not only limit access but shape how access is garnered in many ways form the foundation of how HIV/AIDS is conceptualized. The fact that most of my participants consider access to ART to be a given allows them to reduce the impact of HIV on their lives, both mentally and physically, and "re-normalize." These factors both influence and are influenced by the level of personal agency that each person is able to wield within the healthcare sector and within their personal and sexual lives. This agency is, to a large extent, determined by each person's status in and knowledge of the existing power relationships which shape the American healthcare system. All of these factors, then, contribute to how a person thinks, feels, and responds to their illness, namely a reflexive gaze. That gaze is informed by an individual's biomedical and social understandings of HIV/AIDS, mediated through healthcare providers, friends and family, the media, and, perhaps most importantly, hegemonic constructions of HIV/AIDS. The hegemonic constructions which were of the most importance to my informants are those created and maintained through historic correlations between HIV/AIDS and gay identity. It is, thus, a three-tiered paradigm, with definite transfers and influence between those tiers, which leads to the creation of HIV-related identities, within my study population.

Chapter 7
"This won't be what kills me:" Conclusions and Directions for Future Research.

The findings of this study lend themselves to several conclusions and add to the greater body of literature in a number of ways. The structural factors affecting access to ART are numerous and central to shaping how my informants think about and act towards HIV/AIDS. This issue, coupled with varying levels of personal agency, has profound effects on each person's ability to access not only ART, but the healthcare sector, generally, and information about prevention, available treatment options, and treatment funding sources, specifically. I have found that these issues are paramount to the creation of a HIV-related identity among my informants. In many cases such a process was mediated by the hegemonic influence of public health and media messages which linked gay identity with ubiquitous HIV infection. It is, thus, the combination of a suite of factors – how access is garnered, levels of agency within the healthcare sector, structural factors, hegemonic constructions, behavioral practices, and the presence of preexisting identities – which contribute to the relationship that people with HIV/AIDS create with their illness.

These findings are significant to the scholarly literature in several ways. They continue to demonstrate that structure and agency can not, and should not, be separated for analysis. Many other contemporary social scientists have drawn attention to this issue when discussing HIV/AIDS research, most notably Paul Farmer, whose critique of medical anthropology suggests that anthropologists tend to over-emphasize or assume agency among the populations they study. My findings would suggest that agency and structural factors are unable to be separated and each contributes to the effects and

outcomes of the other. It is this confluence which then shapes that person's relationship with their illness, in conjunction with society-level understandings or that illness, namely cultural models. These cultural models are formed through the merging of how society thinks about and deals with an illness and the hegemonic discourse surrounding that illness. In the case of HIV/AIDS, the development of technology and pharmaceuticals has fostered a re-conceptualization of it as a chronic, preventable, and treatable illness, and my informants echoed this notion. If fact, my informant, Mark said, "I don't think this is what will kill me." In addition, however, the early public health response to HIV/AIDS which characterized it as a "gay plague" continues to influence how my informants think about their condition; an inevitable consequence of social marginalization and a result of being the "other."

We know that cultural models are fluid and dynamic and the introduction of ART has certainly resulted in the re-conceptualization of HIV/AIDS as a chronic illness. However, the continued association of gay men and HIV/AIDS has, disturbingly, not been altered despite drastic epidemiological shifts in incidence and prevalence. The fact that many of my informants justified their serostatus by pointing to their sexual orientation is a disconcerting consequence of not only the hegemonic influence of early public health responses to HIV/AIDS, but also the social marginalization gay men continue to face, specifically within the healthcare sector. It is obvious that this marginalization has been internalized by my informants and when seeking a way to deal with their diagnoses call upon it to explain "why them."

These four factors, structural issues, personal agency, pre-existing identities, and the influence of cultural models and hegemony, have the greatest influence in shaping my

informants' views and relationship with HIV/AIDS. The reflexive gaze, the conduit of information and meaning between person and illness, is not a pure conduit, but manipulated by the cultural forces which shape how we think and act. This does not mean, however, that the authoritative knowledge of the individual is diminished. Individual conceptions of what it means to have HIV/AIDS and "appropriate" responses to such a diagnosis vary and always have the possibility to resist culturally dominant views. My informant, Jake, offers an interesting example of such a case. While the rest of my informants placed their trust in biomedicine and their healthcare provider, Jake sought out alternative therapies and medical practitioners. This is not meant to suggest that his relationship with his illness was any more valid or meaningful, but that the forms which such a reflexive gaze takes are varied and reflect individual agency, which do not always coincide with dominant or hegemonic constructions.

Throughout the course of this research my views about the nature of HIV-related identity have shifted considerably and the structural impediments which people face in obtaining education, testing, and treatment options have come, largely, to the forefront of that view. However, these issues are only one factor in the greater scheme of what it means to be living with HIV/AIDS today. It is clear that my informants developed relationships with their illness that are shaped and molded by these structural factors, but also shaped by cultural and historical notions of HIV/AIDS and personal feelings and beliefs. It is also clear that each of these factors has influence over the others and the extent to which those issues manifest themselves is a byproduct of myriad aspects, including relative agency, the influence of dominant conceptions of HIV/AIDS on the individual, pre-existing identities, individual behaviors, and personal feelings and

experiences. "Where economic access is less the question, the deeper dimensions of the health care system's exploitation of illness are more apparent" (Niehaus 1990: 198). The implications of such a complex web of connection and influence are, likewise, complex. It continues to be necessary to reduce the structural limitations faced by many people in accessing information, testing, and treatment options. The rededication of resources within an American context is vital to achieve this end and a continued and increased outreach which focuses on behaviors, not sub-populations, deemed risky or high risk is essential. Concurrently, debunking the myth that gay identity is a precursor and synonym for HIV infection is necessary. It is a sad fact that most of my informants related these two concepts as a way of justifying their serostatus. Such correlations may have the impact of reducing prevention strategies, such as practicing safer sex, among gay men who believe it is their destiny to become infected, whether such strategies are practiced or not. Furthermore, such correlations maintain the current social marginalization that gay men continue to face as the "other," or outside of "mainstream" society. While the development of ART has brought about significant improvements in the way HIV/AIDS is dealt with and conceptualized in the United States, certain marginalized populations continue to bear the burden of epidemiological and social reality. These trends inform how those people think about their illness and it is not until those hegemonic constructions, created and maintained by existing power relationships, are changed that the damage of early public health responses to HIV/AIDS can be undone.

HIV/AIDS offers a profound example for the disciplines of social science, especially anthropology. Never before had the biological, clinical, pharmaceutical, and social effects of a worldwide pandemic evolved in tandem and been able to be

documented from a holistic perspective. While disease is constantly "emerging," and in many cases, re-emerging, the devastating effects of HIV, from a biological, etiological, social, political, and economic standpoint are unmatched in their severity, breadth, and complexity. It is, perhaps, from the example of HIV, that we can better combat the next "deadly scourge." From an anthropological perspective, the knowledge we have gained about how people, as individuals and society at large, respond to the challenges faced by infection can inform how the public health and academic communities develop and implement prevention and treatment programs in the future.

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Appendix A:

Interview Schedule:

1. When were you first diagnosed with HIV? How old were you? Tell me about that experience?

2. How long have you been living with HIV?

3. Who have you disclosed your HIV status to?

4. How would you say your life changed, if at all, when you were first diagnosed? Medically? Socially?

5. Are you currently antiretroviral therapy or another form of treatment? If yes, how long have you been consistently using ARV treatment?

6. How is your ARV treatment financially provided for? Insurance? Government funding? Out of pocket?

7. What type of ARV therapy are you using (specific drugs and combinations)?

8. Was there ever a period of time after you were diagnosed with HIV that you stopped taking your ARV medications? If so, please tell me about your decision to stop taking your medications.

9. How has your life changed since you began treatment? Physically? Socially? Mentally?

10. Have you done any research about treatment options and how the HIV virus works beyond what your health care provider has given you?

11. How would you characterize your experiences with HIV in the past?

12. How would you characterize your experiences with HIV currently?

13. Do you feel more hopeful, less hopeful, or the same about ARV therapy now, then you did previously?

14. Tell me about the daily challenges regarding your ART regimen? Do you find the process difficult?

15. Would you ever characterize your experiences living with HIV as stigmatizing? Has that feeling changed over time? If so, how?