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The Many Aspects of Stigma: Engagement-in-Care Narratives of HIV Patients at an Oakland Clinic

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The Many Aspects of Stigma: Engagement-in-Care Narratives of HIV Patients at an  
Oakland Clinic

By

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A thesis submitted in partial satisfaction of the  
requirements for the degree of  
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**PART I**  
**LITERATURE REVIEW:**  
**LATE PRESENTATION FOR HIV CARE AND THE ROLE OF**  
**PSYCHOSOCIAL FACTORS**

**Introduction**

Since the first cases of what would later be recognized as AIDS were reported in the US in June of 1981, 23 distinct antiretroviral agents have been approved for the treatment of HIV (CDC, 1981; NIH). When taken in various combinations, these agents constitute what is often known as Highly-Active Antiretroviral Therapy (HAART), a success story of basic and clinical biomedical research, and, it bears remembering, of patient advocacy. For many, the cocktail arrived too late; for millions on treatment worldwide, these compounds are life-saving. However, not everything is rosy in the HAART era. In the developing world, we face a monumental challenge of ensuring access to treatment. In the industrialized world, perhaps the greatest challenges in HIV care currently lie in the timely and equitable engagement of those infected with HIV into medical care, health systems improvement, and public education. This literature review focuses on the first of these. In the US, a country with among the highest per-capita income worldwide that can afford to pay for all of its citizens to receive HAART, it might at first glance seem like fine-tuning to speak of these issues. Despite this societal wealth and the success of HAART, there is in fact much cause for urgency.

Over 20 percent of those infected with the virus in the US unaware of their status, over one-third are diagnosed late in their disease course (this figure may be higher, depending on how “late” is defined, which will be addressed below), and about half of those who are diagnosed are not engaged in regular care (Gardner et al.; Mayben et al.; Moore et al.). Moreover, incidence of HIV in the US has remained above 55,000 new infections yearly since 2000; to frame this figure, note that annual HIV incidence in the US peaked at about 130,000 in 1985 and dropped to about 60,000 by 1991 (Hall et al.; Moore et al.; El-Sadr et al.). Lack of awareness of serostatus and late initiation of treatment fuel new infections, and late treatment initiation is associated with a worse prognosis and greater costs to the healthcare system (Mark et al.; Fleishman et al.). In short, late presentation for HIV care is bad because infected individuals are more contagious and because late presentation contributes greatly to HIV morbidity and mortality. The CDC warns that if engagement in HIV care is not improved, the total number of persons infected with HIV in the US will double over the next 20 years (CDC, MMWR, 2011).

This review seeks to summarize the vast literature describing demographic factors associated with late initiation of antiretroviral therapy and the less-studied psychosocial variables associated with late initiation. First, attention is given to the state of the epidemic and what is meant by "late presentation." Where possible, this literature review explores findings pertinent to the HIV epidemic in the US and in the San Francisco Bay Area, for it supports a qualitative research project examining interviews with HIV patients in Oakland,

CA. The first section gives an overview of the state of the epidemic in the US, with some mention of local issues. The second section briefly summarizes expert consensus on the deleterious health effects of late presentation for HIV care, and begins with a discussion of the problem of defining late presentation. Next, the third section gives an overview of the state of US HIV treatment recommendations along with data about what is actually happening. The fourth section looks at factors associated with late presentation for HIV care, beginning with racial/ethnic and sociodemographic factors and concluding with psychosocial factors, including stigma. Finally, the conclusion describes a "syndemic" approach that takes account of the heterogeneity evident in the various subgroups impacted by the US HIV epidemic, and discusses the importance of qualitative research for illuminating psychological and psychosocial processes involved in late presentation.

#### *A Note: How This Review Was Conducted*

Searches for "late presentation," "delayed presentation," "late initiation," "delayed initiation" and "HIV," "HIV/AIDS," "AIDS," and "HIV care" were entered into PubMed and results were read by relevance. The pertinent review articles that were identified through this process were in turn combed through for further citations. This approach was employed primarily for general epidemiology of HIV and of late presentation, with supplementation by Google searches and California Department of Public Health, Alameda Department of Public Health, and Centers for Disease Control (CDC) website searches for California-specific topics. For psychosocial and psychological factors related to late presentation, Google Scholar searches were added to widen the range of publications and germane citations were then accessed in full-text form through UCSF and UC Berkeley institutional licenses.

### **I. A Snapshot of the HIV Epidemic in the US, California, and Alameda County**

*"Where there is judgment and sexual shaming, there are high rates of HIV. Where there is fatalism, fear and secrecy, there are high rates of HIV."*

- Linda Villarosa, journalist.

#### *The Face of the National Epidemic*

Over the past 30 years, the face of the HIV epidemic in the United States has diversified. In large part this has meant, since the advent of the US epidemic, a transition from predominantly white, male homosexuals to a plurality of black Americans, predominantly male. At the beginning of 2012, there were an estimated 1.2 million persons in the US living with HIV and of these, nearly half, at an estimated 545,000, are black Americans (KFF 2). This translates to a nationwide prevalence of about 2 percent for blacks, the highest among any ethnic group in the US (KFF 2). Not only are existing HIV cases much more likely to be black Americans, new cases are as well. In 2009, the most recent year for which CDC statistics are available, the largest HIV incidence group by race/ethnicity was black American, 66.6 (per 100,000), accounting for 52 percent of all HIV diagnoses (KFF 1). Furthermore, this ethnic disparity is especially stark among the young: although black Americans between the ages

of 13 and 24 represent only 15 percent of the total US youth population, they represent 55 percent of all new cases of HIV infection (Richardson et al.). While the number of HIV infections among black Americans is down from its peak in the late 1980s, the prominent role of new infections among black American youth partly explain how the epidemic continues to grow (KFF 2).

Since the beginning of the epidemic, men have constituted the vast majority of HIV infections, and while this has remained true, the female share of the epidemic has grown. In 1985, women comprised eight percent of new infections; by 2000, they accounted for 27 percent of new infections (KFF 1). Since that time, this portion has remained relatively stable. Within the female epidemic, black American women carry a particularly high burden of HIV: in 2009, this group accounted for 64 percent of new HIV infections among women, yet made up merely 12 percent of the US female population (KFF 1). In addition, women face unique challenges in accessing and utilizing HIV care, including gender roles, pregnancy, and oral contraceptive use (Aziz et al.). These potential barriers to care will be expanded upon below.

Returning to racial/ethnic disparities, there is a trend worth noting with regards to HIV testing. Black Americans have the highest rate of HIV infection *and* of HIV testing of any ethnic group, and, similarly, Latinos have the second-highest rate of HIV infection *and* of HIV testing (KFF 2, KFF 3). Specifically, among individuals aged 18-64, 43 percent of black Americans, 24 percent of Latinos, and 15 percent of white Americans were tested at least once for HIV in the past 12 months, according to the most recent CDC data (KFF 2, KFF 3). Moreover, black Americans report the highest level of concern about becoming infected with HIV among any ethnic group (KFF 2). These data suggest that awareness of the magnitude of the HIV epidemic is manifested within US racial/ethnic groups, broadly speaking. While these levels of testing and concern have not prevented a growth of the HIV epidemic among minority populations, they constitute an encouraging sign of community awareness that can be built upon.

A crucial contour of the US epidemic is the historically high prevalence among men-who-have-sex-with-men (MSM). While gay men, bisexual men, and other MSM make up at least 2 percent of the US population (this figure is likely higher due to under reporting), they account for about 60 percent of new infections annually (KFF 5). Within this population the color lines are stark: rates of infection increased 48 percent between 2006 and 2009 among black MSM between the ages of 13 and 29 (Anderson et al.; Prejean et al.). According to the CDC, young MSM of all races/ethnicities were the only group to experience an increase in infection rates over 2006-2009, with young black MSM disproportionately accounting for this trend (Anderson et al.; Prejean et al.). This crest of the HIV epidemic goes deeper than headcounts of the those infected by the virus, for it has also been found that white MSM are more likely to initiate HIV treatment early, while black MSM are more likely to start treatment late (CDC, 2011). Notably, a stretch of studies going back to the 1980s and 1990s have found that black MSM and white MSM share similar risk behavior profiles; thus, the prevalence and incidence disparities between these groups remain

largely unexplained (Millett et al., 2006).

#### *National Patterns by Geography and SES*

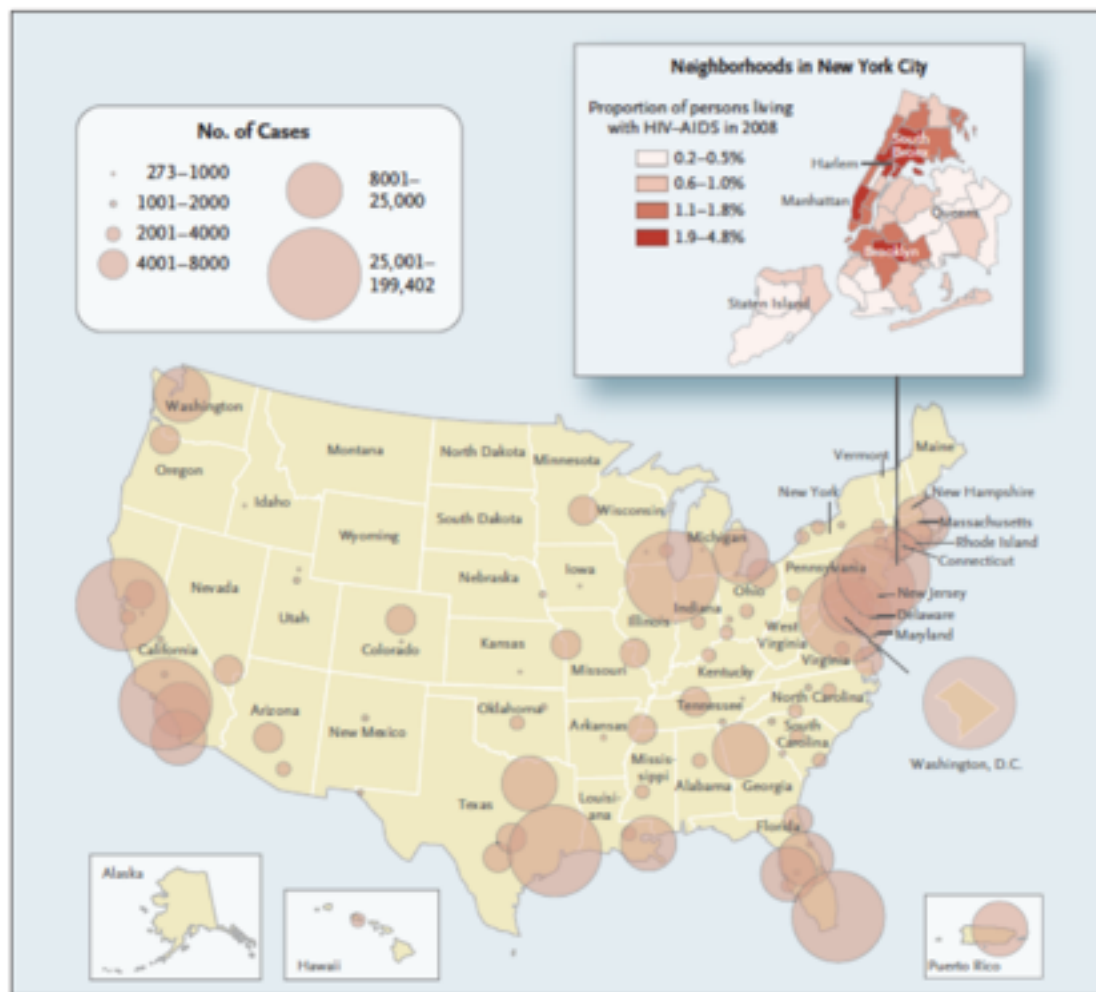
Large US metropolitan areas contain the major concentrations of the HIV epidemic, with 84 percent of cumulative AIDS diagnoses (KFF 5). Within these areas, HIV prevalence is higher among those with less education, lower income, and among the unemployed (KFF 5). According to the "12 Cities Project" of the Department of Health and Human Services (HHS), residents of the 12 metro areas most highly impacted by HIV (which together represent about 44 percent of the nation's AIDS cases) are more likely to rate HIV/AIDS as a serious community problem, more likely to have been exposed to media about HIV/AIDS, and more likely to report getting tested for HIV (KFF 4). Testing is particularly important because it, along with paired counseling, has been shown to reduce high-risk behavior by 68 percent among individuals who find they are infected with HIV (Hall et al.). It is likely that this effect accrues to some degree to those who test negative, as well. However, in addition to increased testing, El-Sadr et al. have argued that a cogent approach to the US HIV epidemic today requires a shift of focus away from the determining power of individual risk behaviors to high-risk sexual networks, which are largely ensconced within insular urban communities (El-Sadr et al.). A high-risk sexual network can be related to the concept of "community viral load," which seeks to quantify the HIV viral burden of a specific, usually urban, geographic area by aggregating the viral load serology for many individuals living in that area (see for example work done by Das et al. that has correlated a decrease in community viral load with a drop in new HIV infections in San Francisco). Many factors, such as access to health insurance and health care, level of engagement in HIV care, poverty, and access to housing impinge on community viral load. In addition, high-risk sexual networks include aspects such as the race, age, and SES of sexual partners; each of these is independently a risk factor for HIV infection. See on the next page a graphic of the most highly impacted urban areas in the US with populations of 500,000 or higher.

#### *National Policy*

In an attempt to increase testing among black American MSM and women, the CDC has recently launched focused campaigns for each group, known as the "Know Where You Stand"/"Testing Makes Us Stronger" and the "Take Charge. Take the Test" campaigns, respectively (CDC, 2012). In addition, New York City, in partnership with Iris House, a community-based organization, has launched a "Keep It 100" public awareness campaign. This campaign, which targets black American youth through several posters, one of which is visible on the next page, is notable because it relied on focus groups to arrive at a slang-based tag line ("Keep It 100"), a positive rather than "scared straight" approach, and images that could appeal to both heterosexual men and MSM (see image below), as well as women (in other posters). However, the nation's principal safety net health insurance program for low-income Americans, Medicaid, does not pay for routine HIV testing nationwide, with only about half of US states covering routine testing (states are required to opt in) (KFF 6). Therefore, the national impact of programs such as these is variable. Furthermore, access to

STD counseling is lower among US racial and ethnic minorities (Institute of Medicine).

*Below: 2007 CDC data superimposed on major national urban centers; 2009 New York City data are inset above. Note that prevalence within certain New York City boroughs approaches 5 percent; prevalence among black men in Washington, D.C., in fact exceeds 6 percent (El-Sadr et al.).*



Gaps in access to services go beyond testing and counseling. The Affordable Health Care Act would help those living with HIV, in part by removing the preconditions exception, making it easier for persons living with HIV to access private insurance, and by raising the minimum income rate for enrollment in Medicaid (White House). Before the impact of this legislation is felt, however, modest increases in national spending dedicated toward the care of those living with HIV are stretched thin, as over 6000 persons are on waiting lists nationwide for the AIDS Assistance Program (ADAP) (Farrow). While the newest public messaging on HIV is laudable, getting a routine HIV test paid for by Medicaid depends on where you live, and newly HIV-positive individuals face under-funded public treatment assistance programs if they do not have private insurance.



Below: The "Keep It 100" campaign in New York City, based on focus groups with youth of color, seeks to reach both heterosexual men and MSM. (Image source: Keepit100NYC.org)



### *The Epidemic in California*

The epidemic is large in California, as would be expected in the nation's most populous state. California led the nation in total AIDS diagnoses in 2010, and in 2009 it was third in HIV and AIDS diagnoses (KFF 5; CDC, 2009). In addition, California contains two of the top 12 metro areas in terms of HIV/AIDS burden, the San Francisco-Bay Area and Los Angeles, where two-thirds of Californians living with HIV reside (KFF 4; CDC 2009). Unfortunately, the funding picture for HIV services in California has recently darkened. California ranks second among US states in terms of the total confirmed cases of HIV/AIDS (about 111,000), yet the 2009-2010 state budget crisis led to a complete elimination of all state funds for HIV testing and prevention services (approximately 20 percent of the previous total is currently maintained through federal funding sources) (Arnold et al.; Flynn). Previously, the total budget for California HIV testing and prevention services was about \$60 million; state cuts of about \$48 million to HIV testing and prevention efforts were part of about \$85 million eliminated from state funding for HIV and AIDS programs (Eakins). A preliminary analysis of the impact of these HIV testing and prevention service reductions conducted by the CDC estimated that, excluding LA and San Francisco metro areas due to incomplete data, 66 new HIV infections were attributable to the cuts in the first year out, carrying \$24 million in life-time HIV treatment costs (Lin et al.).

### *The Epidemic in Alameda County*

At a more local level, Alameda County comprises, along with Contra Costa County and the City of Berkeley, the Oakland Transitional Grant Area (TGA), which included about 7,000 persons living with HIV/AIDS at the end of 2007 (Arnold et al.). More recent figures through 2010 from the Oakland TGA Collaborative Community Planning Council estimate that there are 10,243 persons living with HIV/AIDS (PLWHA) in the Oakland TGA (Oakland TGA). Alameda County accounts for about 73 percent or 7,488 of these. Oakland, the county's most populous city, accounted for between 54 to 65 percent of Alameda County AIDS cases in the years before 2007, the last year that Alameda County issued a comprehensive HIV/AIDS report (Alameda County). Oakland is a major epicenter of the HIV epidemic in California.

What features distinguish the HIV epidemic in Oakland? First of all, the Oakland TGA figures translate to a high prevalence of HIV/AIDS: 1 in every 173 resident of the Oakland TGA is living with HIV/AIDS. The Oakland TGA has a higher HIV incidence than does New York City. Second, while MSM is the leading transmission category in the Oakland TGA, this category constitutes a substantially smaller percentage of cases than in most other metropolitan regions in the western US. Accordingly, heterosexual and IDU exposure categories are higher in the Oakland TGA. Specifically, the Oakland TGA has fewer cases attributable to MSM exposure and more each attributable to heterosexual and IDU exposure than either Los Angeles County or San Francisco. For these reasons the HIV epidemic in the Oakland TGA is more typical of an east coast metropolitan region than a western one.

While 1 in every 173 Oakland TGA resident is living with HIV/AIDS, 1 in every 67 black American resident is affected. Another way of stating this stark disparity is that 41.8 percent of Oakland TGA PLWHA is black American (4,277), while merely 11.3 percent of the Oakland TGA overall population is black American. The table below summarizes the racial breakdown of the estimated total of PLWHA in the Oakland TGA through 2010. Although Latino and API portions of the total are the smallest, these segments are growing: between 2008 and 2010, 19.4 percent and 6.4 percent of new AIDS cases were Latino and API, respectively.

<b>Race</b>	<b>PLWHA</b>	<b>Percentage</b>
Black American	4277	41.8
White	3699	36.1
Latino	1677	16.4
Asian/Pacific Islander (API)	471	4.6

An expanding population of Burmese refugees is contributing to the growth of the PLWHA API population in the Oakland TGA, as at least 21 members of this

community of less than 400 individuals is HIV-positive (Oakland TGA). Finally, there has been evidence that both emergency room-based and community-based HIV testing services have been curtailed in Alameda County as a result of state budget cuts, so there is reason to expect a continuation, if not an acceleration, of current HIV incidence in the Oakland TGA (Arnold et al.).

*Section Conclusion: A Snapshot of the US Epidemic*

HIV in the US has continued to largely impact MSM, but it is also a disease affecting urban persons of color, particularly black Americans. These two categories are not mutually exclusive, but nevertheless they account for the largest traditional risk factors (exposure and race/ethnicity) for HIV. Public health campaigns have sought to create targeted messages to affected subgroups, but there are gaps in access to free testing and HIV treatment that are felt down to the level of Alameda County. Access to testing and treatment is often decreased along lines of societal inequality such as SES and race/ethnicity, making late presentation for HIV care more likely. Section IV will examine disparities in late presentation in more detail, while Sections II and III to follow will define late presentation and describe its current dimensions.

**II. Expert Consensus: Late Initiation of HIV Care Has Negative Health Impacts**

*Defining Late Presentation for HIV Care*

Perhaps the first problem in ascertaining the state of affairs with regards to later-than-optimal initiation of HAART is the issue of defining late presentation. One place to turn to for clarity is the WHO, which defines HIV disease (positive by antibody or other laboratory test) in four clinical stages, by severity of physical manifestations (e.g., generalized lymphadenopathy, weight loss) and opportunistic infections (e.g., herpes zoster, candidiasis, pneumocystis pneumonia) (WHO, 2005). However, this system is meant for application in Africa, where the epidemic is much different than in the US, with late presentation being more common due to limited access to medications and limited availability of laboratory indicators of disease progression, such as CD4+ T-cell count. The CDC's classification scheme, laid out in the chart below, takes into account CD4+ T-cell count and various clinical manifestations, along with less severe symptomatic conditions, including oropharyngeal or vaginal candidiasis, herpes zoster, and chronic diarrhea, and more severe AIDS-indicator conditions, including toxoplasmosis, recurrent bacterial pneumonia, and pneumocystis pneumonia, among others (AETC).

**Table 1. CDC Classification System for HIV-Infected Adults and Adolescents**

CD4 Cell Categories	Clinical Categories		
	A Asymptomatic, Acute HIV, or PGL	B* Symptomatic Conditions, not A or C	C# AIDS-Indicator Conditions
(1) ≥500 cells/μL	A1	B1	C1
(2) 200-499 cells/μL	A2	B2	C2
(3) <200 cells/μL	A3	B3	C3

Abbreviations: PGL = persistent generalized lymphadenopathy

Many investigators have used a cut-off of a CD4+ T-cell count below 200 to define late presentation. However, clinical indicators are often applied in tandem; the cut-off of 200 is powerful because diagnosis at this disease state was associated in 2005 with a 10-fold increase of mortality in the UK (Fisher). In addition, many studies have shown that CD4 count of 350 is a significant tipping point, as well. For example, US data on nearly 1,000 patients showed incomplete reconstitution of the CD4+ cell to CD8+ cell ratios for those individuals who initiated HAART at CD4 counts at or below 350, versus those who started at higher counts, over nearly 3 years of follow-up (Robbins et al.). In 2011, Antinori et al. put forward a two-tiered European consensus categorization of delayed presentation as follows:

- *Late Presentation*: Persons presenting for care with a CD4 count below 350 or presenting with an AIDS-defining event, regardless of CD4 count.
- *Presentation with advanced HIV disease*: Persons presenting for care with a CD4 count below 200 or presenting with an AIDS-defining event, regardless of the CD4 count (Antinori et al.).

It is especially important to consider more than just CD4 count, for an individual's CD4 count can vary by as much as 25 percent over time, with variation increasing at lower values (Hughes et al.). The above scheme has advantages in that it is inclusive enough to capture the deleterious effects of treatment initiation below a CD4 count of 350 and takes clinical features into account (e.g., AIDS-defining events), yet retains the nuance of a more serious category (i.e., CD4 count below 200 or an AIDS-defining event). As such, those presenting with advanced disease state are included within, but also aggregated from, late presenters. A good definition of late presentation would be one that takes into account clinical features, relies on CD4+ T-cell count cut-offs, distinguishes between late presentation and presentation with advanced disease, uses engagement in clinical care as the end point, and is universally implemented. Unfortunately, various investigators employ various schemes, but it is helpful for the purposes of this paper to keep in mind the idealized system described here. The CDC is currently working to improve reporting such that CD4+ T-cell counts will be tallied for all new diagnoses (CDC, MMWR, 2011).

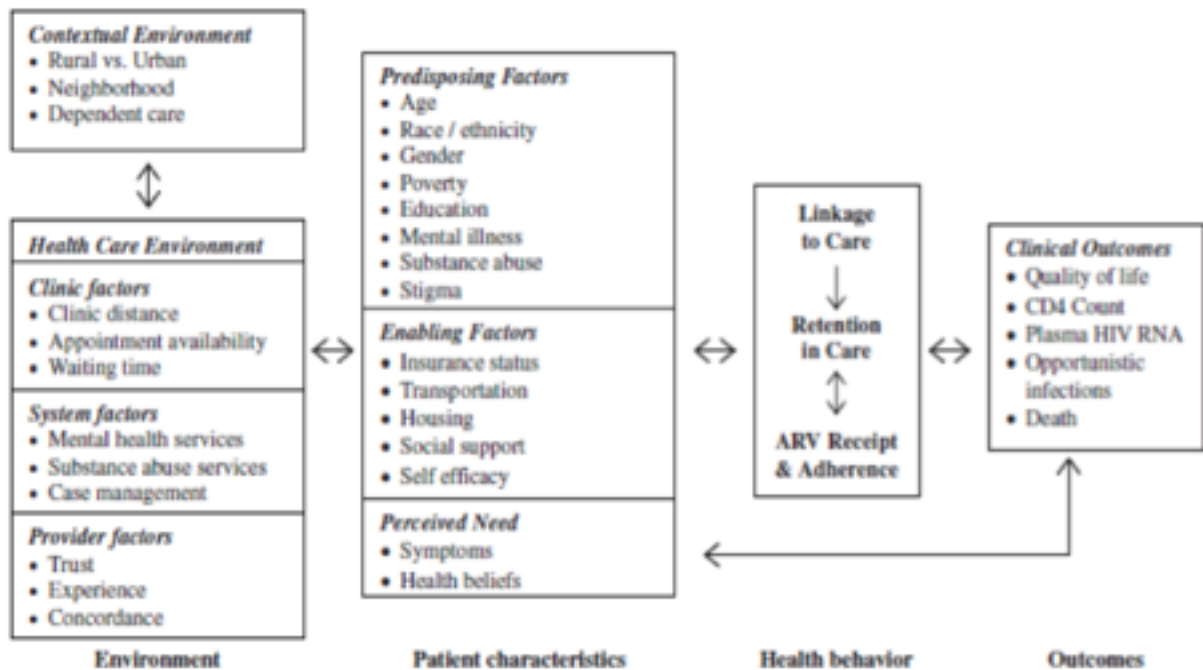
#### *When is the Delay Occurring?*

The natural history of HIV infection is such that an average of between 8 and 10 years intervene between infection and progression to AIDS (Vergis et al.). As seen above, there is evidence to indicate that the delay to entering HIV care is primarily attributable to the gap between acquiring HIV infection and testing positive, not between testing positive and entering care (Girardi et al.; Dennis et al.; Bamford et al.). The overall delay to care is especially significant not only because of the ill effects to the health of individuals who test late, but also because it drives the epidemic: a 2006 study estimated that over half of new sexually transmitted HIV infections result from those who are unaware of their serostatus (i.e., infected individuals who have yet to test positive) (Marks et al.). In the HPTN trial (results published 2011), early initiation of antiretroviral therapy (CD4 count 350-500) was shown to reduce HIV transmission between serodiscordant couples 96 percent versus late initiation, and to reduce all new HIV infections (i.e., not specifically between serodiscordant couples) by 89

percent (Cohen et al.). The mechanism is thought to be decreased levels of virus in genital secretions. Thus, treatment for HIV vastly reduces the likelihood of new infections, in addition to benefiting the health of those individuals engaged in treatment.

*The Negative Impacts of Late Presentation for the Individual*

There have been numerous studies indicating the negative health impacts of late initiation of HAART for HIV-positive individuals. For example, the 2011 UK CHIC study of nearly 18,000 patients between 1996 and 2008 found a strong correlation between CD4 count at the time of starting HAART and mortality (May et al.). Specifically, those patients who started HAART once their CD4 count fell below 200 cells/mm<sup>3</sup> were estimated to have a life expectancy at least *10 years lower* than those who started HAART once their CD4 counts had fallen below 350 (May et al.). However, UK CHIC could not control for factors associated with late HAART initiation or lower life expectancy, such as smoking and socioeconomic status (SES). Indeed, these data may not be generalizable to the US, given the differences between the UK and US populations.



Above: The UK CHIC findings regarding factors impinging on a patient's HIV treatment course. Although these figures pertain to the UK, note the multiplicity of factors believed to be associated with late presentation in this cohort.

What do studies with large US sample sizes show? A 2009 study aggregated US and Canadian data (NA-ACCORD) on nearly 18,000 patients who initiated first-time HIV treatment between 1996 and 2005, finding substantial increases in risk of death when HAART was deferred. Among patients with CD4 counts between 351 and 500, delaying treatment was associated with an increase in risk of death of 69 percent, relative to early initiation; among patients with CD4 counts above 500, delaying treatment was associated with an increase in risk of

death of 94 percent, relative to early initiation (Kitahata et al.). This study's strengths included a sufficiently long follow-up to capture death as an end point; however, as an observational study, it was not able to eliminate confounding by SES or other factors. Nevertheless, putting off the initiation of HAART, even at two relatively high CD4+ T-cell counts, was associated with substantial increases in risk of death, compared to starting early (i.e., six months' time or less from first serology within the ranges of interest).

A smaller 2009 study compared HIV-infected individuals in the US who started HAART with CD4 counts at or above 200 with those who started "late" or "very late," finding that losses of life expectancy were 3.90 years for those who started HAART with CD4 counts below 200 ("late"), and 8.83 years of life lost for those who started with CD4 counts below 50 cells/mm<sup>3</sup> ("very late") (Losina et al.). For comparison, the authors estimated that life expectancy lost due to HIV infection (treated "on time," with standard-of-care) was 11.92 years, meaning that, according to this study, late initiation can further decrease life expectancy, roughly speaking, between 33 and 75 percent, depending on the severity (Losina et al.). Interestingly, the cohort that this study examined had an estimated 8.33-year reduction in life expectancy that was attributable to demographic and risk profile, compared to the HIV-uninfected US population (Losina et al.). This underscores the need to address risk behaviors, such as smoking, independent of HIV infection.

Taking the above study together with the UK CHIC study and the analysis of NA-ACCORD data, these three studies are powerful demonstrations of the life-saving effects of HAART and the deleterious effects of late initiation. Furthermore, they corroborate other studies that have also shown increased risk of progression to AIDS or death with decreasing CD4 count at the time of initiation of anti-retroviral therapy (When to Start Consortium; Egger et al.). In 1996, panel recommendations for the initiation of antiretroviral treatment were to start when a patient's CD4 count dropped below 500 (Carpenter et al.). Subsequent recommendations changed course by adjusting the "starting value" downwards, but today have come back to a similar, even stronger guideline, as will be discussed in the next section. Finally, there is evidence from the Netherlands that if patients were to present for HIV treatment with CD4 counts of at least 400, mortality during the first 3 years of HAART could be reduced by 20 percent (Smit et al.). The next section will consider how the US clinical picture squares with the target of starting HIV antiretroviral therapy in the CD4 count range of 350 to 500, at the latest.

### **III. Late Initiation of HAART is the Norm in the US & Canada**

#### *What are the recommendations?*

The trend in treatment initiation has been to recommend treatment earlier, culminating most recently in the March 2012 recommendation that all treatment-naïve individuals newly diagnosed with HIV should start antiretroviral treatment. The US Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents recommends treatment for all HIV-infected individuals. The strength of the recommendation, however, follows a three-tiered system.

Specifically, the recommendation is strongest for individuals with CD4 counts below 350 cells/mm<sup>3</sup>, strong for those with CD4 counts between 350 and 500, and weakest for those with counts above 500 (HHS). The WHO applied, as of 2010, this strongest recommendation globally (i.e., for all HIV-positive individuals with CD4+ T-cell counts below 350 cells/mm<sup>3</sup>), advising treatment initiation for all HIV-positive individuals with this serology, or with evidence of advanced disease state in settings where CD4 counts are not readily available (WHO). These are expected recommendations, given recent data on the effect of HAART when taking into account initial CD4 count.

### *What is actually happening?*

The previous section discussed that “late presentation” can be understood as engagement in HIV care at two tiers of disease progression: at a late stage, with CD4+ T-cell count below 350 or an AIDS-defining event, and at an advanced stage, with CD4+ T-cell count below 200 or an AIDS-defining event. The dominant path to late presentation is late diagnosis, as opposed to early diagnosis followed by lack of linkage and/or engagement in care. With this in mind, a range of 19.2 to 51 percent of late HIV diagnosis prevalence has been identified in a series of studies in the US, the UK, Ireland, France, Spain, Italy, China, Canada, and Venezuela, with the heterogeneity of percentages likely dependent on differences in how various investigators have chosen to define “late” (Carrizosa et al.). In the US, the figure for late presentation itself is likewise uncertain. The reporting of CD4 counts at diagnosis in the US varies by state, and even in states with comprehensive reporting, data collection has not been well-validated (Dombrowski et al.). This, taken together with the potential unreliability of CD4 counts themselves as indicators of late presentation discussed above, necessitates caution in interpreting data about late presentation. Several reports have placed the US figure in the 30 to 45 percent range. When considering the percentage of individuals newly diagnosed with HIV who receive an AIDS diagnosis within one year, four reports indicated a range of 32 to 38.8 percent (KFF 5; Schwarcz et al.; Dombrowski et al.; CDC, 2009). When considering CD4 counts below 200, one report that analyzed data from 2001 to 2005 showed that 43.1 percent of patients presented in this advanced disease state (Fleishman et al.). However, more in that sample likely presented with late disease (a more inclusive category than advanced disease). What about when a cut-off of a CD4+ T-cell count of 350 is used?

Some studies have found over 50 percent prevalence of late presentation using this metric. A large 2010 study that drew on data from the multi-site, ten-year NA-ACCORD study was able to describe initial CD4 counts for nearly 45,000 treatment-naïve patients entering into HIV care. These data showed a small increase between 1997 and 2007, but, overall, the majority of patients (about 55 percent between 2005 and 2007) continued to present with CD4 counts below 350 (the mean between 2005 and 2007 was 315) (Althoff et al.). A smaller study that spanned 1997 to 2009 and examined the immune status of new patients entering HIV clinical care in Baltimore found that 56 percent had CD4 counts equal to or below 350 (Moreira et al.). These two studies give a picture that perhaps more than half of US patients present for care with CD4 counts below

350; to give this number context, this proportion indicates that, of the individuals diagnosed with HIV in the US annually, perhaps 30,000 can be categorized as presenting late for HIV care. See table below for a summary of the previous two paragraphs.

<i>CD4 Count at Start of HIV Care in the US</i>		
<b>Disease State</b>	<b>CD4 Count</b>	<b>Percentage of Patients</b>
Late	350-200	~55
Advanced	Below 200, or AIDS diagnosis within one year	~32-43.1

Just as the total of late presenters is a subset of all individuals diagnosed, so successively smaller portions of late presenters will be engaged and then retained in HIV care. A recent paper by Gardner et al. found that approximately 75 percent of persons newly diagnosed with HIV are successfully linked to care; of all cases, approximately 50 percent are engaged in care at any given time; and, of those in care, 75 percent of those eligible for treatment are receiving it (Gardner et al.). This "continuum of care" narrows even further at the transition between those receiving antiretroviral treatment and those who are actually virally suppressed. A visualization of the continuum of care is of a stream of attrition between testing positive for HIV and receiving adequate treatment for viral suppression (i.e., viral load at less than 200 copies/mL), with each transition point marking a drop-off in patient numbers (see graphic below reproduced from the CDC) (CDC, MMWR, 2011). These data underscore the importance of increased testing, of medical systems improvement, and of better understanding regarding the reasons for late presentation for HIV care, for only multi-faceted and structural interventions can address the challenges raised by this view of the continuum of care.

#### **IV. What Could Explain High Prevalence of Late Initiation of HAART in the US?**

Many factors have been associated with late presentation for HIV care. The majority of publications investigating late presentation focus on socio-demographic factors, such as male gender, heterosexual orientation, older age, and low SES, all of which have been associated with late presentation (more on each of these below) (Mukolo et al.). Of these, SES stands out as strong candidates for strong explanatory power regarding late presentation. For example, a recent CDC analysis of national data from urban heterosexuals shows that SES, disaggregated as educational attainment, employment, and household income, was associated with higher HIV prevalence, and this association was not explainable by crack cocaine use, trading sex for money or drugs, or being diagnosed with an STI (CDC, 2011, 24 cities). Another study found that low neighborhood-level SES is associated with late presentation for HIV care (Joy et al.). Further, an older study (1994) associated higher SES with slower progression of HIV infection to AIDS, regardless of access to healthcare (Schechter et al.). It is important to bear these data in mind when reviewing research examining race/ethnicity and HIV, for SES remains highly correlated to



race in the US.

In section I, the discussion of the broad features of the US HIV epidemic highlighted the recent surge in infections among MSM, largely driven by young men of color, particularly black American men. In addition, the growth over the past two decades in the female share of the epidemic was mentioned, a share that is disproportionately that of black American women. The majority of infections among any demographic or exposure group continues to be MSM. Given these important features of the HIV epidemic, this section will be organized so as to address each of these. Major headings are "Race/Ethnicity," "Gender," and "Age"; this is an organizational construct and is not meant to imply that one of these features is significantly more important than others. The first part of this section will conclude by returning to the discussion of SES and late presentation. This section will then move on to psychosocial factors associated with late presentation, which constitute a more individual approach, yet play out over a background of each individual's perceived membership in a group, be it gender, race/ethnicity, or sexual orientation. This section will be constrained to the groups that comprise the bulk of the US population of PLWHA, thus the omission of races/ethnicities other than black, Latino, and white, and exposure categories such as intravenous drug use (IDU).

### *Part 1: Sociodemographic Factors*

#### *A. Late Presentation by Race/Ethnicity*

The division of individuals into groups by race/ethnicity<sup>1</sup> is controversial among social scientists and other researchers. Genomic evidence has shown that about 85 percent of human genetic variation is accounted for within, not between, populations, with only 6-10 percent accounted for by genetic differences between major racial/ethnic categories. (Rose and Rose). In other words, genetic differences between members of different racial/ethnic categories are scant relative to background individual variation. However, medical researchers have been more apt to retain a focus on racial/ethnic categories as having at least potential biological meaning, in part because small genetic differences can be significant for certain diseases. One example is breast cancer, which researchers have found expresses biological differences when comparing black American women with white American women, in that the basal-like subgroup of breast tumors is more frequent among black American women (Verma et al.). Although this phenotype is overrepresented in BRCA1-mutated breast cancers, there is no indication that harmful BRCA1 mutations are more common genotypes among black American women (Verma et al.). As such, there is uncertainty as to whether these biological differences in breast cancer tumor type are due to as-of-yet undetected genetic differences between populations, or to epigenetic or other effects. This example

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<sup>1</sup> The term "race" is often understood to refer to physiological features, including skin color, while the term "ethnicity" often refers to the culture and language or dialect of a group of people. This review will refer to "race/ethnicity" as a single, diverse entity, for there is little evidence for distinguishing phenotype from culture and language in discussing the epidemiology of HIV/AIDS.

demonstrates how research areas, such as medicine, may have use for racial/ethnic categories as markers for biological differences. However, there has been a movement to view race/ethnicity as socially constructed, and it is important to resist recourse to essentialist distinctions between racial or ethnic groups when the scientific evidence is not clear, for recent history of racist theories is a specter in any scientific discussion of race/ethnicity. It is this perspective that this review takes, for disparities in HIV/AIDS and late presentation for HIV care have not been attributed to biological differences between populations by racial/ethnic divisions. Rather it is the societal divisions in access to resources, in positions of social standing, in historical and present wealth, in privilege by skin color, in cultural practices and beliefs, and other differences, that most likely underpin these HIV/AIDS disparities. The discussion below seeks to better understand these disparities by examining racial/ethnic categories and SES.

#### *Late Presentation and Other Features among Black Americans*

In general, black American race/ethnicity is associated with later presentation for HIV care when compared to white American race/ethnicity. The large NA-ACCORD study found that for the year 2007, black Americans had a mean CD4 count at first presentation for HIV care of 328, versus 382 and 383 for whites and Latinos, respectively (Althoff et al.). A 2007 study of the Johns Hopkins clinic population found that from 2003 to 2006 black race/ethnicity was associated with a decrement of 71 CD4<sup>+</sup> cells/mm<sup>3</sup> at presentation, compared to white race/ethnicity, and that time to presentation to care following a positive diagnosis was more than two-fold for blacks over whites (264 versus 102 days) (Keruly et al.). The weakness of these data is that SES is rarely aggregated out or controlled for, such that the association of race/ethnicity with SES can be a confounder. With that caveat, later presentation for HIV care seems to be associated with black race/ethnicity. There are plausible explanations for this phenomenon in the literature. For example, a 1999 study in San Bernardino, California, found that 27 percent of respondents to a door-to-door survey of black adults agreed with the statement “HIV/AIDS is a man-made virus that the federal government made to kill and wipe out black people” (Klonoff et al.) These conspiracy beliefs exist in some form and to some extent among all ethnic groups (Clark et al.). However, the history of the Tuskegee syphilis experiments impose particular trust issues between black Americans and the medical establishment. It is possible that decreased trust in the healthcare system and lower SES may be reasons for the finding that black race/ethnicity is associated with later presentation for HIV care (Saha et al.; Clark et al.).

In addition, there is some suggestion in the literature that disparities with respect to other STIs may play a role in relatively high HIV rates among black Americans. In 2009, the last year for which CDC statistics are available, chlamydia was between 10.5 (relative to API race/ethnicity) and two (relative to American Indians) times more common among the black American population than among other races/ethnicities (CDC website). Similar disparities were observed for gonorrhea and syphilis. In addition, black race/ethnicity has been associated with increased risk for bacterial vaginosis (Cherpes et al.). There is

biologic plausibility to the theory that STIs may increase susceptibility to HIV infection by activating CD4+ T-lymphocytes (thereby facilitating HIV viral fusion with these cells), by contributing to a pro-inflammatory state (compromising mucosal barriers), and/or by increasing vaginal pH (reducing the activity of viricidal lactobacilli) (Sewankambo et al.). Although evidence is not clear, the syndemics (a term that will be returned to below) of STIs may play a role in the racial/ethnic disparities in HIV prevalence and, by extension, late presentation. Explaining one disease disparity in terms of others begs the question of why the other disparities exist; this is where psychosocial and historical factors, and SES, may fit in.

Another important feature of the HIV epidemic among black Americans is the recent spike in new infections among MSM. Between 2006 and 2009, rates of infection among black MSM aged 19-29 increased by about 50 percent. This surge is largely unexplained, but attempts have been made to narrow the range of hypotheses. For example, Millet et al., in a 2006 review, discredited several circulating hypotheses and highlighted certain theories regarding the high burden of HIV borne by black MSM. The review found no support for three hypotheses and concluded that (1) black MSM do not engage in more HIV risk behavior than other MSM, (2) HIV risk behavior is not associated with non-gay identity among black MSM (i.e., discrediting the “down low” theory), and (3) black MSM do not engage in greater rates of substance use than other MSM (Millet et al., 2006). Positive findings included that (1) black MSM, compared with other MSM, are more likely to report having had an STI in the past or to have a current diagnosis of an STI (increasing susceptibility to sexual transmission and acquisition of HIV), and (2) black MSM are less likely than other MSM to know their HIV status and to be tested for HIV early in the progression of their disease (Millet et al., 2006). Accordingly, the authors observed that rates of unrecognized HIV infection are higher among black MSM than among MSM of other races/ethnicities (Millet et al., 2006). Although black Americans are more likely than white Americans to test for HIV and to highly rank HIV as a serious community concern, higher rates of HIV infection among black MSM are explained at least in part by higher rates of undiagnosed HIV infection, late testing, and higher rates of STIs, compared to other MSM groups.

In a 2012 paper in the *Lancet*, Millett et al. expanded their analysis to include Canada and the UK, as well as the US. They found that in all three countries, black MSM were as likely to engage in serodiscordant unprotected sex as other MSM, and that in the US and Canada black MSM were less likely to have a history of substance use than other other MSM. These data lend credence to the finding from previous studies that risk behavior differences are not to account for the HIV disparities experienced by black MSM. In addition, the study found that US black MSM had a two-fold odds of having a structural barrier known to increase HIV risk, such as unemployment, low income, previous incarceration, or less educational attainment, compared with other US MSM (Millett et al., 2012). Furthermore, US HIV-positive black MSM were observed to be less likely to have health insurance, have a high CD4 count, to adhere to HAART, or to be virally suppressed, compared to other US HIV-positive MSM.

The picture here is of a significant role of SES in HIV disparities for black MSM in the US.

What about psychosocial factors? Ayala et al., applying bivariate and multivariate analysis to a large sample of cross-sectional data, found that for black and Latino MSM, higher rates of serodiscordant or unknown-status unprotected anal intercourse (UAI) were associated with experiences of social discrimination (racism and homophobia), financial hardship, and lack of social support (Ayala et al.). However, a key difference between the two groups (Latino MSM and black MSM) emerged in that homophobia appeared more important for HIV-positive black MSM, while lack of social support figured more prominently for HIV-negative Latino MSM, suggesting that the complex interplay of psychosocial issues and HIV risk is differentiated across serostatus and racial axes (Ayala et al.).

For black MSM, then, undiagnosed and delayed diagnosis of HIV infection interact with disproportionately higher rates of STIs in this group, raising the risk of transmission and of acquisition of HIV per sexual event. Significantly, theories about the higher prevalence of non-gay identify, risky sexual behavior, or substance use as drivers of the HIV epidemic among black MSM have not been supported by the data. However, possible under reporting of MSM status makes it difficult to rule out the "down low" theory. Some investigators have suggested that segregation in sexual social networks may serve to concentrate risk for black MSM. This suggestion has some basis in the literature, but remains an open question (Ayala et al.). The HIV epidemic among black MSM is complex, but an important role is played by late diagnosis.

Is black race/ethnicity a factor in LP?	Why?	What can be done?
Black American race/ethnicity has been the most consistent racial/ethnic risk factor for late presentation.	Undiagnosed infection, surge in infections among black MSM, and lower SES, relative to white Americans.	Focus on increased testing services in black American communities; offer HIV tests with other STIs tests and vice versa.

*A. Late Presentation by Race/Ethnicity*

*Late Presentations and Other Features among Latinos in the US*

The majority of studies have found that Latinos<sup>2</sup> are more likely to present late for HIV care compared to white Americans, but the picture is less clear when comparing rates of late presentation between Latinos and black Americans. A 2012 review of 25 articles examining delayed diagnosis and survival among

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2 The terms Latino and Hispanic are used interchangeably by some. However, "Hispanic" generally describes an individual with origin in a Spanish-speaking Central or South American country, whereas "Latino" generally denotes origin in any Central or South American country, e.g., including French Guinea. Since the literature rarely distinguishes between these two meanings, the chosen nomenclature for each cited study is retained in this review because Hispanic may be more specific than Latino. For the purposes of this paper, Latino is a racial/ethnic category that includes Hispanic.

Hispanics in the United States found that Hispanics were at significantly greater risk for delayed diagnosis than non-Hispanic whites (Chen et al.). In fact, CDC data have shown that 42 percent of individuals identifying as Hispanic/Latino receive an AIDS diagnosis one year after HIV diagnosis, compared with 39 percent of blacks and 37 percent of whites (CDC, 2009). While these CDC numbers are close, Chen et al. found that all sites in their 25-article review reported lower mean CD4 counts at presentation among Hispanics compared to non-Hispanics: 256 versus 376 cells/m<sup>3</sup> (Chen et al.). Nevertheless, some studies have found that Latinos present for care with less immune deterioration than black Americans (Althoff et al.). The heterogeneity of the Latino population in the US may be behind differing reports of the prevalence of late presentation in this group, as will be further discussed below.

The risk factors associated with late presentation within the Latino population help to tell this story. Hispanic males and foreign-born Hispanics are at greatest risk of late diagnosis, and other associated factors may be difficult to identify given that most studies examine national data, while the US Latino population is highly heterogeneous, with origins in over 20 countries and significant regional differences in the ratio of established versus newly-migrated individuals (Chen et al.; Dennis et al.). For example, Dennis et al. examined a 1999-2009 southeastern cohort of 853 patients (61 percent black American, 28 percent white, and 11 percent Latino) and found that mean CD4 counts at HIV care initiation were 302, 292, and 186 cells/m<sup>3</sup> for black Americans, white Americans, and Latinos, respectively (Dennis et al.). Given that the southeastern region is home to a population that has a higher percentage of foreign-born Latinos than the national average, this study argues for a geographically-nuanced approach to the Latino HIV epidemic.

What is the state of late presentation among Latinos in California, given that the state is home to a well-established population of Latinos, yet borders Mexico? A 2006 study looked at data from 2000-2002 in Northern California's San Mateo County and found that immigrants (78 percent Hispanic) were more likely to present with advanced HIV disease, with 287 versus 333 CD4 counts, 29.8 versus 17.2 percent likelihood of an opportunistic infection (OI), and 20.2 versus 12.5 percent chance of being hospitalized at HIV diagnosis (Levy et al.). This same study conducted interviews and identified lack of knowledge of HIV risk, social stigma, and secrecy as possible contributing factors to late presentation among the Hispanic informants (Levy et al.). In a study conducted in Southern California, completion of study interviews in Spanish was the main factor associated with late HIV testing for a group of largely Mexican-born Latinos (Wohl et al.). This finding underscores results from other studies that language is a key healthcare barrier for HIV-positive Latinos in the US (Lopez-Quintero et al.; Levy et al.).

In sum, Latinos have in most studies been found to be at greater risk for late presentation than non-Latino whites, and this disparity may be due to foreign-born status and language barriers. Another possible factor is fear, for a 2001 study found that 39 percent of a four-city national sample of undocumented

Latinos expressed fear about accessing medical services (Berk and Schurl). Thus, the association of foreign-born status with late presentation for HIV care among the Latino population may in part be mediated by fear of accessing medical care among undocumented persons. SES is also a potential mediator of late presentation for this group. The US Latino population is highly heterogeneous by geographic region and country of origin, making specification within this fastest growing segment of the US population particularly important.

Is Latino race/ethnicity a factor in LP?	Why?	What can be done?
This group has often been associated with an elevated risk for late presentation relative to white Americans, and sometimes relative to black Americans.	Language barriers, immigrant status, and fear of accessing medical care among undocumented persons may be at play.	Offer bilingual services, address fears among undocumented persons, and specify features of local Latino populations, as national population is highly heterogeneous.

*A. Late Presentation by Race/Ethnicity*

*Late Presentation and Other Features among White Americans*

Many studies have found that white Americans are at the lowest risk for late presentation for HIV care. A 2003 *MMWR* highlighted non-white race/ethnicity as a risk factor for receiving an AIDS diagnosis within one year of an HIV diagnosis during the 2000-2003 period in the US (CDC, 2003). A large Canadian and American sample examined by Althoff et al. in 2010 (NA-ACCORD) showed that in 2007, whites in North America were entering HIV care with CD4 counts that were the highest (about 380), along with those of Latinos, of any other racial/ethnic group (Althoff et al.). A study of South Carolina residents, 2004-2008, showed that white Americans entered care more quickly than black Americans; likewise, a 2007 study of 2006 diagnoses in Baltimore found that Americans had higher CD4 counts at diagnosis than black Americans (Tripathi et al.; Keruly et al.). Finally, studies that looked more closely at Latinos and white Americans entering HIV care in the US have on balance found that white Americans enter earlier in their disease course: Chen et al. conducted a 2011 meta-analysis and concluded that 7 of 8 studies reviewed found that Latinos were at greater risk than white Americans for late presentation (Chen et al., 2011).

Two features of late presentation research findings by white race/ethnicity merit notice. First, white race/ethnicity is disproportionately associated with urban MSM and with IDU, two significant risk factors for HIV (Catania et al., 2006; Armstrong, 2007). Although white race/ethnicity overall is weakly associated with late presentation, these other exposure categories may be significant, depending on the individual. Second, having private, rather than public, insurance at time of HIV diagnosis has been associated with increased risk for late presentation (Schwarcz et al.; Yang et al.). Non-Latino whites are significantly more likely than black Americans or Latinos to have private health insurance (75.5 percent, versus 53.3 and 44.2, respectively) (US Census Bureau, 2006). Thus, although SES is likely a major factor in the finding that

white race/ethnicity is least associated with late presentation, private insurance status confers an added risk of late presentation and white Americans are more likely than other racial/ethnic groups to have private insurance. This finding is likely explained by a decreased awareness of HIV risk among individuals with private insurance, underscoring that access to health care is not enough: in order for an individual to benefit from HIV testing and HIV care, that individual must be aware of her or his risk of contracting HIV.

<b>Is white race/ethnicity a factor in LP?</b>	<b>Why?</b>	<b>Any caveats?</b>
Many studies have identified this group as the racial/ethnic group at lowest risk for late presentation.	May be due to higher SES and other societal privileges.	Private insurance, MSM, and IDU are individual features associated with late presentation.

### *B. Late Presentation by Gender*

#### *Late Presentation and Other Features among Women*

Women have been shown in several studies to have a lower risk than men of late initiation of HAART after an HIV diagnosis (Mayben et al.; Keruly et al.; Althoff et al.). Additionally, CDC numbers show that 34.8 percent of newly-diagnosed women progress to AIDS within one year, versus 40.2 percent of men (CDC, 2009). It is likely that test-offering during pregnancy accounts for some of this difference, but other factors may also be at play, such as lower health care utilization among men, lower access to health care among men, lower likelihood of being insured among men, and annual gynecological examination norms for women, during which sexual risk may be discussed. However, other studies have found women presenting later than men (CDC, 2003). Possible reasons for this include that women may face unique barriers to accessing health care, such as arranging for child or other dependent care. In fact, another study found that having children was significantly associated with late presentation (Bonjour et al.). In addition, as mentioned above, women face unique challenges in accessing and utilizing HIV care, including gender roles, pregnancy, and oral contraceptive use, which can interact with HIV medications and complicate care (Aziz et al.). It appears that while women in general present for HIV care earlier than men, specific circumstances also play their role.

Within the female population, black and Latino women have been found to be more likely to test positive late in their disease course and to suffer higher rates of HIV-related OIs than white women (Duffus et al.; Losina et al.). El-Sadr et al. point out that minority women are more likely than white women to live in vulnerable economic conditions in geographic regions that determine high HIV prevalence within their sexual networks (El-Sadr et al.). Furthermore, the researchers acknowledge that little is known about risk factors among women due to difficulty in engaging minority and high-risk women in prevention studies (El-Sadr et al.).

Is female gender a factor in LP?	Why?	Any caveats?
In general, female gender may be slightly protective of late presentation.	May be due to higher healthcare utilization among women, compared to men.	Having children may be a risk factor for late presentation; black American and Latino women are more likely to test late.

## B. Late Presentation by Gender

### *Late Presentation and Other Features among Men*

The relationship between late presentation and MSM was discussed in the above sections addressing risk groups by race/ethnicity. A large number of studies have found delays in entering HIV care associated with male gender, and many have found delays associated with heterosexual exposure. For example, the NA-ACCORD data cited several times above, shows that for the period 1997-2007 across North America, men were entering HIV care with about -40 CD4 counts, vis-à-vis women, and that individuals who reported heterosexual exposure, by 2007, had overtaken MSM as the exposure group most at risk for late presentation (Althoff et al.). Similarly, Houston data over the 2000 period showed that men had a 1.74 odds for late presentation versus women, and that men reporting heterosexual exposure had a 1.4 odds for late presentation versus those reporting sex with men (Yang et al., 2010). Maryland data from the period 1990-2006 also showed depressed CD4 counts at presentation for men, versus women, and those reporting heterosexual exposure versus MSM (Keruly et al., 2007). Finally, data from San Francisco between 2001 and 2005 revealed that, although women and men were at roughly equal risk for late presentation, persons reporting heterosexual exposure were at nearly 20 percent greater risk of late presentation (Schwarcz et al., 2006). With regards to why this might be, another finding from this same Schwarcz et al. study is intriguing: the greatest risk factor for late presentation, among the sociodemographic features examined, was reporting *no risk factor whatsoever*. It seems likely that low perception of risk combined with fewer public health campaigns targeting this group are plausible explanations for the association of heterosexual exposure with delayed presentation for HIV care. With regards to male gender and risk for delayed presentation, Tripathi et al. specifically examined time to entering care after an HIV diagnosis and found, among their South Carolina cohort, that men entered significantly later than women (Tripathi et al., 2011). Thus, it is possible that men are both testing late, due to lack of yearly and/or pregnancy-related healthcare contacts, as women generally have, and entering care late after testing positive, which remains unexplained but may be related to lower habitual healthcare access, relative to women.



<b>Is male gender a factor in LP?</b>	<b>Why?</b>	<b>What can be done?</b>
Most studies have found that male gender is a significant risk factor for late presentation.	(1) It may be that men access healthcare less frequently and thus test less frequently. (2) Heterosexual status may confer a risk due to lack of awareness of HIV risk.	(1) Explore avenues to offer HIV testing to more men. (2) Consistent health provider messages about HIV risk across gender and sexual orientation groups.

### *C. Late Presentation by Age*

Older age has frequently been found to be associated with late presentation for HIV care. The large NA-ACCORD sample found a decrement of 24 CD4 cells at presentation associated with older age, a Duke University clinic sampling between 2002-2004 observed that older patients had a 1.72 odds for late presentation, and a sampling in Philadelphia between 2005 and 2006 found that age over 40 was associated with late presentation (Althoff et al.; Mugavero et al.; Bamford et al.). The reasons for this pattern are not entirely clear, but two possibilities run through the literature: (1) decreased perception of risk among individuals of older age, and/or (2) differential pathophysiology of HIV infections in older individuals. With regards to the first, there is no consensus about whether this is indeed the case, or why it might be, but an interesting study by the UK researchers speculates that decreased sense of risk among older individuals may result from lack of information regarding HIV available in clinics, or a reluctance on the part of older individuals to discuss sexual risk with health practitioners. It was also suggested that such reluctance on the part of health practitioners may also play a significant role (Smith et al., 2010). The second possibility points up that the immunology and pathophysiology of HIV infection are not fully understood. Yang et al. observe that for each 10 years' increase in age at presentation for HIV care, there is a 1.5 odds increase of late presentation (Yang et al., 2010). The fact that this finding is continuous is suggestive of an immunologic explanation, such as increased immunosuppression with age, but this has not been definitively determined.

<b>Is age a factor in LP?</b>	<b>Why?</b>	<b>What can be done?</b>
Many studies have found that older age is associated with a greater risk of presenting late for HIV care.	(1) Possible decreased perception of risk in this population; (2) Possible accelerated immune system degradation.	(1) Produce public health materials for different age groups; (2) Consistent health provider messages about HIV risk across age groups.

### *Part 1 Conclusion: Return to SES*

The discussion above touched upon SES while focusing on racial/ethnic disparities in HIV infection and the timing of HIV care. To what extent are societal disparities in access to resources such as wealth, healthcare, advantageous social connections, and knowledge, to social standing and power, and other inequalities, determined along SES and racial/ethnic divisions? To what extent are these inequalities to blame for disparities in late presentation for HIV care by racial/ethnic category? Above, mention was made

that some research has shown that neighborhood-level SES, independent of access to healthcare, is predictive of late presentation, and that higher SES has been associated with slower HIV disease progression, also independent of access to health care (Joy et al.; Schechter et al.). Rubin, Colen, and Link published in 2010 regarding HIV mortality and its relation to SES and race/ethnicity. They found, importantly, that the HAART era, although responsible for reductions in absolute decreases in HIV mortality in all racial/ethnic groups and SES strata, is strongly associated with an increase in HIV mortality disparities across these same divisions (Rubin, Colen, and Link). This research group defined SES according to education, occupation, and income; their results suggested that the association between SES and HIV mortality and between race/ethnicity and HIV mortality were operating independently. Although this study did not look at late presentation, it is highly suggestive that it examined HIV mortality disparities across time and concluded that the HAART era has exacerbated disparities in HIV mortality. If the benefits of HAART accrue to groups according in part to their levels of discrimination and access to the benefits of higher SES, we would expect similar effects to occur with other diseases, as well.

Cancer researchers are also concerned with disease stage at the time of presentation for cancer care, as for many cancers the stage of disease is highly determinative of treatment success. Breast cancer researchers have found that black American women present at a more advanced disease stage relative to white American women, and that in the UK, black British women and white British women matched by SES showed no differences in stage of disease at presentation (Verma et al.). This finding suggests that race/ethnicity and/or SES play a role in stage of disease at presentation for breast cancer care. A study of colorectal cancer care in the US found that low income, black American race/ethnicity, male gender, and urban residence were associated with stage IV disease at presentation (Paquette and Finlayson). A third study of invasive cervical cancer in Florida concluded that racial/ethnic and SES disparities in cervical cancer survival were explained by late-stage presentation and under treatment (Brookfield et al.). This brief review of cancer studies suggests that race/ethnicity and SES play a role in societal disparities in late disease presentation for cancer care, as well as for HIV/AIDS care.

Rubin, Colen, and Link argue that racial/ethnic and SES divisions in society determine exposure to discrimination and prejudice, and access to money, power, prestige, and beneficial social connections. As medical advances are made, disproportionate access to its benefits can lead to the emergence or exacerbation of health inequalities along these divisions, such as those Rubin, Colen, and Link demonstrated with regards to HAART and HIV/AIDS mortality. It may be that thirty years into the HIV epidemic, late presentation is a problem along these lines: a health disparity largely determined by societal inequalities. This squares with the facts that similar late presentation disparities exist for some cancers and that rates of late presentation for HIV care have been comparable across several countries (Carrizosa et al.; Bonjour et al.). More research is needed in this area, but it is clear that racial/ethnic categories and

SES contribute to the problem of late presentation for HIV care. What can be done? There is certainly a need for structural changes in US health care and HIV care, such as equitable access to medical care and greater funding for prevention and testing efforts. Another answer is to take a closer look at the health care needs of the population of late presenters for HIV care, using this view as a departure point for better contextualization of HIV care. If late presenters for HIV care are more likely to be socially disadvantaged, then there are probably unique health care challenges in this group. This is the approach that will be embarked on below in an examination of psychosocial and psychological factors in late presentation.

*Part 2: Psychosocial Factors*  
*Statistical Associations*

This section summarizes three recent studies that investigated the relationship between late presentation for HIV care and psychosocial factors, by which is meant the interrelation of social factors and individual thought and behavior. A related psychosocial issue, stigma, will be addressed briefly here, as it relates to the results of one of these three studies focusing on psychosocial issues, and separately, in the next section. These studies are summarized together because they are the only studies identified by a 2012 major review to apply statistical analysis to uncover associations between psychosocial factors and late presentation for HIV care (Mukolo et al.). Taken together, these studies stand out for: (1) examining and rejecting the hypothesis that health literacy, at least in one study population, is a significant factor in late presentation (Mayben et al.); (2) a finding suggesting a bidirectional (i.e., variably facilitating or inhibiting) role of fear in HIV disease presentation (Bonjour et al.); and (3) positing a counterintuitive protective effect of social stigma (Carrizosa et al.).

It is a reasonable presumption that health literacy might play a role in late presentation for HIV care. Knowledge about the mechanisms of HIV infection, about HIV's latency period, specific opportunistic infection manifestations, locations of HIV testing sites, etc., could all be expected to depend on an individual's ability to integrate health information from various sources. A major source of health information is the printed word, either through print media, web-based resources, or fliers and pamphlets commonly available in clinics. In fact, according to the National Adult Literacy Survey, approximately 40-44 million (21 to 23 percent) adults in the United States are functionally illiterate and an additional 50 million (25 to 28 percent) adults are marginally literate. Furthermore, poor health literacy has been associated with lower adherence to antiretroviral medications (Kalichman et al.). A 2007 study conducted at four public clinics in Houston, Texas, applied a survey designed to assess health literacy to 119 newly-diagnosed, uninsured HIV patients (diagnosis within the past 3 years). Although this population had a high rate of late disease-state presentation (65 percent had a first CD4+ T-cell count post-diagnosis below 350 cells/mm<sup>3</sup>) and 28 percent had inadequate health literacy, there was no association between the two. This finding suggests that written materials pertaining to HIV either do not reach or do no influence this population (Mayben et al.).

What significant findings were turned up by this health literacy survey? Men had a lower CD4 count at diagnosis than women, which has been seen in prior studies and was discussed above. The main associated factor with low CD4 count at diagnosis was "feeling sick." The use of marijuana or other illicit substances was also correlated with earlier diagnosis, which may signify either that individuals who use these substances have a higher self-perception of risk, or that providers recognize these behaviors as high-risk, or both. Lastly, race/ethnicity was not associated with late presentation in this study, contrasting with CDC data and other findings; interestingly, the study sample was of uniform SES across all races/ethnicities. The authors astutely point out that CDC data are not adjusted for income and insurance status and suggest that these may be the driver of the CDC finding that Hispanic and black American persons are diagnosed later than white persons (Mayben et al.). This potentially confounding effect of income and insurance status may also be at play in other studies.

A 2007 study in Venezuela worked with a national program offering free HIV services and conducted interviews with new patients. The percentage of late presenters among HIV patients in the Venezuelan region of this study is similar to that in the US (41 percent in the Venezuelan region). This group also found that lower SES was associated with late presentation. However, this study's key finding was the contrasting association evinced by risk perception, depending on different proxies. For example, *not-wanting-to-know one's status* was found to be positively associated with late presentation, and *fear to be diagnosed* and *fear of partner unfaithfulness* were both negatively associated. The authors suggest that not-wanting-to-know may be a proxy for fear of stigma or a general avoidant coping strategy. Fear of diagnosis may be a proxy for perception of risk, which, the data suggested, may result in seeking care/testing when combined with another factor, such as feeling symptoms of illness. This finding matches an earlier study that concluded that, on average, individuals who feel at risk for HIV wait a year before testing, usually requiring some sort of "trigger" (Bonjour et al.; Ransom et al.). A trigger could be a health system contact, an emerging symptom of an OI, or any of many possible life events.

A 2010 study of Mexican patients described factors associated with late presentation in Tijuana. The prevalence of late presentation in the study sample (43.2 percent) was within the range for Latinos in the US (23-49 percent). In parallel with the study most recently discussed above, *preferring not to know* showed a strong positive association. This is consonant with an earlier study of French patients (Couturier et al.). Exposure to peers engaging in high-risk sexual behavior was less strongly associated, but still a significant correlate of late testing. The study created two stigma scales and found that higher levels of stigma were *protective* of late testing, which, the authors speculate, may reflect the stigmatizing experience of the testing experience itself (Carrizosa et al.). This interesting finding and speculation raise the issue that there are different sorts of stigma; greater sensitivity in assessing stigma could help to clarify the situation.

### *Psychosocial Factors: Qualitative and Focus Group Studies*

A 2009 focus group study of 37 HIV-positive individuals, who had not been receiving HIV care in the previous six months, turned up three key psychosocial health belief-related barriers: (1) *avoidance and disbelief of HIV serostatus*, (2) *conceptions of illness and appropriate health care*, and (3) *negative experiences with, and distrust of, health care providers and the health care system*. All three of these themes emerged across five focus groups in five cities: Indianapolis, Indiana; Newark, New Jersey; New York, New York; Philadelphia, Pennsylvania; and Seattle, Washington (2006-2007). Interestingly, avoidance of HIV serostatus was in part related to fear of receiving bad news about the laboratory findings related to HIV (e.g., HIV viral load, CD4+ T-cell count). This may reflect a popular belief that negative reinforcement about one's health status can constitute a self-fulfilling prophecy, worsening one's health via the negative reaction to the bad news. This belief can gain traction perhaps in part due to HIV's long latency period before noticeable health deterioration sets in. This aspect of avoidance of HIV serostatus ties in with negative experiences with health providers as many informants in this study described a desire to have an opportunity to process the fact of their infection, which they said was disturbed by the focus on the part of medical providers on the numbers related to HIV infection clinical management (Beer et al.).

Fear of information regarding HIV serostatus ties in with conceptions of illness, as well. Many respondents to the focus group study expressed the belief that HIV medical care is not necessary when one is healthy. Keeping in mind that all of these informants had not received HIV medical care six months or more prior to participating in the study, it is significant that the recently-emerged consensus that HIV treatment is indicated at an early disease state (i.e., at diagnosis) contrasts with the beliefs expressed by this study population. Perhaps this represent a dissonance between clinical consensus and popular belief in the HIV-positive community, or at least those most likely to present late for treatment. This phenomenon may be due to a lag between the consensus in clinical understanding and messaging to the public, or to the segments of the public most at risk for late presentation.

### *Mental Illness and Substance Use*

There is evidence that PLWHA suffer a disproportionate burden of mental illness and substance use. 2008 study of HIV patients in care in Seattle, Washington, found that among 1744 patients, 63 percent had a mental illness (e.g., mood, anxiety, psychotic, or personality disorders), 45 percent had a substance use disorder, and 38 percent had both (Tegger et al.). Furthermore, patients with co-occurring mental illness and substance use disorders took longer to initiate HAART relative to patients with only a mental illness or only a substance use disorder (Tegger et al.). A 2006 review found that the prevalence of co-occurring mental illness and substance use ranged from 10 to 28 percent in PLWHA, a rate higher than that in the general population (Chander et al.). This line of research supports standard screening of HIV patients for mental illness and substance use, the provision of psychiatric and substance use treatment in the HIV primary care setting, and co-screening/testing efforts for

mental illness, substance use, and HIV infection in the general population.

### *Stigma and Coping Styles*

The application of the concept of stigma to HIV/AIDS has a long history and goes back at least to the mid-1980s. Many discussions of HIV/AIDS and stigma have been framed by Goffman's definition of stigma as "an attribute that is significantly discrediting in the eyes of society," creating "a spoiled identity" for the person concerned (Parker et al.). There are controversies within the literature about the extent to which HIV stigma is an individualized phenomenon or a functioning of processes of social inequality, and whether HIV-AIDS-related stigma can be measured across cultural contexts, or is culturally specific (Parker et al.; Genberg et al.). Nevertheless, the importance of stigma overshadows persistent difficulties in measuring and describing it. Stigma can be broken down into three parts: (1) enacted stigma, (2) felt stigma, and (3) internalized stigma; divisions similar to this are common in the literature. Taken as a single entity, stigma can create the feeling of wanting to keep one's HIV status secret, which may create barriers to HIV care (Heckman et al.). In addition, HIV stigma can contribute to individuals delaying testing for HIV and/or putting off HIV care (Fortenberry et al.).

Another feature of stigma is the potential for layering of different forms of stigma. For example, a 2010 study found high levels of both HIV and sexual minority (i.e., non-heterosexual) stigma among a group of black HIV-positive MSM; HIV stigma was significantly associated in this group with engaging in unprotected sex while high or intoxicated (Radcliffe et al.). HIV-positive MSM who are persons of color may be particularly vulnerable to a confluence of forms of stigma due to racial and cultural factors. Furthermore, stigma in young MSM in general has been associated with increased risk for depression, anxiety, and romantic loneliness (Dowshen et al.). Thus the dynamic of stigma layering intersects with a nexus involving stigma and other psychological morbidities; the potential for complex synergistic negative health impacts is great.

It may be that stigma's impact on HIV outcomes is mediated by an individual's coping style for psychological stress such as that arising from stigmatization. In fact, a socially inhibited temperament (i.e., introversion, reduced emotional expression, and social avoidance) has been connected to a higher HIV viral load set-point and impaired virologic and immunologic response to antiretroviral therapy (Cole SW et al.). Furthermore, two coping styles have been found to be associated with different measures of immune function that are themselves associated with HIV disease progression. Specifically, "alexithymia," defined as a deficit in cognitive processing and regulation of emotion and externally-oriented thinking, was related in one study to decreased production of an anti-HIV and anti-inflammatory chemokine (MIP-1 $\alpha$ ). The same study also examined "Type C coping," which is similar to alexithymia but involves a lack of awareness on the part of the individual that she or he is distressed. Type C coping was associated with higher production of IL-6, a pro-inflammatory cytokine that increases HIV replication (Temoshok LR et al.; Lawn et al.). Other

researchers have found that personality types/coping styles are associated with poor HIV disease prognosis (Chida and Vedhara). The link between coping and immune correlates is an emerging area, but offers a bridge between psychosocial factors in HIV disease progression and late presentation, on the one hand, and the specific biology of HIV infection on the other. The possible effect of coping styles is not limited to possible immunologic effects, for maladaptive coping styles may lead to behaviors and/or psychological states, such as substance use or depression, that themselves contribute to late presentation for HIV care.

### *Social Support*

Coping styles and stigma are important social and psychological dynamics with regards to late presentation. Social support may play an important role, as well. For example, a study published in 2012 found evidence that social support among a cohort of Chinese patients living with HIV mediates the impact of stigma on both depressive symptoms and reduced quality of life (Rao et al.). Moreover, a 2012 US study showed evidence that supportive social relationships protect against the risk of unrecognized HIV infection among black and Latino MSM, possibly by lessening fears of rejection upon testing positive for HIV (Lauby et al.). Because this study examined a group of men who were diagnosed through the study procedure, and not a group already in HIV care, the finding that social support may mitigate HIV testing stigma has important implications regarding late presentation for HIV care. Research in this area is developing and more information is needed to illuminate the connections between social support, stigma, and coping styles.

### **V. Conclusion**

The problem of late initiation of HAART in the US involves a collection of many community-specific issues. For instance, research has suggested that among men who have sex with men (MSM), a group that accounts for roughly half of all US HIV infections, intensive case management, health systems navigators, and attention to synergistic health issues specific to MSM are all good potential strategies for improving engagement into HIV care for this group (Christopoulos et al.). Examples of synergistic health issues specific to MSM include the "syndemics" of childhood sexual abuse, poly-substance use, partner violence, and depression (Christopoulos et al.). A "syndemic" can be defined as *a concentration of two or more diseases or other health conditions in which there is an interaction among them that magnifies the negative health effects of one or more of the co-present diseases or health conditions*. A large cross-sectional study of MSM in four large US cities found an independent association between childhood sexual abuse, poly-substance abuse, partner violence, and depression; furthermore, as the number of these factors increased, so too did the odds of high-risk sexual behavior and of being infected with HIV (Stall et al.). This finding supports a multi-pronged approach that addresses the syndemics driving the HIV epidemic in this population.

A high degree of heterogeneity has been appreciated in the various sub-populations of the HIV epidemic. For instance, the sections above on

psychosocial and psychological factors associated with late presentation addressed: social support, coping styles, stigma, mental illness, and substance use disorders. The co-morbidities of mental illness and substance use are higher in the HIV population and may be part of the syndemics in the late presenting population of HIV patients. The psychological features of social support and coping styles may be key to understanding the impact of the stigmas, such as HIV stigma and homosexual stigma, on late presenting HIV patients, as well. Attentiveness to the particular character and syndemic interactions within each sub-population is of special importance in designing strategies for addressing late initiation of HAART. Furthermore, a feature of a syndemic is that structural intervention is generally needed for meaningful effect, in addition to individual interventions.

One of the strengths of qualitative research is in answering *Why* questions; the issue of late presentation for HIV care is one of these questions and the answer to it is most likely multifaceted and complex. Through attentiveness to the particulars of individual stories, connections can begin to be made with the macroscopic trends of the HIV epidemic, many of which have been traced above. The syndemic approach is an example of how an attuned awareness to the interlacing health problems within a specific population can lead to more nuanced statistical methods. The literature on late presentation for HIV care is turning to psychosocial issues in a similar manner: in search of new subtleties with which to tease out more realistic, and more complex, associations from the mass of data available.

The research that this review supports sets out to apply a qualitative approach to analyzing interviews with HIV patients. These narratives touch upon awareness of risk, testing positive for HIV, and entering HIV care. The analysis will center on social support, coping style, and stigma; mental illness, trust in medical care, and substance use will also be addressed. How these factors function to contribute to or mitigate against late presentation for HIV care in a group of Oakland HIV patients will be the focus of the analysis. Furthermore, how these themes interact with each other will also be investigated. One of the lessons of the foregoing review is that late presentation for HIV care is in part determined by syndemics in HIV-positive and HIV-at-risk populations. It is hoped that the analysis resulting from the continuation of this project will contribute to a better understanding of psychological and psychosocial determinants of late presentation. The HIV epidemic in the United States is more than thirty years old and is now deeply entrenched according to lines of societal division, such as SES and race/ethnicity. Many barriers to adequate HIV care converge to keep certain patients out of timely treatment and it is likely that it is precisely this population that is the most disadvantaged and the most complex to serve. Therefore, the continuation of this project seeks to illuminate some of the specific needs of an Oakland population of HIV patients, some of them late initiators and some early initiators of antiretroviral care, so that further study and interventional design may be facilitated, particularly in the psychosocial domains of stigma, social support, and coping styles.



**PART II:  
ANALYSIS:  
THE MANY ASPECTS OF STIGMA: ENGAGEMENT-IN-CARE NARRATIVES  
OF HIV PATIENTS AT AN OAKLAND CLINIC**

**Introduction**

Lack of engagement in HIV care has justifiably come to be a focus of great concern in recent public health literature (e.g., Gardner, McLees, Steiner, del Rio, & Burman, 2011). Engagement in HIV care can be understood as encompassing timely presentation to clinical care, retention in clinical care, initiation of antiretroviral therapy before substantial immune decline, and adherence to medication. More than 1.2 million individuals are infected with HIV in the US today (CDC, 2012[7]). Lack of engagement in HIV care has impacts both for the broader HIV epidemic and for the individual patient: individuals not in optimal medical care are much more infectious and at much greater risk for HIV-related morbidity and mortality (Marks, Crepaz, & Janssen, 2006). The CDC warns that if overall engagement in HIV care is not improved, the total number of persons infected with HIV in the US will double over the next 20 years (CDC, 2011[6]). Sicker individuals and a growing epidemic are the consequences of pervasive lack of engagement in HIV care.

Many factors have been identified that impinge on engagement in care, such as mental illnesses like depression and anxiety, trauma, substance use, lack of social support, poverty, membership in a group not traditionally defined at high-risk for HIV (e.g., heterosexual men), and discrimination (Mukolo, Villegas, Aliyu, & Wallston, 2013). This paper considers in particular the role of stigma as a multi-layered nexus of discrimination and of many of these aforementioned factors. The effects of stigmatization are believed to play a role in HIV-infected individuals avoiding testing, delaying presentation to clinic following diagnosis, and underutilizing available HIV care (Kinsler, Mitchell, Sayles, Davis, & Cunningham, 2007).

In the past decade, key publications in the field of HIV-related stigma have pointed up cardinal features of the field: (1) the term “stigma” is often used in a vague manner; (2) little is known about how stigma operates, especially in its moral dimensions (e.g., instances in which stigma-related values are linked to physical or emotional states); (3) the social context has been underemphasized in stigma theorizing and research; and (4) further ethnographic inquiry and case histories are needed to enrich and “resocialize” survey-dominated research in stigma (Kleinman & Hall-Clifford, 2009; Parker & Aggleton, 2003; Castro & Farmer, 2005). It is with this backdrop that this paper seeks to carry out context-specific conceptual work by applying Pierre Bourdieu’s notion of symbolic violence to a discussion of insidious discrimination and internalized stigma. Also, qualitative interview analysis is employed to illuminate HIV stigma and other relevant and layered instances of stigma, for without better understanding of how HIV-related stigma operates, intervention design is hampered.

**Theoretical Framework**

A focus on what is meant here by the term “stigma” is useful. Erving Goffman (1963), in landmark work on stigma nearly 50 years ago, combined the concepts of (1) attribution and (2) social discreditation to characterize stigma. Several commentators have emphasized that Goffman’s original formulation located stigma as emerging in social relationships (Castro & Farmer; Parker & Aggleton). These commentators have sought to rehabilitate the social dimension of stigma, which has to the contrary often been written about (commonly citing Goffman) as solely or primarily located within the individual. Yang, Kleinman, Link, Phelan, Lee, & Good (2007), and others, have pointed out that stigma research has overemphasized survey methodology in an attempt to characterize the individual dimensions of stigma.

**Table 1: Definitions of Key Terms**

<b>Stigma</b>	Link & Phelan definition (2001). Results in disapproval, rejection, exclusion, and discrimination. See text for more.
<b>Internalized</b>	Internalized stigma describes the process whereby an individual accepts the legitimacy of stigmatization and reproduces some or all of the effects of stigma <i>without the presence of an external stigmatizer</i> .
<b>Discrimination</b>	Maluwa, Aggleton, & Parker definition (2002). An outcome of stigma that arises “when, in the absence of objective justification, a distinction is made against a person that results in that person’s being treated unfairly and unjustly on the basis of belonging or being perceived to belong, to a particular group.”
<b>Individual</b>	Individual discrimination describes the loss of a tangible benefit, such as employment or housing, as a result of labeling and stereotyping--in short, as a result of stigma.
<b>Structural</b>	Structural discrimination describes a wider social process. An example is the placement of a trash incinerator in a neighborhood without sufficient or appropriate social, political, or financial capital to oppose such a proposal.
<b>Insidious</b>	Insidious discrimination describes the subtle process of an individual accepting negative valuations about herself or himself due to stigma and acting in ways that lead to self-deprivation or self-harm.

In the 2000s, Link and Phelan (2001) delineated a sociological formulation of six aspects of stigmatization: “...stigma exists when elements of (1) labeling, (2) stereotyping, (3) separation, (4) status loss, and (5) discrimination occur together in (6) a power situation that allows them.” Link & Phelan go on to elucidate three types of discrimination: individual, structural, and an insidious form that flows from a modified labeling theory (see Table 1 for definitions of key terms). Another important feature of stigmatization as it is considered here is that it occurs as a matter of degree. This is determined by the “steepness” of

the power gradient along which stigma is socially constructed, as well as by cultural, historical, and economic factors. By the same token, multiple forms of stigma can layer upon one another, contributing to a situation in which the degree of power asymmetry and the number of stigmatizing marks (e.g., due to both a homosexual and illicit drug user status) multiply the impact of stigma.

This paper argues that insidious and internalized stigma offer fruitful theoretical territory for working out how the individual features of stigma connect to the wider social spaces in which stigma is produced and reproduced. Specifically, media messages, family attitudes, and clinical interactions were highlighted by the interviews considered here as social settings in which stigmatization occurs and takes root.

### **Setting and Research Methods**

The interviews upon which this paper is based were carried out at a large HIV/AIDS clinic in the city of Oakland in the eastern San Francisco Bay Area. Alameda County (which contains Oakland) and neighboring Contra Costa County together comprise the administrative entity known as the Oakland Transitional Grant Area (TGA), which collects regional statistics relating to HIV/AIDS. Through 2010, the TGA estimated that 10,243 persons were living with HIV within its boundaries (Oakland TGA). Oakland accounted for between 54 and 65 percent of the AIDS cases in Alameda County in the years before 2007, the last year for which Alameda County issued a comprehensive HIV/AIDS report (Alameda County). Of note, the HIV epidemic in Oakland has a different character than the epidemics in the Los Angeles or San Francisco metropolitan areas. Although male-to-male sexual contact is believed to be the major exposure route in all three, Oakland has fewer cases attributable to this exposure and more each believed to be due to heterosexual contact and injection drug use (IDU). Because of these features, the HIV epidemic in Oakland is more typical of that in an East Coast metropolitan region than in a western one.

Interviews were carried out 2007-2008 with 31 patients entering HIV care July 2005 to June 2006. New patients were recruited and screened by a nurse prior to being enrolled; inclusion criteria were (1) greater than 18 years of age, and (2) a newly-enrolled HIV-positive patient in the period July 2005 to June 2006. A concurrent chart review of 113 patients at the same clinic revealed that about 30 percent of new patients entering HIV care were “late presenters,” i.e., had CD4+ counts below 200 or an AIDS diagnosis.<sup>3</sup> Semi-structured interviews explored beliefs and attitudes regarding awareness of HIV risk, testing, entry to care, and maintenance in care. Basic demographic information of informants is summarized in Table 2 (next page); ages at the time of interview are given parenthetically when informants are discussed below. Interviews were carried

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<sup>3</sup> Usually made by the presence of an AIDS-defining opportunistic infection; see the World Health Organization’s website for more information: <http://www.who.int/hiv/strategic/surveillance/definitions/en/>.

**Table 2: Sociodemographic Information for the 31 Informants**

Characteristic	# (N=31)
<i>Age (Years)</i>	-
18-24	3
25-50	19
>50	9
<i>CD4+ Count (First)</i>	-
<200 ("Late")	10
>200 ("Early")	21
<i>Gender</i>	-
Female	6
Male	25
<i>Race/Ethnicity</i>	-
European American	11
African American	9
Latino	9
Native	1
Asian/Pacific Islander	1

out by two study staff members, a non-Hispanic white woman, age 22, who carried out the majority of the interviews, and a non-Hispanic white male in his 30s. Interviews were recorded, transcribed, and then audio recordings were destroyed. Descriptive and analytical open coding was the first step in the analysis. Subsequently, portions of the interviews were revisited through focused coding around the topic of stigma, which emerged early on as a key issue (Emerson, Fretz, & Shaw, 1995). Microsoft Excel was used to organize instrumental quotes. The research question that crystallized was, *How is stigma operating in this sample and affecting the trajectory into and maintenance of clinical HIV care?* The present analysis proceeds from focused coding of 17 interviews that yielded five examples of stigma. A selection of quotes from 8 interviewees represents these five examples.

Original data collection was approved by the Alta Bates Institutional Review Board (IRB). All participants gave prior written consent before interviews were carried out. The present analysis of the preexisting, deidentified interview transcripts was deemed by the University of California, Berkeley IRB to not

meet the federal definition of human subjects research.

## **Findings**

### *(1) HIV Stigma*

Sam (age: 49) is a gay man brought up in a military household where his sexuality was problematic. During the height of the HIV epidemic, he cared for three partners who died of AIDS, yet he avoided infection with HIV. However, he ultimately tested HIV-positive:

I feel that the psychologic and the social stigma-- that's the worst part about the whole disease. Not the treatment or the fact that you have it, but to me it's an enormous psychological stress added to life that you have to manage, but then it's a social stigma, too. Especially if you find somebody that you like being around, being with, if they're negative, or whether they're positive, it turns the whole dating process crazy, it makes it all nuts for me. [...] I accepted it. I just didn't want to deal with the stigma, having it on the health records and being denied life insurance.

For nine years Sam attended no clinic appointments related to his positive HIV test. While it is impossible to fully understand such an experience, we might take at face value Sam's emphasis on his view of the stigma associated with positive serostatus. Sam's story of fearing disclosure of his HIV status to potential sexual partners can be read as insidious discrimination because this aspect plays out internally and leads him to constrain his social network, an example of self-harm. Adding to this precarious position, Sam also underscores in his narrative the anxieties associated with structural discrimination in the form of life insurance jeopardy in the wake of an HIV diagnosis.

Younger interviewees also spoke about the mark of being HIV-positive. Dave (age: 20s) came in for HIV clinical care one month after learning of his HIV-positive status. He went through a period of many months during which he had a strong sense that he was at risk for HIV, but suppressed this foreboding by bingeing with alcohol and drugs, before he sought testing with the support of his parents. However, he couches his analysis of the most challenging aspect of his new HIV-positive status in social terms:

A lot of people's main concern with HIV is probably, "Oh, I'm gonna die! Oh, I'm gonna be sick!" My primary concern is actually the social stigma that goes with it, which is to me much more significant. And the idea that I will now be a leper, not because I think people with HIV are lepers, but because this is the way they're perceived in society, in a way, even though we don't admit it. To a lot of people, it's like, "Oh, HIV!" Especially in the gay world, "Oh, my God, at my age. Oh, my God." If you say that, it's an instant nobody-wants-to-even-be-your-friend kind of thing.

Dave is sure that he has the worst of it now because he will be stigmatized by other gay men. This connects to what we saw with Sam, where labeling by other gay men may be acutely felt by HIV-positive gay men. Although Dave and Sam do not relate specific anecdotes about HIV stigma, it is clear that they have internalized negative attitudes about their HIV status that they experience as socially constraining. Dave describes insidious discrimination, as well, by emphasizing the chilling effect on his ability to connect with others.

Juan (age: 38) is a Mexican-born immigrant to the US who also relates the burden of his HIV status, but from the perspective of a heterosexual man. He

tested positive with an advanced disease state at a free clinic and requested follow-up care as far away as possible from his residence. His main concerns are that his neighbors and his family not know his disease status: “[My family] says that they prefer that the person with AIDS do not even say hello to them. So I say no... my family is not really ready to hear me speak of my condition with them.” He goes on to describe his encounters with medical and dental care:

Many people... even here where this country is considered advanced... you sometimes feel this rejection and/or stigma. I have seen when I enter a clinic they are very friendly at first but when they find out about your condition... that you are HIV infected... I notice how their whole attitude changes towards you. I don't like to hear people gossiping about you. A person who works in a clinic should be more conscious of how to treat a person, or not be surprised. [My doctor] sent me to a dentist that treats people like me with my condition and who have little or no income. I had to write down my condition on seven different pieces of paperwork in order to receive the dental service. They can write them in smaller letters, but no, they write AIDS in large, bold, dark letters. [laughs] There is much rejection. It's as if I come to you to talk to you and I started to note that you act differently.

[Interview translated from Spanish]

Juan describes primarily social rejection and feelings of separation and exclusion, but there is also a component of structural discrimination in terms of his encounter with medical bureaucracy. We don't know whether he has suffered any financial or insurance repercussions, but there is no question that the paperwork magnifies his feelings of being marked. Because Juan maneuvers himself socially in a restricted manner both with his family and his neighbors, and feels rejection in clinical settings, we can distinguish insidious discrimination in his story.

## *(2) Sexuality Stigma*

Identity intersects with the intrinsically social dynamic of stigma, as can be seen from the story of the informant Chris (age: 34). Chris identifies as a gay man and attempted suicide as a teenager in part because of gay stigma in his military family's household. He acquired HIV during what he thought at the time was safe sex. In the following passage, he clarifies why he thinks this happened:

C: To be honest, I think it's the number one most ignored thing in AIDS research and AIDS care today. Because I don't feel depressed. I think it's a suicide by ignorance. I think anybody who gets infected in today's time, they're infected, not because of carelessness, but because of what I would call “suicide by chosen ignorance.”

Int: Do you feel that, looking back on the unsafe oral sex incident, that that was your fault?

C: Oh, yes. A hundred percent my fault.

Int: Do you feel like this taps into some of the same feelings from February 1991 [time of a suicide attempt]?

C: They're inextricably linked. The fact that my upbringing and my background have never allowed me to fully accept my sexuality and who I am-- if you're gay, you get AIDS, you die. That's just the way things are. And that's one of the reasons why I just can't tell my family. It's not telling them who I am, it's the fact that they're gonna say, “I told you so.”

Earlier in the interview, Chris vividly remembers the headlines of “the gay

death,” Ronald Reagan’s prolonged silence on AIDS, and media characterizations of AIDS as inherent to and originating in the gay community. He analyzes his identity formation as fundamentally related to family and media attitudes that made gay death by AIDS seem natural, if not justified. Chris’s story of an upbringing that justified his HIV infection as natural given his sexuality describes structural discrimination insofar as the media and government rhetoric perpetuated this idea. It is individual discrimination insofar as his early family life denied him the opportunity to see himself living an open life compatible with his sexuality.

Returning to Juan (age: 38), we pick up with him as he is relating the experience of a heterosexual man encountering and negotiating with gay labeling because he is HIV-positive:

I have always noted they ask if you are homosexual or... I don’t know... sometimes it bothers me. Not because they think that I may be... but because... well, one supposes that it is not like before when they thought it was a homosexual disease. So I wonder why they think that it continues to be a homosexual disease. That is their first question-- they ask you if you are a homosexual.

Juan returns to this issue again in the interview, giving the sense that it is a present issue for him. Homonegativity may function as the other side of the coin of mainstream male identity, bolstering social performances of male heterosexuality. It is likely that Juan’s unemployed status and his need for medical and dental care from indigent care resources contributes to his needing to fill out paperwork repeatedly (for clinic reimbursement from safety net payors). This layer of structural discrimination helps to contextualize his repeated encounters with gay labeling. It is important to note that here, too, insidious discrimination can play out, even for a heterosexual man, as he navigates the stereotypical equivalency of “HIV-positive” with “homosexual.” It is a subtle but present pressure point that can cause an individual to reappraise his position in the power dynamic of a clinical interaction.

### *(3) Internalized Homogenativity*

Bill (age: 50s) is a Roman Catholic priest of an undisclosed Order that has accorded him acceptance with regards to his HIV status since his diagnosis, and he has been punctilious about his medical care since getting onto the Berkeley Department of Public Health’s AZT program shortly after his diagnosis in 1986. He describes his first positive test:

I remember the letter coming. I opened it and then I read it. I read it again, and then I wept. And I spent the next 24 hours, I don’t know, in the fetal position, in terror-- terror and fear and tears. My worst fears were confirmed that day. In fact, I expected everyone to condemn me and I expected to die in shame. And, so I experienced, probably, a good measure of self-hatred, guilt, shame, utterly low self-esteem, etcetera, all, all of those things. I was just primed at the pump, and when I got the letter, the pump let go. And I had no one to go to for help. No one. No one. I was utterly alone. I didn’t even feel at that time God gave a damn. I was guilty of sin, so there were religious feeling all tied up with this. I wasn’t just a medical issue, it was a religious, ethical issue. I was a priest. You, I, I don’t know if it was possible to feel worse. [laugh]

Bill feels self-hatred and shame, amplified by his priestly role and distilled into a personal hell, given his sexual activity with men since his taking on of his vows.

The interviewer naturally wonders how he has coped:

B: I just wasn't prepared, exactly, for my own deep well of negative feelings that erupted after I actually found out.

Int: How did you handle the deep well? Did it eventually run dry?

B: My dear, I am a survivor, a very strong survivor, thanks to my mother, again. I'll never forget the conversation we had two and a half weeks before she died, in which she, basically, forced me, but with a gentleness beyond description, to tell her, for the first time, that I was gay. "You are my son. I loved you from the day you were born. I never stopped. I haven't. And nothing, nothing on this earth, or in you or about you, would ever cause me not to love you."

These healing words move Bill deeply, but he also carries from this meaningful moment the realization of his "greatest moment of remorse," which was that he should have told his mother sooner of his sexuality. This gives a glimpse into the pain experienced by many homosexual men when societal messages convince them that they cannot be loved because of their sexuality and embed these self-same messages in their internal lives.

Bill's description of diminished self-worth and his constrained ability to be candid with his mother align with the concept of insidious discrimination in that he appears to have internalized societal stigma in the form of homonegativity. This specific outcome of the process of stigmatization is magnified by the lack of power of homosexuals in the 1980s and earlier during his upbringing, and the power of the Catholic Church to decree his sexuality to be of sinful nature. Nevertheless his resistance to these forms of stigmatization is evident in his defiance by serving the Church regardless-- which we get a flavor for in his vehement disagreement with his Church "about issues of celibacy, homosexuality, sexuality in general, etcetera, on and on and on and on." The issue of internalized homonegativity has recently been empirically studied in Europe through the largest-ever sample of men who have sex with men or feel sexual attraction toward men (over 140,000), and greater levels of internalized homonegativity predicted not testing for HIV (Berg, Ross, Weatherburn, & Schmidt, 2013). The Discussion section below will revisit the connections between social values and policies, internal individual attitudes, and individual health-related behaviors such as testing for HIV.

#### *(4) Perceived Sexuality Stigma from Medical Providers*

Negative interactions with medical providers give hints of how stigma is transacted in the healthcare setting. One informant, Vincent (age: 30s) is particularly instructive on this point:

In 1996, I contracted another, I guess it was Chlamydia again, and at this time I was still at the same medical group and the provider that saw me that day, that told me that I should get an HIV test because I probably had HIV-- and that's how he said it-- he also wrote me a prescription for antibiotics for Chlamydia, but as he did so, he was kind of sitting as far away from me as he could-- he was an older, Latino male, probably in his sixties or so, MD, and he treated me very... I felt very, you know-- I wasn't paying for one thing as it was, but he just treated me really nasty, in a way, and it made me feel even dirtier because when he wrote the prescription for the antibiotics down, he handed it to me, but reaching to hand it to me, like he didn't even want to come into any physical contact, which he didn't, he didn't touch me at all during the whole, um, exam and he just -- and I remember



this clearly, very much so... because it left such an impression on me, and then his words again were like, "Oh, well, you should have an H... I'm gonna... We're gonna give you an HIV test, because you probably have it"-- because he also asked me what my behaviors were and I told him that I was gay and that I had sex with men, and that was what prompted his comment, that I felt really upset about afterwards.

As Vincent, 19 years old at the time of his story, notes the race/ethnicity of this particular physician, it is relevant that he identifies as Native American (and as a gay man). He experiences this interaction as resonant with distance, if not disgust, conveyed through non-verbal as well as verbal cues. The test result is positive and Vincent is accidentally told the outcome by a nurse while he is waiting in an exam room. Another doctor then comes in to give Vincent the diagnosis and he breaks down crying. Vincent recalls, as with the first physician, that he is not touched by the doctor, although the nurse ultimately comforts him with touch. The production of social distance in stigmatizing interactions may occur through the withholding of therapeutic touch. Vincent continues in care and is referred to an infectious disease specialist who initiates antiretroviral care, but his course in care is rocky. His story underscores that the responsible and timely offering of HIV testing can nonetheless be done in a stigmatizing manner.

Other informants reported being offered HIV testing by medical providers and turning them down. A key role for healthcare workers in stemming the HIV epidemic is the recognition of common signs of opportunistic infections that could herald HIV infection, and the stories of the informants in this sample speak of successes and failures in this area. The transaction of stigma is more subtle. Research on stigma and mental health in China has pointed out the key role played by health provider "actions that convey a devalued status to patients," particularly early on in the encounter with clinical care (Lee, Chiu, Tsang, Chiu, & Kleinman, 2006). Some writing in a US context have used the phrase "public health citizenship" to denote an ethic of individual responsibility that positions the sick patient as "a failed exerciser of responsibility" (Bourgois & Schonberg, 2009). Survey-based stigma research in the US has identified "perceived stigma" from a health provider as associated with a two-fold increase in the odds of reporting low access to HIV care, after adjusting for various sociodemographic and clinical features (Kinsler, Mitchell, Sayles, Davis, & Cunningham, 2007). Because sexual minorities, particularly gay and bisexual men, are often portrayed in the media and culturally understood to be sexually adventurous and impulsive, the rhetoric of "failed responsibility" may be particularly ready-at-hand for clinicians, as we saw with Vincent's first doctor, when their patients disclose sexual minority risk behaviors or simply sexual minority status. In his story of an unpleasant encounter with a physician at a particularly vulnerable moment, Vincent portrays perceived sexuality stigma that results in his feeling disapproval, rejection, and exclusion. This also constitutes insidious discrimination in that he feels the weight of being stereotyped as "dirty" and the loss of his status as a worthy and responsible medical subject.

##### *(5) Perceived Drug Use Stigma*

Illicit drug use is a risk behavior that is especially apt to entanglement within a rhetoric of blame in healthcare settings. Sarena (age: 57) is a recovering crack user who weaves a narrative of victimhood. She presented to care with an initial CD4+ count below 50, an advanced disease state indicating long-term infection in most individuals, yet she describes testing every two years “because I was hearing a lot about HIV and not all men are honest.” These tests-- prompted initially by a physician-- were negative until the most recent one:

S: You hear about HIV on TV and you automatically associate it with gays, and that was it.

Int: So you were saying your doctor in Florida had said something about HIV?

S: Everywhere I move, I find a doctor. And they were telling me that a lot of AIDS came from Jamaica, and in the neighborhood where I was living there were a lot of people from Jamaica. So, okay, I'll test, no problem. And I tested and everything was fine.

Int: How does that-- because you said that you think that HIV was in your body for 20 years and that you kept testing negative until the most recent time.

S: Yeah!

Int: Was there any explanation for that-- did the doctors find any explanation?

S: No. I still believe it was from the blood transfusion.

Sarena's contention that she was infected by a blood transfusion is difficult to square with her narrative of regular testing. However, her potential lack of understanding about the natural history of HIV infection frames a story that may function to soften the blow of coping with an HIV infection. She describes her reaction as primarily of shame:

The main thing was the depression-- the depression of finding out that all my good efforts to be a good girl-- I'm not gonna say didn't pay off, but I still got a disease that I figured it was sexually.

She contracted a disease that she had thought she could only get sexually-- in this way her infection, for her, is removed from the realm of the sexual and originated in the realm of medical error. Furthermore, she is able to cloak herself in her efforts to be a responsible and good medical subject in the context of a potentially stressful interview touching on her twin roles as recovering drug user and HIV-positive woman.

A recovering African-American heroin injector, Laura (age 43) gave the impression of having reached acceptance regarding her HIV status and she entered HIV care with near-normal immune function (CD4+ of about 480). She describes herself as knowledgeable and careful about risk: “I was an IV drug user but I never shared needles.” When asked to localize her HIV infection, she attributes it to unknowingly injecting with a used needle prepared by a friend, or possibly to a male sexual partner that she later found out was sleeping with men. As the interviewer presses her on these topics, she settles on the grim fact of her drug use and the state it induced in her when she was craving: “When you're doing drugs, it alters your perception in your mind. Only times you care are the times you don't care. Sometimes you're aware-- and the drug I was using, I was so sick, it didn't matter, I just needed to get well.” After a period of depression lasting six months to a year following her testing positive for HIV, Laura entered care. Here she describes her struggles:

I'm 43, just when I thought I was getting my life together, "Boom!" I find out I'm positive. It destroyed a lot of dreams and now I'm in therapy to get help. I started using a different type of drug. It's just been a mess. But the coping with it-- that's really hard, and you almost end up killing yourself. So I tell people all the time, all the time, young kids, wherever I'm at. When I'm not feeling well, I tell 'em. I'm in an outpatient program and you have to go, "Hi, my name is L\_\_\_\_" and how you're feeling. I say, "Hi, my name is L\_\_\_\_ and I'm HIV-positive. Hope I don't offend anybody, but I am, so, today, this is how I feel." I'm always careful washing my hands all the time, because I have stepchildren in the home. I'm always sanitizing. There's a lot that goes along with it if you care. When I go to appointments-- like I just had a tooth pulled, I let 'em know, make sure I don't [unclear] anyone. I'm very careful when it comes... I'm not having much sex at all, really, nowadays. Can please him orally. If he does want to go that way, which is rare, I make him use protection. I slipped once and didn't. It's time for me to test again...

Laura's relapse into drug use following her diagnosis is counteracted by her repeated assertions of her responsible efforts to mitigate her and others' risk, and her three uses of "careful" or "care" highlight her hygienic stance. At one point she challenges the interviewer, a young white woman, about whether she has tested herself for HIV, a moment that clarifies Laura's attempt to assume the mantle of public health citizen. Although unspoken, the specter of judgment regarding past illicit substance use colors these maneuvers.

The words of Sarena and Laura at turns invite both blame and sympathy, playing out an analytic double bind with respect to illuminating the currents impinging on stigmatized populations. Pierre Bourdieu described this double bind as the difficulty of speaking about stigmatized populations "without seeming either to crush or exalt them" (Bourdieu cited in Bourgois, 2001). Even knowing Sarena and Laura's full life stories, disentangling self-destructive behavior from forces beyond their control is impossible. However, we know that Sarena started her treatment late while Laura came in early. Another difference between the two is their disparate early clinical encounters. While Laura speaks glowingly of the warmth of clinic staff, Sarena describes a "very negative" early relationship with a physician:

I didn't wanna come, because he didn't show that he was really enthused with anything that I was telling him-- he was the first doctor I saw-- and he would not give me my meds because I was doing drugs. And once I got myself into drug treatment, there was no encouragement whatsoever, and I stopped coming.

Laura's experience with her doctor who would not prescribe antiretrovirals paints a picture of a cool relationship, for whatever the legitimacy of his concerns regarding Laura's ability to adhere to medication, the lack of encouragement on his part is received by Laura as a vote of no confidence. Whether her first doctor contributed to her not seeking treatment is not something we can know. What crystallizes is Laura's dropping out of care shortly after feeling labeled as unreliable and incapable of ceasing drug use. This aspect of stigma can reproduce itself based on her internalized stigma. We might imagine that for Laura there is a connection between feeling "too dirty"-- that is, tainted with the mark of drug addiction-- for HIV medication, and taking pains to portray herself as a responsible person who is "always sanitizing."

Sarena and Laura's interactions with interviewers are read here as insidious

discrimination, as each constructs a narrative of personal responsibility in the face of the past and anticipated labeling/stereotyping of “former drug user with questionable self-control.” These interactions register the traces of stigmatization in a medical research interview, and are juxtaposed with the stories of family and media stigmatization told by Chris and Sam, and with the overt physician stigmatization due to sexuality and/or possible HIV status recounted by Vincent. These processes do not erase personal responsibility or eclipse personality and coping style, but rather exist alongside them, emerging in charged social situations like the medical clinic or the medical research interview.

## **Discussion**

Why trace subtle forms of discrimination such as those outlined above in the stories of eight HIV-positive individuals? For an example of the role played by layered stigma on health-related behaviors, Link & Phelan’s (2006) short essay in the *Lancet* is arresting: “...we analysed nationally representative data from the USA, in which multiple stigmatising factors were taken into consideration in relation to self-esteem, and found that stigma could explain a full 20% of the variance beyond the effects of age, sex, and years of education.” The interviewees whose voices are heard above speak to how stigma can produce feelings of rejection and encompass acts of concrete, individual discrimination; stigma can layer; can cause individuals to react against the stereotypes of stigma to their own detriment; can become nested in individual psychology as internalized devaluations, such as internalized homonegativity; and stigma can emerge in clinical interactions where steep power imbalances are often in operation. This pervasiveness demands attention.

Stigma can be understood through the lens of Bourdieu’s concepts of habitus and symbolic violence. Wacquant (2007) summarizes habitus as “the system of durable and transposable dispositions through which we perceive, judge, and act in the world. These unconscious schemata are acquired through lasting exposure to particular social conditions and conditionings, via the internalization of external constraints and possibilities.” Through repeated social interactions, stigmatized individuals are labeled, affixed with negative characteristics, and these become reinforced through social separation and episodes of discrimination, both overt and implicit. The notion of habitus captures the cumulative and ongoing qualities of stigmatization that can even be reproduced beyond the dyad of a stigmatizer and the stigmatized, through the processes of internalized stigma and insidious discrimination. Wacquant (2007) distills Bourdieu’s notion of symbolic violence: “the subtle imposition of systems of meaning that legitimize and thus solidify structures of inequality.” When Vincent’s first doctor is sure that Vincent will test positive for HIV, he is buying into the idea that it is natural for promiscuous sexual minorities to have HIV; this is the attitude that Vincent receives, primed as his habitus is for this type of message. When Chris describes his internal narrative that “gay equals AIDS equals death” as part of “suicide by chosen ignorance,” he is buying into the idea that it is apposite for gay men to die helplessly of HIV infection as punishment for violating the natural order. In both the internal and social

transactional levels, the process of stigma relies upon the accumulated and accumulating filter of habitus and on the symbolic violence of viewpoints that legitimize discrimination and suffering.

In their important 2005 article, Castro & Farmer theorize that structural violence, a concept which encompasses broad social forces such as racism, sexism, political violence, poverty, and historical and economic forces that determine vulnerability to HIV, also determines who is affected by HIV-related stigma. This paper seeks to position symbolic violence as a theoretical tool for understanding insidious discrimination and internalized stigma. Insidious discrimination emerges from the above interviewee stories as a process that potentially involves either one or both of the following: (1) reaction against stereotypes emerging from the transaction of stigma in social relationships or in the reception of media messages; (2) the internalization of devaluations originating in stigma, such as with internalized homonegativity. Herek (2004) has advanced theorization on the concept of internalized homophobia, which was originally described by George Weinberg (1971), positing that “everyone in the society internalizes stigma ... whether or not they personally endorse the stratification associated with those roles.” Thus we may set up a theoretical construct that admits of internalization of stigma, with either a reaction against it, or acceptance of the negative valuations that go along with it, as in the case of internalized homonegativity. The application of the concept of symbolic violence-- “the subtle imposition of systems of meaning that legitimize and thus solidify structures of inequality”-- allows for a delineation of the underpinning processes (Wacquant, 2007). Bourdieu has theorized that symbolic violence proceeds through the cognitive moves of recognition/misrecognition, whereby an individual identifies and accepts, or does not fully accept, value judgments produced through social interactions (Bourdieu, 1977). The lens of symbolic violence illuminates the internal (and thus hidden) nature of the cognition behind internalized stigma and insidious discrimination, and helps to explicate how it is that these processes can be perpetuated within the individual.

This study has several limitations. Suggestions about what may be operating in this sample have been made, but no claims to causality are possible. Furthermore, although semi-structured interviews can register dynamics obscured or passed over by surveys, much about the backgrounds, social situations, and economic realities of the interviewees was not ascertained through the present methodology. Also, the above analysis was not carried out by a member of the original research team, thus interpretation is limited to the attenuated meanings recorded in interview transcripts. For example, racial stigma was not uncovered in the sample of interviews, but this could be a shortcoming of the analyst.

Future directions for research in this area might proceed both on the survey and qualitative fronts. Link & Phelan’s (2006) quantification of the effects of stigma on self-esteem and Berg et al.’s (2013) association of homonegativity in Europe with increased risk of not testing for HIV are promising developments in this direction. Further qualitative investigation should heed Castro & Farmer’s

(2005) call for more case studies and ethnographic research methods to elucidate the functioning of stigma. Participant observation of clinical encounters could be particularly illuminating of stigma in the patient-medical provider interaction. Berg et al. (2013) showed that national policies legalizing gay marriage and adoption were associated with populations of men with lower levels of internalized homonegativity. Given these results, and a special urgency granted by the way in which Bill brings the issue to life above, there is great need for implementing societal policies and fostering attitudes that consider and address internalized homonegativity as structural and environmental determinants of the health of gay men and other sexual minorities. But there is need not just for policies that address the stigmatization of gay and bisexual men. Because HIV-related stigma interacts with poverty and power imbalances perpetuate stigmatization, intervention is also needed to address socioeconomic inequality in the United States. Rubin, Colen, & Link (2010) have shown that national ARV roll-out has been associated greater HIV/AIDS mortality disparities by socioeconomic status and race/ethnicity, highlighting the fundamental role played by structural inequalities in the mortality burden of the HIV epidemic and supporting population health interventions such as the Medicaid and Ryan White programs. Finally, there is also need for interventions that give individuals the tools to cope with negative thoughts and behaviors, stemming from internalized homonegativity, drug use stigma, and other processes that involve internalized stigma and insidious discrimination.

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