Social Determinants of Late Stage HIV Diagnosis and its Distributions among African Americans and Latinos: A critical literature review

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ABSTRACT
This critical literature review was conducted to identify both individual- and environmental-level social determinants of health using an ecological framework as a way to contextualize risk for, and distributions of, late HIV diagnosis among African Americans and Latinos in the United States.

Background: Late diagnosis, defined as a diagnosis of AIDS simultaneously with or within one year of an initial HIV diagnosis, disproportionately affects African American and Latino communities; disparities in this health problem thus represent a preventable inequity. Such disparities affect not only late diagnosed individuals but also population levels of HIV incidence, as transmission is unhindered before diagnosis.

Methods: A total of 26 unduplicated studies in 26 peer-reviewed articles were analyzed within a social ecological conceptual framework. Both quantitative and qualitative studies of factors influencing HIV testing were reviewed. To be included, studies had to have been conducted in the United States, published in English within the past 11 years, and to have focused on Latino or African American populations and/or on racial disparities between these and other populations.

Findings: The majority of studies on racial disparities in HIV testing and diagnosis have been either cross-sectional or focused on one racial or ethnic group, often in one geographic location. In all studies that compared racial and ethnic groups, Latinos and African Americans were more likely to receive a late diagnosis than non-Hispanic Whites or Asian Americans. 95.8% of the reviewed studies focused on structural barriers as opposed to individual level risk factors or investigated structural barriers via measurements at the individual level.

Next Steps: Both more quantitative and qualitative studies are needed that will enhance understanding of the social determinants of HIV testing behavior among at-risk groups by measuring variables at the appropriate rung of the ecological model, and not solely on the individual level. Studies that investigate barriers to and facilitators of HIV testing in
partnership with communities will help further interventions that can reduce racial/ethnic disparities in late diagnosed HIV/AIDS.

**Keywords:** HIV testing; late stage HIV diagnosis; social determinants of health; racial/ethnic health disparities; social ecological model; structural factors

**INTRODUCTION**

The interdependence between social determinants of health (SDOH) and racial/ethnic disparities in the HIV/AIDS epidemic has long been recognized (Lane et al., 2004; Moreno, 2007; Poundstone, Strathdee, & Celentano, 2004; Zierler & Krieger, 1997). Poverty, racism, poor access to healthcare, and cultural beliefs are among the factors that help explain why in 2010, 68% of new HIV diagnoses in the United States (US) were among African Americans and Latinos, although together they comprised just 30% of the total US population (Bureau of the U.S. Census, n.d.). Racial and ethnic disparities in HIV/AIDS represent an unjust health inequity in part because they are shaped by social determinants of health (SDOH) including structural, interpersonal, and internalized racism with which people of color contend (Jones, 2000), the ways in which access to opportunities and public goods are differentially structured by race and ethnicity (Massey, 2008), and additional SDOH relating to culture, community and neighborhood.

The above concerns play out in many aspects of the HIV/AIDS epidemic, among them late stage HIV diagnosis, a problem that is far more prevalent among African Americans and Latinos than whites and Asian/Pacific Islanders in the US. Defined as a diagnosis of AIDS simultaneously with or within one year of an initial HIV diagnosis (Tang, Levy, & Hernandez, 2011), late stage diagnosis occurs in between 25% and 47.2% of all HIV diagnoses in the US (Centers for Disease Control and Prevention, 2010). Late-stage diagnosed HIV is presented in this paper as an exemplar demonstrating the importance of examining the SDOH, while also considering the challenges of investigating and measuring SDOH at multiple ecological levels.

A recent report by the Centers for Disease Control and Prevention (CDC) (Centers for Disease Control and Prevention, 2013) on social determinants of HIV incidence among US adults underscores the fact that although men having sex with men (MSM) and men having sex with men and using intravenous drugs (MSM/IDU) are the most prevalent modes of transmission among white adults (81.8% of diagnoses attributable to MSM or MSM/IDU), heterosexual contact transmission and intravenous drug use (IDU) represent a much higher proportion of transmission mode among both Latino (42.7% of diagnoses) and African American (54.5% of diagnoses) adults. While both Latinos and African Americans have higher rates of HIV testing (Ebrahim, Anderson, Weidle, & Purcell, 2004; Robinson, Sanders, & Boyd, 2012) and also higher rates of late stage diagnosis (Schwarz et al., 2006), moreover, they are less likely to test due to a known exposure and more likely to test due to illness or a medical problem (Holmes Jr. et al., 2008).

If risk were evenly distributed across the American population, then focusing on individual risk factors alone would be an effective approach to research and intervention. However, as illustrated, among Latinos and African Americans, high HIV incidence (and prevalence) is not restricted to traditionally high-risk communities, nor is late diagnosed HIV contained by higher rates of protective behavior (HIV testing). Clearly, other forces are at work, at levels well beyond individual risk factors, which must be carefully explored. The importance of better understanding SDOH in this regard is further underscored in the CDC’s (Centers for Disease Control and Prevention, 2013) report on social determinants of HIV incidence among US adults.
Disease Control and Prevention, 2012) recent finding that at some point in their lives, fully one in 16 African American men and one in 32 African American women will acquire HIV/AIDS. Racial/ethnic disparities in HIV/AIDS such as these violate the three normative dimensions of equality as outlined by Ward and colleagues (Ward, Johnson, & O’Brien, 2013): equality of opportunity, substantive equality, and access equality. Briefly, equality of opportunity refers to the possibility of obtaining positions and possessions (including physical and mental wellbeing) not being determined by social status, while substantive equality refers to the equal occurrence of some good (including states of health) across segments of society. Finally, access equality refers to unhindered access to resources (such as healthcare and HIV knowledge) as a necessary condition of agency. This review reveals that many of the SDOH associated with late stage HIV represent a departure from these three dimensions of equality. Studying and addressing the SDOH therefore is critical for improving health equity in late-stage HIV and other health outcomes, while achieving a more equitable society in other arenas as well.

Following some background on the problem of late stage HIV diagnosis and its consequences, we describe the methods used in this systematic review of published studies on racial disparities in late HIV diagnosis, with special attention to SDOH. Using the social ecological model (Bronfenbrenner & Morris, 1998; Dahlgren & Whitehead, 1991; Nancy Krieger, 2001; McLeroy, Bibeau, Steckler, & Glanz, 1988; Poundstone et al., 2004) as a conceptual framework, we then critically analyze the contributions this research literature makes toward improved understanding of the socio-ecological contexts of inequitable distribution of the problem of late stage HIV, as well as identifying existing gaps in the literature. We conclude with a discussion of methodological challenges in teasing apart variables on different levels of the social ecological model. We also discuss gaps in the literature to date and suggest next steps for better understanding social determinants related to late stage testing and diagnosis as a basis for subsequent translation and action.

**BACKGROUND**

Late Diagnosis of HIV: The consequences of late diagnosed HIV are problematic for both the individual and the broader community. First, HIV can only be treated once it is diagnosed; and development of AIDS and AIDS mortality are more difficult to prevent when HIV is not treated early. Second, when HIV is diagnosed early, further transmission of the virus can be reduced through behavior modification (Coleman, Rajabiun, Cabral, Bradford, & Tobias, 2009) and anti-retroviral treatments (Ulett et al., 2009). Thus, when late HIV diagnosis becomes prevalent in a community or population, both HIV incidence and AIDS mortality increase.

Besides increased AIDS mortality and HIV transmission, racial/ethnic disparities in late diagnosis lead to a higher overall burden of morbidity and mortality in communities and populations that are already overburdened with disproportionately high prevalence and incidence of other diseases, including, among others, diabetes, hypertension, cardiovascular diseases, some cancers, gonorrhea, syphilis, and schizophrenia (Bresnahan et al., 2007; Kawachi, Daniels, & Robinson, 2005; Semaan, Sternberg, Zaidi, & Aral, 2007; Williams & Jackson, 2005; Williams, Yu, Jackson, & Anderson, 1997). Each of these health inequities, like HIV, has been linked to disproportionately high rates of poverty, racism, and other SDOH and diseases in people and communities of color (Marmot, 2005; Nuru-Jeter, Sarsour, Jutte, & Boyce, 2010; Phelan, Link, Diez-Roux, Kawachi, & Levin, 2004; Williams & Jackson, 2005). These other diseases can in turn complicate HIV incidence in various ways: for instance, HIV risk behaviors are elevated...
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among people who have mental illness (such as schizophrenia) or addictions (Teplin et al., 2005). Furthermore, the disproportionate disease burden contributes to racial/ethnic inequities in AIDS mortality, because AIDS is an autoimmune disease, making comorbidity more likely to be fatal (Skiest, Rubinstien, Carley, Gloiella, & Lyons, 1996). As population growth among racial and ethnic minorities outpaces growth of the white majority, increasing incidence, prevalence, morbidity and mortality among communities of color increasingly reflects the effect on society as a whole.

The term African American is understood to be inclusive of people who identify as black and American, second-generation African or Caribbean immigrant, and mixed race people. The term Latino is applied to people who identify as having Latin American heritage, from Chicanos who trace their ancestors to parts of the United States which used to belong to Mexico, to immigrants from Mexico, Central and South America and the Spanish-speaking Caribbean. In addition, there is a sizeable population of black Latinos in the US. However, while just one (Lopez-Quintero, Shtarkshall, & Neumark, 2005) of the studies reviewed reports specifically on this population, most focus on non-Hispanic African Americans.

Conceptual model: The social ecological model (Bronfenbrenner & Morris, 1998; Krieger, 2005; Latkin & Knowlton, 2005) used to guide this literature review is based on the concept that a society is an integrated multi-level system that affects each individual organism living within it, and is in turn shaped by those same individuals. To improve individuals’ health outcomes, we must consider the various levels that influence their daily lives and choices through their physical and social environments (Dahlgren & Whitehead, 1991; Knol, Briggs, & Lebret, 2010) (see Figure 1 below for a visual representation of the social ecological model created by Dahlgren and Whitehead (1991), and used by the Institute of Medicine). Although different representations of the model include different levels, they all begin with the individual at the center, and expand out to systems that act on the individual with increasingly remote loci of power.
The social ecological model (Bronfenbrenner & Morris, 1998; Dahlgren & Whitehead, 1991; Krieger, 2001; McLeroy et al., 1988; Poundstone et al., 2004) allows us to identify biological and behavioral factors at the individual, interpersonal, community and societal levels, and investigate how they interact and influence each other. The interpersonal refers to the personal relationships in which the individual is involved, while the community level represents proximal environments including social circles, families, households, neighborhoods, workplaces and other communities such as churches or schools. The outermost level, here referred to as the societal, represents structural and systemic environments including politics, economics, the media and broader culture, where distal factors are located. Encompassing many of the SDOH, these broader conditions or societal factors affect individuals through the effective shaping of the living and working conditions that differentially affect communities and the individuals that constitute them. As will be suggested in our review of the literature, however, conceptual confusion not infrequently occurs with respect to “structural factors,” which may be used in reference to broad indicators such as neighborhood socioeconomic status and levels of education, or to factors such as individual access to testing and perceptions of stigma. Recognizing the influence of interactions between factors at each of these levels is critical to understanding how the SDOH both affect, and are affected by, factors at each level of the social ecological model.

METHODS
A total of 26 unduplicated studies in 26 peer-reviewed articles were analyzed within a social ecological conceptual framework. Both quantitative and qualitative studies of factors
influencing delayed HIV testing were reviewed. To be included, studies had to have been conducted in the United States, published in English in peer reviewed journals during the past 11 years, and to have focused on Latino or African American populations and/or report on racial disparities between these and other populations. The time limit was placed on the studies due to the changing nature of HIV technology; the first rapid HIV diagnostic test was approved by the Food and Drug Administration (FDA) in late 2002, changing the landscape of possibilities in HIV testing programs. The search engines Google Scholar and PubMed were utilized in the process of identifying studies, with Boolean search terms “HIV OR AIDS” AND “late OR delayed” AND “testing OR diagnosis” AND “rac* OR Latino OR Hispanic OR black OR African American.” Search terms could appear in the title, abstract, or key words, ensuring that each component of the focus of this review was also important in the concept of the study.

RESULTS

Factors Affecting HIV Testing: Study findings and results are listed in Table 1, identifying the individual, community, and structural factors associated with various outcomes relevant to HIV testing and/or risk behavior. As indicated in Table 1, the majority of studies on racial disparities in HIV testing and diagnosis have been either cross-sectional (Bond, Lauby, & Batson, 2005; Ebrahim et al., 2004; Holmes Jr et al., 2008; Kellerman et al., 2002; Leibowitz & Taylor, 2007; Osternann, Kumar, Pence, & Whetten, 2007; Robinson et al., 2012; Tang et al., 2011) and/or focused on only one racial or ethnic group, often in one geographic location (Fernández, Perrino, Royal, Ghany, & Bowen, 2002; Foley, 2005; Lopez-Quintero et al., 2005; Moreno, 2007; Nunn et al., 2011; Petroll et al., 2009; Wallace, McLellan-Lemal, Harris, Townsend, & Miller, 2011; Wohl, Tejero, & Frye, 2009). In the 13 studies that compared racial and ethnic groups, Latinos and African Americans were more likely to receive a late diagnosis (Schwarcz et al., 2006; Torrone, Thomas, Leone, & Hightow-Weidman, 2007) than non-Hispanic whites. In addition, being born outside the US (Schwarcz et al., 2006; Tang et al., 2011) and not speaking English as a primary language (Foley, 2005; Wohl et al., 2009) were each independently correlated with not accessing timely testing and treatment services. In ten studies examined which included Latinos, and one with African immigrants, these factors were described as being reflective of the inaccessibility of healthcare and health insurance that many immigrants, and especially undocumented immigrants, face while living and working in the US. The exception was found in an examination of racial disparities among MSM conducted by Behel et al. (2008), who state that, “Differential experience with HIV prevention services does not explain the higher prevalence among Black and Hispanic MSM.” Other demographic factors associated with late diagnosis include female gender (Mayben et al., 2007; Schwarcz et al., 2006), heterosexual orientation (Schwarcz et al., 2006; Tang et al., 2011; Torrone et al., 2007), and age. Age has also been cited as a factor associated with both testing and late diagnosis, however findings were contradictory. Tang et al. (2011) found that in California, age over 35 was significantly associated with late diagnosis of HIV/AIDS, while Kellerman et al. (2002) found that age under 25 was associated with being less likely to test for HIV, and Schwarcz et al. (2006) found that younger age (under 30) was associated with late diagnosis. These studies focused on different populations (people with high-risk behaviors in six states and reported AIDS cases in California and San Francisco respectively), so while each points to different target populations for possible interventions, they do not necessarily negate each other.
Table 1: Peer Reviewed Articles on Late HIV Testing and Diagnosis among Latinos and African Americans in the United States, with Ecological Levels of Analysis, 2002-2012

<table>
<thead>
<tr>
<th>Author, Title</th>
<th>Year, Journal</th>
<th>Sample/Dataset</th>
<th>Individual factors</th>
<th>Community factors</th>
<th>Society factors</th>
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<tbody>
<tr>
<td>Fernández et al. “To test or not to test: are Hispanic men at highest risk for HIV getting tested?”</td>
<td>2002 AIDS Care</td>
<td>Community sample of 1,052 Hispanic men, both heterosexual and homosexual, via anonymous structured interviews</td>
<td>MSM, men with more partners, men with STDs, more likely to have testing history, inconsistent condom use associated with lower intentions to test</td>
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<tr>
<td>Kellerman et al. “HIV Testing Within At-Risk Populations in the United States and the Reasons for Seeking or Avoiding HIV Testing.”</td>
<td>2002 Journal of AIDS</td>
<td>High-risk people defined as MSM who go to gay bars, injection drug users, and heterosexual people visiting STD clinics. Cross-sectional interview study using the HIV Testing Survey I (n=1,599) and II (n=1,711)</td>
<td>Individual risk factors included: age under 25, denial of risk, fear of being positive</td>
<td>Prevention efforts addressing risk perception</td>
<td>Availability of new technologies may be a protective factor</td>
</tr>
<tr>
<td>Lopez-Quintero et al. “Barriers to HIV-Testing Among Hispanics in the United States: Analysis of the NHIS, 2000.”</td>
<td>2005 AIDS Patient Care and STDs</td>
<td>Hispanic sub-groups from the National Health Interview Survey (n=4,261)</td>
<td>Women more likely to test, probably b/c of prenatal VCT and OBGYN recommendations: higher levels of access to healthcare</td>
<td>Puerto Ricans more likely to test likely due to targeting of high-risk populations</td>
<td>Acculturation is hypothesized to affect testing behavior through 1) access to healthcare services 2) cultural norms inducing fear and shame 3) more acculturated people are more likely to</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Design/Method</td>
<td>Findings</td>
<td>Context</td>
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<tr>
<td>Foley, EE “HIV/AIDS and African</td>
<td>2005</td>
<td>Qualitative study of African immigrant women in Philadelphia. Included 8 focus groups with case managers, peer counselors, social workers, and nurse case managers who work with African clients at area hospitals, clinics, and health centers, and individual interviews with HIV+ African women (n=3)</td>
<td>Linguistic problems about modes of transmission and lack of awareness about antiretroviral treatment</td>
<td>Legal status, and fear of the American Health System</td>
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<td>immigrants in Philadelphia: Structural and cultural barriers to care.”</td>
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<tr>
<td>Bond et al. “HIV testing and the role of individual- and structural-level barriers and facilitators.”</td>
<td>2005</td>
<td>Heterosexual men and women in Philadelphia (n=1,643). Personal interviews</td>
<td>Risk behaviors, including sexual and drug-using, were not highly correlated with an increased likelihood of ever having been tested</td>
<td>The authors emphasize the higher correlation of structural level factors with individual level factors, not much mention of meso-level Structural level factors were shown to be more highly correlated with testing, especially access to healthcare and opportunities for testing</td>
<td></td>
</tr>
<tr>
<td>Schwarcz et al. “Late diagnosis of HIV infection: trends, prevalence, and characteristics of persons whose HIV diagnosis occurred within 12 months of developing AIDS.”</td>
<td>2006</td>
<td>AIDS cases in San Francisco 2001-2005 (n=2,139)</td>
<td>Latino/ Black race/ethnicity, female gender, younger age, heterosexual orientation, birth outside of US, all correlated with late HIV diagnosis</td>
<td>Lower education, lack of health insurance, private health insurance correlated with late HIV diagnosis</td>
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<tr>
<td>Taylor et al. “ZIP Code</td>
<td>2006</td>
<td>Random sample of LA</td>
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<td>Residents of areas with high</td>
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<tr>
<td>Study</td>
<td>Title</td>
<td>Year</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Variables</td>
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<tr>
<td>Chopel et al.</td>
<td>Social Determinants of Late Stage HIV Diagnosis and its Distributions among African Americans and Latinos: A critical literature Review</td>
<td>2015</td>
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<tr>
<td>Torrone et al.</td>
<td>“Late Diagnosis of HIV in Young Men in North Carolina.”</td>
<td>2007</td>
<td>Sexually Transmitted Diseases</td>
<td>1,117 men ages 18-30 years identified through chart review</td>
<td>Ethnicity, history of IDU, heterosexual only contact</td>
</tr>
<tr>
<td>Ostermann et al.</td>
<td>“Trends in HIV Testing and Differences Between Planned and Actual Testing in the United States 2000-2005.”</td>
<td>2007</td>
<td>Archives of Internal Medicine</td>
<td>146,868 NHIS participants, 18-64 y.o. during 2000-2005</td>
<td>Individuals with higher risk more likely to get tested, but still &lt;25%</td>
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<tr>
<td>Leibowitz AA, Taylor SL.</td>
<td>“Distance to public test sites and HIV testing.”</td>
<td>2007</td>
<td>Medical Care Research and Review</td>
<td>5,361 Los Angeles County adults, multinomial logit models</td>
<td></td>
</tr>
<tr>
<td>Mayben et al.</td>
<td>“Predictors of Delayed HIV Diagnosis in a Recently Diagnosed Cohort.”</td>
<td>2007</td>
<td>AIDS Patient Care Standards</td>
<td>119 persons recently diagnosed with HIV infection recruited from four publicly funded facilities in Houston, Texas</td>
<td>female gender (p = 0.005), reason tested other than “felt sick” (p &lt; 0.001), and marijuana use (p = 0.004) and other illicit drug use (p = 0.01)</td>
</tr>
<tr>
<td>Holmes Jr. et al.</td>
<td>“Racial variance in rationale for HIV testing in community-based setting in the United States: Evidence from NHIS 2003 (n=29,753)</td>
<td>2008</td>
<td>Journal of International Association Physicians AIDS Care</td>
<td>Compared with Caucasians, African Americans were 37% less likely to be tested due to exposure to sex/drugs, whereas Hispanics were not. African Americans were more likely to test regardless of resident’s own race/ethnicity</td>
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http://digitalscholarship.unlv.edu/jhdrp/
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Journal</th>
<th>Data and Sample Description</th>
<th>Findings</th>
</tr>
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<tbody>
<tr>
<td>National Health Interview Survey.”</td>
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<tr>
<td>Behel et al. “HIV Prevention Services Received at Health Care and HIV Test Providers by Young Men who Have Sex with Men: An Examination of Racial Disparities.”</td>
<td>2008</td>
<td>Journal of Urban Health</td>
<td>2,424 MSM ages 23-29 in 5 cities. Interviewed and tested, randomly sampled from MSM venues</td>
<td>Differential experience with HIV prevention services does not explain the higher prevalence among Black and Hispanic MSM</td>
</tr>
<tr>
<td>Losina et al. “Racial and Sex Disparities in Life Expectancy Losses Among HIV-Infected Persons in the United States: Impact of Risk Behavior, Late Initiation, and Early Discontinuation of Antiretroviral Therapy.”</td>
<td>2009</td>
<td>Clinical Infectious Diseases</td>
<td>Simulated cohorts of HIV-infected persons and compared them with uninfected individuals who had similar demographic characteristics. Data from the national HIV Research Network, stratified by sex and race/ethnicity, were used for</td>
<td>Late treatment initiation resulted in 2.60 additional years of life lost. Losses from late initiation and early discontinuation were greatest for Hispanic individuals (3.90 years)</td>
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</tbody>
</table>
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<table>
<thead>
<tr>
<th>Reference</th>
<th>Year</th>
<th>Study Design/Population</th>
<th>Diagnosis Factors</th>
<th>Health System Barriers</th>
<th>Contextual Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jenness et al. “Missed Opportunities for Testing Among High-Risk Heterosexuals.”</td>
<td>2009</td>
<td>Sexually Transmitted Diseases</td>
<td>846 high-risk people from NYC, mostly Black or Latino, 40-50 years old</td>
<td>Only 31% (men) and 35% (women) had tested in the past year; BUT clients mostly support routine testing</td>
<td>Poverty (via infrequent access to HC), targeting of traditional at-risk groups (?)</td>
</tr>
<tr>
<td>Wohl et al. “Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles.”</td>
<td>2009</td>
<td>AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV</td>
<td>Population based interview study (n=383) with Latinos in Los Angeles</td>
<td>Spanish language primary associated with late diagnosis</td>
<td>Testing at a hospital and due to illness associated with late diagnosis</td>
</tr>
<tr>
<td>Mimiaga et al. “Health System and Personal Barriers Resulting in Decreased Utilization of HIV and STD Testing Services among At-Risk Black Men Who Have Sex with Men in Massachusetts.”</td>
<td>2009</td>
<td>AIDS Patient Care and STDs</td>
<td>Black MSM (n=197) recruited with respondent driven sampling. Assessment with optional testing and counseling. Logistic regression used for analysis</td>
<td>Factors associated with not testing: serodiscordant unprotected sex</td>
<td>Never having been tested in a community clinic, STD clinic, or jail</td>
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<td>Not having access to a healthcare provider</td>
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<tr>
<td>Reed et al. “HIV Testing Factors Associated with Delayed Entry into HIV Medical Care among HIV-Infected Persons from Eighteen States, United States, 2000–2004.”</td>
<td>2009</td>
<td>AIDS Patient Care Standards</td>
<td>HIV+ adults (n=3,942) in 18 states 2000-2004. Multivariable logistic regression models were used</td>
<td>Diagnostic testing-related characteristics associated with delayed care entry included anonymous and first-time HIV testing</td>
<td>Lower levels of education</td>
</tr>
<tr>
<td>McCoy et al. “Barriers and facilitators to HIV testing and linkage to”</td>
<td>2009</td>
<td>AIDS Care</td>
<td>Qualitative interview study of 24 HIV+ persons attending a</td>
<td>The primary barrier to HIV testing prior to diagnosis was [lack of] perception of risk</td>
<td>Contextual factors: Availability of testing services Insurance status Transportation</td>
</tr>
</tbody>
</table>

Jenness et al. “Mished Opportunities for Testing Among High-Risk Heterosexuals.” 2009 Sexually Transmitted Diseases 846 high-risk people from NYC, mostly Black or Latino, 40-50 years old Only 31% (men) and 35% (women) had tested in the past year; BUT clients mostly support routine testing 90% had encountered a “testing setting” homeless shelters, jails/prisons, drug programs, HC providers

Wohl et al. “Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles.” 2009 AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV Population based interview study (n=383) with Latinos in Los Angeles Spanish language primary associated with late diagnosis Testing at a hospital and due to illness associated with late diagnosis

Mimiaga et al. “Health System and Personal Barriers Resulting in Decreased Utilization of HIV and STD Testing Services among At-Risk Black Men Who Have Sex with Men in Massachusetts.” 2009 AIDS Patient Care and STDs Black MSM (n=197) recruited with respondent driven sampling. Assessment with optional testing and counseling. Logistic regression used for analysis Factors associated with not testing: serodiscordant unprotected sex Never having been tested in a community clinic, STD clinic, or jail Not having access to a healthcare provider

Reed et al. “HIV Testing Factors Associated with Delayed Entry into HIV Medical Care among HIV-Infected Persons from Eighteen States, United States, 2000–2004.” 2009 AIDS Patient Care Standards HIV+ adults (n=3,942) in 18 states 2000-2004. Multivariable logistic regression models were used Diagnostic testing-related characteristics associated with delayed care entry included anonymous and first-time HIV testing

McCoy et al. “Barriers and facilitators to HIV testing and linkage to” 2009 AIDS Care Qualitative interview study of 24 HIV+ persons attending a The primary barrier to HIV testing prior to diagnosis was [lack of] perception of risk Several participants described screening events where testing was offered such as prison intake, a testing Contextual factors: Availability of testing services Insurance status Transportation

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primary care: narratives of people with advanced HIV in the Southeast.” | Southeastern HIV clinic who presented with clinically advanced illness | event at a residential substance abuse recovery program, and screening during clinical examinations. In these cases, participants were amenable to testing when it was readily available and free | Incarceration Substance abuse Healthcare utilization

| Millett et al. | 2011 | 1,208 MSM completed computer-assisted interview and HIV test. HIV+ unaware men compared with HIV- men in bivariate and multivariate analysis | Latinos: Nongay identity | Blacks: Gay identity | Both: high perceived risk, belief that sex with other Latino men/Black men reduces risk | Blacks: higher income, health insurance, sexuality disclosure

| Wallace et al. | 2011 | Qualitative study with 26 focus groups (13 male and 13 female) with young heterosexual African Americans in one urban and one rural site | Benefits of testing perceived included emotional relief, not spreading the virus unknowingly, being offered treatment if needed, changing risky behaviors | Concerns included accessing affordable treatment and suffering social stigma

| Tang et al. | 2011 | All of California’s reported 28,382 AIDS cases during the period. Multivariable logistic regression used to identify associated factors | Over 35 years of age, born outside of US (especially born in Mexico), heterosexual or unknown risk | Access to testing. Targeting of traditional risk groups, gay identification less likely among Latinos | Role of migration poorly understood, language and culture among foreign-born people

| Nunn et al. | 2011 | 5,871 | 66% of HIV+ testers

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Individual/ Interpersonal Factors: Many of the studies that aimed to identify factors correlated with late diagnosed HIV examined factors at the level of the individual, such as testing behavior, knowledge about HIV/AIDS, and attitudes toward testing or health services. Regarding testing behavior, Ebrahim et al. (2004) have found that testing rates are higher among both African Americans and Latinos than among whites and Asian/Pacific Islanders, a finding corroborated by other studies. (Robinson et al., 2012) Another individual level factor explored by Ebrahim et al. (2004) is knowledge about the availability and efficacy of antiretroviral treatment for HIV/AIDS, which was found to be significantly lower for African Americans (OR=0.58, 95% CI=0.52, 0.64) and for Latinos (OR=0.67, 95% CI=0.59, 0.75) compared to whites.

While knowledge about treatment is certain to affect people’s testing behavior (cf Wallace et al. (2011), it is not as clear that attitudes toward testing do. Jenness et al.’s (2009) study explored attitudes about testing and reported that a majority of high-risk heterosexuals of color in New York City supported routine HIV testing, while only 31% of male study participants and 35% of females had consented to receiving testing in the past year. As the investigators noted, this disconnect demonstrates that factors other than attitudes regarding testing present obstacles to HIV testing. Similarly, Ostermann et al. (2007) found that among 146,868 National Health Interview Survey (NHIS) respondents, individuals who perceived that they were at greater risk for contracting HIV were not more likely to seek or consent to an HIV test. Further, while those who reported higher risk behaviors were more likely to get tested, still less than 25% of people with high risk actually got tested. Other study findings indicated that people with higher levels of risk behavior were less likely to receive an HIV test, including Bond et al.’s (Bond et al., 2005) study with heterosexual men and women in Philadelphia, Mimiaga’s study of men of color who have sex with men (2009), and Fernández et al.’s (2002) study of
Latino men. Kellerman et al. (2002) found that denial of risk and fear of being positive were related to avoiding testing.

Community Factors: At the level of the community, a number of studies referred to access to testing sites and healthcare as determinants of testing behavior and timely diagnosis. However, the size and direction of the influence was not always straightforward. For instance, Jenness et al. (2009) found that among the 846 high risk people of color in their study, 90% had encountered a testing setting (jail, prison, homeless shelter, drug rehabilitation program, or healthcare provider) while less than 35% of their sample had received an HIV test in the past year. Ostermann et al.(2007) found that access to healthcare services was associated with significantly higher testing rates in their cross-sectional study, and Mimiaga et al. (2009) found the same in their targeted study of African American MSM. Similar results were observed in a study of urban African American men (Petroll et al., 2009). Latinos in Los Angeles studied by Wohl et al. (2009) were more likely to access testing in hospitals and due to illness; that is, once a problem had already presented itself. The issue of access to and quality of healthcare is relevant to racial and ethnic health disparities as disproportionate numbers of African Americans and Latinos lack access to quality healthcare (Nelson, 2002; Saha, Arbelaez, & Cooper, 2003) and health insurance (Zuvekas & Taliaferro, 2003). In a qualitative study (Wallace et al., 2011) where 26 focus groups were conducted with 142 young heterosexual African Americans in Philadelphia, PA and Orangeburg, SC to better understand their attitudes about HIV testing, the ability to access affordable care after receiving a positive result was mentioned in all of the focus groups as an important concern that factored into their decision making about whether or not to seek or consent to an HIV test.

Another community level determinant of testing behavior, explored in seven studies, is targeted HIV prevention efforts. Lopez-Quintero et al. (2005) hypothesized that the relationship they found between Puerto Rican ethnicity and higher rates of testing was related to targeting of prevention efforts toward Puerto Ricans. Similarly, both Tang et al. (2011) and Kellerman et al. (2002) identified the targeting of traditional risk groups as being an important determinant of late versus timely diagnosis of HIV. Specifically, MSM, a group that has been targeted by various prevention and education efforts, are less likely to receive a late diagnosis than heterosexual individuals (Schwarz et al., 2006; Torrone et al., 2007). However, Tang et al. (2011) found that Latino MSM were less likely to identify as gay, suggesting that they would be less likely to receive prevention and screening services targeted to that group. Supporting this suggestion is the finding of Millett et al. (2011) that non-gay identity was associated with being unaware of one’s HIV status among Latino (but not among black) MSM. Community stigmatization of homosexuality in this community thus appeared to increase the risk of late-stage HIV diagnosis via discouragement of gay identification.

Societal Factors: Fewer studies considered societal level factors that impact racial disparities in testing and timely diagnosis of HIV. However, Bond et al. (2005) examined individual- and structural-level environmental determinants of timely HIV diagnosis and found stronger associations for structural level factors (e.g., access to health care and opportunities for testing). Only half of the individual level factors they measured were significantly associated with HIV testing behavior among heterosexual men and women of color in Philadelphia, whereas all of the structural level factors were significant, with odds ratios greater than two. As mentioned above, access to healthcare and opportunities for testing were defined in Bond et al.’s (2005) study as structural level variables, as was exposure to prenatal testing policies, drug
treatment programs, and incarceration. In contrast, drug use and sexual risk behavior were defined as individual level factors. Of the 22 variables these investigators examined, those defined as being at the structural level were more significantly correlated with HIV testing. These included, for men, access to healthcare as measured by doctor visits in the past year (OR=3.82, 95% CI=2.69, 5.42), and for women, exposure to prenatal testing policies (OR=4.89, 95% CI=2.70, 8.84). In contrast, variables that were considered individual level variables were for the most part non-significant for testing behavior, with such exceptions as history of drug use for men (OR=2.18, 95% CI=1.35, 3.51) and knowing someone who is HIV+ for both women (OR=2.35, 95% CI=1.44, 3.83) and men (OR=2.76, 95% CI=2.08, 3.67).

Unfortunately, the authors of this paper do not explicitly describe how they classified factors as structural or individual. Although the structural level factors identified by Bond et al. (Bond et al., 2005) were measured on an individual level, they point to structural impacts on testing behavior that act on the collective and have measurable effects on the individual. For instance, while a person’s number of visits to the doctor per year is an individual measure, a structural perspective considers that broader structures such as public healthcare and insurance policies, employment and education practices, and even discrimination by healthcare providers all affect one’s healthcare seeking behavior. Because the quantitative measure that Bond et al. (2005) used to determine the reasons for the study participants’ frequency of doctor visits was not provided, however, it is difficult to determine whether this factor is indeed a structural level variable.

Leibowitz and Taylor (2007) and Taylor et al. (Taylor, Leibowitz, Simon, & Grusky, 2006) explore the influence of group-level access to care by using ZIP code correlates and measuring distance to testing sites in Los Angeles County. Although ZIP codes may be problematic in capturing a community level factor (since communities with which people identify often are on a geographically smaller scale, such as neighborhood, or not geographically defined), the findings of both studies demonstrate the influence of factors at an aggregate level and on a larger scale than other previous research. In both studies, greater distance to testing site was associated with reduced likelihood of receiving an HIV test only for people who lived in low-income ZIP code areas or were low income.

In addition, various factors associated with immigration status were identified in multiple studies as being important societal level determinants especially among Latinos but also in African immigrants. Immigration status was correlated with certain community norms and attitudes, e.g., stigmatization of homosexuality (Lopez-Quintero et al., 2005; Moreno, 2007) and with fear and mistrust of the healthcare system (Foley, 2005; Lopez-Quintero et al., 2005), particularly with regard to immigration policies around HIV status (Torrone et al., 2007).

Taylor et al. (2006) and Jenness et al. (2009) both classify poverty as a structural determinant of testing and timely HIV diagnosis, and found (in Los Angeles and New York, respectively) that testing was less available to the poor, whether through proximity and costs of travel (Leibowitz & Taylor, 2007) or through lack of access to primary and regular healthcare (Bond et al., 2005; Taylor et al., 2006). In addition, Ebrahim et al. (2004) identified the importance of income and education in obtaining knowledge about HIV/AIDS. These investigators found that the racial gap in knowledge of HIV/AIDS treatment narrows with increasing income and education. Finally, correlations between level of educational attainment and likelihood of not receiving an HIV test (OR=0.31, 95% CI=0.03, 0.99) were identified by Mimiaga et al. (2009) and others (Schwarcz et al., 2006). In each case, lower education was
associated with higher risk. As the authors pointed out, this is important to consider in connection with racial/ethnic health inequities as there exists a large racial/ethnic gap in educational opportunities available to students in the United States (Horwood, Mogridge, & Darlow, 1998; National Center for Education Statistics, n.d.), as demonstrated by the pervasive gap in test scores, high school graduation rates, and advanced placement course enrollment.

Racial/ethnic Disparities in HIV Risk: Despite the fact that testing rates are high among Latinos and African Americans (Ebrahim et al., 2004; Ostermann et al., 2007; Robinson et al., 2012; Taylor et al., 2006), late diagnosis of HIV/AIDS remains a problem that is disproportionately borne by members of these two racial and ethnic groups. Thus, there is a missing link between testing, targeting and risk. Although studies of racial disparities in HIV testing and diagnosis are less focused on societal level factors, more work on multiple levels has been done regarding racial disparities in HIV/AIDS in general.

Lane et al. (2004) investigated African American-white disparities in HIV and found that racial inequities in rates and duration of incarceration, racial residential segregation, stigmatization of homosexuality in communities of color, and the targeting of communities of color in advertisements for and sales of unhealthy goods, including douche products and alcohol, were all societal factors contributing to racial inequities in HIV/AIDS. The authors assert that these societal level factors affect HIV/AIDS outcomes distribution through pathways that include community factors such as higher rates of infection, gang turf, skewed sex ratios and lack of access to health services in urban communities of color where poverty is concentrated. Lane et al. (2004) effectively revealed multi-level factors affecting racial disparities in HIV infection. We were unable to find similar scholarship that makes connections between factors on all social ecological levels on the particular problem of racial disparities in late diagnosis of HIV in the peer-reviewed literature to date.

DISCUSSION

This review of the literature on social determinants of late stage HIV diagnosis used a social ecological framework to analyze findings concerning the multiple levels on which HIV testing and diagnosis may be impacted. The 26 studies examined each contributed important descriptive elements about racial/ethnic inequities in the population distribution of late stage HIV in the US, and useful insights into multi-level contextual factors that shape the disparity.

Study limitations: This study suffered from several limitations. Given that only studies reported in English were included, some important research may have been overlooked, especially with regard to Latino/ Latina immigrants, who may have been the focus of studies that subsequently appeared in Spanish language peer-reviewed journals. In addition, the 11-year time period was limiting. Although as noted, it was chosen to reflect a critical change in testing, we may have missed important earlier studies addressing one or more of the gaps we identify below. It is clear, however, that many of the findings that emerged in this review are not new. For example, 22 years ago, Phillips (1993) found that HIV testing behavior among Latinos and African Americans was correlated with self-perceived risk and individual knowledge, findings that are echoed in more recent studies including those led by Ebrahim (2004), Ostermann (2007), and Kellerman (2002).

In confining our review to peer-reviewed journal articles, we faced another limitation in missing important sources containing valuable insight into this problem, including books such as MacKenzie’s (2013a) “Structural Intimacies: Sexual Stories in the Black AIDS Epidemic,” and
Another limitation lay in the fact that because different investigators defined structural or societal level factors in different ways, some conceptual confusion resulted from our attempt to categorize factors by social ecological level. As an example, Bond et al. (Bond et al., 2005) considered access to healthcare and opportunities for testing to be a structural determinant, because these resources are unevenly distributed by both race and socio-economic position. In contrast, Lane et al. (Lane et al., 2004) asserted that other societal level factors such as racial residential segregation operate through what they define as intermediate community level factors, including limited access to high quality health services. Similarly, access to care and health insurance was discussed as a community level factor in the studies of Jenness (2009), Ostermann (2007), Mimiaga (2009) and Wohl (2009) and their respective colleagues. Although such discrepancies were challenging, they also provided important insights into the need for more refined conceptual development in explorations of the multi-level factors that may impact on late stage HIV testing and diagnosis.

Areas for further research: This review revealed both a number of important studies and, at the same time, several significant gaps in the extant literature on SDOH and other social ecological factors impacting late stage HIV among African Americans and Latinos. Below we focus primarily on the overarching finding of this study—the need for more attention to measurement issues, especially with regard to SDOH and individual v. high levels of analysis—as well as other issues, which appear ripe for further research.

Better measurement of SDOH and other factors on different ecological levels: As Table 1 illustrates, although most studies in this review referred to factors on at least two levels, it was sometimes difficult to ascertain with certainty whether the influential factor was considered by the investigators to constitute a macro-level factor, even when measured on the individual level. Indeed, in all but one (Taylor et al., 2006) of the quantitative studies examined, influential factors were measured at the individual level. While such individual level explorations are critical, to better understand how community and societal factors affect distributions of health outcomes, individual level analyses should be supplemented by efforts to more directly measure aggregate variables at higher levels of the social ecological model.

In quantitative research, capturing relationships between social ecological factors and health outcomes requires thoughtful attention to measurement issues (Diez-Roux, 1998), as many variables can be measured in both individuals and groups. For example, while immigration is often classified as a structural level factor, immigration status is measured on an individual level by most researchers. In some respects, this is logical, since individual immigration status influences health through factors at each level of the social ecological model. Societal level immigration policies interact with individuals’ trust of healthcare systems; community-level availability of multi-lingual services interacts with individual immigrants’ linguistic abilities in determining access to care; and cultural norms from home countries differentially shape immigrants’ power and communication within sexual relationships. Further, and as earlier research has suggested (Franzini, Ribble, & Keddie, 2000; Gee, Ryan, Laflamme, & Holt, 2006; Viruell-Fuentes, 2007), the number of years immigrants have been in the US is also influential, since factors such as adherence to cultural mores from the country of origin, time away from...
regular partners and family, and acculturation may result in changes in sexual behaviors and attitudes toward testing. For example, Moreno et al. (2007) explore some of the ways that *machismo* (defined as “the social domination and privilege that men have over women in economic, legal, judicial, political, cultural and psychological spheres” (Cianelli, Ferrer, & McElmurry, 2008)) and *marianismo* (the complement of machismo, delineating submission as a desirable and praiseworthy feminine characteristic (Cianelli et al., 2008)) shape HIV risk in Latino communities. Further investigation is needed, however, to gain a more complex and nuanced understanding of the multiple pathways and levels through which immigration affects ethnic disparities in health.

The prevalence of individual measurements and paucity of close examination of macro-level factors affecting testing in the quantitative studies reviewed here highlights a need for more qualitative exploration of the multi-level influences on testing behavior. It is possible that higher level determinants of HIV testing rates have been insufficiently studied in part because it is as yet unclear which determinants are truly influential. Qualitative research can facilitate the identification of factors existing at multiple levels of the social ecological model, as well as initial assessment of their relationship to particular outcomes or behaviors. Ethnographic research, focus groups and open-ended questions in semi-structured interviews all can help determine *what* factors, operating at one or more levels of the social ecological model, influence rates of HIV testing in at-risk communities. Subsequent quantitative research then could be employed to understand *which* of the identified factors are more influential determinants and how strongly they are associated with the outcome of late testing and diagnosis.

Moving upstream (without losing sight of the individual level): As suggested above, much of the investigation of racial disparities in testing and diagnosis of HIV remains focused at the individual level, despite the fact that research on inequities in HIV risk and infection demonstrate the comparatively greater importance of “upstream” factors (Lynch, Smith, Kaplan, & House, 2000) such as the distribution of health-enhancing resources and the clustering of health risks (Lane et al., 2004; Phelan et al., 2004).

It is essential to draw the connections between *structural factors* that affect distribution of resources and risks; *community factors* such as those that determine people’s access to prevention, screening and treatment services; and *individual-level factors* including people’s prioritization of testing and decisions to seek or consent to testing. Research on the social determinants of HIV and AIDS disparities led by scholars, including Poundstone (2004), Zeirler and Krieger (1997), Lane and colleagues (2004) Rhodes (Rhodes, Malow, & Jolly, 2010), Moreno (2007) and others points to the intricate connections between broader social forces and disease outcomes. Racial/ethnic inequities in late diagnosed HIV represent both a reflection of the inequities in the larger HIV/AIDS epidemic and a mechanism for a cycle of continued inequities in HIV/AIDS. As noted earlier, HIV among Latinos and African Americans is not contained in the traditional high-risk groups of MSM or MSM/IDU. Considering that late stage HIV is significantly associated with heterosexual orientation and is higher in both these populations, this is an important key to understanding and reducing the large ethnic and racial disparities in HIV/AIDS. Given that such disparities are shaped by social determinants of health interacting with individual determinants, it will likely be impossible to adequately address these disparities without careful attention to macro-level factors as these play out at, and interact with, factors at the interpersonal, community and societal levels, and not merely the level of the individual.
Focus on late treatment, often to the exclusion of late diagnosis: Another gap revealed by this review is that, with the important exceptions discussed here, there is comparatively little research focusing specifically on racial/ethnic disparities in late diagnosed HIV. Among HIV/AIDS researchers in the United States, late treatment is widely recognized as a major problem in the HIV+ population, and many studies have investigated reasons contributing to late treatment and its consequences (Craw et al., 2008; McCoy, Miller, et al., 2009; McCoy, Strauss, et al., 2009; Mugavero et al., 2007; Reed et al., 2009). In addition, there is substantial research on factors contributing to the racial/ethnic disparities in HIV risk and infection (Das et al., 2010; Gilliam, Hanchette, Fogarty, & Gibbs, 2012; Organista, 2012; Thomas & Quinn, 1991). In contrast, fewer recent studies have been conducted to better understand late diagnosis of HIV, disparities in late diagnosis, and the multi-level factors impacting on testing behavior. The heavy focus on treatment and infection, to the exclusion of diagnosis and detection, is not reflective of either the proportion of the HIV+ population affected by the problem of late diagnosis or its relevance to disparities in HIV transmission and treatment (Gardner, McLees, Steiner, del Rio, & Burman, 2011) and AIDS mortality (Losina et al., 2009).

Within the research that does focus on detection and diagnosis, there is a dearth of investigation that focuses specifically on the two racial/ethnic groups consistently found to be most at-risk for late stage HIV: Latinos and African Americans. Many of the studies to date have either been restricted to one racial or ethnic group (Fernández et al., 2002; Foley, 2005; Lopez-Quintero et al., 2005; Nunn et al., 2011; Petroll et al., 2009; Wallace et al., 2011; Wohl et al., 2009), or do not sample based on race or ethnicity and simply report racial characteristics of the sample population.1,2,4-9 Such research does not explicitly investigate influences on racial/ethnic disparities (Chae, Nuru-Jeter, Lincoln, & Francis, 2011; Thomas, Quinn, Butler, Fryer, & Garza, 2011). An example of the former is the community-based study of Latinos in Los Angeles County in which Wohl and colleagues (2009) found that the largest predictor of late testing among Latinos was Spanish as a primary language. While this is certainly an important finding, it does not apply to non-Hispanic African American populations that also have very high rates of late diagnosed HIV/AIDS. More research aimed at identifying factors that apply across these populations is needed to address this inequity effectively. Millett et al.’s (2011) study with a sample of black and Latino MSM provides a useful example in this regard, and revealed the unusual finding that in their sample, being unaware of one’s HIV+ status was associated with higher income and having health insurance for black MSM. But since late stage diagnosis is associated with heterosexual orientation (Schwarcz et al., 2006; Tang et al., 2011; Torrone et al., 2007), and heterosexual transmission among African Americans and Latinos is comparatively much higher than it is among whites (Centers for Disease Control and Prevention, 2013), more research across these heterosexual groups in particular is needed.

Community-engaged research and interventions focused on late stage diagnosis: The racial and ethnic groups disparately affected by late stage HIV diagnosis have a history of being marginalized and suffering from human subjects abuses in health research in the past (Chávez, Duran, Baker, Avila, & Wallerstein, 2008; Malone, Yerger, McGruder, & Froelicher, 2006; Thomas & Quinn, 1991). Against this backdrop, and given that those sub-groups most vulnerable to risk of HIV infection are often the most marginalized of the marginalized (such as African American incarcerated men and undocumented Latino immigrants), it is especially important to engage with community partners in investigating sensitive issues such as late stage HIV diagnosis. Community-based participatory research (CBPR), has been used to investigate health
disparities in partnership with many traditionally marginalized groups, and has often improved the “relevance, rigor and reach” (Morello-Frosch, Pastor Jr, Sadd, Porras, & Prichard, 2005) of the research.

There is a strong tradition in HIV/AIDS research of CBPR, which involves “systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change” (Green & Mercer, 2001). With some important exceptions however, the CBPR literature on HIV/AIDS has focused most heavily on risk behavior prevention with HIV (-) people (Deeds et al., 2008; Marcus et al., 2004; Morin, Maiorana, Koester, Sheon, & Richards, 2003) or on people living with HIV/AIDS (PLWHA) (Hergenrather, Rhodes, & Clark, 2006; Rhodes, Hergenrather, Wilkin, & Jolly, 2008), and rarely on detection or diagnosis. Indeed, in a cursory review of articles on CBPR studies of HIV/AIDS published in the last decade, just three (S. D. Rhodes et al., 2011; Chen et al., 2011; Berkley-Patton et al., 2012) of the 53 identified papers addressed HIV testing, diagnosis and detection. Not one of the three was focused specifically on late stage diagnosis.

The lack of peer reviewed CBPR studies on this issue represents another aspect of this research gap. Many identified and theorized social determinants of health are related to disempowerment or a lack of power, including racism (Nuru-Jeter et al., 2009) poverty (Melchior, Moffitt, Milne, Poulton, & Caspi, 2007) and control over destiny (Syme, 2004). It is therefore particularly important that health researchers be aware of how research, as a form of community intervention, can either contribute to disempowerment and related problems, or to health-enhancing empowerment and capacity building. A good example of the latter can be seen in a seminal early study of transgender health in San Francisco (Clements-Noelle and Bachrach, 2008; Clements-Nolle, Marx, Guzman, & Katz, 2001), in which the local health department hired and trained ten transgender people and worked closely with the community throughout the research process. That study not only resulted in critical health data (e.g., an HIV+ rate of 35% in the male to female transgender community) but also led to numerous interventions in the department and the city, and continued collaboration with this highly marginalized population almost two decades later.

Similarly, Rhodes and his colleagues (Rhodes et al., 2012) partnered with Latina women in North Carolina to study and then systematically address the sexual health needs of Latino/Latina immigrant communities in the rural Southeast US. Through a participatory process, they created an intervention to train Latina women as Lay Health Advisors who provided HIV prevention services as part of a holistic package of sexual health promotion, drawing on existing strengths identified in these communities including the social support and connections among and between Spanish-speaking Latinas.

Beyond research, as we alluded to above, innovative interventions in the form of data- and community-informed programs and policy developments must be designed in order to halt the increasing inequities in late diagnosed HIV and its myriad consequences. One example of such a project recently was concluded in Oakland, California. To better understand and address the problem of late stage HIV/AIDS testing and diagnosis among African Americans and Latinos in Oakland, California, a city heavily impacted by the epidemic, a multi-racial/ multi-ethnic team of community and academic research partners came together in 2010 to conduct a CBPR study. Funded by the Office of AIDS Research at the National Institutes of Health (NIH), the study gathered both qualitative and quantitative data, and pilot tested two community-driven solutions. Two respected community-based organizations (La Clínica de la Raza and Cal PEP- California
Prostitutes’ Education Project), together with the Pangaea Global AIDS Foundation and academic partners from the University of California, Berkeley’s School of Public Health, formed the initial project team. Additional stakeholders (e.g., the Alameda County Public Health Department and Street Level Health Project, a popular “one stop shopping” clinic and health and social service organization) also played a key role. CBPR formed a conceptual and methodological framework for the research, which included the active engagement of community-based co-researchers in most aspects of the scientific investigation, and involvement by professional researchers in the development and evaluation of the community-driven intervention pilot. The results of this study will be forthcoming, but an initial peer-reviewed article (Udoh et al., 2013) on the formation of the partnership and its development and use of a partnership covenant and guiding principles to ensure high level community collaboration is available. (http://www.press.jhu.edu/journals/progress_in_community_health_partnerships/).

CBPR, in sum, appears to be one promising avenue for examining SDOH and the multi-level factors impacting on late stage diagnosis and racial/ethnic health disparities. An orientation to research that has been effectively applied in HIV/AIDS research using social epidemiology, ethnography, mixed-methods research, and other methodologies, while also attending to power imbalance within the research enterprise itself, CBPR, too, may help in our efforts to more effectively study and address the multiple level factors contributing to disparities in late stage HIV diagnosis among two already marginalized populations.

CONCLUSION

Over three decades into the HIV/AIDS epidemic, late stage diagnosis remains a significant and under-studied problem, particularly within the two racial/ethnic groups disproportionately affected by the disease. Further, that research which has been conducted on late stage diagnosis and testing among African Americans and Latinos tends to focus on individual level variables, rather than those at the outer rungs of the ecological model, including, importantly, such SDOH as poverty and racism. As our review suggests, conceptual confusion regarding “structural factors” and SDOH also continues to “muddy the waters,” hampering our ability to more carefully study the pathways from and between factors at different levels of the social ecological model and their impacts.

As MacKenzie (2013b) has pointed out, “It wasn’t until 2010 that the U.S. developed a national plan to fight HIV/AIDS, a plan that focuses on the systemic, social and racial forces that drive the epidemic. The question is, do we have the will to act on that and creates prevention and interventions that address these structural inequalities?”

Lives are lost and the epidemic continues to spread more rapidly when community-engaged research investigating social determinants of and contributors to this enduring problem are not used to help improve data-driven programs, policies and practices. Conducting and helping translate into action new research on social determinants and other factors that together help maintain high rates of late stage HIV diagnosis, particularly among African American and Latino communities, is critical to moving forward.

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