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An Ecological Community-Based Participatory Research Study of Late Diagnosed HIV/AIDS in Oakland, California: Investigating influential factors in racial/ ethnic health inequities

By

Alison Marie Chopel

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Doctor of Public Health

in the

Graduate Division

of the

University of California, Berkeley

Committee in charge:

Professor Meredith Minkler, Chair

Professor Amani Nuru-Jeter

Professor Charis Thompson

Spring 2014

Abstract

An Ecological Community-Based Participatory Research Study of Late Diagnosed HIV/AIDS in Oakland, California: Investigating influential factors in racial/ ethnic health inequities

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Nationwide, there is a racial/ethnic disparity in incidence of HIV infection and AIDS mortality, with African Americans and Latinos having disproportionately higher rates of both HIV and AIDS than Whites and Asian/ Pacific Islanders. The racial disparity in late diagnosis of HIV/AIDS reflects that of timely- diagnosed HIV, suggesting that late diagnosis may be one important driver of the widening racial disparities seen in the AIDS epidemic. Late HIV diagnosis is defined as a diagnosis of AIDS simultaneously with or within one year of an initial HIV diagnosis.

This dissertation research was conducted in conjunction with a larger mixed-methods study to investigate late diagnosis of HIV among Latinos and African Americans in Oakland, and to collaboratively design, implement and evaluate two interventions to address the problem. To conduct a systematic and critical review of the literature on HIV/ AIDS diagnosis among Latinos and African Americans within the United States in order to identify the multi-level social determinants of racial/ ethnic inequities in late-stage HIV. The overarching goal of this dissertation research was to use a Community- Based Participatory Research (CBPR) approach to identify the individual, interpersonal, community, and societal factors, and their interactions, which facilitate or hinder timely HIV testing by at-risk populations among Latinos and African Americans living in Oakland, California. The dissertation had the following aims: 1) To conduct a systematic and critical review of the literature on HIV/ AIDS diagnosis among Latinos and African Americans within the United States in order to identify the multi-level social determinants of racial/ ethnic inequities in late-stage HIV. 2) To analyze qualitative data from the larger parent study in order to identify and examine multi-level factors that exacerbate or attenuate barriers to timely HIV testing and diagnosis among African Americans and Latinos in Oakland, California. 3) To use reflexive analysis and participant observation to examine the benefits and challenges of using a CBPR framework to guide academic/ community collaboration for research and action goals. In order to achieve these aims, I conducted the three studies included in this dissertation.

In the first study, I found that 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 (n=17), Latinos and African Americans were more likely to receive a late diagnosis than non-Hispanic Whites or Asian Americans. Furthermore, 95.8% (n= 23) of the reviewed studies focused on individual level risk factors or investigated structural barriers via measurements at the individual level. However, in my second study I found that significant factors identified by participants as relating to the late diagnosis of HIV lay beyond the traditional individual-level elements of attitude, norms, control beliefs, and power, and were located within the interpersonal, community, and/or societal levels of the ecological model.

In the third study, we found that use of a CBPR approach both benefited the study and presented challenges in four key areas: 1) inclusion/ exclusion; 2) bridging social capital and the role of bridge people; 3) education, status, race/ ethnicity, privilege and power imbalances; and 4) conflicting priorities. The findings from these three studies demonstrate the importance of including communities in investigations of late-stage HIV inequities. Community engagement added value to this study as all partners contributed to aligning every activity toward the dual goals of increased knowledge and improved practice. The study findings also demonstrated that disparities in HIV testing behaviors are shaped and maintained by ecological factors at multiple levels. Especially when investigating health disparities that cluster in marginalized and oppressed communities, community-academic collaboration and multi-level frameworks can enhance findings.

People living with and at high risk of HIV infection by and large have borne the brunt of persistent, and also deepening, forms of economic and social inequality. These inequalities, and [people]'s strategies for living within and against them, make intelligible observed population patterns of HIV among [men and] women both in the United States and elsewhere. To keep in the forefront a vision of women [and men] capable of passion and playfulness, of hard work and creativity, of loving parenting and strong kinship, people who desire full participation in society, to be generative and to make a difference in the world, these are the [people] about whom we are writing. Pushing against such vital possibility are the challenges of economic and political forces and structures that threaten and often take these lives and the lives of their loved ones. [People]'s struggles with and resistance to social and economic subordination include strategies for survival that bear the burden of drug use, violence, hunger, social disintegration, and sexual risk."

> -Zierler S, Krieger N. Reframing women's risk: social inequalities and HIV infection. *Annual review of public health*. 1997;18(1):401–436.

I dedicate this work to all the people who resist oppression, of themselves and others, in their everyday lives.

I specifically would like to honor my son, Khangsing S. Chopel, with this work, as I include him among those who resist oppression, especially as he develops into a man without the guidance of a father. Furthermore, he has shared his only parent with this work for the past three years.

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In addition to my fabulous professors, I must acknowledge my cohort of super-stars. Studying and learning with them over these past three years has been inspirational and supportive. I never imagined that a learning community could be so invigorating, and again, I have gained some wonderful friends in the process. The most terrific part of my cohort is that I have connected with every one of them, so I must acknowledge each of them: Anna Baker, Courtney Henderson, David Rebanal, Evan Vandommelen-Gonzalez, Kara MacLeod, Kathi Schaff, Ryan Petteway, Sara Marques, Solange Gould, Sonia Navani, and Victor Villalobos. Our happy hours, mutual encouragement, study hours, and potlucks easily turned stress into enjoyment, and learning about their research consistently motivated and awed me.

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INTRODUCTION

Racial and Ethnic Inequities in HIV and AIDS

Nationwide, there is a racial/ethnic disparity in incidence of HIV infection and AIDS mortality, with African Americans and Latinos having disproportionately higher rates of both HIV and AIDS than Whites and Asian/ Pacific Islanders.[1,2] According to the Centers for Disease Control and Prevention (CDC), in 2010 African Americans comprised 12% of the national population and 46% of the people diagnosed with HIV,[3] while Latinos comprised 16% of the national population and 20% of the HIV+ population in that year.[3]

In this dissertation, the terms African American and Latino are used to reference social racial and ethnic identities. The racial 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 are included. 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. These racial/ ethnic categories are important because of the structural, interpersonal, and internalized racism with which people who are identified as African American or Latino contend.[4] Further, these racial/ethnic categories matter because of the way that access to opportunities and public goods are structured in this country in ways that result in sharp disparities by race and ethnicity;[5] both of these problems profoundly affect health.

Late Diagnosis of HIV

Late diagnosis is defined as a diagnosis of AIDS simultaneously with or within one year of an initial HIV diagnosis.[6] Late diagnosis is directly related to a lack of access to information, screening and treatment services, and other resources that people use to protect their health;[7–9] disparities in this health problem thus represent a preventable inequity. The consequences of late diagnosed HIV are very different for both the person and the population than the consequences associated with HIV diagnosed in a timely manner. First, HIV can only be treated once it is diagnosed; 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[10] and anti-retroviral treatments.[11] Thus, when late HIV diagnosis becomes prevalent in a community or population, both HIV incidence and AIDS mortality increase.

The racial disparity in late diagnosis of HIV/AIDS reflects that of timely-diagnosed HIV, suggesting that late diagnosis may be one important driver of the widening racial disparities seen in the AIDS epidemic.[12] High rates of late diagnosed HIV/AIDS among African Americans and Latinos are harmful to these racial/ethnic communities, as years are cut off of the lives of people who otherwise would likely have lived longer. In addition, HIV-negative people are unknowingly infected with HIV, keeping HIV rates high in communities of color when they could be reduced if people knew their status, were receiving treatment, and/ or modifying their behavior. Marks et

al.[13] conducted a meta-analysis and found that people tend to reduce risky behavior upon diagnosis even without additional intervention, which suggests that diagnosis itself can be an intervention.

Besides increased AIDS mortality and HIV transmission, late diagnosis leads to a higher overall burden of morbidity and mortality in communities and populations that are already overburdened with disproportionately high prevalence and incidence of several diseases, including, among others, diabetes, hypertension, cardiovascular diseases, some cancers, gonorrhea, syphilis, and schizophrenia.[14–18] Each of these health inequities, like HIV, has been linked to disproportionately high rates of poverty, racism, and other social determinants of health and disease in people and communities of color.[16,19–21] These other diseases can, in turn, complicate the rates of HIV incidence as HIV risk behaviors are elevated, for example, among people who have mental illness or addictions.[22] Furthermore, the disproportionate disease burden of HIV among African American and Latinos contributes to racial/ ethnic inequities in AIDS mortality, because AIDS is an autoimmune disease for which comorbidity can be especially fatal.[23] Finally, as population growth among racial and ethnic minorities outpaces growth of the White majority, the term “minority” becomes inadequate, masking the size of the problem of disproportionate rates of HIV and AIDS among non-White racial groups and obscuring the effect it has on society as a whole.

Other disparities in late diagnosed HIV exist along lines of gender, age, sexuality and occupation (in this case, occupation encompasses the state of being incarcerated as well as willfully employed). The population affected by late diagnosed HIV/AIDS differs from the larger population of people living with HIV/AIDS in a number of ways: on average they are older, more likely to be heterosexual, less likely to be survivors of child abuse, more likely to speak Spanish as their primary language, and (as described above) more likely to be African American or Latino.[24–26] The focus groups in our study were conducted in homogeneous groups with participants who were the same gender, race/ ethnicity, and age group as each other.

Local Context: Oakland, California

Oakland, California, the largest city in Alameda County, is one of the country’s most ethnically and racially diverse with approximately equal proportions of African Americans (28%), Latinos (25.4%) and Whites (25.9%), as well as a sizeable Asian/ Pacific Islander population (17.4%).[27] In response to high rates of HIV/AIDS among African Americans and steep racial disparities in the disease, Alameda County, California, was the first local health jurisdiction to declare a State of Emergency for HIV/AIDS in 1998.[1] More than a decade and a half later, the state of emergency is still in effect due to continuing high HIV incidence and disparities,[28] especially in Oakland (see Figure 1). Among some African American community leaders, there is a sentiment that little is being done to respond to this emergency.[29] In contrast, no parallel state of emergency has been declared for Latinos. Some AIDS activists within the Latino community feel that this translates into a lack of attention to and resources for the problem of HIV/ AIDS within the Latino community.[25]

Insert figure 1 about here

Resources for combatting HIV/ AIDS in general in Alameda County and Oakland are inadequate, making it even more challenging to address entrenched disparities in the disease. Oakland is part of the "shadow city" phenomenon,[31] whereby certain urban centers' HIV/ AIDS problems and responses to them are over-shadowed by neighboring cities that have more money, less diversity, and sometimes longer-standing AIDS epidemics, resulting in a disproportionate amount of HIV/AIDS funding/ programming being allocated between the cities. For instance, in 2010 and 2011, San Francisco received $42.8 million in federal money to address HIV/AIDS, whereas during the same time period Oakland received a mere $8.3 million, despite comparable incidence rates (399 new cases in San Francisco County, 335 new cases in Alameda County in 2009) and very similar prevalence rates.[32]

Late diagnosis of HIV/AIDS is an important component of the epidemic in Oakland that has not yet been examined. Although the rate of late diagnosis of HIV in the nation as a whole is declining (from 37% in 2004 to 32.3% in 2007[33]), late HIV diagnosis in Oakland remains elevated (38.3% in 2010).[34] Furthermore, two marginalized racial/ ethnic minority groups, Latinos and African Americans, are disproportionately affected. In Alameda County almost two-thirds (66.1%) of all people who were diagnosed with HIV and subsequently developed AIDS within one year were either African American or Latino,[34] while these two racial/ ethnic groups comprised just 35.8% of the county's total population. Further, these cases were mostly concentrated in Oakland where African Americans and Latinos represented 53.4% of the city's population.[27] It is clear that in order to address this state of emergency effectively, more information about the racial disparities in late diagnosis is needed.

Research Context: Community-Based Participatory Research Study of Late Diagnosed HIV

This dissertation research was conducted in conjunction with a larger mixed-methods study to investigate late diagnosis of HIV among Latinos and African Americans in Oakland, and to collaboratively design, implement and evaluate two interventions to address the problem. To create space for collaboration between two historically divided[35,36] marginalized groups, African Americans and Latinos, both of which are facing the epidemic of late stage HIV diagnosis, a community-based participatory research (CBPR) orientation was chosen for the study. In this project, the participant community referred to is Oakland's HIV/AIDS service, research and advocacy community, as well as locally- based people with HIV/AIDS in the two racial/ ethnic groups of interest.

Between 2010 and 2013, two well-respected community- based service organizations, and a global AIDS research organization collaborated on the study with university partners in study decision-making, data collection, and data analysis processes. The California Prostitutes' Education Project (Cal-PEP) is an organization dedicated to the treatment and prevention of HIV and other sexually transmitted diseases among high-risk and hard-to-reach populations. Cal-PEP is located in West Oakland, a majority African American neighborhood, and serves mostly African Americans in East and West Oakland. La Clínica de la Raza (La Clínica) is a non-profit community health center that serves the Latino population in the San Francisco Bay

Area's East Bay, with a network of clinics and health education programs staffed by bilingual (Spanish and English speaking) providers. Pangaea Global AIDS Foundation (PGAF) is an applied research organization specializing in HIV/ AIDS research and innovation both globally and domestically. Working together and with researchers from the University of California, Berkeley's School of Public Health (UCB-SPH), these community-based organizations achieved the following specific aims in their joint effort to address the problem of late diagnosed HIV/ AIDS in Oakland:

"Aim 1: To elucidate individual and structural barriers to earlier detection of HIV through 1) qualitative methods including key informant interviews and focus groups, and 2) a case-control study of all individuals who presented in Oakland with a late HIV/AIDS diagnosis within the last 5 years (compared to a sample of non-late diagnosed individuals) to assess 'missed opportunities' for testing and entry into care.

Aim 2: To make existing (but not readily accessible) county and statewide HIV testing and AIDS case data available to local communities for better understanding of late diagnosis and improved programming.

Aim 3: To engage community and other HIV/AIDS stakeholders in reviewing findings from Aims 1 & 2, and promising programmatic and policy strategies that may have the potential to improve early intervention, to identify and/or develop community-driven responses to increase early HIV detection and diagnosis.

Aim 4: To pilot test the most promising of these community-driven responses on feasibility and potential effectiveness, leading to recommended models of implementation in Oakland."[37]

Conceptual Framework: Health Behavior in Ecological Context

Theory of Planned Behavior: Two theoretical frameworks informed this dissertation: the Theory of Planned Behavior and the Social Ecological Model. The Theory of Planned Behavior contributes to our understanding of the components of health decision-making and health behaviors.[22] According to the theory, individuals' intention to act to improve their health is dependent upon their attitude towards the behavior and subjective norms about the behavior, as well as their perceived behavioral control. The former is comprised of their belief about the expected outcome of the action and their assessment of desirability of the expected outcome. For instance, a person's decision about whether to seek or consent to an HIV test is influenced by whether he or she believes they are at risk for a positive result, as well as their fears about the consequences of a positive result. Subjective norms about a behavior affect individual decision making through the person's perceptions about what others in their immediate communities will think about the behavior, as well as their personal motivation to conform to these perceived norms. This component of decision making and behavior is especially important regarding HIV and AIDS, as the disease is highly stigmatized[40] and, in many communities, is connected to stigmas concerning sexual orientation.[41,42] The concept of perceived behavioral control encompasses control beliefs and perceived power. Control beliefs refer to the barriers or facilitators that the individual perceives to be either obtrusive or conducive to the planned behavior. These control beliefs both

influence and are influenced by an individual's perceived power. Whether or not people believe that they have the power to perform the behavior or to overcome perceived barriers to the action in turn greatly impacts their intention to act.

While the Theory of Planned Behavior includes the effect of outside influences such as norms and barriers to action on an individual's intention to act, it does not provide a complete picture of the many proximal and distal factors that influence individuals in their environments. The Social Ecological Model[43–45] is based on the concept that human society, like other natural systems, is an integrated multi-level system that affects each individual organism living within it, and is in turn shaped by those same individuals. In order to improve individuals' health outcomes, we must consider the various levels (individual, interpersonal, community, societal) that influence their daily lives and choices through their physical and social environments. It is important to recognize the influence of interactions between factors at each of these levels: i.e. structural racism results in educational inequities, which translates into differential levels of HIV/ AIDS awareness in communities. The latter then affects interpersonal communication about HIV/ AIDS, which in turn affects community awareness levels. All of these various factors and their interactions over the different levels influence and are influenced by individual knowledge about HIV/ AIDS and protective behaviors. These interacting factors and influences in turn result in inequities in HIV/ AIDS rates which feeds into stereotypes, interpersonal racism and reinforcing structural racism.

Integrating these two models as a framework for this investigation was meant to reduce the possibility of falling into the traps of either of two fallacies outlined by Diez-Roux:[46(p219)] the psychologistic and the sociologistic. The psychologistic fallacy occurs when individual level variables are used in an individual level inference, but relevant group-level variables are left out, confounding the analysis. The sociologistic fallacy results from using group level variables for group level inference but leaves out relevant individual level variables. Although these fallacies relate to causal inferences usually investigated with quantitative methods, both fallacies were essential considerations in this qualitative research as well, since both could inform identification of variables in further quantitative study of the topic. Integrating the Theory of Planned Behavior with the Social Ecological Model supported location of factors that influence HIV testing at multiple ecological levels.

Overview of Dissertation

While it is likely that some of the factors that influence testing may also affect rates of late-stage HIV and AIDS through direct biological pathways, i.e. via mechanisms that result in increased physiological vulnerability to infection or reduced immune function, this study explicitly investigated a behavioral correlate of late-stage HIV; that is, infrequent, irregular or nonexistent testing behavior following risk behavior. For instance, it is possible that living in an isolated, high-crime neighborhood could cause HIV to develop into AIDS more quickly via increased physical reactions to stress which compromise the immune system,[47] while also acting as a behavioral barrier to accessing HIV testing because residents of such communities may be less inclined to go out unnecessarily and/ or HIV testers would be less likely to enter into those

neighborhoods.[*] While it was beyond the scope of this study to investigate the role of decreased immune system functioning in late-stage HIV inequities, it is always important to consider the interaction between behavior and biology, and to keep in mind that poverty and discrimination influence the population distribution of health outcomes through a multiplicity of intersecting pathways. Due to the nature of the data available, this investigation was confined to the influence of multi-level factors on HIV testing behavior and not the influence of multi-level factors on immune functioning, physiological susceptibility or infectiousness of the virus. For example, although studies have shown that social class is directly related to rate of disease progression of HIV/ AIDS,[48] we were unable to investigate the role of rate of disease progression in late-stage HIV disparities.

The overarching goal of this dissertation research was to use a Community-Based Participatory Research (CBPR) approach to identify the individual, interpersonal, community, and societal factors, and their interactions, which facilitate or hinder timely HIV testing by at-risk populations among Latinos and African Americans living in Oakland, California. The dissertation had the following aims:

1. To conduct a systematic and critical review of the literature on HIV/ AIDS diagnosis among Latinos and African Americans within the United States in order to identify the multi-level social determinants of racial/ ethnic inequities in late-stage HIV.
2. To analyze qualitative data from the larger parent study in order to identify and examine multi-level factors that exacerbate or attenuate barriers to timely HIV testing and diagnosis among African Americans and Latinos in Oakland, California.
3. To use reflexive analysis and participant observation to examine the benefits and challenges of using a CBPR framework to guide academic/ community collaboration for research and action goals.

In order to achieve these aims, I conducted the three studies included in this dissertation.

The first study is entitled, “Social Determinants of Late Stage HIV Diagnosis and its Distributions among African Americans and Latinos: A critical literature review.” This literature review used the Social Ecological Model as a conceptual framework for understanding the inequitable distribution of late HIV diagnosis by race and ethnicity in the United States. I argued that identifying social determinants of health is essential to addressing this health inequity, given that population variations in HIV do not match variations in risk and protective behaviors as much as they match variations in social inequalities. I searched Google Scholar and PubMed for studies published between 2002 and 2013 and found 26 unduplicated studies that met eligibility criteria. After analyzing these studies, I concluded that late diagnosis and testing remains under-studied, particularly among the two racial/ ethnic groups that are most impacted by the problem, African Americans and Latinos. Furthermore, I found that existing research was overwhelmingly focused on the individual level and lacked sufficient investigation of

[*] Personal communication, Braunz Courtney, HEPPAC Oakland, October 2012.

social determinants of health such as poverty and racism. I highlighted confusion of terms such as “structural factors,” where such factors were often measured on an individual level and it was often not clear how the authors were defining “structural factors” and “individual factors.” I suggested that more qualitative research could help to identify and define existing multi-level social determinants of disparities in HIV diagnosis. Furthermore, I suggested that public health researchers studying behavioral health issues like HIV testing need to explicitly move “upstream.” Utilizing the Social Ecological Model as a conceptual framework can aid in moving beyond the individual level. Taking the bigger picture view is part of our role as public health researchers and practitioners; similarly, it is important for us to improve understanding of prevention and screening and not just treatment. In this review of the literature, I found an overwhelming focus on late treatment while in contrast, relatively few studies, sought to improve understanding of screening and testing disparities. Based on these findings, I recommend the use of CBPR for further investigation of social determinants of inequities in HIV diagnosis and other behavioral health problems. I further stress that as an orientation to research, CBPR can be employed with quantitative, qualitative, and mixed methods approaches, and that it attends to the power balance that exists in research and influences the research agenda.

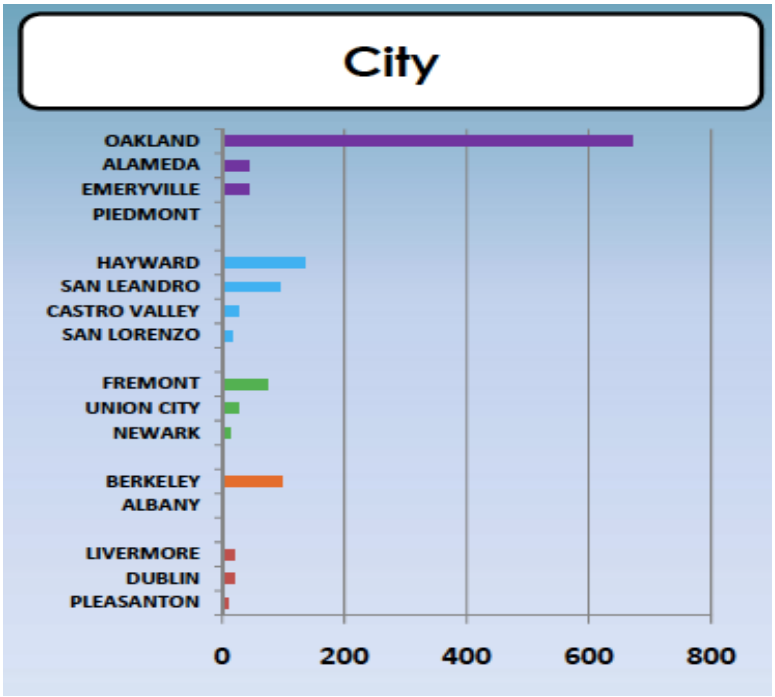
The second study, “Understanding Contextual Influences on HIV Testing Behavior Among Latinos and African Americans in Oakland to Reduce Late Stage HIV Diagnosis Disparities,” was an analysis of all of the qualitative data generated during the parent study through focus group (n=13 groups) and interviews (n=17). Participants included: African American and Latino residents of Oakland who were disconnected from services or had received a late HIV diagnosis, and local leaders in the Oakland HIV community. For this analysis I employed a conceptual framework that combined the Social Ecological Model with the Theory of Planned Behavior. Findings demonstrated the ways that multi-level ecological factors impact individual health behavior, contributing to inequitable population distributions of health and disease that follow the contours of social and economic inequalities.

The final study, “Challenges and Benefits of a CBPR Approach to Studying and Addressing Late Stage HIV/AIDS Diagnosis Among Urban African Americans and Latinos,” was a reflexive analysis of the CBPR approach and processes employed in the parent study. During the last phase of the larger study and after project close, a sub-committee of five Steering Committee members and participatory co-researchers engaged in dialogue and exploration of the challenges and benefits of using the CBPR orientation for the large, three-year, mixed methods research project. Together, we identified several challenges and benefits, with examples illustrating each, and chose four areas on which to report. We found that every one of the challenges we identified also conferred a benefit, which is why we decided to structure our findings around the four issue areas. The first was inclusion and exclusion; while we found that expanded inclusion in the research endeavor was a benefit of CBPR to both the community and the research study, we noted challenges around the populations that remain excluded even after inclusion was broadened. The second issue was bridging social capital and bridge people. The CBPR processes employed improved bridging social capital and underscored the importance of the role of bridge people, “boundary spanner” or “liaison

persons"[49,50] who could help bridge diverse worlds as needed during the course of the project. However when limits on these functions and roles were reached, it strained developing relationships between differently situated co-researchers. The third issue we reported on was power imbalances. Existing social divides came into our research partnership and influenced what was said and not said at meetings as well as who was able to participate in writing up findings and how credit for that work was allotted. The final issue was primarily a challenge and did not seem to have a beneficial side: the conflicting priorities of research and programming, exacerbated by timing of the IRB approval and the funding, were challenging for all to navigate. However, the implicit benefit lay in the fact that we included programming and action components as part of the project, whereas traditional research projects often are restricted to investigation of a problem and leave response and action to practitioners.

Together, these studies highlight the importance of understanding the multi-level contextual determinants of health that shape inequities in late stage HIV through impacting on the health behavior of HIV testing. Qualitative investigation of relationships between multi-level factors can provide a foundation for further quantitative investigation, and could help to address some of the limitations in the existing body of literature on the problem, noted in the first study. By combining investigation and action in response to study findings, CBPR can be effectively utilized to better understand and actively address health inequities such as the racial/ ethnic disparity in late-stage HIV in Oakland. While a CBPR approach inevitably incurs some unique challenges, it provides benefits to both the communities of interest and the scientific endeavor. By investigating the social determinants of late-stage HIV among African Americans and Latinos in the US and in-depth in Oakland, and exploring the use of CBPR to simultaneously improve understanding of the problem and begin to address it in one community, this study aims to improve understanding of the relationship between individual behavior and inequitable population distributions of health and disease.

Figure 1: Geographic Distribution of HIV Incidence in Alameda County: 2006-2011 (n=1299)[34]



References

1. Lane SD, Rubinstein RA, Keefe RH, et al. Structural violence and racial disparity in HIV transmission. *J Health Care Poor Underserved*. 2004;15:319–335.

2. Moreno CL. The Relationship Between Culture, Gender, Structural Factors, Abuse, Trauma, and HIV/AIDS for Latinas. *Qual Health Res*. 2007;17(3):340-352. doi:10.1177/1049732306297387.

3. National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. HIV Surveillance by Race/Ethnicity (through 2010). 2012. Available at: http://www.cdc.gov/hiv/topics/surveillance/resources/slides/race-ethnicity/index.htm. Accessed March 31, 2012.

4. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health*. 2000;90(8):1212.

5. Massey DS. *Categorically Unequal: The American Stratification System*. Russell Sage Foundation; 2008.

6. Tang JJ, Levy V, Hernandez MT. Who are California's late HIV testers? An analysis of state AIDS surveillance data, 2000-2006. *Public Health Rep Wash DC 1974*. 2011;126(3):338-343.

7. Ebrahim SH, Anderson JE, Weidle P, Purcell DW. Race/Ethnic Disparities in HIV Testing and Knowledge About Treatment for HIV/AIDS: United States, 2001. *AIDS Patient Care STDs*. 2004;18(1):27-33. doi:10.1089/108729104322740893.

8. Jenness SM, Murrill CS, Liu K-L, Wendel T, Begier E, Hagan H. Missed Opportunities for HIV Testing Among High-Risk Heterosexuals. *Sex Transm Dis*. 2009;36(11):704-710. doi:10.1097/OLQ.0b013e3181ab375d.

9. Leibowitz AA, Taylor SL. Distance to public test sites and HIV testing. *Med Care Res Rev*. 2007;64(5):568–584.

10. Coleman SM, Rajabiun S, Cabral HJ, Bradford JB, Tobias CR. Sexual Risk Behavior and Behavior Change among Persons Newly Diagnosed with HIV: The Impact of Targeted Outreach Interventions among Hard-to-Reach Populations. *AIDS Patient Care STDs*. 2009;23(8):639-645. doi:10.1089/apc.2008.0092.

11. Ulett KB, Willig JH, Lin H-Y, et al. The Therapeutic Implications of Timely Linkage and Early Retention in HIV Care. *AIDS Patient Care STDs*. 2009;23(1):41-49. doi:10.1089/apc.2008.0132.

12. Losina E, Schackman BR, Sadownik SN, 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. *Clin Infect Dis*. 2009;49(10):1570-1578. doi:10.1086/644772.

13. Marks G, Crepaz N, Senterfitt JW, Janssen RS. Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: implications for HIV prevention programs. *J Acquir Immune Defic Syndr 1999*. 2005;39(4):446-453.

14. Semaan S, Sternberg M, Zaidi A, Aral SO. Social capital and rates of gonorrhea and syphilis in the United States: Spatial regression analyses of state-level associations. *Soc Sci Med*. 2007;64(11):2324-2341. doi:10.1016/j.socscimed.2007.02.023.

15. Bresnahan M, Begg MD, Brown A, et al. Race and Risk of Schizophrenia in a US Birth Cohort: Another Example of Health Disparity? *Int J Epidemiol*. 2007;36(4):751-758. doi:10.1093/ije/dym041.

16. Williams DR, Jackson PB. Social Sources Of Racial Disparities In Health. *Health Aff (Millwood)*. 2005;24(2):325-334. doi:10.1377/hlthaff.24.2.325.

17. Kawachi I, Daniels N, Robinson DE. Health Disparities By Race And Class: Why Both Matter. *Health Aff (Millwood)*. 2005;24(2):343-352. doi:10.1377/hlthaff.24.2.343.

18. Williams DR, Yu Y, Jackson JS, Anderson NB. Racial differences in physical and mental health. *J Health Psychol*. 1997;2(3):335–351.

19. Phelan JC, Link BG, Diez-Roux A, Kawachi I, Levin B. “Fundamental causes” of social inequalities in mortality: a test of the theory. *J Health Soc Behav*. 2004;45(3):265-285.

20. Marmot M. Social determinants of health inequalities. *Lancet*. 2005;365(9464):1099–1104.

21. Nuru-Jeter AM, Sarsour K, Jutte DP, Thomas Boyce W. Socioeconomic Predictors of Health and Development in Middle Childhood: Variations by Socioeconomic Status Measure and Race. *Issues Compr Pediatr Nurs*. 2010;33(2):59-81. doi:10.3109/01460861003663953.

22. Teplin LA, Elkington KS, McClelland GM, Abram KM, Mericle AA, Washburn JJ. Major Mental Disorders, Substance Use Disorders, Comorbidity, and HIV-AIDS Risk Behaviors in Juvenile Detainees. *Psychiatr Serv Wash DC*. 2005;56(7):823-828. doi:10.1176/appi.ps.56.7.823.

23. Skiest DJ, Rubinstien E, Carley N, Gioiella L, Lyons R. The importance of comorbidity in HIV-infected patients over 55: A retrospective case-control study. *Am J Med*. 1996;101(6):605-611. doi:10.1016/S0002-9343(96)00329-4.

24. Mugavero MJ, Lin H-Y, Allison JJ, et al. Failure to Establish HIV Care: Characterizing the “No Show” Phenomenon. *Clin Infect Dis*. 2007;45(1):127-130. doi:10.1086/518587.

25. Girardi E, Sabin CA, Monforte A d'Arminio. Late Diagnosis of HIV Infection: Epidemiological Features, Consequences and Strategies to Encourage Earlier Testing. *JAIDS J Acquir Immune Defic Syndr*. 2007;46(Suppl 1):S3-S8. doi:10.1097/01.qai.0000286597.57066.2b.

26. Jean-Jacques M, Walensky RP, Aaronson WH, Chang Y, Freedberg KA. Late diagnosis of HIV infection at two academic medical centers: 1994-2004. *AIDS Care*. 2008;20(8):977-983. doi:10.1080/09540120701767257.

27. Bureau USC. American FactFinder - Results. Available at: http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1&prodType=table. Accessed March 31, 2012.

28. Brooks J. HIV/AIDS State of Emergency. *The Oakland Post Online*. May 18, 2011.

29. Palacios J, Kennedy HP. Reflections of Native American teen mothers. *J Obstet Gynecol Neonatal Nurs JOGNN NAACOG*. 2010;39(4):425-434. doi:10.1111/j.1552-6909.2010.01149.x.

30. Luker K. *Dubious Conceptions: The Politics of Teenage Pregnancy*. Harvard University Press; 1997.

31. Holmes T. San Francisco, Oakland Kick Off Nationwide Discussion on HIV/AIDS in America. *TheBody.com*. 2011. Available at: http://www.thebody.com/content/64462/san-francisco-oakland-kick-off-nationwide-discussi.html. Accessed October 3, 2012.

32. Wong M, Struzzo M. *Is Your City a Shadow City?* Oakland, California: Greater Oakland Shadow City Coalition; 2012.

33. Satcher Johnson A, Heitgard J, Koenig L, et al. *Vital Signs: HIV Testing and Diagnosis Among Adults --- United States, 2001--2009*. Atlanta, GA: Centers for Disease Control and Prevention; :1550-1555. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5947a3.htm?s_cid=mm5947a3_w. Accessed October 1, 2012.

34. Murgai N. Late Testers- preliminary data. 2012.

35. Falcon A. Black and Latino politics in New York City: Race and ethnicity in a changing urban context. *J Ethn Migr Stud*. 1988;14(3):370–384.

36. Gay C. Seeing difference: The effect of economic disparity on black attitudes toward Latinos. *Am J Polit Sci*. 2006;50(4):982–997.

37. Dunbar M, Udoh I, McCoy S. *Community Based Participatory Research for Late Diagnosis in Oakland*. Pangaea Global AIDS Foundation; 2010.

38. Rosenstock IM, Strecher VJ, Becker MH. Social Learning Theory and the Health Belief Model. *Health Educ Behav*. 1988;15(2):175-183. doi:10.1177/109019818801500203.

39. Ajzen I. The theory of planned behavior. *Organ Behav Hum Decis Process*. 1991;50(2):179–211.

40. Parker R, Aggleton P. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*. 2003;57(1):13-24. doi:10.1016/S0277-9536(02)00304-0.

41. Brooks RA, Etzel MA, Hinojos E, Henry CL, Perez M. Preventing HIV Among Latino and African American Gay and Bisexual Men in a Context of HIV-Related Stigma, Discrimination, and Homophobia: Perspectives of Providers. *AIDS Patient Care STDs*. 2005;19(11):737-744. doi:10.1089/apc.2005.19.737.

42. Rhodes SD, Hergenrather KC, Vissman AT, et al. Boys must be men, and men must have sex with women: a qualitative CBPR study to explore sexual risk among African American, Latino, and White gay men and MSM. *Am J Mens Health*. 2011;5(2):140-151. doi:10.1177/1557988310366298.

43. Bronfenbrenner U, Morris PA. The ecology of developmental processes. In: *Handbook of child psychology: Volume 1: Theoretical models of human development (5th ed.)*. Hoboken, NJ, US: John Wiley & Sons Inc; 1998:993-1028.

44. Sallis JF, Owen N, Fisher EB. Ecological models of health behavior. *Health Behav Health Educ Theory Res Pract*. 2008;4:465–486.

45. McLeroy KR, Bibeau D, Steckler A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Health Educ Behav*. 1988;15(4):351-377. doi:10.1177/109019818801500401.

46. Diez-Roux AV. Bringing context back into epidemiology: variables and fallacies in multilevel analysis. *Am J Public Health*. 1998;88(2):216-222.

47. Leserman J, Jackson ED, Petitto JM, et al. Progression to AIDS: The Effects of Stress, Depressive Symptoms, and Social Support. *Psychosom Med*. 1999;61(3):397-406.

48. Zierler S, Krieger N. Reframing women's risk: social inequalities and HIV infection. *Annu Rev Public Health*. 1997;18(1):401–436.

49. Hatch J, Eng E. Community participation and control: or control of community participation. *Reforming Med Lessons Last Quart Century N Y NY Pantheon*. 1984:223–245.

50. Wallerstein N, Duran B. The conceptual, historical, and practice roots of community-based participatory research and related participatory traditions. In:

Community-Based Participatory Research for Health: From Process to Outcomes. San Francisco: Jossey-Bass; 2003:27-52

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

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,[1] disproportionately affects African American and Latino communities;[2,3] 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.[4,5]

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[1,2,6–11] or focused on one racial or ethnic group, often in one geographic location.[12–18] In all studies that compared racial and ethnic groups (n=17), Latinos and African Americans were more likely to receive a late diagnosis[3,19] than non-Hispanic Whites or Asian Americans. 95.8% (n= 23) of the reviewed studies focused on 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.

INTRODUCTION

The interdependence between social determinants of health (SDOH) and ethnic/ racial disparities in the HIV/AIDS epidemic has long been recognized.[20–23] 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.[24] 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,[25] the ways in which access to opportunities and public goods are differentially structured by race and ethnicity,[26] 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,[1] late stage diagnosis occurs in between 25% and 47.2% of all HIV diagnoses in the US.[27] It 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) [28] 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[6,11] and also higher rates of late stage diagnosis,[3] moreover, they are less likely to test due to a known exposure and more likely to test due to illness or a medical problem.[10]

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 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[29] 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[30] and his colleagues: 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[21,31–34] 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; 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[5] and anti-retroviral treatments.[35] 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.[36–40] 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.[38,41–43] These other diseases can in turn complicate HIV incidence in various ways: for instance, HIV risk behaviors are elevated among people who have mental illness (such as schizophrenia) or addictions.[44] 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.[45] 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 racial 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 included. 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[12] of the studies reviewed report specifically on this population, most focus on non-Hispanic African Americans.

Conceptual model: The social ecological model[31,46,47] 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[33,48] (see Figure 1 below for a visual representation of the social ecological model created by Dahlgren and Whitehead,[33] 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[21,31–34] 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 via 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 socio-economic 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.

FINDINGS

Factors Affecting HIV Testing: As indicated in Table 1, the majority of studies on racial disparities in HIV testing and diagnosis have been either cross-sectional[1-3,6–11] and/or focused on only one racial or ethnic group, often in one geographic location.[12–18] In all 13 studies that compared racial and ethnic groups, Latinos and African Americans were more likely to receive a late diagnosis[3,19] than non-Hispanic whites. In addition, being born outside the US[1,3] and not speaking English as a primary language[13,14] each were 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.,[49] 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,[3,50] heterosexual orientation,[1,3,19] and age. Age has also been cited as a factor associated with both testing and late diagnosis, however findings were contradictory. Tang et al.[1] found that in California, age over 35 was significantly associated with late diagnosis of HIV/AIDS, while Kellerman et al.[8] found that age under 25 was associated with being less likely to test for HIV, and Schwarcz et al.[3] 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.

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.[6] 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.[11] Another individual level factor explored by Ebrahim et al.[6] 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.[16]), it is not as clear that attitudes toward testing do. Jenness et al.’s study[51] 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.[2] 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[7] study with heterosexual men and women in Philadelphia, Mimiaga's study of men of color who have sex with men,[52] and Fernández et al.'s[15] study of Latino men. Kellerman et al.[8] found that denial of risk and fear of being positive was 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.[51] 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.[2] found that access to healthcare services was associated with significantly higher testing rates in their cross-sectional study, and Mimiaga et al.[50] found the same in their targeted study of African American MSM. Similar results were observed in a study of urban African American men.[18] Latinos in Los Angeles studied by Wohl et al.[14] 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[53,54] and health insurance.[55] In a qualitative study[16] 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.[12] 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.[1] and Kellerman et al.[8] 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.[3,19] However, Tang et al.[1] 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.[56] that non-gay identity was associated with being HIV+ unaware among Latinos (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 on racial disparities in testing and timely diagnosis of HIV. However, Bond et al.[7] 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, 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[7] study as structural level variables, as were 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.[7] 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.[7] used to determine the reasons for the study participants' frequency of doctor visits was not provided, however, it is difficult to determine where this factor is indeed a structural level variable.

Leibowitz and Taylor[9] and Taylor et al.[57] 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.[11] Immigration status was correlated with certain community norms and attitudes, e.g., stigmatization of homosexuality[12,23] and with fear and mistrust of the healthcare system,[12,13] particularly with regard to immigration policies around HIV status.[19]

Taylor et al.[57] and Jenness et al.[51] 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[9] or through lack of access to primary and regular healthcare.[7,57] In addition, Ebrahim et al.[6] 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.[52] and others.[3] 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,[58,59] 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,[2,6,11,57] 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.[20] 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.[20] 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 ethnic/ racial 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 critical 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, 20 years ago, Phillips[60] 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,[6] Ostermann,[2] and Kellerman.[8]

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[61] *"Structural Intimacies: Sexual Stories in the Black AIDS Epidemic*," and *"HIV Prevention with Latinos: Theory, Research and Practice"* edited by Organista.[62] Dissertations, monographs, proceedings from professional meetings, and community reports from community-based participatory research (CBPR) studies, also would have been missed in this review.

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.[7] 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.[20] 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,[51] Ostermann,[2] Mimiaga[52] and Wohl[14] 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 on 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.[57]) 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,[63] 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,[64–66] 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.[23] 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"[67]) and *marianismo* (the complement of machismo, delineating submission as a desirable and praiseworthy feminine characteristic[67]) 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[68] such as the distribution of health-enhancing resources and the clustering of health risks.[20,41]

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 issues* 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,[21] Zeirler and Krieger,[22] Lane,[20] Rhodes,[69] Moreno,[23] 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.[70–74] In addition, there is substantial research on factors contributing to the racial/ethnic disparities in HIV risk and infection.[62,75–77] 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[78] and AIDS mortality.[79]

Within the research that does focus on detection and diagnosis, there is a dearth of investigation that focuses specifically on the two ethnic/ racial 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 group,[12–18] or do not sample based on race and simply report racial characteristics of the sample population.[1,2,4–9] Such research does not explicitly investigate influences on racial disparities.[80,81] An example of the former is the community-based study of Latinos in Los Angeles County in which Wohl and colleagues[14] 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[56] 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,[1,3,19] and heterosexual transmission among African Americans and Latinos is comparatively much higher than it is among whites,[28] 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.[77,82,83] 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"[84] 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."[85] With some important exceptions however, the CBPR literature in HIV/AIDS has focused most heavily on risk behavior prevention with HIV (-) people[86–88] or on people living with HIV/AIDS (PLWHA),[89,90] 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[91,92,93] 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[94] poverty[95] and control over destiny.[96] 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,[97,98] 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[99] 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 article[100] 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 in press (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[101] 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 create preventions 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.

FIGURE 1: SOCIAL ECOLOGICAL MODEL, from Dahlgren and Whitehead 1991[33]

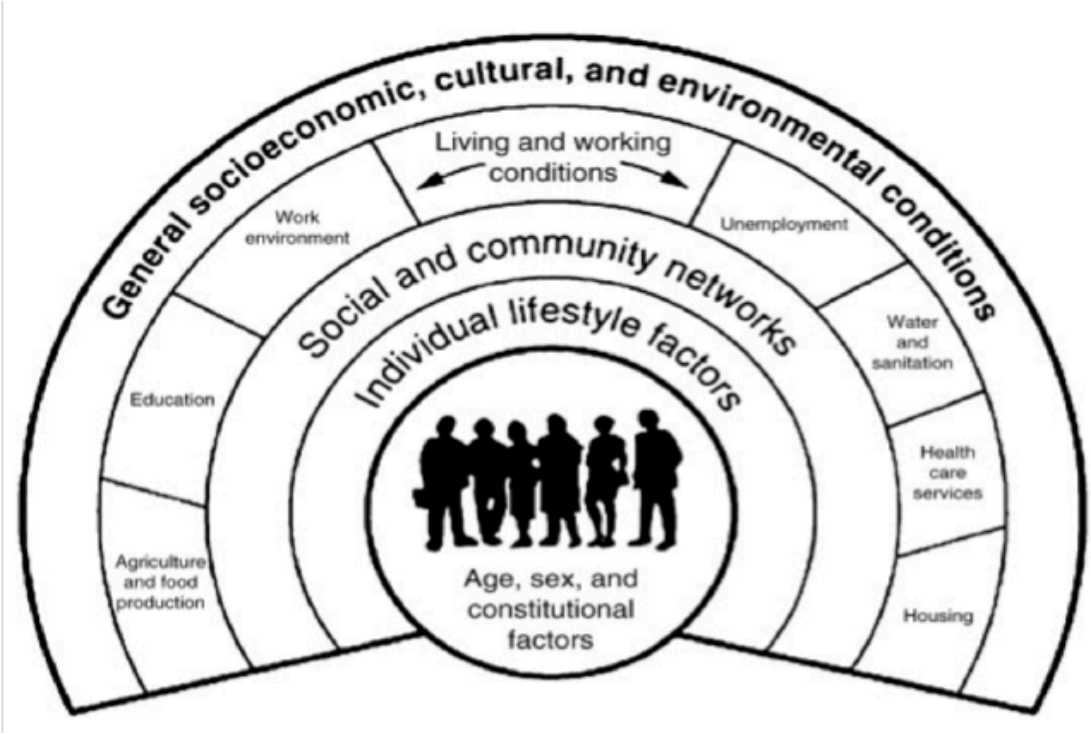


Table 1: Peer Reviewed Articles on Late HIV Testing and Diagnosis among Latinos and African Americans in the United States, with Ecological Levels of Analysis, 2002-2012

Author, Title	Year, Jour-nal	Sample/ Dataset	Individual factors	Community factors	Society factors
Fernández et al. "To test or not to test: are Hispanic men at highest risk for HIV getting tested?"	2002 AIDS Care	Community sample of 1,052 Hispanic men, both heterosexual and homosexual, via anonymous structured interviews	MSM, men with more partners, men with STDs, more likely to have testing history, inconsistent condom use associated with lower intentions to test		
Kellerman et al. "HIV Testing Within At-Risk Populations in the United States and the Reasons for Seeking or Avoiding HIV Testing."	2002 Jour-nal of AIDS	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)	Individual risk factors included: age under 25, denial of risk, fear of being positive	Prevention efforts addressing risk perception	Availab-ility of new technol-ogies may be a protective factor
Ebrahim et al. "Race/Ethnic Disparities in HIV Testing and	2004 AIDS Patient Care and STDs	2001 Behavioral Risk Factor Surveillance System	Testing rates higher among Blacks and Latinos	Knowledge (of ART) significantly lower among Blacks and Latinos than	The gap narrows with increasing income and

Knowledge About Treatment for HIV/AIDS: United States, 2001."				among Whites	education
Lopez-Quintero et al. "Barriers to HIV-Testing Among Hispanics in the United States: Analysis of the NHIS, 2000."	2005 AIDS Pat-ient Care and STDs	Hispanic sub-groups from the National Health Interview Survey (n=4,261)	Women more likely to test, probably b/c of prenatal VCT and OBGYN recommendations: higher levels of access to healthcare	Puerto Ricans more likely to test likely due to targeting of high-risk populations	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 engage in risk behavior
Foley, EE "HIV/AIDS and African immigrant women in Philadelphia: Structural and cultural barriers to care."	2005 AIDS Care: Psych-ological and Socio-medical Aspects of AIDS/ HIV	Qualitative study of African immigrant women in Philadelphia. Included 8 focus groups with case managers, peer counselors, social	Linguistic problems	Misunderstandings about modes of transmission and lack of awareness about antiretroviral treatment	Legal status, and fear of the American Health System

		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)			
Bond et al. "HIV testing and the role of individual- and structural-level barriers and facilitators."	2005 AIDS Care: Psych-ological and Socio-medical Aspects of AIDS/ HIV	Heterosex-ual men and women in Philadelphia (n=1,643). Personal interviews	Risk behaviors, including sexual and drug-using, were not highly correlated with an increased likelihood of ever having been tested	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 opportun-ities for testing
Schwarcz et al. "Late diagnosis of HIV infection: trends, prevalence, and characteris-tics of	2006 AIDS	AIDS cases in San Francisco 2001-2005 (n=2,139)	Latino/ Black race/ethnicity, female gender, younger age, heterosexual orientation, birth outside of US, all correlated with late HIV diagnosis		Lower education, lack of health insurance, private health insurance correlated with late HIV

persons whose HIV diagnosis occurred within 12 months of developing AIDS."					diagnosis
Taylor et al. "ZIP Code Correlates of HIV-Testing: A Multi-Level Analysis in Los Angeles."	2006 AIDS and Beha-vior	Random sample of LA County adults (n=5,475)			Residents of areas with high percent-age of African Americans were more likely to test regardless of resident's own ethnicity/ race
Torrone et al. "Late Diagnosis of HIV in Young Men in North Carolina."	2007 Sex-ually Trans-mitted Dis-eases	1,117 men ages 18-30 years identified through chart review	Ethnicity, history of IDU, heterosexual only contact	Fatalistic beliefs of Mexican-American women	US immigra-tion policies re: HIV infection
Ostermann et al. "Trends in HIV Testing and Differences Between Planned and Actual Testing in the United States 2000-2005."	2007 Arch-ives of Internal Medi-cine	146,868 NHIS participants, 18-64 y.o. during 2000-2005	Individuals with higher risk more likely to get tested, but still <25%	Alcohol and depression related to higher planned and actual testing, but also highest planned but NOT actual	Females and minorities more likely to get tested-> prenatal care and routine testing during checkups seems to

					be successful ->lack of access to healthcare services assoc. with lower testing
Leibowitz AA, Taylor SL. "Distance to public test sites and HIV testing."	2007 Medical Care Res-earch and Review	5,361 Los Angeles County adults, multinomial logit models		When public sites are more distant, poor individuals are less likely to use them and less likely to get tested. Distance from public sites does not affect HIV testing among the nonpoor	
Mayben et al. "Predictors of Delayed HIV Diagnosis in a Recently Diagnosed Cohort."	2007 AIDS Patient Care Stand-ards	119 persons recently diagnosed with HIV infection recruited from four publicly funded facilities in Houston, Texas	female gender ($p = 0.005$), reason tested other than "felt sick" ($p < 0.001$), and marijuana use ($p = 0.004$) and other illicit drug use ($p = 0.01$)	65% were diagnosed late- late diagnosis of HIV is common among users of public health care facilities	
Holmes Jr. et al. "Racial variance in rationale for HIV testing in community-based setting in the United	2008 Journal of Inter-national Asso-ciation Physi-cians AIDS Care	NHIS 2003 (n=29,753) Chi-square statistic and multinomial logistic regression analyses were used	Compared with Caucasians, African Americans were 37% less likely to be tested due to exposure to sex/drugs, whereas Hispanics were not.		

States: Evidence from National Health Interview Survey."			African Americans and Hispanics were less likely to be tested if they were sick or had a medical problem (PRR = 0.66, 95% CI = 0.44-0.99 and PRR = 0.65, 95% CI = 0.43-0.98)		
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."	2008 Journal of Urban Health	2,424 MSM ages 23-29 in 5 cities. Interviewed and tested, randomly sampled from MSM venues		Differential experience with HIV prevention services does not explain the higher prevalence among Black and Hispanic MSM	
Petroll et al. "HIV Testing Rates, Testing Locations, and Healthcare Utilization among Urban African-American Men."	2008 Journal of Urban Health	Self-administered survey with 352 young African American men in a Midwestern city	Having a healthcare provider and a recent visit associated with likelihood of having been tested in the past year		
Losina et al. "Racial and Sex Disparities in Life	2009 Clinical Infect-ious Dis-	Simulated cohorts of HIV-infected persons and compared	Late treatment initiation resulted in 2.60 additional years of life lost. Losses from late		

Expectancy Losses Among HIV-Infected Persons in the United States: Impact of Risk Behavior, Late Initiation, and Early Discontinu-ation of Antiretroviral Therapy."	eases	them with uninfected individuals who had similar demographic characteris-tics. Data from the national HIV Research Network, stratified by sex and race/ ethnicity, were used for estimating CD4+cell counts at ART initiation	initiation and early discontinuation were greatest for Hispanic individuals (3.90 years)		
Jenness et al. "Missed Opportunitie s for Testing Among High-Risk Heterosex-uals."	2009 Sex-ually Trans-mitted Dis-eases	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	Poverty (via infrequent access to HC), targeting of traditional at-risk groups (?)
Wohl et al. "Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles."	2009 AIDS Care: Psych-ological 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	2009	Black MSM	Factors	Never having	Lower

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 Massach-usetts."	AIDS Patient Care and STDs	(n=197) recruited with respondent driven sampling. Assessment with optional testing and counseling. Logistic regression used for analysis	associated with not testing: serodiscordant unprotected sex	been tested in a community clinic, STD clinic, or jail Not having access to a healthcare provider	levels of education
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 Stan-dards	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 primary care: narratives of people with advanced HIV in the Southeast."	2009 AIDS Care	Qualitative interview study of 24 HIV+ persons attending a Southeastern HIV clinic who presented with clinically advanced illness	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 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	Context-ual factors: Availabil-ity of testing services Insurance status Trans-portation Incarc-eration Subs-tance abuse Health-care utilization
Millett et al. "Mistaken Assumptions and Missed Opportunities: Correlates of Undiagno-sed HIV Infection Among Black and Latino Men Who Have Sex With Men."	2011 Journal of AIDS	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. "Why Take an HIV Test:	2011 Health Educ-ation	Qualitative study with 26 focus groups (13 male and	Benefits of testing perceived included emotional relief,	Concerns included accessing affordable	

Concerns, Benefits, and Strategies to Promote HIV Testing Among Low-Income Heterosexual African American Young Adults."	and Behav-ior	13 female) with young heterosexual African Americans in one urban and one rural site	not spreading the virus unknowingly, being offered treatment if needed, changing risky behaviors	treatment and suffering social stigma	
Tang et al. "Who Are California's Late HIV Testers?: An Analysis of State AIDS Surveillance Data 2000-2006."	2011 Public Health Reports	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 under-stood, language and culture among foreign-born people
Nunn et al. "Low Perceived Risk and High HIV Prevalence Among a Predominantly African American Population Participating in Philadelphia's Rapid HIV Testing Program."	2011 AIDS Patient Care and STDs	5,871 individuals participating in a community testing program (89% African American)	66% of HIV+ testers and 87% of HIV- testers assessed their own risk as low. However, risks were high: condom use was low, prevalence was 1.1%		
Robinson et al. "High-Risk HIV	2012 Ameri-can Journal	BRFSS data (n=20,633)		African Americans and other races more	

Minorities in the United States: Who Gets Tested and Where?”	of Health Beha-vior			likely to test than Whites, and more likely to test at hospitals and clinics	

REFERENCES

1. Tang JJ, Levy V, Hernandez MT. Who are California's late HIV testers? An analysis of state AIDS surveillance data, 2000-2006. *Public Heal Reports Wash Dc 1974*. 2011;126(3):338–343.

2. Ostermann J, Kumar V, Pence BW, Whetten K. Trends in HIV Testing and Differences Between Planned and Actual Testing in the United States, 2000-2005. *Arch Intern Med*. 2007;167(19):2128–2135. doi:10.1001/archinte.167.19.2128.

3. Schwarcz S, Hsu L, Dilley JW, Loeb L, Nelson K, Boyd S. Late diagnosis of HIV infection: trends, prevalence, and characteristics of persons whose HIV diagnosis occurred within 12 months of developing AIDS. *Jaids J Acquir Immune Defic Syndr*. 2006;43(4):491.

4. Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *N Engl J Med*. 2011;365(6):493–505. doi:10.1056/NEJMoa1105243.

5. Coleman SM, Rajabiun S, Cabral HJ, Bradford JB, Tobias CR. Sexual Risk Behavior and Behavior Change among Persons Newly Diagnosed with HIV: The Impact of Targeted Outreach Interventions among Hard-to-Reach Populations. *Aids Patient Care Stds*. 2009;23(8):639–645. doi:10.1089/apc.2008.0092.

6. Ebrahim SH, Anderson JE, Weidle P, Purcell DW. Race/Ethnic Disparities in HIV Testing and Knowledge About Treatment for HIV/AIDS: United States, 2001. *Aids Patient Care Stds*. 2004;18(1):27–33. doi:10.1089/108729104322740893.

7. Bond L, Lauby J, Batson H. HIV testing and the role of individual- and structural-level barriers and facilitators. *Aids Care*. 2005;17(2):125–140. doi:10.1080/09540120512331325653.

8. Kellerman SE, Lehman JS, Lansky A, et al. HIV testing within at-risk populations in the United States and the reasons for seeking or avoiding HIV testing. *Jaids J Acquir Immune Defic Syndr*. 2002;31(2):202.

9. Leibowitz AA, Taylor SL. Distance to public test sites and HIV testing. *Med Care Res Rev*. 2007;64(5):568–584.

10. Holmes Jr L, Monjok E, Ward D, et al. Racial variance in rationale for HIV testing in community-based setting in the United States: evidence from the National Health Interview Survey. *J Int Assoc Physicians Aids Care Jiapac*. 2008;7(2):61–68.

11. Robinson KT, Sanders SA, Boyd JL. High-Risk HIV Minorities in the United States: Who Gets Tested and Where? *Am J Health Behav*. 2012;36(3):348–359.

12. Lopez-Quintero C, Shtarkshall R, Neumark YD. Barriers to HIV-Testing Among Hispanics in the United States: Analysis of the National Health Interview Survey, 2000. *Aids Patient Care Stds*. 2005;19(10):672–683. doi:10.1089/apc.2005.19.672.

13. Foley EE. HIV/AIDS and African immigrant women in Philadelphia: Structural and cultural barriers to care. *Aids Care*. 2005;17(8):1030–1043. doi:10.1080/09540120500100890.

14. Wohl AR, Tejero J, Frye DM. Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles. *Aids Care*. 2009;21(9):1203–1210. doi:10.1080/09540120902729957.

15. Fernández MI, Perrino T, Royal S, Ghany D, Bowen GS. To test or not to test: are Hispanic men at highest risk for HIV getting tested? *Aids Care*. 2002;14(3):375–384.

16. Wallace SA, McLellan-Lemal E, Harris MJ, Townsend TG, Miller KS. Why Take an HIV Test? Concerns, Benefits, and Strategies to Promote HIV Testing Among Low-Income Heterosexual African American Young Adults. *Health Educ Behav*. 2011;38(5):462–470.

17. Nunn A, Zaller N, Cornwall A, et al. Low perceived risk and high HIV prevalence among a predominantly African American population participating in Philadelphia's rapid HIV testing program. *Aids Patient Care Stds*. 2011;25(4):229–235.

18. Petroll AE, DiFranceisco W, McAuliffe TL, Seal DW, Kelly JA, Pinkerton SD. HIV testing rates, testing locations, and healthcare utilization among urban African-American men. *J Urban Health*. 2009;86(1):119–131.

19. Torrone EA, Thomas JC, Leone PA, Hightow-Weidman LB. Late diagnosis of HIV in young men in North Carolina. *Sex Transm Dis*. 2007;34(11):846.

20. Lane SD, Rubinstein RA, Keefe RH, et al. Structural violence and racial disparity in HIV transmission. *J Health Care Poor Underserved*. 2004;15:319–335.

21. Poundstone KE, Strathdee SA, Celentano DD. The social epidemiology of human immunodeficiency virus/acquired immunodeficiency syndrome. *Epidemiol Rev*. 2004;26(1):22–35.

22. Zierler S, Krieger N. Reframing women's risk: social inequalities and HIV infection. *Annu Rev Public Health*. 1997;18(1):401–436.

23. Moreno CL. The Relationship Between Culture, Gender, Structural Factors, Abuse, Trauma, and HIV/AIDS for Latinas. *Qual Health Res*. 2007;17(3):340–352. doi:10.1177/1049732306297387.

24. Bureau USC. American FactFinder - Results. Available at: http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1&prodType=table. Accessed March 31, 2012.

25. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health*. 2000;90(8):1212.

26. Massey DS. *Categorically Unequal: The American Stratification System*. Russell Sage Foundation; 2008.

27. Centers for Disease Control and Prevention. *Vital Signs: HIV Testing and Diagnosis Among Adults --- United States, 2001--2009*.; 2010:1550–1555. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5947a3.htm. Accessed June 27, 2013.

28. Centers for Disease Control and Prevention. *Social Determinants of Health among Adults with Diagnosed HIV Infection in 18 Areas, 2005–2009*.; 2013. Available at: http://www.cdc.gov/hiv/pdf/statistics_2005_2009_HIV_Surveillance_Report_vol_18_n4.pdf.

29. Centers for Disease Control and Prevention. *Estimated HIV incidence among adults and adolescents in the United States, 2007–2010*.; 2012. Available at: http://www.cdc.gov/hiv/topics/ surveillance/resources/reports/ index.htm#supplemental.

30. Ward A, Johnson PJ, O'Brien M. The Normative Dimensions of Health Disparities. *J Heal Disparities Res Pr*. 2013;6(1). Available at: http://digitalscholarship.unlv.edu/jhdrp/vol6/iss1/4.

31. Bronfenbrenner U, Morris PA. The ecology of developmental processes. In: *Handbook of child psychology: Volume 1: Theoretical models of human development (5th ed.)*. Hoboken, NJ, US: John Wiley & Sons Inc; 1998:993–1028.

32. McLeroy KR, Bibeau D, Steckler A, Glanz K. An Ecological Perspective on Health Promotion Programs. *Health Educ Behav*. 1988;15(4):351–377. doi:10.1177/109019818801500401.

33. Dahlgren G, Whitehead M. Policies and Strategies to Promote Social Health. *Equity Heal Stockh Inst Future Stud*. 1991. Available at: http://www.framtidsstudier.se/wp-content/uploads/2011/01/20080109110739filmZ8UVQv2wQFShMRF6cuT.pdf. Accessed October 3, 2012.

34. Krieger N. Theories for Social Epidemiology in the 21st Century: An Ecosocial Perspective. *Int J Epidemiol*. 2001;30(4):668–677. doi:10.1093/ije/30.4.668.

35. Ulett KB, Willig JH, Lin H-Y, et al. The Therapeutic Implications of Timely Linkage and Early Retention in HIV Care. *Aids Patient Care Stds*. 2009;23(1):41–49. doi:10.1089/apc.2008.0132.

36. Semaan S, Sternberg M, Zaidi A, Aral SO. Social capital and rates of gonorrhea and syphilis in the United States: Spatial regression analyses of state-level associations. *Soc Sci Med*. 2007;64(11):2324–2341. doi:10.1016/j.socscimed.2007.02.023.

37. Bresnahan M, Begg MD, Brown A, et al. Race and Risk of Schizophrenia in a US Birth Cohort: Another Example of Health Disparity? *Int J Epidemiol*. 2007;36(4):751–758. doi:10.1093/ije/dym041.

38. Williams DR, Jackson PB. Social Sources Of Racial Disparities In Health. *Health Aff (Millwood)*. 2005;24(2):325–334. doi:10.1377/hlthaff.24.2.325.

39. Kawachi I, Daniels N, Robinson DE. Health Disparities By Race And Class: Why Both Matter. *Health Aff (Millwood)*. 2005;24(2):343–352. doi:10.1377/hlthaff.24.2.343.

40. Williams DR, Yu Y, Jackson JS, Anderson NB. Racial differences in physical and mental health. *J Heal Psychol*. 1997;2(3):335–351.

41. Phelan JC, Link BG, Diez-Roux A, Kawachi I, Levin B. “Fundamental causes” of social inequalities in mortality: a test of the theory. *J Health Soc Behav*. 2004;45(3):265–285.

42. Marmot M. Social determinants of health inequalities. *Lancet*. 2005;365(9464):1099–1104.

43. Nuru-Jeter AM, Sarsour K, Jutte DP, Thomas Boyce W. Socioeconomic Predictors of Health and Development in Middle Childhood: Variations by Socioeconomic Status Measure and Race. *Issues Compr Pediatr Nurs*. 2010;33(2):59–81. doi:10.3109/01460861003663953.

44. Teplin LA, Elkington KS, McClelland GM, Abram KM, Mericle AA, Washburn JJ. Major Mental Disorders, Substance Use Disorders, Comorbidity, and HIV-AIDS Risk Behaviors in Juvenile Detainees. *Psychiatr Serv Wash Dc*. 2005;56(7):823–828. doi:10.1176/appi.ps.56.7.823.

45. Skiest DJ, Rubinstien E, Carley N, Gioiella L, Lyons R. The importance of comorbidity in HIV-infected patients over 55: A retrospective case-control study. *Am J Med*. 1996;101(6):605–611. doi:10.1016/S0002-9343(96)00329-4.

46. Latkin CA, Knowlton AR. Micro-social structural approaches to HIV prevention: a social ecological perspective. *Aids Care*. 2005;17(sup1):102–113. doi:10.1080/09540120500121185.

47. Krieger N. Embodiment: a conceptual glossary for epidemiology. *J Epidemiol Community Health*. 2005;59(5):350–355.

48. Knol AB, Briggs DJ, Lebret E. Assessment of complex environmental health problems: Framing the structures and structuring the frameworks. *Sci Total Environ*. 2010;408(14):2785–2794. doi:10.1016/j.scitotenv.2010.03.021.

49. Behel SK, MacKellar DA, Valleroy LA, 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. *J Urban Health*. 2008;85(5):727–743.

50. Mayben JK, Kramer JR, Kallen MA, Franzini L, Lairson DR, Giordano TP. Predictors of Delayed HIV Diagnosis in a Recently Diagnosed Cohort. *Aids Patient Care Stds*. 2007;21(3):195–204. doi:10.1089/apc.2006.0097.

51. Jenness SM, Murrill CS, Liu K-L, Wendel T, Begier E, Hagan H. Missed Opportunities for HIV Testing Among High-Risk Heterosexuals. *Sex Transm Dis*. 2009;36(11):704–710. doi:10.1097/OLQ.0b013e3181ab375d.

52. Mimiaga MJ, Reisner SL, Bland S, 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. *Aids Patient Care Stds*. 2009;23(10):825–835.

53. Saha S, Arbelaez JJ, Cooper LA. Patient–physician relationships and racial disparities in the quality of health care. *J Inf*. 2003;93(10).

54. Nelson A. Unequal treatment: Confronting racial and ethnic disparities in health care. *J Natl Med Assoc*. 2002;94(8):666.

55. Zuvekas SH, Taliaferro GS. Pathways to access: health insurance, the health care delivery system, and racial/ethnic disparities, 1996–1999. *Health Aff (Millwood)*. 2003;22(2):139–153.

56. Millett GA, Ding H, Marks G, et al. Mistaken Assumptions and Missed Opportunities: Correlates of Undiagnosed HIV Infection Among Black and Latino Men Who Have Sex With Men. *Jaids J Acquir Immune Defic Syndr*. 2011;58(1):64.

57. Taylor SL, Leibowitz A, Simon PA, Grusky O. ZIP code correlates of HIV-testing: a multi-level analysis in Los Angeles. *Aids Behav*. 2006;10(5):579–586.

58. Horwood L, Mogridge N, Darlow B. Cognitive, educational, and behavioural outcomes at 7 to 8 years in a national very low birthweight cohort. *Arch Dis Child Fetal Neonatal Ed*. 1998;79(1):F12–F20.

59. National Center for Education Statistics. Trends in High School Dropout and Completion Rates in the United States: 1972–2008. Available at:

http://nces.ed.gov/pubs2011/dropout08/findings1.asp. Accessed November 23, 2011.

60. Phillips KA. Factors associated with voluntary HIV testing for African-Americans and Hispanics. *Aids Educ Prev*. 1993;5(2):95–103.

61. MacKenzie S. *Structural Intimacies: Sexual Stories in the Black AIDS Epidemic*. Rutgers University Press; 2013.

62. Organista KC. *HIV Prevention With Latinos: Theory, Research, and Practice*. Oxford University Press; 2012.

63. Diez-Roux AV. Bringing context back into epidemiology: variables and fallacies in multilevel analysis. *Am J Public Health*. 1998;88(2):216–222.

64. Gee GC, Ryan A, Laflamme DJ, Holt J. Self-Reported Discrimination and Mental Health Status Among African Descendants, Mexican Americans, and Other Latinos in the New Hampshire REACH 2010 Initiative: The Added Dimension of Immigration. *Am J Public Health*. 2006;96(10):1821–1828. doi:10.2105/AJPH.2005.080085.

65. Viruell-Fuentes EA. Beyond acculturation: Immigration, discrimination, and health research among Mexicans in the United States. *Soc Sci Med*. 2007;65(7):1524–1535. doi:10.1016/j.socscimed.2007.05.010.

66. Franzini L, Ribble J, Keddie A. Understanding the Hispanic paradox. *Ethn Dis*. 2000;11(3):496–518.

67. Cianelli R, Ferrer L, McElmurry BJ. HIV prevention and low-income Chilean women: machismo, marianismo and HIV misconceptions. *Cult Health Sex*. 2008;10(3):297–306. doi:10.1080/13691050701861439.

68. Lynch JW, Smith GD, Kaplan GA, House JS. Income inequality and mortality: importance to health of individual income, psychosocial environment, or material conditions. *BMJ*. 2000;320(7243):1200.

69. Rhodes SD, Malow RM, Jolly C. Community-based participatory research: A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *Aids Educ Prev*. 2010;22(3):173–183.

70. McCoy SI, Strauss RP, MacDonald PDM, Leone PA, Eron JJ, Miller WC. Social support and delays seeking care after HIV diagnosis, North Carolina, 2000–2006. *Aids Care*. 2009;21(9):1148–1156. doi:10.1080/09540120902730021.

71. McCoy SI, Miller WC, MacDonald PDM, et al. Barriers and facilitators to HIV testing and linkage to primary care: narratives of people with advanced HIV in the Southeast. *Aids Care*. 2009;21(10):1313–1320. doi:10.1080/09540120902803174.

72. Reed JB, Hanson D, McNaghten AD, et al. HIV Testing Factors Associated with Delayed Entry into HIV Medical Care among HIV-Infected Persons from Eighteen States, United States, 2000–2004. *Aids Patient Care Stds*. 2009;23(9):765–773. doi:10.1089/apc.2008.0213.

73. Craw JA, Gardner LI, Marks G, et al. Brief Strengths-Based Case Management Promotes Entry Into HIV Medical Care. *Jaids J Acquir Immune Defic Syndr*. 2008;47(5):597–606. doi:10.1097/QAI.0b013e3181684c51.

74. Mugavero MJ, Lin H-Y, Allison JJ, et al. Failure to Establish HIV Care: Characterizing the "No Show" Phenomenon. *Clin Infect Dis*. 2007;45(1):127–130. doi:10.1086/518587.

75. Gilliam G, Hanchette C, Fogarty K, Gibbs D. A Geospatial Analysis of CDC-funded HIV Prevention Programs for African Americans in the United States. *J Heal Disparities Res Pr*. 2012;2(2). Available at: http://digitalscholarship.unlv.edu/jhdrp/vol2/iss2/3.

76. Das M, Chu PL, Santos G-M, et al. Decreases in Community Viral Load Are Accompanied by Reductions in New HIV Infections in San Francisco. *Plos One*. 2010;5(6):e11068. doi:10.1371/journal.pone.0011068.

77. Thomas SB, Quinn SC. The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *Am J Public Health*. 1991;81(11):1498–1505.

78. Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis*. 2011;52(6):793–800.

79. Losina E, Schackman BR, Sadownik SN, 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. *Clin Infect Dis*. 2009;49(10):1570–1578. doi:10.1086/644772.

80. Thomas SB, Quinn SC, Butler J, Fryer CS, Garza MA. Toward a Fourth Generation of Disparities Research to Achieve Health Equity. *Annu Rev Public Health*. 2011;32(1):399–416. doi:10.1146/annurev-publhealth-031210-101136.

81. Chae DH, Nuru-Jeter AM, Lincoln KD, Francis DD. CONCEPTUALIZING RACIAL DISPARITIES IN HEALTH. *Bois Rev Soc Sci Res Race*. 2011;8(01):63–77. doi:10.1017/S1742058X11000166.

82. Malone RE, Yerger VB, McGruder C, Froelicher E. "It's Like Tuskegee in Reverse": A Case Study of Ethical Tensions in Institutional Review Board Review of Community-Based Participatory Research. *Am J Public Health*. 2006;96(11):1914–1919. doi:10.2105/AJPH.2005.082172.

83. Chávez V, Duran B, Baker Q, Avila MM, Wallerstein N. The dance of race and privilege in CBPR. *Community Based Particip Res Heal Process Outcomes 2nd Ed San Francisco Ca Jossey-Bass*. 2008:91–105.

84. Morello-Frosch R, Pastor Jr M, Sadd JL, Porras C, Prichard M. Citizens, Science, and Data Judo. *Methods Community-Based Particip Res Heal*. 2005:371.

85. Green LW, Mercer SL. Can Public Health Researchers and Agencies Reconcile the Push From Funding Bodies and the Pull From Communities? *Am J Public Health*. 2001;91(12):1926–1929. doi:10.2105/AJPH.91.12.1926.

86. Deeds BG, Castillo M, Beason Z, Cunningham SD, Ellen JM, Peralta L. An HIV Prevention Protocol Reviewed at 15 National Sites: How do Ethics Committees Protect Communities? *J Empir Res Hum Res Ethics*. 2008;3(2):77–86.

87. Morin SF, Maiorana A, Koester KA, Sheon NM, Richards TA. Community consultation in HIV prevention research: a study of community advisory boards at 6 research sites. *Jaids J Acquir Immune Defic Syndr*. 2003;33(4):513.

88. Marcus MT, Walker T, Swint JM, et al. Community-based participatory research to prevent substance abuse and HIV/AIDS in African-American adolescents. *J Interprof Care*. 2004.

89. Hergenrather KC, Rhodes SD, Clark G. Windows to Work: Exploring Employment–Seeking Behaviors of Persons with HIV/AIDS Through Photovoice. *Aids Educ Prev*. 2006;18(3):243–258.

90. Rhodes SD, Hergenrather KC, Wilkin AM, Jolly C. Visions and Voices: Indigent Persons Living With HIV in the Southern United States Use Photovoice to Create Knowledge, Develop Partnerships, and Take Action. *Health Promot Pract*. 2008;9(2):159–169. doi:10.1177/1524839906293829.

91. Rhodes SD, McCoy TP, Vissman AT, et al. A randomized controlled trial of a culturally congruent intervention to increase condom use and hiv testing among heterosexually active immigrant latino Men. *Aids Behav*. 2011;15(8):1764–1775.

92. Chen JC, Goetz MB, Feld JE, et al. A provider participatory implementation model for HIV testing in an ED. *Am J Emerg Med*. 2011;29(4):418–426.

93. Berkley-Patton J, Thompson CB, Martinez DA, et al. Examining Church Capacity to Develop and Disseminate a Religiously Appropriate HIV Tool Kit with African American Churches. *J Urban Health*. 2012:1–18.

94. Nuru-Jeter A, Dominguez TP, Hammond WP, et al. “It’s The Skin You’re In”: African-American Women Talk About Their Experiences of Racism. An Exploratory Study to Develop Measures of Racism for Birth Outcome Studies. *Matern Child Health J*. 2009;13(1):29–39. doi:10.1007/s10995-008-0357-x.

95. Melchior M, Moffitt TE, Milne BJ, Poulton R, Caspi A. Why do children from socioeconomically disadvantaged families suffer from poor health when they reach adulthood? A life-course study. *Am J Epidemiol*. 2007;166(8):966–974.

96. Syme SL. Social determinants of health: The community as an empowered partner. *Prev Chronic Dis*. 2004;1(1). Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC544525/. Accessed December 12, 2012.

97. Clements-Nolle K, Marx R, Guzman R, Katz M. HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: implications for public health intervention. *Am J Public Health*. 2001;91(6):915–921.

98. Clements-Noelle K and Bachrach AM. CBPR with a hidden population: The transgender community health project a decade later. In Minkler, M and Wallerstein, N (eds.) *Community-Based Particip Res Heal*. Second Edition. 2008:137–152.

99. Rhodes SD, Kelley C, Cashman R, et al. Using Community-Based Participatory Research (CBPR) to Develop a Community-Level HIV Prevention Intervention for Latinas: A Local Response to a Global Challenge. *Womens Health Issues*. 2012. Available at: http://www.sciencedirect.com/science/article/pii/S1049386712000175. Accessed August 4, 2012.

100. Ifeoma Udoh, Chopel A, Minkler M, Dillard Smith C, Walton S, Grijalva C, Yusuf A, Dunbar M. Developing and Using a Partnership Covenant to Guide a Study of Late Diagnosis of HIV. *Prog Community Heal Partnerships Res Educ Action*. In Press.

101. MacKenzie S. The Landscape of AIDS in Black America. *Calif Mag*. 2013. Available at: http://alumni.berkeley.edu/blog/california-magazine/20130621/landscape-aids-black-america.

Ecological Factors Influencing HIV Testing Behavior among Latinos and African Americans in Oakland, California

ABSTRACT

Background: Late diagnosis of HIV occurs when an AIDS diagnosis is received at the same time, or within one year of, an initial HIV diagnosis. Among those people living with HIV or AIDS who received a late diagnosis in Alameda County, California, two-thirds were either African American or Latino. In order to better understand racial and ethnic disparities in late diagnosed HIV in Oakland (the city where Alameda County's epidemic is concentrated), a Community-Based Participatory Research Study of late diagnosis of HIV among African Americans and Latinos was conducted with multiple partners.

Methods: Qualitative data was collected and analyzed using a conceptual framework drawing upon the Theory of Planned Behavior and the Social Ecological Model. Interviews with HIV/ AIDS resource leaders and HIV+ Latino and African American men, women, and transgender individuals (n=17), as well as focus groups with Latino and African American men and women (n= 13 groups) were conducted to fully explore the barriers to and potential facilitators of a timely diagnosis of HIV in Oakland. Two authors dual-coded 33% of the transcripts to establish a codebook that was used and enhanced through coding the remaining transcripts.

Findings: Significant factors identified by participants as relating to the late diagnosis of HIV lay beyond the traditional individual-level elements of attitude, norms, control beliefs, and power, and were located within the interpersonal, community, and/or societal levels of the ecological model. Unique issues identified by recently released African American participants and by young Latina women also revealed complex cross-level connections.

Intro

Background: Late HIV diagnosis is defined as a diagnosis of AIDS simultaneously with or within one year of an initial HIV diagnosis (Tang, Levy, & Hernandez, 2011). Late diagnosis is directly related to a lack of access to information and other resources that people use to protect their health (Ebrahim, Anderson, Weidle, & Purcell, 2004; Jenness et al., 2009; Leibowitz & Taylor, 2007); disparities in HIV thus represent a preventable health inequity. The consequences of late diagnosed HIV are very different for both the person and the population than the consequences associated with HIV diagnosed in a timely manner. First, HIV can only be treated once it is diagnosed; 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, late diagnosed HIV/AIDS is an especially acute threat to population health, and inequities in late diagnosis are of special importance. Late diagnosis occurs when at-risk individuals are not tested regularly or in a timely fashion, and is thought to contribute to racial disparities in HIV/AIDS outcomes (Losina et al., 2009).

Oakland, California, is one of the country's most ethnically and racially diverse cities in the United States (US) (Census Bureau, 2010) and the seat of Alameda County, where racial disparities in HIV/AIDS have been so severe that a "State of Emergency" was declared in 1998 regarding the AIDS epidemic in the African American community (Brooks, 2011). Just over 38% of all Alameda County residents who were diagnosed with HIV were diagnosed late (Murgai, 2012). Among those people living with HIV or AIDS who received a late diagnosis in Alameda County, two-thirds (66.1%) were either African American or Latino (Murgai, 2012).These numbers demonstrate that in addition to the at-risk populations who were recipients of prevention efforts, and the HIV+ diagnosed populations identified for timely treatment, there is a third segment of the at-risk population that must be reached for timely diagnosis: HIV+ people who are not yet aware of their need for treatment because they remain undiagnosed.

In order to better understand and address racial and ethnic disparities in late diagnosed HIV in Oakland, a Community-Based Participatory Research (CBPR) Study of Late Diagnosis of HIV among African Americans and Latinos was conducted in collaboration with multiple partners. California Prostitutes' Education Project (Cal-PEP) is an organization dedicated to the treatment and prevention of HIV and other sexually transmitted diseases among high-risk and hard-to-reach populations. Cal-PEP is located in West Oakland, a majority African American neighborhood, and serves mostly African Americans in East and West Oakland. La Clínica de la Raza is a non-profit community health center serving the Latino population in the San Francisco Bay Area's East Bay with a network of clinics and health education programs staffed by bilingual (Spanish and English speaking) providers. Pangaea Global AIDS Foundation is an applied research organization specializing in HIV/AIDS research and innovation both globally and domestically. The School of Public Health at the University of California, Berkeley is an inter-disciplinary teaching and research institute. The overarching goal of the study was to use a CBPR approach to identify the individual, interpersonal,

community, and societal factors, and their interactions, which facilitate or hinder timely HIV testing by those at-risk of late diagnosis among Latinos and African Americans living in Oakland. The goal of this analysis was to use an ecological perspective to explore the attitudes, behaviors, norms, and perceptions of power which may contribute to racial and ethnic disparities in HIV testing behavior.

Conceptual framework: Two theoretical frameworks informed the research: the Theory of Planned Behavior (TPB) and the Social Ecological Model (SEM). Conceptual framework definitions are provided in Table 1. According to the TPB (Ajzen, 1991), individuals' intention to act to improve their health is dependent upon their attitude towards the behavior and the subjective norms about the behavior, as well as their perceived behavioral control.

INSERT TABLE 1 ABOUT HERE

While the TPB includes the effect of outside influences such as norms and barriers to action on an individual's intention to act, it does not provide a complete picture of the many proximal and distal factors that influence individuals in their environments. The SEM (Bronfenbrenner & Morris, 1998; McLeroy, Bibeau, Steckler, & Glanz, 1988; Sallis, Owen, & Fisher, 2008) is based on the concept that human society, like other natural systems, is an integrated multi-level system that both affects each individual living within it and is shaped by those same individuals. In order to improve individuals' health outcomes, we must consider the various levels that influence their daily lives and their choices as well as the interactions among factors across the various levels over time. Integrating the TPB with the SEM enables location of the facilitators of and the barriers to timely HIV testing at the appropriate levels of influence, leading to more efficient identification of possible points of intervention.

Methods

In order to gather data on multiple aspects of late stage HIV diagnosis and to enhance our understanding of the problem in Oakland, three groups of participants from among the Latino and African American communities were interviewed. The total sample was comprised of 126 people consisting of three distinct groups – local HIV leaders, late-diagnosed Latino and African American individuals, and members of the Latino and African American communities in Oakland. Of these, 17 participated in individual interviews and 109 participated in one of 13 focus groups. The Committee for the Protection of Human Subjects at the University of California, Berkeley approved the research protocol, in addition to the Ethical and Independent Review Services IRB (a private IRB chosen by Pangaea Global AIDS Foundation).

Sampling and Recruitment: First, nine local leaders were selected from among HIV/AIDS advocates and service providers to be interviewed individually and in-depth. These data were deliberately collected first, because the data from this sample were used to iteratively inform the interview guide development and sampling frames for subsequent interviews and focus groups. Both as sources of critical lay knowledge and

as people others look up to, these individuals were expected to contribute important data to the study and to the formulation of evidence-based pilot interventions. The leaders were identified through a purposive sampling process (Patton, 2002) where individuals with the highest intensity of community involvement and relevant information were sought. The final sample size was nine because the Steering Committee determined that the local HIV/AIDS practice and advocacy landscape was well represented by the nine recruited leaders.

Second, in order to learn more about the barriers to testing, and/or factors that eventually facilitate receiving an HIV test, Latinos and African Americans who had experienced late-stage diagnosis of HIV/AIDS were sought for in-depth interviews. The sample for this group consisted of eight participants who were diagnosed late with HIV or AIDS (four Latinos and four African Americans, four males and four females). Due to laws concerning privacy and confidentiality, there were no accessible records that would provide a suitable sampling frame for this population. We therefore recruited service providers and case managers to review their records to identify and recruit participants who met he following eligibility criteria: 1) must have been diagnosed with AIDS within one year of the initial HIV diagnosis; 2) the initial HIV diagnosis must have been within the past five years; 3) participant must live in Oakland, CA; and 4) participant must be either Latino or African American. We did not expect to recruit high numbers of eligible individuals within our timeframe, so a convenience sampling strategy was employed: the first two eligible participants recruited in each of the four categories (Latino male, Latina female, African American male, African American female) constituted the sample. Time constraints did not permit us to expand the sample size further.

Third, we recruited African American and Latino/a community members to participate in focus group discussions who belonged to the sub-groups that were over-represented among cases of late diagnosis and were not connected to HIV prevention, education and screening services. This strategy of theoretical sampling allowed us to include more people who were similar to the late-diagnosed individuals and thus gather more in-depth information on the barriers and hypothetical facilitators to testing experienced by members of these sub-populations. Our theoretical sampling frame was at-risk persons who had not received an HIV test in the past five years. This sampling frame was informed by the ecological model (Bronfenbrenner & Morris, 1998; McLeroy et al., 1988; Sallis et al., 2008): for the supplemental target groups we sought participants who were situated similarly within the local socio-geographic and cultural communities in Oakland and thus were subject to many of the same societal, community, and inter-personal factors as people who were diagnosed late.

The Steering Committee of the research project collaboratively identified priority target groups, relying on community-based co-researchers' expertise on their clients' communities, in conjunction with epidemiologist co-researchers' interpretation of epidemiological data on late-stage HIV within Alameda County. Although the Alameda County data on the socio-demographic patterns of late HIV diagnosis was aggregated and thus limited in its utility, it was used to supplement understanding of the age, gender, and occupational groups within the two racial/ ethnic groups that appeared to be most likely to be at risk for receiving a late-stage HIV diagnosis. This process

resulted in the prioritization of the following four sub-populations: African American women over 40, African American men recently released from prison or jail, Latina immigrant women under 40, and Latino men who work as low-wage immigrant workers (day laborers). In addition to belonging to one of the target sub-populations, eligibility criteria excluded any participant who had received HIV testing or accessed any HIV prevention or education services within the past year.

In order to identify and include members of the above sub-populations for our study, a modified Respondent Driven Sampling (RDS) (Heckathorn, 1997) approach was used. Individuals likely to have connections to the desired population were identified as "seeds" (community peer recruiters who began the chain of recruitment in their social circles) by co-researchers who were knowledgeable about the community. Four to five seeds were identified from among each of the four identified subpopulations, and were asked to recruit others from within their networks. The seeds were provided with three coupons each. Each coupon was labeled with a unique identifying number allowing the researchers to track recruited participants back to their recruiter in order to provide an incentive of a $10 grocery card to the seed per participant recruited. Each participant, in turn, received three recruitment coupons they were able to use to recruit an additional three persons, each of which would also receive three recruitment coupons, and so on. In this way, the final group of participants was not sampled from within the social circle of just one or a few people, which would have reduced sample variability (Heckathorn, 1997).

Data collection: Individual and group interview guides were co-created by the Steering Committee. Interview guides were based on an understanding of the SEM (Bronfenbrenner & Morris, 1998; McLeroy et al., 1988; Sallis et al., 2008) and TPB (Ajzen, 1991), and included the following content areas: a) factors that affect health (through behavioral or other channels of embodiment (Krieger, 2005)) at the individual level; b) community factors, such as community norms, that affect testing behavior; c) perceptions of personal risk and consequences of HIV; d) inter-personal communication around HIV; and e) perceived barriers to testing and participants' power to overcome them. Questions pointing to societal level factors (i.e. political and economic barriers to testing (Latkin & Knowlton, 2005)) were also included. Demographic information was collected from all participants, and risk behavior information was collected from HIV+ individuals.

Focus groups were completed first, with an academic and community team member co-facilitating, thus providing time for co-learning about interview techniques and community-specific culturally appropriate communication, before the one-on-one interviews began. Representatives from each of the subpopulations of target groups were interviewed together in groups of six to 12 (Kitzinger, 1995). Weekly data team meetings enabled discussions of impressions and emerging themes, allowing the team to assess repetition of themes and recognize whether saturation had been achieved or if more focus groups were needed. In addition to using the evidence to improve late stage HIV diagnosis post-investigation, in keeping with CBPR's commitment to action, we created an opportunity to intervene during the course of research. We provided education and information about HIV and AIDS for focus group members either during

the course of the group, where such information was judged to not obfuscate the data, or at the end of the focus group discussion.

Individual interviews were used to gain information from the two key informant groups: leaders in the local HIV/AIDS service and advocacy community and late diagnosed HIV+ individuals. Interviews with Latino participants were conducted in Spanish unless the participant stated a preference for English, and a professional translator translated all transcripts into English. Interviews lasted between 45 and 60 minutes, focus groups were 90 minutes. Both were audio-recorded and transcribed, Spanish-language interviews and focus groups were simultaneously transcribed and translated. A team of two researchers, one who was primarily responsible for taking notes and the other who was responsible for facilitating the group, facilitated each focus group. Researchers involved in data collection conducted memoing and discussed progress and emergent findings during weekly phone meetings.

Analysis: Analysis of the data was driven by the research question: What are the individual, interpersonal, community and societal level factors that impact the HIV testing behavior of African American and Latino Oakland residents who are at-risk of late-stage HIV? *In Vivo* software was used to complete the analysis. To develop the *in vivo* codebook, two of the authors selected 33% of the transcripts for dual coding. These authors generated codes inductively based on the topics identified and prioritized by the participants. The dual-coded transcripts were deliberately chosen to represent the diversity of data sources and participants encompassed by the project—three popular opinion leader interviews, three late-diagnosis in-depth interviews, and three focus group discussions, including both men, women, and transgender individuals of African American, Latino, and White race and ethnicity. Both authors separately coded each of the nine transcripts; the authors ran comparisons on each dual-coded transcript identifying codes with disagreement of 10% or greater. The authors then reviewed the coded segments of high (>10%) disagreement codes and used consensus-building (MacQueen, McLellan, Kay, & Milstein, 1998) to further clarify code definitions and bring all codes to at least 90% agreement (Hruschka et al., 2004). Following the dual coding process, authors divided up and separately coded the remainder of the transcripts. Additional codes added by either researcher during the individual coding process were shared between the authors. The final codebook contained 247 individual codes.

INSERT TABLE 2 ABOUT HERE

Once the codebook was created, the first author created a matrix structure with the four individual-level elements of the TPB (attitude, subjective norms, control beliefs, and perceived power) defined along the vertical axis and four aggregate levels of the SEM (individual, interpersonal, community, and societal) defined along the horizontal axis, such that a square was provided for the intersection of all elements along with squares for each element in isolation (see Table 2). The purpose of the matrix was to facilitate the sorting of the codes as defined in the codebook into the elements defined in the study's conceptual framework. All authors then reviewed the codes and definitions and used a consensus-building strategy to conduct the sorting (see Table 2). The first author next identified the sources of coded text supporting developed concepts in each of the

ecological layers to investigate whether different data sources provided information more closely related to factors operating at certain ecological levels.

Results

All factors relating to testing behavior spanned across levels of the ecological model or impacted HIV testing via factors at other levels. While the TPB illuminated a subset of these factors, many influential factors were found to exist outside of the TPB's theoretical constructs. This was true even when we expanded the TPB constructs beyond the individual level (i.e. subjective norms was expanded to be inclusive of community-created norms and societally-influenced norms such as those communicated broadly through media). Below, we describe the multi-level factors, and the relationships between factors at different levels, that were connected to testing for recently incarcerated men and young immigrant Latina women. We limit this report to our findings regarding these two groups in order to report on the depth of our findings with one example from each of the racial/ ethnic focus populations within the scope of this paper. However, the findings reported draw upon data from several in-depth interviews and multiple focus groups. The rich qualitative data gathered in focus groups and individual interviews, collected and analyzed using the combined conceptual framework described above, allowed for identification of these relationships. These findings also draw upon a rapid assessment process that was conducted with co-researchers and will be reported on elsewhere.

Cross-level connections for recently incarcerated men: Our data reveal that incarceration impacts testing behavior and late HIV diagnosis. In our analysis, incarceration was related to concepts such as: fear, promiscuity, talking about HIV, and motivation to test. In this population, testing behavior was impacted by incarceration (a societal level factor) through its impact on sexual relationships (an interpersonal level factor), whereby community-level norms dictated that HIV testing means infidelity. Recently released men whose relationships were already fragile due to separation during incarceration were less willing to further imperil their relationships by taking any action that might imply infidelity. In response to a question about deciding to get an HIV test, an African American male participant commented:

> It depends on the type of lifestyle you live [*Participants agreeing*]. If you're a family man and you're only having sex with your wife, you don't have to go [get] tested 'cause you know your wife. If y'all had an AIDS test before y'all got together but it all depends on men that's going out every Friday kicking it with different women; then definitely get tested.

Other participants in a focus group of men recently released from incarceration responded to the question, "Do you talk about HIV with your sexual partners?"

> "No. All that comes up is pregnancy."
>
> "No, not with my baby mama. Maybe when the RV pull up but…"
>
> "When a female go through a man's phone, that's probably when it comes up."

When trust was explicitly mentioned, it was immediately linked to testing:

> "Look, at the same time though, what if you're in a long term relationship, you feel me? You're the person that ain't doing nothing though. You're the person that's not doing nothing so you're not tripping off this whole situation. You figure, I'm coming home to my wife. My wife might go out once in a while to the clubs but you're not paying attention to the whole signs and everything. So, it could be having too much trust too."

> "That's what I mean by don't underestimate it. Don't underestimate it just because she only go out now and then… Or even yourself though, don't underestimate it because "oh I only do this now and then." It only take that 1 time."

As the conversation continued, focus was on the trust of the female partner:

> "What if you find out your man was going around, going behind your back getting an AIDS [test] every other month, every month? That's going to make you feel like he didn't trust you. Then it comes back to the trust situation."

> "Then they going to think we're cheating on them 'cause we're getting tested."

> "Cause if a man go get tested, and then the female find out, she's going to be hot like "why you get all these tests then?" But if a man find out a female get all these tests, he like "oh alright."

> "That too, if you bring it up. 'Cause if you bring it up, she's going to be like 'what we need a test for?'"

Cross-level connections for young Latina immigrant women: Immigration status has received less attention as a social determinant of HIV, especially among women. Our analysis has revealed connections between culture and country of origin at the societal level, gender norms (a community level factor), priorities around health (at the individual level), and getting tested for HIV. Immigrant women mentioned not testing because although they weren't sure if their partners were monogamous with them, they deferred to their husbands' preference to not talk about it. Two young (under 40) Latina immigrant participants in a focus group conducted in Spanish commented:

> "Because in my family it's been very hard to talk about it, because it's something that I had never discussed in my life, that only happened to prostitutes or other people. So you never say, 'I'm a mother, I only have my husband.' But you never know if that person has been with someone else."

> "I think it's because they must feel guilty a lot of the time because they've been unfaithful. So they don't want to talk about it. That's what I think."

However, gender norms also encouraged testing when it came to their families, for as mothers they would prioritize their own health and knowledge in order to be active caregivers and to be good role models. Three Latina focus group participants offered different versions of the same concern:

> "Instead, we're more concerned about our children. Do you want one of your kids to go through this? No. So, get informed and educate yourself. [*Infórmese usted y edúquese*]."
>
> "In my case, I haven't thought about it, but I need to do it so I can get information to share with the people closest to me."
>
> "Because those of us who have families want to live for our children. We don't want our children to go through that [*no pasen por ahí*]."

The above examples from recently incarcerated African American men and young immigrant Latina women demonstrate the way that socio-geographic contexts influence health decisions and behaviors from multiple levels. Below, we conclude with study limitations, thoughts about the contribution of our combined conceptual framework, and some practical implications of the above findings.

Conclusions

This study employed a CBPR approach and a conceptual framework combining TPB and SEM to understand ecological factors that impact the testing behavior of African Americans and Latinos in Oakland. We identified factors at multiple ecological levels that seem to influence HIV testing behavior in these communities.

While the conceptual framework and CBPR approach enabled us to employ qualitative methods to generate novel findings, there were some limitations of the study. Authentic CBPR often requires large amounts of human and financial resources, and thus tradeoffs are required. In this study, the decision was made to direct resources toward capacity building and community involvement activities at the expense of putting more energy and resources into finding more late-diagnosed HIV+ individuals to interview. Relatedly, the small sample size of each of the participant groups and the non-random nature of the sample precludes generalizability of the findings to other populations. The study's sample characteristics and qualitative design, as well as the lack of a temporal element linking factors under investigation with the outcome of interest also prohibit causal inference. A second limitation of the study is its limited scope of content. We assume that late testing itself is not the driver of racial disparities but rather one of the mechanisms by which underlying interpersonal, community, and societal factors translate into racial and ethnic disparities in the health outcome of late diagnosed HIV. However, as a beginning step, this study focuses on the single health behavior of testing for HIV to the exclusion of other possible contributory pathways by which racial/ ethnic inequities are embodied and become population health disparities. This ignores the reality that, given existing and growing disparities in HIV/AIDS infection and treatment as measured by community viral load (Das et al., 2010), improving HIV

testing outcomes alone is necessary but not sufficient to address racial, ethnic, economic, gender, occupational, and geographic disparities in late diagnosed HIV.

A major finding of our exploration of individual level factors influencing HIV testing behavior was that emotions are deeply connected to behavioral choices, and are mostly left out of the TPB. At the interpersonal level, subjective norms were influential across populations. For example, notions of what it means to be a “family man” were discussed by many African American participants, and the well-known concept of the “undercover homosexual” came up in abstract terms as a possible threat to reputation (for men) and also in concrete terms as experienced first- or secondhand (by women). Similarly, subjective norms at the community level were extremely influential. This was related to lifestyles, and what African American participants referred to as the “fast life,” and the related environments, or “the streets.” Across populations, norms were greatly influenced by gender, as expected, and reputational concerns were closely related to both lifestyle and gender and in turn influenced testing behavior. Societal level factors shaped the lives of all of the research participants, impacting their health behaviors both directly and through connections and constellations of determinants located at the other levels. Major codes grouped at the societal level included: country of origin, culture, educational level, gang culture, incarceration, military/ veteran, transportation, and work/ job. Above, we elaborated on some of the relationships between these factors and others more proximal to the behavior for the two groups of recently incarcerated men and Latina immigrant women.

Pasick and her colleagues (Burke, Bird, et al., 2009; Joseph, Burke, Tuason, Barker, & Pasick, 2009; Pasick, Barker, et al., 2009; Pasick, Burke, et al., 2009) have explored the constructs of the TPB, noting that in many cases they do not fit well with diverse populations. This is not surprising given that the theory was constructed based upon studies of mostly white, middle class college students (Ajzen, 1991; Pasick, Burke, et al., 2009). Our work corroborates their findings (Burke, Joseph, Pasick, & Barker, 2009), and we suggest that TPB can be more useful if expanded in accordance with the SEM. Such an expansion can be especially useful for public health practitioners who are interested in behavior change, as awareness of the profound influence of multi-level factors on individual behavior is confirmed again and again (Chopel, Minkler, Nuru-Jeter, & Dunbar, 2013; Krieger, 2001; Lane et al., 2004; Syme, 2004; Wallerstein, Yen, & Syme, 2011). The SEM facilitates the translation of findings into recommendations and action steps more readily than TPB, as it is focused on individual cognition.

Interestingly, for example, interview participants who had received a late diagnosis more often mentioned positive changes and feelings of empowerment than the focus group participants who were not accessing services. This points to the possibility that, while HIV services are not yet being accessed by adequate portions of the at-risk populations in Oakland, they can be empowering. An exclusive focus on cognitive processes and decision-making could have eclipsed this finding, as it is emotion-centered. However, this finding points to new possibilities for intervention, such as translating some of the empowering elements of comprehensive HIV treatment services for use in more traditional HIV prevention services. Our findings about the

importance of power at multiple levels of the SEM reinforce the importance of power and empowerment in HIV testing behavior.

Use of the SEM also facilitates the identification of policy opportunities. Incarceration has been recognized by several researchers (Lane et al., 2004; Latkin & Knowlton, 2005; Zierler & Krieger, 1997) as influential in shaping racial inequities in HIV population distribution. We found that incarceration also impacts testing behavior and thus is likely implicated in racial inequities in late-stage HIV. Understanding of the interpersonal factors that mediate this relationship demonstrate that HIV testing just prior to release of inmates may be a more constructive public policy given that other interpersonal factors beyond the availability or accessibility of testing reduce motivation to test post-release.

Similarly, our findings on the way that gender norms influence Latina immigrants' testing behavior suggest some strategic approaches to increasing testing in this population. Given that Latina immigrants expressed a higher motivation to test in their roles as mothers and family caregivers as compared to their roles as sex partners or wives, messaging based on personal sexual risk may not resonate with them. However, being offered education or information on testing services in places (such as schools, parenting groups, or their children's healthcare appointments) where their primary identity is as mother or caregiver may be more effective.

The TPB and SEM employed in conjunction with each other can provide a rich conceptual framework for exploring complex research questions about health behavior. While the TPB has traditionally been limited to individual level factors, its constructs can be expanded to other levels of the SEM. This combination of theories can improve upon use of the SEM on its own as it guides investigation of the relationships between those factors rather than simple identification of factors that exist at different levels of the model.

Racial/ ethnic disparities in late-stage HIV remain steep in our urban communities, and represent a preventable health inequity. In fact, the racial disparity in late diagnosis of HIV/AIDS reflects that of timely- diagnosed HIV (Girardi, Sabin, & Monforte, 2007; Tang et al., 2011), suggesting that late diagnosis may be one important driver of the widening racial disparities seen in the AIDS epidemic (Gardner, McLees, Steiner, del Rio, & Burman, 2011; Losina et al., 2009). While our findings bring us closer to understanding the intricate workings of this problem, and provide clues for possible effective interventions, more work is needed to elucidate causal relationships and test data-informed interventions. CBPR as an orientation to research, and a conceptual framework that combines insights from two or more theoretical approaches, may be central in helping us further uncover and apply findings that can help address this important problem.

TABLE 1: Conceptual Framework Definitions

THEORY OF PLANNED BEHAVIOR: individuals' intention to act to improve their health is dependent upon their *attitude* towards the behavior and the *subjective norms* about the behavior, as well as their *perceived behavioral control*.	SOCIAL ECOLOGICAL MODEL: a conceptual model depicting the nested levels that characterize human interactions with the environment at which various health and disease factors are located.
ATTITUDE: belief about the expected outcome of the action and their assessment of desirability of the expected outcome.	INDIVIDUAL: biological and behavioral factors in the individual.
SUBJECTIVE NORMS: perceptions about what others in their immediate communities will think about the behavior, as well as their personal motivation to conform to these perceived norms.	INTERPERSONAL: the relationships in which the individual is involved.
CONTROL BELIEFS: refer to the barriers or facilitators that the individual perceives to be either obtrusive or conducive to the planned behavior.	COMMUNITY: representing proximal environments including social circles, families, households, neighborhoods, and other communities such as churches or schools.
PERCEIVED POWER: Whether or not people believe that they have the power to perform the behavior or to overcome perceived barriers to the action.	SOCIETAL: structural and systemic environments including the political, economic, media and cultural, where distal factors are located.

Table 2: Theoretical Matrix with Codes

	(1) Ecological Model w/o Theory of Planned Behavior						(2) Attitude		(3) Subjective Norms	(4) Control Beliefs		(5) Power
(A) Individual	anger-frustration	crying - sadness	God-faith	Literacy	relief	talking about testing	being man	it could happen to anyone	Clean of HIV Clothing rejection separating dishes or clothes	awareness – perception of HIV	late diagnosis abstract	accomplishment being in control – not in control boundaries courage – nerve direction and purpose fatalism – why try luck future – goals luck positive change weak
	blood – plasma	diagnosis AIDS	good feeling	loneliness	self esteem	test results - general	breastfeeding	knowledge – lck of knowledge of HIV		awarness of services	lifestyle	
	burdened by diagnosis – weight on your shoulders	diagnosis HIV+ – positive result	having fun	maturity	shock	testing - HIV	cure	misinformation about HIV		barriers to testing	participation in services or programs	
	calm	disease	healthy	mental health issues	sick	timely diagnosis	denial-avoidance	motivation to test		decision to test	prioritizing getting tested	
	caring about self, others, life	don't know why - confusion	homosexual identity	mortality	side effects	transgender	don't want to get tested	perceived risk of catching HIV		drugs + alcohol	should get tested	
	clients	dumb	hope	negative result	state of mind	trauma-anxiety	exposure	responsibilities - priorities		going to the Dr. – seeking care	window period	
	clinicians	embarassment	IDs	pain-suffering	status - documented or not	waiting for test results	fear of HIV	shame		home test kit		
	comfort-discomfort	emotions	IDU-needles-tattoos	PLWHA-HIV infected	symptoms HIV-AIDS	worry-stress	HIV is old news	susceptibility to HIV				
	Coming to terms - acceptance	fear	knowledge of status	pregnancy	T-cells, CDF		immune					
	comorbidity	fear of needles or blood	late diagnosis	psychiatry	taking care of self							
(B) Interpersonal	baby mama	children-baby	oral sex	separation-divorce-or threat	spouse-marriage		peer-to-peer communication bout HIV		abandonment family man hygiene – cleanliness looking healthy – unhealthy normal promiscuity undercover homosexual – MSM	monogamy – being faithful protection during sex – unprotected		blame disclosure to or by pt interpersonal power pimps support – personal
	bisexuality	friends	rape	sex between men	talking about HIV							
	casual v long-term relationship	love	respect	sex partners	transmission-infection		serodiscordant sex partner					
	celibacy - don't really fuck with nobody	older men	rude	sex work-transactional sex								
(C) Community	accountability and transparency	family	language	prevalence-incidence	volunteer		confidentiality - gossip	sexuality and sex ed	fast life gender – men gender – women isolating people with AIDS or suspected of being HIV+ or having AIDS nick names for HIV reputation the streets	accessibility / incentives barriers to services or programs / link to care cell phones for outreach / open hours challenges / Partner Counseling Referral Services community outreach / prevention and screening counseling / routine testing crime / shelter plus care education about HIV / targeting evaluation / testing location homeless / testing van		planning council – SalvaSIDA requirement to test
	black-African American	generation - age	Latinos	safety	whites							
	church	going out	leadership – or lack of leadership	schools	youth							
	collaboration	HIV-ASO providers	loss to care	sororities - frats								
	community	HIV+ community	organizations providing HIV resources or services	support services – HIV support groups and Tx			privacy	trust or distrust				
	day laborers-LWIW	hospital	place-neighborhood-ZIP	testing at events								
	ER	immigrant Latino population	police	violence								
(D) Societal	country of origin		incarceration				data collection and dissemination		conspiracy / Magic Johnson and other celebrities / social marketing criminalization of HIV transmission / media / stigma homophobia / racial discrimination internet / sexuality - media	bureaucracy / HIV testing system comprehensive solution – integrating services / housing funding – resources / life insurance health insurance / opportunity to test healthcare (unspecified) / prevention – general protection against HIV		advocacy / poverty class - economics / rights costs / San Francisco – shadow city income-money / surviving legally mandated disclosure / undocumented policy - politics
	culture		military or veteran				medications - treatment					
	education level		transportation				test accuracy					
	gang culture		work-job									

References

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, *50*(2), 179–211.

Bronfenbrenner, U., & Morris, P. A. (1998). The ecology of developmental processes. In *Handbook of child psychology: Volume 1: Theoretical models of human development (5th ed.).* (pp. 993–1028). Hoboken, NJ, US: John Wiley & Sons Inc.

Brooks, J. (2011, May 18). HIV/AIDS State of Emergency. *The Oakland Post Online*. Berkeley, Oakland, Richmond, San Francisco, South County.

Bureau, U. S. C. (n.d.). American FactFinder - Results. Retrieved March 31, 2012, from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=DEC_10_DP_DPDP1&prodType=table

Burke, N. J., Bird, J. A., Clark, M. A., Rakowski, W., Guerra, C., Barker, J. C., & Pasick, R. J. (2009). Social and cultural meanings of self-efficacy. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *36*(5 Suppl), 111S–28S. doi:10.1177/1090198109338916

Burke, N. J., Joseph, G., Pasick, R. J., & Barker, J. C. (2009). Theorizing social context: rethinking behavioral theory. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *36*(5 Suppl), 55S–70S. doi:10.1177/1090198109335338

Chopel, A., Minkler, M., Nuru-Jeter, A., & Dunbar, M. (2013). Social Determinants of Late Stafe HIV Diagnosis and its Disctributions among African Americans and Latinos: A critical literature review. *Journal of Health Disparities Research and Practice*.

Coleman, S. M., Rajabiun, S., Cabral, H. J., Bradford, J. B., & Tobias, C. R. (2009). Sexual Risk Behavior and Behavior Change among Persons Newly Diagnosed with HIV: The Impact of Targeted Outreach Interventions among Hard-to-Reach Populations. *AIDS Patient Care and STDs*, *23*(8), 639–645. doi:10.1089/apc.2008.0092

Das, M., Chu, P. L., Santos, G.-M., Scheer, S., Vittinghoff, E., McFarland, W., & Colfax, G. N. (2010). Decreases in Community Viral Load Are Accompanied by Reductions in New HIV Infections in San Francisco. *PLoS ONE*, *5*(6), e11068. doi:10.1371/journal.pone.0011068

Ebrahim, S. H., Anderson, J. E., Weidle, P., & Purcell, D. W. (2004). Race/Ethnic Disparities in HIV Testing and Knowledge About Treatment for HIV/AIDS: United States, 2001. *AIDS Patient Care and STDs*, *18*(1), 27–33. doi:10.1089/108729104322740893

Gardner, E. M., McLees, M. P., Steiner, J. F., del Rio, C., & Burman, W. J. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases*, *52*(6), 793–800.

Girardi, E., Sabin, C. A., & Monforte, A. d'Arminio. (2007). Late Diagnosis of HIV Infection: Epidemiological Features, Consequences and Strategies to Encourage Earlier Testing. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, *46*(Suppl 1), S3–S8. doi:10.1097/01.qai.0000286597.57066.2b

Heckathorn, D. D. (1997). Respondent-driven sampling: a new approach to the study of hidden populations. *Social Problems*, 174–199.

Hruschka, D. J., Schwartz, D., St.John, D. C., Picone-Decaro, E., Jenkins, R. A., & Carey, J. W. (2004). Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. *Field Methods*, *16*(3), 307–331. doi:10.1177/1525822X04266540

Jenness, S. M., Murrill, C. S., Liu, K.-L., Wendel, T., Begier, E., & Hagan, H. (2009). Missed Opportunities for HIV Testing Among High-Risk Heterosexuals. *Sexually Transmitted Diseases*, *36*(11), 704–710. doi:10.1097/OLQ.0b013e3181ab375d

Joseph, G., Burke, N. J., Tuason, N., Barker, J. C., & Pasick, R. J. (2009). Perceived susceptibility to illness and perceived benefits of preventive care: an exploration of behavioral theory constructs in a transcultural context. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *36*(5 Suppl), 71S–90S. doi:10.1177/1090198109338915

Kitzinger, J. (1995). Qualitative Research: Introducing focus groups. *BMJ*, *311*(7000), 299–302. doi:10.1136/bmj.311.7000.299

Krieger, N. (2001). Theories for social epidemiology in the 21st century: an ecosocial perspective. *International Journal of Epidemiology*, *30*(4), 668–677. doi:10.1093/ije/30.4.668

Krieger, N. (2005). Embodiment: a conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health*, *59*(5), 350–355.

Lane, S. D., Rubinstein, R. A., Keefe, R. H., Webster, N., Cibula, D., Rosenthal, A., … others. (2004). Structural violence and racial disparity in HIV transmission. *Journal of Health Care for the Poor and Underserved*, *15*, 319–335.

Latkin, C. A., & Knowlton, A. R. (2005). Micro-social structural approaches to HIV prevention: a social ecological perspective. *AIDS Care*, *17*(sup1), 102–113. doi:10.1080/09540120500121185

Leibowitz, A. A., & Taylor, S. L. (2007). Distance to public test sites and HIV testing. *Medical Care Research and Review*, *64*(5), 568–584.

Losina, E., Schackman, B. R., Sadownik, S. N., Gebo, K. A., Walensky, R. P., Chiosi, J. J., … Freedberg, K. A. (2009). 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. *Clinical Infectious Diseases*, *49*(10), 1570–1578. doi:10.1086/644772

MacQueen, K. M., McLellan, E., Kay, K., & Milstein, B. (1998). Codebook development for team-based qualitative analysis. *Cultural Anthropology Methods*, *10*(2), 31–36.

McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An Ecological Perspective on Health Promotion Programs. *Health Education & Behavior*, *15*(4), 351–377. doi:10.1177/109019818801500401

Murgai, N. (2012). Late Testers- preliminary data.

Pasick, R. J., Barker, J. C., Otero-Sabogal, R., Burke, N. J., Joseph, G., & Guerra, C. (2009). Intention, subjective norms, and cancer screening in the context of relational culture. *Health Education & Behavior*, *36*(5 suppl), 91S–110S.

Pasick, R. J., Burke, N. J., Barker, J. C., Joseph, G., Bird, J. A., Otero-Sabogal, R., … Guerra, C. (2009). Behavioral theory in a diverse society: like a compass on Mars. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *36*(5 Suppl), 11S–35S. doi:10.1177/1090198109338917

Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Sage Publications, Inc.

Sallis, J. F., Owen, N., & Fisher, E. B. (2008). Ecological models of health behavior. *Health Behavior and Health Education: Theory, Research, and Practice*, *4*, 465–486.

Syme, S. L. (2004). Social determinants of health: The community as an empowered partner. *Preventing Chronic Disease*, *1*(1). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC544525/

Tang, J. J., Levy, V., & Hernandez, M. T. (2011). Who are California's late HIV testers? An analysis of state AIDS surveillance data, 2000-2006. *Public Health Reports (Washington, D.C.: 1974)*, *126*(3), 338–343.

Ulett, K. B., Willig, J. H., Lin, H.-Y., Routman, J. S., Abroms, S., Allison, J., … Mugavero, M. J. (2009). The Therapeutic Implications of Timely Linkage and Early Retention in HIV Care. *AIDS Patient Care and STDs*, *23*(1), 41–49. doi:10.1089/apc.2008.0132

Wallerstein, N. B., Yen, I. H., & Syme, S. L. (2011). Integration of Social Epidemiology and Community-Engaged Interventions to Improve Health Equity. *American Journal of Public Health*, *101*(5), 822–830. doi:10.2105/AJPH.2008.140988

Zierler, S., & Krieger, N. (1997). Reframing women's risk: social inequalities and HIV infection. *Annual Review of Public Health*, *18*(1), 401–436.

Challenges and benefits of a CBPR approach to studying and addressing late stage HIV/AIDS diagnosis among urban African Americans and Latinos

ABSTRACT

Background: Late diagnosis of HIV/AIDS and consequent delays in treatment may increase illness, premature mortality and forward transmission. To better understand and address this problem among African Americans and Latinos in Oakland, California, a multi-racial/multi-ethnic team of community and academic partners came together to conduct a multi-method study and pilot test community- driven solutions.

Methods: Within a community- based participatory research (CBPR) framework, qualitative data were collected through 13 focus groups and 17 individual interviews which then were collaboratively interpreted and analyzed. Challenges and benefits of using a CBPR approach were identified by a sub-group of the Steering Committee and validated with the entire group.

Findings: Use of a CBPR framework impacted four key areas: 1) inclusion/ exclusion; 2) bridging social capital and the role of bridge people; 3) education, status, race/ ethnicity, privilege and power imbalances; and 4) conflicting priorities. Within each area, we discuss benefits and challenges, and provide examples.

Conclusions: In both its achievements and its shortfalls, our project underscored important lessons about being thoughtful and proactive regarding who is invited to participate in each stage of the research—and of having the commitment and resources to enable their continued and meaningful involvement. Our study also reinforced findings of other CBPR partnerships concerning the importance of “bridge people,” difficulties in openly addressing tensions related to power dynamics, and funding and timeline constraints. Despite challenges faced, our study also illustrated the utility of CBPR for addressing the sensitive area of late stage HIV testing, and of translating findings into action.

INTRODUCTION

Late diagnosis of HIV/AIDS - receiving a diagnosis of AIDS at first HIV positive test, or progressing to AIDS within one year of initial HIV diagnosis[1] - and the consequent delays in treatment, may increase illness, premature mortality[2] and forward transmission.[3,4] To better understand and address the problem of late stage HIV/AIDS testing and diagnosis among African Americans and Latinos in Oakland, California, two populations disproportionately impacted by late-stage HIV in 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 study, funded by National Institutes of Health (NIH), that would gather both qualitative and quantitative data, and pilot test community- driven solutions. Although the originally proposed project utilized a more traditional research approach, after discussion with the funders, it was determined that the sensitivity of the topic combined with the complex interplay of multiple social determinants of health for the target population, warranted a more community- engaged approach.

In this paper, we briefly describe the late stage HIV/AIDS diagnosis project in Oakland. We focus in particular, however, on the benefits and challenges of CBPR as a framework for conducting the study. We conclude by comparing our findings on the benefits and challenges of CBPR in our study to those of other relevant research, and provide lessons learned and implications for further research, policy and practice.

BACKGROUND

Oakland, California reflects the racial inequities in larger society with respect to the disproportionate impact of HIV/AIDS among African Americans and Latinos. In 1988, a State of Emergency was declared in Alameda County to refocus planning scarce resources. Late HIV diagnosis in Oakland remains elevated (38.3% in 2010, compared to a national rate of 32.3% in 2007[5]) with Latinos and African Americans disproportionately affected. In Alameda County (where Oakland is located), two-thirds (66%) of all people who received a late diagnosis in 2010 were either African American or Latino,[5] while these two racial/ethnic groups comprised just 35.8% of the county's total population. Late diagnosis may be one important driver of the widening racial disparities seen in the HIV/AIDS epidemic in urban areas.[2]

Two respected community-based organizations, La Clínica de la Raza and California Prostitutes Education Program (CAL-PEP), together with the Oakland-based Pangaea Global AIDS Foundation and academic partners from the University of California, Berkeley School of Public Health, formed the initial project team. Additional stakeholders, including the Alameda County Public Health Department and Street Level Health Project (SLHP), a popular multi-purpose clinic and health and social service organization, also played an essential role. Community-Based Participatory Research (CBPR) guided the study approach.

CONCEPTUAL FRAMEWORK

CBPR is widely recognized as a promising orientation to research on health and social outcomes among underserved communities and their inequitable distributions within broader populations.[6,7] CBPR is defined as:

> "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a problem of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities."[8,p.2]

Implicit in this definition are many of the core principles of CBPR, including empowerment, recognition of the community as the unit of identity, co-learning, local capacity building and systems development, balancing research and action, and sustainability over the long haul.[9]

STUDY AIMS

Within the context of a CBPR orientation to research, the specific aims of this study were to:
1) Elucidate individual and structural barriers to earlier detection of HIV;
2) Make existing- but not readily accessible- county and state HIV testing and AIDS case data available to local communities for better understanding and improved programming;
3) Engage Oakland HIV/AIDS stakeholders to identify and/or develop community-driven responses to increase early HIV diagnosis; and
4) Pilot test one to three of these responses, leading to recommended models of implementation in Oakland.

METHODS

Partnership formation and functioning

In order to conduct this study, a project Steering Committee (SC) was formed comprised of 12 members representing each of the partner organizations. Meeting on a monthly basis, SC members provided updates on diverse aspects of the work and engaged in project decision-making.

Data collection

For Aim 1, in order to gather data on multiple aspects of the problem, we interviewed nine local leaders in the HIV/AIDS service community and eight Latinos and African Americans who had received a late-stage HIV diagnosis. The number of local leaders was chosen based on the knowledge of the Steering Committee members, many of who were themselves members of the Oakland HIV community and thus able to determine that these nine leaders were sufficiently representative of their community. The number of interviews with late-stage HIV patients was determined by convenience: as we did not have access to patient records we were limited by the number of patients that our HIV provider partners were able to recruit during the study timeframe. We also conducted 13 focus groups with a total of 109 Latino and African American Oakland

residents who were not accessing HIV prevention or education services and who belong to sub-groups identified by the SC as being at-risk of late diagnosis. Weekly team meetings enabled discussions of impressions and emerging themes, allowing the team to assess repetition of themes and recognize whether saturation[10] (i.e. when themes and concepts are repeated by multiple informants and no new themes are emerging) had been achieved or if more focus groups were needed. The expectation was that a minimum of two focus groups for each subpopulation[11] would allow this assessment, as the groups' participants were homogeneous in many characteristics (race, gender, age, occupation, geographic residence). The data were interpreted by a subcommittee of the SC, with representatives from all partner organizations, and by a six-member Community Advisory Board (CAB), convened part way though the project to assist with data interpretation. Systematic analysis of the qualitative data using the software package NVivo 9 is underway. The methods for Aim 2 involved obtaining descriptive quantitative data on HIV testing (including demographic characteristics of who is testing and geographic data on testing numbers and positive test results) from the county health department, performing univariate and bivariate descriptive analyses, including a linear test for trend, and presenting the findings to service providers and other relevant groups.

Aim 3 was accomplished through the cooperative interpretation of the qualitative data obtained in pursuit of Aim 1, as the SC used the identified themes to brainstorm ideas for interventions that would address the barriers to testing experienced by Latinos and African Americans in Oakland. For Aim 4, two interventions were developed and piloted: voluntary HIV counseling and testing (VCT) at mandatory PACT (Police and Communities Together) meetings for men who had recently been released from incarceration; and VCT at SLHP, which serves low wage immigrant workers.

Finally, and of special relevance to this paper, the study included taking a critical look at the utility and challenges of a CBPR framework for meeting the above study aims. While a CBPR orientation for this study addresses the need for a community-engaged approach, the partners also recognized that employing a CBPR approach to research always involves tradeoffs in resources and time. Thus, assessment of the benefits and challenges of such an approach, as experienced by the research team, can inform the choice of whether or not to use CBPR for future studies and, when a CBPR orientation is chosen, can improve preparation for facing similar challenges while maximizing benefits.

Utilizing a CBPR approach

As Morello-Frosch and her colleagues[12] note, CBPR can improve the "relevance, rigor and reach" of research. It is also a time consuming process, and one that presents numerous challenges along the way. To help insure the project's adherence to the spirit and principles of CBPR, SC members began by developing a partnership Covenant and eight principles that would guide its work.[13] The Covenant both adapted relevant principles from other CBPR partnerships[9,14–16] and developed others tailored more specifically to this project, such as: "community partners are not 'field people' but co-researchers and part of a learning community." To help promote adherence to the

Covenant, principles were read aloud, round robin style, at the beginning of most SC meetings during the first year of the project, with time allotted when possible to discuss our adherence or need for improvement in our efforts to live up to the principles.[13]

In addition to the SC and the *ad hoc* CAB, community forums were an essential part of our CBPR approach. The community partner agencies, with help from a Pangaea team member, organized and held four community forums, each at a venue popular with community members. The forums, held separately for Latinos and African Americans (with the exception of a provider forum), included dinner, a presentation of key study findings and related education, and opportunities for community feedback. The forums were held at key junctures in our project timeline, and allowed for two-way communication between the research team and members of the communities of interest.

FINDINGS

Although a full discussion of the overall study findings is beyond the scope of this paper, a selection of key preliminary findings is elaborated in Table 1: Emergent Themes from Qualitative Data Analysis Process.

Challenges and benefits of CBPR for studying and addressing inequalities in late stage HIV diagnosis

Our study was largely successful in meeting its specific aims, and surfaced some important new preliminary information about late stage HIV diagnosis among largely over-looked groups such as older African American women, younger Latinas, and heterosexual males. Yet of equal importance, perhaps, were the findings uncovered about the obstacles encountered in conducting this study, as well as facilitating factors related to our use of a CBPR framework. While our findings on ecological factors that influence HIV testing and late stage diagnosis can contribute to strategies for reducing racial/ ethnic inequities in HIV both in Oakland and in other urban areas, our findings on the process of conducting CBPR with multiple communities are applicable to future research projects on many other health inequities that exist in both rural and urban areas throughout the US. While many CBPR studies have reported their findings and methods in the public health literature,[17–21] and CBPR practitioners have editorialized on the general benefits and challenges of the approach,[7,22,23] there are fewer examples of reflexive analysis of specific CBPR projects written by CBPR practitioners (with a couple exceptions[24,25]). Our team, comprised of three community co-researchers, an academic professor, and her doctoral student, share our experiences and the findings that emerged from our own reflexive analysis of this three-year CBPR study. Although we identified several challenges and benefits of the CBPR orientation for the project, we decided to focus on just four in order to provide rich detail and examples within the scope of this brief paper.

1. Who is included, and who is not?

Including individuals and communities that are often excluded and marginalized in study decision-making is an effective strategy for beginning to address entrenched health

disparities. As in other CBPR, expanded inclusion was a significant benefit of this project, adding value to the study and the pilot intervention, and building capacity among partners. This expanded inclusion of community partners improved the qualitative aspects of the study throughout: providers and community members reviewed and approved interview guides, bringing the language closer to the participants' natural way of communicating, it built capacity of HIV service providers to think like researchers, and added insiders' perspectives to the data analysis.

To improve inclusion further into the project, the SC created a small CAB comprised of community members not connected to any of the organizational partners, yet deeply affected by the HIV/AIDS epidemic in Oakland. As noted earlier, the CAB worked with a subcommittee of SC members on some of the qualitative data interpretation. While this expanded perspectives on themes that had emerged from the preliminary data review to date, it still was not comprehensive, especially since CAB membership was limited to English speakers. This was deemed necessary to allow the CAB to work as a cross-cultural body that could share ideas between three African American and three Latino members, as well as with study staff. However, since much of the data was collected in Spanish, it is likely that some nuances of the original un-translated data were literally 'lost in translation,' and the experiences and knowledge of non-English speakers remained an untapped resource in the data analysis and interpretation process. Further, CAB involvement was cut short due to timing and fiscal constraints, as well as staffing changes. As a result, relationships had been initiated that in most cases were not sustained. This was challenging for all involved, and resulted in some feeling that the input and work of the CAB was devalued.

In contrast, a clear facilitator of cross-cultural communication in this study involved our ability to offer simultaneous translation (translation in real-time, made possible through the use of headphones and a live translator) at community forums. Although these events were held in Spanish in a predominantly Latino neighborhood, and in English at a central location chosen by the organization serving predominantly African Americans, having simultaneous translation at both venues was a decided advantage. Spanish speakers thus were able to participate in environments where they had previously been excluded and monolingual English speakers were able to experience being in a different linguistic culture and still understand what was being said. One participant remarked that this experience helped her to empathize more with non-English speakers in the US, by living the experience of requiring translation and not understanding conversations happening all around her.

2. *Bridging social capital: Two steps forward and one step back*

In our project, "bridging social capital," or mutual trust and reciprocity across communities of identity, [25, 26] proved especially important. The project team thus benefited from having several "boundary spanner" or "liaison persons"[28, 29] who could help bridge diverse worlds as needed during the course of the project. Key among these was our project director, an African American, academically trained researcher who also had deep roots in the local practice community. Her knowledge of the complexity of service organizations, and her willingness to hold regular individual meetings with each organizational representative, proved a critical source of bridging social capital. In

addition, both community-based organizations had previous experiences participating in rigorous research projects, with one SC member actually transitioning during the project from her role as research director at a CBO partner (CAL-PEP) to working at our lead research organization (Pangaea) as community liaison. Although this change benefited the project, it also changed the role of this particular SC member (a boundary spanner), since the new role focused more on lead agency organizational priorities and less on voice and interaction as a CBO partner.

Other staffing changes also had the effect of diminishing social capital, as when resource limitations resulted in the laying off of a community liaison who had played an important role both with the CAB and in organizing community forums. The mutual trust that also is core to social capital may have been compromised as well, as some members felt that the importance of this aspect of the work was thus deprioritized as no one was hired to spearhead it in her place.

Finally, while we were largely successful in our efforts to create and maintain a strong co-learning environment, obstacles also were encountered. For example, the fact that some academic partners were frequently out of the country or otherwise unavailable compromised their regular attendance at SC meetings. As a community partner commented, "co-learning can't take place if you're not in the room." Bringing tensions around this issue into the open enabled the adoption of a more flexible meeting schedule.[13]

3. Education, status, race/ ethnicity, privilege, and power imbalances

As Walter and Hyde have noted, using approaches like CBPR to study and address health disparities "does not inoculate against the dividends that may accrue because of race, class, gender, sexual orientation or other aspects of an individual's cultural identity."[26,p.425] In our project, tensions that sometimes arose at the intersections of different sources of power and privilege were rarely discussed in the full SC meetings, despite the commitment to openness and transparency implicit in our guiding principles. As a result, difficult issues were often unspoken, or discussed outside the group by partners sharing a common bond such as race/ethnicity, age and life stage, or educational background. Particularly later in the project, as time and funding constraints become more severe, sensitive issues often remained "under the radar," or were brought up but discussions were aborted or truncated because there was no time or space for process at that stage. Indeed, it was, in some instances, only after the project's conclusion that feelings of hurt or having been devalued were shared more openly.

Academic partners, most of whom were white, had power, by virtue of their status and often their race. The Covenant emphasized joint ownership of data by research and community partners, also requiring shared credit for publication and dissemination of jointly created findings. The community coordinators, however, needed to focus on field activities in addition to their other daily employment responsibilities. Thus, there was little time for the community coordinators to be able to write about the research process while academics, if they wished, were able to focus only on research. The resulting power imbalance was a reflection of the academic/ community partner divide. However,

it was not as simple as that either, as some community project coordinators from both agencies were graduate students or had master's degrees. Viewed through this more complex lens, it was not a matter of race, but of who gets to document and theorize the work done in the field under their leadership. This reflects the constraints of doing research in a climate of restricted resources, which in turn limits the amount of time and tasks that can realistically take place.

4. Conflict of priorities: timelines, IRB approval, and HIV testing programming

Among the most wrenching challenges we faced involved the inherent conflict between the priorities of CBO partners, such as HIV testing as opposed to research, and the project's mandate linking research and intervention. Although we were able to achieve both objectives (testing and research), in some instances, serious ethical and practical challenges arose. For example, prior to the implementation of the of the pilot study, CAL-PEP had been conducting HIV testing at the parole center on a weekly basis, averaging 25 tests per week, with no restrictions on who could be tested. Once testing was restricted to individuals who had been released in the past two weeks in order to accommodate a study goal, CAL-PEP's testing numbers dropped to an average of five tests per week, impacting the agency's priority of conducting HIV testing with high-risk populations and linking individuals to care when appropriate.

Compounding several of the above obstacles were substantial delays in Institutional Review Board (IRB) approval, which set the project's actual data collection back a full nine months. As Brown and Morello Frosch[12,27] have pointed out, IRBs "were never designed with CBPR in mind." While our project director made considerable efforts to educate the IRB about how CBPR differs from more traditional research, the IRB's discomfort with the extent of community engagement in project decision-making was among the factors that led to this delay. Additionally, some community members themselves noted the considerable time gap between the excitement of the community forums and the beginning of the study many months later. Among the other losses experienced due to IRB delays was an abrupt end to the project, which prevented dissemination of findings to local residents and other interested stakeholders.

DISCUSSION

Community psychologist Trickett[22] differentiates CBPR as a "worldview" from CBPR as an "instrumental strategy." In the "worldview" approach, community is the unit of identity, solution and practice,[22,28] there is extensive community involvement in decision-making, working toward multi-level change goals is emphasized, and reflexivity promotes attention to sustainability. In contrast, the "instrumental strategy" involves using some elements of CBPR when convenient to reach researchers' pre-determined goals (e.g., hiring community health workers to increase a study's response rate).[22]

This study began with a serious attempt to embody the CBPR worldview—something well demonstrated in the equal representation of community and academically-based research partners on the SC, and the project's development and attempted adherence to a set of CBPR guiding principles. At the same time, some of the community representatives felt constrained from fully contributing to project decision-making by real

or perceived power dynamics within the SC. Further, at times we fell into the use of CBPR as an "instrumental strategy," as when the CAB was terminated early due to lack of funding and staff changes.

We now return to the key challenges and facilitating factors discussed above, comparing our findings to those of other CBPR practitioners, and offering some lessons learned.

Inclusion and exclusion

Our inclusion of representatives of each partner on the SC was an important one, as were several of the guiding principles developed to address issues related to inclusion. However, Wallerstein and Duran[29] caution against falling into the common practice of seeking service providers and other health professionals as sole community representatives. While we attempted to heed this caution, (e.g., by adding a CAB of community members not connected to service agencies), we failed to sustain this effort, and later also failed to include members of the two groups with whom our eventual pilot projects were focused– low-wage immigrant workers and men recently released from incarceration.

As in other CBPR projects,[20,30,31] issues of inclusion also reflected linguistic challenges. As Chang et al. suggest,[20] working early on to secure additional funding for simultaneous translation and other language-related expenses may be well worth the effort in terms of community inclusion, the accuracy of data collection and interpretation, and the translation of findings into action. In both its achievements and its shortfalls, our project underscored important lessons about being thoughtful and proactive regarding who is invited to participate in each stage of the research—and of having the commitment and resources to enable their continued and meaningful involvement.

Bridge people and bridging social capital

Our study also reinforced findings of a number of other CBPR partnerships,[20,30,32,24,25] concerning the importance of "bridge people" and bridging social capital. As Rhodes et al.[33] note, "Given the 'syndemic' manner in which HIV tends to cluster around other problems like poverty and other stigmatizing, disempowering, and marginalizing conditions that contribute to health disparities… building individual and community capacity" may be particularly important. Bridge people with a foot in two cultural worlds have been shown to play an especially salient role in this regard.[33,20,30,34,17]

Bi-directional learning and capacity building, core principles of CBPR, were evidenced in our project in improved research skills, and enhanced understanding of local communities, as well as in the cross-cultural experiences to which both community and academic researchers were exposed. As codified in our Covenant, community partners were indeed recognized as equal partners, co-researchers and part of a learning community.[13] Although challenges still arose, returning to and reaffirming our Covenant provided one way we found helpful in supporting a co-learning environment, and providing a framework for addressing power imbalances between academic and community researchers.

Privilege and power in partnerships

As Garzón et al.[25] and others[35–37] have pointed out, "Though practitioners of participatory research routinely draw on the concept that knowledge is power, they seldom publically discuss how power dynamics between researchers and community partners have played out in particular partnerships." Our attempts to openly address tensions related to power dynamics were only partially successful, particularly toward the end of the project, as substantial pressures to focus on tasks and achieving all project aims and deliverables sometimes got in the way of "CBPR check-ins" and other process-focused discussions. In some cases too, partners chose to be silent—a strategy that, as Garzón and her colleagues note, means "…foreclosing on the opportunity to have a dialogue…" either immediately or at another agreed upon point in time. Further, as others[25,38] have noted, partnership tensions based on race/ethnicity and class were difficult to tease apart due to the intersections of such factors with other forms of power and privilege such as income, class, and educational attainment.

Furthermore, as Rhodes and colleagues[33] have pointed out, the fact that academic researchers "may have the qualifications and reputation to apply for funding may create an inherent power imbalance," and "the meanings community members and organizational representatives give to perspectives and assertions may deviate from the academic researcher's intentions." Given that academics and lay community members communicate differently, it is essential to check understanding with each other on a regular basis in order to minimize miscommunications of this kind. Otherwise, because of the underlying power balance referred to by Rhodes et al., community members may assume that academics' messages are meant to assert power rather than to contribute to attaining the common goal. An example is when academic jargon is used without explanation, community members may feel like they are being purposefully left out of a discussion or even a decision that is being made in their presence. Use of exercises such as Hyde's "Challenging Ourselves: Critical Reflections on Power and Privilege"[26] as well as more frequent and candid check-ins in dyads or small groups, that are then shared with the larger group, may also help in keeping lines of communication open and addressing difficult issues surrounding power dynamics as they arise.

Timelines and priorities

Major sources of tension in the project related to funding and timeline constraints, including inadequate funding to accommodate both partnership building and maintenance and the achievement of all project aims, including the piloting of two interventions, within three years. Failure to get IRB approval in a timely way further confounded both funding and timeline issues, and presented particular challenges for the community partners who had counted on allocations at particular points in time, and on the project's ending by the date originally set. Flicker et al.'s[39] guidelines for helping IRBs better assess CBPR projects are among a number of articles and resources now available in this regard.[19] At the same time, as our experience demonstrated, even

careful efforts by a respected Project Director to educate an IRB unfamiliar and/or uncomfortable with CBPR may fail to result in a timely approval process.

CONCLUSION

The disproportionate prevalence of late stage HIV diagnosis among African Americans and Latinos in Oakland and other urban areas is a stark example of a problem, the exploration of which does not easily lend itself to traditional "outside-expert driven" research approaches.

The challenges we experienced are similar in many ways to those reported by other CBPR partnerships working on HIV/AIDS and other health issues with diverse, underserved communities.[40,33,20,41] These challenges may arise, in part, because the systems that shape the inequitable distribution of health outcomes in our society also impact the research processes. Indeed, the fact that our challenges are not unique may reinforce both the long reach of inequitable social systems, and the fact that most all community-academic partnerships struggle with power dynamics and related issues. On a more positive note, the utility of the partnership Covenant that we developed and published, suggests an important contribution to both our own and other partnerships' efforts to "build alliances across differences"[42] as we work to study and address problems like late stage HIV diagnosis with, rather than on, communities. While CBPR is indeed a time-consuming, resource-intensive approach to research, the benefits to the study make a compelling case for its continued and expanded use in investigating health issues. The benefits to communities, especially the increased social capital and capacity building, may in the long term contribute to the shaping of more equitable social systems and, in turn, decreased health inequity.

Table 1: Emergent Themes from Qualitative Data-Rapid Assessment Process

Emergent Themes	
Commonalities Fear of result and social ramifications Experiences of discrimination in healthcare system Lack of resources and knowledge of available resources Limited awareness of risk behaviors Low self-perception of risk Potential confidentiality breaches Communication about HIV and trust in relationships Low prioritization of overall health status Comparison of HIV services Oakland vs. San Francisco	
Female Specific	***Male Specific***
Health concerns tied to family security HIV testing secondary, associated w/pregnancy	Do not seek care until very ill Social construction of gender
African American Specific	***Latino/a Specific***
Distrust amongst partners Existing informal prevention efforts Role of church (positively and negatively)	Language barriers Availability of clinic hours Immigration status

REFERENCES

1. Tang JJ, Levy V, Hernandez MT. Who are California's late HIV testers? An analysis of state AIDS surveillance data, 2000-2006. *Public Health Rep Wash DC 1974*. 2011;126(3):338-343.

2. Losina E, Schackman BR, Sadownik SN, 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. *Clin Infect Dis*. 2009;49(10):1570-1578. doi:10.1086/644772.

3. Coleman SM, Rajabiun S, Cabral HJ, Bradford JB, Tobias CR. Sexual Risk Behavior and Behavior Change among Persons Newly Diagnosed with HIV: The Impact of Targeted Outreach Interventions among Hard-to-Reach Populations. *AIDS Patient Care STDs*. 2009;23(8):639-645. doi:10.1089/apc.2008.0092.

4. Ulett KB, Willig JH, Lin H-Y, et al. The Therapeutic Implications of Timely Linkage and Early Retention in HIV Care. *AIDS Patient Care STDs*. 2009;23(1):41-49. doi:10.1089/apc.2008.0132.

5. Murgai N. Late Testers- preliminary data. 2012.

6. Wallerstein NB, Yen IH, Syme SL. Integration of Social Epidemiology and Community-Engaged Interventions to Improve Health Equity. *Am J Public Health*. 2011;101(5):822-830. doi:10.2105/AJPH.2008.140988.

7. Wallerstein NB, Duran B. Using Community-Based Participatory Research to Address Health Disparities. *Health Promot Pract*. 2006;7(3):312-323. doi:10.1177/1524839906289376.

8. Kellogg Comunnity Health Scholars Program. *The Kellogg Community Health Scholars Program: Stories of Impact*. Battle Creek, MI: TheWK Kellogg Foundation; 2001.

9. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19(1):173–202.

10. Glaser BG, Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. Aldine de Gruyter; 1967.

11. Kitzinger J. Qualitative Research: Introducing focus groups. *BMJ*. 1995;311(7000):299-302. doi:10.1136/bmj.311.7000.299.

12. Morello-Frosch R, Pastor Jr M, Sadd JL, Porras C, Prichard M. Citizens, Science, and Data Judo. *Methods Community-Based Particip Res Health*. 2005:371.

13. Ifeoma Udoh, Chopel A, Minkler M, et al. Developing and Using a Partnership Covenant to Guide a Study of Late Diagnosis of HIV. *Prog Community Health Partnersh Res Educ Action*. In Press.

14. Israel BA, Eng E, Schulz AJ, Parker EA, Satcher D. *Methods in Community-Based Participatory Research for Health*. 1st ed. Jossey-Bass; 2005.

15. Minkler M, Wallerstein N, eds. *Community-Based Participatory Research for Health: From Process to Outcomes*. 2nd ed. Jossey-Bass; 2008.

16. Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA J Am Med Assoc*. 2007;297(4):407–410.

17. Rhodes SD, Eng E, Hergenrather KC, et al. Exploring Latino men's HIV risk using community-based participatory research. *Am J Health Behav*. 2007;31(2):146–158.

18. Bowden P, Rhodes S, Wilkin A, Jolly C, Brown M. HIV among urban Latino males in northwestern North Carolina: Formative results and recommendations for primary and secondary prevention interventions. In: *The 132nd Annual Meeting of American Public Health Association November.*; 2004. Available at: https://apha.confex.com/apha/132am/techprogram/paper_87277.htm. Accessed August 4, 2012.

19. Hergenrather KC, Rhodes SD, Clark G. Windows to Work: Exploring Employment–Seeking Behaviors of Persons with HIV/AIDS Through Photovoice. *AIDS Educ Prev*. 2006;18(3):243–258.

20. Chang C, Minkler M, Salvatore AL, Lee PT, Gaydos M, San Liu S. Studying and Addressing Urban Immigrant Restaurant Worker Health and Safety in San Francisco's Chinatown District: A CBPR Case Study. *J Urban Health*. 2013;90(6):1026–1040.

21. Wang CC. Youth participation in photovoice as a strategy for community change. *J Community Pract*. 2006;14(1-2):147–161.

22. Trickett EJ. Community-based participatory research as worldview or instrumental strategy: Is it lost in translation (al) research? *Am J Public Health*. 2011. Available at: http://health-equity.pitt.edu/2614/. Accessed May 17, 2013.

23. Green LW, Mercer SL. Can Public Health Researchers and Agencies Reconcile the Push From Funding Bodies and the Pull From Communities? *Am J Public Health*. 2001;91(12):1926-1929. doi:10.2105/AJPH.91.12.1926.

24. Alkon AH. Reflexivity and Environmental Justice Scholarship: A Role for Feminist Methodologies. *Organ Environ*. 2011;24(2):130-149. doi:10.1177/1096026611414347.

25. Garzón C, Beveridge B, Gordon M, Martin C, Matalon E, Moore E. Power, Privilege, and the Process of Community-Based Participatory Research: Critical Reflections on Forging an Empowered Partnership for Environmental Justice in West Oakland, California. *Environ Justice*. 2013;6(2):71–78.

26. Walter C, Hyde C. Community building practice: An expanded conceptual framework. In: Minkler M, ed. *Community organizing and community building for health and welfare.* 3rd ed. New Brunswick, NJ: Rutgers University Press.

27. Brown P, Morello-Frosch R, Brody JG, et al. Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study. *Environ Health*. 2010;9(1):39.

28. Hatch J, Eng E. Community participation and control: or control of community participation. *Reforming Med Lessons Last Quart Century N Y NY Pantheon*. 1984:223–245.

29. Wallerstein N, Duran B. The conceptual, historical, and practice roots of community-based participatory research and related participatory traditions. In: *Community-Based Participatory Research for Health: From Process to Outcomes*. San Francisco: Jossey-Bass; 2003:27-52.

30. Lee PT, Krause N, Goetchius C. Participatory action research with hotel room cleaners: From collaborative study to the bargaining table. *Community Based Particip Res Health San Franc CA Jossey-Bass*. 2003:390–404.

31. Graybill P, Aggas J, Dean RK, Demers S, Finigan EG, Pollard RQ. A community-participatory approach to adapting survey items for deaf individuals and American Sign Language. *Field Methods*. 2010;22(4):429–448.

32. Palacios J, Kennedy HP. Reflections of Native American teen mothers. *J Obstet Gynecol Neonatal Nurs JOGNN NAACOG*. 2010;39(4):425-434. doi:10.1111/j.1552-6909.2010.01149.x.

33. Rhodes SD, Malow RM, Jolly C. Community-based participatory research: A new and not-so-new approach to HIV/AIDS prevention, care, and treatment. *AIDS Educ Prev*. 2010;22(3):173–183.

34. Rhodes SD, Hergenrather KC. Recently Arrived Immigrant Latino Men Identify Community Approaches to Promote HIV Prevention. *Am J Public Health*. 2007;97(6):984-985. doi:10.2105/AJPH.2006.107474.

35. Cornwall A, Gaventa J. *From users and choosers to makers and shapers: repositioning participation in social policy*. Institute of Development Studies Brighton; 2001. Available at: http://www.eldis.org/vfile/upload/1/document/0708/DOC2894.pdf. Accessed February 17, 2014.

36. Gaventa J, Cornwall A. Power and knowledge. *Sage Handb Action Res Particip Inq Pract*. 2008:172–189.

37. Thomas SB, Quinn SC, Butler J, Fryer CS, Garza MA. Toward a Fourth Generation of Disparities Research to Achieve Health Equity. *Annu Rev Public Health*. 2011;32(1):399-416. doi:10.1146/annurev-publhealth-031210-101136.

38. Israel BA, Krieger J, Vlahov D, et al. Challenges and facilitating factors in sustaining community-based participatory research partnerships: lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *J Urban Health*. 2006;83(6):1022–1040.

39. Flicker S, Travers R, Guta A, McDonald S, Meagher A. Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards. *J Urban Health*. 2007;84(4):478-493. doi:10.1007/s11524-007-9165-7.

40. Farquhar SA, Michael YL, Wiggins N. Building on leadership and social capital to create change in 2 urban communities. *Am J Public Health*. 2005;95(4):596-601. doi:10.2105/AJPH.2004.048280.

41. Michael YL, Farquhar SA, Wiggins N, Green MK. Findings from a community-based participatory prevention research intervention designed to increase social capital in Latino and African American communities. *J Immigr Minor Health*. 2008;10(3):281–289.

42. Chávez V, Duran B, Baker Q, Avila MM, Wallerstein N. The dance of race and privilege in CBPR. *Community Based Particip Res Health Process Outcomes 2nd Ed San Franc CA Jossey-Bass*. 2008:91–105.

CONCLUSION

The overarching goal of this dissertation research was to use a Community- Based Participatory Research (CBPR) approach to identify the factors which facilitate or hinder timely HIV testing by at-risk populations among Latinos and African Americans living in Oakland, California. These factors included those on the individual, interpersonal, community, and societal factors, and their interactions. I pursued that goal through completion of the following specific research aims, representing the three studies presented above:

1. To conduct a systematic and critical review of the literature on HIV/ AIDS diagnosis among Latinos and African Americans within the United States in order to identify the multi-level social determinants of racial/ ethnic inequities in late-stage HIV.

2. To analyze qualitative data from the larger parent study of racial disparities in late-stage HIV in order to identify and examine multi-level factors that exacerbate or attenuate barriers to timely HIV testing and diagnosis among African Americans and Latinos in Oakland, California.

3. To use reflexive analysis and participant observation to examine the benefits and challenges of using a CBPR framework to guide academic/ community collaboration for research and action goals.

The first study, a systematic and critical literature review of racial/ ethnic disparities in late-stage HIV and social determinants related to HIV testing, found that existing research was overwhelmingly focused on the individual level and lacked sufficient investigation of more distal social determinants of health such as poverty and racism. While the 26 studies examined each contributed important descriptive elements about ethnic/racial inequities in the population distribution of late stage HIV in the US, and useful insights into multi-level contextual factors that shape the disparity, I concluded that more quantitative and qualitative studies could improve understanding of the social determinants of HIV testing behavior among at-risk groups by measuring variables at the appropriate rung of the ecological model. Furthermore, this review highlighted the need for studies that investigate barriers to and facilitators of HIV testing *in partnership with communities* to help further interventions that could reduce racial/ethnic disparities in late diagnosed HIV/AIDS.

For the second study, I analyzed qualitative data collected as part of the larger study. The data included first, transcripts from 17 individual interviews, conducted with local leaders in HIV/AIDS and people who had received a late-stage HIV diagnosis. Second, data were analyzed from 13 focus groups, comprised of a total of 109 people who were disconnected from HIV services and education but may have been at risk for late-stage HIV. Transcripts were dual-coded for an inter-rater reliability rate of 90%, and then analyzed using a combined conceptual framework incorporating the Social Ecological Model (SEM) and the Theory of Planned Behavior (TPB). The qualitative software package NVivo was utilized in this data analysis, with coding categories developed during the original dual coding process. In the second paper above, I elaborated on

multi-level factors that influenced testing decisions and behavior of young Latina women and African American men recently released from incarceration. The TPB and SEM employed in conjunction with each other proved to be a rich conceptual framework for exploring a complex health behavior.

The third study reported on challenges and benefits associated with utilizing a CBPR approach to investigate racial/ethnic inequities in late-stage HIV in an urban community. Through a collaborative reflexive analysis process, we identified four key areas that illustrate the ways that challenges and benefits of CBPR are often inter-connected: 1) inclusion/ exclusion; 2) bridging social capital and the role of bridge people; 3) education, status, race/ ethnicity, privilege and power imbalances; and 4) conflicting priorities. This process, and the examples that we explored and on which we reported, highlighted some important lessons for CBPR practitioners. We found that many of the challenges and benefits experienced in our study were not unique to our partnership, as the overarching issues of power and privilege, inclusion/ exclusion, and constraining timelines with conflicting priorities inevitably have an impact on community-academic research collaborations. We also note, however, that the creation and active use of a partnership covenant facilitated open communication about some of these issues, as did engaging in the reflexive analysis process.

The findings from these three studies demonstrate the importance of including communities in investigations of late-stage HIV inequities. Community engagement added value to this study as all partners contributed to aligning every activity toward the dual goals of increased knowledge and improved practice. The study findings also demonstrated that disparities in HIV testing behaviors are shaped and maintained by ecological factors at multiple levels. Especially when investigating health disparities that cluster in marginalized and oppressed communities, community-academic collaboration and multi-level frameworks can enhance findings.

Improved understanding of the ecological factors that impact on health behaviors enable us to make the connection between more just policies and practices and more healthy policies and practices. This connection is important for the narrative that public health practitioners and researchers communicate, for while social justice is a value that some may dismiss as political, promoting population health, and in particular the eradication of infectious diseases like HIV, are common goals for society. Further, as public health practitioners and researchers, it is important that we examine our own practices and how they impact the people and systems that we study. CBPR is a way to address power inequities in the process of studying health inequities. This dissertation highlights the potential of combined conceptual frameworks, necessarily multi-level, and participatory research, to contribute to our growing understanding of health disparities that. Like late diagnosed HIV, have a large behavioral health component.