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Publication Date
2013

Peer reviewed|Thesis/dissertation
HIV Stigma in Asians Living with HIV

by

Emiko Kamitani

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

Nursing

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
Acknowledgement:

Funding was supported by the UCSF Century Club Funds and UCSF graduate Student Research Award. I also thank study participants and the Asian and Pacific Islander Wellness Center for generously helping me in this study.
HIV Stigma in Asians Living with HIV
Emiko Kamitani

Abstract

Background: Asian Americans had the highest percentage growth of any racial group between 2000 and 2010. Asian Pacific Islander (API) is the only racial group which significantly increased in estimated annual percentage (4.4%) of HIV newly diagnosed individuals between 2001-2008. As rates of HIV infection rise in the Asians population, it is important for us to increase our understanding about what facilitates HIV infection in this population and to focus on decreasing HIV related morbidity and mortality. Stigma, an important concept in the field of international HIV research, is increasingly being associated with access to prevention, care, and treatment outcomes in the population of PLHIV in the US. Because of the limited research among the U.S. Asian population our understanding of HIV stigma in this population is limited.

Objective: The purposes of my dissertation study were: (1) to report on the steps taken to develop items that measure stigma that are specific to, and relevant for Asians living with HIV (ALH); using these items, to modify an abbreviated Berger’s HIV Stigma Scale and to test the psychometric properties of the modified scale; (2) to assess the level of stigma experienced by ALH by using the newly modified HIV stigma scale and explore the association to the acculturation and self-rated general health in a sample of ALH; and (3) to explore the level of knowledge, attitudes, and self-perceived risk of cardiovascular disease (CVD) and acute coronary syndrome (ACS) in a sample of ALH and how these factors are influenced by the stigma.

Setting: The study was conducted at a HIV-care community clinic for uninsured and underinsured PLHIV in San Francisco, California.
Methods: Data were collected via a face-to-face interviews, focus groups, and cross-sectional study.

Participants: A convenience sample comprised 83 economically vulnerable ALH from November 2010 to June 2013 (n = 5 in face-to-face interviews, n = 11 in focus groups, and n = 67 in cross-sectional study).

Results: This study developed the first HIV stigma scale culturally adapted to ALH and found the HIV stigma was often experienced by ALH and negatively associated to acculturation and health outcomes. Also, ALH in my study had limited knowledge of, positive attitude toward, and low self-perceived risk regarding CVD and ACS. HIV stigmatization was independently correlated with attitude; acculturation was an independent predictor of level of knowledge.

Conclusions: Such a high level of HIV stigma experienced by ALH, poor knowledge, positive attitude, and low self-perceived risk of CVD and ACS are matters of concern. Since HIV stigma is negatively associated to acculturation, health outcomes and attitude toward CVD and ACS, we need for an innovative, culturally-appropriate intervention to reduce HIV stigma experienced by ALH.
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Introduction

Statement of the Problem

Due to the advent of a combination antiretroviral therapy, the life expectancy of people living with HIV (PLHIV) has dramatically increased (Palella et al., 2006). People living with HIV who learn their HIV status and initiate timely, antiretroviral therapy can delay the development of AIDS (Centers for Disease Control and Prevention, 2012c; Palella et al., 2006; World Health Organization, 2012). The number of new AIDS diagnoses among Asians living with HIV (ALH) have steadily increased, and a delay in timely, appropriate HIV care is problematic in this population (Centers for Disease Control and Prevention, 2009, 2012b; Hahm, Song, Ozonoff, & Sassani, 2009; Huang, Wong, De Leon, & Park, 2008; Kaiser Family Foundation, 2006; Zaidi et al., 2005).

People living with HIV may live for years without any signs or symptoms of the infection until they develop AIDS. HIV testing and receiving appropriate HIV care is important in delaying the development of AIDS. Several studies have attempted to explain what causes delays in seeking HIV care in the general US population. For racial minorities, such as African Americans and Hispanics, education, lack of insurance, and immigration status are barriers to HIV-related care (Lopez-Quintero, Shtarkshall, & Neumark, 2005; Wohl et al., 2011), however, these barriers fail to explain the delay in seeking HIV care in ALH. Compared with other groups, ALH are more likely to have higher education and literacy levels, private insurance, and legal immigration status (Chin, Kang, Kim, Martinez, & Eckholdt, 2006; Hahm et al., 2009).

Avoiding HIV care might be caused by HIV stigma. Stigma is defined as “the phenomenon whereby an individual with an attribute is deeply discredited by his/her society and
is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity (Goffman, 1963, p.3).” HIV stigma can be characterized as prejudice against, discrimination toward, and discrediting PLHIV and the groups and communities they associate with (Herek & Capitanio, 1997). HIV stigma has been shown to have a negative effect on people seeking voluntary counseling, timely HIV testing, and preventive behaviors, such as asking sexual partners about their HIV status or engaging in safer sex (Bond, Chase, & Aggleton, 2002; Chesney & Smith, 1999; Duffy, 2005; Kalichman & Simbayi, 2003; Letamo, 2003; Reidpath, Brijnath, & Chan, 2005). HIV stigma also significantly negatively correlates to health care seeking behaviors and adherence to HIV care (Cahill & Valadéz, 2013; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012; Vanable, Carey, Blair, & Littlewood, 2006).

As their life expectancy gets longer, PLHIV often live with multiple complex comorbid conditions (Bhaskaran et al., 2008; Palella et al., 2006). Today, up to 69% of PLHIV die from non-AIDS related complications (Palella et al., 2006; The Antiretroviral Therapy Cohort Collaboration, 2010; Weber et al., 2006). Cardiovascular disease (CVD) is a primary cause of non-AIDS related death among PLHIV, accounting for approximately 16% of deaths today (Palella et al., 2006; The Antiretroviral Therapy Cohort Collaboration, 2010; The DAD Study Group, 2007; Weber et al., 2006). The prevalence of CVD in PLHIV is more than two-times higher than the general population in the US (Farley, Tudor, & Dennison, 2010; Lloyd-Jones et al., 2010; Roger et al., 2012).

The health care seeking behaviors for CVD and acute coronary syndrome (ACS) are also greatly associated with knowledge, attitudes, and self-perceived risk (Dracup et al., 2008). Socioeconomic status has a significant influence—individuals with a low socioeconomic status
tend to have poor knowledge, attitudes, and self-perceived risk (Kayaniyil et al., 2009; Park, 2011; Pollitt, Swetter, Johnson, Patil, & Geller, 2012; Wu, Yu, Wei, & Yin, 2003). Even though low socioeconomic status PLHIV have an increased risk of developing CVD and ACS, no studies have explored the relationship between knowledge, attitudes, and self-perceived risk among this population.

The overall purpose of this study is to explore HIV stigma experienced by economically vulnerable ALH and how that stigma influences the health care they receive along with their knowledge, attitudes, and self-perceived risk for HIV-related issues including comorbidities such as CVD and ACS. In order to achieve this goal, my three dissertation papers are; 1) to modify an abbreviated Berger’s HIV Stigma Scale and develop a culturally appropriate HIV stigma scale among ALH, the Stigma Scale for ALH, by including culturally appropriate and relevant items, and to test the psychometric property of the newly developed scale, 2) to assess the level of stigma by using the Stigma Scale for ALH and explore the association between HIV stigma and acculturation and general health outcome, and 3) to understand the level of knowledge, attitude, and self-perceived risk for CVD and ACS and how these are influenced by the HIV stigma.

Background and Significance

The term Asian embraces a great variety of cultures, religions, and traditions although Asians are often considered a homogeneous racial group. Asian, in the US, refers to a person having ancestors from the Far East, Southeast Asia, or the Indian subcontinent. In 2010, approximately 15.3 million people in the US identified themselves as Asians (5% of the total population) (U.S. Census Bureau, 2011a, 2011b). The US Asian population had the highest percentage growth for any racial group between 2000 and 2010 according to the US Census
Bureau. While total US population growth during that time was 9.7%, the population growth for Asians was 43%. (Hoeffel, Rastogl, Kim, & Shahid, 2012).

Lack of timely appropriate HIV care in ALH has been well documented. Data for Asians only is not available, but data for Asian and Pacific Islanders (API) shows that roughly one third of API with HIV were not aware of their HIV status compared with 21% in the general population (Asian & Pacific Islander Wellness Center, 2012; Centers for Disease Control and Prevention, 2011). API had the lowest median number of initial CD4 counts among all racial groups; this finding implies a more advanced stage of HIV. Moreover, nearly half of API with HIV (45.6%) had already developed symptoms caused by their HIV when they were diagnosed (Wong, Campsmith, Nakamura, Crepaz, & Begley, 2004). API are more likely to be diagnosed with HIV at the same time of an AIDS diagnosis than any other racial group (U.S. Census Bureau, 2006; Wong et al., 2011). Furthermore, API were more likely to receive an AIDS diagnosis less than 12 months after their initial HIV diagnosis than individuals from other ethnic groups (Centers for Disease Control and Prevention, 2005, 2007b; Pounds, Conviser, Ashman, & Bourassa, 2002). In nearly half of the API who were diagnosed with AIDS, HIV testing was the initial reason for the medical visit compared to 38.0% for Caucasians (Centers for Disease Control and Prevention, 2002; Wong et al., 2004). This suggests that API are less likely to seek HIV testing to find their HIV at an earlier stage and are at a later stage of HIV infection when they are diagnosed (Cunningham et al., 1998; Hahm et al., 2009; Ickovics & Meade, 2002; Korthuis et al., 2008; Palella et al., 2006; Saha et al., 2011).

Getting a HIV test to determine one’s HIV status and receiving appropriate HIV care are important self-help measures to delay the development of AIDS. However, the lack of HIV testing which causes the delay in HIV diagnoses has been well documented (Brown et al., 2007;
Centers for Disease Control and Prevention, 2006; 2007a; 2009; Hahm et al., 2009; Huang et al., 2008; Kaiser Family Foundation, 2006; Yudin, Moravac, & Shah, 2007; Zaidi et al., 2005). The proportion of Asians tested for HIV is significantly lower than in other groups (Centers for Disease Control and Prevention, 2009; Hahm et al., 2009; Huang et al., 2008; Kaiser Family Foundation, 2006; Zaidi et al., 2005). Among adults aged 18 years or older, only 34.1% of Asians have ever been tested for HIV (Pleis, Ward, & Lucas, 2010). Those rates are lower than the rate for African Americans (60.3%) and other racial groups (45.4% for Hispanics and 37.1% for Caucasians) (Pleis et al., 2010). Even though API account for up to one-third of the population, only 11% of all HIV test administrations in San Francisco were given to API (Asian & Pacific Islander Wellness Center, 2012). Moreover, nearly half of all HIV tests in San Francisco were given to Whites, who account for roughly 44% of the population. African Americans were tested at a rate nearly double their population size, and Hispanics were tested at a rate nearly 1.25 times their population. Based on these reports, it is clear that Asians are less likely to get HIV testing.

HIV stigma is rooted in multiple factors; some causes of the stigma (e.g., fear of HIV contagion) are universal, but others vary from culture to culture or population to population (Hong et al., 2008). The differences may be influenced by societal values, beliefs, or local HIV epidemics (Parker & Aggleton, 2003). For example, in China, injection drug users have the highest risk of HIV transmission; in the US, it is men who have sex with men (MSM; Hall et al., 2008; Wang et al., 2009). In the 1980s in Japan, the primary transmission route for HIV was blood transfusion with non-heat-treated blood products imported from the US. As a result, more than 2,000 hemophiliac patients or their family members were infected (Health and Welfare
Statistics Association, 2001). Such varied causes of HIV epidemics may foster different perceptions of HIV and associated stigma.

In addition, CVD is the leading cause of death in US, with more than 33% of the general population having at least one kind of CVD (Centers for Disease Control and Prevention, 2013a; Lloyd-Jones et al., 2010). Such a high prevalence is problematic enough for the general population, but PLHIV who are also immunocompromised have an even higher CVD prevalence. A recent systematic-review and meta-analysis study found that PLHIV have an increased relative risk of CVD by up to 61% — prevalence of CVD in PLHIV is 73%, which is more than twice the rate in the US general population (Centers for Disease Control and Prevention, 2011; Farley et al., 2010; Roger et al., 2012). CVD is also a major cause of hospitalization in PLHIV. Multisite cross-sectional studies found that 7.5% of all hospitalizations in PLHIV were related to CVD in 2001-2008 (Berry, Fleishman, Moore, Gebo, & Network, 2012). By 2015, 50% of PLHIV in the US will be age 50 or older (High et al., 2008). Thus, more PLHIV will face age-related health issues and the prevalence of CVD in PLHIV is expected to increase.

A literature search found some qualitative studies on HIV stigma in ALH, yet no study measured the level of HIV stigma with a culturally appropriate scale or described how HIV stigma influenced whether individuals sought out HIV care along with the knowledge, attitudes, and self-perceived risk for comorbid conditions.

**Conceptual Framework for HIV stigma in Asians with HIV: Andersen’s Behavioral Model of Health Service Use**

Several theoretical models are available to evaluate HIV stigma as a barrier to receiving HIV care. Specifically, Andersen’s behavioral model of health service use is a well-known and
frequently applied model used to understand health-seeking behavior (Bergman, Haley, & Small, 2011) (see Appendix A). It has been studied in several health care delivery models including complementary and alternative medicine, conventional medical care, and preventive care (Kelner & Wellman, 1997; Pescosolido, Gardner, & Lubell, 1998; Sirois & Gick, 2002; Ting & Hwang, 2009; Upchurch et al., 2008).

The model proposes three phases of an individual’s health care utilization: *predisposing characteristics* (the rationale of the predisposition of the family to receive health services), *enabling resources* (an aspect of the services that enables or impedes family reception of resources), and *need* (the perception of need for health care services). The framework focuses on the family as the unit of analysis, instead of individuals, because individual demographic and socioeconomic characteristics are greatly influenced by the family (Andersen, 1995). This model was initially introduced to understand why people receive health services and the meaning of health-seeking behaviors. The framework successfully explains utilization in ambulatory care, hospital and inpatient care, and dental services that families tend to access on a regular basis (Andersen, 1968).

Andersen’s behavioral model of health services use includes perceptions and knowledge of health services and illness, occupations, the ability to access the resources needed to deal with those problems, the status of a person in the community, and the lifestyle and physical environment in which they are more likely to be in (Andersen, 1995). By applying this model, we can understand the process of receiving HIV-related care, including CVD and ACS care, for ALH. First, they have to know their risk for HIV and the consequences of avoiding care, the availability of a clinic where they can receive appropriate care, and recognize the need for care.
**Predisposing characteristics.** Predisposing characteristics are defined as factors predicting need prior to the onset of a health care need or a reason for a predisposition of the family to receive health services (Andersen, 1968). The factors in the behavioral model are demographic, health beliefs, and social structures; these are typically un-modifiable by individual preferences or choices.

Among these factors, in the phase of predisposing characteristics, social structures are particularly associated with seeking HIV care among ALH. Do and his colleagues (2005) found that Asians who engaged in high risk behaviors had a low awareness of their HIV risk and did not seek HIV care. Kahle and colleagues (2005) found similar findings to the study by Do et al. (2005). Asians often failed to perceive themselves as being at a high risk for HIV infection even though they engaged in unprotected anal intercourse or needle sharing. This is because Asians tend to limit their social network to specific ethnic or Asian sub-groups, and individuals may have the perception that they are in the same communities as those who are at a low risk for HIV. They would not ask their partners about HIV sero-status unless their partners were non-Asians. Therefore, individuals may fail to consider the repercussions of engaging in potentially unsafe behavior with partners, underestimate their risk for HIV, and prevent them from seeking HIV care (Kahle et al., 2005). Thus, social networks limited to a certain ethnic group might prevent the seeking of HIV care.

**Enabling resources.** Enabling resources is defined as the availability of resources if people need to seek care (Andersen, 1968). In general, people who know where they can receive health care are more likely to receive care. However, for Asians, this knowledge is not enough for them to seek health care. Even though Asians know the locations of where they can receive
care, they do not seek it unless they feel comfortable going there (Do, Hudes, Proctor, Han, & Choi, 2006). Especially for ALH who are at high risk of developing ACS, it is important that they get medical attention when they experience ACS since the timing of reperfusion therapy is strongly associated with morbidity and mortality (Asseburg et al., 2007; P. B. Berger et al., 1999; Newby, 1997; Stone et al., 1998).

As a “model minority”, Asians might have fewer enabling resources for HIV care and, therefore, not receive the same quality of health care (Centers for Disease Control and Prevention, 2012). No recent studies are available, but a study by Maldonado (1999) found that US physicians perceived that Asians were at the lowest risk for HIV and were less likely to offer HIV testing to them than any other ethnic group. Hahm and colleagues (2009) found that Asians were less likely to receive HIV testing with routine care. In addition, Yoshioka and Schustack (2001) found that even if Asians saw their primary health care providers, they were not be able to take full advantage of the care because they might not fully disclose private information and HIV risk behaviors with their health care providers.

Need. Need indicates the necessity of receiving health care and includes self-perception of need as well as actual need (Andersen, 1968). Self-perceived risk is included in this phase. Even though Asians face HIV-transmission risks similar to other ethnic groups, they are the least likely to seek HIV care (Zaidi et al., 2005). This might be because they fail to perceive their need for HIV care.

In terms of seeking health care for CVD, especially medical attention while they are experiencing ACS, they have to recognize the need to receive care. They must know what the signs and symptoms of CVD or ACS are and perceive themselves at a higher risk of developing
CVD or ACS than non-PLHIV due to their HIV infections and adverse effects of antiretroviral treatment (Freiberg Ms & et al., 2013; Palella et al., 2006; The Antiretroviiral Therapy Cohort Collaboration, 2010; The DAD Study Group, 2007).

In addition, Asians tend not to receive screening for HIV even with opt-out HIV testing done in the emergency room or during prenatal care (Centers of Disease Control and Prevention, 2006). More than half of Asians (55.7%) who were offered routine emergency department HIV testing declined the test (Brown et al., 2007). This is a much higher rate than for Caucasians (40.6%), African Americans (39.9%) or Hispanics (39.8%; Brown et al., 2007). Yudin, Moravac, and Shah (2007) found that Asian women were significantly less likely to accept HIV testing with prenatal care compared to other racial groups. These findings suggest that even when Asians are offered HIV testing, they do not take advantage of it and are more likely to refuse testing. This might be because they do not believe that they need HIV testing.

HIV stigma experienced by ALH might influence each phase in Andersen’s behavioral model of health services use. Due to the stigma, ALH might not seek or be less likely to receive appropriate HIV care. Based on the theoretical framework, my dissertation study explored how the HIV stigma cause barriers to receive HIV health care and factors associated with the stigma.

Methodological Approaches/ Three Papers Overview

Previous studies found that ALH experienced the greatest level of HIV stigma (Centers for Disease Control and Prevention, 2013b; Kang, Rapkin, & DeAlmeida, 2006; Kang, Rapkin, Remien, Mellins, & Oh, 2005). No study, however, has measured the level of HIV stigma experienced by ALH with a culturally appropriate HIV stigma scale or how the stigma influences
knowledge, attitudes, and risk-perception for CVD or ACS. My dissertation studies explore HIV stigma experienced by ALH and how it has caused barriers to seeking HIV-related care in ALH.

In order to validate the purposes of the study, I conducted a multi-method study comprised of a qualitative study followed by a quantitative study to enhance the validity of the study outcomes or findings (Polit & Beck, 2003). This type of multi-method study can establish the validity of the findings from the initial study and then enhance the validity and reliability of the findings of the subsequent study and is the preferred research method for instrument development (O'Cathain, Murphy, & Nicholl, 2007).

**Paper 1: Abbreviated and Culturally Appropriate HIV Stigma Scale for Asians**

**Living with HIV.** The main purpose of Paper 1 was to revise the abbreviated Berger HIV Stigma Scale for ALH and create the Stigma Scale for ALH. I chose the 10-item abbreviated HIV Stigma Scale instead of the original 40-item Berger HIV Stigma Scale due to concerns of survey fatigue (see Appendix B). The majority of ALH in the US are foreign-born (Centers for Disease Control and Prevention, 2012a). Therefore, the shorter version of the HIV Stigma Scale is more appropriate for ALH since they are more likely to have English as a second language.

The draft of the Stigma Scale for ALH with 13 questions was formulated based on the findings of in-depth interviews and intensive literature reviews and was reviewed by content experts and survey experts. Two focus groups were held to review the revised scale by 11 ALH, and the psychometric properties of the newly developed HIV stigma scale was evaluated with a cross-sectional study among 67 ALH. The findings showed good reliability and validity of the scale, and that the Stigma Scale for ALH was culturally appropriate for the population.
Paper 2: Level of HIV Stigma Experienced by Asians Living with HIV: the influence of acculturation and general health outcome. The purpose of Paper 2 was to explore the level of HIV stigma experienced by ALH and find the association between stigma and (a) acculturation and (b) self-rated general health. Even though several research studies in HIV stigma are available, little is known about level of HIV stigma in ALH. One study measuring the level of stigma in API living with HIV has been published, but the study used the Social Impact Scale which was developed to measure the level of stigmatization of clients with HIV/AIDS or cancer, not specifically HIV or cultural sensitivity for Asians (Fife & Wright, 2000; Kang et al., 2006; Kang et al., 2005).

The majority of ALH are foreign-born—only Asians had the fact that newly HIV infected people were higher in foreign-born than US-born in 2008-2010 (Centers for Disease Control and Prevention, 2012a; Prosser, Tang, & Hall, 2012). Since HIV stigma is strongly influenced by culture, acculturation might be an important consideration among this population (Hong et al., 2008). Thus, this paper also explored how the level of acculturation associated with the level of HIV stigma by examining the correlation between scores on the Stigma Scale for ALH and the Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA).

Previous studies found HIV stigma significantly correlates to health care seeking behaviors and adherence to HIV care (Cahill & Valadéz, 2013; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012; Vanable, Carey, Blair, & Littlewood, 2006). Thus, this study also revealed the association between HIV stigma and their self-rated general health in ALH
This cross-sectional study among 67 ALH showed a high level of HIV stigma experienced by ALH. The level of HIV stigma was strongly correlated with acculturation and self-rated general health—ALH who had a stronger Asian identification than Western identification and poor health outcome were more likely to experience HIV stigma than those who had stronger Western identification or better health outcome.

**Paper 3: Knowledge, Attitudes, and Self-perceived Risk for Cardiovascular Disease and Acute Coronary Syndrome, and the Influence of HIV Stigma and Acculturation among Economically Vulnerable and Racial-minorities Living with HIV.** Finally, the third paper explored the knowledge, attitudes, and risk perception for one of the leading causes of death in PLHIV, CVD and ACS, and assessed the influence of HIV stigma and acculturation (Palella et al., 2006; The Antiretroviiral Therapy Cohort Collaboration, 2010; The DAD Study Group, 2007; Weber et al., 2006).

In this study, knowledge is defined as the ability to recognize the signs and symptoms of CVD and ACS, attitude is defined as the confidence to take actions when they experience ACS, and self-perceived risk is defined as awareness of their risks (Dracup et al., 2008). Knowledge and risk-perception were measured by the Knowledge about Heart Disease and Self-perceived Risk for a Future Myocardial Infarction/Heart Attack questionnaires developed by Dracup, et al. (2008). Attitude was tested with the attitude scale of the ACS Response Index measure (Riegel et al., 2010).

The cross-sectional study of 67 ALH revealed that they had limited knowledge, positive attitudes, and low self-perceived risk, and that HIV stigma independently influenced attitudes regarding ACS, and acculturation independently influenced knowledge about CVD and ACS.
The advent of antiretroviral medication can make it possible for PLHIV to survive longer, yet not all PLHIV have equally access to HIV care. HIV-related health care disparity has been a problem, especially in communities of color (Centers for Disease Control and Prevention, 2012, 2013b). The overall purpose of these three studies is to understand the unique HIV stigma that causes HIV-related healthcare disparity in ALH and how HIV stigma is influenced by their own traditions and culture effecting the HIV-related care in economically vulnerable ALH.
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Figure A: Andersen’s behavioral model of health sciences use

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<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td>Personal/Family</td>
<td></td>
<td>Perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Structure</td>
<td></td>
<td>Community</td>
<td></td>
<td>(Evaluated)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Figure B: abbreviate HIV Stigma Scale

1. I have been hurt by how people reacted to learning I have HIV.
   
   Strongly disagree · Disagree · Agree · Strongly agree

2. I have stopped socializing with some people because of their reactions of my having HIV.
   
   Strongly disagree · Disagree · Agree · Strongly agree

3. I have lost friends by telling them I have HIV.
   
   Strongly disagree · Disagree · Agree · Strongly agree

4. I am very careful who I tell that I have HIV.
   
   Strongly disagree · Disagree · Agree · Strongly agree

5. I worry that people who know I have HIV will tell others.
   
   Strongly disagree · Disagree · Agree · Strongly agree

6. I feel that I am not as good a person as others because I have HIV.
   
   Strongly disagree · Disagree · Agree · Strongly agree

7. Having HIV makes me feel unclean.
   
   Strongly disagree · Disagree · Agree · Strongly agree

8. Having HIV makes me feel that I’m a bad person.
   
   Strongly disagree · Disagree · Agree · Strongly agree

9. Most people think that a person with HIV is disgusting.
   
   Strongly disagree · Disagree · Agree · Strongly agree

10. Most people with HIV are rejected when others find out.
   
   Strongly disagree · Disagree · Agree · Strongly agree

28
Abbreviated and Culturally Appropriate HIV Stigma Scale for Asians Living with HIV

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HIV stigma is rooted in multiple factors; some causes (e.g., fear of HIV contagion) are universal, but others vary from culture to culture or population to population (Hong et al., 2008; Valdiserri, 2002). The differences may be influenced by societal values, beliefs, or local HIV epidemics (Parker & Aggleton, 2003). Asians are less likely to receive HIV-related health care as quickly when compared to Caucasians, and the disparity in HIV care might be caused by HIV stigma (Centers for Disease Control and Prevention, 2010). The Berger Stigma Scale (2001) is used as a gold standard to measure stigma in people living with HIV. However, the scale might not be culturally sensitive enough to capture stigma experienced by Asians living with HIV (ALH). The purpose of this article is to describe the Stigma Scale for ALH, an adaptation of the Berger Stigma Scale, that it is culturally appropriate and valid to use with Asian populations.

**Background and Significance**

Although the Asian population in the U.S. is growing, the proportion of people with HIV who are Asian is low; 1% of people living with HIV in 2009 and approximately 2% of people newly diagnosed with HIV in 2011 were Asian (Centers for Disease Control and Prevention, 2012b, 2013). However, the number of new HIV diagnoses in Asians has increased by 247% from 2006 to 2011; from 332 new diagnoses in 2006 to 821 new diagnoses in 2011 (Centers for Disease Control and Prevention, 2009, 2013). Yet this number may not capture the whole picture of the dramatic rise in HIV incidence among Asians, because the proportion of Asians tested for HIV was lower in this time period than for that of any other racial group (Schiller, Lucas, Ward, & Peregoy, 2012).

Stigma is defined as “The phenomenon whereby an individual with an attribute is deeply discredited by his/her society and is rejected as a result of the attribute. Stigma is a process by
which the reaction of others spoils normal identity (Goffman, 1963, p.3).” HIV stigma can be characterized as prejudice against, discrimination toward, and discrediting people living with HIV and the groups and communities they associate with (Herek & Capitanio, 1997). The Berger Stigma Scale has been tested in several different populations in the U.S as well as abbreviated and culturally adapted to Spanish-speaking populations; however the scale has never been applied or tested in ALH (Franke et al., 2010; Jimenez et al., 2010; Wright, Naar-King, Lam, Templin, & Frey, 2007).

**Research Methodology**

**Study Design**

This study utilized mixed methods to revise and test the reliability and validity of a Stigma Scale for ALH. Using a combination of qualitative and quantitative methods is a preferred and common research method for instrument development (O'Cathain, Murphy, & Nicholl, 2007; Polit & Beck, 2003). Building on findings from a qualitative study, which is good for exploratory research, with quantitative study can verify and enhance the findings. This study had three phases; Phase 1) face-to-face interviews for scale exploration, Phase 2) focus groups for adaptation, and Phase 3) a cross-sectional study for psychometric properties evaluation. The Institution on Human Research at the University of California, San Francisco approved all phases of this study.

**Phase 1: exploration.** Face-to-face interviews were conducted to understand barriers to receiving HIV care and to explore HIV stigma experienced by ALH. Participants were asked about their past perceptions of HIV risks or behaviors and current experiences of living with HIV, with particular emphasis on the influence that their culture, beliefs, and HIV stigma have on
seeking HIV-related care. Additional items to measure ALH stigma were generated by the data from interviews and an intensive review of the literature.

**Phase 2: adaptation.** The main purpose of Phase 2 was to adapt the abbreviated Berger Stigma Scale by adding the new items that emerged from Phase 1 and testing the validity with expert reviews and focus groups. First, potential new items for the Stigma Scale for ALH were reviewed by experts to assess the face validity of the scale. After the items were modified as needed, a draft of the Stigma Scale for ALH was explored in two focus groups to assess its content validity and the acceptability of the scale. Focus group methodology allows the researcher to explore, seek verification, receive feedback, clarify the feedback by asking questions, and engage in a discussion, which individual qualitative interviews usually do not provide (Krueger & Casey, 2000; Nassar-McMillan, Oliver-Hoyo, & Ryder-Burge, 2010). Concepts of the scale were discussed in the first focus group, and then the final draft of the revised scale was discussed for confirmation in the second focus group. The scale was modified as needed at each step.

**Phase 3: psychometric properties evaluation.** The validity and reliability of the new scale was established in this phase. The Stigma Scale for ALH was utilized in a cross-sectional survey among ALH. In order to develop convergent validity of the scale, we explored the correlation between the adapted stigma scale and the self-rated health status scale which measuring the same construct of the Stigma Scale for ALH.
Setting and Sample

All phases of this study took place in an HIV-related community organization in San Francisco. The organization provided services including HIV care to un-insured and under-insured ALH. Criteria for inclusion for all Phases were (a) self-identify as a HIV positive, (b) self-identify as an Asian, (c) being 18 years or order, and (d) being able to speak and read in English. For Phase 1, in addition to these criteria, participants had to identify as being diagnosed with HIV through unintentional testing, such as opt-out testing in an emergency department, having an AIDS diagnosis, or receiving an HIV diagnosis through prenatal care. We established the criterion, finding out their HIV infection through unintentional testing, because individuals who delayed being tested for HIV prior to their HIV diagnosis may have faced a barrier to receiving HIV care (Valdiserri, 2002). For Phases 2 and 3, in addition to the above criteria participants had to have disclosed their HIV status to at least one other person since the HIV stigma scale had the items regarding to reactions toward disclosures.

For Phase 1, interviews with ALH were continued until data saturation was achieved. This technique is commonly seen in the grounded theory approach (Glaser & Strauss, 1967). For Phase 2, the number of experts needed to review new items ranged from three to 10. The number of participants for focus groups was four to 12 individuals (Krueger & Casey, 2000). The sample size for Phase 3 was determined by use of the adequate rule of thumb, a person-to-item ratio of 5:1, in order to reduce the possibility of sampling error (DeVellis, 2003; Nunnally & Bernstein, 1994). The final version of the Stigma Scale for ALH contained 13 questions. Therefore, the cross-sectional study for Phase 3 included 65 ALH.
Measurement

Participants in Phase 3 were asked to answer sociodemographic characteristics questionnaires as well as several others including:

**Stigma Scale for Asians Living with HIV.** A 10-item, abbreviated HIV Stigma Scale developed by Wright (2007) was used for adaptation. This scale was a short version of the Berger Stigma Scale, which in its original form contained 40 items (Berger et al., 2001). Since a majority of ALH are foreign-born and speak English as a second language, the burden of a 40-item scale may be an obstacle to this population (Centers for Disease Control and Prevention, 2012a). The abbreviated scale has only 10 items with four subscales which include: personalized stigma, disclosure, negative self-image, and public attitudes. The scale has been validated in HIV positive youth (Wright et al., 2007). Overall, the abbreviated HIV Stigma Scale has good reliability and validity as do its subscales, which each have a Cronbach’s α of .72 (Wright et al., 2007). In addition, good convergent and construct validity were demonstrated by expected bivariate correlations between the abbreviated HIV Stigma Scale and psychosocial variables, such as brief symptom inventory and social support (Wright et al., 2007).

**Self-rated health status scale.** Participants were also asked to rate their current health status for establishing convergent validity (Nunnally & Bernstein, 1994). They were asked the question “How would you rate your health status?” The response was measured on a 7-point Likert scale anchored with responses, *very poor* (1) to *excellent* (7). A recent study showed that the HIV stigma negatively associated to their self-reported general health status (Emlet et al., 2013).
Analysis

**Phase 1: exploration.** Grounded theory developed by Glaser and Strauss (1967) was used as a methodology to guide and analyze interviews. Each in-depth interview was followed by coding, then categorizing these codes into larger concept areas. Coding and categorizing were done immediately after each interview. For future interviews, these categories were compared to see if upcoming data fit with existing categories (Holloway & Wheeler, 2002). These processes were continued until the gaps between each of the categories and concepts were filled to create the final themestheory (Charmaz, 2006, 2007). All interviews were recorded with a digital voice recorder, and field notes were taken with the participants’ permission. ATLAS.ti Version 6 was used for analyzing the interviews.

**Phase 2: adaptation.** In this phase, face and content validity of the revised scale was established through reviews by experts and focus groups. The additional items to be added to the abbreviated HIV Stigma Scale were assessed for content validity by six experts. Experts in diverse areas of research and health care (N = 6) were asked to evaluate the new items on the scale by using the Content Validity Index by Waltz and Bausell (Waltz & Bausell, 1981). In addition, two focus groups of ALH were conducted to gather information on the content validity of the scale. At each focus group, we went over each new item one-by-one with the group by asking about the clarity and relevance of the new items as well as concepts of the scale as a whole. Then, the revised scale, consisting of the original abbreviated HIV Stigma Scale and three new items for the Stigma Scale for ALH, was read out loud in order to walk group participants through the entire scale.
The data from the focus groups were analyzed with the tape-based approach. This approach involves reviewing a focus group’s discussion that was captured by a recorded device and transcribing only the portion of discussion that is relevant to the study’s purpose (Krueger & Casey, 2000). For data analysis, the notable statements made by participants were coded and evaluated for consistency with themes and categories.

**Phase 3: psychometric properties evaluation.** Descriptive statistics were generated for the frequency and demographics of the study sample. Cronbach’s α was determined to establish internal consistency and the reliability of the abbreviated HIV Stigma Scale and the overall scale and subscales of the Stigma Scale for ALH (Nunnally & Bernstein, 1994).

Exploratory factor analysis (EFA) with varimax rotation was used to examine construct validity of the scale and to determine the best items for use in the final scale. Factors were evaluated based on whether they met a criterion of eigenvalue > 1, and breakpoints on the Scree Test (plotted graph) of eigenvalue were applied to determine meaningful factors and extraction of items (Kleinbaum, Kupper, & Muller, 1998). A variable was considered highly correlated with the particular factor and remained in the scale if loading values were equal or more than 0.55 for that factor and less than 0.55 for other factors (Comrey & Lee, 1992). Each factor was labeled as necessary. A comparison of the psychometric properties of both the Stigma Scale for ALH and the abbreviated HIV Stigma Scale was explored for reliability and validity analyses. Convergent validity was established by evaluating Pearson correlation coefficients for the total stigma scale and self-reported health status scale. All analyses were performed by using IBM® SPSS® Statistics v.19 for Windows.
Results

Five, in-depth, face-to-face interviews were conducted in a private room in Phase 1. Each interview took approximately an hour. The mean age of participants was 48.2 years old. Four participants were male, three Vietnamese, and one Filipino or Indonesian. All were born in Asia and had lived in the U.S. an average of 24.4 years. Of these, two reported either injection drug use (IDU) or being a man who has sex with men (MSM) as their primary risk for HIV infection. One participant reported their risk as heterosexual contact. Analysis of the interviews resulted in three major thematic areas that were unique to Asian cultures and may have affected these participants’ process of avoiding HIV care. These themes were HIV disclosure, family and friends’ reactions, and gossiping. Three statements emerged from the interviews: (a) I did/do not tell my parents my HIV status, because I do not want them to think I am not a good kid anymore, (b) I feel more distance from my family since I disclosed my HIV status to them, and (c) I have somebody who might know my HIV status, but I am afraid to ask if he/she knows.

In Phase 2, content validity for these three possible items was assessed by six doctoral-prepared clinical or/and research experts. These experts were 1) two medical doctors who specialize in racial minorities living with HIV, 2) a research psychologist specializing in Transgender and PLHIV in Asian, 3) a research psychologist specializing in HIV prevention among API and the members of the Banyan Tree Project, 4) a nursing professor who is specialized in intravascular drug users who living with HIV, and 5) a professor who is content experts and survey expert.

A total of 11 ALH participated in focus groups that each lasted about one and half hours (first focus group $n = 4$). The mean age was 46.8 years old ($SD \pm 2.4$) for the first focus group
and 48.7 years old ($SD \pm 6.1$) for the second. Participants were either male ($n = 9$) or transfemale ($n = 2$) and included participants who were Filipino ($n = 4$), Indonesian ($n = 3$), and Chinese ($n = 2$).

At the first focus group, participants shared their thoughts and comments on new items in the Stigma Scale for ALH. They were asked about the clarity of the wording and if these items captured the HIV stigma they experienced. Their feedback included that their preference was for a more specific word that indicated a person close to them instead of the broad term *somebody*. Therefore, *somebody* was changed to *a friend or family member*. Participants were especially concerned about the lack of HIV knowledge in their community and among their family and friends, and expressed the importance of including an item about this issue in the revised scale. After the first focus group, the questions were revised and reviewed again for content validity by experts. The three revised items generated by this review were: (a) *I disappointed my family and feel more distance from them since telling them I have HIV*, (b) *I have a friend or family member who might know I am HIV positive, but I am afraid to ask and find out for sure*, and (c) *most people do not have enough HIV knowledge to understand me*.

At the second focus group, the 13 items on the Stigma Scale for ALH, including the three new items that came out of this study and the ten items taken directly from the abbreviated HIV Stigma Scale, were reviewed by study participants to establish face and content validity. They all agreed the new stigma scale capture HIV stigma and the ALH experience well. The final draft of the HIV Stigma Scale for ALH was finalized to test in Phase 3.

For the psychometric properties evaluation, a total of 88 individuals were recruited for the study. Sixty-seven ALH who met the inclusion criteria completed a self-administered survey.
The mean age was 44.4 years old ($SD \pm 9.5$; see Table 1). More than one third of participants ($n = 30$, 44.8%) were Filipino. The majority of them were born in Asia ($n = 40$, 59.7%). More than three quarters were male ($n = 52$, 77.6%) and reported they got HIV through having sex with men ($n = 53$, 79.1%). Approximately two thirds of participants ($n = 42$, 62.7%) reported less than $20,000$ in household annual income before taxes.

Cronbach’s $\alpha$ calculating by applying the abbreviated HIV Stigma Scale in the current study sample and the Stigma Scale for ALH are shown in Table 2. The table also contains Cronbach’s $\alpha$ obtained from original studies on the Berger Stigma Scale and the abbreviated HIV Stigma Scale (Berger et al., 2001; Wright et al., 2007). The Cronbach’s $\alpha$ for the Stigma Scale for ALH is 0.92, which is higher than one of the 10-item original abbreviated HIV Stigma Scale applying in our study sample ($\alpha = 0.90$). Internal consistency reliability also remains high for all subscales; Cronbach’s $\alpha$ ranged from 0.83 to 0.90 among the subscales.

Exploratory factor analysis found that the modified scale had three factors despite the abbreviated HIV Stigma Scale having four (Table 3). This study found that the Stigma Scale for ALH had no factor differences as compared to items on the personalized stigma and disclosure subscales from the original stigma scale. We renamed the subscales personalized stigma/disclosure. All items directly taken from the abbreviated HIV Stigma Scale had high loading values of more than 0.65. Loading values on the three new items on the Stigma Scale for ALH were 0.57, 0.67, and 0.77.

Factor 1 (personalized stigma/disclosure) explained 51.3% of total variance, while Factor 2 (negative self-image) explained 10.3% and Factor 3 (public attitudes) explained 9.2% of the variance. These three factors explained 70.8% of the total variance of the Stigma Scale for ALH.
All 13 items loaded in any of these three factors. Two of the new items, *I disappointed my family and feel more distance from them since telling them I have HIV and I have a friend or family member who might know I am HIV positive, but I am afraid to ask and find out for sure*, belonged to the **personalized stigma/disclosure** subscale. *Most people do not have enough HIV knowledge to understand me* belonged to the **public attitudes** subscale. All inter-item correlations exceed 0.3 and three-fourth of them were between 0.4 and 0.7.

The total score on the revised stigma scores negatively correlated to self-reported health rate \((r = -0.358, p = .003)\). Significant correlations were found on the subscales for personalized stigma/disclosure and negative self-image \((r = -0.411, p = .001 \text{ and } r = -0.272, p = .026)\) respectively) but not on the public attitudes subscale \((r = -0.110, p = .375)\).

**Discussion**

The purpose of this study was to modify an existing HIV Stigma Scale to be culturally appropriate for Asian populations. This study adapted the abbreviated HIV Stigma Scale by Wright to ALH. The abridged scale, Stigma Scale for ALH, contains 13 items, 10 from the Abbreviated Stigma Scale and 3 new items.

The Stigma Scale for ALH has three subscales with good internal consistency reliability. The new scale captures adequate responses with appropriate variance, and items were not redundant. The new items identified by individual interviews and focus groups enhance the internal consistency of the revised scale and are culturally appropriate for ALH.

Our findings suggest that the Stigma Scale for ALH has three factors that are distinct from the abbreviated HIV Stigma Scale, which had four factors. Even though items on two
factors out of four were combined, other items loaded the way the scale originally was proposed in the abbreviated HIV Stigma. All ten items adapted from the abbreviated HIV Stigma Scale had strong factor loadings of above 0.65, and those for new items were above 0.57. These findings revealed that the newly developed scale still had strong factor loading even after adaptation.

In terms of comparison, two out of ten factor loadings were higher in the Stigma Scale for ALH than in the abbreviated HIV Stigma scale and two were the same in both scales. The loading value ranges were from 0.57 to 0.85 for the Stigma Scale for ALH and 0.70 to 0.86 for the abbreviated HIV Stigma Scale. The loading values for new items were 0.57, 0.67, and 0.77. These correlation coefficient values show that we cannot say one is better than another, yet expert reviews, focus groups, and the factor analysis showed good content and constant validity of the Stigma Scale for ALH. Moreover, the convergent validity of the scale was established by finding the strong negative relationship between self-rated general health status and the total stigma score. This finding is consistent with prior research findings (Emlet et al., 2013).

In conclusion, these findings on psychometric properties evaluation of the Stigma Scale for ALH revealed good reliability and validity of the scale. Numerous studies have found that HIV stigma related to poor physical health outcomes since stigmatized people living with HIV were more likely to have lower antiretroviral treatment adherence and did not seek and receive health care (Cahill & Valadéz, 2013; Mengistu & Chere, 2012; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012). Racial minorities in the U.S. are less likely to receive appropriate HIV care, and HIV stigma may be one of the main barriers to care (Saint-Jean, Dévieux, Malow, Tammara,
& Carney, 2011). It is important for health care providers to understand the quality and quantity of HIV stigma so they can provide appropriate HIV care to racial minorities living with HIV.

This study has some limitations. Asian includes a wide variety of ethnic populations with a number of different cultures, belief systems, and languages; thus, this scale might not be sensitive enough for such a diverse racial group (Centers for Disease Control and Prevention, 2012a). Another limitation is that this study included only Asians who could read and speak in English. Recent immigrants and monolingual Asians were excluded from the study. Finally, participants for all study phases were recruited at a HIV community based organization and all were un-insured or under-insured. This population may not represent other ALH well. Despite these limitations, this is the first study to establish a culturally sensitive HIV stigma scale for Asians living with HIV.

Stigma of racial minorities with HIV is stronger than stigma of Caucasians with HIV (Bogart et al., 2011; Rajabiun et al., 2008), yet no study has measured HIV stigma with culturally appropriate HIV stigma scale in ALH. Culturally appropriate HIV-related care delivery and HIV stigma are an especially concerning problem for ALH since most ALH are foreign-born (Centers for Disease Control and Prevention & National Center for HIV/AIDS, 2012). The stigma they experience might differ from the stigma others experience. It is important to measure ALH level of stigma with the culturally adapted stigma scale to understand their stigma experience and provide culturally appropriate care.
Table 1: Sociodemographic and self-reported health level scale for Phase 3 (*N* = 67)

<table>
<thead>
<tr>
<th>%/(N), Mean±SD</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic</strong></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10.4(7)</td>
</tr>
<tr>
<td>Male</td>
<td>77.6(52)</td>
</tr>
<tr>
<td>Transfemale</td>
<td>11.9(8)</td>
</tr>
<tr>
<td>Age</td>
<td>44.4 ± 9.5</td>
</tr>
<tr>
<td>Asian Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>12.0(8)</td>
</tr>
<tr>
<td>Filipino</td>
<td>44.8(30)</td>
</tr>
<tr>
<td>Japanese</td>
<td>12.0(8)</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>10.4(7)</td>
</tr>
<tr>
<td>Others</td>
<td>21.0(14)</td>
</tr>
<tr>
<td>Generation</td>
<td></td>
</tr>
<tr>
<td>1st generation (born in Asian)</td>
<td>59.7(40)</td>
</tr>
<tr>
<td>2nd generation</td>
<td>25.4(17)</td>
</tr>
<tr>
<td>3rd generation</td>
<td>7.5(5)</td>
</tr>
<tr>
<td>Others</td>
<td>7.5(5)</td>
</tr>
<tr>
<td>Household annual income</td>
<td></td>
</tr>
<tr>
<td>≤ $20,000</td>
<td>62.7(42)</td>
</tr>
<tr>
<td>$20,001-40,000</td>
<td>19.4(13)</td>
</tr>
<tr>
<td>$40,001-75,000</td>
<td>6.0(4)</td>
</tr>
<tr>
<td>Don’t know/Decline to state</td>
<td>12.0(8)</td>
</tr>
<tr>
<td>HIV exposure category</td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>79.1(53)</td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>1.5(1)</td>
</tr>
<tr>
<td>IVDU</td>
<td>4.5(3)</td>
</tr>
<tr>
<td>IVDU+MSM</td>
<td>7.5(5)</td>
</tr>
<tr>
<td>Other/unknown</td>
<td>7.5(5)</td>
</tr>
<tr>
<td><strong>Mean Self-reported Health Level</strong>¹</td>
<td>4.9 ± 1.7</td>
</tr>
<tr>
<td>1: very poor</td>
<td>4.5(3)</td>
</tr>
<tr>
<td>2:</td>
<td>3.0(2)</td>
</tr>
<tr>
<td>3:</td>
<td>11.9(8)</td>
</tr>
<tr>
<td>4:</td>
<td>22.4(15)</td>
</tr>
<tr>
<td>5:</td>
<td>17.9(12)</td>
</tr>
<tr>
<td>6:</td>
<td>17.9(12)</td>
</tr>
<tr>
<td>7: excellent</td>
<td>22.4(15)</td>
</tr>
</tbody>
</table>

¹ Possible ranges from 1(*very poor*) to 7(*excellent*).
Table 2: Reliability Coefficients for Overall Scale and Subscales

<table>
<thead>
<tr>
<th></th>
<th>Abbreviated HIV Stigma Scale among ALH</th>
<th>Stigma Scale for ALH</th>
<th>Berger Stigma Scale</th>
<th>Abbreviated HIV Stigma Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>0.90</td>
<td>0.92</td>
<td>0.96(^1)</td>
<td>0.80(^2)</td>
</tr>
<tr>
<td>Subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized stigma</td>
<td>0.87</td>
<td>0.90</td>
<td>0.93(^1)</td>
<td>0.75(^2)</td>
</tr>
<tr>
<td>Disclosure</td>
<td>0.82</td>
<td></td>
<td>0.90(^1)</td>
<td>0.73(^3)</td>
</tr>
<tr>
<td>Negative self-image</td>
<td>0.86</td>
<td>0.86</td>
<td>0.91(^1)</td>
<td>0.84(^3)</td>
</tr>
<tr>
<td>Public attitude</td>
<td>0.80</td>
<td>0.83</td>
<td>0.93(^1)</td>
<td>0.72(^2)</td>
</tr>
</tbody>
</table>


Table 3: Factor Analysis

<table>
<thead>
<tr>
<th>Statement</th>
<th>Abbreviated HIV Stigma Scale</th>
<th>Abbreviated HIV Stigma Scale</th>
<th>Abbreviated HIV Stigma Scale</th>
<th>Abbreviated HIV Stigma Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have stopped socializing with some people because of their reactions of my having HIV (1)*.</td>
<td>0.85</td>
<td>0.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have lost friends by telling them I have HIV (1)*.</td>
<td>0.81</td>
<td>0.81</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have been hurt by how people reacted to learning I have HIV (1)*.</td>
<td>0.72</td>
<td>0.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am very careful who I tell that I have HIV(2)*.</td>
<td>0.76</td>
<td>0.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I disappointed my family and feel more distance from them by telling them I have HIV.</td>
<td></td>
<td></td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>I worry that people who know I have HIV will tell others (2)*.</td>
<td>0.70</td>
<td>0.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a friend or family who might know I am HIV positive, but I am afraid to ask and find out for sure.</td>
<td></td>
<td></td>
<td>0.57</td>
<td></td>
</tr>
<tr>
<td>Having HIV makes me feel unclean (3)*.</td>
<td>0.85</td>
<td>0.83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I am not as good a person as others because I have HIV (3)*.</td>
<td>0.81</td>
<td>0.83</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having HIV makes me feel that I’m a bad person (3)*.</td>
<td>0.81</td>
<td>0.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Most people with HIV are rejected when others find out (4)*.</td>
<td></td>
<td></td>
<td>0.86</td>
<td>0.84</td>
</tr>
<tr>
<td><strong>Most people do not have enough HIV knowledge to understand me.</strong></td>
<td></td>
<td></td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>Most people think that a person with HIV is disgusting (4)*.</td>
<td></td>
<td></td>
<td>0.80</td>
<td>0.76</td>
</tr>
</tbody>
</table>

**Bold items were new to the Stigma Scale for ALH.**

*Original subscale assignment.*
References


Level of HIV Stigma Experienced by Asians Living with HIV: the influence of acculturation and general health outcome

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Carol Dawson-Rose, PhD, RN, FAAN
Previous studies have reported the challenges of the HIV stigma among people living with HIV (PLHIV) (Andrinopoulos et al., 2011; Audet, McGowan, Wallston, & Kipp, 2013; Gonzalez, Weibust, Miller, & Solomon, 2011; Tanney, Naar-King, & MacDonnel, 2012; Varni, Miller, McCuin, & Solomon, 2012). Stigmatized PLHIV often feel anger, shame, blame, fear, and self-hatred, and these feeling can result in depression, hopelessness, anxiety, and low self-esteem (Emlet, 2006; Lee, Kochman, & Sikkema, 2002; Tanney et al., 2012; Varni et al., 2012). Individuals who experience HIV stigma often report low antiretroviral therapy adherence, concealment their HIV status, barriers to engaging in health care or taking HIV tests, and engagement in unprotected sexual activities (Cahill & Valadéz, 2013; Emlet, 2008; Mengistu & Chere, 2012; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012). Also, in comparison with non-stigmatized PLHIV, stigmatized PLHIV have more mental health and HIV-related symptoms (Vanable, Carey, Blair, & Littlewood, 2006).

*Double stigma*, HIV stigma and second stigma like racism, is often reported by people living with HIV (PLHIV). They are stigmatized due to their sexuality, racial group, age, gender, and other chronic illnesses they have in addition to HIV (Cahill & Valadéz, 2013; Daftary, 2012; Emlet, 2006; Mawar, Saha, Pandit, & Mahajan, 2005; "Older HIV patients deal with the double stigma of having the disease and being old. Big worry: 'Will I get to see grandkids if I tell?'"," 2007; Van Hollen, 2010). For example, racial minorities living with HIV compared with Caucasians living with HIV report stronger HIV stigma (Bogart et al., 2011; Rajabiun et al., 2008). A recent study found stronger HIV stigma in immigrants living with HIV than those of non-immigrants living with HIV (Sumari-de Boer et al., 2012; Vanable et al., 2006). Even though several qualitative studies found that Asians living with HIV (ALH) experience strong
HIV stigma, no study to date has investigated the level of HIV stigma with a culturally appropriate HIV stigma scale.

HIV stigma and culturally appropriate HIV-related care delivery are especially concerns and problem in ALH. Since most ALH are foreign-born, their acculturation, English language proficiency, immigration status, and socioeconomic status create challenges for health care providers trying to deliver culturally appropriate HIV-related care (Centers for Disease Control and Prevention & National Center for HIV/AIDS, 2012). The level of HIV stigma experienced by immigrants or less acculturated racial minorities living with HIV might depend on their level of acculturation; however, this has not been well studied yet (Sumari-de Boer et al., 2012; Vanable et al., 2006).

Some studies have found that stigmatized PLHIV were more likely to have poor health outcomes than were non-stigmatized PLHIV (Sumari-de Boer et al., 2012; Vanable et al., 2006). Few studies look at the health outcomes of racial minorities living with HIV, but one such study found that racial minorities living with HIV had better health outcomes than one in Caucasian living with HIV (Rajabiun et al., 2008). Since racial minorities are more likely to experience stronger stigma than racial majorities, in contrast to a study by Rajaiun (2008) other studies found that PLHIV who experience stigma are more likely to report poor health outcome than those who are not stigmatized (Bogart et al., 2011; Rajabiun et al., 2008; Sumari-de Boer et al., 2012; Vanable et al., 2006). Thus, the relationship between HIV stigma and health outcome among ALH who include immigrants is still not cleared from the current available studies.

Although HIV has received a great deal of attention from researchers in the past two to three decades, little is known about HIV stigma in ALH. The current study explore (a) the level
of HIV stigma experienced by ALH, (b) the association of the level of HIV stigma and acculturation and (c) how the HIV stigma influences self-rated general health in ALH.

**Literature Review**

Racial minorities in the US are less likely to receive appropriate HIV care. Stigma associated with a HIV diagnosis is one of the cultural reasons why they face barriers to HIV-related care (Saint-Jean, Dévieux, Malow, Tammarra, & Carney, 2011). HIV stigma is rooted in multiple factors; some causes of the stigma (e.g., fear of HIV contagion) are universal, but others vary from culture to culture or population to population (Hong et al., 2008). The differences may be influenced by societal values, beliefs, or local HIV epidemics (Parker & Aggleton, 2003). Current study has revealed differences in the level of HIV stigma among people with different sociodemographic characteristics (Cahill & Valadéz, 2013). Several studies have measured the level of HIV stigma experienced by different racial, age, and sexual preference groups (e.g., youth, elders, women of childbearing age, African American men who have sex with men) (Audet et al., 2013; Bogart et al., 2011; Craft, Delaney, Bautista, & Serovich, 2007; Galvan, Davis, Banks, & Bing, 2008; Gonzalez et al., 2011; Grov, Golub, Parsons, Brennan, & Karpiak, 2010; Martinez et al., 2012). In particular, investigators have explored the levels of HIV stigma experienced by several different populations of PLHIV in the US using the Berger HIV Stigma Scale, which has been adapted and validated in populations such as HIV-positive youth and Puerto Ricans (Jimenez et al., 2010; Wright, Naar-King, Lam, Templin, & Frey, 2007). However no study found in adapting the scale among ALH or utilizing the scale to measure the level of HIV stigma experienced by ALH.
Factors influencing HIV stigma, such as depression, sexual orientation or antiretroviral therapy adherence, have been explored by recent researches (Andrinopoulos et al., 2011; Audet et al., 2013; Varni et al., 2012). However, we do not know much about how the HIV stigma is influenced by acculturation among immigrants or racial minorities living with HIV (Cahill & Valadéz, 2013; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Vanable et al., 2006). A study in the US found no correlation between acculturation and HIV stigma; however, other studies found relationships between these variables (Chiapa, 2006; Rajabiun et al., 2008; Sumari-de Boer et al., 2012; Vanable et al., 2006). Rajabium (2008) found that PLHIV interviewed for the study in a language other than English were more likely to have high HIV-related stigma (Rajabiun et al., 2008). Other studies which compared HIV stigma between immigrants and non-immigrants living with HIV found the stronger HIV stigma in immigrants living with HIV than non-immigrants (Sumari-de Boer et al., 2012; Vanable et al., 2006).

Previous studies found the association of HIV stigma toward health outcomes (Sumari-de Boer et al., 2012; Vanable et al., 2006). Vanable et al. (2006) studied in the relationship between the current health status and HIV stigma experience among PLHIV and found that PLHIV who reported more number of HIV-related symptoms were more likely to experience HIV stigma (Vanable et al., 2006) than those who reported less number of HIV-related symptoms. In addition, Sumari-de et al (2012) used objective data, such as plasma HIV viral load values and antiretroviral medication refill rate obtained from pharmacies, to measure their health outcomes among PLHIV. They found that HIV stigma was related to their antiretroviral medications adherence and HIV viral load – stigmatized PLHIV compared to non-stigmatized PLHIV were
more likely to have low adherence rate and detectable HIV viral load (Sumari-de Boer et al., 2012; Vanable et al., 2006).

Despite of these available researches, no study to date has measuring the level of HIV stigma with a culturally appropriate scale among ALH. In addition, we do not know how the HIV stigma correlates with the acculturation and health outcome in immigrants or racial-minorities living with HIV. The purpose of this current study is to explore the level of HIV stigma experienced by ALH and the influence of the HIV stigma toward the acculturation and health outcomes.

Methods

Procedure and Sample

The current study’s procedure and sample have been previously published (Kamitani, Fukuoka, & Dawson-Rose, In Progress). Potential participants were recruited via flyers, clinician referrals, and announcements to monthly support groups at an HIV-related community organization in San Francisco from November 2012 to June 2013. The organization provided services including HIV care to un-insured and under-insured Asians. Eight-eight ALH were screened for eligibility of this study. Inclusion criteria for this study were (a) self-identified as HIV-positive, (b) racial self-identification as Asian, (c) 18 years old of age or older, (d) able to speak and read in English, and (e) to have disclosed their HIV status to at least one other person. Sixty-seven ALH who met all inclusion criteria and provided written consent were asked to complete cross-sectional survey in the presence of a researcher. The study received IRB approval from University of California, San Francisco prior to the subject enrollment.
Instruments

Sociodemographics characteristics and food security. Study participants completed a self-administered survey including sociodemographic characteristics data. Participants were also asked a food security’s question adapted from guide to measuring household food security from U.S. Department of Agriculture Food and Nutrition Service (Bickel, Nord, Price, Hamilton, & Cook, 2000). The question was “in the last 6 months, were you ever hungry but didn’t eat because there wasn’t enough money for food?” Responses were recorded based on the 5-Likert scales, with scores from always (1) to never (5). Lower scores indicated less degree of food security.

HIV stigma. A culturally adapted shortened version of the Berger Stigma Scale was chosen for this study (Berger, Ferrans, & Lashley, 2001). The group of Wright (2007) shortened the Berger Stigma Scale, which including 40 items, and developed the Abbreviated Stigma Scale which including only 10 items with four subscales (Wright et al., 2007). The abbreviated scale showed good reliability; each subscale measured Cronbach’s α > 0.72 (Wright et al., 2007). A culturally adapted version of the abbreviated Stigma Scale, called the Stigma Scale for ALH, was developed and tested in our previous study (Kamitani, Chen, Tokumoto, Portillo, & Dawson-Rose, In progress). The study showed good reliability and validity in the overall stigma scale and three subscales which were (a) personalized stigma/disclosure, (b) negative self-image, and (c) public attitude (Kamitani, Chen, et al., In progress). The scale had good internal validity, with Cronbach’s α of 0.92. Each subscale also had good internal validity as Cronbach’s α of 0.90 for personalized stigma/disclosure, 0.86 for negative self-image, and 0.83 for public attitude.
The response choices in the Stigma Scale for ALH were strongly disagree (1), disagree (2), agree (3), and strongly agree (4). The scores were calculated by total means—summing up the scores on each response and dividing this sum by the number of questions. The scores ranged from one to four. Each three subscale scores were also calculated by the same process. Higher scores indicate individuals experience more stigma.

**Acculturation.** The abbreviated Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA) was applied to measure acculturation in the sample (Suinn, Ahuna, & Khoo, 1992). The abbreviated SL-ASIA includes 19 multiple choice questions (Suinn et al., 1992). Multiple answer choices were formatted on a 5-point Likert scale. In scoring the scale, the values for all 19 items are totaled. The scores are range from 19 to 76, and low scores reflect low acculturation (high Asian identification); high scores reflect high acculturation (high Western identification). This scale has good reliability in this study sample as Cronbach’s α of 0.93.

**Self-rated general health.** To obtain their current self-reported general health status, participants were asked to rate their current health status with the question, “How would you rate your health status?” (Eriksson, Undén, & Elofsson, 2001). Responses were measured on a 7-point Likert scale anchored with scores very poor (1) to excellent (7).

**Data Analysis**

Descriptive statistics were applied to describe the study sample’s sociodemographic characteristics. Mean scores with standard deviations (SD), medians with 25th and 75th interquartile ranges (IQR), and midpoints with possible ranges were computed for both the overall scale and subscales on the Stigma Scale for ALH. Means and SD along with midpoints
with possible ranges were also calculated for both the abbreviated SL-ASIA and self-rated general health.

To assess the associations of HIV stigma to acculturation and self-rated general health, Pearson correlations was utilized. The correlation were determined between overall and subscale on the Stigma Scale for ALH and (a) the abbreviated SL-ASIA and (b) self-rated general health scales. A $p$-value less than 0.05 was considered statistically significant for this exploratory study. All data analysis was conducted by using IBM® SPSS® Statistics v.19 for Windows.

**Results**

**Sociodemographic Characteristics**

Sixty seven ALH took the self-administered survey at the HIV-related organization facility in the presence of a researcher. People who were not eligible for the study were unable to speak or read in English, did not self-report as HIV-positive, or were non-Asian. The majority of the study participants were male or transmale (77.6%) and immigrants (born in Asian; 59.7%), reported less than $20,000 in household annual income (62.7%), and exposed to HIV as men having sex with men (79.1%; see Table 1). About 45% of participants were Filipino. The mean age was 44.4 years old ($SD \pm 9.5$).

**HIV Stigma, Acculturation, and Self-rated General Health**

As seen in Table 2, the mean of the overall scale on the Stigma Scale for ALH was 2.5 ($SD \pm 0.7$) with total scores ranged from one to four. The means for each subscale were 2.6 ($SD \pm 0.8$) for personalized stigma/disclosure, 2.1($SD \pm 0.8$) for negative self-image, and 2.7 ($SD \pm 0.8$) for public attitude. The overall total median ($Median = 34, 25^{th}-75^{th} IQR = 29-39$) and total
mean ($M = 32.8, SD \pm 9.0$) scores were higher than the midpoint of the scale (32.5). In terms of subscales, total median scores on personalized stigma/disclosure ($Median = 19, 25^{th}-75^{th} IQR = 15-22$) and public attitude ($Median = 8, 25^{th}-75^{th} IQR = 7-10$) were also lower than the midpoint of the subscales (17.5 for personalized stigma/disclosure and 7.5 for public attitude).

The mean for the abbreviated SL-ASIA in this study sample was 53.5 ($SD \pm 15.5$) with total scores ranged from 19 to 76 (Table 3). The mean was below midpoint of the scale (47.5). In terms of the self-rated general health, the mean was 4.9 ($SD \pm 1.7$), with a range of very poor (1) to excellent (7). More than 80% of the study sample reported their health was average or better. Moreover, 22.4% of the study sample reported that their health was “excellent”.

**Correlation of HIV Stigma with Acculturation and Self-rated General Health**

Overall score on the Stigma Scale for ALH were significant negatively correlated with one on the abbreviated SL-ASIA ($r = -0.33, p = .006$; Table 4). A sample of ALH who had high levels of Asian identification was more likely to experience stronger stigma than ALH who had high levels of Western identification. In terms of subscale, only personalized stigma/disclosure was significantly correlated with acculturation ($r = -0.37, p = .002$). Neither negative self-image nor public attitude significantly correlated with acculturation ($r = -0.22, p = .07$ and $r = -0.14, p = .25$ respectively).

Stigma was significant negatively correlated with self-rated general health ($r = -0.36, p = .003$). ALH who experienced stronger stigmatization were more likely to report poor health than those who experienced weaker stigmatization. Personalized stigma/disclosure ($r = -0.41, p$
negative self-image ($r = -0.27$, $p = .03$) were significantly correlated with self-rated general health, but not public attitude ($r = -0.11$, $p = .38$).

**Conclusion**

The purpose of this study was to explore the level of HIV stigma held by ALH and how the HIV stigma influence acculturation or self-rated general health among immigrants or racial minorities living with HIV. Our study found that strong HIV stigma is often reported by ALH. They were especially stigmatized related to public attitude, personalized stigma or disclosure. Our study also found that HIV stigma was negatively associated with acculturation and self-rated general health.

No study in the past has utilized the culturally appropriate HIV stigma scale to measure the level of HIV stigma experienced by ALH, though the group of Tanny (2012) used the abbreviated HIV Stigma Scale to explore the level of HIV stigma experienced by youth living with HIV. The abbreviated scale was the one from which the Stigma Scale for ALH was modified. The study by Tanney (2012) showed a lower mean score ($M = 2.4$, $SD \pm 0.6$) than the mean generated by our study (Tanney et al., 2012). Another study used the acculturated Berger HIV Stigma Scale to explore the level of HIV stigma among Puerto Ricans. They reported an total median overall score that was slightly lower than the midpoint of the scale (Jimenez et al., 2010). Similarly, a study of African-American men with HIV also found an overall mean total score ($M = 100.7$, $SD \pm 18.6$) lower than midpoint (102.5) (Galvan et al., 2008). In comparison with the study, the overall mean total score for our study was above the midpoint. Even though all of these studies used a slightly different HIV stigma scale, these scales were modified from the Berger’s HIV Stigma Scale, and concepts and core values of these scales were the same or
very similar. The means or median stigma scores were below the midpoint of possible score ranges in all these studies, except ours. We found that the mean and median of HIV stigma scores in our study sample were on or above the midpoint of the Stigma Scale for ALH; our study sample reported higher score on the stigma scale. The study finding might indicate that our study sample compared to other studies’ samples was more likely to experience HIV stigma.

Our study revealed that HIV stigma was significant negatively associated with acculturation. ALH with Asian identified were more likely to report stronger HIV stigma than those with Western identified. This result is similar to one found by Rajabium et al. (2008). They found that English language proficient was significantly influence to level of HIV stigma experienced by racial minority living with HIV (Rajabiun et al., 2008). The current study also found that ALH with Asian identification compare to those with Western identification were more likely to experience personalized stigma/disclosure including family rejection and social isolation. Sumari-de Boer et al. (2012) compared HIV stigma between immigrants and non-immigrants living with HIV, and they found stronger personalized stigma and disclosure concerns in immigrants than non-immigrants living with HIV (Sumari-de Boer et al., 2012). Based on these findings, the level and type of HIV stigma experienced by ALH might varies in their level of acculturation.

Stigma also negatively correlated with self-rated general health—ALH who experienced more stigmatization were more likely to report poor health than those who experienced less stigmatization. These findings are supported by other studies exploring the associations between HIV stigma and their health outcome. Vanable et al. (2006) found that PLHIV experiencing HIV stigma compared to those who were not stigmatized were more likely to report HIV-related
physical and psychological symptoms (Vanable et al., 2006). Other recent study found that stigmatized PLHIV compared to non-stigmatized PLHIV were more likely to have detectable HIV viral load or low ARV adherence rate (Sumari-de Boer et al., 2012; Vanable et al., 2006). Based on these findings from studies by Vanable et al. (2006) and Sumari-de Boer et al (2012) in addition to our study, HIV stigma greatly influence to their health outcome among PLHIV. Therefore, interventions to improve health outcomes including antiretroviral medication adherence should address HIV stigma. Culturally appropriate intervention to improve their health outcome should focus on minimum the level of HIV stigma experienced by the population.

ALH who experienced personalized stigma/disclosure or had a negative self-image were more likely to report poor general health. The consequences of HIV disclosure among Asian community may differ from other racial groups, and ALH often reported problematic disclosure to and relationships with family and friends (Kamitani, Chen, et al., In progress). Even though other studies found that HIV disclosure had strongly positive relations to quality of life, antiretroviral therapy adherence, and fewer HIV risky behaviors, it seems to not have happened in the immigrants or racial minority groups (Kimberly & Serovich, 1999; Stirratt et al., 2006). The study by Sumari-de Boer et al (2012) also found that immigrants living with HIV compared to non-immigrants living with HIV were more likely to report detectable viral loads and low antiretroviral therapy adherence rate (Sumari-de Boer et al., 2012). The best intervention for ALH may not be encouragement of disclosure, but referring to culturally and linguistic competent HIV organizations. Thus, it is important for health care providers to understand what their ALH patients’ relationships are like with their family and friends, including if the patient
has disclosed their HIV status to their family and friends. The provider will be in a better position to give culturally appropriate care that improves the patient’s general health outcome.

This is the first study that has measured level of HIV stigma among ALH using a culturally adapted HIV stigma scale; however, there are several limitations to the study. Since this study was conducted only in English and all participants were able to speak and read English, the findings might not be generalized to ALH who have low English language proficiency. A future study could test our conclusions in different Asian languages to further understand HIV stigma experienced by ALH. In addition, this study was conducted at a clinic for un-insured and under-insured PLHIV in an urban area. The level of stigma that ALH experience might differ for ALH in a suburb and for non-economically vulnerable populations. Finally, Asians are a heterogeneous group that embraces more than 50 nationalities, about 100 languages, and a great variety of cultures, religious, and traditions (Centers for Disease Control and Prevention & National Center for HIV/AIDS, 2012). The level of HIV stigma experienced by ALH varies within this racial group. Further study could explore stigma by Asian ethnic group.

This study revealed that ALH experience high levels of HIV stigma and that HIV stigma is negatively associated with acculturation and self-rated general health. In comparison with less stigmatized ALH, more stigmatized ALH were more likely to have more Asian identification than Western identification and report poor their general health status. Our finding suggests that it is important to understand HIV stigma experienced by ALH in order to provide culturally appropriate HIV care that improves health outcomes.
<table>
<thead>
<tr>
<th>% (N), Mean±SD</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10.4(7)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>77.6(52)</td>
<td></td>
</tr>
<tr>
<td>Transfemale</td>
<td>11.9(8)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>44.4 ± 9.5</td>
<td></td>
</tr>
<tr>
<td>Asian Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>12.0(8)</td>
<td></td>
</tr>
<tr>
<td>Filipino</td>
<td>44.8(30)</td>
<td></td>
</tr>
<tr>
<td>Japanese</td>
<td>12.0(8)</td>
<td></td>
</tr>
<tr>
<td>Vietnamese</td>
<td>10.4(7)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>21.0(14)</td>
<td></td>
</tr>
<tr>
<td>Generation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1\textsuperscript{st} generation (born in Asian)</td>
<td>59.7(40)</td>
<td></td>
</tr>
<tr>
<td>2\textsuperscript{nd} generation</td>
<td>25.4(17)</td>
<td></td>
</tr>
<tr>
<td>3\textsuperscript{rd} generation</td>
<td>7.5(5)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>7.5(5)</td>
<td></td>
</tr>
<tr>
<td>Prefer language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Only or mostly Asian</td>
<td>19.4(13)</td>
<td></td>
</tr>
<tr>
<td>Bilingual</td>
<td>32.8(22)</td>
<td></td>
</tr>
<tr>
<td>Only or mostly English</td>
<td>47.7(32)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>14.9(10)</td>
<td></td>
</tr>
<tr>
<td>Completed high school</td>
<td>23.9(16)</td>
<td></td>
</tr>
<tr>
<td>Completed some college work, but did not finish</td>
<td>38.3(26)</td>
<td></td>
</tr>
<tr>
<td>Completed college</td>
<td>16.4(11)</td>
<td></td>
</tr>
<tr>
<td>Completed graduate school</td>
<td>6.0(4)</td>
<td></td>
</tr>
<tr>
<td>Household annual income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ $20,000</td>
<td>62.7(42)</td>
<td></td>
</tr>
<tr>
<td>$20,001-40,000</td>
<td>19.4(13)</td>
<td></td>
</tr>
<tr>
<td>$40,001-75,000</td>
<td>6.0(4)</td>
<td></td>
</tr>
<tr>
<td>Don’t know/Decline to state</td>
<td>12.0(8)</td>
<td></td>
</tr>
<tr>
<td>HIV exposure category</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MSM</td>
<td>79.1(53)</td>
<td></td>
</tr>
<tr>
<td>Heterosexual contact</td>
<td>1.5(1)</td>
<td></td>
</tr>
<tr>
<td>IVDU</td>
<td>4.5(3)</td>
<td></td>
</tr>
<tr>
<td>IVDU+MSM</td>
<td>7.5(5)</td>
<td></td>
</tr>
<tr>
<td>Other/unknown</td>
<td>7.5(5)</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Stigma Scale for ALH (N = 67)

<table>
<thead>
<tr>
<th></th>
<th>Mean ± SD</th>
<th>Total mean ± SD</th>
<th>Total median [IQR]</th>
<th>Midpoint of the scale (possible range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>2.5 ± 0.7</td>
<td>32.8±9.0</td>
<td>34 [29-39]</td>
<td>32.5 (13-52)</td>
</tr>
<tr>
<td>Subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized stigma/disclosure</td>
<td>2.6 ± 0.8</td>
<td>18.4±5.6</td>
<td>19 [15-22]</td>
<td>17.5 (7-28)</td>
</tr>
<tr>
<td>Negative self-image</td>
<td>2.1 ± 0.8</td>
<td>6.2±2.5</td>
<td>6 [4-8]</td>
<td>7.5(3-12)</td>
</tr>
<tr>
<td>Public attitude</td>
<td>2.7 ± 0.8</td>
<td>8.1±2.4</td>
<td>8 [7-10]</td>
<td>7.5(3-12)</td>
</tr>
</tbody>
</table>

1 Weak stigmatization – 4 (Stronger stigmatization)
2 13 Weak stigmatization – 52 (Stronger stigmatization)
3 25th – 75th interquartile range

Table 3: Abbreviated SL-ASIA and Self-rated General Health (N = 67)

<table>
<thead>
<tr>
<th></th>
<th>Mean ± SD, n (%)</th>
<th>Midpoint of the scale (possible range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbreviated SL-ASIA</td>
<td>53.5 ± 15.5</td>
<td>47.5 (19-76)</td>
</tr>
<tr>
<td>Self-reported general health</td>
<td>4.9 ± 1.7</td>
<td>4.0 (1-7)</td>
</tr>
<tr>
<td>1: very poor</td>
<td>4.5 (3)</td>
<td>—</td>
</tr>
<tr>
<td>2</td>
<td>3.0 (2)</td>
<td>—</td>
</tr>
<tr>
<td>3</td>
<td>11.9 (8)</td>
<td>—</td>
</tr>
<tr>
<td>4</td>
<td>22.4 (15)</td>
<td>—</td>
</tr>
<tr>
<td>5</td>
<td>17.9 (12)</td>
<td>—</td>
</tr>
<tr>
<td>6</td>
<td>17.9 (12)</td>
<td>—</td>
</tr>
<tr>
<td>7: excellent</td>
<td>22.4 (15)</td>
<td>—</td>
</tr>
</tbody>
</table>

1 Less acculturation; Asian identification-76 (More acculturation; Western identification)
Table 4: Correlation between Stigma Scale for ALH and Acculturation and Self-rated general health ($N = 67$)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Acculturation</th>
<th>Self-rated General Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>-0.33 ($p = .006$)**</td>
<td>-0.36 ($p = .003$)**</td>
</tr>
<tr>
<td>Subscale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personalized Stigma/Disclosure</td>
<td>-0.37 ($p = .002$)**</td>
<td>-0.41 ($p = .001$)**</td>
</tr>
<tr>
<td>Negative self-image</td>
<td>-0.22 ($p = .07$)</td>
<td>-0.27 ($p = .03$)*</td>
</tr>
<tr>
<td>Public attitude</td>
<td>-0.14 ($p = .25$)</td>
<td>-0.11 ($p = .38$)</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01
References


Older HIV patients deal with the double stigma of having the disease and being old. Big worry: 'Will I get to see grandkids if I tell?'. (2007). AIDS Alert, 22(2), 16-17.


Knowledge, Attitudes, and Self-perceived Risk for Cardiovascular Disease and Acute Coronary Syndrome, and the Influence of HIV Stigma and Acculturation among Economically Vulnerable and Racial-minorities Living with HIV

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Knowledge, Attitudes, and Self-perceived Risk for Cardiovascular Disease and Acute Coronary Syndrome, and the influence of HIV Stigma and Acculturation among Economically Venerable and Racial-minorities Living with HIV

The advent of combination antiretroviral therapy has dramatically decreased acquired immunodeficiency syndrome (AIDS)-related mortality and has increased the life expectancy of people living with HIV (PLHIV).\textsuperscript{1} In the early 1980s, more than 74\% of PLHIV died from AIDS within 6 months of HIV diagnosis.\textsuperscript{2} Today, they are expected to survive for at least 20 years after their initial HIV diagnosis; PLHIV have a near-normal life expectancy but often live with multiple complex comorbid conditions.\textsuperscript{1,3,4} Currently, as many as 69\% of PLHIV die from non-AIDS-related complications. One of the leading causes of non-AIDS-related deaths is cardiovascular disease (CVD)—in particular, acute coronary syndrome (ACS). In comparison with non-PLHIV, PLHIV have a 50\% higher risk of ACS.\textsuperscript{1,5-8}

Rapid recognition of ACS symptoms and prompt seeking of care are critical to minimizing morbidity and mortality.\textsuperscript{9-12} Survival rates associated with reperfusion therapy initiated within 60 minutes of symptom onset are as much as 50\% higher than those associated with reperfusion therapy initiated after 60 minutes.\textsuperscript{13-15} Accordingly, in considering the triumvirate of determinants of health behaviors—\textit{knowledge}, \textit{attitude}, and \textit{self-perceived risk}—it is important that individuals (a) know the risks of CVD and signs and symptoms of ACS (knowledge), (b) are confident and proactive in accessing care when they experience ACS signs or symptoms (attitude), and (c) are aware of their risks (self-perceived risk). Currently, however, little is known about these CVD- and ACS-response determinants as they pertain to economically vulnerable PLHIV.

Several studies have found that PLHIV’s knowledge, health-seeking behaviors, and self-
perceived risk are greatly influenced by acculturation and HIV stigmatization. However, no study to date has investigated the influences of acculturation and HIV stigmatization on knowledge, attitude, and self-perceived risk as held by PLHIV who are members of racial minority groups or by PLHIV who are partially acculturated immigrants.

The purposes of this paper are to (a) assess PLHIV’s knowledgeability concerning CVD and ACS, attitudes regarding ACS, and self-perceived risk of having ACS, and (b) explore how the acculturation and HIV stigmatization influences these behaviors in economically vulnerable Asians living with HIV (ALH).

**Background**

Previous studies have reported that PLHIV are 1.75 times more likely to have risk of ACS than are members of the general population. Traditional risk factors of ACS—such as smoking, age, hypertension, diabetes, and dyslipidemia—are commonly seen in PLHIV. A recent study found that 91.4% of PLHIV had at least one of these traditional risk factors. The chronic inflammatory response in HIV infection also independently increases the risk of ACS: by causing chronic inflammation of the arteries and veins; this inflammation can result in the accumulation of more trapped plaque. In addition, adverse metabolic effects of antiretroviral treatment increases the risk of ACS by changing lipid levels, by inducing insulin resistance or diabetes mellitus, and by impairing fibrinolysis. Because of these factors, PLHIV have considerably higher ACS risk than do non-PLHIV.

An individual’s knowledge, attitudes, and self-perceived risk regarding CVD and ACS greatly influence the likelihood that an individual will promptly recognize ACS symptoms and seek medical treatment. Several investigations have found that, in the general population, knowledgeability regarding ACS symptoms and treatment decreases prehospital delay to seek
care for ACS symptoms. In these studies, ACS knowledgeability independently correlated with attitudes about ACS symptoms, response to the symptoms, and self-perceived risk for ACS. Individuals who are more knowledgeable about ACS are more likely to accurately perceive their risk status; this awareness of personal risk may shorten delay time in seeking care for ACS symptoms. Conversely, lower ACS knowledgeability, negative attitude regarding ACS, and low self-perceived risk for ACS can delay seeking care during ACS.

In terms of racial minorities, degree of acculturation may influence knowledge, attitude, and self-perceived risk because immigrants who have low Western identification may have lower English language proficiency. The influences of HIV stigmatization on PLHIV’s knowledge, attitude, and self-perceived risk—not exclusively regarding ACS but regarding health in general—were also well documented.

Accordingly, in the current study we explored the level of knowledge, attitude, and self-perceived risk for CVD and ACS among economically vulnerable racial minorities living with HIV and identified the influences of their HIV stigma and acculturation.

**Methods**

**Design: Sample, Setting, and Data Collection**

We conducted a cross-sectional study to investigate knowledge, attitudes, and self-perceived risk regarding CVD and ACS in a sample of 67 PLHIV from November 2012 to June 2013. The study was approved by IRB prior to the subject enrollment. Participant recruitment was conducted in an HIV-care community organization that provided HIV-related programs including HIV medical care for un-insured and under-insured ALH. Potential participants were recruited via flyers, clinician referrals, and announcements to peer support groups at the
organization. Potential participants were screened for eligibility in person. Inclusion criteria for this study were self-identification as HIV-positive, racial self-identification as Asian, 18 years of age or older, ability to speak and read in English, and to have disclosed their HIV status to at least one other person. Eight-eight PLHIV were screened, and 67 were found eligible for the study (i.e., 21 screened individuals did not meet all inclusion criteria). After participants provided written consent, they were asked to complete questionnaires at the organization facility in the presence of a researcher.

**Measures**

**Sociodemographic characteristics and family and medical history.** The sociodemographic characteristics form included gender, age, level of education, and annual household income. Medical and family history included indication of whether participants had self-reported hypertension, self-reported dyslipidemia, or family history of heart attack.

**Self-rated general health.** Participants were asked to rate their current health status with the question: “How would you rate your health status?” The response was measured on a 7-point Likert scale anchored with responses ranging from very poor (1) to excellent (7).

**Stigma Scale for ALH.** Participant were asked to respond to items on a culturally adapted shortened version of the Berger Stigma scale, the Stigma Scale for ALH. Response choices were strongly disagree (1), disagree (2), agree (3), and strongly agree (4). Total scores were calculated by adding the scores for each response. Total scores ranged from 13 to 52. Higher scores indicated higher degrees of stigmatization. Cronbach’s α in this population was 0.92.
**Abbreviated Suinn–Lew Asian Self-Identity Acculturation scale.** The abbreviated Suinn–Lew Asian Self-Identity Acculturation scale (SL–ASIA) was applied to measure acculturation. The abbreviated SL–ASIA contains 19 multiple choice questions in six categories: language, identity, friendship choice, behavior, generation–geographic history, and attitude. Multiple-choice question responses were formatted on a 5-point Likert scale. In scoring the scale, the values for all 19 items were added up, and total scores ranged from 19 to 95. Low scores reflected low acculturation; high scores reflected high acculturation. This scoring system also indicated that low scores meant high Asian identification, and high scores meant high Western identification. Cronbach’s α in this population was 0.93.

**Knowledge about CVD and ACS and Self-perceived Risk for ACS.** Knowledge of CVD and ACS and self-perceived risk for ACS were assessed using modified versions of the Knowledge scale and Self-Perceived Risk scale used by the research group consisting of Dracup et al. The modified CVD and ACS Knowledge scale had five items, with trichotomous answer choices, either true, false, or don’t know. If participant chose don’t know, the item was considered to be answered incorrectly. Overall knowledge score was calculated by totaling the number of correct responses then dividing that total by the number of questions (n = 5). Overall knowledge assessments ranged from minimally knowledgeable (0) to highly knowledgeable (6). Cronbach’s α on the Knowledge scale in this study sample was 0.80; this finding shows that on this scale, internal consistency was acceptable to good.

Participants’ self-perceived risk for ACS was assessed with two questions regarding that assessed their self-perceived likelihood of having a heart attack (a) within the next 5 years, and (b) during their lifetime. Responses were recorded on a 5-point Likert scale and ranged from
much less likely (1) to much more likely (5). Overall self-perceived risk was calculated by totaling response scores to these two items; self-perceived risk assessments ranged from much less likely (2) to much more likely (10).

**Attitude Regarding ACS.** Riegel et al. developed the 33-item ACS Response Index as a tool for rapid assessment of patient knowledge, attitudes, and beliefs regarding heart attack and response. In the present study, four questions that ascertain attitudes regarding heart attack and response were developed by modifying attitude questions in the Index. The modified scale had two items that tested symptom recognition and two items that tested the questions assessing their confidences to seek medical attentions regarding heart attack. These four scale items were measured using a 4-point Likert scale from not sure (1) to very sure (4). Patients’ overall attitudes about their possible heart attack were calculated by totaling scores for all four items: scores ranged from 4 to 16, with higher scores indicating more strongly positive attitudes. Cronbach’s α in the present study population was 0.80, which was higher than the original attitude scale on ACS Response Index, which had α of 0.71. This finding showed that the scale had good internal consistency.

**Data Analysis**

All analyses used IBM® SPSS® Statistics v.19 for Windows. Descriptive statistics were used to describe sample characteristics, medical history, and family history. Mean and standard deviation were calculated for self-rated general health, stigma, and acculturation.

Mean scores were calculated for overall Knowledge, Attitude, and Self-perceived Risk scales as well as for subscales on the Attitude scale and Self-Perceived Risk scale. The
percentages of correct answers for each question on the Knowledge scale, and those for each responses on both Attitude and Self-perceived Risk scale were also determined.

To ascertain the influences of acculturation and HIV stigmatization on knowledge, attitude, and self-perceived risk, multiple linear regressions was applied. First, to find possible confounding variables relating these outcomes, Pearson correlations or point biserial correlations were used to calculate correlations between sociodemographic characteristics, medical and family history, and self-rated general health. For point biserial correlations, male-transmale for gender and response choice for no on other dichotomous response questionnaires were coded as 0, and female-transfemale and response choice for yes were coded as 1. Characteristics for which outcomes were statistically significant were considered to be possible confounding variables; these characteristics were included in multiple linear regression models in order to explore whether acculturation or HIV stigmatization independently influence knowledge, attitude, and self-perceived risk. Cronbach’s alphas were calculated as necessary to determine internal reliability. A p-value of 0.05 or less was considered statistically significant.

Results

Sample Characteristics

Sociodemographic characteristics, medical and family history, self-rated general health, the Stigma Scale for ALH, and the SL-ASIA are presented in Table 1. The majority of participants was either male or transmale (77.6%), did not complete college (77.1%), had less than $20,000 household annual income (62.7%). The sample’s mean age was 44.4 years (SD ± 9.5). In terms of self-reported medical history, the prevalences of high blood pressure, high total cholesterol (≥ 200mg/dL), and low HDL (≤ 40mg/dL for men or 50 mg/dL for women) were 37.3%, 29.9%,
and 20.9%, respectively. Among participants, 17.9% reported that their mother or sister had a heart attack before age 65, and 9.0% reported that their father or brother had heart attack before age 55. Approximately a quarter of the participants did not know whether they had been told that they had total cholesterol of greater than 200mg/dl. Approximately a half of the participants did not know whether they had been told that they had HDL less than 40mg/dl (for men) or 50mg/dl (for women).

Mean self-rated general health status was 4.9 ($SD \pm 1.7$), with a range of very poor (1) to excellent (7). Nearly a quarter of the participants stated that their health was excellent. The means of the Stigma scale for ALH (possible range, 13–52) was 32.8 ($SD \pm 9.0$), and the mean for the abbreviated SL–ASIA (possible range, 19–95) was 53.5 ($SD \pm 15.5$).

**Knowledge about Cardiovascular Disease and Acute Coronary Syndrome**

Table 2 shows the results of level of knowledge about CVD and ACS. The mean of the overall scale was 2.3 ($SD \pm 1.8$). Regarding individual items, fewer than one third of the study participants knew that CVD is a leading cause of death in the United States. Approximately 40% of PLHIV correctly answered the true–false statement that “almost all heart attacks occur in women occur in people over age 65 or in men occur in people over age 55.” Only about a quarter of the participants knew that there was a racial risk for CVD. More than half of PLHIV knew that the symptoms of heart attacks can be mild and can take days to develop. More than half of the participants knew that hospitals had drugs that can reduce damage caused by heart attack.

**Attitudes Regarding Acute Coronary Syndrome**

Data representing participants’ level of confidence in recognizing signs of heart attack and in seeking medical care were presented in Table 3. The mean overall attitude score (range,
4–16) was 9.6 ($SD \pm 3.6$). About 16% of participants indicated that they were “very sure” that they could recognize the signs and symptoms of heart attack themselves. Moreover, 10.4% of participants were “very sure” that they could tell the difference between the signs or symptoms of heart attack and other medical problems. About 40% of participants said they were “very sure” that they could call an ambulance or dial 911 if they thought they were having heart attack; 37.3% said that they could get to emergency room within 60 minutes of symptom onset.

**Self-perceived Risk for Acute Coronary Syndrome**

As seen in Table 4, the mean of self-perceived risk for ACS was 4.9 ($SD \pm 2.2$) with possible range of 2 (low risk perception) to 10 (high risk perception). Slightly more than half of participants (50.8%) indicated that, during the coming 5 years, their risk of heart attack was lower than that of the general population. Notably, more than a quarter of participants (26.9%) believed they were much less likely to have heart attack than were in the general population. In terms of lifetime risk, more than three fourths of the participants (82.1%) believed that their risk for heart attack was the same as or lower than that of the general population. Moreover, about a quarter of them (23.9%) believed that, during their lifetime, they were much less likely to have a heart attack than were others of their age. Only 4.5% of participants believed that their likelihood of having a heart attack was greater than that of others in their age group in the general population.

**Bivariate Correlations between Demographics, Knowledge, Attitude, Self-perceived Risk, HIV Stigma, and Acculturation**

Knowledge was significant positively correlated with education ($r = 0.29, p = .02$; Table 5). Men were more likely to indicate that they felt confident about their ability to recognize signs
of heart attack and about their ability to seek and access care for heart attack than were women (r = -0.28, p = .02). Finally, older participants (r = 0.43, p < .0005) or participants who reported poorer general health (r = -0.29, p = .02) were more likely to perceive themselves as being at risk for future heart attack. Regarding HIV stigmatization and acculturation, HIV stigmatization was found to be correlated with attitude (r = -0.43, p < .0005), and acculturation was found to be correlated with attitude (r = 0.29, p = .019) and, more strongly, with knowledge (r = 0.36, p = .002).

Adjust Linear Regression Coefficients for Knowledge, Attitude, and Self-perceived Risk Associated with HIV Stigma and Acculturation

Table 6 shows adjusted linear regression coefficients for level of knowledge about CVD and ACS, attitudes regarding ACS, and self-perceived risk for ACS with HIV stigma and acculturation. About 17% of knowledge of CVD and ACS can be explained by stigmatization, acculturation and education (p = .007). Acculturation is an independent predictor of level of knowledge regarding CVD and ACS even when controlling for level of education (B[95% CI] = 0.037[0.008, 0.066], p = .013). Individuals who had low Western Identification were more likely to have limit knowledge regarding CVD and ACS after controlling for level of education.

Stigmatization, acculturation, and gender can explain 24.6% of attitude regarding ACS (p < .0005). HIV stigma is an independent predictor of attitude regarding ACS even when controlling for gender (B[95%CI] = -0.139 [-0.231, -0.046], p =.004). Individuals who had been stigmatized were more likely to report negative attitude regarding ACS after controlling for gender. However, when gender was controlled for, acculturation was no longer independently correlated with attitude (B[95% CI] = 0.033 [-0.021, 0.086], p =.224).
Finally, stigmatization, acculturation, age, and self-rated general health accounted for 25.5% of self-perceived risk ($p = .001$). Neither HIV stigma nor acculturation is an independent predictor of self-perceived risk for ACS when controlling for age and self-rated general health.

**Discussion**

The purposes of this study were to (a) explore three factors regarding to CVD and ACS economically vulnerable PLHIV—knowledge about CVD and ACS, attitude regarding ACS, and self-perceived risk for ACS and (b) identify influences of HIV stigma and acculturation on these outcomes among the sample of economically vulnerable racial minorities living with HIV. This study revealed that its participants had limited knowledge of CVD and ACS, positive attitude regarding ACS, and low self-perceived risk for ACS; in addition, the study found that acculturation independently influence knowledge about CVD and ACS and HIV stigma independently influence attitude regarding ACS.

In the present study, the PLHIV–participants’ limited knowledge of CVD and ACS is troubling and perplexing. Our findings are contrary to those of a study by Cioe, which tested PLHIV knowledgeability about CVD. The investigator reported that a large percentage ($M = 76\%$) of her study’s PLHIV participants were knowledgeable about risks of CVD. Cioe proposed that the high degree of CVD knowledgeability in the PLHIV sample might have been the result of local public health campaigns concerning PLHIV’s risks for CVD (These campaigns had been conducted by the American Heart Association and by Department of Health and Hunan Services.) As with the Cioe study, the present study was also preceded by a number of public health campaigns—specifically, campaigns concerning PLHIV’s risks for heart disease. The present study’s campaigns were conducted in the vicinity of the community clinic where the study was conducted and included education about both CVD and ACS. Our study’s findings
may indicate that our study participants might not have benefitted from exposure to public health campaigns about heart disease (including ACS and CVD) even though the campaigns were conducted in the vicinity of the community clinic that was the site of the current study.

Our study participants’ relatively low CVD and ACS knowledgeability—despite community exposure to heart disease public health campaigns—may have been due to the participants’ being less acculturated than the population norm. Our study revealed that level of education significantly correlated with knowledgeability regarding CVD and ACS—a finding consistent with those of other studies.\textsuperscript{16,44-46} Even when the effects of education were controlled for, acculturation was independently associated with knowledge. Participants in our study were more likely to have limited English language proficiency; accordingly, they might have had low health literacy and might have been unable to take advantage of the knowledge presented in a public health heart disease awareness campaign.\textsuperscript{16} Participants’ limited knowledge of CVD and ACS is a matter of concern, given that lack of such knowledge may have negative consequences for behaviors related to CVD and ACS risk factors. For example, individuals with inadequate knowledge of CVD and ACS might not feel compelled to reduce their risk of CVD—or, more generally, to opt for a healthier lifestyle—or to seek medical care when experiencing symptoms of ACS. Our findings indicate that, to reduce heart disease-related disparities between the diverse subpopulations of PLHIV, educational interventions should be tailored for the specific subpopulations. For example, interventions for low-socioeconomic racial-minority PLHIV should be culture-appropriate and health literacy-appropriate for this subpopulation.

We found that, even though PLHIV were at high risk for ACS, their self-perceived risk for future ACS was actually low. This finding is congruent with that of Homko et al., who found that economically vulnerable individuals who were at high risk for CVD had low self-perceived
Another study, conducted by Dracup et al., specifically examined self-perceived risk among individuals in a sample from the population of people with histories of heart disease. As with our present study, Dracup et al., too, found that their study participants had low self-perceived risk even though their risk for ACS was high. However, our study participants’ self-perceived risk for future ACS was much lower than that of the Dracup et al. study participants. In our study sample, the percentage (43%) of participants who believed that their self-perceived risk for ACS was about as same as or as less than that of the other same-age participants in our sample was approximately twice the percentage reported by Dracup et al.

This finding of low self-perceived risk for ACS was also found in people with diabetes. Choi et al. reported that the 77% of their study’s participants believed that their risk for ACS was the same as or lower than the general population’s risk. These findings may indicate that individuals with a history of heart disease but whose health conditions are well managed and well controlled to prevent for possible ACS may have much higher self-perceived risk than do those who have never had a heart disease—even though they are at high risk for ACS due to current chronic illness(es). Among individuals with multiple chronic illnesses, an inappropriately low self-perceived risk for one particular illness might result from the individuals’ attention being drawn to one of the individual’s other illnesses they are at high risk for or to realize the complications of their current chronic illness(es). Moreover, if the individuals believe that the particular illness is well monitored and well controlled, they might not be concerned about the possibility of their succumbing to an additional concomitant condition. Healthcare providers should pay more attention to educating PLHIV—not only about AIDS but also about their patients’ comorbid conditions. In addition, given that their patients’ life expectancy has been
extended by improvements in antiretroviral therapies, providers should educate their patients about chronic illnesses related to aging.

In contrast to a study by Edelman et al., which found that acculturation to western culture was inversely related to self-perceived risk for CVD, our study found no association between acculturation and self-perceived risk for ACS. Also, Choi et al. found that ACS knowledgeability, self-perceived risk for ACS was higher among those with poor general health than among those with good general health. We found that self-rated general health was negatively correlated with self-perceived risk, but we found no association found between knowledgeability and self-perceived risk. Further studies exploring associations between these factors are necessary to confirm these findings. Our finding of low self-perceived risk is problematic because PLHIV with low self-perceived risk might not act to reduce ACS risk factors or seek care. Adequate awareness of ACS is important for PLHIV, so that they can take appropriate preventive measures.

Our study found that the majority of PLHIV tend to believe that they would recognize the signs and symptoms of heart attack and would seek help. However, because of a lack of appropriate knowledge, many PLHIV might not recognize signs and symptoms of heart attack and might not know when they need to seek help. PLHIV may assume that their knowledge of heart attack is adequate, and they may be overconfident of their ability to take appropriate action during an episode ACS. These assumptions may reduce the likelihood that PLHIV will modify their lifestyles to ameliorate or compensate for their ACS risk factors.

Several studies have found that HIV stigmatization significantly negatively correlates with health-seeking behaviors and adherence to HIV care, such as mental health care and self-
administration of antiretroviral medications.\textsuperscript{17-20} Our study found that, after controlling for covariant, which was gender, stigmatization was also strongly negatively correlated with care-seeking behaviors and with response to ACS symptoms. These findings indicate that, to better understand how to ameliorate stigmatization and to improve the cultural appropriateness of care delivery, further investigation of HIV stigmatization among racial minority PLHIV is warranted.

A previous study by Blanco, San Roman, Vispo, et al. found that, among PLHIV, the prevalence of hypertension and the prevalence of dyslipidemia were approximately 25\% and as high as 54\%, respectively.\textsuperscript{50} In contrast, our present study revealed a much higher prevalence of self-reported hypertension. The prevalence of dyslipidemia in our current study was lower than that found in the previous study; however, many (22\%) of the PLHIV in our study answered “don’t know” in response to the question “Have you ever had or been told you had total cholesterol level (bad cholesterol) greater than 200 mg/dL?”\textsuperscript{50} The high percentage of “don’t know” responses may indicate that PLHIV are relatively unconcerned about their blood pressure, total cholesterol level, and HDL. They may be more concerned about their CD4 counts or HIV viral loads, and pay less attention to other laboratory values that indicate CVD risk factors. Their “don’t know” response might also indicate that (a) they were unfamiliar with cholesterol or with HDL and (b) they could not recall whether they had ever talked with their healthcare providers about cholesterol or HDL. Further research is necessary for assessing health literacy in this population.

The finding of such a high self-rated general health score in our study’s PLHIV was particularly surprising. A study by Kandula, Lauderdale, and Baker found that Asian Americans typically rated their health as fair or poor, even though they actually had a smaller number of types of chronic diseases than did non-Asian Americans.\textsuperscript{51} However, the majority of ALH in our
own study evaluated their health as being an average to excellent. The PLHIVs’ high self-ratings of general health may have been a consequence of (a) a perception that their HIV disease was well controlled by antiretroviral therapy and (b) their having lived with HIV with minimal complications for a long time. (For the PLHIV in this study, the mean number of years of living with HIV was 13 years). The participants in our study might believe that, if they controlled their HIV, they were as healthy as or even healthier than were non-PLHIV.

Although our study of PLHIV was the first to assess patient knowledge about CVD and ACS, attitudes regarding ACS, and self-perceived risk for ACS among economically vulnerable racial minorities living with HIV, several limitations of the study must be recognized. First, due to the fact that convenience sampling was conducted at a community clinic, our study findings may be generalizable to only English-speaking ALH. Future comparative studies should examine low socioeconomic participants from diverse racial–ethnic groups. Second, although several potential confounding factors (such as age, gender, and education) were controlled, there might be other possible confounding variables. Future replicative studies that investigate patient knowledge about CVD and ACS, attitudes regarding ACS and response, and self-perceived risk for ACS and cofounders should be conducted in low socioeconomic individuals from diverse racial groups.

**Summary**

As the life expectancy in PLHIV is extended, non-AIDS-related chronic conditions gain prominence as contributors to mortality. CVD accounts for approximately 16% of non-AIDS-related deaths today. Of this percentage, ACS accounted for 40% of PLHIV who have died from CVD. Early recognition of symptoms of ACS and rapid decisions to get medical attention are essential for decreasing PLHIVs’ mortality rates. While several studies have examined
knowledge, attitudes, and self-perceived risk for CVD and ACS among at-risk population, relatively few studies have examined these phenomena in relation to PLHIV; no study has examined these phenomena in relation to economically vulnerable, less acculturated PLHIV. Notably, this study found that the PLHIV in our sample had extremely limited knowledge of CVD and ACS and low self-perceived risk for ACS. This finding is particularly troubling because such individuals may fail to recognize their symptoms of ACS during heart attack and may not quickly decide to seek medical attention. Delays in seeking care greatly exacerbate mortality and treatment outcome.

This study also revealed that study participants had limited budgets and lacked information regarding their ACS-related medical history and family history of heart attack. Being alert to ACS symptoms and seeking medical care rapidly might not be a top priority for PLHIV. PLHIV might be more worried about current problems or basic needs of daily living (e.g., food, housing, substance abuse, onset of HIV illness, HIV stigma, and English language proficiency) than they are about some future occurrence of ACS. Behavior modification strategies for decreasing risk of CVD and risk of ACS (e.g., healthy food education, counting daily steps) might be less effective with the PLHIV population than with other populations. CVD–ACS risk reduction interventions implemented for PLHIV should be culturally and linguistically appropriate for this particular population.

Although PLHIV are at relatively high risk for CVD and ACS, many of these individuals do not receive adequate attention and care. Our study reveals a need for effective interventions to reduce CVD and ACS-related disparities among PLHIV subpopulations. In particular, the need for such interventions in communities of economically vulnerable–less acculturated PLHIV is especially urgent. These interventions should be geared toward improving CVD- and ACS-
related knowledge, attitudes, and self-perceived risk, and the design of these interventions must be culture- and health literacy-appropriate.
References


Table 1: Sociodemographic and medical and family history (N = 67)

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<tr>
<td>Completed high school</td>
<td>23.9(16)</td>
</tr>
<tr>
<td>Completed some college work,</td>
<td></td>
</tr>
<tr>
<td>but did not finish</td>
<td>38.3(26)</td>
</tr>
<tr>
<td>Completed college</td>
<td>16.4(11)</td>
</tr>
<tr>
<td>Completed graduate school</td>
<td>6.0(4)</td>
</tr>
<tr>
<td>Household annual income</td>
<td></td>
</tr>
<tr>
<td>≤ $20,000</td>
<td>62.7(42)</td>
</tr>
<tr>
<td>$20,001-40,000</td>
<td>19.4(13)</td>
</tr>
<tr>
<td>$40,001-75,000</td>
<td>6.0(4)</td>
</tr>
<tr>
<td>Don’t know/Decline to state</td>
<td>12.0(8)</td>
</tr>
<tr>
<td><strong>Medical History (self-reported)</strong></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>37.3(25)</td>
</tr>
<tr>
<td>Total cholesterol ≥200mg/dL</td>
<td>29.9(20)</td>
</tr>
<tr>
<td>HDL ≤40mg/dL (men) or ≤50mg/dL (women)</td>
<td>20.9(14)</td>
</tr>
<tr>
<td><strong>Family history (self-reported)</strong></td>
<td></td>
</tr>
<tr>
<td>Mother/Sister had heart attack before age 65</td>
<td>17.9(12)</td>
</tr>
<tr>
<td>Father/Brother had a heart attack before age 55</td>
<td>9.0(6)</td>
</tr>
<tr>
<td>Mean Self-rated general health core</td>
<td>4.9±1.7</td>
</tr>
<tr>
<td>Mean HIV Stigma Scale for ALH score</td>
<td>32.8±9.0</td>
</tr>
<tr>
<td>Mean abbreviated SL-AISA score</td>
<td>53.5±15.5</td>
</tr>
</tbody>
</table>

1 4.5% (n = 3) responded with “don’t know”  
2 22.4% (n = 15) responded with “don’t know”  
3 47.8% (n = 32) responded with “don’t know”  
4 9.0% (n = 6) responded with “don’t know”  
5 10.4% (n = 7) responded with “don’t know”  
6 Possible ranges from 1 (very poor) to 7 (excellent): Responses were 1 (very poor): 4.5% (3), 2: 3.0(2), 3:11.9(8), 4:22.4(15), 5:17.9(12), 6:17.9(12), 7(excellent): 22.4(15).  
7 Possible range from 13 (weaker stigma) to 52 (stronger stigma)  
8 Possible range from 19 (Asian identification) to 95 (Western identification).
Table 2: Knowledge of cardiovascular disease and acute coronary syndrome (N = 67)

<table>
<thead>
<tr>
<th>Overall: mean score$^1$</th>
<th>mean ± SD, % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2.3±1.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Individual items: proportion of response</th>
<th>Correct</th>
<th>Wrong</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung cancer (men)/Breast cancer (for women) is the number one cause of death in women. Heart disease is the second leading cause of death for men/women in the US today. [Correct Response: False]</td>
<td>29.9(20)</td>
<td>70.1(47)</td>
</tr>
<tr>
<td>Almost all heart attacks in women occur in people over age 65 or in men occur in people over age 55. [Correct Response: False]</td>
<td>40.3(27)</td>
<td>59.7(40)</td>
</tr>
<tr>
<td>The symptoms of a heart attack are always sudden and severe. [Correct Response: False]</td>
<td>28.4(19)</td>
<td>71.6(48)</td>
</tr>
<tr>
<td>Caucasian men/women face a greater threat from heart disease than men/women of other races. [Correct Response: False]</td>
<td>26.9(18)</td>
<td>73.1(49)</td>
</tr>
<tr>
<td>The symptoms of heart attack can be mild and can take days to develop. [Correct Response: True]</td>
<td>55.2(37)</td>
<td>44.8(30)</td>
</tr>
<tr>
<td>Hospitals have drugs that reduce the damage done when a heart attack occurs. [Correct Response: True]</td>
<td>53.7(36)</td>
<td>46.3(31)</td>
</tr>
</tbody>
</table>

$^1$Possible range from 0 (minimally knowledgeable) and 6 (highly knowledgeable).

Cronbach’s $\alpha = 0.80$
Table 3: Attitudes regarding acute coronary syndrome and response (N = 67)

<table>
<thead>
<tr>
<th>Overall: mean score</th>
<th>mean ± SD, % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9.6±3.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Individual items: mean score and proportion of each answer choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>How sure are you that you could recognize the signs and symptoms of a heart attack in yourself?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>How sure are you that you could tell difference between the signs or symptom of a heart attack and other medical problems?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>How sure are you that you could call an ambulance or dial 911 if you thought you were having a heart attack?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>How sure are you that you could get to an emergency room within 60 minutes after onset of your symptoms?</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

1 Possible range of 4 (negative attitude) to 16 (positive attitude)
2 Possible range of 1 (negative attitude) to 4 (positive attitude)

Cronbach’s α = 0.80
Table 4: Self-perceived risk for acute coronary syndrome ($N = 67$)

<table>
<thead>
<tr>
<th></th>
<th>mean ± SD, % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall: mean score&lt;sup&gt;1&lt;/sup&gt;</td>
<td>4.9 ± 2.2</td>
</tr>
<tr>
<td>Individual items: mean score&lt;sup&gt;2&lt;/sup&gt; and proportion of each answer choice</td>
<td></td>
</tr>
</tbody>
</table>

**Compared to other women/men your age, how likely do you think it is that you could have a heart attack in the next five years?**

<table>
<thead>
<tr>
<th>Mean score</th>
<th>2.2 ± 1.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: much less likely</td>
<td>26.9 (18)</td>
</tr>
<tr>
<td>2: somewhat less likely</td>
<td>23.9 (16)</td>
</tr>
<tr>
<td>3: about the same</td>
<td>31.3 (21)</td>
</tr>
<tr>
<td>4: somewhat more likely</td>
<td>14.9 (10)</td>
</tr>
<tr>
<td>5: much more likely</td>
<td>3.0 (2)</td>
</tr>
</tbody>
</table>

**Compared to other men/women your age, how likely do you think it is that you could have a heart attack in your lifetime?**

<table>
<thead>
<tr>
<th>Mean score</th>
<th>2.2 ± 1.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: much less likely</td>
<td>23.9 (16)</td>
</tr>
<tr>
<td>2: somewhat less likely</td>
<td>25.4 (17)</td>
</tr>
<tr>
<td>3: about the same</td>
<td>32.8 (22)</td>
</tr>
<tr>
<td>4: somewhat more likely</td>
<td>13.4 (9)</td>
</tr>
<tr>
<td>5: much more likely</td>
<td>4.5 (3)</td>
</tr>
</tbody>
</table>

<sup>1</sup>Possible range from 2 (low self-perceived risk) to 10 (high self-perceived risk)

<sup>2</sup>Possible range from 1 (low self-perceived risk) to 5 (high self-perceived risk)
Table 5: Bivariate Correlations among knowledge of cardiovascular disease (CVD) and acute coronary syndrome (ACS)\(^1\), attitudes regarding ACS\(^2\), self-perceived risk for ACS\(^3\), demographic data, medical and family history, stigma, and acculturation (\(N = 67\))

<table>
<thead>
<tr>
<th></th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge(^1)</td>
<td>.19</td>
<td>-.10</td>
<td>-.21</td>
<td>-.15</td>
<td>.29*</td>
<td>.05</td>
<td>-.20</td>
<td>-.09</td>
<td>-.19</td>
<td>-.18</td>
<td>-.08</td>
<td>-.06</td>
<td>-.04</td>
<td>.36**</td>
</tr>
<tr>
<td>Attitude(^2)</td>
<td>--</td>
<td>-.07</td>
<td>-.28*</td>
<td>.03</td>
<td>.14</td>
<td>-.05</td>
<td>-.02</td>
<td>.18</td>
<td>-.01</td>
<td>-.15</td>
<td>-.06</td>
<td>.21</td>
<td>-.43**</td>
<td>.29*</td>
</tr>
<tr>
<td>Risk-perception(^1)</td>
<td>--</td>
<td>-.06</td>
<td>.43**</td>
<td>-.05</td>
<td>-.18</td>
<td>-.11</td>
<td>.11</td>
<td>0</td>
<td>.11</td>
<td>.14</td>
<td>-.29*</td>
<td>.10</td>
<td>-.15</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>--</td>
<td>-.09</td>
<td>-.30*</td>
<td>.08</td>
<td>.22</td>
<td>.05</td>
<td>.04</td>
<td>.06</td>
<td>.05</td>
<td>-.05</td>
<td>.19</td>
<td>-.14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>--</td>
<td>-.41**</td>
<td>-.23*</td>
<td>.26*</td>
<td>.24</td>
<td>.21</td>
<td>.13</td>
<td>.15</td>
<td>-.08</td>
<td>-.06</td>
<td>-.19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>--</td>
<td>-.02</td>
<td>-.39**</td>
<td>-.11</td>
<td>-.15</td>
<td>-.31*</td>
<td>-.20</td>
<td>.14</td>
<td>-.02</td>
<td>.31*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>--</td>
<td>.04</td>
<td>-.03</td>
<td>-.01</td>
<td>-.17</td>
<td>-.14</td>
<td>-.04</td>
<td>.16</td>
<td>-.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>--</td>
<td>.32**</td>
<td>.17</td>
<td>.45**</td>
<td>.35**</td>
<td>.02</td>
<td>.07</td>
<td>-.11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyslipidemia</td>
<td>--</td>
<td>.58**</td>
<td>.12</td>
<td>-.06</td>
<td>-.21</td>
<td>.13</td>
<td>-.20</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HDL</td>
<td>--</td>
<td>.13</td>
<td>.08</td>
<td>-.14</td>
<td>.19</td>
<td>-.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother/Sister heart attack</td>
<td>--</td>
<td>.77**</td>
<td>.15</td>
<td>.08</td>
<td>-.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father/Brother heart attack</td>
<td>--</td>
<td>-.10</td>
<td>.06</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-rated General Health</td>
<td>--</td>
<td>-.36**</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV Stigma</td>
<td>--</td>
<td>.33**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acculturation</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

\(^*\) p-value < .05, \(^**\) p-value < .01
Table 6: Adjusted linear regression coefficients for knowledge of cardiovascular disease (CVD) and acute coronary syndrome (ACS), attitude regarding ACS and self-perceived risk for ACS associated with HIV stigma and acculturation (N = 67)

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Source</th>
<th>$R^2$</th>
<th>B</th>
<th>95% CI</th>
<th>$R^2$-change</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of CVD and ACS</td>
<td>Overall</td>
<td>.172</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.007**</td>
</tr>
<tr>
<td></td>
<td>Intercept</td>
<td>--</td>
<td>-.952</td>
<td>-3.476, 1.573</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td>HIV Stigma</td>
<td>--</td>
<td>.014</td>
<td>-.033, .062</td>
<td>.005</td>
<td>.549</td>
</tr>
<tr>
<td></td>
<td>Acculturation</td>
<td>--</td>
<td>.037</td>
<td>.008, .066</td>
<td>.086</td>
<td>.013*</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>--</td>
<td>.306</td>
<td>-.083, .695</td>
<td>.032</td>
<td>.121</td>
</tr>
<tr>
<td>Attitude regarding ACS</td>
<td>Overall</td>
<td>.246</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>&lt;.0005**</td>
</tr>
<tr>
<td></td>
<td>Intercept</td>
<td>--</td>
<td>12.700</td>
<td>7.870, 17.530</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td>HIV Stigma</td>
<td>--</td>
<td>-.139</td>
<td>-.231, -.046</td>
<td>.108</td>
<td>.004*</td>
</tr>
<tr>
<td></td>
<td>Acculturation</td>
<td>--</td>
<td>.033</td>
<td>-.021, .086</td>
<td>.018</td>
<td>.224</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>--</td>
<td>-1.622</td>
<td>-3.516, .273</td>
<td>.035</td>
<td>.092</td>
</tr>
<tr>
<td>Self-perceived risk for ACS</td>
<td>Overall</td>
<td>.255</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>.001*</td>
</tr>
<tr>
<td></td>
<td>Intercept</td>
<td>--</td>
<td>2.140</td>
<td>-2.593, 6.873</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td>HIV Stigma</td>
<td>--</td>
<td>0.008</td>
<td>-.052, -.068</td>
<td>&lt;.01</td>
<td>.79</td>
</tr>
<tr>
<td></td>
<td>Acculturation</td>
<td>--</td>
<td>-.002</td>
<td>-.035, -.032</td>
<td>&lt;.01</td>
<td>.92</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>--</td>
<td>.094</td>
<td>.042, .146</td>
<td>.158</td>
<td>.001**</td>
</tr>
<tr>
<td></td>
<td>Self-rated general health</td>
<td>--</td>
<td>-.322</td>
<td>-.630, -.014</td>
<td>.052</td>
<td>.041*</td>
</tr>
</tbody>
</table>

*p-value < .05, **p-value < .01
Conclusion / Implications

Asian Americans had the highest percentage growth of any racial group between 2000 and 2010 (U.S. Census Bureau, 2013). Asian Pacific Islander (API) is the only racial group which significantly increased in estimated annual percentage (4.4%) of HIV newly diagnosed individuals between 2001-2008 (Adih, Campsmith, Williams, Hardnett, & Hughes, 2011). As rates of HIV infection rise in the Asians population, it is important for us to increase our understanding about what facilitates HIV infection in this population and to focus on decreasing HIV related morbidity and mortality. Stigma, an important concept in the field of international HIV research, is increasingly being associated with access to prevention, care, and treatment outcomes in the population of PLHIV in the US (Cahill & Valadéz, 2013; Emlet, 2006; Mengistu & Chere, 2012). Because of the limited research among the U.S. Asian population our understanding of HIV stigma in this population is limited.

Today, up to 69% of PLHIV die from non-AIDS related complications (The Antiretroviral Therapy Cohort Collaboration, 2010). Cardiovascular disease (CVD) is a primary cause of non-AIDS related death among PLHIV, accounting for approximately 16% of deaths today (Palella et al., 2006; The Antiretroviral Therapy Cohort Collaboration, 2010; The DAD Study Group, 2007; Weber et al., 2006). A recent systematic-review and meta-analysis found that PLHIV had an increased relative risk of CVD up to 61% compared to non-PLHIV after adjusting for age, gender, race, hypertension, diabetes mellitus, and dyslipidemia (Islam, Wu, Jansson, & Wilson, 2012; Triant, Lee, Hadigan, & Grinspoon, 2007). Despite the high risk of CVD in PLHIV, we do not know much about the level of knowledge, attitude, and self-perceived risk for CVD and acute coronary syndrome (ACS) among PLHIV and the influence of HIV stigma toward knowledge, attitude, and self-perceived risk.
Berger and colleagues (2001), developer’s of Berger’s HIV Stigma Scale which is most widely used HIV stigma scale, report that “being able to identify people with HIV who feel stigmatized opens the possibilities for specific interventions to help the person deal with actual stigmatization, particularly those associated with disclosure experiences” (p.528). Therefore, an appropriate understanding of the level and type of stigma experienced by Asians living with HIV (ALH) could increase our ability as health care providers in delivering culturally appropriate HIV care. Because HIV stigma is strongly influenced by culture and population, the Asian population may have a unique HIV stigma experience that differs from other racial groups (Hong et al., 2008; Parker & Aggleton, 2003). Also because HIV stigma is linked to access to health care and poor health outcomes among PLHIV, this is a critical area to study (Cahill & Valadéz, 2013; Emlet, 2006; Mengistu & Chere, 2012; Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012).

Thus, the main themes of my dissertation study was to develop a culturally appropriate HIV stigma scale, to explore the level of stigma experienced by ALH, and to understand how the stigma associates to acculturation, self-rated general health, CVD and ACS knowledge, attitudes toward ACS, and self-perceived risk for ACS.

**Summary of the Research**

The purpose of these three papers were: (1) to report on the steps taken to develop items that measure stigma that are specific to, and relevant for ALH; using these items, to modify an abbreviated Berger’s HIV Stigma Scale and to test the psychometric properties of the modified scale; (2) to assess the level of stigma experienced by ALH by using the newly modified HIV stigma scale and explore the association to the acculturation and self-rated general health in a
sample of ALH; and (3) to explore the level of knowledge, attitudes, and self-perceived risk of CVD and ACS in a sample of ALH and how these factors are influenced by the stigma.

**Paper 1: Abbreviated and Culturally Appropriate HIV Stigma Scale for Asians**

*Living with HIV.* The purpose of the first paper was to modify an abbreviated Berger’s HIV Stigma Scale to ALH and test the validity and reliability of the scale. First, I conducted face-to-face interviews in 5 ALH and came up with three possible items. Then, these items were assessed for face validity by content experts, survey expert, the members of The Banyan Tree Project which was a national campaign to fight HIV stigma in API, and the researcher’s academic advisor (“The Banyan Tree Project,” 2012; Talmage & Rasher, 1981). After these new items were reviewed by these experts, the newly developed Stigma Scale for ALH was explored in two focus groups (*n* = 4 and *n* = 7). Concepts of the scale were discussed in the first focus group, and then the final draft of the revised scale was discussed for confirmation in the second focus group. The new items for the Stigma Scale for ALH were; *I disappointed my family and feel more distance from them by telling them I have HIV, I have a friend or family who might know I am HIV positive, but I am afraid to ask and find out for sure, and Most people do not have enough HIV knowledge to understand me.*

The revised scale was tested to establish validity and reliability of the scale in a cross-sectional study among 67 ALH. Reliability and Validity such as internal consistency and face, content, and construct validities were established through the data collected for the study. EFA was conducted to examine psychometric properties of the scale and found three subscales (personalized stigma/disclosure, negative self-image, and public attitudes). In order to test if the Stigma Scale for ALH was a better fit than the abbreviated HIV Stigma Scale for this sample of
ALH, the reliability and validity of both scales, the Stigma Scale for ALH and the abbreviated HIV Stigma Scale were determined and compared. The finding showed the Stigma Scale for ALH was an appropriate scale to apply to ALH.

Overall, the study’s findings suggest that the scale is a culturally sensitive and captures the HIV stigma experienced by ALH. One strength of this study was that this was the first study to develop culturally sensitive HIV stigma scale for ALH and, and furthered to examine the level of HIV stigma among ALH. One weakness of the paper was that the Stigma Scale for ALH might not be sensitive enough to measure HIV stigma among the multiple Asians subgroups that were impacted by HIV in the US. Asians refers to a wide variety of ethnicities, and HIV stigma is strongly influenced by culture and population (Hong et al., 2008; Parker & Aggleton, 2003). Several different types of stigma can be observed even in the racial subgroups (Nemoto et al., 2003; Takahashi, Candelario, Young, & Mediano, 2007; Yoshioka & Schustack, 2001). Thus, the generalized scale might not able to detect variation of HIV stigma in one big category.

Despite the limitations, this study developed the first HIV stigma scale culturally adapted to ALH. This measure can help health care providers understand the stigma that may be a barrier that keeps ALH from receiving HIV testing and early care for HIV. Eventually, health care providers may be able to identify HIV-related stigma in these populations and provide culturally appropriate care. Such a culturally competent focus will enable individuals to receive timely HIV care.

**Paper 2: Level of HIV Stigma Experienced by Asians Living with HIV: the influence of acculturation and general health outcome.** I applied the Stigma Scale for ALH among 67 ALH and explored the level of HIV stigma experienced by ALH. I found that ALH often experienced stigmatization, and the HIV stigma was negatively associated with their
acculturation and self-rated general health outcome. These findings suggested ALH who experienced HIV stigma were more likely to report their Asian identification and poor general health than do those who have not experienced HIV stigma.

Moreover, ALH who reported Asian identification were more likely to experience personalized stigma and disclosure than those who reported Western identification. Disclosure concerns were often brought up from study participants also during face-to-face interviews and focus groups. The previous study by Sumari-de Boer et al. (2012), who compared HIV stigma between immigrants living with HIV and non-immigrants living with HIV, found the similar findings. They found that immigrants living with HIV compared to non-immigrants were more likely to report personalized stigma and disclosure concerns. In addition, they found that immigrants living with HIV compared to non-immigrants were more likely to have detectable HIV viral loads and low antiretroviral treatment adherence rate (Sumari-de Boer et al., 2012). Findings from both Sumari-de Boer et al.(2012) and our study suggest that disclosure is a particular concern among immigrants or less acculturated ALH. Findings from several other studies suggests that HIV disclosure has strongly positive associations to quality of life, antiretroviral treatment adherence, and fewer HIV risky behaviors; however, the relationship between disclosure and quality of life, antiretroviral treatment adherence and HIV risky behaviors might not same in the immigrants or racial-minority living with HIV (Kimberly & Serovich, 1999; Stirrat et al., 2006). The culturally appropriate interventions for ALH may not encourage disclosure, but focus on referring ALH to culturally and linguistic competent HIV organizations that can support them in their process of disclosing their HIV status. The
interventions for ALH need to address their disclosure concerns toward their family and friends, which may be more nuanced than encouraging across the board disclosure.

This paper confirmed my hypothesis that ALH experienced high levels of HIV stigma, and level of HIV stigma was negatively associated with acculturation and general health outcome. This study provided us the important aspect of HIV stigma experienced by ALH but also has some limitations. These data were collected at a community clinic for economically vulnerable ALH. ALH who receive care at a clinic which is not specific for Asians, or that have private health insurance might report HIV stigma differently. In addition, the stigma scale is available only in English. One of the inclusion criteria was to be able to read and speak in English, and ALH who had a low English literacy level or low acculturation were more likely to be excluded from the study.

Despite these limitations, this paper is the first study testing the level of HIV stigma with a culturally appropriate scale among ALH. This study found the HIV stigma was often experienced by ALH and negatively associated to acculturation and health outcomes.

**Paper 3: Knowledge, Attitudes, and Self-perceived Risk for Cardiovascular Disease and Acute Coronary Syndrome, and the Influence of HIV Stigma and Acculturation among Economically Vulnerable and Racial-minorities Living with HIV.** This cross-sectional survey included the questionnaires testing knowledge, attitudes, and self-perceived risk for CVD and ACS among a sample of ALH. This study revealed poor knowledge about CVD and ACS and low perceived risk for ACS. The study also found that HIV stigma independently correlated to attitudes regarding ACS, and acculturation independently correlated to knowledge of CVD and ACS even after controlling for confounding variables. These findings suggest that
the intervention to increase knowledge, attitudes, and self-perceived risk for CVD or ACS in ALH should address HIV stigma and acculturation.

The community clinic, where study participants were recruited from, offered monthly, culturally appropriate peer support groups which includes educational sessions related to HIV-treatment, such as information on CVD and ACS. In addition, there were several public health campaigns about CVD and ACS risks among PLHIV by organizations such as the American Heart Association and the U.S. Department of Health and Human Services around the community clinic. Despite these efforts, the sample of my study still had a low level of knowledge about CVD and ACS and perceived themselves to be at low risk for ACS.

Even though this was the first study of PLHIV to describe patient knowledge about CVD and ACS, attitudes regarding ACS, and self-perceived risk for ACS, this study also has some limitations. The study data were collected through convenience sampling of ALH who could read and speak in English; these findings were not generalizable and may not be the same for non-English speaking ALH. Non-English speaking ALH compared to English speaking ALH might have poorer CVD knowledge or less positive attitudes (ex: call to 911 during experience of ACS) due to their limited English language proficiency. Other limitations included that there might be other possible confounding variables even though several potential confounding factors (such as age, gender, and education) were controlled for in this analysis.

Applying Study Findings to Andersen’s Behavioral Model of Health Services Use

Putting these findings about HIV stigma that is experienced by ALH in to a larger framework of access to and use of health services the findings from these papers can be viewed in relation to each phase in Andersen’s behavioral model of health services use. These three
phases were *predisposing characteristics, enabling resources, and need*. Since Asians tend to live with limited social networks where HIV stigma and taboo towards talking about HIV, they might have low awareness and perception of HIV risk (*predisposing characteristics*). Findings from our focus groups revealed that many ALH did not know that they were at risk for HIV before their HIV diagnosis. Meanwhile, some ALH were aware of their risk of contracting HIV, but they had not sought HIV care (Lopez-Quintero, Shtarkshall, & Neumark, 2005). Unable to disclose or fright of being stigmatized by receiving HIV care might prevent ALH from utilizing the available resources (*enabling resources*). This study also revealed that ALH tended to view their general health as good to excellent and failed to perceive their risks of comorbid conditions such as CVD or ACS caused by their HIV infection or adverse effects of antiretroviral treatment (*needs*). The lack of perceived needs in this population might be caused by limited knowledge of HIV or HIV-related issues including comorbidities such as CVD. Also, our study found that HIV stigma independently negatively influences participants’ attitudes toward receiving medical attention. Due to the stigma, ALH might not seek, or be less likely to receive, appropriate and needed HIV care.

**Remaining Questions / Further Research**

Even though several research studies in HIV stigma are available, little is known about HIV stigma in ALH. This is the only study measuring the level of stigma experienced by ALH with culturally appropriate HIV stigma scale. This study revealed that the Stigma Scale for ALH was sensitive enough to identify the unique HIV stigma influenced by Asian culture and customs; it might not be sensitive enough for Asian sub groups. One area for future study would
be a HIV/AIDS study that distinguishes each Asian subgroup and focuses on the unique cultural characteristics of each to understand how this diverse racial group handles HIV/AIDS stigma.

The findings of limited knowledge and low self-perceived risk regarding CVD and ACS are perplexing among medically vulnerable racial minorities living with HIV. Future studies in examining other economically vulnerable participants from diverse racial–ethnic groups of PLHIV are needed. This study also revealed that HIV stigma was an independent predictor of level of knowledge, and acculturation was an independent predictor of attitudes even when controlling for confounding factors. However, there might be other possible confounding factors in this group that were unexplored. Future replicative and more rigorous studies that investigate patient knowledge about CVD and ACS, attitudes regarding ACS and response, and self-perceived risk for ACS and confounding factors in economically vulnerable individuals from diverse racial groups should be conducted.

To improve the level of knowledge, attitudes, and self-perceived risk for CVD and ACS, we need innovative culturally appropriate interventions among low socioeconomic PLHIV. Several interventional studies of the risk for CVD in PLHIV were found, but intervention studies have focused on manipulating antiretroviral regimens as a means to decrease CVD risk (Bavinger et al., 2013; Trevillyan, Cheng, & Hoy, 2013). However, lifestyle modifications to reduce CVD risk factors have been shown to be more effective than other methods, including pharmacologic interventions, and should be considered a priority in this population (Aberg & Ribaudo, 2010; Blanco et al., 2010; de Gaetano Donati, Cauda, & Iacoviello, 2010; Malvestutto & Aberg, 2010; Pour & Dagogo-Jack, 2011).

Lifestyle modification may be especially challenging in economically vulnerable PLHIV due to limited budgets, which impacts resources for basic needs including food and housing.
However, previous studies in behavior modification among economically vulnerable PLHIV demonstrated a good benefit not only in reducing CVD risks, but also in decreasing depression and increasing antiretroviral adherence. (Blashill et al., 2013; Hand et al., 2008).

Finally, all data for this study was collected from only one community health clinic for economically vulnerable ALH in San Francisco. This was a cross-sectional study, and the study inclusion criteria included Asians who were able to speak and read in English. This findings might not be generalizable to other ALH. Also, ALH living in other parts of the US might experience different types or levels of stigma and may have different levels of knowledge, attitudes, and self-perceived risk of CVD and ACS. Further studies in ALH living outside of San Francisco are necessary to generate these data.

**Conclusion**

Only limited numbers of HIV research studies have been applied in ALH; moreover, most of them are ten or more years old. Since the area of HIV/AIDS has changed rapidly and has improved in the past the several years, studies done in 80s or 90s might not be relevant to current situations. In addition, due to advancement of antiretroviral treatment, the life expectancy among PLHIV has been increased. In general, by 2015, 50% of PLHIV will be aged 50 or older in the US (High et al., 2008). More PLHIV will face age-related health issues and the prevalence of CVD in PLHIV is expected to increase. CVD is also a major cause of hospitalization in PLHIV. Multisite cross-sectional studies found that 7.5% of all hospitalizations in PLHIV were related to CVD in 2001-2008 (Berry, Fleishman, Moore, Gebo, & Network, 2012).

This study reveals some aspects of the current HIV situation in the Asian population and the need of more studies in this area. Our findings indicate that, to reduce healthcare disparities
between economically vulnerable racial-ethnic minority living with HIV and the general PLHIV population, public health campaigns should include educational interventions that are culture-appropriate and health literacy-appropriate for economically vulnerable racial-minority living with HIV.

Further study should explore what enables ALH or Asians to identify their risks for CVD or HIV-related issues including comorbidities such as CVD. The study’s finding could lead to increased access to care and result in better health outcomes. Health care settings that demonstrate cultural competency to ALH may increase comfort for ALH to receive care. It may result in less stigmatization with a resulting improvement in general health, health outcomes, knowledge, attitudes, and self-perceived risk.

This study adapted the Berger’s Stigma Scale to ALH and found a high level of HIV stigma, which was associated with acculturation. Also this study found limited knowledge and self-perceived risk among economically vulnerable ALH. The clinic where the study data were collected had anti-stigma campaign toward ALH, yet our study found the HIV stigma was often experienced by ALH and associated with both acculturation and perceived health status (“The Banyan Tree Project”, 2012). Culturally appropriate interventions among ALH should address HIV stigma since this study revealed that HIV stigma greatly influenced to their health outcome, knowledge, and healthcare-seeking behaviors.

In addition, I found that ALH tended to be excluded from research studies. My dissertation was the first research study in which study participants reported that they have ever participated. This was surprising considering the number of HIV studies that have been done in San Francisco and in this community. Participants were also not newly diagnosed but have been HIV positive for more than 10 years (the mean years of living with HIV was 13 years in this
study). At the same time, I understood they had limited involvement in research because I hardly found published articles studying in ALH. My study revealed that more study and attention are needed in this understudied and underserved population.

In summary, this study developed the first culturally appropriate HIV stigma scale for ALH. By applying the scale, I found that strong HIV stigma among ALH, and HIV stigma is associated to health outcome and healthcare-seeking behaviors. A culturally competent HIV clinic, where ALH feel comfortable, might help ALH receive HIV-related care, including for CVD and ACS, and more study is needed in this unique population. Interventions to increase knowledge, attitudes, and self-perception regarding HIV-related issues including comorbidities such as CVD and ACS in ALH should address HIV stigma. Future studies might help decrease HIV-related health care disparity.
References


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