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Information Seeking in Asians-Pacific Islanders with HIV/AIDS

by

Glenda N. Baguso

THESIS

Submitted in partial satisfaction of the requirements for the degree of

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By

Glenda N. Baguso

## Dedication and Acknowledgments

Writing this thesis consumed ten months of my life. In those ten months, I have accumulated a long list of those I wish to thank. For the guidance and encouragement I have received from Dr. Carol Dawson-Rose, my advisor and committee chair, I am filled with gratitude. Under her tutelage, I found that starting this thesis was not as intimidating a task as I thought it would be, and finishing this thesis was not an impossible feat. She is an excellent role model of a researcher, mentor and professor.

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I dedicate this thesis to the Asian Pacific Islanders who have lived without a voice in the tumultuous epidemic of HIV/AIDS.

## Abstract

A recent study has shown a statistically significant increase in the incidence of Asian Pacific Islanders (API) diagnosed with HIV/AIDS (Adih, Campsmith, Williams, Hardnett, & Hughes, 2011). Although the national prevalence of HIV/AIDS among API is lower than that among other groups, the expected increase of HIV/AIDS in the API population—18 million in 2012 to 40 million by the year 2050—signifies a public health risk. The dearth of studies on API living with HIV/AIDS (API-LWHA) and health literacy represents a collective knowledge gap that impinges on prevention strategies, research efforts, policy development, and the lives of API-LWHA. The purpose of this qualitative descriptive study is to explore how API-LWHA seeks information regarding their illness. Individual 1-hour interviews were conducted with API-LWHA who was recruited from the Asian and Pacific Islander Wellness Center (APIWC) in San Francisco. The interviews provided a forum for exploring sources, types of information, and participant self-evaluation of the process used to seek information. Eight participants self-identified as API-LWHA completed the interview. Thematic analysis was applied to identify emerging themes. Professional health care workers, social networks, and media (i.e., Internet and printed media) were the primary sources of information. The types of information participants sought, included general HIV topics, HIV medications, and the use of condoms and clean needles—among other topics. Although the sample size is small and recruitment came from a single community-based organization (CBO), the study's findings reveal ways that API-LWHA seeks information. This study adds to the body of literature regarding ways that health care providers can enrich their contact with this population through health care, education, research, and policy development. Further

studies must be done in order to expand the literature on health literacy and API-LWHA and therefore gain a deeper understanding of the ways API-LWHA explores information regarding their illness.

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## Chapter One: Introduction

Inadequate access to care, poor quality of care, shortages of health care professionals, and other factors contribute to health care disparities among subpopulations in the United States; these disparities have been a major focus in the political, medical, judicial, and media arenas. The resulting public recognition of the need for equitable, high-quality, health care nationwide has prompted comprehensive health care reform and passage of the Patient Protection and Affordable Care Act (ACA) of 2010. This legislation represents the desire to eliminate disparities in health care.

### Diverse Definitions of Health Care Disparities

Although problems associated with health care disparities are widely discussed, this conversation has been complicated by the multiplicity of definitions of health care disparities currently in use. Abercrombie (2008) defines *health care disparity* as a difference in disease, outcome, or access to care between populations; disadvantaged populations tend to be racial or ethnic minorities. Braveman (2006) defines health care disparity as a specific, health-related difference between groups; in such disparate health circumstances, one group—often a minority group—is disadvantaged relative to other groups or to the population as a whole in terms of poorer health status or greater health risk.

The influences of culture, race, and ethnicity on health literacy have long been topics of interest for a number of researchers in the United States—inspired, perhaps, by the nation’s demographic diversity (Andrulis & Brach, 2007; Sentell, Baker, Onaka & Braun 2011; Sentell & Braun, 2012; Shaw, Armin, Torres, Orzech, & Vivian, 2012; Shaw et al., 2008). Studies pertaining to culture, race, and ethnicity have identified a

broad range of disparities, such as between-group differences in infant mortality, cancer management, cardiovascular disease, and diabetes, to name a few examples (Abercrombie, 2008; Gerber, Young, Arozullah, & Lee, 2010; Wu, Lin, So, & Chang, 2007). In HIV/AIDS study findings, racial and ethnic health disparities are similarly diverse—ranging from diagnosis (An, Prejean, & Brach, 2012) to medication adherence (Fogarty et al., 2002; Osborn et al., 2007).

**Reducing health disparities by improving health literacy.** In order to mitigate health disparities that affect disadvantaged subpopulations, factors underlying these disparities must be identified and rectified. One such possible contributor to health disparities is health literacy. Ruffin (2011) has observed that interventions that increase health literacy mitigate health disparities. Andrulis and Brach (2007) have written that effective communication between minority groups and clinicians, staff, and their supporting organization could be achieved by taking into account the health literacy of a person, their culture and their language. In this regard, health literacy research continuously generates new strategies for decreasing health disparities (Osborn et al., 2007; Paasche-Orlow & Wolf, 2010).

### **Diverse Views of Health Literacy**

Health researchers have proposed multiple definitions for health literacy. Shaw, Huebner, Armin, Orzech, and Vivien (2008) use a narrow definition: the comprehension and implementation of a physician's orders. Other investigators view health literacy in terms of reading comprehension. For instance, Kalichman et al. (2000) have assessed health literacy using the Test of Functional Health Literacy in Adults (TOFHLA), a reading comprehension scale. Nokes et al. (2007) have used the Rapid Estimate of Adult

Literacy in Medicine (REALM) and the TOFHLA to assess health literacy. Studies measuring health literacy through use of reading comprehension scales focus on reading and patient education materials (Kalichman et al., 2000; Kalichman, Ramachandran, & Catz, 1999; Kalichman & Rompa, 2000; Miller et al., 2003).

The Medical Library Association uses a more comprehensive definition of health literacy: (a) the capabilities to know when to seek health information; (b) identify and use sources of health information; (c) obtain relevant and useful information; and (d) analyze, comprehend, and apply information to make health decisions (Shipman, Kurtz-Rossi, & Funk, 2009). Ratzan and Parker's (2000) definition of health literacy, accepted by the Institute of Medicine (IOM, 2004) and the U.S. Department of Health and Human Services (2010), is widely accepted and often cited. Ratzan and Parker state that health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (2000, Introduction section, para. 7). The ACA 2010 defines health literacy similarly to that of Ratzan and Parker (2000) and IOM (2004). The wording of ACA (2010) underscores the importance of health literacy—directly mentioning health literacy five times and referring to health literacy in many of the Act's sections (Somers & Mahadevan, 2010). All of these definitions of health literacy place emphasis on the individual's skills (e.g., verbal, reading, decision making) as determinants of health literacy.

#### **Health information practice and health information-seeking behavior.**

Researchers from non-clinical disciplines have viewed health literacy from other perspectives. In the field of library and information science, for example, Lloyd (2011)

notes that the role of community and social interaction is essential in information literacy. Lloyd, Bonner, and Dawson-Rose (2012) state that “health literacy is a socially derived *health information practice* that connects people to ways of knowing, and enables them to draw from a range of information sources to inform the decisions that they make” (Introduction section, para 1). Talja and Hansen (2007) have described *information practices* as “information seeking, retrieval, filtering, and synthesis” (p. 113). *Health information practices* involve a variety of social skills and activities that are used in producing, sharing, and applying information in specific health-related situations (Lloyd, 2011). The term *health information-seeking behavior* pertains to the ways individuals gather information and knowledge regarding their health, risks to their health, and ensuing illnesses (Lambert & Loiselle, 2007). Health information-seeking behavior is important because of its probable impact on individuals’ health and adjustment to illnesses (Lambert & Loiselle, 2007). This view of health literacy ranks social dynamics—rather than the individual’s reading comprehension and communicative competence—as the most important factor in characterizing health literacy (Lloyd et al., 2012).

**Health literacy capacity.** For people who need health care or health care information, navigating through the complex, rapidly evolving health care system presents great challenges (Chin, Kang, Kim & Martinez, 2006; Lloyd, 2011; Zukoski, Thorburn, & Stroud, 2011). Indeed, the individual’s capacities to maneuver within and through the health care system and to gain health care information are key issues in health literacy research.

In a 2004 report, the IOM has noted that an individual's *health literacy capacity* is a function of "innate potential" and skills (e.g., verbal skills, decision making, basic medical tool use) and that this capacity is influenced by education (2004; p. 32). Although the IOM report identifies individual "capacity" as a significant factor in the health literacy equation, the report also notes that demographics (i.e., cultural, linguistic, and social) and health setting characteristics are also defining features of health literacy (IOM, 2004, p. 32). This recognition implies that both the consumer of health care and the health care institution are mutually responsible in determining health literacy adequacy. Accordingly, the IOM identifies three points of intervention for remedying health literacy deficiencies: (a) sociocultural context, (b) education and health systems, and (c) the dynamic relationship between sociocultural context and these systems. Knowledge of these points of intervention can inform plans of action for increasing health literacy and decreasing health disparities.

### **Purpose**

The purpose of this qualitative descriptive study is to explore how API-LWHA seeks information regarding their illness. This study is conducted in collaboration between the University of California, San Francisco, School of Nursing and the Banyan Tree project. The author's role in this study was to perform data analysis and to write a report of the study's findings.

### **Significance of the Study**

According to Census 2010, the nation's diversity is expressed in demographics of approximately 50 million Hispanics, 39 million African Americans, and 15 million Asians/Native Hawaiians/Pacific Islanders (Humes, Jones, & Ramirez, 2011). The

Census Bureau defines Asians as people with background from the Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, Philippines, Thailand and Vietnam (Humes et al., 2011). Native Hawaiian or Pacific Islander included people whose origins were from Hawaii, Guam, Samoa or other Pacific Islands (Humes et al., 2011). In 2012, the estimated API subpopulation grew to over 18 million (U.S. Census Bureau, 2012). In the first decade of the twenty-first century, Hispanic and API populations grew significantly, largely as a result of immigration (Humes et al., 2011). Recent statistics show that the API immigration is now surpassing Hispanic immigration in both absolute numbers and on a percentage basis (Pew Research Center, 2012; Semple, 2012).

**Barriers to conducting health research on the API population.** With the API population anticipated to exceed 40 million by 2050 (The Whitehouse, 2011), this population remains understudied. Although many U. S. studies have investigated health and health care in contexts of culture, ethnicity, and race, the majority of these studies have focused on African American and Hispanic populations (Kim & Keefe, 2010). The few investigators who focused on the API population have encountered significant barriers to obtaining representative sample.

The first two barriers cited are specifically barriers that researchers may experience while conceptualizing and designing their research study. The third and fourth issues—language discordance and stigmatization—are primarily barriers that the APIs experience themselves and can impact participation in research studies. In 1989, the Asian and Pacific Islander Coalition on HIV/AIDS in New York advocated that the API population should be identified as a separate group for HIV research. Prior to the adoption of this recommendation, API research participants were typically included in the

“*Other*” category of most research sample demographic descriptions (Chin, Leung, Sheth, & Rodriguez, 2007). At present, many studies still fail to specifically identify API in their samples, and instead continue to include API participants in their “*Other*” sample demographic descriptions (Kalichman & Rompa, 2000, Kalichman et al., 2000; Osborn et al., 2007). Another barrier is that the API population is not ethnically homogeneous. The API population comprises over 30 ethnic groups and, collectively, communicates in many different languages (Kim & Keefe, 2010; The Whitehouse, 2011). Many API immigrants experience another barrier, limited English proficiency (Nguyen & Bowman, 2007; Kim & Keefe, 2010; The Whitehouse, 2011). For these API immigrants, patient–provider language discordance exacerbates health care disparities (Kim & Keefe, 2010; Nguyen & Bowman, 2007; Sentell & Braun, 2012; Sentell et al., 2011). Stigmatization of HIV/AIDS is yet another barrier to health care that occurs in the API culture and can contribute to health care outcomes (Chin et al., 2007).

**Health disparity research on the API population.** The API population in the United States tends to have higher rates of diabetes, heart disease and cancers (The Whitehouse, 2011). Also, APIs are less likely to be tested for HIV/AIDS than are people from other racial-ethnic groups (Bhattacharya, 2004). Moreover, the API population has a statistically significant increase in HIV diagnosis of 4.4 % from 2001 to 2008, while Hispanics, African Americans and Caucasians have significantly decreased rates (Adih, Campsmith, Williams, Hardnett, & Hughes, 2011). Relatively few studies have investigated API and HIV (Adih et al., 2011; Bhattacharya, 2004; Chin et al., 2007; Jemmott, Maula, & Bush, 1999).

**Health literacy research on the API population and API subpopulations.** As with research on health and healthcare, research on health literacy has examined several racial–ethnic populations (i.e., Caucasian, African American, and Hispanic), but not the API population in the United States (An et al., 2012; Fogarty et al., 2002; Kalichman et al., 2000; Kalichman et al., 1999; Kalichman & Rompa, 2000; Miller et al., 2003; Osborn et al., 2007). Although no studies have examined the API population and health literacy in general, a few studies have examined specific API ethnic subpopulations and health literacy regarding particular diseases. For example, a study on Hmong Americans showed low levels of cancer literacy (Lee & Vang, 2010). Other studies on Hmong youth, Vietnamese college students (Hwang, Huan, & Yi, 2008), Chinese immigrants (Taylor et al., 2006), and Cambodians showed important knowledge deficits regarding Hepatitis B (Taylor et al., 2011). Notably, no health literacy studies have focused on API–LWHA.

**HIV/AIDS research on API–LWHA.** From 2001 to 2008, Adih et al. (2011) shows a 4.4% rise in HIV infection in API population. Indeed, this is the only racial–ethnic group with a statistical significant rise in HIV infection (Adih et al., 2011). Despite the growing numbers of API who are newly diagnosed with HIV/AIDS, studies of HIV/AIDS in this population have focused primarily on API men who have sex with men (MSM; Do et al., 2005; Takahashi, Magalong, DeBell, & Fasudhani, 2006; Wong et al., 2012)—and not on other API groups with HIV/AIDS. A dearth of HIV/AIDS information regarding API–LWHA and their health literacy skills underscores the need for research that can describe and explain the information-seeking experiences in this population.

This present study is one of the first to explore health information-seeking practices of API-LWHA, and the investigators believe that the study will contribute to API-LWHA health research and well-being in several ways. First, the study may elucidate existing and new areas of understanding that can augment both API health literacy and the HIV/AIDS literature as a whole. Second, the study may help to identify core themes in health-seeking information practices in API-LWHA; understanding of these core themes can inform future research on API-LWHA and on health literacy in general. Third, the study may help health care professionals identify strategies for enhancing health knowledge within the API population. Some literature indicates that health literacy can affect health outcomes (DeWalt, Berkman, Sheridan, Loh, & Pignone, 2004; Kalichman et al., 2000; Kalichman et al., 1999; Nokes et al., 2007; Osborn et al., 2007; Paasche-Orlow & Wolf, 2010; Ruffin, 2011).

### **Definitions**

The following are definitions of key terms used in this thesis.

***Culture.*** Culture is a broad concept with multiple meanings that vary significantly according to academic context. This thesis considers culture in the context of health behavior—specifically, with reference to a group’s mutually held ideas and beliefs, shared system of communication, and other factors that uniquely shape and contribute to group members’ health behaviors (Egede, 2006).

***Ethnicity.*** Ethnicity has been described as an ill-defined concept that can be used to further ethnic discrimination between races and different groups (Egede, 2006). For the purposes of this thesis, *ethnicity* is defined as a shared framework of thinking and

beliefs that are based on a group's social, economic, historical, and political background (Watt & Norton, 2004).

***Health disparity.*** For the purpose of this thesis, health disparities are differences in health and health related outcomes that manifest between advantaged and vulnerable or minority groups. These differences in health are unfair and preventable (Braveman, 2006).

***Race.*** The concept of race was based on an assumption that the genes that determined race were related to the genes that determined a group's health (Egede, 2006; Watt & Norton, 2004). For the purpose of this thesis, *race* is viewed as a social construct that distinguishes one group from another—rather than as physical characteristics such as stature, skin color, or bone structure (Watt & Norton, 2004).

## **Organization**

Chapter 2 includes reviews and critiques of the literature on the API-LWHA and their information-seeking practices. Chapter 3 includes a discussion of the methodology of the current study. In Chapter 4, the study's results and findings are presented. Chapter 5 discusses the conclusions of the current study and the implications for health care; this chapter also provides recommendations for future studies.

## **Chapter Two: A Review of Selected Studies Related to Information-Seeking Strategies Used by Asians-Pacific Islanders with HIV/AIDS**

The growth of the API subpopulation in the United States and the mounting HIV incidence in this subpopulation of 4.4% over the period 2001-2008, indicate a public health risk (Adih, Campsmith, Williams, Hardnett, & Hughes, 2011). This risk, if ignored, could contribute to the resiliency of the HIV/AIDS epidemic in the U.S. population as a whole (Chin, Leung, Sheth, & Rodriguez, 2007). Furthermore, because optimizing the public's health literacy is a key strategy for containing the epidemic, assessment and improvement of HIV/AIDS health literacy among the API population constitute important strategies in the health care sector's response. In this regard, API's general level of motivation and ability to seek information and to become knowledgeable about HIV/AIDS are core metrics for measuring the adequacy of API health literacy. Moreover, given the multiple adverse ramifications of the growing API HIV/AIDS epidemic, the current paucity of research on API-LWHA and API health literacy in general is a matter of concern.

Four literature search topics were used to identify articles for this review: (a) health literacy and API; (b) health literacy and API-LWHA; (c) health literacy and HIV/AIDS—specifically, regarding strategies that people use in seeking information about HIV/AIDS; and (d) HIV/AIDS and the API population. Separate keyword searches were conducted on each of these topics in order to identify studies that contribute to the collective knowledge regarding API-LWHA.

Following the discussion of the main-topic search strategies, the second section of this chapter includes critiques of selected articles pertaining to each topic. Because

articles were identified for only three of the four original search topics, the critique of selected studies has three topic sections. This chapter concludes with a summary.

### **General Search Strategy**

**Search terms.** An immense body of research on HIV/AIDS has been published in the fields of medicine, nursing, sociology, and psychology; however, the volume of HIV/AIDS literature is significantly reduced when *health literacy* is included as an additional key search term. When either of the keywords *Asians* or *Pacific Islanders* is added to this set of search terms, the body of relevant literature is further diminished. Indeed, the dearth of studies on the health literacy of API-LWHA represents an information deficiency that may adversely affect design and implementation of prevention strategies, research, and policy; ultimately, this information deficit may adversely affect health and overall quality of life for the API-LWHA themselves.

**Inclusion criteria.** Using the PubMed database, keywords were used to identify research on API-LWHA and health literacy. Due to the paucity of studies identified in initial searches, multiple additional searches were performed in relevant topic areas. The searches included studies published from January 1, 2005 to December 31, 2012; among the studies identified in these searches, only empirical studies published in English were considered. In addition, and with one exception, the studies discussed in this literature review used samples whose participants were 18 years of age or older and living in the United States; the exception—a study by Adih et al. (2011)—is discussed later in the review.

**Exclusion of women-only studies.** In order to ensure that the literature search would yield only studies that were germane to the purpose of the current study, studies

whose participants were exclusively female were excluded. Although recruitment for the current study was open to all male and female, the sample from the current study is male or transgender (male to female). Women did not volunteer for this current study. It is important to note that women—in particular, Asian American women—are underrepresented in the HIV/AIDS literature. To illustrate this point, out of the 102 articles that were initially evaluated for this literature review, only eight articles focused on women, and only two articles focused on API women.

### **Health Literacy and Asians**

The search for empirical articles using keywords *health literacy* and *Asians* resulted in 35 possible articles. *Asians Pacific Islander* used as single compound keywords limited the number of identified articles. After applying the inclusion and exclusion criteria and accepting only studies relevant the health literacy of Asians, a total of three studies could be included in this section literature review.

### **Health Literacy and API-LWHA**

To identify studies relevant to the health literacy of API-LWHA, an initial search of PubMed using the aforementioned inclusion-exclusion criteria and the keywords *health literacy*, *Asians Pacific Islander* (as a single compound keyword), and *HIV/AIDS* was conducted; however, this first search yielded no results. Subsequently, broadened searches used the search terms *Asians*, *Pacific Islander*, *culture*, *ethnicity* and *race* (these terms were used interchangeably with one another and in place of *Asian Pacific Islander*); when these key words were used in conjunction with the inclusion criteria, five articles were found. However, none of these five articles were relevant to this literature

review. Therefore, it was necessary to further broaden the search for relevant articles by combining different keywords.

In the searches for the other three main topics (health literacy and Asians, health literacy and HIV/AIDS, and HIV/AIDS and API population), various keyword combinations were used to identify relevant articles for this literature review.

### **Health Literacy and HIV/AIDS**

The search on this topic, which used the keywords *health literacy* and *HIV/AIDS*, identified 35 studies. While none of this research focused on API populations, these studies are important in elucidating the relationship between health literacy and HIV/AIDS. After applying the inclusion and exclusion criteria, five studies warranted inclusion in the literature review.

### **HIV/AIDS and API Population**

A search using the keywords *Asians Pacific Islander* (as a single compound keyword) and HIV/AIDS identified 27 citations. Of note, the majority of studies focused on API–MSM. After applying the inclusion and exclusion criteria, a total of 17 studies were included for initial review in the topic category “Asians Pacific Islander and HIV/AIDS.” Studies that did not adequately represent or include API and HIV/AIDS in their samples were excluded; as a result, a total of nine studies could be included in the review.

## **Literature Critiques of Selected Studies**

### **Health Literacy and Asians**

**Study: Mental health literacy in Hmong and Cambodian elderly refugees.** In 2010, Lee, Lytle, Yang, and Lum conducted a qualitative mental health literacy study of

Hmong and Cambodian elderly refugees; specifically, this study investigated how these two populations understand and communicate about depression and how they respond to depression in the contexts of their particular sociocultural backgrounds.

***Design and findings.*** In the study by Lee et al., nine health professionals of API descent who were servicing the API community conducted a series of focus groups. The authors found four themes. According to Lee et al. (2010), the first theme was a lack of knowledge regarding mental disorders, specifically depression, as interpreted in the United States. For instance, Hmong participants stated that the concept of depression as a mental disorder did not exist in their culture. Rather, Hmong participants stated that symptoms of depression were considered a normal reaction to life stressors, not a mental disorder. It should be noted here that language constraints within the Hmong language or language discordance between the Hmong language and the English language may contribute to Hmong's lack of understanding of the western concept of depression. That is, the Hmong language's limited relevant terminology pertaining to mental discomfort refers to feeling distressed, not depressed. A second theme that emerged was "culture-specific knowledge and beliefs about the causes of depression" (Lee et al., 2010; p. 329). Some participants stated that some API view depression as being caused by external factors such as children's misbehavior or limited English proficiency (LEP)—rather than by internal or biological cause. However, the Hmong believe that depression is connected to a person's spirit—rather than to the mind or body. A third theme identified in the study was the lack of knowledge of available professional help. Because many API see depression as an external cause that is related to the spirit, API lack of knowledge that depression is treatable through allopathic modalities. For API, seeking

professional help for depression may be difficult, especially when such help includes use of western medicine or allopathic modalities that are unknown in the API culture. Lee et al. found that some of the API in their study believed that depression was a normal reaction to life stressors and mistrusted western medicine or allopathic modalities for treatment of depression. The fourth theme identified in the study concerned “cultural attitudes toward seeking mental health services” (Lee et al., 2010; p. 329).

Stigmatization related to mental health causes elderly Hmong and Cambodians to not seek treatment. Stigmatization among the communities regarding mental health problems makes it difficult for those in need to seek allopathic treatment for depression.

***Critical analysis.*** Lee et al. identified several limitations and strengths of their study. The exploratory study had a small sample size and, as a result, the study’s findings could not be generalized to all Southeast Asian elderly—and much less to the API population as a whole. The Hmong and Cambodians themselves are also separate ethnic groups with their own individual cultures, beliefs, and traditions, and the study was not designed to identify the differences between these groups.

One of the Lee et al. study’s strengths, identified by Lee et al. is that it was one of the first to investigate mental health literacy among Hmong and Cambodian elderly refugees. Although this study targeted mental health literacy and not health literacy in general, the themes that emerged from the study are important and pertinent to health literacy in general. For instance, the theme of lack of knowledge and awareness regarding mental health disorders was evident in the focus group discussions with Hmong and Cambodian elderly refugees. Lee et al. found that language barriers contributed to the lack of mental health literacy, and cultural beliefs influenced the Hmong and

Cambodian's understanding of the causes of depression. Stigmatization regarding mental health disorders was also addressed in the focus groups. These are important themes to consider when looking at mental health literacy, and these themes are applicable to the current study of health literacy in the API-LWHA.

**Study: Low health literacy and poor health status in API in Hawaii.** In 2011, Sentell, Baker, Onaka, and Braun published a cross-sectional study that focused on low health literacy and poor health status in API living in Hawaii. The purpose of the study was to investigate health determinants and outcomes across three API groups: Japanese, Filipino, and Native Hawaiian. In their study report, Sentell et al. did not indicate the nativity or citizenship of the participants described as “Japanese,” “Filipino,” or “White.”

**Design and findings.** The question “How confident are you filling out medical forms by yourself?” is a single self-reported item measuring health literacy; this question has been validated against the REALM and TOFHLA. Study participants who responded “not at all,” “a little bit,” or “somewhat,” were designated as having low health literacy. Other variables, such as health outcomes, were self-reported. The sample racial categories consisted of *Whites* ( $n = 2,277$ ), *Japanese* ( $n = 1,201$ ), *Native Hawaiian* ( $n = 810$ ), *Filipino* ( $n = 731$ ), and *other API* ( $n = 380$ ). This study found a prevalence of poor self-reported health literacy of 18% for API group; this finding was higher than the 13% reported in a previous study that provided population information on API. Low confidence in filling out forms was most severe for Filipinos (23.9%), followed by “other API” (20.6%), Japanese (16.0%), Native Hawaiians (15.9%), and Whites (13.2%),  $\chi^2(4) = 52.22, p < .001$ . This study by Sentell et al. confirmed that low health literacy is a predictor of health status in the API living in Hawaii. API with low health literacy

reported high percentages of poor health: Native Hawaiians (28.3%), Filipinos (24.5%), Japanese (28.5%), “other API” (25.0%), and Whites (23.8%). Self-reported poor health was significantly associated with low health literacy among all groups of API except for Native Hawaiians, odds ratio ranging from 2.31, 95% CI [1.08, 4.94] to 2.72, 95% CI [1.23, 6.02] Filipinos to other API, respectively. Across the API groups, significant variation was noted in the associations between low health literacy and health status measures. Low health literacy was found to be significantly associated with diabetes in Native Hawaiians and Japanese, ranging from 3.03, 95% CI [1.34, 6.83] to 1.78, 95% CI [1.00, 3.16], respectively. Filipinos did not show a significant association in low health literacy and diabetes. Depression was associated with low health literacy for Native Hawaiians, 4.51, 95% CI [1.72, 11.81], but not for Filipinos and Japanese.

***Critical analysis.*** Sentell et al. (2011) stated several limitations and strengths of their study. The findings of Sentell et al. revealed differences in levels of health literacy and association of health literacy with health outcomes across various racial–ethnic groups; these findings indicate that health literacy interventions should be specifically tailored for individual racial-ethnic group. Although this study had a large sample size and used a validated self-reported health literacy instrument, it did not include individuals with LEP. Variation in English proficiency among participants could explain variation in health literacy within and between racial–ethnic groups. Overweight and obesity were not associated with low health literacy in this study; however, this apparent lack of association could have been due to the small size of the study’s sample. This study did not include assessment of English proficiency; as mentioned above, variation in English proficiency among study participants could explain some of the variation in health

literacy. Another limitation of this cross-sectional study is that causation could not be determined. However, Sentell et al (2011) did show that low health literacy is associated with poor health outcomes—a finding that is useful for those who wish to design health-care interventions and policy for the API population. This finding highlights the importance of health literacy for improving health outcomes.

**Study: Low health literacy, LEP and health status.** In 2012, a cross-sectional study by Sentell and Braun reported findings in accord with those of Sentell et al. (2011)—that API groups varied in their relationships between health literacy–English proficiency and health status

***Design and findings.*** The Sentell and Braun (2012) study focused on Asians and Latinos in California. Included in this study sample were Vietnamese ( $n = 466$ ), Koreans ( $n = 622$ ), Chinese ( $n = 1,234$ ), Latinos ( $n = 5,724$ ), Other (including Black, Japanese, Filipino, and other;  $n = 8,042$ ), and 32,339 Whites. (Sentell and Braun [2012] did not indicate nativity or citizenships of participants described as “Vietnamese,” “Koreans,” “Chinese,” Japanese,” “Filipino,” “Black,” or “White.”) The investigators aimed to deepen understanding of the relationships between (a) English proficiency and health literacy among racial-ethnic groups and (b) English proficiency, health literacy, and health. The California Health Interview Survey is a telephone survey used to assess health literacy of non-institutionalized adult residents of California who have access to a telephone. The survey is administered in six languages: English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese.

The percentages of participants within each racial–ethnic group who self-reported LEP were as follows: Koreans (39.3%), Vietnamese (38.5%), Latinos (37.3%), Chinese

(27.4%), “other” (15.2%), and Caucasian (less than 1%). Of the participants who self-reported LEP ( $n = 3,715$ ), 44.9% reported having low health literacy. Among participants who did not report LEP, 13.8% reported low health literacy. Sentell and Braun found that among those with LEP, Chinese had the highest prevalence of low health literacy (68.3%), followed by Latinos (45.3%), “other ethnicity” (44.2%), Koreans (35.6%), Vietnamese (29.6%), and Whites (18.8%). Latinos whose English proficiency was not low had the highest prevalence of low health literacy (17.9%), followed by Chinese (17.8%), Korean (15.1%), other ethnicity–race (15.1%), Whites (12.0%), and Vietnamese (8.1%). Poor health status was more commonly reported by respondents who indicated having LEP (42.9%) than by respondents who did not indicate having LEP (14.9%). Latino, Chinese, and Vietnamese populations with both LEP and low health literacy had significantly poorer health status than did respondents from the same racial-ethnic groups who did not self-report LEP or have low health literacy. The study’s sample revealed that low health literacy was prevalent among those with LEP. However, Sentell and Braun stated that high proportions of racial–ethnic groups with LEP (e.g., Koreans and Vietnamese) did not report low health literacy.

***Critical analysis.*** Sentell and Braun (2012) listed both strengths and limitations of their study. First, this study did not determine causation—specifically, whether LEP and low health literacy resulted in different outcomes. Second, the measures used in this study were self-reported measures, and the validity and meaning of self-reported health status and health literacy can vary across ethnic–racial groups. Sentell and Braun also found that in the API population, health literacy and health status were interrelated. These findings underscored the importance of independently researching the diverse

groups that constitute the API population. Although comparing several API subpopulations is beneficial, Sentell and Braun's findings showed that each racial–ethnic group in API has unique characteristics and would also benefit from studies that look at each group independently. In order to elucidate potential causal relationships between LEP, health literacy and health outcomes, further studies are needed. Sentell and Braun's study supports and enriches the literature on health literacy of API.

### **Health Literacy and HIV/AIDS**

**Study: Functional health literacy and medication adherence.** Recently, Colbert, Sereika, and Erlen (2013) conducted a correlational study based on de-identified baseline data used in a previous study. This study addressed the relationship between functional health literacy and medication adherence, mediated by self-efficacy.

**Design and findings.** The Colbert et al. study used a sample with 302 participants, of whom 58.6% were African American and 41.4% were Caucasian. Health literacy was measured using the Short Test for Functional Health Literacy (S-TOFHLA). An electronic event monitoring (EEM) method was used to measure medication adherence. Participants' medication bottles had a cap that recorded the date and time of every instance in which the bottle was opened. The Self-Efficacy Belief subscale of the HIV Self-Efficacy for Medication Taking measured self-efficacy. This subscale has good internal consistency reliability, with a Cronbach's  $\alpha$  of 0.95. Approximately 9.9% ( $n = 30$ ) of participants scored less than or equal to 75 on the S-TOFHLA—which meant that they had inadequate or marginal functional health literacy, 95% CI [7.05%, 13.83%]. No important difference in adherence levels between inadequate and adequate functional health literacy was found,  $U = 3.845.50$ ,  $Z = -0.521$ ,  $p = 0.602$ . The self-efficacy scores

of individuals whose functional health literacy levels were inadequate were not different from those of individuals whose functional health literacy levels were adequate,  $U = -3997.00$ ,  $Z = -0.183$ ,  $p = 0.855$ . The study's African American participants had significantly lower levels of medication adherence than did White Americans,  $b = -8.23$ , 95% CI [-15.25, -0.57]. Higher self-efficacy scores and medication adherence were associated,  $b = 0.21$ , 95% CI [0.08, 0.35]. Colbert et al. also found that neither functional health literacy nor self-efficacy directly or indirectly affected HIV medication adherence. The findings in Colbert et al. study contradict past findings regarding linkage between functional health literacy and medication adherence.

**Critical analysis.** Colbert et al. (2013) determined that the use of EEM to measure the number of pills taken was a limitation. The EEM does not determine that pills are actually taken by the participant. Requiring participants to complete a daily medication journal attempted to control for the accuracy of medication adherence. Colbert et al. also suggested that selection bias may also have occurred if participants chose not to participate in this study because of its use of EEM (i.e., because they choose to discontinue use of medication reminders). The timing of this study may also have influenced the outcomes, given that the study's data were collected in 2004, when antiretroviral medications were being combined in order to reduce or eliminate the necessity of taking multiple separate medications. Colbert et al. looked at both functional health literacy and medication adherence in relation to the number of medications the participants were taking. The number of prescribed medications—for most participants at this time, from one to five medications—was similar to the number of prescribed medications in current practice. Furthermore, Colbert et al. note that this study may be

limited, because it was a secondary analysis and used measurement tools that were needed to address other primary research questions.

**Study: Stress and poverty predictors of treatment adherence.**

In 2010, Kalichman and Grebler conducted a cross-sectional investigation of poverty (i.e., housing and access to food) and stress predictors (i.e., depression, stigma, and drug use) of medication adherence among people living with HIV/AIDS (PLWHA) who had low health literacy.

*Design and findings.* The study included 130 men and 58 women who were living with HIV/AIDS and who had scored below 90% correct on the TOFHLA. Medication adherence was measured by unannounced telephone-based pill counts. Two pill counts for each antiretroviral (ART) medication were conducted over 21–35 day intervals. Among all participants, 11% ( $n = 20$ ) had 100% medication adherence, 28% ( $n = 53$ ) had less than or equal to 90% medication adherence, 67% ( $n = 127$ ) had less than 85% adherence, and 50% ( $n = 95$ ) had less than 75% adherence. Depression was assessed using the Centers for Epidemiological Studies Depression Scale. Internalized stigma was assessed using items in the Internalized AIDS Stigma Scale. People with poor adherence to medication were found to be more likely to have scores that suggest depression, internalized AIDS stigmatization, and illicit drug use.

Kalichman and Grebler (2010) found that poor medication adherence was significantly related to experiential magnitude of stressor severity (social and health). Poor medication adherence was related to all indicators of food insecurity (choosing between food and medications, running out of food, cutting back on meals, and going hungry). The study found that food insecurity and medication adherence was

consistently related; this finding indicates that addressing these stressors is important—so that they do not eclipse the other benefits of reducing depression and stigmatization. Kalichman and Grebler reported that in this sample of participants with low literacy, reduction of depression, stigmatization, and other stressors resulted in improved medication adherence. It is of note by this current author, that Kalichman and Grebler findings may help explain why Colbert et al. (2013) found no association between functional health literacy and medication adherence.

***Critical analysis.*** Kalichman and Grebler (2010) identified the limitations and strengths of their study. A limitation to the study is the possible introduction of bias—in particular, the desire to be looked upon favorably—when participants answered questions regarding emotional distress, stress, and behavior. In addition, medication adherence data were collected at a single point in time, standardized measures for stress and depression did not have similar time frames, and stress measures were not comprehensive. Due to these limitations, caution must be used when drawing conclusions about possible relationships between stress and depression. The study’s use of convenience sampling and of single-site design constrained the generalizability of these results. Given all of these limitations, the study indicated that some needs, such as an individual’s need for adequate nutrition, should be considered when trying to improve medication adherence.

The principle strength of Kalichman and Grebler’s investigation is it’s finding that alleviating depression, stigma, and other social and health-related stressors may improve medication adherence. The study also found that although psychosocial interventions and stress management can improve medication adherence, in low-resource areas with disadvantaged populations these positive effects may be nullified by food

insecurity. The study's findings may help design adherence interventions in low-resource regions, such as Sub-Saharan Africa.

**Study: Brief screening questions or provider perception.** Ohi et al. (2010) conducted a cross-sectional study to (a) assess the accuracy of provider perception and brief screening questions in assessing health literacy; (b) determine whether the screening questions could be useful in health literacy screening in HIV clinics; and (c) compare the accuracy of the screening questions with provider perception and with self-reported education.

**Design and findings.** In this study by Ohi et al., health literacy was measured by S-TOFHLA. Provider perception, self-reported educational status, and participants' responses to questions on a 7-item literacy questionnaire, were analyzed using the *area under the receiver operator characteristic curve* (AUROC); in this analysis, the AUROC score ranged from .62 to .79. (An AUROC of 1.0 indicates an ideal measure of low health literacy. An AUROC of 0.5 indicates that the measure gave no information.) Using the health-care provider's perception to identify people with low health literacy yielded an AUROC of .63. Participants' responses to the brief screening question "How confident are you in filling out medical forms by yourself?" had an AUROC of .67. Self-reported education was a more accurate discriminator of low health literacy than were either the screening questions or provider perception (AUROC = .79,  $p = .02$ ) comparing education status to provider perception;  $p = .03$  for comparison of AUROCs for educational status and the question, "How confident are you filling out medical forms by yourself?"

**Critical analysis.** Ohi et al. (2010) identified several limitations in their study. This study excluded individuals who were not native English speakers. Also, the study lacked statistical power to reveal small but potentially significant difference between the accuracy of provider perception and that of the screening questions (required  $n = 150$ ; actual  $n = 143$ ). In addition, the two clinics differed in the continuity of care they provided. For example, in one clinic, approximately 40% of the patients had an outside provider, and patients were seen by several different fellows in training on the same team in the clinic; in the second clinic, fewer than 10% of the patients had an outside provider, and individual fellows in training and staff in the clinic saw these patients.

Given these limitations, the study nevertheless did provide important data. The screening questions were found to be insufficient in gathering information. Self-reported education was a more accurate identifier of low health literacy than the other screening questions. Providers were also found to be unaware of their patient's low health literacy. Ohi et al. suggest that the providers should be made aware of their patients' health literacy status in order to prevent misjudgment and medical error. This study showed that better interventions and improved patient-provider communication are needed in order to benefit individuals with low health literacy. The use of health literacy promotion and facilitation approaches such as the "teach back" method, minimization of medical jargon, and patient education using materials written at an elementary level education is clearly warranted.

**Study: Health literacy a predictor of HIV/AIDS knowledge.** In 2006, Hicks, Barragán, Franco-Paredes, Williams, and del Rio reported on their cross-sectional study that explored the association between health literacy and HIV/AIDS knowledge. The

investigators hypothesized that the HIV/AIDS knowledge scores of individuals with adequate literacy would not differ from those of individuals with inadequate or marginal health literacy.

***Design and findings.*** The study used REALM, a tool that uses reading ability through medical word recognition as a measure of health literacy. The instrument that is used to assess HIV/AIDS knowledge is a 22-item questionnaire that ascertains knowledge regarding the accuracy and timing of HIV tests, HIV/AIDS transmissions routes, and HIV/AIDS treatment. Hicks et al. did not specify who developed the HIV/AIDS knowledge questionnaire. Out of the study's 372 participants, 94% of the participants were African American, and 25% had inadequate health literacy as determined by their REALM scores. On the 22-item questionnaire, participant scores on ten questions clearly revealed that HIV/AIDS knowledge was correlated with participants' REALM scores ( $p < .001$ ), thus disproving the investigators' hypothesis. Participants with lower literacy levels were likely to be African American ( $\chi^2 = 6.62, p = .04$ ). In addition, lower literacy scores were also associated with lower income ( $\chi^2 = 8.67, p = .01$ ) and lack of high school diploma ( $\chi^2 = 58.04, p < .001$ ). Hicks et al. (2006) also found that, in comparison with participants with higher health literacy, participants with lower levels of health literacy (a) had more misconceptions about HIV transmission (b) were less likely to trust printed information on HIV/AIDS, and (c) were more likely to trust government authorities on HIV/AIDS. These three differences may be due to participants' with lower health literacy being less likely (a) to use printed materials HIV/AIDS educational materials, (b) to be informed about HIV/AIDS, and (c) to question authority.

**Critical analysis.** The study by Hicks et al. (2006) had both limitations and strengths. Hicks et al. state that providers offered HIV tests to those patients based on risk or medical reasons, and patients who were offered HIV tests were asked to participate in the study. The patients who were asked to participate in the study were more likely to be exposed to information about HIV/AIDS. Thus, participant's knowledge of HIV may have introduced participation bias. The questionnaire was not validated, and the findings in this study can only be generalized to the inner-city population in Atlanta. As noted by this current author, this study did not include API in their sample; 94% of the participants were African American, and 6% were "Other." Therefore, the study findings are not generalizable to the API population. Despite these limitations, the findings nevertheless did reveal a relationship between a patient's level of HIV/AIDS knowledge and the patient's health literacy (with adjustment for patient's income, education, and risk).

**Study: Seeking information about HIV/AIDS.** Zukoski, Thorburn, and Stroud (2011) conducted a qualitative study in order to discover how people living with HIV in rural areas seek information regarding HIV/AIDS.

**Design and findings.** A semi-structured interview was conducted with 16 participants; the interview focused on identifying sources and types of information and barriers related to seeking and obtaining information about HIV/AIDS. When asked to identify their primary source of information, two thirds of the participants listed their doctor; other information sources included the Internet, a contact person in a CBO from which the participants had been recruited, and their health department. Participants indicated that they were seeking information about disease progression and management,

insurance, financial assistance, nutrition, sexual behavior, and finding a romantic relationship. Participants reported encountering the following barriers: stigmatization, general fear, fear of disclosure, embarrassment, and frustration.

**Critical analysis.** Zukoski et al. noted several limitations of their study. The study's principal limitation was that all participants were recruited from a single doctor; however, Zukoski et al. (2011) limited potential bias by recruiting participants through flyers and by maintaining confidentiality. A second limitation was that the investigators were unable to recruit the target number of participants. The study's small sample size examination of within-group differences (e.g., gender, age) difficult; nevertheless, the study's findings did provide direction for future research. The study reported that patients' trust in their physician and stigmatization influenced types of information that the patients sought. Although this study did not include API in their sample, the qualitative study on HIV/AIDS information seeking is highly relevant to the study that this author is currently conducting.

### **HIV/AIDS and the API Population**

The nine studies that examined HIV/AIDS in the API population were classified into one of four subtopic categories: (a) general HIV/AIDS, (b) epidemiology of HIV/AIDS among API in the United States, (c) HIV/AIDS testing, and (d) HIV/AIDS stigmatization.

#### **General HIV/AIDS**

**Study: Target Expansion Project for Outreach and Treatment (TEPOT) program.** The TEPOT was an outreach program that targeted high-risk API in the San Francisco Bay Area. The participants were recruited from San Francisco, San Mateo, and

Santa Clara and were participants in the TEPOT program. In a descriptive, longitudinal study, Nemoto, Iwamoto, Kamitani, Morris, and Sakata (2011) compared substance use and HIV risk behaviors in three groups: API-MSM ( $n = 645$ ), API substance users who were not MSM ( $n = 586$ ), and incarcerated API ( $n = 118$ ); participants were examined both at intake into the TEPOT program and at 6-month following intake. The goal of this investigation was to formulate recommendations for outreach workers and other providers who provide care to API.

*Design and findings.* In assessing intervention outcomes, the investigators examined (a) demographics, substance use, and sexual risk behaviors (using the standard questionnaire, Government Performance and Results Act (GPRA)); and (b) lifetime substance use, HIV status, and sexual behaviors in the 6-month period prior to intake; and HIV knowledge and attitudes about drug and condom use (these latter measures had been developed for use in another study and were modified by Nemoto et al.). The GPRA questionnaire is constructed of the Addiction Severity Index and the Treatment Services Review; both standardized assessments have been used effectively in a variety of settings (Darby & Kinnevy, 2010). Participants' HIV knowledge was tested using 10 true/false questions about HIV scientific facts. No reliability or validity data were reported for these measures.

Nemoto et al. (2011) found that three quarters of all participants reported that they had engaged in illicit drug use, and in some groups, individuals reported preferences for one type of drug over another. Looking at all participants' data, inconsistent condom use for oral sex (90%) and vaginal sex (74%) was reported in the 6 months prior to intake; larger percentages of incarcerated API participants with steady partners had unprotected

vaginal sex (94%) and anal sex (92%). A larger percentage of API-MSM was aware of their steady partner's HIV status (88%) than were substance users (74%) and incarcerated individuals (68%). More API-MSM ( $M = 8$ ) had casual partners in the 6-month period prior to intake than did substance users ( $M = 4$ ) and incarcerated individuals ( $M = 4$ ),  $F(2,654) = 7.50, p < .01$ . More API substance users reported having sex with steady or casual partners under the influence of alcohol than did participants in the other two groups; API incarcerated participants reported having sex more frequently while under the influence of drugs than did the other two groups. The self-reported HIV prevalence rate was higher in API-MSM (6%) than in the other groups. Nemoto et al. found that, in general, API incarcerated participants had a lower level of HIV/AIDS knowledge (i.e., scoring, on average 7 correct answers in response to the 10 questions [ $M = 7$ ]) than did API-MSM ( $M = 8.4$ ) and API substance users ( $M = 8.0$ ),  $F(2, 1338) = 48.93, p < .01$ .

*Critical analysis.* Nemoto et al. identified several strengths and limitations of their study. After finding only minor differences in substance use and HIV risk behaviors between the intake data and 6-month follow-up data, the investigators decided to use only the intake data for the descriptive findings of this study. TEPOT provided referral services to high-risk API groups that were coordinated. The 6-month follow-up period may not have been long enough to reveal differences in the groups over time. Another limitation is that the measurement used to assess HIV/AIDS knowledge was not validated or reliable. Notably, all compiled data were based on self-report. Also, the membership of high-risk groups slightly overlapped. For instance, although no incarcerated participants reported having sex with other men, 3% of the incarcerated participants self-reported as being substance users. Within the API-MSM high-risk group, 8% self-

identified as being substance users. The findings in this study are not generalizable to all of the API population.

Despite its limitations, this study by Nemoto et al. nevertheless makes an important contribution to the literature on HIV/AIDS in the API population. For example, as these investigators noted, prior to the TEPOT study, data on API substance use and HIV risk behaviors were scant. Furthermore, even less was known about the substance use and HIV risk behaviors of the API who were not MSM (Nemoto et al, 2011). The findings of this study contributed to the existing literature by revealing how different the high-risk groups are in their substance use and HIV risk behaviors. These findings enable care providers to better address the specific needs of the various high-risk subgroups in the API community.

***Study: An evaluation of the Bridges Project.*** In 2006, Chin, Kang, Kim, and Martinez reported on findings from an evaluation of the Bridges Project, a community-based intervention designed to reduce deficiencies in health care provided to API-LWHA. The project's specific objective was to accommodate language and cultural barriers through use of bilingual providers of three services: language interpretation, case management, and client escort to appointments.

*Design and findings.* Participants in the Bridges Project completed evaluation forms during intake and follow-up procedures. During intake interviews, the bilingual providers gathered information on participants' service use, perceived barriers to service, and current medical condition—including self-reported CD4 count and HIV viral load. The Medical Outcomes Study Short Form Survey (MOS SF-12) was used to measure physical and mental health. In Chin et al.'s study, 58 Bridges Project participants (57% of

whom were citizens or documented residents and 43% of whom were undocumented) agreed to have their information used for the project's evaluation.

Looking at immigration status, Chin et al. reported that 90% of documented residents had received necessary services in the preceding year; only 55% of undocumented participants received such care ( $z = 2.3, p = .023$ ). At reassessment, most participants (97%) who needed primary care services received the services, regardless of immigration status. The differences between percentages of participants who received services at baseline (78%) and percentage of participants who were receiving services at reassessment (97%) were statistically significant ( $z = 2.2, p = .026$ ). Undocumented immigrants showed the most improvement shown in services received from those who needed it: from 55% at baseline to 100% at reassessment ( $z = 2.6, p = .008$ ). This improvement in primary care utilization attested to the impact of the Bridges Project on service use.

Chin et al. also noted that undocumented immigrants encountered not only more barriers to service, (9.3 vs. 4.0;  $t = 2.14, df = 49, p < .04$ ) but also a broader range of barriers (2.9 vs. 1.4,  $t = 2.8, df = 49, p < .01$ ). The primary types of barriers listed were language, cost, and fear. At the follow-up assessment, the rate of barriers per service decreased in the sample overall. However, at reassessment, undocumented participants and citizen/documented-resident participants did not differ in their rates of encountered barriers. The investigators also showed that the participants in the Bridges Project had significantly lower (i.e., worse) mental health scores from the MOS SF-12 measure than did the general U.S. adult population (49 vs. 42;  $t = 4.76, df = 6962, p < .0001$ ). In comparison with healthy U.S. adults, study participants had lower mental health scores

(healthy U. S. adults, 52.29; Bridges Project participants 42;  $t = 8.01$ ,  $df = 1314$ ,  $p < .0001$ ) and physical health (54 healthy U. S. adults vs. 49 Bridges Project participants;  $t = 5.1$ ,  $df = 1313$ ,  $p < .0001$ ). By the time of the follow-up assessment, the mental health scores of the Bridges Project participants improved—from an average score of 42 at intake to 46 at follow-up ( $t = 2.3$ ,  $df = 37$ ,  $p < .03$ ).

Qualitative data from this Chin et al. (2006) study showed that language interpretation was an important service for API–LWHA in the Bridges Project. Another theme that emerged from these data was the participants' expressed appreciation for their API–LWHA social culture, in which experiences were shared and relationships were nurtured. However, this same culture is also prone to HIV/AIDS stigmatization, and in the study by Chin et al., the theme of HIV/AIDS stigmatization was evident in participants' expressions of fear that their HIV-positive status would be disclosed within the tight-knit API community. The qualitative findings of the study indicate that the participants placed importance on overcoming language and cultural barriers—which was the objective of the Bridges Project.

*Critical analysis.* The study by Chin et al. (2006) had several strengths and limitations. One limitation was that caution must be taken when applying the findings to the general API–LWHA population. This study focused on the demographics and barriers of the Bridges Project participants, who agreed to contribute to the program evaluation. As noted by this current author, this study has a self-selection bias that limits the generalizability of the findings. Chin et al. stated that the findings may not reflect newly diagnosed APIs or APIs with severe deteriorating health. The sample size of the study was small and may have introduced a Type II error (i.e., false negative). The study

did not employ a randomized control design; rather, Chin et al. used convenience sampling for study recruitment. Accordingly, causation cannot be determined—that is, the study could not determine that the Bridges Project was the cause of the improvements seen from intake to re-assessment.

Despite its limitations, Chin et al.'s program evaluation provides important information on (a) health-care barriers that confront API and (b) an intervention that can help API–LWHA surmount these barriers. Provider's language background and proficiency can either ameliorate or exacerbate participants' perceived barriers—regardless of whether such barriers are actual or imagined (Chin et al., 2006). Language discordance between participants and providers can be corrected. However, even if the patient and the provider are proficient in the same primary language, the understanding of medical terminology or the health care system itself can hinder or help the outcome of the participant's health care experience (Chin et al., 2006). Also, the issues of HIV stigmatization and disclosure are difficult, particularly for undocumented API. Another lesson learned from the Bridges Project is that collaborative partnerships that focus on case management, housing, and immigration agencies may contribute to the participant's health care experience as well.

### **Epidemiology of HIV among API in the United States.**

***Study: Analysis of HIV/AIDS data from 1985 to 2005.*** Zaidi et al. (2005)

analyzed HIV/AIDS data using four different datasets: (a) Center for Disease Control (CDC) AIDS data reported by the 50 states and Washington, DC, from 1985 to 2002; (b) CDC AIDS data reported by the 50 states and Washington, DC, from 1999 to 2002; (c) CDC HIV/AIDS data reported by 29 states from 1999 to 2002; these data were derived

from a confidential, name-based HIV surveillance system; and (d) HIV testing and risk behavior data (by race–ethnicity) from 1997 to 2002 that were reported to the CDC-funded Behavioral Risk Factor Surveillance System (BRFSS).

From 1985 to 2002, an estimated 845,896 new AIDS cases were reported. Of the estimated 477,799 PLWHA who died from 1985 to 2002, 3,345 (0.7%) were identified as API. From 1999 to 2002, an estimated 66,638 deaths were reported; 419 (0.6%) of those who died were API (35–54 years of age; 83% were male, and 17% were female). Of the API male deaths, the deaths were attributed to MSM contact (67.1%), heterosexual contact (11.6%), injection drug use (12.2%), MSM contact with injection drug use (4.5%), and “other reasons” (4.6%).

From 1999 to 2002, 160,456 new AIDS cases were reported; in these data, 1,654 individuals were identified as API (ages: 25–44 years; gender: 82.9 % male; transgender status was not reported). The majority of API–LWHA resided in California (42.9%), New York (15.7%), and Hawaii (11.1%). Thirty-nine percent were born in the United States; 16% were from the Philippines, 6.9% were from Vietnam, and 4.9 % were from India; smaller percentages of API–LWHA came from other Asian countries. During this 3-year period, an estimated 102,887 individuals were newly diagnosed with HIV/AIDS; of these individuals, 564 (0.6%) were API. These API–LWHA ranged from 25 to 44 years of age and were mostly male (77.1%). Among API, the incidence of new HIV/AIDS diagnoses increased slightly from 3.4/100,000 persons; 95% CI [3.2, 3.6 per 100,000] in 1999 to 3.8/100,000; 95% CI [3.2, 4.5 per 100,000] in 2002—the lowest rate of increase among all reported racial–ethnic groups. Deaths of API–LWHA declined from 1999 to 2000; indeed, this trend has been seen in all racial–ethnic groups.

Approximately 84.8% of the 3,528 API diagnosed with AIDS in the United States by the end of 2002 were male; most of these individuals were MSM (71.4%). Of the 644 API who were living with HIV in 2002, most were male (73.8%) and categorized as having HIV/AIDS transmission risk from male-to-male sexual contact (65.9%). Using the BRFSS data from 2002, Zaidi et al. (2005) also found that, in general, API were significantly less likely to report being tested than were individuals in the general population (API, 32.6%; general population, 43.5%,  $p < .0001$ ).

*Critical analysis.* The study by Zaidi et al. had several limitations, but it also had some important strengths. According to Zaidi et al., the use of the HIV/AIDS surveillance system itself has severe limitations. Information on AIDS cases represents only the end spectrum of the HIV infection. The information on AIDS cases is limited information because of the inability to see the full spectrum of diagnosis—from initial HIV diagnosis to AIDS diagnosis. Approximately three fourths of the API population lives in ten different states (California, New York, Hawaii, Texas, Illinois, New Jersey, Washington, Virginia, Florida and Massachusetts); however, only three of these states (Florida, New Jersey and Virginia) use the confidential, name-based HIV surveillance system. Therefore, the AIDS data used in this study only represent a small percentage of API—one fifth of the AIDS cases in the United States (Zaidi, 2005). Also the population of API-LWHA was further underestimated due to misclassification of race-ethnicity in medical records, a main source for information (Zaidi et al., 2005).

Although the research by Zaidi et al. had limitations, it had important strengths that are useful for HIV prevention. For example, Zaidi et al. state that taking the diversity of the API ethnic groups and the HIV mode of infections into account is

important in planning HIV prevention strategies. Also, nearly two thirds of API–LWHA was born outside of the United States. It is possible that emigrating from their country of birth to the United States, which has a different culture regarding sexual freedom, may put them at higher risk for HIV/AIDS. This knowledge can inform prevention program planning and education—for example, on the importance of educating new immigrants on safe sex and HIV/AIDS.

***Study: Analysis of HIV data from 2001 to 2008.*** In another study of API in the United States, Adih et al. (2011) found trends that were similar to those reported by Zaidi et al. (2005). Adih et al. used data from 33 states and 4 dependent areas that had used confidential, name-based HIV surveillance systems since 2001. HIV diagnoses from 2001 to 2008 that had been reported to the CDC up until June 2009 were used for this study; an estimated 2,870 API were diagnosed with HIV from 2001 to 2008. Adih et al. estimated that from the early 1980s to 2008, 9,184 API living in the United States were diagnosed with AIDS. Of the total number of HIV diagnoses made from 2001 to 2008 (i.e., 293,534 HIV diagnoses), API HIV diagnoses were 1% (i.e., 2,870 API HIV diagnoses). Of these API who were diagnosed with HIV, most (i.e., 2,253 individuals) were male. By the end of 2007, 3,482 API (approximately 1% of the total number of individuals diagnosed by that time) were living with HIV. The largest age component of this API–LWHA group was 30–39 years (35%); 78% of this group was male, and among the males, 78% were MSM.

Notably, this study included API HIV diagnosis for individuals whose ages ranged from younger than 13 years to over 60 years: (a) for those 12 years and younger, the estimate was 26 HIV diagnoses; (b) for those 13–29 years, the estimate was 746 HIV

diagnoses; (c) for those 30–39 years, the estimate was 1,140 HIV diagnoses; (d) for those 40–49 years, the estimate was 651 HIV diagnoses; (e) for those 50–59 years, the estimate was 232 HIV diagnoses; and (f) 60 years and over, the estimate was 76 HIV diagnoses. This study could be included in this literature review because the percentages of child and adolescents participants were small in comparison with the total sample size. However, the merging of data for adolescents (individuals 13–17 years of age) with adults who were 18–29 years of age into a single “adolescent” category (individuals 13–29 years of age) made differentiation of data for these two age groups impossible. This study was also included in this literature review because it provides important epidemiological insights on the API population.

Adih et al. (2011) found that from 2001 to 2008, API was the only group that showed a 4.4% statistically significant *increase* in HIV diagnosis. Adih et al. used the estimated annual percentage change (EAPC) statistic to describe the amount by which HIV diagnosis rates varied over time. API males’ annual average HIV diagnosis rate increased significantly: EAPC = 5.1, 95% CI [2.1, 8.1]. API females’ annual average HIV diagnosis rate also increased but was not statistically significant, EAPC = 1.9, 95% CI [-3.2, 7.2]. Significant decreases of HIV diagnosis rates occurred in Hispanic/Latino (5.4%), Black/African American (3.8%) and White (1.1%). Adih et al. also reported that among those diagnosed with HIV infection, the HIV-to-AIDS interval was significantly shorter for API older than 30 years than for API who were 13–29 years of age. Also, regardless of sexual orientation, API who engaged in substance use and contracted HIV or contracted HIV through MSM contact *and* substance use were more likely to

experience a short HIV-to-AIDS development interval than those who contracted HIV through MSM contact only.

*Critical analysis.* Adih et al. (2011) state their study may not portray an accurate picture of the epidemic in the API population—given that (a) the data were obtained from 33 states and 4 dependent areas and (b) the study did not include data from California, Hawaii, Washington, and Oregon—four states with substantial API populations. As in the last epidemiology study with Zaidi et al. (2005), misclassification of race–ethnicity in medical records may have contributed to under reporting of HIV in the API community. Although to date the increases in total numbers of API infected with HIV are small in comparison with national statistics of HIV diagnosis, it is likely that the public HIV infection risk will rise as the API population grows during the next few decades. The Adih et al. (2011) and Zaidi et al. (2005) studies reported an increase in API diagnosed with HIV. The trend of increasing API HIV diagnoses has been evident since 1985. The importance of a statistically significant increase of 4.4 % in API HIV diagnosis in the more recent Adih et al. (2011) study highlights the need for more studies in the API population regarding HIV/AIDS.

#### **HIV/AIDS testing.**

*Study: HIV risks and testing behaviors of the API, 2002–2003 (2005).* As part of a national effort to assess HIV testing barriers and surveillance policies, the CDC and University of California–San Francisco collaboratively developed the HIV Testing Survey (HITS); the survey was conducted in 2000 (HITS–2000). Subsequently, Kahle, Freedman and Buskini (2005) used a modified version of HITS–2000 to survey 187 API who were at high risk for HIV; the survey was conducted from June 2002 to June 2003.

The inclusion criteria were (a) being in one of the three highest risk groups (MSM with sexual contact within a 12-month period preceding interview, heterosexuals with two or more partners in the 12-month period preceding interview, or injection drug users who had injected drugs in the 12-month period preceding interview); (b) 18 years of age or older; (c) a resident of Washington State for 6 months; (d) self-identification as API; and (e) English-speaking. Of the 187 individuals interviewed, 165 individuals were included in the study. The investigators' goals were to identify barriers to HIV testing, describe high-risk behaviors, and assess knowledge of HIV surveillance policies within the API community. Kahle et al. found that API who completed HITS-API did not self-report higher levels of unsafe behavior than did those who completed the HITS-2000. More respondents of HITS-API (90%) felt they had higher risk of contracting HIV than did respondents to HITS-2000 (71%), RR = 1.2, 95% CI [1.1, 1.3]. The study also found that consistent condom use was higher among survey participants who completed HITS-API (59%) than for those who completed HITS-2000 (47%). The study also found that belief in having a low risk of contracting HIV was twice as high among respondents to HITS-API than among respondents to HITS-2000 (62% vs. 36%, RR = 1.5, 95% CI [1.3, 1.7]). Significantly more HITS-API respondents' self-reported drinking five or more alcoholic beverages a month than did HITS-2000 respondents (42% vs. 29%, RR = 1.5, 95% CI [1.0, 2.9]). However, HITS-API respondents self-reported significantly fewer non-intravenous drug use than did HITS-2000 respondents (55% vs. 77%, RR = .07, 95% CI [.6, .8]). Kahle et al. also reported that HITS-API respondents (70%) were less likely to be tested for HIV than were HITS-2000 respondents (89%), RR = 0.8, 95% CI [0.7, 0.9]. Although HITS-API respondents who perceived that they might contract HIV

were also less likely to have been tested for HIV in the year preceding study intake than were HITS–2000 respondents, no statistical significant associations were revealed regarding perception of HIV risk.

*Critical analysis.* The study by Kahle et al. had several limitations as noted by the authors. The study’s small sample size resulted from difficulty in recruiting API—which in turn was due to lack of venues where high-risk API congregate. Also, because the survey was conducted only in English, API who speak limited English were excluded from study participation; as a result, an important opportunity to identify health care barriers that confront this API subgroup was missed. Finally, the survey used convenience sampling, and as a result, the generalizability of the study’s findings to the general API population was limited.

***Study: HIV testing patterns in API MSM in San Francisco.*** Do et al. (2005) used data from the Asian Counseling and Testing study database (ACT, Choi et al., 2004). A cross-sectional survey that investigated HIV testing behaviors of API–MSM was conducted together with HIV serological testing in 30 MSM venues; study participants were males 18–29 years of age. The sample was recruited from January 2000 to September 2001. Of the study’s 495 API–MSM participants, 121 (24.4%) had not been tested for HIV prior to this study. Participants who had not yet been tested indicated that their reasons for non-testing were low perceived risk, fear of results, fear of needles, and structural barriers. Among participants who had been tested ( $n = 374$ , 75.6%), common reasons for testing were having sex with a new partner (26.1%), having unprotected oral sex (24.7%), “just to find out” (23.1%), unprotected anal sex (22.8%), and “time for regular test” (13.6%). Of the 13 people who tested HIV-positive in this study, five

perceived themselves to be at low risk of contracting HIV infection, and five reported having unprotected anal sex. The study did not state whether there was an overlap of individuals who both perceived that they were at low risk of contracting an HIV infection and reported unprotected anal sex.

*Critical analysis.* Do et al. noted several limitations of their study. Selection bias may have occurred for several reasons. The surveys were all conducted at MSM venues; MSM who did not attend MSM venues would not have participated in the study. Also, the study sample selection did not include individuals who were unwilling to undergo HIV testing. The study excluded those who did not speak English or who spoke limited English. This study used data compiled from 2000–2001 in the ACT study (Choi et al., 2004); measures used in the ACT study were not validated or reliable. At the time of this study, no previous study had reported on API MSM HIV testing behaviors.

***Study: HIV testing among API–MSM.*** In a recent study on HIV testing in the API–MSM population, Wong et al. (2012) have examined (a) underlying barriers to HIV testing and (b) the care of API MSM who are HIV-positive. This study analyzed data compiled from a national study—Men of Asia Testing for HIV (MATH)—that had used a community-based participatory research design. Data were collected from CBOs in seven U.S. cities from June 2007 to August 2009. The aims of the study were (a) to assess HIV testing of a national sample of API MSM and (b) to compare care and treatment provided to U.S.-born individuals who had tested HIV-positive with care and treatment provided to non-U.S.-born individuals who had also tested HIV-positive.

Of the 445 API–MSM in the Wong et al. study, 35 MSM had never been tested for HIV infection. The untested API–MSM indicated that their reasons for not being

tested were laziness, structural barriers, fear of HIV-positive status, and HIV status disclosure. In this study, naïve testers (i.e., those tested for the first time) indicated that their reason for not having been tested earlier was low perceived risk of contracting HIV. Of the 410 individuals who had been tested, 335 MSM self-reported that they were HIV-negative, 39 MSM reported that they were HIV-positive, and 36 MSM reported an unknown status. Of the MSM who had reported that they were HIV-positive, three individuals turned out to be HIV-negative; of the 36 MSM whose status had been unknown, four subsequently turned out to be HIV-positive. The reasons reported by those who tested were relationship involvement, personal intention, doctor's request, research study or employments. Consistent with past research, per doctor's request, some individuals had not been motivated to undergo testing until after they had become sick and had been asked by their doctor to be tested (Wong et al., 2012). Among HIV-positive individuals, comparison of U.S.-born individuals and non-U.S. born individuals revealed no significant differences in CD4 counts, insurance status, HIV medication regimen, engaging in both care and treatment, and other key factors; Wong et al. attributed the lack of significant differences to small sample size. Although comparison by nativity revealed no significant difference, the study found that 22% of the HIV-positive men were not seeing medical doctors, 19% were not on medication, and 17% did not see a medical doctor nor take medications.

*Critical analysis.* As noted by Wong et al., the study had several limitations in design. For example, sampling bias may have been introduced both by the study's use of purposive convenience sampling and by the use of CBOs that conduct extensive HIV prevention programs. However, using diverse types of study sites in seven cities that had

the largest API populations mitigated against sample bias. The small subsample size of HIV-positive participants precluded assessment of HIV issues related to nativity (U.S.-born vs. non-U.S.-born).

As with the earlier study by Do et al., the Wong et al. study contributes to HIV/AIDS literature by exploring the barriers and the reasons for HIV testing among API-MSM. Wong et al.'s study recruited participants from seven sites (one site in each of seven cities) from 2007 to 2009. Wong et al. (2012) found that perception of risk was the major reason that individuals decided to be tested or not to be tested for HIV. For the naïve testers, a major reason for not being tested was structural barriers (where to get tested or inability to afford testing). These reasons for not being tested suggests a lack of knowledge on the part of some individuals regarding the availability free or inexpensive testing and regarding sites that provide HIV testing. Although health literacy was not assessed in this study, naïve testers' lack of knowledge regarding HIV/AIDS testing indicates the importance of promoting HIV testing in the API community.

#### **HIV/AIDS Stigma.**

*Study: HIV stigma and psychological distress in API-LWHA.* Kang, Rapkin, Remien, Mellins, and Oh (2005) aimed to deepen understanding of the relationships of the multiple dimensions of HIV stigmatization and psychological distress of API-LWHA who were receiving services from a CBO in New York City. The study's findings revealed that psychological distress was significantly associated with multiple dimensions of HIV stigmatization to which API-LWHA are subjected. In this study, 54 HIV-positive API participated in a semi-structured interview. The investigators used the Social Impact Scale to quantify participants' experience in the following dimensions:

*social rejection* ( $R^2 = .137, p = .006$ ); *negative self-worth* ( $R^2 = .126, p = .008$ ); *perceived interpersonal insecurity* ( $R^2 = .147, p = .004$ ); *financial insecurity* ( $R^2 = .081, p = .037$ ); and *discretionary disclosure* (not significant).

Undocumented API had greater degrees of HIV stigmatization than did documented API—as measured by self-reported social rejection,  $t(52) = 2.56, p < .01$ ; negative self-worth,  $t(52) = 2.59, p < .01$ ; and perceived interpersonal insecurity,  $t(52) = 2.79, p < .01$ . Undocumented API also reported having less social support,  $t(52) = -3.52, p < .01$ , and disclosed their status to fewer people,  $t(52) = -3.61, p < .01$ . Considering the dimensions of stigmatization as a set, these factors accounted for 22% of the variance in psychological distress. Kang et al. looked at two-way interaction effects between pairs of the stigmatization dimensions after controlling for physical symptoms, country of origin, and the main effects of the multiple dimensions of stigmatization. Kang et al. (2005) stated that two interactions were significant: financial insecurity compounded the effects of perceived interpersonal insecurity (increasing the adjusted  $R^2$  by 9%), and discretionary disclosure exacerbated the impact of negative self-worth (a 5% increase in adjusted  $R^2$ ).

*Critical analysis.* Kang et al. (2005) identified some limitations and several important strengths of their study. Kang et al.'s use of a cross-sectional design precluded determination of the sequence of events. Thus, the findings could not ascertain whether the relationship between stigmatization and psychological distress was determined by the influence of distress on stigmatization. The study's small convenience sample size also limited the interpretation of the sequence of events and contributed to self-selection bias; as a result, the study's findings could not be generalized to the larger API-LWHA

subpopulation in the United States. However, the study's findings illustrated the fact that HIV stigmatization is multidimensional, involving social rejection, negative self-worth, perceived interpersonal security, and financial insecurity. Kang et al. noted that the dimensions of HIV stigmatization and the relationships between these dimensions and psychological distress have multiple adverse impacts on the lives of API-LWHA.

*Study: Longitudinal study of psychological consequences of HIV stigma.* In 2006, Kang, Rapkin, and DeAlmeida conducted a longitudinal study to further elucidate the mechanisms and effects of HIV stigmatization on psychological distress. In this 2-year follow-up study, Kang et al. again considered stigmatization in terms of the multiple dimensions of social rejection, negative self-worth, perceived interpersonal insecurity, and discretionary disclosure. Kang et al. considered psychological distress in terms of self-esteem, hopelessness, dread, confused thinking, sadness, and anxiety. The study sample comprised 44 API HIV-positive individuals. Stigmatization was measured using the Social Impact Scale explained in Kang et al. (2005).

Kang et al. (2006) found that undocumented API scored lower on self-esteem than did documented API, both at baseline,  $t(42) = 2.70, p < .05$  and at follow-up,  $t(42) = 2.95, p < .01$ . In addition, undocumented API also had higher levels of perceived interpersonal insecurity than did documented participants at baseline,  $t(42) = 2.42, p < .05$  and at follow-up,  $t(42) = 2.76, p < .01$ . Other findings suggest that higher social rejection and social isolation were associated with lower self-esteem over the 2-year follow-up. Changes in dread were predicted by financial insecurity and discretionary disclosure ( $t_{FIXDD} = 2.71, p < .05$ ). These findings indicated the psychological effects of stigma were not transitory and persisted over a 2-year period.

*Critical analysis.* These two studies by Kang et al. (2005, 2006) support the conclusion that HIV stigma has harmful effects on API–LWHA. The strong relationship with stigmatization and psychological distress persisted over a 2-year period. Kang et al. (2006) stated that the generalizability of the study’s findings to the API population is limited by (a) the study’s small sample size and (b) use of convenience sampling, which identified a limited number of API participants who were HIV-positive receiving services from CBOs. Also, the majority of these API were medically stable. Findings might have been different if the sample had included a larger percentage of participants who were medically unstable. Thus the studies by Kang et al. (2005, 2006) make it clear that HIV stigmatization is a multidimensional phenomenon that diminishes the quality of life of many API–LWHA.

### **Summary**

Research shows that the number of API–LWHA in the United States is growing (Adih et al., 2011; Zaidi et al., 2005). The studies described in the preceding literature review substantiate the need for broadened empirical studies on HIV/AIDS and HIV/AIDS health literacy in the API population in general and in API–LWHA in particular.

The studies discussed in this literature review also reveal barriers that impinge on efforts to study the API population. Nemoto et al. (2011) and Chin et al. (2006) studied the subgroups of the API population (API–MSM, API substance users, API incarcerated, API documented and undocumented). Nemoto et al.’s findings show the differences between the high-risk groups in both substance use and HIV risk behaviors. Chin et al.’s findings on health-care barriers that confront documented and undocumented API inform

the providers, researchers, policy makers and the public and inform intervention planning. The API population comprises a broad variety of ethnic groups that are distinguished by significant demographic differences; these differences complicate and inhibit the generalization of research findings to the larger population of API. In addition, Sentell and Braun (2012) found variation between API ethnic subgroups with regard to health literacy, English proficiency, and health status. Taken together, the findings of health literacy studies on HIV/AIDS medication adherence are unclear. On the one hand, Colbert et al. (2012) found that functional health literacy was not associated with medication adherence; on the other hand, Kalichman and Grebler (2010) showed that, for individuals with low health literacy and poverty stressors were associated with medication adherence. The Zukoski et al. (2011) study examined in this literature review discussed how PLWHA in rural and low-HIV-prevalence areas seek information about HIV/AIDS. The aim of the Zukoski et al. study parallels the aim of the current study—to elucidate how API-LWHA seek information about HIV/AIDS.

The literature review reveals deficits in the understanding of health literacy and HIV/AIDS regarding the API population. In addition, the findings of studies that have either focused on API or identified API groups in their samples suggest that API subgroups differ from one another in health literacy and in health outcomes. In order to optimize the success of efforts to decrease HIV/AIDS risk in the API population, more studies are needed. The current study will contribute to the understanding of API-LWHA and of health literacy by exploring the types of information sought, sources of information, and other factors that are essential for improving health literacy in the API community.

### Chapter 3: Methods

The API population in the United States has been increasing every decade and is expected to exceed 40 million by 2050 (The Whitehouse, 2011). Not surprisingly, the API incidence of HIV infections has increased as well. From 2001 to 2008, a total of 2,870 Asians and Pacific Islanders were diagnosed with HIV infections—approximately 1% of total HIV diagnoses ( $N = 293,534$ ) in 37 states and U. S. territories during that period (Adih, Campsmith, Williams, Hardnett, & Hughes, 2011). Notably, during this 8-year period, the API population was the only racial-ethnic group in which HIV diagnoses significantly increased—specifically, by 4.4% in this population (Adih et al., 2011). Accordingly, it is a matter of concern that researchers have paid scant attention to the HIV/AIDS health literacy of API–LWHA—as evidenced by a lack of research on this topic. Given the expected growth of the API population and of API HIV prevalence, studies are urgently needed for the education of healthcare providers, researchers, policy makers—and, of course, of API communities.

The present study is a qualitative descriptive study for which data were collected during November 2011 by the study coordinator, a doctoral student. The goal of this study was to explore how API–LWHA seek information about their illness. One-hour, semi-structured, one-on-one interviews were conducted with participants recruited from the APIWC in San Francisco, California. Interviews were audio-recorded, transcribed, and coded. Thematic analysis was used to evaluate the interview data, and emerging themes were identified from this analysis.

## Setting

**Regional location.** API populations are primarily concentrated in metropolitan areas in the United States; the three cities with largest API populations are San Francisco, Los Angeles, and New York City (Adih et al., 2011). Furthermore, San Francisco's API-LWHA community itself is substantial: in 2010, the city's API-LWHA community comprised 5% of San Francisco's estimated 15,000 PLWHA (*San Francisco Department of Public Health HIV/AIDS Epidemiology Annual Report 2010* [SFDPH HIV/AIDS EAR 2010], 2010). Accordingly, as a national locus of HIV/AIDS education, awareness, prevention, and research, San Francisco is an ideal city in which to study the HIV/AIDS phenomenon in an API population.

**Study site.** In the San Francisco Bay Area, several API-specific organizations provide HIV-related outreach, testing, and other services. Among these organizations, the APIWC, the oldest HIV-related CBO in North America, has been providing services to the API community and to other underserved, marginalized communities for 25 years. The APIWC's mission is to provide health, hope, and shelter to those in need. APIWC offers a variety of services to the API community, to all vulnerable populations living with HIV/AIDS, and to those with other diseases: HIV and hepatitis testing, health education, prevention programs, support groups, and other behavioral and mental health services. The APIWC provides these services free-of-charge to those who have no access to health-care due to financial reasons—regardless of gender identity, sexual orientation, race-ethnicity, and immigration status (APIWC, 2012).

## **Recruitment and Participants**

Purposive sampling was used in recruiting study participants from the APIWC. The study coordinator posted flyers in APIWC's waiting room, hallways, and exam rooms. The study was also announced to approximately 15 people at the Joy Luck Club, an educational and social support group for API-LWHA that meets in the APIWC (APIWC, 2012). In addition, the study was announced to social workers and peer advocates, who also referred their clients to the study. Enrollment was open for approximately 6 weeks. Participants were included in the study if they were men or women who were 18 years or older and who self-identified as HIV-positive. Participants had to be able to provide informed consent and to speak English (those who were unable to provide informed consent were excluded). To reimburse participants for time spent in interview, all participants received a \$20 gift card that could be used at a local grocery store. The study was reviewed and approved by the Internal Review Board at University of California, San Francisco.

## **Data Collection Procedures**

Participant interviews with the study coordinator were scheduled during APIWC business hours, at times that were convenient for the participants. The study coordinator completed the interviews with all eight participants. Interviews were conducted in a private office space at the APIWC and lasted approximately 60 minutes; interviews were scheduled during business hours. Prior to each interview, the study was explained to the participants and informed consent was obtained. During the interview, participants were asked a series of questions regarding their HIV information-seeking practices. The questions, which were specifically designed for this study, used a semi-structured, open-

ended format to facilitate participant's free response (See Table I). During interviews, the interviewer used an interview guide as an aid to directing and refocusing participant discourse (in accordance with recommendation by Polit and Beck, 2012). The interviews were audio recorded, with participant consent.

After the interview, another study staff member transcribed the data verbatim from the digital voice recorder. After data collection, the audio voice recordings and all data that could identify participants were destroyed. Any personal identifiers linked to data were removed and replaced with an identification number. Consent forms and transcriptions of the interviews were and currently are maintained in locked files with limited access. Electronic data and all study data were maintained on a secure server and were password protected. The author's role was to form a concept of the study, perform data analysis, and report findings.

### **Data Analysis**

The study used thematic analysis, a commonly used method of qualitative analysis. As a research tool, thematic analysis identifies broad categories, themes, or patterns within a data set (Braun and Clarke, 2006). As DeSantis and Ugarriza (2000) have noted, the term *theme* has been defined in multiple ways in the nursing literature. According to these researchers, themes are abstract and confer "meaning and identity to a recurrent experience and its variant manifestation" (DeSantis & Ugarriza, 2000, p. 362). Themes characterize important aspects of the data and are related to the study's research question. Themes that emerge from data analysis do not necessarily recur with great frequency in the given data set (Braun & Clarke, 2006). According to Braun and Clarke, determination of themes for any given data set is up to the researcher's discretion.

Table 1: Interview Questions

How do you obtain information about your illness?
What types of information help you to understand your illness and your treatment?
Who gives you the most useful information? <i>Prompts:</i> <ol style="list-style-type: none"> <li>1. Doctor; medical staff</li> <li>2. Nurses</li> <li>3. Other health professionals</li> <li>4. Other patients</li> </ol>
Where do you get information from?
How does that information help you to understand your illness?
Have your skills in seeking information about your illness changed since you were first diagnosed? How?
What would be the best time to give you information about your illness?
How does that information improve your understanding?
What sources of information do you trust the most?
Why do you trust this information?
What sources of information do you trust the least?
Is the Internet a source of information for you? If so when do you use it? How? Why? If not why not?
Do you use online chat rooms to help you understand your illness?
How important is your nurse in providing information?
Can you tell me a story about how the information a nurse has provided you, which has helped you to understand your illness?

Thematic analysis method entails “searching *across* a data set—be that a number of interviews or focus groups, or range of texts—to find repeated patterns of meaning” (Braun & Clarke, 2006, p. 86). Also, because thematic analysis is not particular to a theoretical framework, this statistical method can be used in a variety of studies that use different theoretical frameworks. Braun and Clarke describe thematic analysis as being a *recursive* process that has guidelines and flexibility and involves back-and-forth movement through the phases of this process. Braun and Clarke offer a six-step thematic analysis guideline but advise that thematic analysis can be applied to a data set flexibly (i.e., the six steps are not rigid rules but, rather, can be modified to fit the research question and data).

According to Braun and Clarke (2006), the first step to thematic analysis is to become familiar with the data. For the present study, this author and the principal investigator, Dawson-Rose, read the interviews independently and noted initial ideas. The second step in the study’s thematic analysis involved generating codes, which, according to Braun and Clarke (2006), are the basic element used to identify data features. Braun and Clarke state that coded data differ from themes—that is, coded data are broader as “units of analysis” (p. 88; 2006) than are themes. Codes are developed using the data-driven method—an inductive process that does not classify data according to a preexisting framework (Braun & Clarke, 2006). For the present study, a codebook that defined the code and provided inclusion–exclusion criteria and examples was created to facilitate the coding process. The investigators collaborated and compared codes. Codes that were not relevant to the data were eliminated from the codebook. The investigators independently coded two interviews from participants 1 and 5. Consensus was reached

on coding differences. This author coded the remaining interviews. Collaboration between the investigators continued through the coding process in order to ensure that consensus was reached for all interviews. The third step in the thematic analysis involved listing all of the coded data from the interviews. The different codes were sorted and reviewed. Data (i.e., parts of the interviews) were extracted and organized under potential themes. In the fourth step of the thematic analysis, the investigators reviewed and refined the potential themes. All extracted parts of the interviews under the potential theme are reviewed. Considering how each theme relates to the entire data set further refines themes. In the fifth step of the thematic analysis, themes were defined and named. The investigators provided a written detailed analysis of each theme and identified sub-themes. The sixth and final step entailed selection of texts (from the interviews) that illustrated identified themes. The investigators then reviewed the selected texts and themes. These texts were then used in the final report—a written analytic narrative that tells the story of the data in context with the research goal. Chapter 4 is based on the findings of this study and includes these texts.

## Chapter 4: Findings

This research was conducted in order to explore how API-LWHA seek information. This chapter discusses participants' characteristics, interview findings, and themes that emerged from the interviews.

### Sample Characteristics and Demographics

The sample for this study comprised of eight participants who self-identified themselves as having been born in or having ancestry from Asian countries: Philippines ( $n = 3$ ), China ( $n = 2$ ), Vietnam ( $n = 2$ ), and Laos ( $n = 1$ ). The Laotian participant and one Vietnamese participant self-identified as transgender male-to-female; all other participants were male. Information on participants' sexual orientation was not included on the demographic sheet. Participants ranged in age from 32 to 59 years. Data regarding education, employment status, and indication of whether participants had computer-Internet access were included in the demographic sheet (see Table 2 for demographic information).

### Qualitative Findings

The participants made use of a variety of *sources* of information and also sought out different *types* of information. Participants' sources of information included the Internet, printed materials, social networks, professional health care workers, conferences, community centers, hospitals, bars, and a number of miscellaneous events. Among these sources, three were primary: social networks, the media (Internet and print materials), and health care professionals. The types of information centered primarily on HIV, HIV medications, and safety. The participants stated that depending on the sources of information, the types of information differed. In addition, in the context of this

Table 2: Demographics of Participants

Racial Group	Gender	Age	Highest Level of Education	Work for Pay	Access to Computer	Access to Internet
Filipino	male	32	college BA or BS	yes	yes	yes
Filipino	male	41	2 years of college/AA degree/technical school training	no	yes	yes
Filipino	male	46	college BA or BS	yes	yes	yes
Chinese	male	58	high school or GED	no	no	no
Chinese	male	59	2 years of college/AA degree/technical school training	no	yes	yes
Vietnamese	transgender (male to female)	40	high school or GED	no	no	no
Vietnamese	male	51	11 <sup>th</sup> grade or less	no	no	no
Laotian	transgender (male to female)	49	11 <sup>th</sup> grade or less	yes	yes	yes

particular group, API-LWHA, the participants found that language concordance and stigma were major themes in how they explored information regarding their illness.

Note: In the following discussion of qualitative findings, individual participants are referred to as “P1,” “P2,” etc.; the interviewer is referred to as “I.”

**Source of Information: Social Network.** All participants mentioned seeking information from their social network. For the purposes of this study, the term *social network* is defined as peers, friends, support groups, and communities of PLWHA or API. A patient’s social network does not include health care professionals, community agencies, organizations, events, the Internet, or printed media.

**Major theme: Support.** In describing information seeking from a social network, all participants mentioned the importance of support from peers, friends, and support groups. Such support included emotional support, services or resources offered, and encouragement of initial HIV testing.

*Emotional support and social interaction.* Many participants stated that they rely on their social network for emotional support and social interaction. Participants and their support groups and friends—in particular, those who also live with HIV/AIDS—developed a relationship based on mutual understanding and comfort with one another. This relationship provides encouragement and consolation, as illustrated by participant responses:

- P3: Yeah. If I have—yeah, I have friends who are also HIV and if we have problems or concerns I can always ask them how to handle stuff.
- P4: The support group is mainly for people who wants to be comfortable with other people with HIV. A lot of times people with HIV have a hard time dealing with the public. A lot of times you are tired, you don't want to go out, you know. Friends always say, "Oh, you can do it." They keep on pushing you out. They don't understand your situation, you know. And then, of course, in the '80s HIV was supposed to be a death sentence so at that time it was very serious, yeah. But now people seems to live longer now.
- P6: Mostly I come here in API, you know, the support group in here. Outside we hang out with a friend who HIV, we hang out together, we talk about it, we try to, you know, how to live a longer life, what we have to do.

P8: Yeah, that why I got a friend because I tell you [...?..][4:14] I live here and I still got a couple of friend they live here and when I found out I have HIV I call them, I tell them and—yeah, they say better I have to move here and I—they got - [...?..][4:32] they have [...?..] ACE[?]. Yeah, that's why I have to move back over here.

*Services and resource.* Some participants mentioned that their friends provide assistance in everyday matters such as translating, education, and caring for the sick. The services they provide help the participants in daily activities. This support continues to build and foster the relationships between the participants and their social network, while helping participants have the resources necessary to find information about their illness.

P4: And then my support group friend also, they always—if they hear something they will ask and we talk about it. So I feel comfortable with my HIV friend because they help me a lot. One time I was very sick and ill, I couldn't leave the house so I have no way of getting food. I was so weak. And they didn't have a volunteer for me so I have to call the support group. Oh, the support group, three or four people came and then the one person bring some food and then the next day somebody came and bring me some drinks. So they were so supportive.

P6: I have some friend, you know, we live in the same building and after we meet—I mean the program, they have a program in the [...?..][12:16] Hotel. We have some like curfews and, you know, from Monday to Thursday we have to back into our room before midnight. But from midnight to 5:00 nobody in and out, you have to stay inside your room or, you know, or we

can hang out together but if it's [..?..][12:38] the hotel that's—but sometime I got to his room. You know, he had a computer in his room, he showed me how to do this and that, to check e-mail, to get my e-mail addresses and then I start getting into it.

P6: Yes, we have the peer leader for the support group like [..?..][7:42]. We always keep contact with him, you know, whatever for my appointment, for my, um—um—anything, you know, his support is very good.

P6: Um—yeah, we have—we have to educate like for, you know, if you become HIV positive. We have to educate how to catch HIV, how to take medication, how to live a longer life, what you have to do, this and that, and [..?..][8:56]. [..?..] you always use condom, you know, to practice all the time, you know, come to the class.

P8: Sometimes like there is something I want to tell my cases worker, I don't know how and I ask my friend because my friend they Vietnamese and my friend they come with me and talk with me.

*HIV testing.* Several participants mentioned that their social network was instrumental in initiating the topic of HIV testing. In this instance, the participants' social network acted as a motivator to take action and find out their HIV status.

P4: Oh, it was a long time ago when I tested positive, you know. One of my friend who is a doctor and he say that they have treatment for HIV, we should all go and get treatment, so I went to get tested.

P5: And my friend told me to go to API and get tested so . . . .

P6: Um, yes, since I got here in San Francisco since 1988 and I just  
 [..?..][1:27] some friends or some, you know, people. I mean my friend  
 just tell me to go do this test and where to go, you know, [..?..][1:36]  
 where can we for the HIV test. Something like that.

**Major theme: *Offering support and being a resource for others.*** Several participants found that interaction with their social network led them to become a peer leader. Peer leaders offer support as well as information to their support group. Other participants found themselves functioning as a resource for information for their friend. The action of becoming a resource for others assists the participants in the types of information that they seek regarding their illness while helping others gain information about their illness.

P4: I don't think so because most of my friend are not as educated as I am and I do pretty close updating because I can read and write, you know, I have no problem. Most of my friend who are Asian they are not—they can't read well so they always hear from somebody and then they will ask me about it.

P6: I'm afraid I—before that I volunteer to do peer leader for [..?..][5:15] study, education for HIV and, you know, [..?..] be doing volunteer, just peer, they call peer leader and we have study like 40 hour and then we do pass out, you know, condom or tell how to, you know—I take the class, it take about 40 hour.

Participant 7 described feeling a sense of responsibility toward his friends. He stated that, as the only person living with HIV/AIDS among his circle of friends, he felt that he must educate them and even encourage them to be tested for HIV/AIDS.

P7: I mean when they have like, you know, questions, you know, like—you know, and also like—and also like, for example, like I remember—talking to my friends. Like I have these two friends, one is not sexually active and the other one is, like she is just like really kind of slutty or whatever. And I remember like going through Castro and actually have like the one to walk them into the—because like on Bank of America they were doing like a rapid testing so I actually had to like not drive them but like make them.

I: Make sure.

P7: Yeah, make them actually. So I brought them in, you know, because I already know like what I've got and where I'm at because I'm always—I'm seen here like every—either like I usually get my labs every three months, you know, and then I have like a [..?..][8:29] screening every three months also so—yeah. But, yeah, definitely like—like for me like knowing—like I always used to tell them [..?..][8:40], it's kind of corny but "Knowing is beautiful." So I tell them and they're like, "Okay." And then ,of course, you know, like—and then after the test, you know, and they pass or whatever and then—and I was like, "See that feeling," like "Don't you like that feeling like knowing?" But that only covers the past six months. Like

the past three months you've got to, you know, just have to be good and watch out, you know, and do it again, you know, so they're like, "Okay."

**Source of Information: Media–Internet and Printed.** Participants cited the Internet, magazines, flyers and research articles as important media sources of information. The use of the Internet and printed materials among participants revealed several major themes.

*Major theme: Verification of information and clarification of understanding.*

Participants used these media resources to corroborate information they gathered from their social network and to verify or clarify their understanding prior to asking for additional information from their health providers or social network. The use of the Internet and print media in this verification process helps participants gain a better understanding of their illness.

P1: Well, yeah. The Internet's kind of more—it's like someone saying, "Oh, yeah, I've heard about [..?..][11:56] in [..?..] patients," you know, but then they don't know the whole answer or the whole story. So to go online it's easier. Then you can just get all the facts right there, yeah. But I think it starts with the peer first. The peer [..?..][12:11] and then the interest—I mean they're the ones that bring it up and go, "Oh, that's something to look for online," you know, yeah. Yeah. Well, yeah. The Internet's kind of more—it's like someone saying, "Oh, yeah, I've heard about [..?..][11:56] in [..?..] patients," you know, but then they don't know the whole answer or the whole story. So to go online it's easier. Then you can just get all the facts right there, yeah. But I think it starts with the peer

first. The peer [..?..][12:11] and then the interest—I mean they're the ones that bring it up and go, "Oh, that's something to look for online," you know, yeah. Yeah.

P1: So online would be the easiest, yeah. I rarely have to research anything like that but it would be online for me, yeah. That would be the easiest way to get information, yeah. Yeah. And then once I educate myself I would go to a nurse and say, "Well, I think I have this illness because I have these symptoms, and I learn these symptoms from online. I educate myself online first then I would go to the nurse and say, "I think I have this problem." And I might talk to some friends and say, "I think I have symptoms of this," then they would encourage me to go to see a doctor.

P3: Yes. If I have something in my body, going on in my body I can research it and how they look like, you know, on the Internet and compare it to what I have.

.....

Yeah. I show it to my doctor and address my concern then so that kind of I feel better, you know. Especially if it's nothing to worry about.

P4: Yes, I do use Internet. But I don't think there's anything. The only thing I use Internet is to check what the newspaper or the TV news talk about. Once in a while they talk about HIV research, there's some new research coming out, la-la-la. So I want to find out and then if I miss the TV program I go to the Internet to repeat, yeah.

P4: You know, the gay newspaper become the gay culture. I have a straight friend who didn't—who got positive and he would read the gay paper too because of the information he can find because in the regular like Chronicle they don't say much, they only say about certain research and so on. So I got from my own family, my family told me about the paper, friends, close friends. So in a way it makes me feel good, they are also taking care of me, you know.

P7: Fliers? I like those little brochures that they do have, you know, like because I mean like—even those like list of medicine, for example, or—or like the POS, like [..?..][20:59] like magazines and those are like really helpful like during, um—I don't know, like for example, like this—I didn't notice it until like this year about, you know, the POS belly that they're talking about. And like I'm like, "Oh." Like, yeah, I didn't know at what it is until I saw the brochure and I was like, 'Oh, I guess it does exist, you know, because one of my other—oh, I guess I have three friends that are positive I guess.

**Major theme: Referral for support.** The uses of the Internet and print media are also used as a referral for support. Participants used these sources when seeking educational information or community referrals. The Internet and print media were instrumental in leading participants to settings that assisted in seeking information regarding HIV/AIDS.

P2: Sometimes they will send me the letter and they will tell me the meeting, the time. Sometime in the newspaper like—Bay Area [..?..][13:25].

- P5: Yeah. Yeah. And really you go to—like, you know, people on the street they say, "Oh, here's the flyer. Check out. Check your test." You know, like Gay Pride and like—okay, you know, parade, you know, like Folsom Fair, Gay Pride, you know, like some kind like that and then they have the flyer on the table.
- P6: We are the one who give [..?..][19:23] flyers, you know, to someone who didn't study. [..?..] studied peer leader and, you know, [..?..] little bit pass out a flyer, this and that. I'm like—I work with them like 80 hour, only 40 for the study and another 40 to help them, you know, to [..?..] out-patient, you know, who pass out a flyer, condom, and sometime we had like parade, I maybe go out [..?..][19:56].
- P7: Yeah, like one of my favorite like apps sometimes is like I go through the news and I go through the health, you know, because like whatever kind of development they have or, you know—I mean I even like heard about this guy in London that like he's supposed to be like cured, you know, like he's HIV-free now, you know, not just undetectable. So it's things like that. I still read about that, I like reading those kinds of like, you know, articles. And, of course, like I have to get it from—I don't like doing the search because I mean like, you know, like Google or Bing just because they're too wide.

**Major theme: *Barriers to the Internet.*** Although some participants utilized the Internet, other participants explained why they seldom used the Internet as a primary source of information. The barriers to Internet use varied among participants. Two

major reasons why such participants did not use the Internet were lack of skill in using the Internet and lack of a computer.

P1: Not currently but I have a phone that there's –it goes online, yeah. Yeah.

Not currently but I've had Internet access before, yeah, but I'm staying somewhere where I don't have access right now.

P2: Yeah. If I have computer I will do that but I don't like to go to library, you know, so don't go to library. People will see me [chuckle], they watch [..?..][10:32] online for HIV, you know, so [..?..][10:33]

P5: But I don't know how to use computer that much.

P8: I would like to but I don't know how to use computer. . . . I learned a couple of times but –yeah, now I got a lot of time, you know, and like I go to school for English a couple of times but not work. I don't know [..?..][17:24]I got old[?] or I have HIV because just like every day I take a lot of medicine and I go to school for English. I don't remember.

**Source of Information: Health Care Professionals.** Participants mentioned obtaining information from several categories of health care professionals: physicians, nurses, social workers, case managers, pharmaceutical representatives, and therapists; the main source of information was physicians. The theme of trustworthiness recurred throughout the interviews.

**Major theme: Trustworthiness.** Many participants expressed the view that the physician is the most trustworthy of all of the health care professional sources. The participants confirmed information gathered from other sources with their physician, in part because they trusted that the physician was more knowledgeable or more invested in

their health than were other sources. For some participants their physician was their most trusted source of information about HIV/AIDS.

P1: I'm one of those people that trusts the doctors even if it's [..?..][14:01] online I let them know, "Well, I heard differently." And then I hope that they will either tell me that it's wrong or they admit that maybe they don't know, you know. Yeah. Yeah.

P2: Because the doctor—because [..?..][21:23], the support-the doctors[..?..] take care of the patient health right? Right? The doctor make sure the patient is not sick. And my friend, because he similar, right so my friend he tell me something [..?..]. He even tell me some things that are not true because we are both with HIV. And my doctor- of course, my doctor must tell me about the HIV.

P3: Because I know they're (doctors) more up to date, they talk about it and they study it. The Internet can give false information sometimes.

P3: I rarely talk about that. I felt more- it's more confidential when I talk to the doctor.

P6: . . . better because the primary doctor [..?..][21:28], primary doctor, so anything happening or whatever, you know, I believe, I trust the doctor. So he the one to tell me what to do, what should I do, you know, things like that. But Internet— I like Internet that much. But I just starting learning about—you know, if it said so, I mean whatever the Internet, you know, but mostly I trust the doctor better.

Participant 6 explained his placement of trust with his physician by comparing the information reliability of physicians with that of friends.

P6: With—only with a friend, you know, we have to listen, um, here and there but if we trust—I trust the doctor, it's better, you know. A friend, they can say anything they want to say but the doctor is the one taking care, look out for me.

Another participant spoke of a time when he experienced partial facial paralysis. Instead of seeking emergency help, the participant sought information from a website that had a diagnostic tool; the experience of using a diagnostic tool on the Internet instead of the physician is explored in the following:

P7: I had Bell's palsy and I—I didn't know what was happening because it was just like—you know, I started to drink water and then I couldn't move half of my face, you know. And I remember going there, going on that website because, what is it called, like I had to wait for my doctor's appointment, you know. But I remember getting more freaked out because the result, I guess, that WebMD gave me so not again.

I: Not again.

P7: Yeah, not again.

I: It didn't help.

P7: Yeah. So getting it from like the doctor actually like—you know, because at least here like you see the doctor and then you—you do like certain tests, you know, and then, plus, like it's his job [..?..][4:52] so he knows what's going on, you know, so . . . .

**Summary of sources of information.** Participants in this study made use of various sources—primarily social networks and health care professionals—to gather information regarding their illness. In participants' statements about their social networks, the importance of *support*—emotional and social—emerged as an important theme. The social network also provided services and acted as a resource for interpretative and other educational services. Participants also credited their friends as providing motivation for the participants' initial HIV testing. Although social networks provided support and resource, some participants *provided* support and resource services to their peers, friends and support groups as peer leaders.

Another major source of information used by the participants was the Internet and printed media. Participants' primarily referred to the Internet and print media in order to *verify and clarify information* received from social networks. One participant used the Internet to identify the cause of a symptom; in subsequent conversation with his physician about the symptom, the participant substantiated the validity of his health concerns by referring to this Internet information. Study participants stated that they also use the media as a *referral source for community support*. Participants noted that, when seeking educational information or community support such as HIV testing, they referred to the Internet or to health-related flyers and brochures for information. However, many participants stated that they seldom utilize the Internet; they cited lack of computer skills and lack of computer access as reasons for not using the Internet as a source of health information.

One theme emerged from information obtained from professional health care workers. Many participants spoke about the *trustworthiness of information* obtained

from health care workers, primarily physicians. According to the participants, physicians are one of the most trusted types of health care workers regarding HIV/AIDS information.

**Types of Information.** The types of information that participants gathered from primary sources differed from source to source. Many participants extracted specific types of information from a particular source. For example, participants and their social network informally discussed various topics of HIV information (e.g., HIV medications and safety information) with mutual understanding and leisurely discourse, while health care professionals provided similar information on HIV (e.g., HIV medications, safety) in discourse that was more formal and education-centered.

**Major theme: Seeking different information from different health care professionals.** Many participants indicated that they believe that different types of health care professional (e.g., physician, nurse, case manager, therapist) provide different types of information. Although, according to participants, physicians provide primary patient education on current and accurate information regarding HIV (e.g., HIV medications and their health), physicians do not provide education on safe sex education or social matters. Participants stated that nurses primarily provide secondary education regarding safe sex and condom use; in contrast, case managers and social workers are more likely to provide information about tertiary matters such as housing or insurance. For example:

P1: Too busy for that, yeah. Yeah. But, um—yeah. He really hasn't educated me on anything about what I can do for myself [...?..][2:04]. I think he's concerned that I adhere to my medicine but other than that I think it's up to me to ask a question, yeah.

P2: Yeah [..?..][3:15]. [chuckle] I talk to my HIV doctor [..?..][3:21] HIV. Just tell me my t-cells, something like that...But not—for—but for the other HIV information, you know... No. [..?..][3:36] my health not education.

P4: Yeah, yeah. I go to—if I need health care I go to my doctor and ask him and he is very good at it because he is in the location where they have a lot of HIV patients. It's almost like two thousand. So I feel comfortable because he is—he keep the update about the AIDS research and we talk about it and he seems to know as much as I know.

In discussing other types of health care professionals, participants agreed that nurses and case managers are important sources of information; however, participants noted that the types of information that nurses and case managers provide are different from information that physicians provide.

P1: Exactly. That's the whole—they (nurses) want to take the time and explain, I think that's their mission is to educate people with STDs, yeah. Whereas here I think the doctor—there's just so many things that he has to think about that [..?..][19:39] information—when it comes to information he'd rather—I feel like the doctors would rather help you immediately if you have a problem but education-wise they would rather you ask the nurse or something because they're too busy for that. I mean if you have the problem, you see that you have the problem, I know that they are going to educate me and say, "Well, this is what you have." But when it comes to—if I walk in there and ask them questions then I don't think that

they're—yeah. It just—I only ask my doctor questions when they think that I have a problem, yeah.

P1: I know that they're [*case manager*] concerned. I maybe ask—I may mention it and say, “Well if you're going to have that lifestyle just be very careful,” and so on. But I think—yeah, really I don't ask them about that. There's other things they do for me, the case manager, like housing and—and things like that but not safe sex, yeah.

P1: But when it comes to safe sex, I talk more about that with my therapist because we talk about—the way I'm healing or the issues that I have and so it becomes so like relationships and so on or issues about sex and they're there to support me and say, “Oh, you know, we have—” They always have condoms and so on there and so they're—yeah.

P3: Not—well, I don't talk to about health issues with the social worker and they may—but they can help me with other stuff, you know, that I need. My health, it's my doctor's concerns, priority.

P4: Oh, the case manager here, they already went through a lot so they know. I suppose if I need something, you know, social—like I need housing, I will come here and ask my case worker.

P6: Um—most time the nurse only they just, you know, take the temperature, whatever, how you, you know, [..?..][16:07]. But most only the doctor, you know. Anything happen and we have to talk to the doctor.

P7: Yeah. I mean I like the nurse, you know, but I mostly see them for like doing labs, you know, like taking blood, you know, so—not so much [..?..][5:12]—not so much on the like . . . .

**Major theme: Types of information gathered from social network.** The types of information gathered from social networks are HIV information, medications, and safety issues pertaining to safe sex and clean needles. Participants noted that the information provided by their social network is similar to that of the health care professionals—HIV information, HIV medication, safety. However, information regarding safe sex and clean needles was gathered from their social network in informal discussion that involved exchange of information.

*HIV information and HIV medication.* Participants and their social network shared experiences and information on HIV and HIV medication.

P1: My peers, exactly. They'll say, "Oh, I'm on [..?..][5:50]" or "I'm on this cocktail," and so I find out [..?..][5:54] lesions from taking different medicines and there are different side effects.

P2: Yeah, I have a friend, yeah. Yeah, some of my friends sometime tell me the HIV information, yeah.

P4: Oh, before I forget, I think—a lot of times my friends, my close friend, even my sister too, she has found something about HIV in the paper, she will call me and let me know so I would look for it.

P4: Yeah. We talk about it because sometimes I'm on some medicine and I don't feel well so I usually talk to the people in HIV support group and then they say, "Oh, yeah, I was on that one before." Then he tells me what

his experience is. Usually I think I'm one of the few people who is at the front usually, at the front of the information.

- P7: Yeah, like one of my friends was like talking to me about it and I was like, "Oh, okay." Like I actually don't even know like the actual name of it yet but like he was telling me about—it's—because he just moved from [..?..][30:33] to that medicine because I guess it doesn't have the side effects that [..?..][30:42] does, you know, like the—because sometimes you lose sleep on that. Yeah, so—yes. And, I don't know, like he is in Asia right now but when he comes back I'm going to ask him because he just started taking it.

*Safety: The use of clean needles and safe sex.* Participants were able to discuss safe sex and clean needles with their peers without moral judgments. For example, participant 5 stated the following:

- P5: They show you how to use clean needle, how do you clean needle, how to protect with condom, everything like that.
- P5: Yeah, they [..?..][8:26] too but, you know, some of us we use condom, some of us we don't use condom. And some of us we – we inject crystal meth with a clean needle. Some of us we inject crystal meth with dirty needle and we have sex sometime with condom, some without condom and we get HIV. They understand.
- P6: From my friend, we—we talk about it so whoever educates, you know, HIV positive and safe sex. We talk about it, we practice, whatever, you know, most every, you know.

**Summary of Types of Information.** The *types of information* gathered from support networks included HIV information, HIV medications, and the use of condoms and clean needles—among other topics. Participants stated that physicians provide formal primary patient education about HIV/AIDS; in contrast, nurses primarily provide secondary education regarding safe sex and condom use. Case managers and social workers served as sources of information regarding tertiary matters such as insurance or housing.

**Language concordance and HIV/AIDS stigmatization.** In addition to the *sources* and *types* of information, participants mentioned two themes concerning language concordance and stigmatization of HIV/AIDS. Participants express how the relationship between the physicians and the participants is impacted by language concordance/discordance and HIV/AIDS stigmatization. Participants revealed two important themes of seeking information within the context of being in the population of API-LWHA.

**Major theme: Importance of speaking the same language.** Two Vietnamese participants spoke Vietnamese as their first language. The physician at the APIWC also spoke Vietnamese. Participants were more comfortable in language-concordant clinical encounters (i.e., when participants and health care worker spoke the same language) than in language-discordant clinical encounters. These participants stated that the physician's ability to speak their native language was beneficial:

P5: Very comfortable. I know Dr. [..?..][10:42] a long time and Dr. [..?..], he Vietnamese too so we speak the same language so we're very comfortable.

Participant 8 contrasted his experience in speaking with Vietnamese-speaking health care professionals with his experience in speaking with non-Vietnamese-speaking health care professionals.

P8: Because the nurse—like I don't have the nurse Vietnamese, you know, my doctor Vietnamese, that easy for me, you know, [..?..][11:01]

P8: Yeah, this time I got this guy, he talk Vietnamese before he American. But they are very nice. But this guy like [..?..][19:12] my doctor now. It's better for me because he Vietnamese. Sometime I got some to want to tell him, you know, that easy for me.

P8: The first time I got doctor Vietnamese before like every time I go see doctor they speak English. But like if sometimes like I [..?..][19:57], you know, like I got to tell my doctor I cannot tell everything. That's why that time they call a translator. Like [..?..][20:07] I go checkup I can talk with my doctor, he is okay. But sometime like I'm sick, I got a pain, I got fever, whatever, a lot I have to tell him, you know, that time I need translator.

Participant 8 continued to discuss his concerns with having people explain or translate for him. In his struggle to interpret information that he had received from health care professionals, he sought help from friends, peers, and support group.

P8: Sometime I [..?..][21:15] they have, you know, like sometimes my cases worker over here. They very nice. Sometime like I got the male[?], I don't how I—I want to find out the male and I have to come over here and ask them, they help me about that. Very difficult. I talk with them, I have to because, you know, my English not so good and they not speak

Vietnamese. Before they left the other cases worker Vietnamese but not now.

P8: Oh, yes. Yeah. Yeah, sometime they—like every month with Joy Luck Club the doctor or the nurse they come over, they talk about infection, HIV and the medicine. I understand a little bit, you know, and I got some friend they Vietnamese but my Vietnamese very good and I ask them what going on and they tell me.

**Major theme: Stigmatization of HIV/AIDS.** When speaking about their social network in their interview, some participants expressed their concerns regarding stigmatization—the act of casting shame on PLWHA. HIV/AIDS stigmatization within a participant’s family, the API community, and the general public affects the way one seeks information regarding HIV/AIDS.

P4: So I mean this HIV is a sexually-transmitted disease so it's relate to sex. That's why a lot of Asian people are ashamed of, you know, letting people know they have HIV because it's like a stigma, you know. If you have a lot of sex it means you are a bad person.

In view of one participant who is transgender, the Asian community continues to propagate stigmatization of HIV/AIDS. As participant 5 noted:

P5: The whole town will talk about you. But [..?..][7:30] I don't care because nobody pay my rent, nobody buy me food, everything, but we don't want like, you know, like, you know, [..?..][7:40] stigma about you, talk about you [..?..].

I: So you mean there's a lot of gossiping or wrong information in the Asian community.

P5: In the community, yeah.

I: But how do you feel like which information you can trust and which not?

P5: Well, sometime you talk to them they don't listen. It's—they know you dirty. They say "You dirty, you nasty. You got HIV, you dirty, you nasty. Especially you transgender, you get." Look at you down.

The stigmatization of the gay culture and of HIV/AIDS resulted in one participant's moving from Santa Rosa back to San Francisco. As the participant explained,

P8: Because myself I feel like in Santa Rosa not too many people gay, you know. And—when I find out I have HIV I scared too and I—I talk with my friend, like if I move here I don't feel lonely. Yeah, when I got here I feel that too.

I: You feel you have enough support, you have –

P8: Yes. I got friend and like—a lot of gay they live here and sometime like the people they don't want to talk about you like everything, you know. But like in Santa Rosa they do.

I: They do. They talk about everything.

P8: Yeah, they talk everything. Like sometime, you know, you—everything they will talk about but, anyway, not their business. They talk about you that why I don't want to live there because –

I: Is the talk maybe like gossiping, like they talk behind you or they talk face-to-face?

P8: No, they talk behind you.

I: Behind you.

P8: They don't talk face-to-face, yeah. Like [..?..][7:52]. But another friend, you know, I got a couple of friends in Santa Rosa, I hang out there, like we go to bar or go to [..?..][7:58], whatever. Like my friend they look gay, you know, when you see them you know they gay and sometime they talk about that, that why I feel uncomfortable.

**Summary of language concordance and stigmatization.** The study's findings show that language concordance–discordance affected the participant–provider relationship. Participants were more comfortable in language-concordant clinical encounters (i.e., when participants and health care workers spoke the same language) than in language-discordant clinical encounters. One participant described his struggle with a need for an interpreter and his difficulty in interpreting information. Participants also mentioned the role that their social network had in fostering and perpetuating HIV/AIDS stigmatization. Participants' discussion of stigmatization focused primarily on the factor of community–(i.e., the API community in general and the local neighborhood community.)

## Chapter 5: Discussion

The present descriptive qualitative study explores how API–LWHA seeks information regarding their illness; the study includes interviews conducted with eight API–LWHA who reside in San Francisco. The few previous studies that have examined health literacy and the API population have focused primarily on the MSM population; to date, no studies have examined health literacy and API–LWHA. The present investigation—the first to explore the health information-seeking behaviors of API–LWHA—is intended to contribute and enrich the body of health literacy research on the API and the API–LWHA.

Studies that have used the TOFHLA test or the REALM test to assess health literacy have reported an association between health literacy and health outcomes (Kalichman et al., 1999; Kalichman et al., 2000; Kalichman & Rompa, 2000; Miller et al., 2003; Nokes et al., 2007; Sentell et al., 2011). These studies have also used a restricted definition of health literacy that focuses on the individual’s reading skill. The most commonly cited definition of health literacy, proposed by Ratzan and Parker (2000), focuses on an individual’s capacity to seek, gather, and interpret health information in order to make decisions regarding her or his health. In this regard, *information seeking* refers to the retrieval of information and knowledge regarding health, risks, and illnesses (Lambert & Loiselle, 2007).

### Sources of Health Care Information

The present study’s qualitative findings indicate that API–LWHA obtain information primarily from three sources: professional health care workers, participants’ social networks, and the media (i.e., from the Internet and from print media). These

findings are corroborated by several past studies that identified sources of health information. Zukoski, Thorburn, and Stroud (2011) identified several primary sources of information utilized by PLWHA in rural areas seeking information on HIV/AIDS. The primary sources were the physician, the Internet, an individual active in a CBO, and their caseworker. Another study, by O'Grady (2008), identified several sources of information used by male PLWHA in Canada: websites, printed media, health care professionals, AIDS organizations, and other PLWHA. In this study, sources of information for female PLWHA included physicians, AIDS organizations, printed materials, mailing lists, and other PLWHA. O'Grady also found a theme of verification of information that was similar to a theme found in the current study. Participants in O'Grady's (2008) study stated that they utilized various sources as a way to confirm information. A study by Hogan and Palmer (2005) surveyed 662 participants regarding information preferences and practices. For these participants, primary sources of information were physicians, family, friends, case managers, magazines, and pamphlets. Notably, the Internet did not rate highly as a source of information, but was preferred by people with more education and by those living in metropolitan areas. Huber and Cruz (2000) found that people living with HIV/AIDS in Texas identified AIDS newsletters as their most popular source of information, followed by magazines, physicians, and friends. Other sources of information were pamphlets, brochures, newspapers, social service agencies, and clinics.

### **Types of Health Care Information**

The present study found that API-LWHA sought out three main types of information: general HIV, HIV medications, and safety from the identified sources. The information that was gathered by participants differed depending on the source of

information. For instance, health care professionals offered a formal forum of discussion based on education while their social network provided an informal mutual discussion based on support and sharing of experiences. Zukoski et al. (2011) found that PLWHA in rural areas sought information about drug regimens, side effects, and research. Participants in the Zukoski et al. study also searched for information regarding disease progression, disease management, co-morbidity, insurance, financial assistance, HIV transmission, finding a relationship, sexual behavior, and nutrition. Huber and Cruz (2000) also found that PLWHA sought information regarding drugs, medical treatment, fitness, nutrition, dating, and legal issues; among these topics, information about drugs was of greatest interest.

### **Language Concordance and Stigmatization**

Shaw, Huebner, Armin, Orzech, and Vivian (2008) have asserted that effective patient–physician communication is important for successful outcomes. The use of similar language, contribute to effective communication. Chin, Kang, Kim, and Martinez (2006) noted that, for API–LWHA, language discordance was a barrier to health care services. The present study found that participants were more comfortable with physicians who spoke the participants’ native language.

Notably, while the role of social networks is primarily positive, some participants in this present study pointed out that their social network also played a role in fostering and perpetuating HIV/AIDS stigmatization. Participants’ discussion of stigmatization focused primarily on the factor of community, including both the API community and the general neighborhood community. O’Grady (2008) also found that the issue of stigma

impacted some people when accessing for HIV information. Zukoski et al. (2011) found stigma to be a barrier to seeking information for PLWHA.

### **Limitations and recommendations for future studies**

Although the present study has accomplished its goal of exploring information-seeking behaviors in the API-LWHA, the study nevertheless has several limitations. The study sample comprises only eight participants and represents four different Asian-Pacific Islander nationalities. These participants were recruited solely from a single (albeit well-known) site, APIWC, a design factor that limits the study's generalizability. The study's findings are representative only of API-LWHA who use APIWC (i.e., the findings are not representative of API-LWHA in general). Recruiting from multiple, diverse venues would have resulted in inclusion of experiential data from API-LWHA who does not access services from this center. Also, because the investigation's sample is small and its diversity is limited (relative to the diversity of the API population as a whole), the study's API sample could be viewed erroneously as having a homogeneous demographic identity—rather than as comprising many unique ethnicities. In subsequent studies, use of larger samples would enable inclusion of a broader range of API ethnicities and, potentially, discovery of ethnically unique health care experiences.

Although recruitment was open for women and men, women did not participate in this study. Voisin et al. (2013) found minimal gender differences regarding sources of information. Males reported more Internet use for prevention information than females (Voisin et al, 2013). Voisin et al. also found that males preferred more statistical information than their females. Huber and Cruz (2000) reported that based on percentages, females sought more information than males on several topics such as

wellness, dating and relationships, finances, death and dying and HIV/AIDS disclosure. Females were also more likely than males to consult AIDS telephone hotlines, support groups, pharmacists, therapists, pamphlets brochures, Internet and other printed materials for information. More studies on gender differences can help shape prevention strategies to help inform women on HIV/AIDS.

The demographic information sheet completed by participants in the current study did not call for identification of participant's sexual orientation; such information may have enabled analysis of unique information-seeking experiences specific to different sexual-orientation groups. Also, increasing the number of transgender participants may have enabled a deeper understanding about the ways in which this subgroup of API-LWHA seeks information.

Important themes that emerged from the study's findings merit further research. For example, future studies should explore the theme of provider-participant language compatibility; better understanding of this theme could potentially result in improved access to general HIV information, increased knowledge, and enhanced use of knowledge concerning HIV/AIDS. These advantages might in turn lead to reduced health and health care disparities. Also, because newspapers and journals are increasingly converting to electronic formats (and becoming paperless), further research that explores the use of the Internet for API-LWHA health information gathering should explore the experiences of this group relative to Internet accessibilities, skills, and barriers to use. Although stigmatization is well documented in the HIV/AIDS literature, studies on HIV/AIDS stigmatization in API-LWHA communities would provide insight into this population's particular needs.

## Conclusion

The present study's findings regarding the means by which API-LWHA seek information about their illness lead to several conclusions. First, participants evaluated their sources of information on the basis of trustworthiness. Interviews revealed that the participants rank their information sources according to a hierarchy of trustworthiness, with physicians viewed as being most trustworthy. Although the study's participants put physicians at the apex of trustworthiness, the study also revealed that the participants use multiple sources of information concurrently and analytically. For example, some participants obtain HIV/AIDS information from a friend or support group and verify this information using Internet sources and/or consultations with their doctor. Similarly, some participants obtain information from print media and then corroborate this information (or gain more detailed information) via informal consultations with peers, support groups, or community sources.

The finding that study participants trusted their health care provider more than they trusted less formal sources has implications for health care professionals—in particular, nurses, who play a key role in educating their patients. The responsibility of tailoring the information so that the specific population of API-LWHA can understand, process and act on the information falls to the nurses and health care providers. It may be possible to improve health outcomes by (a) improving the readability of health information materials (using strategies such as providing printed and Internet materials in the native languages of API-LWHA), (b) increasing the effectiveness of participant-provider communication, (c) and making information relevant and applicable to API-LWHA. Advanced practice nurses (APN) are ideally suited to assume a leadership role

in the health care environment and community and can contribute to improving health literacy of API-LWHA. By joining educational boards, contributing to interdisciplinary team meetings and conferences, conducting research and promoting awareness to health literacy in the API population and to nurses in the community and acute care, APNs can impact the health literacy of API-LWHA.

This present study also found that API-LWHA need and seeks support from friends, peers, and support groups. The diversity of types of support (e.g., emotional, social, educational, language-related, and health care) sought by the study's participants indicates that the health knowledge needs of this population are multifaceted. Many participants reported that they employ their social networks to fulfill service needs that health care professionals and the Internet are not able to address. Given that various sources of information are used by PLWHA, it may be hypothesized that a single source of information is inadequate for providing the multiple types of information sought by PLWHA. Further studies are recommended to test this hypothesis.

Finally, API-LWHA face many barriers to seeking information—such as stigmatization of HIV/AIDS, language discordance, deficiencies in computer skills and information access. Some of the barriers that confront API-LWHA have characteristics that are unique to the API population. The API-LWHA population potentially faces stigmatization by the general public, by the Asian community, and by family members and friends. The compounded distress of trying to understand information presented in a different language provides an additional barrier to understanding HIV/AIDS. The lack of resources and skills needed to access the Internet limits the potential pathways to seek information about HIV/AIDS.

In the ongoing effort to decrease health care disparities, studies on health literacy focus on the individual's capacity to maneuver within and through the health care system and to gain health care information. As the API population in the United States grows, addressing the health care needs of the API-LWHA subpopulation will become increasingly important. The importance of research studies, policy developments, and prevention interventions for the API is paramount in HIV/AIDS prevention and treatment.

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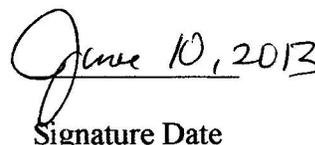
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