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## Examining barriers to care: Provider and client perspectives on the stigmatization of HIV-positive Asian Americans with and without viral hepatitis co-infection

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Between 1999 and 2003, Asian Americans and Pacific Islanders (APIs) in the US experienced more rapid growth in the number of AIDS cases than any other racial or ethnic group. In addition, the prevalence of HBV and HIV co-infection is estimated to be significantly higher among APIs in the US than in other racial/ethnic groups. High rates of HIV and hepatitis B or C (HBV and/or HCV) co-infection, in concert with language and cultural barriers, create significant challenges to effective coordination of treatment. The purpose of this study is to identify barriers to care and treatment in APIs with HIV with and without hepatitis co-infection. Specifically, we analyze results from semi-structured interviews with health care providers ( $N = 23$ ) and Asian Americans who are HIV and hepatitis (HBV and/or HCV) co-infected ( $N = 17$ ) in order to clarify how stigma in particular may impede/limit access to coordinated health care provision. Providers and clients recognize the need for integrated, culturally and linguistically appropriate access to care while simultaneously acknowledging that stigma is a severe barrier to access to care. This article sheds light on the complexities of the stigma experienced by HIV and hepatitis co-infected Asian Americans and suggests a need for further research and renewed efforts by caregivers to reduce stigma in these communities.

**Keywords:** HIV-viral hepatitis co-infection; barriers to care; stigma; Asian Americans

### Introduction

Hepatitis co-infection is a critical issue for Asian Americans and Pacific Islanders (APIs) living with HIV. APIs have a higher prevalence of hepatitis B (HBV) infection than any other racial or ethnic group in the US (Chao, Lee, Praong, Su, & So, 2004; Hsu, Zhang, Yan, Shang, & Le 2010; Lee, Lok, & Chen, 2010; Taylor et al., 2011), with one study finding that 85% of API men who have sex with men with HIV has past or chronic HBV infection (Choi et al., 2005). The epidemiology of HBV and hepatitis C (HCV) infection is different in APIs as compared to the general US population as most APIs acquire HBV perinatally from infected mothers or in childhood (Grytdal et al., 2009; Lin, Chang, & So, 2007), while HCV infection is most commonly transmitted early in life from unsanitary medical practices or blood transfusions. Therefore, by the fourth or fifth decade of life, many APIs are at much higher risk for long term complications of HBV and HCV than the general US population, such as cirrhosis, end stage liver disease and hepatocellular carcinoma (Chang, Nguyen, & So, 2008; Nguyen & Keefe, 2003). To reduce the risk of these

complications, treatment for HCV and HBV infection is essential.

Although no population based estimates exist, APIs with HIV likely have higher rates of HIV and HBV co-infection and have comparable if not higher rates of HIV and HCV co-infection. Co-infection with HIV and HBV or HCV is frequently observed, as these infections are transmitted via similar routes (Marcellin et al., 2011). Despite availability of effective treatments for HCV, only 10% of co-infected individuals complete treatment (Shafran, 2007).

Asian Americans and Pacific Islanders living with HIV are a stigmatized and vulnerable group who are frequently unable to access medical care and social services (Kang, Rapkin, Springer, & Kim, 2003; Pounds, Conviser, Ashman, & Bourassa, 2002). In particular, APIs who are recent immigrants, undocumented immigrants or who have low English proficiency experience marked barriers to care. APIs are an incredibly diverse group, and many medical and social service agencies are simply unable to provide culturally and linguistically competent services to such a broad spectrum. As a result, many APIs living

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with HIV are unable to access needed care and treatment (Chin, Kang, Kim, Martinez, & Eckholdt, 2006). In sum, APIs are less likely to be tested for HIV, more likely to present later in the course of their illness, and have less knowledge of their disease and of services available to them than other racial and ethnic groups (Wong, Campsmith, Nakamura, Crepaz, & Begley, 2004; Zaidi et al., 2005).

Few studies have focused on the perceptions of API clients living with HIV-viral hepatitis co-infections concerning barriers to care or of practitioners providing HIV and HBV-HCV services and their experiences working with this client group though anecdotal evidence suggests there are significant barriers to care (Meyer et al., 2008). Thus, the purpose of this study was to identify barriers to care and treatment in APIs with HIV with and without hepatitis co-infection. Specifically, in this article we identify structural, systemic, and individual mediators of and barriers to access to care and treatment in APIs with HIV with and without HBV or HCV co-infection. We anticipate that among APIs, systemic and structural barriers will include availability, organization, and coordination of services as well as financial barriers such as lack of health insurance and poverty (Cooper, Hill, & Powe, 2002; Penchansky & Thomas, 1981). Individual barriers might include acceptability of medical and social services, involvement in care, English proficiency, education, income, and cultural factors such as acculturation of immigrants (Cooper, Hill, & Powe, 2002).

In addition, we argue that stigma acts as a particularly strong barrier to care. We define stigma as the result of socially defined norms regarding what individuals and actions are deemed acceptable or unacceptable (Goffman, 1963). Social expectations may also lead to the stigmatization not just of certain individuals or groups but also of certain places that may be considered discredited or discreditable based on the types of individuals who inhabit such places as well as the activities perceived to occur within them (Balfe, Brugha, O'Connell, McGee, & O'Donovan, 2010; Takahashi, 1997). These barriers may impede appropriate use of medical and social services, such as HIV or hepatitis provider visits, mental health and substance abuse services as well as other social services (Chin, Botsko, Behar, & Finkelstein, 2009). While the argument that stigma is a barrier to care is not new, we argue that with co-infection, stigma is a particularly important barrier to coordinating treatment and care.

### **Description of qualitative interview methodology**

Little is known about how the multiple barriers outlined earlier may be complicated by the stigma attached to both HIV and viral hepatitis in API communities and the ways in which stigma may be experienced in unique and complex ways by API co-infected individuals. In order to explore how individual and structural factors may result in barriers to care for HIV and HBV/HCV co-infected Asian Americans, in 2008 and 2009 we interviewed both HIV positive and HIV – HBC/HCV co-infected Asian Americans and HIV and HBV/HCV healthcare providers focusing on barriers to seeking health services.

### ***Client interview guide preparation and sampling design***

Seventeen HIV positive Asian Americans residing in Los Angeles and Orange County, CA and able to speak English, Chinese (Mandarin), or Vietnamese were recruited into the study using a chain referral/respondent driven sampling strategy (see Table 1) (Heckathorn, 1997; Heckathorn, 2002; Magnani, Sabin, Saidel, & Heckathorn, 2005). There were no restrictions placed on whether or not participants were co-infected with HBV or HCV. The initial 11 seed participants were drawn from clients at the APAIT Health Center, a partner in the research study and provider of HIV/AIDS prevention and care services for APIs in Los Angeles and Orange Counties. Each participant was given a cash incentive of \$50 for participating in the interview (which included use of a semi-structured interview guide, completion of a questionnaire, and a phlebotomy). Additional participants were recruited via anonymous respondent driven sampling. Respondent driven sampling was chosen with the goal of doing a prevalence study and to access clients not currently affiliated with our partner organization to get a better sense of barriers to care (e.g., clients affiliated with the organization would have fewer barriers because they are already accessing care). Each study participant could refer up to three individuals and received an additional \$10 for referrals which met referral criteria. Six additional participants were recruited through chain referral/respondent driven sampling.

Trained interviewers who spoke English and either Mandarin or Vietnamese conducted the interviews. Informed consent documents were available in Chinese, Vietnamese, and English. All interviews were audio-recorded. Qualitative semi-structured interviews focused on (1) barriers and mediators of access to care and treatment, (2) knowledge of

Table 1. Descriptive Statistics for HIV positive participants ( $n = 17$ ).

Age [median (range)]	46 (20–61)
Gender:	
Male	87.5% (14/16)
Transgender male to female	12.5% (2/16)
Ethnicity:	
Filipino	41% (7/17)
Chinese	35% (6/17)
Vietnamese	18% (3/17)
Indonesian	6% (1/17)
Place of birth	
Born in US	6% (1/17)
Foreign-born	94% (16/17)
Citizenship:	
US citizens	53% (9/17)
Permanent residents	47% (8/17)
Hepatitis B infection:	
Chronic (+cAb, +sAg)	12% (2/17)
Past (+cAb, –sAg)	47% (8/17)
Vaccinated (+sAb, –cAb, –sAg)	35% (6/17)
Susceptible (–sAb, –cAb, –sAg)	6% (1/17)
Hepatitis C infection (+Ab)	12% (2/17)
Hepatitis B and C infection	6% (1/17)

co-infection status, (3) social support and stigma, and (4) social services, mental health, and other unmet needs. After the interview, participants were tested for HIV and HBV/HCV and received counseling to ensure that participants were aware of their own personal risks and gaps in knowledge for viral hepatitis and HIV.

#### **Health care provider qualitative interview guide preparation and sampling design**

The study recruited 23 providers in Los Angeles and Orange Counties, CA. Providers were asked questions about their knowledge of medical and social issues unique to APIs with HIV and HBV/HCV co-infection and perceived barriers to and gaps in care for APIs with HIV. The research team used convenience sampling and snowball sampling to recruit provider participants. Potential participants from providers/agencies were identified from existing HIV/AIDS and viral hepatitis coalitions in both Los Angeles and Orange County. For every agency identified, the research team attempted to recruit one medical provider and one social service provider. From this initial round of identification and recruitment, the participants were asked for help identifying other potential participants. All interviews were conducted in English. Of the 23 providers interviewed, 15 provided services primarily for HIV and eight provided services primarily for viral hepatitis.

#### **Method of qualitative data analysis**

All English qualitative interviews were audio-recorded and transcribed verbatim. Mandarin interviews were first transcribed into Chinese by professional transcribers then written Chinese was translated to English; all Vietnamese interviews were directly translated directly from the audio recording into English. A system of coding categories was developed based on themes that consistently showed up within the qualitative interviews. Team members developed a consensus coding scheme based on these themes, talking through the discrepancies between different team member's codes until the themes were consistent. Each interview transcript was coded by two coders and themes were compared. The analysis presented later explores the themes as they relate to barriers to health services and provides illustrative quotes.

#### **Findings and discussion**

In this section we describe barriers to care specific to Asian Americans with HIV and/or co-infected with HIV and HBV/HCV from the perspectives of health care providers and co-infected clients. Structural barriers identified include availability and coordination of services as well as lack of health insurance; individual barriers include English proficiency and immigration status. We then turn to a more detailed discussion of how stigma is a powerful barrier to coordinated care for HIV and HBV/HCV co-infected Asian Americans.

#### **Individual and structural barriers to care**

Results suggest that the lack of English proficiency is an important barrier to seeking services. Providers indicate that for many Asian immigrants, navigating the health care system is difficult due to language barriers as well as lack of knowledge about the US health care system. For example, Provider 110586 commented on a woman who delayed treatment until she experienced near fatal conditions and had to seek emergency care because “she didn't know how else to get any care in this city, uh, she did not speak English at all, and she just tolerated it”.

In addition to language, immigration status is also a barrier to care. Undocumented immigrants “tend to stay away from the medical system... for fear of being reported or being deported back to their country” (Provider 110594). Clients then wait to seek services until they become seriously ill. But, even those who live legally within the country fear deportation.

Immigrant Asians are also afraid of deportation because their home countries may lack the appropriate services to manage their HIV. Client HH302 discusses her fear of deportation because she does not have a green card and is HIV positive: “If they send me back to China, I have AIDS, and my medicines will be greatly affected. So I don’t know how I’m going to be able to keep on going. In China I might, might die, because Chinese medicine isn’t as effective.”

In addition to language and immigration status, Asian immigrants may display an attitude of submissiveness towards their doctors. Asian patients see the doctor as an authority figure, and therefore sometimes do not feel comfortable asking questions. Client HH101 reports that he wrote down symptoms and complications such as swelling and brought it up to his doctor. However, when his doctor did not pay attention, Client HH101 said, “They’re busy so... it’s okay, yeah.”

Clients may be more comfortable asking medical questions of someone they do not perceive as an authority figure, even if he/she does not have an expertise in medicine. Provider 110599, a social worker, states that her clients ask medical questions to her, after the doctor has already left the room. In this way, deference to authority may lead clients to forgo asking questions of their care providers – an important component for co-infected clients being treated by multiple physicians.

In the context of multiple individual barriers including language, immigration status, and challenges acculturating to a new health care system, clients face structural challenges due to a highly fragmented system of care. This is especially difficult for HIV-infected individuals who are co-infected with HBV or HCV. Provider 110586 comments that individual barriers are complicated by the fact that clients must seek care in multiple clinics and service centers; as a result “some of those individuals basically get lost in follow-ups, um, partly because they feel that they don’t want to go to too many different centers...” In other words, individual barriers are exacerbated by the highly fragmented system clients must navigate to receive care, a particular challenge for co-infected individuals.

### **Stigma**

For both clients and providers, stigma was the most commonly recognized barrier to care. For example, Provider 110594 explains that fear of stigmatization prohibits some clients from seeking ethnically or linguistically appropriate care:

One thing we hear a lot from the Vietnamese community is that they will not actively a lot of time seek out treatment within their own community because they’re afraid that it will get out in the community, because it’s a very close bonded group, and so, you know, their doctor who may be Vietnamese who they go to for HIV care may also be sitting next to them in church.

Providers state that the fear that HIV positive Asian Americans have of the stigma within their communities extends beyond avoiding providers of the same ethnicity but also leads to avoiding accessing services locally within their own communities. Providers indicate that not only do clients avoid providers who might be able to identify them but these clients also avoid places where they might be identified by members of their community. For them, the “stigmatism of HIV is still so bad in the community that they don’t want to expose themselves... [to] someone you know or just the street, like cousin, uncle, or whatever” (Provider 110579). In order to provide services for one client who was terrified of being recognized, Provider 110579 would make separate appointments a half an hour after the clinic closed, after the nurses and everyone else had left.

HIV positive Asian American study participants reported that they withheld information to avoid situations that would compromise their anonymity. For example, one client notes that when accessing general health care he withholds information on his medical forms as a means of protection against stigma:

There’s some things that I don’t tell them, so they probably know why I have HIV, because if it’s not through being bisexual, then it’s through being homosexual... that’s why. But at the time when I was going to the clinic, my wife was by my side. My little sister also accompanied me... I couldn’t fill out forms in front of them or... speak the truth like that. So... at the time, they didn’t know about some of the things. They didn’t know about my HIV things. So I didn’t speak honestly. (Client HH10)

Furthermore, providers and clients both report that clients do not always follow through on referrals, particularly when the referral is for a primarily Asian American provider or social service agency. Both Provider 110587 and Provider 110593 mention frequently referring clients to Asian health care organizations; these providers believed that their clients would fail to follow through on the referrals because they were fearful of having their HIV status disclosed. Provider 110593 describes the reasons why clients do not follow up on their API-specific referrals:

Yeah, they'll, you know, they'll give you excuses like, "Well, I'm too busy" or "I'm not sure, I'm not comfortable in a group" uh to "don't want help", "they must be all gay and I don't want to be there." "I don't want to be known that I have HIV." That's the most common.

In short, although numerous providers express interest in more closely coordinating ethnically and linguistically appropriate care, they also report that client fear of stigma is a powerful barrier to clients pursuing follow-up care.

Providers and clients also comment specifically about stigma and HIV and HBV/HCV co-infection. Both clients and providers note that co-infected clients may be willing to talk about their HIV status in specific, controlled settings such as support groups but tend to compartmentalize their conditions and avoid disclosing their viral hepatitis infection. For example, Provider 110587 discusses bringing presenters to speak to HIV positive clients about co-infection. His co-infected clients, he noticed, did not voluntarily disclose to the group their co-infection status, which he says, "is a big red flag for me that they're still ashamed of it and... they really haven't dealt with it." This provider later states, "all the co-infection support groups that have come up, died because people are that afraid."

Providers even report that the stigma associated with HIV positive status and/or HBV or HCV infection in the Asian American community extends to the stigmatization of physicians who provide HIV services. Asian providers stigmatize not only their clients but can also stigmatize providers of HIV services as well. Provider 110577 comments, "[Other providers] come up to me and say, 'Are you scared of getting AIDS?' Uh, you're the physician. You know how AIDS [is] come by. Why [do] you ask me this kind of question?"

### Conclusion

In this article, we examined how individual and structural factors, especially stigma, create barriers to care for Asian Americans with HIV with and without HBV or HCV co-infection via qualitative interviews with both clients and medical and social service providers. This issue of barriers to culturally and linguistically appropriate care is particularly timely given new priorities set under the Patient Protection and Affordable Care Act that call for increased coordination of care by ethnically/linguistically appropriate service providers (APIAHF, 2011). Providers and clients interviewed in this study generally recognized that structural and individual

factors such as access, language proficiency, fear of deportation, and difficulty acculturating to the US healthcare system are all barriers to care for HIV and HBV/HCV co-infected Asian Americans. However, stigma in particular plays a profound and powerful role in the way that Asian Americans with HIV access health care, and stigma extends even to their providers. Thus, despite the clear need for culturally and linguistically appropriate care for this diverse population, stigma around HIV (and to a lesser extent viral hepatitis) can create additional barriers for clients seeking ethnically/linguistically specific care and for providers within the Asian American community interested in filling this gap in care. Providers and clients in this study both recognized the need for integrated culturally and linguistic access to care but also acknowledged that fear of stigma is a severe barrier to accessing coordinated services. This article provided preliminary insights on the complex role that stigma experienced by HIV and viral hepatitis co-infected Asian Americans plays in accessing health care services, and suggests a need for renewed efforts by caregivers to decrease stigma in these communities, especially concerning multiple conditions.

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