

HIV Care in Asian and Pacific Islanders in Kansas

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Abstract

A complex cultural dynamic within the Asian and Pacific Islander (APIs) population contributes to barriers in HIV care. This qualitative narrative study investigated how awareness, resource accessibility, and cultural taboo impact HIV care in APIs in Kansas. Eleven HIV-infected API patients were interviewed. Two evaluators independently completed a qualitative themes analysis. Important themes impacting HIV care included lack of awareness, sex as a taboo topic, and misconceptions about HIV infection. These factors create a closed community regarding HIV prevention and care. Clinicians must be aware of these barriers and provide specific culturally sensitive information and care to this population.

Keywords

human immunodeficiency virus, Asian continental ancestry group, oceanic ancestry group, Kansas, culturally competent care

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What Do We Already Know about This Topic?

HIV prevalence among Asian and Pacific Islanders (APIs) is one of the lowest in the United States but they are the only ethnic group with a significant annual increase in HIV diagnosis rates since 2001.

How Does Your Research Contribute to the Field?

As a qualitative narrative study, APIs directly expressed their personal experiences related to how education, resource accessibility, and cultural taboo contributed to the effectiveness of HIV care in Kansas.

What Are Your Research's Implications toward Theory, Practice, or Policy?

Asian and Pacific Islanders in Kansas diagnosed with HIV expressed a lack of awareness and misconceptions about HIV prevention and care as well as cultural taboos with the topic, thus leading clinicians to better understand the need to provide culturally sensitive education and care to this group.

Introduction

HIV prevalence among APIs is one of the lowest in the nation.¹ However, APIs are the only ethnic group with a statistically significant average annual increase in HIV diagnosis rates since 2001.² The US Centers for Disease Control and Prevention (CDC) estimates 2% of the 50 000 people diagnosed with HIV infection each year in the United States are APIs.^{3,4} Although prevalence is low, there are additional cultural, linguistic, economic, and legal barriers to HIV prevention causing the increased incidence among APIs in the United States.^{2,5,6}

The trend for delayed detection of HIV in APIs is alarming because low prevalence is misunderstood as lack of disease rather than underdiagnosis.^{7,8} As an underserved population, misunderstandings of the HIV epidemic in APIs contribute to limited public health resources and funding for culturally sensitive HIV care.^{9,10}

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The complex cultural dynamic within this diverse population contributes to the barriers of HIV prevention.^{11–15} The shared struggles faced by APIs in their attempts to assimilate, such as language and racial discrimination, create a heightened intergroup vigilance and a community that keeps to itself.¹⁶ A strong stigmatization of HIV and its associated behaviors influence how HIV-infected APIs seek treatment.^{12–15} Although stigmatization of HIV impacts all people living with HIV/AIDS, a lack of research exists on how the cultural dynamic influences APIs seeking HIV care.

A total of 1.5% of the 3178 HIV cases in Kansas is identified as API.¹⁷ Even though HIV infection among APIs in Kansas is lower than national prevalence, it is of interest whether Kansas HIV prevalence follows national US trends. This study investigated how education, resource accessibility, and cultural taboo contribute to the effectiveness of HIV care in APIs in Kansas.

Methods

Ethical Approval and Informed Consent

This study was approved by the Institutional Review Board at the KU School of Medicine – Wichita (Study00004185, KUMC Human Subjects Committee 2). Only patients who provided informed verbal consent were interviewed. Verbal consent was approved to protect the identities of HIV-positive patients.

Study Population

Thirteen eligible API patients were receiving HIV care at the university patient care clinic. Approximately 75% of all HIV-positive patients in Kansas received care in this clinic. All patients who spoke English were 18 years of age or older with a confirmed HIV diagnosis and self-identified as an API. Eleven (85%) were contacted and agreed to interview.

Table 1 includes a summary of patient demographic information. The largest Asian subgroup represented in the study and in Kansas was Vietnamese.¹⁸

Study Design

Approximately 1-hour, audio-recorded, individual face-to-face interviews with HIV-infected API patients were conducted in this qualitative narrative study. Patients were asked leading questions about their perceptions of HIV in the API community (Table 2). All interviews, except one, were conducted in person at a university patient-care clinic. The exception was a secure video conference with a participant at a different location.

Interview questions were modified from the CDC's Real AIDS Prevention Project¹⁹ to focus on the effectiveness of HIV care in influencing the participant's journey to diagnosis. Follow-up and clarifying questions were added by the investigator as needed. One investigator (P.P.) conducted all interviews.

Table 1. Patient Demographics.

	N
Asian Subgroup	
Vietnamese	4
Hawaiian, Pakistani	2 each
Korean, Japanese, Hmong	1 each
Gender	
Male	9
Female	1
Transgendered	1
Age at time of interview	
20s	5
30s	3
40s	2
50s	1
Age at diagnosis	
<25 years	3
25-30 years	5
30-40 years	3
Years living with infection	
<5 years	5
5-10 years	5
>10 years	1

Table 2. Sample Questions Used to Guide Patient Interviews.

1. When and where were you diagnosed?
2. Prior to your diagnosis, how did you think HIV was transmitted?
 - a. Where did you learn of this information?
3. Prior to your diagnosis, have you ever been formally educated of HIV/AIDS by an established institution? (School, health clinic, community center, etc.)
 - a. How accessible is this information to other members of your API community?
4. Does your family know of your diagnosis? Why or why not?
 - a. If so, how did they react?
 - b. If not, what do you think they will say?
5. What perception do you think the API community has of HIV-infected patients?
 - a. How do you think this affects those suspicious of infection but are not diagnosed?
6. How do people feel about HIV testing in your API community?
 - a. What are the reasons why someone would not want to get tested? Why or why not?
 - b. Is it easy to get an HIV test in your community?
7. Do any stores, businesses, or other organizations provide information about HIV or condoms in your community?
 - a. If yes, which ones? (What types of establishments?)
 - b. If yes, what do they provide?
8. Have there been past attempts to address HIV in your API community?
 - a. What succeeded?
 - b. What failed?
9. What do you think can be done to help people learn about HIV and other STDs?

Abbreviations: API, Asian and Pacific Islander; STDs, sexually transmitted diseases.

Themes Analysis

Audio recordings of the interviews were transcribed by a research assistant and evaluated by 2 investigators (P.P. and S.P.). A qualitative themes analysis was performed where general themes within the interview narratives were documented independently, then compared noting commonalities and differences. Common themes were created by consensus.

Results

Six common themes emerged from the analysis of the interview narratives. The themes were (1) lack of patient awareness of HIV care, (2) taboo of sex in the community, (3) sources of HIV information, (4) misconceptions about HIV infection, (5) community perceptions of individuals who are HIV infected, and (6) the need for cultural preservation.

Lack of Patient Awareness

A prominent theme in every interview was the lack of patient awareness concerning HIV care. Participants had incomplete or incorrect information about HIV transmission, progression, and treatment prior to diagnosis and to a lesser degree after diagnosis. Patients did not know how or where to access preventive resources before their diagnoses.

Taboo of Sex

Another common theme identified in every interview was the taboo of sex. Two participants described sex as “dirty” and “immoral” (both Vietnamese males) because it demonstrated a lack of self-control outside of cultural mores. One participant noted the API community will label and shame the offender. Talking about anything associated with sex, puberty, condoms, and safe sex practices was “not proper” (27-year-old Pakistani) because it reflected on family image and respectability in the community.

Sources of HIV Information

The source of information for HIV-infected individuals was limited, in part, because of the taboo. Much of what is learned about HIV came from formal instruction through the school systems without supplemental information coming from the family or community. Except for the 3 participants not educated in US schools, patients learned most of what they knew about HIV prior to diagnosis from sex education classes. The education was not reinforced from within the community and became ineffective in preventing HIV infection in our patients.

Another common source of HIV information for the API community was the public media. Extensive media coverage of the 1980s was so effective in raising awareness about the severity of the epidemic that decades later it continued to reinforce the stigma associated with HIV that is a barrier to successful prevention.²⁰ For many older APIs who witnessed

media reports during that time, it was their only exposure to HIV education.

Misconceptions about HIV Infection

Lack of awareness and limited sources of HIV information created misconceptions about the disease. A common misconception was that “they think HIV is AIDS. They think HIV is death” (Pakistani female). This misconception in the community was noted by all participants. The media-influenced stigma associated with being HIV positive challenged norms, such as gender identity, sexuality, and premarital sex. A recurring misconception was the community’s perception that HIV is a “gay disease” (Japanese male). The media’s focus on death and AIDS in the gay community during the AIDS epidemic fostered this misconception. Those who did not identify as being homosexual or did not engage in homosexual intercourse believed they could not be infected with HIV because this misconception created a false sense of security.

Asian and Pacific Islander Community Perceptions of HIV

The perception that HIV-infected individuals are bad people is engrained in the API community. This stigma stems from the misconception that HIV infection results from “risky behavior of bad people” (Vietnamese male). Every patient described this perception of the community’s view of HIV-infected individuals. It influenced their own perceptions of HIV infection as well.

Some patients attributed the negative perception of HIV-infected people to originate from prominent religious influences in the community. HIV infection was seen as “God penalize you,” and being “condemned and cursed by God” (Pakistani female). It was seen as a “curse” (Vietnamese male) and as karma for past wrongdoings. A Pakistani female said HIV was a “punishment from God.” Her infection was a punishment for being a “bad” daughter, wife, mother, and Muslim. The stigma associated with HIV was so prominent in APIs that the fear of being associated with HIV overshadowed their desire to seek HIV testing prior to diagnosis.

Need for Cultural Preservation

The stigmas associated with HIV are reinforced with the group’s need for cultural preservation. Vietnamese patients tended to seek Vietnamese physicians. Physicians who share a similar culture likely are more understanding of the struggles within that community and the patients felt less vulnerable and more trusting of their providers. However, this relationship reinforces the stigmas associated with HIV because Vietnamese physicians most likely understand and share similar taboo in talking about sex and HIV. Out of respect for the patient and culture, safe sex practices are not talked about during clinic visits by most physicians.²¹ The majority of patients who had an API physician stated that their provider did not discuss sex history or preventive HIV care with them. No patient

voluntarily disclosed their sexual history or sought out HIV testing because of the fear of gossip in the community.

Within the theme of cultural preservation, family was viewed as the foundation of the culture. One patient stated, “what’s in your home, stays in your home” (Vietnamese male). An HIV diagnosis or the risk of an HIV infection was regarded as a family shame. A Vietnamese male explained, “It’s already an embarrassment me being gay and if I bring HIV into the mix it would be like a double shame.” In contrast, a Hawaiian female patient defined family as the community. Thus, Hawaiians were more open about their infections because of the support of the community. She explained, “As a community, we are here to support you . . . you know, Mālama: We take care of you. We’re here for you.”

Discussion

The average annual increase in HIV diagnosis rates in APIs may be related to the lack of patient awareness of HIV education and resource accessibility. Lack of patient awareness is present among other ethnic groups²² but the shared struggles faced by APIs in their attempts to assimilate create a heightened intergroup vigilance and a community that keeps to itself.¹⁶ The creation of a closed-intolerant community gives a false sense of security stemming from misconceptions and misunderstandings of HIV-associated stigma. In associating shame and disgrace with sex and its associated topics, people were reluctant to discuss safe sex practices and HIV care because of potential repercussions within the API community. By not talking about it, school systems became one of few resources for sex and HIV/STD education and prevention.

The misconceptions observed about HIV infection included that the individual was either gay or a “bad person” or both. With loose definitions of a “bad person” and being gay, those not identifying as either were under false impressions that they could not contract HIV. This false sense of security was a convincing factor to not engage in HIV prevention thus contributing to its ineffectiveness.

The complex cultural dynamic created a closed, intolerant community that lead to a false sense of security which was reinforced by the desire for cultural preservation. This desire originated from many APIs being recent immigrants. In seeking comfort and familiarity from those of the same culture, members strengthened the taboo and stigma by keeping a closed community. Their intolerance stemmed from individuals who expanded their culture experiences to the greater US population. For those API subgroups with a culture that keeps within the immediate family (eg, Vietnamese), HIV care may be more of a challenge as the community is less accepting. For those subgroups with the community as the family (eg, Hawaiian), they may be more receptive to care. Many subgroups share commonalities but with so many diverse subgroups, a unifying classification for all is misleading.

Limitations to the study included the small sample size in one geographic location. With APIs infected with HIV being a

small population nationally, it was a challenge to recruit a larger sample size in Kansas.

Despite limitations, themes from this study can be used to develop effective HIV care in this population. Culturally inclusive materials should be created with information available in different languages. Battling cultural barriers will allow more accurate and complete information to reach this population.

For clinicians, API patients most likely are not going to offer information about their sex history or increased risks. Healthcare providers should ask API patients about these topics and incorporate HIV testing into the patient’s routine medical care.²³ The healthcare provider can make the clinic a safe environment to discuss and seek HIV care even though the stigma exists within the community. Finally, providers should be aware that their own personal customs and cultures affect patient care. With a better understanding of the causes that lead to APIs being the only ethnic group with a significant average annual increase in diagnosis rates since 2001, initiatives can be taken to ensure HIV care is more effective in this group.

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References

1. Adih WK, Campsmith M, Williams CL, Hardnett FP, Hughes D. Epidemiology of HIV among Asians and Pacific islanders in the United States, 2001-2008. *J Int Assoc Physicians AIDS Care (Chic)*. 2011;10(3):150–159.
2. Zaidi IF, Crepaz N, Song R, et al. Epidemiology of HIV/AIDS among Asians and Pacific islanders in the United States. *AIDS Educ Prev*. 2005;17(5):405–417.
3. US Centers for Disease Control and Prevention. HIV in the United States: At A Glance. Centers for Disease Control and Prevention, 2015. <http://www.cdc.gov/hiv/statistics/overview/ataglance.html>. Accessed December 11, 2017.
4. US Centers for Disease Control and Prevention. *HIV Among Asians*. <https://www.cdc.gov/hiv/group/raciaethnic/asians/index.html>. Updated May 23, 2018. Accessed December 19, 2018.
5. Wong FY, Campsmith ML, Nakamura GV, Crepaz N, Begley E. HIV testing and awareness of care-related services among a group of HIV-positive Asian Americans and Pacific Islanders in the

- United States: findings from a supplemental HIV/AIDS surveillance project. *AIDS Educ Prev*. 2004;16(5):440–447.
6. US Centers for Disease Control and Prevention. Racial/ethnic disparities in diagnoses of HIV/AIDS—33 states, 2001–2004. *MMWR Morb Mortal Wkly Rep*. 2006;55(5):121–125.
 7. US Centers for Disease Control and Prevention. HIV Surveillance—United States, 1981–2008. *MMWR Morb Mortal Wkly Rep*. 2011;60(21):689–693.
 8. Bau I. Asians and Pacific Islanders and HIV prevention community planning. *AIDS Educ Prev*. 1998;10(suppl 3):77–93.
 9. Chin JJ, Leung M, Sheth L, Rodriguez TR. Let's not ignore a growing HIV problem for Asians and Pacific Islanders in the U.S. *J Urban Health*. 2007;84(5):642–647.
 10. Nemoto T, Operario D, Soma T, Bao D, Vajrabukka A, Crisostomo V. HIV risk and prevention among Asian/Pacific Islander men who have sex with men: listen to our stories. *AIDS Educ Prev*. 2003;15(1 suppl A):7–20.
 11. Chin D, Kroesen KW. Disclosure of HIV infection among Asian/Pacific Islander American women: cultural stigma and social support. *Cult Divers Ethnic Minority*. 1999;5(3):222–235.
 12. Yoshioka MR, Schustack A. Disclosure of HIV status: cultural issues of Asian patients. *AIDS Patient Care STDs*. 2001;15(2):77–82.
 13. Loue S, Lane SD, Lloyd LS, Loh L. Integrating Buddhism and HIV prevention in U.S. Southeast Asian communities. *J Health Care Poor Underserved*. 1999;10(1):100–121.
 14. Kang E, Rapkin BD, Springer C, Kim JH. The “Demon Plague” and access to care among Asian immigrants living with HIV disease in New York City. *J Immigrant Health*. 2003;5(2):49–58.
 15. Bhattacharya G. Health care seeking for HIV/AIDS among South Asians in the United States. *Health Soc Work*. 2004;29(2):106–115.
 16. Yoo HC, Gee GC, Takeuchi D. Discrimination and health among Asian American immigrants: disentangling racial from language discrimination. *Soc Sci Med*. 2009;68(4):726–732.
 17. Kansas HIV Surveillance Program. *Kansas Bureau of Disease Control and Prevention. HIV in Kansas: Bi-Annual Report for January-June 2016*. Topeka, KS: Kansas Department of Health and Environment; 2016.
 18. Hoeffel EM, Rastogi S, Kim MO, Shahid H. The Asian Population 2010: 2010 Census Briefs. 2012. <https://www.census.gov/prod/cen2010/briefs/c2010br-11.pdf>. Accessed December 11, 2017.
 19. US Centers for Disease Control and Prevention. Real Aid Prevention Project Evaluation Plan and Instruments. Division of HIV/AIDS Prevention. Key Informant Interview Guide. 2008. https://effectiveinterventions.cdc.gov/files/Key_Informant_Interview_Guide.doc. Accessed December 11, 2017.
 20. Merson MH, O'Malley J, Swerwadda D, Apisuk C. The history and challenge of HIV prevention. *Lancet*. 2008;372(9637):475–488.
 21. Haas DM, Coe RM. Do physicians discuss HIV and AIDS with patients? A survey of physician practices. *J Community Health*. 1997;22:401–416.
 22. Kuo AM, Haukoos JS, Witt MD, Babaie ML, Lewis RJ. Recognition of undiagnosed HIV infection: an evaluation of missed opportunities in a predominantly urban minority population. *AIDS Patient Care STDs*. 2005;19(4):239–246.
 23. US Preventive Services Task Force. Final Recommendation Statement: Human Immunodeficiency Virus (HIV) Infection: Screening. 2016. <https://www.uspreventiveservicestaskforce.org/Page/Document/RecommendationStatementFinal/human-immunodeficiency-virus-hiv-infection-screening>. Accessed December 11, 2017.