

The Unspoken Plight of HIV Gripping Asian/Pacific Islander Communities in America

Sharon E. Shaw*

The Human Immunodeficiency Virus (HIV) pandemic has had a significant impact on various communities and demographics in the United States. Although special attention has been given to African, Latin, Hispanic, and non-Hispanic white American communities, Asian American and Pacific Islander (A/PI) communities are often overlooked in HIV prevention efforts. Regardless of how statistically reassuring HIV diagnoses by ethnicity may seem, HIV poses a threat to the A/PI community. The “model minority” stereotype, lack of cultural and linguistic accommodations in HIV education, and cultural barriers may account for the lack of HIV testing and prevention in A/PI communities. The “model minority” stereotype projected onto A/PI individuals and their health gives a false sense of security about their current health status. Lack of education leads to misconceptions around HIV spread and transmission within A/PI communities. Cultural barriers continue to impact disclosure of HIV status among A/PI individuals and have a role in limiting HIV prevention efforts in these communities. Personal accounts and studies on HIV-positive Asian Americans show the lasting impact the “model minority” label, gap in HIV education, and cultural barriers have on combating HIV in A/PI communities. HIV needs to be addressed in A/PI communities, and public health measures, HIV education, and A/PI HIV support groups may encourage greater HIV awareness, testing, and prevention in A/PI communities.

Keywords

Asian/Pacific Islander • HIV prevention • HIV education • model minority • cultural barriers

Introduction

When we picture Human Immunodeficiency Virus (HIV)-plighted communities, the focus seems to be on how it has ravaged African American, Latin/Hispanic American, and non-Hispanic white

*University of Michigan, shshaw@umich.edu

doi: 10.3998/ujph.3951

Conflicts of interest:

The author has no conflicts of interest to disclose.



American communities. Research on these groups is necessary as they encompass the majority of HIV diagnoses in the United States. The breakdown of HIV diagnoses by ethnicity shows that in 2019 African Americans accounted for 42% of new diagnoses, 29% for those of Hispanic/Latino origin, 25% for white Americans, and a mere 2% for those of Asian origin (CDC, 2021). Given the demographics of HIV cases, Asian American communities are often overlooked as they represent a small proportion of U.S. cases. For instance, Ivy Arce, a Chinese American and New York resident, recounts her own experience as an underrepresented HIV-positive Asian American. She noted that while living with HIV through the early 1990s, Asian/Pacific Islander Americans (A/PIA) with HIV only represented 0.02% of NYC cases, which “made me feel like I wasn’t even a full number as a person” (Murphy, 2021). However, HIV prevention efforts among Asian Americans should not be overlooked. HIV does exist in Asian American communities, regardless of how insignificant the percentage seems in comparison to those of other minority groups. Lack of attention to HIV prevention methods among Asian Americans could have significant consequences: Low HIV incidence now does not guarantee that HIV rates among A/PIA communities will not drastically increase in the near future.

With the United States’ commitment to end the HIV/AIDS epidemic by 2030, it seems even more essential to address nuances hindering HIV prevention efforts within the A/PI community (White House, 2021). However, contrary to the United States’ goal to end this epidemic, numbers have been increasing, with nearly 42% more Asian American and Pacific Islanders testing HIV positive from 2010 to 2016 (Sen, 2021). Yet there are a variety of limitations in reaching A/PIA communities about HIV prevention and treatment. Most notably, the “model minority” stereotype and lack of HIV education, coupled with cultural barriers, are significant drivers of low rates of HIV testing and misconceptions around HIV among A/PI communities today.

“Model Minority” and the Mirage of Exemplary Health Outcomes

Misconceptions about HIV among Asian Americans are pervasive, and those revolving around the “model minority” stereotype place A/PI communities at risk for increasing HIV transmission and spread.

The term “model minority” was derived from sociologist William Peterson in the 1960s and his characterization of Japanese Americans in the *New York Times* (Lee, 2017). Peterson’s emphasis on how “inherent cultural qualities . . . enabled Japanese Americans to overcome racial prejudice and succeed where other minorities have failed” has expanded to include all Asian Americans (Lee, 2017, p.15). Although this concept of model minority emphasizes positive characteristics such as the resilience and hard-working attitude of Asian Americans and Pacific Islanders, this stereotype perpetuates false ideologies and beliefs, including ones regarding the health outcomes of A/PI individuals (Sabato, 2014). This “model minority” stereotype has in fact allowed an “association of positive health outcomes with Asian Americans” to “become ingrained in American society” (Lee, 2017, p. 19).

Ivy Arce’s experience with the AIDS activist group ACT UP resonates with misconceptions regarding Asian American health outcomes in society. Arce recalls how she lived almost “entirely alone as a woman of Chinese descent living with HIV” (Murphy, 2021). She endured suspicion in the broad HIV community in her participation with ACT UP during the 1980s–90s: “People constantly asked me why I was there. . . . Was I for somebody else? Was I a nurse? A mole with

the police?” (Murphy, 2021). Suspicion over Arce’s HIV-positive status shows how the “model minority” stereotype can perpetuate beliefs that Asian Americans are unlikely to have HIV as they are perceived to have positive health outcomes.

False Perceptions of Cleanliness and Safety

Arce’s experience is not an isolated incident. The stereotype of “model minority” has not only affected how other Americans respond to HIV-positive Asian Americans but has been internalized by A/PI individuals themselves. The “model minority” designation has affected their own response and attitudes toward HIV, especially toward prevention methods such as routine HIV testing. Asians are known to have one of the lowest rates of HIV testing than any other race in America and the highest rates of undiagnosed HIV. In 2013, 22% of Asians or around one in five Asians had undiagnosed HIV (CDC, 2017). According to John Guigayoma, a gay Filipino American, among the top reasons cited for Asian American and Pacific Islander hesitance in testing is that “Asians are clean” (Guigayoma, 2014). Even a Vietnamese participant in a HIV study expressed the common misconception in the A/PI community that HIV is a result of “risky behavior of bad people” (Pichetsurnthorn, 2019). Considering this within the context of the “model minority” label, Asians may seem unlikely to engage in risky or “unclean” behaviors that would put them at risk for contracting HIV.

Previous studies have shown that contrary to the model minority stereotype, “young Asian men who have sex with men (MSM) are as likely as or more likely than other MSM groups to engage in *unsafe sex*” (Bingham et al., 2003; Choi et al., 2004, p. 475; Peterson et al., 2001; Ruiz et al., 1998). Even Guigayoma (2014) himself states that he has realized that the sex life he was living “of multiple partners and unpredictable condom use . . . was actually the sex life I wanted to have.” Guigayoma’s personal account and prior studies on MSM among Asian American and Pacific Islander men serve as clear indicators that Asian Americans do engage in risky behaviors, regardless of stereotypes implicating that Asians are “clean” as America’s “model minority” group.

Interactions Increasing Risk of HIV Transmission and Spread

Given that Asian Americans do engage in risky sexual behaviors, contrary to the false mirage of exemplary behavior associated with “model minority,” interactions between sexual partners can be indiscriminate of race. Although HIV is statistically more prevalent in other minority groups, risky behaviors involving Asian Americans with other demographics will likely affect HIV rates among A/PIA communities. For instance, Daniel Tsang, a professor of politics of sexualities at the University of California Irvine (UCI), notes that Vietnamese Americans may not have many homosexual Vietnamese friends and therefore “tend to find their sexual partners mostly through ‘the institutions of the Anglo gay world’” (Tsang, 1993). Given that the CDC reports that white Americans make up 25% of new HIV diagnoses, the interaction between homosexual Asians and white Americans likely impacts HIV diagnoses among Asian Americans and Pacific Islanders (CDC, 2021).

Tsang (1993) also mentions how Joseph Carrier, a UCI-trained anthropologist, warns that although the incidence appears low, sexually active men in the Vietnamese gay community with Anglo and Latino interactions are capable of spreading AIDS within the Vietnamese American community. Carrier’s study underscores how six AIDS-positive Vietnamese individuals he

interviewed have all claimed to have only sexual interactions with Anglo partners. In the cases of these six men, where A/PI individuals have multiple partners and unpredictable condom use, sexual encounters with HIV-positive non-Hispanic white, African, or Latin/Hispanic Americans can further the spread of HIV in A/PI communities.

Ignorance around the impact of the “model minority” stereotype contributes to the complacent HIV approach to A/PIA communities and can lead to a delayed preventative response to HIV spread in these populations. Guigayoma recounts how he first tested for HIV at 21 and realized that he “didn’t really know anything about any of the men I’d [he’d] ever been with” (Guigayoma, 2014). Considering that Guigayoma had encountered men of unknown HIV status, a positive diagnosis would have led to multiple partners being exposed to HIV, potentially setting off a dangerous string of HIV spread and transmission. Fortunately, Guigayoma’s test results have been negative, but there have been incidents where lack of testing among A/PIA individuals led to a sudden positive diagnosis and exposure of partners to HIV. A study on homosexual A/PIA men in San Francisco found that out of the 13 participants who tested positive for HIV, eight men (62%) did not know they were infected with the virus beforehand (Choi et al., 2004, p. 477). Furthermore, five of these eight men had engaged in unprotected intercourse within the past six months. The study concluded that “a large proportion of men had never tested and many who were HIV-positive were unaware of their infection and engaged in unprotected anal intercourse” (Choi et al., 2004, p. 477). This study and Guigayoma’s personal account show how essential it is to address model minority stereotypes to encourage higher rates of HIV testing and prevention in A/PIA communities.

Lack of Comprehensive HIV Knowledge and Education Within A/PIA Communities

Misconceptions around HIV and the lack of testing not only stem from the wide acceptance of the model minority stereotype but can be attributed to the lack of knowledge about HIV among immigrant families and friends as well. A study by Yoshika and Schustack (2001) found that most of the Asian men interviewed cited their families’ lack of knowledge about HIV as a barrier to disclosure of their HIV status. One interviewee stated that his main concern with informing friends was their misconceptions around HIV transmission: “he’s scared of something . . . like if you talk to him you will give him AIDS. They are not educated. They have the same mind like back home” (Yoshioka & Schustack, 2001). His comment gives insight as to why HIV remains a highly stigmatized and sensitive topic among Asian Americans, considering that education on HIV abroad may be minimal. Even Tsang (1993) noted that a Vietnamese volunteer at an AIDS show in the UCI’s Fine Arts Gallery was “shocked when he realized that Vietnamese-Americans can and do get AIDS.” A recent study in Kansas on HIV-positive A/PI individuals found that “participants had incomplete or incorrect information about HIV transmission, progression, and treatment” (Pichetsurnthorn, 2019). Particularly, a Japanese male in the study expressed his perception that HIV is a “gay disease” rather than one that can be transmitted heterosexually as well (Pichetsurnthorn, 2019). Without comprehensive education on HIV transmission, scientifically unfounded beliefs, including that Asians are not susceptible to HIV/AIDS or that HIV is solely transmitted homosexually, can limit HIV testing and prevention efforts in A/PI communities.

Another study by Chin and Kroesen (1999) on HIV-positive Asian/Pacific Islander American (A/PIA) women found that lack of knowledge about HIV in Asian communities can lead to

discriminatory behaviors. One woman recounted how after informing her church leader about her diagnosis, she was told to bring her own plate and utensils to church lunches (p.230). This incidence clearly illustrates how even an “emotionally compassionate” church leader engaged in discriminatory behaviors due to a lack of knowledge about HIV transmission, which has long ago been shown to not be transmissible by casual contact (Chin & Kroeson, 1999, p. 230). Another respondent confirmed that fear of disclosure among HIV-positive A/PIA individuals stems in part from fear of discrimination, including reactions such as “oh my gosh, don’t go near, don’t eat what she give you, things like that” (Chin & Kroeson, 1999, p. 230). As shown by these incidents, misconceptions around the transmission of HIV and its influence on the treatment of HIV-positive A/PIA individuals seem to stem from a lack of HIV education among A/PI communities. Without adequate resources and access to comprehensive HIV education, misconceptions around HIV transmission and stigma around HIV diagnosis can lead A/PI individuals to conceal their status or refuse HIV testing.

Culture as a Limiting Factor in HIV Disclosure and Prevention Efforts

Although heavy emphasis has been placed on the role of the model minority stereotype and lack of education in spreading misconceptions around HIV among the A/PIA community, culture does play a notable role as well. The impact of culture is largely seen in the disclosure of HIV status to family members and friends. HIV-positive Asian patients, both male and female, have cited cultural barriers that prevent them from disclosing their status to family members and culturally related friend groups (Chin & Kroeson, 1999; Choi, 2004; Yoshioka & Schustack, 2001). Asian cultures emphasize collectivism, and the struggle of one family member can become a burden for the whole family to carry (Chin & Kroeson, 1999). Additionally, the HIV diagnosis of an A/PI individual can be regarded as a shame the whole family must carry (Pichetsurnthorn, 2019). HIV-positive Asian American individuals share similar concerns about overburdening others in their family. In an interview with an Asian American woman, although she wanted to tell her brother about her HIV diagnosis, her concerns about burdening him (i.e. “I don’t want to bog him down with my problems”) prevented disclosure of her HIV status (Chin & Kroeson, 1999). Another woman expressed concern for her mother’s health if she revealed her HIV diagnosis and caused her mother to bear her responsibilities for being HIV positive. Male HIV-positive Asian American patients expressed similar views, with one Indonesian man noting that he refused to disclose his HIV status to his family because they would “feel sad and they feel they lose face” (Yoshioka & Schustack, 2001, p. 79). A Vietnamese male also emphasized how being gay was already a source of embarrassment to his family and revealing HIV would bring “double shame” to his family (Pichetsurnthorn, 2019). Yet these cultural attitudes limit disclosure and fuel the model minority stereotype that Asian Americans rarely contract or are less susceptible to HIV and typically have good health.

Many interviewees have also confessed that they would rather tell family members that they have another disease such as terminal cancer or, more commonly, pretend that they are healthy than disclose their HIV-positive status (Yoshioka & Schustack, 2001). This may be linked to stigma around homosexuality in Asian cultures, as seen in a study in Beijing, China. Participants in the Chinese study identified fear of others knowing about their homosexual behaviors as the main reason for avoiding HIV testing (Song et al., 2011). Cultural factors are therefore important to consider when addressing preventative approaches to HIV in A/PI communities.

Intervention Methods

Certainly, the model minority ideal and lack of HIV education have perpetuated misconceptions while undermining the agency for HIV testing among A/PI communities. Yet there are methods to promote greater HIV awareness among Asian Americans today.

Educational interventions, such as educational workshops or programs, and counseling are promising methods to address misunderstandings around HIV susceptibility and transmission in A/PIA communities (Sen, 2021). A study targeting Chinese massage parlor women in Los Angeles showed that HIV knowledge increased with participation in an HIV prevention program (Takahashi et al., 2013, p. 516). A three-month follow-up survey to the program showed long-term retention of HIV knowledge as well (Takahashi et al., 2013, p. 516).

Additionally, educational methods should be language inclusive, particularly in Asian communities where some may not be fluent in English and are more comfortable speaking in their native language, especially when discussing sensitive topics like sexually transmitted diseases and HIV. Sabato (2014) notes that A/PI communities face a “profound language barrier for a demographic group with more than 100 languages and dialects,” considering that most HIV-related programs and services are only offered in English and Spanish. Given that over 50% of Vietnamese and Chinese individuals are not fluent in English and less than 20% of Samoans and Guamanians have English proficiency, educational interventions must be language inclusive to reach Asian American and Pacific Islander communities (Sabato, 2014).

Networking and support groups should also be more publicized. This would allow A/PI individuals with HIV and their family members to build a safe community and receive emotional support and information on how to cope with and handle HIV. Group interactions fostered by networking and support groups can also “encourage meaningful exchange” between stigmatized HIV-positive A/PI individuals and those in their community who are perceived as non-stigmatized and likely unfamiliar with or harbor misconceptions around HIV (Sen, 2021). In particular, networking is likely more effective in the dissemination of information on HIV prevention. For instance, Guigayoma notes that he discovered pre-exposure prophylaxis (PrEP) only through a friend, which led him to contacting his doctor about beginning the prevention regimen. The impact of support groups on family members is apparent as Pham, founder of a local Orange County organization called The Vietnamese Parents and Friends of Lesbians and Gays (Hoi Than Huu Viet Nam Dong Tinh), recounted how he had an emotional meeting with a mother. The mother, who only spoke Vietnamese, gratefully told Pham how “my son was so lucky to have found you” (Tsang, 1993). Furthermore, Pham notes that “Most of the parents who come to the meeting do not speak English” (Tsang, 1993). Therefore, although publicizing support groups is necessary, meetings should be language inclusive as well to make information accessible to all community members, particularly immigrant parents of individuals who have contracted HIV.

Overall, it seems evident that HIV among A/PI communities cannot be overlooked despite the reassurance provided by statistics on HIV-positive Asian Americans today. The false comfort provided by the model minority stereotype does not ensure that HIV-positive diagnoses among A/PI communities will remain low and insignificant to public health measures that prioritize the plight of HIV among other minority groups. Both the model minority stereotype and lack of HIV education contribute to misconceptions around HIV transmission and lead to the lack of HIV testing in A/PIA communities. Using culturally and linguistically informed HIV education methods and publicizing A/PI HIV support groups to spread awareness of HIV transmission

are potential ways of addressing this unspoken plight of HIV gripping A/PI communities in the United States today.

Acknowledgments

The author has no conflicts of interest to disclose. Special thanks and immense gratitude to Dr. Powel Kazanjian, an infectious disease doctor at Michigan Medicine and expert in the history of infectious disease. Dr. Kazanjian has fostered my passion for the rich history of health and medicine and the necessity of it in healthcare today.

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