

# The “Demon Plague” and Access to Care Among Asian Undocumented Immigrants Living With HIV Disease in New York City

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Access to and utilization of care for HIV-positive Asians (A) and Pacific Islanders (PI) have been largely unaddressed despite the rising influx of immigrants from Asia and the Pacific to the United States and the growing HIV prevalence in these regions. This paper describes the cultural attitudes, behaviors, and perceptions that affect access to and utilization of care among Asian undocumented noncitizens living with HIV/AIDS (UNWHA) in New York City. Sixteen semistructured interviews with HIV-positive UNWHAs revealed that their access to care was influenced by community misperceptions of HIV transmission, discriminatory attitudes towards persons living with HIV, competing immigration related stressors, and difficulty navigating service systems. These findings underscore the importance of integrating HIV treatment with primary prevention and awareness of immigration-related stressors to ensure timely access to screening services and care among Asian UNWHAs.

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**KEY WORDS:** HIV/AIDS; Asian immigrants; stigma; medical service needs; social service needs.

## INTRODUCTION

Access to and utilization of care among Asians (A) and Pacific Islanders (PI) living with HIV disease have been focal concerns in New York City where A&PIs constitute the fastest growing ethnic group.<sup>5</sup> Despite their growing presence and emerging HIV problem, A&PIs delay in accessing HIV-related

services. Eckholdt and Chin (1) found that A&PIs delay accessing HIV-related prophylaxis treatments and other services, rendering them more vulnerable than other racial groups to opportunistic infections. Similarly, Hu *et al.* (2) reported that foreign-born persons living with HIV/AIDS (PWA) were more likely to be diagnosed with AIDS-defining conditions such as extrapulmonary TB, toxoplasmosis, or isosporiasis than U.S.-born persons. Cultural values, beliefs, and experiences coupled with a fragmented and daunting service delivery system present formidable challenges for A&PIs to access services that effectively and efficiently meet their needs. Moreover, for A&PI immigrants with limited English proficiency, navigating through systems

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<sup>5</sup>The term “Asian and Pacific Islander” is used in this study to signify persons of Asian and/or Pacific Islander heritage in the United States, who represent a diverse, heterogeneous group of people, encompassing over 50 different ethnic groups and over 100 lan-

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guages and dialects. The classification of “Asians” with “Pacific Islanders” represents a sociopolitical label often used in race and ethnicity-level data collection and health research. While the authors acknowledge that the specific HIV and/or health needs of Pacific Islanders can differ significantly from Asians, the aggregate term “A&PI” is used in this study in order to emphasize that Pacific Islanders are included in and affected by policy recommendations from this study.

of care constitutes a significant stressor and may affect the recognition and treatment of illness. Gock (3) highlighted several reasons why A&PI PWHAs delay seeking early intervention and treatment: (a) lack of knowledge about the availability of appropriate treatment resources; (b) fear of being identified as HIV-infected and the risks of being ostracized by family members and friends; and (c) the shame of accepting HIV status because it implies that one has engaged in behaviors that are considered social and cultural taboos.

Public health officials have noted that unlike documented noncitizens who are lawful permanent U.S. residents, undocumented individuals who either entered the United States illegally or entered the country legally but violated their immigration status delay early screening and treatment of communicable disease because they are wary of being detected by immigration authorities (4). As a result, undocumented noncitizens are admitted to hospitals at a later stage of illness with more medical complications (5).

### **A&PI Immigration and HIV**

Although New York City (NYC) constituted less than 3% of the U.S. population, it received 14% of all immigrants to the country (6). Since the early 1990s, Asia has accounted for one quarter of the immigration to NYC. China, which includes the mainland, Hong Kong, and Taiwan, has consistently been the third highest source of immigrants since the early 1970s, averaging 11,900 annually. Bangladeshi immigration to NYC nearly doubled in the 1995–96 period, placing it as the sixth highest source of immigrants followed by India. Depending on how they arrived to NYC, these immigrants fall into one of several categories. Although most immigrants were legal U.S. residents, 18% of the annual NYC population between 1997 and 1999 were undocumented noncitizens, defined as individuals who enter the United States illegally or those who have overstayed their visas (7).

It is important to consider these recent immigration patterns in the context of the rising HIV prevalence levels in Asia and the Pacific, which represent nearly 60% of the world's population. At the end of 2000, the Joint United Nations Programme on HIV/AIDS estimated 5.8 million persons in South and Southeast Asia, and 640,000 persons in East Asia and the Pacific were living with HIV/AIDS (8). Epidemiologists further point out that the growing number of HIV infections in China and India will “profoundly

influence the future history of the HIV/AIDS pandemic” (9). The conjunction of these patterns with continued high rates of immigration to U.S. cities implies that rates of HIV infection will continue to rise among A&PI immigrant groups in the United States. As of June 2000, 783 A&PI cumulative AIDS cases were reported in NYC, 66% of whom were non-U.S.-born (10). Despite the growing HIV prevalence in Asia and the rising influx of immigrants from these regions to NYC, no studies to date have specifically examined barriers and facilitators to care among Asian undocumented noncitizens living with HIV disease.

The goal of this study was to understand factors that affect access to care among Asian undocumented noncitizens living with HIV/AIDS (UNWHA) in NYC. We specifically examined the following questions: (a) What are cultural attitudes about HIV transmission and risks of infection among Asian UNWHAs? (b) How do broader A&PI community attitudes about HIV transmission, levels of HIV knowledge, and cultural beliefs about HIV/AIDS affect Asian UNWHAs' decisions to access HIV services? (c) How do stressors associated with immigration status affect Asian UNWHAs' decision to access HIV services? and (d) What experiences do Asian UNWHAs have with social service agencies and medical providers?

We adopted a qualitative research methodology because it allowed participants to speak about their illness “in their own voice, rather than conforming to categories and terms imposed on them by others” (11). The danger of not hearing the experiences of individuals is particularly pronounced when examining the challenges faced by Asian UNWHAs because the contexts of their illness differ markedly from those of more privileged social groups.

## **METHODS**

### **Participants and Procedures**

We conducted individual 2- to 3-h semistructured interviews with 16 HIV-seropositive UNWHAs selected from a nonrandom convenience sample 37 A&PI who participated in this study. The cohort was referred to this study by community-based organizations, hospitals, and acquaintances that had completed the interview. A written informed consent was obtained prior to each interview, during which participants were assured that the information gathered

would be strictly confidential and that refusal to participate would in no way influence or jeopardize the services received at the participating agencies. The interviewer also explained the purpose of audio-taping the interview and option to discontinue the recording upon the participant's discretion. All participants consented to be audiotaped, completed the interview, and were reimbursed for their involvement in the study. Interviews were conducted at community-based organizations, the principal researcher's office, or the participants' place of residence. Interviews with UNWHAs were conducted in English, Cantonese, Mandarin, Korean, Bengali, or Hindi. The principal researcher conducted all the interviews with English, Cantonese, and Mandarin-speaking participants (with the assistance of a Mandarin-speaking psychiatrist). The remaining interviews with Bengali, Hindi, and Korean speaking participants were conducted by a clinical psychologist and trained graduate students. Each interview was transcribed and translated into English if necessary. At the conclusion of each meeting, participants were debriefed on their interview experience and invited to ask questions or raise concerns about issues discussed during the interview. Appropriate referrals and follow-ups were arranged upon consent of the participant.

## Measures

The domains for the semistructured interview with UNWHAs were selected by (a) conducting a literature search on cultural conceptions of illness, stigma, health-related quality of life, and service access and utilization among PWHAs; (b) facilitating a focus group with Asian UNWHAs; and (c) reviewing data and findings from three separate but complementary lines of research on health and access to care among people living with HIV/AIDS in NYC.<sup>6</sup> After identifying the interview domains, we constructed specific questions through an iterative process, whereby themes that emerged during an interview were further explored and probed in

subsequent interviews. We explored how access to and utilization of services among participants might be influenced by pre- and post-illness perceptions of HIV/AIDS, circumstances that led to initial screening and entry into care, quality of daily functioning, attitudes towards HIV treatment, experiences with providers, and social support.

## Data Analyses

Our approach to data analysis was informed by the principals of feminist participatory research and qualitative thematic analysis (12). A feminist participatory research approach underscores the importance of recognizing the power differential between the researcher and participants, and how it influences the analysis and interpretation of data (13). In preparing to analyze the data, the principal researcher was guided by three key points described by Abrums (14) in her study of health beliefs among African American women: (a) make every effort to regard UNWHAs as agents rather than helpless victims; (b) minimize judgments about participants by maintaining an active curiosity about "what" rather than "why" certain themes emerge from the data analysis; and (c) anticipate that readers might misuse study findings to perpetuate anti-immigration sentiments that will hamper the delivery of services for Asian UNWHAs. To address this concern, we established an advisory committee of 14 community leaders to review the content, presentation, and implications of findings.

After reading each interview transcript, the principal researcher used Boyatzis' (12) process of thematic analysis to systematically identify and make sense of patterns that emerged from the interviews. The specific steps of analysis were (a) sampling by immigration status (documented vs. undocumented); (b) reducing raw information by creating an outline or synopsis of each interview; (c) identifying themes within samples by comparing all the summaries from each subsample.

## Participants

Thirty-seven ( $n = 37$ ) HIV-seropositive A&PIs consented to be interviewed. Twenty-one participants were U.S. citizens or documented noncitizens (mean age = 41 years old,  $SD = 8.5$ ) who have lived in the United States for a mean of 24 years ( $SD = 10.2$ , range = 1–44 years). Sixteen participants were

<sup>6</sup>HIV/AIDS Client Cohort Study (Memorial Sloan-Kettering Cancer Center) evaluates access and barriers to care in a longitudinal study of New York State PWHAs receiving Medicaid. *BRIDGES Project* (Asian Pacific Islander Coalition on HIV/AIDS, Inc.) evaluates a program developed to improve access to services and care among A&PIs living with HIV/AIDS in the NYC. *Community Health Advisory and Information Network* (Columbia University School of Public Health) is a longitudinal study of PWHAs' access and utilization of health and human services in NYC.

UNWHAs (mean age = 38 years old,  $SD = 7.9$ ) who have lived in the United States for a mean of 7 years ( $SD = 4.0$ , range = 2–15 years). UNWHAs were Chinese (63%), Japanese (13%), Indian (6%), Bengali (6%), Burmese (3%), and Mixed (6%). The mean years of education completed by UNWHAs was 10 years ( $SD = 6.4$ ). Nineteen percent ( $n = 3$ ) of UNWHAs self-identified as homosexual and 81% ( $n = 13$ ) self-identified as heterosexual. Thirty-eight percent ( $n = 6$ ) were single, 56% ( $n = 9$ ) were married, and 6% ( $n = 1$ ) were divorced or widowed.

## RESULTS

### Communal and Personal Fears

In many A&PI communities, perceptions of HIV/AIDS as a casually transmitted illness perpetuate fears of interacting with PWHAs and reinforce negative attitudes towards them. UNWHAs consistently described a lack or distorted knowledge of HIV transmission and risk behaviors within their ethnic communities. This was partially due to the minimal attention given to the illness and widespread beliefs that A&PIs were less susceptible to HIV infection than other ethnic groups. According to many UNWHAs, their friends and family commonly regard HIV/AIDS as an illness that afflicts “foreigners” or westerners. Ignorance about HIV transmission coupled with overt and covert discrimination against PWHAs exacerbates the isolation experienced by UNWHAs. A 42-year-old Chinese man who tested HIV-positive shortly after he arrived to the United States from Fujian, a coastal region of mainland China, described how others perceived him as a “ghost.”

We hope that the government can advertise the spread of AIDS. For example, how does it spread? If people found out that we have AIDS, we are like ghosts to them. They hide from us. The government needs to let people know that AIDS patients are just like normal people. It does not spread easily. To let them know how the virus is spread, how it is not spread, so they will not be prejudiced against us.

UNWHAs also harbored personal misperceptions of HIV transmission that predated their illness. Chinese participants, for example, were overwhelmed by fear of transmitting the virus to family and friends from casual contact. Consequently, they preferred to live alone and minimized their interactions with friends and family. Although many acknowledged that their perpetual fears of transmitting the virus to

others in the household were unfounded, overcoming them proved difficult if not impossible. A caseworker explained that this fear was partially accounted for by a belief that one’s current situation was the result of bad fortune in their previous life. In order to ensure a better life beyond the present, the Chinese were cautious about not inflicting suffering upon others. A 27-year-old Chinese woman recounted her experience of living with three “normal” roommates shortly after she arrived to the United States:

Because we live with normal people and they don’t know we have this illness, I feel guilty. I feel that I owe them, afraid that I will infect them. I feel scared, even though I know I won’t infect them that way. I’m still afraid everyday.

### The Secret Demon Plague

Asian UNWHAs and those within their ethnic communities regard HIV/AIDS as a highly stigmatized illness because of its strong association with shameful behavior. HIV/AIDS was commonly referred to as the “demon-plague” and PWHAs as the “demon.” Perceptions of HIV/AIDS as a population-specific illness that only affected homosexuals, patrons of commercial sex workers, drug users, and foreigners reinforced these references. HIV/AIDS stigma is unique because UNWHAs believe that individuals are personally responsible for contracting the virus and that one’s illness is the consequence of deliberate behavior. Comparisons were drawn between HIV/AIDS and other forms of chronic illness such as cancer, which a 37-year-old Chinese man regarded as “naturally acquired.” He elaborated on this distinction:

You didn’t have this disease [HIV/AIDS] in the first place but you went and got it yourself. You get cancer because of your health, it’s different. But if you have this disease, it is shameful. You cannot lift your head up; there is no meaning in life.

As a result of stigma, secrecy was central to managing and reorienting one’s life. Living a double life emotionally drained and affected various dimensions of their lives. Although the majority of participants did not report overt discrimination, they feared ensuing rejection if their illness was publicly revealed. Sixty-two percent ( $n = 10$ ) of UNWHAs in the study had not disclosed their HIV status to anyone except their caseworkers, compared to 10% ( $n = 2$ ) among documented participants. By keeping one’s illness a secret, UNWHAs sought and received

no support from family and friends. As a result, UNWHAs preferred to live and find employment outside their ethnic enclave in fear that others might suspect their HIV status. A 28-year-old Chinese man from Fujian explained his reluctance to find employment in Chinatown after he tested HIV-positive:

Before, if I wanted a job I needed to find one in Chinatown because there were a lot of jobs. But after my illness, there was no way I would work there. There are a lot of Fu-Chou people in Chinatown . . . too many people who know me. If I wanted to work, I would have to go to a foreigners' place to find a job. And if I went to foreigners' place, I needed to know English. But my English wasn't good enough.

In fear of being ostracized, UNWHAs avoided social interactions that led others to suspect their HIV status. A 31-year-old Chinese man described his experience this way:

Now when I go to friends and relatives' home, I sit there and feel awkward. For example, in general they offer a plate of food, and you use your own chopstick to pick it up. But when I use the spoon, they will wonder, "nobody uses spoon, why do you use the spoon?" Once, it's okay, but you do it two or three times, they will look at you strangely and think that you have some disease.

UNWHAs sought minimal support from family and friends because it was considered self-serving and imposing. A 27-year-old Chinese woman and her HIV-positive husband described their reservations of troubling others with their illness.

Before I had many friends, so we went out a lot. On our days off, we have tea or watch TV or go places to have fun. Right now, I have this illness; I don't want to trouble my friends. I feel uneasy to stay at their home to watch TV and eat. If I go out with a friend his wife might fight with him about how he can go out with someone with AIDS. You enjoy yourself but other people are unhappy. So I think I should stay home by myself and not trouble others and that will be better.

UNWHAs experience heightened guilt for contracting HIV and causing friends and family members to worry about their condition. Not disclosing one's HIV status to avoid emotionally burdening family members was clearly articulated by a 45-year-old Japanese man:

I don't want to have them worry too much. The information they have is much less so they will worry a lot. They are worried, embarrassed, and ashamed even though they may not say it to me directly they go through it and I feel bad about that.

Given their reluctance to seek support from family members, UNWHAs underscored the importance of being a part of a social network of other A&PIs living with HIV illness. Meeting and openly exchanging experiences of being an immigrant living with HIV in NYC challenge fears that one is alone in the A&PI community. Pan-Asian AIDS service organizations create such opportunities for persons to garner mutual support, as attested by a 36-year-old Chinese man:

Here at [Pan-Asian AIDS service organization] I meet many people who are from my hometown. We become friends over the same illness. Because we are all the same, we understand each other. It is very comfortable because we don't have any secrets between us. We sympathize and respect each other.

### Broken Roads: HIV and Competing Immigration Stressors

All of us come to America to make our fortunes. To establish some kind of business . . . after all, it was your family who sent you to the United States. You have to know, all Fujianese work either in a restaurant or garment factory. If you do well, you can open your own restaurant. This kind of road, originally it was my road too. Now this road is broken for me. I can't go on this road any more.

For countless UNWHAs, ambitious plans to financially support their family while paving a more promising future for them in the United States were thwarted by the physical and emotional toll of their illness. Negotiating the disparity between what they anticipated life to be and how they actually lived in the United States was an immense challenge. Shattered hopes of securing a future for their families were coupled with a fear of deportation from the United States. This fear was heightened among UNWHAs because HIV treatment was unavailable or unaffordable in their countries of origin. Moreover, the stigma attached to HIV/AIDS in Asia and the Pacific would significantly compromise their quality of life should they return. Remaining in the United States therefore was not simply a passage to a better life, but a necessity to their survival and health. A 27-year-old Chinese woman who tested HIV-positive in Fujian recounted at length the draconian treatment of HIV patients in her village.

Once I tested HIV positive, I was in the newspaper. Then it spread gradually. It was their way of preventing the spread of the epidemic. They used postcards to notify the next department—the lower level of government. The province quarantine station

notified the county by way of a postcard, sent without an envelope. And they would broadcast inside the village saying that I had this kind of illness. Then they notified the town hospital saying that they should be careful with this person and that was put on a poster and it was on the wall.

UNWHAs underscored the importance of securing employment because of financial obligations to support family members living abroad and to repay an exorbitant debt to “snakeheads”—the smugglers who arrange for their transport to the United States. According to Chinese UNWHAs, the current cost for illegal transport from Fuzhou to the United States range from \$35,000 to \$55,000 per person. Many Chinese UNWHAs received loans from friends and extended relatives who were assured that the participant would quickly earn enough money to repay the debt. Securing employment upon their arrival to the United States was therefore critical. Not surprisingly, 69% ( $n = 11$ ) of UNWHAs in the study were employed compared to only 19% ( $n = 4$ ) of documented A&PIs. Inability to work due to health deterioration was a significant source of stress for UNWHAs, as explained by a 46-year-old Chinese man:

The biggest difficulty is that I haven't worked very long. I don't have much money. I have a lot of people in my family. I borrowed money to send home. I always think about that. I am concerned most about my work. If I work too much I feel sick. My feet ache and my back hurts. I think if I can't work, I won't earn enough money to support my wife and children.

### Access to HIV Care

UNWHAs delay utilizing screening and medical services because of their non-English proficiency, precarious immigration status, and employment demands. Although early detection is critical for treatment, 38% ( $n = 6$ ) of UNWHAs in the study consented to an HIV-antibody test after self-admitting to a public hospital for untreated HIV-related symptoms, and 25% ( $n = 4$ ) were tested during a required medical exam for lawful permanent U.S. residence. Despite early presentation of severe symptoms, UNWHAs were reluctant to seek treatment because they feared being reported to immigration or labor officials. As a result, many Chinese UNWHAs, such as this 38-year-old native of Fujian, initially sought out doctors who practiced independently in Chinatown, spoke their dialect, and did not require documentation of their immigrant status.

I did not know about this disease, I just coughed, took cough pills, but no help. I spent money to visit doctors several times. Every time, I took X-rays. Some are from my homeland. They practiced medicine at the mainland, and now they practice medicine here. I find private doctors from my homeland in the newspapers. I cannot speak English, so I do not want to go to the government hospital because when they ask me questions, I would not understand.

Although UNWHAs did not contend with language or cultural barriers, countless of them received inadequate care from these private physicians. HIV-related symptoms were treated as a common cold, and X-rays were commonly recommended rather than an HIV-antibody test. Given the critical timing of initiating antiretroviral therapy, seeking care from less experienced physicians significantly compromised the health of UNWHAs.

After receiving their HIV-antibody test results from a public hospital, UNWHAs were referred to a Pan-Asian AIDS service organization and assigned a caseworker. UNWHAs described the caseworkers as their primary sources of emotional support and HIV treatment information. In addition to their ability to communicate with UNWHAs, bilingual caseworkers were likely the first and only members within their community to openly accept and assist them without judgment. A 27-year-old Chinese man recounted his experience shortly after learning his HIV diagnosis at a public hospital:

At that time, I thought I would die of this disease. I didn't want to do anything. I was prepared to die in 2 or 3 months. That was my thought. I didn't want to contact anyone or talk with anyone. I was very lonely. At that time people from [Pan-Asian AIDS service organization] knew that I got this disease, they came to help me. They told me they would help me visit the doctor and get medication. I gradually calmed down so that I wanted to talk to them about my disease.

Although assigned medical interpreters at hospitals provided necessary language services, UNWHAs emphasized that translation was insufficient. Critical dimensions of language services, particular for a newly diagnosed UNWHA included inquiries about treatment options and assistance navigating the service system, both of which were beyond the responsibilities assigned to hospital interpreters. The demands of keeping multiple medical appointments and adhering to a rigorous antiretroviral treatment regimen were new and daunting for UNWHAs. Even without a language barrier they have limited knowledge of what to ask or report to their medical provider. The benefits of working with a bilingual caseworker familiar with

their “histories” extended beyond those of working with a hospital interpreter, as attested by a 46-year-old Chinese UNWHA.

Interpreters don't know the history of my disease. [Caseworker] knows me for a long time. She knows my history and remembers what the doctor said before. She tells me everything. When they [medical interpreter] first interpreted for me, they only interpret what the doctor says or what I say. They don't know the history.

Medical providers in the current study acknowledged the importance of embedding treatment within the context of their patients' lives. However, the dual responsibilities of listening to an UNWHA's illness experience while treating their HIV disease proved challenging. UNWHAs' experiences of living with HIV/AIDS were shaped by a host of factors including fear of deportation, unemployment, inadequate housing, social isolation, and fear of HIV disclosure. An infectious disease specialist in the study described the challenges of accounting for these experiences in treatment:

This is a very technical field. Patients are coming in with a very primary care basis and focus. I do very specific things. HIV infection, especially at this low T-cell level spectrum is very, very complicated . . . and I have a very narrow spectrum of things I do in order to address the huge variety of problems. Patients are so complicated that we simplified and we say that all these terrible things are going to get better if you just do this one simple thing that I'm talking about. Now getting people who have no concept of HIV infection in general and have to deal with all the extraneous cultural and social and all that nasty business of not wanting people to know . . . you put that together with the non-specific nature of a lot of the things they feel . . . that's very difficult.

In the primary care setting, UNWHAs underscored the importance of devoting more attention to the personal and social circumstances surrounding their HIV disease. Medical providers need to balance their clinical acumen with an awareness of how HIV hovers like a “shadow” over every dimension of life, as described by a 31-year-old Chinese asylee:

I want this doctor, besides understanding AIDS, if he can also understand me more. For example, my life habits, personality . . . like general living situation, if he can understand them all; that will be best. Why? Because I think the shadow of AIDS always covers you. Sometimes without notice, the shadow will appear. Like when you are eating, you will suddenly think about your AIDS. It is always a kind of shadow. If the doctor can understand; this will be best.

## DISCUSSION

The needs of Asian undocumented noncitizens living with HIV/AIDS have been largely ignored despite the rapid influx of Asian immigrants into U.S. cities and the escalating rates of HIV-infection in Asia and the Pacific. Similar to other immigrant groups in the United States, Asian UNWHAs encounter multiple barriers to health care services including financial (15), language (16), and service navigation barriers (7). However, the current study highlighted several unique challenges faced by Asian UNWHAs.

First, Asian UNWHAs regard themselves as socially unacceptable and are deeply ashamed about contracting HIV. Scrambler and Hopkins (17) defined this self-perception as felt stigma or the fear of being rejected if others knew of their illness. Felt stigma is shaped by both individual perceptions of HIV/AIDS and the dominant attitudes in one's community. Alonzo and Reynolds (18) added that illness stigma was “intrinsically entwined with the disease course but is uniquely tied to the responses of the broader society, family, peers, strangers, health professionals and the identity of the individual” (p. 305). As such, inadequate levels of HIV knowledge that pervade A&PI communities (19) coupled with the marginalization of persons living with HIV/AIDS strongly influence UNWHAs' quality of life and their access to treatment and care. The interplay of individual and social forces that shape illness stigma underscores the importance of challenging A&PIs' misperceptions of HIV transmission, risk behaviors, and treatment without reinforcing the stigma and rejection of people living with HIV/AIDS. Primary prevention efforts to promote greater understanding of the illness and wider acceptance of those inflicted contribute to normalizing the disease and facilitating UNWHAs' access to screening services and care in a timely manner.

Second, UNWHAs are socially isolated and seek minimal support from family and friends. They harbor deep seeded fears of casually transmitting the virus to others, which discourage them from pursuing supportive relationships. In addition, most UNWHAs live alone in NYC and maintain minimal contact with family members living abroad. Disclosing their HIV status to family members seemed pointless given how little they know beyond the stigma attached to their illness. Moreover, seeking family support for one's HIV illness placed an unnecessary burden upon loved ones and entailed “interpersonal costs.”(20). Although

social networks can buffer against disruptive life events, the costs and benefits of social support are not equally shared across groups (21). For women with low resources, Belle (22) found that participation in social networks might be more harmful than helpful because they face greater demands from their support networks. Rather than garnering support from family members, many UNWHAs found support from interacting with supportive A&PI providers and other UNWHAs at Pan-Asian AIDS service organizations (23). This underscores the importance of identifying appropriate support networks that challenge UNWHAs' internalized feelings of being the token A&PI living with HIV/AIDS.

Third, the importance of maintaining gainful employment and minimizing the risks of deportation overshadow the need to access supportive and medical services. It is not uncommon for the demands of daily living to compete with the need to seek timely medical care, particularly for socially marginalized groups infected with HIV (24, 25). In Chin's (26) study of undocumented Chinese immigrants, 61% of his respondents relocated to the United States to earn money. For them, sickness and inability to work were comparable to "death" (27). Deportation from the United States was also a fear that UNWHAs encountered daily. Leaving the United States would certainly jeopardized their health and compromise their quality of life. Recent studies have found inadequate levels of HIV/AIDS knowledge among health professionals in Asia. For example, a survey of 1400 health professionals in China showed that only 41% correctly answered questions regarding vertical HIV transmission, and 28% correctly answered questions regarding length of incubation period (28). In Molassiotis *et al.*'s (29) study of PWHAs in Hong Kong, 67% of their study sample reported unmet needs in one or more area of functioning. The challenge of addressing these immigration and employment-related stressors predated UNWHAs' illness. However, once they become ill, UNWHAs are forced to make difficult choices between attending to their immediate needs such as repaying exorbitant smuggling fees and financially supporting family members, and seeking medical care whose benefits are may not be immediately recognized. This underscores the importance of supplementing medical services for UNWHAs with interventions that alleviate competing financial and immigration-related concerns.

Fourth, UNWHAs have limited understanding of their HIV disease course and treatment-related

issues. Even if patients and their physician spoke the same language, studies have found that communication was hindered by patients' unfamiliarity with diagnostic and treatment jargon (4, 30). Poor health literacy among people living with HIV/AIDS, which entails limited understanding of their HIV-health status and treatment related issues, was associated with poor adherence to combination antiretroviral therapies and declined immune functioning (31). Bilingual case workers at Pan-Asian AIDS organizations therefore fill a critical role in clarifying and reinforcing UNWHAs' knowledge of HIV-treatment and maintenance. It is insufficient to simply provide language interpretation for UNWHAs without helping them understand the significance of illness markers (CD4 count and viral load) and the importance of antiretroviral medication adherence.

Fifth, UNWHAs valued efforts to embed HIV treatment into their experiences of daily living. Medical anthropologists have highlighted a conceptual distinction between illness and disease. In a western medical paradigm, disease is the "malfunctioning of biologic and psychophysiologic processes in the individual, whereas illness represents personal, interpersonal, and cultural factors governing perception, labeling, explanation, and valuation of the discomforting experience" (32). Stein (33) suggested that "the more closely physicians listen to their patients, the more thoroughly they incorporate the contexts of the patient's and the family's life cycles into their clinical thinking... and the better they can address the 'needs' behind the 'wants' [of patients]" (p. 135). The ability and willingness of providers to listen to and understand the financial obligations of UNWHAs, the illness stigma that resonates from their community, and their fear of deportation, will largely determine the course and success of their treatment.

Several aspects of the study warrant cautious interpretation of our findings. First, interviews were conducted with UNWHAs who were willing and able to talk about their illness experiences. Moreover given that most participants were referred by Pan-Asian AIDS service organizations, the current findings might not accurately reflect the experiences of newly diagnosed A&PI PWHAs unconnected with services or those with deteriorating health conditions. This self-selection bias may limit the generalizability of the findings, and therefore be less characteristic of more assimilated Asian Americans or Pacific Islanders living with HIV disease. In addition, 63% ( $n = 10$ ) of UNWHAs were Chinese and the mean

age of UNWHAs was 38 years old. As such, the implications of the current findings might be less relevant to younger UNWHAs and other A&PI ethnic groups living with HIV/AIDS. It is important to emphasize that while patterns of social and cultural perceptions of HIV/AIDS were observed within specific A&PI groups, the diversity of perceptions and attitudes must also be acknowledged.

The current findings offer several directions for future research: (a) develop creative outreach strategies to identify other vulnerable A&PI groups such as women, commercial sex workers, and South Asians who isolate themselves from the HIV-care system and to explore their distinctive needs and resources; (b) broaden current conceptions of illness stigma in order to develop interventions and policies that will address this formidable barrier to HIV-care; and (c) explore the transferability of findings and recommendations regarding access to care among UNWHAs in the United States to Asian countries where HIV/AIDS caseloads are mounting, most notably in China and India.

## CONCLUSIONS

Previous needs assessment studies have recognized the importance of identifying barriers to accessing HIV primary care and supportive services among A&PIs. In 1992, the National AIDS Commission concluded that,

In particular, persons who have only recently immigrated to the United States require special attention, both in terms of prevention messages and in access to health care. Legal uncertainties and complexities frequently deter undocumented immigrants from seeking appropriate care and services for which they qualify. Helping such individuals overcome their reluctance to utilize services to which they are entitled deserves urgent attention. (34)

After nearly a decade, it is disconcerting to find that the challenges that face Asian undocumented immigrants living with HIV/AIDS remain urgent and relatively unchanged. Our findings should direct the attention of policymakers to the unique challenges faced by Asian UNWHAs. In order to ensure timely access to medical and supportive service, perceptions of HIV/AIDS as a demon plague within A&PI communities must be swiftly challenged and dispelled, and the competing immigration-related needs must be addressed along with the provision of medical care.

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