

Disclosing Status and Accessing Social and Institutional Support: HIV-positive Asians and Pacific Islanders in New York City

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Executive Summary

Background

The Sample

The Research Questions

Results

Revealing HIV status to family members

Revealing HIV status to friends

Utilizing social services

Executive Summary

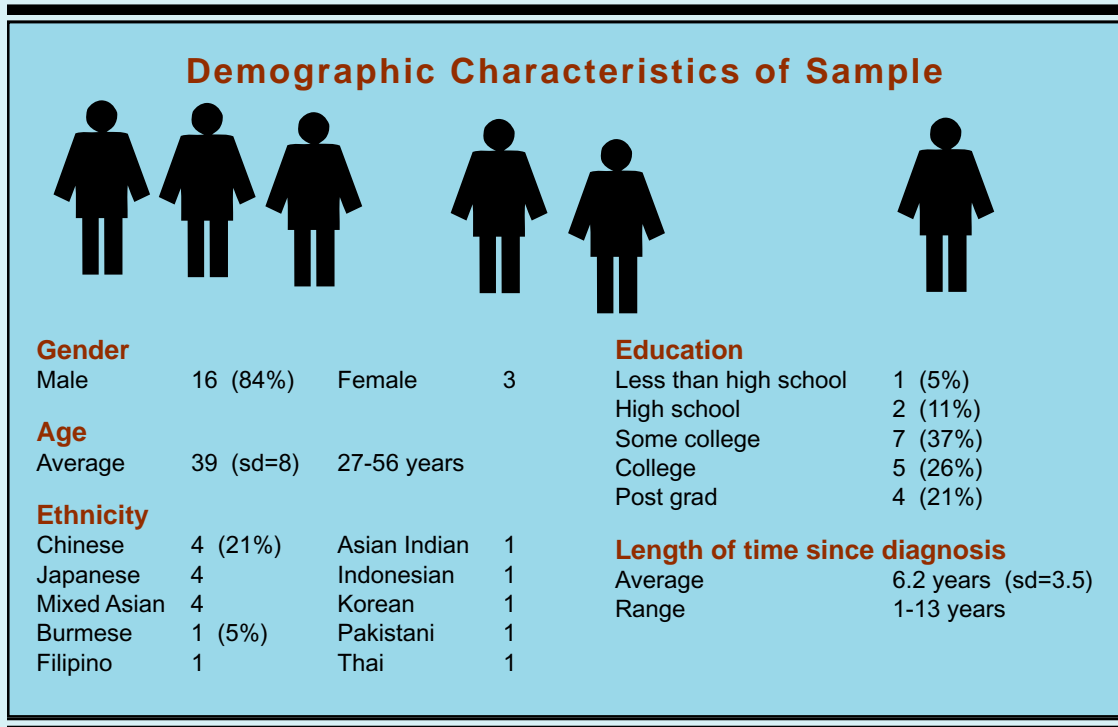
Asians and Pacific Islanders (A&PIs) are influenced by culturally specific considerations when making decisions when and if to inform family and friends of their HIV status. Individuals who have immigrated may feel particularly unable to access social support from family living overseas because of unacceptability of their sexual orientation, their desire to protect family members who are so far away, and/or their parents' lack of information and understanding of HIV.

Typically decisions to inform family were framed in relation to becoming sick rather than in terms of rights to information. Decisions to inform friends stemmed more from desire for emotional support.

While most participants contacted a number of AIDS agencies to obtain services, language differences and cultural unfamiliarity were reported as significant barriers. Having the opportunity to discuss treatment and emotional concerns with others who speak the same language in a culturally familiar environment was an important way to mitigate feelings of isolation and facilitate hope.

Background

Asians and Pacific Islanders living with HIV/AIDS in the U.S. face both self-imposed and externally imposed barriers when attempting to access social and institutional support. These barriers are related to their cultural training and their status as racial/cultural minorities in the U.S. Currently there is little information available concerning how the cultural context of this population affects their access to social and institutional support. Yet such information has clear treatment and service implications. The purpose of this study was to identify the sources of social



and institutional support accessed by HIV-positive A&PIs, and the barriers to and facilitators of access to such support.

The research was undertaken by the Asian and Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA). APICHA is a community-based organization located in New York City. Founded in 1989, APICHA's mission is threefold:

- To support and empower Asians and Pacific Islanders in the greater New York City metropolitan area through prevention education, client service, community organizing and training/legal assistance;
- To combat AIDS related discrimination; and
- To enhance the quality of life particularly those community members living with AIDS and HIV infection.

APICHA provides HIV risk prevention, direct services to those who are HIV positive (asymptomatic to those with AIDS), and community outreach and advocacy.

The Sample

Between March and December 1995, a total of 21 Asian and Pacific Islander men and women who were HIV positive were interviewed as a part of a larger study on coping with HIV. Transcribed data from interviews were available for 19 participants. HIV-positive individuals were recruited from current client lists at APICHA, solicitations to other New York AIDS agencies, and/or posters and flyers. Although they varied in terms of level of acculturation, all resided in the New York City area.

Data limitation: a convenience sample was used, therefore findings cannot be generalized beyond the sample.

The Research Questions

In particular we were interested in identifying how the cultural context (e.g., values, family structure) influence:

- When and to whom they reveal HIV-positive status, and
- What may facilitate or hinder accessing both social and institutional support

Qualitative interviews were held with participants. Their responses were content analyzed by two independent raters. From content areas, response themes were identified.

Results

Revealing HIV status to family members: to whom and when

Of the 19 individuals for whom data are available, one has not yet told anyone of his/her status, six have never told any immediate family members of their HIV status although they have told friends; and five have informed a sibling, but have expressly not told a parent. In total, 12 of the 19 participants have not yet told their parents of their HIV status although they may have informed other family members or friends. All seven participants who had informed their parents reported that although the initial reaction was one of shock and sadness, their parents have been supportive. Examination of responses that address to whom participants have disclosed their HIV status and under what circumstances, produced a number of themes that speak to the nature of family relationships among Asians and Pacific Islanders.

Protection

Participants framed their reasons **not** to disclose status to family members as a way of protecting them from something that would only worry them. This was especially true when family members are elderly and live overseas.

I don't want to give them [elderly parents] pressure or give them headache to think about my case. My sister—she's, because she's a woman you know, so maybe not strong to accept this idea. But definitely is very nice to me, very close, my sister. I think I don't want to tell her.. Sometimes I call, I call to Taiwan. Because they don't see me in person so my voice is still good, so maybe they think that I'm healthy. I just pretend that I'm really healthy.

I was born from a 42-year-old mother... and brother also too old now. So how can I ask them for help anyway? So I rather not let them know.

Losing face

For many participants, revealing their HIV status is, by implication, revealing their sexual orientation. They choose not to disclose their HIV status to their families because they anticipate the shame family members will feel.

I don't want my family [parents] to know my health is deteriorating, if they find out, they feel sad and they feel they lose face.

Let's say I pass away, they will announce a stomach problem, cancer... they say [if you have AIDS] it's virtue problem... they cannot accept AIDS, but they can accept stomach cancer... because not related to my sexual behavior... because they don't know I'm gay.

We don't talk about it

Some participants frame various aspects of disclosure in terms of what kinds of topics are permissible within their relationships. In some cases, participants cannot disclose their HIV status to family members because it lies outside the realm of discussible topics. In other cases, participants have told family members that they are HIV positive, but cannot tell their family that they are gay. Finally, other participants have disclosed their HIV status to family members, but since have never talked about it.

I don't talk to my family about my personal problems.

I have not disclosed to my parents or brother because they can't deal with it. Our relationship is concrete, not emotional or spiritual.

I talk about that I was very sick and that I have HIV. But they [my brother and sister-in-law] didn't know what is HIV meaning. So finally I said I got AIDS and they got shocked... They are very good help... They call me so many times, what I am feeling... I never told them [that I am gay]. They never asked me... maybe they might know.

[My parents give me] financial support if I need it... but they don't want to talk about this issues. So we'll talk on the phone or I would write them or they would write me, but we don't really even talk about this issue. We talk about something else.

My family has no knowledge of HIV

One of the barriers to telling family members that they are HIV positive is the family's lack of knowledge about HIV—particularly when family members are overseas where there is less HIV-related information and fewer HIV services.

Interviewer: Why wouldn't you tell them [your family]?
They have no knowledge of AIDS or HIV...

Interviewer: Have you spoken to your family members?
Yes, I did. It takes a few weeks... because they really can't understand fully about my situation and my health status. But my doctor helped explain what is going on.

Disclosing status in relation to getting sick

When asked when they did or would be likely to disclose their status to others, only two participants framed disclosure in terms of including significant others in important life events (they were my family and I had to be honest with them. I didn't want to wait until it was a medical issue). Most participants reported that the decision to inform family members about their status was made in relation to getting sick.

When it became AIDS is when I sat the [my family] down and told them... When I got pneumocystis, it was like flag that said you should tell them now.

My close friends they think that because I'm very, very sick... at least one in the family know my problem and come to USA to see me... so they ask me... and then I say okay, only my brother.

Revealing HIV status to friends

Getting emotional support

Disclosing to friends was described as a way of getting support, although this was not always the result. In most cases, the friends of the participant knew and accepted the participant's sexual orientation and/or were gay themselves. Thus, disclosing HIV status didn't require the participant to reveal his sexual orientation in addition.

I've talked to some friends, those who are HIV+, talk to friends about problems. They understand and give emotional support.

It [the first person I would talk to] would have to be a really, really good friend... and only because he's informed.

Other treatment issues

Two additional and notable issues reported by participants were:

Suicide attempts

Three participants reported having attempted suicide or contemplated it after diagnosis. These attempts were reported within a context of isolation which, to some extent, was influenced by being an immigrant.

I was working in Boston and I got diagnosed with that there, but friends' reaction is not too good so I left Boston... and came to New York... I tried to kill myself a couple of times... I passed out in the street and then... an ambulance took me to the hospital... before that I never had treatment. I didn't even think I was going to get treatment. If I am going to die, I don't need to get treatment. That's what I thought.

Since I have found APICHA, I have felt that there is still hope in this society... if APICHA didn't exist, I would have probably [committed] suicide.

Visa/Green card worries

Two participants described worries about how their immigration status might affect services they can get.

They [government] cut a lot of financial, so I'm worried that maybe green card cannot get any help.

They [hospital social work staff] tried to get for me

Medicare card and tried to get benefits for me, too. I have a problem with visa problem, so they tried to fix everything.

Utilizing social services

Identifying the role of an Asian/Pacific Islander AIDS agency

Most participants had contacted several agencies and/or projects for social services and emotional support. In very few cases, participants entered the social service network in a systematic fashion with the aid of a case manager. Most likely, they learned of institutional services in a more haphazard way through word of mouth, flyers, and the yellow pages. Participants “shopped” for services contacting different agencies for different reasons, (e.g., financial assistance, legal assistance with green card application, housing assistance). Several mentioned looking specifically to become involved in medical treatment research projects as a way to keep their doctor on track and to receive free service.

Based on participant responses, the benefits that an Asian agency such as APICHA offers are:

Services are offered in the client's first language

Being able to speak in one's first (and for some, only) language was described as important for more effective treatment (“I can talk in my own language, it's easier to talk about emotional things”) and also because it allowed other family members to be included (If something was written in Chinese, my parents could read it”). Not surprisingly, the importance of offering services in an Asian language varied by level of acculturation. More acculturated participants did not emphasize the importance of language.

A culturally familiar environment

Participants described the comfort they experience in being around other Asian individuals who are HIV positive. This was described in terms of being with their own kind.

Interviewer: Why would you seek an Asian organization specifically?

Because my own kind of people... [at a non-Asian agency] I think that people were talking about Asians coming in and make obnoxious remarks (about Asian people).

Most of my friends are Chinese. Most of them come from the support group because they are HIV positive, so for me it's more easy, more comfortable to talk each other.

Gaining emotional support through being able to share culturally specific foods, in being able to discuss traditional homeopathic medicines (e.g., Chinese herbs, acupuncture), having the opportunity to play culturally specific games (e.g., mah jong) and in being around the familiar sounds of language.