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Serving Asians and Pacific Islanders with HIV/AIDS: Challenges and Lessons Learned

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Abstract: This paper reports on findings from an evaluation of the Bridges Project, a community-based intervention implemented at the Asian and Pacific Islander Coalition on HIV/AIDS (APICHA), to reduce disparities in care for Asians and Pacific Islanders (APIs) living with HIV/AIDS in New York. Comparisons of participants by primary language (Asian language vs. English) and immigration status (undocumented vs. documented/citizen) show that Asian-primary-language and undocumented participants at baseline had a significantly lower rate of receipt of primary care services and experienced significantly more barriers per service than English-primary-language and documented participants. At follow-up, however, differences by primary language and immigration status disappeared, indicating that the Bridges Project was effective in improving service utilization and reducing barriers for the Asian-primary-language and undocumented participants. Barriers to services reported most frequently by participants were language and cost barriers, not knowing where to go for services, and confidentiality concerns. Study findings indicate that the capacity to address multiple API languages and cultures is essential in providing culturally competent care to APIs living with HIV.

Key words: AIDS, Asians and Pacific Islanders, immigrants, health disparities, cultural competence.

The availability of highly active antiretroviral therapy (HAART) and increased rates of HAART utilization, resulting from early access to and consistent utilization of medical care and ancillary services,¹⁻³ have reduced HIV-related morbidity and mortality and improved health-related quality of life⁴ for people living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) in the United States (U.S.). However, disparities in care based on gender,⁵

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race,^{6,7} and socioeconomic class⁸ prevail despite efforts to address both individual and systems-level contributing factors. This paper reports on findings from an evaluation of the Bridges Project, a community-based social service intervention designed to reduce disparities in care for Asians and Pacific Islanders (APIs) living with HIV/AIDS in New York City (NYC).

Inadequate access to and inconsistent utilization of care among APIs living with HIV are focal concerns in NYC, where APIs constitute the fastest growing ethnic/racial group. According to the 2000 census, more than 1 in 10 NYC residents identifies as Asian.⁹ As of December 2004, at least 1,168 APIs in NYC had been diagnosed with AIDS,¹⁰⁻¹² accounting for a substantial portion (16%) of the 7,317 cumulative API AIDS cases in the U.S.¹³ Where country of birth is known, 72% of cumulative API AIDS cases in NYC and 60% of API cases in the U.S. have been among foreign-born APIs,^{14,15} proportions that reflect the general API populations in NYC and the U.S., which are 78% and 61% foreign-born, respectively.^{9,16}

There are few studies in the literature reporting on the characteristics and service needs of APIs with HIV/AIDS. The information that does exist indicates that despite a growing HIV problem, APIs delay in engaging HIV-related services,¹⁷⁻¹⁹ rendering them more vulnerable than other racial groups to opportunistic infections.¹⁷ Between 1994 and 2000, APIs in the U.S. had the highest rate of AIDS at the time of initial HIV diagnosis (34% vs. 29% for non-Hispanic Whites and Hispanics, 23% for non-Hispanic Blacks, and 22% for American Indians/Alaska Natives).²⁰ National trends are mirrored in NYC, where 50.6% of HIV-seropositive APIs were diagnosed with AIDS from 1998 to 1999 because of an opportunistic infection (rather than a low CD4 count), a rate higher than any other racial/ethnic group (43% for Native Americans, 35% for Blacks, 29% for Hispanics, and 25% for Whites).²¹

Divergent cultural values and language barriers present formidable challenges for APIs seeking to use services that meet their needs. Difficulties in meeting the cultural and language needs of this population are compounded by the intra-group diversity of APIs, a category made up of numerous national, cultural, and linguistic groups. Systems of care that lack linguistic and cultural resources constitute a significant stressor, particularly for recent API immigrants with limited English proficiency, and may result in poor symptom recognition, failure to provide appropriate medical treatment, and low service utilization.

The Bridges Project was developed at the Asian and Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA), a community-based AIDS service organization in New York City, to assist HIV-seropositive APIs, particularly those with limited or no English proficiency, in overcoming barriers to utilization of HIV-related medical and supportive services. Andersen and Newman conceptualized service utilization as individual behavior influenced by both individual and societal determinants.²² This model distinguishes three categories of factors affecting utilization: (1) predisposing factors, which include individual characteristics that pre-date the onset of illness (e.g., demographic, attitudinal-belief characteristics); (2) enabling factors, which include resources that promote service use (e.g., income, insurance coverage); (3) and illness level, which reflects perceived symptoms or health status that motivate individuals to seek care. Client services at APICHA were aimed at addressing the

first two types of factors in particular, predisposing factors and enabling factors. For example, to address clients' predisposing factors, such as limited English proficiency and cultural beliefs that posed barriers to utilizing health care, the Bridges Project provided language interpretation and client escort and also provided medical providers with cultural competency training. To address enabling factors, such as lack of insurance, the Bridges Project provided case management services to ensure that clients received benefits for which they were eligible. The Bridges Project also addressed system integration problems, which exacerbated other barriers to utilization, by creating formal links between APICHA and health care providers.

As there is little information on this study population, this article provides information on Bridges Project participants' basic demographic characteristics. It then reports on service utilization, barriers to service use, and health-related quality of life of the participants. The analysis also begins to examine the effectiveness of the Bridges Project by examining changes in these measures at follow-up. Qualitative data drawn from Bridges Project clients in a related study are also introduced to aid in understanding the study's implications for developing and sustaining community-based services for APIs living with HIV/AIDS.

Methods

Bridges Project description. The Bridges Project, based at APICHA, was funded under the Special Projects of National Significance (SPNS) program of the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services from 1996 through 2001 and was part of the SPNS national multi-site evaluation. Aiming to improve HIV-positive APIs' ability to utilize existing services, the primary Bridges Project intervention objective was to bridge language and cultural barriers to existing HIV medical services through language interpretation, client escort, and comprehensive case management by bilingual part-time peer workers and full-time case managers employed by APICHA. The work of the bilingual peer workers and case managers to help clients overcome barriers was supported by establishing formal links with a range of hospitals and clinics offering HIV primary care and providing cultural competency training to the providers at these institutions. At the start of the project, APICHA established formal linkage agreements with three hospitals and three community-based clinics, all providing comprehensive HIV primary care services. Sites were chosen because of their geographic proximity to large API communities, proximity to neighborhoods with significant numbers of APIs living with HIV, and availability of special services for immigrants (both documented and undocumented), women and families, and gay/bisexual men. In entering into these agreements, the sites agreed to identify a contact person for facilitating referrals and to have their staffs participate in annual cultural competence training provided by the Bridges Project staff. The training also provided an orientation to the sites' staffs on the services available at APICHA and the procedure for making referrals. In addition to helping clients overcome barriers to utilizing HIV medical services, peer advocates and case managers assisted participants in using social services that were not available at APICHA.

Upon entry into the program, a client was assigned to a bilingual case manager and, if needed, to a bilingual peer advocate, who escorted clients to their service appointments and provided language interpretation and advocacy services. After a bilingual case manager made a medical referral and scheduled an appointment, for example, the bilingual peer advocate arranged to accompany the client in order to facilitate his or her participation in treatment. Peer advocates were hired to work on a part-time basis to make it financially feasible for the project to maintain an on-call corps of 12 to 15 trained peer advocates with the combined capacity to speak 12 different API languages and dialects.

Participant recruitment and procedures. The Bridges Project received clients through a number of means, including self-referral from APICHA's community-wide outreach and HIV prevention efforts (street outreach and ethnic media advertising), from New York City HIV testing sites, and from medical and social service providers who were unable to provide adequate services due to lack of linguistic and cultural competency. Some referrals were from hospital emergency rooms, which often referred APIs who visited the emergency room with an opportunistic infection and learned they were HIV-positive and had an AIDS diagnosis all in the same visit. The two Bridges Project sites were strategically located in Manhattan and Queens, the two NYC boroughs with the largest API populations. Although all adults (18 years old and older) with HIV, regardless of race or ethnicity, were eligible to participate in the project, the project enrolled almost entirely API clients because its specialized services attracted such referrals. Many Bridges Project clients were receiving medical care when they entered the Bridges Project, but some were not or had just recently entered the care system. It is important to note that even clients who had received HIV medical care may have had difficulty staying in care because of linguistic and cultural barriers. Especially for individuals who experience relatively strong barriers to care, accessing care may be viewed as a recurring rather than a one-time problem.

The Bridges Project made up the bulk of the client services program at APICHA. Project services were integrated with the other services targeted to HIV-positive clients at APICHA that were funded by other sources; these services included acupuncture, legal services, an Asian food pantry, and various support groups. Thus, any HIV-positive person who enrolled as a case-managed client at APICHA was a client of the Bridges Project and was able to receive the full range of client services available at APICHA.

The quantitative data from the Bridges Project reported here were gathered through intensive program evaluation activities as part of the SPNS national cross-site evaluation. To reduce the burden of the evaluation on the staff and clients, data collection for the evaluation was integrated with intake and follow-up procedures that were required for service provision. Thus, all APICHA clients completed at least some part of the research-related assessments for the Bridges Project. In order to use the data for the evaluation research, researchers asked clients for written consent. The evaluation research activities and consent forms were reviewed and approved by the Institutional Review Board at Columbia-Presbyterian Hospital, where the national cross-site evaluation was based.

At intake, bilingual case managers interviewed study participants to gather information on participants' medical and social service needs, barriers to services, current medical condition and medical history (including self-reported CD4 count and HIV viral load results), insurance coverage, provider information, and socio-demographics. Physical and mental health function was measured using the Medical Outcomes Study (MOS) SF-12, a health-related quality of life measure.²³

Reassessment of the same measures was intended as a 6-month follow-up, but the mean time period between baseline and reassessment was, in practice, 16.9 months. A major reason for the delay in reassessment was related to the difficulties of incorporating research activities into the social service activities. While the data show that most clients returned to the project for services frequently and well before the 6-month reassessment target, completion of the reassessment form for the study was not always a top priority for them. The longer than expected time period between baseline and reassessment did not negatively affect our ability to study change in service use and barriers for participants.

The case managers, trained by the research team, used a close-ended survey form developed by the research team in collaboration with APICHA's client services staff and the national cross-site evaluation center. Case managers and peer advocates also tracked the number of client visits and barriers to service use with a short service utilization form that was administered each time the client was provided with assistance. Intake and follow-up interviews were approximately 1.5 hours long if the participant spoke English or if the case manager and participant spoke the same Asian language. Interviews requiring language interpretation could take up to 3 hours, in which case the interview would be completed in 2 separate visits.

Analysis. Data were reviewed and distributions were assessed for outliers, errors, and departures from expectation. Transformations were performed as necessary as reflected throughout the results section. Our analyses examined service utilization and barriers to service use, focusing on variation by immigration status and English proficiency, since these are characteristics specifically salient to the immigrant experience that colors much of APIs' lives. Thus, our primary variables of interest for comparing study participants were (a) immigration status (undocumented immigration status vs. documented immigration status or citizen), and (b) primary language (English as primary language vs. an Asian language as primary language). Our sample was small, suggesting that power for a two-sample t-test or a correlation analysis was around 0.50 for medium effect sizes ($\alpha = 0.05$, variances similar).²⁴ There was insufficient sample size to assess multivariate models. However, descriptive analyses were conducted to examine relevant differences in the sample that may have influenced or obscured our modeling. Immigration status and primary language were not related to other demographic characteristics in the sample (gender, race/ethnicity, sexual orientation, and age were examined).

Results

Sample description. One-hundred sixteen HIV-positive participants were enrolled as clients of APICHA and thus were recipients of Bridges Project services between

April 1997 and March 2001. Of the 116, there were 73 participants who enrolled in the project after June 10, 1997, the date on which the full data collection protocol for the study was implemented. Of the 73 participants, 58 consented to have the data collected on them be used for research purposes. Thus there is true baseline and reportable data for 58 participants. Of the 58 participants, 43 completed at least one reassessment. Reasons for drop-out included death, relocation to another state or country, refusal of further project services, refusal to continue participation in the study, and being lost to follow-up with reason unknown. There were no statistically significant differences between the baseline sample and the reassessment sample by immigration status, primary language, gender, ethnicity, sexual orientation, or age.

Baseline characteristics of participants ($n=58$) are reported in Table 1. In the baseline sample, 83% of participants were men, and 15% were women; there was 1 male-to-female transgendered person. The mean age of participants was 38 years. Fifty-seven percent of the participants were U.S. citizens or permanent residents (documented participants) and 43% were undocumented immigrants (a category that included temporary/expired visa holders). There was significant ethnic diversity among the API participants in the sample: 29% were Chinese, 20% South Asian (including Indian, Pakistani, Bangladeshi), 10% Japanese, 9% Filipino, 9% Southeast Asian (including Thai, Vietnamese, Burmese and Malaysian), 7% mixed race, 5% Korean, and 3% other Asian. Sixty percent of the participants identified an Asian language as their primary language. Forty-three percent of the sample self-identified as gay/homosexual (all were male). Nine percent of the participants had no form of health insurance at all, 27% had Medicaid or Medicare coverage, and 23% had private insurance. The remaining participants (41%) were covered by AIDS Drug Assistance Program (ADAP) Plus, which in New York State covers most aspects of HIV primary care for undocumented immigrants and others not eligible for Medicaid. Seventy-four percent reported having a regular physician in charge of their care at baseline. Thirty-seven percent completed less than a high school degree, and 46% reported being unemployed.

The following sections describe our findings with regard to service utilization, barriers to service utilization, and health-related quality of life, at baseline and at follow-up. As noted earlier, our analyses focus mainly on variation by immigration status and primary language. There is significant overlap in the sample between being undocumented and having an Asian language as primary language (84% of undocumented participants had an Asian primary language). However, a substantial proportion of documented participants (42%) also reported an Asian language as their primary language.

Rates of receipt of primary care services. Overall, at baseline, 32 participants reported retrospectively that they needed primary care services in the preceding 12-month period. Of the 32 participants reporting a need for primary care services, 25 participants (78%) reported receiving such services (see Table 2). Analysis by immigration status shows that undocumented immigrants had significantly less success in receiving primary care services: 55% of undocumented participants who needed primary care services received them, while 90% of documented participants

Table 1.
BASELINE CHARACTERISTICS OF STUDY PARTICIPANTS, N=58

Characteristic	Percent
Gender	
Male	83
Female	15
Transgender (male to female)	2
Immigration status	
Undocumented	43
Documented and U.S. citizen	57
Ethnicity/nationality	
Chinese	29
South Asian	20
Japanese	10
Filipino	9
Southeast Asian	9
Mixed race (all are part Asian)	7
Other race	7
Korean	5
Other Asian	3
Primary language	
Asian language	60
English	40
Sexual orientation	
Heterosexual	50
Gay/homosexual (all were male)	43
Undisclosed	5
Bisexual	2
Insurance	
ADAP Plus	41
Medicaid/Medicare	27
Private insurance	23
No insurance	9
Has a regular physician	74
Unemployed	46
Less than high school diploma	37

who needed such services received them ($z=2.3, p=.023$). A similar difference was found for Asian-primary-language participants compared with English-primary-language participants: there was a 67% rate of receipt of primary care services as opposed to 93% (the difference was not statistically significant at $\alpha=.05$, but noteworthy, with a p value of .075).

Table 2.

NUMBER OF PARTICIPANTS REPORTING NEEDING AND RECEIVING PRIMARY CARE SERVICES 12-MONTHS PRECEDING BASELINE AND 6-MONTHS PRECEDING REASSESSMENT, BY IMMIGRATION STATUS AND PRIMARY LANGUAGE

	Needed primary care services		Received primary care services		Rate of service receipt	
	Baseline	Reassess	Baseline	Reassess	Baseline	Reassess
All participants	32	31	25	30	78%*	97%*
Immigration status						
Undocumented	11	12	6	12	55%**	100%**
Documented and U.S. citizen	20	18	18	17	90%	94%
Primary language						
Asian language	18	20	12	19	67%*	95%*
English	14	11	13	11	93%	100%

* $p < .05$, ** $p < .01$ (comparing baseline rate of service receipt with reassessment rate)

To assess the impact of the Bridges Project on participants' service use, we examined the same measures at reassessment. Table 2 shows how many participants at reassessment reported needing and receiving primary care services in the 6-month period preceding the reassessment date. A comparison of the baseline and reassessment measures shows clearly that service utilization improved between baseline and reassessment. Overall, at reassessment, 97% of participants who needed primary care services received them, and the differences between the service receipt rates for participants by immigration status and primary language at reassessment all but disappeared. The difference between the baseline rate of service receipt for the entire sample (78%) and the reassessment rate (97%) is statistically significant ($z = 2.2$, $p = .026$). The large difference between baseline and reassessment is accounted for primarily by the significant improvement for undocumented immigrants (55% service receipt rate at baseline, 100% at reassessment; $z = 2.6$, $p = .008$) and non-English-speakers (67% receipt rate at baseline, 95% at reassessment; $z = 2.2$, $p = .024$). In contrast, there was no significant change between baseline and reassessment for documented participants and English speakers, who started out at baseline with a high rate of service receipt.

Barriers to service utilization and service utilization patterns. Drawing on the more comprehensive and contemporaneous data (rather than the retrospective data reported in the previous section) captured each time a client used Bridges Project assistance to access other services, we examined patterns of service use and barriers

encountered during the first 6 months in the Bridges Project. During this period, 51 participants used case manager or bilingual peer advocate assistance to receive services directly or to connect with other services external to APICHA, mostly medical and social services, with very few mental health services and almost no substance use services. Of the participants who used services in their first 6 months in the project, 80% reported encountering some kind of barrier in the service system outside of APICHA. Participants overall reported a mean of 6.4 barriers, 9.5 services used, and 0.67 barriers per service during the first 6 months after intake. Barriers were field coded into 13 categories; the distribution across these categories for all participants is shown in Table 3.

Comparing by immigration status and primary language in the first 6 months of service utilization, we found that undocumented participants were more likely than documented participants to seek Bridges Project assistance to use medical services (87% vs. 61%; chi-square=4.36, $p<.04$). As shown in Table 4, undocumented participants encountered significantly more barriers (9.3 vs. 4.0; $t=-2.14$, $df=49$, $p<.04$) and more kinds of barriers (2.9 vs. 1.4; $t=-2.80$, $df=49$, $p<.01$) than documented participants. Undocumented participants also experienced more barriers per service, with the difference not statistically significant but noteworthy

Table 3.

**BARRIERS REPORTED BY STUDY PARTICIPANTS,
FIRST SIX MONTHS AFTER INTAKE, N=51**

Barrier	Participants reporting barrier	Participants reporting service use, %
Staff does not speak client's language	28	55
Client not sure where to go	17	33
Costs too much	12	24
Other	10	20
Afraid of what provider might say	7	14
Staff is not competent	7	14
Unsure that HIV status would be kept confidential	7	14
Afraid providers would not understand client's problem	7	14
Staff are not good at listening	6	12
Fear of revealing status to family members	3	6
Staff are not polite	2	4
Lack of child care	0	0
Lack of transportation	0	0

(0.83 vs. 0.50; $t = -1.80$, $df = 49$, $p < .08$). Compared with documented participants, undocumented participants were more likely to report cost barriers (40% vs. 11%; $\chi^2 = 5.66$, $p < .02$) and confidentiality concerns (26% vs. 4%; $\chi^2 = 5.4$, $p < .03$).

In a similar analysis comparing English-primary-language and Asian-primary-language participants (see Table 4), we found that Asian-primary-language participants reported significantly more barriers (8.7 vs. 2.2; $t = -2.63$, $df = 49$, $p < .02$) and more barriers per service (0.85 vs. 0.28; $t = -3.22$, $df = 49$, $p < .01$). Asian-primary-language speakers were more likely to report language barriers (76% vs. 17%; $\chi^2 = 16.4$, $p < .01$) and not knowing where to go for services as a barrier (45% vs. 11%; $\chi^2 = 6.18$, $p < .02$).

To examine whether changes occurred after the initial 6-month period, we also analyzed service utilization patterns and barriers in the follow-up period starting 6 months after intake through case closure or the end of the study. The mean follow-up period was 7.7 months, and 38 participants reported using services in this time period. We found that the rate of barriers per service decreased at follow-up for the sample overall (although not significantly). Also, not surprisingly, the differences between undocumented and documented, and Asian-primary-language and English-primary-language participants, seen in the 6-month period after intake, disappeared in the follow-up period. Although Asian-primary-language participants continued to report more barriers than English-language speakers (19.5 vs. 5; $t = -2.28$, $df = 38$, $p < .03$) there were no differences in the number of barriers per service between the groups, as service utilization for the Asian-primary-language speakers had increased considerably over time without a similar increase in barriers encountered. There was also no difference in the rate of barriers per service between undocumented and documented participants.

Table 4.

MEAN BARRIERS REPORTED BY IMMIGRATION STATUS AND PRIMARY LANGUAGE, FIRST SIX MONTHS AFTER INTAKE, N = 51

	No. of barriers	No. of kinds barriers	No. of barriers per service
All participants (N=51)	6.4	2.1	.67
Immigration status			
Undocumented (n=23)	9.3*	2.9**	.83
Documented and U.S. citizen (n=28)	4.0*	1.4**	.50
Primary language			
Asian language (n=33)	8.7*	2.5	.85**
English (n=18)	2.2*	1.3	.28**

* $p < .05$, ** $p < .01$ (comparing immigration status and primary language sub-groups)

Health-related quality of life. We examined functional health status of the participants using the Medical Outcomes Study (MOS) SF-12 measure.²³ One advantage of using this measure is that U.S. population norms are available for comparison. At baseline, we found that our sample had a lower mental health component score than the general U.S. population (49 vs. 42; $t = -4.76$, $df = 6962$, $p < .0001$). In comparison with a U.S. population of well adults, our sample had lower mental health (52.29 vs. 42; $t = -8.01$, $df = 1314$, $p < .0001$) and physical health (54 vs. 49; $t = -5.1$, $df = 1313$, $p < .0001$) component scores. All of these differences persisted at the follow-up assessment. However, the mental health scores for the overall Bridges Project sample improved from baseline to follow-up (42 vs. 46; $t = 2.3$, $df = 37$, $p < .03$). There were no differences in the mental health or physical health component scores by primary language or immigration status within our sample at baseline or follow-up.

Shared language and cultural familiarity. In order to create a more complete understanding of the aspects of Bridges Project services important to APIs living with HIV and to aid in understanding the study's implications for developing and sustaining community-based services for this population, analysis of quantitative data was supplemented by analysis of qualitative interviews of 17 Bridges Project clients who participated in a separate but related study. In particular, clients' descriptions of Bridges Project services in response to two open-ended questions were examined. These questions were: (1) *Has APICHA helped you in ways that are different from other non-API specific agencies? Explain;* and (2) *What are unique qualities about the services you receive at APICHA?*^{*25}

To analyze the qualitative data, the research team used Boyatzis' method of thematic analysis systematically to identify and make sense of patterns that emerged from the interviews.²⁶ The specific steps of analysis were: (a) sampling by salient characteristics (e.g., immigration status); (b) reducing raw information by creating an outline or synopsis of each interview; and (c) identifying themes within samples by comparing all the summaries from each sub-sample.

Analysis of the qualitative interview data confirm that language interpretation was a key ancillary service provided by bilingual case managers and bilingual peer advocates, especially for participants who presented with acute HIV illness. A 45-year old Japanese man, who has lived in the U.S. for 12 years, explained the benefits of language interpretation services during hospitalization even when one can speak English:

You know when you are really sick laying in the bed in a hospital and when your doctor comes up and says something with all of those difficult medical terms and everything, it doesn't register in your brain. I had a hard time in the hospital. And

*The qualitative data originated with a separate but related study that focused on API clients from APICHA and from other social service agencies providing support to HIV-seropositive APIs. The data presented here are drawn only from Bridges Project clients. As described earlier in the paper, because the Bridges Project made up the vast bulk of APICHA's client services, asking clients to describe their experiences with APICHA's services was equivalent to asking about the Bridges Project services.

[when] I was freshly out of the hospital I really appreciated everything explained in my own language, in my native tongue.

In addition to simple language interpretation, having a familiar cultural milieu was also seen as important, particularly for APIs who had assimilated less fully into American culture. The 45-year-old Japanese man described the comfort of being understood by providers without words:

So I feel comfortable coming here, I mean culture-wise I feel I have a better chance to be understood without saying or explaining much. . . . Our mannerism [is] almost like being a little reserved about expressing your own feelings. For instance if something happened in the public place when you feel offended, you don't pick up a battle right away but you have a tendency to kind of withdraw at the beginning. And all sorts of very subtle things Asian cultures basically share. It's really a comfort that you don't really have [to] explain it and are being understood without saying that.

A 37-year-old Burmese man, who has lived in the U.S. for 7 years, described the comfort of shared culture, particularly in encountering other API clients, as being like visiting his mother's house:

To see the other friends who are sick like me, other Asian friends and Asian people. Sometimes they have the meeting and eat dinner together. . . . I feel like I go visit my mother's house. I could feel it. I could relax, sit down, drink a cup of coffee, and open the refrigerator.

Some participants described the foundation of their relationships with other API clients as based largely on their beliefs about how their illness intersected with ethnicity. Some believed that HIV affected APIs differently from other ethnic groups. In the words of a 53-year-old Filipino man:

I always seem to think that Asian people have a different immune system than Americans, White or Black. I feel more close to them [Asians] having to experience the same side effects. I believe them more than White people when they speak because White people's immune system is different from mine. Even when just taking regular medicine—it will take them four Tylenol to get rid of a headache, and with us Asians it takes like one or two.

Other participants were comforted by being able to meet and openly share their experiences with other APIs without fear of being ostracized, as attested by a 36-year-old Chinese man:

I met many people who are from my hometown. Once we met, we all know what was going on. Then, we become friends over same illness. Because we are all the same, then we also can understand each other . . . it's particularly comfortable, because we don't have any secret between us. It's like having mutual sympathy. We all respect each other.

Receiving services from API providers and support from other API clients, however, also created a dilemma for some clients who were concerned about issues of anonymity and confidentiality. The same 45-year old Japanese man who highlighted the importance of cultural familiarity within a service setting said:

As you probably know Asian communities are very close knitted and everyone knows everyone else. . . . Even though I know all of those rules like confidentiality and all of that, but I still get worried. It's a very closed society and many Asians are, as I said, still conservative about it and I worried about the rumors speculating.

Discussion

The quantitative analyses presented show that undocumented and Asian-primary-language participants in the Bridges Project experienced improvements in their service utilization experiences after enrollment. The qualitative data indicate that the focus of the project design on overcoming language and cultural barriers were critically important to the project's success.

Rates of receipt of primary care services for those who expressed a need for such services show clearly that undocumented and Asian-primary-language participants, compared with documented and English-primary-language participants, had much less success in receiving primary care services prior to enrollment in the Bridges Project. For them, the services of the Bridges Project appeared to be more of a necessity than an enhancement. In contrast, documented and English-language participants could choose from a wider range of service providers in New York City's substantial HIV service system. The qualitative data indicate that cultural familiarity provided by the Bridges Project was an important source of comfort and support, even for English-speaking APIs.

The major barriers to services were language barriers, cost barriers, and not knowing where to go for services. Undocumented participants were also more likely than documented participants to report confidentiality concerns as a barrier to service utilization. Undocumented and Asian-language participants reported more barriers overall and more barriers per service in their first six months in the program, indicating that the problems they encountered prior to enrollment persisted for some time after enrollment as they settled into the project and became familiar with how to use the assistance offered.

At follow-up, the changes in primary care receipt rates and barrier rates are quite dramatic and indicate that the Bridges Project was successful in improving service utilization and reducing barriers, to the point where undocumented and Asian-language participants caught up to documented and English-language participants. The large differences in the rate of receipt of primary care services all but disappeared between undocumented and documented participants and Asian-language and English-language participants. Similarly, the differences between these groups in the number of barriers encountered per service disappeared.

Many of the barriers that are specifically related to being an undocumented immigrant can be addressed in a relatively short time period at the start of care

when case managers direct their energy towards ensuring these individuals receive all the benefits and care for which they are eligible within existing policy restrictions. Undocumented immigrants in New York State are fortunate to be eligible for ADAP Plus, a program that covers HIV medications and HIV primary care for those who are not eligible for Medicaid. Completing the paperwork for programs like ADAP Plus can open up a whole range of services to which the individuals did not previously have access. Language barriers can be more persistent since overcoming them requires the consistent presence of interpreters or staff who speak the necessary languages. This may explain why issues such as shared language and culture and relief from isolation were more often discussed than immigration status in the qualitative interviews.

Health-related quality of life, as measured by the MOS SF-12, was lower at baseline for the participants overall than for a representative sample of adults in the U.S. While there was a statistically significant change overall in the mental health score at follow-up, there was no similar change in the physical health score. It is difficult to interpret the lack of change in the physical health score since our study did not control for stage of illness and the services of the Bridges Project were not medical services but rather social services designed to improve utilization of medical care. The mental health score improved, however, indicating that the reduction in barriers and greater success in receiving services helped participants feel more empowered about their situations. This interpretation of the project's having an important effect on participants' emotional well-being is supported by the qualitative data.

The Bridges Project was developed to address inadequate access to and inconsistent utilization of care among APIs living with HIV/AIDS in NYC. Findings from this study were drawn from APIs who were willing and able to talk about their illness and might not accurately reflect the experiences of newly diagnosed APIs who are not linked to services or those with severely deteriorating health conditions. In addition, our relatively small sample size may have resulted in null findings where a larger sample would have revealed significant differences (a Type II error). Finally, because the study did not use a randomized controlled design, it is not possible to isolate causation definitively for changes observed between baseline and reassessment. However, the findings from this study highlighted a number of lessons for serving APIs living with HIV/AIDS.

One important lesson is that language capacity of providers is an essential component in delivering competent care. Sixty percent of the study participants reported an Asian language as their primary language, and language barriers were the most frequently reported barriers. Even bilingual clients, when they present with acute HIV illness, have diminished capacity to understand medical and treatment jargon in English. Moreover, for bilingual clients, the cultural meanings associated with mental health, substance abuse, and HIV-risk behaviors are more easily navigated in their native language.

Providing language services is a necessary, but not sufficient, component of delivering culturally competent care. HIV-positive APIs may have limited understanding of their HIV disease course and treatment-related issues, regardless of language.

Even when patients and physicians speak the same language, communication can be hindered by patients' unfamiliarity with diagnostic and treatment jargon.^{27,28} Bilingual case managers and peer advocates fill a critical role in clarifying and reinforcing APIs' knowledge of HIV treatment, helping them understand the significance of illness markers (e.g., CD4 count and viral load), and emphasizing the importance of antiretroviral medication adherence.²⁵ Participants in the present study also emphasized the importance of having providers who understand their cultural norms of interaction and communication. They expressed the comfort of meeting other clients from their hometowns or countries and that their shared histories and life circumstances were as important a conduit for mutual support as shared language.

In most cases, sufficient language and cultural capacity for serving APIs means the ability to address multiple language and cultural needs, which can be costly, depending on the service model used. Participants in this study represented 13 different countries of origin, many of which are homes to multiple linguistic and cultural sub-groups. Participants from China, for example, spoke different Chinese languages (including Mandarin, Fujianese, Cantonese, and Hakka) depending on their home region. As discussed earlier, to address diverse cultural and linguistic needs, the Bridges Project developed and trained a corps of part-time bilingual peer advocates to provide linguistic interpretation for clients when they utilized services outside of APICHA as well as within the agency when no full-time staff person could speak their language. Working with a multi-cultural and multi-lingual group of paraprofessionals presents challenges of its own. In the Bridges Project, bilingual peer advocates were part-time non-permanent staff, and, therefore, they required the kind of support that volunteers often receive to stay informed and motivated. In addition, because the peer advocates were sometimes the only individuals who could speak directly to certain clients without linguistic interpretation, it was important to define roles clearly to prevent peer advocates from carrying out duties more appropriately executed by full-time case managers. To address some of these issues, APICHA implemented regular team case conferences for peer advocates and case managers. Increased efforts were also made to acknowledge peer advocates for their work through more frequent peer advocate appreciation events.²⁹

Recent studies have underscored the importance of ancillary HIV services such as case management, housing assistance, benefits counseling, and transportation in facilitating an individual's access to and retention in primary HIV medical care.³ As such, early collaborative partnerships were forged and maintained between the Bridges Project and legal aid organizations, housing placement services, ambulatory care services, and immigrant advocacy agencies. Moreover, APICHA's client services program developed an acupuncture clinic, an Asian food and nutrition program, and organized social events that further addressed the support needs that APIs presented.

The study findings indicate that services for HIV-positive APIs must address issues of HIV-stigma and disclosure. The quantitative analysis indicates that confidentiality was a major concern, especially for undocumented participants. In the

qualitative interviews, participants expressed feeling a tension between the desire for familiarity and the fear of a breach in confidentiality. While clients appreciated being with people who spoke their languages and shared their cultures, and who perhaps even came from the same hometowns, they also expressed the fear of having their HIV status becoming widely known. This fear was magnified by their perception that personal information could easily spread through the small, tightly knit structures of many Asian immigrant communities.

Finally, the precariousness of undocumented immigration status results in significant barriers to services for many API immigrants living with HIV. In our sample, almost half of the clients were undocumented. While undocumented immigrants living with HIV in New York State can receive HIV primary care through the ADAP Plus program, they are not eligible for a number of other benefits, including Medicaid, which provides more comprehensive coverage for general health care.

Asians and Pacific Islanders in the U.S. living with HIV/AIDS require considerable assistance navigating the service system. This is particularly true for APIs whose primary language is an Asian language and undocumented immigrants who may experience greater barriers to care and have fewer personal resources or sources of support. In addition to having adequate linguistic capacity to serve multiple language groups, agencies must be culturally competent. Developing and maintaining cultural competence requires a commitment at all levels of the institution since true cultural competence extends beyond the patient-provider interaction to include agency-level practices, such as hiring, scheduling, and design of the physical space. Most mainstream institutions that strive for cultural competence may not be able to provide the more intangible support offered by ethnically targeted agencies such as APICHA, where the majority of the leadership, staff, and clientele are of API descent. Ethnically-specific agencies serving smaller populations, however, are generally limited in their capacity to provide a full range of services, even though, as this study shows, they can be effective in reducing barriers to services and improving service utilization. Ethnically-specific agencies and mainstream institutions must continue to work alongside each other to ensure that APIs with HIV receive the strong support made possible by shared culture and language while also being ensured access to the full range of services available in the larger service system.

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Notes

1. Cook JA, Cohen MH, Burke J, et al. Effects of depressive symptoms and mental health quality of life on use of highly active antiretroviral therapy among HIV-seropositive women. *J Acquir Immune Defic Syndr*. 2002 Aug 1;30(4):401–9.
2. Gardner LI, Holmberg SD, Moore J, et al. Use of highly active antiretroviral therapy in HIV-infected women: impact of HIV specialist care. *J Acquir Immune Defic Syndr*. 2002 Jan 1;29(1):69–75.
3. Messeri PA, Abramson DM, Aidala AA, et al. The impact of ancillary HIV services on engagement in medical care in New York City. *AIDS Care*. 2002 Aug;14 Suppl 1: S15–29.
4. Cunningham WE, Hays RD, Ettl MK, et al. The prospective effect of access to medical care on health-related quality-of-life outcomes in patients with symptomatic HIV disease. *Med Care*. 1998 Mar;36(3):295–306.
5. Cook JA, Cohen MH, Grey D, et al. Use of highly active antiretroviral therapy in a cohort of HIV-seropositive women. *Am J Public Health*. 2002 Jan;92(1):82–7.
6. Turner BJ, Cunningham WE, Duan N, et al. Delayed medical care after diagnosis in a U.S. national probability sample of persons infected with human immunodeficiency virus. *Arch Intern Med*. 2000 Sep 25;160(17):2614–22.
7. Andersen R, Bozzette S, Shapiro M, et al. Access of vulnerable groups to antiretroviral therapy among persons in care for HIV disease in the United States. HCSUS Consortium. HIV Cost and Services Utilization Study. *Health Serv Res*. 2000 Jun; 35(2):389–416.
8. Cunningham WE, Markson LE, Andersen RM, et al. Prevalence and predictors of highly active antiretroviral therapy use in patients with HIV infection in the United States. HCSUS Consortium. HIV Cost and Services Utilization. *J Acquir Immune Defic Syndr*. 2000 Oct 1;25(2):115–23.
9. Asian American Federation Census Information Center. New York City Asian American census brief. New York: Asian American Federation of New York, 2004.
10. Bureau of HIV/AIDS Epidemiology, New York State Department of Health. New York State HIV/AIDS surveillance semiannual report, for cases diagnosed through June 2004. Albany, NY: New York State Department of Health, Bureau of HIV/AIDS Epidemiology, 2005 Nov.
11. New York City Department of Health and Mental Hygiene (NYC DOHMH). HIV Epidemiology Program (HEP), 2nd quarter report. (vol. 3, no. 2.) New York: NY DOHMH, HEP, 2005 Apr.
12. New York City Department of Health and Mental Hygiene. HIV epidemiology program, 4th quarter report. (vol. 3, no. 4.) New York: NY DOHMH, HEP, 2005 Oct.
13. Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report, 2004. Vol. 16. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, 2005.
14. Bureau of HIV/AIDS Epidemiology, New York State Department of Health. Custom data report. Albany, NY: New York State Department of Health, Bureau of HIV/AIDS Epidemiology, 2005 Jan 4.
15. Zaidi IF, Crepez N, Song R, et al. Epidemiology of HIV/AIDS among Asians and Pacific Islanders in the United States. *AIDS Educ Prev*. 2005 Oct;17(5):405–17.
16. United States Census Bureau. Profile of the foreign-born population in the United States: 2000. (Current Population Reports: Special Studies, P23–206.) Washington, DC: U.S. Census Bureau, 2001.

17. Eckholdt H, Chin J. Pneumocystis carinii Pneumonia in Asians and Pacific Islanders. *Clin Infect Dis*. 1997 Jun;24(6):1265–7.
18. Pounds MB, Conviser R, Ashman JJ, et al. Ryan White CARE Act service use by Asian/Pacific Islanders and other clients in three California metropolitan areas (1997–1998). *J Community Health*. 2002 Dec;27(6):403–17.
19. Kang E, Rapkin BD, Springer C, et al. The “Demon Plague” and access to care among Asian undocumented immigrants living with HIV disease in New York City. *J Immigr Health*. 2003 Apr;5(2):49–58.
20. Centers for Disease Control and Prevention (CDC). Diagnosis and reporting of HIV and AIDS in states with HIV/AIDS surveillance—United States, 1994–2000. *MMWR Morb Mortal Wkly Rep*. 2002 Jul 12;51(27):595–8.
21. Office of AIDS Surveillance, New York City Department of Health and Mental Hygiene. Custom data report at request of author. New York: NYC DOHMH, 2001 May 22.
22. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Q Health Soc*. 1973 Winter;51(1):95–124.
23. Ware JE, Jr., Kosinski M, Turner-Bowker, DM, et al. How to score version 2 of the SF-12 health survey (with a supplement documenting version 1). Lincoln, RI: Quality-Metric Incorporated, 2002.
24. Cohen J. *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Lawrence Erlbaum Associates, 1988.
25. Kang E, Rapkin B, Kim JH, et al. An assessment of needs among Asian and Pacific Islander undocumented non-citizens living with HIV disease in New York City. New York: Memorial Sloan-Kettering Cancer Center, 2000
26. Boyatzis RE. *Transforming qualitative information*. Thousand Oaks, CA: Sage Publications, 1998.
27. Quesada GM. Language and communication barriers for health delivery to a minority group. *Soc Sci Med*. 1976 Jun;10(6):323–7.
28. Loue S. Access to health care and the undocumented alien. *J Leg Med*. 1992 Sep; 13(3):271–332.
29. Chin JJ, Wong F. Improving access to care for cultural, linguistic, and racial minorities: the bilingual peer advocate program of the Asian & Pacific Islander Coalition on HIV/AIDS. In: Erwin J, Smith DK, Peters BS, eds. *Ethnicity and HIV: prevention and care in Europe and the USA*. London: International Medical Press, 2003.