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Strategies for Engaging and Retaining Latinos in HIV Care

by Margaret Hargreaves, Julia Hidalgo, Vivian Byrd, Ann Bagchi, and Jung Kim

This brief is based on Mathematica's study of strategies used by health care providers funded by the Ryan White HIV/AIDS Program (RWHAP) to improve Latinos' access to and use of HIV medical and supportive services. Data sources included a review of the literature, site visits to 10 exemplary HIV providers, and analysis of providers' service use and clinical outcome data. The study identified 43 service strategies, administrative policies, and organizational practices that help Latinos overcome barriers at the individual, clinician, organization, system, and community levels.

Addressing Barriers to HIV Care

Hispanics and Latinos (referred to here as Latinos) are the largest ethnic group in the United States and include many different subgroups, such as Puerto Ricans, multiple generations of residents in the southwest, and newer arrivals from Cuba. Latinos are disproportionately represented among people with HIV/AIDS in the United States.[1] They comprise 14 percent of the U.S. population, but 17 percent of those diagnosed with HIV/AIDS. In addition, they represent 19 percent of all people reported to be living with AIDS.[2] They also experience disproportionately high rates of delayed diagnosis and entry into HIV care. Latinos are less likely than whites to remain engaged in HIV care, less likely to use highly active antiretroviral therapy (HAART) and other HIV medications, and more likely to become lost to care.[3] Barriers at multiple levels hinder Latinos' ability to access and remain in HIV care.

The study team conducted site visits with 10 RWHAP-funded providers across 6 states with larger (California, Florida, New York, and Texas) and smaller (Minnesota and North Carolina) Latino HIV populations (see Table 1). Each provider was recognized by program grantees, project officers, and other providers for the high quality of care provided to their HIV-positive Latinos clients. Analysis of provider clinical data confirms that HIV-positive Latinos at these 10 sites receive comparable, if not better, care than their non-Latino counterparts, as measured by being prescribed HAART and having at least one CD4 count or viral load test done in the last year.[4] In addition, qualitative analysis of provider practices found that they use a combination of 43 strategies designed to help overcome barriers at different levels that limit Latinos' access to and engagement and retention in HIV care. Of the 10 providers, 9 share half or more of the strategies and 7 share two-thirds or more of them.

ABOUT THE STRATEGIES

All 10 providers helped clients access health care benefits and services for basic needs (individual level); hired Spanish-speaking staff and interpreters familiar with Latino cultural practices, values, and traditional remedies and who treated clients with warmth and respect (clinician level); created "one-stop shop" centers of HIV ambulatory outpatient care and supportive services with flexible scheduling and Spanish-language materials (organization level); and developed networks of referrals from agencies that serve Latinos (system level). Nine of the 10 providers also conducted outreach to Latino subgroups, including men-who-have-sex-with-men (MSM), women, migrants, incarcerated, transgender, or undisclosed MSM (community level).

Individual-Level Barriers and Strategies

HIV-positive Latinos experience various socio-demographic factors (including immigration status, acculturation, English proficiency, health literacy, fear of disclosure of their HIV status, social isolation, incarceration, and domestic violence), economic factors (including lack of income, unemployment, low educational attainment, and housing instability), and health factors (HIV/AIDS status, co-occurring mental health issues, addictions, and other chronic conditions) that limit their access to and engagement and retention in HIV care. The health care providers we visited have developed a range of strategies to address these individual-level barriers to care (see Table 2).

TABLE 1: STUDY SITE CHARACTERISTICS, STRATEGIES, AND CLINICAL OUTCOMES

Study Site and Location	Clinic Type and RWHAP Funding	Number of HIV Clients (Percentage Latino)	Populations Served	Number and Percentage of Strategies Used (n=43)	Percentage of Latino Patients		
					> 1 CD4 Count[1]	>1 Viral Load Test[1]	Prescribed HAART
Community AIDS Resource, Inc. Miami, FL	ASO[2] A, B, MAI, SPNS	1,334 (52%)	ME, CA, SA, CB	17 (40%)	87	81	5[3,4]
CommWell Health Dunn, NC	FQHC MAI B, C, D, F	250 (20%)	ME, CA, SA	30 (70%)	89	89	51[4]
Elmhurst Hospital Center-ID Clinic Queens, NY	Hospital OPD A, B, C, D, MAI	1,326 (57%)	ME, CA, SA, CB	24 (56%)	93	93	81[4]
Centro de Salud Familiar La Fe El Paso, TX	FQHC B, C	895 (87%)	ME, CA, MI	28 (65%)	91[4]	91[4]	81[4]
Miami Beach Community Health Center-ISP Miami Beach, FL	FQHC A, C, MAI	964 (61%)	ME, CA, SA, CB	22 (51%)	66[4]	66[4]	54[4]
Mission Neighborhood Health Center, Clinica Esperanza San Francisco, CA	FQHC A, B, C, MAI	481 (71%)	ME, CA, SA	33 (77%)	66[4]	66[4]	54[4]
Montefiore AIDS Center Bronx, NY	Hospital OPD A, B, C, MAI	2,665 (53%)	ME, CA, SA	33 (77%)	95	93	90
San Ysidro Health Center Coordinated Assistance Services Advocacy San Ysidro, CA	FQHC A, B, C	945 (61%)	ME, CA, SA, CB	39 (91%)	91[4]	89	89[4]
Valley AIDS Council Harlingen, TX	FQHC MAI B, C, D, F	1,136 (88%)	ME, CA, MI	30 (70%)	83.6[4]	83.6[4]	43[4]
West Side Community Health Center-Clinic 7 St. Paul, MN	FQHC A, B, D, MAI	160 (71%)	ME, CA, SA, CB	32 (74%)	49[4]	49[4]	37[4]

Data Source: Site visit interviews, 2009 RWHAP Program Reports (RDRs), and RWHAP Services Reports (RSRs).

Notes:
[1] Percent receiving lab test in past twelve months.
[2] Care Resource was designated an FQHC in 2010.
[3] Rate is due to reporting method.
[4] Latino rate is same or higher than non-Latino rate.

ASO=AIDS Service Organization; FQHC=Federally Qualified Health Center; ID=Infectious Disease; ISP=Immune Support Program; MAI=Minority AIDS Initiative; OPD=Outpatient Department.

Populations: CA=Central America; CB=Caribbean, including Puerto Rico; ME=Mexico; MI=Migrant farm workers; SA=South America.

Clinician-Level Barriers and Strategies

Because some HIV-positive Latinos have little or no experience with health care systems, ineffective communication and lack of trust between Latino clients and their doctors create significant barriers to care. Health care quality suffers when clinicians, case managers, and other health care workers lack basic linguistic and cultural competence or the necessary skills to communicate effectively with low-literacy clients or clients with limited English proficiency. Discrimination, stereotyping, and uncertainty also weaken relationships between practitioners and patients. Clinician-level strategies are found in Table 3.

Organizational Barriers and Strategies

Organizational barriers also impede Latinos' access to and use of HIV care, including policies and practices that limit the availability, acceptability, or affordability of HIV care and supportive services. Limited clinic hours; lack of client privacy, case coordination, and Spanish-language materials; and confusing, unwelcoming facilities keep some HIV-positive Latinos from seeking or staying in HIV care. To address these barriers, health care providers use a range of solutions shown in Table 4.

TABLE 2. NUMBER OF PROVIDERS USING STRATEGIES TO ADDRESS INDIVIDUAL-LEVEL BARRIERS TO HIV CARE	
Help completing applications and obtaining eligibility documentation for Medicaid, Medicare, AIDS Drug Assistance Program, Social Security Assistance, RWHAP, Supplemental Nutrition Assistance Program	10
Referrals for social services, including food and housing assistance, domestic violence services, legal aid, immigration services	10
Transportation assistance, including vans and metro/bus cards	9
Targeted Latino support groups for MSM, women, transgender, Spanish speakers, hepatitis C, treatment adherence, substance abuse, domestic violence, HIV education	8
Peer health educators, peer counselors, buddies, who provide health education, system navigation, social support, and client advocacy	7
Reinforcement of treatment adherence messages geared to client literacy levels, using reminder calendars, pictures, symbols, color codes, pill boxes, key chains, directly observed therapy, literacy lessons	7
Home or clinic delivery of HIV medications by pharmacy or clinic staff	3
Client social groups, knitting, arts, crafts	3

System-Level Barriers and Strategies

System-level barriers include policies limiting eligibility for publicly funded medical and supportive services for undocumented immigrants, lack of funding for Latino-centered HIV medical care and supportive services, lack of organizational capacity to provide comprehensive, co-located HIV services, and lack of care coordination across providers. Strategies shown in Table 5 deal with system-level barriers.

TABLE 3. NUMBER OF PROVIDERS USING STRATEGIES TO ADDRESS CLINICIAN-LEVEL BARRIERS TO HIV CARE	
Knowledge of traditional home remedies, foods, cultural values, religious beliefs, and differences among Latino subpopulations	10
Showing warmth, respect, friendship to clients and their families; having a passion for the work	10
Fluent Spanish speakers, interpreter lines, translation support from bilingual staff, and certified interpreters	10
Staff "willing to go the extra mile" for clients	7
Home visits, hospital visits, and long-term follow up	7
Mostly Latino/Hispanic staff	5
Avoidance of culturally loaded terms such as *gay, mental health,* and *psychiatry*	5
Training in cultural competency	3

Community-Level Barriers and Strategies

Cultural stigmas against HIV, homophobia, and transgender issues, as well as a lack of knowledge in the Latino community about HIV and HIV treatment, create additional barriers. Cultural values related to *machismo*, *marianismo*, *familismo*, *simpatia*, *respeto*, *personalismo*, religion, and use of traditional home remedies also limit Latinos' willingness and ability to recognize and acknowledge their HIV status, tell family and friends about their condition, and take the steps needed to get tested, diagnosed, and enrolled in HIV care. Strategies used to address these barriers are in Table 6.

TABLE 4. NUMBER OF PROVIDERS USING STRATEGIES TO ADDRESS ORGANIZATION-LEVEL BARRIERS TO HIV CARE	
Comprehensive one-stop shop of HIV ambulatory outpatient care and supportive services	10
Flexible scheduling, double-booking, walk-ins, open slots for emergencies	10
Clinic materials in Spanish (signs, notices, videos, website, brochures, medication labels, posters)	10
Frequent appointment reminder calls, missed appointment follow-up calls, free cell phones to receive reminders	9
Close tracking of visits, labs, medications, and contact information for treatment adherence and retention purposes	9
Client confidentiality policies and practices	8
Universal screenings for mental health and/or substance abuse to reduce treatment stigma	7
Discreet name and location of clinic	6
Long appointment times for visits with clinicians, case managers, and counselors	6
Multidisciplinary teams, team meetings, patient briefings, case conferences	6
Expanded clinic hours, evening hours	5
Comfortable, home-like environment	3
Offices arranged to facilitate staff/client interaction and communication	3
HIV clinician team includes specialists (for example, dermatology, OB-GYN)	3

Implications for Latino HIV Care

This study identified a wide range of strategies that health care providers use to reach out to HIV-positive Latinos, link them into HIV care, and help them remain in treatment. Some strategies are linguistically or culturally specific to Latino populations, such as the use of bilingual, bicultural

providers and Spanish-language materials. Other strategies address barriers that Latinos share with other underserved groups, such as lack of economic resources, fear of disclosure of their HIV status, and lack of understanding of HIV. Many strategies cost little or nothing to implement, including practices to protect client privacy, use of peers to help clients navigate the health care system, and development of referral networks and partnerships among Latino-serving organizations to create an integrated care system. While limited in scope, this study does provide qualitative evidence that, by addressing the barriers to care experienced by HIV-positive Latinos at multiple levels, health care providers can reduce or eliminate disparities in Latinos' access to, use of, and retention in HIV care.

TABLE 5. NUMBER OF PROVIDERS USING STRATEGIES TO ADDRESS SYSTEM-LEVEL BARRIERS TO HIV CARE

Network of client referrals from Latino-serving organizations; no wrong door entry into system	10
Partnerships, consortia, and collaborations of Latino-serving organizations	8
HIV care tracking and coordination across inpatient/outpatient settings, agencies, states, U.S./Mexican border	7
Latino representation on HIV prevention and treatment planning councils	6
Health policy or funding advocacy for Latino HIV services	5
Expedited, client hand-offs among testing, linkage, bridge, and retention services staff	4

TABLE 6. NUMBER OF PROVIDERS USING STRATEGIES TO ADDRESS COMMUNITY-LEVEL BARRIERS TO HIV CARE

Targeted outreach to Latino subpopulations—MSM, women, incarcerated, transgender, migrants, undisclosed MSM	9
Discrete identity of outreach and linkage staff to protect client privacy	7
Pride events and Latino celebrations to reduce stigma	6
Regional HIV conferences and retreats to improve HIV care	4
HIV talks to community groups, in churches, on radio, TV	3
Latino theatre troops to increase awareness of HIV	2

End Notes

[1] Health Resources and Services Administration. "The Ryan White HIV/AIDS Program: Hispanics and HIV/AIDS." Rockville, MD: U.S. Department of Health and Human Services, 2008. Available at hrsa.gov/hab/Hispanics.pdf.

[2] Centers for Disease Control and Prevention. "HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States and Dependent Areas, 2007, Vol. 19." Atlanta: U.S. Department of Health and Human Services, CDC, 2009. Available at www.cdc.gov/hiv/topics.

[3] Tobias, C., W. Cunningham, and M. Pounds. "Making the Connection: The Importance of Engagement and Retention in HIV Care." *AIDS Patient Care and STDs,* vol. 21, supp. 1, June 2007, pp. S3-S8.

[4] The CommWell Health site serves a Latino subpopulation (migrants) that is significantly different from the clinic's non-Hispanic population.

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