

**ILLUMINATING  
THE NEEDS OF THE FORGOTTEN**

**“OLVIDADOS”**

**A NATIONAL HEALTH ASSESSMENT  
OF LATINOS GROWING OLDER  
WITH HIV**



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**Illuminating the Needs of the Forgotten “Olvidados”:  
A National Health Assessment Of Latinos Growing Older with HIV**

**Iluminando las Necesidades de “Olvidados”:  
Un Diagnóstico Nacional Sobre la Salud de los Latinos Mayores Viviendo con VIH**

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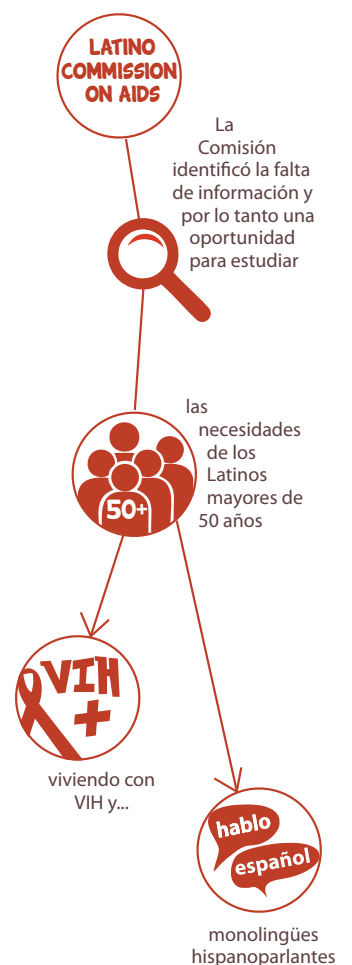
The Latino Commission on AIDS is a nonprofit organization dedicated to addressing the health disparities and responding to the impact of HIV & AIDS, viral Hepatitis and STIs in our communities. The Commission is the leading organization coordinating Latinos in the Deep South; National Hispanic Hepatitis Awareness Day (May 15), National Latino AIDS Awareness Day (October 15), and other prevention, research, capacity building, and advocacy programs in the United States and its territories. The Commission is the founder of the Hispanic Health Network.  
[www.latinoaids.org](http://www.latinoaids.org)

# SOBRE ESTE REPORTE

La Comisión Latina sobre el SIDA, en asociación con la Red Hispana de Salud, está comprometida en promover la investigación rigurosa, culturalmente adecuada, diseñada para influenciar la política y la práctica. Con una experiencia de 27 años en este campo, estamos trabajando para identificar diversos factores que afectan la salud de los Hispanos/Latinos en los Estados Unidos y los territorios de los Estados Unidos, para este reporte, con especial atención al impacto del VIH/SIDA. Mediante la investigación y programas sociales, la Comisión se dedica a reducir las nuevas infecciones del VIH, señalar los determinantes sociales de la salud e identificar las necesidades de los Latinos que viven con la infección del VIH. Nuestro trabajo se enmarca en la justicia social, estamos estudiando poblaciones marginadas y a menudo ignoradas para entender mejor los efectos que tienen raza, etnia, género, orientación sexual, edad y clase social sobre la salud y la atención médica. Al mismo tiempo, queremos contribuir al campo social con investigaciones que identifiquen las tendencias emergentes y temas poco estudiados que afectan a la población Latina.

La motivación para este diagnóstico nacional fue nuestra preocupación de que la investigación actual no aborda adecuadamente las necesidades de la población Hispana/Latina mayor de cincuenta años que viven con VIH. Una revisión de la literatura sobre adultos mayores con VIH/SIDA encontró que muy pocos estudios incluyeron muestras sólidas de Latinos y, aun así, recopilaron información de Latinos angloparlantes, ignorando el impacto del VIH en adultos mayores que son monolingües hispanoparlantes y entre nuevos inmigrantes. Debido a que los Latinos generalmente enfrentan muchos obstáculos para poder tener acceso a la atención médica, es importante entender si estas barreras permanecen constantes durante el curso de su vida o si se agravan entre estos subgrupos más ignorados y vulnerables.

La Comisión agradece el trabajo colaborativo con nuestras organizaciones hermanas. Cada una de las organizaciones que contribuyeron a este diagnóstico nacional de las necesidades comunitarias tienen un historial de servicios para los Latinos que viven con el VIH. Reconocemos a AltaMed en Los Ángeles, Fundación Latinoamericana de Acción Social (FLAS, Inc.) en



Houston, Mujeres Unidas en San Antonio, Texas; PrideLines en Miami, Florida; Camuy Health Services Inc. en Camuy, Bill's Kitchen en San Juan y Fajardo, en Puerto Rico, proporcionaron un apoyo increíble a este proyecto. También estamos agradecidos con Gilead Sciences, la Federación Hispana y AIDS United por su apoyo y dedicación a este esfuerzo nacional.

Por último, fallaríamos si no agradeciéramos y dedicáramos este informe a todos los participantes que compartieron sus historias y testimonios. Son sus vivencias las que dan apoyo a los cambios necesarios en las políticas públicas. Este documento pretende validar sus luchas y lecciones aprendidas, con la esperanza de que podamos ayudar a mejorar la calidad de vida, no sólo para estos encuestados, sino también para el rápido y creciente número de Latinos en todo el país que están envejeciendo con el VIH.

Una nota sobre el uso de términos: hemos utilizado los términos Hispanos/Latinos, Hispanos y Latinos de forma intercambiable en este informe, sin la intención de excluir a cualquier persona que se identifique como parte del grupo étnico más amplio entre las minorías en los Estados Unidos.

# RESUMEN EJECUTIVO

Las personas mayores representan una proporción considerable de personas que viven con VIH en los Estados Unidos. En 2013, alrededor del 42% de las personas con diagnóstico positivo al VIH en el país tenían 50 años o más (CDC, 2017a). Este segmento poblacional presenta retos particulares de prevención: las personas mayores muestran los mismos factores de riesgo sexual que las personas más jóvenes, pero son menos conscientes de su vulnerabilidad al VIH. También es menos probable que discutan sus experiencias sexuales con sus doctores o proveedores de servicios sociales, resultando en oportunidades perdidas para la detección del VIH y la educación sobre temas relevantes a las prácticas sexuales. Al mismo tiempo, los retos de tratamiento especial de esta población son recalcados por el hecho de que son más propensos a ser diagnosticados tarde con el VIH, impactando sus opciones de tratamiento (CDC, 2017a).

Los Hispanos/Latinos, que pueden ser de cualquier raza, representan la población étnica y minoritaria de más rápido crecimiento de la nación hoy en día, así como la población envejeciente de más rápido crecimiento. A pesar de representar el 18% de la población total de los EE.UU., representaron aproximadamente el 24% de los nuevos diagnósticos de VIH en 2015 (CDC, 2017b). Los Latinos mayores tienen un mayor riesgo de infección en comparación con sus homólogos blancos no latinos. En el 2015, las personas Latinas de 50 a 54 años de edad tenían una tasa de infección diagnosticada de VIH dos veces más alta que la de blancos no latinos en el mismo grupo de edad (CDC, 2017c).

Por lo tanto, hay una necesidad más apremiante de examinar los servicios de atención de salud de una población que a menudo es ignorada: **“Olvidados”**. Este informe, el primero de su tipo, describe los resultados de un diagnóstico comunitario de las necesidades a nivel nacional, principalmente Hispanos/Latinos, mayores de 50 años, que viven con el VIH/SIDA. En un proyecto de más de un año, la Comisión visitó ciudades con altos índices de VIH, incluyendo Houston (Texas), San Antonio (Texas), Fajardo (Puerto Rico), Camuy (Puerto Rico), San Juan (Puerto Rico), Nueva York (Nueva York), Los Ángeles (California) y Miami (Florida).

42%

DE LAS PERSONAS CON DIAGNÓSTICO DE VIH EN LOS EE.UU. EN EL 2013 TENÍAN 50 AÑOS O MÁS

18.3  
de 100,000



Latinos

7.6  
de 100,000



Blancos no Latinos

LAS PERSONAS LATINAS DE 50 A 54 AÑOS DE EDAD TENÍAN UNA TASA DE DIAGNÓSTICO DE INFECCIÓN DE VIH DOS VECES MÁS ALTA QUE LA DE BLANCOS NO LATINOS

A través de colaboraciones con organizaciones comunitarias y clínicas en cada ciudad, se recogió y analizó data cuantitativa y cualitativa. Este reporte (un primer paso hacia una investigación más integral de este complejo tema) tiene como objetivo proporcionar una imagen más matizada del estado de salud y las necesidades de la población diversa de latinos mayores de 50 años que viven con VIH. Nuestros hallazgos destacan los factores sociales y estructurales que perpetúan las disparidades y comorbilidades en la salud relacionadas con el VIH entre esta población.

El estudio incluyó a 157 hispanos/latinos viviendo con VIH, de 50 a 80 años, con una edad media de 58,5 años. Sesenta por ciento identificados como varones, 36% como mujeres y 3% como transgéneros. La mayoría de los encuestados eran nacidos en el extranjero y una abrumadora mayoría eran de muy bajos ingresos, con el 91% de los encuestados viviendo con menos de \$20,000 por año. Además, todos los encuestados tomaron parte en las discusiones de grupos focales, que a menudo proporcionan una imagen más precisa de los obstáculos que muchos de ellos enfrentan.

Los encuestados fueron invitados a participar a través de organizaciones de servicios comunitarios y clínicas, por lo que, por definición, ya estaban vinculados de alguna manera con los servicios de VIH/SIDA. Por lo tanto, los resultados de la encuesta, aunque apuntan a algunas preocupaciones críticas, no deben tomarse como representativas de toda la población de Latinos envejecientes viviendo con VIH, nuestro equipo investigador cree que la data y opiniones incluyen personas que viven en aislamiento, temor, miedo o ignorados de su condición relacionada al VIH. Por lo tanto, nuestras conclusiones subrayan los desafíos para los investigadores en general y oficiales encargados de establecer políticas públicas.

## Principales Resultados

→ La encuesta confirmó el bajo nivel socioeconómico y de educación entre los encuestados, factores que son asociados con resultados deficientes para la salud.

→ La mayoría de los encuestados dijeron que tienen un proveedor de servicios médicos, están asegurados y reportaron cargas virales (cantidad de VIH) indetectables (aspectos clave para

# 157

NÚMERO DE LATINOS  
VIVIENDO CON VIH DE  
50 A 80 AÑOS DE EDAD  
QUE PARTICIPARON EN  
EL ESTUDIO



ENCUESTADOS  
REPORTARON  
UN CARGA VIRAL  
INDETECTABLE



ENCUESTADOS  
REPORTARON ALGUNA  
DISATISFACCIÓN CON  
SU SERVICIOS DE SALUD

permanecer recibiendo atención médica continua). Sin embargo, una proporción considerable de los participantes, alrededor de uno de cada cuatro, informó estar *menos satisfecho* con algún aspecto de la atención médica de su proveedor. Esto es importante notar, ya que la satisfacción con el proveedor de servicios de salud ha demostrado que es crítica para la participación y para mantenerse recibiendo atención médica, así como también aumenta significativamente los resultados positivos en la salud.

→ En promedio, alrededor del 40% de los participantes informaron que sus proveedores de servicios durante las visitas en los últimos seis meses les preguntaron acerca de aspectos relacionados con la salud, como salud mental, cáncer, consumo de sustancias, infecciones de transmisión sexual y violencia. Esto indica que una parte significativa de los encuestados *no fue aconsejada* durante las visitas acerca de relevantes preocupaciones de salud, exámenes y riesgos de comorbilidad.

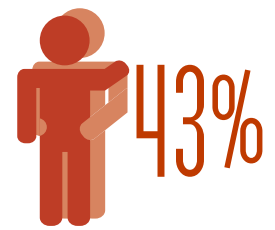
→ Uno de cada tres encuestados indicó algún nivel de dificultad con mantenerse apegado a su tratamiento médico, lo que condiciona seriamente una futura exploración y mejor explicación.

→ Una proporción significativa de la muestra, el 43%, indicó alguna actividad sexual en los últimos 3 meses, pero las discusiones sobre la salud sexual con los proveedores de servicios fueron relativamente infrecuentes, lo que indica la necesidad de que los proveedores se interesen más activamente en las historias, prácticas sexuales de los pacientes mayores de cincuenta años.

→ Aunque la muestra de los participantes reportó un uso de sustancias relativamente bajo, el 12% indicó que estaban en recuperación por uso de drogas. Los encuestados pueden estar subestimando estos problemas debido al estigma de lo considerado como correcto socialmente, pero independientemente, las conversaciones de los proveedores relacionadas con el uso de sustancias también se reportaron como escasas.

→ La mitad de los encuestados reportó problemas con la depresión, destacando la importante brecha en los servicios de salud mental.

Las discusiones en los grupos focales proporcionaron una visión a menudo más aguda de las preocupaciones y barreras que enfrentan los Latinos mayores. Los obstáculos cruciales identificados para



**PARTICIPANTES QUE REPORTARON ALGUNA ACTIVIDAD SEXUAL EN LOS ÚLTIMOS 3 MESES**



**PARTICIPANTES QUE REPORTARON SÍNTOMAS DE DEPRESIÓN CLÍNICA**

la salud óptima y el bienestar incluyen **miedo y desconfianza, experiencia de comorbilidades y desafíos de acceso a la atención y cuidado médico**. Tales obstáculos complican el mantenerse apegado a su tratamiento médico y cómo manejar los efectos secundarios asociados al tratamiento, así como la probabilidad de aumentar el aislamiento social, que a su vez puede incrementar la depresión, aumentar el estrés, poniendo en riesgo aún más el sistema inmunológico. Los más vulnerables pueden tener más dificultades para auto-regularse, y en su lugar pueden usar mecanismos de adaptación no adecuados como el uso de sustancias, mala dieta, falta de ejercicio, comportamientos adictivos o participar en relaciones no saludables.

La encuesta y los grupos focales señalaron “lo que funciona y ayuda” a los Latinos mayores para lograr una salud óptima y bienestar en sus vidas. Las cosas que ayudan para mejorar la calidad de vida y la salud incluyeron: **una fuerte relación con su proveedor de servicios médicos, altos niveles de poderse conectar a redes sociales o sistemas de apoyo, positividad sexual y compromiso con trabajo o voluntariado**.



# RESUMEN DE RECOMENDACIONES

## **Aumentar los servicios culturalmente sensibles y adecuados:**

La falta de servicios bilingües, culturalmente sensibles, apropiados para la edad y servicios de VIH/SIDA libres de estigma, es un obstáculo clave para la población envejeciente de los Latinos viviendo con el VIH. Asimismo, se necesitan más fondos, colaboración e integración de programas para iniciativas que incrementen la cantidad de Latinos en la fuerza laboral relacionada con el VIH, incluyendo los que proveen servicios médicos.

**Iniciativas de educación sexual y bienestar sexual:** Es urgente desarrollar iniciativas comunitarias de educación sexual para la población Latina de más de 50 años. Entender las prácticas sexuales de esta población será la base para desarrollar programas comunitarios que mejor aborden las necesidades de los que envejecen con VIH, o en riesgo de exponerse al VIH.

**Más capacitación y entrenamientos:** Los proveedores de salud, trabajadores directos en servicios sociales y los encargados de formular políticas públicas necesitan tener una mayor comprensión de las experiencias de los Latinos envejeciendo con VIH / SIDA. Integración de la Salud Mental y de Comportamiento con el VIH y la población envejeciente: Hay una escasez de servicios especializados de apoyo mental y del cambio de comportamiento para abordar las necesidades únicas de atención emergente de la población envejeciente con VIH, incluido el rápido crecimiento de sobrevivientes a largo plazo, así como los recién diagnosticados con el VIH. Los asuntos de salud psicosocial, mental y de comportamiento que enfrenta esta población necesitan una atención mucho mayor.

**Más investigación:** Es importante estudiar los determinantes estructurales y sociales de la enfermedad del VIH/SIDA entre los Latinos mayores y otros grupos vulnerables para ayudar a optimizar los recursos de la sociedad y desarrollar respuestas efectivas. Se debe prestar especial atención para entender las realidades únicas tanto de las personas Hispánicas nacidas en Estados Unidos como los nacidos en el extranjero.



ES IMPORTANTE  
PROVEER EDUCACIÓN  
DE SALUD SEXUAL A  
LOS LATINOS MAYORES  
DE 50 AÑOS VIVIENDO  
CON VIH



ES IMPORTANTE  
PROVEER MÁS  
CAPACITACIÓN Y  
ENTRENAMIENTO,  
PRIORIZANDO  
SERVICIOS  
CULTURALMENTE  
SENSIBLES



ES IMPORTANTE  
INTEGRAR SALUD  
MENTAL EN LOS  
SERVICIOS OFRECIDOS  
A PERSONAS MAYORES  
DE 50 AÑOS QUE  
ADEMÁS VIVEN CON VIH

Centrarse en los esfuerzos de prevención y tratamiento: Es crucial que las pruebas de VIH y las iniciativas de tratamiento estén adaptadas a los adultos mayores para poder llegar a esta población vulnerable y a menudo invisible.

**El acceso al cuidado de la salud es un derecho humano:** Pedimos un mayor apoyo para ayudar a los responsables políticos en todos los niveles a entender que todos tienen derecho a la atención médica, incluyendo atención de salud mental y servicios críticos de apoyo (vivienda, formación profesional, compromiso social, orgullo cultural y afirmación personal, entre otros).

**Llamado a la Acción:** La Comisión Latina sobre el SIDA, la Red Hispana de Salud y las redes comunitarias con las que trabajamos pedimos a los departamentos de salud de la ciudad, del condado y del estado que tomen medidas para atender las necesidades de la población envejeciente Latina que vive con VIH/SIDA y otras condiciones crónicas en nuestra nación y en los territorios de los Estados Unidos. Envejecer saludablemente debe ser una meta nacional para todos nosotros.

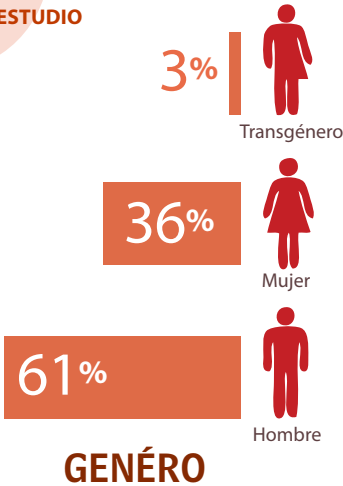
**TABLA 1. Características Demográficas de la Muestra (N=157)**

	<i>N</i>	<i>%</i>		<i>N</i>	<i>%</i>
<b>IDENTIDAD DE GÉNERO</b>			<b>ESTADO LABORAL</b>		
HOMBRE	96	61.1	TRABAJO TIEMPO COMPLETO	6	3.8
MUJER	56	35.7	TRABAJO MEDIO TIEMPO	26	16.6
TRANSGÉNERO	5	3.2	DESEMPLEADO	41	26.1
			RETIRADO	23	14.6
<b>ORIENTACIÓN SEXUAL</b>			DISCAPACITADO	58	36.9
HETEROSEXUAL	64	40.8	VOLUNTARIO	3	1.9
GAY/HOMOSEXUAL	65	41.4			
LESBIANA	3	1.9	<b>RELACIÓN DE PAREJA</b>		
BISEXUAL	13	8.3	SOLTERO	90	57.3
INSEGURO/A	9	5.7	COMPROMETIDO	17	10.8
SIN ESPECIFICAR	3	1.9	CASADO	15	9.6
			DIVORCIADO	23	14.6
<b>EDAD</b>			VIUDO	12	7.6
50-54	45	23.9			
55-59	37	19.7	<b>NIVEL DE EDUCACIÓN</b>		
60-64	30	15.9	MENOS QUE SECUNDARIA	29	18.5
65-69	3	15.9	ALGO DE SECUNDARIA	20	12.7
70 & MAYOR	10	6.3	SECUNDARIA O GED	38	24.2
<i>EDAD PROMEDIO =58.5,</i>			ALGO DE UNIVERSIDAD	39	24.8
<i>DE=6.5</i>			GRADUADO DE UNIVERSIDAD	21	13.4
<b>LENGUAJE DE PREFERENCIA</b>			MAESTRIA O DOCTORADO	8	5.7
INGLÉS	19	12.1	SIN ESPECIFICAR	1	0.6
ESPAÑOL	100	63.7			
BILINGÜE (ING & ESP)	38	24.2	<b>SITUACIÓN DE VIVIENDA</b>		
			VIVE CON FAMILIA	31	19.7
<b>NACIDO EN LOS EE.UU. O TERRITORIOS</b>			VIVE CON AMIGOS	7	4.5
SI	67	42.7	VIVE CON COMPAÑERO DE CUARTO	9	5.7
NO	90	57.3	VIVE CON PAREJA	14	8.9
			VIVE EN VIVIENDA ASISTIDA	11	7
<b>INGRESO ANUAL</b>			VIVE EN ASILO DE ANCIANOS	1	0.6
≤ 20,000	143	91.1	VIVE SOLO	78	49.7
\$20,000 - \$39,999	9	5.7	VIVE EN ALBERGUE	2	1.3
\$40,000 - \$54,999	3	1.9	SIN HOGAR	4	2.5
≥ \$55,000	1	0.6			
SIN ESPECIFICAR	1	0.6			

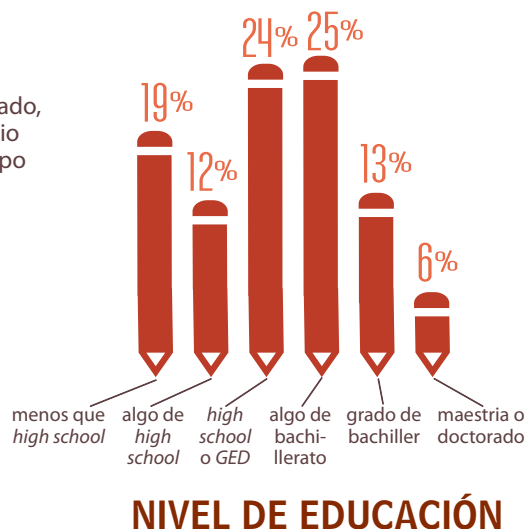
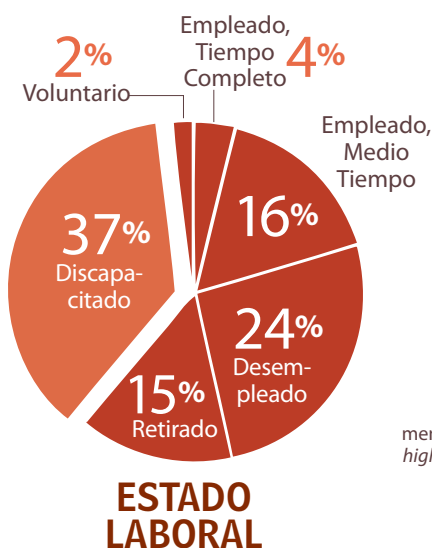
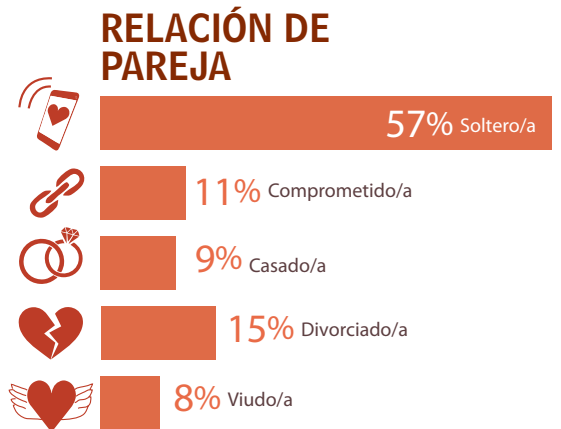
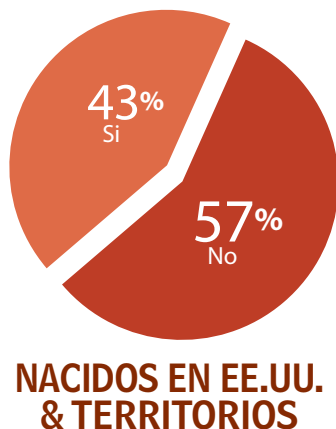
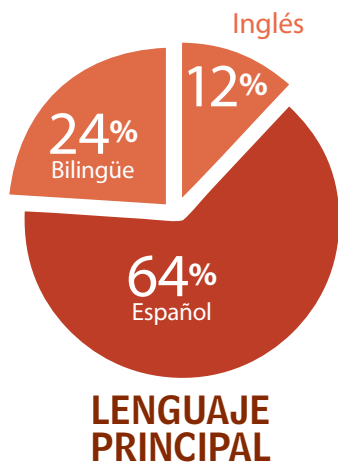
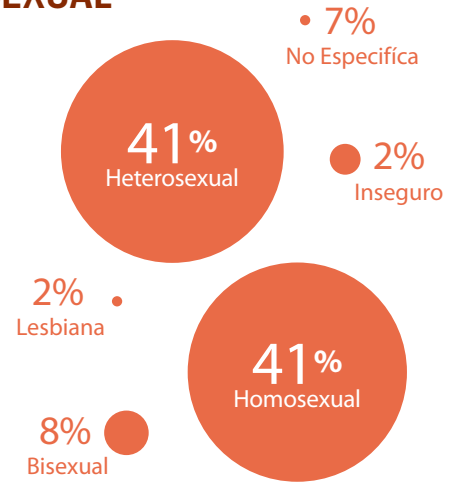


# UN DIAGNÓSTICO NACIONAL SOBRE LA SALUD DE LOS LATINOS MAYORES VIVIENDO CON VIH

**157** NÚMERO DE PARTICIPANTES EN EL ESTUDIO



## ORIENTACIÓN SEXUAL

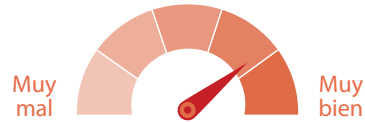


19 Años promedio que los participantes han sido diagnosticados con VIH

16 Años promedio que los participantes han recibido tratamiento de VIH



## VIVIENDO CON HIV

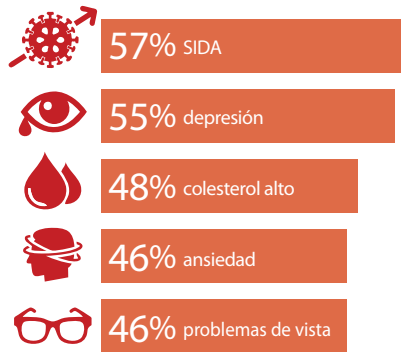


**BUENA SALUD**  
PARTICIPANTES CALIFICARON SU SALUD COMO BUENA



PORCENTAJE DE PARTICIPANTES QUE TIENEN SEGURO MÉDICO

## ACCESO AL CUIDADO DE SALUD



## COMORBILIDADES



## INSATISFACCIÓN



## PAREJAS SEXUALES

52% PORCENTAJE DE PARTICIPANTES QUE EXPERIMENTAN DEPRESIÓN



## DEPRESIÓN

familia, finanzas, salud física, nutrición y salud mental son las 5 preocupaciones principales en la vida de los encuestados



## PREOCUPACIONES

LOS ENCUESTADOS REPORTARON BAJOS NIVELES DE:



## COFACTORES

**TABLA 2. Preocupaciones de la Muestra (N=157)**  
Preocupaciones en los últimos 3 Meses (1=No en lo absoluto – 5=Todo el tiempo)

	<i>M</i>		<i>(SD)</i>
FAMILIA	3.24		(1.58)
DINERO/FINANZAS	3.15		(1.56)
SALUD FÍSICA	3.09		(1.55)
NUTRICIÓN	3.04		(1.52)
SALUD MENTAL	2.98		(1.65)
VIVIENDA	2.94		(1.74)
NO PODER MOVERME COMO ANTES	2.79		(1.60)
ENVEJERCER SOLO	2.76		(1.62)
VISIÓN	2.74		(1.61)
AMIGOS	2.59		(1.45)
SALUD GASTROINTESTINAL	2.56		(1.66)
VIH/SIDA	2.39		(1.65)
SITUACION DE EMPLEO	2.33		(1.58)
SALUD SEXUAL	2.32		(1.58)
AUDICIÓN	2.29		(1.58)
HIJOS/NIETOS	2.28		(1.63)
MEMORIA/DESORIENTACIÓN	2.21		(1.41)
ENFERMEDADES DE TRANSMISION SEXUAL	2.11		(1.58)
ESTATUS MIGRATORIO	2.02		(1.64)
RETIRO	2.00		(1.51)
ESPOSO(A)/NOVIO(A)	1.95		(1.46)
ENCONTRAR PAREJA	1.88		(1.32)
ENCONTRAR PAREJA SEXUAL	1.84		(1.30)
ENCONTRAR ALGUIEN PARA SALIR	1.72		(1.21)

**TABLA 4. Síntomas de Depresión de la Muestra - CES-D-10 (N=157)**  
0=Raramente/Nunca; 1=Algunas veces (1-2 días); 2=Ocasionalmente (3-4 días); 3=Siempre (5-7 días)

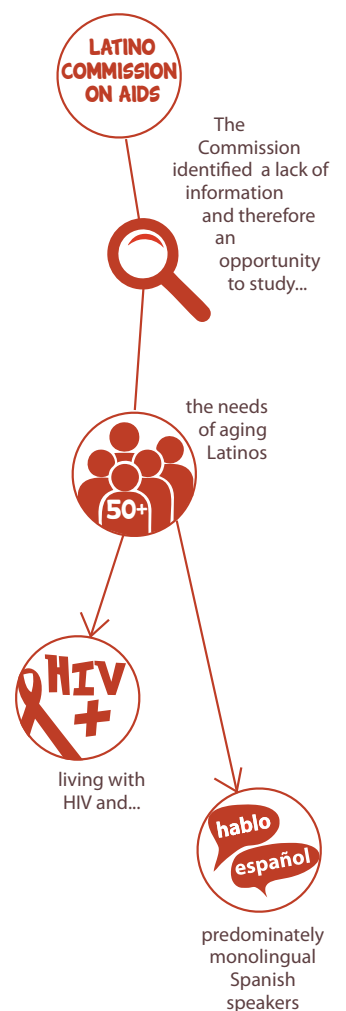
	<i>M</i>		<i>(DE)</i>
ME MOLESTAN COSAS QUE ANTES NO ME MOLESTABAN	0.74		(0.84)
ME CUESTA ENFOCARME	0.89		(0.95)
ME SIENTO DEPRIMIDO	0.94		(0.94)
LO QUE HAGO ME TOMA MUCHO ESFUERZO	0.97		(0.94)
(REVERSE) ME SIENTO ESPARANZADO EN EL FUTURO	1.54		(1.15)
ME SIENTO TEMEROSO	0.81		(0.98)
NO DUERMO BIEN	1.19		(1.16)
(REVERSE) YO ESTABA CONTENTO	1.55		(1.03)
YO ME SIENTO SOLO	0.95		(0.98)
ME CUESTA EMPEZAR EL DÍA	0.71		(0.92)
SCORE	10.10		(5.85)

# PREFACE

The Latino Commission on AIDS, in partnership with the Hispanic Health Network, is committed to promoting culturally responsive, rigorous research designed to influence policy and practice. Drawing on 27 years of experience in the field, we are working to elucidate the varied factors that affect the health of Hispanics/Latinos in the United States and U.S. territories, with special attention to the ongoing scourge of HIV/AIDS. Through research as well as social programs, the Commission is dedicated to reducing new HIV infections, unravelling the social determinants of health and identifying the unmet needs of Latinos living with HIV infection. Operating within a social-justice framework, we are studying marginalized and often ignored populations in order to better understand the effects of race, ethnicity, gender, sexual orientation, age and social class on health and medical care. At the same time, we also aim to contribute to social science with research that identifies emerging trends and understudied issues affecting the Latino population.

The impetus for this assessment was our concern that current research does not adequately address the needs of the aging Hispanic/Latino population that is living with diagnosed HIV infection. A literature review on older adults with HIV/AIDS found that very few studies included robust samples of Latinos and, even then, gathered information from English speakers -- ignoring the impact of HIV on older adults who are monolingual Spanish speakers and among relatively recent immigrants. Since Latinos generally encounter many obstacles in accessing health care, it is important to understand whether these barriers remain constant through the life course and whether they are worse among these more ignored and vulnerable subgroups.

The Commission is grateful for the collaborative work of our national partners. Each of the organizations contributing to this assessment has a history of providing services to aging Latinos living with HIV. AltaMed in Los Angeles, Fundacion Latinoamericana de Accion Social (FLAS, Inc.) in Houston, Mujeres Unidas in San Antonio, PrideLines in Miami, Camuy Health Services, Inc. in Camuy and Bill's Kitchen in San Juan and Fajardo all provided invaluable assistance and support. We are also grateful to Gilead



Sciences, the Hispanic Federation and AIDS United for their financial sponsorship and dedication to this project.

Lastly, we would be remiss if we did not thank and dedicate this report to all the participants who shared their stories. It is their narratives that provide support for needed changes in public policy. This document is intended to validate their struggles and lessons learned, in the hope that we can help improve the quality of life, not only for these respondents, but also for the fast-growing number of Latinos across the country that are aging with HIV.

A note on usage: we have used the terms Hispanics/Latinos, Hispanics and Latinos interchangeably in this report, with no intention to exclude anyone who identifies as part of the broader ethnic group.



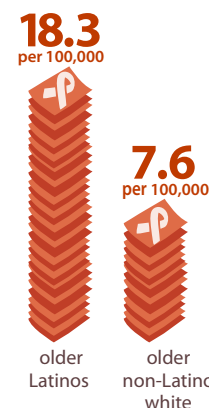
# EXECUTIVE SUMMARY

Older individuals represent a considerable proportion of people living with HIV infection in the United States. In 2013, about 42% of individuals with diagnosed HIV in the country were aged 50 and older (CDC, 2017a). They pose particular prevention challenges: older individuals exhibit the same sexual risk factors of younger people, but are less aware of their HIV vulnerability. They are also less likely to discuss their sexual lives with providers, creating missed opportunities for HIV screening and education. At the same time, the special treatment challenges among this population are underscored by the fact that they are more likely to be diagnosed late with HIV, compromising their treatment options (CDC, 2017a).

42%

OF HIV DIAGNOSES IN THE U.S. IN 2013 WERE AMONG INDIVIDUALS AGES 50 YEARS AND OLDER

Hispanics/Latinos, who can be of any race, represent the nation's fastest-growing minority and ethnic population as well as the fastest-growing aging population. Although they represent 18% of the U.S. population, they accounted for approximately 24% of new HIV diagnoses in 2015 (CDC, 2017b). Older Latinos are at an increased risk of infection compared to their non-Latino white counterparts. In 2015, those aged 50-54 had a rate of diagnosed HIV infection more than twice the rate of non-Latino whites among the same age group (CDC, 2017c).



LATINOS AGED 50-54 HAD A DIAGNOSED HIV INFECTION RATE THAT WAS MORE THAN TWICE THE RATE OF WHITE NON-HISPANICS

Hence, there is a pressing need to examine the health care of a population that is too often forgotten—“**Olvidados.**” This report, the first of its kind, describes the results of a nationwide community needs assessment for primarily Spanish speaking Hispanics/Latinos, aged 50 and older, who are living with HIV/AIDS. In a yearlong project, the Commission visited cities with high rates of HIV including Houston, Texas; San Antonio, Texas; Fajardo, Puerto Rico; Camuy, Puerto Rico; San Juan, Puerto Rico; New York City, New York; Los Angeles, California, and Miami, Florida.

Through collaborations with community-based organizations and clinics in each city, quantitative and qualitative data were collected and analyzed. This report – only a first step toward a deeper understanding of this complex challenge – aims to provide a more nuanced picture of the health status and needs of the diverse

population of Latinos 50 years and older who are living with diagnosed HIV. Our findings highlight the social and structural factors that perpetuate HIV-related disparities and comorbidities among this population.

The study sample included 157 HIV-positive Hispanics/Latinos, ages 50 to 80, with a mean age of 58.5 years. Sixty-one percent identified as male, 36% as female and 3% as transgender. A majority of respondents were foreign-born and an overwhelming majority were very low-income, with 91% of the respondents living on less than \$20,000 per year. In addition, all the respondents took part in focus group discussions, which often provided a sharper picture of the obstacles many of them face.

The respondents were enlisted via community service organizations and clinics, so by definition they were already linked up in some way with HIV/AIDS services. Thus the survey results, while pointing toward critical gaps and concerns, should not be taken as representative of the entire population of aging, HIV diagnosed Latinos, which we believe includes some people who are living in stark isolation or fear, or are unaware of their condition. As such, our findings, if anything, understate the challenges to researchers and policy-makers.

## Key Findings

→ The survey confirmed the low socio-economic status and education levels among respondents, factors known to be associated with poor health outcomes.

→ Most respondents said they have a provider, are insured, and reported undetectable viral loads (all key aspects for remaining in the continuum of care). But a sizeable share, on average about one in four participants, reported being *less than satisfied* with some aspect of their provider's care. This is important to note, as provider satisfaction has been shown to be critical in engaging and maintaining individuals in care, and significantly increases optimal health outcomes.

→ On average, about 40% of participants reported that their providers asked about related health issues during visits within the last six months, such as mental health, cancer, substance use, sexually transmitted infections, and violence.

# 157

NUMBER OF HIV  
POSITIVE LATINOS  
AGES 50 TO 80 THAT  
PARTICIPATED IN THE  
STUDY



RESPONDENTS  
REPORTED AN  
UNDETECTABLE  
VIRAL LOAD



RESPONDENTS  
REPORTED SOME  
DISSATISFACTION  
WITH THEIR  
MEDICAL CARE

This indicates that a significant share of respondents *was not being counseled* during visits about relevant health concerns, screenings, and comorbidity risks.

→ One in three respondents indicated some level of difficulty with treatment adherence, warranting further exploration and explanation.

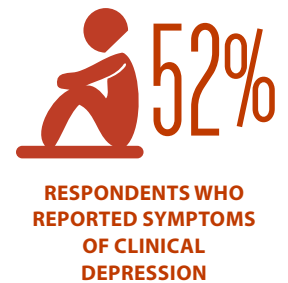
→ A significant proportion of the sample, 43%, indicated some sexual activity within the last 3 months, but discussions of sexual health with providers were relatively infrequent, indicating a need for providers to engage aging patients proactively about their sexual histories.

→ Although the sample reported relatively low frequency of substance use, 12% indicated that they were in recovery. Respondents may be under-stating such problems because of social-desirability bias, but regardless, provider conversations related to substance use were also reported as low.

→ Fully half of the respondents reported issues with depression, highlighting the critical gap in mental-health services.

The focus group discussions provided an often sharper view of the concerns and barriers facing older Latinos. Crucial obstacles identified to optimal health and wellbeing include **fear and mistrust, experience of comorbidities, and access-to-care challenges**. Such obstacles complicate patient adherence and management of side effects as well as increasing the likelihood of social isolation, which can in turn exacerbate depression, increase stress and further compromise the immune system. The most vulnerable may find it harder to self-regulate, and may instead use maladaptive coping mechanisms such as substance use, poor diet/exercise, addictive behaviors or participating in unhealthy relationships.

The survey and focus groups, together, also pointed to “what works for/helps” aging Latinos in achieving optimal health and wellbeing. The facilitators for improved quality of life and health included **a strong relationship with their provider, high levels of social capital or support systems, sex positivity, and work/volunteer engagement**.



# SUMMARY OF RECOMMENDATIONS

**Increase Culturally Sensitive and Responsive Services:** A lack of bilingual, culturally sensitive, age-appropriate and stigma free HIV/AIDS services is a key obstacle for the aging population of HIV diagnosed Latinos. Likewise, more funding, collaboration, and program integration is needed for initiatives that increase the pipeline of Latinos into the HIV-related workforce, including those providing medical services.

**Sexual Education and Sexual Wellness Initiatives:** It is urgent to customize community initiatives on sexual education for the Latino population over 50. Understanding the sexual practices of this population will be the foundation for crafting community programs that better address the needs of those aging with HIV, or at risk of exposure to infection.

**More Capacity Building and Training:** Healthcare providers, front-line workers and policymakers need to have a greater understanding of the experiences of aging Latinos with HIV/AIDS.

**Integrating Mental and Behavioral Health into HIV and Aging:** There is a dearth of specialized mental and behavioral support services to address the unique emerging care needs of a population aging with HIV, including the fast-growing number of long-term survivors as well as the newly diagnosed. Psychosocial, mental and behavioral health issues facing this population need far greater attention.

**More Research:** It is important to study the structural and social determinants of HIV/AIDS disease among older Latinos and other vulnerable groups to help optimize societal resources and develop effective responses. Special attention must be dedicated to understanding the unique realities of both U.S.-born and foreign-born Hispanic populations.

**Focus on Prevention and Treatment Efforts:** Tailored HIV testing and treatment initiatives for older adults are crucial to reaching this vulnerable and often invisible population.



IT IS IMPORTANT TO PROVIDE OLDER HIV + LATINOS WITH COMPREHENSIVE SEXUAL HEALTH EDUCATION



IT IS IMPORTANT TO PROVIDE MORE CAPACITY BUILDING AND TRAINING; PRIORITIZING CULTURALLY RESPONSIVE SERVICES



IT IS IMPORTANT TO INTEGRATE MENTAL HEALTH INTO HIV AND AGING SERVICES

**Access to Health Care is a Human Right:** We call for increased advocacy to help policy-makers at all levels understand that everyone has the right to health care, including mental health care and critical support services (housing, vocational training, social engagement, cultural pride and personal affirmation, among others).

**Call to Action:** The Latino Commission on AIDS, the Hispanic Health Network, and the community networks we work with call on city, county and state health departments to take action to address the needs of the aging Latino population living with HIV/AIDS and other chronic conditions in our nation and U.S. territories. Growing older and healthy must be a national goal for all of us.

# INTRODUCTION

Advances in treatment and care have transformed HIV/AIDS into a chronic disease, permitting diagnosed individuals to live longer, healthier lives. People living with HIV/AIDS in the United States are growing older and the number of HIV-positive older adults today is larger than ever. The Centers for Disease Control and Prevention (CDC) predicts that by 2020, more than half of all individuals living with diagnosed HIV infection in the U.S. will be 50 or older (Brooks, Buchacz, Gebo & Mermin, 2012).

Although the success of HIV treatment contributes to this “graying” of the epidemic, prevention and screening efforts remain crucial for older adults. An estimated 17% of the total cases newly diagnosed with HIV in 2014 involved people 50 and older. From the cases diagnosed in 2014 among older individuals, the largest portion, or 44%, was among those aged 50 to 54 (CDC, 2017a). Moreover, older individuals are more likely to be diagnosed late with HIV, compromising their treatment options (Brooks et al., 2012). Cities across the United States, recognized as HIV/AIDS epicenters, are reporting increasing numbers of older adults living with the disease— including newly diagnosed individuals and long-term survivors (Emler, 2006; Karpiak & Shippy, 2006). This presents a growing population with increased health needs due to aging, per se, as well as HIV.

Older people with HIV face unique psychosocial and health challenges in dealing with multiple comorbidities that affect their mental health, neurocognitive functioning, access to social support, and use of healthy coping strategies. Research has found that HIV increases the risk of age-associated diseases and causes chronic inflammation throughout the body. Specific health challenges of aging such as heart disease, diabetes, and cancer are occurring sooner and/or more often for many people as they age with HIV (Brooks et al., 2012; Cahill & Valadez, 2013). Therefore, it is critical to gain a better understanding of the health and wellness needs of this burgeoning, vulnerable population.

## ***Olvidados/ The Forgotten Population***

Hispanics/Latinos, a multiethnic and multiracial population, represent one of the nation’s fastest growing minority and ethnic groups as well as the fastest growing aging population. They encounter many obstacles in accessing health care and historically are burdened with disproportionate rates of HIV infection among all age groups. They represent 18% of the U.S. population, yet accounted for approximately 24% of HIV infections among adults and adolescents in 2015 (CDC, 2017b). Among the population 50 years and older, Latinos are at an increased risk of infection. In 2015, Latinos aged 50-54 had a diagnosed HIV infection rate (18.3 per 100,000 population) that was more than twice the rate of white non-Hispanics (7.6 ) (CDC, 2017c).



**“OLVIDADOS”  
IS A NATIONWIDE  
COMMUNITY NEEDS  
ASSESSMENT FOR  
LATINOS 50+ WHO ARE  
HIV+ AND PRIMARILY  
SPEAK SPANISH**



**AMONG OLDER  
LATINOS, NEWLY  
DIAGNOSED AND LONG-  
TERM SURVIVORS HAVE  
INCREASED NEEDS  
DUE TO BOTH HIV AND  
AGING**

Yet a paucity of information exists on the specific needs and concerns of these older Latino patients. The few existing surveys of older adults with HIV/AIDS gathered information from small samples of Latinos and only those that could speak and write in English. Thus they have ignored the many others who are linguistically isolated due to their inability to communicate or read in English. These individuals, who mainly speak Spanish, are often forgotten by researchers, health planners and policy analysts; their voices, experiences and needs are at times not recognized or validated.

Engagement of this population is hampered by many potential barriers including language, cultural nuances, immigration status, mistrust/fear, and socio-economic status. Therefore, an urgent need exists, in particular, to understand the impact of HIV on older adults who are predominately Spanish speakers, and among more recent immigrants. The current assessment sought to examine the needs and concerns of a wider sample of older Latinos with diagnosed HIV in hopes of casting light on the social determinants that affect their health and quality of life.

## Barriers to Care

Older Latinos are one of the most vulnerable minority populations in the U.S., facing multiple barriers to accessing health care that are perpetuated by stigma, poverty, low education, financial insecurity, food insecurity, lack of affordable housing, lack of health insurance, and lack of mental health care. By these indicators, this population fares worse than any other senior minority population.

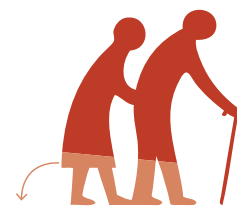
**Stigma.** HIV/AIDS is highly stigmatized in Latino communities. Perpetuating stigma are the cultural values of *simpatia* and *familismo*, which are highly esteemed and broadly shared by Latino populations in the United States (Brown, 1998). *Simpatia* refers to “a cultural script that mandates politeness, respect, and harmonious interpersonal relations” (Mason et al., 1995). Under the *simpatia* aura, HIV diagnosed Latino individuals fear causing pain, distress, and disruption to their kin, and therefore avoid revealing their status. Given their highly respected positions within the family unit and community, older people may be especially fearful that disclosure of HIV status would result in family disruption and humiliation (Brown, 1998). Ultimately, this fear leaves Latino individuals with HIV feeling shame, and may reduce the likelihood they will seek care until an emergency arises.

**Low Levels of Educational Attainment.** Older Latinos are among the least educated groups in the United States, with significantly lower levels of secondary and higher education than the general population. Thirty-eight percent of Latinos 50 and over have less than a high school education compared with 17% of African-Americans and 7% of non-Hispanic whites. Only 28% of Latinos have a high school diploma, compared to 36% of African-Americans and 32% of non-Hispanic white individuals aged 50 and above. Fifteen percent of Latinos aged 50 and over have earned a bachelor’s degree or higher, compared to 20% of their African-American and 33% of their non-Hispanic white counterparts (U.S. Census Bureau, 2017).

**Financial Insecurity.** Older Latino adults are also among the least financially secure minority groups in the United States. Eighteen percent of Latino older adults (ages



**OLDER LATINOS LIVING WITH HIV MAY FEAR DISCLOSING TO FAMILY MEMBERS**



**18%** OF OLDER LATINOS IN THE U.S. LIVE BELOW THE POVERTY LINE



**70%** OF OLDER LATINOS RELY ON SOCIAL SECURITY BENEFITS

65 and older) in the U.S. live below the poverty line (U.S. Census Bureau, 2016). Seventy percent of older Latinos (ages 65 and older) rely on social security benefits. Additionally, they receive lower Social Security payments on average than other beneficiaries, reflecting lower earnings over their lives (Social Security Administration, 2016). For example, in 2014, the median income from Social Security received by Hispanic/Latino beneficiaries was \$13,559 compared to the median payments to white older adults of \$18,056 (National Hispanic Council on Aging, 2016; Social Security Administration, 2016). Such low income leaves Latino seniors in a precarious position: an illness, a rise in housing costs, or loss of employability can plunge them into poverty (National Hispanic Council on Aging, 2016; Social Security Administration, 2016). Chronic poverty has consistently been associated with poorer health and greater vulnerability to illness and disease (Williams et al., 1997).



Latinos Whites  
**LATINOS RECEIVE LOWER SOCIAL SECURITY PAYMENTS, A REFLECTION OF LOWER EARNINGS OVER THEIR LIVES**

**Housing Instability.** Past research has repeatedly shown that homelessness is associated with a range of chronic health problems including substance abuse and mental illness, physical and sexual violence, and infectious diseases such as HIV (Aidala, Lee, Abramson, Messeri, & Siegler, 2007; Krieger & Higgins, 2002; Zolopa et al., 1994). Access to quality, affordable housing is a major challenge among the Latino community. Rates of homeownership are relatively low. According to a 2016 report by the National Hispanic Council on Aging, 55% of the U.S. Hispanic population rents a residence, compared to 34% of non-Hispanics of all races. Likewise, the 2015 Annual Homeless Assessment Report to Congress found that Hispanics comprised one-fifth of the homeless population in 2015. Almost half of the homeless population in the United States in 2015 was in the following four states, each of which has large Hispanic/Latino populations: California - 21%, New York - 16%, Florida - 6%, and Texas - 4% (Henry et al., 2015).



**ACCESSING AFFORDABLE HOUSING REPRESENTS A CHALLENGE FOR OLDER LATINOS; HAVING A BIGGER IMPACT ON THOSE WHO HAVE CHRONIC HEALTH PROBLEMS**

Research exploring the effects of homelessness on people with HIV/AIDS found that unstably-housed individuals tend to exhibit higher levels of HIV in the blood compared to those with stable housing (Knowlton et al., 2006). High viral loads severely compromise the health of these individuals and also increases their biological potential to transmit HIV to others. Access to health care and adherence to medication are imperative for suppressing an individual's viral load. Unfortunately, research has shown that homeless individuals with HIV are more likely to delay entering care, more likely to have poorer access to regular care, less likely to receive optimal antiretroviral therapy, and less likely to adhere to therapy than those with secure housing. (Aidala et al., 2007; Kidder et al., 2007; Leaver et al., 2007; Smith et al., 2000).



**OLDER LATINOS ARE MORE LIKELY TO BE UNDERINSURED, WITH BENEFITS THAT DO NOT COVER THEIR MEDICAL EXPENSES**

**Inadequate Health Coverage.** Older Hispanics face many health disparities and burdens resulting from their lack of access to quality health care. Access to care remains a major challenge among the Hispanic community more generally: in 2016, about 25% of Hispanic adults (18-64 years of age) lacked health insurance, compared to 9% of non-Hispanic whites and 15% of non-Hispanic blacks (CDC, 2017d). According to a report by the National Hispanic Council on Aging, in 2013 and 2014, Hispanics were less likely to have a medical-care provider than either African Americans or whites (National Hispanic Council on Aging, 2016). They are more likely to be underinsured, with benefits that do not adequately cover their medical expenses.



**Mental Health Concerns.** Older individuals living with HIV/AIDS tend to exhibit higher rates of psychological disorders. There is no doubt that living with HIV, a chronic, life-threatening, and highly stigmatized illness, can exacerbate or even trigger certain debilitating mood disorders. Clinical depression, generalized anxiety disorder and post-traumatic stress disorder are among the most prevalent diagnoses affecting older individuals with HIV. Depression is the most common psychiatric condition affecting HIV diagnosed adults, with those aged 65 and older reporting higher rates both of depressive symptoms and suicidal behaviors (Brooks et al., 2012).

As HIV-positive adults grow older, they face added social, psychological, and physical challenges compared to their younger counterparts, particularly higher levels of psychological distress (Groves, Golub, Parsons, Brennan, & Karpiak, 2010). Intense anxiety, depressed mood states, suicidal tendencies, and post-traumatic stress disorder have been widely reported in numerous studies on the mental health of individuals living with HIV/AIDS (Cohen et al., 2002; Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000; Miles, Isler, Banks, Sengupta, & Corbie-Smith, 2011).

The strong correlation between HIV and depression is partly due to poorer cognitive/physical function resulting from HIV's impact on the body as well as to the side effects of antiretroviral medicines, health-induced anxiety, stress, stigma, and social isolation (Groves et al., 2010). Depression and anxiety undoubtedly affect the physical health outcomes of HIV-positive individuals. Research has found that chronic depression and anxiety severely affects HIV's progression-- associated with decreased CD-4 count, increased viral load, and greater risk for clinical decline (Leserman, 2008; Vanable, Carey, Blair, & Littlewood, 2006).

Due to a multitude of social and physical factors, older individuals living with HIV/AIDS are at a higher risk of developing severe, debilitating psychological disorders. These may ultimately affect their ability and willingness to access health care. Stresses associated with racial and ethnic discrimination, in conjunction with the experiences of lifelong poverty and low income, also contribute to poorer health and wellbeing in older age. Furthermore, the interaction of these stressors and experiences over the life course may result in a compromised immune system that leaves older HIV-positive minorities more vulnerable to the development of AIDS, as well as at increased risk for comorbidities such as cardiovascular illnesses and diabetes.



**OLDER INDIVIDUALS LIVING WITH HIV TEND TO HAVE HIGHER RATES OF PSYCHOLOGICAL DISORDERS**



**RESEARCH FOUND THAT CHRONIC DEPRESSION AND ANXIETY IS ASSOCIATED WITH INCREASED VIRAL LOAD AND DECREASED CD-4 CELLS**

# METHODS

The study used a mixed-methods, cross sectional design to collect quantitative and qualitative data. A diverse sample of Hispanic/Latino participants were recruited from the following cities with demonstrated high rates of diagnosed HIV disease and dense concentrations of Hispanic/Latino populations: Houston, Texas; San Antonio, Texas; Camuy, Puerto Rico; Fajardo, Puerto Rico; San Juan, Puerto Rico; New York City, New York; Los Angeles, California, and Miami, Florida.



high rates  
of HIV infection



dense concentration  
of Latino population

**THE SAMPLE OF THE STUDY WAS RECRUITED FROM CITIES WITH HIGH RATES OF HIV INFECTION AND DENSE LATINO POPULATION**

The survey sought to collect the following information: demographic profile, health status, sexual behaviors, social support, and use of alternative medicine. Two validated scales were used to assess depression and stigma. The Center for Epidemiologic Studies Depression Scale (CES-D-10) is a shortened scale designed to measure depressive symptomology and the HIV Stigma Scale (HSS-13) developed by Sowell et al. (1997) measures experiences of stigma. Survey questions and the focus-group discussions sought to identify barriers as well as facilitators to accessing health care.

Recruitment efforts for respondents to take the online version of the survey included a social marketing campaign with printed palm cards and emails highlighting the survey website using Survey Monkey technology. Emails were sent to a list of providers across the U.S. and Puerto Rico to share with their clients who qualified. Additionally, palm cards were disseminated at national conferences and delivered to the community based organizations in the eight prioritized cities. Despite our efforts, recruitment for online administration remained low and fewer than ten individuals filled out the survey online. As a result, nearly all surveys were administered using the paper version, before the start of focus groups. These surveys were mainly administered in Spanish. Many of the respondents required assistance with filling out the survey due to difficulties arising from low literacy or poor eyesight.



**QUANTITATIVE DATA WERE COLLECTED THROUGH SURVEYS ADMINISTERED IN SPANISH AND COMPLETED MANUALLY BY PARTICIPANTS**

The study collected qualitative data and narrative information through semi-structured, facilitated focus groups. Information gathered from these focus groups sought to fill the gaps in understanding the needs in treatment and care. The ultimate goal was to identify policies and interventions that can not only improve access to care, but also improve quality of life beyond simple viral suppression for a vulnerable and underserved population. The focus groups were primarily done in Spanish, except for the San Antonio group, which chose to have the discussion in English.



**QUALITATIVE DATA WERE COLLECTED THROUGH FOCUS GROUPS; ALL BUT ONE WERE DONE IN SPANISH**

Focus groups were convened in the selected cities with the support of national partners, which helped advertise for and recruit participants. AltaMed in Los Angeles, Fundacion Latinoamericana de Accion Social (FLAS, Inc.) in Houston, Mujeres Unidas in San Antonio, Pridelines in Miami, Camuy Health Services, Inc. in Camuy and Bill's Kitchen in San Juan and Fajardo hosted the group discussions.

Lunch or dinner was provided and all attendees received a gift certificate for their participation. All individuals gave informed consent to participate and agreed to recording the discussion.

All respondents were enlisted via community service organizations and clinics, so by definition they were already linked up in some way with HIV/AIDS services. Thus the survey results, while pointing toward critical gaps and concerns, should not be taken as representative of the entire population of aging, HIV diagnosed Latinos, which we believe includes some people who are living in stark isolation or fear, or are ignorant of their condition. As such, our findings, if anything, understate the challenges to researchers and policy-makers.



RESPONDENTS  
WERE ENLISTED VIA  
COMMUNITY SERVICE  
ORGANIZATIONS AND  
CLINICS

## Cities Visited

**Houston, Texas.** Texas is home to one of the largest Latino populations in the nation. As of July 2015, Latinos made up 39% of Texas' total population (U.S. Census Bureau, 2015a). In 2013, approximately 10% ( $n=4,836$ ) of the total number of new HIV diagnoses in the U.S. ( $n=47,165$ ) came from Texas, placing Texas third among the 50 states in the number of new diagnoses (CDC, 2015a). Moreover, a 2015 Texas state surveillance report found that approximately 52% of all individuals living with diagnosed HIV in the state were 45 years of age or older, and approximately 31% of all individuals living with diagnosed HIV infection were Latino.

As of 2010, Latinos made up 44% of the population of Houston. According to the 2015 surveillance report, Harris County—housing the city of Houston—ranked first in the total number of individuals living with HIV/AIDS in the state of Texas (Texas Department of State Health Services, 2016). According to another state report, the Houston area saw a 5% increase in the total number of people living with HIV/AIDS, as well as the number of new HIV diagnoses, between the years 2011 and 2012 (Finley et al., 2014). That same report indicated that in 2012, the rate of new HIV cases and prevalence in the Houston area exceeded rates both for Texas and the entire nation. That year, Latinos made up 35% of new HIV diagnoses and 24% of people living with HIV/AIDS in the Houston area. Older individuals (ages 45-plus) made up 22% of newly diagnosed individuals and 49% of individuals with HIV/AIDS in the Houston area.



**San Antonio, Texas.** As of 2010, Latinos made up 63% of the population in San Antonio, Texas (U.S. Census Bureau, 2015d). In 2015, Bexar County—housing San Antonio—ranked third in the state in the total number of people living with HIV. By year-end 2013, Latinos constituted 63% of all individuals with diagnosed HIV infection in Bexar County (Texas Department of State Health Services, 2016).

**Fajardo, Hatillo and San Juan - Puerto Rico.** From the beginning of the epidemic to June 2015, 47,007 cases of HIV were diagnosed in Puerto Rico (Puerto Rico Health Department, 2015). About 44% of all diagnoses among adults and adolescents in Puerto Rico have been attributed to injection drug use, 29% to heterosexual contact, and 19% to male-to-male sexual contact. Hispanics bear the greatest burden, accounting for

99.8% of cases on the island (CDC, 2015b). Geographically, the epidemic is heavily concentrated, with 73.7% of total HIV cases in the metropolitan statistical area including San Juan, Carolina, and Caguas.

An estimated 686 new cases of HIV were diagnosed in Puerto Rico in 2014 with an estimated rate of 22.7 per 100,000 adults and adolescents (CDC, 2015b). This placed Puerto Rico sixth among the top ten states or territories in the U.S. in terms of new diagnoses that year. By mid-year 2015, about two thirds of those living with diagnosed HIV infection were 45 years of age or older (Puerto Rico Health Department, 2015).

***Los Angeles, California.*** California is home to the largest Latino population in the country (U.S. Census Bureau, 2015b). Latinos made up approximately 39% of the state's total population in 2015. In 2013, approximately 11% ( $n=5,315$ ) of the total number of new HIV diagnoses in the U.S. ( $n=47,165$ ) came from California, with about 41% of them involving Latinos. In the same year, California ranked second among the 50 states in the number of new HIV diagnoses (CDC, 2015c).

In Los Angeles, approximately half of the city's population (48.5%) was Latino in 2010 (U.S. Census Bureau, 2015b). By year-end 2013, Latinos accounted for 45% of all newly diagnosed HIV infections and 42% of all people living with HIV/AIDS in Los Angeles County. Though persons over 50 made up only 14% of new HIV diagnoses in Los Angeles in 2013, nearly half (45%) of all individuals with diagnosed infection were 50 or older (Los Angeles County Department of Public Health, 2014), indicating the presence of a large population that has aged with chronic HIV.

***Miami, Florida.*** In Florida, Latinos constituted approximately 25% of the total population in 2015 (U.S. Census Bureau, 2015c). In 2013, approximately 11% ( $n=5,364$ ) of the total HIV diagnoses in the U.S. ( $n=47,165$ ) occurred in Florida, with about a quarter of them among the Latino community. In the same year, Florida ranked first among the 50 states in the number of new HIV diagnoses (CDC, 2015d). In Miami-Dade County, two-thirds of the city's population was Latino in 2015 (U.S. Census Bureau, 2015b). By year-end 2015, Latinos accounted for 44% of all people living with HIV/AIDS in the county, and over half of them (65%) were 45 years of age or older (Florida Department of Health in Miami-Dade County, 2016).

***New York, New York.*** Latinos made up 18% of New York State's total population in 2015, and 29% of New York City's total population (U.S. Census Bureau, 2015d; New York State Department of Health, 2016). In 2013, approximately 8% ( $n=3,800$ ) of the total number of HIV diagnoses in the US ( $n=47,165$ ) came from New York State. In the same year, New York ranked fourth among the 50 states in new diagnoses (CDC, 2015e). At year-end 2014, the rate of adults/adolescents living with diagnosed HIV infection in New York state (781.6 per 100,000 adults and adolescents) was more than two times higher than the national average (357.8) (CDC, 2015b). The New York City metropolitan area includes more than four in ten, or 42.6%, of New York State residents (New York State Department of Health, 2016). According to a surveillance report by the New York City Department of Health, in 2014, of 2,718 new HIV diagnoses in the city, 32% ( $n=875$ ) were among Latinos. The same report

found that in 2014, one-third ( $n=38,795$ ) of all individuals living with HIV/AIDS ( $n=119,550$ ) in the city were Latino and about half ( $n=60,857$ ) of all individuals living with HIV/AIDS were 50 years of age or older (NYCDOHMH, 2015).

## Data Analysis Plan

Quantitative data were analyzed with SPSS software and descriptive statistics were used to calculate means, standard deviations, and percentages. All focus group discussions were tape-recorded, transcribed, and analyzed using a grounded theory approach. Qualitative data was coded using a content analysis approach to reveal emergent themes (Krippendorff, 1980; Elo & Kyngäs, 2008). This process permitted the development of theoretically derived categories and themes that emerged from the participants across all study sites.

# SURVEY RESULTS

**Demographics.** A total of 157 participants were collected for the current study (see Table 1). Of the 157 surveys completed, 92% ( $n=144$ ) were done in Spanish and 8% ( $n=13$ ) in English. English was the primary language for 12% ( $n=19$ ) of participants, Spanish was the primary language for 64% ( $n=100$ ) of participants, and 24% ( $n=38$ ) of participants considered themselves bilingual. Sixty-one percent ( $n=96$ ) of participants identified as male, 36% as female ( $n=56$ ), and 3% as transgender (male-to-female) ( $n=5$ ).

Participants ranged from 50 to 80 years of age with a mean age of about 58.5 years ( $SD=6.5$ ). Approximately two thirds of participants, 68%, were between 50 and 60 years old ( $n=106$ ), and the remaining third were between 61 and 80 years old ( $n=51$ ). All participants were Hispanic ( $N=157$ ). In addition to their Hispanic background, participants self-identified as the following races: white – 38% ( $n=59$ ), African American – 6% ( $n=9$ ), and Native American – 3% ( $n=5$ ). Fifty-three percent of participants ( $n=84$ ) did not identify with any race.

The largest concentration of participants, 57%, was foreign born ( $n=90$ ), with 29% from Mexico ( $n=46$ ). Fourteen percent were born in South America [Colombia – 6% ( $n=10$ ), Ecuador – 3% ( $n=4$ ), Peru – 2% ( $n=3$ ), Uruguay – 1% ( $n=1$ ), Chile – 1% ( $n=1$ ), and Venezuela – 1% ( $n=2$ )]. Seven percent were born in the Spanish-speaking Caribbean [Cuba – 6% ( $n=9$ ), Dominican Republic – 1% ( $n=1$ )]; and 7% in Central America [Honduras – 5% ( $n=8$ ), Guatemala – 1% ( $n=1$ ), Nicaragua – 1% ( $n=2$ )], while 1% did not specify their country of origin ( $n=1$ ). On average, foreign-born participants had lived in the United States for 28.2 years ( $SD=13.4$ ).

Approximately 43% ( $n=67$ ) were born in the United States and Puerto Rico -- 13% ( $n=20$ ) on the mainland and 30% ( $n=47$ ) in the territory of Puerto Rico. Twenty-six percent ( $n=41$ ) of the participants currently resided in Puerto Rico, with the rest in the following states: 26% ( $n=40$ ) California, 19% ( $n=30$ ) Florida, 18% ( $n=28$ ) New York, and 12% ( $n=18$ ) Texas.

With regards to sexual orientation, participants identified as the following: Gay/Homosexual, 41% ( $n=65$ ); Bisexual, 8% ( $n=13$ ); Straight/Heterosexual, 41% ( $n=64$ ); Lesbian, 2% ( $n=3$ ); Unsure, 6% ( $n=9$ ), and Other—not specified, 2% ( $n=3$ ). When asked about their current relationship status, 57% ( $n=90$ ) reported being single, 15% ( $n=23$ ) divorced or separated, 11% ( $n=17$ ) committed to a partner, and 10% ( $n=15$ ) married. Almost one-third of the participants, 31%, did not have a high school diploma or equivalency. Half of the participants ( $n=78$ ), reported living alone and a fifth said they lived with their families ( $n=31$ ). A large portion of participants, 37% ( $n=58$ ), were on disability, 26% ( $n=41$ ) were unemployed, 15% ( $n=23$ ) were retired, and only one-fifth, ( $n=32$ ) of participants were currently in the workforce. An overwhelmingly majority, 91% ( $n=143$ ), had annual incomes of \$20,000 or below. See Table 1.

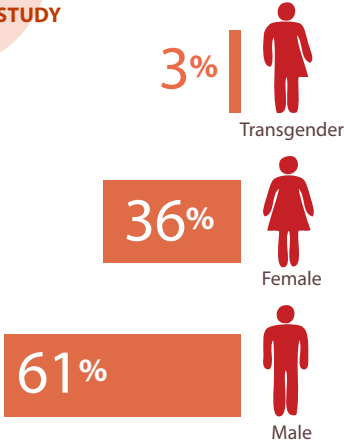
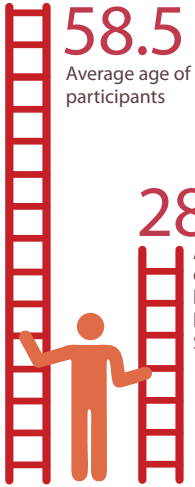
TABLE 1. Demographic Characteristics of Sample (N=157)

	<i>N</i>	<i>%</i>		<i>N</i>	<i>%</i>
<b>GENDER IDENTITY</b>			<b>EMPLOYMENT STATUS</b>		
MALE	96	61.1	EMPLOYED, FULL-TIME	6	3.8
FEMALE	56	35.7	EMPLOYED, PART-TIME	26	16.6
TRANSGENDER (MTF)	5	3.2	UNEMPLOYED	41	26.1
			RETIRED	23	14.6
<b>SEXUAL ORIENTATION</b>			DISABILITY	58	36.9
STRAIGHT/HETEROSEXUAL	64	40.8	VOLUNTEER	3	1.9
GAY/HOMOSEXUAL	65	41.4	<b>RELATIONSHIP STATUS</b>		
LESBIAN/HOMOSEXUAL	3	1.9	SINGLE	90	57.3
BISEXUAL	13	8.3	COMMITTED	17	10.8
UNSURE	9	5.7	MARRIED	15	9.6
NOT SPECIFIED	3	1.9	DIVORCED	23	14.6
			WIDOWED	12	7.6
<b>AGE</b>			<b>EDUCATION LEVEL</b>		
50-54	45	23.9	LESS THAN HIGH SCHOOL	29	18.5
55-59	37	19.7	SOME HIGH SCHOOL	20	12.7
60-64	30	15.9	HIGH SCHOOL OR GED	38	24.2
65-69	3	15.9	SOME COLLEGE OR TECHNICAL COL.	39	24.8
70 & OLDER	10	6.3	BACHELOR'S DEGREE	21	13.4
<i>MEAN AGE =58.5, SD=6.5</i>			GRADUATE OR DOCTORAL DEGREE	8	5.7
			NOT SPECIFIED	1	0.6
<b>PRIMARY LANGUAGE</b>			<b>LIVING SITUATION</b>		
ENGLISH	19	12.1	WITH FAMILY	31	19.7
SPANISH	100	63.7	WITH FRIENDS	7	4.5
BILINGUAL (ENG & SPAN.)	38	24.2	WITH ROOMMATES	9	5.7
			WITH ROMANTIC PARTNER	14	8.9
<b>U.S BORN &amp; TERRITORIES.</b>			ASSISTED LIVING FACILITY	11	7
YES	67	42.7	NURSING HOME	1	0.6
NO	90	57.3	ALONE	78	49.7
			SHELTER	2	1.3
<b>ANNUAL INCOME</b>			HOMELESS	4	2.5
≤ 20,000	143	91.1			
\$20,000 - \$39,999	9	5.7			
\$40,000 - \$54,999	3	1.9			
≥ \$55,000	1	0.6			
NOT SPECIFIED	1	0.6			



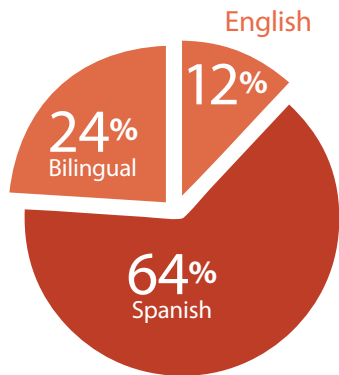
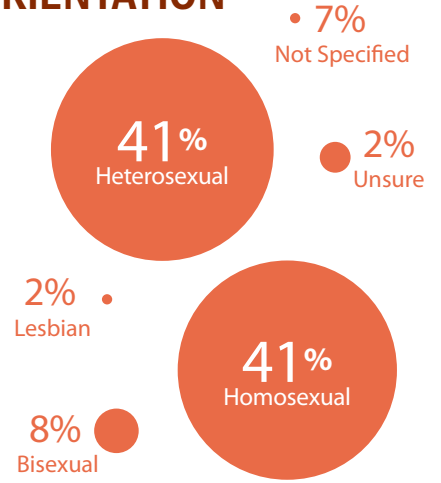
# NATIONAL HEALTH ASSESSMENT OF LATINOS GROWING OLDER WITH HIV

**157** NUMBER OF PARTICIPANTS IN THE STUDY

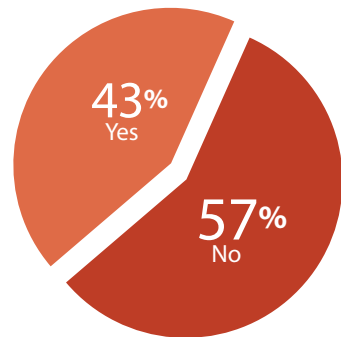


## GENDER

## SEXUAL ORIENTATION

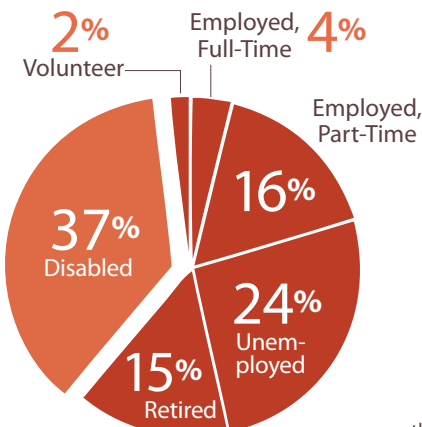
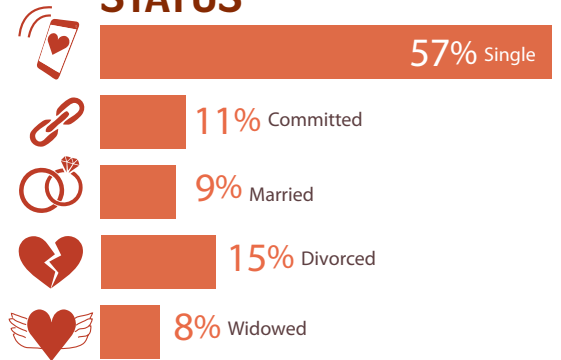


## PRIMARY LANGUAGE

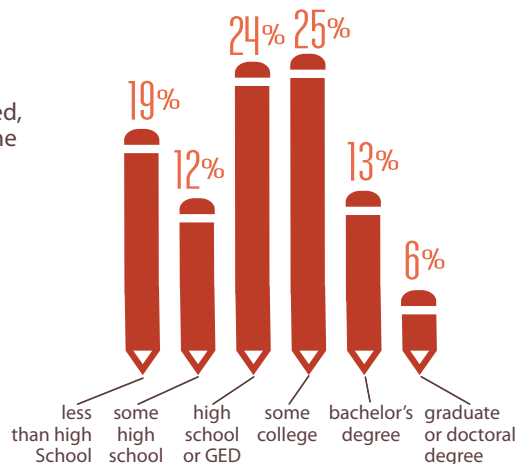


## U.S. & TERRITORIES BORN

## RELATIONSHIP STATUS



## EMPLOYMENT STATUS



## EDUCATION LEVEL

**9 IN 10** OF THE RESPONDENTS HAD ANNUAL INCOMES OF \$20K OR BELOW



## ANNUAL INCOME



**19**  
Average number of years participants had been diagnosed with HIV

**16**  
Average number of years participants received HIV treatment



## LIVING WITH HIV

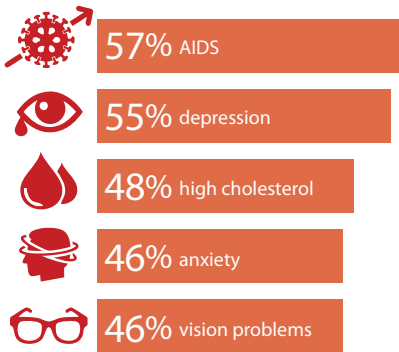
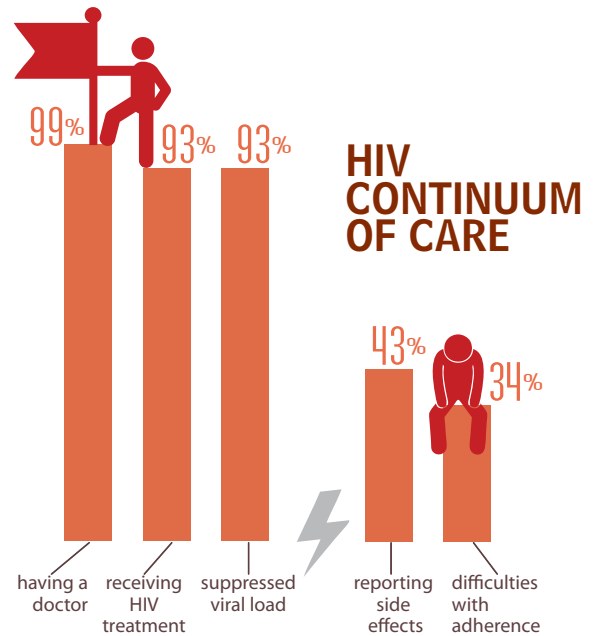


**GOOD HEALTH**  
RESPONDENTS RATED THEIR HEALTH AS FAIR TO GOOD



PERCENTAGE OF RESPONDENTS WITH MEDICAL INSURANCE

## ACCESS TO CARE



## COMORBIDITIES



## DISSATISFACTION



## SEXUAL PARTNERS

**52%** OF PARTICIPANTS EXPERIENCE SYMPTOMS OF CLINICAL DEPRESSION

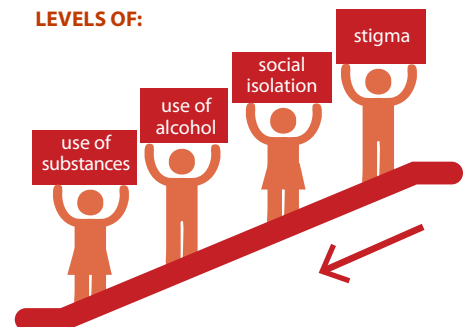


## DEPRESSION



## LIFE CONCERNS

THE RESPONDENTS REPORTED VARYING LEVELS OF:



## COFACTORS

**Health Care.** Participants were asked to rate their current health using a 5-point Likert scale (1=Very Poor to 5=Very Good). On average, participants rated their health as fair to good ( $M=3.73$ ;  $SD=0.90$ ). Participants were also asked to identify comorbidities that they have been told they have by a medical professional. Participants reported the following ailments: AIDS (57%;  $n=90$ ), depression (55%;  $n=86$ ), high cholesterol (48%;  $n=75$ ), anxiety (46%;  $n=72$ ), vision problems (46%;  $n=72$ ), hypertension (45%;  $n=70$ ), insomnia (41%;  $n=64$ ), arthritis (29%;  $n=45$ ), diabetes (25%;  $n=39$ ) asthma (24%  $n=37$ ), allergies (22%;  $n=35$ ), hepatitis C (20%;  $n=31$ ), sexually transmitted infections (18%;  $n=28$ ), cardiovascular problems (13%;  $n=21$ ), immobility (11%;  $n=17$ ), hearing loss (10%;  $n=15$ ), substance abuse (8%;  $n=13$ ), dementia (6%;  $n=10$ ), and cancer (5%;  $n=8$ ).

In addition to these more common health issues, 9% of the participants also reported others, including: chronic pancreatitis, blindness, hepatitis B, neuropathy, osteoporosis, (sleep apnea, Steven Johnsons Syndrome, and chronic thrombosis. On average, participants indicated five comorbidities ( $M=5.36$ ;  $SD=2.97$ ) out of the given list of 20 common comorbidities, with a range of zero to 14.

Virtually all participants, 99%, reported having a doctor or health care provider they visited regularly. Participants were asked to rate their level of satisfaction with their care using a 5-point Likert scale. On average, participants were satisfied with the amount of waiting time to see their providers ( $M=4.17$ ;  $SD=1.27$ ) and with the providers' knowledge of health issues related to HIV ( $M=4.39$ ;  $SD=1.08$ ), and they felt respected as patients by their providers ( $M=4.44$ ;  $SD=1.05$ ). However, about 30% of the sample reported being less than satisfied with their waiting time and about 20% reported being less than satisfied with their providers' knowledge and demeanor.

Ninety-five percent of participants reported visiting their doctor within the 12 months prior to survey completion. When asked to describe topics discussed with medical providers within the last 5 months, participants reported the following: mental health issues - 59% ( $n=92$ ), cancer screenings - 54% ( $n=84$ ), alcohol use - 52% ( $n=81$ ), healthy relationships - 49% ( $n=77$ ), smoking - 47% ( $n=74$ ), STIs - 46% ( $n=72$ ), substance use - 43% ( $n=67$ ), security - 41% ( $n=65$ ), sexual history - 36% ( $n=57$ ), nicotine use - 33% ( $n=52$ ), eating disorders - 27% ( $n=43$ ), and domestic violence - 19% ( $n=29$ ).

**Medical Insurance.** Of the 157 participants, 92% ( $n=144$ ) had some form of medical insurance. Participants reported having the following insurance plans: Medicare – 47% ( $n=74$ ), Medicaid/Family Health Plus – 45% ( $n=71$ ), ADAP/Ryan White – 25% ( $n=39$ ), employer private insurance, – 5% ( $n=7$ ), individual private insurance – 3% ( $n=5$ ), Veteran – 1% ( $n=1$ ) and marketplace insurance – 1% ( $n=2$ ). The remaining 8% of participants ( $n=13$ ), who indicated that they did not have health insurance, gave the following reasons why: unaffordability, no previous insurance plan, lack of knowledge of where to go, lack of transportation, lack of time, and lack of time off work.

Some participants with insurance indicated in the comments section that while they did have insurance they did not receive full coverage for certain medications, and that their insurance plans (particularly Medicare) did not cover mental health care. Forty-five percent ( $n=70$ ) of the participants indicated using an alternative health-care

practice (such as acupuncture) or practitioner (such as a *santero* or *curandero*/healer). Thirty-percent ( $n=30$ ) indicated using alternative medicinal shops (such as a *botánica*, *yerbero*, or “Chinese pharmacy”) for health remedies; 55% ( $n=87$ ) reported using home remedies/remedios caseros, and 31% ( $n=49$ ) using prescription medication (such as antibiotics) obtained outside of the United States.

***HIV Treatment & Adherence.*** On average, participants reported having been diagnosed with HIV for 19 years ( $SD=8.5$ ) and receiving HIV treatment for 16 years ( $SD=7.1$ ). The large majority, 93% ( $n=144$ ) reported that they were “currently taking medications to treat their HIV/AIDS.” For those participants who reported otherwise, the reasons cited for discontinuing treatment included: cost (prohibitive expense of medication), lack of knowledge/awareness (where to go for services), lack of resources (insurance, medical provider) and fear/mistrust (fear of discrimination, distrust of medical provider, fear of disclosed status, fear of disclosed sexual orientation).

Side effects and “not feeling ill” were also cited as reasons for forgoing medication treatment. Forty-three percent of participants indicated that they had experienced some side effects while on antiretroviral treatment. Participants were asked a series of questions to measure factors that may be a barrier to adherence. Roughly a third of participants, 34% ( $n=53$ ) admitted that they found adhering to their medications “a little difficult,” “somewhat difficult,” “difficult,” and “very difficult.” An overwhelming majority of participants, 93% ( $n=146$ ) reported having undetectable viral loads.

***Sexual Activity.*** When asked about sexual behaviors (oral, anal, or vaginal sex) within the last 6 months, 31% ( $n=49$ ) of participants indicated that they had engaged in sexual activity within the last month, 12% ( $n=18$ ) indicated that they had sex within the last 3 months, 24% ( $n=38$ ) indicated that they had sex within the last year, and 32% ( $n=50$ ) indicated that they did not have sex in over a year. Of all the participants indicating that they had sex within the past year ( $n=105$ ), 82% ( $n=86$ ) reported that their sexual partners were male, and 18% had female partners. Participants indicated they engaged in the following sexual activities: oral sex – 38% ( $n=59$ ), insertive anal sex – 26% ( $n=40$ ), receptive anal sex – 12% ( $n=18$ ), and vaginal sex – 22% ( $n=34$ ).

Just under half of these sexually active participants, 46% ( $n=48$ ) indicated that their sexual partners were HIV-positive, while one-fifth, 20% ( $n=21$ ) said that they were not sure about their sexual partner’s HIV-status. Of the 36 participants who said their sexual partners were HIV-negative, fewer than half – 13 of 36 -- said those partners were taking Pre-Exposure Prophylaxis (PrEP). A little under one-third of participants, 30% ( $n=47$ ), reported using condoms. About a fifth of participants, 21% ( $n=32$ ) reported ever using Viagra/Levitra/Cialis during intercourse.

***Substance Use.*** Participants were asked to rate the frequency of substance use in the last month on a Likert scale. On average, participants reported relatively low frequency in use of alcohol ( $M=1.57$ ;  $SD=0.79$ ), substances such as marijuana ( $M=1.21$ ;  $SD=0.69$ ), injected substances ( $M=1.01$ ;  $SD=0.11$ ); cigarettes or tobacco ( $M=1.44$ ;  $SD=1.04$ ), and electronic cigarettes and “vapes” ( $M=1.03$ ;  $SD=0.18$ ). Participants also reported low frequency of sexual activity without a condom while intoxicated or “high” ( $M=1.24$ ;  $SD=0.74$ ). Twelve percent ( $n=18$ ) of participants indicated that they were currently

in recovery for substance-use disorders. More specifically, participants indicated they were in recovery for the following: alcohol abuse – 11% ( $n=17$ ), sexual addiction – 7% ( $n=11$ ), eating disorders – 7% ( $n=11$ ), methamphetamine use – 5% ( $n=8$ ), heroin use – 5% ( $n=7$ ), and gambling – 1% ( $n=1$ ).

**Life Concerns.** Participants were asked how often they were concerned about certain topics within the past 3 months, and on average, participants seemed to be most concerned with family, finances, physical health, and nutrition. See Table 2 below for means and standard deviations. (*Note* – not all of the participants provided a rating for each concern, as they were able to disclose if the concern was not applicable.) Participants reported an average of 11 concerns within the last 3 months ( $M=11.26$ ;  $SD=5.90$ ).

**TABLE 2. Life Concerns Of Sample (N=157)**  
**Concerns in the Past 3 Months (1=Not at all – 5=All of the time)**

	<i>M</i>		<i>(SD)</i>
FAMILY	3.24		(1.58)
FINANCES	3.15		(1.56)
PHYSICAL HEALTH	3.09		(1.55)
NUTRITION	3.04		(1.52)
MENTAL HEALTH	2.98		(1.65)
HOUSING	2.94		(1.74)
NOT ABLE TO MOVE LIKE I USED TO	2.79		(1.60)
AGING ALONE	2.76		(1.62)
EYESIGHT	2.74		(1.61)
FRIENDS	2.59		(1.45)
GASTROINTESTINAL ISSUES	2.56		(1.66)
HIV/AIDS	2.39		(1.65)
EMPLOYMENT STATUS	2.33		(1.58)
SEXUAL HEALTH	2.32		(1.58)
HEARING	2.29		(1.58)
CHILDREN/GRANDCHILDREN	2.28		(1.63)
MEMORY/DISORIENTATION	2.21		(1.41)
STIS	2.11		(1.58)
IMMIGRATION STATUS	2.02		(1.64)
RETIREMENT	2.00		(1.51)
SPOUSE/BOYFRIEND/GIRLFRIEND	1.95		(1.46)
FINDING A ROMANTIC PARTNER	1.88		(1.32)
FINDING A SEX PARTNER	1.84		(1.30)
FINDING SOMEONE TO GO OUT WITH	1.72		(1.21)

**Social Isolation.** Participants were asked a series of three items designed to measure their level of social isolation-- how often they felt that they lacked companionship, felt left out, and felt isolated from everyone else. On average, participants reported relatively low levels of social isolation.

Additionally, items from the Social Provisions Scale (Russell & Cutrona, 1984) were used to examine the degree to which respondents' social relationships provide various dimensions of social support. Participants were presented with a series of statements related to their social relationships and asked to rate the degree to which they agreed with each on a Likert scale (1=Strongly Disagree and 5=Strongly Agree). On average, participants reported moderate levels of social capital – and most indicated that they do feel part of a group or family and have someone to share interests and concerns with. See Table 3.

**TABLE 3. Social Isolation and Social Capital of Sample (N=157)**

<b>Social Isolation (1=Hardly ever – 2=Sometimes – 3=Often)</b>		
<b>HOW OFTEN DO YOU FEEL...?</b>	<b>M</b>	<b>SD</b>
LIKE YOU ARE LACKING FOR COMPANIONSHIP	1.79	(0.70)
LIKE YOU ARE LEFT OUT	1.63	(0.68)
ISOLATED FROM EVERYONE ELSE	1.63	(0.69)
<b>Social Capital (1 = Strongly Disagree - 5 = Strongly Agree)</b>		
I HAVE SOMEONE I CAN SHARE MY INTERESTS AND CONCERNS	3.90	(1.15)
I FEEL PART OF A GROUP OR FAMILY	3.80	(1.13)
I HAVE SOMEONE I CAN TALK WITH ABOUT IMPORTANT DECISIONS IN MY LIFE	3.79	(1.20)
I HAVE PEOPLE I CAN DEPEND ON WHEN I NEED IT	3.62	(1.22)
I HAVE CLOSE PERSONAL RELATIONSHIPS WITH OTHERS	3.49	(1.22)
I HAVE PEOPLE THAT DEPEND ON ME	3.42	(1.29)

Participants reported turning to the following individuals when they needed someone to talk to in the past two months: biological family - 51% (n=80), female friends - 45% (n=71), social worker - 43% (n=68), male friends - 39% (n=61), main partner - 23% (n=36), church members - 20% (n=32), neighbors - 16% (n=25), priest/pastor - 11% (n=17), online friends - 10% (n=15), co-workers - 8% (n=12), sexual partners - 5% (n=7), strangers on the street - 2% (n=3), and doctor - 1% (n=2). But one in 20 respondents (n=7) reported they did not have anyone to turn to when they needed someone.

**Depression.** The Revised 10-item version of the Center for Epidemiologic Studies Depression Scale (CES-D-10) was used to determine if participants exhibited symptoms of depression or depressive disorder (Eaton, Smith, Ybarra, Muntaner, & Tien, 2004). According to this test, a little over half of participants (52%) were considered depressed. The average depression score for the sample was 10.10 ( $SD=5.85$ ), indicating that on average, participants scored at a level that would be defined as depressed according to the measure. See Table 4.

**TABLE 4. Symptoms of Depression of Sample - CES-D-10 (N=157)**

0=Rarely or Never; 1=Sometimes (1-2 days); 2=Occasionally (3-4 days); 3=All the time (5-7 days)

DEPRESSION ITEMS	M	(SD)
THINGS BOTHER ME THAT USUALLY DO NOT	0.74	(0.84)
I HAD A HARD TIME KEEPING MY MIND FOCUSED ON WHAT I AM DOING	0.89	(0.95)
I FELT DEPRESSED	0.94	(0.94)
I FELT LIKE EVERYTHING I DID WAS A HUGE EFFORT	0.97	(0.94)
(REVERSE) I FEEL HOPEFUL ABOUT THE FUTURE	1.54	(1.15)
I FEEL FEARFUL	0.81	(0.98)
MY SLEEP IS RESTLESS	1.19	(1.16)
(REVERSE) I WAS HAPPY	1.55	(1.03)
I FELT ALONE	0.95	(0.98)
I FEEL LIKE I CANNOT START THE DAY	0.71	(0.92)
SCORE	10.10	(5.85)

**Stigma.** The HIV Stigma Scale developed by Sowell et al. (1997) was used to measure the phenomenon of HIV stigma and discrimination among participants. On average, participants indicated experiencing relatively low levels of stigma ( $M=1.51$ ;  $SD=0.57$ ). See Table 5.

**TABLE 5. Perceptions of Stigma and Discrimination of Sample (N=157)**  
 Stigma and Discrimination (1=Not at all – 4=Often)

	<i>M</i>	<i>(SD)</i>
I FEEL THAT OTHERS BLAME ME FOR MY ILLNESS	1.55	(0.94)
I FEEL ASHAMED OF MY ILLNESS	1.68	(1.02)
I BELIEVE MY ILLNESS IS MY PUNISHMENT FOR THINGS I DID IN THE PAST	1.47	(0.88)
I FEAR LOSING MY JOB IF SOMEONE FINDS OUT ABOUT MY ILLNESS	1.41	(0.85)
I FEEL LIKE I HAVE TO CHANGE WHERE I LIVE BECAUSE OF MY ILLNESS	1.30	(0.73)
I AVOID GETTING TREATMENT FOR FEAR OF SOMEONE FINDING OUT ABOUT MY ILLNESS	1.14	(0.50)
I FEAR THAT MY FAMILY WILL BE HURT IF OTHERS FIND OUT ABOUT MY ILLNESS	1.44	(0.86)
I FEEL THAT OTHERS ARE UNCOMFORTABLE AROUND ME	1.74	(0.95)
I FEEL LIKE PEOPLE AVOID ME BECAUSE OF MY ILLNESS	1.68	(0.92)
I FEAR THAT I WILL LOSE MY FRIENDS IF THEY FIND OUT ABOUT MY ILLNESS	1.85	(1.07)
I FEAR THAT MY FAMILY WILL REJECT ME IF THEY FIND OUT ABOUT MY ILLNESS	1.58	(0.98)
I FEAR THAT MY HEALTH WILL NOT BE WELL CARED FOR IF OTHERS FIND OUT ABOUT MY ILLNESS	1.47	(0.89)
THE PEOPLE THAT KNOW THAT I AM HIV POSITIVE TREAT ME WITH "KID GLOVES"	1.38	(0.75)
SCORE	19.54	(7.48)
SCALE	1.51	(0.57)

**Conclusions.** In summary, our survey sample represented a sizeable portion of individuals that were single (over 50%) and lived alone (about half). Roughly one-third of the sample had less than a high school education and the majority (91%) a household annual income of \$20,000 or less. These traits indicate the sample’s relatively low socio-economic status, which has been linked to poor health outcomes. The results also indicate that a sizeable portion of the sample is dealing not only with HIV, but also with several comorbidities -- an average of five illnesses. Roughly half of the sample cited AIDS, cholesterol, anxiety, vision loss, and hypertension. It is important to note that many of the cited comorbidities are modifiable – but *behavior change alone at the individual level* has not proven to be effective in the long term.

Although a large majority of the sample said they had a provider and health insurance, and reported undetectable viral loads (all key aspects for remaining in the continuum

of care), a significant minority reported being *less than satisfied* with some aspect of their provider's care. This is important to note as provider satisfaction has been shown to be critical in engaging and maintaining individuals in care, and significantly increases optimal health outcomes.

About 40% of the sample reported that providers asked about related health issues during visits within the last five months, including mental health, cancer, substance use, STIs, and violence. But this indicates that a sizable share was *not being counseled during visits* about relevant health concerns, screenings, and comorbidity risks. Furthermore, roughly 34% of respondents indicated some level of difficulty with treatment adherence, warranting further exploration and explanation.

About 43% of the sample indicated some sexual activity within the last 3 months, but reported discussions of sexual health were relatively infrequent. Although the sample indicated a relatively low frequency of substance use, 12% indicated that they were in recovery. These estimates may be conservative due to social desirability bias, but regardless, provider conversations related to substance use were also reported as low. Participants reported frequently worrying about family, finances, physical health, and nutrition. Although social isolation and stigma scale scores on average were low, fully half the sample indicated signs of depression, pointing up the need for more attention to mental health.



# FOCUS GROUP RESULTS

The focus-group discussions provided vivid illumination of the issues and concerns of aging Latinos with HIV/AIDS, sometimes highlighting issues that may have been understated in the survey because of biases in self-reporting. All focus groups were recorded and transcribed. The texts were analyzed using a content analysis technique with a directed approach to unveil specific needs or obstacles to optimal health that were universal across all cities.

The crucial obstacles that emerged from the research include **fear and mistrust, experience of comorbidities, and access-to-care challenges**. Such obstacles may complicate adherence to care and the management of side effects. They can also increase the likelihood of social isolation, which in turn can exacerbate depression, increase stress, and further compromise the immune system. The most vulnerable may find it harder to self-regulate, and may instead use maladaptive coping mechanisms such as substance abuse, poor diet/exercise, addictive behaviors or participating in unhealthy relationships.

## Obstacles to Optimal Health

**Fear and Mistrust.** Fear and mistrust emerged as barriers to health, most poignantly in the forms of **stigma and discrimination**. Participants shared experiences of discrimination from providers, community members, family, and friends, as well as the effects of discrimination associated with their HIV status.

*“I was discriminated against by a doctor. The doctor thought I didn’t speak English and told a former student, ‘This is what happens in the Latino culture, when the person is positive and has a boyfriend who isn’t positive; the boyfriend gets HIV like a gift for life’”*

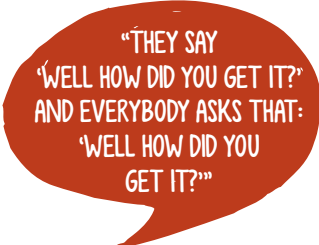
*“I have an experience when I was sick and the person didn’t know I was even there, when my wife went to look for me and the nurse was cleaning up and said, ‘Look, this should be washed with chlorine because there was someone here who had AIDS.’”*

*“I get stigma from the ignorant people—especially when you go to a new doctor or a new PCP that’s not your infectious disease doctor. They say ‘well how did you get it?’ and everybody asks that: ‘Well how did you get it?’ And I go: ‘It doesn’t matter!’ I am living with it and that’s how I’ve basically answered.”*

*“I remember when they looked at my file, the doctor, the dentist, and the dental assistant, they all said clearly in English, ‘after my patient leaves, use Lysol and clean with the sanitizer and clean all the seats and everything he touches.’”*



“...AND SAID, ‘LOOK, THIS SHOULD BE WASHED WITH CHLORINE BECAUSE THERE WAS SOMEONE HERE WHO HAD AIDS.’”



“THEY SAY ‘WELL HOW DID YOU GET IT?’ AND EVERYBODY ASKS THAT: ‘WELL HOW DID YOU GET IT?’”

Such experiences highlight the continued need for education and culturally-sensitive training of medical and non-medical service providers at all levels—not just the advanced clinicians.

Many participants said that aside from the experiences of discrimination due to their HIV status or perceived “infectiousness,” they faced barriers simply because they were gay, Hispanic or immigrants.

*“We are immigrants, but they don’t have to treat us that way. They should help us, because there are some really negative people who see you as trash and it shouldn’t be that way.”*

*“Oh, there is another form of discrimination. For example, people who are gay, stay away from other gay people who are positive. For example, in certain places where we all are, they discriminate against you as well”.*

*“Because there always is someone saying, ‘those are gay.’ And when you go walking down the street and see for example some male gang members who live in the area, suddenly they are staring at you differently, making you feel like you don’t belong. And this makes us feel like we are living in a dangerous community.”*


**Isolation.** Experiences like those described above leave people fearful for their safety and wellbeing, and stressed. This in turn may lead them to become reclusive and isolated, resulting in a vicious cycle that further complicates illness and the effects of aging.

*“Sometimes we don’t talk with one another. We isolate ourselves. And I’ve noticed this in various friends that they don’t want to talk. They prefer to stay distant, and deal with their own problems in their own way and they don’t want to expose it.”*

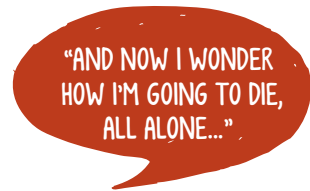
*“What does a person over 50 do? Isolate yourself, stay quiet, never go out. And not because you don’t want to, but because you don’t feel comfortable in certain environments. Now, other things are important, there is no longer the same need or feeling to go out dancing, or no need to just go out and be social.”*

*“For example, disclosing to someone as part of a commitment and being afraid to tell them what I have, afterwards I decided it’s just better to stay alone. I decided some time ago that at the age I am now, that I need to be on my own, just spend more time being alone. And now I wonder how I’m going to die, all alone, because when I do, it scares me. It makes me afraid to even just say it.”*

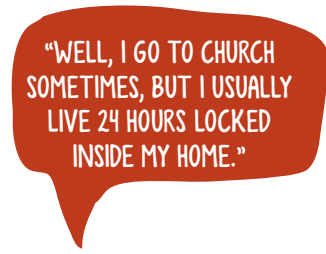
*“I stay home 24 hours a day, I don’t do anything, and I live in a building with older people. Everyone stays in their apartment, I just have one friend. I have family but they don’t want me around due to my condition. Well, I go to church sometimes, but I usually live 24 hours locked inside my home.”*



“PEOPLE WHO ARE GAY, STAY AWAY FROM OTHER GAY PEOPLE WHO ARE POSITIVE”



“AND NOW I WONDER HOW I’M GOING TO DIE, ALL ALONE...”



“WELL, I GO TO CHURCH SOMETIMES, BUT I USUALLY LIVE 24 HOURS LOCKED INSIDE MY HOME.”

**Coping with Comorbidities.** Another challenge to achieving optimal health and wellbeing is the difficulty posed by comorbidities. Many participants in the focus groups shared that although their HIV was under control and well cared for, they experience challenges with the management of other diseases or conditions as well as the consequences of aging.

*“My concern is about my heart health because of all the high levels of cholesterol that makes it difficult for me. Also I don’t follow a diet as I should because I eat fried foods and bread and those things. I try to limit them but mostly (my concern) is my cholesterol.”*

*“On top of HIV I have Hepatitis C and I have the liver very damaged. What happens next? I just have to learn how to live with the pain.”*

*“Later they diagnosed me with Hepatitis C, but I did not show any of the symptoms for Hepatitis. It’s been 10 years since they diagnosed me with kidney stones. And also, still no symptoms are present today, none. I’ve opted since the start to not give any importance to what they were diagnosing me with.”*

**Coping with Depression and Anxiety.** Mental health issues such as depression and anxiety consistently emerged in both qualitative and quantitative data as comorbidities that significantly impact one’s health, sense of wellbeing, and ability to care for oneself. Many felt frustrated and bereft, sometimes experiencing suicidal ideation and in some cases attempting suicide.

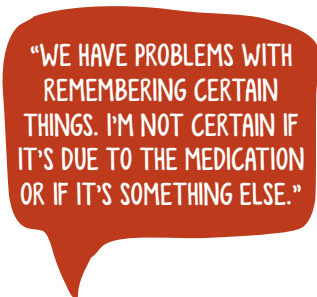
*“For me, my main concern at this moment that has me worried is my state of mind, more than anything, my mental health. I have seen for some of us, we have problems with remembering certain things. I’m not certain if it’s due to the medication or if it’s something else that is within us because the medication is a like a land mine in our head.”*

*“For me it is not easy to live with this illness because I know what I feel, that I am not a normal person anymore. I suffer from a lot of sadness, of feeling lonely.”*

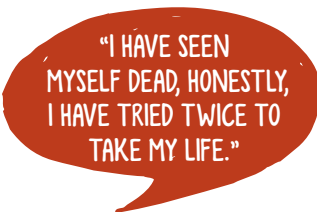
*“I reached the realization that I am depressed and there are times or moments where you feel you no longer are experiencing the true splendor of life.”*

*“I am telling you the truth, I feel – there are moments that I feel a little tense. I want to leave all together in those moments. I have tried to kill myself and end my life. I have seen myself dead, honestly, I have tried twice to take my life.”*

*“You’re chasing after a doctor, psychiatrist, or therapist that’s familiar with HIV and depression. It’s not out there. Not only that, but then you’re chasing after co-pays. Because nowadays, a co-pay could be like 40 bucks to see a psychiatrist. A lot of people can’t afford that.”*



“WE HAVE PROBLEMS WITH REMEMBERING CERTAIN THINGS. I’M NOT CERTAIN IF IT’S DUE TO THE MEDICATION OR IF IT’S SOMETHING ELSE.”



“I HAVE SEEN MYSELF DEAD, HONESTLY, I HAVE TRIED TWICE TO TAKE MY LIFE.”

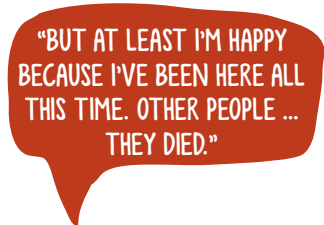
**Managing Side Effects.** The ability to manage not only co-occurring conditions but also the side effects of medication can be difficult, resulting in compliance failures when support is lacking.

*“For me it’s a health problem as the medications that I take hurt my kidneys, gallbladder, pancreas. And after you have to live through those situations that make get you sick.”*

*“Whatever medications you take, they have side effects, side effects that already compromise your body. Now they tell you it’s only a single pill; but let me tell you, as a group and as individuals, we don’t want to just take a single pill. We want a cure.”*

*“But there are so many side effects. There begins the gastritis, effects to your vision, the kidneys, and many other things. You have to learn so much, there is a lot of information to know, all those labs, you have to know, so they can change your medications. You know, they have to change our medications, because if they don’t, the same medication will be like what AZT did in that time. They all died of those evils from the virus at that time.*

*“I just wanted to share that I was diagnosed in 1993 and that was over 23 years ago. And when I was diagnosed here, I thought I was gonna die because people were dying from left to right... I thought I was gonna die... and here, over 23 years yet I’m still here. And they have these medications that are gonna ruin you. Well because it messes you up like your liver and kidneys. But at least I’m happy because I’ve been here all this time. Other people that were infected before, they died. But hey, I lasted over 23 years already, it doesn’t affect me and I’m still here.”*



“BUT AT LEAST I’M HAPPY BECAUSE I’VE BEEN HERE ALL THIS TIME. OTHER PEOPLE ... THEY DIED.”

**Access.** Both quantitative and qualitative data highlight the importance of language, knowledge, cultural competency, finances, transportation, service location, and insurance coverage to either facilitating or hindering access to quality care.

*Appointments—“I think that good quality care is when you can get easy access to a medical appointment. Easy access to a specialist and in many cases that’s not possible, actually in the majority of cases it is not possible. And the problem starts from the moment when you call a provider to get an appointment, they leave you waiting a long time.”*

*Appointments—“There are times when you go to an appointment for the doctor and you have to wait over an hour, two hours, and the doctor arrives 10 to 15 minutes before they kick you out.”*



“...MAKES ME WORRY BECAUSE THEY HAVE SENT ME A LOT OF LETTERS FROM MY INSURANCE...”

*Coverage—“My insurance has become more limited, how can you say, more restricted, and the truth is that they are limiting a lot. This then makes me worry because they have sent me a lot of letters from my insurance, and my pharmacy saying that the insurance is not paying for my medication that the pharmacy is trying to bill them.”*

Coverage— *“For me the problem is that the doctors when they visit you, the first question they ask you is, ‘What insurance do you have?’”*

Cultural Competency - *“For me being over 50, I have felt frustrated because I feel I receive less medical attention. I go to doctors, including specialists, and they don’t tell you directly what’s wrong, and you feel that they don’t give you the right amount of attention.”*

Cultural Competency - *“Good quality care is when you have a connection with the doctor. You feel like you can identify with the doctor, like a patient and that the doctor understands and knows you, and your life experiences based on your status and based on your disease.”*

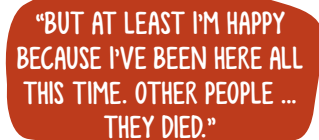
Transportation - *“I think there needs to be more funding, so that there can be more support services and so that for those people who don’t drive, that there be better transportation services”*

Transportation - *“I would like better advocacy to improve transportation. I don’t have a car, for example, and I need to get to a certain place, a pharmacy, it will take me an hour and half on the bus and train.”*

Service Location – *“Where you go (clinic location), everyone is pointing at you. The whole world knows you have HIV. Then, wherever you go, there’s this pointing at you”*



“THE FIRST QUESTION THEY ASK YOU IS, ‘WHAT INSURANCE DO YOU HAVE?’”



“BUT AT LEAST I’M HAPPY BECAUSE I’VE BEEN HERE ALL THIS TIME. OTHER PEOPLE ... THEY DIED.”

## Facilitators for Well Being

The analysis of focus groups helped to highlight “what works/helps” in achieving optimal health outcomes and a sense of wellbeing. The facilitators included the following:

**❶ Strong Relationship with Provider** – Participants noted that a good relationship with their provider was crucial to their engagement in care. This included liking one’s provider; having a provider that takes time to talk or is available, and a provider that is respectful of their needs and culture. They also noted that providers that take a “team approach” to care were helpful. These factors emerged to be more important than simply the ability to communicate in Spanish with clients.

**❷ High Social Capital** – The importance of having a support network (family, friends, community) marked by trust, shared values, reciprocity and cooperation are crucial to the health of aging Latinos with HIV. This assists with coping with their loneliness or isolation and was further supported in the survey data. (See Table 3.) Moreover, the role of family is central to the Hispanic/Latino community and, if relatives are supportive, family can provide a source of resiliency against stress, depression/anxiety and other barriers to wellness.

**❸ Sex-Positivity** – The need for providers and society to acknowledge their sexuality in a positive manner is crucial to the health of aging Latinos with HIV. Sex

and romance are still important; a significant share of the sample reported engaging in sex within the last 3 months, and many older patients, it seems clear, want to have active, healthy sexual lives.

④ ***Work/Volunteer Engagement*** – The sample said they wanted to feel “productive” through various ways including employment and engagement in other activities that make one feel part of society. This included a desire for more opportunities to socialize with peers and for workforce development programs to provide training opportunities.

⑤ ***Affordable and Sustainable Housing*** – Every focus group reported a need for more affordable and sustainable housing and every group had individuals who were currently homeless or in a transitional living facility. Many said that their fixed incomes were inadequate in the face of rising rents and noted a need for an established home to feel safe, secure, and stable. Sustainable housing was pervasively seen as vital to facilitate their health and wellbeing.

## Assessment Limitations

The limitations of the needs assessment include: the use of self-reported data that is not validated, including the risk of participants providing socially desirable responses; the potential burden of time on study participants; and, the difficulty of engaging a stigmatized, hard to reach population, potentially limiting the sample size and reach. Also, the assessment used a sample of convenience that will limit generalizability.

# RECOMMENDATIONS

## **Increase Culturally Sensitive and Responsive Services:**

A lack of bilingual, culturally sensitive and age-appropriate HIV/AIDS services is a key obstacle for the aging population of HIV diagnosed Latinos. Culturally appropriate initiatives that increase HIV testing rates, improve linkage to care, and improve engagement in care and treatment adherence are needed. Likewise, more funding is needed for initiatives that increase the pipeline of Latinos into the HIV-related workforce, including those providing medical services. Culturally competent strategies for advocates and care providers must integrate specific information about local immigrant communities and the diversity among Latinos in the United States and Puerto Rico.

## **More Capacity Building and Training:**

Healthcare providers, front-line workers, and policymakers need to have a greater understanding of the experiences of aging Latinos with HIV/AIDS. Capacity building and training programs are crucial to help programs and services mitigate the psychosocial and cultural challenges facing this group. More training on cultural humility is needed that addresses the diverse realities of Latino culture, going beyond providing services in Spanish or having a translator present and addressing issues of race, discrimination, immigration, stigma, sexual activity, substance use, and mental health.

## **Integrating Mental and Behavioral Health into HIV and Aging:**

There is a dearth of specialized mental and behavioral support services to address the unique emerging care needs of a population aging with HIV, including the fast-growing number of long-term survivors as well as the newly diagnosed. Psychosocial, mental and behavioral health issues need far greater attention in the discussions of HIV and aging. Opportunities exist for collaboration at the community, city, state and federal levels including working more closely with the Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Health and Human Services (HHS) and Centers for Disease Control and Prevention (CDC) on HIV and aging program initiatives. Key partners in this work will include HIV and LGBT service organizations, faith-based communities, clinics, mental health and substance use facilities, and senior centers. There is a need to provide safe spaces where older adults living with HIV can socialize and increase their social networks, potentially improving their quality of life and reducing the risk of depression.

## **More Research on Aging Latinos Living with HIV:**

It is important to study the structural and social determinants of HIV/AIDS disease among older Latinos and other vulnerable groups to help optimize societal resources and develop effective, targeted responses. Novel intervention research needs to address the issues surrounding disclosure, social support, and coping strategies. Likewise, research is needed to identify prevention and treatment interventions that are age and culturally appropriate. We call on the National Institutes for

Health (NIH) and other research institutions to devote funding to the cultural and psychosocial factors this population is experiencing so that aging Latinos will not be left behind and forgotten.

**Targeted Prevention and Treatment Efforts:** The need to implement targeted and tailored HIV testing and treatment initiatives for older adults is crucial to reaching this vulnerable and often invisible population. The following initiatives need to be part of this approach: (1) Develop and implement training curricula on the sexual health of older adults for both medical and non-medical providers. (2) Assess mental health, assess sexual histories, provide risk-reduction strategies and conduct routine screening for HIV, STIs and viral hepatitis. (3) Address PrEP and nPEP as a prevention tool for HIV-positive patients who are in sero-discordant relationships. (4) Target outreach for HIV prevention and treatment services for older adults through social marketing campaigns and with posters/flyers/brochures. A multi-faceted approach to reaching older adults where they live and socialize is required in order to engage them on their mental and behavioral health needs.

**Access to Health Care is a Human Right:** We call for increased advocacy to help policy-makers at all levels understand that everyone has the right to health care, including mental health care. As outlined in the United Nations' Universal Declaration of Human Rights Article 25: "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services."

**Call to Action:** The Latino Commission on AIDS, the Hispanic Health Network and the community networks we work with call on city, county, and state health departments to take action. Health departments at all levels must recognize and fund initiatives that prioritize the growing segment of the population that is aging with HIV/AIDS. The federal government must follow suit and earmark funding specifically dedicated to this population. Nothing less is required if the HIV/AIDS epidemic in the United States and Puerto Rico is to be seriously abated.



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