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Limited English proficiency among adults with HIV in the United States – Medical Monitoring Project, 2015–2018

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Abstract

Research suggests that language barriers in health care settings may adversely affect clinical outcomes and patient satisfaction. We describe the characteristics of adults with limited English proficiency (LEP) and diagnosed HIV in the United States. The Medical Monitoring Project is a complex sample survey of adults with diagnosed HIV in the United States that uses two-stage, probability-proportional-to-size sampling. We analyzed weighted interview and medical record data collected from June 2015–May 2018. The prevalence of LEP among adults with HIV was 10%. Higher percentages of adults with LEP, compared with adults with English proficiency (EP), were female, Hispanic/Latino, less educated and poor, only had Ryan White HIV/AIDS Program (RWHAP) health care coverage, attended RWHAP-funded facilities, were satisfied with their HIV medical care, were prescribed antiretroviral therapy (ART), were virally suppressed and received testing for sexually transmitted diseases. We found no statistical difference in ART adherence among adults with LEP and EP. Despite the association between LEP and the risk for health disparities, more persons with LEP were virally suppressed compared with persons with EP. One possible explanation is attendance at RWHAP-funded facilities by adults with LEP; however, future studies are needed to explore other possible explanations.

Keywords

Limited English proficiency; HIV; HIV care; language services

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Disclosure statement

No potential conflict of interest was reported by the author(s).

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.

Introduction

According to the 2015 American Community Survey, approximately 21% of people in the United States spoke a language other than English at home; of those, 41% had limited English proficiency (LEP) (U.S. Census Bureau). Persons with LEP accounted for 9% of the overall U.S. population in 2015 (Batalova & Zong, 2016). Research suggests that language barriers in health care settings adversely affect clinical outcomes and quality of care. Higher percentages of persons with LEP, compared with persons with English proficiency (EP), have reported difficulty understanding medication use, trouble communicating with providers, lower medication adherence, and lower patient satisfaction (Karliner et al., 2012; Morales et al., 1999; Wilson et al., 2005). These factors are negatively associated with retention in HIV care and adherence to antiretroviral therapy (ART), which are key determinants of HIV viral suppression (Dang et al., 2013; Paterson et al., 2000).

Previous studies have examined how LEP affects knowledge and receipt of HIV testing. One study found that adults with LEP were less knowledgeable about HIV testing recommendations, which may contribute to disparities in HIV testing and infection (Arya et al., 2013). In a study of Latinos with diagnosed AIDS, LEP was associated with late HIV testing (Wohl et al., 2009). Additionally, a comprehensive literature review found that LEP is a barrier to HIV testing by physicians (Burke et al., 2007). Despite the breadth of work on other patient populations with LEP, we found few studies specific to adults with LEP and HIV. To fill this gap, we present the only nationally representative estimates of the sociodemographic, behavioral, and clinical characteristics of adults with LEP and diagnosed HIV in the United States. We also describe differences between adults with LEP and EP.

Materials and methods

The Medical Monitoring Project (MMP) is an annual cross-sectional survey designed to produce nationally representative estimates of the behavioral and clinical characteristics of adults with diagnosed HIV in the United States. Briefly, MMP used a two-stage sampling method. During the first stage, 23 jurisdictions were sampled from the United States, the District of Columbia, and Puerto Rico. During the second stage, simple random samples of persons with diagnosed HIV, aged 18 years, were drawn for each participating state or territory from the National HIV Surveillance System, a census of persons with diagnosed HIV in the United States. We analyzed pooled data from interviews and medical record abstractions collected during June 2015–May 2018.

Bilingual staff interviewed participants who primarily spoke Spanish using the Spanish-language version of the questionnaire. Interpreters were used for languages other than Spanish, or when a jurisdiction did not have bilingual staff. We excluded Puerto Rico from this analysis because English is not the main language spoken there; thus, our findings are limited to adults living in U.S. states ($N = 11,371$). MMP methods, including response rates, are described in detail elsewhere (Centers for Disease Control and Prevention [CDC], 2016). We weighted data to account for unequal selection probabilities and nonresponse.

Measures

Respondents were asked “Do you speak a language other than English at home?” (“yes”, “no”) and “How well do you speak English?” (“very well, well, not well, not at all”). Respondents who spoke a language other than English at home and selected any option less than “very well” were classified as having LEP ($n = 1,090$). This question, a valid measure of English proficiency, has been the U.S. Census Bureau’s main survey question for assessing English proficiency (Vickstrom et al., 2015).

Sociodemographic variables included age, gender, race/ethnicity, education attainment, and whether respondents were born in the United States. Poverty level and health insurance coverage were reported for the 12 months before interview. Household poverty level was determined using the U.S. Department of Health and Human Services poverty guidelines for the calendar year about which the household income question was asked (U.S. Department of Health and Human Services [HHS], 2009).

We ascertained whether participants’ primary HIV care facility received any Ryan White HIV/AIDS Program (RWHAP) funding. Additionally, respondents were asked, “In general, how satisfied are you with the outpatient HIV medical care you received in the past 12 months?”. “Very satisfied” responses were classified as satisfied with HIV medical care and all other responses were classified as not satisfied. Respondents were asked about adherence to ART during the past 3 days using a validated three-item adherence scale (Wilson et al., 2014; Wilson et al., 2016). Respondents who reported not missing a dose during the past 3 days were classified as ART-adherent. Viral suppression, measured by the most recent viral load documented as undetectable or <200 copies/mL, was determined from medical records. Sexually transmitted disease (STD) testing was also determined from medical records; specifically, whether the respondent was tested for gonorrhea, chlamydia, and syphilis in the past year, as recommended in national guidelines (CDC, 2019). If testing for 1 of these STDs was not documented in the medical record, respondents were classified as not having received STD testing.

Data analysis

We computed frequencies and weighted percentages describing characteristics of adults with diagnosed HIV and 95% confidence intervals (CIs) for these descriptive parameters. We used modified Rao-Scott chi-square tests to assess sociodemographic, behavioral, and clinical differences between adults with LEP and EP ($P < .05$ considered significant). We performed all analyses by using SAS 9.3 (SAS Institute, Cary, NC).

Ethics statement

MMP data collection is part of routine public health surveillance and was determined to be non-research (CDC, 2010). Local institutional review board approval was obtained at participating states and territories when required. Informed consent was obtained from all interviewed participants.

Results

Adults with LEP accounted for 9.6% (CI = 8.7–10.4) of all adults with diagnosed HIV in the United States (data not in table). Higher percentages of adults with LEP, compared with adults with EP, were 40–49 years old (33.7% vs. 23.8%), female (26.5% vs. 23.4%), Hispanic/Latino (79.4% vs. 13.1%), less than high-school educated (40.6% vs. 15.1%), living at or below the poverty level (54.6% vs. 41.1%), insured by RWHAP health care coverage only (23.2% vs. 7.3%) and born outside of the United States (82.1% vs. 7.4%). Higher percentages of adults with LEP, compared with adults with EP, received care at RWHAP-funded facilities (79.0% vs. 67.0%), were satisfied with their HIV care (83.7% vs. 80.3%), were prescribed ART (89.7% vs. 83.5%), were virally suppressed (77.5% vs. 69.6%), and received STD testing (49.9% vs. 33.4%). We found no statistically significant differences in ART adherence (Table 1).

Discussion

Approximately one in ten adults with diagnosed HIV had LEP. Although adults with LEP lack resources to support health – including education, income, and health insurance – they were more likely than adults with EP to receive recommended HIV treatment and achieve viral suppression, which are both key to ending the HIV epidemic. A possible explanation for this seeming paradox is that a higher percentage of adults with LEP than adults with EP received care at RWHAP-funded facilities, which are twice as likely as other facilities to provide support services – including interpreter and social services – necessary for marginalized populations to achieve successful outcomes (Weiser et al., 2015). More than half of adults with LEP and HIV have incomes below the federal poverty level. People living in poverty are more likely to achieve viral suppression if they receive care at RWHAP-funded facilities (Weiser et al., 2015). The RWHAP – designed as a payer of last resort for high quality HIV care and treatment for low-income, uninsured and underinsured individuals and families – may mitigate some of the challenges to health faced by persons with LEP (U.S. Health Resources and Services Administration).

Title VI of the Civil Rights Act of 1964 protects persons with LEP from discrimination by requiring programs or institutions that receive Federal financial assistance – including RWHAP-funded facilities and other non-RWHAP-funded hospitals and clinics – to provide access to language services (HHS). Research shows that accessing a language-concordant physician or a professional interpreter substantially improves medication adherence, communication, and patient satisfaction (Karliner et al., 2007; Lee et al., 2002; Moreno & Morales, 2010). Thus, language might not be a barrier to seeking care and support for persons with LEP attending RWHAP-funded facilities.

Recent immigrants are more likely to have LEP (Wilson, 2014). The immigrant health paradox has often been used to explain better health outcomes among immigrants compared with persons born—or having spent more time—in the United States (Teruya & Bazargan-Hejazi, 2013). Future studies may explore the role that language and other measures of acculturation—e.g., Length of time in the United States, acculturative stress, immigration status—play in better HIV clinical outcomes.

These results were subject to several limitations. The behavioral data were self-reported, thus subject to social desirability and recall bias. Our data are cross-sectional; thus, causality cannot be inferred. Our analysis only includes adults aware of their HIV diagnosis; therefore, our estimates of LEP may be lower than what might be found among all persons with LEP and HIV. As noted earlier, LEP is a barrier to HIV testing and has been associated with late HIV testing; therefore, more adults with LEP may have undiagnosed HIV compared with adults with EP and thus may be excluded from MMP (Burke et al., 2007; Wohl et al., 2009). Furthermore, we did not measure access to language services among persons with LEP.

Despite the association between LEP and the risk for health disparities, the clinical outcomes for adults with LEP were better than those of persons with EP—but still suboptimal. One possible explanation is that a higher percentage of adults with LEP attended RWHP-funded facilities. Access to health care with substantial support services is critical to ensuring positive health outcomes. Future studies might explore the role that facility type and acculturation plays in better viral suppression among adults with LEP compared with adults with EP.

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References

- Arya M, Amspoker AB, Lalani N, Patuwo B, Kallen M, Street R, Viswanath K, & Giordano TP (2013). HIV testing beliefs in a predominantly Hispanic community health center during the routine HIV testing era: Does English language ability matter? *AIDS Patient Care and STDs*, 27(1), 38–44. 10.1089/apc.2012.0230 [PubMed: 23305261]
- Batalova J, & Zong J (2016). Language diversity and English proficiency in the United States. Migration Policy Institute. Retrieved January 23, 2019, from <http://www.migrationpolicy.org/article/language-diversity-and-english-proficiency-united-states>
- Burke RC, Sepkowitz KA, Bernstein KT, Karpati AM, Myers JE, Tsoi BW, & Begier EM (2007). Why don't physicians test for HIV? A review of the U.S. literature. *AIDS*, 21(12), 1617–1624. 10.1097/QAD.0b13e32823f91ff [PubMed: 17630557]
- Centers for Disease Control and Prevention. (2010). Distinguishing public health research and public health nonresearch. Published July 2010. Retrieved January 23, 2019, from <https://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf>
- Centers for Disease Control and Prevention. (2016). Behavioral and clinical characteristics of persons receiving medical care for HIV infection—Medical Monitoring Project, United States, 2015 cycle (June 2015–May 2016). HIV Surveillance Special Report. Published November 2016. Retrieved January 23, 2019, from <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hivsurveillance-report-2015-vol-27.pdf>.
- Centers for Disease Control and Prevention. (2019, December). 2015 Sexually transmitted diseases treatment guidelines. <https://www.cdc.gov/std/tg2015/default.htm>

- Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC, & Giordano TP (2013). Examining the link between patient satisfaction and adherence to HIV care: A structural equation model. *PLoS ONE*, 8(1), e54729. 10.1371/journal.pone.0054729 [PubMed: 23382948]
- Health Resources and Services Administration. HIV/AIDS Program. Retrieved December 2, 2019, from <http://hab.hrsa.gov/>
- Karliner LS, Auerbach A, Nápoles A, Schillinger D, Nickleach D, & Pérez-Stable EJ (2012). Language barriers and understanding of hospital discharge instructions. *Medical Care*, 50(4), 283–289. 10.1097/MLR.0b013e318249c949 [PubMed: 22411441]
- Karliner LS, Jacobs EA, Chen AH, & Mutha S (2007). Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *Health Services Research*, 42(2), 727–754. 10.1111/j.1475-6773.2006.00629.x [PubMed: 17362215]
- Lee LJ, Batal HA, Masselli JH, & Kutner JS (2002). Effect of Spanish interpretation method on patient satisfaction in an urban walk-in clinic. *Journal of General Internal Medicine*, 17(8), 641–646. 10.1046/j.1525-1497.2002.10742.x [PubMed: 12213146]
- Morales LS, Cunningham WE, Brown JA, Liu H, & Hays RD (1999). Are Latinos less satisfied with communication by health care providers? *Journal of General Internal Medicine*, 14(7), 409–417. 10.1046/j.1525-1497.1999.06198.x [PubMed: 10417598]
- Moreno G, & Morales LS (2010). Hablamos juntos (Together we speak): Interpreters, provider communication, and satisfaction with care. *Journal of General Internal Medicine*, 25(12), 1282–1288. 10.1007/s11606-010-1467-x [PubMed: 20703951]
- Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, Wagener MM, & Singh N (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*, 133(1), 21–30. 10.7326/0003-4819-133-1-200007040-00004 [PubMed: 10877736]
- Teruya SA, & Bazargan-Hejazi S (2013). The immigrant and Hispanic Paradoxes: A systematic review of their predictions and effects. *Hispanic Journal of Behavioral Sciences*, 35(4), 486–509. 10.1177/0739986313499004 [PubMed: 26120244]
- U.S. Census Bureau. American Community Survey: Summary data, 2011–2015 ACS 5-year estimates. Retrieved August 1, 2017, from <https://www.census.gov/programs-surveys/acs/data/summary-file.2015.html>
- U.S. Department of Health and Human Services. Office of Civil Rights. Retrieved December 2, 2019, from <http://www.dhhs.gov/ocr>
- U.S. Department of Health and Human Services. (2009). Annual update of the HHS poverty guidelines. *Federal Register*, 74, 4199–4201.
- Vickstrom ER, Shin HB, Collazo SG, & Bauman KJ (2015). How well—still good? Assessing the validity of the American Community Survey English-ability question. Social, Economic, and Housing Statistics Division (SEHSD). Working Paper Number 2015–18. Retrieved January 23, 2019, from <https://www.census.gov/content/dam/Census/library/working-papers/2015/demo/SEHSDWP2015-18.pdf>
- Weiser J, Beer L, Frazier EL, Patel R, Dempsey A, Hauck H, & Skarbinski J (2015). Service delivery and patient outcomes in Ryan White HIV/AIDS program-funded and -nonfunded health care facilities in the United States. *JAMA Internal Medicine*, 175(10), 1650–1659. 10.1001/jamainternmed.2015.4095 [PubMed: 26322677]
- Wilson JH (2014). Investing in English skills: the limited English proficient workforce in US Metropolitan areas. Metropolitan Policy Program at Brookings. Retrieved September 6, 2020, from https://www.brookings.edu/wp-content/uploads/2014/09/metro_20140924_investing_in_english_skills_report.pdf
- Wilson E, Chen AH, Grumbach K, Wang F, & Fernandez A (2005). Effects of limited English proficiency and physician language on health care comprehension. *Journal of General Internal Medicine*, 20(9), 800–806. 10.1111/j.1525-1497.2005.0174.x [PubMed: 16117746]
- Wilson IB, Fowler FJ, Cosenza CA, Michaud J, Bentkover J, Rana A, Kogelman L, & Rogers WH (2014). Cognitive and field testing of a new set of medication adherence self-report items for HIV care. *AIDS and Behavior*, 18(12), 2349–2358. 10.1007/s10461-013-0610-1 [PubMed: 24077970]

- Wilson IB, Lee Y, Michaud J, Fowler FJ, & Rogers WH (2016). Validation of a new three-item self-report measure for medication adherence. *AIDS and Behavior*, 20(11), 2700–2708. 10.1007/s10461-016-1406-x [PubMed: 27098408]
- Wohl AR, Tejero J, & Frye DM (2009). Factors associated with late HIV testing for Latinos diagnosed with AIDS in Los Angeles. *AIDS Care*, 21(9), 1203–1210. 10.1080/09540120902729957 [PubMed: 20024781]

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Table 1. Limited English proficiency among adults with diagnosed HIV – Medical Monitoring Project, 2015–2018.

Characteristics	Total (n = 11,371)		Limited English Proficiency (n = 1,090)		English Proficiency (n = 10,281)		Rao-Scott chi-square P value
	Weighted %	CI	Weighted %	CI	Weighted %	CI	
<i>Age in years</i>							
18–29	9.1	8.3–9.9	4.3	2.8–5.9	9.6	8.8–10.5	<i>P</i> < 0.001
30–39	16.8	16.0–17.7	20.1	17.3–22.9	16.5	15.6–17.4	
40–49	24.7	23.7–25.8	33.7	30.6–36.7	23.8	22.7–24.9	
50	49.3	47.9–50.7	41.9	38.4–45.5	50.1	48.6–51.6	
<i>Gender</i>							
Male	74.8	73.2–76.4	71.1	67.7–74.4	75.2	73.4–77.0	<i>P</i> = 0.032
Female	23.7	22.0–25.3	26.5	23.1–29.8	23.4	21.6–25.2	
Transgender	1.5	1.2–1.8	2.5	1.2–3.7	1.4	1.1–1.7	
<i>Race/ethnicity^a</i>							
White, non-Hispanic	30.8	27.2–34.3	2.5	1.6–3.4	33.8	29.7–37.8	<i>P</i> < 0.001
Black, non-Hispanic	42.6	37.8–47.4	13.2	10.7–15.8	45.7	40.6–50.8	
Hispanic/Latino	19.5	18.0–20.9	79.4	76.1–82.7	13.1	11.8–14.4	
Other	7.2	6.3–8.1	4.9	3.1–6.7	7.5	6.5–8.4	
<i>Education</i>							
< High school	17.6	16.3–18.9	40.6	37.2–44.1	15.1	13.7–16.6	<i>P</i> < 0.001
High school diploma or equivalent	25.6	24.5–26.8	25.0	22.2–27.8	25.7	24.5–27.0	
> High school	56.8	55.0–58.6	34.4	31.2–37.6	59.1	57.1–61.2	
<i>Poverty</i>							
Above federal poverty level	57.6	55.4–59.8	45.4	41.5–49.3	58.9	56.5–61.3	<i>P</i> < 0.001
At or below federal poverty level	42.4	40.2–44.6	54.6	50.7–58.5	41.1	38.7–43.5	
<i>Health insurance coverage during the last 12 months</i>							
Yes	89.3	87.5–91.1	74.8	70.7–78.8	90.8	89.0–92.7	<i>P</i> < 0.001
Uninsured	1.9	1.4–2.5	2.0	0.5–3.5	1.9	1.3–2.5	
Uninsured (RWHAP only)	8.8	7.2–10.3	23.2	19.1–27.4	7.3	5.7–8.8	
<i>Born in the United States</i>							
Yes	85.5	84.4–86.7	17.9	15.1–20.8	92.6	91.8–93.5	<i>P</i> < 0.001

Characteristics	Total (n = 11,371)		Limited English Proficiency (n = 1,090)		English Proficiency (n = 10,281)		Rao-Scott chi-square P value
	Weighted %	CI	Weighted %	CI	Weighted %	CI	
No	14.5	13.3–15.6	82.1	79.2–84.9	7.4	6.5–8.2	
<i>Attended RWHPAP-funded facility</i>							<i>P</i> < 0.001
Yes	68.2	62.7–73.7	79.0	74.5–83.6	67.0	61.2–72.9	
No	31.8	26.3–37.3	21.0	16.4–25.5	33.0	27.1–38.8	
<i>Satisfied with outpatient HIV medical care</i>							<i>P</i> = 0.019
Yes	80.6	79.7–81.6	83.7	81.2–86.2	80.3	79.3–81.3	
No	19.4	18.4–20.3	16.3	13.8–18.8	19.7	18.7–20.7	
<i>ART adherent (100% dose adherence in previous 3 days)^b</i>							<i>P</i> = 0.986
Not adherent	56.3	55.1–57.6	56.4	52.8–60.0	56.3	55.0–57.7	
Adherent	43.7	42.4–44.9	43.6	40.0–47.2	43.7	42.3–45.0	
<i>Prescribed ART</i>							<i>P</i> = 0.001
Yes	84.1	82.6–85.6	89.7	87.1–92.3	83.5	81.9–85.1	
No	15.9	14.4–17.4	10.3	7.7–12.9	16.5	14.9–18.1	
<i>Viral suppression</i>							<i>P</i> < 0.001
Most recent viral load undetectable or <200 copies/mL	70.4	68.4–72.3	77.5	74.1–80.9	69.6	67.7–71.6	
Most recent viral load documented detectable, 200 copies/mL or missing/unknown	29.6	27.7–31.6	22.5	19.1–25.9	30.4	28.4–32.3	
<i>Received STD testing</i>							<i>P</i> = < 0.001
Yes	35.0	33.5–36.5	49.9	46.3–53.4	33.4	31.8–34.9	
No	65.0	63.5–66.5	50.1	46.6–53.7	66.6	65.1–68.2	

All percentages are weighted. *P* values were calculated by using the Rao-Scott chi-square test.

All percentages are weighted. *P* values were calculated by using the Rao-Scott chi-square test.

^aRace and ethnicity are mutually exclusive. Hispanic/Latinos could be of any race.

^bDenominator is persons currently taking ART (n = 11,209).