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Disability among adults with diagnosed HIV in the United States, 2017

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Abstract

In the United States, one in four adults is living with a disability. Age-related changes, disease-related pathology and treatments can place a person with HIV at risk for a disability. We analyzed nationally representative data to describe disability status among adults 18 years with diagnosed HIV in the United States and Puerto Rico by demographic characteristics, health behaviors, quality of care, clinical outcomes and mental health status. We reported weighted percentages and prevalence ratios with predicted marginal means to evaluate significant differences between groups ($P < .05$). Overall, 44.5% reported any disability; the most frequently reported disabilities were related to mobility (24.8%) and cognition (23.9%). Persons who lived in households at or below the poverty level or who experienced homelessness in the last 12 months reported a higher prevalence of any disability than persons who were not poor or not homeless (60.2% vs. 33.4% and 61.8% vs. 42.8%, respectively). Prevalence of depression and anxiety was higher among persons with any disability compared with those with no disability (32.8% and 26.6% versus 10.1% and 7.0%, respectively). Enhancing support from clinicians and ancillary providers may help optimize long-term health outcomes among HIV-positive persons with disabilities.

Keywords

Disability; depression; Smoking; HIV infection

Introduction

The Centers for Disease Control and Prevention (CDC) defines a disability as a condition that makes it more difficult for a person to do certain activities and interact with the world

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Disclaimer

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

around them. In the United States, 61 million adults are living with some type of disability (Okoro et al., 2018) and the three most frequently reported disabilities were related to mobility (13.7%), cognition (10.8%) and independent living (6.8%). Prevalence of disability increases with age (Courtney-Long et al., 2015). With the advances in antiretroviral therapy (ART) treatments, people with HIV are living longer (Antiretroviral Therapy Cohort Collaboration, 2008). Persons with HIV infection may be more likely to have disabilities because nearly half of the people with HIV are over 50 years (CDC, 2018) and many older adults with HIV experience health-related deterioration from aging (Pathai et al., 2014), HIV-related comorbidities (Leveille & Thapa, 2017), as well as negative long-term effects of HIV treatments (Onen & Overton, 2011). It is important to know how disability can affect people with HIV and understanding who is disproportionately affected by disability may be helpful for public health prevention. The purpose of this analysis was to use Medical Monitoring Project (MMP) data to describe the prevalence of disability status overall and by selected characteristics, among adults with diagnosed HIV living in the United States and Puerto Rico.

Materials and methods

MMP is a surveillance system that produces nationally representative estimates of behavioral and clinical characteristics of adults aged 18 years with diagnosed HIV living in the United States and Puerto Rico. We used interview and medical record data collected from 4222 adults living with HIV collected from June 2017 through May 2018. Details about MMP sampling, data collection and weighting processes were described previously (Beer et al., 2019). All analyses were conducted using SAS callable SUDAAN version 11.03 (RTI International, Research Triangle Park, NC) to account for the complex survey design and weights. We estimated the weighted prevalence and 95% confidence interval (CI) of reporting at least one disability overall and by variables capturing socio-demographics, any Ryan White HIV/AIDS Program (RWHAP) assistance, unmet needs, quality of care, clinical outcomes, health behaviors and mental health. To compare groups, unadjusted prevalence ratios (PR) with CIs were calculated using logistic regression with predicted marginal means (Bieler et al., 2010).

MMP included six questions about disabilities related to hearing, vision, cognition, mobility, self-care and independent living (HHS, 2011). Respondents were asked “Are you deaf or do you have serious difficulty hearing?” (hearing disability); “Are you blind or do you have serious difficulty seeing, even when wearing glasses?” (vision disability); “Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?” (cognition disability); “Do you have serious difficulty walking or climbing stairs?” (mobility disability); “Do you have difficulty dressing or bathing?” (self-care disability) and “Because of a physical, mental or emotional condition, do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?” (independent living disability). Respondents could report more than one disability. Persons who responded “yes” to at least one of these questions were identified as having any disability and those who responded “no” to all six questions were identified as having no disability. Socio-demographics, RWHAP assistance, unmet needs, mental health, adherence to ART, and health behaviors were self-reported for the past 12 months unless otherwise

indicated. Mental health status included symptoms of depression or anxiety in the past two weeks prior to the interview. ART prescription and viral suppression measures were abstracted from medical records.

Results

Overall, 44.5% (CI 42.7–46.4) of adults with diagnosed HIV reported any disability; 13% reported three or more disabilities. The most frequently reported disability was difficulty related to mobility (24.8%, CI 23.2–26.4), followed by cognition (23.9%, CI 22.2–25.6), independent living (12.5%, CI 11.3–13.8), vision (12.5%, CI 11.0–14.1), hearing (9.7%, CI 8.5–11.1) and self-care (7.0%, CI 6.1–8.1) (not in tables). The prevalence of any disability differed across MMP project areas, ranging from 33.6% in Georgia to 57.0% in Puerto Rico (Table 1).

Women reported a higher prevalence of any disability than men (53.6% vs. 41.3%) (Table 2). Among age groups, the prevalence of any disability was highest among adults aged 65 years or older (60.4%) and lowest among those aged 18–24 years (32.2%). Among racial/ethnic groups, Hispanic/Latino adults reported the highest prevalence of any disability (48.9%). Persons who lived in households at or below the poverty level were 80% (PR = 1.80, CI 1.65–1.96) and who were homeless in the last 12 months were 44% (PR = 1.44, CI 1.31–1.59) more likely to report any disability than persons who were not poor or not homeless. Persons who went without food due to lack of money or who had at least one unmet ancillary service need were 76% (PR = 1.76, CI 1.65–1.89) and 66% (PR = 1.66, CI 1.51–1.81) more likely to report any disability than their counterparts, respectively.

There was no association between disability status and ART prescription, adherence to HIV medications, and viral suppression (Table 3). Persons with any disability were 34% (PR = 1.34, CI 1.24–1.46) as likely to be current smoker than person with no disability. Similarly, compared with persons who did not have a disability, person with disability were over three times (PR = 3.27, CI 2.87–3.27) as likely to report depression and nearly four times (PR = 3.81, CI 3.12–4.65) as likely to report anxiety. When we stratified the analysis by number of disabilities (data not presented in table), compared with persons who did not have a disability, persons with three or more disabilities were 10% (PR = 0.90, CI 0.83–0.98) less likely to be adherent to HIV medicine, 57% (PR = 1.57, CI 1.40–1.75) more likely to be a current smoker, over four times (PR = 4.36, CI 3.73–5.11) as likely to report depression, and over five times (PR = 5.31, CI 4.08–6.91) as likely to report anxiety. There was no association between number of disabilities and ART prescription or viral suppression.

Discussion

The prevalence of any disability among adults with diagnosed HIV is higher than in the general population (44.5% vs. 25.7%) and is also higher among those aged 45–64 years (49.6% vs. 28.6%) and 65 or more years (60.4% vs. 41.7%) – indicating the substantial burden of disability among persons with HIV (Okoro et al., 2018). Like previous studies among the general population (Courtney-Long et al., 2015), the wide variation in the prevalence of disabilities among adults with diagnosed HIV across U.S. jurisdictions may

reflect geographic differences in demographic factors, health behaviors, health care access or combinations of these factors, and highlights the importance of monitoring of disability status in this population by area.

With advances in efficacy and tolerability of ART, people diagnosed with HIV are living longer; as the number of older persons living with HIV increases (Pathai et al., 2014), the prevalence of disabilities may also increase. Similar to what has been found among the general population (Okoro et al., 2018), disabilities related to difficulties with mobility and cognition were the most frequently reported. The CDC-recommended self-management intervention, “Living Well with a Disability” (Ravesloot et al., 2016), may be an effective tool to improve the health and quality of life among adults with HIV who are living with disabilities.

Our findings indicate that adults with HIV who are living with any disability may need enhanced access to ancillary services that can support their needs for housing, food or nutrition, substance abuse and mental health services to improve their health outcomes (Conviser & Pounds, 2002). We did not find any difference in RWHAP assistance between persons with and without disability, although persons with a disability may have a higher need for services available through Ryan White. The federally funded Ryan White HIV/AIDS Program provides access to medical and support services for nearly half a million persons living with HIV in the USA (Kaiser, 2019) and expanding its patient-centered medical home model may improve access to care for persons with disabilities (Pappas et al., 2014).

The findings of this analysis are subject to limitations. First, self-reported information may be subject to biases that may lead to measurement error. Second, disability measures were self-reported and are not official designations for any Social Security benefit. However, self-report is the most commonly used method to assess disability for surveillance purposes. A strength of this analysis was the use of the Department of Health and Human Service’s standard self-reported six-question measure of any disability, which facilitates monitoring of disability status among people with HIV and enables comparisons of disability prevalence across different population-based studies. Third, we cannot assess causality due to MMP’s cross-sectional design.

Successful treatment and management of HIV infection have transformed HIV into a chronic disease. However, optimizing health outcomes among persons with HIV with a disability may require enhanced support from clinicians and ancillary providers.

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Table 1.

Prevalence of any disability among U.S. adults with diagnosed HIV by area – Medical Monitoring Project, 2017 ($N = 4222$).

| MMP project areas | Total N^* | Any disability | | |
|--------------------|----------------|----------------|--------------|--------------|
| | | n^* | $\%^\dagger$ | 95% CI § |
| National | 4202 | 1886 | 44.5 | (42.7–46.4) |
| Puerto Rico | 183 | 105 | 57.0 | (48.5–65.1) |
| New York-State | 424 | 212 | 50.2 | (44.6–55.8) |
| New York City | 349 | 177 | 51.3 | (44.7–57.8) |
| Illinois-State | 253 | 120 | 48.1 | (40.9–55.4) |
| Chicago | 176 | 83 | 42.0 | (33.8–50.6) |
| Washington | 183 | 83 | 47.3 | (39.7–55.1) |
| Mississippi | 139 | 70 | 46.8 | (36.4–57.5) |
| Delaware | 186 | 88 | 46.4 | (39.3–53.7) |
| California-State | 582 | 271 | 45.6 | (40.6–50.6) |
| Los Angeles County | 171 | 91 | 50.8 | (42.0–59.5) |
| San Francisco | 185 | 74 | 40.7 | (33.7–48.1) |
| Michigan | 180 | 82 | 45.6 | (37.6–53.8) |
| North Carolina | 179 | 80 | 45.5 | (38.1–53.1) |
| Indiana | 173 | 77 | 44.8 | (36.9–53.0) |
| Florida | 289 | 126 | 43.7 | (37.2–50.5) |
| Oregon | 218 | 95 | 43.6 | (34.9–52.6) |
| New Jersey | 228 | 98 | 43.3 | (36.0–50.9) |
| Pennsylvania-State | 251 | 105 | 41.0 | (33.7–48.6) |
| Philadelphia | 165 | 70 | 42.5 | (33.0–52.7) |
| Texas-State | 358 | 140 | 40.7 | (34.9–46.8) |
| Houston | 173 | 63 | 35.8 | (28.3–43.9) |
| Virginia | 165 | 63 | 37.5 | (29.5–46.3) |
| Georgia | 211 | 71 | 33.6 | (27.4–40.5) |

CI, confidence interval.

* Numbers are unweighted.

† Percentages are weighted row percentages.

§ CIs incorporate weighted percentages.

Table 2.

Prevalence of any disability among U.S. adults with diagnosed HIV by selected characteristics – Medical Monitoring Project, 2017 (N = 4222).

| Participant characteristics | Total | | | Any disability | | | Prevalence ratio (95% CI) | p-value of t-test $\beta = 0$ |
|---|-------|------|----------------|---------------------|----------------|---------------------|---------------------------|-------------------------------|
| | N* | n* | % [†] | 95% CI [§] | % [†] | 95% CI [§] | | |
| Total | 4202 | 1886 | 44.5 | (42.7–46.4) | - | - | - | - |
| Gender | | | | | | | | |
| Female | 1035 | 574 | 53.6 | (49.8–57.4) | 1.30 | (1.21–1.40) | <0.001 | <0.001 |
| Male | 3096 | 1270 | 41.3 | (39.5–43.1) | Referent | | - | - |
| Self-identified sexual orientation | | | | | | | | |
| Lesbian or gay | 1801 | 642 | 35.8 | (33.4–38.2) | Referent | | - | - |
| Heterosexual or Straight | 1923 | 1006 | 51.2 | (48.5–53.9) | 1.43 | (1.33–1.53) | <0.001 | <0.001 |
| Bisexual | 363 | 177 | 48.8 | (42.4–55.2) | 1.36 | (1.16–1.60) | <0.001 | <0.001 |
| Other ^{††} | 86 | 43 | 48.0 | (37.2–59.0) | 1.34 | (1.05–1.71) | 0.030 | 0.030 |
| Age at time of interview (years) | | | | | | | | |
| 18–24 years | 92 | 29 | 32.2 | (21.9–44.6) | Referent | | - | - |
| 25–44 years | 1366 | 451 | 32.9 | (30.2–35.7) | 1.02 | (0.70–1.50) | 0.911 | 0.911 |
| 45–64 years | 2400 | 1203 | 49.6 | (47.5–51.8) | 1.54 | (1.07–2.23) | 0.010 | 0.010 |
| 65 or more | 344 | 203 | 60.4 | (53.8–66.6) | 1.88 | (1.25–2.83) | <0.001 | <0.001 |
| Race/Ethnicity | | | | | | | | |
| White non-Hispanic | 1200 | 480 | 41.7 | (38.6–45.0) | 0.93 | (0.80–1.07) | 0.316 | 0.316 |
| Black non-Hispanic | 1717 | 773 | 44.1 | (41.4–46.8) | 0.98 | (0.86–1.11) | 0.742 | 0.742 |
| Hispanic/Latino ^{**} | 954 | 479 | 48.9 | (44.7–53.1) | 1.09 | (0.93–1.27) | 0.309 | 0.309 |
| Other ^{††} | 331 | 154 | 45.0 | (39.3–50.9) | Referent | | - | - |
| Education status | | | | | | | | |
| Less than high school | 690 | 452 | 63.4 | (58.9–67.6) | 1.67 | (1.51–1.85) | <0.001 | <0.001 |
| High school diploma or GED | 1113 | 525 | 46.5 | (43.8–49.3) | 1.22 | (1.12–1.33) | <0.001 | <0.001 |
| More than high school | 2395 | 906 | 38.0 | (35.4–40.6) | Referent | | - | - |
| Employment status | | | | | | | | |
| Employed ^{§§} | 1992 | 527 | 26.3 | (24.2–28.5) | Referent | | - | - |
| Not employed | 1762 | 1155 | 65.4 | (63.0–67.7) | 2.49 | (2.29–2.70) | <0.001 | <0.001 |

| Participant characteristics | Total | | Any disability | | Prevalence ratio (95% CI) | p-value of t-test $\beta = 0$ |
|---|-------|------|----------------|-------------|---------------------------|-------------------------------|
| | N* | n* | %† | 95% CI‡ | | |
| Other¶¶ | 441 | 201 | 44.8 | (39.9–49.9) | 1.71 (1.49–1.95) | <0.001 |
| Household income at or below poverty level in the past 12 months *** | | | | | | |
| Yes | 1660 | 1008 | 60.2 | (57.3–62.9) | 1.80 (1.65–1.96) | <0.001 |
| No | 2263 | 752 | 33.4 | (31.1–35.8) | Referent | - |
| Time since HIV diagnosis | | | | | | |
| <5 years | 658 | 219 | 33.2 | (29.3–37.4) | Referent | - |
| 5–9 years | 865 | 353 | 42.2 | (38.7–45.6) | 1.27 (1.08–1.49) | 0.003 |
| 10 or more years | 2679 | 1314 | 48.1 | (45.4–50.8) | 1.45 (1.27–1.65) | <0.001 |
| Homelessness at any time in the past 12 months ††† | | | | | | |
| Yes | 390 | 252 | 61.8 | (56.7–66.7) | 1.44 (1.31–1.59) | <0.001 |
| No | 3812 | 1634 | 42.8 | (40.9–44.8) | Referent | - |
| Any Ryan White HIV/AIDS Program (RWHAP) assistance, past 12 months | | | | | | |
| Yes | 1985 | 911 | 45.7 | (43.5–47.9) | 1.06 (0.98–1.14) | 0.149 |
| No | 2114 | 918 | 43.2 | (40.7–45.7) | Referent | - |
| Needed or used SSI,§§§ in the past 12 months | | | | | | |
| Yes | 782 | 527 | 66.1 | (62.4–69.7) | 1.68 (1.57–1.80) | <0.001 |
| No | 3380 | 1328 | 39.3 | (37.4–41.3) | Referent | - |
| Needed or used SSDI,§§§ in the past 12 months | | | | | | |
| Yes | 948 | 661 | 68.6 | (65.7–71.4) | 1.83 (1.72–1.94) | <0.001 |
| No | 3216 | 1199 | 37.5 | (35.5–39.5) | Referent | - |
| Went without food due to lack of money in the past 12 months | | | | | | |
| Yes | 863 | 582 | 67.6 | (64.5–70.6) | 1.76 (1.65–1.89) | <0.001 |
| No | 3338 | 1304 | 38.4 | (36.5–40.4) | Referent | - |
| At least one unmet ancillary service needs in the past 12 months ¶¶¶ | | | | | | |
| Yes | 2191 | 1197 | 54.7 | (52.0–57.4) | 1.66 (1.51–1.81) | <0.001 |
| No | 1998 | 682 | 33.0 | (30.6–35.5) | Referent | - |

CI, confidence interval; GED, general educational development; SSI, supplemental security income; SSDI, social security disability insurance.

* Numbers are unweighted.

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[‡] Percentages are weighted row percentages.

[§] CIs incorporate weighted percentages.

[¶] Includes something else.

^{**} Hispanics or Latinos might be of any race. Persons are classified in only 1 race/ethnicity category.

^{††} Includes American Indian/Alaska Native, Asian, Native Hawaiian/Other Pacific Islander, and multiple races.

^{§§} Employed includes employed for wages, self-employed, or homemaker.

^{¶¶} Includes a student and retired.

^{***} Poverty guidelines as defined by HHS: <https://aspe.hhs.gov/frequently-asked-questions-related-poverty-guidelines-and-poverty>.

^{†††} Living on the street, in a shelter, in a single-room–occupancy hotel, or in a car.

^{§§§} Disabilities are self-reported and are not official designations for any Social Security benefits.

^{¶¶¶} Unmet need was defined as an ancillary service that the participant reported as needed but not received during the 12 months before the interview. Ancillary services for which unmet need was assessed were: HIV case management, adherence counseling, AIDS Drug Assistance Program, patient navigator, HIV peer group support, dental health, drug or alcohol counseling, mental health, transportation assistance, SSI, SSDI, food assistance, meals or food services, domestic violence, interpreter, and lawyer or legal.

Clinical outcomes, health behaviors and mental health status of U.S. adults with diagnosed HIV by disability status – Medical Monitoring Project, 2017 (N = 4222).

Table 3.

| | Any disability | | | No disability | | | Prevalence ratio [¶] (95% CI) | p-value of t-test $\beta = 0$ |
|--|----------------|----------------|-------------|---------------|------|-------------|---|-------------------------------|
| | n | % [†] | 95% CI | n | % | 95% CI | | |
| Clinical Outcomes | | | | | | | | |
| Prescribed ART in the past 12 months ^{**} | 1684 | 85.8 | (83.1–88.1) | 2040 | 83.0 | (80.4–85.2) | 1.03 (1.00–1.07) | 0.077 |
| 100% adherent to HIV medicine in the past 30 days ^{††} | 1039 | 59.1 | (56.6–61.6) | 1355 | 62.2 | (60.1–64.2) | 0.95 (0.90–1.00) | 0.048 |
| Most recent viral load documented undetectable or <200 copies/mL in the past 12 months | 1394 | 69.9 | (66.0–73.0) | 1780 | 70.1 | (65.5–74.3) | 1.00 (0.95–1.05) | 0.896 |
| All viral load measurements documented undetectable or <200 copies/mL in the past 12 months | 1253 | 63.3 | (59.7–66.8) | 1598 | 63.2 | (59.0–67.2) | 1.00 (0.94–1.07) | 0.944 |
| Health behaviors | | | | | | | | |
| Current Smoker | 719 | 39.1 | (35.7–42.5) | 640 | 29.1 | (26.8–31.5) | 1.34 (1.24–1.46) | <0.001 |
| Binge drinking in the past 30 days ^{§§} | 260 | 13.7 | (12.0–15.7) | 413 | 17.0 | (15.1–19.0) | 0.81 (0.70–0.94) | 0.004 |
| Heavy drinking in the past 30 days ^{¶¶} | 95 | 4.8 | (3.9–5.9) | 135 | 5.4 | (4.5–6.6) | 0.89 (0.65–1.21) | 0.447 |
| Any drug use in the past 12 months | 590 | 31.8 | (28.8–35.0) | 713 | 29.6 | (26.9–32.6) | 1.07 (0.96–1.20) | 0.202 |
| Mental health | | | | | | | | |
| Had major or other depression (based on DSM-IV) ^{***} during the two weeks before the interview | 607 | 32.8 | (29.8–36.0) | 222 | 10.1 | (8.9–11.4) | 3.27 (2.87–3.72) | <0.001 |
| Had anxiety based on GAD ^{†††} scale during the two weeks before the interview | 501 | 26.6 | (24.1–29.3) | 162 | 7.0 | (5.9–8.3) | 3.81 (3.12–4.65) | <0.001 |

CI, confidence interval; ART, antiretroviral therapy.

* Numbers are unweighted.

† Percentages are weighted row percentages.

§ CIs incorporate weighted percentages.

¶ Comparing people with no disability vs. who had any disability.

** ART prescription documented in medical record; persons with no medical record abstraction were considered to have no documentation of ART prescription.

†† Did not miss a single dosage of any HIV medicines in the past 30 days.

§§ Defined as drinking 5 alcoholic beverages in a single sitting (4 for women) during the 30 days before the interview.

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^{††} Defined as consuming an average of >2 drinks/day or >14 drinks/week (for men) or consuming an average >1 drink/day or >7 drinks/week (for women) during the 30 days before the interview.

^{***} Responses to the items on the PHQ-8 were used to define "major depression" and "other depression", according to criteria from the DSM-IV. "Major depression" was defined as having at least five symptoms of depression; "other depression" was defined as having two to four symptoms of depression.

^{†††} Responses to the Generalized Anxiety Disorder Scale (GAD-7) were used to define anxiety according to criteria from DSM-IV. Anxiety was defined as having a score of 10.