U.S. Centers for Disease Control and Prevention
MMWR
Morbidity and Mortality Weekly Report
Weekly / Vol. 74 / No. 20
June 5, 2025

Prescriptions for Obesity Medications Among Adolescents Aged 12–17 Years with Obesity — United States, 2018–2023

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Abstract

Obesity affects approximately one in five U.S. adolescents. Although an increasing number of medications are approved for adolescent obesity as an adjunct to health behavior and lifestyle treatment, national data on the prevalence and correlates of obesity medication prescribing for adolescents are sparse. Ambulatory electronic medical record data were analyzed to assess trends in the proportion of U.S. adolescents aged 12–17 years with obesity (body mass index ≥95th percentile) who were prescribed Food and Drug Administration (FDA) –approved obesity medications during 2018–2023. Log-binomial models were used to estimate characteristics of adolescents associated with receiving an obesity medication prescription in 2023. The proportion of U.S. adolescents who were prescribed obesity medications increased substantially in 2023 (by approximately 300% compared with 2020), the year after FDA expanded its approval of two obesity medications to include adolescents and after publication of the 2023 American Academy of Pediatrics clinical practice guideline. Despite this substantial relative increase, 0.5% of adolescents with obesity were prescribed an obesity medication in 2023, with a majority (83%) of prescriptions received by adolescents with severe obesity. Semaglutide (Wegovy, indicated for persons aged ≥12 years with obesity), and phentermine or phentermine-topiramate were most commonly prescribed. Prescribing prevalence was higher among girls than among boys (adjusted prevalence ratio [aPR] = 2.05), among adolescents aged 15–17 years than among those aged 12–14 years (aPR = 2.24), and among those with severe (class 2 or class 3) obesity than among those with class 1 obesity (aPR = 4.03 and 12.78, respectively). Prescribing prevalence was lower among Black or African American adolescents than among White adolescents (aPR = 0.61). Continued monitoring of the use of these medications could help guide strategies to ensure that all adolescents with obesity have access to evidence-based obesity treatment, including medications and health behavior and lifestyle interventions.

Introduction

Approximately one in five U.S. adolescents has obesity.* Obesity is a complex chronic disease that affects a child's physical, social, and emotional health and increases the risk for adult obesity, type 2 diabetes mellitus (T2DM), and heart disease.† In 2022, the Food and Drug Administration (FDA) expanded its approval of phentermine and topiramate extended-release capsules and semaglutide for chronic weight management in adults to include adolescents aged 12–17 years.§ In early 2023, the American Academy of Pediatrics (AAP) released the

* Obesity is defined as body mass index (kg/m^2) ≥95th percentile for sex and age.
† CDC. About Obesity
§ Food and Drug Administration. New Drug Therapy Approvals 2022

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Clinical Practice Guideline for the Evaluation and Treatment of Children and Adolescents with Obesity, which recommended that clinicians offer obesity medications, including glucagon-like peptide-1 receptor agonists (GLP-1RAs), for adolescents aged ≥12 years with obesity as an adjunct to health behavior and lifestyle treatment that facilitates sustained healthier habits, including improved nutrition and physical activity (*1*).

Data on use of obesity medications among adolescents are limited. A 2024 study reported an increase of 504% (among boys) to 588% (among girls) in the number of GLP-1RAs dispensed to U.S. adolescents during 2020–2023 (*2*). The analysis focused on GLP-1RAs, only two of which are FDA approved for obesity treatment in adolescents, and did not ascertain the body mass index (BMI) of participants or assess differences by obesity class (*2*). Another 2024 study found that the 2023 release of the AAP guideline was associated with increases in prescriptions of medications (both FDA-approved obesity medications and those used off-label for obesity treatment) among children and adolescents aged 8–17 years who had obesity but did not have T2DM (*3*). However, the analysis did not describe factors associated with prescribing after release of the guideline. This report, which focuses on FDA-approved obesity medications, assesses trends in prescription prevalence among adolescents with obesity, as well as patient characteristics associated with receiving an obesity medication prescription.

Methods

Data Source

IQVIA Ambulatory Electronic Medical Records (EMR) data[¶] were used to identify U.S. adolescents aged 12–17 years with at least one health care visit during 2018–2023 in which their BMI was recorded as ≥95th percentile for age and sex (i.e., obesity).[**] Among adolescents included in each year,[††] this analysis identified those prescribed an FDA-approved obesity medication at least once during the calendar year

[¶] Observational Medical Outcomes Partnership (OMOP), version 5, May 2024 data release. IQVIA's ambulatory EMR database includes structured clinical data for approximately 90 million health care–seeking patients, including 15 million children, from all 50 states. Data come from a single electronic health record vendor that collects data from approximately 100,000 health care providers who are affiliated with approximately 800 medium to large ambulatory practices and physician networks across the United States. All data were extracted using IQVIA's Health Data Engine, a web-based software as a service platform (Real World & Health Data Sets - IQVIA).

[**] Measured height and weight data during 2018–2023 for adolescents aged 12–17 years in IQVIA were cleaned longitudinally using growthcleanr, an open-source R package (version 2.2.0; R Core Team) for cleaning pediatric growth data (GitHub - carriedaymont/growthcleanr). Height and weight measurements were merged using a 30-day nearest-neighbor rolling join and cleaned cross-sectionally using CDC growth charts (exclusions: height-for-age z-score of <−5 or >5; weight-for-age z-score <−10 or >5; BMI-for-age z-score of <−4 or >10; and BMI >150 kg/m^2).

[††] The highest BMI per calendar year per person was used to calculate sex-specific BMI-for-age percentiles for 2018–2023. The final sample included adolescents with obesity (BMI ≥95th percentile). Pregnant adolescents were excluded. The study identified 526,973 adolescents with obesity who had a total of 789,057 annual BMI measurements.

The *MMWR* series of publications is published by the Office of Science, U.S. Centers for Disease Control and Prevention (CDC), U.S. Department of Health and Human Services, Atlanta, GA 30329-4027.

Suggested citation: [Author names; first three, then et al., if more than six.] [Report title]. MMWR Morb Mortal Wkly Rep 2025;74:[inclusive page numbers].

during which obesity was recorded. Medications included orlistat, phentermine, a combination of phentermine and topiramate (phentermine-topiramate), and setmelanotide, as well as two newly approved high-dose GLP-1RAs: liraglutide (Saxenda, indicated for patients aged ≥12 years with obesity; maximum daily dose = 3 mg, approved in 2020) and semaglutide (Wegovy, indicated for patients aged ≥12 years with obesity; maximum weekly dose = 2.4 mg, approved in 2022). Semaglutide that was indicated only for adults with T2DM (Ozempic; maximum weekly dose = 2 mg) and liraglutide that was indicated for persons aged ≥10 years with T2DM (Victoza; maximum daily dose = 1.8 mg) were not included in the list of obesity medications because they are indicated for T2DM and not for obesity. Semaglutide and liraglutide of undetermined brands were also not included. A sensitivity analysis was performed in which the Ozempic brand of semaglutide, the Victoza brand of liraglutide, and undetermined brands of semaglutide and liraglutide were included.

2018–2023 Analysis

The primary study outcome in this multiyear analysis was the presence of a prescription for an obesity medication per patient, per year. Adolescents were considered to have experienced the outcome if they had received an obesity medication prescription at least once during the year that obesity was recorded, and contributed an independent outcome count each year if their prescriptions spanned >1 year. Crude percentages of adolescents prescribed obesity medications were plotted for 2018 through 2023 (total and by medication type). Adjusted percent differences in prescription prevalence in each year (compared with 2020) were obtained from a generalized linear model with log link and binomial distribution to model the outcome variable (any obesity medication prescription) with two possible results (yes or no). The covariate of interest was the year indicator, with the year 2020 selected as a referent for comparison with a published 2024 report that examined the dispensing of GLP-1RAs to adolescents and young adults during 2020–2023 (*2*). The model controlled for age (12–14 and 15–17 years), sex (male and female), and obesity class (classes 1, 2, and 3, with classes 2 and 3 representing severe obesity).[§§]

2023 Patient-Level Analysis

Two models were used to conduct the patient-level analysis. Model 1 was a generalized linear model with log link and binomial distribution used to test associations between patient characteristics (i.e., age, sex, obesity class, and U.S. Census Bureau region[¶¶]) and having received at least one obesity medication prescription in 2023. This analysis focused on only 2023 because 1) 2023 represented the period after publication of the AAP clinical practice guideline and the most recent FDA approval of a medication for adolescents with obesity (semaglutide [Wegovy]), 2) 2023 was the most recent complete year with available obesity medication data in IQVIA, and 3) obesity medication prescription rates before 2023 were very low. A secondary analysis using the same model tested the association between covariates (age, sex, and U.S. Census Bureau region) and presence of severe obesity (class 2 or 3). Estimates of association from the model were expressed as adjusted prevalence ratios.

Models did not adjust for race and ethnicity because these data were missing for 26.1% of the sample. Model 2 was restricted to the subpopulation of patients who were Black or African American (Black) or White and included an additional covariate of race (Black/White). Analyses were conducted using R software (version 4.4.1; The R Foundation) and Stata (version 15.1/MP; StataCorp). This activity was reviewed by CDC, deemed research not involving human subjects, and was conducted consistent with applicable federal law and CDC policy.[***]

Results

Prevalence of Adolescents Who Received Obesity Medication Prescriptions

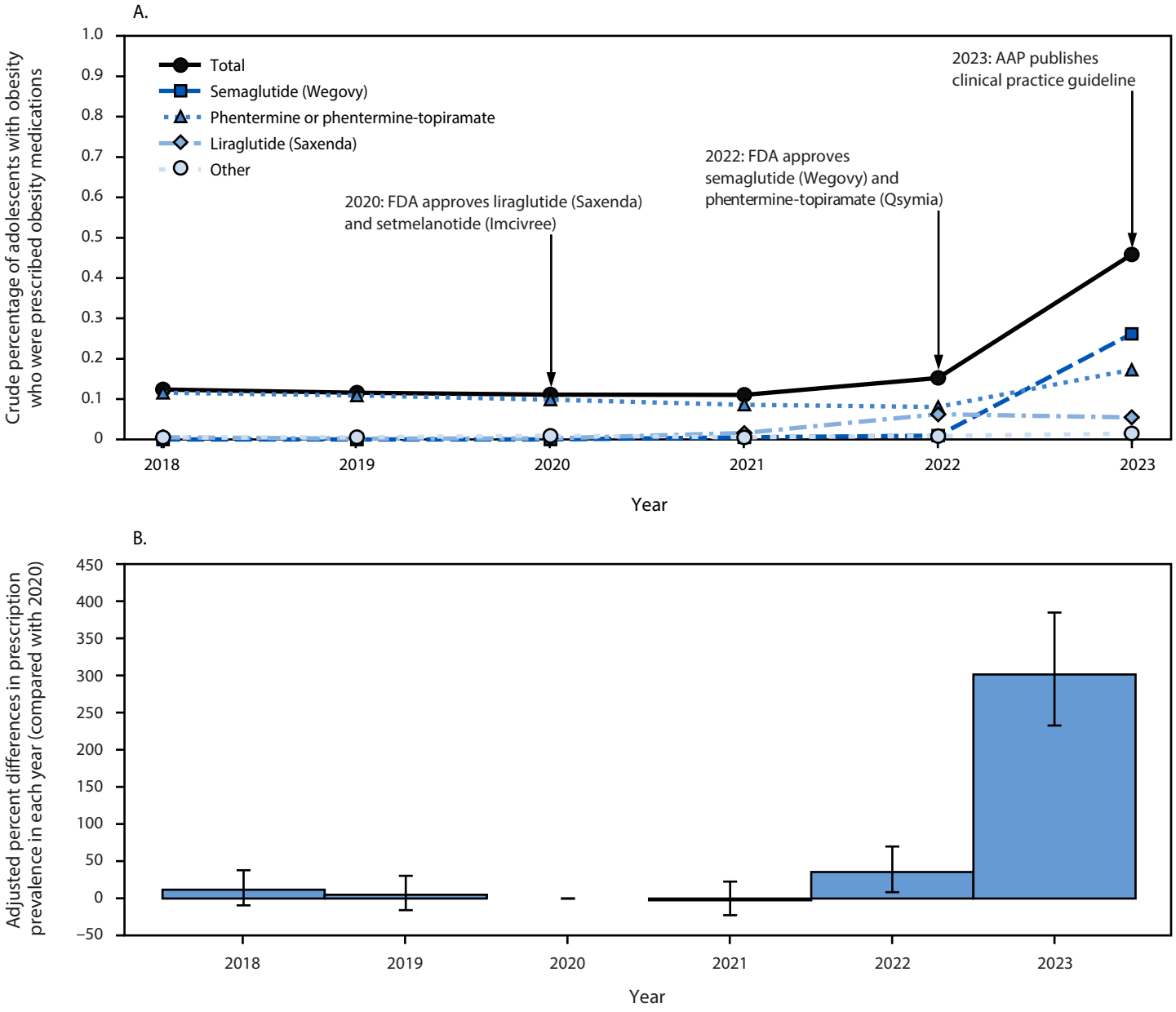
Among 526,973 U.S. adolescents aged 12–17 years with obesity (789,057 person-years) during 2018–2023, the crude percentage of adolescents with obesity who received obesity medication prescriptions was low overall, increasing from 0.1% in 2020 to 0.2% in 2022, then increasing sharply to 0.5% in 2023 (Figure 1). Compared with 2020, the adjusted proportion of adolescents with obesity who received an obesity medication prescription was 301.7% higher (95% CI = 232.8%–385.0%) in 2023. In 2023, 57.1% of adolescents with obesity who were prescribed obesity medications received a prescription for semaglutide (Wegovy), followed by phentermine or phentermine-topiramate (37.7%), liraglutide (Saxenda) (11.9%), and others (3.3%) (Table). A sensitivity analysis that included semaglutide

[§§] Obesity classes are as follows: class 1 obesity or BMI ≥95th percentile to BMI <120% of the 95th percentile [referent group], class 2 obesity or BMI of 120% to <140% of the 95th percentile, and class 3 obesity or BMI ≥140% of the 95th percentile. Classes 2 and 3 represent severe obesity.

[¶¶] *Northeast*: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont; *Midwest*: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; *South*: Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; and *West*: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

[***] 45 C.F.R. part 46; 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d), 5 U.S.C. Sect. 552a, 44 U.S.C. Sect. 3501 et seq.

FIGURE 1. Crude percentages (A) and adjusted percent differences in prevalence compared with 2020 (B)* of adolescents aged 12–17 years with obesity who received an obesity medication prescription† — IQVIA Ambulatory Electronic Medical Records, United States, 2018–2023§



Abbreviations: AAP = American Academy of Pediatrics; BMI = body mass index; FDA = Food and Drug Administration.

* Adjusted percent differences in prescription prevalence in each year (compared with 2020) were obtained from a generalized linear model with log link and binomial distribution. The adjusted model controls for sex, age category, and obesity class. Obesity was defined as BMI ≥95th percentile for age and sex. 95% CIs indicated by bars.

† In November 2020, FDA approved setmelanotide (Imcivree) for treating obesity in persons with monogenic or syndromic obesity aged ≥6 years. In December 2020, FDA approved liraglutide (Saxenda) for treating obesity in adolescents aged ≥12 years. In June 2022, FDA approved phentermine-topiramate (Qsymia) for treating obesity in adolescents aged ≥12 years. In December 2022, FDA approved semaglutide (Wegovy) for treating obesity in adolescents aged ≥12 years. In January 2023, a new AAP clinical practice guideline recommended that clinicians offer obesity medications as part of evidence-based multicomponent treatment for adolescents aged 12–17 years with obesity (AAP Clinical Practice Guideline for the Evaluation and Treatment of Children and Adolescents With Obesity).

§ The sample included 526,973 U.S. adolescents aged 12–17 years with obesity who had a total of 789,057 annual BMI measurements during 2018–2023.

TABLE. Percentage of adolescents aged 12–17 years with obesity* who were prescribed obesity medications, by selected demographic characteristics, obesity class, and medication type — IQVIA Ambulatory Electronic Medical Records, United States, 2023

Characteristic	No. of adolescents with obesity (%)	No. of adolescents prescribed obesity medication (%)
Total	**93,121 (100)**	**427 (100)**
Age group, yrs, mean (SD)	**14.4 (1.7)**	**15.2 (1.6)**
12–14	49,584 (53.2)	139 (32.6)
15–17	43,537 (46.8)	288 (67.4)
Sex		
Female	41,683 (44.8)	266 (62.3)
Male	51,438 (55.2)	161 (37.7)
Race		
Asian	1,203 (1.3)	5 (1.2)
Black or African American	12,192 (13.1)	47 (11.0)
White	51,900 (55.7)	254 (59.5)
Other	3,506 (3.8)	14 (3.3)
Unknown	24,320 (26.1)	107 (25.1)
U.S. Census Bureau region†		
Northeast	9,372 (10.1)	23(5.4)
South	22,994 (24.7)	132 (30.9)
Midwest	46,243 (49.7)	186 (43.6)
West	14,497 (15.6)	86 (20.1)
Unknown	15 (—)	0 (—)
Obesity class§		
Class 1	55,073 (59.1)	73 (17.1)
Class 2 (severe obesity)	25,019 (26.9)	133 (31.1)
Class 3 (severe obesity)	13,029 (14.0)	221 (51.8)
Obesity medication¶		
None	—	0 (—)
Semaglutide (Wegovy)	—	244 (57.1)
Phentermine or phentermine-topiramate	—	161 (37.7)
Liraglutide (Saxenda)	—	51 (11.9)
Other (orlistat or setmelanotide)	—	14 (3.3)

Abbreviation: BMI = body mass index.

* Obesity was defined as BMI ≥95th percentile for age and sex.

† *Northeast*: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont; *Midwest*: Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Nebraska, North Dakota, Ohio, South Dakota, and Wisconsin; *South*: Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, and West Virginia; and *West*: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming.

§ Obesity classes: class 1 (BMI ≥95th percentile to <120% of the 95th percentile), class 2 (BMI of 120% to <140% of the 95th percentile), and class 3 (BMI ≥140% of the 95th percentile).

¶ More than one obesity medication could have been prescribed.

and liraglutide (regardless of indication) showed a slightly higher total prevalence (0.7% in 2023) (Supplementary Figure 1).

Characteristics of Adolescents Who Received Obesity Medication Prescriptions

In 2023, among 93,121 adolescents with obesity, a total of 38,048 (40.9%) had severe obesity, including 25,019 (26.9%) and 13,029 (14.0%) with class 2 and class 3 obesity, respectively. Among 427 adolescents with at least one obesity medication prescription in 2023, a total of 354 (82.9%) had severe obesity, including 133 (31.1%) and 221 (51.8%) with class 2 and class 3 obesity, respectively (Table).

In adjusted analyses, compared with referent populations (boys, adolescents aged 12–14 years, and residents of the Northeast region), adolescents were more likely to be prescribed obesity medications if they were girls (adjusted prevalence ratio [aPR] = 2.05; 95% CI = 1.69–2.49), aged 15–17 years (aPR = 2.24; 95% CI = 1.83–2.74) and lived in the West region (aPR = 2.65; 95% CI = 1.68–4.19), South region (aPR = 2.35; 95% CI = 1.51–3.65), or Midwest region (aPR = 1.58; 95% CI = 1.03–2.43) (Figure 2). Adolescents with class 2 obesity were more likely than those with class 1 to be prescribed obesity medications (aPR = 4.03; 95% CI = 3.03–5.36), as were those with class 3 obesity (aPR = 12.78; 95% CI = 9.82–16.64).

One half (50.0%) of Black adolescents with obesity in 2023 had severe obesity, compared with 39.0% of White adolescents (Supplementary Table). When the analysis was restricted to 12,192 Black adolescents and 51,900 White adolescents, Black adolescents were 39% less likely to be prescribed obesity medications than White adolescents (aPR = 0.61; 95% CI = 0.44–0.84) (Figure 2), despite being 27% more likely to have severe obesity (aPR = 1.27; 95% CI = 1.24–1.29) (Supplementary Figure 2).

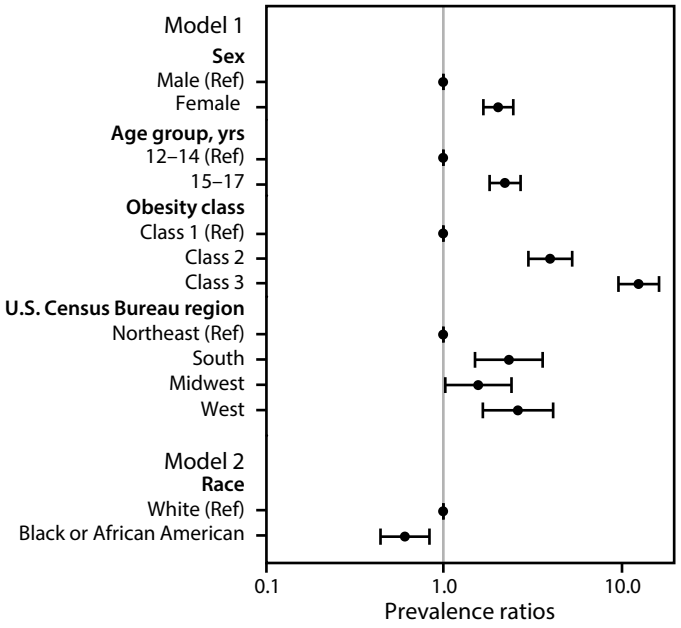
Discussion

This pharmacoepidemiologic study using a large ambulatory EMR database detected a substantial relative increase (approximately 300%) in the proportion of U.S. adolescents with obesity who were prescribed an obesity medication in 2023, which was the year after FDA expanded its approval of two obesity medications to include adolescents††† and after publication of the AAP clinical practice guideline in January 2023 (*1*). Despite this substantial relative increase, <1% of adolescents with obesity were prescribed an obesity medication in 2023, with a majority (83%) of prescriptions received by adolescents with severe obesity.

A recent study reporting prescriptions filled from 93.6% of U.S. retail pharmacies showed an approximate 500%–590% increase in the dispensing of GLP-1RAs to adolescents aged 12–17 years between 2020 and 2023 (*2*). This report, which focuses on prescribing of FDA-approved obesity medications, including 2 GLP-1RAs, for adolescents, demonstrated a lower but still substantial (approximately 300%) increase, indicating rising use of multiple classes of obesity medications. A recent

††† Food and Drug Administration. Wegovy Highlights of Prescribing Information; Food and Drug Administration. QSYMIA (phentermine and topiramate extended-release capsules for oral use) Highlights of Prescribing Information

FIGURE 2. Adjusted prevalence ratios* for receiving an obesity medication prescription among adolescents aged 12–17 years with obesity,† by selected demographic characteristics and obesity class§ — IQVIA Ambulatory Electronic Medical Records, United States, 2023



Abbreviations: BMI = body mass index; Ref = referent.

* 95% CIs indicated by bars.

† Obesity was defined as BMI ≥95th percentile for age and sex.

§ A generalized linear model with log link and binomial distribution (model 1) was used to estimate characteristics associated with the outcome of receiving an obesity medication prescription in 2023: age (12–14 years [Ref] and 15–17 years), sex (male [Ref], female), obesity class (class 1 [Ref], class 2, and class 3), and U.S. Census Bureau region (Northeast [Ref], South, Midwest, and West). Model 2 was restricted to adolescents who were Black or African American (Black) or White and included the same covariates as model 1, with an additional covariate of race (Black/White). Obesity classes were as follows: class 1 obesity or BMI ≥95th percentile to BMI <120% of the 95th percentile [Ref], class 2 obesity or BMI of 120% to <140% of the 95th percentile, and class 3 obesity or BMI ≥140% of the 95th percentile. Classes 2 and 3 represented severe obesity. Estimates of association from the model were expressed as adjusted prevalence ratios and plotted on a log(10) scale.

study also reported an increase in prescribing of FDA-approved and off-label medications among children and adolescents with obesity after publication of the AAP clinical practice guideline in 2023 (*3*). Given this increase in prescriptions, postmarketing monitoring is essential to track potential increases in unanticipated side effects or adverse events associated with the use of these medications (*4*). Because of recent GLP-1RA shortages, safety concerns also might arise for persons filling prescriptions with counterfeit medications or compounded medications (formulations that are created for specific patients or settings, rather than for commercial distribution, and that are not FDA approved); the safety, effectiveness, and quality of these products are not evaluated by FDA before dispensation to the patient (*5*).§§§ All adolescents with obesity, including those who receive obesity medications, should receive evidence-based health behavior and lifestyle interventions, which can help them and their families build skills that promote healthier nutrition, physical activity, and related behaviors; lower their health risk; and improve quality of life and self-esteem (*1*).¶¶¶ This study could not elicit data on whether adolescents were also receiving these recommended interventions. Public health and health care organizations might need to assess their capacity and readiness to provide these evidence-based interventions to the millions of U.S. children and families who need them.

Semaglutide indicated for persons aged ≥12 years with obesity (Wegovy) and phentermine or phentermine-topiramate were the most prescribed obesity medications in 2023. The oral administration, lower out-of-pocket costs, and more consistent availability of phentermine or phentermine-topiramate (compared with semaglutide, which is administered by weekly subcutaneous injections) might be factors in the increased use among adolescents in 2023 compared with previous years (*6*).

This study excluded medications that were not FDA approved for obesity treatment in adolescents but are often used off-label for this purpose (e.g., metformin, semaglutide [Ozempic], and liraglutide [Victoza], all indicated for persons with T2DM). A sensitivity analysis including semaglutide and liraglutide regardless of indication resulted in a slightly higher

Summary

What is already known about this topic?

Obesity medications are recommended as part of evidence-based, multicomponent treatment for obesity in adolescents. In 2022, the Food and Drug Administration expanded its approval of two obesity medications to include adolescents aged 12–17 years. In January 2023, the American Academy of Pediatrics released a new clinical practice guideline recommending that clinicians offer obesity medications for adolescents with obesity as an adjunct to health behavior and lifestyle treatment.

What is added by this report?

This pharmacoepidemiologic study using ambulatory electronic medical record data found that despite the increasing proportion of adolescents with obesity who were prescribed an obesity medication, <1% were prescribed one in 2023. Prescribing prevalence was higher among girls, White adolescents, those aged 15–17 years, and adolescents with severe obesity.

What are the implications for public health practice?

Continued monitoring of the use and safety of obesity medications could guide development and implementation of strategies to ensure that all adolescents have access to evidence-based obesity treatment, including medications and health behavior and lifestyle interventions.

§§§ Food and Drug Administration. FDA warns consumers not to use counterfeit Ozempic (semaglutide) found in U.S. drug supply chain; Food and Drug Administration. Human Drug Compounding Laws

¶¶¶ CDC. CDC-Recognized Family Healthy Weight Programs

prescription prevalence (0.7% in 2023). Future analyses could focus on medications prescribed off-label for obesity or for other conditions that also help with weight management.

The findings in this report indicate that health care providers tended to prescribe obesity medications to adolescents with severe obesity. Approximately 83% of adolescents who received an obesity medication prescription had severe obesity (class 2 or 3), including 52% with class 3 obesity. Higher obesity class is associated with increased cardiometabolic risk, lower health-related quality of life, and declines in physical function (*7*,*8*), which might prompt providers to prescribe obesity medications to this population.

Prescribing of obesity medications also differed by sex, race, and U.S. Census Bureau region. Girls were more likely than boys to be prescribed obesity medications. In addition, although the prevalence of severe obesity among Black adolescents was 27% higher than among White adolescents, Black adolescents were 39% less likely than White adolescents to receive an obesity medication prescription. Factors that might explain differences in prescribing or low prescription rates include limited availability of the medications because of production shortages (*9*), high out-of-pocket costs (*6*), and insurance restrictions, such as lack of coverage or complex prior authorization processes.**** In addition, concerns among adolescents and health care providers about long-term use and safety, as well as health care provider knowledge and self-efficacy in prescribing obesity medications, could impact prescription rates (*10*).

Limitations

The findings in this report are subject to at least five limitations. First, although this analysis included a geographically diverse sample of health care–seeking adolescents with measured height and weight, the sample was not representative of all U.S. adolescents; this analysis should be replicated with other datasets, particularly those that are population based. Second, although prescriptions documented in ambulatory EMR data were able to be tracked, some prescriptions might have been provided in outpatient visits that were not captured in this database. Third, although prescribing behaviors were tracked, information about whether the medications were dispensed or used was not available. Fourth, missing data on race and ethnicity limited the ability to examine differences in obesity medication prescribing. Finally, this analysis did not adjust for household income, insurance status, or other factors that might be associated with receiving an obesity medication prescription.

**** Institute for Clinical and Economic Review. Affordable Access to GLP-1 Obesity Medications: Strategies to Guide Market Action and Policy Solutions

Implications for Public Health Practice

Despite the increasing proportion of adolescents with obesity who were prescribed an obesity medication from 2018 to 2023, <1% were prescribed one in 2023. Continued monitoring of the use and safety of these medications in adolescents, as well as barriers to availability and access, could help guide the development and implementation of strategies to ensure that all adolescents have access to evidence-based obesity treatment, including medications and health behavior and lifestyle interventions.

Acknowledgment

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All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. Kao-Ping Chua reports institutional support from the National Institute on Drug Abuse and consulting fees from the U.S. Department of Justice. No other potential conflicts of interest were disclosed.

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Field Testing and Validation of a New Question Set to Measure Housing Status — Fulton County, Georgia, August–September 2023

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Abstract

Although data on housing status can guide health promotion and effective public health response, a validated question set to measure housing status is not available. In June 2023, the Fulton County Board of Health (FCBOH) requested CDC technical assistance to field test a housing status question set for public health case interviews and surveillance. The question set can be asked of any relevant period to determine both homelessness status and residence in a congregate setting. Field testing was performed at food pantries and FCBOH tuberculosis, vaccination, and sexual health clinics in Fulton County, Georgia, during August 2–September 1, 2023. Among 481 respondents who were asked about their living situation during the previous 2 weeks, 139 (28.9%) reported experiencing homelessness and 75 (15.6%) reported living in congregate settings. Twenty-six of these 481 respondents were identified in a local housing database (the Homeless Management Information System [HMIS]); for 24 of these 26 respondents (92%), the housing status recorded in HMIS matched that determined by the question set. The question set would benefit from validation in additional settings and could help health agencies improve housing data accuracy and consistency, optimizing measures to assist persons at higher risk.

Introduction

Homelessness and congregate setting residence are dimensions of housing status that are particularly important to public health surveillance and action. Persons experiencing homelessness and those living in congregate settings are at higher risk of morbidity and mortality than are those with individual housing (*1–3*). Housing status data can guide interventions to promote health and effectively respond to outbreaks (*4*). However, no question set to measure these aspects of housing status has been validated against an independent data source, an important step to ensure that collected data provides a reliable measure of housing status. In June 2023, the Fulton County Board of Health (FCBOH) requested CDC technical assistance to establish a validated housing status question set for public health case interviews and surveillance.

Methods

Using all combinations of one of the search terms "housing," "homeless," "homelessness," or "unhoused," and another of the search terms "questions," "questionnaire," "screening instrument," "screener," or "measurement," the following internet sites were searched in November 2022 for English-language measurement tools that have been used to determine housing status: U.S. Department of Housing and Urban Development (HUD), Veterans Administration, Centers for Medicare and Medicaid Services, Google Scholar, and PubMed. Partners and subject matter experts in housing and homelessness were also contacted to identify any additional tools. The search retrieved 21 tools, which were then reviewed to determine whether they had undergone validation, were aligned with HUD definitions (*5*) (for comparability with HUD data sources and alignment with federal support programs), and elicited sufficient information for public health use (e.g., ability to differentiate between sheltered and unsheltered homelessness and identify persons housed in a congregate setting).

One of the existing tools had undergone validation with an external data source,* none elicited sufficient detail to align with federal definitions of homelessness (*5,6*), and none met public health use case requirements (measurement of sheltered or unsheltered homelessness and congregate or noncongregate living situations). In response, a new question set was developed using an iterative process involving CDC subject matter experts, federal partners, local public health officials, service providers, and clinician–researchers to align with federal definitions and public health use case needs. The question set was also reviewed by CDC subject matter experts and persons with lived experiences of homelessness who serve on the consumer panel of a national partner organization.

Question Set

The question set (Supplementary Table) included three components that could be asked for any relevant period: 1) whether the respondent stayed in one place or several; 2) open-ended description of the places where the respondent stayed, which the interviewer then matched to a prespecified list; and 3) multiple-choice questions to clarify the housing type, such as whether the respondent's current arrangement was short- or long-term. Combined answers indicated whether a respondent was housed (i.e., had a fixed, regular, and adequate nighttime residence), was experiencing sheltered homelessness (i.e.,

* Informatics for Health: Connected Citizen-Led Wellness and Population Health | IOS Press

staying in emergency shelters, transitional housing programs, or safe havens), or was experiencing unsheltered homelessness (i.e., had a primary nighttime location that is not designated for sleeping accommodations [e.g., streets, passenger vehicles, or parks]). Answers also indicated whether a respondent was living in a congregate setting (i.e., facilities where a majority of persons are not related, living or staying overnight and using shared spaces [e.g., group homes, assisted living facilities, or correctional facilities]) (Box).

Questions prioritized brevity, with an intended average completion time of <2 minutes. The question set was not geographically specific (i.e., living situations not present or common in Fulton County such as "beach" or "boat" were included in the prespecified list).

Data Collection

During August 2–September 1, 2023, FCBOH field-tested the question set with CDC technical assistance at food pantries and FCBOH tuberculosis, vaccination, and sexual health clinics in Fulton County. To allow respondents to be matched across data sources to validate housing status data, the question set was embedded within a survey that included demographic information and other identifiers. Teams of two to three interviewers visited clinics each weekday during all operating hours. The number of participants recruited at clinic sites typically varied from 10 to 30; however, one data collection day yielded 78 participants. A team of five to six interviewers visited the food pantry during their 2 operational days per week, recruiting 50 and 35 participants on those 2 days; visits were then

BOX. Congregate setting and housing status determination based on housing categories field-tested by Fulton County Board of Health — Fulton County, Georgia, August–September 2023

Housed

Congregate Setting

- Residential facility for workers or students
- Correctional or detention facility*
- Facility that provides medical or behavioral health treatment*
- Group home or residential facility not provided by employer or school*
- Multiple†

Noncongregate Setting

- Private residence in a long-term arrangement
- Hotel or motel or vacation rental in a long-term arrangement
- Multiple§

Sheltered Homelessness

Congregate Setting

- Shelter or safe haven
- Correctional or detention facility¶
- Facility that provides medical or behavioral health treatment¶
- Group home or residential facility not provided by employer or school¶
- Multiple**

Noncongregate Setting

- Private residence in a short-term arrangement of ≤14 days††
- Hotel or motel or vacation rental in a short-term arrangement of ≤14 days††
- Multiple§§

BOX. (*Continued*) Congregate setting and housing status determination based on housing categories field-tested by Fulton County Board of Health — Fulton County, Georgia, August–September 2023

Unsheltered Homelessness

Congregate Setting

- Buildings with shared facilities not meant for human habitation
- Open air, part of an established encampment
- Multiple¶¶

Noncongregate Setting

- Structure not meant for human habitation
- Vehicle not meant for human habitation
- Open air, not part of an established encampment
- Multiple***

* If stay is ≥90 days regardless of previous situation, or if stay is <90 days and previous situation was not unsheltered homelessness, a shelter, or a safe haven.
† If one or more places is in a congregate setting and is not unsheltered, a shelter, or a safe haven.
§ If none of the places is a congregate setting and is not unsheltered, a shelter, or a safe haven.
¶ If stay is <90 days and previous situation was unsheltered homelessness, a shelter, or a safe haven.
** If one or more places is in a congregate setting and is a shelter or a safe haven.
†† A short-term arrangement is classified as sheltered homelessness only if no subsequent residence is identified (e.g., would not include a person who is currently traveling and has more permanent housing in place). This situation falls under Homelessness Category 2: Imminent Risk of Homelessness as defined by U.S. Housing and Urban Development under the McKinney-Vento Homeless Assistance Act As Amended by S.896 Homeless Emergency Assistance and Rapid Transition to Housing Act of 2009. CoC and ESG Homeless Eligibility - Category 2: Imminent Risk of Homelessness | HUD Exchange
§§ If one or more places is in a noncongregate setting and is a shelter or a safe haven.
¶¶ If one or more places is in a congregate setting and unsheltered.
*** If one or more places is in a noncongregate setting and unsheltered.

discontinued to avoid duplicate responses, because many clients returned weekly to the pantry. Respondents received a $10 gift card to their choice of a pharmacy or grocery store. The survey collected data on personal identifying information, demographic characteristics, and responses to the housing question set. Interviewers conducted the survey and then noted the respondent's engagement level and comfort with answering the questions (i.e., acceptability) and recorded any challenges with administering the survey. Both electronic and paper versions of the questions were tested. Interpretation services were available to all respondents, either by testing site personnel, an accompanying family member, or a CDC interpretation phone line with interpretation capabilities for 171 languages. Interview feasibility was determined by the ability to provide the question set to a wide range of clients without substantial difficulty. Interviewers recorded subjective impressions of respondent engagement with five options: 1) very hesitant or distracted, 2) somewhat hesitant or distracted, 3) neutral, 4) somewhat engaged and willing, and 5) fully engaged and willing to answer questions. This activity was reviewed by CDC, deemed not research, and was conducted consistent with applicable federal law and CDC policy.[†]

Validity Analysis

The internal validity assessment compared data gathered from respondents, recruited at the same time, who reported staying at the same. Surveys for these respondents were completed separately, and answers were later linked and compared. The local Homelessness Management Information System (HMIS) was used as an independent comparator to measure external validity (*7*). Despite low coverage of all persons experiencing homelessness (*8*), HMIS is the most comprehensive client-level data source for persons in the covered area who receive housing-associated program (e.g., rent vouchers, street outreach, and homeless shelters) or auxiliary (e.g., food support, laundry, or shower) services funded by HUD.

Survey respondents were included in the external validation analysis if 1) a service that the respondent received was recorded in HMIS as related to housing type (e.g., housing vouchers, homeless shelter stays, or outreach at an encampment), and 2) data in HMIS were within 2 weeks before the survey date or the most recent HMIS entry before the survey date was listed as stable housing, under the assumption that this housing status was accurate at the time of the survey. Survey and HMIS records were matched on full name and birth date, accounting for common typographical errors in manual entry fields (i.e., fuzzy matching[§]) to determine agreement in reported housing status between the two. Data analysis was conducted using SAS software (version 9.4; SAS Institute).

Results

Acceptability and Feasibility

A convenience sample of 481 respondents completed the survey (Table). Twenty-six surveys (5.4%) were conducted in a language other than English: Spanish (4.6%), Creole (0.4%), Korean (0.2%), and Mandarin (0.2%). Among 478 participants (three had missing observations), interviewers recorded that 99.2% were somewhat or completely engaged when answering the questions. Although some participants declined to answer certain personal information and demographic questions, no respondent declined to answer or expressed reservation about answering questions in the housing question set. One survey was not completed due to time; the participant was called for their clinical visit during survey completion.

Electronic (n = 20) and paper (n = 461) versions performed equally well in respondent engagement. Interviewers reported being initially uncertain when selecting from the prespecified list of housing types; once familiar with this list, their confidence increased.

During the 2 weeks before the survey, 331 (68.8%) respondents reported being housed and 139 (28.9%) experienced homelessness; housing determination was unclear for 11 (2.3%) respondents who were uncertain about the expected length of time of their current living arrangements. Among the 139 respondents experiencing homelessness, 56 (40.3%) were sheltered, 58 (41.7%) were unsheltered, and 25 (18.0%) had stayed in both sheltered and unsheltered locations. Among all respondents, 75 (15.6%) reported living in congregate settings (e.g., residential facility, shelter, or safe haven).

Validity Analysis

In the assessment of internal validity, among respondents staying together, 20 of 21 paired survey responses (95.2%) resulted in the same classification for housing and congregate residence status. Twenty-six respondents (5.4%) met inclusion criteria for the external validity analysis; these respondents collectively gave responses corresponding to 10 of the 14 housing types (Box). The housing status determined by the question set was consistent with the HMIS status for 24 of these respondents (92.2% concordance; 18 experiencing homelessness, and six housed). When responding to the questions, two respondents were recorded as housed in the most recent HMIS entry but reported at least one living situation meeting the definition of homelessness during the previous 2 weeks.

[†] 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

[§] Fuzzy matching is a data matching technique used to find approximate matches for strings, phrases, or words in a database when an exact match is not available.

TABLE. Characteristics of respondents in field testing of question set to measure housing status — Fulton County, Georgia, August–September 2023

Characteristic	No. (%)
Total	**481 (100)**
Age group, yrs	
18–29	70 (14.6)
30–39	138 (28.7)
40–49	96 (20.0)
50–59	82 (17.0)
60–69	71 (14.8)
≥70	19 (3.9)
Declined to answer	5 (1.0)
Race and ethnicity*	
American Indian or Alaska Native	18 (3.7)
Asian	8 (1.7)
Black or African American	382 (79.4)
Hawaiian or Pacific Islander	0
Hispanic, Latino, or of Spanish origin	55 (11.4)
White	52 (10.8)
No race provided†	6 (1.2)
Other	40 (8.3)
Sex§	
Female	201 (41.8)
Male	276 (57.4)
Other	4 (0.8)
Language in which survey was completed	
English	455 (94.6)
Creole, via family member interpreter	2 (0.4)
Korean, via phone line	1 (0.2)
Mandarin, via phone line	1 (0.2)
Spanish, via staff member interpreter	18 (3.8)
Spanish, via phone line	4 (0.8)
Survey site	
Tuberculosis, vaccination, and sexual health clinics	396 (82.3)
Food pantry	85 (17.7)
Engagement and willingness of the respondent¶	
Fully engaged and willing to answer questions	456 (95.4)
Somewhat engaged and willing	18 (3.8)
Neutral	1 (0.2)
Somewhat hesitant or distracted	2 (0.4)
Very hesitant or distracted	1 (0.2)
Missing**	3 (—)
Housing status	
Housed	331 (68.8)
Sheltered homelessness	56 (11.6)
Unsheltered homelessness	58 (12.1)
Both sheltered and unsheltered homelessness	25 (5.2)
Unclear	11 (2.3)
Living in a congregate setting?	
Yes	75 (15.6)
No	406 (84.4)

* Not mutually exclusive.
† Explicitly selected by the respondent.
§ Sex was self-reported at the time of the survey; four participants self-reported an identity other than male or female sex.
¶ Recorded by interviewer.
** Missing responses were not included in the denominator.

Summary

What is already known about this topic?

Housing status data can guide health promotion and effective public health responses. A validated tool to evaluate homelessness and congregate setting residency that aligns with federal definitions and distinguishes sheltered from unsheltered homelessness is not available.

What is added by this report?

A new question set to evaluate housing status was field-tested during August–September 2023 among a convenience sample of 481 respondents at food pantries and public health clinics in Fulton County, Georgia. Twenty-six of these respondents were identified in a local housing database; housing status determined by the question set was consistent with data in this database for 24 (92%) respondents, suggesting external validity of the question set.

What are the implications for public health practice?

This question set would benefit from validation in additional settings and could help health agencies improve housing data accuracy and consistency, optimizing measures to support persons facing homelessness or living in group settings and their communities.

Discussion

The housing status question set demonstrated acceptability, feasibility, and validity when field tested in Fulton County, Georgia. Among a small subset of respondents identified in a local HMIS, agreement between the tested question set and HMIS data was approximately 90%. However, future activities might try to confirm this external validity and expand assessment of the question set to other geographic populations. To increase feasibility, it is important that interviewers become familiar with the prespecified options for housing types and the names of local shelters and safe havens before use in the field. Data standards are necessary for meaningful exchange of health-related information between modern data systems; therefore, a corresponding data standard is needed for housing status. CDC is working with partners to develop such a standard for consideration by organizations overseeing standard data classes and elements used in systems across the United States, such as the U.S. Core Data for Interoperability.

Limitations

The findings in this report are subject to at least five limitations. First, question set acceptability, feasibility, and validity

might not generalize to other settings outside of Fulton County, Georgia. Second, the external validation analysis relied on the matching of survey data to HMIS, which was limited to approximately 5% of respondents. Errors in name and birth date in both data sets might have contributed to the low proportion of responses eligible for matching. Third, external validation analysis included responses corresponding to 10 of the 14 housing types; the same level of validity might not apply to the remaining types. Fourth, internal validation was restricted to respondents who cohabitated or lived in a congregate setting and might not be generalizable to those who live alone. Finally, although feasible and acceptable, integration of this question set into existing public health, social services, and clinical workflows and data systems might be a challenge because training is required to administer the question set effectively. This concern could be addressed through more user-friendly approaches such as those including a free-text interface with automated selection from the prespecified housing list (e.g., application of a large language model).

Implications for Public Health Practice

This question set provides the first approach to determining housing status shown to be externally valid for a small subpopulation of respondents; all respondents reported as unhoused in HMIS were determined to be unhoused by the question set. Thus, this tool might help health agencies and other organizations screen for homelessness. Standardized and accurate housing data allow public health practitioners to quickly and efficiently focus activities to assist groups at higher risk for adverse outcomes, particularly during a public health emergency. This tool might also be valuable in health care settings because housing status affects both individual and population health. Because data are increasingly integrated across systems, consistency in how information is collected and transmitted is an important component to optimization of data quality.

Acknowledgments

Fulton County Board of Health; Intown Cares; The MITRE Corporation; Mechelle Claridy; Adi Gundlapalli; Sarah Kriz; Gabriella Lamb; Shelley Lucas; Izraelle McKinnon; Xingran Weng.

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All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflicts of interest were disclosed.

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Missed Opportunities for Congenital Syphilis Prevention — Clark County, Nevada, 2017–2022

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Abstract

In 2022, Nevada ranked eighth in the United States in incidence of congenital syphilis, a disease that can lead to stillbirth, miscarriage, or neonatal death. Appropriate and timely screening of pregnant females for syphilis and treatment, when indicated, are crucial for preventing congenital syphilis. Southern Nevada Health District (Clark County) disease surveillance data for 2017–2022 were reviewed to identify females of reproductive age (aged 15–44 years) with confirmed or probable syphilis who had a liveborn or stillborn infant with congenital syphilis and to assess their receipt of prenatal care, syphilis testing and, when indicated, syphilis treatment. Clark County emergency department (ED) visit data were reviewed for these females to explore whether ED visits might represent an opportunity to screen pregnant females for syphilis. Among 195 females identified, 43.1% (84) reported receiving prenatal care during pregnancy. Over one half (57.4%) of the females had at least one ED encounter ≥30 days before delivery and had not yet received testing for syphilis at the time of the encounter; syphilis testing was performed at 68.4% of these encounters. Lack of prenatal care was a considerable barrier to timely testing and treatment in Clark County, Nevada. Encounters in nontraditional care settings, including but not limited to EDs, could provide an opportunity for syphilis screening of pregnant females who do not access prenatal care. If linked to timely treatment, such encounters might help prevent congenital syphilis.

Introduction

Cases of primary and secondary syphilis among females of reproductive age (aged 15–44 years) approximately tripled in the United States during 2018–2022.* Congenital syphilis can lead to stillbirth, miscarriage, or neonatal death, as well as blindness, deafness, developmental delay, and skeletal abnormalities among surviving infants (*1*). Screening for and treatment of syphilis at appropriate times during pregnancy has been indicated to prevent syphilis morbidity in pregnant females and prevent congenital syphilis (*1*,*2*). Missed opportunities for congenital syphilis prevention in the United States have been previously identified (*3*,*4*), with lack of timely testing and inadequate treatment during pregnancy contributing to 88% of congenital syphilis cases reported nationally in 2022 (*3*). In 2022, Nevada ranked eighth in the United States in rates of reported cases of primary and secondary syphilis and congenital syphilis. Clark County is the most populous county in Nevada. Surveillance data on syphilis cases identified in pregnant females during 2017–2022 were analyzed to identify missed opportunities for congenital syphilis prevention in Clark County.

Methods

Data Sources and Study Population

Two data sources were used: Southern Nevada Health District (SNHD) disease surveillance data and emergency department (ED) discharge diagnosis data from all hospitals in Clark County. Quarterly ED discharge data from hospitals and intermediate care facilities were obtained from the Center for Health Information Analysis.† Cases meeting the Council of State and Territorial Epidemiologists' syphilis case definition§ among females aged 15–44 years, and reported by electronic laboratory testing results to SNHD during 2017–2022, were included. Pregnancy status was obtained from surveillance data collected during standard disease investigation interviews. To identify associated congenital syphilis cases, a linkage was performed through a unique parent identification variable between mother and 1) stillborn infants with congenital syphilis and 2) liveborn infants who met surveillance criteria for confirmed and probable congenital syphilis. After linkage, the resultant matched dataset was de-identified before analysis.

Classification of Missed Opportunities for Congenital Syphilis Prevention

To identify potential missed opportunities for congenital syphilis prevention among mothers who delivered an infant with congenital syphilis, a cascading framework of missed prevention opportunities was applied. The cascading framework classified missed opportunities as follows: 1) no reported prenatal care during pregnancy, 2) prenatal care accessed <45 days before delivery, 3) prenatal care accessed ≥45 days before delivery with syphilis testing performed <45 days before

* STI Statistics | STI Statistics | CDC

† Nevada Healthcare Quarterly Reports (NHQR) (CHIA) - NRHP Reporting and Data

§ Syphilis (*Treponema pallidum*) 2018 Case Definition | CDC

delivery, and 4) prenatal care accessed and syphilis testing performed ≥45 days before delivery with treatment initiated <30 days before delivery. A median interval from diagnosis to treatment of 14 days that has been observed for other sexually transmitted infections (*5*) was factored into the definition for timely care.[¶] Timely care was defined as 45 days before delivery given the time required for the patient to seek care, have appropriate testing performed, receive laboratory results, and start appropriate treatment if recommended. If prenatal care was reported but date of first prenatal visit was not available, the date of first syphilis testing was considered the date of first prenatal care access. Syphilis testing performed outside of the prenatal care setting was also quantified.

Syphilis Testing During ED Encounters

Because ED visits that occurred during the woman's pregnancy could be an opportunity for mothers not accessing traditional prenatal care to be tested and treated, a fuzzy match[**] was performed between SNHD surveillance data and Clark County ED diagnosis data for all cases in which a woman delivered an infant with congenital syphilis. A possible opportunity for testing was defined as an encounter for care in the ED of a woman meeting the following criteria: pregnant at time of encounter, encounter ≥30 days before delivery, had possible syphilis at time of encounter based on surveillance staging,[††] and did not have previous syphilis testing documented in surveillance data on the date of the ED visit. To determine if pregnancy status was known at the time of ED encounter, ED diagnosis data were reviewed to identify *International Classification of Diseases, Tenth Revision* (ICD-10) codes associated with pregnancy (ICD-10 O00–O9A). This activity was reviewed by CDC, deemed not research, and was conducted consistent with applicable federal law and CDC policy.[§§]

Data Analysis

Rates of syphilis (all stages[¶¶]) among females aged 15–44 years during 2017–2022 were calculated and expressed as cases per 100,000 population. Descriptive characteristics were stratified by the presence or absence of linkage to a congenital syphilis case. Missed opportunities for prevention were reported as counts and percentages. Analyses were completed using RStudio (version 6.1; RStudio).

[¶] Timely care was defined as 45 days before delivery given the time required for patient to seek care, have appropriate testing performed, receive laboratory results, and start appropriate treatment if recommended.

[**] Fuzzy matching is a technique to link persons across data sources. Typically, this uses numerous fields which combine to make an approximate match, and for this analysis, a unique variable was created using letters from first name, last name, and digits from date of birth.

[††] Estimated incubation period based on surveillance staging assigned during investigation. Syphilis |Pocket Guide for Providers | CDC

[§§] 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.

[¶¶] Syphilis diagnoses of any stage (e.g., primary, secondary, early nonprimary nonsecondary, and syphilis of unknown duration or late) as defined by the Nationally Notifiable Diseases Surveillance System syphilis case definition were included.

Results

Syphilis Cases in Reproductive Aged and Pregnant Females

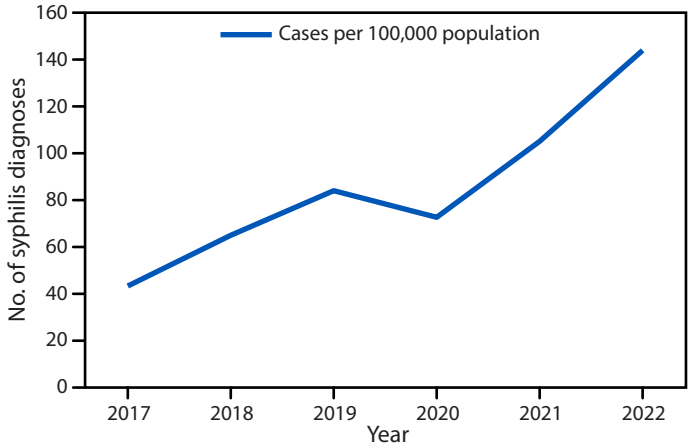
During 2017–2022 in Clark County, Nevada, the incidence of syphilis (all stages) among reproductive aged females increased from 43.1 to 143.9 per 100,000 population representing a relative increase of 333.9%[***] (Figure 1). During this period, 530 pregnant females received a syphilis diagnosis, 195 (36.8%) of whom delivered an infant with congenital syphilis (Table).

Missed Opportunities for Congenital Syphilis Prevention

Among 335 mothers with diagnosed syphilis whose pregnancy did not result in an identified case of congenital syphilis, most (85.4%) received prenatal care (Table). Among the 195 mothers who delivered an infant with congenital syphilis, 84 (43.1%) reported having received prenatal care during their pregnancy, with 21 (25.0%) initiating care in the first trimester, 24 (28.6%) in the second trimester, and 28 (33.3%) in the third trimester; information on trimester of prenatal care initiation was missing for 11 (13.1%) mothers. Among the

[***] Population estimate based on 2022 American Community Survey population data for Clark County, Nevada.

FIGURE 1. Syphilis diagnoses*,† among females of reproductive age§ — Clark County, Nevada, 2017–2022



* Syphilis diagnoses are for all stages.

† Syphilis diagnoses of any stage (e.g., primary, secondary, early nonprimary nonsecondary, and syphilis of unknown duration or late) as defined by the Nationally Notifiable Diseases Surveillance System syphilis case definition were included. Syphilis (*Treponema pallidum*) 2018 Case Definition | CDC

§ Females aged 15–44 years.

TABLE. Demographic and clinical characteristics of pregnant females who received a syphilis diagnosis,* by pregnancy outcome — Clark County, Nevada, 2017–2022

Characteristic	Delivered an infant with congenital syphilis, no. (%) n = 195	Did not deliver an infant with congenital syphilis, no. (%) n = 335
Age, yrs, mean (SD)	27.9 (5.7)	26.8 (5.7)
Race and ethnicity†		
American Indian or Alaskan native	1 (0.5)	2 (0.6)
Asian or Pacific Islander	0 (—)	12 (3.6)
Black or African American	81 (41.5)	154 (46.0)
Hispanic or Latino	39 (20.0)	83 (24.8)
White	66 (33.8)	72 (21.5)
Other/Multiracial	4 (2.1)	6 (1.8)
Unknown	4 (2.1)	6 (1.8)
Syphilis surveillance staging		
Primary or secondary syphilis	24 (12.3)	49 (14.6)
Early nonprimary nonsecondary	43 (22.1)	61 (18.2)
Unknown duration or late	130 (66.7)	225 (67.2)
Prenatal care accessed		
Yes	84 (43.1)	286 (85.4)
No	111 (56.9)	40 (11.9)
Unknown	0 (—)	9 (2.9)
Trimester prenatal care first accessed§		
First (wks 1–12)	21 (25.0)	—
Second (wks 13–28)	24 (28.6)	—
Third (wks 29–40)	28 (33.3)	—
Unknown	11 (13.1)	—

* Syphilis diagnoses of any stage (e.g., primary, secondary, early nonprimary nonsecondary, and syphilis of unknown duration or late) as defined by the Nationally Notifiable Diseases Surveillance System syphilis case definition were included. Syphilis (*Treponema pallidum*) 2018 Case Definition | CDC

† Persons of Hispanic or Latino (Hispanic) origin might be of any race but are categorized as Hispanic; all racial groups are non-Hispanic.

§ Trimester of first prenatal care access among those who accessed prenatal care was available only for pregnant females associated with a congenital syphilis case. Trimester of care data are collected as part of the congenital syphilis case investigation and are not captured in surveillance data for all pregnant females with a syphilis diagnosis.

84 mothers who delivered an infant with congenital syphilis and who reported accessing prenatal care, 49 (58.3%) reported accessing this care ≥45 days before delivery; 35 (71.4%) of these mothers received testing for syphilis ≥45 days before delivery, while the remaining 14 (28.6%) received late or no testing (Figure 2). Among the 35 (17.9%) mothers who delivered an infant with congenital syphilis and who accessed prenatal care and received testing for syphilis ≥45 days before delivery, 14 (40.0%) were treated with a recommended regimen for syphilis ≥30 days before delivery; the remainder were treated with a recommended regimen <30 days before delivery. Among those treated with a recommended regimen ≥30 days before delivery, seven (50.0%) had serologic data available to assess treatment response. All seven had serologic test results compatible with reinfection or treatment failure; five (71.4%) of these mothers were treated for syphilis in their first trimester of pregnancy and did not receive retesting until the time of delivery. Among the 111 mothers who delivered an infant with congenital syphilis and who did not report accessing prenatal care, 36 (32.4%) had syphilis testing documented before the health care encounter for delivery; for most (72.2%) of these mothers, testing was received <45 days before delivery. Of the 10 females who received testing >45 days before delivery, none received timely treatment.

Syphilis Testing During ED Encounters

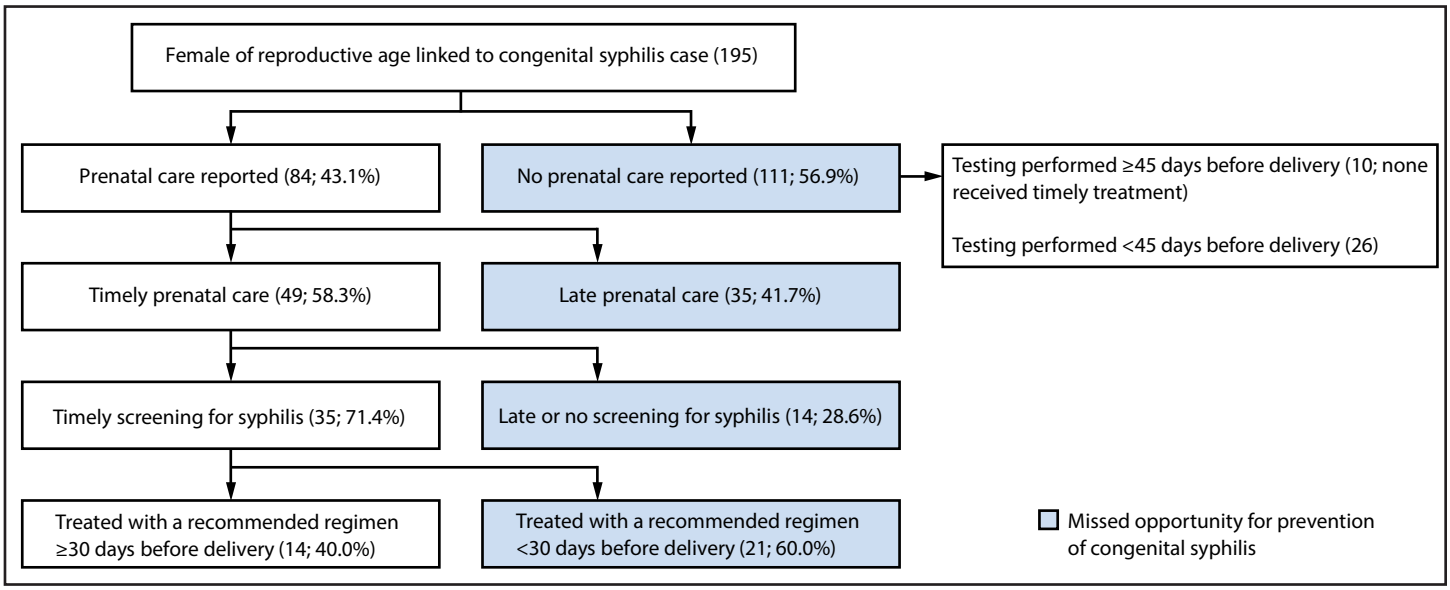
Among the 195 mothers who delivered an infant with congenital syphilis, 112 (57.4%) had one or more documented ED visit that met the defined criteria (pregnant at time of the encounter which occurred ≥30 days before delivery, had possible syphilis at time of the encounter based on surveillance staging, and did not receive previous syphilis testing documented in surveillance data on the date of the ED visit) as a possible opportunity for ED syphilis testing, 53 (47%) of whom reported not receiving prenatal care. Of the 112 females, 59 (53%) received testing during an ED visit. A total of 250 ED visits meeting the defined criteria were identified among these 112 females. Positive pregnancy status was documented in the ED medical record in 54 (21.6%) of these visits. Syphilis testing was performed at 171 (68.4%) of these visits.

Discussion

Lack of timely prenatal care was a considerable barrier to timely testing and treatment for syphilis during pregnancy and subsequent prevention of congenital syphilis in Clark County, Nevada, during 2017–2022. Since 2021, Nevada law has required that health care providers screen pregnant females for syphilis during their first prenatal visit, early in the third trimester of pregnancy (28–32 weeks gestational age), and at the time of delivery.††† However, not all pregnant females access traditional prenatal care. Providing testing in alternative settings for females who do not access prenatal care has been shown to improve timely identification and treatment of persons with syphilis during pregnancy (*4*,6–*8*) and might prevent congenital syphilis. For example, novel interventions have been piloted to increase syphilis screening among at-risk populations during ED encounters (e.g., providing routine screening of patients meeting defined criteria, with the option to "opt-out" based on patient declination or provider documentation that the patient is not a candidate for screening during the encounter) (*6*,*9*). In this analysis, approximately one half of mothers who delivered an infant with congenital syphilis had at least one ED visit that might have represented an opportunity for syphilis testing; however, testing was not

††† NRS: Chapter 442 – Maternal and Child Health; Abortion

FIGURE 2. Cascading framework of missed opportunities for congenital syphilis prevention — Clark County, Nevada, 2017–2022*,†,§



* Timely is defined as ≥45 days before delivery for prenatal care and screening and ≥30 days before delivery for initiation of appropriate treatment.
† Testing among females with no prenatal care reported included 26 females who received testing <45 days before delivery, but before health care encounter for delivery.
§ Females of reproductive age are those aged 15–44 years.

Summary

What is already known about this topic?

U.S. syphilis cases approximately tripled during 2018–2022. Congenital syphilis can result in severe infant morbidity and death but is preventable through appropriate screening and treatment of pregnant females.

What is added by this report?

During 2017–2022, in Clark County, Nevada, prenatal care was accessed by approximately one half of females who had an infant with congenital syphilis. Approximately one half of these mothers had an emergency department encounter during pregnancy that was a possible opportunity for timely testing; syphilis testing was performed at 68% of these encounters.

What are the implications for public health practice?

Lack of prenatal care was a barrier to timely syphilis testing and treatment. Encounters in nontraditional settings such as emergency departments could provide an opportunity for timely testing and, if linked to timely treatment, might help prevent congenital syphilis.

performed at approximately one third of these encounters. Further, approximately one third of mothers who delivered an infant with congenital syphilis and who did not access prenatal care received testing for syphilis during pregnancy, although testing occurred <45 days before delivery in approximately 70% of these cases, and none received timely treatment. These data suggest an opportunity might exist to improve prevention of congenital syphilis in Clark County by offering syphilis testing to reproductive-age persons during health care visits, including at EDs, and by ensuring linkage to appropriate treatment for those who receive a positive test result.

Limitations

The findings in this report are subject to at least four limitations. First, case data included in this analysis include only syphilis diagnoses reported in one county in Nevada, and findings might not be generalizable to all populations. However, surveillance data used for this analysis represent complete laboratory testing performed for Clark County residents, and Clark County constitutes the majority of syphilis morbidity in the state, representing approximately 78% of the primary and secondary syphilis cases reported in 2021. Second, surveillance data contain limited information regarding a number of individual- and community-level factors that could influence congenital syphilis prevention, such as access to prenatal care, lack of transportation, and health insurance status. Third, data were not available on the results of syphilis testing received in the ED or on treatment of those females who received positive test results. To prevent congenital syphilis, it is imperative that systems are in place to ensure that test results are reviewed and that females who received positive test results are linked to timely and appropriate treatment. Finally, the analysis did not include reasons for ED encounters, and the treating clinician might have determined that a patient was not a candidate for syphilis testing at a given encounter.

Implications for Public Health Practice

Lack of access to timely prenatal care was a major barrier to congenital syphilis prevention in Clark County, and efforts should be made to improve access to prenatal care. In addition, in high-prevalence settings such as Clark County, opt-out syphilis testing of females of reproductive age during any health-related encounter, such as at appropriate ED visits or in other nontraditional care-related settings, might increase timely testing of pregnant females who are unable or unlikely to access prenatal care. If systems are in place to ensure follow-up for timely and appropriate treatment of females who received positive test results, this approach could help prevent cases of congenital syphilis.

Acknowledgments

Staff members at the Southern Nevada Health District assisting with the project and for their work caring for the Clark County community; subject matter experts in the Division of STD Prevention, CDC.

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All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflicts of interest were disclosed.

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Notes from the Field

Public Health Response to Surveillance for Recent HIV Infections — Malawi, May 2024

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Despite Malawi's progress toward HIV epidemic control, an estimated 12,000 new HIV infections occurred in the country in 2023.* Surveillance for recent HIV infections (recent HIV infection surveillance) involves use of a recent infection testing algorithm that combines the result of a rapid test for recent infection with a viral load result to classify newly diagnosed HIV infections as recent (likely acquired during the past 12 months) or long-term (acquired >12 months ago) (*1*). Recent HIV infection surveillance enables detection of geographic areas associated with potential ongoing HIV acquisition (*2,3*). This report describes the public health response to a signal (i.e., the detection of a rate of recent HIV infection that is higher than expected) at a public health clinic in Malawi's southern region in May 2024.

Investigation and Outcomes

As part of routine recent HIV infection surveillance in Malawi, data collected during April–September 2023 were analyzed using spatial scan statistics, a method for detecting signals (clusters of health care facilities with rates of recent HIV infections that are statistically significantly higher than those expected due to random variation) (*3*). Rates of recent infection were calculated as the number of recent HIV infections per 100,000 persons at risk for HIV.† Among 289 facilities implementing recent HIV infection surveillance, 26 facilities were identified through eight signals with rates of recent HIV infections that were higher than expected; public health responses were initiated at all 26 facilities. This report details the response at one of two public health facilities in Malawi's southern region within a signal (expected recent HIV infection rate = 3.36 per 100,000; actual recent HIV infection rate = 16 per 100,000). These activities were reviewed by CDC, deemed not research, and were conducted consistent with applicable federal law and CDC policy.§

After verifying facility-level HIV testing and diagnosis data using nationally reported data, a multidisciplinary public health team, including governmental and nongovernmental interest holders and facility health care workers (HCWs), initiated response activities. Data were reviewed from seven predetermined program indicators included in the U.S. President's Emergency Plan for AIDS Relief Monitoring Evaluation and Reporting Database¶ (covering testing, prevention, and treatment programs during April 2022–September 2023) alongside site-level data to identify gaps in HIV service delivery.** Two focus groups including 19 community representatives used a semistructured interview guide to discuss the identified gaps. Community representatives included faith-based community leaders, shop owners, and leaders from HIV community groups. The program indicators, identified service gaps, and interview findings were summarized and presented to the multidisciplinary public health team, which developed recommendations and action plans to address the identified service gaps.

One service gap identified at the public health facility was that levels of viral load suppression†† among persons receiving antiretroviral therapy (ART) were consistently lower than the established target of ≥95%. This issue was particularly apparent among adolescents and young adults aged 15–19 years, whose viral load suppression range was 53%–59%. ART adherence is central to achieving viral load suppression. Although adherence to ART was not measured, barriers identified through qualitative interviews with interest holders included parental hesitancy to disclose HIV status to adolescents and young adults who had acquired HIV infection perinatally (*4,5*), inaccurate care and treatment information from faith-based community leaders, and a lack of privacy during ART adherence counseling.§§

* 2024 Data – Joint United Nations Programme on HIV/AIDS
† The number of recent HIV infections divided by the sum of the number of recent infections plus the total number of negative HIV test results multiplied by 100,000.
§ 45 C.F.R. part 46.102(l)(2), 21 C.F.R. part 56; 42 U.S.C. Sect. 241(d); 5 U.S.C. Sect. 552a; 44 U.S.C. Sect. 3501 et seq.
¶ Site-level monitoring evaluation and reporting indicators reviewed for the previous 18 months included 1) the number of persons who received HIV testing services and received their test results; 2) the number of persons aged ≥15 years who received HIV testing services and received a positive test result; 3) the number of persons who were identified and received testing using Index Testing Services (a voluntary service by which HCWs assist persons who receive a positive HIV test result with identifying sexual partners and biological children and adolescents and young adults aged <19 years at risk for HIV infection) and received their test results; 4) the number of persons newly enrolled for antiretroviral therapy (ART); 5) the number of persons receiving ART; 6) the percentage of persons receiving ART and who had a suppressed viral load result; and 7) the number of persons who were newly enrolled to receive preexposure prophylaxis to prevent HIV infection.
** Monitoring, Evaluation, and Reporting Indicator Reference Guide – U.S. President's Emergency Plan for AIDS Relief
†† A viral load test result of <1,000 copies of HIV per mL of blood.
§§ Consolidated Guidelines on HIV Prevention, Testing, Treatment, Service Delivery and Monitoring: Recommendations for a Public Health Approach – World Health Organization

Summary

What is already known about this topic?

Surveillance for recent HIV infections (i.e., recent HIV infection surveillance) classifies newly diagnosed infections as recent (acquired during the past 12 months) or long-term (acquired >12 months ago), allowing for potential identification of geographic areas with ongoing acquisition.

What is added by this report?

In Malawi, spatial analysis of surveillance data identified eight clusters of facilities with higher-than-expected recent HIV infections, prompting a facility-level public health evaluation and response. The public health response team used program data and semistructured interviews with community representatives to identify and address service delivery gaps, which included low viral load suppression levels among persons receiving HIV antiretroviral treatment and low rates of prescribing preexposure prophylaxis.

What are the implications for public health practice?

Combined with other data sources, recent HIV infection surveillance can identify opportunities for interest holder engagement and targeted interventions to enhance HIV programming and contribute to HIV/AIDS epidemic control.

A second identified service gap was stagnation at low levels in the number of preexposure prophylaxis (PrEP) prescriptions despite a general increase in availability of PrEP during the preceding 18 months. The number of persons newly initiated on PrEP fluctuated from 13 to 36 clients with no increase during the 18-month period. Semistructured interviews revealed that slow adoption of PrEP use might be attributed to HIV-related stigma, low awareness of PrEP availability in the community, and insufficient numbers of HCWs trained in PrEP provision. PrEP services had been relocated away from ART services in early 2023, in an effort to address HIV-associated stigma; however, this action and the continued availability of PrEP were not well communicated to the community.

Preliminary Conclusions and Actions

To increase levels of viral load suppression, the response team recommended enhanced adherence counseling,[¶¶] educating and involving faith-based community organization leaders in ART advocacy, and promoting HIV disclosure sessions among parents and adolescents. To improve adoption of PrEP, interest holders agreed to train more HCWs as PrEP providers, integrate PrEP provision at multiple service points, and conduct community awareness campaigns. This application of a public health response to recent HIV infection surveillance highlights one way to use timely surveillance data to identify service delivery gaps and contribute toward a goal of controlling the HIV/AIDS epidemic.

[¶¶] Enhanced adherence counseling includes a baseline individual needs assessment, adherence counseling and education sessions, and follow-up telephone calls.

Acknowledgments

Participants in Malawi who took part in recent HIV infection surveillance; HIV testing services providers at the public health response sites; district program coordinators; district health offices; Malawi National AIDS Commission; Malawi Ministry of Health leadership.

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All authors have completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflicts of interest were disclosed.

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ISSN: 0149-2195 (Print)