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Pivoting from in-person to phone survey assessment of alcohol and substance use: effects on representativeness in a United States prospective cohort of women living with and without HIV

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Author contributions

HRT, PCT, JCP, and YM contributed the original concept and design of the study. MCK, DLJ, LFC, AAA, AC, ALF, ABS, JD, AS, JCP, PCT were involved in data collection. YM and HRT performed data analysis and all authors interpreted the data. HRT drafted the manuscript. PCT and JCP are responsible for project supervision. All authors have critically revised this article and approved the final version to be published.

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Abstract

Background: Many clinical and population-based research studies pivoted from in-person assessments to phone-based surveys due to the COVID-19 pandemic. The impact of these transitions on survey response remains understudied, especially for people living with HIV. Given that there are gender-specific trends in alcohol and substance use, it is particularly important to capture these data for women.

Objective: Identify factors associated with responding to an alcohol and substance use phone survey administered during the COVID-19 pandemic in the Women's Interagency HIV Study, a multicenter US prospective cohort of women living with and without HIV.

Methods: We used multivariable logistic regression to assess for associations of pre-pandemic (April–September 2019) sociodemographic factors, HIV status, housing status, depressive symptoms, alcohol use, and substance use with response to an early-pandemic (August–September 2020) phone survey.

Results: Of 1,847 women who attended an in-person visit in 2019, 78% responded to a phone survey during the pandemic. The odds of responding were lower for women of Hispanic ethnicity (aOR 0.47 95% CI 0.33–0.66, ref=Black/African American) and those who reported substance use (aOR 0.63 95% CI 0.41–0.98). By contrast, the odds were higher for White women (aOR 1.64 95% CI 1.02–2.70, ref=Black/African American) and those with stable housing (aOR 1.74 95% CI 1.24–2.43).

Conclusions: Pivoting from an in-person to phone-administered alcohol and substance use survey may lead to underrepresentation of key subpopulations of women who are often neglected in substance use and HIV research. As remote survey methods become more common, investigators need to ensure that the study population is representative of the target population.

Keywords

COVID-19 pandemic; HIV; women; alcohol consumption; substance use; survey methods

Introduction

The COVID-19 pandemic led to unprecedented changes in the way clinical care and research are conducted in the United States (US). Early in the pandemic, many clinical research and population studies pivoted from in-person survey administration to phone-

based survey methods (1). The shift in survey methods offers an opportunity to examine the effect of rapidly adapting research study methods in the context of a widespread crisis as well as specific patterns in participant study engagement based on survey method.

Phone survey methods are convenient for collecting real-time data but have higher nonresponse rates than in-person visits, introducing a nonresponse selection bias if certain subgroups who are more or less likely to have the outcome do not respond (1,2). Survey nonresponse for alcohol and substance use has been described in studies prior to the COVID-19 pandemic and has variably resulted in biased prevalence estimates of alcohol and substance use related outcomes (3-10). Furthermore, self-reported alcohol consumption may vary by survey method. The National Alcohol Survey of 1990 found similar response rates between in-person and phone surveys. However, there was an underrepresentation of low-income participants and lower reported alcohol consumption quantities with phone surveys compared to in-person surveys (10). The 1985 National Household Survey on Drug Abuse also found lower reports of substance use by phone surveys compared to in-person surveys, especially among racial minorities (3). Since then, similar results have been replicated in other large epidemiology studies such as the National Survey on Drug Use and Health and the Canadian Addiction Survey (7,9).

Phone communication norms have shifted over the years with the decreasing use of landlines, and widespread use of cell phones, caller identification and text messages, creating an ongoing need to reevaluate phone survey modalities. Furthermore, widespread shifts in participant priorities due to economic insecurity, role strain, and health considerations early in the COVID-19 pandemic made data collection during this time period unique compared to pre-pandemic surveys. At the same time, substance use-related deaths and alcohol consumption have been increasing in the US, underscoring the importance of accurately estimating alcohol and substance use among at-risk subpopulations (11-14). This is particularly relevant for women, who may have been disproportionately impacted by the COVID-19 pandemic and had greater increases in alcohol consumption compared to men (12,13,15-18). However, the impact of changes from in-person assessments to phone survey methods on the response rate to alcohol and substance use questionnaires among women during the COVID-19 pandemic remains unexplored.

Leveraging data collected from the Women's Interagency HIV Study (WIHS), a multicenter US prospective cohort of adult women living with and without HIV, we aimed to 1) determine the response rate to an alcohol and substance use phone survey administered early in the COVID-19 pandemic among women recently engaged in in-person assessments; 2) identify sociodemographic and clinical factors associated with response to an alcohol and substance use phone survey; and 3) assess the impact of phone survey nonresponse on COVID-19 pandemic prevalence estimates of alcohol and substance use.

Materials and methods

Data source

Established in 1994, WIHS is the longest prospective cohort study of women living with and without HIV enrolled from 10 US sites (19). In 2019, WIHS merged with the MACS

(Multicenter AIDS Cohort Study), a long-standing cohort study of men living with and without HIV, to become the MACS/WIHS Combined Cohort Study (MWCCS) (20). At the time of the merger, 86% of participants from both cohorts had completed a visit within the previous year. There were 2,115 WIHS participants and the majority of participants had been enrolled for at least 5 years, as the last enrollment wave for WIHS was from 2011 to 2015. The WIHS is representative of women living with HIV in the US and also includes demographically similar women living without HIV for comparison. Recruitment, retention, and other study procedures are described in detail else-where (19-22). Briefly, women were recruited from a wide variety of venues including community-based organizations, support groups, substance use treatment programs, medical settings such as HIV and STI clinics, and other research studies. This was done primarily through flyers and word-of-mouth. Visits and phone surveys were conducted in English and Spanish, and participants were compensated. Study staff made multiple attempts to contact a participant. Contact methods (e.g., phone, text, e-mail) were site dependent and based upon preexisting modes of reaching participants for study visits. Data collection forms are available publicly (https://statepi.jhsph.edu/mwccs/). Clinical assessments and self-report surveys on medical, psychiatric, and social measures in WIHS were collected at in-person semiannual visits through February 2020. From April through September 2020, participants were invited to complete surveys by phone regarding COVID-19 symptoms, testing, and hospitalization, as well as mental health, alcohol, and substance use.

Ethics statement

The WIHS and now MWCCS are approved by the Institutional Review Board at each study site. Written consent was obtained from all participants. Participants were also verbally consented before proceeding with the phone survey.

Study sample

Women living with and without HIV who had a pre-pandemic visit from April 2019 through September 2019 and who remained enrolled in the study during 2020 were included. This pre-pandemic visit was considered the index visit for the current analysis. If index data were missing, data from the preceding visit (October 2018 to March 2019) were carried forward and only observations that ultimately had complete index data were retained in the analysis.

Alcohol and substance use measures

A survey on alcohol and substance use was conducted in-person at the index pre-pandemic visit and by phone during the pandemic from August to September 2020 (Table 1). In both instances, participants were asked questions adapted from the Alcohol Use Disorders Identification Test – Consumption (AUDIT-C), and responses were used to calculate the average number of drinks per week either since their last visit (during the pre-pandemic index visit) or since pandemic start (in the 2020 phone survey), respectively (23). Responses were used to assess risky drinking (>7 drinks/week or >3 drinks/day). Participants were also asked a single question about substance use since their last visit or the pandemic start for each substance (i.e., heroin, crack, cocaine, methamphetamine, sedatives, other non-prescribed drugs). Responses were dichotomized into any substance use versus none. Pandemic phone survey response was the primary study outcome. Participants were

considered “responders” or “nonresponders” based on whether they had available alcohol and substance use data for this survey.

Sociodemographic measures

Age, study site region, race/ethnicity, education, employment, health insurance, annual household income, housing status, HIV serostatus, depressive symptoms (20-item Center for Epidemiologic Studies Depression Scale [CES-D], range 0–60, score >16 indicative of depression) (24,25), tobacco use, and cannabis use were captured from the index visit. These variables were selected based on previously published and hypothesized associations with phone survey nonresponse and retention in clinical research studies among women living with HIV (5,7,9,21,22,26-29). Study site region (categorized as Midwest, Southeast, Northeast, West) was included due to potential differences in demographic and clinical characteristics as well as the varying impact of the COVID-19 pandemic and related policies in different regions across the US. Homelessness and unstable housing was broadly defined as staying outdoors, in a transitional setting, or staying with someone else.

Statistical analysis

Descriptive statistics were used to assess index demographics, clinical characteristics, and alcohol and substance use measures. Univariable and multivariable logistic regression models were used to identify factors associated with phone survey response. Inverse response probability weights (IRPW) generated from the multivariable logistic regression model were used to obtain nonresponse-adjusted estimates of risky drinking and substance use prevalence in the COVID-19 pandemic. These were compared to the estimates from the unweighted sample to assess for the presence of selection bias due to participant nonresponse. For example, if the weighted estimates were higher than the unweighted estimates it would indicate that the sample was biased due to lower response rates among those with greater alcohol or substance use. There were no extreme weights on visual assessment, so all observations were retained. RStudio version 1.4.1717 was used for the analysis (30).

Results

There were 1,968 women with an index pre-pandemic visit. Missing data included educational attainment (2.8%), employment (2.9%), health insurance (3.2%), annual household income (6.8%), housing status (2.8%), drinks per week (3.1%), tobacco use (3.1%), cannabis use (3.1%), substance use (3.1%), depression (3.4%). These data were imputed by carrying forward data from the visit prior. After excluding participants who still did not have complete index visit data, or who were no longer followed in the study, 1,847 women qualified for this analysis, of whom 1,433 (77.6%) responded to the pandemic alcohol and substance use phone survey (Figure 1).

The majority of participants were Black/African American (61.9%), had stable housing (88.2%), and were living with HIV (71.2%); nearly, half (46.0%) had an annual income <$12K (Table 2). The median age was 53 (IQR 46–59) years. Tobacco and cannabis use

were relatively common (39.5% and 23.5% respectively), while risky drinking and substance use were less common (12.7% and 7.4% respectively).

In univariable analysis, nearly all sociodemographic and clinical measures – except racial and ethnic groups, HIV serostatus, risky drinking, and cannabis use – had statistically significant associations with response to the pandemic alcohol and substance use phone survey (Table 3). In the adjusted model, the odds of responding were lower among women residing in the Western (aOR 0.35 95% CI: 0.21–0.57) and Southern (aOR 0.29 95% CI: 19–0.44) regions compared with Midwestern US regions; among women of Hispanic ethnicity (aOR 0.47 95% CI: 0.33–0.66, ref=Black/African American); and among those who reported pre-pandemic substance use (aOR 0.63 95% CI: 0.41–0.98) (Table 3). By contrast, the odds were higher for White women (aOR 1.64 95% CI: 1.02–2.70, ref=Black/African American) and those with stable housing (aOR 1.74 95% CI: 1.24–2.43). Unweighted versus IRPW prevalence estimates were 11.03% vs. 11.55% (standard error 0.89%) for risky drinking and 6.07% vs. 6.86% (standard error 0.73%) for substance use (Table 4). While the difference between the weighted and unweighted estimates of risky drinking represents a 4.77% increase, the unweighted estimate falls within the standard error of the weighted estimate. The difference between the weighted and unweighted estimates of substance use represents a 13.00% increase, with the unweighted estimate falling just outside of the standard error for the weighted estimate.

Discussion

The transition from in-person to remote survey methods in population and clinical research studies during the COVID-19 pandemic is an important opportunity for understanding the impact of rapid adaptations of remote research methods and to inform future best practices for study retention. Examining this question in a longitudinal cohort of socioeconomically disadvantaged US women living with and without HIV is critically important, because these women are underrepresented in research studies and may be more difficult to retain using traditional methods (32,33).

When we examined women from our cohort who were previously engaged in in-person assessments, over one-fifth did not respond to a phone-based alcohol and substance use survey. After adjusting for sociodemographic factors, HIV serostatus, and evidence of depression, we found that Black/African American and Hispanic women, those who were unstably housed or homeless, and women who reported pre-pandemic substance use had lower odds of responding to the phone survey. These findings raise concern that the transition to phone survey methods led to the underrepresentation of subgroups of women. Furthermore, these same subgroups were disproportionally burdened by COVID-19 illness and early pandemic policies, making data collection for these participants all the more important (34-36). Despite differences in survey response by sociodemographic and clinical subgroups, we found only small increases in prevalence estimates of risky drinking and substance use early in the COVID-19 pandemic after applying survey IRPW to the sample.

Our findings of differential survey response by sociodemographic factors and substance use are consistent with previous studies of survey nonresponse and study retention in both

alcohol and substance use research as well as more broadly in cohort studies of men and women (3,5,21,22,27,28,37). A WIHS analysis among participants observed from 1994 through 2006 found that in-person study visit nonattendance was associated with temporary housing, substance use, and study site (22). Our findings in the context of these earlier WIHS data raise additional concern that a switch to phone survey methods could exacerbate low engagement rates in vulnerable subgroups given that we only included participants who were already engaged in the cohort. General population surveys including the U.S. Census Bureau Current Population Survey Annual Social and Economic Supplement (29,38) and National Health Interview Survey (26) also found similar results to our study when they switched to phone survey methods in the pandemic.

Underlying factors that mediate the lower response rates in these subgroups remain understudied. Members of racial and ethnic minority groups are more likely to be essential workers, experienced disproportionate job loss in the pandemic, had higher COVID-19 related hospitalization rates, and often have a higher number of medical comorbidities, making the navigation of early COVID-19 pandemic changes even more challenging (36). These factors may have contributed to lower response rates among these subgroups. While some of these circumstances were unique to the COVID-19 pandemic, persistent factors that underpin these disparities such as multilevel racism and the social marginalization of people who use drugs and people experiencing homelessness could continue to influence survey response moving forward. In the MACS/WIHS, in-person visits were resumed later in 2020, so it is unknown if lower response rates among these subgroups have persisted beyond the early phase of the COVID-19 pandemic with the use of phone surveys.

The use of phone surveys in research will continue to grow, underscoring the need for best practices and additional or alternative retention methods for phone surveys that are tailored toward specific participant populations, especially those who have been underrepresented in research historically and often face worse social and health outcomes (33). Current best practices for retention in longitudinal cohort studies focus on in-person study assessments (39). Future research should expand on the role of phone retention interventions such as calling at different times of day, providing participants with cell phones, and ensuring participants save study phone numbers at enrollment so that an unrecognized number is not ignored (2,40-42). Furthermore, having contingencies for contacting participants is important for future periods of social disruption and crisis.

Tradeoffs in the use of phone surveys in clinical research should be considered in the context of study populations and participant preferences. In addition to avoiding disease transmission, phone surveys can facilitate real-time data collection and reach of subgroups who have difficulty attending in-person study visits, such as people in rural locations, those with full-time work schedules, or those without access to transportation or childcare (43). However, these methods may exclude participants who do not have access to a personal phone or a private space to participate in a phone call, which is especially important in the context of discussing sensitive matters such as substance use (44). In a survey of participants enrolled in clinical research studies at one medical center early in the COVID-19 pandemic, about one-fifth to two-fifths preferred participating in study visits over the phone or internet, while others were neutral or preferred in-person visits, highlighting diverse participant

preferences (31). In a discrete choice experiment of preferences for engaging in medical care early in the COVID-19 pandemic among PLWH who were experiencing homelessness/unstable housing, telehealth was not preferred to in-person visits even if patient navigation was available to help with technology barriers (45). Given that phone survey methods will continue to become more common, investigators should consider these tradeoffs, account for participant preferences, and try to mitigate the risk of selection bias.

After applying IRPW, we found small increases in the prevalence estimates of risky drinking and substance use that may be partially attributable to statistical imprecision and are therefore unlikely to have public health implications. However, true increases in alcohol and substance use among women living with HIV and their demographically similar peers could translate to important health and social consequences given that this population is already at greater risk for poor health outcomes. In the National Epidemiologic Survey on Alcohol and Related Conditions, where there were also no meaningful differences in prevalence estimates of alcohol use after adjusting for survey nonresponse (27). These findings contrast with previous studies such as the Canadian Addiction Survey, where there was a doubling of prevalence estimates for substance use after adjusting for nonresponse (9) and the Mental Health Surveillance Study, where there were differences in 53% of alcohol and substance use measures after applying response weights (7). The variability in these findings highlights the importance of testing missing data assumptions and assessing for bias in each data source.

Limitations

This study focuses on adult women in the US who are socioeconomically disadvantaged and have a high burden of medical comorbidities, limiting the generalizability of these findings. It is also limited to a single, early COVID-19 pandemic time point. The longitudinal nature of the WIHS introduces a selection bias toward response due to the participants' demonstrated history of ongoing engagement in research. Furthermore, we excluded those with missing data at the index visit, including alcohol and substance use data, which could result in an overestimation of response rates, but an underrepresentation of subgroups in the overall sample for this study. Due to the sensitive nature of alcohol and substance use, these measures are also subject to social desirability bias, which can lead to underestimated alcohol and substance use prevalence. There may be factors associated with phone survey response and our outcome measures that were not included in our adjusted analysis, leading to inaccurate weighted prevalence estimates of risky drinking and substance use. Furthermore, the factors in the analysis were derived from a pre-pandemic index visit and may have changed in relation to the pandemic (e.g., employment, income, and housing changes).

Conclusion

Among a sample of women living with and without HIV who previously attended in-person study visits, participants of Hispanic ethnicity (compared to Black/African American race) and those who reported pre-pandemic substance use had lower odds of responding to an alcohol and substance use phone survey administered early in the COVID-19 pandemic,

while those of White race (compared to Black/African American race) and those with stable housing had increased odds of responding, suggesting an underrepresentation of those most impacted by the COVID-19 pandemic. As remote survey methods become more common, best practices for using remote study methods are needed to ensure that data remain representative of the target population and investigators should assess for selection bias.

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Data availability statement

Access to individual-level data from the MWCCS may be obtained upon review and approval of a MWCCS concept sheet. Links and instructions for online concept sheet submission are on the study website (http://mwccs.org/).

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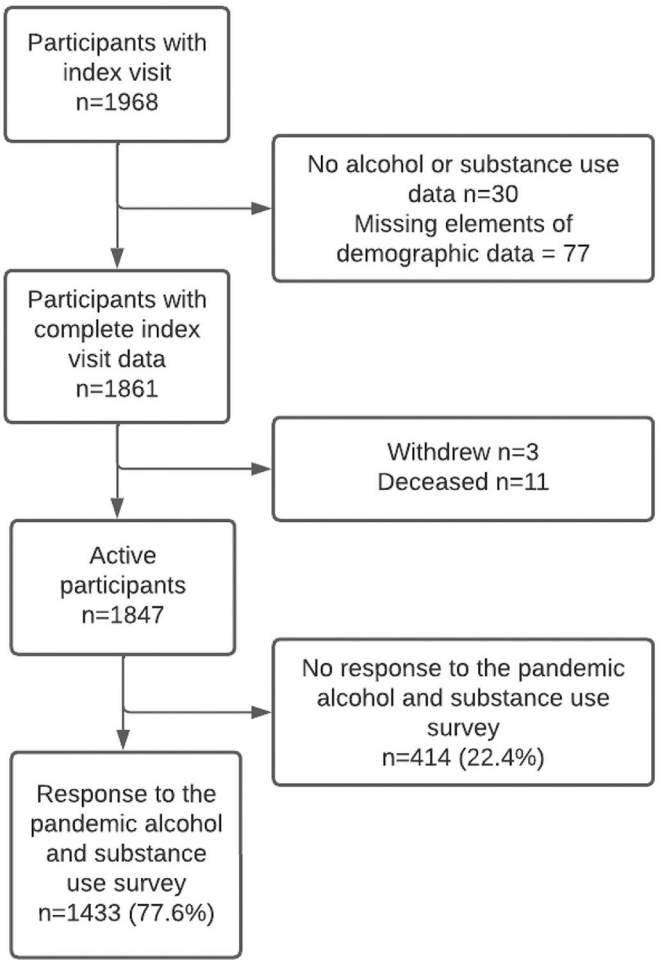

Figure 1.
Participant Flow Diagram.

Table 1.

COVID-19 pandemic data collection timepoints in the Women's Interagency HIV Study.

Measures	Pre-pandemic Index Visit (April-Sept 2019*)	Early Pandemic Timepoint (Aug-Sept 2020)
Study visit type	*Semiannual in-person visit*	*Telephone survey*
Sociodemographic	x	x
Clinical characteristics	x	x
Alcohol use	x	x
Substance use	x	x

* Data were obtained from a study visit that occurred between 10/2018–03/2019 when data for 04/2019–09/2019 visit were missing.

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Table 2.

Index visit sociodemographic and clinical factors for participants who did and did not respond to the alcohol and substance use phone survey early in the COVID-19 pandemic (August–September 2020).

	Total ***n*** **= 1847**	**Responders** ***n*** **= 1433 (77.6%)**	**Nonresponders** ***n*** **= 414 (22.4%)**
N (%)			
Age, years, median (IQR)	53 (46–59)	53 (47–60)	52 (44–57)
Region			
Northeast	772 (41.8)	678 (47.3)	94 (22.7)
South	612 (33.1)	398 (27.8)	214 (51.7)
Midwest	223 (12.1)	192 (13.4)	31 (7.5)
West	240 (13.0)	165 (11.5)	75 (18.1)
Race and Ethnicity			
Black/African American	1144 (61.9)	884 (61.7)	260 (62.8)
Hispanic	263 (14.2)	191 (13.3)	72 (17.4)
White	151 (8.2)	126 (8.8)	25 (6.0)
Multiracial	257 (13.9)	212 (14.8)	45 (10.9)
Other/Unknown	32 (1.7)	20 (1.4)	12 (2.9)
Educational attainment			
High school incomplete	606 (32.8)	451 (31.5)	155 (37.4)
High school complete	565 (30.6)	446 (31.1)	119 (28.7)
Some college or above	676 (36.6)	536 (37.4)	140 (33.8)
Employed	716 (38.8)	577 (40.3)	139 (33.6)
Health Insurance*	1777 (96.2)	1392 (97.1)	385 (93.0)
Annual household income			
<$12,000/year	850 (46.0)	633 (44.2)	217 (52.4)
$12,000–30,000/year	560 (30.3)	441 (30.8)	119 (28.7)
>$30,000/year	437 (23.7)	359 (25.1)	78 (18.8)
Stable Housing	1629 (88.2)	1296 (90.4)	333 (80.4)
HIV Positive	1315 (71.2)	1014 (70.8)	301 (72.7)
Number of drinks per week, mean (sd)	2.6 (7.5)	2.4 (7.2)	3.1 (8.7)
Risky drinking	234 (12.7)	175 (12.2)	59 (14.3)

	Total ***n* = 1847**	**Responders** ***n* = 1433 (77.6%)**	**Nonresponders** ***n* = 414 (22.4%)**
Tobacco use	730 (39.5)	535 (37.3)	195 (47.1)
Cannabis use	434 (23.5)	326 (22.7)	108 (26.1)
Substance use **	137 (7.4)	85 (5.9)	52 (12.6)
Depression (CESD ≥16 ***)	545 (29.5)	398 (27.8)	147 (35.5)

* Includes the Ryan White HIV/AIDS Program.

** Includes heroin, crack, cocaine, methamphetamine, sedatives, other non-prescribed drugs.

*** Center for Epidemiologic Studies Depression Scale (CESD), range 0–60, score > 16 suggestive of depression.

Table 3.

Logistic regression for response (vs. no response) to the alcohol and substance use phone survey early in the COVID-19 pandemic (August–September 2020).

	Unadjusted OR (95% CI)	*p*-value	Adjusted OR (95% CI)	*p*-value
Age, years	**1.02 (1.01–1.03)**	<.001	1.01 (1.00–1.03)	.066
Region				
Midwest	REF		REF	
Northeast	1.17 (0.74–1.78)	.494	1.20 (0.75–1.86)	.440
South	**0.30 (0.20–0.45)**	<.001	**0.29 (0.19–0.44)**	<.001
West	**0.36 (0.22–0.56)**	<.001	**0.35 (0.21–0.57)**	<.001
Race and Ethnicity				
Black/African American	REF		REF	
Hispanic	0.78 (0.58–1.06)	.110	**0.47 (0.33–0.66)**	<.001
White	1.48 (0.96–2.38)	.087	**1.64 (1.02–2.70)**	.046
Multiracial	1.39 (0.99–1.99)	.068	1.33 (0.92–1.94)	.138
Other/Unknown	0.49 (0.24–1.05)	.055	**0.41 (0.18–0.93)**	.028
Educational Attainment				
High school incomplete	REF		REF	
High school complete	1.29 (0.98–1.69)	.069	1.23 (0.92–1.66)	.164
Some college or above	**1.32 (1.01–1.71)**	.039	1.17 (0.86–1.58)	.321
Employed	**1.33 (1.06–1.68)**	.014	1.25 (0.93–1.67)	.140
Health Insurance*	**2.56 (1.56–4.15)**	<.001	1.66 (0.96–2.87)	.069
Annual household income				
<$12,000/year	REF		REF	
$12,000–30,000/year	1.27 (0.99–1.64)	.065	1.13 (0.85–1.50)	.416
>$30,000/year	**1.58 (1.19–2.12)**	.002	0.97 (0.67–1.39)	.852
Stable Housing	**2.30 (1.70–3.10)**	<.001	**1.74 (1.24–2.43)**	.001
HIV Positive	0.91 (0.71–1.16)	.442	0.79 (0.59–1.04)	.095
Number of drinks per week	0.99 (0.98–1.00)	.124	1.01 (0.99–1.02)	.309
Tobacco use	**0.67 (0.54–0.84)**	<.001	0.84 (0.65–1.09)	.186
Cannabis use	0.83 (0.65–1.08)	.159	1.09 (0.82–1.46)	.577

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	Unadjusted OR (95% CI)	*p*-value	Adjusted OR (95% CI)	*p*-value
Substance use**	**0.44 (0.31–0.64)**	<.001	**0.63 (0.41–0.98)**	.037
Depressive symptoms (CESD ≥16)***	**0.70 (0.55–0.88)**	.002	0 90 (0.70–1.17)	.425

Statistically significant values are bolded.

* Includes the Ryan White HIV/AIDS Program.

** Includes heroin, crack, cocaine, methamphetamine, sedatives, other non-prescribed drugs.

*** Center for Epidemiologic Studies Depression Scale (CESD), range 0–60, score > 16 suggestive of depression.

Table 4.

Weighted and unweighted prevalence of risky drinking and substance use early in the COVID-19 pandemic.

	Unweighted %	Weighted % (SE %)	Absolute Difference %	Relative Difference %
Risky Drinking	11.03	11.55 (0.89)	0.53	4.77
Substance Use	6.07	6.86 (0.73)	0.79	13.00