

Alcohol use among sexual minority women: Methods used and lessons learned in the 20-Year Chicago Health and Life Experiences of Women Study

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Abstract

Background: Two decades ago, there was almost no research on alcohol use among sexual minority women (SMW, e.g., lesbian, bisexual). Since then, a growing body of scientific literature documents substantial sexual orientation-related disparities in alcohol use and alcohol-related problems. Research has identified multiple risk factors associated with high-risk/hazardous drinking among SMW. However, this research has almost exclusively used cross-sectional designs, limiting the ability to draw conclusions about processes through which sexual minority status affects alcohol use. Longitudinal designs, although very rare in research on alcohol use among SMW, are important for testing mediational mechanisms and necessary to understanding how changes in social determinants impact alcohol use.

Aim: To describe the processes and lessons learned in conducting a 20-year longitudinal study focused on alcohol use among SMW.

Methods: The Chicago Health and Life Experiences of Women (CHLEW) study includes five waves of data collection (2000–present) with an age and racially/ethnically diverse sample of 815 SMW (ages 18–83) originally recruited in the Chicago Metropolitan Area in Illinois, a midwestern state in the United States (U.S.). Measures and focus have evolved over the course of the study.

Results: The CHLEW study is the longest-running and most comprehensive study of SMW's drinking in the U.S. or elsewhere. Findings reported in more than 50 published manuscripts have contributed to understanding variations in SMW's risk for hazardous/harmful drinking based on sexual identity, age, race/ethnicity, sex/gender of partner, and many other factors.

Conclusions: By describing the process used in conducting this long-term study, its major findings, and the lessons learned, we hope to encourage and support other researchers in conducting longitudinal research focused on SMW's health. Such research is critically important in understanding and ultimately eliminating sexual orientation-related health disparities.

Introduction

The Chicago Health and Life Experiences of Women (CHLEW) is the longest running, most comprehensive study of sexual minority women's (SMW, e.g., lesbian, bisexual) drinking and health worldwide. The CHLEW was initiated in the 1990s to address major gaps in the research literature.

Despite limited scientific evidence, in the 1980s and 1990s heavy drinking and drinking-related problems were viewed as prevalent among lesbian women (Finnegan & McNally, 1990; McKirnan & Peterson, 1989; Skinner, 1994). Although alcohol research among women in the general population increased dramatically during that time (Brady et al., 2009; Wilsnack & Wilsnack, 2013), lesbian women were largely ignored (Hughes & Wilsnack, 1994, 1997; Hughes et al., 2007a, 2007b, 2016). Epidemiologic studies of alcohol use rarely assessed sexual orientation, and sexual minority

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(SM) health surveys seldom assessed alcohol use. Although the AIDS crisis stimulated research on substance use among men who have sex with men (Hughes & Eliason, 2002; Institute of Medicine [IOM], 2011), few studies explored alcohol use among lesbian women or risk and protective factors associated with SMW's hazardous drinking (HD): a pattern of alcohol use that increases risk of harmful consequences (World Health Organization, 1994). Early studies of lesbian women's drinking were limited by many methodological problems including small nonrepresentative samples, lack of appropriate control/comparison groups, and inconsistent definitions of sexual orientation (IOM & Solarz, 1999).

Lesbian Women's Use of Alcohol

In the late 1990s and early 2000s researchers began using existing national data sets to estimate HD prevalence among lesbian women (Cochran & Mays, 2000; Gilman et al., 2001; Sandfort et al., 2001; Valanis et al., 2000). However, these studies used sexual behavior as a proxy for lesbian identity. The researchers found higher rates of current drinking, heavy drinking, and/or alcohol dependence symptoms among women who reported having had female partners than those reporting only male partners.

Beyond general agreement that lesbian women were at heightened risk for alcohol-related problems, few studies examined factors contributing to HD among lesbian women (Bloomfield, 1993; Heffernan, 1998; McKirnan & Peterson, 1989; Parks, 1999). Those studies that did, found that "cultural vulnerability" factors (e.g., bar orientation, drinking norms, minority stress) did not fully explain differences between lesbian and heterosexual women.

In 1997 a U.S. Institute of Medicine committee was convened to study lesbian health research. The committee's report (IOM & Solarz, 1999) highlighted large knowledge gaps and emphasized the need for longitudinal research to better understand the physical and mental health of lesbian women; substance abuse was highlighted as a key health issue. It was within this context that the CHLEW study was designed.

Methods

Study Design

The purpose of the baseline CHLEW (1999–2002) was to examine risk and protective factors for heavy drinking and drinking-related problems among lesbian-identified women. Following IOM recommendations, the study aimed to improve upon previous research by including a more diverse and representative sample and an appropriate comparison group, using a well-tested questionnaire, and collecting contact information to facilitate follow-up.

We designed CHLEW to replicate and extend the National Study of Health and Life Experiences of Women (NSHLEW), a 20-year longitudinal study (1981, 1986, 1991, 1996, 2001) of more than 1600 women in the U.S. general population (Wilsnack et al., 1984, 1991, 1998). Using the same measures in both studies allowed us to use age-

matched urban and suburban women from the NSHLEW as a comparison group in the first two waves of CHLEW.

CHLEW Wave 2 was funded in 2002 (2002–2007) and aimed to compare patterns of drinking (drinking levels, heavy episodic drinking [HED], intoxication), drinking consequences, and alcohol dependence symptoms in lesbian versus heterosexual women across age and racial/ethnic groups, and to examine changes in drinking patterns (and predictors of change) between data collected in Wave 1 and Wave 2.

In Wave 3 (2009–2015) we used cross-sectional and longitudinal data to model effects of cumulative stress on HD. Our research has shown that SMW's vulnerability begins with early risk factors, especially childhood sexual abuse (CSA; Hughes et al., 2001; Hughes et al., 2007), and continues with adult sexual or physical victimization (Hughes et al., 2001, 2010a, 2010b, 2014). SMW also experience chronic SM-related stressors, such as prejudice and discrimination. Wave 3 aimed to study the cumulative effects of multiple stressors on mental health (Pearlin et al., 2005) and understand how these stressors may result in HD as a coping mechanism (Johnson et al., 2013).

Waves 4 and 5 of the CHLEW (2016–2022) were designed to evaluate the impact of legalization of same-sex marriage on SMW's drinking and health and to examine the associations of long-term drinking trajectories with SMW's health (Wave 5 is currently in progress and we are just beginning to analyze data from Wave 4).

Study Instrument

In the NSHLEW, women's drinking patterns and consequences were posited to result from the direct and indirect effects of five sets of influences: (a) origins, upbringing, and early life experiences; (b) adult life experiences; (c) personality characteristics; (d) roles and relationships; and (e) expectancies about alcohol's effects. We considered these important in understanding lesbian women's drinking, but speculated some would operate differently (e.g., variables related to marriage/committed relationships). We also recognized the importance of including factors unique to lesbian women's lives and experiences.

The NSHLEW survey was designed in cooperation with the University of Chicago's National Opinion Research Center (NORC). The 80-page questionnaire included nearly 400 initial questions, with multiple follow-up questions for positive responses that permitted in-depth assessments of many early and later risk factors associated with women's drinking (Wilsnack & Wilsnack, 1995; Wilsnack, 1991). Measures used in the NSHLEW were selected, whenever possible, from instruments validated in previous research. The NSHLEW questionnaire was refined over time to retain measures with the highest reliability and validity. Questions were designed to maximize women's comfort and valid self-reporting of potentially sensitive behaviors. Interviewer probes were worded to avoid stigmatization of heavy drinking, and self-administered handouts (with privacy

envelopes) were used for sensitive questions such as adult sexual behaviors.

We closely replicated the NSHLEW instrument to allow comparisons between heterosexual women in the general population and lesbian women in CHLEW. In early 1996, we worked with NORC staff to conduct two pretests of the survey, in part to determine whether self- or interviewer-administration was more effective. In one session eight SMW were interviewed by NORC interviewers; seven others responded using a self-administered questionnaire. All 15 SMW then participated in one of two focus group interviews. The interviewer-administered method was preferred and more reliable than the self-administered method (Hughes et al., 2005). Based on pretest and focus group results, we added or revised several questions, including sexual orientation questions, to be more inclusive of lesbian women's experiences. These changes were also incorporated in NSHLEW Wave 5 (2001). Population-specific questions, such as sexual identity development benchmarks and sexual identity disclosure, were added to CHLEW. We conducted a full-scale pre-test in 1997–98 with 63 lesbian and 57 heterosexual women (Hughes et al., 2003, 2005; Hughes et al., 2001). We have conducted more limited pretests prior to each wave of the CHLEW study.

Study Measures

Across waves we dropped measures that had not proven useful. However, to permit longitudinal comparisons, we retained most drinking measures and measures of key risk and protective factors.

Sexual Orientation

In the late 1990s, health researchers were just beginning to consider sexual orientation an important variable (Sell & Becker, 2001). Like race/ethnicity and socioeconomic status (SES), sexual orientation is a complex construct—commonly defined as including behavioral, affective (attraction or desire), and cognitive (identity) dimensions. Although these dimensions are generally strongly correlated, they are not perfectly congruent (Geary et al., 2018; Talley et al., 2015). For example, women who have had same-sex partners do not uniformly identify as lesbian, and those who do may have both female and male sexual partners or not be sexually active.

The choice of which dimension(s) of sexual orientation to measure depends on the study purpose (IOM, 2011). In studies of sexually transmitted infections, sexual behavior is an obvious choice, but in research on health concerns for which societal stigma and discrimination play an important role, identity is more relevant (Hughes, 2011; Hughes, et al., 2015). We included questions about all three major dimensions of sexual orientation in both NSHLEW Wave 5 and CHLEW Wave 1. We also expanded the sexual orientation response options. For example, rather than asking women if they identified as heterosexual, lesbian, or bisexual, as many researchers continue to do, we included the intermediate responses of “mostly heterosexual” and “mostly lesbian.” Subsequent studies have demonstrated that substance use outcomes vary based on whether these

response options are included (Hughes et al., 2015, 2020; McCabe et al., 2012; Talley et al., 2016). The same sexual orientation questions have been asked at each wave.

Drinking Measures

As in the NSHLEW, we assessed participants' *drinking levels* using estimates of mean ounces of ethanol consumed per day. We combined information about drinking frequency and quantity, typical drink size, and ethanol content in the past 30 days, adjusting for frequency of HED. Light drinking was defined as 0.01–0.21 oz. ethanol/day (0.01–4.90g); moderate drinking as 0.22–0.99 oz. ethanol/day (5.0–22.9g); and heavier drinking as 1.00 or more oz. ethanol/day (23.0g or more). This drinking levels definition considered that a 12-ounce beer contains 4% ethanol, a 4-ounce glass of wine contains 15% ethanol, and a mixed drink contains 1 ounce of 45% ethanol liquor. HED in the NSHLEW and in the first three waves of CHLEW was assessed by asking about 12-month frequency of consuming six or more drinks per day. (The definition of HED or “binge” drinking changed over the course of the study. Binge drinking is now defined for women as four or more drinks on one occasion [National Institute on Alcohol Abuse and Alcoholism, 2020]). We also asked about 12-month frequency of *intoxication* (“drinking noticeably affected your thinking, talking, and behavior”). Measures of *drinking consequences* assessed lifetime and previous 12-month experiences of eight adverse drinking consequences (e.g., “driving a car while high from alcohol”). Examples of *symptoms of potential alcohol dependence* included blackouts, rapid drinking, and morning drinking. After Wave 3 we created a HD index of responses to four 12-month indicators: (a) HED, (b) intoxication, (c) adverse drinking consequences, and (d) symptoms of potential alcohol dependence (Riley et al., 2017). Other drinking measures (in all waves) include age of drinking onset, drinking contexts, drinking expectancies, and 30-day and 12-month quantity and frequency of partner's drinking. We asked participants in every CHLEW wave if they think they have/had a drinking problem, if they had sought help for a drinking problem, and if they are in recovery. We have retained most measures of drinking patterns, drinking problems, and major theoretical risk and protective factors across all waves.

Other Measures

In Wave 2 we added questions about current and early lesbian-specific drinking contexts, drinking norms, internalized homophobia, social support, and anti-gay workplace harassment. We omitted questions asked at baseline about early life experiences (e.g., childhood abuse, parental drinking problems) that did not need to be repeated. We also changed timeframes from lifetime or past five years to “since your previous interview” (with interview date specified) for many questions about adult experiences. In Wave 3, we added several new measures (e.g., lifetime changes in sexual identity, gender identity, legal relationship status and history, discrimination) and more comprehensive measures of posttraumatic stress disorder. Wave 4 added questions about perceived stress, coping, resilience, suicidality, family reactions to sexual identity disclosure, community connectedness, partners' race/ethnicity,

perceived impact of same-sex marriage legalization, and expanded measures of intimate partner aggression (IPA). In this wave we also conducted an online survey to gather additional contextual information about the perceived impacts of legalized same-sex marriage and the 2016 U.S. Presidential election (Riggle et al., 2020). In addition, Hughes and colleagues conducted a national online survey (Drabble et al., 2019; Riggle et al., 2018b; Veldhuis et al., 2018) and a qualitative interview study with 20 SMW (Riggle et al., 2018a) to further disentangle the potential contradictory impacts of legalized same-sex marriage and the election of a conservative governing party.

In Wave 5 we broadened the range of questions to include factors found in recent literature to influence drinking patterns and problems (e.g., emotion regulation, positive and negative affect, and perceived stress). Wave 5 asks a full battery of questions about IPA, including whether the participant experienced or perpetrated various forms of IPA. We abbreviated measures of depression and CSA and included fewer drinking-related questions. Because more SMW now identify as queer, pansexual, polyamorous, or asexual (Suen et al., 2020), we added open-ended questions to better understand our sample's sexual identity label preferences. As in Wave 4 we included an online survey in Wave 5. In March 2020 we added questions to the online survey about the impact of COVID-19 on participants' lives and well-being, and conducted a qualitative study about impacts of the pandemic using a diverse subgroup of 18 CHLEW participants (Bochicchio et al., 2021).

Recruitment, Retention and Description of the Study Sample

Minority sexual orientation is relatively rare in the general population (Laumann et al., 1994). Even large general population surveys seldom include enough SMW to permit reliable statistical estimation. To obtain a large sample, and to maximize sample diversity, we used a range of recruitment methods and sources. At Wave 1 we targeted clusters of social networks such as formal community organizations and informal social groups, particularly those that included women of color, older women, and women of lower SES groups underrepresented in studies of lesbian health. Interested women were asked to call the project office to complete a brief eligibility screening. In addition to questions about age (18+), residence (the Greater Chicago [Illinois] Metropolitan Area) and language (English proficiency), we asked "Do you consider yourself to be lesbian, bisexual, heterosexual, transgender, or something else?" (At the time it was customary to include transgender identity in the same question as sexual identity.) Because resources in Wave 1 limited the number of interviews, we excluded women who identified as bisexual, heterosexual, or transgender. Participants recruited in Wave 1 were 18–83 years old (37.5 years \pm 11.7). Fewer than half identified as non-Hispanic white and most identified as exclusively lesbian. Although we excluded women who identified as bisexual when screened for eligibility, during the Wave 1 interview 11 (2%) participants identified as such. The sample closely matched the racial/ethnic composition of adult females in Cook County, Illinois, where most participants lived (Chicago Fact Finder, 2002).

Wave 3 included a new supplemental sample recruited in 2010 to 2012. Based on an emerging literature showing that bisexual identity was at least as common as lesbian identity (Bostwick et al., 2010; Hughes et al., 2010) and that bisexual women were at greater risk than lesbian women of HD and other negative health behaviors (King et al., 2008; McCabe et al., 2009; Wilsnack et al., 2008), we added bisexual women in this wave. To increase their overall numbers, we added additional Black and Latinx women; we also added young women, ages 18–25. We made a concerted effort to recruit SMW with lower SES. This supplemental sample included 372 SMW of which 33% were ages 18–25, 37% identified as bisexual and 76% as racial/ethnic minority (Black/African American, Hispanic/Latinx, mixed or multi-racial). Demographic characteristics of the sample at each wave of the study are summarized in Table 1.

This supplemental sample was recruited using a modified version of respondent-driven sampling (RDS; Heckathorn, 1997, 2002). According to Heckathorn (2002), if referral chains are sufficiently long, the composition of the sample will be independent of the seeds that began the process. We contacted SMW-serving organizations in Chicago and asked for help identifying SMW with large social networks. SMW who served as initial seeds were invited to recruit women with the desired sample characteristics. They were given three serially numbered coupons with a study description and a toll-free telephone number to distribute. New recruits were in turn interviewed, given three coupons, and invited to recruit other SMW. Women received \$45 for participating and \$20 for each eligible recruit (up to three). To protect confidentiality, interviewers did not know who made the referrals; participants were paid the recruitment incentive when coupons were turned in but did not necessarily know which of their contacts participated in the study. This recruitment method was less successful than anticipated (Martin et al., 2015) and we eventually invited all women enrolled in CHLEW to recruit other SMW to participate. (See the Lessons Learned subsection below for more information.) We continued this process with each newly recruited participant.

Retention

Data for Wave 1 were collected from April 2000 to October 2001. This 18-month timeframe helped ensure a large racially/ethnically- and age-diverse sample. In Wave 2, interviews were completed between July 2003 and May 2005; most were completed in 2003–2004, but data collection was extended to locate and interview harder-to-reach participants. We retained 86% ($n=384$) of Wave 1 participants. For Wave 3 (May 2010–August 2012), we located and interviewed 79% of the Wave 1 sample ($n=354$). As in Wave 2, this extended timeframe allowed us to maximize retention and to standardize the timeframe between interviews for each participant. We retained four participants who transitioned to male gender between Waves 2 and 3 but excluded them in analyses. In Wave 4 (April 2017–July 2019) we retained 73% ($n=297$) of the original sample and 62% ($n=228$) of the supplemental sample. Fifty participants were confirmed deceased and 93 were lost to follow-up; 16 women declined to participate, and we removed three participants who suffered from dementia and

four who reported they had always identified as heterosexual. See Table 1 for sample sizes at Waves 1 to 4; Wave 5 data collection is currently in process.

To evaluate potential bias associated with attrition we examined 16 variables, including baseline sociodemographic variables, two major risk factors (CSA, depression), and drinking variables. Using stepwise logistic regression, we identified several predictors of retention (see Tables 3 and 4). Participants with higher education levels were more likely to be retained, as were those who reported a history of CSA at baseline. One or more drinking consequences in the last 12 months was associated with

attrition at Wave 2; however, participants who reported any lifetime problem drinking consequences were more likely retained. At Wave 3 baseline education and CSA history were again associated with retention, as was younger participant age, whereas children <18 living at home and any past 12-month alcohol dependence symptoms were negatively associated. At Wave 4, education, CSA, younger age, and higher baseline household income were associated with retention; having children <18 living at home was associated with attrition in the original sample. For the supplemental sample, education was positively associated with retention, and any PTSD symptoms were negatively associated.

Table 1

CHLEW sample demographic characteristics

CHLEW Study Wave	Wave 1 Original Sample (n=447)	Wave 2 Original Sample (n=384)	Wave 3 Original Sample (n=354)	Wave 3 New Sample (n=372)	Wave 4 Original Sample (n=297)	Wave 4 New Sample (n=228)	Wave 4 Total Sample (n=525)
Retention Rates	--	86%	79%	--	73%	62%	68%
Age							
18–24	14.5	5.6	0.0	32.7	0.0	0.2	0.2
25–30	17.0	12.5	5.1	24.9	0.0	9.9	9.9
31–40	28.6	24.8	26.6	16.8	12.1	43.0	25.5
41–50	23.3	24.2	27.1	14.1	30.3	13.6	23.0
51–60	14.3	14.3	24.3	9.2	29.0	10.1	20.8
61 or older	2.2	4.5	16.9	2.4	28.6	10.1	20.6
Race/Ethnicity							
AA/Black	27.5	25.0	27.1	44.1	24.9	38.3	30.7
Hispanic/Latinx	19.7	18.8	15.5	30.3	19.5	27.8	23.1
White	47.7	51.0	51.4	24.1	50.5	30.8	42.0
Biracial/Multiracial	5.1	5.2	5.9	1.6	5.1	3.1	4.2
Sexual Identity							
Only lesbian	70.5	68.8	62.2	48.1	61.6	37.7	51.2
Mostly lesbian	26.6	21.6	18.8	14.3	18.2	16.7	17.5
Bisexual	2.5	5.5	12.5	37.0	10.4	25.9	17.1
Mostly heterosexual	--	1.8	2.0	0.3	3.4	3.5	3.4
Only heterosexual	--	0.5	1.7	0.0	1.3	2.2	1.7
Asexual	--	--	0.0	0.0	0.7	0.0	0.4
Other	0.4	1.8	1.7	0.3	4.4	14.0	8.6
Educational Level							
Less than HS	2.9	1.3	0.6	14.6	0.3	7.0	3.2
High school	10.7	7.3	6.8	17.0	5.1	12.8	8.4
Some college	30.2	26.0	21.5	40.3	19.5	32.6	25.1
Bachelors	26.4	29.7	27.2	16.2	26.3	23.3	25.0
Graduate degree	29.8	35.7	43.9	11.9	48.8	24.2	38.2
Household Income							
Less than \$15,000	19.3	10.5	10.3	44.3	6.9	19.0	14.3
\$15-\$29,999	16.1	14.4	11.2	14.5	7.9	23.1	14.1
\$30-\$49,999	25.9	25.2	17.0	20.6	15.1	17.2	15.6
\$50-\$99,999	26.3	34.4	31.9	16.6	32.3	26.2	28.9
\$100,000 or more	12.5	15.5	20.6	4.1	37.8	14.5	27.1
Relationship Status^a							
Not living together	22.0	16.8	15.1	29.3	11.5	15.4	13.1
Living together /married	47.0	52.4	49.1	29.6	54.7	39.5	48.0
Separated	0.7	3.1	7.1	2.2	2.4	5.7	3.1
Divorced	4.5	--	--	--	--	--	--
Not in committed relationship	5.7	27.7	27.6	38.3	30.4	38.2	33.7
Never married	19.5	--	--	--	--	--	--
Widowed	0.5	--	1.1	0.5	1.0	1.3	1.1
Children < 18 yrs. living in home	19.1	19.0	19.6	20.3	16.8	21.3	18.9

Notes: Four original sample participants identified as transgender in Wave 3; all identified as sexual minority.

^aRelationship status categories are not mutually exclusive.

Data Collection

For each study wave, we conducted 2-day training sessions with a diverse group of five or six female interviewers shortly before data collection. Wave 1 training was conducted by NORC staff, the project manager, and Drs. Hughes and Wilsnack. All subsequent trainings were conducted by members of the research team. Trainings included self-study materials covering interview content, exercises to increase sensitivity to SMW and other stigmatized populations, and completion of several mock interviews. Although we moved from paper-pencil interviewing in Wave 1 to computer-assisted interviewing in Waves 2 to 5, and from in-person interviews in Waves 1 to 3 to telephone interviews in Waves 4 to 5, the same content was covered in trainings for all study waves.

In Wave 1, participants responded to some questions (e.g., sexual behavior) in a self-administered handout that they completed privately, inserted into an envelope, sealed, and returned to the interviewer. In Waves 2 to 3 participants interviewed in person were handed the laptop computer for the self-administered section. For phone interviews this section was mailed to participants who completed and returned it by mail. Waves 4 and 5 did not include self-administered handouts. Instead (to reduce respondent burden from lengthy phone interviews) participants completed a separate, online survey that included the more sensitive questions as well as a number of other questions. See Table 2 for dates and modes of data collection.

Informed Consent

At each study wave, following a review of the study’s purpose, participants were instructed to read, ask any questions, and sign a consent form approved by the University of Illinois at Chicago (UIC) Institutional Review Board. Because the CHLEW PI moved from UIC to Columbia University, Waves 4 and 5 were also reviewed and approved by that institution’s Institutional Review Board.

Changes in Modes of Data Collection

In Wave 1 all participants were interviewed face-to-face in a private setting. In Wave 2 we followed the same procedures as in Wave 1 except we switched from paper and pencil data collection to computer-assisted personal interviewing (CAPI). Advantages of CAPI include: (a) preventing interviewers from incorrectly skipping; (b) preventing inadmissible responses; and (c) reducing data entry errors and (d) data processing time (Bradburn et al., 1991).

Between Waves 1 and 3, 102 participants moved from the Chicago area, requiring many Wave 3 interviews to be conducted by telephone. Other additional interviews were conducted by phone because of scheduling difficulties or participant preference. To assess potential mode effects, we compared self-reports of alcohol and drug use among participants interviewed in person with those interviewed by telephone. Although women interviewed by telephone were less likely to report use of cocaine, we found no differences in any of the HD outcomes. These findings were consistent with assessments of the 1990 and 2000 National Alcohol Surveys (Greenfield, 2000; Midanik & Greenfield, 2008). By Wave 4, 180 participants had moved outside the Chicago area. Given participant mobility and the costs of in-person interviewing, we transitioned fully to computer-assisted telephone interviewing (CATI) in Waves 4 and 5. Our finding of limited mode effects in Wave 3 indicated that this would not significantly influence self-report on key measures.

Across all waves interviews have lasted 90 minutes on average. Interview length has generally not been a problem in our surveys (rather, many participants have expressed appreciation for the opportunity to talk about their life experiences). Although potentially sensitive questions are asked, few participants have become upset and nearly all have answered all questions.

Table 2

Dates, modes of data collection, and number of questions

	Wave 1	Wave 2	Wave 3	Wave 4	Wave 4 online supplemental survey
Field dates	April 2000 to October 2001	July 2003 to May 2005	May 2010 to August 2012	April 2017 to July 2019	April 2017 to July 2019
Mode(s) of data collection	PAPI	CAPI	CAPI	CATI	Online self- administered Qualtrics survey
Number of Questions	355 (poss. 1006 with follow-up)	417 (poss. 1300)	Original sample 426 (poss. 1750) RDS sample 447 (poss. 1914)	467 (poss. 785)	12 open-ended 59 close-ended

Note: PAPI - paper and pencil in-person interview; CAPI - computer assisted in person interview; CATI – computer-assisted telephone interview. Number of follow-up questions substantially fewer for participants who reported not having consumed alcohol in the previous 12 months. Single participants asked 1–25 fewer questions, depending on survey wave.

Results

The 20-year CHLEW has produced a wealth of findings (see [Appendix 1](#) for a summary of 56 publications) and is a valuable resource for examining mechanisms underlying SMW's heightened risk of HD. The study's large subsamples of women over 50 years old, and of Black, Hispanic/Latinx, and bisexual women, provide rare opportunities to examine the impact of age, race/ethnicity, and sexual identity—and their intersections—on relationships between risk and protective factors and HD. Below we provide brief summaries of key findings from a few of our published papers.

Comparisons of Drinking across Sexual Identity Groups

In a combined sample of women ages 21–70 in CHLEW Wave 1 (2000–2001) and NSHLEW Wave 5 (2001) we compared rates of HD (HED, intoxication, drinking-related problems, alcohol-dependence symptoms) across exclusively heterosexual, mostly heterosexual, bisexual, mostly lesbian, and exclusively lesbian subgroups. Exclusively heterosexual women had lower rates than all other groups on all measures of HD. Exclusively heterosexual women also reported less childhood sexual abuse, early alcohol use, and depression. Bisexual women reported more HD indicators and depression than did exclusively or mostly lesbian women (Wilsnack et al., 2008).

Victimization

To understand how differences in sexual identity and victimization experiences influence risk of HD and depression we pooled data from CHLEW Wave 1 and NSHLEW Wave 5 to compare rates of victimization, HD, and depression across five sexual identity subgroups. Rates varied substantially by sexual identity, with bisexual and mostly heterosexual women showing significantly higher risk than exclusively heterosexual women on one or both of the study outcomes. The number of victimization experiences explained some, but not all, of the risk of HD and depression among SMW, suggesting that other factors, such as stigma and discrimination, likely play a role in HD and mental health disparities among SMW (Hughes et al., 2014).

Models of HD

Using data from the first two waves of CHLEW we tested models that included HD, depression, and anxiety along with early risk factors and unique social stressors experienced by SMW. Consistent with a self-medication process, anxiety was prospectively associated with HD. And, consistent with an impaired functioning process, HD was prospectively associated with depression. These findings support a life course perspective that interprets the mental health of adult SMW as influenced by adverse childhood experiences, age at drinking onset, first heterosexual intercourse, and first sexual identity disclosure, as well as by processes associated with self-medication and impaired functioning during adulthood (Johnson et al., 2013).

Changing Sexual Identities

Although a good deal has been written about fluidity of women's sexual orientation (Diamond, 2016; Mereish et al., 2017; Ott et al., 2011), the dearth of prospective studies limits relevant empirical evidence. In the CHLEW 26% of the sample reported a sexual identity change between Wave 1 and Wave 2, and 25% reported a change between Waves 2 and 3. Women who reported a change also reported more depressive symptoms subsequent to identity change. This effect was moderated by the length of time participants had identified in a particular way and whether they had initiated a romantic relationship with a male partner (Everett et al., 2016b).

Drinking, Aging and Health

There is ample evidence that self-perceptions of mental and physical health are important predictors of health outcomes and well-being, particularly among older adults. We examined associations among age, drinking, and self-rated mental and physical health in CHLEW Wave 3 (Veldhuis et al., 2017). Heavy drinking among older adult SMW (55+) was less prevalent than among those ages 18–39, but similar to rates among SMW ages 40–54. In addition, older SMW reported significantly better mental health than SMW in the younger age groups, but we found no significant associations between age and self-rated physical health. Across all age groups, moderate drinkers reported better self-rated physical health than alcohol abstainers. These results suggest that drinking does not decline as sharply with age among SMW as among women in general population surveys.

Risk of Mortality

Forty-nine of CHLEW participants recruited in 2000–01 or 2010–12 (6.3% of the sample) were confirmed dead by 2019. The mean age at death was 56.5 years. Adjusting for key sociodemographic, SM stress, and health variables (e.g., race/ethnicity, education, HD, smoking, depression, internalized homophobia), we found that level of sexual identity disclosure was the most robust predictor of mortality. SMW who had disclosed their sexual identity to 100% of their immediate family members had a 70% lower risk of mortality than SMW who disclosed to less than one-third of their immediate family. These results suggest that facilitating family acceptance of SMW may have important implications for health and life expectancy among SMW (Everett et al., 2021).

Drinking Trajectories

We recently examined adult role acquisitions and exposure to SM stress as predictors of latent trajectories of HD in Waves 1 to 3. SMW who transitioned to parenthood were less likely to show persistent elevated risk of HED and less likely to report HED beyond young adulthood. Consistent with minority stress theory, SMW who reported higher levels of perceived SM stigma, and those who reported higher levels of masculinity showed persistently elevated risk of alcohol dependence (Talley et al., in review).

Impact of Supportive Policies

In Wave 3 we conducted a quasi-experiment to test the impact of the Illinois Civil Unions Bill (which provided some, but not all, of the rights afforded by marriage). We compared minority stressors, mental health, and HD among SMW interviewed before the Bill passed in late 2010; after passing, but before signed into law; and after signed into law in June 2012. Civil union legislation was associated with lower levels of stigma consciousness, perceived discrimination, depressive symptoms, and HD among all SMW in CHLEW. For several other outcomes, the benefits of this supportive policy were largely concentrated among racial/ethnic minorities and those with lower education levels. These results suggest that policies supportive of SM civil rights may be most beneficial for women with multiple marginalized statuses (Everett et al., 2016a).

Table 3

Results of stepwise logistic regression to predict original sample panel retention (1=yes; 0=no) at Waves 2 to 4 using Wave 1 baseline variables.

	Wave 2	Wave 3	Wave 4
Socio-demographics			
Respondent education	2.03 (1.51-2.73)***	1.60 (1.27-2.03)***	1.36 (1.08-1.70)**
Respondent age	--	0.97 (0.95-0.99)**	0.96 (0.94-0.98)***
Children <18 at home (Wave 1)	--	0.38 (0.21-0.68)***	0.57 (0.34-0.96)*
Household income (Wave 1)	--	--	1.06 (1.02-1.11)**
Alcohol use			
Any past 12-month alcohol dependence symptoms (Wave 1)	--	0.40 (0.22-0.72)**	--
Any past 12-month problem consequences (Wave 1)	0.20 (0.09-0.45)***	--	--
Ever any problem consequences (Wave 1)	2.39 (1.07-5.34)*	--	--
Other risk factors			
Felt sexually abused when growing up (Wave 1)	2.86 (1.34-6.08)**	2.66 (1.44-4.94)**	1.66 (1.03-2.68)*
Nagelkerke R-square	0.20	0.15	0.12
(n)	(423)	(423)	(423)

* $p < .05$; ** $p < .01$; *** $p < .001$

Lessons Learned

Recruitment and Retention

In conducting a longitudinal study over more than 20 years with a marginalized population group, we have learned a great deal. First, recruitment and retention are challenging, especially when the sample is as diverse as CHLEW's. Community involvement and relationship building are key. As a member of the SMW community, Dr. Hughes deeply engaged with various community organizations that serve SMW in Chicago. This "insider" position assists in gaining

Generalizability of Findings

Using data from the U.S. National Alcohol Survey (NAS), a probability sample, and CHLEW Wave 3, we compared findings related to HD, drug use, and depression. Regardless of sample type, we found significantly greater odds among SMW than heterosexual women in 21 of 23 comparisons (12 with the full sample and 11 with drinkers only). Odds of HD were elevated in the NAS SMW sample relative to heterosexual women, but differences did not reach significance. Findings suggest that high levels of HD, drug use, and depression found in non-probability samples of sexual minorities are not artifacts of the sampling method (Drabble et al., 2018).

See [Appendix 1](#) for key findings from all CHLEW publications to date

the trust of gatekeepers and potential study participants. We strive to include interviewers who are SMW of various ages and racial/ethnic backgrounds. Dr. Hughes and the first project manager, a self-identified Latinx lesbian, attended multiple community events to present information about SMW's health, describe CHLEW, and distribute materials encouraging eligible women to participate. Images of our Black and Latinx interviewers on flyers and brochures served to increase SMW of color's interest. Although a successful recruitment method in some studies, especially men who have sex with men (Johnston et al., 2016), our use

of RDS to recruit SMW in Wave 3 was less successful (Martin et al., 2015). More recent reports describe greater success using RDS to recruit SMW (Hequembourg & Panagakis, 2019; Michaels et al., 2019).

Table 4
Results of stepwise logistic regression to predict supplemental sample panel retention (1=yes; 0=no) at Wave 4 using Wave 3 variables

Level of education (Wave 3)	1.377 (CI=1.107-1.713)**
Any past 12-month PTSD symptoms (Wave 3)	0.607 (CI=0.370-0.995)*
Nagelkerke R-square	0.069

* $p < .05$; ** $p < .01$; *** $p < .001$

An important recruitment (and retention) strategy has been graduated monetary incentives for study participation (\$35 in Wave 1, \$45 in Wave 2, \$50 in Wave 3, \$60 in Waves 4 and 5). Incentives are a tangible recognition of the value of participants' time and contribution (Holbrook et al., 2019). In Waves 1 to 3 we provided cash incentives. Following the move to telephone interviews we began mailing money orders to participants. Participants prefer cash or money orders over gift or bank cards which are not as easy to use.

Over time we have adapted other strategies to support retention. For example, we initially asked participants to provide contact information for two people who would always know their whereabouts, but in Wave 3 we increased the number to four people. We also expanded our use of locating strategies to include the Social Security Death Index and social media platforms such as Instagram, Twitter, and Facebook.

Because we learned that intensive follow-up and contact improves participation, we communicate with participants multiple times each year (e.g., we send letters with return postcards requesting address changes or confirmation at 6-month intervals, and birthday and holiday cards every year; we also periodically send newsletters with basic study findings) and small gifts (e.g., magnets with the CHLEW logo) as tokens of appreciation. We provide all participants our toll-free telephone number and email address and encourage them to contact us with any suggestions, questions, or concerns. We send letters informing participants when new funding is obtained and clearly communicate our appreciation of their role in CHLEW's continuing success. We strive to communicate study benefits (e.g., improving healthcare providers' understanding of SMW's unique health concerns). We emphasize confidentiality and convenient scheduling and provide participants a list of local substance use treatment and mental health resources should they want to seek help.

Despite these multiple retention strategies, attrition has increased over the years, partly because we deliberately targeted hard-to-reach SMW, especially when recruiting the Wave 3 supplemental sample. A substantial number of new Wave 3 participants were low-SES and transient; some lived in group homes. However, a growing number of original

(Wave 1) participants have also dropped out of the study. Over the past 20 years SM people have become much more visible and accepted (Flores, 2019), perhaps making studies such as the CHLEW less salient. Another factor is the loss of participants who have died (54 deaths as of May 2021).

Funding

Funding was not always timely and this affected our capacity to answer some key policy questions. For instance, the Wave 4 and 5 grant application was submitted in November 2014, but not funded until September 2016. We had proposed two waves of data collection in this phase because we hoped to gather data soon after same-sex marriage was legalized in Illinois (June 2014) and again two years later—to determine whether the impact of this presumably positive policy change would be sustained over time. We anticipated that this new law would have beneficial effects for all SMW, and that married SMW would demonstrate many of the health benefits of marriage observed among women in the general population. We were unable to begin data collection until 2017, three years after Illinois legalized same-sex marriage and two years after it was legal throughout the U.S. (June 2015), which will make it difficult to determine whether observed drinking changes were the result of the new marriage law or other factors, such as the election of a conservative federal government in November 2016. Because the study was not funded on first submission, we applied for and received bridge funding that allowed us to retain core research staff and continue efforts to track and retain study participants.

Changing Definitions of Key Variables

As in all long-term prospective studies, changing definitions of key variables (e.g., alcohol use disorder, HED) has been a challenge. Carrying forward “old” measures to permit longitudinal analyses and adding new, improved versions in each wave increase the length of the interview, adding to respondent burden. Over time we have learned that managing participant burden is more important than including all variables that seem important to assess.

Because the CHLEW was designed to focus on SMW, questions in Waves 1 to 3 did not ask about gender identity. Given the growing visibility of individuals who identify as transgender or gender nonbinary we expanded our gender identity questions in Wave 4. More than 20 participants identified as transgender, nonbinary, genderqueer, or “other.” As mentioned above, we have observed substantial changes in the way participants describe their sexual identity. To address these changes, we ask several open-ended questions to better understand participants' choice of identity labels.

Possible Misrepresentation of Sexual Identity

All researchers who rely on self-report data must recognize that some study participants may misrepresent themselves so that they meet eligibility criteria and can receive participant incentives; this is an even greater challenge when participants can easily “hide” their marginalized identities. In CHLEW this was most apparent when we used RDS to recruit the Wave 3 supplemental sample. Once interviewed,

participants could receive \$20 per referral for up to three successful recruits. We noticed a potential problem when a few participants appeared unfamiliar with the acronym LGBT or reported no history of same-sex attraction or behavior. The problem became clearer in Wave 4 when four participants reported they had always identified as heterosexual. This seemed to be less of an issue in our original sample, but we identified two Wave 2 participants who appeared to have mischaracterized their sexual identity in Wave 1. We learned to train our interviewers to pay particular attention to unusual or inconsistent responses, and the research staff learned to be cautious about tapping into social networks of women who share similar characteristics not related to their sexual identity when recruiting study participants. For example, in Wave 3, after receiving several referrals of women with the same address, we learned that one study participant from a homeless residential service had spread the word about the study and its financial incentive to other residents. Hence, we learned to pay close attention to duplicate addresses of referred women.

Falsification of Data

About six months into data collection in Wave 1 we discovered that one of the study interviewers had falsified several interviews. We reviewed all interviews conducted by this interviewer to ensure that her other interviews were valid, and we telephoned most of the participants she had interviewed to do further validation checks. Based on this experience we began conducting validation checks on 10% of all completed interviews (i.e., the project manager or field coordinator calls study participants and asks a few “quality assurance” questions). The project staff also meets regularly with interviewers to discuss work quality, problems encountered in conducting interviews, and strategies for dealing with difficult situations.

Despite the challenges, longitudinal research provides invaluable benefits, such as understanding changes in health behaviors and mechanisms underlying such changes. One of the gratifying aspects of the longitudinal CHLEW study is that many participants feel invested in the research. Examples of participant comments include “I haven’t read any study results, but I know that there isn’t a lot of information out there about our community,” “Happy to be in the study. It is rare. I never imagined it would go on so long.” “I really like the cards that you send to keep me involved through the years.” Another participant stated, “I really like being a part of something that will hopefully give results and information to benefit others.”

Conclusion

Findings from the CHLEW study have made substantial contributions to understanding variations in SMW’s risk for hazardous/harmful drinking based on sexual identity, age, race/ethnicity, relationship status and commitment, and sex/gender of partner. We have also added to knowledge about the associations of HD with violence/victimization, mental health, unintended pregnancy, smoking, and cardiovascular health. Our findings highlight the negative impact of minority stress on SMW’s health and the importance of supportive policies and societal acceptance in

mitigating such risks. By describing the process used in conducting this long-term study, its major findings, and the lessons learned, we hope to encourage and support other researchers in conducting longitudinal research focused on SMW’s health. Such research is critically important in understanding and ultimately eliminating sexual orientation-related health disparities.

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