Differences in Family Health History Knowledge Among Bisexual and Lesbian Women

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Abstract

Purpose: We aimed to determine whether there are differences between sexual minority women and heterosexual women in family health history knowledge.

Methods: We used data from Dr. Susan Love Research Foundation's The Health of Women Study[®]. We included women who completed two of six online surveys between 2012 and 2015 ($n=22,410$).

Results: Compared with heterosexual women, bisexual and lesbian women had consistently greater odds of not knowing their family health history (e.g., odds ratios of 2.59 and 1.56 for breast cancer, respectively).

Conclusion: To avoid exacerbating existing health disparities, in the era of precision medicine, we must address gaps in knowledge of family health history.

Keywords: cancer, disparities, family health history, high cholesterol, precision medicine

Introduction

IDENTIFYING INDIVIDUALS with hereditary genetic conditions will be important to provide targeted, risk-based prevention and control; however, implementation of risk-based testing among sexual minority populations may be limited due to estranged family relationships and limited knowledge of family health history.¹ The Centers for Disease Control and Prevention has identified three "tier one" genetic conditions for which there is sufficient evidence to test for related mutations,² including hereditary breast and ovarian cancer, Lynch syndrome (increased risk of colorectal and endometrial cancers), and familial hypercholesterolemia (FH) (high cholesterol that leads to premature cardiovascular disease). In the absence of universal genetic testing, a patient's ability to recall their family health history is important to assess the need for risk-based genetic testing.

Research has demonstrated that the accuracy of family health history knowledge is low and varies by disease type.^{3,4} In addition, individual recall of family health history can differ across sociodemographic characteristics,⁵ cultural factors,⁶ and according to whether relatives are diagnosed with or affected by a disease.⁴ Furthermore, family dynamics may play a role in communication about health history. Groups who are distanced or estranged from family may have lower family health history knowledge. Sexual minority individuals in the United States have faced decades of stigma and intolerance¹ that has affected their familial relationships. Estrangement from family of origin may limit the informa-

tion that sexual minority individuals have about the health history of biological relatives. This is particularly concerning for sexual minority women, who may be at a higher risk of conditions such as breast cancer⁷⁻⁹; thus, additional risk factors such as family health history may be especially important. To date, no studies have characterized family health history knowledge in this underserved population.

The objectives of this study were to (1) examine family history knowledge related to tier one genetic conditions, including breast, ovarian, and colorectal cancers, as well as high cholesterol, and (2) determine whether there are differences between sexual minority women and heterosexual women in knowledge of family health history. By identifying correlates of family health history knowledge, we can target future interventions to collect more accurate and complete health history data by population and disease type.

Methods

Data

We used data from Dr. Susan Love Research Foundation's The Health of Women (HOW) Study[®],¹⁰ an online study aimed to advance our understanding of breast cancer causes and breast cancer survivors' experiences. Participants are 18 years of age or older and have access to the internet to complete the surveys. There were no explicit exclusion criteria. Participants provided informed consent online for the parent study. The study included more than 40,000 individuals with and without breast cancer, who had the opportunity to

respond to six, cross-sectional online surveys between 2012 and 2015. Not all individuals responded to all six surveys and, therefore, the sample sizes varied for each survey. We included those who completed both the basic health overview survey (including sociodemographic information) and a personal and family health history survey. We also restricted our sample to women ($n=22,410$). Data were obtained through a collaborative agreement with the Dr. Susan Love Research Foundation. Study procedures were reviewed and exempted by the Office of Human Subjects Research Protections at the National Cancer Institute as this secondary data analysis was considered nonhuman subjects research.

Measures

We included four dependent variables that measured whether or not a respondent knew her family history of breast cancer, ovarian cancer, colorectal cancer, and high cholesterol. Respondents were asked if they had any family history for each disease type, and could reply *yes*, *no*, or *I don't know*. We then categorized this measure as “do not know family history” (*I don't know* responses) or “knows family history” (*yes/no* responses) for each disease type. Our key independent variable, sexual orientation, was measured using the following item: “Please indicate how you primarily self-identify with respect to sexual orientation: heterosexual, bisexual, homosexual, other, I'd rather not say.” Data for individuals who responded “I'd rather not say” or who skipped the item were marked as missing. Our covariates included sociodemographic variables (education, ethnicity, and race) along with variables that have previously been shown to be associated with family health history knowledge (age, insurance, marital status, and personal disease history).^{5,11,12} For personal disease history, we included disease history related to the dependent variable of interest (as an example, for our breast cancer model, we controlled for personal breast cancer status).

Statistical analyses

We examined the proportion of respondents who reported not knowing their family history for breast, ovarian, and colorectal cancers and high cholesterol. We performed chi-square tests to compare the proportion of individuals who did not know their breast cancer family history with the proportion who did not know their family history for ovarian and colorectal cancers and high cholesterol. Using multivariable logistic regression, we assessed which sociodemographic variables were associated with not knowing family history for breast, ovarian, and colorectal cancers as well as high cholesterol, separately. We implemented complete case analyses using Stata SE 14 (StataCorp LP, College Station, TX). Of note, those with missing data were similar to those without missing data by sociodemographic characteristics, except by race in which those with missing data were less likely to be White than those with no missing data (85.1% vs. 94.2%).

Results

The demographics of the population are shown in Table 1, including the proportion of respondents with a *personal* history of each disease. Ability to recall family history varied greatly by disease type (Table 2). Women were most likely

TABLE 1. STUDY POPULATION CHARACTERISTICS ($N=22,410$)

	Mean (SD) or n (%)
Age	53.1 (12.9)
Education	
High school	1039 (4.6)
Some college/associate degree	4198 (18.8)
4-year college degree	7220 (32.3)
Graduate degree	9898 (44.3)
Ethnicity	
Hispanic	551 (2.5)
Race	
White	21,063 (94.0)
Black	271 (1.2)
Asian	182 (0.8)
American Indian/Alaska Native	31 (0.1)
Other	123 (0.5)
Unknown	61 (0.3)
Multiracial	679 (3.0)
Personal disease history	
Breast cancer history	7619 (34.0)
Ovarian cancer history	119 (0.5)
Colon cancer history	79 (0.4)
High cholesterol history	7356 (33.2)
Insurance	
No insurance	446 (2.0)
Insured	16,895 (75.9)
Medicaid	421 (1.9)
Medicare	4495 (20.2)
Marital status	
Married/living as married	16,678 (74.7)
Divorced	2393 (10.7)
Widowed	772 (3.5)
Never married	2493 (11.2)
Sexual orientation identity	
Heterosexual	21,076 (94.4)
Bisexual	487 (2.2)
Lesbian	702 (3.1)
Other	53 (0.2)

Missing data were excluded from column percentages.
SD, standard deviation.

to report not knowing their family history of high cholesterol (24.59%), despite a strong genetic component for this disease. Women were most likely to report knowing their family history of breast cancer ($p<0.001$), with only 3.11% reporting that they did not know their family history of breast cancer; 9.67% and 9.92% did not know their family history of colon and ovarian cancers, respectively (Table 2).

TABLE 2. PROPORTION OF RESPONDENTS WHO REPORT NOT KNOWING THEIR FAMILY HISTORY FOR EACH DISEASE TYPE ($N=22,105$)

Do not know family health history	n (%)
Breast cancer	688 (3.11)
Colon cancer	2137 (9.67)
Ovarian cancer	2193 (9.92)
High cholesterol	5436 (24.59)

A total of 305 of 22,410 (1.4%) respondents did not answer the family health history items and are not included in this table.

TABLE 3. ASSOCIATION BETWEEN SEXUAL ORIENTATION IDENTITY AND NOT KNOWING ONE'S FAMILY HISTORY OF BREAST, OVARIAN, AND COLON CANCERS AND HIGH CHOLESTEROL

	<i>Breast cancer</i> (n=20,973 ^a)		<i>Ovarian cancer</i> (n=20,947)		<i>Colon cancer</i> (n=20,947)		<i>High cholesterol</i> (n=20,943)	
	<i>aOR</i>	<i>95% CI</i>	<i>aOR</i>	<i>95% CI</i>	<i>aOR</i>	<i>95% CI</i>	<i>aOR</i>	<i>95% CI</i>
Sexual orientation identity (vs. heterosexual)								
Bisexual	2.59	1.79–3.75	1.62	1.23–2.14	1.62	1.23–2.13	1.21	0.97–1.50
Lesbian	1.56	1.07–2.29	1.27	0.99–1.62	1.46	1.15–1.86	1.08	0.90–1.29

^aDifferent numbers across models due to complete case analysis. Adjusted model controls for age, education, ethnicity, race, insurance status, marital status, and personal history of the outcome (i.e., breast cancer, ovarian cancer, colon cancer, or high cholesterol). For aORs of covariates, see Supplementary Table S1. Bold indicates statistical significance at $p < 0.05$. Due to small sample size, “other” sexual orientation identity is not shown.

aOR, adjusted odds ratio; CI, confidence interval.

Factors associated with family health history knowledge varied by disease type (Supplementary Table S1); however, lesbian and bisexual women had consistently greater odds of not knowing their family history compared with heterosexual women (Table 3). Bisexual women had higher odds of not knowing their family health history for breast, ovarian, and colon cancers compared with heterosexual women (adjusted odds ratio [aOR]=2.59, 95% confidence interval [CI]=1.79–3.75; aOR=1.62, 95% CI=1.23–2.14; and aOR=1.62, 95% CI=1.23–2.13, respectively). This finding was not statistically significant for knowledge about family history of high cholesterol. Similar findings were found among lesbian women who had higher odds of not knowing their family history of breast and colon cancer (aOR=1.56, 95% CI=1.07–2.29 and aOR=1.46, 95% CI=1.15–1.86). Findings were nonsignificant for knowledge about family history of ovarian cancer (aOR=1.27, 95% CI=0.99–1.62) and high cholesterol (aOR=1.08, 95% CI=0.90–1.29).

Discussion

Overall, we found that the majority of participants reported knowing their family health history. High rates of knowing one's family history of breast cancer may be due, in part, to the study population—an activated population, participating in a research study. However, lesbian and bisexual women had lower family health history knowledge compared with their heterosexual counterparts. This finding may reflect differences in familial relationships that are strained by acknowledgment of sexuality. For some sexual minority individuals, their biological families have rejected them.¹³ For others, systematic migration to major cities to avoid discrimination and marginalization has resulted in weaker ties to their families of origin.¹⁴ Weaker ties with family may result in lower family health history knowledge, possibly exacerbating health disparities, including in breast cancer, which are already experienced by this underserved population.^{15,16} Another potential contributor to lower family health history knowledge among lesbian and bisexual women may be lower health care access¹¹ compared with heterosexual women; thus, they may have lower knowledge, in part, because of fewer opportunities to reflect on this topic during health care encounters.

We also found that family health history knowledge does vary by disease type, as reported previously.^{3,4} Characteris-

tics of the disease, disease awareness,⁵ and stigma¹⁷ associated with certain diseases may influence this variation. Given the focus of the HOW Study, it is not surprising that the proportion of individuals who did not know their breast cancer family history was lower than for any other disease category. Furthermore, we found that the factors associated with family health history knowledge varied by disease type, potentially driving variation in knowledge. For instance, higher levels of education were associated with lower odds of not knowing your family health history of breast, ovarian, and colon cancers; however, this association was not found for family health knowledge of high cholesterol. These findings demonstrate the importance of tailoring family health history collection efforts not only by patient-level factors (e.g., education) but also by disease type (e.g., high cholesterol).

Limitations

This study is the first to examine differences in family health history knowledge among sexual minority women; however, there are several limitations. First, our study sample is not nationally representative, and reflects a highly motivated and educated population of women. Future studies should be repeated using nationally representative data from men and women to assess generalizability of these study findings. Family health history was self-reported, and may not be accurate or complete; thus, our findings may overestimate respondents' true family health history knowledge. For the identification of individuals with FH, family health history of heart disease (due to high cholesterol) is important. Unfortunately, we did not have access to such data. Future studies should examine family health history knowledge of heart disease. Finally, small cell size may partially explain nonstatistically significant findings for knowing family health history of ovarian cancer (among lesbian women) and high cholesterol.

Conclusion

Our study findings identify, for the first time, consistent differences in family health history knowledge among lesbian and bisexual women compared with heterosexual women. In the era of precision medicine, it is imperative that we address these gaps in knowledge in order not to further exacerbate documented health disparities in these groups. Moving forward, tailored approaches for improving

family health history collection should incorporate patient and disease characteristics to more effectively address gaps in women's knowledge about family health history.

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Disclaimer

The ideas and opinions expressed in this article are those of the authors and do not necessarily represent the official positions of the National Cancer Institute or the U.S. Department of Health and Human Services.

Author Disclosure Statement

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Supplementary Material

Supplementary Table S1

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