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Disparities in Cancer Screening in Individuals with a Family History of Breast or Colorectal Cancers

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Abstract

Background—Understanding racial/ethnic disparities in cancer screening by family history risk could identify critical opportunities for patient and provider interventions tailored to specific racial/ethnic groups. We evaluated whether breast cancer (BC) and colorectal cancer (CRC) disparities varied by family history risk using a large, multiethnic population-based survey.

Methods—Using the 2005 California Health Interview Survey, BC and CRC screening were evaluated separately with weighted multivariate regression analyses, and stratified by family history risk. Screening was defined for BC as mammogram within the past 2 years for women aged 40 to 64 years; for CRC, as annual fecal occult blood test, sigmoidoscopy within the past 5 years, or colonoscopy within the past 10 years for adults aged 50 to 64 years.

Results—We found no significant BC screening disparities by race/ethnicity or income in both the family history risk groups. Racial/ethnic disparities were more evident in CRC screening, and the Latino-white gap widened among individuals with family history risk. Among adults with a family history for CRC, magnitude of the Latino-white difference in CRC screening (OR 0.28; 95%CI: 0.11 -0.60) was more substantial than that for individuals with no family history (OR 0.74; 95%CI: 0.59 -0.92).

Conclusions—Knowledge of their family history widened the Latino-white gap in CRC screening among adults. More aggressive interventions that enhance the communication between Latinos and their doctors about family history and cancer risk could reduce the substantial Latino-white screening disparity in Latinos most susceptible to CRC.

Keywords

family history; cancer screening; cancer disparities; breast cancer; colorectal cancer

Introduction

Having a family history of breast or colorectal cancer is associated with an increased risk of developing these cancers compared to those with no family history.¹⁻³ Breast cancer (BC) and colorectal cancer (CRC) are among the most common types of cancers as well as among the top leading causes of cancer death in the United States, and both have evidence-based recommendations for screening and prevention.⁴ Nationally, among the estimated 8% of the population who report a family history of breast cancer and 5% who report a family history of CRC, screening rates for these cancers are higher than among average-risk individuals.⁵ Although on average, knowledge of family history clearly motivates individuals to receive cancer screening, less is known whether there are racial/ethnic disparities in screening among this higher risk group, as indicated in many studies on average-risk populations.⁶⁻¹⁰ Understanding racial/ethnic disparities in cancer screening by family history risk could identify critical opportunities for patient and provider interventions tailored to specific racial/ethnic groups. Focusing on individuals who are most susceptible to breast and colorectal cancers could effectively target resources to reduce the disproportionate burden of cancer incidence and mortality in racial/ethnic minority populations.^{6, 11, 12}

Among adults with a family history, racial/ethnic differences in individual and physician factors, and in the communication between individuals and their physicians, may result in variations in preventive screening behavior.¹³ Recent evidence indicates that racial/ethnic minorities are less likely than non-Latino Whites to recognize family history as a potential risk factor for familial cancers.¹⁴ This suggests that racial/ethnic minorities are underestimating their cancer risk compared to non-Latino whites, and/or their physicians are not appropriately counseling them on their risk. Even if adults are aware of their family history as a risk factor, risk awareness could manifest differently across racial/ethnic groups: some may vigilantly seek preventive screening, but others may avoid screening due to fear,^{15, 16} anxiety, and distress.¹⁷ Moreover, researchers have suggested that compared to non-Latino Whites, some racial/ethnic minorities are less likely to discuss experiences of cancer due to cultural stigma and taboos surrounding disclosure of cancer experiences,^{18, 19} There is also evidence that racial/ethnic minorities compared to non-Latino Whites are less likely to receive a provider recommendation for cancer screening.^{20, 21} We suspect that many of these factors, already established among average-risk groups, would be amplified among individuals with a family history, especially with the recent population-based finding of lower perceived cancer risk among racial/ethnic minorities with a family history.¹⁴

We hypothesized that racial/ethnic screening disparities among individuals reporting family history of breast/ovarian cancers or CRC will be wider than the racial/ethnic screening disparities in screening among individuals reporting no family history of these cancers. Using a population-based survey in California, a diverse state, we examined the non-elderly California adult population to evaluate how family history affects screening behavior. We separately examined racial/ethnic disparities in screening behavior by family history risk.

Methods

Data Source

We used data from adult respondents who participated in the 2005 California Health Interview Survey (CHIS). CHIS is a population-based random-digit dial telephone survey conducted every other year since 2001 among residents of California.²² CHIS employs a multi-stage sampling design to ensure that minority subgroups and rural populations in California are represented in the data.²² The 2005 CHIS was administered in five languages, including English, Spanish, Chinese (Cantonese and Mandarin), Korean, and Vietnamese. Data were collected on a range of health and health related topics, including cancer

screening behavior, personal history of cancer, health status, insurance status, mental health, health behaviors and other health related topics. The response rate for the CHIS 2005 adult sample was 26.9%, comparable to other large population-based telephone surveys, including the 2005 California Behavioral Risk Factor Surveillance System survey.²³

In 2005, CHIS administered a Family History of Cancer module to adult participants under the age of 65 (n = 33,187).²⁴ Respondents were asked about any cancer history of first-degree (parents, siblings, children) and second-degree (grandparents, uncles, aunts) blood relatives, including half brothers and sisters. For each female relative diagnosed with cancer, two additional questions were asked: 1) whether the female relative had breast, ovarian, uterine, colon, or rectum cancer and 2) whether the female relative was diagnosed with any of these specific cancers before age 50. For each male relative diagnosed with cancer two additional questions were asked: 1) whether the male relative had prostate, colon, rectum or breast cancer and 2) whether the male relative was diagnosed with any of these specific cancers before age 50.

Study Population & Outcome Variables

The study assessed breast cancer screening adherence and CRC screening adherence separately. The breast cancer (BC) screening population was defined as women aged 40-64 years old with no personal history of breast cancer or ovarian cancer, and who received a mammogram within the past 2 years (Total: n= 11,885; with a family history: n= 1,884; without a family history: n=10,001). We included ovarian cancer in the family history of breast cancer group because a family history of ovarian cancer may also increase a woman's risk of breast cancer.²⁵ Studies on breast cancer screening behavior have included a family history of ovarian cancer as a risk factor for breast cancer risk.^{17, 26}

The colorectal cancer screening population was defined as adults aged 50-64 years old with no personal history of colon cancer, who received a fecal occult blood test (FOBT) the past year, a sigmoidoscopy within the past 5 years, or a colonoscopy within the past 10 years (total: n=11,988; with family history: n= 1,175; without family history: n=10,813). We could not identify individuals with a personal history of rectal cancer from the CHIS public use data, so only personal history of colon cancer was excluded. For both analyses, the lower age limits were based on the U.S. Preventive Services Task Force guidelines for routine breast and CRC screening at the time the CHIS data was collected in 2005, prior to the recent changes in the mammogram guideline recommendations in 2009.²⁷⁻²⁹

Although individuals with a family history risk for cancer may be recommended to begin routine cancer screening at earlier ages than the screening guidelines for average-risk individuals, we conducted our analysis on the recommended screening age group for average-risk (aged 40 and older for mammograms; aged 50 and older for FOBT, sigmoidoscopy or colonoscopy) for two reasons: 1) to identify subgroups among individuals with a family history who are not even receiving screening per the average-risk guidelines and 2) to assess racial/ethnic screening disparities among individuals with a family history compared to those with no family history.

Risk Stratification by Family History of Cancer

We categorized family history of either cancers (breast/ovarian or colon/rectum) as average-risk (no family history) or above average (with family history) based on an algorithm developed by Scheuner et al. 1997.³⁰ This risk stratification algorithm is suitable for our data and our analysis as it employs both first and second-degree relative information and does not require clinical information typically absent in health surveys. Average-risk individuals were those with no family history of cancer (breast/ovarian or colon/rectum) or

only one second-degree relative diagnosed at any age. Above average-risk of family history was defined otherwise. We initially classified the above average-risk category into “Moderate” and “High” risk, but due to sample size limitations, these two risk groups were combined in the study analyses. Screening rates for the moderate and high-risk groups were not statistically different (Table 1).

Independent Variables

Our independent variable of interest was race/ethnicity, specified using the UCLA Center for Health Policy Research classification that coded Latino ethnicity and major race categories as mutually exclusive (white, Latino, Asian/Pacific Islander, African American, and other single race or multiracial). In multivariate analyses we included predictors based on the Andersen Behavioral Model,³¹ and prior literature assessing screening behavior in multiethnic samples.^{7, 10, 13, 32-39} Individual predisposing factors included income status as a percent of the Federal poverty level (FPL) (0-99%, 100%+), age (continuous in years), gender (for the CRC screening model), marital status (married versus never married, divorced, or widowed), education status (no formal education or less than high school graduate versus high school graduate), English proficiency (speaks English less than “well” versus native speaker and speaks English “well” or “very well”), foreign-born versus U.S.-born, and rural versus urban residence. Enabling characteristics were specified as having no health insurance for all or part of the past year and not having a visit to the doctor in the past 12 months. Need was specified as self-rated health status (fair, poor health vs. good, very good, excellent health) and number of chronic conditions (from among the following seven conditions: diabetes, heart disease, hypertension, asthma, cancer, arthritis, and epilepsy).

Statistical Analysis

We evaluated use of recommended BC and CRC screening separately in two study populations: 1) individuals reporting a family history of the cancer associated with the screening test, and 2) individuals reporting no family history of the cancer associated with the screening test. We obtained weighted estimates for each study population using sample weights provided in the CHIS Public Use Files. Average-risk (no family history) and above average-risk (no family history) sample distributions were compared using two-sample test of proportions. Using weighted multivariate logistic regression, we constructed odds ratios and confidence intervals. F-tests of joint significance with a Bonferroni adjustment were conducted for the race/ethnicity categorical variable. Statistical significance was assessed with a 2-tailed test and alpha of 0.05. Further to evaluate whether racial/ethnic disparities significantly varied by family history risk, we estimated models that included all individuals eligible for screening with family history risk, then tested the significance of the interaction effect of race/ethnicity and family history. Data management, variable construction, and regression modeling were conducted using STATA version 10.1.

Results

A greater proportion of non-Latino white, higher-income individuals and those with more education were represented in the population reporting a family history compared to the population reporting no family history—for both the BC and CRC screening population (Table 2). Regardless of risk stratification, whites and individuals with incomes greater than 100% FPL comprised the majority of both the BC and CRC screening populations.

Breast Cancer Screening

We found no significant racial/ethnic, income or education disparities in mammography use among women in both (i.e. above average risk versus average-risk) family history risk groups, controlling for other characteristics in our models (Table 3). Factors that were

significant in predicting BC screening among the group reporting no family history risk were mirrored and amplified in the group reporting a family history risk. These factors included marital status, insurance status, annual doctor's visit, self-rated health and age. Interestingly, rural status, which was not significant in the group with no family history was significant for the group with a family history (Table 3).

Colorectal Cancer Screening

Race/ethnicity was significant for both family history risk stratifications (Table 4). However, the racial/ethnic disparities (Latinos, Asians and Pacific Islanders, other race compared to non-Latino whites) seen in the group with no family history risk were only evident among Latinos compared to non-Latino whites. Latinos reporting no family history had 0.74 times the odds of being screened for CRC compared to non-Latino whites. This gap was more substantial among the group with family history risk (OR 0.28; 95% CI: 0.11 -0.60). Based on a model testing the interaction term of Latino and family history (data not shown), the difference in the magnitude of the Latino-white disparity between those with and without a family history was statistically significant ($p < 0.05$). The gender disparity seen in the group with no family history group was not significant in the group reporting a family history of CRC. Lacking insurance and not having an annual doctor visit were significantly associated with CRC screening in both family history risk categories.

Discussion

Our study had three major findings. First, in California, where mammography rates are high,⁴⁰ we found no significant disparities by race/ethnicity and income in both family history risk groups. Although our study may not be generalizable nationally, this finding is consistent with Wu et al.'s study using the National Health Interview Survey.⁴¹ Second, racial/ethnic disparities were more evident in CRC screening, and we found evidence of a Latino-white gap among the group with a family history. As this is the new contribution of the study, these results should be further explored and confirmed in national population-based data and in medical claims data that contain information on family history. Third and most importantly, personal knowledge of family history did not close the Latino-white gap in CRC screening. This finding is relevant and new, not found in previous diverse population-based studies that have included Latinos with a family history.^{5, 41} Our estimate that Latinos with a family history risk had 0.28 times the odds of being screened for CRC compared to non-Latino whites points to a considerable disparity, greater than most of the detected disparities from other factors in our model, and of greater magnitude than the Latino-white difference among individuals with no family history (OR 0.74; 95%CI: 0.59 -0.92).

There are several explanations why Latinos are not getting screened for CRC as much as non-Latino whites, even if they know that they have a family member with CRC. On the patient side, the most relevant study to put our results in context is the recent national population-based study conducted by Orom et al. 2010 using the national 2007 Health Information Trends Survey (HINTS). In that study of a multiethnic sample, Orom and her colleagues found 1) that Latinos had lower perceived cancer risk than non-Latino whites, 2) that the lower rates of perceived cancer risk was associated with lower rates of reported family history of cancer among Latinos compared to non-Latino whites, and most importantly, 3) that reporting a family history of cancer was positively associated with higher perceived cancer risk among non-Latino whites, but not among Latinos. Their last finding supports our study results of the widening Latino-white disparity in CRC screening among the group with a family history of CRC. The authors further posit that Latinos with a family history may be less aware of their cancer risk "due to language and other barriers that can make the dissemination of health information difficult."¹⁴

Even among Latinos who do perceive their family history of colorectal cancer to be associated with increased risk of colorectal cancer, some studies have suggested that compared to non-Latino Whites, on average, Latinos may harbor greater fear or denial of this risk that they delay or fail to seek colorectal cancer screening.^{16, 17, 32} However, in a study with a diverse sample of women recruited from primary care clinics in San Francisco (42% reported having a family history of cancer), among Latinas who had the highest perceived risk of three cancers, including colon cancer, their perceived risk was associated with obtaining cancer screening tests.⁴² The study's participants, women associated with a primary care clinic, may be a select sample of women who may tend to value preventive care and who may have a regular provider. Thus, they may be more motivated to be screened for CRC than the average Latino with a family history of CRC. Nevertheless, interventions are needed that address the spectrum of reactions to knowledge of a family history of CRC—i.e. fear, denial, anxiety, and indifference—among affected Latinos to mobilize their CRC screening behavior

On the provider side, studies suggest that rates of family history inquiries are low in routine clinical encounters,^{13, 43} We found no studies that determined whether there is a differential rate of obtaining family histories by race/ethnicity. We therefore posit that since obtaining family history and explaining increased risks and recommended screening intervals may require more time in the patient-physician encounter, language and cultural barriers may, on average, differentially deter this knowledge transfer of CRC risk to Latinos but not to whites. In Guerra et al.'s qualitative study on barriers and facilitators to physician recommendation of CRC screening, physicians caring for non-English speaking patients reported that they “had a particularly difficult time recommending CRC screening because translation of the recommendation takes up much of the time allotted for the visit.”⁴⁴ Similarly, Wee et al.'s study found that Latino adults are less likely to receive counseling from their physicians about CRC tests than non-Latino whites.²¹ Wee et al.'s study implies that the Latino-white disparity could be more pronounced among those with a family history, since family history counseling requires an even greater time investment.

The differential knowledge transfer of CRC risk may also result when the patient-provider interaction is racially/ethnically discordant. For example, Ge et al. 2009 found that “physicians did not solicit or address cultural barriers to CRC screening and patients did not volunteer culture-related concerns regarding CRC screening” in ethnically discordant physician-patient interactions.⁴⁵ Drawing on Guerra et al.'s study previously discussed,⁴⁴ since counseling for family history risk is more complex than average-risk screening recommendations and would require more time, the Latino disadvantages in linguistically and culturally discordant physician relationships may be greater in individuals with a family history of CRC. Discordant ethnic patient-physician relationships are certainly prevalent in California as Latinos are more than a third of California's population, but make up only 5 percent of the state's physician population.⁴⁶ Thus, racial/ethnic variations in the provider-patient interaction could be a source of the CRC screening disparity, and has a potentially greater penalizing effect on Latinos with a family history of CRC. Finally, our results in California are likely to be present for Latinos across the US, and could be more pronounced in areas with fewer cultural and linguistic services for Latinos.

A key limitation of our study is that it is based on self-reported survey data. Family history reports appear to be generally accurate: validation studies on self-reports of cancer family history suggest reports of first degree relatives are highly accurate^{2, 47-49} and reports of second degree relatives to be moderately accurate. One study suggests that the validity of self-reported family history is better for breast and colorectal cancers, than ovarian and endometrial cancers. While self-reported family history is generally valid, recent meta-analysis on the accuracy of self-reported cancer screening suggests screening use in

population-based surveys tend to be over-reported⁵⁰ especially among ethnic minority respondents; thus, the racial/ethnic disparities we report here may be underestimated. The sample size of minority racial/ethnic groups in the CHIS strong family history population may also have limited our capability to detect any disparities in screening by population subgroups. However, we detected a significant effect for Latinos, whose sample size was comparable to that of Asians and Pacific Islanders and African Americans. Finally, our study approach evaluated screening beginning at the age recommended for average-risk adults to compare across all risk categories. Due to smaller samples, we could not ascertain whether disparities may be narrower or wider in evaluating adults with a family history who received mammograms below age 40 years and CRC screening below age 50 years.

Despite these limitations, our study provides a compelling picture on how a family history analysis could direct where efforts are most needed in reducing cancer disparities by race and ethnicity.^{51, 52} Among California adults, our troubling finding was that knowledge of their family history of colorectal cancer (CRC) did not close the Latino-white gap in CRC screening, but actually widened the disparity. More aggressive interventions that enhance the communication between Latinos and their doctors about family history and cancer risk are needed and could reduce the substantial Latino-white screening disparity in Latinos most susceptible to CRC...^{51, 52}

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Table 1

Risk Categories Based on Family History

Risk Category	Family History Stratification	Breast Cancer (BC)* (Women, Aged 40-64 years) n = 11,885		Colorectal Cancer (CRC)† (Adults, Aged 50-64 years) n=11,988			
		n	Percentage by CDC Risk Category	BC Screening Rates‡, by CDC Risk Category % [95%CI]	n	Percentage by CDC Risk Category	CRC Screening Rates§ by CDC Risk Category % [95%CI]
Average	No Family History	10,001	85.9%	76.0% [74.7%-77.3%]	10,813	91.6%	50.5% [49.5%, 51.6%]
Above Average	Has Family History	1,884	14.1%	83.5% [81.0%, 85.9%]	1,175	8.4%	71.2% [67.3%, 75.0%]

* No personal history of breast or ovarian cancer

† No personal history of colon cancer

‡ Mammography in past 2 years.

§ Fecal occult blood testing in past year or sigmoidoscopy in past 5 years or colonoscopy in past 10 years

Frequency and Rates are weighted estimates.

	Population recommended for BC screening (Women, Aged 40-64 years)		Population recommended for CRC screening (Adults, Aged 50-64 years)	
	Has family history risk n=1,884	No family history risk n=10,001	Has family history risk n=1,175	No family history risk n=10,813
	Weighted % or mean	n	Weighted % or mean	n
	[1.00, 1.12]		[1.00, 1.20]	
[median,SD]				[1.00, 1.16]

* p<0.05 Proportion of group with Has Family History significantly differs from group with No Family History

Table 3

Mammography use in women, aged 40-64 years

	Has family history risk for breast or ovarian cancer		No family history for breast or ovarian cancer			
	OR	p-value	95% CI	OR	p-value	95% CI
Race/ethnicity (ref: White)			F-stat = 0.14			F-stat = 0.09
Latino	0.89	0.81	0.35	2.25	1.04	0.81
Asian & Pacific Islander	1.18	0.73	0.47	2.98	0.83	0.62
African American	1.88	0.13	0.83	4.24	1.36	0.99
Other Race	0.58	0.15	0.28	1.22	0.90	0.65
Income as % FPL (ref: >=100% FPL)						
0 - 99% FPL	0.55	0.13	0.25	1.20	0.81	0.63
Education (ref: High School graduate)						
< High School	0.98	0.98	0.35	2.80	0.92	0.68
Single/Not Married	0.59*	0.03	0.37	0.95	0.71*	0.61
Rural	0.58*	0.03	0.35	0.95	0.90	0.73
Limited English Proficiency	1.96	0.26	0.61	6.31	1.06	0.76
Foreign-born	2.00	0.13	0.82	4.85	1.11	0.86
Insured part/none of past year	0.25*	<0.01	0.15	0.43	0.45*	0.37
No doctor's visit in past year	0.19*	<0.01	0.12	0.29	0.32*	0.27
Self-rated Health: Fair/Poor	0.55*	0.02	0.33	0.92	0.77*	0.59
Chronic conditions	1.04	0.66	0.88	1.22	1.07	0.98
Age	1.08*	<0.01	1.05	1.11	1.08*	1.07

* Significant at p < 0.05; F-test of joint significance of Race/Ethnicity with Bonferroni adjustment

