

# NIH Public Access

Author Manuscript

Patient Educ Couns. Author manuscript; available in PMC 2013 August 01.

Published in final edited form as:

Patient Educ Couns. 2012 August; 88(2): 291–297. doi:10.1016/j.pec.2011.11.013.

# Factors affecting frequency of communication about family health history with family members and doctors in a medically underserved population

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# Abstract

**Objective**—Family history contributes to risk for many common chronic diseases. Little research has investigated patient factors affecting communication of this information.

**Methods**—1061 adult community health center patients were surveyed. We examined factors related to frequency of discussions about family health history (FHH) with family members and doctors.

**Results**—Patients who talked frequently with family members about FHH were more likely to report a family history of cancer (p=.012) and heart disease (p<.001), seek health information frequently in newspapers (p<.001) and in general (p<.001), and be female (p<.001). Patients who talked frequently with doctors about FHH were more likely to report a family history of heart disease (p=.011), meet physical activity recommendations (p=.022), seek health information frequently in newspapers (p<.001) and in general (p<.001), be female (p<.001), and not have experienced racial discrimination in healthcare (p<.001).

**Conclusion**—Patients with a family history of some diseases, those not meeting physical activity recommendations, and those who do not frequently seek health information may not have ongoing FHH discussions.

**Practice Implications**—Interventions are needed to encourage providers to update patients' family histories systematically and assist patients in initiating FHH conversations in order to use this information for disease prevention and control.

Conflicts of interest

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The authors have no conflicts of interest to disclose.

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### Keywords

Provider-patient communication; family history; health information seeking

## 1. Introduction

Family history is an important contributing risk factor for many common chronic diseases, reflecting shared genetic, behavioral, and environmental risk [1, 2]. Diseases that affect millions of U.S. adults (e.g., cardiovascular disease, diabetes, several cancers) are all influenced by family history [3–9]. For most common, chronic conditions, a moderate familial risk increases disease risk about two-fold compared to a weak familial risk; this figure rises to a three-fold or higher increase for those with a strong familial risk when compared to a weak familial risk [2, 10]. Although family history information has most often been used for risk assessments for rare, highly penetrant, hereditary conditions, this information may have the greatest impact when used for common diseases in population-based settings [11, 12]. Currently, family history can guide medical care (e.g., screening recommendations) for common conditions including diabetes, coronary heart disease, stroke, and several cancers [13, 14, 15]. Targeting disease prevention initiatives in primary care toward those with a moderate or strong familial risk may be an effective approach that could supplement initiatives targeting the general population [16–18].

The pathway by which family history information could be used in primary care for disease prevention is based on two domains of communication behaviors: patients' collection of family health history (FHH) information from family members and discussion of the information with health care providers (see Figure 1). Optimally, such conversations would be repeated over time to develop and update an in-depth FHH. Research on communication about FHH information has mainly focused on provider and health care system factors that affect provider-patient communication. Prior research has shown that physicians often do not collect adequate FHH information from patients [19–21], and even those in primary care who believe that collection of family history information is important spend little time on this activity [22]. Most FHH information is collected in new patient visits, and this information is generally not discussed in subsequent visits [23, 24]. Potential barriers affecting provider-patient communication about FHH have been identified, including visit length, reimbursement criteria, and provider training, knowledge and skills [25–27].

However, less research has examined patient factors that affect communication about FHH with providers or with family members over time. The results of a national survey of U.S. adults showed that women, Whites, those with a personal history of diabetes, and those with higher educational attainment were more likely to engage in active collection of FHH information from family members [1]. Social network research conducted within families at high genetic risk of cancer has shown that women are more likely to gather health information [28], but limited research has considered this communication as an ongoing process.

A number of different patient factors could affect communication about FHH with family members or health care providers. Patients at increased risk of disease based on their family history or behavioral risk factors might be more likely to have such conversations in order to discuss possible disease prevention or control strategies [28, 29]. Health information seeking may also be related to these communication behaviors. Prior research based on a national sample of U.S. adults has shown that those who believed that knowledge of family history or genes could reduce cancer risk were more likely to have searched for cancer information [30], but the relationship between health information seeking and FHH communication

behaviors has not been systematically investigated. In addition, the role of patient characteristics, such as race/ethnicity and gender, that are known to affect provider-patient communication related to other health topics [31–36], needs to be explored further. Research is also needed to examine factors affecting communication about FHH in diverse, underserved populations.

This study was therefore designed to examine predictors of communication about FHH with family members and doctors among a medically underserved population. We examined whether family history of chronic disease, behavioral risk factors, health information seeking behaviors, and patient characteristics were related to frequency of communication about FHH with family members and with doctors. We hypothesized that those with a family history of chronic disease, those at greater behavioral risk, more frequent health information seekers, and patients who were female, younger, and more highly educated would engage in these communication behaviors more frequently. Understanding how patient factors affect frequency of communication about FHH is critical to using this information effectively in disease prevention.

# 2. Methods

#### 2.1. Data collection

For this study, we administered a cross-sectional survey to a diverse patient population. We approached patients in the waiting rooms of eight community health centers located in medically underserved areas. These community health centers serve as safety net providers of health care, accepting Medicaid and providing no/low-cost care on a sliding scale for uninsured/underinsured patients. Surveys were administered at each of the health centers on different days of the week and at different times of the day based on a rotating schedule. Trained data collectors approached all patients in the waiting room while they were at the health center and asked them to complete a survey in either English or Spanish. Inclusion criteria were that patients be at least 18 years old and speak either English or Spanish. Approximately 65% of patients who were approached agreed to complete the survey. Of the 1,318 patients who agreed to participate, 1,061 (81%) completed all components of the survey; there were no significant differences in demographic characteristics between individuals with complete surveys and those with incomplete surveys. This study was approved by the Stony Brook University Committee on Research Involving Human Subjects, the Suffolk County Department of Health Services Institutional Review Board, and the National Institutes of Health Office of Human Subjects Research.

#### 2.2. Measures

### 2.2.1. Outcome variables

**Frequency of family health history discussions:** We assessed how frequently patients talked with family members and with doctors about family health history using two Likert-scale items (e.g., "I talk with family members about our family health history: Not at all/not very often/somewhat often/very often").

#### 2.2.2. Predictor variables

**Family history of chronic disease:** We assessed family history of diabetes, heart disease and cancer with three items ("Does heart disease run in your family? yes/no/don't know") [37]. Responses of "no" and "don't know" were combined for analyses.

**Behavioral risk factors:** We created a continuous measure of body mass index (BMI) based on self-reported height and weight. We characterized patients' weight perceptions using one item ("Do you consider yourself to be at an average weight, underweight, or overweight?")

Physical activity was assessed using the activity scale of the Rapid Assessment of Physical Activity, which is a 7-item validated measure that asks patients to report their level and intensity of physical activity [38]. For analyses, respondents were classified as "active" (i.e., meeting current physical activity recommendations) vs. non-active.

**Health information seeking:** We assessed patients' health information seeking through different media (i.e., newspaper, television, and Internet) using three items adapted from the Health Information National Trends Survey [39] (e.g., "In the past 12 months, how often have you watched health segments on local news? Would you say every day, several days a week, 2 or 3 times per month, about once a month, 5 to 10 times a year, less than 5 times a year"). In analyses, this measure was dichotomized as every day/several days a week vs. less frequent. We also asked patients about health information seeking in general using the item: "In the past 30 days, how often would you say you have looked for information about ways to stay healthy or to feel better? Would you say very often, somewhat often, not very often, not at all" [39]. This item was dichotomized (very often/somewhat often vs. less frequently) in analyses.

**Racial discrimination in health care:** We asked about patients' perceptions of racial discrimination in health care using the Behavioral Risk Factor Surveillance System (BRFSS) item "Within the past 12 months, when seeking health care, do you feel your experiences were: worse than other races; the same as other races; better than other races; worse than some races, better than others" [40]. This item was dichotomized as worse than other races vs. other categories in analyses.

**Patient characteristics:** Health literacy was assessed using the Newest Vital Sign (NVS), a six-item measure requiring reading comprehension and numeracy skills [41, 42]. Participants received a score from 0 to 6 based on number of correct answers: scores from 0–1 reflect a high likelihood of limited literacy, 2–3 a possibility of limited literacy and 4–6 adequate health literacy [41]. We also asked patients to report their educational attainment, age, race/ethnicity, and gender. In analyses, educational attainment was categorized as less than high school; high school degree/GED/some college; or college degree or higher, and race/ethnicity as Black; White; Hispanic; or other. Age was treated as continuous.

**2.2.3. Covariates**—We assessed whether patients had a personal diagnosis of diabetes, heart disease, or cancer using three items (e.g., "Has a doctor ever told you that you have diabetes?"). We also recorded the language in which the survey was completed and country of birth.

#### 2.3. Statistical analysis

Descriptive statistics were examined for all variables. Bivariate analyses were conducted to examine the associations between each outcome variable and possible predictor variables and covariates using chi-square tests and univariate logistic regression models. Possible predictors of frequency of discussion about FHH with family members and doctors (i.e., family history, behavioral risk factors, health information seeking, health care experiences, patient characteristics) were identified from a theoretical model of risk information seeking and processing [43] and prior empirical research on provider-patient communication and family health history, as described above. We then built two multivariable logistic regression models to examine the independent contributions of predictor variables found to have significant bivariate associations with the outcome variables. The outcome variables were dichotomized in the logistic regression models (very often/somewhat often vs. not very often/not at all). Data were analyzed using Stata 10 (College Station, TX: StataCorp LP

2007) and SAS/STAT® 9.2 for Windows (Cary, NC). Statistical significance was assessed as p<0.05.

# 3. Results

The majority of patients were female (75%) and 51% were 35 years of age or older (see Table 1). About 26% self identified as being non-Hispanic White, 31% as non-Hispanic Black, and 35% as Hispanic. A majority (60%) had been born in the U.S. Although 83% had at least a high school degree or GED, only 34% had adequate health literacy as measured by the NVS. A larger proportion had been diagnosed with diabetes (14%) than with heart disease (10%) or cancer (6%). More than half (57%) of patients reported that they had a family history of diabetes, while 41% reported a family history of heart disease and 44% a family history of cancer.

#### 3.1. Discussion with family members

Overall, about 66% reported talking with family members about FHH somewhat or very often, only 9% said not at all (data not shown). Fifty-eight percent reported talking with a doctor somewhat or very often about FHH. As shown in Table 2, in bivariate analyses, those with a family history of diabetes (p=.002), heart disease (p<.001), and cancer (p<.001) were more likely to report talking frequently with family members about FHH. Patients who met physical activity recommendations reported talking more frequently with family members about FHH (p=.002). Patients who frequently sought health information through newspaper (p<.001), television (p<.001), and Internet sources (p=.004) were also more likely to report talking frequently with family members about FHH, as were those who frequently looked for health information in general (p<.001). Females (p<.001), those with higher educational attainment (p=.043), and those who were younger (p=.035) were more likely to frequently talk with family members about FHH. Experiences with racial discrimination in health care were not significantly associated with this outcome.

In a multivariable model, talking frequently with family members about FHH was associated with reporting a family history of cancer (OR: 1.50; 95% CI: 1.09, 2.05) and a family history of heart disease (OR: 1.52; 95% CI: 1.10, 2.08), but not a family history of diabetes (see Table 3). Those who had frequently sought health information in newspapers (OR: 1.89; 95% CI: 1.30, 2.73) or in general (OR: 2.45; 95% CI: 1.75, 3.44) were also more likely to report talking frequently with family members about FHH. Women were more likely to talk frequently with family members about FHH than men (OR: 1.98; 95% CI: 1.42, 2.77).

#### 3.2. Discussion with doctors

In bivariate analyses, a similar pattern was observed for the outcome variable of talking frequently with doctors about FHH (see Table 2). Patients with a family history of diabetes (p=.022), heart disease (p=.009), and cancer (p<.001) were more likely to report talking frequently with doctors about FHH. Patients who met physical activity recommendations reported talking more frequently with doctors about FHH (p=.010). This outcome was also significantly associated with having frequently sought health information through newspaper (p<.001), television (p<.001), and Internet sources (p=.0012) and with frequently looking for health information in general (p<.001). Females (p<.001) and younger patients (p=.028) were more likely to talk frequently with doctors about FHH. There was a marginal association with experiences of racial discrimination in health care (p=.059).

As shown in Table 4, in a multivariable model, talking frequently with doctors about FHH was associated with reporting a family history of heart disease (OR: 1.66; 95% CI: 1.22, 2.24), but not a family history of cancer or of diabetes. Patients who reported meeting physical activity recommendations were more likely to report talking frequently with

doctors than those who did not meet recommendations (OR: 1.43, 95% CI: 1.05, 1.93). Those who had frequently looked for health information in newspapers (OR: 1.96; 95% CI: 1.37, 2.82) or were more frequent health information seekers in general (OR: 2.46; 95% CI: 1.73, 3.49) were more likely to talk frequently with doctors about FHH. Women were more likely to talk frequently with doctors about FHH. Women were more likely to talk frequently with doctors about FHH. Women were more likely to talk frequently with doctors about FHH than men (OR: 1.86; 95% CI: 1.32, 2.60). Patients who reported experiencing racial discrimination in health care were significantly less likely to report talking frequently with doctors about FHH (OR: 0.47; 95% CI: 0.29, 0.78).

# 4. Discussion and conclusion

#### 4.1. Discussion

The findings presented here show that multiple domains of patient factors impact frequency of discussion about FHH with family members and with doctors in a medically underserved population of community health center patients. Patients reporting a family history of heart disease talked more often about FHH with family members and doctors. In addition, reporting a family history of cancer was related to more frequent communication about FHH with family members, but not with doctors. The results therefore indicate that reporting a positive family history of diabetes prompted less conversation about FHH than did a positive family history of other common, chronic health conditions, despite the large proportion of patients with a family history of diabetes in our sample.

These family history findings are in contrast to results from the 2005 Oregon BRFSS, which showed that respondents with a positive family history of diabetes were more likely to report that their health care provider collected family history information about diabetes, discussed the risk of developing diabetes, and made dietary or exercise recommendations to reduce diabetes risk [44]. In addition, Hariri et al. (2006) found that, among non-diabetics, those with familial risk were most likely to talk with family members about diabetes [45]. The difference in results between these studies and the present study may be because of differences in populations or because our measure was intended to capture ongoing communication about FHH. It is also notable that, in our study, provider-patient communication about FHH was not related to reporting a family history of cancer, since current screening recommendations for breast, colorectal, ovarian, and prostate cancer are based at least in part on family history [15, 46]. These findings therefore suggest that strategies are needed to encourage more systematic collection and follow-up of FHH information in clinical settings in order to tailor disease prevention and screening recommendations to patients' family history.

These findings provided partial support for our hypothesis of a relationship between behavioral risk factors and discussions of FHH with family members and with doctors. We found a relationship between physical activity and discussions of FHH with doctors, in that individuals meeting physical activity recommendations were more likely to have these discussions, but did not find a relationship between BMI or weight perceptions and this communication variable. The physical activity finding suggests that despite the advantage of family history capturing shared genetic, behavioral, and environmental risk within families [1, 2], FHH might not be used by providers to develop integrated prevention recommendations (e.g., to increase physical activity for those not meeting recommendations) based on both familial and behavioral risk. Prior research has shown that as behavioral risk increased in a sample of primary care patients, inclination toward genetic explanations also increased, while interest in how health habits affect disease risk decreased [47], suggesting that those at greatest need for behavior change may hold disease attributions that diminish their interest in receiving behavior change information. These

findings, together with our results, suggest that patients at increased behavioral risk may have less inclination toward collecting and discussing FHH information.

Health information seeking in general and specifically from newspaper sources was positively related to more frequent discussions about FHH with both family members and doctors. Strikingly, health information seeking variables were more important predictors of the frequency of FHH discussions than were demographic or illness-related variables. These findings suggest that FHH may be one of many types of health information sought by those individuals who frequently search for health information. In previous research, health information seeking has been associated not only with sociodemographic, health care access, and cancer history variables [48, 49] but also with colonoscopy and prostate cancer screening behaviors [49], suggesting a possible prevention orientation to those who frequently engage in health information seeking behaviors. A recent Internet-based survey revealed that different patterns of motivations may underlie health information seeking behaviors related to wellness as compared to illness [50], indicating that it will be important to examine which type of information seeking pattern best describes health information seeking related to the domain of FHH. Patients who are interested in discussing FHH information may generally have a positive wellness orientation. Investigation of motivations for discussing FHH with family members and doctors may be a fruitful area of research in developing family history-based prevention initiatives. In addition, it may be critical to develop novel ways of motivating patients who are not frequent health information seekers to discuss FHH information.

Patients who reported having experienced racial discrimination in health care were less likely to have frequently discussed FHH with their doctors, but this variable was not related to discussions with family members. Racial and ethnic disparities in health care have been documented, and death rates for most common, chronic diseases are significantly higher among racial and ethnic minorities than among Whites [51]. Individual and institutional measures of racial discrimination have been associated with individual health status [52]. In addressing this issue, the role of culturally competent communication in reducing ethnic and racial healthcare disparities has been highlighted [53, 54]. The findings from the present study highlight the importance of developing culturally competent FHH disease prevention initiatives, an area that has not yet received sufficient attention in the family history literature. Interventions to improve provider-patient communication generally may also improve communication about FHH.

In the present study, women were more likely to discuss FHH frequently with both family members and with doctors, which is consistent with other studies of communication related to family history and genetic susceptibility information [1, 28, 55]. Gender has also been found to be a predictor of differences in provider-patient communication behaviors [56]. However, we did not observe the differences in communication by educational attainment or race/ethnicity that have been found in other studies on family history [1, 42]. This difference may be because most research on communication about family history or genetic susceptibility has not included diverse or underserved populations [57]. Factors predicting communication about FHH information may well differ in a medically underserved population of patients served by community health centers. These findings also highlight that in order to use FHH information for disease prevention on a population level, it will be critical to develop strategies to engage men.

This study had a number of limitations that should be considered in interpreting the results. First, qualitative studies have suggested that factors such as emotional closeness and personal likeness, as well as biological relatedness, may affect how individuals understand their family history of disease [58–60], and, therefore, their perceptions of their family

history may differ from their objective family history. Second, our outcome variables assessed patients' perceptions of the frequency of discussions about FHH, but we were not able to examine these conversations objectively or over time. Patients may have found it socially desirable to report having frequent discussions about family health history with their doctors or family members, or, conversely, may not have recalled some discussions about family health history, which could affect their responses about the frequency of these discussions. In addition, we were unable to examine the content of the communication occurring between patients and their family members or providers, and investigating whether these discussions are initiated by patients or providers is an important issue for future research. Third, the included measures of behavioral risk only captured a subset of possible risk factors. Fourth, because of the cross-sectional design of this study, the direction of observed associations is not clear. Fifth, while we were able to gather responses from a racially and socioeconomically diverse group of community health center patients, the results of this study may not be generalizable to other populations as factors unique to community health centers could have influenced the observed results.

#### 4.2. Conclusion

The findings from this study indicate that having ongoing discussions about FHH with family members and doctors may be related to patients having a family history of some common chronic diseases, but not others. Those patients who are frequent health information seekers also report engaging in conversations about FHH more frequently. However, patients who may be most in need of discussion about disease prevention and control strategies based on an increased behavioral risk (e.g., not meeting physical activity recommendations) might be less inclined to have frequent conversations about FHH. Patients who have experienced racial discrimination in health care also talk less with providers about FHH. These results therefore add to our understanding of patient factors that might affect the collection and use of FHH in disease prevention and control initiatives in primary care. Important next steps include investigating whether and how these communication behaviors affect the adoption of tailored behavioral recommendations by patients. Understanding the mechanisms that underlie how discussion of FHH information might influence downstream behaviors is essential to planning effective clinical intervention approaches that can improve the health of patients.

#### 4.3. Practice implications

The results presented here indicate that interventions might be needed to encourage providers to follow up on patients' family history more systematically and to assist patients in initiating these conversations with their family members and doctors. These findings suggest that it will be particularly important to target interventions to increase discussion of FHH to patients with a family history of diabetes, those who are not meeting physical activity recommendations or do not generally seek health information, and men. The results also point to the importance of developing culturally competent interventions to improve provider-patient communication about FHH. In order for FHH information to be used to tailor disease prevention and control recommendations to improve patients' health, providers will need to discuss and update this information with patients over time and to reach those patients who might not initiate these conversations.

# Acknowledgments

This research was supported by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health. We would like to thank the Suffolk County Department of Health Services, the Health Center Administrators, the data collectors, and the patients who agreed to participate in this study.

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Kaphingst et al.

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Kaphingst et al.



#### Figure 1.

Steps to using family history information in primary care

#### Table 1

Characteristics of participating community health center patients.

Variable	N (%)
Family history	
Diabetes (n=1052)	604 (57.4)
Heart disease (n=1047)	429 (41.0)
Cancer (n=1040)	458 (44.0)
Personal diagnosis	
Diabetes (n=1056)	148 (14.0)
Heart disease (n=1038)	107 (10.3)
Cancer (n=1039)	60 (5.8)
Education (n=1038)	
Less than high school degree	182 (17.5)
High school degree/GED or some college	724 (69.8)
College degree or higher	132 (12.7)
Gender (n=1048)	
Male	266 (25.4)
Female	782 (74.6)
Age (n=1016)	
Less than 35	495 (48.7)
35 or greater	521 (51.3)
Race/ethnicity (n=1006)	
White, non-Hispanic	266 (26.4)
Black, non-Hispanic	307 (30.5)
Hispanic	347 (34.5)
Other	86 (8.5)
Health literacy (n=1015)	
High likelihood of limited health literacy	307 (30.3)
Possibility of limited health literacy	362 (35.7)
Adequate health literacy	346 (34.1)
Country of birth (n=1061)	
USA	637 (60.0)
Outside USA	424 (40.0)
Language of survey administration (n=1061)	
English	873 (82.3)
Spanish	188 (17.7)

#### Table 2

Bivariate associations between predictor variables and frequency of discussion about family health history with family members and doctors.

	Talking frequently wit	h family members	Talking frequently with doctors	
	$\chi^2$ or t value	p-value	$\chi^2$ or t value	p-value
Family history				
Diabetes	10.0	0.002	5.3	0.022
Heart disease	14.9	< 0.001	6.8	0.009
Cancer	15.7	< 0.001	15.1	< 0.001
Behavioral risk factors				
Body mass index	-0.20	0.84	-0.29	0.77
Perceived overweight	0.22	0.64	0.17	0.68
Meeting physical activity recommendations	9.9	0.002	6.7	0.010
Health information seeking				
Newspaper	27.1	< 0.001	34.3	< 0.001
Television	18.1	< 0.001	22.8	< 0.001
Internet	8.5	0.004	6.2	0.012
General	62.3	< 0.001	55.9	< 0.001
Health care discrimination	0.04	0.84	3.6	0.059
Patient characteristics				
Health literacy	0.24	0.89	3.5	0.17
Education	6.3	0.043	1.6	0.44
Age	-2.1	0.035	-2.2	0.028
Race/ethnicity	0.51	0.92	1.8	0.60
Female	27.4	< 0.001	19.0	< 0.001
Covariates				
Diagnosis of diabetes	0.16	0.69	4.3	0.037
Diagnosis of heart disease	2.2	0.14	8.1	0.004
Disease of cancer	0.14	0.71	0.11	0.74
Survey language	0.18	0.67	0.29	0.59
Country of birth	0.02	0.88	0.75	0.78

#### Table 3

Predictors of talking frequently with family members about family health history in a multivariable model (n=881).

Variable	Odds ratio	95% confidence interval	p-value
Family history			
Cancer	1.50	(1.09, 2.05)	0.012
Heart disease	1.52	(1.10, 2.08)	0.010
Health information seeking			
Newspaper	1.89	(1.30, 2.73)	0.010
General	2.45	(1.75, 3.44)	< 0.001
Gender <sup>a</sup>	1.98	(1.42, 2.77)	< 0.001
Age	1.00	(0.99, 1.01)	0.74
Educational attainment <sup>b</sup>			
Less than high school degree	0.72	(0.46, 1.10)	0.23
High school degree/GED or some college	0.84	(0.60, 1.16)	0.94
Race/ethnicity <sup>C</sup>			
White	0.91	(0.51, 1.65)	0.29
Black	1.13	(0.64, 2.01)	0.62
Hispanic	1.22	(0.69, 2.16)	0.29

<sup>a</sup>Male is comparison category

<sup>b</sup>College degree or higher is comparison category

 $c_{"}$ Other" is comparison category

#### Page 16

#### Table 4

Predictors of talking frequently with doctors about family health history in a multivariable model (n=844).

Variable	Odds ratio	95% confidence interval	p-value
Family history			
Heart disease	1.66	(1.22, 2.24)	0.011
Meeting physical activity recommendations	1.43	(1.05, 1.93)	0.022
Health information seeking			
Newspaper	1.96	(1.37, 2.82)	< 0.001
General	2.46	(1.73, 3.49)	< 0.001
Health care discrimination <sup>a</sup>	0.47	(0.29, 0.78)	< 0.001
Gender <sup>b</sup>	1.86	(1.32, 2.60)	< 0.001

 $a_{\text{``Worse than other races'' compared to other categories}$ 

<sup>b</sup>Male is comparison category