Association between screening family medical history in general medical care and lower burden of cancer worry among women with a close family history of breast cancer

Robert Gramling, MD [1], David Anthony, MD [1], Jan Lowery, PhD [2], Lori Ballinger, MS [3], Deb Ma[4], Rana Habbal, MA [5], Nancy Leighton, RD[5], Deborah Bowen, PhD[6]

Purpose: Soliciting family medical history (FMH) is the initial step in the process of screening for heritable cancer risk in medical care. We investigate whether recent solicitation of FMH in general medical care is associated with cancer worry among a sample of women having a first-degree relative with a breast cancer diagnosis. **Methods:** Surveys were mailed to women registered with the Cancer Genetics Network having a first-degree relative with a breast cancer diagnosis and a regular source of medical care. The independent measure consisted of two items for solicitation of FMH based on validated measures of clinical interactions with one's physician; the dependent measure was a novel measure of cancer worry based on validated patient-centered measure of distress; and the secondary measures were 6-point scales for perceived likelihood of developing breast cancer and perceived severity of breast cancer as a health outcome. **Results:** A total of 353 women responded and met eligibility criteria (76.4% minimum response rate). One fifth reported no cancer worry during the past 4 weeks. After adjustment for age, education, pedigree features, and clustering within families, recent FMH solicitation was associated with lower odds of cancer worry (odds ratio = 0.58; 95% confidence interval = 0.51–0.70). FMH solicitation was associated with lower perceptions of the severity of developing breast cancer but not with the perception of cancer likelihood. **Conclusions:** Our data do not support the hypothesis that FMH solicitation in general medical practice causes cancer worry. In fact, we observed a protective association possibly explained by influences on perceptions of breast cancer severity. Prospective research among less select populations is necessary. ***Genet Med* 2005:7(9):640–645.**

Key Words: *screening, genetics, primary care, psychosocial functioning, cancer worry*

Soliciting a family medical history (FMH) is the first step toward identifying women with clinically relevant degrees of genetic breast cancer risk. For this purpose, FMH constitutes a genetic screening tool[1–5] that is commonly used in medical practice[4,6] and is endorsed by the U.S. Surgeon General.[7] Evidence is mounting in support of tailoring preventive care for women with high degrees of genetic breast cancer risk,[8–10] yet little evidence is available to describe the psychosocial impact of FMH screening processes designed to identify such women. As computer-based supports for pedigree analysis emerge,[11–15] understanding the beneficial and adverse effects of screening FMH becomes a salient and pressing public health concern.

Anxiety is a frequent unintended outcome of many screening interventions.[16] Worry about developing breast cancer is a specific symptom of anxiety that can promote dysfunctional coping behaviors[17] and is more indicative of which women will seek DNA testing than general anxiety.[18] Although it has been established that many women with a close FMH of breast cancer experience cancer worry[19–23] and that such worry is greater among those women having a family history than those without,[22] it remains unclear how handling of FMH information by one's regular doctor impacts preexisting cancer worry. Understanding whether, and how, current FMH screening practices impact cancer worry is essential to guide subsequent translation of genetic advances into clinical practice settings.

This study was designed to describe the relationships between recent exposure to FMH solicitation in the context of routine medical care and the presence of worry about developing breast cancer.

From the [1]Brown Medical School, Providence, Rhode Island; [2]University of Colorado Health Sciences Center, Denver, Colorado; [3]University of New Mexico Health Sciences Center, Albuquerque, New Mexico; [4]Huntsman Cancer Institute, University of Utah, Salt Lake City, Utah; [5]University of California, Irvine, California; [6]Fred Hutchinson Cancer Research Center, Seattle, Washington.

Robert Gramling, MD, Center for Primary Care and Prevention, Memorial Hospital of Rhode Island, 111 Brewster Street, Pawtucket, RI 02860.

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MATERIALS AND METHODS

Design

We performed a cross-sectional survey using a mailed questionnaire during the winter of 2003 to the spring of 2004 among women registered with the Cancer Genetics Network (CGN).

Setting

The CGN[24–26] is a federally funded, collaborative project that aims to provide infrastructure for studying the genetic basis of cancer susceptibility; to understand the psychosocial, ethical, legal, and public health issues related to genetic susceptibility to cancer; and to investigate the best means for incorporating such information into medical care. One major objective of the CGN is to recruit individuals having a family history, but no personal history, of cancer to create a contact registry for future studies related to cancer susceptibility. All consenting participants complete a baseline telephone interview consisting of a four-generation pedigree and sociodemographic information. All enrollees agree to be approached for participation in future research studies and are contacted annually to update their baseline data.

The CGN comprises eight recruitment sites across the United States. Half of these sites recruit participants with population-based methods, and the other half use clinic-based recruitment strategies.[26] This study was restricted to participants recruited to the CGN by population-based strategies to minimize the selection bias represented by recruiting individuals from high-risk cancer centers and genetic counseling programs. All CGN recruitment, interviews, and follow-up protocols were standardized across centers and approved by the site institutional review board for protection of human subjects.

Participants

We mailed a cover letter, refusal card, and survey to 585 women registered with the CGN who met the following criteria as established by the baseline telephone interview completed on recruitment to the CGN: 25 to 65 years of age, family history of breast cancer in a first-degree relative (FDR), and no personal history of a major cancer (i.e., any cancer other than nonmelanomatous skin cancer). Final eligibility for this study included women who had a regular source of medical care and who visited their doctors within the past year. These final criteria could be assessed only for those completing the study questionnaire. Our response rate calculations assume that all nonresponders would have met these final eligibility criteria and therefore are likely to have biased our response rates downward.

Data collection

The 7-page questionnaire consisted of 34 multiple-choice items. Participants were provided postage-paid return envelopes and refusal postcards. Ten days after the initial mailing, three attempts were made to contact nonresponders by telephone over a 1-week period. Those contacted could refuse participation or request another questionnaire. Those unable to be reached by telephone were mailed a second questionnaire within 3 weeks after the initial mailing.

Measures

The independent and dependent measures were designed explicitly for the goals of this study and underwent qualitative evaluation before arrival at the final items. All measures were subsequently pretested in the final instrument for question comprehension, response option comprehension, and response burden among 25 women of diverse educational backgrounds.

Independent variable

Family medical history solicitation

We defined FMH solicitation to be marked by at least the active collection of first-degree family history. FMH can be solicited by written or spoken methods in the clinical setting. Therefore, we operationalized our definition by including the following two questions: "Have you ever **filled out forms** for your regular doctor that asked you for information about health problems in your immediate family (parents, brothers or sisters)?" or "Has your regular doctor **ever asked you** for information about health problems in your immediate family (parents, brothers or sisters)?"

Response options for both of the above independent variable items included "Yes, in the last year," "Yes, more than 1 year ago," "Yes, I don't remember when," and "No." A response of "Yes, in the past year" to either item was considered positive for FMH solicitation. These items were adapted from a similar validated measure of patient interactions with their regular physician.[27] To reduce recall error, we limited our timeframe to the last year. Self-report about topics arising in the medical encounter have been demonstrated to be valid,[28] particularly when the issue is relevant to the patient.

Main dependent variable

Cancer worry

We considered using the Cancer Worry Scale (CWS), but chose not to do so for the following reasons: The CWS has neither thresholds nor minimally important differences established by which to interpret the clinical significance of mean scores; others have challenged the validity of the CWS as a linear scale;[22] many versions of the CWS exist in the literature;[21,22,29,30] and prior related work demonstrates a floor effect with the CWS[22] in which much of the variability at the low end of the scale is captured by one item related to frequency of cancer-related thoughts, a measure of awareness rather than distress. The Impact of Events scale[18] also has been used to measure breast cancer worry; however, the Impact of Events scale addresses levels of distress related to more traumatic life events than we thought FMH solicitation would represent. Therefore, we chose to develop a new patient-centered measure with explicit goals of establishing a clinically interpretable and sensitive measure of whether the individual is

bothered by any thoughts about her breast cancer risk during the past month or not.

Given these concerns, we modeled our measure of cancer worry on the validated wording and pictograph metric (emotive faces) of the Dartmouth COOP Chart triage measure for emotional distress:[31] "During the past 4 weeks. . .how much have you been bothered by thoughts or worry about your chances of getting breast cancer?" Responses included "Not at all [happy face]," "Slightly," "Moderately [neutral face]," "Quite a bit," and "Extremely [sad face]."

Intermediate outcomes

We were interested in gaining insight into processes by which FMH solicitation might influence cancer worry. We considered both the perceived likelihood of developing breast cancer and the perceived severity of breast cancer as a health outcome for potential explanatory variables for this relationship because identification of an FDR during FMH screening is likely to stimulate some consideration of the probability of developing breast cancer and the survivability of breast cancer. These explanatory variables represent intermediates in the association under study, so they are considered to be neither confounders nor effect modifiers. For both constructs, we used single-item measures with 6-point scales that have been advocated in the risk perception literature.[32,33] For perceived likelihood, we asked the following: "How likely do you believe it is that you will get breast cancer someday?"(Response options: 1 = No chance, 6 = Certain to happen.) For perceived severity, we asked the following: "Getting breast cancer would be a very serious problem." (Response options: 1 = Strongly disagree, 6 = Strongly agree.) We assessed the association with FMH using the Student *t* test for crude analyses and a multiple linear regression model for adjustment.

Potential confounder/effect modifying variables

We considered the following variables as potential confounders or effect modifiers of our main association between FMH solicitation and cancer worry: age, education, and presence of higher risk family history characteristics. All eligible women had at least one FDR diagnosis with breast cancer. We defined high-risk family history characteristics by the method advocated by Scheuner et al.:[2] presence of an affected male FDR, multiple affected FDRs, or an FDR with age of onset of 50 years or less. We chose these criteria because they are all manifest in a first-degree FMH and are likely to attract physician attention on solicitation of FMH. We categorized women with no such characteristics (N = 173) into a lower family history risk group and those with at least one of the above criteria into a higher family history risk group (N = 180) for the purposes of stratified analyses.

Human subjects

The development and pretesting of the measures were approved by the Miriam Hospital Review Board for Protection of Human Subjects (Rhode Island).

The main study was approved by the institutional review boards for Miriam Hospital (Rhode Island), the University of New Mexico, the University of California at Irvine, the University of Colorado Health Sciences Center, and the University of Utah.

Analyses

Crude and stratified comparisons

Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated for comparisons involving dichotomous measures. Crude and stratified analyses were conducted for the association between FMH solicitation and cancer worry to investigate potential confounding or effect modification. Standard chi-square tests were used to identify statistically different proportions.

Control of confounding

We chose to fit a multiple logistic model for all potential confounding variables and proceeded with a backward model reduction procedure. The procedure involved inclusion of all covariates exhibiting at least a 10% change in effect on stratified analysis and removal if the absence of the covariate from the model resulted in less than 10% overall change in the final adjusted measure of effect.

Subanalyses to estimate recall bias

Recall bias occurs when the dependent variable (cancer worry) or a major confounding variable causes the participants to misclassify the independent variable (FMH solicitation during the past year) in the same direction. This study is susceptible to recall bias; however, simple subanalyses that address the relationship between FMH factors and recall of FMH solicitation can estimate the extent to which such biases are active. Recall is enhanced by the perceived relevance of the exposure to the individual.[34] Therefore, women with criteria for higher degrees of familial risk (early-onset disease in an FDR, multiple FDRs) would be expected to have more reliable recall than women without such characteristics. If we observe an association between high-risk FH characteristics and recall of FMH solicitation, then we would be more suspicious of recall bias than if we observe no such association. Therefore, we performed crude and adjusted analyses to identify whether the presence of high-risk FH characteristics predicted recall of FMH solicitation within the past year.

Clustering

We addressed the potential for clustering of both exposure and outcomes by family unit. Our sample contained 353 individuals from 325 families. Individuals within families might share common exposures and attitudes, thus making statistical assumptions of independence faulty. Ignoring such potential clustering primarily results in an underestimation of the true variance of a given variable, but can also influence the point estimate of effect. We performed a bootstrapping procedure[35] to better estimate the true variance by taking into account fa-

milial clustering. In this method, we created 500 sets of observations from the original data set, each time sampling only one member from each family. Sampling was done randomly and with replacement. The distribution of coefficients from the analysis of the 500 samples allows an estimate of the variance without the effect of clustering by family.

RESULTS

Response rate

Of the 585 women meeting initial eligibility criteria, 476 women returned a completed questionnaire. A total of 353 women met the final eligibility criteria of having and visiting a regular doctor within the past year. We calculated the minimum response rate of 76.4% as standardized by the American Association for Public Opinion Research.[36] This assumes that all of the 109 nonresponders would have met final eligibility criteria, and therefore the true response rate is likely to be underestimated. Table 1 compares the study sample with nonresponders. No statistically significant differences in mean age, education, family history, or major ethnicity characteristics were identified.

Descriptive

Table 1 presents the frequencies and distributions of all study variables. Approximately half of the sample (48%) reported having FMH solicited during the past year, and approximately one fifth reported no cancer worry over the past 4 weeks.

Main associations

A report of having an FMH solicited from one's regular doctor during the past year was associated with a lower odds of current cancer worry on both crude (OR 0.53; 95% CI 0.31, 0.89) analyses and analyses adjusted for age, education, higher risk family history characteristics, and clustering by family unit (OR 0.53, 95% CI 0.30–0.90). We observed an important degree of modification in our estimates of the relationship between FMH solicitation and cancer worry based on whether the woman's family history exhibited higher versus lower risk characteristics. Among women with a family history characterized as high risk, the magnitude of effect was lower and far less precise than among women whose family history did not exhibit any high-risk criteria (Table 2). Among those exposed to FMH solicitation (N = 163), neither mode of FMH collection (i.e., filling our forms vs. direct questioning) was more strongly associated with cancer worry than the other.

Intermediate associations

Women reported a high perceived severity of developing breast cancer (mean = 4.21; SD = 0.95; 0–5 scale) and a somewhat lower perceived likelihood of developing breast cancer someday (mean = 2.75; SD = 0.96; 0–5 scale). FMH solicitation within the past year was associated with lower perceived severity of breast cancer (mean difference = −0.30, $P = .01$) but not with perceived likelihood of developing breast cancer (mean difference = −0.03; $P = .75$). No effect modification by family history risk group was demonstrated for either association.

Table 1
Description of study sample

Characteristic	Study Sample (N=353)	Non-Responders (N=109)
	N (percent)	
Age		
mean (SD)	47.3 (10.48)	45.15 (13.30)
Education		
HS grad or less	48 (10)	14 (13)
Some college	125 (35)	50 (46)
College grad	180 (51)	45 (41)
Family history characteristics		
Higher risk criteria:		
Affected father or brother	0 (0)	1 (1)
FDR with onset ≤ age 50 years	161 (46)	49 (45)
Multiple affected FDR's	61 (17)	21 (19)
Any of the higher risk criteria	180 (51)	61 (56)
No higher risk criteria	173 (49)	48 (44)
Non-white	7 (2)	1 (1)
Ashkenazi	8 (2)	1 (1)
FMH solicited within past year	163 (48)	
Presence of cancer worry during last 4 weeks	283 (78)	
Perceive developing breast cancer to be very serious problem		
Strongly agree	160 (46)	
Agree	130 (37)	
Somewhat Agree	39 (11)	
Somewhat Disagree	11 (3)	
Disagree	6 (2)	
Strongly Disagree	2 (<1)	
Perceived likelihood of developing breast cancer in lifetime		
Certain to happen	11 (3)	
Very likely	56 (16)	
Likely	144 (42)	
Unlikely	107 (31)	
Very unlikely	21 (6)	
No chance	5 (1)	

SD, standard deviation; FDR, first-degree relative; FMH, family medical history.*Statistically significant difference at $P < .05$.

Recall bias analysis

Women with high-risk family history characteristics were neither more nor less likely to report FMH solicitation than

Table 2
Crude and adjusted estimates of association between family medical history solicitation and breast cancer worry stratified by family history risk group

	Any cancer worry	No cancer worry	OR (95% CI)	OR_{adj} (95% CI)
Lower risk family history group (n=159)				
FMH solicited	52	27	0.44 (0.21, 0.92)	0.47 (0.42, 0.52)
FMH not solicited	65	15	–-	–-
Higher risk family history group (n=172)				
FMH solicited	64	18	0.65 (0.30, 1.43)	0.68 (0.53, 0.91)
FMH not solicited	76	14	–-	–-

FMH, family medical history; OR, odds ratio; CI, confidence interval.Logistic regression model: breast cancer worry = FMH solicited in last year, age, education. Control of clustering within families by repeated random sampling with replacement

those without such FMH characteristics after adjusting for age and education (OR_{adj} 0.94; 95% CI 0.60–1.45).

DISCUSSION

We observed a protective association between recent FMH solicitation in medical practice and the likelihood of currently being bothered by worry about developing breast cancer among women with a close family history of breast cancer. We also found this association to be stronger for women with lower-risk family history characteristics compared with those with high-risk. To our knowledge, this is the first study that describes the potential relationship between screening FMH and cancer worry among women with a close family history of breast cancer.

Little previous work has been done that addresses the psychosocial outcomes of screening family histories for inherited disease risk among undifferentiated patient populations. Qureshi et al. conducted a small randomized trial (N = 76) among a general practice population to assess whether administering an FMH questionnaire (not limited to cancer) resulted in an increase in anxiety.[37] They observed an increase in short-term generalized anxiety symptoms and a long-term increase in pessimistic views about one's future health. Leggatt et al.[38] conducted a descriptive study among 2265 patients of a general practice in England. Individuals were mailed a family history screening questionnaire to identify individuals at high genetic risk of colorectal or breast cancer. Among the 604 patients completing the study, 568 were informed of a screen-negative result. No change from baseline cancer worry was found at 4 weeks postscreening.

Physicians lack confidence in their ability to assess inherited cancer risk.[39] Our results found no association between FMH solicitation and the perceived likelihood of breast cancer. This suggests that probability feedback subsequent to FMH solicitation might be absent, weak, or generally enough as not to challenge a patient's existing understanding of her risk.[40] Newly developed pedigree assessment tools will support the physician to provide more explicit probability feedback. Their use in primary care might represent an important change from existing FMH screening processes and will warrant close evaluation of their impact on cancer worry.

In contrast with its impact on perceived likelihood, our findings did identify an association between FMH solicitation and reduced perceptions about the severity of developing breast cancer. Physicians frequently assess FMH in the context of preventive recommendations that emphasize the benefits of detecting cancer early. It is possible that FMH solicitation facilitates a window for optimistic messages about the controllability of breast cancer and therefore alleviates cancer worry. Many emerging FMH screening interventions focus on providing women with feedback about their probability of developing cancer. However, our findings suggest that intervention developers should not underestimate the importance of feedback about the controllability of breast cancer.

This study has important limitations. First, this is a cross-sectional study from which causal relationships cannot be clearly understood, and reverse-causality (i.e., "outcome" actually causing "exposure") is of concern. Our observed association is not explained by reverse causality because this would indicate that physicians are preferentially soliciting FMH from women who are not concerned about breast cancer. Our clinical experience suggests that physicians either solicit FMH as part of their usual clinical habits (i.e., true screening test) or as reaction to inquiries, concerns, or symptoms experienced by the patient. Under either of these two scenarios, reverse-causality would be expected to demonstrate a *higher* level of distress among women whose FMH was solicited.

Second, recall bias is of concern if our dependent variable, worry, affects one's recollection of having her FMH solicited. We performed a subanalysis to estimate what degree of recall bias might be present in this study. Recall is enhanced by the salience of the issue to the individual.[34] Therefore, if recall bias was a major contributor to our observed associations, we would expect women with higher-risk family histories to recall FMH solicitation to a greater degree than women with lower-risk family histories. We found no such association on subanalyses and conclude that recall bias is likely not a major threat to validity in this study.

Finally, selection bias is possible. Women registered with the CGN might be more interested in information related to inheritance, be more active in prevention efforts, or demonstrate different levels of cancer worry than other nonregistered women. We sought to minimize such selection bias by recruit-

ing women only from population-based CGN recruitment centers, not from clinic-based centers that capture women engaged in genetic-related activities. Furthermore, we included only women with a regular source of routine medical care that they have used in the past year. We believe this sample provides a useful first step toward better understanding of the implications that screening FMH has on cancer worry among women with a close family history of breast cancer. More research among less differentiated patient populations is essential to better understand the public health impacts of screening for heritable cancer risk in the routine medical care setting.

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