Published in final edited form as:

J Cancer Educ. 2009 ; 24(4): 351–356. doi:10.1080/08858190902876304.

Beliefs About Heritability of Cancer and Health Information Seeking and Preventive Behaviors

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Abstract

Background—Individuals' beliefs about cancer heritability could affect their health information seeking and health behaviors.

Methods—Data from 5,813 English-speaking adult respondents to the 2003 Health Information National Trends Survey were analyzed.

Results—Individuals who believed that knowledge of family history or genes can reduce cancer risk were significantly more likely to have ever looked for cancer information. Ever smokers who believed that genes are the main cause of lung cancer were significantly more likely to smoke currently.

Conclusions—Patients need to be educated about genetic susceptibility to cancer in ways that support information seeking and engagement in protective behaviors.

INTRODUCTION

The rapidly advancing pace of research in genetics and genomics means that much information about the inherited component of cancer risk is becoming available to the public through a variety of sources. Genetic discoveries appear regularly in the mass media,¹ for example, and these stories may affect individuals' beliefs about the role of genes in cancer causation,¹⁻³ as well as their subsequent preventive behaviors. This study was designed to address the question of whether beliefs about the heritability of cancer are correlated with individuals' health information seeking and protective health behaviors.

This analysis is based on an adaptation of the Common Sense Model, which states that the effects of genetic susceptibility information on health information seeking and behaviors might depend upon individuals' cognitive representations of disease risk, such as their beliefs about the causes of cancer, and how these representations are then translated to behavior.⁴ The posited relationship between beliefs about genetic causation of cancer and health information seeking has not previously been examined empirically. Some prior research indicated that diseases with a genetic cause may be conceptualized as less controllable or not preventable,⁵⁻⁷ beliefs that might inhibit individuals' information seeking. Alternatively, beliefs about genetic susceptibility to cancer could increase patients' perceptions of personal risk,⁸ thereby increasing their motivation to seek health information.⁹ Previous research has shown that cancer information seeking is related to sociodemographic characteristics, cancer knowledge, health care access, and personal and family history of cancer.^{10, 11} Here we investigated whether health information seeking was correlated with beliefs about the heritability of cancer.

We also examined the relationship between these beliefs and protective health behaviors. Prior related research has generally been limited to examining screening behaviors among high-risk families, communication within families, or interest in genetic testing.^{5, 12} The association of beliefs about genetic causation with health behaviors in the context of the general public and common cancers has been largely unexplored. Related studies investigating the effect of providing new genetic susceptibility information on health behaviors have had mixed findings.⁸ Genetic risk information has alternatively been hypothesized to increase motivation to change behavior by increasing perceived risk or to decrease motivation by weakening efficacy beliefs or heightening fatalism.¹³ Empirical research is needed to examine how pre-existing beliefs about the genetic basis of cancer are related to protective health behaviors.

Data from the first wave of the Health Information National Trends Survey (HINTS), which was conducted with a nationally representative sample of U.S. adults,⁹ provided a unique resource with which to investigate these questions. Based on our theoretical model, we hypothesized that endorsing beliefs about the heritability of cancer would be positively associated with health information seeking and engaging in protective health behaviors; we also explored the role of educational attainment in these associations.

MATERIALS AND METHODS

2003 Health Information National Trends Survey

This study analyzed data from adult respondents to the 2003 HINTS wave.⁹ Trained interviewers administered the telephone survey to a representative sample of households drawn from U.S. telephone exchanges; exchanges with high proportions of Black and Hispanic residents were oversampled. One adult aged 18 or older was selected within each household. Interviews were completed in English and Spanish. The response rate for the household screener was 55% and for the interview was 63%.⁹ Due to the small number of Spanish-speaking respondents, we included only those who completed the English interview (n=5,813). This study was approved by the National Institutes of Health Office of Human Subjects Research.

Information Seeking and Health Behavior Variables

Information Seeking—Health information seeking was assessed with two dichotomous items: “Have you ever looked for information about cancer from any source?” and “In the past 12 months, did you use the Internet, whether from home or somewhere else to look for health or medical information for yourself?”

Health Behaviors—Respondents were asked whether they had ever smoked at least 100 cigarettes in their lifetimes; ever smokers who reported that they currently smoked cigarettes at least some days were classified as current smokers. For physical activity, respondents were asked whether they engaged in regular activity at least once a week.

Beliefs About Inherited Cancer Risk

1. Belief that knowledge about genes and family history can reduce the chance of cancer was a dichotomous variable scored “yes” if answers to either of two open-ended questions about ways to reduce risk of cancer (e.g., “Can you think of any thing people can do to reduce their chances of getting cancer?”) included knowledge of family history, good genes, or genetic testing.
2. Belief in family history as a cancer risk factor was assessed by categorizing respondents (a lot vs. a little/not at all) based on the item: “Do you think that having

a family history of cancer increases a person's chance of getting cancer a lot, a little, or not at all?"

3. Belief that genes are the main cause of lung cancer was assessed by dichotomizing responses (strongly agree/somewhat agree vs. somewhat disagree/strongly disagree) to the item "Whether a person gets lung cancer depends more on genes than anything else."

We did not combine these into a scale because different subsets of respondents were asked the items (belief 1: all respondents; 2: randomly selected half of respondents; and 3: ever smokers).

Control Variables

Media Exposure—The survey assessed hours per typical weekday watching television or listening to the radio; days in the past week reading a newspaper or magazine; and ever use of Internet or e-mail. Responses to continuous items were dichotomized with a median split.

Access to Health Care—Respondents reported whether they had a particular health professional that they saw most often and whether they had any kind of health care coverage.

Personal and Family Cancer History—Self-reported health and whether respondents had a personal or family history of cancer were assessed.

Sociodemographics—Respondents were asked to report their height and weight, race/ethnicity, annual household income, educational attainment, marital status, age and sex.

Analysis

SUDAAN 9.0.0 was used for the analysis. Descriptive statistics were examined for all variables. Bivariate associations were assessed with chi-square tests for dichotomous variables and t-tests for continuous variables. Multivariate models were built for all significant bivariate associations. For multivariate logistic and linear regression models, backwards elimination with forward checking was first used to select a model with control variables that were associated with the outcome variable ($p < 0.2$). The primary predictor variable was then added to the model; statistical significance was assessed as $p < 0.05$. Interactions with education were tested in the information seeking multivariate models. Respondents with missing data were excluded.

RESULTS

Description of Sample

The majority of respondents were female (61%) and white, non-Hispanic (75%). About half were 50 years of age or older (46%). Sixty percent reported a household income of less than \$50,000; 39% had no education beyond high school. Almost all respondents (90%) had some type of health care; 69% had a usual health care provider. About half described themselves as being in excellent or very good health (46%). Two-thirds reported having a family history of cancer (65%), while about 13% had been diagnosed with cancer themselves. Forty-eight percent reported ever smoking; 42% of ever smokers were current smokers. About 59% were overweight or obese (body mass index of 25.0 kg/m² or higher).

Beliefs about Heritability of Cancer

Few respondents offered that knowledge of family history, good genes or genetic testing could reduce the chance of getting cancer in response to open-ended questions (see Table 1). However, about 80% believed that having a family history of cancer increases a person's chance

of getting cancer “a lot” compared to “a little” or “not at all.” One-third of ever smokers (33%) somewhat or strongly agreed that genes were the main cause of lung cancer.

Information Seeking and Media Exposure

About half of respondents reported having ever looked for cancer information (49%) or having used the Internet to look for personal health or medical information in the previous 12 months (54%). Approximately 32% watched more than three hours of television and listened to more than one hour of radio on a typical weekday. In the past week, 47% had read a newspaper on more than 3 days and 45% had read a magazine on more than 1 day. About two-thirds (66%) had ever gone online to use the Internet.

Relationships of Cancer Heritability Beliefs With Information Seeking and Health Behaviors

We examined the significant bivariate associations shown in Table 2 in multivariate models. Individuals with the belief that knowledge of family history/genes can reduce cancer risk were about twice as likely to have ever looked for cancer information (estimated odds ratio 1.88, 95% confidence interval: 1.11-3.18), controlling for educational attainment, personal and family history of cancer, magazine reading in previous week, ever use of Internet, race/ethnicity, gender, age, income, and having a usual health care provider (see Table 3). We did not observe significant effect modification by educational attainment in this model. Education was, however, a significant correlate of having ever looked for cancer information; individuals with less than a high school degree were about half as likely to have ever looked for cancer information as those with a college degree or higher (estimated odds ratio 0.50, 95% confidence interval: 0.36-0.70), controlling for the other variables in the model.

In a multivariate model, among ever smokers, those having the belief that genes are the main cause of lung cancer were more likely to smoke currently (estimated odds ratio 1.45, 95% confidence interval 1.14-1.83), controlling for educational attainment, self-reported health, television use, ever use of Internet, age, income, marital status, having health care coverage, and having a usual health care provider (see Table 4).

DISCUSSION

Beliefs about Inherited Cancer Risk and Health Information Seeking

This study investigated whether beliefs about the heritability of cancer were associated with health information seeking and protective health behaviors in a nationally representative sample of U.S. adults. We found that individuals who believed that knowledge of family history or genes can reduce cancer risk were more likely to have searched for cancer information, which adds a new dimension to what is known about the correlates of health information seeking.^{10, 11} Interestingly, however, belief in genes as the main cause of lung cancer was not associated with health information seeking, at least among ever smokers, which suggests that respondents might view risk based on family history differently from risk based on genes.

Some prior research provides support for the proposition that individuals might perceive these risks differently. For example, adult children of Alzheimer Disease patients who received disease risk information based on genotype had lower perceived risk and lower anxiety than those who received the same disease risk based on family history.¹⁴ Robb et al. (2007) have observed that individuals do not necessarily equate having a family history of colorectal cancer with having genetic susceptibility to the disease.¹⁵ These findings, together with our results, indicate the need for research on how individuals perceive similarities and differences between family history of and genetic susceptibility to cancer as shown by DNA testing, and how these beliefs affect subsequent behaviors. Future studies are needed that use additional items which separate more clearly beliefs related to family history from those related to genes.

Understanding the pathways by which beliefs about the heritability of cancer affect health information seeking will likely be of increasing importance for cancer education efforts. Concomitant with the generation of large amounts of genetic susceptibility information is the increasing emphasis being placed on patient empowerment in seeking information about cancer risk.¹⁶ Patient health information seeking is therefore likely to be increasingly affected by the challenges of genetic and genomic information.^{17, 18} Even today, patients seeking information about cancer quickly encounter changing facts about genetic susceptibility and genetic testing.¹⁷

The ability to engage with genetic information might depend upon individuals' educational level.¹⁸ In these analyses, education was a strong inverse correlate of information seeking, as has been observed by others.¹⁰ Patients with less education might be most strongly impacted by the rapid rate of growth in information about genetic susceptibility to cancer. While for some patients, new technologies and interactive media may enable innovative information interactions,^{16, 19} those with limited education or limited literacy may lack the skills necessary to seek health information in such environments. These findings therefore suggest that it will be critical to develop understandable ways of presenting information about the hereditary component of cancer risk to individuals who might not seek such information on their own.

The results presented here showed that individuals who believed that knowledge of family history or genes can reduce cancer risk were more likely to have ever searched for cancer information. Although these analyses were cross-sectional, they at least indicate that beliefs about heritability might lead individuals to seek out information about cancer. Longitudinal research is needed to explore further this association. The findings suggest that some individuals might be looking for information about how genes or family history affect cancer risk. Additional research is needed to examine the types of cancer information that different patients are seeking and whether and how they apply the information to their own health.

Beliefs about Inherited Cancer Risk and Preventive Health Behaviors

The results presented here showed that ever smokers who believed that genes were the main cause of lung cancer were more likely to smoke currently. This intriguing observation suggests that patients who do not engage in healthy behaviors may have reinforcing beliefs that genetic rather than lifestyle factors determine their cancer risk. Very little research has been done, however, to examine the relationship between beliefs about genetic causation of common cancers and health behaviors in the general public.

Prior related research has examined the effect of providing genetic risk information on health behaviors, particularly smoking. Although giving individuals genetic susceptibility information has led to some effects on upstream predictors of behavior change, long-term behavior change has not generally been observed.²⁰⁻²³ More research is needed, however, to examine how individuals' pre-existing beliefs about inherited cancer risk are associated with risk-reducing behaviors. If individuals believe that diseases with a genetic cause are less preventable, and this lessens their motivation to engage in preventive behaviors upon learning information about genetic susceptibility,⁶ this pathway would have important public health implications for education about genetic susceptibility to cancer. Further research is critical to developing ways of providing information about genetic susceptibility without eroding patients' motivation to engage in preventive behaviors. Our findings also imply that behavior change interventions might need to address individuals' beliefs about the genetic versus behavioral causes of cancer. These questions will become increasingly important as genetic susceptibility information is integrated into healthcare settings serving a more general population of patients.²⁴

Conclusion

There are several limitations of these analyses. The cross-sectional data do not allow inferences about causality. Non-respondents might have been significantly different than respondents on examined characteristics. The survey items related to beliefs about family history and genes as causes of cancer were limited, and the items were asked of different subgroups. One belief item was specific to lung cancer, and patients' beliefs about other cancers, as well as other common, complex diseases, might differ from the patterns observed here.

However, no other national surveys have simultaneously collected data on beliefs about inherited risk of disease, media use, information seeking and health behaviors using items that are theoretically grounded in health communication and behavior change theory.⁹ In addition, the large nationally representative sample allows for the analysis of subgroups.²⁵

Additional research regarding the associations observed here will be important to support the development of effective cancer education strategies that convey genetic susceptibility information. Longitudinal research is needed to examine how educational approaches based on genetic susceptibility or family history information affect beliefs about the causes of disease, and, in turn, how these beliefs affect behavioral outcomes. As our understanding of the genetic component of cancer risk advances, it is critical to develop strategies that educate patients about cancer risk while supporting their health information seeking and health protective behaviors.

Acknowledgments

This research was supported by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health. The authors thank Colleen McBride for comments on an earlier version of the manuscript and Amanda Parsad for her statistical assistance.

Supported by the Intramural Research Program of the National Human Genome Research Institute, National Institutes of Health.

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Table 1

Beliefs about heritability of cancer and health information seeking among respondents.

Characteristic	n (%) ^a
Beliefs about inherited risk	
Knowledge about genes/family history can reduce chance of cancer	
Yes	80 (1%)
No	5733 (99%)
Family history as a cancer risk factor	
A lot	2267 (80%)
A little/not at all	572 (20%)
Genes as main cause of lung cancer	
Strongly agree/somewhat agree	812 (33%)
Strongly disagree/somewhat disagree	1666 (67%)
Ever looked for information about cancer	
Yes	2864 (49%)
No	2939 (51%)
Used Internet to look for health/medical information in past 12 months	
Yes	2039 (54%)
No	1765 (46%)

^aPercentage values may not total 100 due to rounding. Values are percentages of available cases who were asked question.

Table 2

Bivariate associations between beliefs about heritability of cancer and information seeking and health behaviors.

Beliefs about heritability of cancer	Ever looked for cancer information Used Internet for health information		Current smokers (among ever smokers)		Exercise at least once per week	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Knowledge of family history/genes can reduce cancer risk						
Yes	76% ^a	24% ^a	46%	54%	84%	16%
No	47% ^a	53% ^a	45%	55%	76%	24%
Family history as a cancer risk factor						
A lot	49% ^b	51% ^b	46%	54%	77%	23%
A little/not at all	38% ^b	62% ^b	42%	58%	75%	25%
Genes as main cause of lung cancer	46%	54%	50% ^c	50% ^c	70% ^d	30% ^d
Strongly agree/somewhat agree	47%	53%	44% ^c	56% ^c	76% ^d	24% ^d
Strongly disagree/somewhat disagree						

^a p<.0001

^b p<.001

^c p<.01

^d p<.05

Table 3

Correlates of ever having looked for cancer information in a multivariate logistic regression model (n=5140).

Parameter	Estimated odds ratio (95% confidence interval)
Belief that knowledge of family history/genes can reduce cancer risk	
Yes	1.88 (1.11-3.18)
No	1.00 -----
Education	
Less than high school	0.50 (0.36-0.70)
Completed high school	0.51 (0.42-0.63)
Some college	0.65 (0.52-0.80)
College graduate or higher	1.00 -----
Personal history of cancer	
Yes	3.59 (2.73-4.72)
No	1.00 -----
Family history of cancer	
Yes	2.11 (1.78-2.50)
No	1.00 -----
Read magazines in past seven days	
More than 1 day	1.31 (1.12-1.54)
Less than or equal to 1 day	1.00 -----
Ever used Internet	
Yes	1.90 (1.54-2.35)
No	1.00 -----

^aControlling for race/ethnicity, gender, age, income, and having a usual health care provider.

Table 4

Correlates of current smoking among ever smokers in a multivariate logistic regression model (n=2283).

Parameter	Estimated odds ratio (95% confidence interval)
Belief that genes are main cause of lung cancer	
Strongly agree/somewhat agree	1.45 (1.14-1.83)
Strongly disagree/somewhat disagree	1.00 -----
Education	
Less than high school	1.49 (1.04-2.13)
Completed high school	1.75 (1.23-2.47)
Some college	1.66 (1.20-2.29)
College graduate or higher	1.00 -----
Self-reported health	
Excellent/very good	0.66 (0.52-0.85)
Good/fair/poor	1.00 -----
Watch television on average weekday	
More than 3 hours	1.26 (0.96-1.66)
Less than/equal to 3 hours	1.00 -----
Ever used Internet	
Yes	0.73 (0.51-1.06)
No	1.00 -----

^aControlling for age, income, marital status, having health care coverage, and having a usual health care provider.