

Perceptions of genetic discrimination among at-risk relatives of colorectal cancer patients

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Purpose: To explore the concerns of at-risk relatives of colorectal cancer patients about genetic discrimination and their awareness of current legislative protections. **Methods:** A questionnaire was sent to unaffected individuals with a family history of colorectal cancer who had enrolled in the Johns Hopkins Hereditary Colorectal Cancer Registry ($N = 777$). **Results:** Of the 470 respondents, approximately half rated their level of concern about genetic discrimination as high. The majority of respondents, 79%, learned about genetic discrimination from at least one media source (television, newspapers, magazines, and radio). If they were to pursue genetic testing, respondents with a higher level of concern about genetic discrimination would be significantly more likely to pay out of pocket, use an alias, or ask for test results to be excluded from their medical record. Awareness and understanding of legislation regarding genetic discrimination was found to be minimal. **Conclusion:** Findings from this study demonstrate the negative effect of concerns about genetic discrimination on decisions about utilization of genetic services. Stronger legislative protections against genetic discrimination and increased public education through the scientific community and media sources are needed. *Genet Med* 2004;6(6):510–516.

Key Words: genetic discrimination, genetic testing, legislation, media, colorectal cancer

Remarkable advancements in gene discovery and the development of genetic tests hold great promise for revolutionizing the practice of medicine. Accompanying these achievements, however, is the potential for misuse of genetic information. Due to the personal and predictive nature of genetic information, concerns have been raised about access to genetic information by insurers and employers. The term “genetic discrimination” has been used to describe the differential treatment of individuals or their relatives based on actual or presumed genetic differences as opposed to discrimination based on phenotype.¹ Little is known about the nature and extent of genetic discrimination despite a decade of debate among researchers and policy makers. Several anecdotal cases of genetic discrimination have been documented^{1–3} but few have been filed with the courts. Well-publicized cases include the Equal Employment Opportunity Commission (EEOC) case against Burlington Northern Santa Fe Railroad^{4,5} and that of Terri Sergeant

who was fired by her employer due to the costs of preventative treatment for $\alpha 1$ -antitrypsin deficiency.⁶

Several studies have demonstrated concerns about genetic discrimination in the general population as well as in those affected with genetic disorders and their families.^{7–9} Fear of genetic discrimination has been cited as a reason that patients decline genetic counseling and testing for conditions including cancer,^{10–15} Huntington’s Disease,^{16,17} and Fragile X syndrome.⁹ The Health Insurance Association of America maintains that public concerns are unwarranted as health insurers are not misusing genetic information, and that current federal law already provides sufficient protections.¹⁸ One study on the effectiveness of state genetic discrimination laws concluded that a person who is presymptomatic for a serious genetic condition faces little or no difficulty in obtaining health insurance.^{18,19}

Protections against genetic discrimination are afforded through both federal and state legislation. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) provides some protection against genetic discrimination, such as prohibiting the use of genetic information in denying or limiting health insurance coverage for members of a group plan. Forty-one states have enacted legislation on genetic discrimination in health insurance and thirty-one states have enacted legislation concerning the workplace.²⁰ At the federal level, the Americans with Disabilities Act (ADA) is also felt to provide some protection from genetic discrimination by employers; however, this has not been tested in the courts. Additionally, Executive Order 13145 prohibits federal government agencies from obtaining or using genetic information in hiring and pro-

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motion decisions. Most recently, the U.S. Senate passed the "Genetic Information Nondiscrimination Act of 2003" which, if enacted, would close some of the loopholes left by HIPAA. At the time of publication, the House had not considered this Act.

Because of the reported high level of concern about genetic discrimination despite legislative protections and few documented cases, we explored the concerns of at-risk relatives of colorectal cancer patients about genetic discrimination and the potential effect on utilization of genetic services. Additionally, we examined awareness and understanding of current state and federal legislation addressing genetic discrimination.

MATERIALS AND METHODS

Participants and procedures

A questionnaire was mailed in May 2002 to 777 participants identified from the Johns Hopkins Hereditary Colorectal Cancer Registry. Eligible individuals were those at least 18 years old with a family history of colorectal cancer (CRC) and without a personal history of CRC or known associated cancers. All eligible participants received a personalized letter of invitation explaining the purpose of the study, a questionnaire and a stamped return envelope from the Johns Hopkins Hereditary Colorectal Cancer Registry. Nonrespondents received a second mailing of all materials four weeks later.

Measures

A 10-page questionnaire was designed by the researchers for this study. Sociodemographic and medical information, including respondents' personal and family history of colorectal cancer and/or polyps, were collected. Respondents were asked to rate their level of concern about genetic discrimination on a 5-point Likert scale, and to describe the reasons for their concern or lack of concern. An open-ended question allowed respondents to describe any personal or family experience with genetic discrimination. Through multiple choice and Likert scale questions, respondents indicated awareness of and sources of information about genetic discrimination and legislation. Likert scale questions were also posed to determine respondents' hypothetical decisions about utilization of genetic services.

Data analysis

Data were stored and analyzed using SPSS 10.0 (Statistical Package for the Social Sciences). Descriptive statistics are reported for respondents' level of concern about genetic discrimination, source of information about genetic discrimination, interest in and utilization of genetic services, and awareness and impressions of genetic nondiscrimination legislation. Bivariate ordinal regression was performed to determine if decisions about utilization of genetic services were associated with level of concern about genetic discrimination. For each set of ordinal regressions, odds ratio estimates, corresponding 95% confidence intervals, and two-sided *P*-values were computed (*P* < 0.05 was considered statistically significant).

RESULTS

Response rate and sample description

Of the original 777 questionnaires sent, 544 were returned and 23 were undeliverable. Of those questionnaires returned and completed, 22 surveys were excluded from analysis because respondents either did not complete the family history section (*N* = 10), had a personal history of colorectal cancer (*N* = 5), or did not have a family history of colorectal cancer (*N* = 7). An additional 52 questionnaires were returned not completed, as the recipient declined to participate. Reasons cited were no time, no interest, concerns about privacy, other priorities, and compromised health. Thus, a response rate of 62% (*N* = 470/754) was achieved.

A description of the sample is presented in Table 1. More than half of the respondents were in the age range of 41 to 60 years and had a college degree or above. Reflecting the composition of the registry, respondents were predominantly female, Caucasian, and married with children. There were respondents from 48 states.

Table 1

Respondents' Sociodemographic Information (<i>N</i> = 470)	
Age (yrs)	
19–40	16.8%
41–60	58.1%
61+	25.1%
Gender	
Female	79.1%
Male	20.9%
Race	
Caucasian	94.9%
Hispanic	1.9%
African-American	1.5%
Asian	0.6%
Mixed/Other	1.1%
Education	
High school or less	15.9%
Some college	23.0%
College graduate +	61.1%
Marital status	
Single	10.3%
Married	70.9%
Separated/Divorced	13.6%
Widowed	5.2%
Children	
Yes	81.2%
No	18.8%

Concerns about genetic discrimination

A definition of genetic discrimination was provided in the survey so that all participants would have an understanding of the concept. The definition read: “When people or organizations make unfair decisions about someone who is currently healthy based on genetic information (results of genetic testing or family history information).” To determine the extent of concern about genetic discrimination, respondents were asked to rate their level of concern on a 5-point Likert scale (Fig. 1). Level 1 was labeled as “not concerned” and level 5 was labeled as “very concerned.” Approximately half of respondents, 45%, rated their level of concern as high, at level 4 or 5. About a third, 37%, rated their level of concern as lower, at level 2 or 3. Notably, 18% of respondents indicated no concern about genetic discrimination, corresponding to level 1. Reasons provided for lack of concern included trust in insurers, employers, health care providers or legislation ($N = 12$), age/medicare coverage ($N = 14$), belief that everyone has some level of risk ($N = 8$), that the benefits of genetic testing outweigh the risks ($N = 3$), and never having thought about it before ($N = 13$).

Experiences with genetic discrimination

Approximately 7% of respondents reported that they or a family member had experienced genetic discrimination. Respondents’ open-ended descriptions of their experiences were categorized as rated/higher premiums for life or long-term care insurance ($N = 7$), denial of health or life insurance coverage ($N = 4$), difficulty obtaining health or life insurance coverage ($N = 4$), problems with health insurance coverage ($N = 2$), denial of coverage for screening ($N = 5$), and perceived inability to change jobs ($N = 1$). Some of the reported experiences with discrimination were not related to colorectal cancer, but to conditions such as arthritis, diabetes, heart conditions, Charcot-Marie Tooth syndrome, and hip dysplasia.

With the limited information provided, it is difficult to unequivocally determine if any of the reported experiences involve actual genetic discrimination.

Source of information about genetic discrimination

The majority of respondents, 68%, were aware of genetic discrimination before receiving the survey. Those aware of genetic discrimination most commonly received their information from media sources, including television (58%), newspapers (58%), magazines (43%), and radio (16%) (Fig. 2). Learning about genetic discrimination from at least one media source was reported by 79% of respondents. Less often, respondents learned about genetic discrimination from a doctor (15%), genetic counselor (10%), other health care professional (5%), or researcher (3%). “Other” sources of information mentioned by 7% of respondents included “college,” “scientific journals,” “insurance agent,” “legislators,” “common sense,” and a “family member.”

Decisions about utilization of genetic services

The majority of respondents, 80%, were interested in pursuing genetic testing for colorectal cancer risk. Although 16% of the study population had been previously offered genetic testing, 8% chose to undergo testing. Respondents were asked about their previous or hypothetical decision-making concerning genetic testing (Table 2). Sixty-two percent reported that they would be likely or very likely to submit charges for genetic testing to their insurance company, whereas 35% would be likely or very likely to pay out of pocket to avoid submitting a claim. Fifteen percent would be likely or very likely to use an alias so that test results could not be connected with their name. The vast majority of respondents, 92%, would be likely or very likely to share their genetic information with

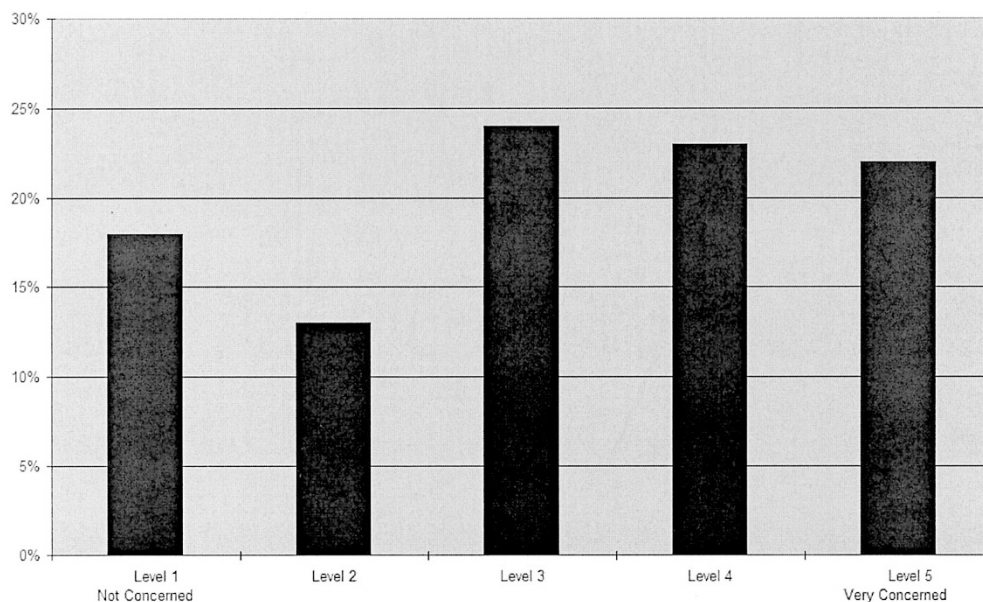


Fig. 1. Respondents’ level of concern about genetic discrimination ($N = 455$).

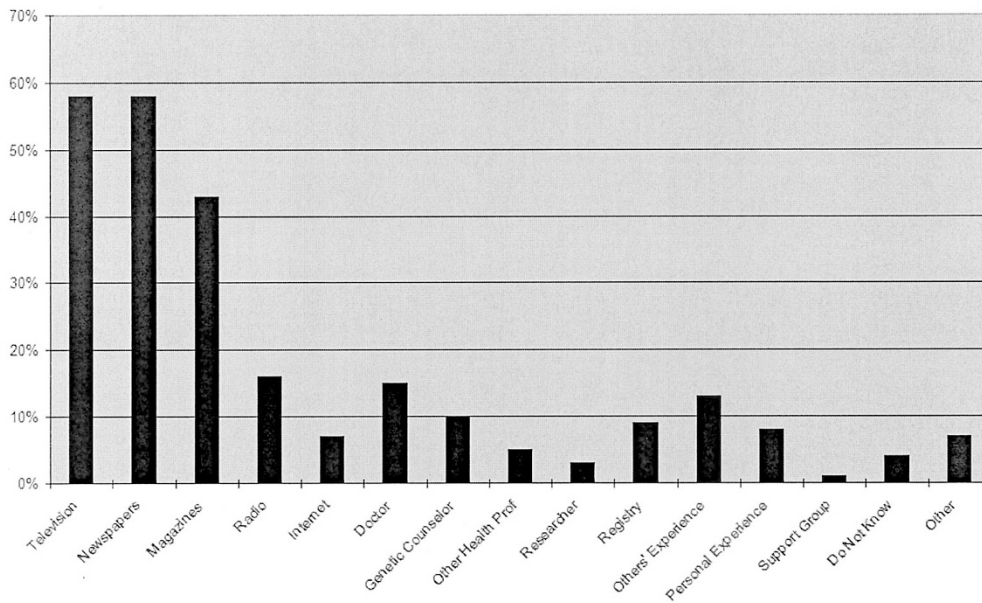


Fig. 2. Respondents' source of information about genetic discrimination (N = 312).

doctors. However, 47% would be likely or very likely to ask that genetic test results be excluded from their medical record.

Bivariate ordinal regression tests revealed a statistically significant association between higher level of concern about genetic discrimination and all five decisions related to utilization of genetic services ($P < 0.001$) (Table 3). Respondents who were more concerned about genetic discrimination would be 0.67 times or 33% less likely to submit the charges for genetic testing to their insurance company. Those who were more concerned would be 1.5 times more likely to pay out of pocket and use an alias when undergoing genetic testing. Respondents with a higher level of concern would be 0.74 times or 26% less likely to share their genetic information with doctors, and would be 1.6 times more likely to ask for genetic test results to be excluded from their medical record.

Awareness and impressions of genetic nondiscrimination legislation

Respondents had minimal awareness of current state and federal laws protecting against genetic discrimination. The ma-

jority, 88%, were not aware of any federal legislation regarding genetic discrimination. When asked specifically about the Health Insurance Portability and Accountability Act (HIPAA), 73% had never heard of the legislation. Regarding the existence of laws in their home state, 96% of respondents did not know, 1% responded that their state did not have a law, and 3% that their state did have a law addressing genetic discrimination.

Respondents were considered to be aware of genetic nondiscrimination legislation if they had knowledge of either federal or state laws. Among those aware of the legislation (N = 140), understanding was limited as 59% reported that they did not understand the laws at all (Table 4). Approximately half responded that that the legislation does "not at all" provide adequate protection against employment and insurance discrimination. Those who were considered the most aware of legislation (N = 92), answering either "to some extent" or "to a great extent" about how much they had heard or understood about the legislation, were significantly more likely to have a higher educational level ($P = 0.005$) and to have undergone genetic testing ($P = 0.04$).

Table 2
Respondents' Decisions about Utilization of Genetic Services (N = 457)

If you were to have or ever had genetic testing, how likely is it that you would:	Very unlikely	Unlikely	Likely	Very likely
1. Submit the charges for genetic testing to your insurance company?	22%	16%	17%	45%
2. Pay "out of pocket" for genetic testing to avoid submitting a claim to your health insurance company?	45	20	18	17
3. Use a fake name so that your genetic test results could not be connected to you?	71	14	8	7
4. Share your genetic information with your doctors?	2	6	17	75
5. Ask for your genetic test results to be excluded from your medical record?	36	17	20	27

Source of information about genetic nondiscrimination legislation

Those who were aware of laws regarding genetic discrimination identified the source of their information (Fig. 3). Respondents cited media sources most often, including newspapers (47%), television (42%), magazines (27%), and radio (22%). Approximately 57% indicated at least one form of media as their source of information about genetic nondiscrimination laws. Less often cited sources were a doctor (5%), genetic counselor (4%), researcher (4%), and other health care professional (6%). “Other” sources of information about the legislation mentioned by 10% of respondents were “employer,” “medical literature,” “legal literature,” “college,” and a “long-term care insurance” brochure.

DISCUSSION

While debate will likely continue regarding the nature and extent of genetic discrimination, significant concern about the misuse of genetic information by insurers and employers is undeniable. This study revealed substantial concern about genetic discrimination among members of a hereditary colorectal cancer registry. Few respondents reported that they or a family member had actually experienced genetic discrimination and none of the described experiences, though limited in detail, provide a clear-cut example. Thus, our data support previous studies suggesting that fear of discrimination may be discrepant with actual experience.^{9,15}

The most frequently cited source of information about genetic discrimination in our study was the media, whereas

health care professionals were mentioned less often. This is consistent with genetic counselors’ reports that many patients hear about genetic discrimination through the media.²¹ In particular, several genetic counselors described a 1998 *Parade Magazine* article as the source of cancer patients’ information and concern. Information provided by media sources is often minimal and dramatized. An analysis of media content surrounding the announcement of the human genome mapping found that discussion of privacy and discrimination, although frequently mentioned as a risk of genetic research, was generally limited in scope and depth.⁸ The result may be public misconception about the magnitude of risks and increased concern about genetic discrimination.

Interest in genetic testing was high in this population of individuals at increased risk for developing cancer, as supported by other studies.^{22,23} However, interest was tempered by concerns about genetic discrimination. Hypothetical decisions about utilization of genetic services were significantly influenced by a higher level of concern about genetic discrimination. Those with higher levels of concern would be more likely to pay out of pocket and use an alias when undergoing genetic testing. To avoid submitting an insurance claim, more than a third of respondents would pay out of pocket for genetic testing. As genetic testing can be costly, those who can not independently afford testing and are concerned about discrimination risks will be less likely to pursue genetic testing even when interested in obtaining the results. Some respondents would be likely to be tested using an alias to lessen the risks of genetic discrimination. In one study, interviews with genetics specialists who facilitated pseudonymous and anonymous genetic testing for Huntington’s disease revealed that the more information a patient withheld, the less comfortable the provider felt and the more difficult and time-consuming it was to document family history, provide genetic counseling, and obtain informed consent.²⁴ Thus, patients’ desire for privacy protection may hinder the relationship between the provider and patient, and make accurate risk assessment and provision of genetic services problematic.

Respondents with a higher level of concern about genetic discrimination would be less likely to share genetic information with doctors and more likely to ask for results to be excluded from their medical record. Although the majority would share the results with doctors, approximately half would

Table 3

Associations between Level of Concern and Decisions about Utilization of Genetic Services

	OR	CI	P value
Submit to insurance (Q1)	0.67	(0.58–0.76)	<0.001
Pay out of pocket (Q2)	1.5	(1.3–1.7)	<0.001
Use fake name (Q3)	1.5	(1.3–1.8)	<0.001
Share genetic information with doctors (Q4)	0.74	(0.63–0.87)	<0.001
Exclude from medical record (Q5)	1.6	(1.4–1.8)	<0.001

Independent variable is level of concern; dependent variables are decisions about utilization of genetic services.

Table 4

Understanding and Impressions of Laws Regarding Genetic Discrimination (N = 140)

If you are aware of the laws regarding genetic discrimination:	Not at all	To some extent	To a great extent
1. How much have you heard about laws regarding genetic discrimination?	35%	61%	4%
2. How well do you feel you understand the laws regarding genetic discrimination?	59	37	4
3. Do you think there is adequate protection in the laws to prevent employment discrimination based on genetic information?	47	48	5
4. Do you think there is adequate protection in the laws to prevent health insurance discrimination based on genetic information?	56	40	4
5. Do you feel adequately protected by the laws against genetic discrimination?	53	43	4

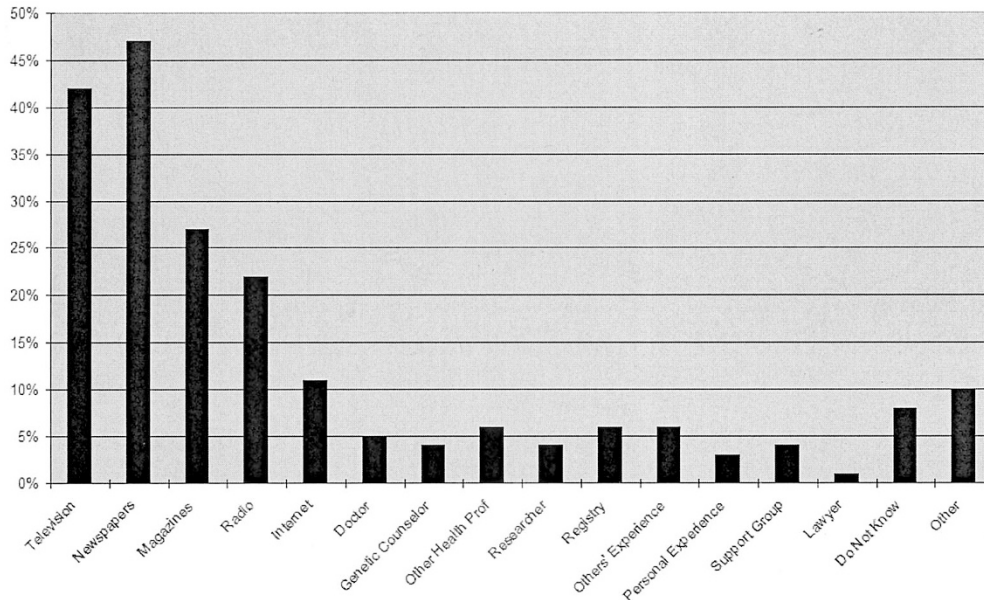


Fig. 3. Respondents' source of information about genetic nondiscrimination legislation ($N = 110$).

ask for the test results to be excluded from their medical record. Withholding genetic information from health care professionals and from inclusion in their medical record may reduce the probability of patients' receiving appropriate and comprehensive care, although this has not been determined through research.

By joining a research registry and accordingly demonstrating interest in genetics and health issues, one might expect registry members to be more aware of relevant legislation than the general public. However, the vast majority of respondents were unaware of the federal or state laws. Even among those who were familiar with the legislation, more than half did not understand the laws. This may be related to their source of information about genetic nondiscrimination legislation, which was most often the media. Presumably little detail and explanation about the legislation was supplied by the media sources due to inherent time and/or space constraints.

The belief that the legislation does not offer adequate protection against insurance and employment discrimination was held by the majority of those respondents who were aware of the legislation. Another study documented reasons that individuals do not feel adequately protected, with concerns stemming from unenforceability, lack of protection in some states, and worry that the law could be changed or revoked in the future.¹⁴ Interestingly, awareness of legislation did not significantly affect level of concern about genetic discrimination. This may be due to respondents' lack of confidence in the current legislation to adequately protect against discrimination, as well as an overall limited understanding of the protections involved.

Findings from this study suggest a clear need to educate the public about existing legislative protections against genetic discrimination. Media sources, relied on by much of the public for health information, provide insufficient information about

the risks and legislative protections regarding genetic discrimination. Consequently, accurate and comprehensible information must be supplied by the scientific and medical communities through patient interaction, and by collaboration with the media to better inform the public.

In addition, effective and enforceable protections through legislation are necessary to increase the confidence of both health care professionals and patients that genetic discrimination cannot occur. If enacted, the legislation currently pending before the U.S. House of Representatives would provide comprehensive protections against discrimination in insurance and employment. The legislation applies to health insurance markets and bans the collection and use of genetic information for purposes of underwriting. Additionally, the legislation prohibits the use of genetic information in employment decisions as well as specifically prohibits employers from requesting, requiring, or purchasing genetic information of employees or family members, but would allow employers to conduct genetic monitoring of the biological effects of toxic substances in the workplace.^{25,26} Leaders in the genetics field have strongly endorsed this legislation as it successfully addresses the concerns of the biomedical research and health communities.²⁷ Enacted legislation should provide assurances that individuals at heightened risk for genetic conditions and for whom genetic test results may offer beneficial health management information do not have to fear loss of insurance or employment. Once further legislation has been established, the scientific community and the media should inform the public about the increased protections to allay concerns. Lastly, more dialogue between insurers and health care professionals may reduce the division of views about the risks of genetic discrimination and the most effective and fair means of protecting patients.

There are several limitations to this study to be considered. First, the study sample was composed of individuals who volun-

tarily enrolled in a high-risk research registry and, therefore, results may not be generalizable to all individuals with a family history of colorectal cancer. Those who join a research registry and provide family history information may differ in their concerns and decisions regarding genetic discrimination from other individuals. People with the most concern about genetic discrimination may not have been included in the study population, as these individuals would be unlikely to contact the registry initially. In addition, because only a small percentage of the respondents and their family members had already pursued genetic testing, there was limited opportunity for actual genetic discrimination to occur. Further limitations are that the registry population is an ethnically homogeneous sample, and females and those with higher education are over-represented.

Conclusions

Although the prevalence of genetic discrimination is unknown, significant public concern exists and should be addressed through education and legislative protections. As indicated by our study findings, the disproportionate fear of genetic discrimination relative to actual experience may be due in part to individuals' reliance on information provided by the media as well as lack of confidence in or familiarity with the existing legislative protections to prevent genetic discrimination. This study documented that concerns about genetic discrimination might influence the utilization of genetic services. Future research should explore how exaggerated concerns about genetic discrimination might be reduced so as to eliminate barriers to utilization of potentially valuable genetic services. Research could focus on the possible impact of modifying or supplementing media messages, educating the public about existing legislation, or identifying effective means of reassuring those with exaggerated fears about genetic discrimination.

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