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Evolving perspectives on genetic discrimination in health insurance among health care providers

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Abstract Previous studies have documented that concerns about genetic discrimination (GD) may influence access to and participation in medically necessary care. We sought to characterize how GD issues influence current cancer genetics professional (CGP) practice, determine if their attitudes regarding GD have changed over time, and compare their knowledge and attitudes regarding laws prohibiting GD to a contemporary cohort of non-genetics clinicians. Members of the National Society of Genetic Counselors Familial Cancer Special Interest Group were invited to complete a 39 item online survey, adapted from previously published instruments. The resulting data were compared to a survey of CGPs published in 2000 and to a contemporary cohort of non-genetics clinicians ($n = 1{,}181$). There were 153 qualified respondents. Compared to the historical CGP cohort ($n = 163$), a significantly greater proportion said they would bill insurance for the cost of genetic testing for themselves ($P < 0.0001$). Most CGPs (94%) considered the risk of GD to be low to theoretical, concordant with 64% who expressed confidence in existing federal laws prohibiting GD. The mean knowledge score of CGPs regarding GD protective laws was significantly greater than that of non-genetics clinicians ($P < 0.001$). As barometers of change, CGPs show a migration in opinion over the past 8 years, with decreased fear of GD and greater knowledge of laws prohibiting GD compared to non-genetics clinicians. Better knowledge of GD and protective legislation, may facilitate non-genetics clinician utilization of genetics and personalized medicine.

Keywords Genetic discrimination · Cancer genetics · Genetic testing · Health insurance · Cancer genetics professional

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Introduction

Genetic Cancer Risk Assessment (GCRA) has emerged as a distinct area of practice for genetics professionals. The greatest experience and application to date is with hereditary breast and ovarian cancer (HBOC), associated with mutations in *BRCA1* and *BRCA2*, and Lynch syndrome, also known as hereditary nonpolyposis colorectal cancer (HNPCC), associated with mutations in the mismatch repair (*MMR*) genes *MLH1, MSH2, MSH6,* and *PMS2*. Genetic testing for these and other hereditary cancer syndromes has become standard of care in part due to the documented efficacy of screening and risk reduction interventions.

Concern about genetic discrimination (GD) has been identified as a barrier to GCRA and cancer predisposition genetic testing by patients and clinicians in the United States [1–12]. *Genetic discrimination* refers to discrimination directed against an individual or family "based solely on an apparent or perceived genetic variation from the 'normal' human genotype" [8] and applies primarily to those who are not affected with the condition [13].

Laws have been enacted in the United States to protect genetic information and prevent GD by employers and health insurance companies. The Health Insurance Portability and Accountability Act (HIPAA) of 1996 provides some protections against GD for those covered under group health insurance policies, but does not protect those with individual policies. Additionally, at least 48 states as of January 2008 have passed laws providing varying levels of protection against GD (Table 1) [14]. Since these laws were enacted, there have been few documented cases of health insurers asking for or using presymptomatic genetic test results in underwriting decisions, suggesting that a person with a genetic condition who is asymptomatic should have little or no difficulty in obtaining health insurance [13, 15]. On May 21, 2008, President George W. Bush signed the Genetic Information Nondiscrimination Act of 2008 (GINA) into law, which will provide more comprehensive and uniform protections for those covered by both group and individual insurance plans.

Despite protective legislation and the lack of well-documented cases of health insurance GD, recent studies have shown that patients and non-genetics clinicians continue to perceive the risk of GD to be high, which may be a barrier to obtaining medically necessary care [1–3, 5, 12, 16–18]. A survey of 163 cancer genetics professionals (CGPs) conducted in 1998 found that 68% would not bill insurance for the cost of genetic testing due to fear of GD [19]. A 2003 study of a small sample ($n = 25$) of CGPs found a lower level of fear of potential GD (84% believed the risk of GD to be low, very low, or theoretical), suggesting a possible shift in attitudes over time [20]. We recently surveyed 1,121 non-genetics clinicians in California and documented perceptions of high risk for GD and little knowledge of existing protective legislation [1].

We hypothesized that CGPs, who provide education and facilitate genetic testing for hereditary cancer syndromes, may be a barometer for changing perspectives about GD. Therefore, we surveyed a current cohort of CGPs regarding their knowledge, practices, and beliefs about health insurance GD to assess whether beliefs have evolved over time, and whether knowledge of laws protecting against GD is different for CGPs and non-genetics clinicians.

Table 1 US state protective legislation: genetics and health insurance

Components of protective legislation	
Prohibits establishing eligibility rules based on genetic information	
Prohibits requiring genetic tests or information from applicants	
Prohibits use of genetic information for risk selection or classification	
Prohibits disclosure of information without informed consent	
Coverage level	**# of states**
Comprehensive	12
State has laws in all 4 categories and covers group and individual policies	
Moderate	28
State has laws in all 4 categories but covers only group or individual policies, OR	
State has laws in 3 categories, OR	
State has laws in 2 categories and covers group and individual policies	
Low	8
State has laws in <2 categories but covers only group or individual policies, OR	
State has laws in 1 category	
None	2
State has no protective legislation	

Adapted from http://www.ncsl.org/programs/health/genetics/ndishlth.htm. [14]

Methods

Design

A quantitative, cross-sectional survey of the 450 members of the National Society of Genetic Counselors (NSGC) Familial Cancer Special Interest Group (Cancer SIG) listserv was conducted and the results were compared to two previous studies (cohorts described below). The NSGC is an international society of health care professionals, primarily genetic counselors (96%), involved in providing genetics services. The NSGC Cancer SIG is open to all NSGC members interested in cancer genetics.

Survey instrument

A 39-item survey was created using SurveyMonkey [21] as a composite of three previously published instruments, and included additional items created specifically for this study [1, 19, 20]. The survey contained items on demographics (10 items), knowledge of US federal and state protective legislation (3 items), attitudes and behavioral intent regarding GD (11 items), practices related to GD (13 items), and open ended questions (2 items). Five items on behavioral intent were taken from Matloff et al. [19] and three items on professional practices were adapted from Pfeffer et al. [20] Coefficient alpha values for internal consistency/reliability for validated items ($n = 4$) used previously in Lowstuter et al. [1] were as follows: attitudes toward genetic testing (2 items) 0.65; and knowledge of GD protective laws (8 sub-items within 2 items) 0.77.

Questions were Likert-scale, multiple-choice, true/false, or fill-in-the-blank format. An expert panel ($n = 6$) including genetic counselors, research coordinators, and doctoral level nurses piloted the survey and recommendations were incorporated and re-tested prior to survey distribution.

Procedures

The study was approved by the California State University, Northridge Institutional Review Board. A letter of explanation and invitation to participate was e-mailed to the NSGC Cancer SIG listserv and contained a link to the online survey. Five reminders were sent to the listserv according to a modified Dillman's methodology [22]. The first page of the survey made explicit the voluntary and anonymous nature of the study. Participant consent was implied by reading this page and continuing with the survey and the website randomly assigned a study ID number to each completed survey. The survey was open from January 22, 2007 through March 9, 2007 and a log of potential validity threats was kept throughout this time period.

Comparison cohorts

The CGP comparison data were obtained from a 1998 study of NSGC Cancer SIG members [19]. There were 163 respondents (a 55% response rate); 93% were female and 76% had a masters degree in genetic counseling.

The non-genetics clinician comparison data were obtained from our recent survey of California non-genetics clinicians regarding cancer genetics and GD, conducted from November 2004 through December 2006 [1]. Of the 1,181 non-genetics clinician participants, 62.2% were physicians, 37.8% were nurses, 47.3% were male, 52.7% were female.

Data analysis

Data were analyzed using SPSS version 8.0 (SPSS Inc., Chicago, Illinois) and SAS version 9.0 (SAS Institute, Inc., Cary, North Carolina). We excluded student respondents and those who quit the survey prior to completing the knowledge portion. Respondents who live outside the United States only answered items related to behavioral intent and practice as the GD legislation knowledge items were not applicable. Knowledge questions were coded as correct or incorrect ("uncertain" was considered incorrect) and a knowledge score (percent answered correctly) was calculated for each participant. Statistical comparisons were performed using *t*-tests, chi-square, and Pearson correlations. Probability values less than 0.05 were used to represent statistical significance.

Tables from the Matloff et al. [19] study state how many participants answered each question, however, the number who answered "yes" and the number who answered "no" does not add up to that total. This implies that another response such as "uncertain" was allowed, however, the authors were not able to confirm whether or not this was the case. Consequently we excluded responses of "uncertain" for the Matloff et al. [19] comparison questions in this study.

Results

Sample characteristics

Of the 450 NSGC Cancer SIG members registered on the listserv, 162 responded to the survey (36% response rate). The actual response rate may be higher given that members who elected to turn off e-mail notifications would not have received the invitation to participate in this survey. We excluded 8 respondents because they did not complete the knowledge portion of the survey and one respondent due to student status, leaving 153 qualified respondents. Not all participants answered every item. Most respondents were genetic counselors (94%), female (92%), and younger than age 35 (52%, Table 2). Respondents were from 36 of the 50 United States and Washington D.C., and three were from Canada. Overall, the demographics of the respondents were similar to the CGP comparison cohort [19].

Attitudes and behavioral intent regarding genetic testing and genetic discrimination

The majority of CGPs in the current cohort (95 and 96%) and in the previous study by Matloff et al. [19] (85 and 91%) would choose to undergo *BRCA* or *MMR* gene testing if they had a 50% probability of carrying a mutation. However, none in the current cohort said they would refuse testing as compared to 8% for *BRCA* ($P < 0.001$) and 4% for *MMR* genes ($P < 0.01$) in the historical CGP comparison cohort (Table 3) [19]. Of those who would undergo genetic testing, significantly more (88% vs. 24%) would seek insurance coverage for the cost of genetic testing and significantly fewer (2% vs. 26%) would pursue testing anonymously, using an alias, compared to the respondents in the 1998 survey ($P < 0.0001$) [23].

Ninety-four percent of participants in the current study believed the level of GD risk to be low, very low, or theoretical (22, 40, and 32% respectively). Only 6% believed

Table 2 Sample demographics

Characteristic	*N* (%)
Professional position	
Genetic counselor	143 (93.5)
Physician	3 (2.0)
Nurse	5 (3.3)
PhD Medical geneticist	1 (0.7)
Other	1 (0.7)
Sex	
Female	141 (92.2)
Male	12 (7.8)
Age	
20–34	80 (52.2)
35–49	52 (34.0)
≥50	21 (13.8)
Years providing cancer genetics services	
0–4	72 (47.1)
5–9	49 (32.0)
10–14	21 (13.7)
≥15	10 (6.6)
Never provided cancer genetics services	1 (0.6)
Number of patients counseled for hereditary cancer risk in the past 12 months:	
0–25	19 (12.5)
26–50	22 (14.5)
51–75	18 (11.8)
>75	93 (61.2)
Work setting	
University or academic health center	81 (52.9)
Private medical facility	42 (27.5)
Public medical facility	11 (7.2)
Health maintenance organization	8 (5.2)
Physician's private practice	4 (2.6)
Laboratory	3 (2.0)
Other	4 (2.6)

the risk to be moderate and none perceived the risk to be high or very high. The majority felt very or somewhat confident in the ability of US federal and state laws to protect against GD for hereditary cancer (64 and 70%, respectively), 11% were neutral, and a minority felt somewhat unconfident (15 and 7%) or not at all confident (9 and 5%) in the US federal and state laws.

Among CGPs, 36% agreed that genetic testing is likely to be declined by patients because of fear of health insurance discrimination (Table 4). The majority disagreed with the statements that genetic testing creates health insurance problems for patients with or without cancer (93 and 79% respectively). In contrast to CGPs, a significantly greater proportion (57%) of non-genetics clinicians believed that genetic testing causes health insurance problems for patients ($P < 0.001$).

Genetic discrimination discussions with patients

All but one CGP respondent ($n = 152$) indicated that some proportion of their patients are concerned about GD with 40 respondents indicating that greater than 50% of their patients are concerned (data not shown). All respondents reported discussing GD issues with at least some of their patients and 87% believe they are somewhat or very reassuring to their patients regarding the risk of GD (Table 5). There was a small positive correlation ($r = 0.289$, $P < 0.01$) between how reassuring participants are about GD risk and their average confidence in US federal and state protective legislation. Participants with a lower perceived risk of GD were more reassuring to their patients ($r = 0.320$, $P < 0.01$).

With respect to requests from patients for confidential genetic testing in the past year, 41% of CGPs have not received any and 64% have not facilitated confidential testing for any patients (Table 5).

Knowledge of protective legislation regarding genetics and health insurance

The majority of CGPs (89–91%) answered three of the four questions regarding HIPAA protections correctly, but only 38% correctly identified that HIPAA does not define genetic information. The mean HIPAA knowledge score was significantly lower for non-genetics clinicians (24%) compared to CGPs (77%, $P < 0.001$, Table 6).

Most CGPs (93%) correctly identified whether or not the state in which they practice has protective legislation related to genetics and health insurance and whether the laws apply to group health insurance. The majority correctly identified whether or not their state laws prevent insurers from establishing eligibility rules based on genetic information (76%), prohibit insurers from requiring genetic testing or genetic information (62%), or prevent the use of genetic information for risk selection or risk classification purposes (64%). Only 49% knew whether their state requires written consent for disclosure of genetic test results to any third party by an insurance company and 42% knew whether the legislation applied to individual health insurance policies. The mean State Protective Legislation knowledge score among CGPs (69%) was significantly greater than that of California non-genetics clinicians (33%; $P < 0.001$, Table 6). California CGPs ($n = 19$) had a similar mean State Protective Legislation knowledge score (74%) to that all CGPs, which was therefore also significantly greater than that of California non-genetics clinicians ($P < 0.001$).

Table 3 *BRCA* and HNPCC genetic testing decisions among CGPs

Question	Response	*N* (%)		*P*-value
		Matloff et al. study	This study	
If your own risk to carry a *BRCA* mutation was determined to be 50%, do you think you would undergo genetic testing?	Yes	136 (84.5)	143 (94.7)	0.0003
	No	13 (8.1)	0	
	Uncertain	N/A	8 (5.3)	
If your own risk to carry an HNPCC mutation was determined to be 50%, do you think you would undergo genetic testing?	Yes	145 (90.6)	144 (96)	0.0092
	No	7 (4.4)	0	
	Uncertain	N/A	6 (4)	
If you did choose to undergo genetic testing, would you:				
a. bill the charges to your insurance company?	Yes	38 (23.9)	132 (88)	<0.0001
	No	108 (67.9)	3 (2)	
	Uncertain	N/A	15 (10)	
b. use an alias?	Yes	41 (25.8)	3 (2)	<0.0001
	No	111 (69.8)	140 (93.3)	
	Uncertain	N/A	7 (4.7)	
c. share this information with your physician?	Yes	132 (81.5)	146 (97.3)	0.0002
	No	18 (11.1)	2 (1.3)	
	Uncertain	N/A	2 (1.3)	
d. share this information with family members?	Yes	162 (97.5)	150 (100)	[a]
	No	0	0	
	Uncertain	N/A	0	
e. share this information with friends?	Yes	95 (58.6)	96 (64)	<0.0001
	No	50 (30.9)	10 (6.7)	
	Uncertain	N/A	44 (29.3)	
f. share this information with colleagues?	Yes	49 (30.4)	50 (33.3)	0.0004
	No	97 (60.2)	37 (24.7)	
	Uncertain	N/A	63 (42)	

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[a] Analysis not done because all participants answered "yes."

Table 4 CGP and non-genetics clinician genetic discrimination beliefs

	Genetic testing is likely to be declined by patients because of fear of health insurance discrimination[a]		Genetic testing creates health insurance problems for my patients who have or have had cancer[b]		Genetic testing creates health insurance problems for my patients who have not had cancer[c]	
	Percent		Percent		Percent	
	CGPs	Non-genetics clinicians	CGPs	Non-genetics clinicians	CGPs	Non-genetics clinicians
5 Strongly disagree	4.0	0.9	61.3	1.7	32.7	1.1
4 Disagree	42.0	23.8	31.3	41.8	46.7	41.5
3 Neutral	18.0	N/A	4.0	N/A	16.0	N/A
2 Agree	34.7	55.4	2.7	44.1	4.7	47.5
1 Strongly agree	1.3	19.9	0.7	12.5	0	9.9
Mean Likert score	2.9 (Neutral)	3.7 (Agree)[d]	1.5 (Disagree)	3.2 (Neutral)[d]	1.9 (Disagree)	3.2 (Neutral)[d]

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[a] $n = 150$ and 1,155 for CGP and non-genetics clinician respondents, respectively

[b] $n = 150$ and 1,144 for CGP and non-genetics clinician respondents, respectively

[c] $n = 150$ and 1,141 for CGP and non-genetics clinician respondents, respectively

[d] Difference between CGP and non-genetics clinician mean Likert score is statistically significant at $P < 0.001$

Table 5 Discussion of genetic discrimination with patients

Question		*N* (%)
How often do you discuss genetic discrimination with your patients? ($n = 151$)	Always	77 (51.0)
	Almost always	49 (32.5)
	Often	16 (10.6)
	Sometimes	5 (3.3)
	Rarely	4 (2.6)
	Never	0
How reassuring do you think you are to your patients regarding the risk of genetic discrimination? ($n = 150$)	Very	60 (40.0)
	Somewhat	71 (47.3)
	Neutral	14 (9.4)
	Minimally	5 (3.3)
	Not at all	0

Discussion

Our study indicates a notable change in perceptions and behavioral intent among CGPs over time, with decreased fear of GD since 1998 when the previous study [19] was conducted. Further, non-genetics clinicians have a significant gap in knowledge compared to CGPs and their behavioral intent is influenced by GD perception. The greater confidence expressed by CGPs may be due, in part, to greater awareness of increased legislative protections that have been passed since 1998, as well as the lack of documented cases of GD in the intervening decade.

Several studies have reported a high perceived risk of GD among non-genetics health care providers [2, 3, 24]. Our study demonstrates that CGPs believe the risk for GD to be significantly lower than non-genetics clinicians, who also perceive their patients to have a higher level of fear of GD. Critically, the non-genetics clinicians in our study who believed there to be a significant risk of GD were less likely to refer patients for GCRA (OR = 0.8; $P < 0.05$) [1].

The majority of CGPs in this study reported they were very or somewhat confident in the ability of both federal and state laws to protect against GD. However, more participants were confident in state laws than in federal laws. Now that GINA has been signed into law, we would expect confidence in health insurance and employment protections to increase. GINA generally stipulates the following:

1. GINA prohibits employers from requesting, requiring, or purchasing genetic information, requiring an individual to take a genetic test as a condition of employment, or discriminating on the basis of genetic information.
2. GINA does not apply to individuals who have a "manifestation of a disease, disorder, or pathological condition."
3. GINA prohibits health insurance companies from denying or canceling coverage based on genetic information or from using genetic information to determine premiums. Since GINA does not provide comprehensive protection against GD outside of health insurance and employment protections and only applies to those who are asymptomatic, it remains unclear whether GINA will affect the willingness of at-risk individuals to undergo genetic testing [25, 26]. Additionally, Rothstein cited systematic problems with the handling of medical records; specifically that broad disclosure of records when only specific data are necessary is already a problem and will only be more problematic as institutions increasingly employ electronic medical records [26]. This emphasizes the continued importance of state legislation to fill in the gaps left by federal legislation.

Due to the sample size, we cannot rule out bias since most participants (86%) came from states with moderate or comprehensive protective legislation. However, this mirrors the state GD legislative protections in the nation as a

Table 6 Knowledge of US federal and state protective legislation regarding genetics and health insurance among CGPs and non-genetics clinicians

	Percent		
	Correct answer	CGPs	Correct non-genetics clinicians
The health insurance portability and accountability act of 1996 (HIPAA)…		($n = 149$)	($n = 1{,}155$)
…prohibits health insurance discrimination in the group insurance market on the basis of genetic test results	True	89	39
…prohibits health insurance discrimination in the individual insurance market on the basis of genetic test results	False	91	17
…defines genetic information	False	38	19
…states that genetic information can be considered a pre-existing condition	False	91	19

CGP cancer genetics professional

whole (Table 1) and the practical value of the observation stands: the most populous states tend to have the greatest GD protective legislations and the largest numbers of CGPs. Thus, we believe that given the emerging limitations of GINA, the combination of state and federal legislation may be important in patient protection and as items about which health care providers must be knowledgeable.

Fewer CGPs said that they did not receive any requests for confidential testing than said that they did not facilitate it. This implies that some participants are receiving requests for confidential testing that they are not facilitating, suggesting that CGPs are either refusing to facilitate confidential testing or more likely, indicates that counseling has value in educating and reassuring patients about legal protections.

Previous studies have shown that among primary care providers and other non-cancer genetics professionals, perceived risk of GD is high while knowledge of existing protective legislation is low [1–3]. The results of this study show that CGPs have significantly greater knowledge of GD protective laws than non-genetics clinicians and a low perceived risk of GD. It also appears that CGPs' knowledge of protective legislation has increased since a 2000 study by Hall and Rich [27].

Limitations

Although our 153 respondents represented 36% of the sample, this was approximately the same size as the Matloff et al. [19] cohort ($n = 163$) and the demographic composition was comparable to that of the NSGC membership [28]. In addition, the non-genetics clinician sample represented only California practitioners, while the CGP participants practiced in 36 different states, with varying protective laws, many of which were less comprehensive than California. Consequently, the observed difference in awareness about legal protections and greater confidence on the part of CGPs is likely an underestimate of the differences.

One of the two items on state law knowledge contained six sub-items which were adapted from Lowstuter et al. [1] to be generalizable because of the differences in state of residence for participants in the two studies. Four of the six sub-items were used in both studies.

In the survey instrument, confidential genetic testing was defined as testing that the patient pays for out-of-pocket or that involves using a number identifier or alias rather than the patient's name. It is apparent, based on seven open responses to the survey, that some respondents included patients who pay for genetic testing out-of-pocket (the results of which still go in the medical record) in their response to the question asking under what conditions they are willing to facilitate confidential testing. It is possible that others misinterpreted the definition as well, possibly inflating the amount of confidential genetic testing that they reported.

As with all voluntary surveys, there may have been a response bias such that CGPs with a greater interest in GD may have been more likely to complete the survey. Such individuals may have had greater knowledge of GD protective laws, more extreme beliefs, or different practices regarding GD.

One potential threat to validity was a presentation by Mark Hall, JD on GD at the 2006 National Society of Genetic Counselors Annual Education Conference [29]. This presentation could have influenced the knowledge level of study participants who attended it (51%). However, there was no significant difference in knowledge score between those who did and did not attend this talk.

Conclusions

This study demonstrated a decrease in concern regarding GD among CGPs over the past 8 years. This may be partially due to increased awareness of GD protective laws or due to the fact that the laws are now more well-established. This study found that CGPs, clinicians who discuss genetic testing routinely in their practice, have a higher level of knowledge about GD protective legislation than non-genetics clinicians, for whom it is not a routine topic of discussion.

Increased knowledge among providers and the lay public about laws protecting against GD along with apparent lack of documented cases of GD or adverse experiences for patients, should lead to decreased fear of GD and increased appropriate referral for genetics services among non-genetics clinicians, increased uptake of genetic testing among patients, and ultimately, better patient care. This process may be facilitated by development of educational tools for patients and providers. Future studies should be done to monitor the awareness and impact of GINA on practice.

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