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Survey of unaffected *BRCA* and mismatch repair (MMR) mutation positive individuals

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Abstract

Many individuals do not proceed with cancer predisposition testing due to fears of genetic discrimination (GD). We report the results of a survey of 47 unaffected, mutation positive individuals regarding insurance outcomes. Participants recruited from six different Cancer Risk Programs across the country were queried about their experiences with health, life, and disability insurance, as well as employment issues. Eighty-seven percent of participants carried a *BRCA* mutation and 87% were part of a group insurance plan at the time of testing. Forty-seven percent of participants self-paid for testing. Less than 10% of participants reported that their results were placed in the general medical record, while 43% did not know where their results were placed. Due to concerns about GD, 13% of participants stated they avoided changing jobs. Thirteen percent stated that their at-risk relatives had not undergone testing for the familial mutation due to

fears about GD. Adverse events following genetic testing included two denials from private health insurers, one denial for average life insurance coverage and one denial for additional disability insurance. There were no reports of job discrimination. Results suggest fear of GD is prevalent, yet data do not support evidence that GD exists.

Keywords

Genetic discrimination; Genetic counseling; Insurance

Introduction

Approximately 5–10% of all breast cancer diagnoses are due to an inherited predisposition with the majority due to mutations in the *BRCA1* and *BRCA2* genes [1]. It is estimated that 1 in 200–800 women carries an altered *BRCA* gene [2] and in the Ashkenazi Jewish population, this figure has been estimated to be approximately 1 in 40, due to the presence of three founder mutations in that ethnic population [3]. Women who carry mutations in either *BRCA1* or *BRCA2* are estimated to have a lifetime risk for developing breast cancer of 50–85% and a lifetime risk for developing ovarian cancer of 10–60% [4]. Options for screening and prevention include increased surveillance, chemoprevention, and prophylactic surgery [5]. Prophylactic mastectomy reduces the risk for developing breast cancer by greater than 90% [6]. Prophylactic oophorectomy reduces the risk for developing ovarian cancer by greater than 90%, and also reduces the risk for developing breast cancer by up to 50% in pre-menopausal women [7–9].

Approximately 5–10% of all colon cancer diagnoses are due to an inherited predisposition with the majority caused by inherited mutations in the mismatch repair genes (MMR) associated with hereditary non-polyposis colon cancer (HNPCC), also known as Lynch syndrome [10]. Individuals who carry a mutation in one of these genes have a 70–80% lifetime risk for developing colon cancer and women with a mutation have up to a 40–60% lifetime risk for developing endometrial cancer [11]. Regular clinical surveillance among individuals with HNPCC has been shown to reduce mortality from colon cancer substantially [12]. In addition, data on chemoprevention is emerging as a risk reducing option [13].

Given the effectiveness of management options, genetic counseling/testing for individuals at risk for *BRCA* or MMR mutations is considered medically necessary care [14, 15]. There is great public awareness of and interest in genetic testing for cancer risk [16]. Predictive genetic testing for individuals who are members of *BRCA* or HNPCC/Lynch families offers the potential to distinguish those individuals who truly are at high-risk (mutation positive) from those individuals who are not at high-risk (mutation negative). Individuals at high-risk (mutation positive) can be offered increased screening and prevention options, whereas those at average risk for cancer development (mutation negative) can be relieved of worry and frequent examinations.

Although genetic testing can impact the medical management of thousands of individuals at increased risk, many do not undergo such testing because of concern about possible insurance discrimination [17–20]. Fear of losing insurance has been reported to be one of the main reasons for declining predictive genetic testing for cancer risk. [21, 22] Paradoxically, the concerns expressed in the above cited studies do not appear to reflect the experience of individuals who have undergone genetic testing for cancer risk. Nowlan [23] argues that the evidence for genetic discrimination with respect to health insurance is primarily anecdotal.

Most states have passed laws against genetic discrimination. The degree of protection from these laws varies widely among the different states. The Health Insurance Portability and Accountability Act of 1996 and 2002 (HIP-PA) is the federal law that addresses the issue of genetic discrimination; however, it only applies to employer-based and commercially issued group health insurance. The Genetic Information Nondiscrimination Act (GINA) of 2008 is the newest federal law that protects Americans from being treated unfairly because of differences in their DNA that may affect their health. This new law, when enacted, will prevent discrimination from health insurers and employers [24]. Some states have enacted protections with regards to life insurance such that a life insurer cannot require genetic testing at the time of application for a policy; however, once testing has been done, results may be used in the actuarial process [25]. Americans with Disabilities Act (ADA) has been interpreted to include protection for individuals at increased risk for developing a disease due to a genetic test result in the workplace [26].

No specific documented cases of discrimination of individuals with susceptibility to cancer have been reported in the literature to date. Given that predictive genetic testing for cancer risk is relatively new and given that the protective legislation has not been tried in the court system, it is possible that cases of discrimination exist but have not yet been reported.

The aim of this study was to determine whether unaffected individuals who have been found to carry a mutation in a cancer susceptibility gene, have encountered problems with insurance and/or employment after receiving their positive genetic test result.

Materials and methods

A survey was developed to address issues related to experiences with health, life, and disability insurance, as well as, employment following the receipt of a positive genetic test result. The survey development team consisted of members of the National Society of Genetic Counselors Cancer Special Interest Group (NSGC Cancer SIG) and the Medical Biostatistics Department at the University of Vermont. The survey contained questions pertaining to demographics, payment for testing, reimbursement for testing, understanding of protective legislation at the time of genetic testing, and confidentiality of results, including which of their healthcare providers received a copy. Participants were asked about their experiences with insurance, including health, life, and disability, as well as experiences in the workplace, both before and after genetic testing to determine if there were any adverse outcomes associated with the receipt of results. Participants were also asked whether their relatives had undergone testing for the specific mutation identified in the family.

Participants were recruited from a several different cancer genetics programs including the Familial Cancer Program of the Vermont Cancer Center in Burlington, Vermont, the Mass General Hospital Center for Cancer Risk Analysis in Boston, Massachusetts, the University of Washington Medical Center in Seattle, Washington, the North Memorial Cancer Genetics Program in Robbinsdale, Minnesota, the University of Michigan in Ann Arbor, Michigan, and the City of Hope Cancer Screening and Prevention Program (COH) in Duarte, California. The protocol and survey were approved by Institutional Review Board (IRB) at all institutions.

Eligibility

Individuals meeting the following criteria were eligible for participation: received genetic counseling and testing through one of the participating cancer genetics programs, were at least 21 years of age, English speaking, were known to carry a deleterious *BRCA* or *MMR* gene mutation, did not have a diagnosis of invasive or in situ cancer prior to study

participation. Individuals who carry variants of uncertain significance were excluded. Receipt of results was at least 2 years prior to entry into the study.

Recruitment and data collection

Eligible individuals were identified from each site's database of patients who had received genetic counseling through their program. All eligible individuals were sent a letter inviting them to participate in the study and a prepaid, pre-addressed postcard to return if they were interested in participating. The invitation letter explicitly stated the goal of the study was to evaluate insurance outcomes post receipt of a positive genetic test result. A list of names and phone numbers of the individuals who agreed to participate were forwarded to the UVM Medical Biostatistics Department and called for an interview by a research assistant. The individual had the opportunity to decline at the time of the phone call. Interviews took approximately 20 min to complete. Participants from COH were interviewed by telephone by a COH Genetic Counselor, using the same interview guide, and the data was sent to the University of Vermont for collective analysis.

Data analysis

The Medical Biostatistics Department at the University of Vermont entered the data at the time of the interview using Computer Aided Telephone Interviewing (CATI) system. Data analyses were performed using the SAS software package. Data was screened for logical consistencies and appropriate ranges. Basic descriptive statistics and tabulations were developed to characterize the data.

Results

A total of 47 interviews were performed. Fifty-seven percent of participants were recruited from the City of Hope Cancer Screening and Prevention Program. The remaining participants were from cancer genetics programs in Vermont, Michigan, Washington, Massachusetts, and Minnesota (Table 1). The participation rate (excluding the University of Washington and Mass General Hospital participants due to incomplete data) was approximately 50%. Reasons for non-participation include: no response to the mailing; not able to be reached for the interview; development of cancer since genetic testing; refused participation; and no current contact information available. Exact tallies for non-participation reason cannot be calculated due to incomplete data from two of the participating sites. See Table 1.

The mean age of the participants was 43 (range: 22–62) and the majority (83%) were female. The group was highly educated (72% had at least a college education), married or partnered (74%), Caucasian (96%), with 78% having an income greater than \$50,000. The majority had group health insurance plans at the time of genetic testing (87%) and was *BRCA1* or *BRCA2* positive (87%). Individuals received test results between the years of 1997 and 2005, with nearly 50% receiving their results between 2001 and 2002. See Table 2. Eighty-seven percent said that at least one of their relatives had undergone testing and 13% stated that at least one of their at-risk relatives had *not* undergone testing for the familial mutation due to fears of genetic discrimination.

Thirty-six percent of those surveyed ($n = 17$) reported that they did not have a good understanding of current protective legislation against genetic discrimination at the time they underwent testing. Forty-seven percent of participants ($n = 22$) self-paid for their genetic testing. Twenty individuals provided an explanation for self payment. Fifteen did so because of concerns about genetic discrimination and confidentiality of results while five did so because testing was not a covered benefit with their insurance plan. No correlation was seen

with form of payment for genetic testing and the year that an individual was tested or with level of understanding of legislation issues. Sixty-seven percent of those who self paid said they had a good understanding of legislation issues, while 59% of those whose insurance paid said they had a good understanding of legislative issues. None of the participants used an alias for testing.

When participants were asked which of their healthcare providers received a copy of their test result, 40% ($n = 19$) stated that none of their providers received the result. Among the remaining 60%, the primary care provider was the most common type of provider to receive the result. In regards to placement of the genetic test result, 8.5% ($n = 4$) of those surveyed reported that their test result was placed in the general medical record and 49% ($n = 23$) in a research or shadow file, while 43% ($n = 20$) said they did not know where their result were placed. When the genetic counselor at each institution was queried about their program's policy for record keeping of results, the majority stated that results were placed in the general medical record.

Ninety-eight percent of those surveyed ($n = 46$) had health insurance at the time of genetic testing. The majority reported to be part of a group insurance plan (41/87%). Two reported to have individual insurance, one reported to have Medicaid insurance, one reported no insurance and two were not sure what type of plan they had. Sixty-eight percent of participants ($n = 32$) had a life insurance policy in place at the time of testing, while 34% ($n = 16$) had disability insurance at the time of testing. Seventy-two percent of participants ($n = 34$) were employed at the time of testing.

Two adverse events were reported to have occurred when individuals changed health insurance. These individuals stated that they were denied private health insurance and they provided the following details:

“Can’t get private policy, been denied twice, now have high premiums/deductibles. Also have other medical problems, including fibromyalgia.”

“Rejected for private insurance twice since genetic testing because of double mastectomy and TAH/BSO. Also, my surgeon told the insurance company about my testing.”

There were reports of increased premiums, but these were global increases ($n = 4$). There were no reports of anyone being dropped from their insurance and the majority had no difficulty obtaining coverage for increased surveillance and preventative surgeries. One did state that her CA125 was not covered and three stated that aspects of their reconstruction were not covered.

With regards to life insurance, two individuals (6%) increased their life insurance prior to getting genetic testing and both were asked about their family history of cancer. Eight individuals (25%) increased their life insurance after genetic testing and three were asked about their test result. None were denied coverage. For those who did not have a life insurance plan prior to genetic testing ($n = 15/32\%$), 6 obtained life insurance after testing. One of these individuals was denied an average or limited coverage policy.

With regards to disability insurance, two individuals made changes in their disability policy following genetic testing. One of these individuals changed carriers not related to test results. The other was declined additional disability insurance following testing. Of those who did not have a disability insurance policy in place prior to testing (31/66%), 5 obtained policies following testing. No adverse events were reported.

Seventy-two percent of participants ($n = 34$) were employed at the time of genetic testing. Thirty percent of those surveyed sought new employment following genetic testing while 13% stated that they were reluctant to seek new job opportunities due to concerns about insurance coverage related to their genetic status. No reports of job discrimination due to genetic status or family history of cancer were found in this study.

Discussion

This study is the largest of its kind in the US documenting experiences of unaffected gene mutation carriers, with regards to insurance issues. There is little evidence for genetic discrimination in this study. It is unclear whether the few adverse outcomes reported were directly related to the positive genetic test results. Four adverse events are reported that could *possibly* be related to the results of genetic testing (8.5%). Two individuals were denied private health insurance, though one had other co-morbidities. One individual was denied an average life insurance policy and one individual was denied additional disability insurance. It should be noted that the individual with co-morbidities, who was denied private health insurance following testing, was the same individual who was denied an average life insurance policy- it is unclear whether this played a role in these denials. For the second individual who was denied private health insurance due to her double mastectomy and total hysterectomy, it is unclear if she may have been classified as a cancer patient based on these surgeries. Another participant in this study was also initially denied private insurance due to her use of tamoxifen, which was being used for chemoprevention. Upon further investigation, it was determined that she was rated as a cancer patient due to tamoxifen use. After legal input, the issue was finally resolved and this individual was provided an average risk insurance policy.

We found that fear of genetic discrimination was prevalent. In this population, there was a high rate of self-pay due to concerns about genetic discrimination and confidentiality (32%). Persistent concerns post-genetic counseling are evidenced by the reported fear of seeking new job opportunities due to concerns about genetic status among 13% of those surveyed. Consistent with anecdotal clinical experience, 13% of participants reported that at least one at-risk family member had not proceeded with genetic testing because of concerns about genetic discrimination.

It will be of interest to see if passage of recent federal legislation, Genetic Information Non-Discrimination Act of 2008 (GINA), has an impact on the attitudes and behaviors of individuals considering genetic testing for cancer risk. It is hoped that once this bill goes into effect, more at-risk individuals will seek genetic testing that could have far reaching benefits to their health and to the health of their families without fear of genetic discrimination. Of note, GINA will protect against genetic discrimination in health insurance and employment, but will not have any impact on life insurance, disability or long-term care insurance. In our study, we found one adverse event related to disability/long-term care insurance and one adverse event with life insurance post-receipt of a positive genetic test result. Similarly, a study of 636 women who underwent genetic counseling and/or genetic testing for *BRCA* between 1995 and 2000 found that fear of GD by life insurance companies was associated with the decision not to undergo *BRCA* testing but there was no evidence of actual insurance discrimination from *BRCA* testing [26].

Taylor and colleagues recently published a large survey of 2267 clinical genetics clients in Australia investigating possible genetic discrimination [27]. Their population comprised asymptomatic or unaffected individuals presenting for clinical genetics services. They had a 44% ($n = 1185$) response rate. Eighty-seven percent of individuals surveyed were at-risk for neurological conditions or familial cancers. They found a 10% rate of alleged negative

treatment, with nearly one-half of incidents related to life insurance. Individuals at-risk for neuro-degenerative conditions were more likely to report incidents. It is difficult to compare our study with this Australian experience given the differences in the study populations. Neurologic conditions, such as Huntington disease, which have no treatment or prevention and which have impact on cognitive and physical abilities are likely to be viewed differently by insurers than inherited predisposition to cancer. Additionally, differences in health care systems make it difficult to compare the results of the two studies. However, overall rates of adverse events are similar in the two studies, suggesting that genetic discrimination is not a widespread problem in either country.

This study highlights the need for education on several levels. Most individuals did not realize that their genetic test results were placed in their general medical record and this needs to be explained prior to initiation of testing. Over one-third of participants surveyed stated they did not have a good understanding of current legislative issues regarding genetic discrimination at the time they underwent genetic testing. This emphasizes the need for inclusion of information about protective state and federal legislation during the pre-test counseling session. Educating primary care doctors about these issues is important as well, as these providers are often the first person that a patient will approach about genetic testing. A recent study of 1,181 non-genetics clinicians in California revealed that the higher the belief in genetic discrimination, the less likely a participant was to refer for counseling/testing (OR = 0.72 [95% CI .518–.991], $P < .05$), while more knowledge of genetic discrimination law was associated with comfort recommending (OR = 1.18 [95% CI 1.11–1.25], $P < .001$) and actual referral (OR = 3.55 [95% CI 2.24–5.63], $P < .001$) [28].

Despite these limitations, the critical observation in this study is that the majority of participants reported no adverse outcomes following receipt of a positive genetic test result. These results in conjunction with increased legal protections will hopefully ease concerns of patients and healthcare providers.

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Table 1

Cancer genetics programs represented

Program	Location	Number eligible subjects	Number participated	Participation rate (%)
City of Hope Cancer Screening and Prevention Program	Duarte, CA	47	27	57
Familial Cancer Program of the Vermont Cancer Center	Burlington, VT	13	10	77
University of Michigan	Ann Arbor, MI	10	4	40
University of Washington Medical Center	Seattle, WA	?*	3	Incomplete data
Mass General Hospital Center for Cancer Risk Analysis	Boston, MA	?*	2	Incomplete data
North Memorial Cancer Genetics Program	Robbinsdale, MN	7	1	14

* Total number of eligible subjects for the study were not provided by these sites

Table 2Characteristics of study population: $N = 47$

	<i>N</i>	%
Gender		
Female	39	83
Male	8	17
Education		
High school	2	4
Some college or technical school	11	23
College diploma	10	21
Some graduate or professional school	5	11
Graduate or professional school	19	40
Marital status		
Single	9	19
Married/partnered	35	74
Widowed	1	2
Divorced	2	4
Family Income		
Less than 20,000\$	3	7
20,001–35,000\$	4	9
35,001–50,000\$	3	7
50,001–75,000\$	8	17
Greater than 75,000\$	28	61
Racial background		
White	45	96
Asian/Pacific Islander	1	2
Other	1	2
Type of health insurance at the time of genetic testing		
Medicaid	1	2
Group (HMO and non-HMO)	41	87
Individual	2	4
None	1	2
Do not know	2	4
Gene mutation status		
<i>BRCA1</i> + or <i>BRCA2</i> +	41	87
<i>MLH1</i> + or <i>MSH2</i> +	6	13
Year tested		
1997	5	11
1998	2	4
1999	7	15
2000	7	15
2001	12	26

	<i>N</i>	%
2002	11	23
2003	1	2
2004	1	2
2005	1	2