Consumer Issues Related to Life Insurance and Genetic Testing: Preliminary Findings for the BRCA1 Gene Mutation

Questions are being raised about the information generated by the growing number of genetic tests that are available. Within the life insurance industry, insurers fear consumers may use genetic information to obtain high levels of insurance at rates that are below actuarially fair values. We present preliminary findings from a study that examines how asymmetric information regarding genetic test status affects life insurance purchases and public opinion about the appropriate use of genetic information in this market.

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Introduction

As the number of genetic tests for inherited diseases grows, a variety of public and private interest groups are raising questions about what individuals and society should do with such genetic information. Within the life and health insurance markets, ethical concerns regarding genetic discrimination are clashing with the underwriting needs of insurance companies.

Consumers fear that if insurers gain access to genetic test results they will use this information to deny coverage and/or raise rates to individuals who carry particularly serious gene mutations --even when the individuals in question are still asymptomatic. Simultaneously, insurers worry that if consumers are allowed to keep genetic test results private, then those who test positive for serious gene mutations will be able to obtain high levels of insurance at prices that are below actuarially fair values. In essence, each group worries that the other will exploit new genetic information to gain an advantage in the insurance market.

Both sides of the insurance and genetic testing debate have made assertions based on little data. In this panel session, we present preliminary survey information from two groups of women to assess (a) insurers' claims regarding adverse selection, and (b) public opinion regarding the appropriate use of genetic information in the life insurance market.

The Data

The first group is comprised of women in a large kindred, known as K2082, whose members are at risk of carrying a specific mutation of the BRCA1 gene that dramatically increases their risk of developing breast and ovarian cancer (N=117). These women have been tested for this mutation and they know their genetic status. Their insurance companies do not have this information unless these women chose to reveal their test results to them. Survey data on insurance coverage and opinions regarding insurance industry practices were collected from these women four months after they learned their genetic test results (see Botkin et al., 1996 for further details on the sample). The second group of women come from the general public and they have not undergone genetic testing (N=169). In this group we over-sample women with a family history of breast/ovarian cancer. Comparisons across these groups allow us to assess the potential behavioral implications of asymmetric information in the life insurance market attributable to this particular gene mutation and how genetic testing influences public opinion.

All women in both groups are Caucasian, between the ages of 18 and 55, and living in Utah or Idaho. The women who test positive for the BRCA1 gene mutation (32%) are told by genetic counselors that they have an 85% lifetime risk of getting breast and/or ovarian cancer. Women who test negative and women who are not tested have a risk for breast/ovarian cancer equal to that in the general population (i.e., about 11%).

Preliminary Survey Results

Women in the combined sample are typically married (80%), have minor children in the home (71%), and are employed (62%). Their average education is 13.85 years, and their average age is 37. Mean annual household income is $46,491. These socio-demographic characteristics vary in only trivial ways across the two groups.

Seventy-six percent of the K2082 women report having one or more life insurance policies four months after learning their genetic test results. The corresponding figure for women in the non-tested sample is 73%. Table 1 presents a crosstabulation of the number of life insurance policies a respondent has stratified by family history and genetic testing status. The associated chi-square statistic of 7.86 (p=.64) indicates that there is no evidence of adverse selection.

Respondents were overwhelmingly not supportive of genetic test results being used in life insurance underwriting. There are moderate differences in opinions across the two groups however. Among the non-tested sample, 22% agree that life insurance companies should be allowed access to genetic test results while only 6% of the tested sample agree with this statement. Almost 8% of the public sample agree that life insurance companies should be allowed to require that the people they insure have genetic tests done while the corresponding figure for the tested group is 2%. Finally, only 8% of the non-tested sample agree that life insurance companies should be allowed to increase their rates for people who test positive for the BRCA1 gene mutation while 3% of the tested sample agree with this statement.

Summary

A strong test of the adverse selection hypothesis awaits the completion of the on-going collection of price and quantity information and the addition of more K2082 sample members who will soon be completing four-month post-test interviews. Nonetheless, the preliminary analyses suggest that adverse selection in the life insurance market is not strongly evident among women who have learned that they carry the BRCA1 gene mutation.

Although the current work is preliminary and its generalizability may be limited, our findings suggest that policymakers should be very cautious as they move forward in the legislative process. They should view with skepticism the insurance industry's contention that denial of access to genetic test results will threaten the industry's economic viability.

The findings also suggest that consumers have serious reservations about the use of genetic test results in the life insurance underwriting process. To date, three states (Arizona, Maryland, and Montana) have passed laws that legitimize the use of genetic test results in the underwriting process if there is an actuarial justification for doing so. Before promulgating more laws in this area, it is imperative that we learn more about (1) why consumers have reservations regarding the use of genetic information, and (2) in society's opinion, what would constitute ethically responsible uses of such tests and the genetic information they reveal.

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References

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Endnotes

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Table 1
Number of Life Insurance Policies by Group Membership (row fractions reported)

Group	Number of Policies		
	0	1	≥2
Family History, Tested Positive (N=28)	.21	.50	.29
Family History, Tested Negative (N=52)	.29	.46	.25
No Family History, Tested Positive (N=10)	.20	.70	.10
No Family History, Tested Negative (N=27)	.19	.48	.33
Family History, Not Tested (N=99)	.26	.41	.32
No Family History, Not Tested (N=70)	.31	.34	.34