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Life Insurance and Breast Cancer Risk Assessment: Adverse Selection, Genetic Testing Decisions, and Discrimination

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Life insurance industry access to genetic information is controversial. Consumer groups argue that access will increase discrimination in life insurance premiums and discourage individuals from undergoing genetic testing that may provide health benefits. Conversely, life insurers argue that without access to risk information available to individuals, they face substantial financial risk from adverse selection. Given this controversy, we conducted a retrospective cohort study to evaluate the impact of breast cancer risk information on life insurance purchasing, the impact of concerns about life insurance discrimination on use of *BRCA1/2* testing, and the incidence of life insurance discrimination following participation in breast cancer risk assessment and *BRCA1/2* testing. Study participants were 636 women who participated in genetic counseling and/or genetic testing at a University based clinic offering breast cancer risk assessment, genetic counseling, and *BRCA1/2* testing between January 1995 and May 2000. Twenty-seven women (4%) had increased and six (1%) had decreased their life insurance since participation in breast cancer risk assessment. The decision to increase life insurance coverage was associated with predicted breast cancer risk (adjusted OR 1.03 for each 1% absolute increase in risk, 95% CI 1.01–1.10) and being found to carry a mutation in *BRCA1/2* (OR 5.10, 95% CI 1.90–13.66). Concern about life insurance discrimination was inversely associated with the decision to undergo *BRCA1/2* testing (RR 0.67, 95% CI 0.52–0.85). No respondent reported having life insurance denied or canceled. In this cohort of women, these results indicate that information about increased breast cancer risk is associated with increase in life insurance purchasing, raising the possibility of adverse selection. Although fear of insurance discrimination is associated with the decision not to undergo *BRCA1/2* testing, there was no evidence of actual insurance discrimination from *BRCA1/2* testing.

KEY WORDS: insurance selection bias; genetic screening; *BRCA1*

INTRODUCTION

As opportunities increase for members of the public to obtain genetic tests that can predict future disease, some life insurers are concerned that their financial solvency will be threatened unless they have access to the same genetic information as insurance purchasers [Kinzler et al., 1991; McEwen et al., 1993; Bronner et al., 1994; Miki et al., 1994; Wooster et al., 1995; Schmidt, 1996]. For the life insurance market, the threat of adverse selection arises when individuals who learn through

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genetic tests, for example, that they are at higher risk of early death purchase more life insurance than they would have bought without the test, while those who learn they are at lower risk reduce their life insurance coverage [Berger and Cummins, 1991; Black and Skipper, 1994]. Under these circumstances, insurers will experience a higher overall rate of death per premium dollar collected, and will raise premiums for all buyers to cover their higher costs. Higher premiums may then lead individuals at low or average risk to buy less life insurance and may even drive some of the lowest risk individuals entirely out of the insurance market, increasing the average risk level of those who remain insured, and further increasing the price of life insurance. The result could be a vicious circle, often termed a "death spiral," in which life insurers leave the market (Fig. 1).

The risk of adverse selection associated with genetic test information is likely to be greater for life insurance than for health insurance. More than 90% of private health insurance contracts in the US provide benefits limited to health care costs incurred, are obtained through an employment-based group that offers a limited menu of choices, and offer little room to increase coverage in response to individual risk information [Wilcox, 1997]. In contrast, most life insurance contracts are sold individually with premium schedules that are guaranteed for years in advance and with the opportunity to increase coverage [Black and Skipper, 1994; Hartwell, 1998]. Furthermore, although an insurance purchaser can cancel the policy at any time, the life insurer is required to renew coverage at the prespecified premium schedule, leading to extended financial exposure.

Many life insurance industry representatives in the US and UK point to the theory of adverse selection to suggest that all genetic information available to individuals be similarly available to insurers, so that they can price individual policies appropriately [McEwen et al., 1993; Schmidt, 1996]. At the same time, consumer groups struggle to increase the privacy protection of genetic information [Gostin, 1991; McEwen, 1992; Natowicz et al., 1992; Ostrer et al., 1993]. These groups voice concerns that insurance industry access to genetic information will lead to discrimination of the very kind the insurance industry argues may be necessary to maintain its solvency. Consumer groups also argue that concerns about insurance discrimination may prevent individuals from pursuing genetic testing, thereby hindering them from adopting measures that may reduce disease risk.

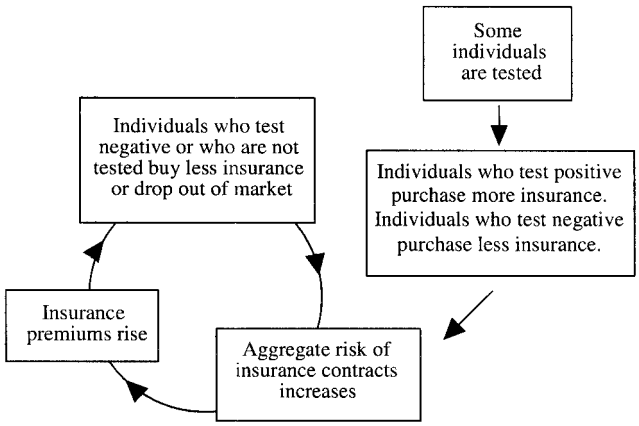

Fig. 1. Adverse selection.

The language of this debate is confusing because the word "discrimination" is often used neutrally by economists and actuaries, but is interpreted negatively by the public. Moreover, actuarially fair differences in life insurance pricing are often tolerated (e.g., lower premiums for women vs. men), but sometimes seen as socially inappropriate (e.g., higher premiums for African-Americans vs. Caucasians). In the setting of breast cancer risk, actuarially fair life insurance policies would charge more to women with higher risks of dying from breast cancer. However, the public may believe differential pricing based on breast cancer risk would be socially intolerable, even though actuarially fair. But if life insurers ignore breast cancer risk information or are prevented from using it, adverse selection might eliminate the possibility of life insurance for all, and thus threaten this important social interest.

Although adverse selection could represent a significant threat to life insurance markets in the setting where genetic risk information is available to individuals but not to insurers, it will be a real threat only if individuals who know they are at high risk purchase more life insurance, or if those who know they are at low risk purchase less. Testing for mutations in the two major breast cancer susceptibility genes, *BRCA1* and *BRCA2*, provides a useful model for studying adverse selection because it represents a current challenge for both patients and insurers, and because similar challenges are likely to arise from comparable tests for other conditions in the future [Hoskins et al., 1995]. Despite the urgent need to address the tensions between the legitimate interests of the insurance industry and the legitimate interests of individual patients, little empirical work is currently available to move these discussions beyond rhetoric and anecdote. Thus, the purposes of this study were to determine the effect of breast cancer risk information on subsequent life insurance purchases, to characterize the influence of concerns about life insurance discrimination on testing for *BRCA1/2* mutations, and to describe the incidence of life insurance discrimination, if any, following participation in breast cancer risk assessment and genetic testing.

METHODS

Study Setting

The Breast Cancer Risk Evaluation Program is a multidisciplinary clinical and research program established at the University of Pennsylvania in 1994 to provide breast cancer risk assessment, genetic counseling, and genetic testing for breast cancer susceptibility to interested individuals. Women may become involved in this program by attending the clinical risk assessment practice and/or through participation in research

protocols involving genetic susceptibility testing. The clinical risk assessment program involves two or three visits. In the first visit, a detailed family history is collected and general information is provided about breast cancer risk and *BRCA1/2* testing. In the second visit, an individualized estimate of breast cancer risk and risk of carrying a *BRCA1/2* mutation is provided using published prediction models, and women who decide to undergo *BRCA1/2* testing submit a blood sample for analysis. In the third visit, women who underwent genetic testing are provided with their test results and further counseling. Women who do not undergo testing at the second visit may return later if they decide to pursue testing. Women who participate in research protocols outside of the clinical risk assessment program also undergo counseling prior to agreeing to participate and prior to receiving their test results. This counseling may be performed by the staff of the clinical risk assessment program or, for participants who live far from the University of Pennsylvania, at local qualified facilities. Because the University of Pennsylvania was one of the first centers to offer testing for *BRCA1/2* mutations, the Breast Cancer Risk Evaluation Program offered a unique opportunity to evaluate the life insurance purchasing decisions of a large cohort of women considering participation in genetic susceptibility testing.

Study Design and Subject Selection

We conducted a mailed survey of two complementary cohorts of individuals: (1) 926 women who had participated in the clinical risk assessment program between January 1995 and May 2000; and (2) 262 individuals who had been found to have a *BRCA1/2* mutation through research testing protocols. For both groups, the questionnaire asked about current life insurance coverage, changes in life insurance made since going through the program, and occurrence of life insurance discrimination since participation in risk assessment. In addition, for the women who had participated in the clinical risk assessment program, items were included assessing concerns about life insurance discrimination and its impact on their decisions to undergo *BRCA1/2* testing. Of the 926 women who had participated in the clinical risk assessment program, 28 were excluded because they had previously requested not to participate in further research, 53 because their questionnaires were returned for incorrect addresses, and 11 because the intended recipient had died. Of the remaining 834 individuals, 574 returned questionnaires for a response rate of 69%. Of the 262 individuals who had been found to have a mutation through research testing protocols, 135 completed questionnaires, 10 had died or were too ill to complete the questionnaire, 40 were no longer at the recorded mailing address, and 1 was in the process of getting his test results for a response rate of 55%. From the 135 individuals who returned completed questionnaires, 47 had been included in the prior survey, 9 were men and 17 did not know the results of their *BRCA1/2* test at the time of the survey—leaving a total of 62 additional *BRCA1/2* mutation carriers. Thus, there were a total of 636 women in the final study cohort. The study protocol was approved by the Institutional Review Board of the University of Pennsylvania.

Statistical Analysis

All variables were analyzed using descriptive statistics to assess data quality, data distribution, and the need for data transformation. In general, statistical analyses were conducted first within the clinical risk assessment cohort and then within the entire study cohort (clinical risk assessment participants + mutation carriers identified through research participation). Because Mantel–Haanszel tests of homogeneity suggested that the results did not differ statistically (P-values > 0.10) between these two approaches, the results for the entire cohort were presented. Because the research participants were not asked about the effect of concerns about insurance discrimination on testing decisions, these analyses were restricted to the clinical risk assessment cohort. The predicted lifetime risk of breast cancer for each subject without a *BRCA1/2* mutation was calculated from prediction tables developed from the Cancer and Steroid Hormone Study, a large, population based case-control study of breast cancer [Claus et al., 1994]. These tables provide breast cancer risk estimates up to age 80 according to the family history of breast cancer. The predicted lifetime risk of breast cancer for women with a *BRCA1/2* mutation was estimated to be 85% [Easton et al., 1995]. Associations between concern about insurance discrimination and the testing decision were examined using the Wilcoxon rank-sum test for concern as an ordered variable and the chi-square test for concern dichotomized between very important/moderately important and a little important/not at all important. Associations between potential predictor variables and increase in life insurance were examined using independent sample t-test for continuous variables and Fisher's exact test for categorical variables. Because predicted risk of breast cancer had a skewed distribution, the Wilcoxon rank-sum test was used in confirmatory analyses. Multivariate analyses were conducted to adjust the association between potential predictor variables and insurance purchasing for confounding and effect modification. All P-values are two sided.

RESULTS

The characteristics of the 636 women in the study cohort are reported in Table I. Two hundred thirty-eight women had undergone *BRCA1/2* testing and 109 were found to carry a *BRCA1/2* mutation.

Among the subgroup of 574 women who had participated in the clinical risk assessment program, fear of life insurance discrimination was rated as a moderately or very important factor by 294 participants (55%). Women who were concerned about life insurance discrimination were less likely to undergo genetic testing (RR 0.67, 95% CI 0.52–0.85). Fear of discrimination was not associated with breast cancer risk or change in insurance coverage ($P > 0.24$).

TABLE I. Subject Characteristics

	Overall[a] (n = 636)	Increased life insurance (n = 27)	Did not change life insurance (n = 599)	Two tailed *P*-value
Mean age, year (range)	48.4 (20–80)	45.9 (32–74)	48.3 (20–80)	0.27
Caucasian (%)	95.8	96.3	95.6	0.86
Ashkenazi (%)	26.8	16.0	27.2	0.24
Married (%)	80.9	54.5	82.1	0.02
Divorced/separated (%)	6.9	36.4	5.5	0.0001
College education (%)	83.6	75.0	84.0	0.41
Employed (%)	81.7	88.9	81.2	0.56
Life insurance (%)	72.4	96.3	73.7	0.01
BRCA1/2 testing (%)	38.5	52.0	33.9	0.06
BRCA1/2 mutation (%)	17.6	32.0	11.7	0.003
Breast cancer diagnosis (%)	34.5	32.3	32.7	0.65
Ovarian cancer diagnosis (%)	2.1	0	1.8	—
Predicted lifetime breast cancer risk, mean (SD)				
Including *BRCA1/2* mutation carriers	24.6 (19.5)	36.3 (25.1)	24.1(19.0)	0.01
Excluding *BRCA1/2* mutation carriers	20.0 (10.3)	25.9 (10.6)	19.8 (10.2)	0.02

[a]Includes the six women who decreased coverage.

Two women reported that they had been told to keep their participation in genetic counseling for *BRCA1/2* testing "quiet" by their life insurance agent. Of these two women, one had tested negative for *BRCA1/2* mutations and the other had not undergone testing. One woman said her application for a new policy had asked about testing for genetic susceptibility but she had not completed the application process yet. No woman reported having life insurance denied or canceled, or any other negative experience with life insurance coverage, since participating in genetic counseling.

Thirty-seven women (6%) reported changing their life insurance coverage since participation in genetic counseling and/or testing. Twenty-seven women (4%) increased their insurance coverage, 6 women (1%) decreased or canceled their insurance coverage, and 4 women (1%) did not provide further information about their change in coverage. Compared to women who did not increase their life insurance coverage, women who increased insurance coverage were more likely to have been found to carry a *BRCA1/2* mutation (RR 2.75, 95% CI 1.5–5.1) and, among women without a breast cancer diagnosis, had a higher predicted lifetime risk of breast cancer (mean predicted risk 36.1% vs. 24.3%, $P = 0.01$). In addition, women who owned life insurance at the time of their visit were over eight times more likely to have increased their coverage than women who did not own life insurance (RR 8.11, 95% CI 1.1–9.2). After adjustment for age, race, breast cancer diagnosis, ovarian cancer diagnosis, and Ashkenazi background, the decision to increase life insurance remained associated with testing positive for *BRCA1/2* mutation (OR 5.10, 95% CI 1.9–13.7, $P = 0.003$) and owning life insurance at the first visit (OR 2.50, 95% CI 1.1–5.6, $P = 0.03$). In a separate model of women without a diagnosis of breast cancer, after adjustment for age, race, and Ashkenazi background, predicted lifetime risk of breast cancer was also strongly associated with the decision to increase life insurance (adjusted OR 1.03 for each 1% absolute increase in risk 95% CI 1.01–1.10). The decision to increase life insurance coverage was not associated with age, race, Ashkenazi background, education, or employment outside of the home.

Among women who had life insurance at the time they underwent risk assessment, decreasing life insurance coverage was not associated with predicted breast cancer risk or results of *BRCA1/2* testing ($P > 0.10$). Of the 6 women who decreased or canceled life insurance coverage, 1 had tested positive for a *BRCA1/2* mutation, 2 had tested negative for a *BRCA1/2* mutation, and 3 had not undergone testing. Decreasing coverage was not associated with age, race, Ashkenazi background, education, or employment outside of the home.

DISCUSSION

Genetic testing is a powerful tool for predicting the risk of future disease. The promise of genetic testing for targeting preventive care to high-risk individuals competes with the danger that the same information will lead to discrimination in social and financial settings. Current policy debates focus on this conflict. This study has four main findings that offer some of the first empirical evidence in this debate.

First, almost one half of the women we studied expressed concern about future life insurance discrimination if they underwent genetic testing. Furthermore, heightened concern was associated with a decision to forgo genetic testing. As women in this group had an average breast cancer risk over 20%, genetic testing might have been able to identify women who would be most likely to benefit from interventions to reduce breast cancer risk, such as prophylactic mastectomy and tamoxifen [Fisher et al., 1998; Meijers-Heijboer et al., 2001]. For this sample, then, fear of insurance discrimination may lead to underuse of prevention and avoidable cancer deaths.

Second, although concern about insurance discrimination is high, we found no evidence of actual life insurance discrimination among women who participated in risk assessment and genetic testing through this clinical program. This information should alleviate

some of the concern for women considering undergoing risk assessment or genetic susceptibility testing.

Third, although women in general may be less likely to carry personal life insurance than men, 72% of the women in our sample were insured [American Council of Life Insurance, 1996]. Overall, women interested in obtaining information about their risk of heritable breast cancer are highly educated and employed. Although life insurance purchasing may be lower among women in other settings, it is high in this setting.

Fourth, the decision to increase life insurance coverage is associated with information about the predicted risk of breast cancer, including *BRCA1/2* mutation status. This association was not found in the only other published study of life insurance purchasing and breast cancer risk [Zick et al., 2000]. However, this prior study examined life insurance coverage (rather than change in coverage) among a single kindred in Utah who had not necessarily received breast cancer risk counseling. Although the association between breast cancer risk and increasing insurance coverage support insurers' concerns that some women will change their life insurance in response to breast cancer risk information, the overall impact of these changes remains unclear. Only 4% of women increased their coverage after receiving risk information. The ultimate effect of this behavior depends on multiple factors including how such changes affect insurance costs and pricing, how changes in insurance pricing affect purchasing decisions of women at average risk, the level of uptake of genetic testing in the population and the incremental impact of genetic information over family history information. In prior studies using actuarial models, we have found that most of the actuarially powerful information comes from family history, not genetic test results. [Subramanian et al., 1999; Lemaire et al., 2000]. With the widespread distribution of software programs to assess the risk of breast cancer by the pharmaceutical company marketing tamoxifen, many more women are likely to receive information about their risk of breast cancer in the next several years than are likely to participate in *BRCA1/2* testing [Armstrong et al., 2000]. Currently, life insurers ask about family history and other factors related to breast cancer risk, but it is not known whether or how that information is used for underwriting [McEwen et al., 1993; Lemaire et al., 2000]. Little is known about current levels of uptake of predictive genetic tests in the general population and determining the level of uptake that would result in significant adverse selection will require further actuarial modeling. Perhaps most importantly, if genetic or other types of risk assessment lead to use of effective cancer risk reduction interventions, the threat of adverse selection will be replaced by a welcome reduction in overall mortality attributable to risk assessment and genetic testing, benefiting patients and insurers alike.

This study is subject to several limitations. We used patients drawn primarily from a single clinical site, although one that draws women from across the Mid-Atlantic and lower New England. We relied on self-reported information regarding insurance purchasing. Although our small sample size limits the precision of some of our estimates, it was sufficient to demonstrate statistically and clinically significant associations between breast cancer risk and insurance purchasing. Because of the small sample, we cannot provide reliable estimates of the magnitude of change in life insurance benefit amount among those who changed policy size. Women who entered this program earlier have had more opportunity to change their life insurance coverage, and those who entered late may change them in the future. For this reason, point estimates likely understate the changes that would be observed over time. We did not evaluate a comparable group of women who did not enter the Breast Cancer Risk Evaluation Program. Some of these women may have forgone breast cancer risk evaluation because of their concerns about subsequent insurance discrimination. Thus, we do not have a comparison group against which to assess the changes in insurance purchasing exhibited by our overall sample; nevertheless, within our sample, insurance changes were associated with higher risk of breast cancer.

Despite these limitations, this study demonstrates that some women concerned about breast cancer risk incorporate that information into their life insurance purchasing decisions and that concern about insurance discrimination is an important barrier to the use of genetic testing despite the absence of evidence that such discrimination actually occurs. Further study is needed to determine the magnitudes of these effects, and their impact both on genetic testing and on life insurance markets. These studies will require larger and more longitudinal assessments of behavior and will need to be combined with actuarial models of the impact of these behaviors on life insurance pricing and subsequent demand.

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