Letters to the Editor

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Health, Life, and Disability Insurance and Hereditary Nonpolyposis Colorectal Cancer

To the Editor:

With the discovery of germ-line mutations in the mismatch-repair genes, genetic testing for hereditary nonpolyposis colorectal cancer (HNPCC) has become a reality. However, concern about potential genetic discrimination, with regard to insurance and employment, has surfaced among affected individuals and health-care providers. Owing to the lack of information regarding insurance providers' attitudes toward both HNPCC individuals diagnosed with cancer and asymptomatic gene carriers, we decided to assess the insurance-industry attitude regarding the offering of health, life, and disability insurance to HNPCC gene carriers and at-risk family members.

An anonymous survey with 14 questions, which included a self-addressed, stamped envelope, was mailed to 1,000 health, life, and disability insurance company presidents. An insurance company database consisting of 5,178 companies was purchased from NAIC Database products. Twenty companies, from each state, that were reported to sell health, life, and disability insurance were chosen randomly from the purchased database. An introductory letter defining HNPCC and the anonymous nature of the study accompanied each mailed questionnaire. Only one mailing was sent. A gene carrier was defined as someone with a germ-line mutation in one of the genes responsible for HNPCC. An at-risk family member was defined as someone who had a 50% chance of carrying the mutation for the defective gene.

Of the 1,000 surveys mailed, 4 were not delivered and 79 were returned. Two of the returned surveys were excluded, since they were mailed to different locations of the same company. There were 77 (7.7%) responses to the mailing. Five surveys were returned unanswered, and 6 were returned labeled "not applicable." Even though we did not know the size of the companies that responded to our survey, we estimated, on the basis of our response rate, that our respondents probably issue <5% of the insurance policies sold in the United States.

The survey consisted of three sections, with six questions on health insurance, four questions on life insurance, and four questions on disability insurance. A total of 66 usable questionnaires were returned, but not all were completed for all three types of insurance: Responses were as follows: 49/66 responded as health insurance providers, 46/66 as life insurance providers, and 30/66 as disability insurance providers. These 66 questionnaires served as the basis for this report.

With regard to health insurance, 48 (98%) insurance providers responded that they would insure at-risk family members, whereas 1 (2%) insurer would not. Three of the 48 insurers would provide the insurance, with the following conditions: a higher premium (1); if the insured "does not carry a bad gene" (1); and depending on a guarantee (1). Forty-four (90%) of the insurers would provide insurance to a gene carrier. Those who would not provide the insurance had the following reasons: no explanation (1); not unless state mandated (1); cost of surveillance and treatment too high (1); would offer colorectal cancer rider (1); and depends on guarantee (1).

Thirty-seven (76%) providers would not increase the premium for an at-risk member. However, 9 (18%) providers would increase the premium for an at-risk member, whereas 2 providers were not sure whether the premium would be increased. One company answered that it would not increase the premium but would consider inserting an exclusion rider. With regard to health insurance for gene carriers, 38 (78%) providers would not increase the premium, 10 (20%) providers would, and 1 (2%) provider was not sure.

Tables 1 and 2 indicate the responses to the questions regarding (1) payment for colonoscopy at more-frequent intervals for HNPCC at-risk individuals than for the general population and (2) payment for prophylactic abdominal colectomy and ileorectal anastomosis for an HNPCC gene carrier. It can be seen that the majority (61%) of the health insurance providers would pay for more-frequent colonoscopies and that 35% of the insurers would pay for prophylactic surgery for a gene carrier.

With regard to life insurance, 32 (70%) companies would sell life insurance to at-risk individuals, 2 (4%) would not, and 12 (26%) would sell it at a higher pre-

Table 2

Health Insurance Providers' Willingness to Pay for Prophylactic Surgery for an HNPCC Gene Carrier

	No. (%) of Providers
Yes	17 (35)[a]
No	22 (45)[b]

[a] Three providers responded that payment would be made if medical necessity had been established, one that payment would be made if there was no rider, and one that payment would be made if medical necessity had been established and if the procedure was not experimental.

[b] One provider responded that payment would not be made unless the procedure was standard care, one responded that payment was subject to review of each case, and one responded that payment normally is not made for preventive surgery.

Table 3

Access to DNA Test Results, by Type of Insurance Provider

Access to DNA Test Results	No. (%) of Life Insurance Providers	No. (%) of Disability Insurance Providers
Yes	26 (57)[a]	20 (67)
No	14 (30)	8 (30)
Not applicable	2 (4)	1 (3)
Do not know	1 (2)	1 (3)
Maybe	1 (2)	…
No answer	2 (4)	…

[a] One provider stated that they would have access to test results but would decline to insure for economic reasons.

mium. Thirty-two (70%) of the respondents would sell life insurance to gene carriers, whereas 2 (4%) would not, 10 (22%) would sell it at a higher premium, 1 (2%) was not sure, and 1 (2%) did not answer the question. Forty-three (93%) of the life insurance providers did not require genetic testing prior to insuring a member of an HNPCC kindred. One company did require genetic testing. Two companies would require genetic testing prior to selling life insurance if the coverage was >$50,000–$100,000 or >$350,000, respectively.

With regard to disability insurance, 24 (80%) companies would sell disability insurance to at-risk individuals, 1 (3%) would not, and 5 (17%) would sell it at a higher premium. Gene carriers would be insured by 23 (77%) companies. Three (10%) companies would not sell disability insurance to gene carriers, whereas 4 (13%) would charge a higher premium.

Twenty nine (97%) of the disability insurance providers did not require genetic testing prior to insuring a member of an HNPCC kindred. One company did require genetic testing. As shown in table 3, the majority of the life and disability insurance providers would be allowed access to DNA test results.

In the interpretation of our results, there are several factors that should be kept in mind. Even though our survey was completely anonymous, only 79 (7.9%) of the surveys were returned. This is a limitation of our data set. This could have been improved if we had sent additional mailings. However, because of the anonymity of the survey, the logistics of remailing 1,000 questionnaires was insurmountable, and, hence, the decision was made to mail the survey only once. There were several potential reasons for the poor response rate. Among them was that the survey may have been mailed to an inappropriate insurance company executive, which could have led to fear of identification and of adverse public relations for the company or fear that the company could be held accountable, in the future, for any answers provided. Importantly, we do not claim that the results reflect the whole insurance industry. However, they at least provide some information about insurance-provider attitudes toward HNPCC gene carriers and at-risk individuals.

Even though we had a limited response (7.7%) to the questionnaires and the survey respondents probably issue <5% of the insurance policies sold in the United States, our results indicate that the majority of health, life, and disability insurance providers with an opinion would be willing to sell insurance to both HNPCC gene carriers and at-risk individuals. Nevertheless, there were some that would not insure these individuals. The interpretation of our results indicates that there is probably a minority of insurance providers that potentially will discriminate against HNPCC gene carriers and at-risk individuals. It is the latter insurance providers who need to be educated about the condition and the benefits of surveillance and early detection.

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