BRCA Genetic Testing: Ethical, Legal and Policy Considerations

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There is a concern that life insurance companies will use genetic tests to deny coverage or charge increased premiums to patients with mutations for genetic disorders. Those in favour of restricting an insurer’s ability to use genetic information suggest that the fear of genetic discrimination will deter patients from pursuing important genetic testing. Others argue that restriction will disrupt the insurance industry because it will allow high-risk patients to purchase life insurance policies at rates that underestimate the true risk of mortality. This essay focuses on the BRCA genes and reviews the literature to evaluate the possibility that (1) mutation positive individuals will purchase additional insurance to the detriment of other insured individuals, or that (2) women will avoid genetic testing and therefore forego the opportunity to benefit from prophylactic therapies. The paper discusses the current state of the law, possible policy directions, and the need for lawmakers and insurers to develop appropriate measures before emerging genetic technologies can calculate genetic risks with greater certainty.

Introduction

One of the most important ethical debates of the Human Genome Project arises from the possibility of ‘genetic discrimination’. Many people are concerned that one’s genetic status, as revealed by genetic testing, could serve as a basis for wrongful discrimination relating to the provision of consumer services. There is a particular concern that life insurers could charge increased premiums to those predisposed to genetic disorders. It is controversial as to whether the use of genetic information by insurance companies would be an acceptable business practice or conduct akin to racial discrimination.

The BRCA genes, which are more fully described below, are particularly relevant in evaluating the potential role of genetic information in the insurance underwriting process as mutated BRCA genes confer a calculable risk of breast and ovarian cancer in women. Moreover, prophylactic therapies are available to affected women. The BRCA genes will thus serve as a model in the following discussion of the ethical, legal, and policy considerations related to the use of genetic information by life insurers.

The BRCA genes

Breast-cancer associated genes 1 and 2 (BRCA1 and BRCA2) were discovered in 1994 after extensive studies and molecular testing of women in hereditary breast and ovarian cancer (HBOC) families. Both BRCA1 and BRCA2 are tumor-suppressor genes which, when mutated or defective, result in some loss of cell-cycle regulation and a 50-80% risk for developing breast cancer, along with increased susceptibility to ovarian cancer.1 The BRCA genetic test involves direct nucleotide sequencing of the BRCA1 and BRCA2 genes and costs thousands of dollars in a US laboratory. Interventions available to affected women include chemoprevention, and bilateral prophylactic mastectomy and oophorectomy.2

Evidence to guide policy direction

Policy relating to genetic testing should be guided by a thorough understanding of the tests and their implications, as well as evidence regarding decisions pre- and post-testing. With genetic tests such as BRCA, an issue relating to the business of life insurance is the information asymmetry that results after a genetic test, resulting in the consumer having more information about their health if they choose not to disclose their test results to a prospective insurer. The tendency of high-risk individuals to purchase insurance at rates that underestimate risk is termed ‘adverse selection’ and is recognized as an undesirable
consequence of restricting an insurer’s ability to utilize a prospective customer’s genetic test results.\(^3\) Insurance companies seek mandatory disclosure in order to accurately value insurance plans, whereas genetic interest groups argue that mandatory disclosure results in discrimination and public reluctance to be tested, and that voluntary disclosure is the best method.\(^4\)

The decision to be tested for a BRCA mutation is one that has important repercussions and all testing must be accompanied by proper genetic counseling. A study of women in a high prior-risk clinic in Michigan showed that out of 184 candidates for testing, only 106 (58\%) underwent testing and of those who declined, 48/78 (62\%) cited concerns about cost and insurance discrimination as the reasons for not undergoing the test.\(^5\) This same study estimated that half of patients declining testing for insurance concerns would be positive, and in high prior-risk clinics, approximately 25\% of patients will decline testing for reasons of cost, confidentiality and insurance concerns. Fear of genetic discrimination are prevalent even in those highly educated in health policy; in a survey of the Special Interest Group in Cancer of the National Society of Genetic Counselors (USA), 68\% undergoing genetic testing would not attempt reimbursement from their insurance company for the test for fear of later discrimination, and 26\% claim they would use an alias for the test.\(^6\) Policy must be in place to clarify confidentiality issues and the use of genetic testing in insurance and healthcare settings in order to prevent public reluctance to be tested, which would decrease the positive benefits of testing.

As described above, insurance companies fear that those with the informational advantage of positive genetic tests will purchase additional policies, and cite this possibility of adverse selection as a reason for mandatory disclosure of tests. In a one year follow-up of a group of Utah women who underwent BRCA1 testing, it was found that consumers do not exploit the information asymmetry caused by genetic testing: none of family history, testing status or participation in early BRCA1 research seemed to be indicators of demand for life insurance, and the only factors found to influence insurance policy purchase were socioeconomic ones.\(^7\) The women who tested positive were found to have statistically similar amounts of life insurance in comparison to those who tested negative. Conversely, another study of women undergoing BRCA testing or counseling revealed that the decision to increase life insurance coverage was associated with a positive BRCA test.\(^8\) The paucity of empirical research, along with conflicting results of studies described above, suggests that much more research is need to determine if restricting insurers’ ability to use genetic information for actuarial calculation will result in adverse selection.

**The Concept of Genetic Discrimination**

The precise meaning of discrimination is often confused in the context of risk calculation based on genetic status in the life insurance industry. Insurers intentionally use the word ‘discrimination’ in the sense of merely drawing distinctions among individuals based on generally accepted principles of actuarial science. Discrimination utilized in this neutral sense must be distinguished from the kind of discrimination that is deemed illegal and wrongful under human rights legislation. In Ontario, the *Human Rights Code* prohibits discrimination relating to such areas as services, accommodation, and employment on a discreet number of enumerated grounds including race, ethnic origin, sexual orientation and age.\(^9\) However, one who discriminates on one of these or other enumerated grounds can often justify discriminatory behaviour by demonstrating that a distinction was drawn on *bona fide* and reasonable grounds. The Supreme Court of Canada has acknowledged that the calculation of insurance premiums does not fit easily with concepts of human rights norms, but has justified the practice of differential treatment that is based on sound and accepted underwriting procedures and if there are no practical alternatives.\(^10\)

Some leading Canadian commentators on this topic suggest that discrimination on the basis of genetic status, as revealed by a predictive genetic test, will be wrongful in the insurance industry only if there is no actuarial basis for concluding that a customer is at increased risk.\(^11\) These critics often call attention to the fact that family history—which often serves as a proxy for genetic risk—plays a valid role in life insurance premium calculation. Other critics highlight the fact that some patients oppose the practice of drawing distinctions on genetic status, even if genetic tests can accurately predict the risk of mortality. In discussing BRCA predicting genetic testing, one scholar notes that “the public may believe differential pricing based on breast cancer risk would be socially intolerable, even though actuarially fair.”\(^12\) It has been noted that Canadian human rights law is evolving and might place restrictions on the ability of insurers to use genetic information when calculating premiums.\(^13\) There is a good probability, however, that differential premiums based on genetic status will be justified if based on sound scientific principles and in the absence of alternatives.
Policy Alternatives

Potential strategies at addressing the inevitable problems created by life insurers’ use of genetic information include legislative prohibition, the establishment of moratoria upon insurers, and maintenance of the status quo. Many European Countries including Austria, Belgium, and Denmark have embraced the first option and have enacted legislation that places an outright restriction on a life insurer’s ability to request or use genetic testing in calculating premiums.12 The Netherlands has adopted a similar approach but only to policies below a predetermined monetary figure, thereby ensuring that all individuals can purchase a basic amount of life insurance.11 Moratoria are usually established by the insurance industry but often at the behest of governments. Insurers within the United Kingdom utilized the moratorium method in the past, but reserved the right to use genetic information when approved by a governmental committee and when the insurance contract was over a specified amount. The rationale of this moratorium was to give the industry and the relevant authorities more time to converse and possibly develop a framework for the use of genetic information in life insurance premium calculation.13 Finally, the status quo approach leaves it to the life insurance industry to decide for itself how to use genetic information. Canada appears to have opted for the status quo; there did not exist any provincial or federal legislation regulating life insurers’ use of genetic information or a self-imposed industry moratorium during the preparation of this article.

In 2004, insurers, patient advocates, and researchers knowledgeable in genetics policy established the Canadian Genetics and Life Insurance Task Force to suggest policy options relating to life insurance and genetics.14 The task force urged policy-makers, insurers and physicians to debate the merits of either (1) imposing a temporary moratorium on the use of genetic information for life insurance policies below a specified amount, or (2) creating an independent standing body that would oversee the use of genetic information by life insurers. It is not clear whether stakeholders took up this challenge.

Concluding Comments

Reports of actual discrimination on the basis of predictive genetic test results have hitherto been scarce.15 Policy makers, therefore, have some time to debate the benefits and drawbacks of regulating a life insurers’ ability to use a customer’s genetic status in their underwriting activities. On the other hand, the number of diseases for which there are genetic tests increased 600% from 1997 to 2006.16 It is therefore crucial to have policy directing the use of genetic testing which strikes an appropriate balance between encouraging patients to access beneficial genetic testing and promoting a fair and effective life insurance regime.

References


