

Genetics and Life Insurance: Medical Underwriting and Social Policy

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Reference: Rothstein MA, ed. *Genetics and Life Insurance*. Cambridge, Mass: The MIT Press; 2004: (304 pages). Available at 800-405-1619 or <http://mitpress.mit.edu> (\$34.00)

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The year 2004 was a disappointing one for proponents of legislation aimed at combating genetic discrimination. In July after several years of debating model regulations that would have specifically applied to life and disability insurance, the National Conference of Insurance Legislators tabled the issue entirely after concluding that there was no problem to address. In December, the US House of Representatives adjourned without ever considering an anti-discrimination bill that the Senate had passed unanimously in 2003.

Publication of *Genetics and Life Insurance* comes just as interest in a legislative "solution" to genetic discrimination appears to be fading. Indeed, all the original assumptions that inflamed the fear of genetic discrimination have proven incorrect. Despite completion of the Human Genome Project in 2003, the anticipated flood of new and highly predictive genetic tests has not materialized. Life insurers can now point to a number of studies that demonstrate a pattern of responsible behavior when underwriting known genetic risks. And critically, the central dogma of genetic exceptionalism (the idea that genetic information is qualitatively different from other

medical information and therefore raises unique social issues) has undergone reexamination and was found to be invalid.

The book is the final product of a year 2000 ELSI grant of \$736,808¹ for the purpose of investigating whether there should be limits placed on life insurers' use of predictive genetic information in risk classification. This was still an important and unresolved question at the time that the grant was approved. The study design included a survey of consumer attitudes towards life insurance and genetic information, as well as the organization of a conference that involved major stakeholders, such as industry representatives, consumer advocates, ethicists, and specialists in insurance law. The goal of the conference was to focus on building consensus and advancing understanding in areas of disagreement. Some participants were asked to contribute a book chapter in their particular area of expertise. The final chapter of the book is an effort by Mark Rothstein, the investigator and the book's editor, to arrive at specific policy recommendations.

The book begins with the results of the consumer survey. Not surprisingly, the public be-

believes that insurers are eager to use unfavorable genetic information to deny coverage or offer substandard rates: "only 26.7% said that companies would agree to sell the policy at the regular price." I wonder what is the real value of such data in the formulation of public policy, unless the goal of such policy is to accommodate uninformed public opinion.

The next four chapters (by a representative of the ACLI, an actuary, and two medical directors) present the industry perspective. This section of the book generally succeeds at being both informative and persuasive. The contribution by J. Alexander Lowden includes a very helpful review of basic genetics. Lowden also argues effectively that the results of most genetic tests will have a neutral or even favorable impact on mortality.

One more chapter in this section specifically devoted to the practical realities of the life insurance marketplace would have been a welcome addition. For example, it would be helpful to non-industry readers to have a better understanding of the mitigating influence of the insurance agent. Also, a more complete discussion of acquisition costs and the importance of persistency would be relevant to any discussion regarding why insurers are in fact motivated to offer the lowest possible rates.

Except for a chapter devoted to anti-trust issues, consumer advocates and ethicists write the remainder of the book. I was pleasantly surprised by the mostly balanced tone of these chapters. Each author expressed an understanding that, for purposes of life insurance underwriting, genetic information cannot logically be treated differently than other medical information. But once this reality is acknowledged, it becomes difficult for these authors to then offer targeted policy recommendations. One chapter ends with this amorphous formulation: "Therefore, it would be beneficial for both consumers and insurers if a fair approach could be worked out regarding the use of genetic information to insure that coverage remains widely available at affordable rates for all."

A representative of the Consumer Federation of America provides a more strident per-

spective. He quickly concedes the futility of restricting use of genetic information and instead issues a call for all Americans to be given a one-time right to \$100,000 of coverage at standard rates. This proposal is, of course, unworkable for numerous reasons, and its rationale ignores the survivorship benefits already available under Social Security. These benefits are significant and they should have been acknowledged more often throughout the text of this book.

Most disappointing is Rothstein's concluding chapter. Perhaps, in order to justify the considerable investment that his ELSI grant represents, he felt obligated to deliver specific policy recommendations where logically none are warranted. Boxed in by a rejection of genetic exceptionalism, he is forced to overshoot his mandate and offer a variety of unnecessary and unworkable recommendations relating to the general business of medical underwriting. He advocates the establishment of high-risk life insurance pools and suggests that state insurance commissions annually publish lists of diagnostic and predictive tests that are approved for medical underwriting. He also suggests that appeal mechanisms be established to formally consider adverse underwriting decisions, and he favors laws that would eventually require all insurance medicine physicians to be board certified. Regardless of the merits of his proposals, this is supposed to be a book about genetics and life insurance.

I wish that Rothstein had maintained his focus and concluded this otherwise worthwhile book with a frank and thoughtful exploration of the growing awareness that the concept of genetic discrimination has proven to be an intellectual dead-end. Such a timely discussion would have served the spirit and stated intent of the ELSI program, while providing the American taxpayer with a better return on investment.

REFERENCE

1. University of Houston Health Law and Policy Institute. *Health Law News*. December 2000. Available at <http://www.law.uh.edu/healthlawnews/12-2000.html>