Assurances

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Volume 59, Number 2, 1991

URI: https://id.erudit.org/iderudit/1104837ar
DOI: https://doi.org/10.7202/1104837ar

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Publisher(s)

HEC Montréal

ISSN

0004-6027 (print)
2817-3465 (digital)

Explore this journal

Cite this document

Mélançon, M., De Braekeleer, M., Gagné, R. & Leclerc, B. (1991). The Ethics of Genetic Testing for Insurance Purposes: Ethics of Genetic Solidarity or Ethics of Genetic Exclusion? *Assurances*, *59*(2), 223–233. https://doi.org/10.7202/1104837ar

Article abstract

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The Ethics of Genetic Testing for Insurance Purposes: Ethics of Genetic Solidarity or Ethics of Genetic Exclusion?[1]

by

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Cette réflexion multidisciplinaire de généticiens et d'éthiciens porte sur l'utilisation éventuelle des nouveaux tests génétiques pour la sélection des candidats aux assurances. Les auteurs en arrivent aux principales conclusions suivantes. L'emploi des marqueurs génétiques est résolument à écarter. Des critères de sélection génétique très sophistiqués pourraient conduire à de la discrimination génétique. Les compagnies doivent maintenir leur rôle social et opter pour une éthique de la solidarité génétique plutôt qu'une éthique de l'exclusion, en partageant avec l'État, la société et les familles les risques liés aux maladies génétiques.

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Introduction

The authors of this communication are outsiders to the insurance field. However, we will go beyond our field of expertise and

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try to put ourselves in the place of the individuals confronted to genetic testing for insurance selection.

A recent article written by Lowden and Dowsley[3] raised some serious questions about using such new genetic testing in the insurance industry. Indeed, these authors are right on this particular point: several social, ethical and legal questions are raised by using such genetic testing. We used this article as a starting point for our thought which is based mainly on the experience acquired in using genetic tests in the clinical field.

In the first part of this presentation, we will define some fundamental notions in ethics. The second part will discuss the nature and the implications of the use of genetic tests in the clinical environment. We will also try to show that their use in the insurance field could create problems which might be very difficult to deal with. The last part will present a new option for the insurance industry, that is, to choose between an ethics of genetic solidarity or an ethics of genetic exclusion.

Part I — Ethics, Bioethics and Business Ethics in Insurance

Ethics could be defined as the art of taking reasonable decisions in agreement with fundamental values based on moral principles. Ethics strives to balance individual blossoming and common good, individual freedom and responsibility to others.

Bioethics is "the analysis, examination and critical evaluation of normative issues arising in health care, in health promotion and in the life sciences."[4]

The physician (M.D.) who is employed by an insurance company has two allegiances.

As an M.D., the physician ought to serve the interests of his patients. The fundamental ethical principles which must guide him are as follows.

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[3]J.A. Lowden, and G. Dowsley: "Genetic Research and Insurance." *Canadian Insurance/Agent & Broker*, July 1990: 22-23.

[4]Canadian Society of Bioethics. Bylaws, 1987.

1. The respect of individuals, who are human beings and thus should be considered as subjects and not as objects, as ends and not as means for something else;
2. The respect of the autonomy and the informed consent, which means that the patient needs to have all the necessary information to make decisions without pressures;
3. The respect of the patient's privacy and confidentiality;
4. The respect of justice and equity, which means that no discrimination should be made, whether social, genetic or else. The principle of justice involves the physician's social responsibility.

As an employee of an insurance company, the physician has to serve the interest of his employer in participating in the selection of the candidates. However, the objectives and the methods of selection should be in agreement with the four principles of medical deontology mentioned above to insure the credibility and the reputation of the medical profession, and to be consonant with the physician's conscience.

Therefore, in some cases, an ethical dilemma could arise for a physician when his moral obligations towards his patients and towards society are in conflict with his professional obligations as an employee. Although the objective of this presentation is not to solve that dilemma, we think that medical ethics should prevail. That implies that, in some cases, the physician should withdraw. Furthermore, we think that the medical file of an individual should be distinct and kept separate from his genetic file because the latter may contain data related to other members of his family, by the very nature of the genetic ties between those members.

Insurance companies, joint stock companies as well as mutual benefit insurance companies, must justify themselves from a social and ethical standpoint. Insurance companies have an important role to play in society, but they must justify their decisions on the ethical level in the same way as pharmaceutical companies or potentially polluting industries, etc., because their activities have consequences on human beings.

They have social objectives such as to help their insureds financially in case of disease or death; they also help collectivity and State in sharing the burden related to disease and death.

Insurance companies also have an objective of profit. Within the context of liberal societies, it is widely accepted that services provided by firms yield a profit. However, this profit must be reasonable on the ground that money is a value that must be subordinated to other values in society.

Making profit for insurance companies means a selection of the

candidates following criteria that tend to decrease the risks taken by the companies. As outsiders and insured individuals, we recognize that some kind of selection can be justified, if it is based on population statistics such as the probability of dying or surviving depending upon sex, life style, and so on.

So some selection appears to be acceptable. However, we raise three questions regarding the possibility of using highly sophisticated genetic tests:

1. What kind of selection would be done, and come out?
2. Would insurance companies maintain their social objective of sharing the burden of disease and death?
3. Is there any danger that the objective of profit might prevail over the objective of social solidarity?

Part II — New Genetic Testing for Insurance Purposes: A Genetic Selection or A Genetic Discrimination?

Medical tests for insurance purposes are not new. They have been used in Canada since the twenties, and maybe earlier. Starting in the fifties, but mainly by the sixties, the development of new biomedical techniques has led to the improvement of tests and to the development of screening programs for some hereditary diseases. Nevertheless, it is mainly from the mid-eighties that spectacular progress in molecular biology has refined the genetic tests.

The new genetic tests that might be used by insurance companies belong to two different categories: those using genetic markers and those using the gene itself.

1) Test Using Genetic Markers

A gene is a DNA sequence which usually encodes for a protein. A genetic marker[5] is a known polymorphic DNA sequence located near the unknown gene responsible for a given genetic disorder.

Ideally, such markers should always segregate, that is, be transmitted, with the disease. However, that is not always the case. Their highly predictive value (ninety-five percent and more) allows a more reliable screening of carriers of genopathies in families or populations at risk. Therefore, these genetic markers give information on individuals, the impact of which it is very difficult to evaluate. That is, what might be the consequences of knowing years in advance that you are affected with a hereditary disorder usually without any possible cure although the first symptoms are not evident yet. The Huntington disease is a perfect example.[6] Therefore, the genetic markers raise an ethical dilemma: to know?... not to know?... to refuse to know?... to avoid knowing?... to be forced to know?

These genetic markers also raise a lot of new ethical, legal, and social questions which were never raised by previous tests. We must emphasize the difficulties related to their use in the clinical context to better underline the huge problems the companies would be confronted to.

Firstly, the genetic markers are a much more reliable technique of diagnosis, compared to previous tests or to risk calculations based on the family history. However, their reliability is not absolute. Errors are possible. Furthermore, the results obtained by these genetic markers are valid only for one given family and may not be extrapolated to other families. False positive and false negative results are possible.

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[5]M. De Braekeleer : «Les marqueurs génétiques». In: B. Leclerc, M. J. Mélançon, R. Gagné, éds: Génétique et éthique. Montréal, ACFAS, *Les Cahiers scientifiques* 68, 1989: 37-53.

[6]M. J. Mélançon: «Les marqueurs génétiques : les dilemmes éthiques du savoir/non-savoir sur la condition génétique pour les personnes et familles à risque». In: G. Bouchard, M. De Braekeleer, éds: Histoire d'un génome. Sillery (Québec), Les Presses de l'Université du Québec, 1991: 543-587.

Used for insurance purposes, the tests using genetic markers would notably raise the following questions:

What about the financial costs of setting up and operating such laboratories highly specialized in molecular biology; what about the qualification of the professionals who will run these laboratories; what about quality control? How to deal with false positive and false negative results? Would any government accept that these tests be performed in subsidized hospitals?

Secondly, genetic markers give data on the genetic constitution of an individual. They allow to predict a long time before the first symptoms if an individual will develop or is at risk of developing the disorder. However, they do not necessarily give information on the evolution of the disease nor on its severity. Such an incomplete knowledge for an individual may have detrimental psychological and social consequences.

Used for insurance purposes, these tests may raise other questions and problems. Would insurance companies be obliged to set up genetic counseling and follow-up services? If they do not, could they be "accused" of disregarding their social and moral duties of helping individuals in need — all this for higher profits?

Thirdly, the diseases detected by the genetic markers are usually incurable. Gene therapy on a large scale is not feasible before the next twenty years or even more. The absence of treatment raises a major ethical question for those asking for genetic markers in the clinical context: which reasons may justify the use of these tests in the absence of therapy? What might be the patient's reaction knowing that there is no cure for his disorder?

Should the markers be used in the insurance context, the following questions would be raised.

If companies start using such tests, should they organize some follow -up for those screened? What would be the financial costs of such a follow-up? Might they send those excluded from coverage to health care institutions? What would be the reaction and the attitude of physicians not involved in the insurance industry? What about governments' reaction spending public money while companies make even higher profits?

Fourthly, the use of genetic markers requires the collaboration of proxies. This is a major issue, and even more, *the* major issue. In other words, it could be an iceberg for companies.

Indeed, these genetic tests require blood samples from proxies, that is, parents, siblings, and so on. Of course, questions are raised in the clinical context: Could there be pressures to obtain the collaboration of those proxies? Are the results to be transmitted to those who participate but have not asked for them?

In the insurance context, the following questions would be raised:

Will proxies easily accept to participate, knowing that they are involved in genetic testing without any clinical purposes for themselves — but only for insurance for a proxy? Furthermore, the results obtained by genetic markers give data on proxies' genetic condition; should physicians be obliged to ask for informed consent of the candidate and his proxies? Could there be court actions by proxies in these matters? How would the data generated from genetic testing in a family be handled, stored and possibly used in the future? Could this information be circulated between the insurance companies?

Fifthly, in clinical research, collected data on genetic markers are computerized and the leftover DNA is usually stored. This information, and sometimes the DNA, are exchanged between researchers and research centers. How to control data exchange? Could insurance companies and/or employers have access to these data? Should the genetic file of a patient, as well as data on his family, be kept separate from his medical file?

The same questions would be raised in the insurance context. How would the data generated from such genetic testing in a family be handled, stored, and possibly used in the future? Information about individuals already circulates between companies. However, the exchange of genetic data on individuals and families would be a completely different issue.

We know how often our privacy is already disclosed; there are files everywhere, concerning for example our social insurance number, income, financial situation, school records, credit cards, driver's licence, passport. Our genetic identity may be the ultimate

piece of privacy we still own. If that piece is disclosed and exchanged between insurance companies, what do we have left? And what about the proxies?

Finally, genetic markers can lead to unexpected findings such as non paternity by artificial insemination, non declared adoption, extra-marital affair, — or sex chromosome abnormalities.

How would insurance companies deal with this kind of information? How would companies handle the problem of accepting to insure an individual in a family because of non paternity, but not the other members of the same family, without telling them why?

In summary, given the experience and the problems related to the use of genetic markers in the clinical context, we think that such a use in the insurance field would create practical, ethical, and legal problems which may be very difficult to overcome. Several authors and groups are already aware of these problems and their consequences for privacy in society.[7] If companies used genetic markers, we think that they ought to adopt an ethics of solidarity towards individuals excluded from coverage. If they did not, it is reasonable to think that a social or governmental reaction might force them to do so.

2) Tests Using the Gene Itself

With the development of biotechnology, the knowledge in molecular biology is increasing very rapidly. The Human Genome Project, whose goal is to identify, sequence and locate all fifty thousand to one hundred thousand genes in the human genome, should be completed within the next fifteen years. Therefore, the genes involved in several diseases will be identified through this project and others.

Using the gene itself will considerably modify the approach of the problem. Indeed, the collaboration of proxies will no longer be

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[7]Ph. L. Bereano: "DNA Identification Systems: Social Policy and Civil Liberties Concerns." *International Journal of Bioethics* 1990; 1(3): 146-155.

Council for Responsible Genetics: "Genetic Discrimination." *International Journal of Bioethics* 1990; 1 (4): 214-220.

B. Knoppers: *Human Dignity and Genetic Heritage*. Ottawa, Law Reform Commission of Canada 1991:50.

required. Only the given individual, who will ask to be insured, will have to be tested. This test will show whether he carries the gene of a given disorder or not. However, when the gene responsible for a disorder is found, like the cystic fibrosis gene, it does *not* mean that all the mutations in that particular gene are or will ever be identified. Furthermore, the gene does *not* necessarily give information on the clinical course of the disease. In these cases, the test could be used, provided that an informed consent has been given by the candidate.

Several ethical, legal and social problems related to the use of the genetic markers will no longer exist. However, we must emphasize that many other problems will remain, notably the disclosure of the information in case of a positive diagnosis, the follow-up of screened individuals, and the information exchange between companies.

Part III — The Ethics of Exclusion or the Ethics of Solidarity?

The traditional way of selecting candidates, as previously mentioned, can be acceptable, as a general rule, provided that they give their free and informed consent. A reasonable profit is considered to be ethically acceptable, given all the advantages for society, state, families and individuals in case of disease or death. In that sense, companies keep playing their social role of solidarity with persons and populations needing help.

However, the possibility that companies use sophisticated genetic tests, mainly the markers, raises serious questions from an ethical, deontological, legal and social point of view. We tried to give a sample of these problems.

We believe that companies, until now, have had an ethics of selection towards their candidates. However, the use of the markers could lead to a practice of exclusion or discrimination on a genetic basis. Consequently, companies will have to choose between going on with selection or opting for exclusion.

The basis of an ethics of exclusion (in this case, we could wonder if it is still possible to speak of "ethics") would be maximizing profits for shareholders, while minimizing risks as much as possible, thanks to the use of sophisticated genetic tests. "Perfect," and therefore "profitable," candidates would be selected, and the others would be excluded from coverage.

However, we, as citizens already insured by companies, make the following very practical reflection, a reflection that could be made by many other people: Too much maximizing the profits and at the same time too much minimizing the risks taken by the insurance companies could lead to a social move asking for cooperatives and non-profit organizations within the insurance field. Such a social move could be accelerated by "pressure groups" to convince the legislator to include a non-genetic discrimination clause in the Canadian Charter of Rights and Liberties. According to us, highly restrictive criteria of genetic selection of the candidates for insurance purposes could mean criteria of genetic discrimination; therefore, the very existence of the insurance companies, as we know them, could be jeopardized. Is this view too pessimistic? Maybe yes, but it is reasonable to think that it is a realistic one.

What choice is left to companies? According to us, they must opt for an ethics of solidarity based on genetic non-discrimination and on the acceptance of a certain level of risk. This policy of solidarity will still allow a reasonable margin of profit for insurance companies which could keep playing their social role of sharing the burden of disease and death with society, and showing solidarity with the human condition. If insurance companies stopped taking risks or if they reduced risks to such a point that they would be almost inexistent, we believe that they would lose their traditional role, and that they would turn into profit-making enterprises in the same way as other companies whose primary goal is making money, as for example some oil companies feeling very little or not at all concerned for environmental risks.

The ongoing project of mapping and sequencing the human genome will reveal the similarities of our genetic constitutions more than their differences, and that genetic discrimination has no scientific foundation. Until now, a distinction has been made between persons affected by "hard genetic diseases" and non-affected persons. Yet it will be shown more and more that every human being carries "soft genetic diseases" in the form of genes of susceptibility. These genes, in conjunction with environment, work place or life style, and so on, can trigger off certain diseases. By excluding people carrying certain genes of susceptibility, companies could lose very good candidates.

Nobody can be held responsible for his genes, but everybody is responsible for his life style, or at least part of it. Morally speaking, insurance companies should not be given the right to overincrease the premium rates of people who are not responsible for their genetic constitution. However, if people consciously adopt hazardous life styles such as smoking, for example, then insurance companies would be morally legitimated in increasing premium rates.

Conclusion

Our conclusion is fourfold.

Firstly, the physicians will be faced with new deontological, ethical and social responsibilities related to the use of new genetic tests in molecular biology, namely the genetic markers.

Secondly, insurance companies ought to, for several reasons, keep on sharing with the State, the Society and the Families the burden of genetic diseases.

Thirdly, for the reasons previously given, the use of genetic markers should be definitely excluded for insurance purposes, for two reasons. First, they are too difficult to manage technically, scientifically, ethically, and so on. Second, their use is temporary and they will be replaced by direct tests on the genes themselves. On the other hand, the perspective of using the gene itself for insurance purposes would require an in-depth multidisciplinary examination of its legal, ethical and social implications.

Fourthly, highly restrictive criteria of genetic selection of the candidates for insurance purposes could mean criteria of genetic discrimination. The very existence of the insurance companies, as we know them, could be jeopardized.

Therefore, the only foreseen way for the insurance companies has to be the ethics of genetic solidarity with individuals, families and society.