Genetic discrimination in life insurance: empirical evidence from a cross sectional survey of genetic support groups in the United Kingdom

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Abstract

Objectives To gather empirical evidence on any discrimination based on genetic information shown by the insurance industry in the United Kingdom and to assess how society is likely to handle future genetic information from tests for polygenic multifactorial conditions.
Design Postal questionnaire survey.
Subjects Sample (n = 7000) of members from seven British support groups for families with genetic disorders and a representative sample (n = 1033) of the general public who answered questions on applying for life insurance as part of an omnibus survey.
Main outcome measures Subjects were asked about their experiences with insurers, the medical profession, employers, and social services. Experiences with insurers are reported here.
Results Altogether 33.4% of the study group had problems when applying for life insurance compared with 5% of applicants in the omnibus survey. Thirteen per cent of study respondents from subgroups who represented no adverse actuarial risk on genetic grounds reported that their treatment by insurers seemed to represent unjustified genetic discrimination.
Conclusions Life insurers may not be operating a consistent policy for assessing genetic information or acting in accord with the actuarial risks brought to them. The inconsistency suggests error rather than a corporate policy of discrimination based on genetic characteristics. Any future proposals for genetic testing for common or multifactorial disorders should be examined carefully.

Introduction

Modern human genetics holds out hope of better diagnosis and, ultimately, better treatment for some of today's most intractable disorders. However, there are fears that some of the non-medical consequences may be disadvantageous rather than beneficial.

In 1996, the Wellcome Trust conducted a postal survey of representative samples from seven support groups for families with genetic disorders. This survey aimed to gather the first empirical evidence in the United Kingdom on the current extent of discrimination on genetic grounds and also to assess, from evidence assembled in the simpler case of monogenic conditions, how society is likely to handle the genetic information expected in future from tests for polygenic, multifactorial conditions.

The questionnaire addressed four specific areas—how families with genetic disorders feel they have been treated by the insurance industry, the medical profession, employers, and the social services. This preliminary account of the findings concentrates on the life insurance aspects of the survey.

In Britain, private insurance is used to help deliver housing—a "public" good. Most mortgages are backed not only by the value of the house but also by an insurance policy on the life of the mortgagee. In 1996, these policies accounted for nearly half (£572 million) of all new premiums for life insurance.[1] One potential hazard for insurers is that genetic testing could lead to an increase in adverse selection—the possibility that individuals may know the odds of their mortality better than the company and take unfair advantage of this private knowledge. Insurers believe that access to results of genetic tests can help them to prevent this and can provide information about age specific mortality rates during the term of the policy. However, access to housing could be affected if genetic test results were used to deny some people life insurance.

Recognising this possibility, the Association of British Insurers instituted a temporary moratorium on the use of genetic test results for insurance policies backing mortgages of less than £100 000 and introduced a code of practice.[2,3] The Human Genetics Advisory Commission also recommended a complete moratorium on using genetic test results for all forms of insurance for a minimum of 2 years.[4] This survey aimed to test whether insurers are currently perceived to be treating appropriately the genetic information they claim to need to avoid adverse selection.

Methods

Subjects

Given the obvious difficulty of contacting those affected by genetic disorders in the general population, we decided to a study a representative sample of the members of the following support groups for

Table 1 Respondents' knowledge about their genetic status. Values are numbers (percentages)

	Huntington's disease (n=529)	Myotonic muscular dystrophy (n=413)	Cystic fibrosis (n=526)	Duchenne muscular dystrophy (n=393)	Marfan's syndrome (n=531)	Neurofibromatosis (n=480)	Tuberous sclerosis (n=497)	All groups (n=3369)
Knowledge of genetic status*:								
Definitely have gene	203 (38)	338 (82)	440 (84)	209 (53)	301 (57)	288 (60)	158 (32)	1937 (57.5)
Probably have gene	6 (1)	15 (4)	33 (7)	42 (11)	101 (19)	27 (6)	29 (6)	253 (7.5)
Don't know	183 (35)	17 (4)	22 (4)	52 (13)	69 (13)	48 (10)	106 (21)	497 (14.8)
Unlikely to have gene	28 (5)	14 (4)	4 (1)	26 (7)	21 (4)	43 (9)	118 (24)	254 (7.5)
Definitely do not have gene	98 (19)	24 (6)	17 (3)	50 (13)	36 (7)	66 (14)	77 (16)	368 (10.9)
Have taken a genetic test	192 (36)	314 (76)	278 (53)	232 (59)	186 (35)	142 (30)	241 (49)	1585 (47.0)
Physical health affected	167 (32)	345 (84)	132 (25)	219 (56)	403 (76)	264 (55)	180 (36)	1710 (50.8)

*Information not given by some respondents.

those with genetic disorders: Cystic Fibrosis Trust; Huntington's Disease Association; Marfan Association, UK; (Duchenne) Muscular Dystrophy Group; Myotonic Dystrophy Group; Neurofibromatosis Association; Tuberous Sclerosis Association.

A 1 in n sample was chosen from the membership databases of the above groups. A sample of 1000 members from each group was sent a structured questionnaire and asked to complete it. Subjects were asked questions about their experiences and were given possible answers to choose from. Reminders were sent to non-responders to ensure as high a response rate as possible.

To compare the experiences of the study population with the general population, similar questions were posed in an omnibus survey. Organisations that wish to gather opinions from a representative sample of the entire United Kingdom population, but do not want to pay for an entire survey, can pay instead for their questions to be included with those of other organisations in one large survey. This type of survey is carried out regularly by some large market research agencies. In this case the questions posed differed slightly from those asked of the study group. Respondents were asked whether they had experienced any problems in obtaining life insurance, not whether they felt that a genetic disorder was the specific cause of the problems.

Patterns of inheritance

The differences in patterns of inheritance and expression of the selected genetic conditions enables us to examine different levels of risk to insurers. Huntington's disease and myotonic muscular dystrophy are dominantly inherited conditions with a late onset. That is, those who inherit a single copy of the gene will go on to develop the disorder, usually later in life. Cystic fibrosis is a recessive inherited condition that begins in childhood—the child has to inherit a copy of the gene from both parents, who will usually be symptomless carriers. Duchenne muscular dystrophy is linked to gender and manifests itself during childhood. Some of the conditions—Duchenne muscular dystrophy, Marfan's syndrome, tuberous sclerosis, and neurofibromatosis—may arise as a consequence of spontaneous mutation; they are not always inherited conditions. In addition, the degree to which people with Marfan's syndrome, tuberous sclerosis, and neurofibromatosis are affected varies considerably, even for people with apparently similar genotypes.

Results

We achieved a response rate of 53% after excluding replies from people who were not affected or had no family member affected by a genetic disorder. The respondents' knowledge of their genetic condition and health status is shown in table 1. Most respondents (65%; 2190/3369) knew they had the gene for the condition affecting their family, and the physical health of half the respondents (50.8%; 1710) had been affected by a genetic disorder. Most respondents were aware of their genetic status, even though less than half of them (47%; 1585) had taken a genetic test.

Table 2 shows the total numbers who had applied for life insurance and the numbers and types of problems encountered by each group. A third of respondents in the study group (723/2167) reported problems when applying for life insurance compared with only 5% (39/736) of applicants from the sample of the general population. This difference is significant at the 0.01% level, but is to be expected since so many in the study group reported that their health was affected by their condition.

Table 2 Problems experienced in applying for life insurance in representatives from each genetic support group and the general public. Values are numbers (percentages)

	Huntington's disease (n=338)	Myotonic muscular dystrophy (n=282)	Cystic fibrosis (n=323)	Duchenne muscular dystrophy (n=267)	Marfan's syndrome (n=338)	Neurofibromatosis (n=316)	Tuberous sclerosis (n=303)	All groups (n=2167)	General public (n=736)
No problems	182 (54)	150 (53)	266 (82)	177 (66)	197 (58)	235 (74)	237 (78)	1444 (66.6)	697 (94.7)
Problems	156 (46)	132 (47)	57 (18)	90 (34)	141 (42)	81 (26)	66 (22)	723 (33.4)	39 (5.3)
Types of problem*:									
Refused outright	68 (44)	63 (48)	33 (58)	47 (52)	69 (49)	28 (35)	42 (64)	350 (48.4)	—
Higher premiums	81 (52)	54 (41)	10 (18)	45 (50)	54 (238)	30 (37)	27 (41)	301 (41.6)	—
Unnecessary medical examinations	36 (23)	19 (14)	8 (14)	25 (28)	39 (28)	20 (25)	6 (9)	153 (21.2)	—
Other	41 (26)	34 (26)	29 (51)	17 (19)	42 (30)	27 (33)	16 (24)	206 (28.5)	—

*Percentages based on the numbers who reported having problems. Some people reported more than one type of problem.

Table 3 Problems experienced by applicants for life insurance who represent no genetic risk. Values are numbers (percentages)

	Unaffected carriers of recessive disorders* (n=264)	Healthy non-carriers of late onset disorders† (n=59)	Non-carrier parents of children with disorders of spontaneous mutation‡ (n=210)	Total (n=533)
Applicants reporting problems	28 (11)	27 (46)	16 (8)	71 (13)
Types of problem§:				
Refused outright	13 (46)	6 (22)	6 (38)	25 (35)
Higher premiums	8 (29)	22 (82)	3 (19)	33 (47)
Unnecessary medical examinations	4 (14)	5 (19)	0	9 (13)
Other	21 (75)	7 (26)	8 (50)	36 (51)

*Duchenne muscular dystrophy, cystic fibrosis.
†Huntington's disease, myotonic muscular dystrophy.
‡Marfan's syndrome, tuberous sclerosis, neurofibromatosis, myotonic muscular dystrophy.
§Percentages based on the numbers who reported having problems. Some people reported more than one problem.

In the omnibus survey, 736 out of 1033 people (71%) had applied for life insurance and answered general questions on problems with obtaining it. Ninety five per cent (697/736) had not experienced any problems, 4% (31) had problems or had to pay more for their insurance policies, and 1% (8) were refused life insurance outright.

Subgroups with adverse actuarial risk

Analysis of the three subgroups whose genetic disorder does not represent any adverse actuarial risk, and who should therefore be able to obtain insurance on normal terms, suggested that unjustified genetic discrimination had occurred. Table 3 shows that a greater percentage (13%; 71/533) of people in these three subgroups (healthy carriers of recessive genetic conditions or of sex linked conditions, healthy non-carriers of genes for late onset disorders, and parents of children whose condition is the result of a spontaneous mutation) reported problems in obtaining life insurance than did the comparison group from the omnibus sample of the general population (5%; 39/736). They believed that their genetic status was the reason for this.

Late onset conditions

A small group from families affected by late onset conditions (Huntington's disease and myotonic muscular dystrophy) reported that they were healthy and definitely did not have the gene for the condition. Nearly half of this group (27/59; 46%) reported having problems in obtaining life insurance (table 3).

Childhood onset conditions

Some carriers of the conditions that begin in childhood (Duchenne muscular dystrophy and cystic fibrosis) seemed, mistakenly, to be treated by insurers as if they had the disease. Twenty eight of 264 (11%) symptomless carriers had problems with insurance. Thirteen (5%) of the cystic fibrosis group reported being turned down outright, while six (2%) reported being charged higher premiums than normal.

Uninherited conditions

Because a condition is genetic does not mean that it has been inherited. Several of the disorders included in this survey—Marfan's syndrome, tuberous sclerosis, neurofibromatosis, and myotonic muscular dystrophy—can arise as a consequence of a spontaneous mutation.[5] Sixteen of 210 (8%) from this subgroup, who reported that they had applied for life insurance did not have the gene but had a child whose condition resulted from a spontaneous mutation, experienced problems.

Discussion

This survey obtained perceptions of discrimination, rather than providing any objective measure of it. Interpreting these reports is complicated by the degree to which the respondents' health has been affected by their genetic condition. It may be difficult to disentangle discrimination on purely genetic grounds from that on the grounds of disablement.

However, the design of this survey made it possible to overcome this problem to a certain extent. The whole sample could be disaggregated into subgroups representing different levels of risk to insurers. It was then possible to analyse whether everyone in these subgroups was being treated appropriately for the risk they represented. Three subgroups were identified whose members should represent no adverse actuarial risk to insurers on genetic grounds. These subgroups are healthy carriers of recessive or sex linked conditions (Duchenne muscular dystrophy and cystic fibrosis), healthy non-carriers of late onset disorders (Huntington's disease and myotonic muscular dystrophy), and the parents of children whose condition is the result of a spontaneous mutation (Marfan's syndrome, tuberous sclerosis, neurofibromatosis, and myotonic muscular dystrophy). We suggest that when respondents from these subgroups report problems in obtaining life insurance and believe that these problems result from the genetic condition affecting their family, this treatment by life insurance companies is inappropriate and unjustified.

Discrimination in insurance is "justified" under the Disability Discrimination Act 1995 if it is based on actuarial or other reliable information—that is, on statistical data or a medical report.[6 7] The insurance industry provides life insurance to 95% of applicants at a standard rate.[8] Of the remainder, 4% have to pay higher premiums and 1% are refused life insurance outright. This 95:4:1 ratio was mirrored by the results of our omnibus survey of the general population. However, the ratio contrasts significantly with the experience of the 13% of people (71/533) in the study sample who experienced problems that they believed resulted from their family's genetic history, but who actually presented no adverse actuarial risk on genetic grounds. In the language of the Disability Discrimination Act, their treatment seems to represent unjustified genetic discrimination in life insurance.

The results show that people belonging to support groups for families with genetic disorders were not treated consistently by insurers. That there is no clear pattern may be the most important finding; it suggests error on the part of insurers rather than a coherent industry wide policy of genetic discrimination. Practical and ethical constraints make it impossible to check whether the decisions by insurers in these cases were fair and justified. Furthermore, genetic support groups in Britain do not have universal membership of all families affected by the specific disorder. This makes it impossible to extrapolate the results of this survey to

Key messages

- People who represent no adverse actuarial risk on genetic grounds report having had difficulties in obtaining life insurance
- Genetic information is liable to be misunderstood outside of the clinical context
- There seems to have been unjustified genetic discrimination by insurers in the United Kingdom
- Gathering representative empirical evidence on the extent of genetic discrimination is not straightforward and needs further research

a numerical estimate of the extent of genetic discrimination throughout the United Kingdom.

The response rate, although lower than might be achieved in research conducted in a clinical setting, is reasonable for a postal survey. The expected response rate for postal surveys in Britain is around 46%.[9] The low response rate may have resulted in some bias, but reviews of survey research have concluded that provided response rates exceed 50% on surveys of homogenous groups "the widespread fear that non-response bias seriously affects mail surveys is not justified."[10 11] It is possible that those who have not experienced discrimination may have been less likely to respond to the survey, thus introducing a bias. However, in this preliminary study we could not gain enough useful information on the non-responders to compare them with responders. But the characteristics of non-responders are not relevant to this study's principal finding that there was an identifiable subgroup of respondents (71/533; 13%) who represented no actuarial risk on genetic grounds, but perceived that they had been discriminated against on this basis. This should never have occurred, however small the numbers, and suggests an error in handling genetic information by the insurance industry

These findings agree with those from several studies in the United States which also showed that confusion and ignorance in interpreting genetic information is central to the problem of genetic discrimination.[12–14] For instance, it has been shown that chief medical officers of United States insurers[13] and the state insurance commissioners, who regulate the insurance industry,[14] are surprisingly ignorant of modern human genetics. There is no evidence on how well informed sales agents, underwriters, and other insurance industry personnel are about genetics.

Our findings suggest that in less clear cut instances, where genes confer an increased susceptibility rather than 100% or zero probability, some people might be charged high premiums that cannot be justified on the actuarial risk they present. Furthermore, these results are limited to monogenetic conditions, where the patterns of inheritance and the risk factors are comparatively well known. Tests for polygenic disorders and genetic predisposition to common diseases will yield lower probability information about an individual's life expectancy, and it is arguable that this will be so imprecise as to play no important part in life insurance.[15 16] The significance of genetic test results can differ according to the type of insurance (medical or life, for example).[17] However, if insurers look at genetic information with a lower probability, they will have to ensure not only that they interpret it correctly but that they are seen to interpret it correctly. In the light of our results for monogenetic conditions, serious consideration will have to be given (and not just by insurers) to the difficulties of fulfilling both duties.

This study presents preliminary empirical evidence of genetic discrimination occurring in our society. Further investigations are needed to establish in more detail the character of such problems and its sources.

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Contributors: SK was responsible for input on social survey research methods, questionnaire design, and data interpretation. LL was responsible for data management and analysis. TW was responsible for data interpretation and the overall concept of the study and is guarantor for the paper. The manuscript was drafted by LL and TW and reviewed by all the authors.

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Endpiece

Not born to be idle

"I also know," said Candide, "that we must cultivate our garden."

"You are right," said Pangloss, "for when man was put into the Garden of Eden, he was put there to work, which proves that man was not born to be idle."

"Let us work, then, without arguing," said Martin; "it is the only way of making life bearable."

Voltaire, *Candide* (1758)