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Perceived genetic knowledge, attitudes towards genetic testing, and the relationship between these among patients with a chronic disease

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ABSTRACT

Objective: Genetics increasingly permeate everyday medicine. When patients want to make informed decisions about genetic testing, they require genetic knowledge. This study examined the genetic knowledge and attitudes of patients with chronic diseases, and the relationship between both. In addition, patients were asked about their preferred source of genetic information.

Methods: Questionnaires were mailed to participants of a nationwide representative sample of patients with chronic diseases in the Netherlands (n = 1916).

Results: The response rate was 82% (n = 1496). Perceived genetic knowledge was low, particularly among older and lower educated patients.

Attitudes towards genetics were rather positive, especially among younger and higher educated patients. Some concerns were also documented, mainly about the consequences of genetic testing for employment and taking insurance. Patients who perceived to have little knowledge found it difficult to formulate an opinion about genetic testing. Higher levels of genetic knowledge were associated with a more favourable attitude towards genetics. Chronic patients prefer to receive genetic information from their GP.

Conclusion: Chronic patients are ill prepared when they require genetic knowledge to make decisions regarding the treatment of their disease.

This seems to result from a knowledge deficiency rather than from disagreement with the genetic developments.

Practice implications: When chronic patients are in need of information about genetics or genetic testing, their general practitioner should provide this.

1. INTRODUCTION

The recent completion of human genome sequencing [1] will fuel research aiming to identify genetic factors in the aetiology of disease [2]. Identification of such disease genes allows the development of genetic or DNA-tests to determine whether people are at risk of or affected by a disease [3,4]. As the availability of these tests increases, genetics will slowly but surely permeate medical practice, and may one day become routine. Genetic insights have the potential to change the very conception of disease, and consequently clinical diagnosis and treatment [5]. This transformation has started the moment

genetic testing was introduced, allowing diagnosis and treatment of disease even before its clinical manifestation. For example, genetic tests have enabled women with a genetic susceptibility to breast and ovarian cancer to decide on prophylactic oophorectomy or mastectomy [6].

Acknowledging the growing importance of genetics to western society, and particularly to health care, in 2001, the Netherlands Advisory Council for Science and Technology Policy stated that medicine could be expected to change from being disease-oriented to risk-oriented, and that this would eventually affect the entire health care system. Novel scientific knowledge about the human genome generates new medical insights, which will affect individuals who utilise health care services, and confront them with a new type of decision-making. How individuals handle such decisions depends on their knowledge, and on their view of human genetics and human genetics research. The capacity of individuals to make these decisions on the basis of general and disease-specific genetic information largely depends on successful communication of scientific information to the public [7]. In addition, a scientifically knowledgeable public is required for democratic participation in issues of science and technology, and tends to be more positively disposed towards these [8].

This raises the question what people actually know and think about genetics and DNA-testing. Hitherto, most studies investigated knowledge of and attitudes towards genetics in the general population, for instance of Finland [9–11], the United Kingdom [12], the Netherlands [13,14] or Europe [8]. These studies show that the public have a reasonable understanding of the relationship between genes, heredity, and disease [7,14]. Also, a higher level of knowledge has been associated with female gender, younger age, and higher socioeconomic status [12,13]. In general, genetics are seen as something positive and potentially beneficial for future medicine, particularly among younger and higher educated individuals [10,13,14]. On the other hand, there are concerns on the long-term effects of genetics and commercial misuse [8,12,14].A higher level of knowledge seems to be associated with a more favourable attitude toward genetic testing, but also with being more critical [10,12], although the direction of this connection may go both ways [8]. Individuals with a relative lack of genetic knowledge find it more difficult to formulate an opinion [9].

Unlike population-based studies (see above), studies investigating genetic knowledge and attitudes in patients usually concentrate on specific disease-related issues [e.g., 15–18]. The present study aimed to investigate knowledge and attitudes related to genetics and genetic testing in general, among patients with chronic illnesses (e.g., diabetes, heart disease, musculoskeletal disease). Once diagnosed, these patients must deal with their illness for the rest of their life, and often have to rely heavily on health care services [19,20]. Thus, they become closely involved with issues of health and disease, which may translate into more knowledge. In addition, the role of genetics in chronic disease is rising because the number of patients with chronic diseases is growing [21], and genetic tests become increasingly available for chronic diseases [22]. The present study surveys perceived genetic knowledge and attitudes, and the relationship between these, in patients with chronic diseases. In addition, we asked these patients whether they had sought information about genetics and genetic testing, and from what source they would prefer to receive such information.

2. METHODS

2.1. Participants and procedure

Our sample comprised respondents of the ‘Panel of Patients with Chronic Diseases’ (PPCD). PPCD is a nationwide research programme investigating the consequences of chronic illness for patients and their families in the Netherlands [19]. Patients were recruited in 2001 via a representative sample of 51 general practices. Inclusion criteria were: a diagnosis of a chronic disease (not in a terminal stage), age at least 15 years, living independently, being aware of the diagnosis, being mentally and physically fit to participate, and adequate command of the Dutch language.

Patients were selected by their GP on the basis of diagnoses of chronic diseases as defined by the Health Council of The Netherlands [23]. Diagnoses of chronic illness were then classified according to the International Classification of Primary Care [24]. In total, 1916 patients participated in the panel study. They were classified into eight diagnostic groups on the basis of their first diagnosis: cardiovascular disease, asthma/COPD, musculoskeletal disease, cancer, diabetes mellitus, neurological

disease, gastrointestinal disease, and other chronic disease. The current data were drawn from a postal questionnaire sent in April 2002, which was returned by 1496 patients (82%).

Before patients enrolled in PPCD, their informed consent was obtained. PPCD is registered with the Dutch Data Protection Authority, and the data were collected according to the privacy protection guidelines of the Authority.

2.2. Questionnaire

We constructed a questionnaire to measure perceived knowledge and attitudes of genetics and DNA-testing. Items were selected to cover major issues in relevant literature, and included medical aspects of genetic testing, the pros and cons of testing, and the consequences for relatives, daily life, insurance, and job opportunities [12,25]. Perceived knowledge of genetics was measured with 11 items (see Table 2) for which respondents indicated their own level of knowledge (1 = nothing; 2 = a little, but not sufficient; 3 = sufficient). Genetic attitudes were assessed by 13 statements of the pros and cons of genetic testing (see Table 3). Items were answered on a 5-point scale (i.e., 1 = totally disagree; 2 = disagree; 3 = don't know; 4 = agree; 5 = totally agree). Respondents also indicated ('yes' or 'no') whether they had previously sought information about genetics. Finally, they checked in a list of sources of genetic information which ones they would prefer (see Table 5 for the full list).

[TABLE 2-3]

[TABLE 5]

2.3. Data analyses

The analyses were carried out using the Statistical Package for Social Sciences (SPSS). Because very few respondents were aged 15–24 years (see Table 1), for the purpose of analysis this age category was collapsed with the adjacent age category (25–44 years). Group differences in frequencies were examined by means of χ^2-tests, mean scores by means of *t*-tests. To facilitate interpretation of the frequency distributions of the attitude items, the items were recoded into three categories: agree (combining the responses ''totally agree'' and ''agree''), disagree (combining ''totally disagree'' and ''disagree''), and don't know.

[TABLE 1]

Exploratory factor analyses were carried out to obtain a limited number of knowledge and attitude scales. Principal components factor extraction was used, with oblique (oblimin) rotation. The number of factors to be drawn was decided on the basis of Kaiser's eigenvalue ≥1.0 criterion [26] and Cattel's scree test [27]. Items were retained if they loaded at least 0.45 on their factor. Total and subscale scores of the resulting scales were to be obtained by summing relevant items scores, such that higher scores indicate the presence of more knowledge or a stronger attitude.

The resulting sum scores were then used to investigate whether demographic and disease variables were related to perceived genetic knowledge and attitude. For this purpose, four linear regression analyses were executed with the knowledge and attitude subscale scores as the dependent variable: gender, age, education, disease category, and number of years since diagnosis were entered into the equation as independent variables.

Relationships between perceived genetic knowledge and attitudes towards genetics were examined in two ways. Firstly, high and low knowledge groups were composed using a median split procedure on the sum score of all knowledge items. The frequency distributions of responses from both groups to the attitude items were compared by means of χ^2-tests. Secondly, to explore whether perceived genetic knowledge scores would predict genetic attitude, a second step was added to the four regression analyses with the attitude subscales as dependent variables. On this step, the knowledge subscales were entered alternately into the analysis. Similarly, the attitude subscales were entered alternately as a second step to the analyses with the knowledge scales as dependent variables.

3. RESULTS

3.1. Sample characteristics

Demographic and disease characteristics of the sample are listed in Table 1. The majority of the respondents were female (57.7%), aged over 45 years (83.4%), and married or cohabiting (74.6%). The mean age was 59.6 years (S.D. = 14.9), and the men were some 3 years older than women [$t(1494) = 4.3$, $p < 0.001$], probably because women were over-represented in younger age groups [$\chi^2(3) = 17.3$, $p < 0.001$]. Education was classified as basic (no, primary, or lower vocational education), intermediate (secondary or intermediate vocational education), or high (higher vocational education and university). There were more men than women in the highest educational category [$\chi^2(2) = 11.0$, $p = 0.004$]. The average time post-diagnosis was 10.1 years (S.D. = 9.4).

3.2. Perceived genetic knowledge

Respondents generally reported having little knowledge about genetics (Table 2); some 10% report having sufficient knowledge, whereas half to three quarters indicate they have no knowledge. Items 1 and 2 are an exception: more than 50% report having at least some knowledge of early detection and preventive treatment of genetic disorders.

More men than women indicated having no or insufficient knowledge about genetics on most items [χ^2s$(2) > 6.2$, ps < 0.05], except with respect to the consequences of DNA-testing for insurance, daily life and work, and the privacy of test results [χ^2s$(2) < 3.2$, ns]. Older respondents reported significantly less knowledge [χ^2s$(4) > 18.5$, ps < 0.001]. For all items but item 1 (about knowledge on the possibility of DNA-testing to detect disease) less than 10% of the respondents aged 65 years and older were satisfied with their own knowledge level, while more than two thirds indicated having no knowledge. Note that the relevance of item 8 (about the consequences of DNA-testing for work) is probably low for respondents over age 65 years because the majority will be retired. Respondents with more education indicated less often having no knowledge, and more often having sufficient knowledge [χ^2s$(4) > 17.1$, ps < 0.01]. However, even in this well educated group, at least 40% reported a lack of knowledge on most items, and the percentage of respondents perceiving to have sufficient knowledge remained below 35%. For more details, see Table 2S in the Appendix.

3.3. Genetic attitudes

Table 3 shows the attitudes of respondents towards the various aspects of genetics. The majority (70–80%) of respondents approve of DNA-testing and find genetic research a positive medical development in view of future treatment of disease. Still, DNA-testing frightens some 25% of the respondents (half are not afraid). Just over two thirds would like to know whether their disease is genetic. Furthermore, although 30% do not want to know whether they are at risk for a genetic disorder, over 40% do. If no appropriate treatment is available, more than 40% of chronic patients will refrain from DNA-testing, whereas 25% would not know what to do. Most respondents think that family should be informed about test results, and would share the results with their children (70%) and siblings (65%). Almost 40% have no clue as to whether DNA-testing will change one's future, whereas almost half of the respondents belief it would. More specifically, nearly 50% worry about how DNA-testing will influence one's prospects of getting insurance or a job.

Men and women held similar views of genetics, although women were slightly more inclined to inform their siblings about test results. Women were less eager to submit to DNA-testing if no treatment were available [for both items, $\chi^2(2) > 6.2$, $p < 0.05$]. On all attitude items, older, lower educated respondents were significantly more likely to check the ''don't know'' box [χ^2s$(4) > 13.0$, ps < 0.05]. For more details, see Table 3S in the Appendix.

3.4. Relationship between perceived genetic knowledge and attitudes

To investigate the relationship between perceived genetic knowledge and attitudes towards genetic testing, high and low knowledge groups were cross-tabulated with the attitude items. Respondents who perceived to know little were about twice as likely to indicate that they had no opinion about the various aspects of testing [χ^2s$(4) > 33.8$, ps < 0.001]. Nevertheless, more perceived knowledge was associated with a positive attitude towards genetic testing.

3.5. Exploratory factor analyses of the knowledge and attitude items

Separate exploratory factor analyses with oblimin rotation were carried on the knowledge and attitude items. For both item sets, the Kaiser–Meyer–Olkin measure for sampling adequacy (> 0.790) and Bartlett's test of sphericity (χ^2s > 3315, *p*s = 0.000) justified continuation of the analysis. Analysis of the knowledge items yielded two factors with eigenvalues > 1 (i.e., 7.2 and 1.1), which accounted for 74.9% of the total variance. These factors reflected knowledge about the 'medical possibilities' (a = 0.91), and about the 'social consequences' of genetic testing (α = 0.93; see Table 2). The factors correlated significantly (r = 0.75, p < 0.001). For the attitude items, there were four factors with an eigenvalue > 1 (i.e., 3.5, 2.1, 1.3, and 1.0), explaining 60.4% of the variance. However, inspection of the scree plot pointed towards a solution of two factors, which were correlated (r = -0.19, p < 0.001). These factors were labeled 'favourable' (α = 0.80) and 'reserved' (α = 0.63; see Table 3) attitude.

3.6. Predictors of perceived genetic knowledge and attitudes

Linear regression analyses were carried out to determine whether demographic and disease characteristics of patients with a chronic illness would predict their level of knowledge of and attitude towards genetics. In addition, we examined whether respondents' attitudes would predict their perceived knowledge, and oppositely, whether their knowledge would predict their attitudes. Older and lower educated respondents perceived to know less about the medical possibilities and social consequences of genetic testing. Females and patients with a longer time postdiagnosis perceived to have more medical knowledge (Table 4). In addition, patients with a musculoskeletal disease presented more knowledge about the medical possibilities of genetic testing than the reference group of patients with other chronic diseases. Patients who perceived having more knowledge about medical and social aspects of genetic testing also were more positive towards genetics. This was also true when the direction of this relationship was reversed (Table 4). No significant relationships involving reserved attitudes emerged. Genetic attitudes did not vary between respondents with different chronic diseases.

[TABLE 4]

3.7. Preferred source of genetic information

Only a small minority of respondents had actively sought information about genetics (3.4%). The most preferred source of information about genetics (Table 5) was the GP (51%), followed by information sheets (36%), and the medical specialist (26%).

4. DISCUSSION AND CONCLUSION

The purpose of this study was to examine to what extent patients with chronic diseases perceive to have genetic knowledge and what their attitudes towards genetics and genetic testing are. It was found that while chronically ill patients indicate they know little about genetic testing, their general view is positive, although they also expressed some fears and worries. In addition, older and less educated patients perceived to have relatively little genetic knowledge and found it more difficult to form an opinion about genetics. We also investigated the relationship between knowledge and attitudes among chronic patients. Higher levels of genetic knowledge were associated with a more favourable attitude towards genetics. As this study is cross-sectional, the direction of this connection remains undecided. Finally, the most preferred source of genetic information was the GP, followed by information sheets and the medical specialist.

4.1. Discussion

Chronic patients perceived to have very little knowledge about genetics and DNA-testing; on average, about 65% reported they had no knowledge, which seems low compared to the general population [11,12]. In a recent study among the general public in the Netherlands, 57% perceived a lack of genetic knowledge [13], which is corroborated by other recent studies in the Netherlands [28,29] and abroad [30,31]. This finding was unanticipated as we expected chronic patients to be relative experts owing to their long-standing experience with health care. An explanation may be the relatively old age and low education of our sample, factors that have been associated with low genetic

knowledge in both the current and previous studies [11–13]. Nevertheless, a positive association emerged between time post-diagnosis and knowledge level. It is important that people are to some degree informed about genetics and genetic testing. Knowledge deficiency may lead people to refrain from taking a genetic test when necessary. This may lead to poorer health, reduce the quality of life, and increase the medical costs when an easily preventable disorder requires later treatment [32]. Of course, this will benefit healthy individuals at risk for developing a genetic disorder more than chronic patients.

Notwithstanding their low level of perceived knowledge, chronic patients held generally positive genetic attitudes, especially younger and higher educated groups [8,10,12– 14,33]. This is striking because previous research has shown that higher levels of knowledge coincide with a more favourable attitude [9,12,34]. Note, however, that we did find that patients who perceived having more knowledge were also more positive about genetic testing [9]. In addition, chronic patients who perceived low knowledge were often indecisive about genetic testing [9]. The main worries of chronic patients concerned the consequences of genetic testing for insurance or finding a job [12,14,35], a realistic concern because as individuals with a genetic disorder in the Netherlands and the United Kingdom have more trouble getting insurance [25,36]. Furthermore, higher levels of perceived genetic knowledge were associated with a more favourable attitude towards genetic testing, but not with reserved attitudes. Thus, it is quite likely that people's beliefs about genetic testing are positively affected when their genetic knowledge increases. It should be noted, however, that due to the cross-sectional design of our study no inferences can be drawn concerning the direction of this relationship. Thus, it is equally possible that having a favourable attitude motivates people to learn more about genetics. Nevertheless, these results are encouraging for public information campaigns, because they show that is unlikely that education will instate a negative view of genetics; if anything, people will get more sympathetic with genetics.

Public campaigns are not the only means to inform people. Patients with chronic diseases preferred their GP as source of genetic information, and to a lesser degree information sheets, medical specialists, and the media [28,29]. As a family doctor, the GP is in a good position to provide genetic information [37], which is something GPs themselves agree with [38,39]. Unfortunately, GPs feel unconfident about their ability to do so, as their genetic expertise falls short [38–40]. The Netherlands Ministry of Health, Welfare and Sport acknowledges that health care providers lack the knowledge and skills to adequately provide genetic information. The Ministry has set out policy to resolve this deficiency, for instance by encouraging both formal and informal training initiatives of relevant professionals (including GPs). Furthermore, additional resources will be made available to communicate genetic knowledge to the public [41]. Chronic patients in this study also like to learn about genetics via information sheets (i.e., brochures or leaflets). However, although this medium is helpful to explain broad genetic (disease-related) issues, it is useless when information must be tailored to the individual. Well-designed Internet sites may provide both general and specific information, but may not reach certain groups of people (e.g., older individuals) [42]. In addition, information on the Internet (and provided by the media) is not always high quality and objective, and it is difficult for lay-people to determine whether this is the case.

4.2. Limitations

Respondents were asked to evaluate their own level of genetic knowledge, but it is not clear how the accuracy of such a subjective evaluation of genetic knowledge relates to more objective assessments, as in Jallinoja and Aro's studies [9,11]. When compared, however, both approaches yielded a highly similar pattern of results. Nevertheless, it seems obvious that the motivation to seek genetic information will be inspired by a subjective rather than an objective lack of genetic knowledge, although it should be acknowledged that the two will often coincide. A second issue is the response format of the knowledge items, in which patients had to give a value judgement of their own knowledge (i.e., 'sufficient' or 'a little, but not sufficient'). More reliable ratings might be obtained using a Likert scale, which requires respondents to indicate their agreement with a number of statements (i.e., strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, strongly agree). For example, item 1 in Table 2, i.e., ''How much do you know about the possibility of early detection of certain disorders with DNA-testing'', could be rephrased as: ''I know a lot about the possibility of early detection of certain disorders with DNA-testing''.

4.3. Conclusion

Although one might expect patients with chronic diseases to be relative experts on health-related issues, the findings suggest that this does not apply to genetics. Chronic patients seem to be ill informed about genetics and the possibilities of genetic testing, which will hinder their decision-making when confronted with taking a test. However, these patients might underreport their genetic knowledge because their informational demand is high due to their relative expertise in health issues. On the other hand, the present sample of chronic patients resembled the general population in that older and less educated individuals possessed the least knowledge. Also similar to the general population, chronic patients were mostly positive about genetics. It is important that the relationship between objective and subjective knowledge receives attention in future research, and that it is examined how both types of knowledge relate to people's inclination to seek information to increase their knowledge.

When chronic patients must be informed about genetics and genetic testing, the GP seems an ideal source for such information. Not only do almost all chronic patients visit their GP several times a year [20], this study shows that they also prefer to receive genetic information from their GP. Alternatively, public information campaigns might be developed which draw special attention to chronic diseases. We found that chronic patients generally take a positive stance towards genetics, which suggests that they keep an open mind to receiving such information. It is also reassuring that a more positive attitude towards genetic issues, but not a more reserved attitude, coincides with a higher level of genetic knowledge. The effectiveness of the ways genetic information can be communicated to patients or the public also requires future attention.

4.4. Practice implications

When chronic patients must learn more about genetics and genetic testing, preferably this information should be provided by their GP. The GP should realize, however, that the baseline level of knowledge of most patients is very low. Information provided by the GP might be supplemented with information sheets.

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APPENDIX A. SUPPLEMENTARY DATA

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.pec.2006. 07.005.

TABLES

Table 2
Perceived genetic knowledge of chronically ill patients, in percentages

	n	Sufficient	Some, but insufficient	None
Medical possibilities				
1. The possibility of early detection of certain disorders using DNA-testing	1309	17.0	47.2	35.8
2. The significance of DNA-testing for my relatives	1210	12.3	31.7	56.0
3. The significance of DNA-testing for my offspring	1214	11.5	30.1	58.3
4. The possibility to use genetic knowledge to prevent or treat a disorder	1251	11.0	37.6	51.5
5. The possibilities and risks of gene therapy	1178	6.2	23.5	70.3
Social consequences				
6. Your rights to refuse DNA-testing	1222	7.6	18.5	73.9
7. The consequences of DNA-testing for my daily life	1219	6.8	17.1	76.1
8. The consequences of DNA-testing for my work	1160	6.5	14.3	79.2
9. The consequences of DNA-testing for taking out insurance	1220	6.4	17.1	76.5
10. Your own possibilities to apply for a DNA-test	1220	5.3	18.0	76.7
11. The rights of third parties to inquire about the results of a DNA-test	1212	4.6	14.9	80.5

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Table 1
Demographic and disease information for the present sample ($n = 1496$)

	n	%
Gender		
Male	633	42.3
Female	863	57.7
Age		
15–24	22	1.5
25–44	227	15.2
45–64	650	43.4
65 and older	597	39.9
Marital status		
Married/cohabiting	1116	74.6
Single/divorced/widowed	349	23.3
Education		
Basic	693	46.3
Intermediate	505	33.8
High	188	12.6
Disease category		
Heart disease	158	10.6
Asthma/COPD	265	17.7
Musculoskeletal disease	235	15.7
Cancer	66	4.4
Diabetes mellitus	241	16.1
Neurological disease	121	8.1
Digestive disease	51	3.4
Other chronic disease	359	24.0
Time post-diagnosis (in years)		
0–5	508	34.0
5–10	422	28.2
10 or more	481	32.2

Table 4
Results of the series of linear regression analyses predicting perceived genetic knowledge and attitude scores

	Knowledge		Attitude	
	Medical	Social	Favourable	Reserved
Female gender	0.08*	0.02	−0.01	0.05
Age	−0.23***	−0.13***	−0.06	0.03
Marital status	−0.03	0.01	−0.03	−0.01
Education (basic)[a]				
Intermediate	0.12***	0.05	0.07	−0.04
High	0.23***	0.14***	0.04	−0.06
Disease category (other disease)[a]				
Heart disease	−0.00	−0.01	−0.04	0.07
Asthma/COPD	−0.04	−0.04	0.03	−0.05
Musculoskeletal disease	0.08*	0.01	−0.01	0.00
Cancer	0.03	0.01	0.05	0.02
Diabetes mellitus	−0.01	−0.03	−0.02	0.04
Neurological diseases	−0.00	−0.06	−0.02	0.03
Digestive diseases	−0.06	−0.05	0.01	0.04
Time post-diagnosis	0.07*	0.05	−0.01	−0.01
Knowledge				
Medical possibilities	–	–	0.18***	−0.07
Social consequences	–	–	0.11**	−0.06
Attitudes				
Favourable	0.16***	0.11**	–	–
Reserved	−0.06	−0.06	–	–

Standardised β is significant at $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.
[a] Reference category in parenthesis.

Table 3
Attitudes towards genetics of chronically ill patients, in percentages

	n	Agree	Disagree	Don't know
Favourable				
1. I think the development of DNA research is hopeful for the treatment of diseases	1274	81.9	2.2	15.9
2. I think that the development of DNA research is a positive medical progress	1244	80.9	2.2	16.9
3. I approve of using DNA-testing for early detection of diseases	1315	79.9	3.6	16.5
4. I would inform my children about the results of a DNA-test for a specific disease	1223	70.9	6.1	23.1
5. I want to know whether my disease is hereditary	1216	67.2	12.0	20.8
6. I would inform my siblings about the results of a DNA-test for a specific disease	1225	65.8	11.3	22.9
Reserved				
7. I worry about the consequences of DNA-testing for being able to take out insurance	1262	46.4	19.6	34.0
8. The possibility of a DNA-test will change one's future	1243	46.4	15.5	38.1
9. As long as a disease cannot be treated, I don't want a DNA-test	1225	41.5	32.7	25.8
10. If I had a DNA-test done, my family need not know about the result	1263	34.3	44.2	21.5
11. I don't want a DNA-test to tell me that I am at risk for a certain disease	1268	31.9	40.9	27.2
12. I worry about the consequences of DNA-testing for the chances of finding a job	1169	29.3	33.0	37.7
13. The idea of a DNA-test frightens me	1260	25.9	48.3	25.8

Table 5
Preferred sources of genetic information

	n	%
General practitioner	550	50.6
Information sheets	391	36.0
Medical specialist	281	25.9
Special internet site	201	18.5
Media (TV, papers, magazines, etc.)	169	15.6
Patients' association	99	9.1
Genetic counselor	51	4.7
Family, friends, or acquaintances	40	3.7
Special helpdesk	34	3.1
By telephone	32	2.9
Nurse	30	2.8
Genetic information centre (ERFO centre)	15	1.4
Other	18	1.7

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