Original Research

Knowledge and Attitudes Towards Genetic Testing: A Two Year Follow-Up Study in Patients with Asthma, Diabetes Mellitus and Cardiovascular Disease

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Adequate knowledge and personal attitudes towards DNA-testing are major determinants of optimal utilization of genetic testing. This study aims to (1) assess the genetic knowledge and attitude towards genetic testing of patients with asthma, diabetes mellitus type II and cardiovascular diseases, (2) determine whether their knowledge or attitude changed since 2002, and (3) investigate the predictive role of knowledge on attitude. Data were collected within the Panel of Patients with Chronic Diseases in 2002 and 2004, resulting in 398 data-pairs. Results show that factual knowledge mainly relates to associations between genes and diseases, less is known on associations between genes, chromosomes, cells and body. The perceived knowledge on DNA-testing has not increased since 2002. The attitude towards genetic testing also appeared to be rather consistent. Less perceived medical genetic knowledge and more perceived social genetic knowledge were found predictive for a more reserved attitude towards genetic testing. In conclusion, advanced developments in the field of genetics are not accompanied by increased knowledge of patients with common multi-factorial diseases. The finding that more perceived social genetic knowledge results in more reluctance can be considered an indicator for the necessity of social debates on genetic testing.

KEY WORDS: genetic knowledge; attitudes; longitudinal; asthma; diabetes mellitus; cardiovascular diseases; genetic counseling; genetic testing.

INTRODUCTION

Scientific knowledge in the field of medical genetics is growing fast. The completion of the Human Genome project in 2003, and the eventual identification of thousands of human genetic variants, have heightened the expectations of health benefits (Khouri *et al.*, 2004). This rapidly accumulating knowledge will generate many possibilities for health care and is expected to improve the quality of life of individuals and families (Henneman *et al.*,

2004). DNA tests become more and more available; at the moment for hundreds of hereditary diseases (Oosterwijk and Ausems, 2005). Until recently, scientific and public attention was mainly directed at monogenetic diseases, such as Huntington disease (Leschot and Willems, 2004). However, there is growing insight that genes also play a role in the development of more common diseases, like asthma or diabetes. The development or the seriousness of a disease is then influenced by the environment in which the genetic components are exposed; a person with a genetic defect will thus be more sensitive to certain environmental factors, e.g. nutritional factors (Leschot and Willems, 2004).

Several chronic diseases are already known to have a genetic component. Asthma, diabetes mellitus and cardiovascular diseases are highly prevalent

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examples of chronic diseases of which it is assumed that both genetic and environmental factors are involved in the development of the disease. Research is taking place at this moment to determine what specific genes play a role in the development of asthma (Leschot and Willems, 2004; Thakkinstian *et al.*, 2005). Diabetes mellitus is distinguished in two types, Insulin Dependent Diabetes Mellitus (type 1), in particular prevalent in children and young adults, and Non-Insulin Dependent Diabetes Mellitus (type 2), in particular prevalent in older adults and often accompanied by obesity. The genetic predisposition in the cause of diabetes mellitus still becomes clearer, especially regarding type 2 diabetes, while environmental factors, such as physical inactivity and adiposity mainly seem to play a role in the tempo of the disease's development (Illig *et al.*, 2005; Kavvoura and Ioannidis, 2005; Leschot and Brunner, 1998). Regarding cardiovascular diseases, the most common cause of death in the developed world, it is now well established that both genetic and environmental factors influence the development of several cardiovascular disorders and its risk factors, such as hypertension, particular fatty acids and obesity (Hall, 2005; Iliadou and Snieder, 2004; Leschot and Willems, 2004).

Adequate knowledge regarding the genetic component of diseases, as well as personal attitudes towards DNA-testing, are major determinants of optimal utilization of genetic testing (Capelli *et al.*, 1999; Hietala *et al.*, 1995). Several population studies, e.g. in the Finnish and Dutch populations (Henneman *et al.*, 2004; Jallinoja and Aro, 1999), generally show a lack of understanding of genes and heredity. Because of the significance to chronically ill, to themselves as well as to their families and offspring, Morren and colleagues (in press) examined perceived knowledge in chronically ill patients and their attitudes towards DNA-testing. Their results also showed low levels of perceived knowledge, especially in older and lower educated chronic patients. Attitudes towards genetic testing, on the other hand, were found to be generally favorable, mostly in younger and higher educated patients. Higher levels of perceived knowledge were associated with more favorable attitudes.

As the developments in genetic research are believed to be accompanied by due media attention, it was decided to follow the patients with asthma, diabetes mellitus type 2, and cardiovascular disease, who participated in the study of Morren *et al*. This resulted in a repeated measurement two years later,

in 2004. Additionally, in order to help interpret the level of genetic knowledge, a factual knowledge-scale on genes and heredity was added to the survey. Our first aim is to contribute to current insights into the genetic knowledge of patients with common multi-factorial diseases, and into the relationship between genetic knowledge and attitudes towards genetic testing. We furthermore aim to reveal developments in perceived knowledge and attitudes over a period of two years, as media attention goes hand in hand with developments in genetic science. For these purposes, we investigated whether patients with asthma, type 2 diabetes and cardiovascular disease differ in their genetic knowledge or in their attitude towards genetic testing. In addition, we looked at the degree to which patients consider their illness as hereditary, and whether this would explain the variation in genetic knowledge and attitudes towards genetic testing. Finally, we examined whether patients' perceived knowledge and attitudes changed over a period of two years, and whether perceived knowledge can be considered predictive for the genetic attitudes of patients with asthma, diabetes, and cardiovascular disease.

METHODS

Sample

Patients were selected from the Panel of Patients with Chronic Diseases, a nationwide longitudinal study on medically diagnosed chronically ill, conducted in the Netherlands since 1998 (Rijken and Bensing, 2000). All diagnoses were registered by the general practitioners of the patients. For this study, all patients with asthma, diabetes mellitus type 2 (DM), and several cardiovascular diseases (CVD) were selected from the Panel on the basis of the patient's first diagnosis according to the following codes of the International Classification of Primary Care (Lamberts and Wood, 1987): R96 (asthma), T90.2 (diabetes mellitus type 2), and K74, K75, K76, K87, K90, and K91 (cardiovascular disease). The first survey was held in April 2002, in which 577 patients responded: 299 patients with asthma, 144 with diabetes mellitus type 2, and 134 with cardiovascular disease (response 79.1%, 82.3%, and 80.2% respectively). The survey was repeated in April 2004. From the 2002-group, 113 patients could not be approached because of death ($n = 13$), health-related reasons ($n = 9$), admission in a nursing home ($n = 3$), or

because they just wished to stop participating in the Panel ($n = 88$). Thus, 464 patients could be approached, of whom 398 patients responded: 206 patients with asthma, 102 patients with diabetes mellitus type 2, and 90 patients with cardiovascular disease (response 83.7%, 87.9%, and 88.2% respectively). Non-respondents were reminded twice to obtain as many respondents as possible.

Before patients enrolled in our panel, their informed consent was obtained. The Panel of Patients with Chronic Diseases is registered with the Dutch Data Protection Authority. The data were collected according to the privacy protection guidelines of this Authority.

Measurement

Data were gathered using a postal survey. No information on genetics was given in the cover letter, nor in the questionnaire's introduction. Apart from gender, age, and educational level as sociodemographic characteristics, illness duration and comorbidity (number of chronic physical diseases) were assessed. Data on these disease related characteristics were collected via general practitioners, after permission of the patients, at the moment of enrolment in the panel. Illness duration reflects the number of years since the first chronic illness (in this study asthma, diabetes type 2 or cardiovascular disease) was diagnosed. Only for presenting frequency distributions, educational level was classified into a basic level (no, primary, or lower vocational education), an intermediate level (secondary or intermediate vocational education), and a high level (higher vocational education or university).

Factual knowledge was assessed in the survey of April 2004. It was measured by means of 16 structured items on genes and heredity in general. These items were derived from Jallinoja and Aro (1999) and translated into Dutch. The items measure the knowledge about the association of genes and diseases and the association of genes, chromosomes, cells and the body. According to Jallinoja and Aro, a summary index of the correct answers was formed (score 1 correct, score 0 incorrect/don't know). If some items were not completed ('user missing') but other items were answered, user missings were replaced by "don't know" (thus scored as a 0). Only when the total question of 16 items was missed, the case was excluded from analyses. This resulted in 306 valid and 92 missing cases. The reliability of this summary index was found equal to Jallinoja and Aro (Cronbach's alpha 0.86).

Perceived knowledge of genetics was measured by means of 11 items about the possibilities and consequences of DNA-testing, in April 2002 as well as in April 2004. Items were selected to cover major issues in relevant literature (Morren *et al.*, in press). Respondents indicated whether they had knowledge about every item on a 3-point scale (0 = nothing, 1 = something, 2 = much). Because of slightly different answering categories for the scores (1) and (2) in 2004, comparisons on item level are reported only for the answering category (0) "I know nothing," thus reflecting possible changes in the proportion of patients who indicate to have no knowledge about that particular subject. Following Morren *et al.*, two scales were created: knowledge about the medical possibilities of genetic testing (5 items), e.g. "The possibility to use genetic knowledge to prevent or treat a disorder," and knowledge about the social consequences of genetic testing (6 items), e.g. "The consequences of DNA-testing for my work" (see Table IV). Pearson correlation between both scales was 0.67. Subsequently, total perceived genetic knowledge was computed by means of a summary score of the total scale (Cronbach's alpha 0.91), with a range of 0–22. In the same way summary scores were computed for the two separate scales: perceived medical knowledge (range 0–10) and perceived social knowledge (range 0–12). The reliability of both scales (Cronbach's alpha) was 0.88 and 0.86 respectively. Test-retest reliability (intraclass correlation coefficient) of the scales was 0.66 (total), 0.68 (medical), and 0.60 (social).

Attitude towards genetics was examined by means of 13 statements on genetic testing (see Table VII), in 2002 and in 2004. These items were also selected from the literature (Morren *et al.*, in press). Items were scored on a 5-point scale (1 = totally disagree; 2 = disagree; 3 = don't know; 4 = agree; 5 = totally agree). To facilitate interpretation of the frequency distributions, the items were recoded into three categories: 'agree' and 'disagree' (combination of the original responses 'totally (dis)agree' and '(dis)agree') and 'don't know.' Like Morren and colleagues, two scales were then composed, measuring a favorable attitude (6 statements on pros of genetic testing), e.g. "I approve of using DNA-testing for early detection of diseases," and a reserved attitude (7 statements on cons of genetic testing), e.g. "I worry about the consequences of DNA-testing for the chances of finding a job" (see Table VI). Both scales were computed by means of

adding up the item scores, with favorable attitude ranging from 6–30 (Cronbach's alpha 0.82), and reserved attitude ranging from 7–35 (Cronbach's alpha 0.70). The intraclass correlation coefficient (reflecting test-retest reliability) was 0.66 in both scales. As the scales measure two different concepts, hardly correlating with each other ($r = -0.18$), they were not added up to create one total genetic attitude scale. This phenomenon of creating two independent dimensions measuring a rather positive and a rather negative attitude is supported by former research. For example, Parisi and Katz (1986) constructed attitude scales to measure the public's views towards posthumous organ donation, which resulted in a reliable measurement of two independent dimensions, namely prodonation and antidonation ($r = .003$).

Considering own disease as hereditary was assessed by one item on a 7-point scale, from (1) not at all genetic, to (7) totally genetic. Just for presenting frequency distributions, the answers were regrouped into three categories, representing hardly genetic, half genetic, and mainly genetic. In the analyses we used the original 7-point scale.

Statistics

Group differences in frequencies and mean scores were examined by means of chi square tests, or analyses of variance. In analyses of variance, Scheffé or Tamhane's T2 were used for post hoc comparisons, dependent on the Test of Homogeneity of Variances (Scheffé in case of equal variances).

To determine whether the three diagnostic groups differ regarding factual genetic knowledge, perceived genetic knowledge and attitude towards genetic testing, multivariate analysis of variance was applied. McNemar change tests and paired samples *t*-tests were applied, for dichotomous and continuous variables respectively, in order to assess significant changes in perceived knowledge and genetic attitudes from April 2002 to April 2004.

To assess the association between considering the illness as hereditary on the one hand, and factual knowledge, perceived knowledge (total, medical and social) and attitude (favorable and reserved) on the other hand, linear regression analyses were performed using the enter-method. In these regression models, socio-demographic variables as age, gender and educational level were first entered into the model. Next, disease related characteristics, such as diagnosis (dummy's), comorbidity and illness

duration were entered in a separate block, followed by the variable 'considering their illness as hereditary.' Finally, to assess the predictive value of perceived knowledge to genetic attitudes, perceived genetic knowledge in 2002, together with factual genetic knowledge and attitude in 2002, was added to the regression equation.

RESULTS

Characteristics of The Sample

Table I presents the socio-demographic and disease related characteristics of the sample. The three diagnostic groups differed with regard to all measured background characteristics. The asthma and CVD samples consist of more, respectively less female respondents compared to the DM group. Concerning the age and educational distributions, the asthma group is deviating from the other two samples, in the sense of younger and higher educated respondents. With regard to illness duration, respondents with asthma and DM had a shorter illness history than CVD patients, generally. Furthermore, asthma patients are less often characterized by comorbidity, whereas CVD respondents have more often comorbidity compared with DM patients. Finally, more asthma patients reported to consider their illness as hereditary, compared to DM and CVD patients (Fig. 1). This difference, however, disappears when the differences regarding socio-demographic characteristics are taken into account.

The distribution of respondents among the diagnostic groups in 2002 and 2004 was equal to one another with regard to the response. Only the age distribution in the loss in follow up was found to be different from that in the respondents in 2004, with especially the older patients failing to participate for the second time. The composition of the loss in follow-up was equal to that of the respondents with regard to the other background characteristics (data not shown).

Factual Genetic Knowledge

The best-known items of genes and heredity relate to statements on the associations between genes and diseases (Table II). For example, the statement "The onset of certain diseases is due to genes, environment and lifestyle" was correctly answered

Table I. Socio-Demographic and Disease Characteristics of Patients with Asthma, Diabetes Mellitus Type 2 (DM), and Cardiovascular Disease (CVD) Who Responded in Both Surveys, in April 2002 and April 2004 ($n = 398$)

	Asthma ($n = 206$)	DM ($n = 102$)	CVD ($n = 90$)	
Gender (% female)	65.5	51.0	35,6	*
Age (%)				
15–44 years	44.7	5.9	2,2	
45–64 years	39.8	46.1	44.4	
≥65 years	15.5	48.0	53.3	
Mean (SD), range 16–86	47.4 (15.5)	63.8 (11.6)	65.8 (9.8)	*
Educational level (%)				
Basic	31.9	60.9	57.1	
Intermediate	43.1	27.2	34.5	
High	25.0	12.0	8.3	
Mean (SD), range 1–8	4.8 (1.8)	3.7 (1.6)	3.7 (1.4)	*
Illness duration (%)				
0–5 years	28.0	55.2	35.7	
5–10	25.3	31.3	35.7	
>10 years	46.8	13.5	28.6	
Mean (SD), range 1–64	2.9 (11.5)	6.4 (5.5)	8.1 (6.0)	*
Comorbidity (number of chronic diseases, %)				
One	81.1	75.5	50.0	
Two	13.6	15.7	36.7	
Three or more	5.3	8.8	13.3	*
Consider own illness as hereditary (%)				
Hardly genetic	39.8	64.9	69.4	
Half genetic	29.6	20.8	15.3	
Mainly genetic	30.6	14.3	15.3	
Mean (SD), range 1–7	3.5 (1.9)	2.5 (1.8)	2.4 (1.8)	*

*$p < 0.05$.

by more than 70% in all diagnostic groups. The least-known items concern statements on associations among genes, chromosomes, cells and body, e.g. "Genes are bigger than chromosomes" (correctly answered by 30% or less).

At first sight, asthma patients show more factual genetic knowledge than patients with DM and CVD ($F(2) = 13.53$, $p < 0.000$). However, this difference disappears, when we take the differences in age, gender and educational level into account. Regression analysis (Table III) revealed a younger age and higher educational level, as well as the perceived extent of heredity of the own illness, as important factors for the level of factual knowledge. The total model, also including gender and disease related characteristics, accounted for 41% of the variance (AR^2 measured 0.39).

Perceived Genetic Knowledge

Table IV shows the proportions of patients with asthma, DM and CVD reporting to have no knowledge on the several statements measuring the medical possibilities and social consequences of genetic testing in 2002 and 2004. Most patients report to have no knowledge about the consequences of DNA-testing in the social sphere, of which the consequences of DNA-testing for work are least-known. In 2004, these percentages vary between 78% in asthma patients and 89% in CVD patients. With regard to medical possibilities, the least-known
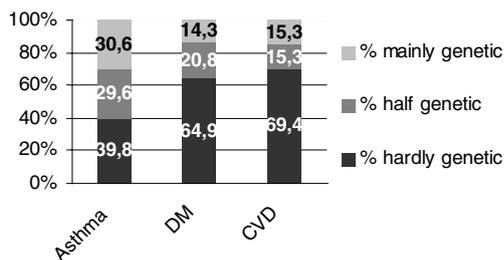

Fig. 1. Distribution of patients with asthma, diabetes mellitus type 2 (DM), and cardiovascular disease (CVD) considering their illness as hereditary.

Table II. Factual Genetic Knowledge of Patients with Asthma, Diabetes Mellitus Type 2 (DM) and Cardiovascular Disease (CVD), in 2004 (% of respondents with a correct answer)

Statement	Patients with		
	Asthma ($n = 181$)	DM ($n = 61$)	CVD ($n = 64$)
1. One can see a gene with the naked eye. (not correct)	87	71	73
2. Healthy parents can have a child with a hereditary disease. (correct)	84	79	66
3. The onset of certain diseases is due to genes, environment and lifestyle. (correct)	83	74	73
4. A gene is a disease. (not correct)	82	62	73
5. The carrier of a disease gene may be completely healthy. (correct)	79	69	55
6. All serious diseases are hereditary. (not correct)	72	62	47
7. A gene is a molecule that controls hereditary characteristics. (correct)	61	53	44
8. Genes are inside cells. (correct)	60	41	39
9. The child of a disease gene carrier is always also a carrier of the same disease gene. (not correct)	56	36	33
10. A gene is a piece of DNA. (correct)	56	44	28
11. A gene is a cell. (not correct)	44	25	19
12. A gene is a part of a chromosome. (correct)	43	31	30
13. Different body parts include different genes. (not correct)	32	20	17
14. Genes are bigger than chromosomes. (not correct)	30	20	13
15. The genotype is not susceptible to human intervention. (correct)	17	21	11
16. It has been estimated that a person has about 30,000 genes. (correct)[a]	12	5	9
Total mean score (range 0–16) (SD)	9.0 (4.0)	7.1 (3.8)	6.3 (3.5)

[a]At the time of the questionnaire, this estimation was correct. The number of genes is now estimated at 22,000.

subject relates to the possibilities and risks of gene therapy, with percentages 'having no knowledge' varying from 61% in asthma patients to 74% in DM patients in 2004. The best-known subject concerns the possibility of early detection of certain disorders using DNA-tests, with 20% of the patients with

Table III. Regression Analysis of Factual Knowledge of Genes and Heredity

	Factual knowledge of genes and heredity	
	Beta[a]	$\triangle p$
Socio-demographic characteristics		***
Gender (ref. male)	−0.07	
Age	−0.30***	
Educational level	0.42***	
Disease-related characteristics		ns
Diagnosis DM (ref. asthma)	0.03	
Diagnosis CVD (ref. asthma)	−0.02	
Illness duration	−0.03	
Comorbidity	0.01	
Consider own illness as hereditary	0.13*	*
F-value (df)	20.61 (8,234)***	
R^2–adjusted	0.39	

Note. DM: diabetes mellitus; CVD: cardiovascular disease.
$\triangle p$: Significance of the F change-statistic; ns: not significant.
[a]Final betas and significance levels.
*$p < 0.05$. **$p < 0.01$. ***$p < 0.001$.

asthma to 36% of the patients with DM or CVD reporting to have no knowledge about this.

In general, the perceived genetic knowledge has not increased over a period of two years. On the contrary, mean scores in asthma patients on the scale total knowledge, as well as on the separate scales are significantly lower in 2004 compared to 2002, in particular with regard to the consequences of DNA-testing for work and the rights of third parties to inquire about the results of a DNA-test.

The three diagnostic groups differ from each other in their perceived genetic knowledge, with asthma patients reporting more knowledge than patients with DM or CVD. However, again, when we take the composition differences into account, this difference disappears. The same results emerged when perceived medical knowledge and perceived social knowledge were considered separately. Table V shows the results of the multivariate regression analyses of perceived genetic knowledge in 2004.

The regression model revealed educational level as most important factor for perceived genetic knowledge in 2004, especially with regard to knowledge on medical possibilities of genetic testing. The total model, however, only accounted for 9% and 14% of the variance, respectively (AR^2 0.07 and 0.12). The perception of heredity of own illness only

Table IV. Perceived Knowledge of Patients with Asthma, DM and CVD on Genetic Testing, in 2002 and 2004

% Reporting to have no knowledge	Asthma 2002	Asthma 2004	DM 2002	DM 2004	CVD 2002	CVD 2004
On medical field						
The possibilities and risks of gene therapy	61	61	77	74	78	71
The significance of DNA-testing for my relatives	44	47	68	61	58	61
The significance of DNA-testing for my offspring	43	49	74	64	60	63
The possibility to use genetic knowledge to prevent or treat a disorder	35	33	64	52	61	51
The possibility of early detection of certain disorders using DNA-testing	20	20	46	36	39	36
Mean score on knowledge on medical field (range 0–10) (SD)	3.9 (3.0)	3.1* (2.3)	2.0 (2.7)	2.1 (2.0)	2.3 (2.5)	2.3 (2.3)
On social field						
The consequences of DNA-testing for my work	71	78*	86	88	88	89
The consequences of DNA-testing for taking out insurance	68	73	83	80	82	82
The rights of third parties to inquire about the results of a DNA-test	70	78*	85	86	83	80
The consequences of DNA-testing for my daily life	67	73	84	82	79	82
Your rights to refuse DNA-testing	68	66	82	74	75	75
Your own possibilities to apply for a DNA-test	64	68	83	67*	79	81
Mean score on knowledge on personal sphere (range 0–12) (SD)	2.5 (3.6)	1.8* (2.4)	1.1 (2.4)	1.3 (2.3)	1.3 (2.6)	1.1 (2.0)
Mean score on TOTAL perceived knowledge (range 0–22) (SD)	6.5 (6.2)	5.0* (4.3)	3.2 (4.7)	3.4 (3.9)	3.6 (4.6)	3.5 (4.0)

*Change between 2002 and 2004, $p < .05$.

showed to be a small contributor to perceived medical genetic knowledge. The regression model did not explain any variance of perceived knowledge on social consequences of genetic testing.

Attitudes Towards Genetic Testing

In all three diagnostic groups, the majority agreed on several statements measuring a favorable view towards DNA-testing, in 2002 as well as in 2004 (Table VI). Most positive were patients about the more broadly formulated statements, e.g. '... hopeful for the treatment of diseases' (78% to 86%) or '... early detection of diseases' (76% to 85%). Most opinions on specific statements did not change over a period of two years. Looking at the total scale score, both the asthma group and DM group scored lower in 2004, reflecting a less favorable attitude towards genetic testing. The diagnostic groups did not differ

Table V. Regression Analyses of Perceived Genetic Knowledge in 2004

	Total knowledge Beta[a]	Total knowledge Δp	Medical knowledge Beta[a]	Medical knowledge Δp	Social knowledge Beta[a]	Social knowledge Δp
Socio-demographic characteristics		***		***		ns
Gender (ref. male)	−0.03		0.01		−0.06	
Age	0.01		−0.05		0.05	
Educational level	0.19**		0.23***		0.12	
Disease-related characteristics		ns		ns		ns
Diagnosis DM (ref. asthma)	−0.02		−0.02		−0.02	
Diagnosis CVD (ref. asthma)	−0.04		−0.02		−0.04	
Illness duration	0.10		0.09		0.10	
Comorbidity	−0.02		0.01		−0.03	
Consider own illness as hereditary	0.13	ns	0.15*	*	0.08	ns
F-value (df)	3.37 (8,263)	***	5.36 (8,256)	***	1,48 (8,260)	
R²–adjusted	0.07		0.12		0.01	

Note. DM: diabetes mellitus; CVD:cardiovascular disease.

Δp: Significance of the F change-statistic ns: not significant.

[a]Final betas and significance levels.

*$p < 0.05$. **$p < 0.01$. ***$p < 0.001$.

Table VI. Attitudes Towards Genetic Testing of Patients with Asthma, Diabetes Mellitus Type 2 (DM), and Cardiovascular Disease (CVD), in 2002 and 2004

Favorable (% agree)	Asthma ($n = 206$)		DM ($n = 102$)		CVD ($n = 90$)	
	2002	2004	2002	2004	2002	2004
I think the development of DNA research is hopeful for the treatment of diseases	86	86	83	78	79	81
I think that the development of DNA research is a positive medical progress	85	82	82	79	77	84
I approve of using DNA-testing for early detection of diseases	81	85	77	76	78	80
I would inform my siblings about the results of a DNA-test for a specific disease	74	75	65	61	65	75
I would inform my children about the results of a DNA-test for a specific disease	75	72	65	57	68	73
I want to know whether my disease is hereditary	70	56*	68	50	68	56
Mean score on favorable attitude (range 6–30) (*SD*)	24.0 (3.8)	23.5* (4.0)	23.9 (4.1)	22.8* (3.5)	24.4 (4.4)	23.9 (4.7)

Reserved (% agree)	Asthma		DM		CVD	
	2002	2004	2002	2004	2002	2004
The possibility of a DNA-test will change one's future	58	52	51	40*	43	44
I worry about the consequences of DNA-testing for being able to take out insurance	50	51	55	46	46	37
As long as a disease cannot be treated, I don't want a DNA-test	41	40	46	39	55	41
If I had a DNA-test done, my family need not know about the result	35	33	45	34*	36	22*
I worry about the consequences of DNA-testing for the chances of finding a job	35	31	30	30	30	28
I don't want a DNA-test to tell me that I am at risk for a certain disease	32	38	37	40	34	33
The idea of DNA-tests frightens me	26	25	28	28	26	21
Mean score on reserved attitude (range 7–35) (*SD*)	20.9 (4.9)	20.4 (4.7)	22.1 (4.3)	21.7 (4.7)	22.7 (5.0)	20.1* (5.0)

*Change between 2002 and 2004, $p < .05$.

from each other with respect to a favorable attitude towards genetic testing.

Concerning the rather reserved opinions on genetic testing, a minority agreed on most items. Least reserved are patients about the idea of DNA-tests, although still 21% of the CVD-patients to 28% of the DM-patients experience the idea of DNA-tests as frightening. Also, relatively many patients indicated to worry about the consequences of DNA-testing for taking out insurances. Again, most views on these aspects of genetic testing were found to remain stable. In 2004, less patients with DM and CVD reported that in case of a DNA-test, their family need not to know about the results. Furthermore, less patients with DM think that the possibility of a DNA-test will change one's future, than they did in 2002. Looking at the total scale score, the CVD group scored lower in 2004, reflecting a less reserved attitude towards

genetic testing. The diagnostic groups did not differ from each other with respect to a reserved attitude.

Table VII shows the results of two regression models of a favorable and reserved attitude towards genetic testing. Model A reflects the regression model assessing the association between considering the illness as hereditary on the one hand, and attitude on the other hand, taking socio-demographic and disease-related characteristics into account. Considering their own illness as hereditary appeared to be positively related to a favorable attitude towards genetic testing. A similar, but less significant relationship was found for comorbidity.

In regression model B perceived genetic knowledge was added in order to examine whether perceived genetic knowledge can be considered predictive for the attitude towards genetic testing. These analyses revealed a relationship between perceived

Table VII. Regression Analyses of Favorable and Reserved Attitudes Towards Genetic Testing in 2004

	Favorable attitude in 2004				Reserved attitude in 2004			
	Model A		Model B		Model A		Model B	
	Beta[a]	$\triangle p$	Beta[a]	$\triangle p$	Beta[a]	$\triangle p$	Beta[a]	$\triangle p$
Socio-demographic characteristics		Ns		*		ns		ns
Gender (ref. male)	0.03		−0.01		0.01		0.10	
Age	0.12		0.16		−0.06		0.02	
Educational level	0.03		0.07		−0.14		−0.14	
Disease-related characteristics		*		ns		ns		ns
Diagnosis DM (ref. asthma)	−0.05		0.01		0.05		−0.03	
Diagnosis CVD (ref. asthma)	0.04		0.05		0.01		0.06	
Illness duration	0.08		0.08		−0.05		−0.01	
Comorbidity	0.16*		0.10		−0.10		−0.09	
Consider own illness as hereditary	0.21**	***	0.11	*	−0.03	ns	−0.10	ns
Attitude in 2002				***				***
Favorable attitude			0.44	***			—	
Reserved attitude			—				0.49	***
Genetic knowledge				ns				**
Factual knowledge (2004)			−0.03				0.18	*
Perceived medical knowledge in 2002			− 0.02				−0.24	*
Perceived social knowledge in 2002			−0.03				0.28	**
F-value (df)	2.95 (8,248)	**	5.33 (12,163)		1.32 (8,240)	ns	6.53 (12,156)	
R^2–adjusted	0.06		0.23		0.01		0.28	

Note. DM: diabetes mellitus; CVD: cardiovascular disease.

$\triangle p$: Significance of the F change-statistic; ns: not significant.

[a]Final betas and significance levels.

*$p < 0.05$. **$p < 0.01$. ***$p < 0.001$.

knowledge (in 2002) and a reserved attitude (in 2004): more perceived medical genetic knowledge was found to be associated with a less reserved attitude, whereas more social genetic knowledge was found to be associated with a more reserved attitude. Furthermore, a positive relationship was found between factual knowledge and a reserved attitude. The total model, also including socio-demographic and disease related characteristics, and reserved attitude in 2002 (which was the strongest predictor), accounted for 33% of the variance (AR^2 0.28). Perceived knowledge did not predict a favorable attitude.

DISCUSSION

Scientific knowledge on genetic testing is rapidly increasing. This is not the case with the genetic knowledge perceived by patients with highly prevalent chronic diseases that are known to be partially caused by genetic defects. Our results show that perceived knowledge on genetic testing has not increased in patients with asthma, diabetes mellitus type 2, and cardiovascular disease, in a period of two years. On the contrary, with regard to specific sub-jects, perceived knowledge of asthma patients even decreased. According to Berth and colleagues (2002) it is likely that the vast quantity of information about new achievements and promises of gene technology reported by the mass media leaves the public in a state of confusion, resulting in misconceptions. However, another possible explanation for our results is that, due to media attention, people learn that scientific knowledge on genetics is rapidly increasing, so that more attention in the media might just cause people to realize more and more that their own knowledge of genetics only comprises a small part of what is known. Perceived genetic knowledge was found to be associated with a higher educational level, especially knowledge about the medical possibilities of genetic testing. This finding is in line with our results on factual knowledge of genes and heredity; our results also show a positive relationship with a higher level of genetic knowledge. Apart from the educational level, age was found to be associated with factual knowledge, that is, a higher age is related to a lower knowledge level. These findings on age and educational level are consistent with findings of other studies (e.g. Henneman *et al*, 2004; Jallinoja and Aro, 1999). Possibly, elderly people are

less likely to be influenced by the media. AAlternatively, the younger subjects are more likely to have studied biology and genetics in their schooling, regardless of their level of education.

In addition, our results on factual knowledge in patients with asthma, diabetes, and cardiovascular disease are in line with the results of Jallinoja and Aro (1999) in the Finnish general population with regard to the best-known and least-known subjects. We also found the same distributions in socio-demographic characteristics (data not shown). However, in our study relatively many respondents (23%) skipped the complete question, which consisted of 16 items. This possibly indicates a low interest in genetics, or may be the items were valuated as too difficult or 'too far from my bed.' Further analyses, in this connection, show that only 12 respondents reported to have actually applied for or attended a DNA- test (data not shown). One can also take into consideration that the frame of reference of the majority of our sample is to treat the illness and the environment so that they can get better, since they have already been diagnosed. In addition, further analyses show that the non-respondents on factual knowledge generally were older and had a lower educational level (data not shown). Jallinoja and Aro also attribute their moderate response to the topic of their questionnaire. As the so-called system-missings were not taken into account in calculating the factual knowledge score, our findings may be an overestimation of the factual knowledge of genes and heredity.

Apart from the level of genetic knowledge and possible shifts in two years time, we wished to investigate whether the three diagnostic groups differed from each other with regard to genetic knowledge as well as to the attitude towards gene testing, and whether these differences could be explained by the extent of considering the illness as hereditary. Taking the socio-demographic composition differences among the diagnostic groups into account, we did not find any differences between patients with asthma, diabetes, and cardiovascular disease. However, we did find positive relationships between considering the own illness as hereditary on the one hand, and factual knowledge, perceived medical knowledge and favorable attitude on the other hand, again, taking socio-demographic and disease related characteristics into account. This means that the perception of heredity of the own illness is of additional value in studying genetic knowledge and attitude.

The attitude of patients with asthma, diabetes, or cardiovascular disease towards genetic testing is rather stable. The majority appeared to be in favor of the medical possibilities of gene tests in general. When it comes to more social consequences, such as consequences for taking out insurances, patients are more concerned. High approval on gene tests is also found in the general public, as well as in specific samples at risk for genetic diseases (Berth et al., 2002; Capelli et al., 2001; Hietala et al., 1995).

An interesting finding of our study is that a reserved attitude appeared to be partly determined by the level of perceived knowledge; more medical genetic knowledge was found predictive for less reluctance, whereas more social genetic knowledge results in more reluctance. These results offer opportunities for health educational programs on the one hand, but at the same time, can be considered a signal for the necessity of social debates on these possible consequences. In other words, as adequate knowledge and personal attitudes are major determinants of optimal utilization of genetic testing, more attention to the increasing medical possibilities should go hand in hand with discussion on what this brings about regarding daily life, work, or taking out insurances.

Study Limitations

We have to take into consideration, in the interpretation of the results, that we lost relatively many patients in the follow-up study, possibly causing a selection of patients. This loss in follow-up can partly be explained by the fact that patients with diabetes and cardiovascular disease who participate in the panel are requested to fill in and return a questionnaire twice a year, asthma patients even three times a year. That means that three (or five) other questionnaires have been distributed among the panel members between April 2002 and April 2004, which can be considered a strenuous task. Furthermore, patients with chronic illnesses are characterized by a high age, resulting in an even higher loss in follow up because it takes too much effort to participate in a study. On the other hand, the representativeness of the Panel of Patients with Chronic Diseases can be considered an important strength of this study. In relation to the sample size, we did not determine effect-sizes in advance of this study. The findings of the first part of this study (carried out in 2002, Morren et al., in press) were interesting in such a way that it was decided to repeat the study two years later. We therefore reported and discussed only statistically significant effects. However, this does not mean that

non-significant findings in our study are not worthwhile for further investigation. With our sample size we were able to detect the effects as described. With larger sample sizes possibly more effects could have been found, on, for instance, the changes in knowledge and attitude in two years. Yet, the period of two years might be too short to detect these possible changes.

Another consideration concerns the genetic-related issues that we have measured, as genetic knowledge comprises more issues than we could include in our questionnaire. We have tried to compensate this limitation by combining perceived knowledge with a factual knowledge-scale, in order to facilitate the interpretation of the level of knowledge. However, repeated measurement of factual knowledge is also needed when monitoring changes in genetic knowledge levels.

CONCLUSIONS

In conclusion, rapid developments in scientific knowledge in the field of medical genetics are not accompanied by increased knowledge in patients with asthma, diabetes mellitus type 2, and cardiovascular disease. Also, the attitudes towards DNA-testing were rather stable over a period of two years. Genetic knowledge and attitude of patients with chronic diseases that are known to be partially genetic, seem to be comparable to the knowledge and attitude of the general public. However, study into genetic knowledge and attitude towards genetic testing has shown that the perception of heredity of the own illness can be of additional value. Perceived knowledge of the medical opportunities genetic testing can offer, was found predictive for less reluctance towards DNA-testing, which paves the way for health education programs. On the other hand, the finding that more perceived knowledge of social consequences results in more reluctance can be considered an indicator for the necessity of a social debate and the involvement of patients when approaching these possible consequences. For future research, it is important to continue monitoring perceived knowledge, as our findings point out that perceived knowledge determines the attitude of patients with asthma, diabetes, and cardiovascular disease. However, without repeated measurement of factual knowledge at the same time, the interpretation of perceived knowledge levels remains difficult.

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