

QUOTE-GENE^{CA}: DEVELOPMENT OF A COUNSELEE-CENTERED INSTRUMENT TO MEASURE NEEDS AND PREFERENCES IN GENETIC COUNSELING FOR HEREDITARY CANCER

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SUMMARY

Counselees' motives for seeking genetic counseling for hereditary cancer have already been investigated, however not using instruments based on counselees' perspective. In addition, expectations regarding the process of counseling have scarcely been assessed. This article describes the construction and psychometric properties of the QUOTE-gene^{ca}, a counselee-centered instrument intended to measure needs and preferences in genetic counseling for hereditary cancer. Formulation of the items involved input from counselees and the instrument was derived from a conceptual framework for measuring patient satisfaction. Two-hundred new counselees completed a questionnaire containing the instrument and measures of coping style (TMSI), generalized anxiety (STAI) and cancer-related stress reactions (IES), prior to their first consultation. Results showed that the instrument captures relevant issues of concern with high internal consistency, and was associated, as expected, with validated measures of coping style and distress. Responses showed that major concerns prior to counseling relate to: receiving information about risk and preventive strategies; the procedure of counseling; and preferences on how the interaction with the counselor proceeds. Receiving emotional support and discussing emotional aspects were considered relatively less important. Increasing insight into individual needs may help counselors in better addressing these concerns, potentially increasing the likelihood of successful counseling. Copyright © 2004 John Wiley & Sons, Ltd.

INTRODUCTION

Genetic counseling and testing has become available for individuals with a (family) history of cancer who wish to learn of their own or their family members' risk. Cancer genetic counseling is most frequently requested by individuals with breast or colon cancer and by healthy individuals with affected relatives. With the discovery of breast (Miki *et al.*, 1994; Wooster *et al.*, 1994) and colon (reviewed by Bellacosa *et al.*, 1996)

cancer susceptibility genes, genetic testing can be offered to selected patients. A primary goal of genetic counseling and testing is to educate individuals about cancer risk and cancer prevention, with the aim of reducing morbidity and mortality. Crucial in the process of counseling is the individual's autonomy and ability to make well-informed decisions with regard to testing and the adoption of preventive strategies, as put forward in the World Health Organization guidelines (1998) as well as in the American Society of Clinical Oncology policy statement (1996, 2003). This principle underlines the significance for clinicians to elicit counselees' needs and preferences at the outset, and to try to adapt their counseling accordingly. Results from a study on

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genetic counseling for hereditary breast cancer showed that in the counselors' opinion, identifying the counsees' individual needs and concerns plays a key role in supporting counsees, lowering their anxiety and discussing the complex issues of genetics (Lobb *et al.*, 2001). Indeed, in a study of 131 counsees attending genetic counseling, it was found that counselors' incorrect perceptions of the counsees' concerns prior to the initial visit, lowered the counsees' satisfaction with the information received and was associated with the idea that their expectations had not been met (Michie *et al.*, 1998). Also, a sizeable minority of the counsees reported not to have received what they had been expecting. Their anxiety diminished more when their expectations on receiving reassurance or advice were met (Michie *et al.*, 1997a). Yet, in order to adapt genetic counseling in case of hereditary cancer to individual needs, insight is needed in counsees' concerns prior to counseling.

Presumed type of needs and preferences prior to counseling

Various studies have explored what reasons individuals have for seeking genetic counseling for hereditary cancer, and especially individuals from families in which no DNA-test has yet been conducted. Important informational motives were to discuss own and/or family members' risk of cancer and to receive information on early detection of cancer and preventive actions (Bleiker *et al.*, 1997; Brain *et al.*, 2000; Collins *et al.*, 2000a; Hallowell *et al.*, 1997; Julian-Reynier *et al.*, 1996; van Asperen *et al.*, 2002), know the risk for one's children, or of passing on increased susceptibility to them (Bleiker *et al.*, 1997; Collins *et al.*, 2000a; Julian-Reynier *et al.*, 1996; van Asperen *et al.*, 2002), and to discuss one's family history and/or find out about genetic testing (Brain *et al.*, 2000; van Asperen *et al.*, 2002). A recent review (Bleiker *et al.*, 2003) showed that these were also main motives for requesting genetic testing for hereditary cancer. Another important motive for seeking counseling was to receive emotional support or reduce worries (Brain *et al.*, 2000; Collins *et al.*, 2000b; van Asperen *et al.*, 2002). This is in accordance with heightened levels of cancer-related anxiety that have been documented in women with family histories of cancer (Valdimarsdottir *et al.*, 1995), and in women seeking genetic counseling for cancer specifically (Audrain *et al.*,

1997; Lloyd *et al.*, 1996). Furthermore, even if a counsee is the first and only one seeking counseling within a family, genetic counseling clearly is a family affair. Not only does genetic risk concern the individual's first- and second-degree family members, but they may also play a vital role in the acquisition of information on family history of cancer. Consequently, communication with family members will often need to take place, and evidence suggests that within families, genetic risk is a difficult topic to discuss (Evers-Kiebooms *et al.*, 2000; Green *et al.*, 1997). It is therefore likely that counsees wish to discuss family issues during counseling. Finally, results suggest that counsees often are unfamiliar with the process of genetic counseling, including uncertainty about what will occur during counseling (Collins *et al.*, 2000a; Hallowell *et al.*, 1997) and the exact role of the counselor amongst other health care providers (Bernhardt *et al.*, 2000). Apart from discussing medical and emotional issues, counsees may thus also wish to receive information on the procedure of counseling.

Measuring needs and preferences prior to counseling

To our knowledge, there are no questionnaires available that measure needs and preferences in genetic counseling for hereditary cancer, through the eyes of the counsees. Although Michie and others (1997b) did assess counsees' expectations, the study was not specifically restricted to counseling for hereditary cancer, and counsees' expectations were determined by responses to a set of options based on what counselors say they aim to provide. Therefore, in the present study an instrument for measuring needs and preferences was developed that explicitly involved the input of counsees for hereditary cancer. The instrument was derived from Sixma and others (1998)'s conceptual framework for measuring patient satisfaction, by means of importance and performance (*i.e.* actual experience) scores they attach to different health care aspects. This latter instrument or QUOTE scale ('Quality of Care Through the patients' Eyes') is based on Zastowny and others (1983)'s concept of quality of care, which they define as the degree to which (perceived) performances of health and social care services meet the needs of people with respect to important aspects. The scale contains a set of items on generic as well as category-specific quality aspects of health care.

QUOTE scales have been developed for various groups of health care consumers, such as elderly people (Sixma *et al.*, 2000) and patients suffering from chronic illnesses, including cataract patients (Nijkamp *et al.*, 2002), patients with rheumatism (van Campen *et al.*, 1998) and patients with non-specific lung diseases (van Campen *et al.*, 1997). These scales were aimed at measuring perceptions of patients receiving health care during a longer period of time. In our study the health care provided, i.e. genetic counseling, is for individuals who may or may not themselves be affected with cancer. Moreover, they will see a counselor for one or at most a few consultations, depending on the available pedigree data and the possibility of genetic testing. We therefore generated a new set of items, including a set of generic items on genetic counseling and testing for late-onset diseases, and a set of disease-specific items on hereditary cancer. The instrument (referred to as the 'QUOTE-gene^{CA}') was specifically designed to investigate what issues are of (most) concern to counselees for hereditary cancer prior to their first consultation. It was also intended to assess counselees' experience during counseling with regard to these issues, that is, the extent to which the issues were addressed during counseling in counselees' perception. Data reported here will only concern importance scores. Data on counselees' actual experience during counseling will be reported elsewhere.

Aim of this study

This article describes the construction and psychometric properties of the QUOTE-gene^{CA}. We aimed (a) to describe the underlying dimensions of needs and preferences or issues of concern of counselees for hereditary cancer, prior to their first genetic counseling consultation; (b) to determine the absolute and relative importance that counselees assign to the various issues of concern; and (c) to assess the construct validity of the instrument by examining whether issues found, are supported by measures of individual characteristics assumed to be related to those specific needs and preferences, namely, a monitoring coping style, generalized anxiety relating to genetic counseling and cancer-related stress reactions. Based on previous research, we made several predictions for the present study. We expected that needs and preferences would include need for

information on risk and preventive strategies regarding oneself and/or family members, need for procedural information and need for emotional support. As a coping style, monitoring characterizes individuals' need for information under stress (Miller, 1987). An important aspect of the ability to cope with threat, including a serious illness such as cancer or the potential of having a genetic predisposition to develop cancer, is the desire for information about its various facets. It is therefore expected that a monitoring coping style is related to an increased preference for information. Generalized anxiety associated with genetic counseling and cancer-related stress reactions are expected to be related to an increased need for emotional support.

METHODS

Participants

Participants were recruited from all consecutive new counselees at the Department of Medical Genetics of the University Medical Centre Utrecht, the Netherlands, between March 2001 and August 2003. Inclusion criteria were referral for hereditary cancer, aged 18 years or older and being the first in the family to seek genetic counseling. This study is part of a prospective study on communication during genetic counseling for hereditary cancer, which included video-recordings of the consultations and a feedback training for counselors.

Procedure

Eligible counselees were sent a letter two weeks prior to their initial visit at the clinic to inform them about the study, including the video-recordings, and to ask them to participate. The counselees were all requested to return a reply slip to give notification about whether or not they agreed to participate. The counselees who agreed to participate, were sent a questionnaire a few days before their first consultation and were asked to complete it before their visit at the clinic. They were also sent an informed consent form that they were asked to sign. During the initial consultation, conducted by either one or two counselors, the counselor collected the questionnaire and the

signed informed consent form. The prospective study, including this present study, was approved by the Medical Ethical Committee of the University Medical Centre Utrecht.

Measures

A questionnaire was developed containing items assessing age, gender, referral pathway, type of cancer for which counseling was sought, and (family) history of cancer. For eligible counsees who declined participation, these background data were retrieved from a clinical database.

Measurement instrument on needs and preferences. In 2000, a pilot study was conducted in order to generate specific needs and preferences amongst counsees of genetic counseling for hereditary cancer, who recently visited the clinic. Ninety-eight counsees were approached by mail to answer the questions 'What did you like about the genetic consultation you just had?' and 'What didn't you like about the genetic consultation you just had?' Fifty counsees responded, making a total of 265 responses to the above two questions. Independent raters categorized the answers, regardless of appreciation, into four main categories: medical information, procedure of genetic counseling and testing, counselor-counsee interaction, and family issues. Based on these results and similarly to the construction of the existing QUOTE-scales, a set of generic items and a set of disease-specific items were formulated. The generic part referred to what a counsee expected a counselor should do during counseling, whereas the disease-specific part included items related to receiving explanations on hereditary cancer in particular. The items were formulated as importance statements ('During counseling, the counselor should...'), to be answered on a four-point scale from 1 = 'not important' to 4 = 'extremely important'.

Coping style. Monitoring was measured using the shortened version of the threatening medical situation inventory (TMSI) (Miller, 1987; Ong *et al.*, 1999; van Zuuren and Hanewald, 1994). It includes two descriptions of threatening medical situations: vague, suspicious headache and choosing uncertain heart surgery. Each situation is followed by items that measure either 'monitoring' (6 items) or 'blunting' (5 items) and are arranged in

random order. Items are to be answered on a five-point scale from 1 = 'not at all applicable to me' to 5 = 'strongly applicable to me'. Prior research has reported the blunting scale to have poorer psychometric properties compared to the monitoring scale (Ong *et al.*, 1999). Consistent with our hypotheses as well as prior research using a self-report measure of coping style with women at high risk of cancer (Audrain *et al.*, 1997; Schwartz *et al.*, 1995), we only used the monitoring score (Cronbach's $\alpha = 0.72$). Total monitoring scores were calculated by adding up the scores on the relevant items (range of the scale 6–30).

Generalized anxiety. Current levels of generalized anxiety were measured with the shortened version of the Dutch version of the State-Trait Anxiety Inventory (STAI) (Spielberger, 1983; van der Ploeg *et al.*, 1980). The STAI is a well validated questionnaire asking respondents to state how they currently feel regarding 10 statements that are worded either positively (e.g. 'I feel calm') or negatively (e.g. 'I feel strained'). Responses to the statements range from 1 = 'not at all' to 4 = 'very much so' and total scores range from 10 to 40. Cronbach's alpha for the scale was 0.93.

Cancer-related stress reactions. Cancer-related stress reactions were measured with the Dutch version of the impact of events scale (IES) (Brom and Kleber, 1985; Horowitz *et al.*, 1979). This questionnaire assesses how the individual feels in the context of experiences with a specific event, in this study 'seeking genetic counseling for hereditary cancer'. It consists of an intrusion subscale (7 items) and an avoidance subscale (8 items) assessing intrusive and avoidant thinking, respectively. Participants rated the frequency of intrusive and avoidant cognitions using a four-point scale (0 = 'not at all', 1 = 'rarely', 3 = 'sometimes', 5 = 'often'). Cronbach's alpha for the intrusion and the avoidance subscales was 0.82 and 0.72, respectively. Total intrusion and avoidance scores were calculated as the total scores on the relevant items (range of the scales 0–35 and 0–40, respectively).

Statistical analyses

Participants and decliners were compared using a *t*-test and the Pearson's Chi-square test. In order

to determine the dimensionality of the generic items and the cancer-specific items, Principal component analysis (PCA) with varimax rotation was performed on the importance scores rather than on the performance scores. Importance scores, obtained before the consultation, are assumed to be less subject to situational changes than performance scores, as importance scores are linked to individuals' attitudes and opinions (Nijkamp *et al.*, 2002). The appropriateness of the factor analytic model was tested using the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy and Bartlett's test of sphericity. Items failing to load at least 0.40 on any factor were left out. The number of components for either list was determined on the basis of the scree plots and by selecting interpretable factors with as high a variance explanation as possible. The stability of the final result was checked by dividing the material in a random 50/50 split and rerunning the PCA. The internal consistency of the various dimensions was further assessed by calculating Cronbach's alpha for the subscales. Importance scores on the various dimensions were calculated for each dimension as the mean of the scores on the relevant items (range of the subscales 1–4). Regression analyses (method ENTER) were used to test whether the importance scores could be predicted from socio-demographic characteristics, referral pathway to counseling, and personal and family history of cancer. The analyses were performed in two steps. First, all predictors were included. Second, the analysis was reran with only the significantly ($p < 0.05$) related predictors. Correlations (Pearson's r) were calculated to assess the relationship between the dimensions and the validating measures. If 25% or less of the values was missing on the subscales of the various dimensions and the validating measures, the missing values were replaced by the mean on the (sub-) scale. Analyses were carried out using SPSS 11.5. Significance was tested two-tailed on $\alpha = 0.05$ level.

RESULTS

Participants

Of all eligible counselees, 204 (33%) agreed to participate and data were available for 200 of them (98%). Of these 200 participants, 182 (91%) were

female counselees and 18 (9%) were male. Mean age at the start of counseling was 45.1 years, (S.D. = 10.0, range 18–72). One hundred and fifteen (58%) counselees had completed education up to high school level and 84 (42%) had completed higher vocational or university education (1 missing value). One hundred and twenty-seven (63%) were counseled for suspected hereditary breast cancer, 41 (20%) for colon cancer, 11 for either both breast and colon cancer (6%), 10 for ovarian cancer (5%), and 11 for other types of cancer (6%). The counselees found their way to counseling through referral by their general practitioner in 55 (29%) of the cases, 105 (55%) were referred by their specialist, 11 (6%) by family members, and for 21 (11%), it was their own initiative (8 missing values). One hundred and twelve participants (56%) were healthy people with a family history of cancer, whereas 87 (44%) were affected themselves (1 missing value). Of affected counselees, 22 (25%) were the only ones in their family diagnosed with cancer at the time of counseling. The counselees with a family history of cancer had an average of 1.6 first-degree relatives (range 1–5, Mode = 1), and 2.3 second-degree relatives (range 1–8, Mode = 1) with cancer. A comparison between decliners and participants showed that participants were on the average 2.1 years older than decliners ($t = 2.29$; $p = 0.022$). There were no significant differences in gender, referral pathway, type of cancer or family history of cancer.

Generated items on generic and cancer-specific aspects of genetic counseling

A set of 25 generic items on genetic counseling for late-onset diseases and a set of 19 cancer-specific items were formulated, which are listed in Tables 1 and 2. With regard to generic aspects of counseling, the counselees considered it (very) important that counselors be skilled and considerate towards them, by taking them seriously, listening carefully, and by providing clear explanations (see Table 1). Moreover, the counselees considered it (very) important to receive medical and risk information, including a DNA-test, as well as information on the procedure of genetic counseling. In addition, the majority of the counselees considered receiving advice as important, as well as taking part in the decisions to be made.

Table 1. List of generic items on needs and preferences and number (%) of counselees' perceived importance responses to each item^a (N = 200)

During counseling, the counselor should ...	(Fairly) Important		(Very) Important	
	N	%	N	%
Take me seriously	0	0.0	198	100.0
Provide me with clear and understandable explanations	0	0.0	198	100.0
Be skilled	1	0.5	197	99.5
Involve me in the decisions that are made	1	0.5	196	99.5
Tell me what my risk is or the risk for my family	2	1.0	196	99.0
Explain the procedure of genetic counseling	3	1.5	192	98.5
Listen carefully	3	1.5	195	98.5
Give me enough time and attention	3	1.5	195	98.5
Give medical information	5	2.5	193	97.5
Give me the opportunity to ask questions	5	2.5	193	97.5
Inform me sufficiently about what to expect	6	3.0	192	97.0
Give advice	9	4.6	188	95.4
Co-operate well with e.g. my GP or specialist	18	9.1	180	90.9
Be open to my wishes, values and my opinion	18	9.1	180	90.9
Be punctual with appointments	21	10.6	177	89.4
Give the opportunity to ask questions at any time	24	12.2	173	87.8
Carry out a DNA-test on me or a family member	24	12.3	172	87.7
Explain the division of roles between the counselors present	30	15.1	168	84.9
Provide me (also) with written information	31	15.6	167	84.4
Analyze the family history	42	21.7	151	78.3
Talk about the emotional aspects of the diagnostic procedure	55	27.8	143	72.2
Show understanding and sympathy	56	28.3	142	71.7
Tell me how much time the diagnostic procedure takes	67	33.9	131	66.1
Discuss communication with family members	77	39.3	119	60.7
Reassure me	80	40.8	116	59.2

^aSample sizes vary due to missing data.

With regard to cancer-specific aspects, over 90% of the counselees considered it (very) important to discuss whether they or their family members were at increased risk, and if so, what to do about it (see Table 2). Also, over 90% of the counselees considered it (very) important to receive explanations on the meaning of genetic susceptibility and when it is or is not further examined.

Underlying dimensions of needs and preferences or issues of concern

Principal component analysis (PCA) was conducted on the perceived importance scores on the set of generic items. The appropriateness of conducting PCA was assessed by KMO (0.88) and Bartlett ($\chi^2 = 2172.6$; $p = 0.000$) and demonstrated the legitimacy of the procedure. Based on

the criteria as described, a four-component solution that explained 56.7% of the variance was deemed most fit and this solution was chosen (see Table 3). All items loaded more than 0.40 on one or more components. One item, namely 'receive clear and understandable explanations', was left out as it was ambiguous, loading equally high on two dimensions. The items clustered together into four distinguishable components that appeared to represent 'procedural aspects of counseling', 'sensitive communication', 'emotional support', and 'assessment of susceptibility to the disease', respectively. The Cronbach's alpha estimate of internal consistencies for the four generic subscales were 0.86, 0.84, 0.80 and 0.67, respectively.

Similarly, PCA was used to examine the set of cancer-specific items. Again, KMO (0.76) and Bartlett ($\chi^2 = 1536.7$; $p = 0.000$) demonstrated the legitimacy of the procedure. One item ('how

Table 2. List of cancer-specific items on needs and preferences and number (%) of counselees' perceived importance responses to each item^a (N=200)

During counseling, the counselor should explain...	(Fairly)		(Very)	
	Important		Important	
	N	%	N	%
My family member's risk of developing cancer	6	3.0	191	97.0
Why I am / am not considered for further examination	8	4.1	187	95.9
What it means to be a carrier of a cancer gene	10	5.0	188	95.0
Whether the cancer in my family is hereditary	10	5.1	185	94.9
Possibilities of DNA-testing	11	5.5	188	94.5
My risk of developing cancer	12	6.2	183	93.8
What to do if I have an increased risk of cancer	13	6.8	179	93.2
What it means to be a carrier of a certain gene	14	7.0	184	93.0
Limitations of DNA-testing	22	11.2	173	88.8
How risks for myself and my family are computed	22	11.3	174	88.7
The procedure of DNA-testing	28	14.3	167	85.7
How cancer inherits in a family	32	16.1	166	83.9
The procedure of the study of the family history	38	19.7	155	80.3
Emotional consequences for my family as a result of genetic counseling	47	24.2	148	75.8
What it means not to be a carrier of a cancer gene	54	27.3	144	72.7
What to do if I do not have an increased risk of cancer	55	28.9	135	71.1
Emotional consequences for me as a result of genetic counseling	59	30.3	136	69.7
How often the type of cancer occurring in my family is hereditary	70	35.5	127	64.5
The prevalence in the Netherlands of the type of cancer occurring in my family	147	74.3	51	25.7

^aSample sizes vary due to missing data.

risks for myself and my family are computed') loaded less than 0.40 on any component and was left out of the analysis. The four-component solution, explaining 59.3% of the variance, was judged to be best interpretable and this solution was chosen (see Table 4). The components could be interpreted as 'determination and meaning of being a carrier of a cancer gene' ($\alpha = 0.82$), 'emotional aspects for counselee and family' ($\alpha = 0.74$), 'own risk of developing cancer' ($\alpha = 0.79$), and 'heredity of cancer in general' ($\alpha = 0.76$), respectively.

Importance assigned to the various issues of concern

The mean assessments of perceived importance on all dimensions representing various issues of concern lay on the right-hand side of the scale (see Table 5). Prior to counseling, the generic issue that was considered most important was related to the interaction with the counselor, namely 'sensitive communication'. The cancer-specific issue considered as most important was related to explanations

about the determination of being a carrier of a cancer gene and what this entails. Generic and specific issues considered to be least important were related to emotional aspects of counseling and heredity of cancer in general, as was also suggested by the counselees' responses to the individual items.

Regression analyses showed that mean importance that was attached to the issues of concern prior to counseling did not depend on background variables, except for the need for emotional support and desire for explanations on one's own risk of cancer. Specifically, the counselees attached greater importance to receiving emotional support if they were female ($\beta = -0.232$; $p = 0.001$), lower educated ($\beta = -0.241$; $p = 0.000$), and if they had more first-degree affected relatives ($\beta = 0.183$; $p = 0.007$). Also, they considered receiving explanations on their own risk of cancer as more important if they were not themselves diagnosed with cancer ($\beta = 0.257$; $p = 0.000$). Mean importance that counselees attached to the other generic and cancer-specific issues were unrelated to their gender, age, educational level, referral pathway to

Table 3. Varimax rotated component matrix with a four-factor solution on the generic items prior to counseling, capturing 56.7% of the variance, and variance explained by each factor^a (*N* = 200)

Items	Factor			
	1	2	3	4
<i>Procedural aspects of counseling</i>				
Sufficient information about what to expect	0.77			
Information on the procedure of genetic counseling	0.76			
Punctuality with appointments	0.70			
Division of roles between counselors	0.67			
Opportunity to ask questions at any time	0.65			
Information on how long the diagnostic procedure takes	0.63			
Receive medical information	0.53	0.46		
Good co-operation with GP or specialist	0.50			
<i>Sensitive communication</i>				
Counselee is taken seriously		0.81		
Skill counselor		0.78		
Counselor listens carefully		0.72		
Counselor gives enough time and attention		0.57	0.40	
Counselee involved in decisions		0.56		
Counselor open to counselee's wishes, values and opinion		0.47		
Opportunity to ask questions (during the consultation)		0.47		
Receive advice		0.45		
<i>Emotional support</i>				
Counselor shows understanding and sympathy			0.81	
Receive reassurance			0.79	
Emotional aspects of the diagnostic procedure			0.72	
Communication with family members			0.66	0.44
(Also) written information provided			0.42	
<i>Assessment of susceptibility to disease</i>				
DNA-test done on counselee or on a family member				0.80
Analysis of the family history				0.79
Risk of counselee or of family members		0.43		0.60
Percentage of explained variance	17.5	16.0	13.9	9.3

^aLoadings below 0.40 are not shown.

counseling, whether or not they were affected with cancer, or the number of affected first- or second-degree relatives.

Construct validity assessment of the issues of concern

As shown in Table 6, a higher score on monitoring as coping style correlated significantly with a higher perceived importance score on all eight issues of concern, except for the two generic issues *emotional support* and *assessment of susceptibility to the disease*. Heightened levels of general-

ized anxiety and a higher score on cancer-related stress reactions, through experiencing intrusive thoughts and avoiding thinking about cancer, were significantly related to considering emotional support and discussing emotional aspects for oneself or family as more important. Higher levels of generalized anxiety and cancer-related stress reactions were also significantly related to a higher importance score on procedural aspects of counseling. Higher levels of cancer-related stress reactions were significantly related to considering receiving explanations on the determination and meaning of carrying a cancer gene as more important, and experiencing more intrusive

Table 4. Varimax rotated factor matrix with a four-factor solution on cancer-specific items prior to counseling, capturing 59.3% of the variance, and variance explained by each factor^a (*N* = 200)

Items	Factor			
	1	2	3	4
<i>Determination and meaning of being a carrier of a cancer gene</i>				
Possibilities of DNA-testing	0.86			
The procedure of DNA-testing	0.78			
Limitations of DNA-testing	0.77			
What it means to be a carrier of a cancer gene	0.56			
Why the counselee is (not) considered for further examination	0.56			
What it means to be a carrier of a certain gene	0.48	0.41		
Whether the occurrence of cancer in the family is hereditary	0.41			
<i>Emotional aspects for counselee and family</i>				
Emotional consequences for the family as a result of genetic counseling		0.89		
Emotional consequences for the counselee as a result of genetic counseling		0.75		
Family member's risk of developing cancer		0.64		
The procedure of the analysis of the family history		0.46		
What it means not to be a carrier of a cancer gene		0.44		
<i>Own risk of developing cancer</i>				
What to do if the counselee has an increased risk of developing cancer			0.91	
Counselee's risk of developing cancer			0.82	
What to do if the counselee does not have an increased risk of developing cancer			0.70	
<i>Heredity of cancer in general</i>				
The prevalence in the Netherlands of the type of cancer occurring in the family				0.85
How often the type of cancer occurring in the family is hereditary				0.83
How cancer inherits in a family				0.67
Percentage of explained variance	19.6	14.8	13.3	11.6

^a Loadings below 0.40 are not shown.

Table 5. The counselees' mean assessment (and standard deviation) of the importance of the various generic and cancer-specific issues of concern prior to the initial consultation, and number of respondents

Issue of concern	<i>Mean importance</i>		
	(scale 1-4)	S.D.	<i>N</i>
<i>Generic issues of concern</i>			
Procedural aspects of counseling	3.19	0.43	197
Sensitive communication	3.46	0.36	197
Receive emotional support	2.79	0.61	197
Assessment of susceptibility to disease	3.26	0.54	192
<i>Cancer-specific issues of concern</i>			
Determination and meaning of being a carrier of a cancer gene	3.35	0.45	195
Emotional aspects for counselee and family	3.08	0.53	196
Own risk of developing cancer	3.30	0.66	190
Heredity of cancer in general	2.62	0.66	197

thinking was significantly related to perceiving the assessment of the susceptibility to the disease as more important. The measures generalized anxiety

and cancer-related stress reactions were not significantly related to importance scores on the interaction with the counselor, or receiving

Table 6. Correlations between monitoring, state anxiety, and intrusive and avoidant thinking about seeking genetic counseling for hereditary cancer, and the perceived importance of generic and cancer-specific issues of concern ($N = 200$)

Validating measures	<i>Generic issues</i>			
	Procedural aspects of counseling	Sensitive communication	Emotional support	Assessment of susceptibility to disease
Monitoring	**0.22	**0.26	0.13	0.12
State anxiety	*0.16	0.09	**0.22	0.11
Intrusive thinking	*0.14	0.14	**0.23	0.14
Avoidant thinking	*0.15	0.11	*0.18	0.07
	<i>Cancer-specific issues</i>			
	Determination and meaning of carrying a cancer gene	Emotional aspects for counselee and family	Own risk of developing cancer	Heredity of cancer in general
Monitoring	**0.22	*0.17	*0.17	*0.15
State anxiety	0.14	**0.28	0.04	0.03
Intrusive thinking	**0.23	**0.25	-0.03	0.10
Avoidant thinking	*0.14	**0.19	-0.01	0.09

* $p < 0.05$; ** $p < 0.01$.

explanations about own risk of cancer or heredity of cancer in general.

DISCUSSION

In this study we developed an instrument (the QUOTE-gene^{ca}) for measuring needs and preferences prior to genetic counseling for hereditary cancer, involving explicitly the counselee's perspective. The instrument captures relevant issues of concern of counselees prior to their initial genetic counseling visit. Increasing insight into individual needs may help counselors in better addressing these during counseling, potentially increasing the likelihood of successful counseling (Hallowell *et al.*, 1998). The items contained in the instrument appear relevant to the counselees and responses showed that major concerns prior to counseling relate to receiving information, about risk and preventive strategies for oneself and/or family members and about the procedure of genetic counseling, and relate to preferences on how the interaction with the counselor proceeds. Receiving emotional support and discussing emotional aspects are considered relatively less important beforehand. Issues of concern were found to be associated as expected with validated measures of coping style and distress.

From the response rate and the answers to the individual items contained in the QUOTE-gene^{ca},

it can be concluded that the counselees considered the various items to be relevant. It should be noted that a large majority (87.8%) of the counselees considered DNA-testing in itself as (very) important, prior to their initial visit. DNA-testing as a predictive tool is limited however, because only a restricted number of genes are known to date (Fearnhead *et al.*, 2002; Wooster and Weber, 2003). Moreover, the initial search for a mutation within a family is only carried out in a family member who is or has been affected by cancer (Meiser *et al.*, 2000). As a result, a number of counselees who in principle have an indication for testing due to a family history of cancer, and in whose families a mutation has not yet been determined, will be faced with the impossibility to undergo a DNA-test. Others, including also affected counselees, will receive an inconclusive DNA-test result in case no mutation is found, or alternatively, a mutation is detected that is not (yet) known to be related to increased susceptibility to cancer. In both cases, counselees are faced with the impossibility to demonstrate (non-) heredity through DNA-testing.

Four generic components and four cancer-specific components, each with high internal consistency, were found that could meaningfully describe counselees' needs and preferences. One item from the generic list, namely receiving clear and understandable explanations, appeared to be ambiguous as it loaded evenly on the dimensions

'procedural aspects of counseling' and 'sensitive communication'. Presumably, the counsees responded either to receiving *explanations* and to receive *clear* explanations. One item from the cancer-specific list, namely, how risks for the counselee and his or her family members are computed, was considered as (very) important by a majority (88.8%) of the counsees, however failed to load on any component. This was perhaps due to the fact that the item did not relate to heredity of susceptibility to cancer specifically, but more generally to one's risk of cancer. It may be advisable to exclude these two items in further use of the instrument.

In line with matters deemed as important based on prior studies and apart from the importance attached to each specifically, generic and cancer-specific issues of concern prior to counseling included receiving information on risk and preventive strategies for oneself and/or family members as well as on the procedure of genetic counseling. Moreover, in accordance with Engel (1988)'s formulation of patients' basic needs to 'know and understand' and to 'feel known and understood' (p. 124), translated to medical practice by Bensing and others (1996), counsees were also found to be concerned about how the interaction with the counselor proceeds. Specifically, the counselor should take the counselee seriously, have adequate expertise, give the counselee enough opportunity to make clear where he or she stands, and involve him or her in decisions to be made. Furthermore, the results showed the counsees' concern with receiving emotional support and discussing emotional aspects of counseling. It can be noted that concern about emotional aspects related both to counsees themselves, in terms of receiving support and reassurance, and to their family, as it included items on communication with family members, a family member's risk of developing cancer and the procedure of the analysis of the family history. Apparently, communication with family members, and communication about another's risk of cancer in particular, is indeed expected to be or is experienced as being emotionally laden. Although empirical evidence on counsees' experience with informing family is mixed (Dudok de Wit *et al.*, 1997; Peterson *et al.*, 2003), individuals who are the first in their families to seek genetic counseling, as in this study, may (expect to) experience their informational role as a burden and need additional support in this task. The association between

proceeding with the analysis of the family history and emotional aspects may be due to its (perceived) relation to communication, as information should be gathered on family members' history of cancer. In addition, the provision of written information was associated with emotional aspects. This finding seems in accordance with studies reporting that receiving written information reduces patients' anxiety (Weinman, 1990) and is experienced as reassuring (Austoker and Ong, 1994). It might also be that counsees who anticipate counseling to be an emotional experience, expect written information to assist them in spreading their newly acquired knowledge within their families and/or to assist their own comprehension, as was suggested by a study among female counsees for hereditary cancer (Hallowell and Murton, 1998). Moreover, emotional aspects included the meaning of not carrying a cancer gene. Prior to counseling, individuals may anticipate to experience the discovery that they are not at heightened risk of cancer as emotionally laden. Such an expectation is not supported by empirical evidence. Receiving a negative test result, that is, finding out one does not carry a mutation associated with heightened risk of cancer, has not been shown to result in increased levels of distress, such as feelings of guilt (Bleiker *et al.*, 2003). However, especially counsees as in this study, who are the first in their families to seek counseling, may hold this expectation, since a negative test outcome may question the perceived validity or necessity of seeking counseling and confronting family members with a difficult topic.

With regard to the importance attached to the various issues prior to the initial visit, it appeared that the counsees considered them all as important, replicating counsees' motives for seeking counseling found in earlier studies. Concerns however, were not equally weighted. The mean importance that was assigned to the various issues of concern reflected the relative lesser weight that counsees attached to emotional aspects of counseling, as well as to information on inheritance that is not specifically related to themselves or their families. The findings further suggest that apart from wanting information on risk of cancer, what it entails to be at increased risk, and what they can expect from genetic counseling, counsees consider the process, or how they will be involved and treated by the counselor, as a key aspect of this type of health care. This preference is

in agreement with Kessler (1997)'s argument that promoting counsees' autonomy requires from counselors an active and appropriate involvement with them. These findings though, average over all the participating counsees. Relating perceived importance to individual characteristics of counsees, showed that female, lower educated counsees who have more first-degree affected relatives, attached greater importance to receiving emotional support. Also, healthy counsees desired more strongly to discuss their own risk of cancer. This result is concordant with Fraser and others (2003)'s finding that healthy individuals seeking cancer genetic counseling were more concerned about reducing their personal risk than their affected counterparts. Possibly, counsees who have (had) cancer incorrectly assume that, having already been affected, risk of cancer is not applicable to them anymore, thereby underestimating recurrence risk.

Corroborative measures were found to be related to the perceived importance of issues of concern. In particular, as expected a coping monitoring style was found to be positively related to perceiving the reception of information as important, including receiving information on procedural aspects of counseling and explanations on cancer-specific issues, namely, the determination of susceptibility to cancer and the implications of carrying a cancer gene, what to expect as emotional consequences for oneself and family, and information on heredity of cancer in general. Those who were more inclined to engage in a monitoring coping style also tended to consider how the interaction with the counselor proceeds, counselor's sensitive communication, as more important. These results are in line with earlier research in 118 patients visiting a primary care setting for acute medical problems (Miller *et al.*, 1988). Among these patients, high monitors were more concerned about being treated with kindness and respect. The sensitive communication dimension also included an item on desire for involvement in decisions. Miller and others (1988)'s study showed that high monitors generally desired to play a less active role in decisions about their medical care than did low monitors. In contrast, Ong and others (1999) reported that in their sample of cancer patients, a monitoring coping style was positively related with a preference for participation in medical decisions, i.e. an increased preference for assuming responsibility for decision-making. Our results appear more in line with

Miller and others' findings. Specifically, a preference for being involved in decisions and considering it important to be listened to carefully, does not imply a desire for taking over control over the process of counseling. As Miller (1995) argued, high monitors may be more inclined 'to yield control over to another, more competent individual' (p. 171). Similarly, Beisecker and Beisecker (1990) suggested, based on their study in 106 rehabilitation medicine patients on their information-seeking behaviors in communicating with doctors, that wanting to be more knowledgeable about one's medical care, does not in effect mean desiring to become more responsible for medical care decisions. Furthermore, a monitoring coping style and preference for receiving emotional support were positively related, however not significantly. This result appears contradictory with findings showing that monitoring and psychological distress were positively correlated before counseling (Audrain *et al.*, 1997; Nordin *et al.*, 2002). However, a desire for additional information in individuals who feel more anxious does not necessarily imply a stronger desire for emotional support, as they may specifically expect that receiving more information will relieve their anxiety. Moreover, monitoring was not significantly related to perceiving the assessment of increased susceptibility to cancer as important. This issue clearly connects to receiving information on risk, however its focus is more on the counselor's behavior. Nonetheless, it is opposite to Miller and others (1988)'s finding that higher monitoring levels were positively associated with a desire for tests to be performed.

As expected, levels of generalized anxiety and of cancer-related stress reactions were positively related to perceiving emotional aspects of counseling as important. Apparently, counsees as a rule consider factual information as important prior to counseling and more so than emotional aspects. However, the more threatened they feel, the more important emotional support becomes to them. Heightened levels of generalized anxiety and of cancer-related stress reactions were also associated with considering procedural aspects of counseling as important. Moreover, increased cancer-related stress reactions were associated with considering it important to receive explanations on finding a cancer gene and the implications. Possibly, counsees with heightened levels of anxiety and of cancer-related stress specifically, foresee to find something to hold on to in knowing what to expect

regarding the procedure of counseling as well as in understanding how increased susceptibility to the disease is determined.

This study has a number of limitations. As the proportion of participating counsees (33%) compared to those eligible was low, it is questionable how representative our sample is for the larger population. A comparably low participation rate (34%) was found in Fraser and others (2003)'s study on motives for seeking advice about family history of cancer. Low participation may be partly explained by the extra step or effort that was required from potential participants, as they were asked to send back a reply slip. Helmes and others (2000)'s study on predictors of participation in genetic research supports this suggestion. Their results showed that interest in participation in a study on genetic counseling decreased as study requirements increased. In a similar vein, low participation may have been due to the fact that participants were asked to consent with their counseling visit(s) to be videotaped. Howe (1997) investigated patient factors related to refusal to have one's consultation videotaped in a convenience sample of 1393 GP patients. Results suggest that refusal may be associated with complex contextual and socio-demographic factors. Interestingly, one of the main factors associated with refusal was decreasing age. In our study, participants indeed were older than decliners. In addition, the fact that eligible counsees probably often were unfamiliar with the process and content of counseling, that details about family members would be discussed, and that the visit had in potential an emotionally laden character, may have contributed to a majority of them declining participation. Apart from age, participants and decliners did not differ on other background measures, including being affected or not by cancer themselves. Differences between the two groups underline the need for administering the instrument in other samples of counsees for hereditary cancer, before results can be generalized. In addition, participants were mainly (91%) female, which may partly be explained by the fact that a majority of the counsees were seeking counseling for hereditary breast cancer as was found in other studies (e.g. Fraser *et al.*, 2003). The unbalanced gender distribution indicates that caution is called for in extrapolating the findings to genetic counseling for late-onset diseases that men and women seek more equally. Indeed, further research is required to find out whether the instrument can

meaningfully be adapted to counsees for other types of late-onset hereditary diseases.

Results of this study on the importance assigned to the various issues prior to genetic counseling for hereditary cancer, suggest which matters counselors may need to address during counseling. Specifically, besides receiving risk information for themselves and their families, counsees considered being able to clarify their situation and being involved in decision-making, as important aspects of counseling. Also, it appears that adequate emotional support should be provided to counsees who feel more anxious about cancer. In addition, counsees felt unfamiliar with genetic services and perceived a need to receive procedural information on counseling. The importance that was attached to receiving a DNA-test prior to the initial visit illustrates counsees' lack of understanding of what genetic counseling actually involves. Education targeted at the general public may need to focus more on the limitations of genetic testing. During counseling, counsees' unrealistic expectations should preferably be identified at the start and brought back to realistic proportions.

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