
Original Research

Cancer Genetic Counseling: Communication and Counselees' Post-Visit Satisfaction, Cognitions, Anxiety, and Needs Fulfillment

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Little is known about the relation between communication during cancer genetic counseling and outcome. We assessed associations between counselor-counselee communication and counselee satisfaction, cognitions, anxiety, and fulfillment of major needs, corrected for pre-visit levels as appropriate. In total 171 consecutive new counselees, mainly referred for breast or colon cancer, received pre- and post-visit questionnaires assessing needs/fulfillment, knowledge, perceived control (PPC), anxiety (STAI), and satisfaction. Initial visits were videotaped and counselor eye gaze was recorded. Verbal communication was rated by Roter Interaction Analysis System (RIAS). Asking more medical questions was associated with lower satisfaction levels. Receiving more medical information was related to higher correct knowledge scores, higher reported fulfillment of some needs, and unrelated to perceptions of control. Receiving more psychosocial information and longer counselor eye gaze were related to higher anxiety scores. Longer visits were related to higher correct knowledge scores. Providing medical information appears the most powerful communication aspect to increase counselee satisfaction and address needs. More research is needed on how to address adequately (emotional) needs and increase feelings of control.

KEY WORDS: communication; cancer genetic counseling; needs; outcome.

INTRODUCTION

A primary goal of cancer genetic counseling is to educate individuals about cancer (recurrence) risk, cancer prevention, and early detection (ASCO, 1996; Biesecker, 2001; Richards, 1999). Initial visits are

largely concerned with the exchange of medical information regarding personal and family history of cancer, hereditary cancer, personal and family cancer risk, DNA-testing, and risk management options (Butow & Lobb, 2004). An important motive for counselees to seek counseling is indeed to receive medical information (Collins *et al.*, 2000; Pieterse *et al.*, 2005a; Van Asperen *et al.*, 2002) and receive emotional support or reduce worries (Collins *et al.*, 2000; Pieterse *et al.*, 2005a; Holloway *et al.*, 2004; Van Asperen *et al.*, 2002). Addressing pre-visit needs well was found associated with higher perceptions of control and lower feelings of anxiety after the first visit (Pieterse *et al.*, 2005b).

Central to the process of counseling is counselor-counselee communication, and insight

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in communication–outcome associations may help achieve improved counselee outcomes. A number of studies have assessed actual communication during genetic counseling (Aalfs *et al.*, 2006; Armstrong *et al.*, 1998; Benkendorf *et al.*, 2001; Kessler & Jacopini, 1982; Michie *et al.*, 2005; Pilnick, 2002; Smith *et al.*, 2000; Van Zuuren *et al.*, 1997; Van Zuuren, 1997) and in *cancer* genetic counseling in particular (Butow & Lobb, 2004; Ellington *et al.*, 2005; Pieterse *et al.*, 2005c; Richards *et al.*, 1995). Notwithstanding calls for process–outcome research (Biesecker & Peters, 2001; Pilnick & Dingwall, 2001; Wang *et al.*, 2004), including how communication fulfills counselees' expectations (Meiser & Halliday, 2002), only few included outcome measures (Duric *et al.*, 2003; Lobb *et al.*, 2004, 2005; Michie *et al.*, 1997a). In breast cancer counseling, discussing more aspects of genetic testing was shown to be associated with decreased post-visit anxiety in female clients (Lobb *et al.*, 2004). Anxiety was higher when counselors used more supportive communication. Inquiring about women's agenda did not improve outcomes. Results from this sample showed that counselors differ in their facilitating behaviors and discussion of prophylactic mastectomy (Lobb *et al.*, 2005). Differences in counselor behavior affected counselees' decrease in depression. Additionally, counselors' empathy in dyadic interactions was related to lower post-visit depression yet unrelated to counselees' satisfaction and post-visit anxiety (Duric *et al.*, 2003).

Evidence from studies on doctor–patient communication in other medical fields and oncology in particular, suggests patient satisfaction to be related to doctor information-giving and patient question-asking, and doctor and patient affective behavior (Ong *et al.*, 2000). Clear factual information appears beneficial to patients' perceptions of control (Rutter *et al.*, 1996). Others did not find a relationship between doctors' affective behavior and patient satisfaction, recall or psychological adjustment, nor between ratio doctor to patient talk and length of consultation and satisfaction (Butow *et al.*, 1995). In contrast, results in primary care patients suggest that seeing a more dominant doctor lowers satisfaction (Bertakis *et al.*, 1991); and that longer visits (Hall *et al.*, 1988; Mead *et al.*, 2002), doctor eye gaze (Bensing, 1991; reviewed by Hall *et al.*, 1988), and discussion of psychosocial topics (Roter *et al.*, 1997) increase satisfaction. Additionally, information-giving and eye gaze increased patient recall/understanding (Hall *et al.*, 1988).

This study investigated the influence of communication during initial cancer genetic counseling visits on counselee outcomes. We assessed (1) in how far counselor and counselee communication is related to counselees' satisfaction and post-visit knowledge, perceived control, and anxiety; and (2) in how far counselor communication is related to counselees' perception of their major pre-visit needs being met. We expected positive associations between counselee–counselors talk on counselee agenda and medical and psychosocial issues, their respective expressions of concern and empathy, and counselor eye gaze, with favorable post-visit outcomes. It was further expected that counselor communication devoted to medical information, signs of empathy, and attention to psychosocial issues, would result in counselees' informational and emotional needs being better fulfilled. Hypothesized associations are summarized in the first two columns of Tables I and II.

METHODS

Participants

Counselees were recruited from consecutive new counselees aged 18 years or older and being the first in their family to seek cancer genetic counseling, at the Department of Medical Genetics of the University Medical Center Utrecht, the Netherlands, between March 2001 and August 2003.

Counselors included all clinical geneticists, residents in clinical genetics (two of whom were finishing training), and genetic nurses (four finishing training) providing cancer genetic counseling at the clinic during the study period.

Procedure

The current study was approved by the Medical Ethical Committee of the university hospital. The procedure of approaching eligible counselees is described elsewhere (Pieterse *et al.*, 2005a). Respondents were asked to complete an informed consent form and a pre-visit questionnaire assessing socio-demographics, type of cancer for which referred, and family history of cancer in the week before their first consultation. The consultation was videotaped. Recordings showed counselors' full face and counselees from behind or from the side. A clinical geneticist was also present if a counselor was in training. At the end of the consultation, the counselor

Table I. Results^a on Hypothesized Positive Associations Between Counselor and Counselee (CE) Communication and Outcome Measures

Outcome measure	Communication measures	N	Beta ^b	SE	95% CI	P-value	
Satisfaction	Counselor	164					
	Empathy		-0.01	0.09	-0.18-0.16	—	
	Medical information		0.21	0.10	0.02-0.40	0.032	
	Psychosocial information		0.02	0.10	-0.18-0.21	—	
	Verbal dominance		-0.02	0.08	-0.13-0.17	—	
	Eye gaze	0.08	0.08	-0.07-0.23	—		
	Counselee						
	Concern	-0.08	0.08	-0.24-0.08	—		
	Medical questions	-0.31	0.08	-0.47-0.14	0.000*		
	Counselor and counselee						
Discuss CE agenda	-0.14	0.09	-0.31-0.03	—			
Discuss CE Psychosocial issues	0.19	0.10	-0.01-0.39	—			
Visit length	0.05	0.08	-0.10-0.20	—			
Correct knowledge ^c	Counselor	153					
	Medical information		0.22	0.08	0.07-0.37	0.004*	
	Eye gaze		0.17	0.07	0.03-0.31	0.018*	
	Counselee						
	Medical questions		0.06	0.08	-0.09-0.21	—	
Counselor and counselee							
Visit length	0.18	0.07	0.04-0.32	0.011*			
Perceived control ^c (PPC)	Counselor	156					
	Medical information		0.13	0.07	-0.01-0.28	—	
Anxiety ^c (STAI)	Counselor	160					
	Empathy		-0.08	0.06	-0.20-0.04	—	
	Medical information		-0.05	0.07	-0.18-0.08	—	
	Psychosocial information		0.20	0.07	0.06-0.33	0.005*	
	Verbal dominance		0.12	0.05	0.01-0.22	0.033	
	Eye gaze	0.17	0.05	0.06-0.28	0.002*		
	Counselee						
	Concern	0.14	0.06	0.02-0.26	0.025		
	Counselor and counselee						
	Discuss CE Agenda	-0.06	0.07	-0.19-0.07	—		
Discuss CE psychosocial issues	0.09	0.07	-0.06-0.24	—			
Visit length	0.13	0.06	0.02-0.24	0.018			

Note. CI = Confidence Interval.

— = P > 0.059.

*Significant after Bonferroni-Holmes correction, overall $\alpha = 0.05$.

^aAll analyses were controlled for counselor and counselee background variables.

^bSignificance of predictors was tested using chi-square tests.

^cAnalysis was controlled for pre-visit level.

handed out the post-visit questionnaire along with a pre-stamped envelope and asked the counselee to complete it within a day and post it to the research institute.

Measures

Information on counsees’ disease status and indication for DNA-testing was collected from their medical file. At the start of the study, counselors’ gender, age, and profession were assessed.

Pre-counseling, counselee needs were assessed using a counselee-centered instrument, the QUOTE-

gene^{ca}. As described elsewhere (Pieterse *et al.*, 2005a), based on a pilot study amongst another sample of counsees for hereditary cancer, a set of 25 generic items and a set of 19 cancer-specific items were formulated. Generic items refer to what a counselor should do during counseling and specific items refer to receiving explanations on hereditary cancer in particular. Post-counseling, identical items were administered to measure perceived fulfillment of needs. Respondents indicated pre-visit importance (not important, fairly important, important, extremely important) and post-visit fulfillment (too little, not really enough, adequate, largely adequate). Principal Component Analysis (PCA) identified four

Table II. Results^a on Hypothesized Positive Associations Between Counselor Communication and Counselee (CE) Post-Visit Perceptions of the Fulfillment of Major Pre-Visit Needs

Extent of pre-visit need fulfillment	Counselor communication	<i>N</i>	Beta ^b	<i>SE</i>	95% CI	<i>P</i> -value
Generic need						
Procedural aspects of counseling	Medical information	130	0.09	0.09	−0.08–0.26	—
Sensitive communication ^c	Questions CE agenda	166	0.05	0.08	−0.11–0.21	—
	Verbal dominance ^c	105	0.00	0.08	−0.15–0.15	—
	Eye gaze		0.08	0.08	−0.07–0.24	—
Emotional support	Empathy	104	0.08	0.10	−0.12–0.28	—
	Psychosocial questions		0.00	0.10	−0.19–0.19	—
	Psychosocial information		0.01	0.10	−0.18–0.21	—
	Eye gaze		−0.02	0.10	−0.22–0.18	—
Assessment of cancer susceptibility	Medical information	105	0.07	0.09	−0.09–0.24	—
Cancer-specific need						
Determination/meaning of cancer gene	Medical information	146	0.20	0.08	0.04–0.36	0.017*
Emotional aspects of counseling for counselee/family	Empathy	118	0.16	0.09	−0.02–0.34	—
	Psychosocial questions		−0.07	0.08	−0.23–0.10	—
	Psychosocial information		−0.18	0.11	−0.39–0.03	—
	Medical information		0.31	0.11	0.09–0.52	0.005*
Counselee own risk of cancer	Empathy	122	0.14	0.09	−0.04–0.32	—
	Psychosocial questions		−0.05	0.09	−0.22–0.12	—
	Psychosocial information		−0.21	0.11	−0.44–0.01	—
	Medical information		0.23	0.11	0.02–0.45	0.030
Heredity of cancer	Medical information	82	−0.12	0.11	−0.34–0.10	—

Note. CI = Confidence Interval.

— = $P > 0.061$.

*Significant after Bonferroni-Holmes correction, overall $\alpha = 0.05$.

^aAll analyses were controlled for counselor and counselee background variables.

^bSignificance of predictors was tested using Chi-square tests.

^cA negative association was expected between need and this communication aspect.

generic and four cancer-specific needs with satisfactory internal consistencies (Table III). Scores on each need range from 1 to 4 with high scores indicating high importance/fulfillment.

Satisfaction with the counseling visit was assessed using eight items (Appendix A). Scores range

from 8 to 80, with high scores indicating high satisfaction. PCA (Kaiser-Meyer-Olkin measure of sampling adequacy = 0.92; Bartlett's test of sphericity: $P = 0.000$) revealed one component explaining 69.7% of the variance; items loaded 0.64 to 0.93. Internal consistency was high ($\alpha = 0.92$).

Table III. Pre- and Post-Visit Internal Consistencies^a of the Various Needs, and Mean Levels and Standard Deviation of Post-Visit Need Fulfillment (Scale 1–4) in Counsees Who Considered Need Important Pre-Visit

Pre-visit need	Items (<i>n</i>) ^b	α pre-visit	α post-visit	Post-visit fulfillment		
				<i>N</i>	<i>M</i>	<i>SD</i>
Generic need						
Procedural aspect of counseling	8	0.85	0.82	131	3.20	0.50
Sensitive communication	8	0.83	0.92	166	3.50	0.47
Emotional support	5	0.79	0.78	104	3.09	0.57
Assessment of cancer susceptibility	3	0.66	0.66	105	3.30	0.53
Cancer-specific need						
Determination/meaning of cancer gene	7	0.82	0.91	146	3.15	0.65
(Emotional) aspects of counseling	5	0.72	0.83	118	3.00	0.62
Counselee own risk of cancer	3	0.83	0.83	122	3.00	0.67
Heredity of cancer	3	0.76	0.72	82	3.22	0.66

^aComputed over $N = 171$.

^bOne generic and one cancer-specific item were left out as they loaded < 0.40 on any dimension.

Knowledge about hereditary breast (7 items) or colon (6 items) cancer was assessed using items adapted from Claes *et al.* (2003) as described elsewhere (Pieterse *et al.*, 2005b). Only counsees visiting for hereditary breast or colon cancer were asked to respond to the corresponding items. Respondents indicated whether each item was correct, incorrect, or if they didn't know. Correct scores range from 0 to 1 with higher scores indicating more correct knowledge.

Perceived control was assessed using the Perceived Personal Control questionnaire (PPC) (Berkenstadt *et al.*, 1999), translated in Dutch using a forward-backward procedure (Smets *et al.*, 2006). Scores range from 0 to 2, high scores indicating high perceived control. Pre- and post-visit internal consistencies were high ($\alpha_{\text{pre}} = 0.82$; $\alpha_{\text{post}} = 0.82$).

Anxiety was measured with the state version of the State-Trait Anxiety Inventory (STAI; 10 items) (Van der Ploeg *et al.*, 1980). Scores range from 10 to 40, higher scores indicating greater anxiety. Pre- and post-visit internal consistencies were high ($\alpha_{\text{pre}} = 0.92$; $\alpha_{\text{post}} = 0.93$).

Coding of Videotapes

Four coders rated verbal communication using an adaptation of the Roter Interaction Analysis System (RIAS), a widely used observation system for coding doctor and patient communication (Roter and Larson, 2002). The adaptation is described elsewhere (Pieterse *et al.*, 2005c) and included adding categories to code the exchange of pedigree data, medical information about relatives, communication within the family, and agenda. Within the RIAS, a communication unit or utterance is defined as the smallest speech segment to which a classification may be assigned, i.e. which conveys a single thought or relates to a single item of interest. An utterance may vary in length from a single word to a lengthy sentence.

The main coder coded 54% of all consultations and recoded 10% of her own consultations. The other coders recoded 10% of the main coder's consultations. Reliability coefficients (Pearson r) for categories with mean occurrence greater than 2% (Roter *et al.*, 1991) proved to be adequate. Intra-coder reliability for counselor and counselee categories averaged 0.81 (range, 0.54–0.96) and 0.91 (range, 0.75–0.97), respectively. Inter-coder reliability for counselor and counselee categories averaged

0.78 (range, 0.54–0.98) and 0.83 (range, 0.59–0.97), respectively.

Additionally, *counselors' contribution* to the encounter relative to the total count of utterances, as a measure of verbal dominance; *eye gaze*, as the time the counselor looked directly into the face of the counselee or his/her companion(s); and *visit length* were coded.

Statistical Analyses

Participants returning both questionnaires, and those returning the pre-visit questionnaire only were compared on socio-demographics, history of cancer, and levels of pre-visit measures using a Chi-square test, a Mann-Whitney test, and a t -test. Descriptive statistics were used to describe pre- to post-visit change in outcome measures.

Frequencies of counselee and counselor utterances were calculated. If two counselors were present, their utterances were added. Utterances of individuals accompanying counsees were not considered as the focus of this paper was on counselee-specific needs. Relevant verbal coding categories were combined on the basis of their content (Appendix B) in line with the hypotheses. As encounters for one counselor could resemble, multi-level regression analysis was used.

Multilevel regression analyses were conducted in two steps. First, counselee (gender, age, education, personal history of cancer, number of first- and second-degree affected relatives, indication for DNA-testing) and counselor background variables (gender, age, profession), and number of counselors present were included in the model. Where two counsees were seen together, data were used for one randomly selected counselee only. If two counselors were present, characteristics of the counselor with the largest amount of utterances were used. The categories 'clinical geneticist' and 'resident' were aggregated into 'doctor' as opposed to 'nurse'. Only significant background correlates ($p < 0.05$) were retained.

Second, for research question 1 all counselor and counselee communication variables were included in the model as hypothesized (Table I) and analyses were controlled for pre-visit levels of correct knowledge, PPC, and STAI. For research question 2, all counselor communication variables were included in the model as hypothesized (Table II). Separate analyses were conducted for each need within the subgroup of counsees with pre-visit importance scores higher than 2.5 on the respective needs.

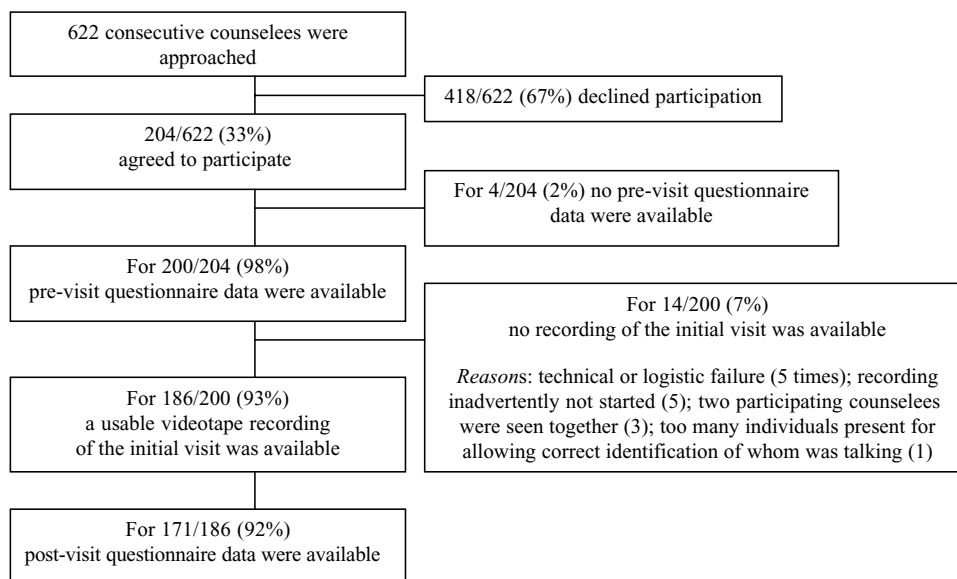


Fig. 1. Details of inclusion of counselees.

Frequency predictors and duration predictors (visit length, eye gaze) were tested using separate models. Eye gaze was assessed both as length in minutes and relative to total visit length. Predictors at interval level measurement were recoded to standardized z -scores. If 25% or less of the values was missing on the satisfaction, PPC, STAI, and QUOTE-gene^{ca} scales, missing values were replaced by the mean. Significance of the regression coefficients was tested using Chi-square tests. Analyses were carried out using SPSS 11.5 and MLwiN 1.10.

Significance of counselee outcome measures was tested two-sided at $\alpha = 0.05$. In testing the hypotheses presented in Tables I and II, the Bonferroni-Holmes correction was used to control for Type I error. This is an alternative for the Bonferroni correction and aims to keep the overall α under control when a large number of statistical hypotheses are being tested. In this procedure the p -values for the k hypotheses are ordered from the smallest to the largest. Hypotheses corresponding with the ordered p -values are then numbered from 1 to k . If i is the smallest integer from 1 to k , then alternative hypotheses (H_1) with a p -value smaller than $\alpha/(k-i+1)$ are being accepted, while H_1 hypotheses with a p -value larger than $\alpha/(k-i+1)$ are being rejected (Holland & Copenhaver, 1988). Following this procedure, overall α was kept at 0.05 in testing the hypotheses formulated in Tables I and II. We chose to present all p -values smaller than $\alpha = 0.05$ in these tables but to discuss only those findings significant after Bonferroni-Holmes correction.

RESULTS

Pre- and post-visit data and a video-recording of the initial visit were available from 171 counselees (Fig. 1). The counselees with a family history of cancer (Table IV) had one to five (MD = 1) first-degree and one to eight (MD = 2) second-degree affected relatives. Participants were, on average, 2.1 years older than decliners ($P = 0.022$); other background characteristics did not differ (Pieterse *et al.*, 2005a). Participants returning the pre-visit questionnaire only were more likely to be unaffected by cancer ($\chi^2 = 9.76$, $P = 0.002$) than participants returning both questionnaires. They considered it more important to receive explanations on procedural aspects of counseling ($t = 2.17$, $P = 0.031$) and heredity of cancer in general ($t = 2.00$, $P = 0.047$), and to receive emotional support ($t = 2.35$, $P = 0.020$).

Five clinical geneticists (four female, one male), four residents in clinical genetics (three female, one male) and five genetic nurses (all female) participated. Counselors were aged 29–46 years ($M = 38.3$; $SD = 5.8$). Counselors conducted in total 1–30 visits ($M = 18.8$, MD = 14, $SD = 9.2$), either alone or as one of two counselors with the largest amount of utterances.

Consultations lasted 44.2 min ($SD = 14.1$) on average. The counselors conducted 135/171 (79%) visits alone. During 36/171 consultations, a clinical geneticist accompanied a counselor in training. Consultations conducted by 1 *versus* 2 counselors did

Table IV. Counselor Demographics, History of Cancer and Indication for DNA-Testing ($N = 171$)

	<i>N</i>	%
Age (years)		
Mean (<i>SD</i>)	45.0 (10.2)	
Range		18–72
Gender		
Female	155	91
Male	16	9
Education		
High school level	93	55
Secondary level	77	45
Type of cancer		
Breast cancer	109	64
Colon cancer	35	21
Breast and colon cancer	9	5
Ovarian cancer	9	5
Other cancers	9	5
Personal history of cancer		
Counselor affected with cancer	83	49
Counselor unaffected with cancer	88	51
Family history of cancer		
1st or 2nd degree relatives affected with cancer	151	90
No 1st or 2nd degree relatives affected with cancer	17	10
DNA-test		
Indicated ^a	102	62
Not indicated	32	19
Uncertain ^b	31	19

Note. Summations vary due to missing data.

^aIndication for testing the counselor or a relative as judged after the initial visit.

^bIndication for testing uncertain after the initial visit due to missing medical information.

not significantly differ in mean number of counselor and counselor utterances per communication category as used in the subsequent analyses, nor in pre- to post-visit change in counselors' correct knowledge, perceived personal control, and state anxiety, nor in their post-visit satisfaction and reported need fulfillment (data not shown).

In 77/171 (45%) visits, counselors were seen alone. During all other consultations, counselors were accompanied by one ($N = 82$) or two or more ($N = 12$) companions. Utterances of counselors comprised an average of 40% of the total communication, compared to 7% for companions.

The counselors' knowledge and perceived control significantly increased pre- to post-visit, and their anxiety significantly decreased (Table V). The counselors were overall (very) satisfied about the fulfillment of their major pre-visit needs (Table III).

Communication and Counselors' Post-Visit Satisfaction, Cognitions, and Anxiety

Asking medical questions was related to lower levels of satisfaction and receiving medical information was related to higher levels of correct knowledge (Table I). Receiving psychosocial information was related to higher levels of anxiety. Visit length was related to higher levels of correct knowledge. Counselor eye gaze was associated with higher levels of correct knowledge and anxiety. The latter association remained significant after controlling for visit length (Beta = 0.27, $SE = 0.12$, $P = 0.022$). Counselor communication was unrelated to perceived control.

Counselor Communication and Counselors' Perception of Needs Fulfillment

The counselors who considered it important to receive explanations on determination and implications of carrying a cancer gene or (emotional) aspects of counseling, perceived these needs as significantly better fulfilled, if they had received more medical information (Table II). Counselor communication was further unrelated to counselors' perceptions of need fulfillment.

Analyses were reran in the whole sample ($N = 171$), controlling for pre-visit importance scores on needs. Similar results were found (data not shown). Results further showed that importance scores were unrelated to the perceived fulfillment of the various needs, except for counselor sensitive communication, where importance was positively related to perception of need addressed (data not shown).

DISCUSSION

This study was designed to enhance understanding of how communication during initial cancer genetic counseling visits relates to counselor satisfaction and post-visit cognitions and anxiety, and how counselor communication is associated with addressing counselors' pre-visit needs.

As with cancer patients, results showed that the counselors were less satisfied if they had asked more medical questions (Ong *et al.*, 2000; Siminoff *et al.*, 2000). It is unclear whether counselors asked medical questions out of discontent with the information they were receiving, or whether asking questions in itself was related to lower satisfaction, perhaps

Table V. Mean Levels and Standard Deviation on Pre- and Post-Visit Measures

Outcome measure	Scale	N	Pre-visit		Post-visit	
			M	SD	M	SD
Satisfaction	8–80	165	—	—	63.27	9.37
Correct knowledge ^a	0–1	153	0.67	0.20	0.83***	0.19
Perceived control (PPC) ^b	0–2	156	1.10	0.45	1.35***	0.45
Anxiety (STAI) ^b	10–40	160	20.63	6.24	18.32***	6.10

Note. Samples sizes vary due to missing values.

^aWilcoxon signed ranks test.

^bt-test for paired samples.

*** $P < 0.001$.

inducing a feeling that they needed to be active in order to receive all desired information. Alternatively, counsees may have had the impression that questions were not welcome. Siminoff *et al.* (2000) suggested that patients asking more questions are more prepared and may thus have higher expectations of the physician and/or information. Yet, in our sample considering needs more important was unrelated to perceptions of need fulfillment, except for counselor's sensitive communication. Seemingly, these counsees' dissatisfaction had mainly to do with how the visit proceeded.

As expected and in line with findings in primary care (Hall *et al.*, 1988), counsees who received more medical information had more correct knowledge after the visit, regardless of prior knowledge. Counsees who were looked at longer and who had longer visits also reported more correct knowledge after the visit. These results contradict those from Butow *et al.* (1995) in cancer patients. As discussed in Bensing *et al.* (1995), length of eye gaze and of the visit are strongly interrelated; however what causal mechanism actually shapes this relationship is unclear. Evidently, looking more at counsees may provide counselors with more cues as to counsees' understanding of the information, and longer visits may be associated with taking more time to explain medical matters. Alternatively, when looked at longer, counsees may sense greater counselor interest and may then listen more carefully, retaining the information better (Larsen & Smith, 1981).

In line with Lobb *et al.*'s (2004) findings, counsees' anxious feelings were associated with attention given to emotional matters, i.e. counselors' talk about psychosocial issues. Previously (Pieterse *et al.*, 2005b), we found that lower anxiety was related to perceiving one's need for emotional support better fulfilled. Apparently, addressing counsees' need for emotional support is not (only) achieved by providing (more) psychosocial information. In line with

Duric *et al.*'s (2003) results, counselor empathy was unrelated to counsees' satisfaction and anxiety. Our finding that counsees' anxiety was related to counselor eye gaze, may directly be related to the extensiveness of talk on emotional matters. As anxiety was measured shortly after the visit, follow-up data are necessary to determine whether heightened anxiety levels persisted. Evidence suggests it often does not (Aktan-Collan *et al.*, 2001; Van Oostrom *et al.*, 2003). In principle, it is not surprising that discussing emotional matters does not reduce anxiety, the more so if counsees' anxious feelings are addressed as being legitimate. Differently from Lobb *et al.* (2004), receiving medical information did not relieve anxiety but appeared unrelated, suggesting that receiving medical information is not necessarily anxiety-provoking nor-diminishing. This is in line with findings in patients, which show that providing fuller information (on prognosis or test results) does not usually lead to adverse reactions (Ley, 1982). Differences between Lobb *et al.*'s and our findings may be explained by varying measurements; we did not differentiate the medical information in content. Understandably, it is not *amount* but rather *what* information is given, that may help relieve fears.

Unexpectedly, communication was unrelated to perceived control. Perceived control may particularly be related to specific information about what to expect (McVey *et al.*, 2001). Berkenstadt *et al.* (1999) found more perceived control among counsees seeking counseling for various genetic conditions and who had been given a definite diagnosis, a specific recurrence risk, or were offered prenatal diagnosis. In initial cancer genetic counseling visits, the family history of cancer often needs to be assessed further and (if conducted) results from genetic testing are not yet available. Associations may thus rather be found in concluding visits. Moreover, satisfaction and anxiety were unrelated to discussing counsees' agenda. Eliciting counsees' agenda is considered

as helpful in better addressing counselees' needs (Lerman *et al.*, 1995; Michie *et al.*, 1997b). As Butow and Lobb (2004) found, counselors asked counselees about their agenda in most (95%) visits. However, it is unclear to what extent counselees' agenda was indeed followed.

Regarding perceptions of fulfillment of major needs, it appeared that providing medical information is helpful in addressing well need for explanations on some, but not all, medical and emotional issues. Findings were similar within the whole sample of counselees, suggesting that importance attached to needs was not critical to these associations. Lack of association between medical information and meeting the need for explanation on several medical issues may result from a ceiling effect, as counselees were overall satisfied or very satisfied about their fulfillment.

Counselees' need for emotional support and explanations on (emotional) aspects of counseling and their risk of cancer were not better fulfilled with more counselor empathy, psychosocial communication, or longer eye gaze. With regard to own risk of cancer, some authors (Meiser *et al.*, 2001) suggested that counseling healthy women about breast cancer risks is effective unless also addressing anxious pre-occupations. Our data do not support an association between counselor empathy and psychosocial communication, and counselees' satisfaction about information on their own risk. However, communicating empathy and being attentive to psychosocial issues may still be helpful in increasing counselees' correct interpretation and recall of risk information.

LIMITATIONS

This study was based on one clinic and the response rate of counselees, discussed elsewhere (Pieterse *et al.*, 2005a), was low. Most participants were female and a majority was referred for hereditary breast cancer. Furthermore, 55% of counselees were higher educated, a proportion similar to that found in another study amongst Dutch counselees (Van Asperen *et al.*, 2002), however appreciably higher than in Dutch adult general practice patients (Van Lindert *et al.*, 2004). The results should therefore only be generalized with caution to men, to the broader population of relatively lower educated females at increased risk of cancer, and to other types of hereditary cancers.

Second, 15/171 counselees did not return the post-visit questionnaire, and they attached more importance to several pre-visit needs than those who did. It is unclear whether non-response was related to lower need fulfillment.

Third, expected group differences were unknown at the start of the study, so an *a priori* power analysis to determine the number of counselees needed was not possible. Sample sizes may have been too small to detect differences.

Finally, communication was assessed during initial visits; associations may be different in return visits (Graugaard *et al.*, 2005), especially if increased risk of cancer is demonstrated.

CONCLUSION

The provision of medical information appears the most powerful communication aspect to increase counselees' satisfaction and fulfill needs on explanations about hereditary cancer. This finding is concordant with the primary goal of counseling, which is to inform and educate counselees about risk of cancer and risk management. Reservations in this regard do not appear necessary, as receiving medical information does not seem related to feeling more anxious. A recent meta-analysis supports this contention (Braithwaite *et al.*, 2004). In contrast, ways need to be found as to address counselees' medical questions satisfactorily. Also, affective and psychosocial communication was found unrelated or even contrary to relieving counselees' worries or addressing their need for emotional support. No indications were found as to how communication may help increase counselees' feelings of control. More research is needed in finding ways to address adequately counselees' informational and emotional needs, and increase their feelings of control.

APPENDIX

Items Used for Measuring Satisfaction

Finally, we ask about your satisfaction about the consultation *you just had* at the Department of Medical Genetics. Below, you may express your satisfaction using a report mark from 1 (very bad) to 10 (excellent). *Please, circle one mark for each question.*

To what extent are you satisfied about . . .

Appendix A

1. The expertise of the counselor(s)									
1	2	3	4	5	6	7	8	9	10
2. The communication of the counselor(s) with you (and your partner)									
1	2	3	4	5	6	7	8	9	10
3. The degree of 'client-centeredness,' that is, the degree to which the counseling was tuned to you									
1	2	3	4	5	6	7	8	9	10
4. The information that the counselor(s) gave you									
1	2	3	4	5	6	7	8	9	10
5. The manner in which norms and values that are important to you were discussed									
1	2	3	4	5	6	7	8	9	10
6. The degree to which you experience the Department of Medical Genetics as accessible for advice									
1	2	3	4	5	6	7	8	9	10
7. The organization, structure, and procedures of the Department of Medical Genetics									
1	2	3	4	5	6	7	8	9	10
8. This consultation in general									
1	2	3	4	5	6	7	8	9	10

Appendix B Counselor (CR) and counselee (CE) communication categories used in the analyses

Categories used in analyses	Component categories (if applicable)	Explanation of category
Socio-emotional communication		
CR Empathy	Concern Verbal attention Reassurance	Immediate emotional or psychosocial worries Legitimize, empathy, partnership, support Give reassurance
CE Concern	—	Immediate emotional or psychosocial worries
Task-related communication		
CR Medical information	—	Statements or facts relating to medical condition or screening or prophylactic surgery
CE Medical questions	—	Questions that ask for information on medical condition or screening or prophylactic surgery
CR Psychosocial questions	—	Questions that ask for information on psychosocial issues ^a or current feelings
CR Psychosocial information	CR Psychosocial information CR Psychosocial education	Statements or facts relating to psychosocial issues ^a or current feelings Statements which suggest resolution or action to be taken by the other relating to psychosocial issues ^a or statements aimed at education about psychosocial issues ^a
Discuss CE Agenda	CR question Agenda CE information Agenda	Questions that ask for information on CE's agenda Statements or facts relating to CE's agenda
Discuss CE Psychosocial issues	CR Psychosocial questions CE Psychosocial information	Questions that ask for information on psychosocial issues ^a or current feelings Statements or facts relating to psychosocial issues ^a or current feelings
Overall communication measures		
CR verbal dominance	—	Computed as the ratio of all CR utterances to the total count of utterances during the visit
CR Eye gaze	—	Length in minutes of time that the CR looks directly into the face of the CE or his/her companion(s)

^aPsychosocial issues encompass the discussion of feelings and emotions that are not active at the moment, as well as discussion about ways in which counselees (or relatives) make decisions related to the problem for which they sought counseling.

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