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ORIGINAL ARTICLE

Who is being referred to cancer genetic counseling? Characteristics of counselees and their referral

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Abstract Both physician and patient play a role in the referral process for cancer genetic counseling. Access to such counseling is not optimal because some eligible patients are not being reached by current referral practice. We aimed to identify factors associated with the initiator of referral. During a 7-month period, we recorded demographic characteristics like gender, personal and family history of cancer, ethnicity and eligibility for genetic testing for 406 consecutive counselees using a specially designed questionnaire. Counselees were seen in a university hospital or a community hospital ($n=7$) in the Netherlands. We also recorded educational level of each counselee, clinical setting and who initiated referral. Descriptive statistics were used to describe the counselees' general characteristics. We analysed the association between counselee characteristics and the initiator of referral by logistic regression. The majority of counselees seemed to have initiated referral themselves but were indeed eligible for genetic testing. In comparison to the general population in the Netherlands, the counselees had a higher level of education, and there were fewer immigrants, although a higher level of education was not found to be a facilitating factor for referral. The clinical setting where a counselee was seen was associated with initiator of referral, although this relationship was not straightforward. There is a complex interaction between clinical setting and initiator of referral, which warrants further research to elucidate the factors involved in this relationship. Patients seen in cancer genetic counseling do not reflect the general population in terms of educational level or ethnicity.

Keywords Cancer genetic counseling · Initiative · Referral process · Education · Accessibility

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Introduction

Cancer genetic counseling is increasingly being offered to patients who have cancer and/or to their healthy relatives. In the Netherlands, genetic counseling is covered by compulsory health insurance and is therefore available to all patients, who must be referred to a family cancer clinic by a physician [general practitioner (GP) or medical specialist]. However, physicians often feel they lack sufficient knowledge to select patients eligible for cancer genetic counseling correctly (Ardern-Jones et al. 2005; McCann et al. 2005; Nippert et al. 2011), or they may desist from bringing up subjects like family history, genetic testing and hereditary cancer and only discuss them if the patient initiates it as shown for the Netherlands (Van Riel et al. 2010) and the UK (Al-Habsi et al. 2008). In general, the quality of family history taking by GPs and medical specialists is poor as has been reported for 14 West European countries (Vasen et al. 2010) so that patients who fulfil the criteria for cancer genetic counseling are not always identified and referred. For example, a study in the USA shows that half of the ovarian cancer patients at a substantial risk of being a BRCA mutation carrier were not referred for genetic counseling

(Meyer et al. 2010), and of all colorectal cancer patients eligible for genetic counseling in the Netherlands and Australia, only a small proportion was actually referred and visited a family cancer clinic (Overbeek et al. 2008; Wong et al. 2008). So a large proportion of the patients eligible for cancer genetic counseling is not being reached by our current referral practice as shown for the USA and Australia (Brown et al. 2005; Nathanson et al. 2008; Wong et al. 2008); this implies that there is suboptimal access to counseling, leading to inequality in patient care.

It is known that only 45% of patients with early-onset breast cancer and 10% of healthy women at high risk for hereditary breast and ovarian cancer in the USA had discussed genetic testing with a health professional (Brown et al. 2005; Levy et al. 2009), which would lead to poor referral rates for them and their family members. For the UK, it has been reported that characteristics of counselees may be associated with their ability to bring up a positive family cancer history, or to ask questions about the possible hereditary aspects (Brain et al. 2000; Wonderling et al. 2001) and may thus play a role in initiating a referral. It has been shown that counselees who were referred for cancer genetic counseling and participated in studies on psychosocial aspects of counseling more often had a higher educational background, suggesting that less well-educated patients have less easy access to a family cancer clinic in the Netherlands (Pieterse et al. 2006), the UK (Armstrong et al. 2002) and the USA (Bluman et al. 1999). Next to suboptimal referral of counselees willing to undergo genetic testing, some counselees eligible for genetic testing may decline referral. How large this group is, is not easily determined. It is known that factors like anxiety (Geer et al. 2001), financial barriers (Armstrong et al. 2005; Forman and Hall 2009) and problems with contacting family members about their specific cancer diagnosis (Appleby-Tagoe et al. 2011) play a role.

The aim in this study was to explore whether any demographic factors influence whether patient or physician takes the initiative for referral to cancer genetic counseling. In daily practice, we would expect to see fewer counselees with a foreign background and more with a higher educational level compared to the general population. We therefore investigated whether counselees' level of education influenced who initiated the referral.

In the Netherlands, there are nine family cancer clinics. Eight are situated in university medical centres and one is in a specialized oncology hospital. However, the clinical geneticists and genetic counselors from these centres also hold clinics in some community hospitals. The same standard of care is provided, but with the advantage of providing it in a hospital which is familiar and closer to the counselee, and therefore more easily accessible. The counselee population and referral practice for consultations in community hospitals might differ from those in university hospitals. We tried to elucidate who played the main role in initiating a referral for cancer genetic counseling (the physician or counselee) and which counselee characteristics played a role in the referral process.

Materials and methods

Participants

Participants in this study were 406 newly referred counselees for cancer genetic counseling from June to December 2007. They were seen either at one university hospital or at one of seven community hospitals (general hospitals) in the region of the university hospital. All the counselees were seen by a genetic counselor or a clinical geneticist (n=11) from the Department of Medical Genetics, University Medical Centre Utrecht.

Study design and data collection

A specially designed questionnaire was used prospectively for all new counselees referred for cancer genetic counseling during the study period (see Appendix). The following counselee characteristics were recorded: gender, personal and family cancer history, and eligibility for genetic testing together with the clinical setting where the counselee was seen, university hospital or community hospital. Eligibility for genetic testing was determined by appropriate national and/or international guidelines for the different hereditary cancer syndromes either applied to the counselee or to an affected relative, based on family history. These guidelines are roughly the same as the guidelines for referral and were used by all family cancer clinics in the Netherlands. Information on family history was collected from the medical records, covering types of cancer and the number of affected members in the family. Genetic testing included diagnostic DNA testing of genes involved in hereditary cancer syndromes and predictive DNA testing when there was already a mutation known in a family. In addition, microsatellite instability testing and immunohistochemistry analysis (MSI/IHC) of the MMR proteins in tumour tissue were performed if Lynch syndrome was suspected (Tops et al. 2009; Allain 2008).

We also recorded the ethnicity of the counselee, as determined by Dutch definitions. A counselee was considered to be an immigrant if at least one of the parents was born outside the Netherlands (Statistics Netherlands 2008). A subdivision was made between immigrants originating from Western countries (Europe, North America, Australia, New Zealand, Indonesia and Japan) and non-Western countries

(Turkey and countries in Africa, Latin America and Asian countries). Indonesia and Japan are grouped under Western countries according to guidelines of Statistics Netherlands because of their socioeconomic and sociocultural bonds with the Netherlands.

For each counselee, we recorded the highest level of education achieved. The level was assessed using the classifications of Statistics Netherlands (2006). Four levels were defined according to national and international standard classifications of education (Statistics Netherlands 2006; UNESCO 2006): low=(pre-)primary education or first stage of basic education; intermediate-1=lower secondary or second stage of basis education; intermediate-2=secondary or upper secondary education and high=tertiary education. Each counselee was asked who the initiator of the referral was, that is, who played the main role in initiating the referral for genetic counseling (counselee, a relative, the physician or both counselee and physician).

Most items of the questionnaire are routinely discussed in daily clinical genetic practice during the first consultation. In addition, ethnicity and educational level were asked, and the counselee was told that these items were asked for this study. The counselor explained briefly the purpose of the study and filled in the questionnaire after the consultation.

Statistical analysis

Descriptive statistics were used to describe the counselees' general characteristics in both clinical settings (university or community hospital). Both groups were compared on educational level and eligibility for genetic testing using SPSS 15.0.1 and on who took the initiative for referral. To see if our counselee population reflected the general population, we compared our data on ethnicity and educational background with that for the general population in the Netherlands (Statistics Netherlands 2008, 2009) using chi-squared tests.

We dichotomised the variable initiative for referral into initiative for referral taken by the patient or by the physician. 'Initiative taken by the patient' also included cases where the counselee has indicated that a relative urged them to make an appointment, so that the relative was in fact the initiator. Also, when there was a combined initiative, we grouped 'initiative more from physician' with 'initiative taken by physician' and 'initiative more from counselee' with 'initiative taken by patient'. We excluded cases in which the initiative was taken by the counselee and physician together because the numbers were too low to analyse properly. Logistic regression analysis was used to assess the association between the characteristics of counselees (gender, personal cancer history, ethnicity and educational level) and the clinical setting with the initiator of the referral for counseling.

Results

Counselees

In total, 406 counselees were referred for cancer genetic counseling; more than half (55%) were seen in the university hospital. The majority of counselees in this study were female (Table 1), and over 35% of counselees were affected by cancer, mostly breast cancer. Three percent of the affected counselees did not have a positive family history for any kind of cancer (Table 1).

Affected counselees were seen more in the community hospitals than in the university hospital (p=0.000), while more unaffected counselees were seen in the university hospital (p=0.008) (Table 1).

Eligibility for genetic testing

Most counselees were eligible for genetic testing (e.g. diagnostic or predictive DNA testing, or MSI/IHC testing) either for themselves or an affected relative (Table 1). Significantly more diagnostic testing (p=0.049) and MSI/IHC testing (p=0.000) was performed in the community hospitals, while predictive testing occurred more often in the university hospital (p=0.000; Table 1). More unaffected than affected counselees did not meet the criteria for genetic testing (p=0.000). There were no differences in eligibility for MSI/IHC testing between affected and unaffected counselees (p=0.458).

Educational level

Almost 70% of all counselees had finished secondary or tertiary education. When we compared clinical settings, no differences were seen between the lowest and highest educational levels. However, there were more counselees with intermediate-1 (p=0.004) and fewer counselees with intermediate-2 (p=0.018) seen at the consultations in community hospitals (Table 1). Compared to the general population, counselees less often had a low education (p=0.002) and an intermediate-2 education (p=0.001), and more counselees have a high level of education (p=0.000; Table 2).

Ethnicity

Only a minority of all counselees were considered to be immigrants. There was no difference in the number of immigrants seen in the university hospital and in the

Table 1 Characteristics of 406 counselees requesting cancer genetic counseling

Variable		Both clinics combined % (*n*)	University hospital % (*n*)[a]	Community hospitals % (*n*)[a]	*p* value
Gender	Male	21.7 (88)	23.2 (52)	19.8 (36)	0.502
	Female	78.3 (318)	76.8 (172)	80.2 (146)	0.771
Personal cancer history	Affected	36.5 (148)	24.6 (55)	51.1 (93)	0.000*
	Unaffected	63.5 (258)	75.4 (169)	48.9 (89)	0.008*
Affected with	Breast cancer	62.8 (93)	63.6 (35)	62.3 (58)	0.941
	Ovarian cancer	6.1 (9)	1.8 (1)	8.6 (8)	0.113
	Colon cancer	15.5 (23)	16.4 (9)	15.1 (14)	0.856
	Endometrial cancer	0.7 (1)	0 (0)	1.1 (1)	0.443
	Other cancers[b]	14.9 (22)	18.2 (10)	12.9 (12)	0.455
Eligibility for genetic testing in counselee or relative	Diagnostic DNA testing	44.0 (179)	37.0 (83)	52.7 (96)	0.049*
	MSI/IHC	8.0 (33)	2.7 (6)	14.8 (27)	0.000*
	Predictive testing[c]	27.3 (111)	39.3 (88)	12.6 (23)	0.000*
	Did not meet criteria for testing	20.0 (83)	21.0 (47)	19.8 (36)	0.808
Initiator of referral	Counselee	61.3 (228)	69.9 (144)	50.6 (84)	0.061
	Physician	38.7 (144)	30.1 (62)	49.4 (82)	0.012*
Educational level[d]	Low	4.0 (16)	3.6 (8)	4.5 (8)	0.643
	Intermediate-1	26.3 (105)	20.7 (46)	33.3 (59)	0.004*
	Intermediate-2	33.3 (133)	38.3 (85)	27.1 (48)	0.018*
	High	36.3 (145)	37.4 (83)	35.0 (62)	0.626
Ethnicity[e]	Dutch native	90.4 (367)	91.5 (205)	89.0 (162)	0.848
	Immigrant	9.6 (39)	8.5 (19)	11.0 (20)	0.439

MSI microsatellite instability testing, *IHC* immunohistochemistry for MMR proteins

*$p<0.05$, a two-sided p value is considered significant

[a] Data calculated for type of clinic (i.e. within each column)

[b] Multiple primary tumours or less common tumours

[c] Predictive testing for a known mutation in the family (genes involved in hereditary breast- and ovarian cancer, Lynch syndrome, polyposis coli or FAMMM)

[d] Low=(pre-)primary education or first stage of basis education; Intermediate-1=lower secondary or second stage of basis education; Intermediate-2=(upper) secondary education; High=tertiary education

[e] Dutch native=counselee of who both parents are born in the Netherlands; immigrant=counselee of who at least one of the parents is not born in the Netherlands

community hospitals (Table 1). There were fewer immigrants in our counselee population than expected from the make-up of the general population (Table 2). The majority of the immigrants (63%) originated from a Western country.

Initiative for referral

The majority of counselees seen for cancer genetic counseling initiated the referral themselves (Table 1). This group includes a small subgroup of counselees who indicated that a relative urged them to make an appointment ($n=43$). The only significant factor associated with the initiative for referral was the clinical setting: counselees seen in community hospitals were less likely to have taken the initiative themselves ($p=0.002$; Table 3). Although not statistically significant, women tended to take the initiative less often ($p=0.06$), while counselees with a personal history of cancer were more often referred on the initiative of their physician ($p=0.08$; Table 3).

Discussion

Our expanding knowledge on counselee characteristics and referral practice for cancer genetic counseling might lead to identifying factors that facilitate or hinder referral. Knowing more about these factors could contribute to better access to such counseling and improving patient care. We found that

Table 2 Educational level and ethnicity of counselees in this study and in the general population of the Netherlands

		Counselees in this study		General population[a]		*p* value
		%	*n*	%	*n*	
Ethnicity[b]	Dutch native	90.6	368	80.6	13,184,541	0.000*
	Immigrant	9.4	38	19.4	3,173,451	
Educational level[c]	Low	4	16	8.4	914,000	0.002*
	Intermediate-1	26.3	105	23.9	2,597,000	0.264
	Intermediate-2	33.3	133	41.9	4,551,000	0.001*
	High	36.3	145	25.7	2,790,000	0.000*

*$p<0.05$, a two-sided p value is considered significant

[a] Data from Statistics Netherlands, 2007

[b] Dutch native=counselee of who both parents are born in the Netherlands; immigrant=counselee of who at least one of the parents born outside the Netherlands

[c] Low=(pre-)primary education or first stage of basic education; intermediate-1=lower secondary or second stage of basic education; intermediate-2=(upper) secondary education; high=tertiary education

counselees seen for cancer genetic counseling are more often of Dutch origin and have a high educational background compared to the general population in the Netherlands. Contrary to our expectations, higher educational level is not a facilitating factor for initiating referral. We also found that the type of clinic is a factor associated with initiating referral. Some counselee characteristics, like educational level, differed between the two types of clinic studied, although this interaction was more complex than expected.

A substantial number of our counselees had a high educational background, which is in accordance with other studies on cancer genetic counseling in the UK (Brain et al. 2000), the Netherlands (Van Asperen et al. 2002) and the USA (Morgan et al. 2010) and on reproductive genetic counseling (Aalfs et al. 2007) in the Netherlands. However, since our results show that it is not a facilitating factor for initiating referral, other factors, like socioeconomic status, may play a role. It has been shown that counselees for cancer genetic counseling are less socially deprived and more affluent than the general population (Holloway et al. 2008). Cognitive ability is often associated with socioeconomic status, but explains only some of the differences in socioeconomic inequalities in health (Batty et al. 2006). Since genetic counseling and testing are covered by compulsory health insurance in the Netherlands, financial barriers do not play a role. This was also shown in a study by Culver et al. in which they offered genetic counseling for free (Culver et al. 2001). Participants who accepted genetic counseling were more often better educated than those who declined (Culver et al. 2001). Other factors, like health

Table 3 Logistic regression analysis: demographic factors for referral to genetic counseling

	Own initiative vs. initiative of physician	
Factors	Odds ratio	*p* value
Gender (female vs. male)	0.590	0.064
Personal cancer history (affected vs. unaffected)	0.659	0.083
Ethnicity (immigrant vs. Dutch native)	0.909	0.799
Clinical setting (community hospital vs. university hospital)	0.495	0.002*
Educational level[a]		
Intermediate-1 vs. low	0.575	0.358
Intermediate-2 vs. low	0.788	0.689
High vs. low	0.748	0.627
Nagelkerke R^2	0.089	

*$p<0.05$, a two-sided p value is considered significant

[a] Low=(pre-)primary education or first stage of basic education; intermediate-1=lower secondary or second stage of basic education; intermediate-2=(upper) secondary education; high=tertiary education

literacy and the level of empowerment of counselees, may also play a role. Counselees with a higher educational level are more often able to explain their need for genetic counseling to their physician, or know more about the aspects of genetic factors in cancer and are therefore more often referred to a genetics service. Studies have shown that patients with a higher educational level know more about genetics (Etchegary et al. 2010) and have more often heard about genetic testing (Baer et al. 2010). From our data, we cannot explain the high proportion of counselees with a higher educational background. It would be interesting to see if our counselees with a higher educational background did indeed know more about hereditary cancer and genetic counseling and therefore discuss this subject earlier with their physician, leading to more referrals of the better educated counselees. In this view, also empowerment can play an important role. Patients, who bring information from other sources to their physician, are also more often referred by their physician to other sources of information (Lewis et al. 2009). Physicians often refer to other health professionals (Lewis et al. 2009), so this might include referring to a genetic counselor of clinical geneticist when patients ask questions about hereditary cancer. We found that unaffected counselees eligible for predictive genetic testing more often found their way to a family cancer clinic without the help of a physician. These counselees are self-referred, but brought a written referral from their GP. This could be partly due to the procedure in the Netherlands: when a mutation in a cancer gene is first identified in a family, the genetics departments provide a letter for the proband to give to his/her family members. They thus have some information about the genetic testing procedure and know where to go for further help.

Less than 20% of the counselees were not eligible for genetic testing, suggesting physicians can accurately select candidates for cancer genetic counseling, although this is contraindicated by studies in other West European countries in which physicians are reported to lack confidence in making their selection (Ardern-Jones et al. 2005; McCann et al. 2005; Nippert et al. 2011). Similar percentages of counselees seen in the two clinical settings were not eligible for genetic testing. Prior to the study, we expected cancer genetic counseling to be more accessible in the community hospitals, due to less travelling distance and more familiarity with the hospital where they are treated, which could have resulted in a higher percentage of ineligible counselees. This effect might be counterbalanced by our finding that the initiative for referral is more often taken by a physician in the community hospitals, and they apparently select patients suitable for counseling correctly. If counselees are not eligible for genetic testing, this does not mean that they are not at increased risk of getting cancer and referral is useless since genetic counseling also involves cancer risk assessment and assessing eligibility for screening (e.g. mammography and colonoscopy) and reassurance of counselees. Due to the design of our study, we cannot deduce how many counselees eligible for referral are not being referred for cancer genetic counseling. Other studies suggest that this percentage is high: only 22% of the Australian patients who might benefit from cancer genetic counseling were actually referred (Wong et al. 2008) and only 30% of Dutch patients with colon cancer at a young age visited a genetics department (Overbeek et al. 2008). This should be a cause for concern given the consequences for at least the part of such patients (and their relatives) which are eligible for genetic counseling and are willing to be referred, but are unaware of this possibility themselves.

Our study included only a low number of immigrants, like previous studies in the UK and the USA (Wonderling et al. 2001; Armstrong et al. 2003). We found that significantly fewer immigrants were seen for cancer genetic counseling than would be expected from data on the general population. Next to possible confounding factors like lower socioeconomic status (Culver et al. 2001; Chin et al. 2005), low level of acculturation (Heck et al. 2008) and traditional beliefs (Barlow-Stewart et al. 2006), the low number of immigrants can partly be explained by the lower incidence of cancer and cancer mortality rates in different countries of origin (Turkey, Morocco, Surinam, Netherlands Antilles and Aruba) when compared to the Netherlands (Arnold et al. 2011; Stirbu et al. 2006; Visser et al. 2004). However, since specific approaches to immigrant populations improve their access to genetic counseling, as shown for the enrolment of African-American families in a genetic research project in the USA (Spruill 2010), we still recommend future studies to look carefully at the reasons why immigrants are not referred for counseling.

There are more highly educated counselees in our study than in the general population. Albada et al. has compared the UK and the Netherlands and found similar results on the educational background of Dutch counselees. They also found that, in the UK, less well-educated counselees were not underrepresented in breast cancer genetic counseling (Albada et al. 2011b). A mildly confounding factor in our study could be that the percentage of highly educated inhabitants in our service area is slightly greater than in the general Dutch population (Statistics Netherlands 2003), which might explain part of our results. The interaction between people undertaking cancer genetic counseling and

their educational level is shown to be very complex: we found no linear association with educational level. There were less counselees with a low or intermediate-2 level of education, while the number of intermediate-1 level of education does not differ from the general population. It would be interesting to determine more detailed characteristics of these groups to find clues to a possible explanation. For example, are there any differences in the counselees' profession or type of work, in their predicted cancer risk, or cancer worry, between better and less well-educated counselees, or between counselees seen in the different clinical settings? Also, reasons for declining referral for cancer genetic counseling can give more insight in the complexity of the referral process. For example, it has been reported that counselees declining referral are more anxious to hear more about their own risk and that of family members of getting cancer than counselees who accept referral (Geer et al. 2001). Also, not wishing, or not be able to contact family members for specific information about their cancer diagnosis (Appleby-Tagoe et al. 2011) might result in declining referral. More insight into all of these factors should be obtained in future studies in order to improve the access to cancer genetic counseling.

An interesting finding in our study was the association of clinical setting with who took the initiative for referral. Counselees seen in community hospitals were less likely to have taken the initiative themselves. There was also a trend for counselees with a personal history of cancer to be referred by their physician more often, which might explain part of the effect seen, given that more counselees are seen with a personal history of cancer in community hospitals, who might feel more dependent on their physician. Non-affected counselees who are self-referred might be less familiar with the possibility of genetic counseling in a community hospital.

Other features, in addition to counselee characteristics, might play a role. For example, if counselees are unaware of the possibility of undertaking cancer genetic counseling close to home and the distance is a barrier, they are less likely to take the initiative to request a referral. Differences in physicians' characteristics are also important in the referral process and may vary between types of clinic. Unfortunately, we do not have data on this subject. Also, our numbers are too low to compare demographic characteristics of counselees between different community hospitals. Theoretically, how physicians and their patients communicate might differ between clinics, which could influence the referral process. It would therefore be interesting to study the interaction between (potential) counselees and their physician and other aspects of communication about cancer genetic counseling and the referral process. Thus, characteristics of the physician and counselee, e.g. health literacy and affluence, could be studied. Observing series of consecutive consultations would also have an important advantage since making decisions in cancer genetic counseling occurs over a period of time. This could for instance be done by videotaping or audiotaping consultations of patients possibly fulfilling criteria for genetic counseling (Pieterse et al. 2007; Albada et al. 2011a).

Limitations

An important limitation of our study was the accuracy of recall about the way the referral was initiated. Counselees were asked who took the initiative for referral, but their answer might be compromised by the time between referral and the actual consultation, which was about 3 months. Butow et al. showed that both patients' and physicians' self-reporting on the usefulness of an intervention differed from the results of verbatim transcripts of audiotaped consultations (Butow et al. 2004), underscoring the limited reliability of recall. Our data cannot easily be generalized to the whole of the Netherlands or to other countries because educational level and the amount and origin of migrants may vary among different regions.

An alternative study design to identify more reliably who initiated referral and identify decliners of referral might be helpful in the future. Recording details about patients by referral centres would be useful since in that way also details about decliners can be analysed. To gather more information about who initiated referral, a detailed questionnaire or checklist should be used in which not only initiator of referral is recorded but also who first brought up family history, risk of getting cancer and advice for screening. We would also like to expand our knowledge about reasons and motivations of physicians to decide not to refer a patient.

Implications for daily practice

For clinicians, this study shows that the patient plays an important role in the process of referral for genetic counseling. Special attention of physicians is needed for migrants and lower educated counselees eligible for genetic counseling. On the side of the genetics departments, the results of this study stress the need for continuous attention for educating physicians, patients and the general population about cancer genetic counseling, genetic testing and hereditary cancer.

Conflict of interest The authors declare that they have no conflicts of interest.

Appendix

Clinical setting: ❑ university hospital ❑ community hospital		Date of consultation:
Research number:		
Counselee: ❑ affected: ❑ breast cancer ❑ ovarian cancer ❑ colon cancer ❑ endometrial cancer ❑ other: …… ❑ not affected	*In family* ❑ breast cancer ❑ ovarian cancer ❑ colon cancer ❑ endometrial cancer ❑ other: ……..	*Eligibility for genetic testing:* ❑ diagnostic testing ❑ predictive testing ❑ not eligible for genetic testing ❑ MSI/IHC ❑ other:

Highest level of education achieved by counselee**:

❑ no education
❑ primary education
❑ lower secondary education
❑ preparing for vocational education
❑ general and vocational programmes preparing for tertiary education
❑ higher secondary education
❑ tertiary education

*Low = no education, primary education
Intermediate-1 = lower secondary education, preparing for vocational education
Intermediate-2 = general and vocational programmes preparing for tertiary education, higher secondary education
High = tertiary education

Initiator of referral

❑ counselee
❑ family member
❑ general practitioner
❑ medical specialist
❑ combined initiative:
  ○ initiative more from physician
  ○ initiative more from counselee
  ○ initiative equally
❑ other: ……

In which country are counselee and his/her parents born?

Counselee	*father*	*mother*
❑ The Netherlands	❑ The Netherlands	❑ The Netherlands
❑ Surinam	❑ Surinam	❑ Surinam
❑ Marocco	❑ Marocco	❑ Marocco
❑ Turkey	❑ Turkey	❑ Turkey
❑ Netherlands Antilles	❑ Netherlands Antilles	❑ Netherlands Antilles
❑ Aruba	❑ Aruba	❑ Aruba
❑ Other: ……..	❑ Other: ……..	❑ Other: ……..

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