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A pre-visit tailored website enhances counselees' realistic expectations and knowledge and fulfils information needs for breast cancer genetic counselling

AKKE ALBADA[1] , SANDRA VAN DULMEN[1], DICK LINDHOUT[2], JOZIEN M. BENSING[1], [3] AND MARGREET G. E. M. AUSEMS[2]

(1) NIVEL (Netherlands Institute for Health Services Research), P.O. Box 1568, 3500 BN Utrecht, The Netherlands

(2) Department of Medical Genetics, University Medical Center Utrecht, Utrecht, The Netherlands

(3) Department of Health Psychology, Utrecht University, Utrecht, The Netherlands

ABSTRACT

Counselees who are the first in their family to request breast cancer genetic counselling often don't know what to expect or have unrealistic expectations of genetic counselling. Receiving tailored information might help them to prepare for their first visit. We conducted a study of the effects of a pre-visit website providing computer-tailored information (E-info gene^{ca}), on counselees' expectations, knowledge about breast cancer and heredity and information needs. Counselees were randomized to receive usual care (UC) or UC plus website. All counselees completed a baseline questionnaire and those randomized to the intervention group also completed a questionnaire after having viewed the website. After having accessed E-info gene^{ca} counselees (n = 101) better knew what to expect of their first visit ($\chi^2 = 4.43$; P = .04) and less often showed unrealistic expectations about possibilities for DNA-testing ($\chi^2 = 4.84$; P = .03) than counselees in the UC group (n = 89). In addition, the website increased counselees' knowledge of breast cancer and heredity (B = .23; P = .003) and lowered their information needs (B = −.16; P = .000) compared to the UC group. Especially, information concerning procedural aspects and emotional consequences of genetic counselling was considered less important. This study showed that counselees know more and need less when they are provided with extended pre-visit information through a tailored website and counselees enter the visit with more realistic expectations of genetic counselling. This might facilitate and focus communication within the subsequent consultation.

INTRODUCTION

Increasingly breast cancer patients and their family members attend genetic counselling because they want to be informed about the genetic nature of the disease, their own and/or their children's risk and to receive surveillance advice [1–4]. Breast cancer genetic counselling aims to educate about these topics [5, 6].

However, a primary challenge for genetic counsellors is to communicate with counselees who do not know what to expect or have unrealistic expectations [7, 8].

Breast cancer genetic counselling consists of one to three visits. During the first visit, the occurrence of breast cancer and other cancers in the family is explored. This visit is mainly educative; counsellors explain the prevalence, indicators and inheritance of hereditary breast cancer, possibilities and limitations of diagnostic DNA-testing and the meaning of being carrier of a BRCA1/2 gene mutation [9]. Based on counselees' personal and family history of cancer, the likelihood that hereditary cancer is running in the family is estimated. Within most European countries and Australia, counselees may opt for a diagnostic DNA-test of the BRCA1/2 genes only after receiving an indication from the counsellor [10]. If there is no indication for diagnostic DNA-testing, the visit will include a risk estimation for the counselee and first degree family members and advice for surveillance when appropriate. If the counselee is opting for DNA-testing or confirmation of medical data from affected family members is needed, a second visit will follow. This second visit may serve to disclose DNA-test results, to further discuss the family medical history, or to discuss the option for DNA-testing. About two-third of all counselees is indicated for a follow-up visit [9].

Probands typically are unsure about what to expect from genetic counselling or have unrealistic expectations [11, 12]. They expect to be offered a DNA-test independent of their disease status and risk profile [7, 13, 14] and expect a clear-cut result about whether the breast cancer in their family is hereditary [15, 16]. However, the presence of hereditary cancer can not be ruled out, it can only be confirmed when a BRCA1/2 mutation is found. These unrealistic expectations need to be corrected during the first visit. Also, counselees pre-visit levels of knowledge about breast cancer and heredity show considerable scope for improvement, e.g. many women are unaware of modes of inheritance and incomplete penetrance [17, 18]. Generally, lay knowledge about hereditary breast cancer, autosomal dominant inheritance and possibilities of DNA-testing is poor [19–23] and therefore counsellors need to invest a large part of the consultation in explaining these topics [24, 25]. This results in large amounts of standard information transferred in the consultation [8, 9] and reduces the time available for discussing whether the counselee wants to be tested, the psychosocial consequences of testing and communication with family members. Consequently, counselees still report unfulfilled needs post-visit [26].

Provision of pre-visit information might help counselees to better prepare themselves for genetic counselling, which might increase realistic expectations and decrease information needs. Counselees have difficulties finding information [27]. While there is information on the internet, they find it difficult to decide whether it is reliable and applicable to them [28] and they prefer information from their hospital [29]. Information tailored to the individual increases the expected effects, since tailored information is perceived as more personally relevant [30], stimulates cognitive activity [31, 32] and is better recalled than generic information [33–36]. Web-based pre-visit information has shown to increase counselees' knowledge about breast cancer and heredity. It was however never evaluated as whether counselees felt the information prepared them for genetic counselling and whether it fulfilled their needs [37–39]. Evaluation of effects on counselees' expectations and information needs derived from the counselees' perspective is thus needed [25].

Therefore, the current study investigated whether access to a website with computer-tailored information increased counselees' realistic expectations, breast cancer knowledge and decreased their information needs. This website, called E-info gene[ca], provided extended information about genetic counselling and hereditary breast cancer, which was tailored to the individual counselee based on a number of characteristics e.g. her risk of being a carrier of a BRCA1/2 gene mutation [40]. Additionally, we studied whether time spent on the website influenced improvements in knowledge and information needs, as longer use is likely to increase learning [41, 42].

METHODS

Study design

This study was conducted at the department of Medical Genetics of the University Medical Center Utrecht (UMCU). Consecutive new counselees were included from February 2008 to April 2010 (Fig. 1). Adult female counselees who were the first of their first degree family to seek breast cancer genetic counselling received information about the study and an opt-out form. The opt-out form included a question about reasons of withdrawal. Counselees were ineligible if they lacked internet or email access or when they requested presymptomatic DNA-testing because of an identified BRCA1/2 gene mutation in a relative. All

counselees who did not return the opt-out form were allocated to the usual care (UC) or intervention group (UC + website E-info gene^{ca}) by use of sequentially numbered, sealed, opaque envelopes. UC comprised of a brief standard leaflet with information about the genetic counselling procedure. Counselees received a login to access the web-based baseline questionnaire a week before their first visit (T0). Upon completion the intervention group respondents received a link to access E-info gene^{ca}. Directly after having viewed E-info gene^{ca} they completed the post-website questionnaire (T1). The study was approved by the medical ethical committee of the UMCU and was registered in the Netherlands Trial Register (ISRCTN82643064).

[FIGURE 1]

E-info gene^{ca}

The pre-visit website, called E-info gene^{ca}, provided extensive information about the genetic counselling procedure, hereditary breast cancer, surveillance, DNA-testing, the meaning of being carrier of a cancer gene and emotional consequences of genetic counselling. These topics were based on a needs assessment [14]. The information was tailored to the individual counselee based on her age, disease status, whether she had children and her risk of being a carrier of a BRCA1/2 gene mutation. A high risk of being a mutation carrier meant that there was a chance of 10% or more that a BRCA1/2 mutation was present in the counselee or an affected family member, implying an indication for diagnostic DNA-testing. An algorithm for this risk included personal and family medical history (see Table 1) and was based on the Dutch national guidelines on diagnostics for hereditary cancers [43]. E-info gene^{ca} did not offer information on the risk for the individual counselee, as the website was meant as preparation for the face-to-face counselling. The website has been described in full elsewhere [40].

[TABLE 1]

Counselee characteristics

Age, whether the counselee had children, educational attainment, disease status, type of referral, initiative for the referral and whether first degree family members had (had) breast cancer were collected at T0.

Outcome measures

Counselees' expectations were assessed with an open question, 'What do you expect from your appointment at the department of Medical Genetics?' This was the last question of T0 for the UC group and the first question of T1 for the intervention group. Both T0 and T1 questionnaires included an assessment of the level of accurate knowledge about breast cancer and heredity with 7 items [18, 44]. Respondents indicated whether each item was correct, incorrect, or whether they did not know. An accurate knowledge score was computed as the number of correct answers. At T1 additionally, knowledge about the need for an indication for DNA-testing and the possibility of an inconclusive DNA-test outcome was assessed with two items. Finally, information needs were assessed at T0 and T1 with the QUOTE-gene^{ca} [14]. The items referred to explanations counselees wanted to receive during the first consultation and were answered on a 4-point scale (not important to extremely important). Earlier identified factors were used to summarize data (Table 4) [14].

Process measures

Usage of E-info gene^{ca} was recorded with web tracking services. Process analyses showed that counselees viewed on average 11 of the 19 web pages and spent a median of 14 min on E-info gene^{ca} [45].

Analysis

Counselees' answers to the open question about their expectations of the consultation were content-analyzed based on the items of the QUOTE-gene^{ca} (see Table 4). The coders were blinded for the intervention/UC condition. The first 30% of the responses were coded independently by both the first (AA) and the last author (MA). Agreement between coders was 80%. Disagreements were discussed and AA coded the remaining 70% of the responses. Additionally, both raters coded all answers to assess whether the

expectation was (partly) realistic or unrealistic concerning the counselling process, possibilities for and possible results of DNA-testing. Disagreements were discussed until consensus was achieved.

To check for baseline differences between the study groups, χ^2 and t tests were performed. To check for between-group differences we conducted χ^2 and multivariate regression analyses controlled for counselees' age, disease status, educational level, whether they had children and baseline levels. We conducted proportion tests and paired t tests to check for within-group differences of the intervention group (T0–T1). Two-sided tests of significance were performed and results were considered statistically significant when $P < .05$. Cohen's D effect sizes were calculated. Additionally, multivariate linear regression analyses were conducted for knowledge and needs at T1 with time spent on E-info gene^{ca}, baseline levels and counselee characteristics as independent variables. All analyses were conducted with Stata 10.

We compared the outcomes of two intention-to-treat analyses with an available case analysis for the effects of the website on the overall knowledge score and information needs [46]. The intention-to-treat analyses included all 190 cases with complete data at baseline (Fig. 1). Firstly, baseline outcomes were taken forward for the drop-outs. Secondly, we conducted regression imputation with random residuals.

RESULTS

Response

As shown in Fig. 1, few counselees were ineligible because of lack of internet or email access (24 of 371; 6.5%). The response was 58.6%. Half of the decliners gave a reason (72 of 139; 50.4%). Most preferred the visit not to be videotaped (46 of 72; 65.7%), which was part of the larger study. There were no significant differences between participants and decliners in age ($t = 1.62$; $P = .11$), disease status ($\chi^2 = .05$; $df = 1$; $P = .81$), family history of cancer ($\chi^2 = .06$; $df = 1$; $P = .82$) and referral pathway ($\chi^2 = 87$; $df = 1$; $P = .35$).

Counselee characteristics

As shown in Table 1, UC and intervention group respondents were similar with regard to age, having children, educational attainment, referral pattern and the risk of being a carrier of a BRCA1/2 mutation. However, the intervention group respondents tended to be affected more often with breast cancer themselves ($\chi^2 = 3.84$; $df = 1$; $P = .053$). Therefore, we checked the association between having (had) breast cancer and baseline knowledge ($t = .12$; $P = .91$) and controlled all analyses for disease status. One counselee was affected with ovarian cancer. There were no significant baseline differences in knowledge and information needs between the groups (Table 3).

Drop-out

All 101 intervention group respondents accessed E-info gene^{ca}, 7 viewed only the homepage. Sixteen (15.84%) did not complete the T1 questionnaire (drop-out). Amongst them were five of the respondents who had viewed only the homepage and therefore their baseline knowledge and information needs values were taken forward to T1. The other 11 drop-outs visited the website for on average 40:03 (min:sec), which is almost twice as long than the mean duration of 21:05 of all 101 intervention group counselees. Their baseline knowledge score was 3.82 (SD = 1.54), which is .82 lower than the mean of the intervention group (Table 3). These drop-outs were not included in the available case analysis.

Comparison of the outcomes with the conservative (baseline values forwarded) and regression imputation (predicted values imputed) intention-to-treat analyses showed that the intervention effects on the overall knowledge score, the information needs score and the need for information about procedural and emotional aspects of counselling were statistically significant for all three analyses, with smallest effect sizes in the conservative intention-to-treat analysis and largest effect sizes in the regression imputation intention-to-treat analysis. The conservative intention-to-treat analysis is likely to underestimate the effects because progress due to website visit was assumed to be zero [47]. The regression imputation resulted in the largest intervention effects. The available case analysis might thus give a small underestimation of the intervention effects and we therefore choose to report the results of this analysis as a relatively conservative approach.

Expectations of genetic counselling

More UC group than intervention group respondents indicated that they did not know what to expect of genetic counselling ($\chi^2 = 4.43$; $df = 1$; $P = .04$; Table 2). The other counselees wrote down an expectation and these were more often (partly) unrealistic in the UC than the intervention group. In the UC group 13 counselees expected to have a DNA-test irrespective of their risk profile, compared to four intervention

group respondents (χ^2 = 4.84; df = 1; P = .03). Respondents in the UC group tended to more often expect certainty about whether they were a carrier of a hereditary breast cancer gene than intervention group respondents (χ^2 = 3.08; df = 1; P = .08). Another expectation classified as unrealistic was "getting certainty about whether the breast cancer in our family is hereditary or not". Frequency of this unrealistic expectation was similar in the UC and intervention group.

[TABLE 2]

Eight intervention group respondents mentioned a particularly realistic expectation, namely to find out whether there would be an indication for DNA-testing in their family, compared to none of the UC group respondents (χ^2 = 7.36; df = 1; P = .007). Counselees also expected to receive information, mainly about their own and their family members' risks. The intervention group respondents significantly less often expected to receive information about the procedure of genetic counselling and about indications for hereditary breast cancer.

Knowledge of breast cancer and heredity

After having accessed the website, counselees had more knowledge of breast cancer and heredity compared to the UC group (B = .23; P = .003). The intervention group had increased their knowledge by reading the website, with a Cohen's D of .43, which is a medium effect size (t = 4.25; P = .000). Counselees had particularly gained knowledge concerning inheritance and penetrance of BRCA1/2 mutations (Table 3). The largest increase in knowledge concerned the chance to inherit a BRCA1/2 mutation via a father who is carrier. Additionally, after having accessed the website, the majority of counselees (67, 80.72%) knew that a DNA-test is not always indicated, and most (73.53%) of the counselees at high risk of being a mutation carrier were aware of the fact that a DNA-test can give an inconclusive test result.

[TABLE 3]

Multivariate analysis showed that only educational level predicted baseline knowledge (B = .19; P = .01). Less highly educated counselees levelled up their knowledge by using E-info gene^{ca}, as knowledge at T1 was unrelated to education (B = .06; P = .58). Analysis of knowledge at T1 controlled for baseline values showed that older counselees tended to benefit less from the website (B = −.17; P = .08). Time spent on the website was not associated with knowledge gain (B = .03; P = .75). However, there were several relations between website use and knowledge gain per item. First, duration of having viewed the page about inheritance predicted knowledge gain concerning paternal inheritance of hereditary breast cancer (B = .28; P = .001). Second, those who viewed the webpage about the meaning of being a carrier of a BRCA1/2 mutation tended to have more knowledge concerning the penetrance of those mutations (B = .14; P = .09). And third, counselees who had viewed the webpage about possible results of DNA-testing were more often aware of the possibility of an inconclusive test result (χ^2 = 22.3; df = 1; P = .000).

Information needs

After having accessed the website E-info gene^{ca}, counselees had significantly lower information needs compared to the UC group (B = −.16; P = .000). Overall information needs of intervention group counselees had decreased with a Cohen's D of .32 (t = −3.59; P = .001). Table 4 describes the factors and items for pre-visit information needs. At T1, the intervention group counselees had significantly lower needs for information about procedural aspects of counselling (d = .16) and there was a trend towards decreased needs for information about determination and meaning of being carrier of a cancer gene compared to baseline (d = .19). Additionally, information needs about emotional aspects for the counselee and her family had significantly decreased, the Cohen's D for this factor was .37. Concerning the heredity of breast cancer, the effect size was medium (.21), but the information needs only decreased for the topic of inheritance and not for the topic of prevalence. However, the need for information about prevalence tended to be lower if the web page about prevalence was viewed longer (B = −.16; P = .07). The need for information about the own risk of developing cancer and screening options did not significantly decrease.

[TABLE 4]

DISCUSSION

This is the first study of the effects of a pre-visit tailored website on counselees' realistic expectations of breast cancer genetic counselling and their feeling of information needs being addressed [48]. The study found positive effects on both these expectations and needs. Additionally, the study confirms previous findings that pre-visit web-based education enhanced breast cancer knowledge [33, 37–39] and this result is consistent with the established positive relationship between web-based patient education and knowledge levels [48, 49]. Now that a large majority of the counselees (94%) and of the general population (90% in the Netherlands and 74% in the USA) [50, 51] has access to the internet, it is feasible to provide web-based education. As extended pre-visit information does not seem to be provided routinely [11, 52], the results of this study hold advice for other cancer genetics centres. These show promise of a pre-visit tailored website as a way that genetic counselling can become more efficient without compromising the quality of care [25, 53].

First, results suggest that counselees better knew what to expect after having visited the website. Counselees in particular had more realistic expectations of possibilities for DNA-testing, i.e. not expecting a DNA-test irrespective of their risk profile. Additionally, counselees in the intervention group less often expected to receive information about the genetic counselling procedure and about indications of hereditary breast cancer during the visit, compared to the UC group. This improvement in counselees' expectations might limit their disappointment in case the risk assessment in the consultation does not result in an indication for DNA-testing in their family.

Second, after having read the website E-info gene^{ca} counselees in the intervention group had significantly higher levels of accurate breast cancer knowledge than the UC group. Counselees learned to avoid common mistakes, such as the negligence of inheritance through the father's pedigree and the assumption that all carriers will develop breast cancer. Since this study lacked a comparison group receiving non-tailored extended information, we can not disentangle the effects of the information being extended and tailored. However, given the evidence for effectiveness of computer-tailored information it seems plausible that tailoring has contributed to the effects [30, 33, 35, 54]. Moreover, tailored information has been found to enhance recall in cancer patients [55].

Third, the pre-visit tailored website significantly lowered counselees' information needs, especially concerning procedural and emotional aspects of counselling and determination and meaning of being carrier of a breast cancer gene. These improvements might alleviate the strain of education about the procedure of genetic counselling and DNA-testing within the first visit [56]. Also, the more realistic expectations and alleviated information needs might facilitate more in-depth and interactive discussion about the counselee's risk, whether she considers DNA-testing, emotional consequences for herself and her family members and communication with these relatives [57]. The need for information related to the own breast cancer risk remained counselees' priority and should thus be the main focus of the first visit.

Lastly, time spent on the website was not significantly associated with the overall knowledge score, but more time spent on the web page about inheritance significantly increased counselees' knowledge about inheritance through the paternal side.

Strengths and limitations

The website studied in the current report was integrated in everyday clinical practice and counselees accessed the website from their homes. This is promising for future implementation outside the study context [58] and limits bias to participation. There are some limitations. First, this was a mono-centre study. However, the UC condition consisting of a brief generic leaflet is comparable to the pre-visit information of other centres, as both nationally and internationally, centres do not seem to provide extended pre-visit information [4, 7, 11, 52]. Second, the full intention-to-treat analysis with imputed predicted values might result in a more accurate estimation of the effect size [47]. However, we choose to present the available case analysis. This might have resulted in a small underestimation rather than an overestimation of intervention effects. Third, the knowledge scale showed a ceiling effect. On at least two of the items hardly any improvements from baseline were possible and this might have hampered the effect size. Furthermore, based on the use of the breast cancer knowledge scale in prior studies [18, 44, 59], the learning effect of filling in the scale alone is negligible and could thus not bias the current study. Repeated measures of the scale show a gradual decrease in knowledge over time instead of an increase due to a learning effect [59].

However, completing the knowledge items could have enabled intervention group counselees to better process the website information, because the questions made them aware of their lack of knowledge. Educational websites could provide information in a feedback format, i.e. show the counselee's answer and provide explanation on the right answer, which was shown to enhance learning [60]. And finally, further study should investigate the longer-term impact of pre-visit education.

CONCLUSION

This study showed that counselees enter their first visit for breast cancer genetic counselling with more realistic expectations of genetic counselling if they are provided with extended pre-visit information through a tailored website. Additionally, these counselees know more and need less information. Use of a pre-visit tailored website might therefore reduce disappointment about the need for an indication for DNA-testing, reduce the amount of standard information to be transferred in the consultation and increase the time available for discussion of the counselee's risk perception, emotional issues and communication with relatives.

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FIGURES AND TABLES

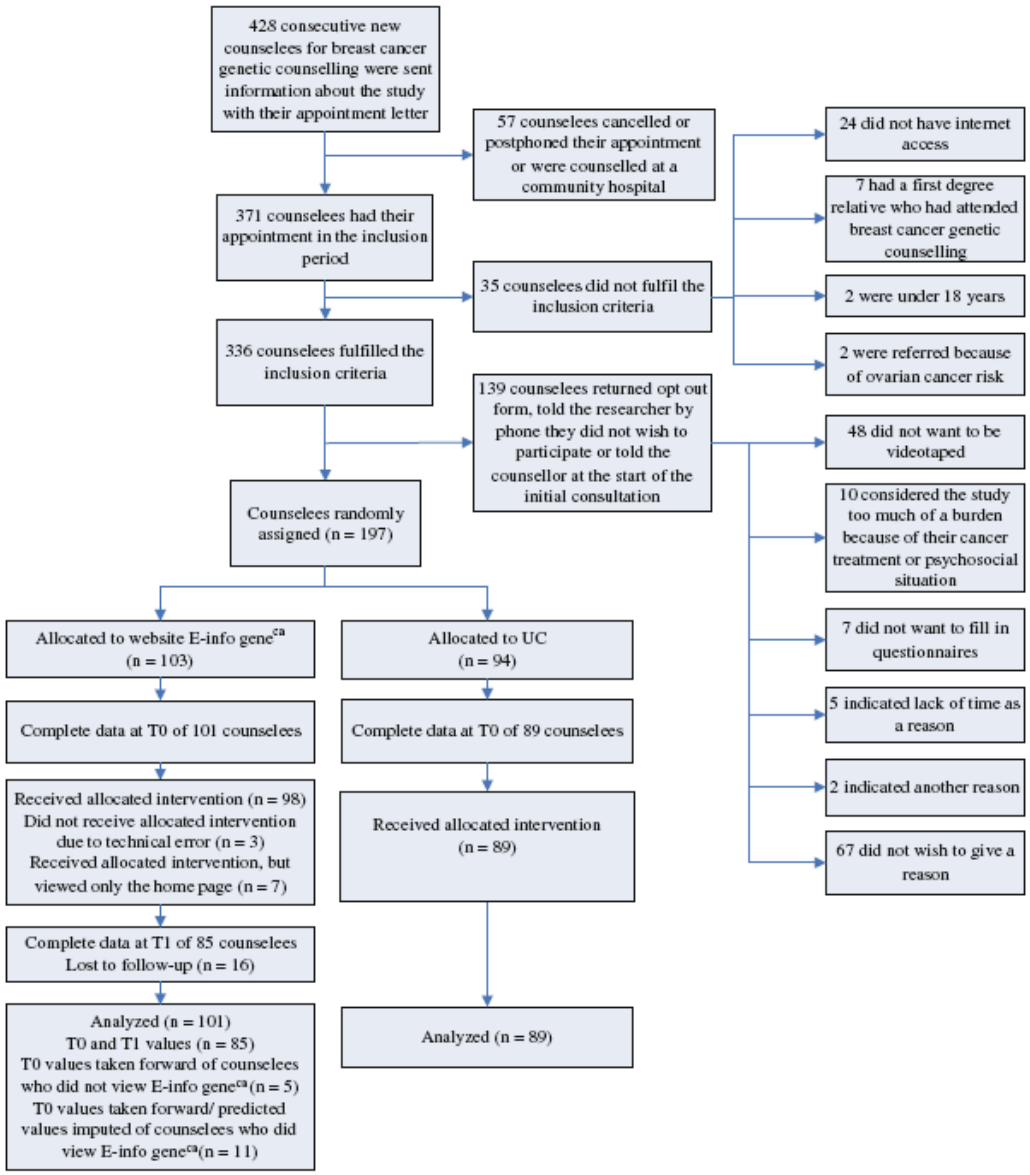

Fig. 1 Flow diagram

Table 1 Respondent characteristics ($N = 190$)

	UC group ($n = 89$)				Intervention group ($n = 101$)				P
	n	%	Mean	SD range	n	%	Mean	SD range	
Age (years) (age ≤ 50)[a]	71	79.78	41.18	11.76 21–68	75	74.26	41.76	11.35 21–69	.82
Children (having children)[a]	61	68.53			69	69.00			.78
Educational attainment									
University (MSc/BSc)/higher vocational education (BSc)	42	47.19			36	35.64			.22
Middle vocational education	22	24.72			31	30.69			
High school/secondary education	22	24.72			33	32.67			
<High school level	3	3.37			1	.99			
Referral pathway									
GP	48	55.17			43	43.00			.19
Specialist consultant UMC	21	24.14			26	26.00			
Specialist consultant peripheral hospital	18	20.69			31	31.00			
Initiative for referral									
Counselee	34	38.20			28	28.00			.30
Both counselee and physician	27	30.34			44	44.00			
Consultant	18	20.22			18	18.00			
GP	7	7.87			4	4.00			
Personal history of breast cancer (affected)[a]	29	32.58			47	46.53			.053
1st degree relatives affected with breast cancer	47	52.81			54	53.47			.93
Risk of being BRCA1/2 mutation carrier (high)[a,b]	39	46.99			43	43.88			.72

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[a] Variables used to tailor the information on the website E-info gene[ca]

[b] Algorithm for this tailoring variable: IF (bc affected AND age at diagnosis ≤ 40) OR (bc affected AND oc affected) OR (bc affected AND first/second degree family members affected with oc) OR (number of first degree family members affected with bc > 1) OR (number of first degree family members affected with oc ≥ 1) OR (first/second degree family members affected with bc AND first/second degree family members affected with oc) OR (bilateral bc AND 1st diagnosis at age < 50) OR (oc affected AND first/second degree family members affected with bc): risk of being BRCA1/2 mutation carrier = high

an indication for DNA-testing and the possibility of an inconclusive DNA-test outcome was assessed with two items. Finally, information needs were assessed at T0 and T1 with the QUOTE-gene[ca] [14]. The items referred to explanations counselees wanted to receive during the first consultation and were answered on a 4-point scale (not

based on the items of the QUOTE-gene[ca] (see Table 4). The coders were blinded for the intervention/UC condition. The first 30% of the responses were coded independently by both the first (AA) and the last author (MA). Agreement between coders was 80%. Disagreements were discussed and AA coded the remaining 70% of the responses.

Table 2 Topics of counselees' expectations concerning their first visit for breast cancer genetic counselling

Expectations[a]	UC group ($n = 86$)[b]		Intervention group ($n = 78$)[c]		P*
	n	%	n	%	
Don't know what to expect	7	8.14	1	1.28	.04
Unrealistic expectations					
DNA-test (irrespective of risk profile)	13	15.12	4	5.13	.03
Certainty about whether the breast cancer in the family is hereditary	9	10.47	9	11.54	.92
Knowing whether I am a carrier	18	20.93	9	11.54	.08
Realistic expectations					
Get to know more about whether there is an indication for DNA-testing in the family	0	.00	8	10.26	.007
Information/advice about					
Counselee's own risk	44	51.16	39	50.00	.13
Family members' risk	11	12.79	18	23.08	.41
The procedure of genetic counselling	19	22.09	9	11.54	.02
Options for breast cancer screening	14	16.28	9	11.54	.15
Possibilities of DNA-testing	12	13.95	12	15.39	.74
The meaning of being carrier of a BRCA1/2 mutation	6	6.98	3	3.85	.22
Indications for hereditary breast cancer	10	11.63	3	3.85	.02
Inheritance of breast cancer	3	3.49	6	7.69	.41

* Between-group differences of UC and intervention group

[a] More than one expectation is possible

[b] Three missing values

[c] Seven missing values

Table 3 Counselees' level of accurate knowledge about breast cancer and heredity

Scale	Baseline (T0)				Post-website (T1)		P*	P**
	UC group ($n = 89$)		Intervention group ($n = 101$)		Intervention group ($n = 90$)			
	Mean	SD	Mean	SD	Mean	SD		
Accurate knowledge (0–7)*	4.65	1.46	4.64	1.60	5.29	1.39	.003	.000
True/false knowledge items	Correct answer		Correct answer		Correct answer			
	n	%	n	%	n	%		
Early detection and treatment of bc lead to longer survival than late detection and treatment (true)	86	96.63	98	97.03	89	98.89	.24	.37
All women who are carrier of an altered gene (mutation) for bc, will develop bc in the long term (false)	39	43.82	47	46.53	54	61.36	.01	.04
A woman who has a sister with an altered gene (mutation) for bc, has a 50% chance (1 in 2) to also carry the mutation herself (true)	31	35.23	34	33.66	42	47.73	.02	.049
A woman who does not have an altered gene (mutation) for bc, can nevertheless develop bc (true)	70	78.65	77	77.78	73	81.11	.39	.57
Physical examination is necessary only when you have complaints; at that point it is soon enough to prevent bc (false)	84	94.38	93	93.00	80	88.89	.24	.32
If a father has an altered gene (mutation) for bc, then his children have 50% chance (1 in 2) of also having this mutation (true)	27	30.34	38	37.62	49	56.32	.003	.01
If in a family, in which bc frequently occurs, no altered gene (mutation) for bc is found, then regular breast surveillance is no longer necessary (false)	77	86.52	82	81.19	80	88.89	.33	.14

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* Between-group differences of UC and intervention group; ** within-group differences of intervention group baseline versus T1

Table 4 Counselees' information needs concerning breast cancer genetic counselling

	Baseline (T0)				Post-website (T1)		*P**	*P***
	UC group ($n = 89$)		Intervention group ($n = 101$)		Intervention group ($n = 90$)			
	Mean	SD	Mean	SD	Mean	SD		
Information needs (1–4)	3.12	.38	3.10	.41	2.96	.46	.000	.001
Factors and items								
'During the counselling, the counsellor should provide information about…'								
Procedural aspects of counselling	2.93	.52	2.82	.58	2.73	.59	.000	.047
Clear division of roles between counsellors	3.19	.58	3.08	.67	2.86	.70	.003	.01
How long the diagnostic procedure takes	2.87	.74	2.70	.83	2.71	.74	.48	.24
Communication with family members	2.72	.74	2.65	.79	2.49	.72	.10	.02
Emotional aspects of the diagnostic procedure	2.96	.74	2.86	.88	2.63	.81	.008	.000
Determination and meaning of being a carrier of a cancer gene	3.32	.47	3.33	.49	3.23	.55	.03	.054
Possibilities of DNA-testing	3.23	.69	3.25	.62	3.20	.69	.26	.44
Limitations of DNA-testing	3.17	.74	3.23	.63	3.12	.72	.03	.07
Procedure of DNA-testing	3.21	.68	3.18	.67	3.10	.72	.10	.18
What it means to be a carrier of a breast cancer gene	3.43	.56	3.49	.58	3.34	.67	.055	.11
Why the counselee is (not) considered for further examination	3.55	.52	3.44	.50	3.33	.50	.04	.10
What it means to be a carrier of a certain gene	3.32	.58	3.41	.60	3.27	.70	.15	.28
Emotional aspects for counselee and family	3.13	.55	3.08	.59	2.87	.55	.000	.000
Emotional consequences of genetic counselling for the family	3.17	.73	3.08	.82	2.83	.78	.000	.001
Emotional consequences of genetic counselling for the counselee	3.06	.77	2.99	.84	2.81	.78	.000	.001
Procedure of analysis of the family history	3.38	.57	3.39	.57	3.06	.31	.04	.04
What it means not to be a carrier of a cancer gene	3.11	.63	3.20	.75	2.90	.86	.001	.003
Own risk of developing breast cancer	3.44	.47	3.46	.56	3.36	.58	.13	.14
What to do if the counselee has an increased risk of developing breast cancer	3.70	.46	3.69	.52	3.63	.53	.21	.32
What to do if the counselee does not have an increased risk of developing breast cancer	3.18	.67	3.23	.73	3.06	.79	.04	.03
Heredity of breast cancer	2.67	.53	2.80	.53	2.67	.70	.07	.12
The prevalence of breast cancer	2.35	.77	2.29	.75	2.31	.89	.76	.65
How often is breast cancer hereditary	2.76	.66	2.84	.66	2.72	.77	.34	.37
How breast cancer inherits in a family	3.18	.62	3.27	.55	3.00	.75	.001	.002

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* Between-group differences of UC and intervention group; ** within-group differences of intervention group baseline versus T1