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## Follow-up effects of a tailored pre-counseling website with question prompt in breast cancer genetic counseling

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### ABSTRACT

**Objective:** Pre-counseling education helps counsees to prepare for breast cancer genetic counseling and might subsequently result in more positive experiences, improved cognitive outcomes and more experienced control. This study assessed the effects of a website with tailored information and a blank sheet to fill in questions (question prompt; QP), at 1 week and 1 year post-counseling.

**Methods:** Consecutive counsees were randomized to the usual care group (UC) or the intervention group (UC + website + QP). Counsees completed questionnaires pre- and post-counseling and 1 year follow-up. We conducted multilevel regression analyses corrected for time.

**Results:** Intervention group counsees (n = 103) were more satisfied about their final visit ( $\beta = .35$ ; CI: .06–.65; P = .02; n = 156) than UC group counsees (n = 94). Intervention group counsees also reported more positive experiences with the counseling ( $\beta = .32$ ; CI: .06–.59; P = .02; n = 188) and higher perceived personal control 1 year post-counseling ( $\beta = .51$ ; CI: .18–.84; P = .002; n = 193). No significant effects were found on recall, knowledge, anxiety, cancer worry, risk perception alignment and adherence to breast surveillance advice.

**Conclusion:** This study shows that pre-counseling education providing tailored information and QP, might lead to improvements in experiences with the counseling and perceived personal control 1 year post-counseling.

**Practice implications:** Online pre-visit information is a feasible tool to enhance counsees' experiences.

## 1. INTRODUCTION

Breast cancer patients and their relatives can be referred to genetic counseling to receive education about their breast cancer risk and risk management advice [1]. Genetic counseling aims to enhance feelings of personal control [2] and adherence to surveillance recommendations and to lower breast cancer worry [3]. To make (informed) decisions, counsees need to correctly recall the provided risk information, the surveillance recommendations and the advice on how to communicate the test results with relatives [4] and [5].

Breast cancer genetic counseling has proven to be reasonably effective in achieving improvements in counsees' level of breast cancer worry [6] and in their perceived personal control [7] and [8]. However, counsees' recall of information from the counseling and the transmission of this information to their relatives are still impaired [9] and [10]. Furthermore, while most counsees intend to adhere to the surveillance advice [11], their actual surveillance uptake remains suboptimal [12]. Moreover, genetic counseling appears to lead to improvements in counsees' knowledge about breast cancer genetics [12] and in their risk perception but anxiety levels only show a modest decrease [7], [13], [14] and [15]. Besides, after genetic counseling most counsees continue to overestimate their risks [7], [13] and [16]. To enhance breast cancer genetic counseling outcomes, counsees have been provided with pre-counseling information. Such information shows to improve counsees' satisfaction [17] and their levels of knowledge after the first visit [18] and [19]. Pre-counseling information might become even more effective by tailoring such information to the individual, since tailored information is better recalled than generic information [20] and [21]. Apart from tailored information, a pre-counseling Question Prompt (QP) on which counsees can write their questions might have additional effect by stimulating more active counselee communication during the counseling [Henselmans 22] and thereby enhancing counsees' recall of information [23], [24] and [25]. To this purpose, the web-based intervention E-info gene<sup>ca</sup> was developed with information about, for instance, the procedure of counseling and DNA-testing and emotional consequences [26]. The information was computer-tailored [20] to individual counselee's breast cancer status, her risk (based on the cancer family history), age and having children [27]. Additionally, the website provided a blank QP where counsees could write their questions and gave communication advice for the consultations, e.g. 'please pose all your questions and ask for clarification' [28].

In evaluating the effects of pre-counseling information, relevant long term key outcomes of genetic counseling, i.e. information recall, breast cancer worry, perceived personal control and adherence to surveillance recommendations, have not yet been studied. Also, counsees' experience with genetic counseling has not been considered, while this is an important outcome to involve the counsees' perspective [2]. Therefore, an RCT was conducted to test the effects of the pre-counseling, preparatory website E-info gene<sup>ca</sup>. Prior papers about this study showed that intervention group counsees were better prepared for the counseling, in terms of knowledge of breast cancer and heredity and in terms of information needs, after being provided with access to the website [29]. In their first visit, these counsees showed more assertive communication, such as orienting and paraphrasing statements, than counsees in the usual care (UC) group [30]. However, counsees did not ask more questions [30].

As a result of the increased levels of pre-counseling knowledge and more assertive communication during the first visit, counsees might be able to better process the information [31] and [32]. This might result in higher levels of knowledge, information recall and a more positive evaluation of the counseling. Increased recall of information received in the final consultation might be beneficial for the alignment of the counsees' risk perception with the counselor's estimation, breast cancer worry and adherence to the surveillance recommendations. More positive experiences with the counseling have been shown to be associated with improved perceived personal control and lower anxiety rates [5] and [33].

The present paper focuses on the intermediate and long-term effects of E-info gene<sup>ca</sup>. We hypothesize that the intervention group will show better outcomes than the usual care group for the key outcomes of genetic counseling, i.e. information recall post-counseling and breast cancer worry, perceived personal control and adherence, 1 year post-counseling. We also hypothesize that counsees in the intervention group will have higher scores on satisfaction, experiences with the counseling, knowledge, risk perception alignment and lower rates of anxiety at 1 week and 1 year post-counseling.

## 2. METHODS

### 2.1. Study design

This study was conducted at the department of Medical Genetics of the University Medical Center (UMC) Utrecht. The study was approved by the institutional medical ethical committee and registered in the Dutch Trial Register (ISRCTN82643064). All new consecutive counsees, aged 18 years or older, who were the first in their family to seek breast cancer genetic counseling, were sent information about the study and an opt-out form from February 2008 to April 2010. Counsees were ineligible if they lacked Internet or email access or when they requested pre-symptomatic DNA-testing in the presence of an identified *BRCA1/2* gene mutation in a relative. All counsees who did not return the opt-out form were randomly assigned 1:1 to the Usual Care (UC) group or the intervention group (UC + website + QP) by a secretary unaware of respondent characteristics using sequentially numbered, sealed, opaque envelopes. UC included a brief standard pre-visit leaflet with information about the counseling procedure and breast cancer genetic counseling according to the Dutch guideline [34] and similar to that provided by the other eight family cancer clinics in the Netherlands. Both UC and intervention group respondents received a login to access the web-based baseline questionnaire (T0). Upon completion of this questionnaire the intervention group respondents received a link to the website E-info gene<sup>ca</sup>. At the start of the first consultation the counselor collected the informed consent form. In the first visit the counselor estimated the risk that the breast cancer in the family was hereditary. There was an indication for DNA-testing for the counslee or an affected relative if the risk of carrying a *BRCA1/2* gene mutation was estimated to be at least 10%. If a DNA-test was performed, counsees attended a follow-up visit approximately 4–6 months later to receive the test results. Regardless of whether there was an indication for DNA-testing, counsees received an estimation of the breast cancer risk for themselves and, if relevant, for first degree relatives. The visits were videotaped with an unmanned camera directed at the counselor. Counslee survey assessments were at approximately 1 week after the final visit (which could either be the first consultation

or the follow-up consultation): T3, and approximately 1 year after the final visit (T4), ( Fig. 1). Counselees received a summary letter approximately 1 month after the final visit. Ninety-six counselees attended a (intermediate) visit before their final visit. Six of these counselees also had a second intermediate visit. The broader study also included short-term survey assessments after these visits, T1 and T2 respectively. Only questionnaires at T0, T3 and T4 were taken into account in the current paper.

#### [FIGURE 1]

All fourteen breast cancer genetic counselors of the department participated and counseled 4–29 counselees each. Six were genetic counselors of whom three were in training; three were clinical geneticists and five were residents in clinical genetics.

### 2.2. Counselee characteristics

Age, having children, family cancer history and education were assessed in the baseline counselee questionnaire. All but the latter two were derived from the medical file if missing. The breast cancer disease status, referral, indication for DNA-testing and test uptake were derived from the medical file. The indication was unclear for three counselees and was therefore derived from what the counselor had filled in on a questionnaire after the final visit. This questionnaire also assessed the counselor's estimation of the counselee's risk to (re-)develop breast cancer in the future on a visual analog scale (VAS) from 0 to 100%. When applicable, this risk estimation was updated with information from the medical file in case of changes in the family cancer history. Risk estimations were based on the Claus tables and the Claus extended formula as integrated in the Dutch guideline [35].

### 2.3. Questionnaires

The T3 questionnaire assessed the *satisfaction* with the final consultation with the Patient Satisfaction Questionnaire (PSQ) [36]. The PSQ consists of five items assessed on a VAS anchored by 'not at all satisfied' and 'extremely satisfied'. The items assess the satisfaction with needs being addressed, the involvement, information, emotional support and the interaction in general. One additional item [36] assessed the satisfaction with the level of shared decision making. The mean of all six items was computed.

Counselees' recall of information from the visit was assessed in the T3 questionnaire with seven questions. Each question prompted a topic of the final consultation based on the counselees' information needs, e.g. limitations of DNA-testing and involving family members [26]. Each question started with an indication of whether the topic was discussed. Answer options were (1) no, not discussed, (2) yes, discussed but I don't remember what was said, (3) yes, namely. With the latter, the counselee was invited to write down what she recalled [37]. Coders assessed whether the topic was discussed and compared the recalled items with the items mentioned by the counselor in the videotaped final visit. If all items regarding a topic discussed were (correctly) recalled two points were given, if not all items were correctly recalled one point was given and if no items were correctly recalled 0 points were given. The percentage of accurate recall was calculated by dividing the sum of these points for all seven topics by the highest possible score based on the number of discussed topics. A second coder coded a random 10%. Interrater reliability (intra class correlation) of the recall percentage was .94.

Intention to adhere and adherence to breast surveillance recommendations were only determined for breast cancer unaffected counselees as affected counselees receive surveillance recommendations of their surgeon based on the national guideline [34]. At T3 the intention was assessed with the question, 'Do you think you will have a mammogram every year or at least once every 2 years if indicated?' [11]. The T4 questionnaire assessed whether the counselee had mammography and/or MRI in the past year (no/yes, if yes, how many times) and whether she had risk reducing breast surgery [38] and [39]. Adherence to surveillance recommendations was determined with algorithms (syntax available on request) comparing the mammography/MRI uptake in the last year to the advice according to the Dutch guideline based on the counselees' breast cancer risk and age [34, Appendix A]. If the advice was to participate in the National Screening Program that involves biennial mammography, then the mammography uptake in the year before the final visit was also considered based on the questionnaire after the final visit. The medical file was checked to see if the counselor's advice deviated from the guideline. For some counselees the counselor had recommended surveillance from younger age and this was incorporated in the determination of the adherence. Adherence to surveillance recommendations was scored one in case of agreement and zero in case of no agreement.

Experiences with the counseling were measured at T3 and T4 using the evaluation scale of the QUOTE-gene<sup>ca</sup> (quality of counseling through counselees eyes scale for cancer genetic counseling). This scale evaluates experiences regarding counselees' needs assessed before the counseling [26] and [29]. Evaluation scores indicating how well a need was addressed range from 1 to 4 (inadequate–more than adequate) [33]. The QUOTE-gene<sup>ca</sup> includes experiences regarding generic needs (procedural aspects, sensitive communication, emotional support and assessment of susceptibility to disease) and cancer genetic information needs (determination and meaning of being a carrier, emotional aspects of counseling for counselee and family, counselees' risk and heredity of cancer) [26]. The mean of all items, the mean of all 25 items of generic needs and the mean of all 19 items of cancer genetic information needs were computed separately.

#### **2.4. Additional measures assessed at T0, T3 and T4**

*The level of accurate knowledge about hereditary breast cancer*, using seven items [33]. Respondents indicated whether each item was correct, incorrect, or whether they did not know. The number of correct answers was computed; *Anxiety*, assessed with the validated Dutch state version of the State-Trait Anxiety Inventory (STAI; 10 items) [33]. Scores range from 10 to 40; Counselees' feelings of being in control as related to the possibility of carrying a hereditary condition, assessed using the 9-item validated Dutch version of the *Perceived Personal Control* questionnaire (PPC) [33] and [40]. The mean score of all items ranges from 0 to 2 with high scores indicating high perceived control; The *cancer worry* scale to assess the breast cancer-specific worry in the past 2 weeks [41]. Three questions assessed the frequency of worry about breast cancer, influence on mood and interference with daily activities with 4-point response categories (almost never to almost always). One item assessed the extent of the worry (1 not at all to 4 very much). The mean of the four items was computed; Finally, counselees rated their perceived risk that they would (re-)develop breast cancer on a VAS from 0 to 100%. *Risk perception alignment* was defined as the agreement between counselee's and counselor's estimation within the categories of

breast cancer population risk: slightly increased (<20%), moderate (20–30%) or high risk ( $\geq 30\%$ ). This measure of risk perception accuracy was chosen because the surveillance advice is based on these risk categories [3].

## 2.5. Analysis

Participants vs. decliners and intervention vs. UC group counsees were compared on socio-demographics and disease status using Chi-squared tests and *t*-tests. Seven missing values on education were imputed with the median. Six missing values for breast cancer risk were imputed with the mean risk of the group of counsees with the same disease status and DNA-test result (for five counsees: breast cancer affected with an uninformative result, for one counselee: unaffected and no indication for DNA-testing in the family).

To account for the multilevel structure of counsees (level 1) nested within counselors (level 2), multilevel regression analyses with random intercept were conducted. This method corrects for the number of counsees that were counseled by the same counselor. Counsees were nested with the counselor of their first consultation and the final consultation was mostly (90 out of 96) performed by the same counselor. The percentage of variance explained at the counselor level (ICC) ranged from zero for knowledge to 12% for experiences with the counseling. All analyses were controlled for counselee age, breast cancer disease status, education, whether there was more than one consultation, whether the counselee or a relative received an indication for DNA-testing. All analyses, except for risk perception alignment, were also controlled for breast cancer risk.

For variables with a baseline value available, i.e. knowledge, anxiety, perceived personal control, breast cancer worry and risk perception alignment, repeated measures analyses were conducted, as these adjust for missing values while incorporating all cases with at least one data point available. Five counsees failed to complete both T0 and T3 and could therefore not be included in the repeated measures analyses. There were no significant differences in age, disease status, breast cancer risk and indication for DNA-testing between these five counsees and the responders. Also, there were no significant differences in these characteristics with non-responders of T4. The reported *P*-value of the repeated measures analyses concerns the interaction between time and group allocation, while controlling for the main effects of these variables.

Missing values for experiences with the counseling were imputed with the nearest earlier data point (T3) or (T1), (Last Observation Carried Forward, LOCF).

Consequently, only counsees of whom no data point was available were excluded, resulting in 181 (T3) and 188 (T4) counsees in the analyses. The outcome measures satisfaction with the final visit, recall of information from the final visit, surveillance intention and adherence were measured only once and therefore the analyses with these measures included only counsees with complete data (available case analyses). The reported *P*-values of the LOCF and available case analyses concern the group allocation. Analyses were conducted using Stata 12.

## 2.6. Sensitivity analyses

We ran sensitivity analyses by additionally conducting available case analyses for the experiences with the counseling, knowledge, anxiety, breast cancer worry, perceived personal control and risk perception alignment. The analyses were controlled for counselee age, breast cancer disease status, education, whether there was more than

one consultation, whether the counselee or a relative received an indication for DNA-testing, breast cancer risk and the baseline value (except for experiences with the counseling as no baseline value was available for this variable).

### 3. RESULTS

#### 3.1. Response

Few counselees were ineligible because of lack of internet or email access (24 of 371; 6.5%; Fig. 1). 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 (48 of 72; 66.7%). There were no significant differences between participants and decliners in age, disease status, family history of cancer and referral pathway.

#### 3.2. Counselee characteristics

As shown in Table 1, UC and intervention group respondents were similar with regard to all background characteristics except for the personal history of breast cancer ( $\chi^2 = 4.34$ ;  $P = .04$ ). Therefore, all analyses were controlled for breast cancer status. One counselee was affected with ovarian cancer. About three-quarters of counselees received an indication for DNA-testing for themselves or an affected relative. In more than half of these cases the DNA-test was performed. Reasons for not performing this test were that the counselee or affected relative refrained from further testing or that the affected relative was deceased. There were no significant differences in uptake of DNA-testing or in baseline values of knowledge, anxiety, perceived personal control, breast cancer worry and risk perception alignment between the study groups. Most DNA-test results were uninformative, i.e. no BRCA mutation was detected. Four counselees had prophylactic breast surgery. These four counselees were breast cancer affected and two of them were BRCA1/2 carriers.

[TABLE 1]

#### 3.3. Outcomes 1 week post-counseling (T3)

Counselees in the intervention group were more satisfied about their final visit than counselees in the UC group ( $\beta = .35$ ; CI: .06–.65;  $P = .02$ ). Information recall and intention for adherence to surveillance advice were similar in both study groups (Table 2). At T3, there were no significant differences between the study groups in experiences with the counseling (Table 3), knowledge of breast cancer and heredity, anxiety, perceived personal control, breast cancer worry and breast cancer risk perception alignment (Table 4).

[TABLE 2][TABLE 3][TABLE 4]

#### 3.4. Outcomes 1 year post-counseling (T4)

The percentage of breast cancer unaffected counselees who adhered to the surveillance advice was similar in both study groups (Table 2). Almost all non-adherent counselees performed more surveillance (mammography/MRI) than recommended. At T4, intervention group counselees had higher evaluation scores for experiences with the counseling than UC group counselees ( $\beta = .32$ ; CI: .06–.59;  $P = .02$ ) and this held true for both experiences concerning cancer genetic information and generic experiences (see Table 3). Intervention group counselees also reported higher levels of perceived personal control at T4, compared to UC group counselees

( $\beta = .51$ ; CI: .18–.84;  $P = .002$ ; Table 4). There were no significant differences between the study groups in knowledge of breast cancer and heredity, anxiety, breast cancer worry and breast cancer risk perception alignment.

### 3.5. Improvements over time

There was a significant increase in knowledge and risk perception alignment and a significant decrease of breast cancer worry between T0 and T3 (main effect of time; Table 4). Between T0 and T4, there was a significant increase of knowledge and a significant decrease of anxiety.

### 3.6. Sensitivity analyses

Available case analyses, which are less stringent and inferior as they include only the counselees with complete data, reported significant group differences on anxiety after the final visit ( $N = 166$ ;  $P = .02$ ) and experiences with the counseling after the final visit ( $N = 172$ ;  $P = .049$ ). Notably, the group difference for generic experiences 1 year after the counseling was not significant ( $N = 162$ ;  $P = .08$ ). Other significant group differences as reported were also significant in the available case analyses, i.e. experiences with the counseling 1 year post counseling ( $N = 162$ ;  $P = .02$ ), experiences with cancer specific information 1 year post counseling ( $N = 161$ ;  $P = .01$ ) and perceived personal control 1 year post counseling ( $N = 157$ ;  $P = .01$ ). Available case analyses showed no significant group differences for knowledge, breast cancer worry and risk perception alignment.

## 4. DISCUSSION AND CONCLUSION

### 4.1. Discussion

This study suggests that pre-counseling web-based education (E-info gene<sup>ca</sup>), providing tailored information and a QP, leads to improvements in experiences with genetic counseling for hereditary breast cancer and perceived personal control 1 year post-counseling. Counselees in the intervention group were also more satisfied about the final visit compared to the UC group. As these results reach further than only cognitive outcomes and concern long term effects, the current study extends findings of prior studies on pre-visit education for breast cancer genetic counseling [18] and [19]. Prior studies of E-info gene<sup>ca</sup> showed that counselees were better prepared for the counseling due to the website [29]. The current study shows that this leads to more positive experiences with counseling and to higher levels of personal control in the long term, one of the key outcomes of genetic counseling.

However, the current study showed no improvements in the other key outcomes, such as information recall, breast cancer worry and adherence. Information recall showed no significant group differences, while only half of the important information was recalled correctly. Future endeavors should find ways to further increase recall. Moreover, the short term improvements in knowledge as a result of pre-counseling education [18], [19] and [29] did not last as there were no effects on knowledge post-counseling. The pre-counseling website did also not induce improvements in alignment of the counselee's risk perception with the counselor's risk estimation. Many counselees still overestimated their risk post-counseling as found in prior studies [13]. There were also no significant effects on anxiety. Both anxiety and breast cancer worry decreased from baseline to follow-up, in accordance with earlier research [6], [7] and [8]. As most counselees were at population risk or slightly increased risk, this decrease is appropriate. However, the website did not



further enhance this improvement. As an explanation, the pre-counseling website provided information, but was little affect-oriented and did not provide coaching about how to deal with risks and fears. Additionally, there was not more psychosocial talk in the consultations [30]. Counselors' pre-counseling preparation with an informative website thus shows to be insufficient to enhance recall and to lower counselors' breast cancer worry, but does seem to give counselors tools to better handle their risk as they perceived increased personal control.

#### **4.2. Methodological reflections**

There are some limitations. First, we cannot be sure that the outcomes for satisfaction, recall, surveillance intention and adherence extend to the counselors who did not complete the last questionnaires. Second, counselors were not blinded to group allocation as they received counselors' QP. Third, the response rate is moderate, but relatively high for studies using video recordings of genetic counseling visits [33]. Importantly, there were no significant differences between responders and decliners and the results are therefore representative for breast cancer genetic counselors. Fourth, the high percentage of missing values on risk perception and satisfaction were due to a technical error in the web-based questionnaire and are therefore unlikely to be related to counselor characteristics. Fifth, as we have studied the effects of a combined intervention, we cannot distinguish effects of tailored information and the QP. The counselors could have learned from reading information on the website [29] and from the endorsement of the QP in the first visit [30]. Finally, as the usual care consisted of a brief leaflet with generic information about the genetic counseling procedure, we are unable to conclude whether more elaborate tailored web information results in better outcomes than similar generic web information. Further studies should show which component induces most effects.

#### **4.3. Conclusion**

This study showed that when counselors were offered a website with tailored information and QP to prepare for their first visit, this leads to more positive experiences with counseling and higher rates of perceived personal control 1 year post-counseling.

#### **4.4. Practice implications**

Online pre-counseling information is a feasible tool to enhance counselor's experiences. The studied website was only accessible before the first visit. Additional tailored information in between the visits and post-counseling could be studied for extended benefits.

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## [APPENDIX A. SUPPLEMENTARY DATA]

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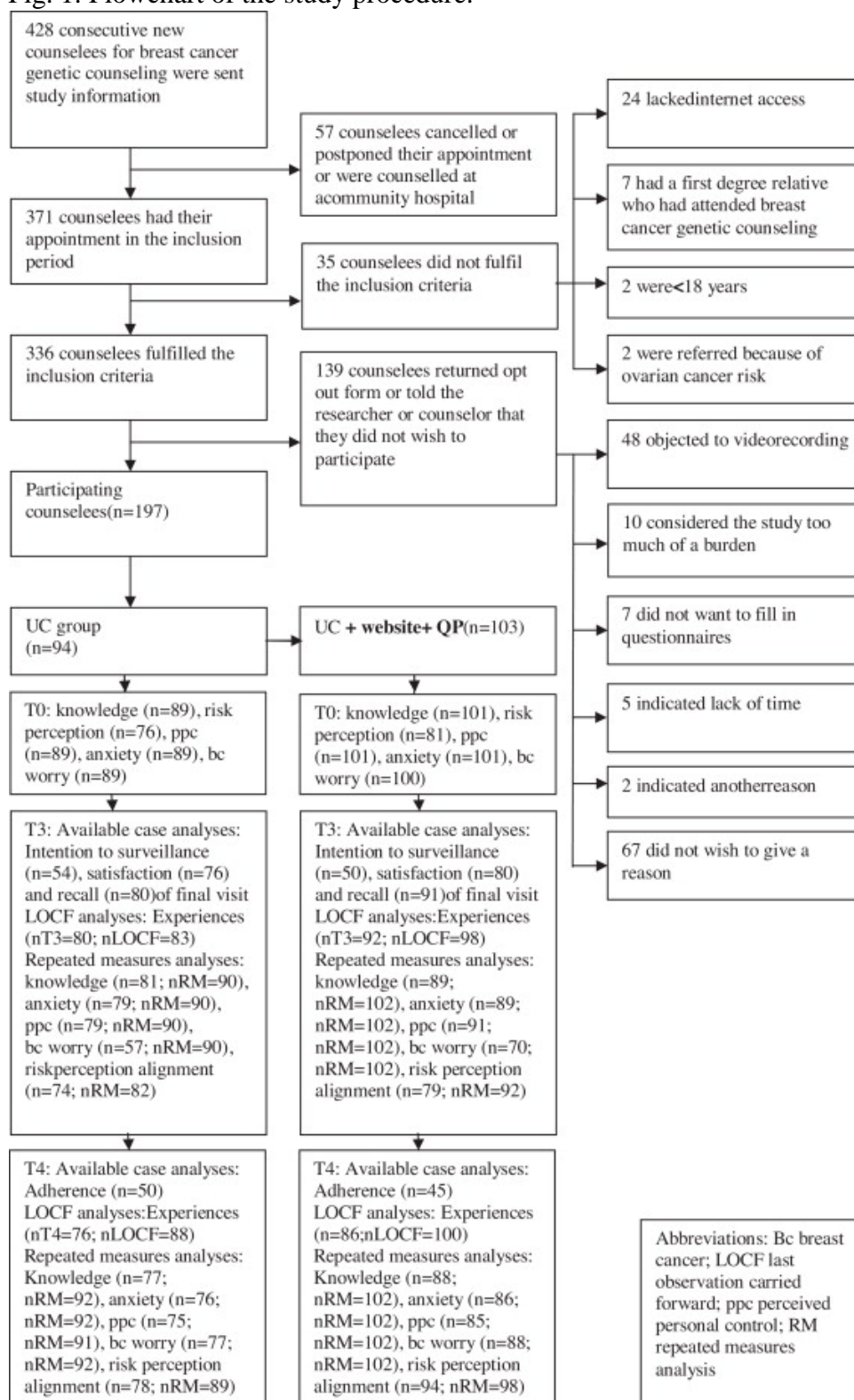
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**FIGURES AND TABLES**

**Fig. 1. Flowchart of the study procedure.**



**Table 1**  
Counselee characteristics (N= 197).

	UC group (n=94)		Intervention group (n=103)	
	Mean	SD (range)	Mean	SD (range)
Age (years)	41.1	11.5 (21-68)	41.6	11.3 (21-69)
	UC group (n=94)		Intervention group (n=103)	
	N	%	N	%
Children (having children)	64	68.1	71	68.9
Personal history of breast cancer (affected)	31	33.0	49	47.6
Having one or more first degree relatives affected with breast cancer <sup>a</sup>	47	52.8	54	52.9
Educational attainment <sup>a</sup>				
University (MSc/BSc)/Higher vocational education (BSc)	42	47.2	36	35.6
Middle vocational education	22	24.7	31	30.7
High school/Secondary education	22	24.7	33	32.7
<High school level	3	3.4	1	1.0
Referral pathway				
General practitioner	52	55.3	48	46.6
Specialist consultant	42	44.7	55	53.4
Indication for DNA-testing <sup>b</sup>	71	75.5	83	80.6
DNA-test uptake	36	38.3	50	48.5
Follow-up consultation (more than one consultation)	39	41.5	57	55.3
BRCA1/2-test result <sup>c</sup>				
Uninformative test result	28	29.8	42	40.8
BRCA1/2 mutation carriers	5	5.3	2	1.9
50% risk of being a BRCA1/2 mutation carrier <sup>d</sup>	0	0.0	3	2.9
Variant of Unexplained Clinical Significance (VUCS)	4	4.3	3	2.9
Breast cancer risk category				
Population (<20% lifetime risk)	44	46.8	59	57.3
Moderate (20-30% lifetime risk)	35	37.2	32	31.1
High (≥30% lifetime risk)	15	16.0	12	11.7
Risk reducing breast surgery at follow-up <sup>e</sup>	3	3.2	1	1.0

<sup>a</sup> Affected first degree relatives six missing values, education seven missing values, breast cancer risk category six missing values.

<sup>b</sup> Indication for testing the counselee or an affected relative according to the medical file.

<sup>c</sup> Total in UC group counts 37 instead of the 36 counselees with test uptake as one test result indicated a BRCA1/2-mutation as well as a VUCS.

<sup>d</sup> Breast cancer unaffected counselees with a first degree relative who tested positive for a BRCA1/2 mutation.

<sup>e</sup> The number of counselees having had risk reducing breast surgery at 1 year post counseling since the start of the counseling.

**Table 2**  
Results of multilevel regression on satisfaction with the final visit, recall of the final visit, intended and reported adherence to surveillance advice.<sup>a</sup>

	1 week post-counseling (T3)		1 year post-counseling (T4)		Available case analysis	
	UC group (n = 76) <sup>b</sup>	Intervention group (n = 80) <sup>b</sup>			T0-T3 (n = 156) <sup>b</sup>	
	Mean (SD)	Mean (SD)			P <sup>*</sup>	
Satisfaction with the final visit (0-100)	81.25 (21.72)	87.37 (13.06)	-	-	<b>.02</b>	
Recall of information from the final visit (0-100)	48.00 (23.42)	47.36 (25.75)	-	-	.64	
	1 week post-counseling (T3)		1 year post-counseling (T4)		Available case analysis	
	UC group (n = 54) <sup>b</sup>	Intervention group (n = 50) <sup>b</sup>	UC group (n = 50) <sup>b</sup>	Intervention group (n = 45) <sup>b</sup>	T0-T3 (n = 104) <sup>b</sup>	T0-T4 (n = 95) <sup>b</sup>
	N (%)	N (%)	N (%)	N (%)	P <sup>*</sup>	P <sup>#</sup>
Intend to adhere to breast surveillance advice after the final visit (yes) <sup>c</sup>	50 (92.6)	45 (90.0)	-	-	.55	
Adherent to breast surveillance advice 1 year after the final visit <sup>c,d</sup>	-	-	40 (80.0)	32 (71.1)	.36	

The bold *P*-values are <.05.

<sup>a</sup> Means and standard deviations of available cases and *P*-values of available-case analyses in random effects multilevel linear regression with level of counselees (1) and counselors (2), controlled for counselee age, disease status, education, whether there was more than one consultation, breast cancer risk and whether the counselee or a relative received an indication for DNA-testing.

<sup>b</sup> The number of counselees for the outcome with the smallest number of counselees, see flowchart for numbers per outcome.

<sup>c</sup> Only for breast cancer unaffected counselees as affected counselees follow surveillance advice of their surgeon according to the breast cancer treatment guidelines.

<sup>d</sup> The surveillance uptake was compared to the advice given. Adherence was scored as one in case of agreement and zero in case of no agreement.

<sup>\*</sup> Between group difference at T3.

<sup>#</sup> Between group difference at T4.

**Table 3**  
Results of multilevel linear regression on counselees' experiences with the provided counseling.<sup>a</sup>

	1 week post-counseling (T3)		1 year post-counseling (T4)		LOCF	
	UC group (n=80) <sup>b</sup> Mean (SD)	Intervention group (n=92) <sup>b</sup> Mean (SD)	UC group (n=76) <sup>b</sup> Mean (SD)	Intervention group (n=86) <sup>b</sup> Mean (SD)	T0-T3 (N=181) <sup>b</sup> P <sup>*</sup>	T0-T4 (N=188) <sup>b</sup> P <sup>#</sup>
Experiences with genetic counseling (1-4)	3.22 (.49)	3.36 (.47)	3.11 (.59)	3.30 (.43)	.08	<b>.02</b>
Experiences with the provided cancer specific information <sup>b</sup>	3.15 (.55)	3.28 (.52)	3.07 (.62)	3.28 (.48)	.14	<b>.02</b>
Generic experiences <sup>b</sup>	3.28 (.48)	3.41 (.47)	3.16 (.63)	3.31 (.44)	.08	<b>.04</b>

The bold *P*-values are <.05.

<sup>a</sup> Means and standard deviations of available cases and *P*-values of last observation carried forward (LOCF) in random effects multilevel linear regression with level of counselees (1) and counselors (2), controlled for baseline value, counselee age, disease status, education, whether there was more than one consultation, the breast cancer risk and whether the counselee or a relative received an indication for DNA-testing.

<sup>b</sup> The number of counselees for the outcome with the smallest number of counselees, see flowchart for numbers per outcome.

<sup>\*</sup> *P*-value of the between group difference at T3.

<sup>#</sup> *P*-value of the between group difference at T4.



**Table 4**  
Results of multilevel linear regression on knowledge, anxiety, perceived personal control and breast cancer worry and risk perception alignment.<sup>a</sup>

	Baseline (T0)		1 week post-counseling (T3)		1 year post-counseling (T4)		Time* group	
	UC group (n=89) <sup>b</sup>	Intervention group (n=100) <sup>b</sup>	UC group (n=57) <sup>b</sup>	Intervention group (n=70) <sup>b</sup>	UC group (n=75) <sup>b</sup>	Intervention group (n=85) <sup>b</sup>	T0-T3 (n=192) <sup>c</sup>	T0-T4 (n=193) <sup>c</sup>
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	P <sup>e</sup>	P <sup>e</sup>
Knowledge of breast cancer and heredity (0-7)	4.65 (1.46)	4.64 (1.60)	5.73 <sup>#</sup> (1.49)	6.01 (1.21)	5.55 <sup>@</sup> (1.34)	5.72 (1.15)	.28	.52
Anxiety (10-40)	19.89 (6.26)	19.78 (5.80)	18.6 (7.02)	17.07 (5.54)	18.08 <sup>@</sup> (6.27)	17.38 (5.92)	.06	.41
Perceived personal control (0-2)	1.22 (.43)	1.15 (.41)	1.30 (.46)	1.33 (.47)	1.22 (.50)	1.38 (.46)	.20	<b>.002</b>
Breast cancer worry (1-4)	1.85 (.55)	1.78 (.54)	1.66 <sup>#</sup> (.48)	1.60 (.48)	1.72 (.48)	1.64 (.48)	.59	.63
	Baseline (T0)		1 week post-counseling (T3)		1 year post-counseling (T4)		Time* group	
	UC group (n=89) <sup>b</sup>	Intervention group (n=100) <sup>b</sup>	UC group (n=57) <sup>b</sup>	Intervention group (n=70) <sup>b</sup>	UC group (n=75) <sup>b</sup>	Intervention group (n=85) <sup>b</sup>	T0-T3 (n=192) <sup>c</sup>	T0-T4 (n=193) <sup>c</sup>
	N (%) (n=76)	N (%) (n=81)	N (%) (n=74)	N (%) (n=79)	N (%) (n=78)	N (%) (n=94)	(n=174)	(n=187)
Breast cancer risk perception alignment	20 (26.3)	18 (22.2)	33 <sup>#</sup> (44.6)	40 (50.6)	23 (29.5)	33 (35.1)	.40	.45

The bold *P*-values are <.05.

<sup>a</sup> Means and standard deviations of available cases and *P*-values of repeated measures analyses in random effects multilevel linear regression with the levels of counsees and counselors, controlled for counselee age, disease status, education, whether there was more than one consultation, whether the counselee or a relative received an indication for DNA-testing, time and group allocation. All analyses except for risk perception alignment were also controlled for the breast cancer risk.

\* The reported *P*-value is of the interaction between time and group allocation.

<sup>b</sup> The number for the outcome with the smallest number of counsees is reported.

<sup>c</sup> Repeated measures analyses included all counsees of whom at least one observation (baseline or follow-up) was available.

<sup>#</sup> Main effect of time (T3 vs. T0) *P* < .05; @ Main effect of time (T4 vs. T0) *P* < .05.

## Optional e-only supplementary file

**Appendix A** Recommendations for mammography and/or MRI for breast cancer unaffected women as stated in the Dutch Breast Cancer guideline<sup>a</sup>

*Lifetime breast cancer risk <20%*

-From 50 to and including 75 years of age, biennial mammography screening in the National Screening program.

*Lifetime breast cancer risk 20-30%*

-From 40 to 50 years of ages, annual mammography. -From 50 to and including 75 years of age, biennial mammography screening in the National Screening program.

*Lifetime breast cancer risk 30-40%*

-From 35 to 60 years of age, annual mammography. -From 60 to and including 75 years of age, biennial mammography screening in the National Screening program.

*BRCA1/2 carriers and those at 50% risk of being a BRCA1/2 carrier* -From 25 to 60 years of age, annual MRI. -From 30 to 60 years of age, annual mammography. -From 60 to 75 years of age, biennial mammography. -After preventive prophylactic bilateral mastectomy no indication for surveillance.

<sup>a</sup> Dutch Breast Cancer Guideline [34]