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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 counselees 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 counselees were randomized to the usual care group (UC) or the intervention group (UC + website + QP). Counselees completed questionnaires pre- and post-counseling and 1 year follow-up. We conducted multilevel regression analyses corrected for time.
Results: Intervention group counselees (n = 103) were more satisfied about their final visit (β = .35; CI: .06–.65; P = .02; n = 156) than UC group counselees (n = 94). Intervention group counselees also reported more positive experiences with the counseling (β = .32; CI: .06–.59; P = .02; n = 188) and higher perceived personal control 1 year post-counseling (β = .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 counselees' experiences.
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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, counselees need to correctly recall the provided risk information, the surveillance recommendations and the advice on how to communicate the test results with relatives [4,5].

Breast cancer genetic counseling has proven to be reasonably effective in achieving improvements in counselees' level of breast cancer worry [6] and in their perceived personal control [7,8]. However, counselees' recall of information from the counseling and the transmission of this information to their relatives are still impaired [9,10]. Furthermore, while most counselees intend to adhere to the surveillance advice [11], their actual surveillance uptake remains suboptimal [12]. Moreover, genetic counseling appears to lead to improvements in counselees' knowledge about breast cancer genetics [12] and in their risk perception but anxiety levels only show a modest decrease [7,13–15]. Besides, after genetic counseling most counselees continue to overestimate their risks [7,13,16].

To enhance breast cancer genetic counseling outcomes, counselees have been provided with pre-counseling information. Such information shows to improve counselees' satisfaction [17] and their levels of knowledge after the first visit [18,19]. Pre-counseling information might become even more effective by tailoring such

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information to the individual, since tailored information is better recalled than generic information [20,21]. Apart from tailored information, a pre-counseling Question Prompt (QP) on which counselees can write their questions might have additional effect by stimulating more active counselee communication during the counseling [Henselmans 22] and thereby enhancing counselees' recall of information [23–25]. To this purpose, the web-based intervention E-info gene[ca] 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 counselees 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, counselees' experience with genetic counseling has not been considered, while this is an important outcome to involve the counselees' perspective [2]. Therefore, an RCT was conducted to test the effects of the pre-counseling, preparatory website E-info gene[ca]. Prior papers about this study showed that intervention group counselees 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 counselees showed more assertive communication, such as orienting and paraphrasing statements, than counselees in the usual care (UC) group [30]. However, counselees 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, counselees might be able to better process the information [31,32]. 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 counselees' 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 [5,33].

The present paper focuses on the intermediate and long-term effects of E-info gene[ca]. 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 counselees 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 counselees, 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. Counselees 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 counselees 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[ca]. 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 counselee 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, counselees 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, counselees 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. Counselee 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.

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.

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