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The impact of genetic counseling on knowledge and emotional responses in Spanish population with family history of breast cancer

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ABSTRACT

Objective: To assess a genetic counseling intervention measuring the distress, cancer risk perception, anxiety, worry and level of knowledge in people with familial history of breast cancer.
Methods: One group pre- and post-test design. A total of 212 individuals completed a baseline questionnaire, 88.6% completed a second questionnaire one month later and 75.4% six months later.
Results: Counseling intervention significantly increased the knowledge level of the individuals who received genetic education and significantly decreased the cancer worry levels. Persons with low perception of their cancer risk also had low worry levels. There were no significant changes over time in cancer risk perception or in quality of life.
Conclusion: Counseling in a high risk population seems to decrease cancer worry and to increase cancer knowledge thus enabling a counselee to take well-informed decisions. Furthermore, according to our results, such interventions do not increase anxiety and do not modify the quality of life, but do not adjust their cancer risk perception.
Practice implications: Providing individuals at increased risk of breast cancer genetic services seem to enhance their understanding of breast cancer without causing adverse psychological effects or changes in their quality of life, and it could improve their preventive behaviours.

1. Introduction

As in most of the European countries, breast cancer in Spain is the most common carcinoma in women. One in every eleven women will develop breast cancer in her lifetime [1]. However, we know that the majority of cancers are sporadic, and only between 5% and 10% of breast cancer cases are hereditary. Because of this, people with family histories of breast cancer attend Genetic Cancer Counseling. A genetic risk assessment is performed in order to inform the client about personal and hereditary risk of cancer. The genetic counseling process includes risk assessment and education, facilitation of genetic testing, pre- and post-test counseling and the provision of individually designed cancer risk management options [2–4]. Counselees must assimilate new concepts to be able to take informed decisions adapted to their personal risk. Terms like risk, screening, DNA, chemoprophylaxis, prophylactic surgery, genetic mutations, and BRCA1/2 are concepts that must be comprehensible to the persons receiving genetic counseling [5].

Recent research in the area of breast cancer genetic counseling has concentrated on the individual's psychological status and risk perception. Evidence from systematic reviews illustrates that a genetic counseling intervention does not appear to increase distress and therefore could improve the accuracy of individuals' perceptions of their personal risk [6]. One of the key issues in the counseling process is risk assessment for both developing and transmitting the disease. Most patients come to genetic counseling units with inaccurate perceptions of their cancer risk, and this can frequently cause them to be less receptive to obtaining proper information [7–9]. Genetic counselors advise their patients about probability, and it is necessary to have an open dialog with such persons and their families. The meaning of cancer risk is not always understood in the same way by the different family members involved in the process. Moreover, there is a wide variety of emotional (e.g. anxiety, worry, beliefs, and personality types), social and cultural factors related to this process, and therefore health professionals must adapt their educational strategies to patients and families.

Genetic counseling intervention tends to reduce the worry levels in women with familial history of breast cancer [10]. Nevertheless, previous distress, anxiety and excessive worry decrease the efficiency of the intervention [11,12].

This study used the Health Belief Model (HBM) as a conceptual framework to explain the preventive behaviour of individuals with

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increased risk of breast cancer [13]. The HBM is used to predict an individual's use of preventive measures to decrease their risk of developing the disease or to facilitate early diagnosis that would lead to more efficient treatment. Variables of the model are analyzed within the context of individuals who come to the Genetic Counseling Unit (GCU). According to the HBM, the counselee must hold the following beliefs before he or she will adopt preventive behaviours:

(a) She/he personally feels "threatened" by hereditary breast cancer. She/he believes or perceives that she/he is vulnerable to the disease or has higher risk than the general population.
(b) She/he believes or perceives that the breast cancer is a disease that is serious enough to be concerned about.
(c) She/he believes or perceives that benefits of preventive measures indicated (mammograms, self, ultrasound, and surgery) or genetic testing (if indicated) outweigh their corresponding costs and inconvenience.

Given these assumptions and according to the literature, we hypothesize that those who have a higher risk of breast cancer will perceive the disease as life-threatening because of their perceived risk, or their estimated risk, combined with increased worry about the disease whether the genetic intervention variables can be changed or not. We predict that genetic counseling will adjust these variables according to the needs of individuals and families of those who request it. We further predict that during this process counselees will have the opportunity to adjust their perceptions of risk, to increase their knowledge about the disease, and to receive detailed information on recommended screening measures [14,15].

We have already described the socio-demographic and emotional characteristics of the patients who attend our Genetic Counseling Unit (GCU) in Barcelona (Spain) [16], but a lack of knowledge about the psychological outcomes of the genetic counseling intervention over the time persists. The aim of this study was to investigate a genetic counseling intervention measuring the distress, cancer risk perception, anxiety, worry and level of knowledge in people with familial history of breast cancer before and after the genetic intervention.

2. Methods

We carried out a longitudinal study that involved a single group of participants undergoing pre- and post-genetic intervention. Participants were recruited from consecutive new referrals for cancer genetic counseling at the Genetic Counseling Unit of the Institut Català d' Oncologia in L'Hospitalet del Llobregat, Barcelona, Spain, between January 2006 and June 2007. Inclusion criteria were familial history of breast cancer, age of 18 years or older, and capacity to read and write in Spanish. Exclusion criteria were previous participation in genetic counseling and a diagnosis of cancer or mental disease. All of the subjects enrolled in this trial had an increased risk of breast cancer and at least one relative with cancer. Permission to proceed with the study was granted by the director of the Cancer Center and the Universitat Internacional de Catalunya (UIC) ethical and research committee and approval from the institutions internal review board was obtained. Participants who met the eligibility criteria were provided with written and verbal information on the study and signed a written consent. Voluntary participation, confidentiality and the reassurance of freedom to withdraw from the study at any time without compromising their medical care were provided.

A total of 212 individuals completed the baseline date before the genetic counseling intervention, and of these 188 (88.6%) completed the second questionnaire one month later (post 1), and 160 (75.4%) completed the third questionnaire six months post-intervention (post 2). A total of 152 (71.6%) individuals completed all three data collection measures.

Participants completed a baseline questionnaire before the genetic counseling intervention. While waiting for their medical visit, each participant was informed of the study aims and follow-up, the need to complete the three questionnaires and to mail them to the cancer unit in a self-addressed stamped envelop (Fig. 1). The breast cancer risk-counseling protocol was a standardized, multicomponent intervention that included the followings contents: (1) hereditary breast cancer and genetic information, (2) discussion of individual and familial factors contributing to the breast cancer risk, (3) presentation of individualized risk data, (4) available prevention measures according to their risk, and genetic test information. All the participants received the same information based on their needs and expectations. According to their medical charts and family trees, participants were classified as low, moderate or high breast cancer risk. This information was given to each patient during the genetic counseling process together with information regarding personal screening measures, and the possibility, if needed, of genetic testing. Psychological counseling was offered, and all personal and familial concerns were discussed.

2.1. Instruments

Subjects were asked to record their socio-demographic data: age, gender, and educational level in the baseline questionnaire. The following outcome measures were assessed.

2.1.1. Knowledge about breast cancer

In order to assess participants' understanding of breast cancer risk factors, the research team created a questionnaire. This instrument included 13 questions with different response options to elicit information about the respondents' basic knowledge regarding prevention, diagnosis and treatment of breast cancer. The questionnaire also asked what they knew about the risk of developing breast cancer, hereditary breast cancer and breast cancer susceptibility. Of these 13 questions 11 had a single correct answer and 2 questions had several correct answers. It was decided to give each subject a total knowledge score ranging from 0 to 31; a higher score indicates a higher level of familial breast cancer knowledge.

2.1.2. Psychological measures

Cancer worry was assessed by the Spanish version of the Cancer Worry Scale (CWS) [17,18]. The CWS assesses concerns or worries about developing cancer and their impact on daily functioning. This six-item scale had been previously validated in a Spanish population and it has adequate psychometric properties (internal consistency of Cronbach's alpha coefficient was 0.82 for the total scale and test–retest reliability ($r = 0.75$; $p < 0.001$). Total scores range from 6 to 24 where a higher score indicates higher levels of cancer's worry.

Psychological distress was assessed by the Hospital Anxiety and Depression Scale (HADS). The HADS is designed to measure anxiety and depression levels by two subscales: anxiety (7 items) and depression (7 items). The subscales scores range from 0 (no distress) to 21 (maximum distress) [19]. The HADS has been widely used in genetic cancer literature, and it was validated in a Spanish population with optimal psychometric properties [20].

2.1.3. Subjective risk assessment

There is no validated scale in the Spanish language to assess patients' risk perception of breast cancer. Therefore, we asked the participants about their own lifetime risk of developing cancer

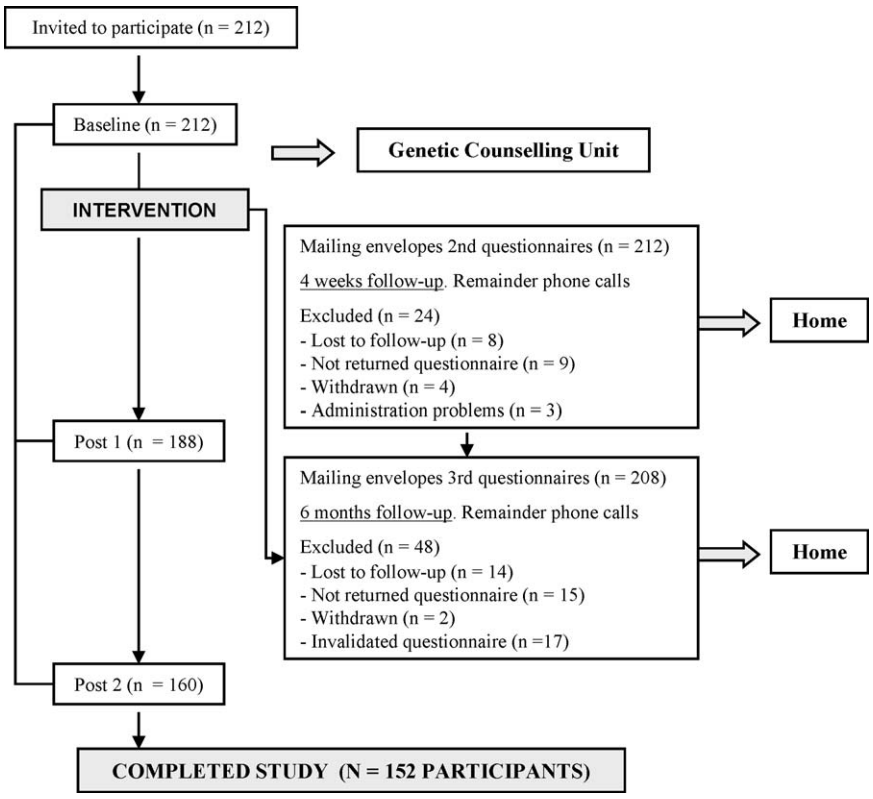

Fig. 1. Progress of participants through the study.

through a single item; "I believe I will develop breast cancer at some time in my life". The possible answers were: I completely disagree or disagree (indicating low risk), I am not sure (indicating moderate risk), and I agree or totally agree (indicating high risk).

2.1.4. Risk estimation

Risk estimations were calculated according to the Tyrer–Cuzick model [21,22] based on personal and familial information. This model takes into account both environmental and genetic factors to estimate the breast cancer risk. Once the risk was estimated, all patients were distributed into three groups: a low risk group (life time risk less than 10%), a moderate risk group (life time risk between 10 and 30%) and a high risk group (life time risk greater than 30%). The subjective risk estimation before and after the counseling intervention was compared to the risk estimation done by the counselors, and patients were classified according to whether they had overestimated, underestimated or provided correct estimates of their own risk.

2.1.5. Quality of life

The EuroQuol 5 dimension is an instrument used throughout Europe and validated in different languages, including Spanish [23]. The EuroQuol 5 D scale contains a description of the health state in 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. There are three levels of severity for each item: 1 (no problem), 2 (some problem) and 3 (unable to do/severe problem). For each item, the respondent must indicate the level of severity that best describes his/her personal health state at that time. The EurolQuol 5D also contains a Visual Analogical Scale (VAS) ranging from 0 the worst to 100 the best imaginable health state. The respondent rates his/her current health state by drawing a line in the box marked "your own health state today" to the appropriate point on the EQ-VAS.

2.2. Statistical analysis

Descriptive statistics analyzed the demographic and medical variables to describe the study participants. In order to compare results it was essential that the patient complete all three questionnaires. Groups were compared by means of x^2 test. Dependent variables were analyzed using McNemar's test (cancer's knowledge, cancer risk perception, quality of life, anxiety and depression, cancer's worry and socio-demographics and health believes). Comparisons of mean values among the three groups were calculated by ANOVA followed by a post hoc Fisher's test, and between two groups by a paired *t*-test. The correlation between risk estimation by the individual and that by the genetic counselor was computed by Spearman's rank correlation coefficient. Finally, comparisons of psychological outcomes over time between groups of individuals were performed by repeated measures ANOVA.

3. Results

Socio-demographic and the baseline assessment in the genetic counseling unit are shown in Table 1. Of the 212 participants who met the inclusion criteria 152 completed and returned the three questionnaires. The mean age of respondents was 38.4 years (s.d.: 11.4) and most of them were married and had children (mean number of children, 1.2; s.d.: 1.1).

3.1. Cancer knowledge

The mean knowledge scores on genetic cancer risk factors prior to counseling intervention were 16.3 (s.d.: 4.1). The impact of genetic risk assessment and counseling showed that changes in cancer knowledge over time were associated with variables such as risk perception, education, age and number of children (Table 2). A significant increase in knowledge ($p < 0.05$) was noted subsequent

Table 1
Descriptive characteristics of respondents.

Personal characteristic	*n*	% Per cent
Sex		
Women	200	94.3
Men	12	5.7
Age—mean (s.d.) 38.4 (11.4)	209	98.5
Marital status		
Single	45	22.5
Married	143	71.5
Separated/divorced or live alone	7	3.5
Widowed but live alone	3	1.5
No answered	2	1.0
Number of children		
0	70	36.3
1	37	17.5
2	68	32.1
3 or more	26	12.2
Education		
None but writing and reading Spanish	8	3.8
Basic education	76	35.8
High school	59	27.8
College or university degree	69	32.5
Estimate risk (by counselor)		
High risk	123	58
Moderate risk	86	40.5
Low risk	3	1.4

to the study intervention in all groups, classified by age, estimated risk, number of children and education there was significant increase of knowledge. Less significance was associated with older ages, lower levels of education and having 4 or more children.

Knowledge about preventive measures also increased after genetic counseling intervention. Breast self-examination remained the best known screening measure (94.7%), followed by mammography (93.6%), clinical examination (80%) and breast ultrasound (73.4%). While the percentage of those individuals recognizing prophylactic surgery and chemoprophylaxis as preventive measures also increased at post-intervention, the increase was very low. Only 15.4% of patients recognized mastectomy as a preventive measure. The same percentage was seen for salpingo-oophorectomy (15.4%), and fewer recognized chemoprophylaxis (7.4%). Less than 40% of the participants identified lifestyle changes, such as a daily increase in fibre intake in, smoking cessation, or a daily increase in physical activity, were as preventive measures.

3.2. Cancer worry and anxiety/depression

Multivariate analysis indicated that the mean of cancer worry decreased significantly ($p < 0.01$) after counseling intervention in all groups classified by their estimated cancer risk. For instance, participants with a low cancer risk presented a significant decrease (baseline: 11.5, s.d.: 0.7; one month follow-up: 9.50, s.d.: 0.7; and six months follow-up: 8.0; s.d.: 1.4). Similar results were found in those with moderate risk (baseline: 11.5, s.d.: 3.2; one month follow-up: 10.2, s.d.: 3.1; and six months follow-up: 10.8, s.d.: 3.2)

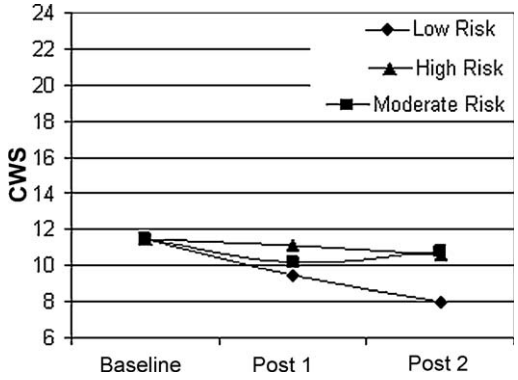

Fig. 2. Changes in cancer's worry after counselling.

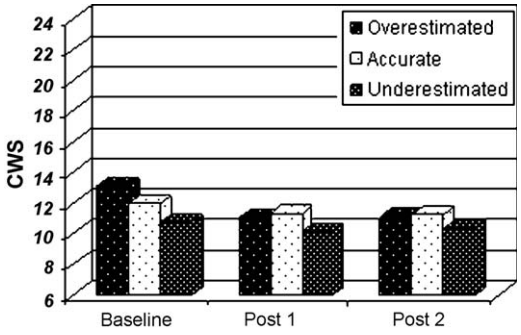

Fig. 3. Cancer worry and risk perception.

and participants classified as a high cancer risk patients (baseline: 11, s.d.: 3.3; one month follow-up: 11.2, s.d 3.5; and six months follow-up: 10.7, s.d.: 3.6) (Fig. 2). People with higher levels of education had a significant ($p < 0.005$) lower levels of cancer worry (baseline: 11.8, s.d.: 3.3; one month follow-up: 10.7, s.d.: 3.1; and 6 months follow-up: 10.6, s.d.: 3.3).

Before genetic counseling intervention, high levels of worry were observed in those individuals who overestimated their cancer risk (mean: 13.0; s.d.: 3.4). However, after genetic counseling intervention the levels of cancer worry decreased (one month follow-up: 11.0, s.d.: 1.9; and six months follow-up: 11.0, s.d.: 3.5). Similar results were observed for those who accurately estimated their risk (baseline: 11.0, s.d.: 3.5; one month follow-up: 11.7, s.d.: 3.4; and six months follow-up: 10.9, s.d.: 3.8) and those who underestimated their risk (baseline: 11.2, s.d.: 3.0; one month follow-up: 10.4, s.d.: 2.8; and six months follow-up: 10.4, s.d.: 2.9) (Fig. 3). The individuals who felt certain they would develop breast cancer at some point in their lifetimes presented high levels of cancer worry.

Pearson's correlation coefficient showed a significant association between the level of cancer worry and the level of anxiety ($r = 0.452$; $p < 0.001$) and depression ($r = 0.345$; $p < 0.001$), indicating a positive relationship (participants with high anxiety levels and depression had high levels of cancer worry). However, there were no significant changes in anxiety after counseling, and the

Table 2
Changes in cancer's knowledge and emotional variables over the time.

	Baseline		Post 1		Post 2		*p*-Value		
	Mean	S.d.	Mean	S.d.	Mean	S.d.	Baseline post 1	Basaline post 2	Post 1–2
Cancer's knowledge	16.37	4.1	19.6	4.3	19.6	4.2	0.001	0.005	0.923
CWS	11.42	3.16	10.79	3.32	10.74	3.42	0.001	0.001	0.903
EuroQol-VAS	77.96	20.1	80	17.6	78.9	19.2	0.525	0.908	0.393
HADS	11.26	6.91	11.71	7.99	12.33	7.96	0.009	0.411	0.076

$p < 0.05$.

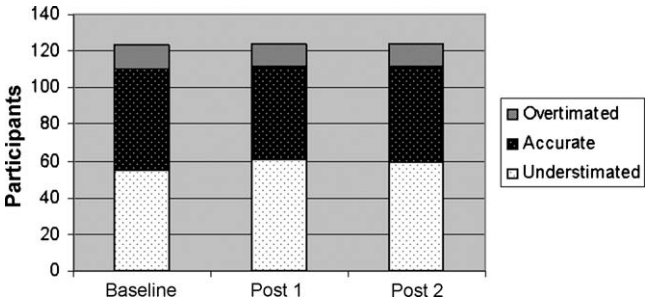

Fig. 4. Risk comprehension by time study group.

sample did not report having more distress with increased knowledge about the disease or their personal risk.

3.3. Perceived and estimated cancer risk

The risk assessment performed by the genetic counselor classified 58% of the sample as having a high risk of developing cancer in their lifetime, 40.5% as having a moderate risk and 1.5% of the participants as having a low risk. However, self-assessment scores obtained from the participants indicated that 19.8% thought that their cancer risk was high; 68.9% thought that it was moderate, and 10.8% of the participants answered that their risk of developing cancer was low.

Participants who overestimated or underestimated their cancer risk showed no improvement in their perception after the genetic counseling intervention. There were no significant changes over time in cancer risk perception (Fig. 4).

3.4. Quality of life

The mean VAS scores for quality of life based on the VAS-EuroQuol remained stable throughout study (baseline: 77.9, s.d.: 20.1; one month post-intervention: 80.0, s.d.: 17.6; and six months post-intervention: 78.9, s.d.: 19.2). Similar results were observed by the following dimension values: mobility problems (92% baseline, 88% post 1, 93% post 2), self-care (99% baseline, 98% post 1, 97% post 2), daily life activities (87% baseline, 86% post 1, 91% post 2), pain/discomfort (69% baseline, 64% post 1, 69% post 2) and anxiety/depression (63% baseline, 65% post 1, 64% post 2).

4. Discussion and conclusion

4.1. Discussion

A large number of outcome studies in genetic counseling assessing the efficacy of counseling over the time have been published. However, this is the first Spanish study that explores the psychological outcomes following genetic risk-counseling for individuals with a family history of breast cancer. In our setting, the genetic counseling intervention has been shown to induce changes in relation to cancer knowledge and cancer worry, but it does not adjust the cancer risk perception of the participants. This study confirms earlier published findings [24,10,25] that the intervention of genetic counseling seems to improve cognitive aspects, and indicate that it is not harmful to general mental health, and quality of life.

At baseline the participants showed a moderate level of cancer worry. This pre- and post-intervention clinical trial corroborates findings from other studies [26–28] suggesting that the genetic counseling intervention significantly decreases cancer worries. In our study worry levels among all the different age groups diminished after receiving genetic counseling and significantly decreased in individuals between 30 and 41 years and between 54 and 65 years of age. Moderate levels of worry may be beneficial; Loescher [29] suggested that these levels of worry in women at high risk of breast cancer could motivate screening behaviours. This situation would be the case of sixty-seven study individuals identified by the counselors as high risk subjects whose worry levels decreased after the intervention. The current findings suggest that in individuals at lower and higher cancer risks, cancer worry and anxiety were reduced after receiving personal risk information and their cancer knowledge improved. In these cases, genetic counseling seems does not significantly adjust their perception of cancer risk but allows them to reduce their levels of concern so they could approach monitoring prevention measures of breast cancer without excessive fear. However, these data reveal an important fact that warrants special attention; the worry levels of fifty-five women who had underestimated their risk before the intervention significantly decreased after the visit with the professional. These results show that the intervention reduced their levels of worry but did not adjust their perception of risk for cancer. This represents a significant underestimation. These findings differ from some studies reviewed where the intervention appears to improve and adjust this perception to a closer awareness of the real risk [25]. However, other studies reported similar to our findings, where women perceived their risk lower than researchers expected after intervention [30].

This lack of perception adjustment can be interpreted in different ways. The Spanish people, as a cultural factor, may not be realistic when it comes to expressing their threat to cancer risk. According to Garcia et al., the development of a person's definition of risk is influenced by psychological (thoughts, beliefs, previous experiences, personality type, religious, coping strategies, emotional state), social (family influence, friends, colleagues, and media communication) and cultural factors. This previous Spanish study concluded that it is difficult to assess risk perception in our cultural environment because the way people perceive health issues and risk or make choices about their own behaviour does not always follow a predictable or rational pattern [31]. The assessment of risk perception continues to be subject of discussion and should be taken as a limitation to this study. The lack of a standardized instrument to measure risk perception requires the existence of numerous approaches, and their results are difficult to compare [32]. Katapodi et al. [33] demonstrated this limitation in a meta-analysis conducted in relation to the perception of risk. There are several means to assess perceived risk, such as relative lifetime risk perceptions, absolute ratings of perceived risk compared to relative ratings, specific percentage estimates or odd ratios. Further research in genetics is needed to develop new instruments, with good validity and reliability properties to assess perceived risk. The data ascertained from any measurement instrument should allow for clear and objective interpretation and communication with others research outcomes [34].

4.2. Conclusion

One of the most complicated parts of the genetic counseling process is providing good risk communication that could have positive psychological outcomes in high-risk patients. Informing people of their hereditary risk or about their likelihood of carrying the mutation responsible for breast cancer and about their risk of suffering from the disease may be difficult in terms of efficacy and understanding. Genetic counselors provide education about risk of hereditary cancer, and during this process patients are informed about their probability of developing breast cancer. This information is given not in absolute certainties, but in most cases it gives counselors the

opportunity to explain the concept of breast cancer risk [35]. Women after genetic counseling for breast cancer feel that it could help their families' members to make better decisions about health care and it could provide useful information about their own risk [36].

4.3. Practice implications

The present findings have important resource implications. Most of the healthy participants had been appropriately referred to the Genetic Counseling Unit. Their familial history of breast cancer indicated that they were at an increased risk; fifty-eight percent were at high risk and 40.5% at moderate risk, but their levels of distress were similar to the general Spanish population. However, no data is available in regards to the percentage of people who have high breast cancer risk but do not seek genetic counseling. In some cases, it is necessary to find out why patients may not be referred to a cancer genetic service, when it provides clear benefits to high-risk persons [3].

The intervention of genetic counseling seems to be effective; it improved participants' knowledge about hereditary breast cancer, and such knowledge could help them to adopt effective personal strategies to prevent breast cancer. In addition, the results show that this process also reduced worries about cancer without causing any increased level of distress and changes in quality of life. Managing patient expectations as well as ensuring better information from the genetic counselor may help patients to develop a more realistic understanding of what genetic family history assessment can achieve and to ultimately increase their confidence in counseling. There is also a challenge to provide this information in an effective way such that the lay public could inform their relatives about choices without causing them undue psychological distress. Improving knowledge about hereditary breast cancer increases awareness about screening measures to help prevent breast cancer.

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Conflict of interest

All the authors of this paper confirm that there is no conflict of interest and there is no relationship with other people or organizations that may inappropriately influence the author's work now and in the future.

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