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RUNNING HEAD Readiness of young women for BRCA testing

Are young women ready for BRCA testing? Comparing attitudes and comprehension of two age groups of healthy Italian women

Teresa Gavaruzzi[a,b], Alessandra Tasso[c], Marzena Franiuk[d], Liliana Varesco[d], Lorella Lotto[a]

Department of Developmental Psychology and Socialization, University of Padova, Padova, Italy
Department of Surgical, Oncological and Gastroenterological Sciences, University of Padova, Padova, Italy
Unit of Hereditary Cancer, Ospedale Policlinico San Martino, Genova, Italy
Department of Developmental Psychology and Socialization, University of Padova, Padova, Italy
teresa.gavaruzzi@unipd.it
mfraniuk@gmail.com
liliana.varesco@hsanmartino.it
lorella.lotto@unipd.it

Corresponding author at Department of Humanities, University of Ferrara, Via Paradiso 12, 44121 Ferrara, Italy, tel. +39-0532-455226, fax +39-0532-455234
alessandra.tasso@unife.it

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Abstract

Background. Mutations in the BRCA 1/2 genes increase the risk of developing breast and/or ovarian cancer compared with the general population. However, the risk is low at age 30, and for women younger than 25, no preventive or screening options are available. Scientists wonder whether genetic predictive BRCA testing is appropriate at a very young age. Furthermore, although young women have positive attitudes toward testing, their understanding of genetic information seems scarce.

Objective. To assess how young (18-24) *versus* adult (30-45) women at general population- level risk understand information about BRCA testing.

Methods. 302 women read an informative pamphlet and answered an *ad-hoc* questionnaire assessing usefulness of the information for decision making, intention to undergo predictive testing, and comprehension (perceived, general, and risk comprehension; open-ended questions).

Results. Younger women had a lower comprehension of important BRCA information; it was more difficult for young women to identify the risk figures of cancer, and they showed errors when answering open-ended questions.

Limitations. Results are limited by the study's hypothetical nature.

Conclusions. Young women seem to have particular difficulty understanding BRCA information.

Practice implications. Counsellors should be aware of the difficulties young women have in understanding information about BRCA predictive testing.

Keywords

BRCA mutation; breast and ovarian cancer; oncology; preventive genetic testing; young women.

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1. Introduction

Mutations in the BRCA 1/2 genes increase the risk of developing breast and/or ovarian cancer compared with general population. By age 70, BRCA1 carriers face approximately a 60% lifetime risk of breast cancer and a 60% risk of ovarian cancer; the corresponding cumulative lifetime risks for BRCA2 carriers are approximately 60% and 20%, respectively. [1] Several surveillance options are available for breast and ovarian cancer, including breast examination, breast ultrasound, mammography or magnetic resonance imaging (MRI), transvaginal ultrasound, and cancer antigen screening. Risk-reduction strategies include surgical options (i.e., mastectomy and salpingo-oophorectomy) and pharmacological options (oral contraceptive pills, SERMs).

A small percentage of BRCA1/2 carriers develop cancer by age 30. Specifically, the risk of breast cancer is approximately 2% for BRCA1 and 1% for BRCA2, and the risk of ovarian cancer is 1% for BRCA1 and <1% for BRCA2. [2] Guidelines recommend that medical prevention options should start no earlier than 25-30 years of age, with the exception of breast examinations, which are recommended from the age of 18-20. [3] Nonetheless, young women who meet the criteria for Hereditary Breast and/or Ovarian Cancer Syndrome (HBOC) [3] are legally allowed to undergo BRCA1/2 genetic testing upon turning 18.

An extensive debate has been developing on whether genetic predictive BRCA testing is appropriate at such a young age. On one hand, at this age, the risk of cancer is still low, screening or risk-reducing strategies are not generally available, and the impact of a positive test result may be psychologically detrimental. [4-6] Furthermore, psychological qualitative research has highlighted that young women with a positive test result face a challenging situation, as they have to make decisions on how to manage cancer risk in the absence of consistent evidence-based options and recommendations. [7-8] On the other hand, young people who know about the presence of a BRCA mutation in their family may choose to undergo predictive testing to gain information about themselves, solve uncertainty, plan their lives, and manage a possible increased risk of developing cancer. [9] Hence, the decisional process is a complex one, and it encompasses age, fertility, relationships with other people, body image, family history, and risk perception. [10-11] The aforementioned implications and possible consequences of testing in this specific age group clearly mean that it is very important that young women fully understand all the information received during genetic counselling. Indeed, if the result is positive, they may feel pressured to realize important life events such as marriage, childbearing, and breast feeding as soon as possible before having prophylactic surgery. [12] In summary, very young women who are deciding whether to undergo genetic testing are entering what has been defined as a "clinical limbo", as screening or risk-reducing strategies are not generally recommended until age 25, and testing does not correlate with direct benefit from intervention or prevention. [13] Despite the debate on the appropriateness of genetic predictive BRCA at a very young age, young women often have positive attitudes toward testing and are willing to undergo it, and at the same time, their understanding of genetic information and the consequences of testing seems scarce. [14]

From this perspective, genetic counselling is a very important part of the decision-making process, aimed at giving the counselees all the relevant information (genetic, medical, and psycho-social) to enable them to make an informed decision and to give informed consent for the procedure. [3,15,16] Even if this may

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sound obvious, several studies have shown that although patients tend to perceive the amount of information they are given as sufficient, actual understanding of the various components of the informed consent process may be far from satisfactory. [17,18] Indeed, although receiving genetic counselling from a genetics clinician is associated with better knowledge and understanding of BRCA, [19] even after counselling, women's average knowledge scores are around 70% of the total possible score. [20-22]

Therefore, for women deciding whether to undergo predictive testing, it is essential to ensure that they understand the purpose of genetic testing, appreciate the consequences of testing and of receiving a positive or a negative result, and the available options.

Previous studies on young people's understanding of inherited conditions, recently summarized in a systematic review, have shown that children and adolescents in families at high risk of a genetic condition (e.g., BRCA, Lynch syndrome) are aware of their increased risk of the condition and seem to understand the condition's heritability, but they also misunderstand important genetic concepts. [14] Moreover, their understanding is not grounded in specific genetic knowledge, as it originates from family narratives. [14] Communication about genetic risk between parents and their children is often incomplete, filtered, and potentially inaccurate. [23] The difficulties parents experience in communicating with their children about their increased cancer risk may be attributed to a desire to protect them from stressful or scary information and a feeling of guilt for having passed the mutation on to them. [24] It follows that high-risk women are likely to have heterogeneous information on BRCA when entering counselling for the first time.

It is also worth noting that most studies on young people's understanding of inherited conditions are qualitative. [14] Qualitative research has its specific strengths, but as it attempts to understand a small number of participants' frames of reference or worldviews, it is characterized by a scarce generalizability of findings and difficulty in comparing various groups and controlling for the effect of multiple variables. [25] To date, quantitative studies on young women's understanding of genetic conditions are scarce.

In this quantitative study, we had multiple goals. First, we simulated a first-time counselling situation by involving women at general population-level risk. Participants at general population-level risk are less likely to have received heterogeneous information about BRCA mutation, thereby allowing for a much stronger experimental control on the information they are given. This control is important, as we aimed at assessing women's comprehension of genetic information, risk, heritability, and consequences of BRCA testing. A second aim of our study was to provide some insight into potential differences in the aforementioned measures, depending on the participants' age. Indeed, whereas for older women, preventive or screening options are available upon knowing the test result, young women are in a situation where no preventive or screening actions can be performed in the short term. Therefore, we compared a group of young women (18-24 years) with a group of adult women (30-45 years) to assess differences in their comprehension of information about BRCA testing and risk perception. The relevance of our study is based on the assumption that a thorough understanding of the various decision-making options available is the fundamental starting point for patients to make informed choices. As some studies suggest that young people's comprehension of genetic information is scarce, [14] should our results show differences in

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comprehension between the two age groups, the age of the woman who asks for genetic consultation should be accurately considered an essential ingredient in any consultation's future success.

2. Methods

2.1 Participants

Participants were women from the general population recruited with announcements and flyers between September 2014 and June 2015: women between the ages of18 and 24 were recruited at a local university, and women between 30 and 45 were recruited in gathering places not primarily related to health (e.g., offices, cafés, gyms). Cancer survivors and cancer patients were excluded.

2.2 Procedure

Potentially eligible women were approached and briefly given the study's aim and eligibility criteria. Those eligible and interested in participating were provided with an informative leaflet about the study, and women who agreed to participate in the study were invited to a quiet place nearby, where they signed the informed consent and then received the study material. If participants were not available right away, a later appointment was scheduled. The study instructions asked participants to imagine having a family history of breast and ovarian cancer and that one of their parents has a genetic mutation that increases the risk of these illnesses, which they could have inherited. They were then asked to read one of the two versions of the 6-page pamphlet, entitled 'The predictive genetic test for BRCA1 (or BRCA2)'. The two pamphlets only differed in the risk estimates associated with the two mutations. In each age group, the pamphlets were distributed randomly. Participants were asked to read the pamphlet at their own pace and for as long as they desired. They were then asked to fill out an *ad hoc* questionnaire (see Table 1 and section 2.3). Finally, participants were thanked and debriefed. Participation was voluntary, and participants were not compensated for their participation. The Psychology Research Ethic Committee of the University of Padova approved the study (Protocol number 1429).

2.3 Material

The pamphlet has been described in a prior study. [26] Briefly, based on current local guidelines for BRCA testing and decision science guidelines, the pamphlet described BRCA mutations, risk estimates, predictive testing, consequences of testing, and risk management and reduction strategies available in the case of a positive test result, with a flowchart summarizing the main information.

The questionnaire included questions about subjective variables, usefulness of the information material for decision making, intention to undergo predictive testing, three open-ended questions (about the consequences of not testing, testing negative, and testing positive), comprehension, risk perception, and socio-demographic information. Specifically, subjective variables included self-assessment of the extent to which participants felt involved with the topic (breast and ovarian cancer), considering their personal experiences (i.e., *Personal involvement with topic*); the extent to which participants were aware of BRCA

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genetic testing before reading the information material (i.e., *Previous awareness of BRCA genetic testing*); and the extent to which participants were aware of Angelina Jolie's case reported in the news (i.e., *Previous knowledge of Jolie case*). Responses ranged from 0 ("not at all") to 6 ("extremely"). These variables were drawn from a previous study. [26] The usefulness of the information material for decision making was assessed with the Preparation for Decision-Making scale. [27] This scale includes 10 items assessing the extent to which the information material helped the participant appraise the decision, options available, each option's pros and cons, personal values involved, and other prerequisites for informed decision making. The responses range from 1 ("not at all") to 5 ("a great deal"), and the average score of the 10 items was used in the analyses. The internal consistency of the scale was .88, and item-total correlation values ranged from .52 to .69. Participants indicated their *Intention to undergo predictive testing* on a scale from 0 ("I would definitely NOT undergo it, at least for now") to 6 ("I would definitely undergo it as soon as possible"). Participants' comprehension was assessed with various questions. Three open-ended questions were used to ascertain participants' comprehension of the consequences of not testing, testing negative, and testing positive, as expressed in their own words. The extent to which participants felt they had comprehended all the consequences of genetic testing based on the information material (i.e., *Perceived comprehension*) was also self-assessed on a scale from 0 ("not at all") to 6 ("extremely"). Finally, 15 true/false questions (i.e., *General comprehension score*) and 4 questions about the risk of breast and ovarian cancer for mutated and non-mutated women (i.e., *Risk* comprehension *score*) were adapted from a previous study. [26] Regarding risk perception variables, we distinguished a measure of cognitive appraisal of risk (perceived likelihood) and two affect-based measures, one directly linked to likelihood appraisal (feelings of risk) and one more general (anticipated worry) based on previous literature. [28-30] Each of these three variables was assessed for breast and for ovarian cancer separately on a scale from 0 ("not at all") to 6 ("extremely", see Table 1 for details). Finally, participants indicated their age, highest level of education attained, and current type of studies or employment. The wording of the questions was assessed with a convenience sample of 15 people reading the study material and evaluating the questions' comprehensibility. Two questions were slightly reworded to improve comprehension.

2.4 Data analysis

Continuous variables are described with means and standard deviations, and categorical variables and errors in open-ended questions are described with percentages and frequencies. Differences between the two groups were assessed with t-tests and chi-square tests.

We performed a content analysis on the open-ended questions to classify (Table 2) and quantify (Table 1) the most common mistakes. As exemplified in Table 2, five types of errors were identified: 1) whether carrying the mutation implies developing the disease; 2) incorrect likelihood of developing the disease, with or without mutation; 3) incorrect likelihood of inheriting or transmitting the mutation to offspring; 4) incorrect description of one or more options for risk management and reduction; and 5) risk-reduction options referred to as cures (i.e., treatment of a disease) or surveillance considered a primary prevention option. Errors were coded by two independent judges (AT, TG). Discrepancies were solved

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through discussion with a supplementary judge (MF). Data were analysed using SPSS (version 20, SPSS, Chicago, IL, USA).

3. Results

The sample (N = 302) included 121 participants 18 to 24 years old (*M* = 21.27, *S.D.* = 1.90), mainly BA (65.3%) or MA (19.8%) students with high school (72.7%) as the most frequent highest level of education attained, and 181 participants aged 30 to 45 (*M* = 36.76, *S.D.* = 4.67), mainly employees (45.6%) or professionals (12.8%), primarily with high school (42.0%) or MA (28.7%) degrees. No differences emerged between participants reading the BRCA1 or BRCA2 pamphlet; results are presented together.

Descriptive statistics and tests of the differences between the two groups are reported in Table 1. The two age groups did not significantly differ in personal involvement with the topic; all women had a similar awareness of BRCA genetic testing and previous knowledge of the Jolie case. Young and older participants showed similar scores in preparation for decision making and intention to undergo predictive testing. The majority of participants indicated the material prepared them to make a decision (on average, about 3.5 on a scale from 1 to 5) and that they would undergo the test (65-68%). Interestingly, the two groups differed significantly on all measures of comprehension. Compared to older participants, younger participants reported having a lower comprehension of the consequences of genetic testing, answered fewer comprehension questions correctly, and were less able to correctly identify the risk figures associated with breast and ovarian cancer for people with and without the BRCA mutation. Regarding risk perception, perceived likelihood judgments were lower in the younger group, but anticipated worry and feelings of risk did not differ between groups. According to their open-ended answers, exemplified in Table 2 and quantified in Table 1, the younger group was more likely than the older group to a) think that carrying the mutation meant developing the disease for sure, b) incorrectly report the risk of developing the disease, c) misreport the likelihood of having inherited or transmitting the mutation to offspring, and d) erroneously describe one or more options. The two groups equally incorrectly referred to options as cures or considered surveillance a primary prevention option. Also, when they reported the consequences of a positive test result, the proportion of participants mentioning all three options and the options mentioned in the two groups did not differ.

4. Discussion and Conclusion

4.1 Discussion

In the present study, we simulated a first-time counselling situation, as our aim was to investigate in what way women from the general population understood and interpreted controlled information about BRCA testing. We compared a group of young women (18-24 years) with a group of adult women (30-45 years) to investigate differences in their interpretation, comprehension, and risk perception.

Results showed no differences between the two age groups in personal involvement with the topic, previous knowledge of BRCA, preparation for decision making, or intention to undergo predictive genetic BRCA testing. Young and older women equally believed that they were prepared to make a decision, and

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they would consistently prefer to become aware of their genetic condition. These results are consistent with previous studies, showing that young and older women have similar motives for testing, such as gaining control of their lives as well as better awareness and knowledge. [12] Furthermore, people younger than 25 who had undergone genetic testing for BRCA1 and 2 and Lynch Syndrome showed little or no regret over their decision and would recommend testing at the same age to other people with high risk of mutations. [31] Young and older women also did not differ in previous awareness of BRCA genetic testing, probably due to their knowledge of the Jolie case, which was relatively recent at the time of data collection.

Nevertheless, results also showed that younger women significantly differed from older ones regarding important BRCA information. Young women showed a lower comprehension score and a lower comprehension of the consequences of testing. Also, it was more difficult for young women to correctly identify the risk figures of breast and ovarian cancer for people with or without the mutation. Errors in the open-ended questions were made more frequently by younger women than by older women. Specifically, the risk of getting the disease if carrying the mutation, the chances of having inherited or transmitting the mutation, and the available options for managing or reducing risk were misreported more frequently by young participants than by older ones. Some errors might have originated from ambiguities in everyday language, in which the term 'prevention' is generally used to refer to primary and secondary prevention whereas in this context, it was used to specifically refer to secondary prevention.

Our results are consistent with previous studies showing that children and young adolescents have scarce knowledge about BRCA genes that are found not only in children and adolescents at general population-level risk but also in those from families with a strong history of breast cancer. They also showed erroneous conceptions about risk. For example, although they were aware of their increased risk, children and adolescents from high-risk families believed that breast cancer can occur in women as young as 20 years old. [32,33]

Although young women from BRCA families have been the focus of numerous qualitative studies highlighting important emotional and psychological factors that characterize their unique situation, quantitative results are very scarce. Our quantitative study provides some information on the cognitive aspects of a hypothetical decision-making process in the BRCA context. Of course, further research is needed to investigate comprehension, risk perception, and likelihood judgments in young and adult women from a high-risk population. Indeed, knowledge and comprehension represent the cornerstone of informed decisions, one of the main goals of genetic counselling.[34] Should our results be confirmed, they might be useful to improve genetic counselling with young women, as they find themselves in a 'grey zone' not only because they face important decisions about their lives and future without evidence-based options and recommendations [35-38] but also because they may make decisions to undergo testing despite specific difficulties in managing all pertinent information.

4.2 Limitations

Our study has some limitations. First, we chose to recruit women at general population-level risk to control for BRCA information received by participants. Indeed, high-risk young women are likely to have

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heterogeneous information on BRCA when entering counselling for the first time, as it has been shown that communication about genetic risk in high-risk families is often incomplete. [19] Our results cannot be generalized without further research confirming that actual high-risk young women also show comprehension difficulties, along with their motivation, emotional, and psychological needs.

A second limitation is that the two groups of women were recruited in different places: a local university for young women and gathering places not primarily related to health (e.g., offices, cafés, gyms) for adult women. However, as young university students are, by definition, highly educated, if the differences that we found were attributable to the recruitment locations, we would have expected young women (i.e., those with higher education) to show better comprehension, but we found the opposite.

Third, although participants were asked to imagine that they have a family history of breast or ovarian cancer with one parent having a genetic mutation, we did not record whether these participants actually had a family history of breast or ovarian cancer. However, we asked participants to what extent they were involved with the topic of breast and ovarian cancer considering their personal experiences, and no differences emerged between young and adult participants.

Finally, participants were instructed to read the pamphlet for as long as they desired, but we did not measure the time spent reading. Future studies should ensure that younger women spend the same time reading the information as older ones.

4.3 Conclusion

Even with their limitations, we think that our results highlight that cognitive factors related to comprehension of information play an important role in judgment and the decision-making process.

Our results suggest that positive attitudes shown by young women towards genetic testing might not always be based on a true and deep understanding of the nature and purpose of testing, which is required by informed consent and the ultimate goal of genetic counselling. [13] Therefore, we suggest that genetic counselling with young women be shaped to fit their comprehension difficulties. Indeed, young women feel prepared for decision making but seem to be missing important information about the nature of testing and its consequences. Furthermore, although they are aware of their limited comprehension, they think they are ready to make a decision, which is often to undergo the test. Although it is possible that their decision would be the same regardless of their comprehension, our results suggest that some basic concepts are more difficult to grasp for younger women. Finally, it should not be forgotten that young people are increasingly exposed to genetic information: genetic technologies are evolving rapidly, and genetic testing is increasingly easily accessible, including the increasing direct-to-consumer advertising for do-it-yourself tests. These considerations should lead us to ponder the age factor very carefully from the very beginning of the counselling process.

4.3 Practice Implication

Experts recommend that before treatment, the patient's capacity to make an informed decision is ensured. [39] This is also important in the context of BRCA testing, in which the decision to undergo testing could have

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lifelong consequences. Our results suggest that young women could have difficulty understanding BRCA information, which is necessary to make an informed choice. Therefore, special attention should be paid in the course of genetic counselling to make sure that counselees correctly comprehend genetic information about BRCA and the consequences of testing.

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Table 1. Means (standard deviations) and *t* tests for continuous variables; percentages (frequencies) and chi-square tests for categorical variables.

Variable names	**Questions and scoring**	**18-24 (n = 121)**	**30-45 (n = 181)**	**Test of difference**
Subjective variables				
Personal involvement with topic	Involvement with topic (breast and ovarian cancer), considering personal experiences (0-6[a])	3.93 (1.51)	4.03 (1.58)	t (300) = - .589, p = .557
Previous awareness of BRCA genetic testing	Awareness about BRCA genetic testing before reading the information material (0-6[a])	2.28 (1.97)	1.92 (1.93)	t (299) = 1.594, p = .112
Previous knowledge of Jolie case	Familiarity with Angelina Jolie's case reported in the news (0-6[a])	2.58 (1.58)	2.59 (1.76)	t (275,15) = - .082, p = .935
Usefulness of information material for decision making				
Preparation for decision making score	Average score of 10-item Preparation for decision making scale (1-5) [23]	3.45 (0.53)	3.57 (0.66)	t (289.41) = -1.742, p = .083
Intention to undergo predictive testing				
Continuous	"If you were to decide now whether to undergo predictive testing…" (0-6[b])	3.92 (1.65)	4.17 (1.99)	t (285.93) = -1.180, p = .239
Categorised	Intention not to test (scores 0-2)	19.8% (24)	19.3% (35)	X^2 (2) = .610, p = .737
	Undecided about testing (scores 3)	15.7% (19)	12.7% (23)	
	Intention to be tested (scores 4-6)	64.5% (78)	68.0% (123)	

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Comprehension				
Perceived comprehension	Perceived comprehension of all the consequences of genetic testing, based on the information material (0-6[a])	4.49 (1.11)	4.85 (1.18)	t (300) = -2.638, p = .009
General comprehension score	Number of correct answers to 15 true/false questions (0-15)	9.79 (2.21)	10.61 (2.18)	t (300) = -3.166, p = .002
Risk comprehension *score*	Number of correct answers to questions about risk of breast and ovarian cancer for mutated and non mutated women (0-4)	2.34 (1.33)	3.02 (1.11)	t (224.96) = -4.683, p < .001
Errors in open-ended answers	Carrying the mutation means developing the disease	31.4% (38)	11.6% (21)	X^2 (1) = 18.091, p < .001
	Incorrect likelihood of developing the disease	23.1% (28)	14.4% (26)	X^2 (1) = 3.804, p = .051
	Incorrect likelihood of having inherited or transmitting the mutation to offspring	15.7% (19)	3.3% (6)	X^2 (1) = 14.656, p < .001
	Incorrect description of one or more options	12.4% (15)	3.3% (6)	X^2 (1) = 9.245, p = .002
	Treatment options are referred to as cures or surveillance is considered a preventative option	26.4% (32)	19.3% (35)	X^2 (1) = 2.123, p = .145
Risk perception	Questions adapted from previous studies, [24-26] referring to the case of a positive test result			
Breast cancer				
Perceived likelihood	Likelihood to get breast cancer at some point in life (0-6[a])	4.09 (1.25)	4.38 (1.35)	t (296) = -1.873, p = .062
Anticipated worry	Worry about getting breast cancer (0-6[a])	5.12 (1.09)	4.97 (1.41)	t (291.89) = .999, p = .319
Feelings of risk	Feeling to be going to get breast cancer (0-6[d])	4.02 (1.39)	3.90 (1.66)	t (295) = .639, p = .523
Ovarian cancer				
Perceived likelihood	Likelihood to get ovarian cancer at some point in life (0-6[a])	3.55 (1.35)	4.02 (1.48)	t (293) = -2.785, p = .006
Anticipated	Worry about getting ovarian cancer (0-	5.12	5.02	t (291.67) = .831, p =

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worry	6[a])	(1.04)	(1.42)	.407
Feelings of risk	Feeling to be going to get ovarian cancer (0-6[d])	3.81 (1.41)	3.74 (1.70)	t (278.77) = .334, p = .739

[a] 0 = "Not at all", 6 = "Extremely"

[b] 0 = "I would definitely NOT undergo it, at least for now", 6 = "I would definitely undergo it as soon as possible"

[c] 0 = "I would definitely NOT choose it", 6 = "I would definitely choose it"

[d] 0 = "Strongly disagree" to 6 = "Strongly agree"

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Table 2. Examples of errors in open-ended answers.

Carrying the mutation means developing the disease
No testing If you don't undergo testing, you're uncertain until you are 30 and you have 50% probability to be ill without knowing it (ID 8, 18-24); **Negative result** You are not carrying the cancer (ID 12, 18-24); I won't pass on the cancer to my children (ID 219, 30-45); **Positive result** You're carrying the disease, and when you know it you can have negative reactions, such as anxiety, depression. Then, you have to make important decisions about it (ID 153, 18-24); If it is positive I have to choose how to manage it. With surgery, or taking drugs, or simply checking the situation. Anyway, I know I'm ill (ID 429, 30-45).
Incorrect likelihood of developing the disease
Negative result If the result is negative, the probability to develop a breast or an ovarian cancer is 90% (ID 54, 18-24); There is a 20% risk to get breast cancer and a 5% risk to get ovarian cancer (ID 117, 18-24); **Positive result** You have a 60% higher probability to develop ovarian or breast cancer, if compared to people who don't carry the BRCA mutation (ID 152, 18-24); If the result is positive, you have a very high probability (or you are certain, I don't remember) to get cancers between 40 and 60 years (ID 37, 18-24).
Incorrect likelihood of having inherited or transmitting the mutation to offspring
No testing If I don't undergo testing, there is 50% probability […] that my daughters will have one or both of the cancers (ID 2, 18-24); If one parent has the mutation, I'm a carrier anyway, thus the risk of getting cancer is higher than normal women (ID 149, 18-24); **Negative result** The probability of finding the mutation (or to pass it on) is very low (percentages around 5-10%) (ID 41, 18-24); If the result is negative, it means it is less likely to have a mutation, thus, to pass it on, even if there always is a very low percentage of uncertainty (ID 56, 18-24); **Positive result** My children will definitely inherit the mutation and they will have higher probability to develop the disease (ID 449, 30-45).
Incorrect description of one or more options

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No testing You don't know if you're carrying the BRCA mutated genes, and you can only undergo regular checks (through blood tests). You can't get breast or ovaries surgery if you are too old (ID 117, 18-24); You can anyway get checked, but the possibility to surgically remove breast and/or ovaries is very far (ID 12, 18-24); **Negative result** It means that there are different possibilities, more frequent checking, breast/ovarian surgery, or pill (ID 413, 30-45); **Positive result** […] to have your breast checked every two years (ID 102, 18-24); […] breast surveillance is recommended (ID 452, 30-45).
Risk-reduction options are referred to as cures (i.e. treatment of a disease) or surveillance is considered a primary prevention option
No testing You don't have the possibility to really prevent the disease (ID 54, 18-24); […] you can't have cures meant to prevent cancer before it turns out (ID 454, 30-45); **Positive result** If positive, you can undergo intense surveillance, and you can undergo cures (ID 56, 18-24).

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