Development and validation of a breast cancer genetic counseling knowledge questionnaire

Joel Erblich a,*, Karen Brown b, Youngmee Kim c, Heiddis B. Valdimarsdottir a, Barbara E. Livingston d, Dana H. Bovbjerg a

a Derald H. Ruttenberg Cancer Center; Mount Sinai School of Medicine, One Gustave L. Levy Place, Box 1130, New York, NY 10029-6574, USA
b Department of Human Genetics, Mount Sinai School of Medicine, New York, NY 10029-6574, USA
c Behavioral Research Center; American Cancer Society, New York, NY 10029-6574, USA
d Oncology Care Center; Mount Sinai School of Medicine, New York, NY 10029-6574, USA

Received 10 October 2003; received in revised form 23 January 2004; accepted 20 February 2004

Abstract

Women who undergo genetic counseling concerning their increased risk of developing breast cancer confront large quantities of complex information in a short period of time. Clinical reports have suggested that many women may not retain what they learned during counseling. A validated questionnaire to measure their knowledge, however, is lacking. In this study, we describe the development and validation of a questionnaire to assess knowledge of information typically included in genetic counseling for breast cancer. Items were empirically derived from detailed content analyses of actual genetic counseling sessions. The instrument’s content validity was high, as evidenced by high levels of independent interrater agreement (0.93) on items. Subsequent data reduction and confirmatory factor analytic techniques yielded a highly reliable (alpha = 0.92) 27-item Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ). Direct comparison of this questionnaire to a scale previously developed in the literature (BCHK; [Breast Cancer Res. Treat. 53 (1999) 69]) supported the utility of the new questionnaire for evaluation of knowledge after counseling. Compared to non-counseled groups (n = 45), women who had undergone genetic counseling (n = 28) scored significantly higher (P < 0.0001) on the BGKQ, but not on the other questionnaire, establishing the BGKQ’s criterion validity. The BGKQ may, thus, provide a useful clinical and research tool for assessing knowledge of information provided during genetic counseling and exploring the potential impact of distress on knowledge, as well as the impact of knowledge on screening behaviors.

© 2004 Elsevier Ireland Ltd. All rights reserved.

Keywords: Breast cancer; Genetic counseling; Knowledge; Decision making; Test development

1. Introduction

Breast cancer is the most frequently diagnosed cancer in the world; it is estimated that over 1 million people are newly diagnosed with the disease in annually [1]. Current estimates from the US indicate that women’s cumulative lifetime risk of developing breast cancer is about 12% [2]. In addition, women with the disease in one or more first-degree relatives are at even higher risk for the disease [3], escalating further with the presence of other risk factors (e.g. early menarche, nulliparity, etc.) [4]. The past decade has seen major advances in our understanding of this increased risk for breast cancer. A study by Claus et al. [5] estimated that, while only a small minority of women (5–10%) carry known mutations in breast cancer susceptibility genes, those who are carriers are at extremely high lifetime risk of developing the disease, upwards of 92%. Subsequent studies identified \textit{BRCA1} and \textit{BRCA2} as strong risk factors for the development of breast cancer, with estimates of up to 85% cumulative lifetime risk for carriers of these mutations [5–7], and a lifetime risk of ovarian cancer of 40–60% for carriers of \textit{BRCA1} [6]. Moreover, studies have indicated that exogenous factors, such as low parity and young age at last childbirth, can further increase risk for these diseases in women who are carriers of susceptibility genes [4]. The rapid increase in risk information available has engendered a need to better communicate to women the numerous risk factors, their implications for women’s disease risks, as well as the implications for their family members’ risks. Indeed, many women with family histories of breast cancer...
undergo genetic counseling, and often genetic testing for BRCA1 and BRCA2/other susceptibility genes. During these "pretest" genetic counseling sessions, women are faced with complex information about basic genetic transmission, implications of carrying mutations on their health, implications for their family members’ health, more intensive screening recommendations, and options for prophylaxis, including chemoprevention (e.g. Tamoxifen) and mastectomy. These considerations, while critical in and of themselves, may also, to some extent, serve as a woman’s basis for making the difficult decision of whether or not to undergo genetic testing and/or to be notified of test results [8]. Previous work from our group [9] and others [10] has demonstrated that women at elevated risk for breast cancer can experience substantial levels of psychological distress, and it comes as no surprise that women facing the threat of learning of their elevated breast cancer risk also exhibit high levels of distress, especially around the time of genetic counseling [11–13]. Literature in the cognitive sciences has long demonstrated that information processing at times of stress can be severely impaired [14]. In a recent report, we have demonstrated that such impairments exist among women with family histories of breast cancer [15]. Consistent with this research, clinical reports have suggested that while women undergoing genetic counseling do come away more informed than they had been prior to counseling, they do not retain much of what had been presented during the session [16]. Other factors such as cultural background and education level may have an impact on knowledge, as well [17]. Unfortunately, few empirical studies have examined women’s processing of information presented in pretest genetic counseling for breast cancer risk. One significant barrier to this endeavor is the lack of an empirically derived, psychometrically validated instrument to assess such knowledge retention. In the first phase of the present study, a novel breast cancer knowledge questionnaire designed to assess women’s knowledge of information presented during breast cancer genetic counseling is generated. In the second phase, the initial validation and psychometric evaluation of the instrument is described, and the utility of the novel instrument is compared to another instrument previously developed in the literature to assess knowledge among low- to moderate-risk women [18].

2. Method—Phase 1

2.1. Overview

In the first phase of this study, we generated a questionnaire based on the content analyses of three genetic counseling sessions held at the Mount Sinai School of Medicine. As part of initial data reduction, questions were screened for clarity and readability by expert genetic counselors. Content validity was then assessed using interrater agreement (IR) indices.

2.2. Item development

To generate items for the Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ), we performed a detailed content analysis of three separate pretest genetic counseling sessions of three different counselees, two who had histories of breast cancer in first-degree relatives, and one with a family history of breast and ovarian cancer, who had already had breast cancer herself. The sessions were conducted by a cancer genetic counselor (K.B.) at the Mount Sinai Medical Center, consistent with consensus guidelines for breast cancer genetic counseling [19]. The sessions lasted about 1 h each, and covered a broad range of topics, from basic Mendelian transmission to information about prophylactic measures. During two of the sessions, an investigator took detailed notes in a corner of the room, with the patients’ consent. The key points of a third session were transcribed by a counselor herself, after the session. The approach yielded content from both the viewpoint of a counselee and an independent observer. A pool of potential questions were then formed, based on the material presented in the sessions. Because session content followed consensus guidelines, there was much overlap of information presented in these three sessions. It was deemed, therefore, that three sessions were sufficient for the development of appropriate questionnaire items.

2.3. Data analyses

Four different genetic counselors from Mount Sinai’s Department of Human Genetics screened the questions for appropriateness. Counselors were asked to agree or disagree that the each of the questions was appropriate for the questionnaire. To meet selection criteria, knowledge questionnaire items needed to have an interrater agreement of at least 0.75 (3/4 agreed on appropriateness). Items that did not meet criterion IR were either modified to increase clarity or dropped. Overall IR was calculated as the mean of the IRs for all retained items, and served as an index of content validity.

3. Results—Phase 1

3.1. Item characteristics

Content analysis of the three genetic counseling sessions yielded an initial pool of 50 items. To minimize the burden of the questionnaire, items were generated with true/false responses whenever possible. As a result, there were 36 true/false format items, and 14 multiple choice items. Consistent with session content, the questionnaire included items assessing basic Mendelian genetic information, transmission of genetic risk for breast cancer, implications of BRCA1/BRCA2 carrier status for risk of developing other cancers, implications of carrier status for one’s own risk,
implications for family members’ risks, implications for one’s screening behavior, and information regarding the utility of prophylactic measures.

3.2. Content validity

Results of the four genetic counselors’ ratings of the questionnaire items indicated high levels of content validity. Of the 50 items, 39 had IRs of 1.00 (4/4 endorsed the item), 8 had IRs of 0.75, 2 had IRs of 0.50, and 1 item received an endorsement from only one of the raters. Overall IR for the instrument was 0.92. After re-examination of questionable items, five were dropped from the questionnaire. In addition, based on recommendations of the raters and the principal genetic counselor, six items were modified to increase clarity and re-rated. As a result of the modifications, the final IR for the questionnaire increased slightly, to 0.93.

4. Method—Phase 2

4.1. Overview

In Phase 2 of the study, women (n = 75) completed the initial 45-item version of the Breast Cancer Genetic Counseling Knowledge Questionnaire (BGKQ), along with the Breast Cancer and Heredity Knowledge Questionnaire (BCHK), an 11-item instrument previously developed to assess knowledge among lower risk women [18]. Confirmatory factor analysis was employed to establish the psychometric properties of each questionnaire. In addition, to establish criterion validity, scores of women who underwent genetic counseling were compared to those of women who did not. Finally, the relative utility of the two instruments for assessing knowledge of information presented in genetic counseling of high-risk women was compared.

4.2. Participants

To validate the BGKQ, women who had undergone breast cancer genetic counseling (n = 28) at Mount Sinai’s Department of Human genetics were recruited. Participants were sequential counselees who visited the chief cancer genetic counselor at Mount Sinai (K.B.). For purposes of comparison, two additional groups of women were recruited: (1) nurses employed at Mount Sinai (n = 26) thought to be familiar with the type of complex health information covered in genetic counseling, recruited by advertisement, and (2) employees of Mount Sinai who were not health care providers (e.g. administrative staff), who were “graduates” of a recent study of healthy women with different family histories of breast cancer at the medical center (n = 25).

In the first comparison group, nurses with (n = 11) and without (n = 15) oncology certification were recruited, as they were thought to have differing levels of familiarity with the information. Similarly, in the second comparison group, employees with (n = 11) and without (n = 10) histories of breast cancer (FH+, FH−) in one or more first-degree relatives were recruited, as they were thought to have different levels of knowledge as well. In sum, five groups of women (n = 75), including one Counselee group and four Comparison groups, participated in Phase 2 of the study.

4.3. Procedure

Counselees were given the BGKQ-45 and the BCHK by their genetic counselor (K.B.) at the end of their genetic counseling session. The BCHK was administered in order to compare the utility of the BGKQ for assessing genetic counseling knowledge with an instrument that has already been validated for use with low-to-moderate risk women, and which may not be as appropriate to assess knowledge of information from genetic counseling of higher risk women. They were instructed to complete the questionnaire within two weeks of the session and anonymously return it in a prepaid mailer. A cover letter attached to each questionnaire described the purpose of the study (to help develop a valid questionnaire), ensured respondents that their responses were voluntary and anonymous, labeled only with a code indicating that they belonged to the “Counselee Group”, and requested that they did not consult outside references to answer the questions.

Nurses were recruited by advertisement to a “questionnaire lunch”, during which time they completed the BGKQ-45 and the BCHK. Advertisements were placed around the medical center with more concentrated placement in and around the Oncology Care Center, to increase the likelihood of recruiting a subset of oncology certified nurses. As in the Counselee Group, nurses’ questionnaires included a cover letter describing the study. Questionnaires administered to the “Nurse Group” included an additional question assessing whether or not they were certified in oncology.

Employees not involved in provision of health care consisted of graduates of a previous study at the cancer center. Women were re-contacted and asked if they could be sent a questionnaire. As above, questionnaires were anonymous, respondents were asked to return them within two weeks (in a prepaid mailer), and were asked not to consult any references in completing the questionnaire. Study procedures were approved by the Mount Sinai IRB.

4.4. Data reduction and analyses

The first step of the analyses was focused on item reduction. Items that were correctly answered or incorrectly answered by at least 80% of the sample were dropped, as they were deemed to be too simple or too difficult, respectively. Next, the data were subjected to confirmatory factor analysis using Normal Ogive Harmonic Analysis Robust Method (NOHARM) analysis software [20,21], specially...
5. Results—Phase 2

5.1. Response rate

A total of 105 questionnaires were administered, either in person (genetic counselees, nurses) or via mail (employees not involved in health care provision). A total of 77 women returned the questionnaire, an overall response rate of 73.3%. The response rates were similar across groups: 40% for genetic counselees, 54% for nurses, 40% for oncology, 37% for other employees, and 38% for patients with only FH−. The mean age of the women in the sample was 42.8 years (S.D. = 11.0). Not surprisingly, as many of the women were nurses and other professionals, 44% of the sample reported having some postgraduate education, and 69% reported household annual income levels of at least $60,000. Sixty-one percent of the sample reported being Caucasian, 15% reported being Black, 13% reported being Hispanic, and 11% reported other racial/ethnic backgrounds. In addition, 61% reported being currently married, 20% reported being never married, 17% reported being divorced or separated, and one respondent reported being widowed. Comparisons of the five groups of women revealed few systematic differences on demographic variables (Table 1). Counselees were older than FH− non-provider employees, and had the largest percentage of Caucasian women (96%). Counselees and nurses reported higher incomes than the FH+ and FH− employees who were not directly involved in health care provision. To take a conservative approach, age, ethnicity, and income, were included as covariates in subsequent analyses of group differences.

5.2. Demographic characteristics

The mean age of the women in the sample was 42.8 years (S.D. = 11.0). Not surprisingly, as many of the women were nurses and other professionals, 44% of the sample reported having some postgraduate education, and 69% reported household annual income levels of at least $60,000. Sixty-one percent of the sample reported being Caucasian, 15% reported being Black, 13% reported being Hispanic, and 11% reported other racial/ethnic backgrounds. In addition, 61% reported being currently married, 20% reported being never married, 17% reported being divorced or separated, and one respondent reported being widowed. Comparisons of the five groups of women revealed few systematic differences on demographic variables (Table 1). Counselees were older than FH− non-provider employees, and had the largest percentage of Caucasian women (96%). Counselees and nurses reported higher incomes than the FH+ and FH− employees who were not directly involved in health care provision. To take a conservative approach, age, ethnicity, and income, were included as covariates in subsequent analyses of group differences.

5.3. Data reduction and construct validation

In the first phase of data reduction, item analyses were performed to identify questions that were either too easy (>80% correct) or too difficult (<20% correct). Results of these analyses revealed that, of the 45 items, four were too simple and four were too difficult (items labeled in Appendix A). Because it was possible that the difficult items were good “discriminators” between the Groups, we ran individual group analyses on these items and found that Groups answered the four items correctly at comparable rates. Based on these findings, all eight questions were dropped from the questionnaire.

The remaining 37 items were entered into a confirmatory factor analysis, as described above, in which a parsimonious one-factor solution was tested against two- (“basic genetic information”, “clinical implications”) and three-factor solutions (“basic genetic information”, “risk information”,...
at or above the 0.5 level (see Appendix A for final 27-item version). We revealed that 27 of the 37 items loaded on the single factor while the single-factor solution, the parsimonious one-factor solution, did not significantly fit the data better than the multifactorial models. The indices (TGFI) ranging from 0.86 to 0.87. Because the fit with the data (Table 2), with Tanaka Goodness-of-Fit results indicated that all three models were an excellent screening recommendations”) hypothesized a priori. Re-

Table 2

<table>
<thead>
<tr>
<th>Solution</th>
<th>Sum of squared residuals (SSR)</th>
<th>Root mean squared residuals (RMSR)</th>
<th>Tanaka Goodness-of-Fit index (TGFI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BGKQ-37, one factor</td>
<td>0.314</td>
<td>0.022</td>
<td>0.86</td>
</tr>
<tr>
<td>BGKQ-37, two factors</td>
<td>0.304</td>
<td>0.021</td>
<td>0.87</td>
</tr>
<tr>
<td>BGKQ-37 three factors</td>
<td>0.304</td>
<td>0.021</td>
<td>0.87</td>
</tr>
<tr>
<td>BGKQ-27 one factor (final version)</td>
<td>0.178</td>
<td>0.025</td>
<td>0.93</td>
</tr>
<tr>
<td>BCHK</td>
<td>0.023</td>
<td>0.021</td>
<td>0.93</td>
</tr>
</tbody>
</table>

“screening recommendations”) hypothesized a priori. Results indicated that all three models were an excellent fit with the data (Table 2), with Tanaka Goodness-of-Fit indices (TGFI) ranging from 0.86 to 0.87. Because the multifactorial models did not significantly fit the data better than the single-factor solution, the parsimonious one-factor solution was accepted. Examination of factor loadings revealed that 27 of the 37 items loaded on the single factor at or above the 0.5 level (see Appendix A for final 27-item version, items asterisked). These items were retained for the final version of the questionnaire. The 27-item version of the BGKQ displayed excellent internal consistency (reliability), with a Cronbach’s alpha of 0.92 and a final TGFI of 0.93. Cronbach’s alpha for the 37-item version was similarly high, at 0.91. In contrast, while a one-factor solution of 0.93, Cronbach’s alpha for the 37-item version was similar high, at 0.91. In contrast, while a one-factor solution to the BCHK demonstrated an excellent fit (TGFI = 0.93), Cronbach’s alpha for the BCHK was only 0.48, exhibiting poor internal consistency. Consistent with these findings, only two of the items on the BCHK had factor loadings of at least 0.5.

5.4. Criterion validation

To determine whether or not the 27-item BGKQ demonstrated criterion validity, we conducted an ANOVA, comparing the five groups’ scores, controlling for demographics, as above. A significant main effect of Group was observed, F(4,67) = 8.39, P < 0.0001. Planned comparisons of covariate-adjusted means (least-squares) indicated that counselees scored significantly higher than all other groups on the BGKQ-27. Also as expected, oncology nurses scored higher than general practice nurses and other FH+ employees, and marginally higher than FH− employees (P < 0.07). In contrast, groups did not differ significantly in their performance on the BCHK, F(4,67) = 0.96, P < 0.45 (see Table 3).

To rule out independent effects of family history of breast cancer on knowledge, we compared women with and without such family histories, independent of the Group. In each of the nurse subgroups, one woman reported having a family history of breast cancer in a first-degree relative. Not surprisingly, 60% of the counselees were FH+, as well as the remainder having family histories of ovarian cancer or multiple second-degree relatives with breast cancer. We found, however, that FH+ women (n = 30–11 FH+ employees, two nurses, and 17 counselees) and FH− women (n = 45) did not differ in their performance on the BCHK, suggesting that effects were not due to family history status per se.

Finally, to compare the differential utility of the BGKQ-27 and the BCHK head to head, we performed a simultaneous entry logistic regression analysis, using the two instruments as predictors of group membership, and age, income, and ethnicity as covariates. To simplify analyses, Group was dichotomized as Counselee versus Other. Results indicated that the BGKQ-27 accurately predicted group membership; χ²(1) = 10.44, P < 0.002, but the BCHK did not; χ²(1) = 0.29, P < 0.59 (see Table 4).

6. General discussion

In this report, we describe the development of a questionnaire assessing knowledge of information generally provided during breast cancer genetic counseling and the empirical evaluation of its validity. Based on content analysis of actual breast cancer genetic counseling sessions, the instrument evidenced excellent initial psychometric properties, including high levels of content validity. Evaluation with selected
samples of test-takers demonstrated that the instrument has excellent reliability and criterion validity, and evidences a confirmed single-factor structure. Reliability and validity of this new instrument exceeded that of an existing measure (BCHK) previously employed in the literature. Unlike the BCHK, which was developed to assess knowledge in the general population [18], items on the BGKQ-27 were specifically generated to assess information from genetic counseling sessions. Thus, while the BGKQ-27 is longer than this other instrument, it may prove more useful for assessment of knowledge specifically acquired during counseling. As breast cancer genetic counseling becomes increasingly standardized to cover key areas of information, the utility of a standardized validated questionnaire to assess for knowledge will become even greater. Thus, it is anticipated that the BGKQ-27 may become increasingly useful to clinicians interested in assessing how much information their patient obtain/retain during counseling.

As indicated above, studies have suggested that distress and worry associated with risk for breast cancer [9,10] and attending genetic counseling [11,13] may have an impact on processing of information [14–16]. The BGKQ-27 may provide one way to more accurately assess the impact of stress and other factors (e.g. educational background) on knowledge. In addition, initial reports have raised the possibility that knowledge may be an important predictor of decisions to undergo testing [8], engaging in health behaviors, and adherence to screening guidelines [22,23]. Indeed, a major goal of counseling is to allow women to make informed decisions about both their own health and that of their family members [23,24]. While studies have examined the impact of counseling on behaviors such as undergoing genetic testing [8] and screening/prophylactic treatments [22–24], researchers have not had a validated questionnaire to examine whether or not women who come away from counseling better able to make informed decisions about their health care (e.g. changing dietary habits, screening). Similarly, research must still determine whether or not levels of knowledge persist over time, and whether they predict subsequent compliance with recommended screening guidelines and/or other potentially risk modifying behaviors (e.g. diet, exercise). One important approach to test the possibility that knowledge is gained through genetic counseling, short of a clinical trial, would be to compare women’s performance on the BGKQ before and after counseling. The possibility that pretesting might influence the counselee’s behavior during the session (i.e. requesting that the counselor address questions that the counselee could not answer during the pretest), however, would need to be addressed. From a clinical standpoint, such “pretest sensitization” may actually prove useful—as a method of guiding the counseling session toward those points that require the most attention for that individual.

Larger scale randomized trials of this possibility may be warranted.

It must be emphasized, though, that while the BGKQ-27 exhibited sound psychometric properties in this sample, it would be important to validate the instrument on additional diverse samples, varying in cultural and demographic characteristics, to confirm generalizability and to address the inevitable statistical phenomenon of “shrinkage”, the apparent decrease in statistical effects upon cross-validation. In addition, the possibility that a shorter version of this 27-item instrument could be developed to perform equally well needs to be examined in a larger sample. A brief version of the BGKQ would further enhance its utility in both the research and clinical settings. In addition, as genetic counseling is a dynamic process, with the content being modified and updated as new research becomes available, a test such as the BGKQ-27 would also need to be modified periodically to keep up with such changes. The instrument might also require the addition of site/session-specific items if genetic counseling sessions do not follow consensus protocols. At the same time, it must be emphasized that the empirical approach to discarding items (e.g. those that were too simple or too difficult) necessarily resulted in a more streamlined questionnaire, representing only a sampling of the total information covered. In spite of this fact, though, the questionnaire accurately discriminated groups, indicating that the 27-item version is a valid index of knowledge.

Finally, the use of this approach to develop brief knowledge questionnaires for other types of genetic counseling, and more generally, for other types of critical medical interactions (i.e. counseling about risk for cardiovascular disease), might prove useful, as well. In sum, the reliability and validity of the newly developed BGKQ-27 suggest its potential utility. Research on the knowledge obtained by women during genetic counseling may help clinicians better understand women’s decisions about undergoing genetic testing, and engaging in health and screening behaviors, ultimately enhancing informed decision-making and compliance with recommended health and screening guidelines.

Acknowledgements

This research was sponsored in part by grants from the National Cancer Institute (#R01 CA72457—Bovbjerg) and the Department of Defense (#DAMD 17-99-1-9305—Erblich; DAMD 17-99-1-9305—Erblich). We are required to indicate that the content of the information contained in this report does not necessarily reflect the position or policy of the United States Government.
Appendix A

*Item included in final 27-item scale
*Item dropped-too simple
*Item dropped-too difficult
*Item dropped-low factor loading

<table>
<thead>
<tr>
<th>Please try to complete all items even if you're unsure of an answer</th>
<th>True</th>
<th>False</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1* 50% of inherited genetic information (about breast cancer risk) is passed down from a person’s mother.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2* 25% of inherited genetic information (about breast cancer risk) is passed down from a person’s father.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3* A breast cancer gene mutation inherited from a parent is present in every cell of the body.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4* About 1/3 of all breast cancers are hereditary.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5* There is more than one gene that can increase the risk of breast cancer.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6* A woman who has a mother with a breast cancer gene mutation has a 50% chance of having a gene mutation herself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7* A woman who has a sister with a breast cancer gene mutation has a 1 in 4 chance of having a gene mutation herself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8* A father can pass down a breast cancer gene mutation to his daughters.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9* One in 10 women has a breast cancer gene mutation.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10* All women who have a breast cancer gene mutation will get cancer.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11* If a woman learned from genetic testing that she does not have a breast cancer gene mutation, then that means the breast cancer in her family cannot be hereditary.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If the currently available genetic tests were to indicate that a woman has a breast cancer gene mutation, she is at increased risk for:

| 12* Breast cancer | | |
| 13* Ovarian cancer | | |
| 14* Lung cancer | | |
| 15* Bladder cancer | | |

If a woman who already had breast cancer was found to have a breast cancer gene mutation, she is at increased risk for developing:

| 16* Another breast cancer | | |
| 17* Ovarian cancer | | |
| 18* Lung cancer | | |
| 19* Bladder cancer | | |

Women who test positive for breast cancer gene mutations are generally more likely to develop breast cancer at a young age.
<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>False</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>21*</td>
<td>A woman with a breast cancer gene mutation has an increased risk of ovarian cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22*</td>
<td>A woman who does not have a breast cancer gene mutation can still get breast cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23*</td>
<td>A man who carries a breast cancer gene mutation has an increased risk of developing breast cancer himself.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24*</td>
<td>If a woman tests positive for a breast cancer gene mutation, her male relatives’ risk for developing prostate cancer are lowered.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25*</td>
<td>It is possible to have several relatives with breast cancer solely due to chance.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26*</td>
<td>A woman may be at greater risk for developing breast cancer if she has several close relatives with breast cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27*</td>
<td>A woman may be at greater risk for developing ovarian cancer if she has several close relatives with ovarian cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28*</td>
<td>A woman may be at greater risk for developing ovarian cancer if she has several close relatives with breast cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29*</td>
<td>A woman who has her healthy ovaries removed will definitely not get ovarian cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30*</td>
<td>A woman who has her breasts removed will definitely not get breast cancer.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31*</td>
<td>Screening for ovarian cancer often does not detect a tumor until it is more advanced.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32*</td>
<td>If a genetic test were to indicate that a woman inherited a breast cancer gene mutation, then she should be screened more often.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33*</td>
<td>If a genetic test were to indicate that a woman did not inherit a breast cancer gene mutation previously identified in her family, she should still practice more frequent breast screening than the general public.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34*</td>
<td>Clinical breast exams can detect breast tumors that cannot be seen on x</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
38a. How many copies of a non-working breast cancer gene must one have to actually develop inherited breast cancer?
   a. 0
d. 3
   b. 1
e. Don’t know
c. 2

39a. How many copies of a working breast cancer gene must one inherit to NOT be at inherited risk for breast cancer?
   a. 0
d. 3
   b. 1
e. Don’t know
c. 2

40a. What is the approximate risk that the average woman in the United States will develop breast cancer in her lifetime?
   a. 12%
d. 72%
   b. 24%
e. Don’t know
c. 58%

41a. What is the approximate risk that the average woman in the United States will develop ovarian cancer in her lifetime?
   a. 1-2%
d. 40-60%
   b. 5-10%
e. Don’t know
c. 20-25%

42a. If a genetic test were to indicate that a woman inherited a breast cancer gene mutation, then how likely is she to develop breast cancer in her lifetime?
   a. up to 15% chance
d. up to 50% chance
   b. up to 25% chance
e. up to 85% chance
   c. up to 40% chance

43a. Unless a woman has a particular risk factor, she should start getting regular mammograms at age:
   a. 50
d. 45
   b. 35
e. 50
c. 40
   f. Don’t know

44a. Breast self-examination should be performed:
   a. once a day
d. once every six months
   b. once a week
e. once a year
   c. once a month
   f. Don’t know

45a. Select the procedure that is NOT appropriate for the detection of ovarian cancer
   a. ultrasound
d. pelvic examination
   b. pap smear
e. Don’t know
c. CA-125 blood test
References


