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The Cancer Worry Scale Revised for Breast Cancer Genetic Counseling

KEY WORDS

BRCA1

BRCA2

Cancer worry

Cancer worry scale

Genetic counseling

Risk perception

Background: The Cancer Worry Scale was revised to be used in breast cancer genetic counseling (CWS-GC). This scale is used to identify dimensions that are relevant in the genetic counseling context, such as worry about developing breast cancer, impact of worries on daily life, and risk perception in women attending a counseling session for *BRCA1/2* mutations. **Objective:** The aim of this study was to estimate the psychometric properties of the CWS-GC in a sample of Italian women. **Methods:** A total of 304 women aged 19 to 90 years, 58% with history and 42% with no history of breast or ovarian cancer, participated in the study. Validity, reliability, and sensitivity to change of the CWS-GC were assessed. **Results:** Confirmatory factor analysis suggested a 2-factor structure of the CWS-GC measuring cancer worry and risk perception and with Cronbach's α coefficients of .90 and .70, respectively. Criterion validity was attested by substantial yet not overlapping correlations with anxiety and fear of medical procedures. In a subsample of 50 women, test-retest reliability at a 4-week interval ranged from 0.70 to 0.87, and the CWS-GC was able to detect small to medium changes 1 month after genetic counseling. **Conclusions:** Overall, the CWS-GC showed good psychometric characteristics in this population. **Implications for Practice:** The CWS-GC would be appropriate for use by healthcare professionals to better understand how women react and adapt to information on genetic cancer risk to provide them with emotional support and encourage surveillance behaviors.

Genetic predisposition is estimated to account for 5% to 10% of the breast cancer cases that are diagnosed each year, and approximately one-third of these cases are attributable to mutations in *BRCA1* or *BRCA2* genes.¹ In

BRCA1/2 mutation carriers, the overall breast cancer risk by the age of 70 years is 51% to 59%, and the overall ovarian cancer risk is 11% to 34%.² An overall *BRCA1/2* mutation prevalence of 13.7% to 41.9% was observed in persons with a

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family history of breast/ovarian cancer, which varies depending on the number of family members affected.³ Genetic testing provides an opportunity to enhance health promotion and long-term health outcomes by identifying at-risk individuals before cancer develops.⁴ Provision of genetic counseling to women with a family history of breast/ovarian cancer indeed aims to help them understand and process the information received about their genetic risk. To achieve these objectives, we should examine those variables that are closely related to health-oriented behaviors in cancer genetic counseling.

Many social factors have been linked to health-oriented behaviors including sociodemographic variables⁵; however, only modifiable factors may help planning effective interventions. The most researched variables in this field are cancer worry (CW) and perception of risk^{6,7} for several reasons: they are amenable to change and offer an opportunity to intervene⁵; women with a family history of breast cancer report elevated CW⁸; perceived breast cancer risk, which is often overestimated, is a stronger predictor of breast CW⁹; and both variables are highly associated with health behaviors, such as decision to undergo genetic testing, adherence to screening mammogram, and choices about prophylactic surgery.^{5,10–14}

Although risk and worry have been frequently used interchangeably,⁵ they are conceptually different. In fact, risk perception (RP) is a cognitive dimension that refers to one's belief about the likelihood that an adverse event, such as cancer, occurs.¹⁵ Cancer worry is instead an emotional reaction to the threat of cancer.¹⁶ Cognitive (risk) and affective (worry) perceptions of vulnerability have a central role in self-regulation and may interact in determining health behaviors according to various health behavior theories and models.¹⁷ Therefore, it is important to investigate both RP and worry, but it is also important to distinguish between the two because they may influence behavior differently.¹⁴ Indeed, RP and worry have been described as driving behaviors in parallel,¹⁸ or interacting in determining behavior,¹⁴ and were found to be modestly related.¹⁹ For example, CW was found to predict interest in genetic testing⁷ and breast cancer screening²⁰ even after controlling for perceived risk.

Previous Measures

Researchers have used a variety of measures to assess breast cancer–related worries²¹ including generally standardized questionnaires such as the revised Impact of Event Scale and Spielberger State Anxiety Scale; however, purposely designed scales are preferable in terms of the precise source of anxiety they target.⁵ One of the earlier breast CW scales was developed by Lerman and her colleagues²²: the Cancer Worry Scale (CWS). This is a 4-item scale that measures the current level of worrying about getting breast cancer, the impact of worry on mood and performing daily activities, and worry about future mammographic results. Although other specific measures have been also developed, such as the Cancer Attitude Inventory,²³ the Breast Cancer Fear Scale,²⁴ and the Cancer Worry Chart,²⁵ the CWS still remains the most used tool, with approximately 400 studies across more than 10 countries showing good psychometric

properties, such as Cronbach's α in the range of .82 to .86.^{26,27} The advantage of CWS as compared with other similar instruments is that it measures both CW and impact of worry. Instead, the Cancer Attitude Inventory measures attitudes, the Breast Cancer Fear Scale measures fear and physiological arousal, and all these dimensions are different from the worry construct. The Cancer Worry Chart is a single pictograph item, which measures how much a person has been bothered by thoughts or worries about the chance of getting breast cancer and was tested for comparative validity using the CWS as the criterion standard measure.

In the years, researchers have adapted the CWS to the specific needs of their studies on breast and other cancers.^{13,21,28,29}

Most studies using the CWS considered it a unidimensional measure.^{26,29} However, we observed in Italy that it was formed by items that could identify 2 clearly related but potentially distinguishable concepts: the presence of thoughts and concerns about developing cancer and how these concerns may impact on or interfere with one's mood and daily life. In the original study, Lerman et al²² summed the 2 worry impact items to create a worry impact index as a separate variable because these items do not ask about experiencing worry per se. The importance of distinguishing between these 2 concepts also emerges from a study of women at a high risk for breast cancer.³⁰ Two-thirds of the respondents perceived worries about breast cancer as interfering with their daily functioning, whereas one-third did not. In addition, the impact of worry predicted anxiety, confusion, and a reduced mental health after the effects of other variables such as the frequency of CW and having a family history of cancer.³⁰

In the literature, the assessment of RP has been carried out through a variety of nonvalidated measures such as a numerical rating scale of 0% to 100%,³¹ with 100 representing the highest risk, or descriptive scales with Likert-type response format (eg, ranging from “not at all likely” to “extremely likely”).³² However, there is evidence that the numerical rating scale has the best performance based on several criteria, such as being predictive of health-oriented behaviors, correlating with similar measures, and being associated with the actual risk.³³ Within cancer genetic counseling, the perception of risk is understood as the likelihood to be a carrier of a genetic mutation such as the *BRCA1/2* (genetic RP [GRP])¹⁵ and, consequently, the probability of developing cancer (cancer RP [CRP]).³² A previous Italian study¹¹ assessed both GRP and CRP with 2 items answered on a scale of 0% to 100%.

Aim

This study aimed to validate a revised form of the CWS²⁰ to assess both breast CW and RP of being positive to *BRCA1/2* or developing breast cancer in women attending cancer genetic counseling in Italy. We hypothesized that this tool could be formed by 2 independent indexes measuring CW and CRP/GRP, respectively. We also hypothesized that CW consists of 2 highly interrelated but distinct dimensions: the frequency/intensity of CW and the impact of CW on mood and daily functioning.

To be useful for clinical practice and research, this measure should be feasible to administer in clinics and have sound psychometric attributes, including validity, reliability, and sensitivity to change.

■ Methods

Study Design

This is a cross-sectional multicenter study conducted across Italy and approved by the ethics committees of the 7 participating hospitals. The study design was based on 3 steps.

In step 1, a pool of items was selected from existent tools, forward-backward translated using a standard procedure,³⁴ and then piloted in a small group of patients. Two bilinguals translated the original items into Italian, and 2 independent translators back-translated it into English. An independent translator, who was a native speaker of the target language and fluent in the source language, was used to carry out the reconciliation, and minor differences were corrected at this stage. Participants in the pilot study filled in the self-report questionnaire and then were asked to provide feedback regarding the clarity of each item and any additional comments.

In step 2, the questionnaire was administered to a larger sample of participants, along with measures of potentially associated variables, to assess structural validity, criterion validity, and internal consistency. To assess criterion validity, we used standard measures of fear of medical procedures, anxiety, and depression. We expected high correlations of CW with fear of medical procedures and with anxiety because worry, anxiety, and fear are all emotional states characterized by hyperarousal, although they refer to different constructs. In fact, it has been suggested that cancer fear refers to a rating range that may be dysfunctional in the upper extreme and CW refers to a lower, more manageable range of the affect.⁵ Anxiety is a more general emotional condition that was found to be highly associated but not overlapping with CW, which was therefore clearly identifiable from anxiety.³⁵ We also expected higher correlations with anxiety and fear of medical procedure than with depression because depression is a mood condition characterized instead by hypoarousal. We expected significant but lower associations between RP and mood disturbance (anxiety, fear of medical procedure, and depression) because they are cognitive and emotional perceptions, respectively. We also used group comparisons to evaluate the extent to which the scale was able to discriminate between subgroups of patients with different current symptoms (ie, asymptomatic vs symptomatic). We expected that women who had experienced cancer perceived a higher CW than asymptomatic women.³⁶ On the contrary, we expected that potentially asymptomatic mutation carriers perceived less controllability of their condition than women with manifest disease and then reported a lower RP. However, this analysis was explorative because results of the literature are controversial.^{36,37}

In step 3, the questionnaire was administered again after approximately 1 month to a subsample of participants to assess both test-retest reliability and sensitivity to change. Patients were

expected to have CW reduced 1 month after a genetic counseling informative session.³⁷

In steps 1 and 2, the consenting patients completed the questionnaire immediately before genetic consultation; in step 3, participants completed a 4-week follow-up at the same genetic clinic. Each participant signed informed consent to the study, and data were handled in accordance with the Italian privacy law.

Participants

Volunteer patients for the pilot study were recruited in 2 of the 7 participant hospitals. This was a convenience sample formed by patients with similar characteristics to those of the instrument audience, yet not strictly representative of the study population. Indeed, we gave preference to patients who read at or lower than the eighth grade level because concepts such as genetic testing and RP are highly complex. This complexity could be a major barrier to comprehension for adults with low literacy skills, who have been found to provide answers on self-reports to questions that they do not completely understand.³⁸ The main purpose of the pilot study was to ensure readability, absence of ambiguity, and understanding of scaling and content of the questionnaire and not to make the results of the pilot study directly generalizable to the ultimate study. A practical rule is that a simple and clear tool that is appropriate for persons with limited literacy is also suitable for those with well-developed literacy.³⁹

The main study sample was recruited at the 7 cancer genetic clinics participating in the study. The required sample size was estimated a priori based on confirmatory factor analysis (CFA) model identification, as described hereinafter in the Data Analysis section. All self-referred eligible women attending a first visit for genetic counseling were informed about and invited to participate in the study. Eligible participants were women 18 years or older having at least 1 first-degree relative with breast and/or ovarian cancer and/or who were members of families that had not been previously tested for *BRCA1/2* mutation and had not attended any genetic counseling session. The study sample included asymptomatic women with no personal history of cancer, as well as affected women, because inherited susceptibility has implications for the risk of cancer recurrence. Care was also taken to ensure that unaffected women were not waiting for the results of cancer screening. Although the study focus is on breast cancer, participants attending cancer genetic clinics may have ovarian cancer or relatives with ovarian cancer because *BRCA1/2* mutation predisposes to both types of cancer.

To form the subsample participating in the 4-week follow-up, 5 of the 7 hospitals randomly selected 10 patients among those who completed the first wave survey. Estimates of the minimum sample size required for test-retest reliability, at the conventional values α of .05 and β of 0.20, for reliability values of 70% or higher and 2 replications include approximately 41 subjects.⁴⁰ However, 50 subjects were selected to handle potential nonresponse to the follow-up.

Measures

Demographic and medical characteristics included age, educational level, information on previous diagnosis of cancer and

treatments made, and the number of first-degree relatives affected by breast, ovarian, or other cancers.

CWS FOR GENETIC COUNSELING

The CWS for Genetic Counseling (CWS-GC) measures anxiety that is specific to getting breast cancer and CRP/GRP. It is formed by the original CWS,²² which includes 4 items measuring the intensity of worry about developing breast cancer, anxiety for future mammograms, and impact of breast CW on mood and daily functioning, answered using a 5-point scale (from 0, “not at all/never,” to 4, “very much/very often”). We added 1 item on the frequency of worries about developing breast cancer taken from one of the numerous revised versions of the CWS²⁸ because we considered frequency an important aspect within the global level of CW. We completed this tool adding 2 items to measure, respectively, the perceived risk of having an altered breast cancer gene¹⁵ and of developing breast cancer.³² In this way, we obtained a brief tool to assess both cancer worries and perceived risk, although measured with different response formats. Indeed, the last 2 items were rated using a visual analog scale ranging from “no perceived risk” (0%) to “the highest perceived risk” (100%) because this format showed the best performance with perceived risk questionnaires.³³ We did not expect that different response formats may affect the results of the CFA because multiple-group invariance was found across different response formats, differing in the type of anchor points using horizontal rating scales.⁴¹

An Italian version of the items used to form the CWS-GC was made and then revised, pretested, again revised, and subsequently approved to be used in this study. Items of the CWS-GC are shown in the Appendix.

STATE-TRAIT ANXIETY INVENTORY

The State-Trait Anxiety Inventory (STAI) is a well-validated questionnaire that measures general anxiety.⁴² The trait 20-item scale asks participants to indicate, on a 4-point scale, how they generally feel regarding 20 statements, whereas the state 20-item scale asks participants to describe how they currently feel regarding the same 20 statements. Total scores for each scale range from 20 to 80. A higher score of the trait scale indicates a general negative affectivity, and a higher score of the state scale indicates higher state anxiety.

COGNITIVE BEHAVIORAL ASSESSMENT-FORM H

The Cognitive Behavioral Assessment-Form H⁴³ is an Italian well-established battery of tests that provides a comprehensive clinical assessment. Three of the included scales were used in this study: A1 (9 items) measures a general state of anxiety, A2 (5 items) assesses fear reactions to situations related to health management and diagnostic/curative treatments or medical procedures, and A3 (5 items) investigates the presence of depressive thoughts. Items are answered with true/false.

Data Analysis

Scores obtained from 5 of the 7 CWS-GC items were rescaled to a 0 to 100 basis to facilitate their manipulations according to

percentage of scale maximum scores [$\%SM = (\text{score}) \times 100 / (\text{number of scale points} - 1)$].

To allow considering the main sample as homogeneous, although 7 different institutions contributed patients, similarity was preliminary investigated among subsample characteristics and scores of measures. Comparisons were computed using analysis of variance (ANOVA) at item level for the CWS-GC and at scale level for the other measures.

Confirmatory factor analysis was used to examine the extent to which the CWS-GC items can be combined into the 3 hypothesized multi-item scales referring to frequency/intensity of CW, worry impact, and CRP/GRP, respectively. The proposed 3-factor model was compared with a 1-factor model to exclude that the scale was best represented as a single dimension. It was also compared with a 2-factor model, one formed by the items related to CW and the other formed by the items related to perceived risk. The robust maximum likelihood method was used to estimate model parameters: Satorra-Bentler scaled χ^2 statistic (S-B χ^2),⁴⁴ root mean square error of approximation (<0.08),⁴⁵ standardized root mean square residual (<0.08),⁴³ nonnormative fit index (≥ 0.95),⁴⁶ and comparative fit index (≥ 0.95).⁴⁶ The previously mentioned indices were examined for the 3 tested models, whose goodness of fit was compared by an S-B χ^2 difference test with the correction needed when the S-B scaled χ^2 is used.⁴⁴

To establish the minimum required sample size for CFA model identification, focusing our interest only on obtaining an adequate sample size to estimate the factor loadings, we conducted a Monte Carlo simulation following the guidelines described by Muthén and Muthén.⁴⁷ We used a 3-factor model indicated by 2 or 3 indicators, with standardized factor loadings of 0.50 and less than 2% missing data per indicator, because it was more demanding than a 2- or 1-factor model. The minimum required sample size was approximately 290.

The internal consistency of scales was assessed by Cronbach's α coefficient, whose desirable value is .70 or greater.⁴⁸

As evidence of criterion validity, zero-order correlations were calculated between the CWS-GC and criteria (ie, STAI and Cognitive Behavioral Assessment-Form H scales), and ANOVA was used to evaluate whether the CWS-GC was able to discriminate between asymptomatic and symptomatic women.

Intraclass correlation was used to provide an estimate of the questionnaire test-retest reliability at 4 weeks using a subsample of patients, with a value greater than 0.70 as acceptable. These 2 administrations of the CWS-GC were also used to examine the sensitivity of the questionnaire to change using repeated-measures ANOVA.

In the evaluation of estimates, we based conclusions on both statistical significance ($P < .05$) and standardized measures of effect, with Cohen d of 0.2 considered small, 0.5 considered medium, and 0.8 considered large and Pearson r of 0.10 considered small, 0.30 considered medium, and 0.50 considered large.⁴⁹ Cohen d was corrected, where appropriate, for dependence between means using Morris and DeShon's⁵⁰ equation 8.

Confirmatory factor analyses were performed using LISREL 880 (Scientific Software International, Lincolnwood, Illinois); all other analyses were performed with IBM SPSS 20 (SPSS Inc, Chicago, Illinois).

■ Results

Participants’ Characteristics

Participants in the pilot study were 25 women aged from 45 to 75 years. Most of them (64%) had an eighth grade level of education, and two-thirds (64%) had a history of previous breast or ovarian cancer.

Participants in the main study were 304 women aged from 23 to 83 years. Approximately 58% were given a diagnosis of or treated for breast or ovarian cancer. There were no statistically significant differences in the characteristics of patients from the 7 hospitals.

The subsample participating in the 4-week follow-up was formed by 50 women. This subsample has characteristics that are comparable with those of the entire sample, except for a larger proportion of women affected by cancer (Table 1).

THE PILOT STUDY

Sixty percent of the participants in the pilot study reported having spent 10 to 15 minutes to complete the test, whereas 32% reported having spent less than 10 minutes. Eight participants (32%) found an item (“What do you think are the odds that you have mutations in *BRCA1/2* genes?”) difficult to understand, and thus, it was reformulated until it was deemed completely understandable (“How likely is that you have one of the genes for predisposition to breast cancer altered?”). The other items were all rated clear and understandable. Overall, the CWS-GC was found by patients to be quick and simple to complete. We examined response sets because they may lower the validity of a test. Response errors and item nonresponses were not found. Extreme responding, which is a form of response bias driving respondents to only select the most extreme answers available, that was previously found in low-educated people⁴⁶ was observed in only 2 of 25 respondents (8%). As regards item discrimination, the discrimination index D was computed from equal-sized high- and low-scoring groups on the test, with D values of 0.40 and greater regarded as high.⁵¹ All items of the CWS-GC showed adequate discrimination

both on high scores (D between 0.57 and 0.86) and low scores (D between 0.50 and 0.86).

VALIDITY AND INTERNAL CONSISTENCY

Comparisons among patients from different institutions showed no significant differences on scores of all the measures; therefore, we considered the main sample as a whole.

In the CFA 1-factor model, none of the indices met its respective criterion, indicating that a model with a single latent variable was not a good representation of the CWS-GC structure (Table 2). The 2-factor model (Table 2, Figure 1) provided a significantly better fit to the data, although χ^2 values were still significant. The 3-factor model (Table 2, Figure 2) showed a better fit with a significant improvement in χ^2 fit compared with the 2-factor model. However, the correlation between CW and worry impact was extremely high ($r=0.94$) supporting the concept of a unitary global score. In general, a second-order factor can be postulated behind highly correlated factors, but it should be taken into consideration in the consequential multicollinearity if these factors are used in further analyses with other variables. To make a final decision regarding the model to choose, we evaluated the discriminant validity of each factor and compared it among the 3- and 2-factor solutions.⁵² Discriminant validity is satisfied when a latent variable is able to account for more variance in the observed variables associated with it than the amount of variance shared with other factors within the conceptual framework. Results indicated that, in the 3-factor solution, there was a questionable discriminant validity for CW and worry impact because the average variance extracted by these 2 factors (0.88 and 0.81, respectively) was not larger than the amount of variance shared between the two ($\gamma^2=0.88$). Instead, in the 2-factor model, average variance extracted values were 0.89 for CW and 0.59 for RP, which were both larger than their shared variance ($\gamma^2=0.49$). On the basis of consideration of discriminant validity, the 2-factor model was chosen for the CWS-GC, although it led to some decrement in model fit. Standardized factor loadings for this model were higher than 0.55 ($P<.001$). The 2 factors were named CW and RP, respectively. The intercorrelations among these factors confirmed that they are linked but not overlapping concepts.^{6,14,30} Mean (SD) values are presented in Table 3.

In the whole sample, the CW scale correlated substantially but not overlapping (r in the 0.51–0.60 range) with state and trait anxiety and medical fears, whereas they correlated moderately ($r=0.34$) with depression. The RP scale showed small to medium correlations with criterion variables (Table 3). Correlations with age were negligible ($r=0.11$, $P=.06$, for CW; $r=-0.10$, $P=.07$, for RP).

Group differences were statistically significant only in RP, although with a small effect size, with patients affected by cancer reporting a lower perceived risk than women with no cancer history (Table 4).

Internal consistency of the CWS-GC was good to acceptable, with Cronbach’s α coefficients of .90 for CW and .70 for RP. Corrected item-total correlations for each subscale were in the range of 0.50 to 0.72.

❁ Table 1 • Participant Characteristics			
	Sample (n=304)	Retest Subsample (n=50)	
Age, mean (SD) (range), y	46.85 (11.9) (19–90)	45.96 (8.69)	(26–66)
Level of education, n (%)			
Lower secondary	63 (20.7)	9	(18)
Higher secondary	145 (47.7)	24	(48)
Tertiary	96 (31.6)	17	(34)
Cancer affected, n (%)	176 (57.9)	39	(78)
Breast cancer	162 (92)	38	(97.4)
Ovarian or other cancer	14 (8)	1	(2.6)

❁ **Table 2 • Confirmatory Factor Analysis' Goodness-of-Fit Indices for 3 Models of the CWS-GC**

Fit Indices	1-Factor Model	2-Factor Model	3-Factor Model
χ^2 (df)	83.74 (14) ^a	34.48 (13) ^a	15.78 (11)
S-B χ^2 (df)	78.96 (14) ^a	33.42 (13) ^a	16.14 (11)
Δ S-B χ^2 (Δ df) ^b	-	24.84 (1) ^a	14.09 (2) ^a
RMSEA (90% CI)	0.13 (0.10–0.15)	0.07 (0.06–0.10)	0.04 (0.00–0.08)
SRMR	0.06	0.03	0.02
NNFI	0.95	0.98	0.99
CFI	0.96	0.99	1.00

Abbreviations: CFI, comparative fit index; CI, confidence interval; NNFI, nonnormative fit index; RMSEA, root mean square error of approximation; S-B χ^2 , Satorra-Bentler scaled χ^2 statistic; SRMR, standardized root mean square residual.

^a $P < .001$.

^b Δ S-B index was calculated between 2- and 1-factor models and between 3- and 2-factor models, respectively.

TEST-RETEST RELIABILITY AND SENSITIVITY TO CHANGE

Test-retest stability for a 4-week period in a subsample of patients ($n=50$) was acceptable, with intraclass correlation values of 0.87 (95% confidence interval, 0.78–0.93) for CW and 0.70 (95% confidence interval, 0.41–0.81) for PR.

As regards sensitivity to change, the CWS-GC scales were able to detect changes in CW that were statistically significant, with a medium effect size among patients with cancer and a large effect size among patients with no cancer. In RP, change was significant and of a medium effect size among patients with no cancer and of a small effect size among patients with cancer (Table 5).

■ Discussion

Genetic cancer risk assessment has been increasingly incorporated into clinical care, but planning supportive care for women seeking genetic counseling requires knowledge of their health

beliefs and emotional reactions. Cancer worries and RP play an important role in psychological reactions and adaptation to the information received, as well as in promoting surveillance behaviors that help minimize the risk of developing cancer.^{5,12,13} Therefore, precounseling RP and CW should be routinely assessed for new referrals to genetic counseling clinics.

In this study, we tested, in a sample of Italian women with a family history of breast/ovarian cancer attending a screening for *BRCA1* or *BRCA2* mutations, the psychometric properties of a brief tool where these 2 constructs are integrated. We added to the CWS,²² a measure of cancer worries widely used at an international level, 2 items on perceived risk of having an altered breast cancer gene and developing breast cancer, respectively. Previous studies^{26,29} used exploratory factor analysis to test the dimensionality of CWS in different countries, whereas items related to cancer RP have not been validated, although they have been previously used in different countries.^{15,32} Therefore, this tool was intended to be used also in countries other than Italy for all women undergoing genetic susceptibility testing for *BRCA1/2*. This is the first study that

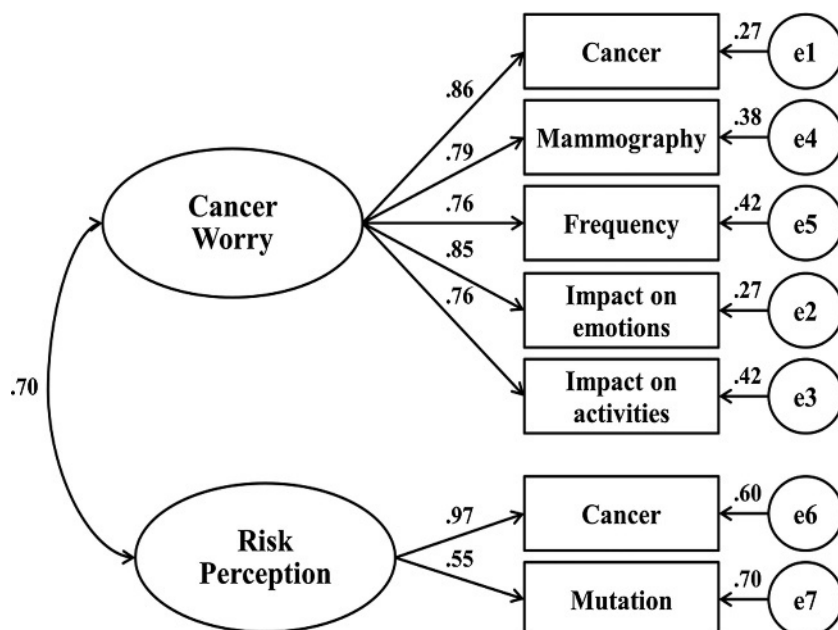


Figure 1 ■ Two-factor model of the CWS-GC.

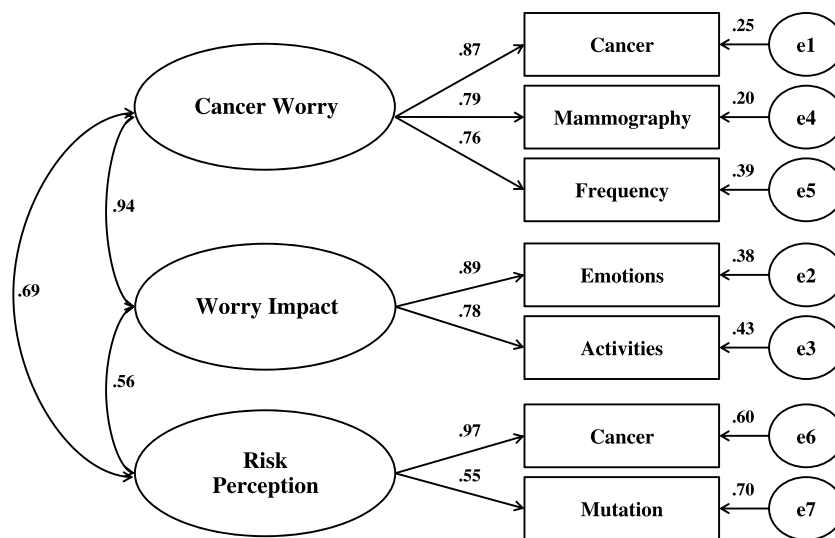


Figure 2 ■ Three-factor model of the CWS-GC.

validates a tool measuring both breast CW and RP using CFA, which offers greater modeling flexibility than exploratory factor analysis and allows comparing different models for the factor structure of a tool. On the basis of the results of CFA and discriminant validity, a 2-factor model was chosen for the CWS-GC, which showed acceptable internal consistency and test-retest reliability for a 4-week period. This structure, based on CW and RP, may add more information to the CWS because previous research has shown that high perceived risk of breast cancer may result in high levels of CW.⁵³ On the other hand, CW was related to preventive health behaviors, such as cancer screening⁵⁴ or interest in genetic testing.⁷

The CWS-GC showed correlations of CW with anxiety and medical fears that were higher than those with depression, as in a previous study,³⁵ attesting that the questionnaire is sensitive in detecting specific concerns related to the situation rather than measuring a general state of negative affectivity. In addition, the scale was able to detect changes that were statistically significant. The decrease of CWS-GC score after the genetic counseling session confirmed the results of previous studies showing a reduction on both CW and perceived risk after a genetic counseling informative session.³⁷

Group differences were statistically significant in perceived risk, although with a small effect size, with patients affected by cancer reporting a lower perceived risk than women with no cancer history. Findings from the literature are controversial about this issue. For example, women who had already had breast/ovarian cancer showed raised perceptions of risk in comparison with nonaffected women in a study,³⁶ but unaffected women believed that they were at a higher risk for breast cancer than affected women in another study.³⁷ Results from the literature also indicated that women who had already had breast/ovarian cancer showed more concerns about cancer than nonaffected women,³⁶ whereas in this study, there was no difference between groups. Therefore, there is a need for further investigation regarding the differences in both CW and perceived risk between nonaffected and affected women.

Limitations

Our study has some limitations. First, its prevalent cross-sectional nature did not allow examining longitudinally all participants' experiences, which may change over time. Nevertheless, we may expect that the CWS-GC is suitable for evaluating changes occurring in the course of the genetic counseling process because it showed in the subsample of patients re-evaluated at 4 weeks after genetic counseling. Second, the predictive validity of the scale on health behaviors, such as adherence to surveillance programs, still remains to be explored.

❁ **Table 3 • Descriptive Data and Correlations Among Study Variables (N=304)**

	Mean (SD)	Min-Max	Pearson Correlations	
			CW	RP
CW	38.55 (23.44)	0–100		
RP	49.16 (21.62)	0–100	0.52	
STAI-T	42.17 (10.35)	20–80	0.56	0.28
STAI-S	44.63 (12.48)	20–80	0.60	0.38
A1	3.29 (3.14)	0–9	0.55	0.33
A2	2.19 (1.30)	0–5	0.51	0.28
A3	0.47 (0.85)	0–5	0.34	0.20

Abbreviations: A1, general anxiety; A2, fear of medical procedures; A3, depression; CW, cancer worry; RP, risk perception; STAI-S, anxiety state; STAI-T, anxiety trait.

All correlations are significant at the $P < .001$ level.

❁ **Table 4 • Descriptive Data and Differences Among Health Conditions (N=304)**

Variable	Condition	Mean (SD)	F	P	d
CW	No cancer (n=128)	36.21 (22.76)	2.21	.14	0.17
	Cancer (n=176)	40.26 (23.84)			
RP	No cancer (n=128)	52.06 (20.56)	3.99	.04	0.24
	Cancer (n=176)	46.99 (21.62)			

Abbreviations: CW, cancer worry; d, Cohen d value; RP, risk perception.

❁ **Table 5 • Descriptive Data and Sensitivity to Change Analysis (N=50)**

Variable	Condition	Pretest	Follow-up	P	d
		Mean (SD)	Mean (SD)		
CW	No cancer (n=11)	43.18 (31.76)	28.41 (20.48)	.02	1.15
	Cancer (n=39)	43.91 (25.38)	34.40 (19.25)	.001	0.67
	Total (n=50)	43.75 (26.56)	33.08 (19.47)	.001	0.75
RP	No cancer (n=11)	62.27 (23.24)	48.72 (25.17)	.05	0.64
	Cancer (n=39)	51.68 (22.16)	49.65 (21.13)	.56	0.09
	Total (n=50)	54.01 (22.60)	49.45 (21.04)	.04	0.21

Abbreviations: CW, cancer worry; d, Cohen d value; P, P value of ANOVA within groups; RP, risk perception. Within-condition interaction was nonsignificant in all cases ($P>.05$).

Implications for Practice

The 7-item CWS-GC is reliable, valid, and short enough to avoid burden to the patient. At the same time, it makes possible for nurses to screen women attending breast cancer genetic counseling for overestimated RP and severe levels of CW and assist them in accessing available support. Recognizing when patients are experiencing breast CW has been indeed considered an essential first step toward patient-centered counseling.²⁵ The CWS-GC would be very appropriate for use to better understand how women react and adapt to information on genetic risk and the results of genetic testing. It can also help identify those women who are more vulnerable to developing anxiety and depression, which are both associated with CW,³⁵ because women undergoing genetic susceptibility testing for *BRCA1/2* reported increased long-term psychological distress, in terms of anxiety and depression, that warrants clinical attention.⁵⁵

At a more general level, this understanding is necessary to implement effective intervention protocols to prevent counseling dropout and facilitate surveillance behaviors. Moreover, this brief and reliable tool could be adapted for other contexts. For example, a modification of the CWS has been recently adapted to detect fear of cancer recurrence in breast cancer survivors,²⁹ and thus, it could be adapted and applied in genetic counseling for diseases other than breast cancer.

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Appendix • Cancer Worry Scale Revised for Genetic Counseling (CWS-GC).

1. How worried are you about the possibility of getting breast cancer someday?
2. How much this worry affects your mood?
3. How much this worry interferes with your ability to do your daily activities?
4. How much do you worry about the results of future mammograms?
5. How often do you worry about developing breast cancer?
6. How likely is that you have one of the genes for predisposition to breast cancer altered?
7. How likely is that you get breast cancer in the course of your life?