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Psychological distress in women at increased risk for breast cancer: the role of risk perception

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Abstract

The magnetic resonance imaging screening (MRISC) study evaluates a surveillance programme for women with a hereditary risk for breast cancer. The psychological burden of surveillance in these women may depend on inaccurate risk perceptions. To examine differences in risk perceptions between three predefined risk categories and associations with psychological distress. BC-specific distress, general distress, and RP (cognitive and affective) were assessed, two months before a surveillance appointment. Cumulative lifetime risk (CLTR) of developing breast cancer was trichotomised into: (1) CLTR of 60–85% (mutation carriers), (2) CLTR of 30–50%, and (3) CLTR of 15–30%. In a total group of 351 women (mean age 40.5 years, range 21–63 years) the three risk categories significantly differed in their accuracy of assessing cognitive risk perceptions. In category 1, 60% had an accurate risk perceptions, in category 2, 43.7% and in category 3, 33.3%. Overestimators reported significantly more breast cancer-specific distress. After adding affective risk perception to the model, this effect disappeared. Affective risk perceptions showed significant associations with breast cancer-specific and general distress. Affective risk perception is a more important determinant for psychological distress than cognitive risk perception. This knowledge should be used during surveillance appointments in order to improve and individualise support for these women.

Keywords: Risk perception; Increased risk; Surveillance; Psychological distress; *BRCA1/2*

1. Introduction

One in every ten women in Western industrialised countries will develop breast cancer during her life-time. A genetic predisposition is suspected in approximately 5–10% of all breast cancer cases. In the mid-1990s, the BRCA1 and BRCA2 genes were identified [1,2]. Carriers of a mutation in one of these genes have a significantly increased cumulative lifetime risk (CLTR) of developing breast cancer that has been reported to be between 60% and 85% [3–5], while Antoniou and colleagues [6] recently provided evidence for lower risk percentages in breast cancer patients unselected for family history. Other breast cancer susceptibility genes may also play a role, such as CHEK2 [7], but either their role still has to be elucidated or such genes are not yet identified. Women from families with a clear family history of breast cancer where a mutation has not (yet) been found are also at increased risk, which has mainly been estimated using the risk tables developed by Claus and colleagues [8]. Since the Claus model does not account for bilateral breast cancer, the occurrence of breast cancer in multiple family members as well as the occurrence of ovarian cancer, other models are

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also being developed, and may eventually provide more accurate risk estimations [9]. One of the management options for women at increased risk is regular surveillance mostly by use of an annual mammography and biannual clinical breast examination. A monthly breast self-examination is recommended.

Perceptions of the risk of developing breast cancer in 'high-risk' women are frequently found to be inaccurate, but also show a wide variability. In the literature, between 9% and 57% of 'high-risk' women are reported to have accurate risk perceptions [10–16]. This variability can partly be explained by which the risk perception is measured, either before or after counselling. Meiser and colleagues conducted a meta-analytical review in order to obtain an effect size of the impact of genetic counselling on the accuracy of risk perception. They found a significant medium effect size ($r = 0.56; P < 0.01$) which demonstrates the efficacy of genetic counselling in improving risk perception [17]. Despite improvements in accurate risk perception after genetic counselling, there are still women who continue to overestimate or underestimate their breast cancer risk [10,12,14,18–21]. Several reasons for sustained inaccurate risk perceptions can be given. Lacking sufficient numerical skills or overall education levels can cause inaccurate risk perceptions [22]. Processing information about heredity can lead to wrong assumptions about one's risk of developing the disease, for instance on the basis of physical or psychological identification with an affected relative [23]. Personal experience with breast cancer in the family may obstruct the adoption of realistic risk perceptions [24]. The format in which the risk information is given may also influence the accuracy of recall of the risk estimation. Watson and colleagues found that recall of risk is more accurate when risk information is given in Odds Ratios than in other formats [12].

Women with higher risk perceptions often display more psychological distress, both breast cancer-specific and general [11,12,15,16,20,25]. Hopwood and colleagues [16] found more cancer worries in overestimators than in women who underestimated or who estimated their risk accurately. Meiser and colleagues [15] found that overestimators had both higher state anxiety, as well as breast cancer anxiety. These data result from studies that addressed the level of knowledge of risk, i.e., the cognitive dimension. Women had to indicate how they *think* about their own risk by ticking a number. Hopwood suggested that not only the objective risk information may be of importance, but also the way this information is processed by the individual [13]. This led us to hypothesise that, women may give an accurate or inaccurate estimation of their breast cancer risk, the way they *feel* about this risk may be very much lower or higher. Further, this felt or affective risk perception may have a more powerful association with psychological distress than cognitive risk perception.

In November 1999, the observational magnetic resonance imaging screening (MRISC) study started in the Netherlands evaluating a surveillance program for women at increased risk of breast cancer due to a genetic or familial predisposition (MRISC-part A). The programme consisted of an annual magnetic resonance imaging (MRI) scan and mammography, biannual physical examination and monthly breast self-examination. The participants were classified into one of three risk categories, corresponding to a CLTR of either more than 60%, a CLTR of 30–50%, and a CLTR of 15–30% [26]. A psychological follow-up study started in September 2000 (MRISC-part B). Herein, we describe the association between psychological distress and risk perception in women participating in the MRISC-part B. First, we differentiated between a cognitive and an affective component of risk perception in the three different levels of objective risk status. Next, we determined the association between general and breast cancer-specific distress, and cognitive and affective risk perception. We hypothesised that the women in the different risk categories differed in the perception of their risk; in a way that higher risk perceptions were associated with elevated levels of both types of psychological distress; and that affective risk perception was more prominently associated with psychological distress than cognitive risk perception.

2. Material and methods

2.1. Participants

A total of 351 women were included in this study; 322 women participated in the MRISC-A study and 29 women adhered to surveillance, but were not enrolled in MRISC-A. One hundred and eight women from MRISC-A did not participate in the psychological follow-up study. At entry, participants did not have a history of breast cancer, and had a cumulative lifetime risk of developing breast cancer of at least 15%, based on risk tables by Claus and colleagues [8]. For this study, participants were categorised in one of three risk categories by means of a decision tree, which is an adapted form of the tables of Claus that has been developed for this study by a genetic subcommittee [25]. Women in category 1 were identified BRCA1 or BRCA2 mutation carriers with a cumulative lifetime risk (CLTR) of developing breast cancer of between 60% and 85%. Women in category 2 had a CLTR of between 30% and 50%, and were first-degree family members of a proven *BRCA1/2* mutation carrier, who did not opt for the test themselves, or first-degree relatives from a breast cancer patient from a non-*BRCA1/2* mutation family or a family where genetic testing was not performed. Women in category 3 had a CLTR of between 15% and 30% and

belonged to families with an increased frequency of breast cancer incidence, or were 25% risk carriers from a proven *BRCA1/2* mutation family [27,28]. Participants signed informed consent and had an adequate understanding of the Dutch language. The Medical Ethical Committee of the Erasmus MC in Rotterdam approved the study.

2.2. Measures

2.2.1. Independent variables

Age and the number of years adhering to regular surveillance were measured in years. Educational level was divided into lower, medium and higher levels. Lower levels meant primary education or lower vocational education; medium levels included lower or higher general secondary education or intermediate vocational education; higher levels included pre-university education, higher vocational education or university.

Being in a committed relationship and having children were dichotomised into yes and no. The risk categories were 1, 2 or 3 (see participants) [27,28].

Risk perception was measured by two questions (see Fig. 1). The first one measured the women's knowledge about her personal risk estimate of developing breast cancer in terms of "1 in x" in combination with percentages (cognitive). The second question assessed risk perception in terms of her feelings about her chance of developing breast cancer with answer-categories in words (affective).

Question 1:

"How do you estimate your chance of developing breast cancer ?"
My chance of developing breast cancer is:

- ☐ very unlikely
- ☐ about 1 in 20 (i.e. 5%)
- ☐ about 1 in 10 (i.e. 10%)
- ☐ about 1 in 7 (i.e. 11 – 19%)
- ☐ about 1 in 4 (i.e. 20 – 29%)
- ☐ about 1 in 3 (i.e. 30 – 39%)
- ☐ about 1 in 2 (i.e. 40 – 50%)
- ☐ greater than 1 in 2 (i.e. 60 – 80%)

Question 2:

Besides this estimated chance, you possibly have a certain feeling about your chance of developing breast cancer.
"What do you feel your chance of developing breast cancer is?"
I feel my chance of developing breast cancer is:

- ☐ very small
- ☐ small
- ☐ reasonably small
- ☐ not small, not high
- ☐ reasonably high
- ☐ high
- ☐ very high

Fig. 1. Questions measuring risk perception.

2.2.2. Dependent variables

Intrusion and avoidance were measured using the Impact of Event Scale (IES). This questionnaire developed by Horowitz and colleagues comprises 15 items and can be tailored to a specific event, namely 'breast cancer' in this study [29]. The IES measures two common responses to stressful situations: avoidance (8 items) and intrusion (7 items) and has four answer categories: not at all (0), seldom (1), sometimes (3) and often (5). Reliability analysis in this study revealed Cronbach Alpha's of 0.84 (avoidance) and 0.86 (intrusion).

The Hospital Anxiety and Depression Scale (HADS) is a 14-item questionnaire, measuring anxiety (7 items) and depression (7 items) [30]. Each subscale has a score range between 0 and 21. Reliability analysis in this study revealed Cronbach Alpha's of 0.83 for anxiety and 0.86 for depression.

Somatic impact was measured with the somatic subscale derived from the Symptom Checklist-90 (SCL-90). This 12-item list consists of physical symptoms often reported when functional problems occur. Each item can be answered with: not at all (1), a little (2), quite (3), very (4) or extremely (5), providing a score ranging between 12 and 60 [31]. Reliability analysis in this study revealed a Cronbach Alpha of 0.81 for this subscale.

2.3. Design

The study was part of a longitudinal observational study on psychological impact and quality of life within the MRISC-study. This article concerns the first assessment at 2 months prior to the women's subsequent appointment in the clinic. The assessments took place between November 2000 and April 2003.

2.4. Procedure

Women participating in MRISC-A were sent a letter about the study along with written patient information, an informed consent form, a form on which women could indicate that they did not want to participate and a reply-paid envelope. Additionally, for women who had not received the mailed information but who were adhering to breast surveillance, the physician or oncologist of the family cancer clinic introduced the study and handed out the patient information at the scheduled control visit. After sending back the signed informed consent from women received their baseline questionnaire at home two months prior to their next surveillance appointment at the family cancer clinic, together with a reply-paid envelope. Women who did not return their questionnaire within 4 weeks were sent a reminder.

2.5. Genetic counselling

Women from identified BRCA mutation families were eligible for a DNA test and received extensive genetic counselling during the decision process. The identified *BRCA1/2* mutation carriers (risk category 1) were again elaborately informed about their risk of developing breast cancer and ovarian cancer at the moment of the test result. Women not choosing to proceed with genetic testing were categorised in risk category 2. All these women received a written summary of the information provided. Risk category 2 also includes women who received inconclusive DNA results after extensive counselling, and a written summary. These women have to face inaccurate risk estimations, although empirical evidence allows improved risk estimation models [9]. The same holds for women belonging to risk category 3. As not all women in this risk category were eligible for a DNA test, a subgroup in this risk category has also not received genetic counselling. However, this group of women was extensively informed about their breast cancer risk by the physician or oncologist seeing the women for surveillance at the family cancer clinic of our institution.

2.6. Statistics

The characteristics of the study sample were tested for differences between the three risk categories by the one-way analysis of variance method in case of continuous data and by the χ^2 method (Linear-by-Linear Association) in case of ordinal data. The cognitive risk perception question was trichotomised into underestimation, accurate estimation and overestimation of one's own risk. For risk category 1, the answer: *greater than 1 in 2* was considered as an accurate answer; for risk category 2, the answers: *about 1 in 2* and *about 1 in 3* were both considered as an accurate answer; and for risk category 3, the answers: *about 1 in 4* and *about 1 in 7* were both considered as accurate answers. Subsequently, this variable was recoded into dummy-variables. The affective risk perception question was considered as a continuous variable. An analysis of covariance (ANCOVA) was applied to explore how affective risk perception was related to cognitive risk perception for the three risk categories. Covariables were: age, number of years of adherence, educational level, having a relationship and having children.

Missing values in the dependent variables were handled as follows: for women who filled in more than 75% of the questions per subscale, a total score has been computed, corrected for the total number of questions of the subscale. For women who filled in less than 75% of the questions per subscale no total score was computed. With the dependent variables, a two-component structure was determined (details submitted elsewhere). The first component (Component I) constituted the outcome variables intrusion and avoidance. These are measures of distress as a consequence of intense experience or active avoidance of thoughts and feelings about breast cancer and, therefore, Component I can be characterised as breast cancer-specific distress. Component II is characterised by anxiety, depression and the somatic subscale of the SCL-90. Because the questions are to be answered without bearing in mind thoughts and feelings about breast cancer, this component can be considered to be an expression of general distress.

Multiple linear regression was used to determine differences between the three risk categories and cognitive and affective risk perception. Multiple linear regression was also used to determine the association between cognitive and affective risk perception and general and breast cancer-specific distress. The meaning of statistical adjustment is that the relationship between the variables of interest (i.e., independent variables) and the dependent variable may be biased, if possible confounding variables are not taken into account. For example, the relationship between risk perception and distress might be biased if age was not taken into account. In this study, we considered risk category, age, number of years of adherence, level of education, having a relationship and having children as potential confounder variables that require inclusion as covariates. As a measure of the relative importance the standardised regression coefficient was used. All statistical testing occurred at the 0.05 level of significance (two-sided). All analyses were carried out using the Statistical Package for the Social Sciences (SPSS 11).

3. Results

3.1. Sample characteristics

The characteristics of 351 participants are shown in Table 1. The women who did not want to participate in the psychological follow-up study did not differ significantly from the women who did participate, with respect to age and risk status. The three objective risk categories were not equally represented; 11.4% ($n = 40$) of the sample was BRCA1 or BRCA2 mutation carriers, 56.7% ($n = 199$) of the women belonged to category 2, and 31.9% ($n = 112$) belonged to risk category 3. The mean age of the total group of women was 40.5 years (range 21–63 years.). Age did not significantly differ between the three risk categories. The mean duration of adherence to a surveillance programme was 5.3 years (range 0–30 years). Women in category 1 showed significantly shorter adherence to surveillance than women in the other 2 categories (3 years and around 5.5 years, respectively) ($P < 0.004$). Post-hoc comparisons of the three categories resulted in a statistical significant

Table 1
Demographic characteristics of the study sample

Variable	Risk category 1 ($n = 40$)	Risk category 2 ($n = 199$)	Risk category 3 ($n = 112$)	Total ($n = 351$)
Mean age (SD)	40.7 (10.3)	41.0 (8.8)	39.5 (8.3)	40.5 (8.8)
Mean number of years to surveillance adhering (SD)*	3.0 (12.4)	5.6 (4.4)	5.6 (4.7)	5.3 (4.4)
Educational level				
Lower level	6 (15%)[a]	34 (17%)	21 (19%)	61 (17%)
Middle level	23 (58%)	106 (53%)	59 (53%)	188 (54%)
Higher level	11 (28%)	59 (30%)	32 (29%)	102 (29%)
Having a partner (yes)	38 (95%)	173 (87%)	97 (87%)	308 (88%)
Having children (yes)	25 (63%)	147 (74%)	79 (71%)	251 (72%)

SD, standard deviation.
[a] Percentages indicate column percentages.
* Significantly different between the three risk categories.

difference between the following categories: 1 versus 2 and 1 versus 3 (Bonferroni's correction was applied). Most women had a middle level education (54%, $n = 188$). Most of the women (88%, $n = 308$) had a relationship and 72% ($n = 251$) had one or more children.

3.2. Relationship between risk perception and risk categories

In risk category 1 more than half (60%) accurately estimated their own risk of developing breast cancer (Table 2). Due to the format of the cognitive risk perception question, it was impossible for women in category 1 to overestimate their risk. Underestimation in this category was therefore 40%. In risk category 2, slightly more women underestimated their personal breast cancer risk compared with those accurately estimated it (47.2% and 43.7%, respectively). Overestimation occurred in 9.1% of the women in this category. In risk category 3, 33.3% of the women had an accurate estimation of their own risk, as opposed to 25% underestimating it and 41.7% overestimating it. For the total sample, an accurate risk estimate was given by 42.3% of the women. The differences between accurate estimation, over- and underestimation in the three risk categories were significant ($P < 0.001$). Additionally, cognitive risk perception distinguished by risk category was related to affective risk perception. The estimated means, adjusted for the co-variables, are shown in Fig. 2. Both risk category and cognitive risk perception were significantly related to affective risk perception

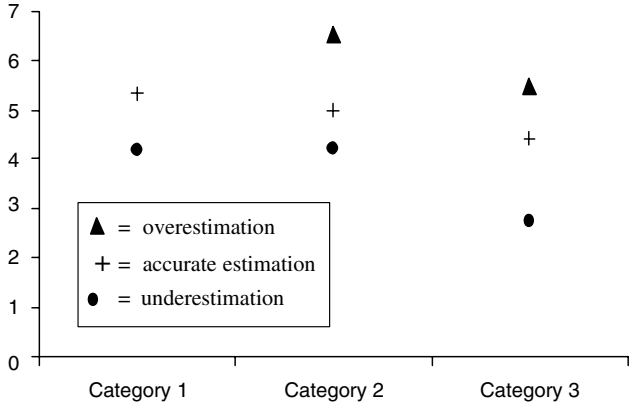

Fig. 2. Mean scores (were adjusted for the covariables) on affective risk perception for each risk category distinguished by cognitive risk perception. Mean scores numbers on the Y-axis correspond with the answer categories of the affective risk perception question: 1 = very small, 2 = small, 3 = reasonably small, 4 = not small, not high, 5 = reasonably high, 6 = high, 7 = very high.

($F = 26.8, P < 0.001$ and $F = 86.3, P < 0.001$, respectively). When testing for a possible interaction between risk category and cognitive risk perception in relation to affective risk perception, we found a non-significant result ($F = 2.5, P < 0.07$).

3.3. Psychological distress in relation to cognitive and affective risk perceptions

The association between cognitive risk perception and general distress was non-significant. However, the

Table 2
Accurate risk estimation divided by risk category

Risk category	Underestimation of own risk	Accurate estimate of own risk	Overestimation of own risk
Category 1	40.0%[a]	60.0%	Does not apply
Category 2	47.2%	43.7%	9.1%
Category 3	25.0%	33.3%	41.7%
Total sample	39.4%	42.3%	18.3%

[a] Percentages indicate row percentages, $P < 0.001$ (linear-by-linear association).

Table 3a
Association between cognitive risk perception and general and breast cancer-specific distress ($n = 345$)

Variable	General distress		Breast cancer-specific distress	
	β^a	P-value	β^a	P-value
Underestimation	0.004	0.95	−0.05	0.39
Overestimation	0.09	0.16	0.16	0.02

[a] Standardised regression coefficient as a measure of relative importance.

Table 3b
Association between affective risk perception and general distress and breast cancer-specific distress ($n = 344$)

Variable	General distress		Breast cancer specific distress	
	β^a	P-value	β^a	P-value
Affective risk perception	0.22	0.002	0.16	0.02
Underestimation	0.09	0.16	0.007	0.92
Overestimation	0.01	0.95	0.10	0.13

[a] Standardised regression coefficient as a measure of relative importance.

association between overestimation and breast cancer-specific distress was significant ($\beta = 0.16, P < 0.02$) (Table 3a). Women overestimating their risk reported relatively more breast cancer-specific distress. Furthermore, significant positive associations were found for affective risk perception with both breast cancer-specific distress ($\beta = 0.16, P < 0.02$) and general distress ($\beta = 0.22, P < 0.002$) (Table 3b). The association between overestimation and breast cancer-specific distress was no longer significant after adding affective risk perception to the regression model ($\beta = 0.10, P < 0.13$). This means that, regardless of accurate estimation, overestimation or underestimation, women who had a higher affective risk perception showed higher scores for general distress and breast cancer-specific distress.

4. Discussion

Our findings underscore Hopwood's notion that the affective risk perception is important [13] and is profoundly associated with psychological distress. Moreover, this association remains irrespective of the accuracy of risk perception.

Less than half of the women in our sample accurately estimated their personal risk of developing breast cancer. Underestimation of risk was most prominent in risk category 2, whereas overestimation was most prominent in risk category 3. Several factors can explain this observation. First, this effect may be a consequence of the genetic counselling. Women in risk category 1 received extensive counselling, with the inclusion of comprehensive information and a written summary of the consultation. The risk figures provided are rather definite and exact. More than half of this subsample (60%) reported an accurate risk perception, which could reflect a good memory and recall of clear data. Information about an elevated risk of developing breast cancer in the categories 2 and 3 is more complex and less concrete, and may therefore not be discussed as thoroughly, and/or remembered as accurately. Second, women in category 2 who received inconclusive DNA-test results (i.e., a *BRCA1/2* mutation could not be identified) may have previously anticipated a higher risk in accordance with a *BRCA1/2* mutation. Subsequently, the underestimation of the remaining personal risk may reflect their relief at not being identified as a mutation carrier. Moreover, the women who were not identified as a mutation carrier were not offered prophylactic surgery as an option, and this may have prompted additional relief in the patient. The opposite may be true for women in category 3 who may have had no separate genetic counselling and mostly were not given written information. Their knowledge about their elevated risk is not assuaged by a favourable DNA result for *BRCA1/2*. Further, self-selection may play its part for women in category 3 overestimating their risk may be more eager to enrol in a surveillance programme than those who are less worried. Third, the format of the answer categories may have influenced the observed results. Having a relatively higher risk implies that the chance to estimate it lower is higher. When the objective risk is relatively lower, there is a higher chance to overestimate it. Due to the format of the answer categories, it is impossible to become an overestimator in risk category 1, because the greatest chance i.e., "greater than 1 in 2" is the accurate answer for women in this category.

Women who reported breast cancer-specific distress overestimated their objective risk. However, a higher awareness of (affective) risk was associated with both breast cancer-specific and general distress, independent of the adequacy of risk estimation. Women carrying a BRCA mutation (risk category 1) who underestimated their risk had a relatively lower affective risk perception which was associated with lower distress scores for both general and breast cancer-specific distress. This observation may reflect denial or minimisation of their elevated risk, in order to protect themselves against (unnecessary) worries. However, these women, in spite of their underestimation and possible denial as a way of self-protection, continue to adhere to the surveillance programme. Indeed, otherwise they would not have been included in this psychological follow-up study. So, in our study sample we did not find indications that the lower distress scores result from a lack of motivation to

adhere to recommended guidelines, in contrast to the conclusions of Lerman and colleagues [32].

In a previous study at our institution, we found lower distress scores in mutation carriers opting for surveillance than in mutation carriers opting for bilateral prophylactic mastectomy [33]. Mutation carriers with an accurate risk perception showed a mean affective risk perception of 'reasonably high' (Fig. 2) indicating a relatively low distress, which is consistent with the lower distress scores of mutation carriers opting for surveillance in the study conducted by Lodder and colleagues. This suggests that women adhering to the surveillance programme feel comfortable and, possibly, are confident that an eventual breast tumour will be detected at an early stage. It is interesting to note that 8 mutation carriers with an accurate cognitive risk perception had an affective risk perception of 'very high', indicating a higher psychological distress. It is possible that these women are in the middle of a decision-making process about an eventual mastectomy. Van Dijk and colleagues recently reported that a higher perceived risk and more breast cancer worry were both significantly associated with the intention to undergo a prophylactic mastectomy [34].

In all three risk categories, a considerable number of women had inaccurate risk perceptions, either an underestimation or overestimation. How much effort should be made to improve the perception of these women? Despite this level of inaccuracy, all women were adhering to regular surveillance. Inaccurate risk perception therefore did not seem to adversely influence health behaviour.

However, from this study, it is not clear how many women do not adhere to screening, or do not even come forward for risk assessment.

Our study showed the importance of affective risk perception and the lesser relevance of adequate risk estimation with regard to distress. Counselling should address the way in which women process information about their given risk estimate (the cognitive dimension). Obviously, more attention is needed to achieve tolerable levels of psychological distress (the affective dimension). The study conducted by Hopwood and colleagues showed no significant reduction in cancer worries after risk counselling, implying that it is not sufficient to provide only numerical information [16]. Nevertheless, there are studies demonstrating a decrease in psychological distress after genetic counselling [19,35]. Watson and colleagues found that one year after counselling the level of breast cancer worries remained similar, but this worry was perceived assess of a problem by the women [12]. The different outcomes of these studies may be partly explained by the different content and quality of the counselling. We speculate that a significant reduction in distress can be achieved if the counsellor or psychosocial worker comprehensively addresses the emotional issues associated with breast cancer. The psychological approach should be tailored to specific women experiencing high distress, and is dependent on intellectual resources and motivation, introspective capacities and the support systems of these women. Specific psychological interventions could include psycho-educational programmes, and interventions from a cognitive-behavioural, psychodynamic, or family-system perspective. In this way, women can be helped to come to terms with any problems and find an adequate and creative adjustment. It is important that future studies address the factors that cause a high affective risk perception, which in turn is significantly associated with higher distress. Moreover, both the quality of counselling and intervention strategies should be further studied.

In conclusion, physicians and researchers need to be aware of the importance of the affective component of risk perception. We recommend that future research focuses on the exact relationship between both cognitive and affective risk perception, and psychological distress. Furthermore, interventions to reduce distress to tolerable levels in women with a high affective risk perception need to be developed and studied.

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