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ORIGINAL ARTICLE

Cancer-related distress in unselected women with newly diagnosed breast or ovarian cancer undergoing *BRCA1/2* testing without pretest genetic counseling

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ABSTRACT

Background: Genetic testing is increasing in patients newly diagnosed with cancer. This study investigated the levels, course and predictors of cancer-related distress, defined as intrusion and avoidance, in women undergoing *BRCA1/2* testing without pretest genetic counseling shortly after a diagnosis of breast or ovarian cancer.

Material and methods: Unselected for family history or age, 259 women with breast cancer and 50 women with ovarian cancer, underwent *BRCA1/2* testing shortly after diagnosis. Cancer-related distress was measured with the Impact of Event Scale before and after genetic testing. In order to identify predictors of distress, the subscale scores were regressed on baseline predictor variables including sociodemographic and medical variables, perceived social support, and decisional conflict regarding genetic testing.

Results: The mean levels of intrusion and avoidance were in the moderate range both before and after genetic testing with a statistically significant decline during follow-up. Younger age, shorter time since diagnosis, lower levels of social support, and a diagnosis of ovarian cancer predicted higher levels of both intrusion and avoidance. In addition, higher levels of decisional conflict and living with a partner predicted higher levels of intrusion.

Conclusions: Women having genetic testing shortly after a diagnosis of breast or ovarian cancer had a moderate mean level of cancer-related distress, which decreased with time. Health personnel offering genetic testing to newly diagnosed women with breast or ovarian cancer should be aware of the potential predictors for increased cancer-related distress identified in this study: younger age, less perceived social support, higher levels of decisional conflict regarding genetic testing, and living with a partner.

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Background

Genetic testing has become increasingly important in patients diagnosed with breast or ovarian cancer in recent years, as the presence of germline variants not only predicts a high risk of breast and ovarian cancer, but also gives an opportunity for personalized cancer treatment. After the introduction of poly-(ADP-ribose) polymerase (PARP) inhibitors for treatment of ovarian cancer in *BRCA1/2* mutation carriers, diagnostic genetic testing of patients with ovarian cancer has been implemented in routine clinical practice in several countries [1–3]. Although less established, similar procedures are gradually introduced in breast cancer clinics, since decisions regarding surgery and neoadjuvant chemotherapy might be directed by *BRCA1/2* carrier status [4–6]. This new approach often implies that the genetic test is performed a short time after diagnosis, without traditional pretest genetic counseling or risk assessment. While previously cancer-related distress has been thoroughly investigated in persons receiving traditional genetic counseling for hereditary cancer [7–10], less is known about the cancer-related distress in women newly affected with breast or ovarian cancer who are offered genetic testing regardless of age and family history, and who undergo genetic testing without pretest genetic counseling. In contrast to women seeking genetic counseling because of a suspicious family history of hereditary breast and ovarian cancer, the women who are tested as part of the routine diagnostic work-up in a cancer clinic may be less aware of the possibility that their cancer can have a hereditary cause, and thus be less prepared for a decision making process regarding genetic testing. Obviously, receiving a potential

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life-threatening cancer diagnosis is associated with significant distress [11–14]. Concern has been raised that introducing genetic testing shortly after diagnosis would impose an additional psychological burden for women in this stressful situation [15], but so far, the evidence does not support this concern [16].

High levels of distress interfere with the patients' ability to perceive important information given by health personnel [17] and may constitute an obstacle for understanding the consequences of genetic testing [18]. More attention should therefore be drawn to the patients with higher levels of distress.

We define distress as intrusive thoughts and avoidance responses in this study. Intrusion and avoidance are often associated with post-traumatic stress disorder (PTSD), but are also studied as reactions to actual or possible threatening events without implicating the status of a PTSD-diagnosis [8,9], as in this article. Intrusion symptoms include unbidden thoughts and images both awake and during sleep, waves of overwhelming feelings of fear and repetitive behavior. Avoidance responses include denial of the meaning and consequences of the threatening event, blunted sensation, emotional numbness, and attempts to block out unpleasant feelings and memories [19].

The relatively low correlation between stressful life events on one hand, and adverse outcome on the other, has stimulated the search for moderating variables [20,21], and social support has a central position in this research. To seek social support seems to be one of the most successful coping strategies and is often associated with favorable health outcome [22,23]. One theory, 'the buffer theory', states that social support protects against the potential pathogenic effects of stressful life events, and that this protective property is activated when needed, e.g., when a person is diagnosed with cancer and/or is undergoing genetic testing [20,24].

While some people find it easy to make a choice about genetic testing, others have stronger ambivalence toward this. Women who are newly diagnosed with breast or ovarian cancer are often overwhelmed with information and choices they have to make [18]. Underlying decisional conflict regarding genetic testing may have an impact on the experienced distress for these women.

There are some well-described predictors of psychological distress among cancer patients, e.g., young age and short time since cancer diagnosis, while other predictors have shown more ambiguous effects in different studies, e.g., educational level, employment status, marital status, and cancer type [13,14,25–27].

The aim of this study was to document the level, course and predictors of cancer-related distress, in patients undergoing genetic testing a short time after the diagnosis of breast- or ovarian cancer.

Material and methods

Study design and participants

The patients participated in a prospective multi-site study in which genetic testing for pathogenic *BRCA1/2* variants and familial cancer risk assessment were offered to all women newly diagnosed with breast or ovarian cancer, the DNA-BONus study. The study protocol and the results of the genetic testing have been published in details elsewhere [28]. All patients with newly diagnosed breast or ovarian cancer, unselected for age and family history, were consecutively invited to participate, from September 2012 to April 2015. The participants could choose to participate only in the genetic testing study, in an associated psychosocial study, or both. This article presents data exclusively from patients participating in the psychosocial study. The participants did not receive genetic counseling prior to testing, but were given written information about hereditary breast and ovarian cancer in addition to brief information from their treating physician or nurse. The genetic test result was given to the patient in a letter from a genetic counselor if the test result was normal and there was no indication for further genetic testing. Patients who tested positive for a *BRCA1/2* mutation, or had a personal or family history suspicious of elevated familial cancer risk, received a phone call from a genetic counselor with information about the result and were invited to a post-test face-to-face genetic counseling session.

The first questionnaire in the psychosocial sub study was given to the participants along with the invitation to the study (T1). The second and third questionnaires were mailed to the participants 1 week (T2) and 6 months (T3) after disclosure of the *BRCA1/2* test result, respectively.

The study protocol was approved by the Regional Committee for Medical and Health research Ethics (REK Vest 2012-62).

Study measurements

Clinical and sociodemographic variables

Self-reported family history was retrieved from all participants in the DNA-BONus study through a structured written questionnaire linked to the blood sampling for genetic testing [28]. Clinical information was collected from the participants' medical files. Questions about education level, biological children, cohabitation, and employment status were included in the first questionnaire (T1).

Subjective distress

Subjective distress was measured with the Impact of Event Scale (IES-15) [19]. This is a 15-item questionnaire comprising two subscales: intrusion thoughts (IES-I), which includes seven items and is scored from 0 to 35, and avoidance behavior (IES-A), which consists of eight items, and is scored from 0 to 40. The scale was developed to measure current stress reactions after any specific traumatic event [19]. In the present study, 'cancer diagnosis' was defined as the specific event. The sub-scale scores are considered low in the range of 0–8, moderate at 9–19 and severe at 20 and above [19].

Social support

The concept of perceived social support was measured by the version of the Interpersonal Support Evaluation List (ISEL) used by King and colleagues, which consists of 30 items that

are answered with a score from 1 to 4 [7,29]. The average sum score for each participant was used.

Decisional conflict

To measure the participant's ambivalence toward making a choice of undergoing *BRCA1/2* genetic testing we used the Decisional Conflict Scale (DCS) [30,31]. In the DCS, 16 items are scored from 0 to 4, where three dimensions of decisional conflict are measured: uncertainty about selection of alternatives (three items), specific factors contributing to uncertainty (nine items), and perceived effectiveness of decision making (four items). Higher scores indicate higher levels of decisional conflict. The sum score of all items was converted to a 0–100 scale, where total scores below 25 are associated with low level of decisional conflict and scores above 37.5 are associated with problems in implementing decisions [31].

Statistical methods

Missing values were replaced by the respondent's own average score for each questionnaire if at least 60% of the items were filled in by the respondent. Descriptive statistics were used to describe the sociodemographic, clinical and psychological variables, reporting the mean values, median values, standard deviation (SD), standard error of means (SEM), range and proportions. Paired sample *t*-tests and paired Wilcoxon–Mann–Whitney tests were used to compare changes in IES scores between the different time points.

To identify the characteristics related to the levels of IES-I and IES-A and to test the changes of IES-I and IES-A over time, the subscale scores were regressed on the baseline predictor variables using mixed linear modeling. The mixed linear model uses all available data, and can account for correlations between repeated measurements on the same subjects and has sufficient flexibility to model time effects [32]. All predictors were entered into the mixed linear models to assess both main effects and possible interactions with time. The regression analyses were run backwards stepwise, both with and without interaction with time. The significance level was set at .05 for all statistical tests, and results were reported as estimates with 95% confidence intervals. All statistical analyses were performed using IBM Statistical Package for the Social Sciences (SPSS, version 24.0) (SPSS Inc., Chicago, IL).

Results

Study sample

Of 772 eligible women in the DNA-BONus study, 403 (52.2%) underwent genetic testing and 309 (40.0%) gave consent for the psychosocial sub study: 259 women diagnosed with breast cancer and 50 women diagnosed with ovarian cancer. The mean age of the participants was 56.1 years (range: 24–89 years). The mean time from diagnosis to returning the first questionnaire (T1) was 45 (median: 26) days for patients with breast cancer and 156 (median: 76) days for patients with ovarian cancer. On average, participants returned T1 two days before blood sampling for the genetic test. Cancer treatment was initiated for 256 patients before T1, 31 participants had not started cancer treatment before T1, and treatment status was unknown for 22 participants at T1. The sociodemographic and clinical characteristics of the study sample are provided in detail in Table 1.

Level of intrusion (IES-I) and avoidance (IES-A) before and after genetic testing

Table 2 show the mean levels of IES-I and IES-A scores at the three measurement points. The mean IES-I score was 14.6 (median 14.0) at T1 and decreased statistically significantly to 12.1 (median 9.0) at T2 ($p < .001$) and with a further statistical significant decrease to 9.7 (median 7.0) at T3 ($p < .001$). The overall decrease from T1 to T3 was 5.2, which corresponds to 14.9% of the total IES-I scale (0–35). The mean IES-A score was 12.7 (median 11.0) at T1, decreased statistically significantly to 10.2 (median 8.0) at T2 ($p < .001$), but with no further statistical significant decrease from T2 to T3 (mean score 9.7, median 8.0). The overall decrease in IES-A score from T1 to T3 was 3.0, 7.5% of the total IES-A scale (0–40). At inclusion nearly one-third and one-fourth of the patients, respectively, had IES-I and IES-A scores indicating a severe stress response, Table 2. At T3 the proportions of patients with scores in the severe range were reduced to 14.0 and 16.0% for IES-I and IES-A, respectively, Table 2.

Mixed linear models for intrusion and avoidance

The results of the mixed linear regression analyses for IES-I and IES-A scores are given in Table 3. After backward stepwise selection, the final model showed that younger age was a predictor of higher IES-I, i.e., for each 10 years decrease in age the mean value of IES-I score increased with 1.80, Table 3. Additional predictors of higher levels of IES-I were shorter time since diagnosis, lower level of perceived social support, higher level of decisional conflict regarding the genetic test, diagnosis of ovarian cancer and living with a partner. Higher levels of IES-A was associated with younger age, shorter time since diagnosis, lower level of perceived social support and a diagnosis of ovarian cancer. For both IES-I and IES-A, none of the predictor variables retained in the final model showed significant interaction with time. For full overview over the mixed linear regression analyses for IES-I and IES-A, see online Supplemental Tables S1 and S2.

Discussion

We found that women who chose *BRCA1/2* genetic testing shortly after a diagnosis of breast- or ovarian cancer had mean levels of intrusion and avoidance in the moderate range both before and after genetic testing, with a statistical significant decrease during a mean time of 7.5 months follow-up. Younger age, shorter time since diagnosis, a diagnosis of ovarian cancer, lower levels of social support, higher levels of decisional conflict, and living with a partner, predicted higher levels of distress.

Table 1. Baseline variables for the study population.

Diagnostic group	Breast cancer, $N = 259$		Ovarian cancer, $N = 50$		All respondents, $N = 309$	
Continuous variables	Mean	(SD)	Mean	(SD)	Mean	(SD)
Age, years	55.7	(11.5)	58.3	(11.4)	56.1	(11.5)
Time from diagnosis to T1[a], days	45	(72)	156	(259)	63	(129)
Time from T1 to T2[b], days	52	(48)	46	(21)	51	(46)
Time from T1 to T3[c], days	226	(39)	225	(30)	226	(38)
DCS[d], range: 0–100	19.7	(15.2)	15.3	(13.3)	19.0	(15.2)
ISEL, range: 1–4	3.46	(0.46)	3.46	(0.48)	3.46	(0.47)
Categorical variables						
Categories	*N*	(%)	*N*	(%)	*N*	(%)
Education						
Primary school	42	(16.2)	8	(16.0)	50	(16.2)
High school	91	(35.1)	24	(18.0)	115	(37.2)
University	121	(46.7)	17	(34.0)	138	(44.7)
Missing	5	(1.9)	1	(2.0)	6	(1.9)
Employed	161	(62.2)	28	(56.0)	189	(61.2)
Missing	4	(1.5)	1	(2.0)	5	(1.6)
Having biological children	228	(88.0)	44	(88.0)	272	(88.0)
Missing	4	(1.5)	0	(0.0)	4	(1.3)
Living with a partner	180	(69.5)	38	(76.0)	218	(70.6)
Missing	3	(1.2)	0	(0.0)	3	(1.0)
Detection method						
Screen-detected	106	(40.9)	0	(0.0)	106	(34.3)
Symptomatic	137	(52.9)	50	(100)	187	(60.5)
Other	16	(6.2)	0	(0.0)	16	(5.2)
Stage[e]						
I	123	(47.5)	4	(8.0)	127	(41.1)
II	108	(41.7)	9	(18.9)	117	(37.9)
III	21	(8.1)	23	(46.0)	44	(14.2)
IV	7	(2.7)	13	(26.0)	20	(6.5)
Unknown	0	(0.0)	1	(2.0)	1	(0.3)
DCS category						
Low (0–24)	150	(59.1)	35	(70.0)	185	(60.9)
Intermediate (25–37.5)	75	(29.5)	9	(18.0)	84	(27.6)
High (>37.5)	29	(11.4)	6	(12.0)	35	(11.5)
Post-test genetic counseling						
Not offered	156	(60.2)	18	(36.0)	174	(56.3)
Offered, not accepted/received	34	(13.2)	8	(16.0)	42	(13.6)
Offered and received	69	(26.6)	24	(48.0)	93	(30.1)
BRCA1/2 mutation found	6	(2.3)	9	(18.0)	15	(4.9)
FDR with breast or ovarian cancer	56	(21.6)	3	(6.0)	59	(19.1)
FDR with other cancer	86	(33.2)	20	(40.0)	106	(34.3)

Sociodemographic and clinical characteristics of the 309 participants in a study of psychosocial aspects of genetic testing in women newly diagnosed with breast or ovarian cancer in western Norway between September 2012 and April 2015 (the DNA-BONus study).

SD: standard deviation; T1/T2/T3: successive time points for questionnaires in the study; DCS: Decisional Conflict Scale; ISEL: Interpersonal Support Evaluation List; FDR: first degree relative.

[a]Five missing breast cancer, one missing ovarian cancer; [b]233 valid breast cancer, 39 valid ovarian cancer; [c]218 valid breast cancer, 41 valid ovarian cancer; [d]5 missing breast cancer; [e]breast cancer stage according to Union for International Cancer Control (UICC), ovarian cancer stage according to International Federation of Gynecology and Obstetrics (FIGO).

The majority of the participants had a high level of education, were working and living with a partner. In addition, they reported a high average level of perceived social support. This may indicate that the participants represent a self-selected group of resourceful women. We know from previous studies that patients seeking traditional genetic counseling for hereditary cancer are highly selected and resourceful [7,8]. The same tendency of self-selection might have occurred in our study. The finding of low levels of decisional conflict may, not surprisingly, reflect that those with higher levels of decisional conflict declined genetic testing and/or to answer the questionnaires.

The mean levels of intrusion and avoidance symptoms in the present study were in the moderate range (IES subscale scores 9–19) at all measurements, with mean IES scores ranging from 14.6 (IES-I) and 12.7 (IES-A) at T1 to 9.7 (IES-I and IES-A) at T3. The change in mean IES-I score from T1 to T3 is of a magnitude (14.9% of the total IES-I scale) which may indicate a clinical significant reduction in intrusion during a mean follow-up of 7.5 months. Our results are in line with previous reports on patients newly diagnosed with breast cancer [12,16]. Wevers et al. [16] found in their study of breast cancer patients at high risk of hereditary breast cancer mean levels of IES-I at 18.6–18.7 before surgery, and 11.8–12.4 at 6 months follow-up. The corresponding IES-A scores were 14.0–15.0 before surgery and 10.1–10.5 at 6 months follow-up [16]. In a large study of more than 3000 women with breast cancer unselected for hereditary cancer

Table 2. Levels of IES intrusion and IES avoidance.[a]

Time point: subscale	At inclusion (T1)	One week after disclosure of genetic test result (T2)	Six months after disclosure of genetic test result (T3)
IES-Intrusion (scale 0–35), *N*	308	277	257
Mean score (SEM)	14.6 (0.5)	12.1 (0.6)	9.7 (0.5)
Median (IQR)	14.0 (7.0–22.0)	9.0 (4.0–19.0)	7.0 (4.0–14.0)
Grouped, *N (%)*			
Minor, score 0–8	102 (33.1)	132 (47.7)	147 (57.2)
Moderate, score 9–19	107 (34.7)	77 (27.8)	74 (28.8)
Severe, score ≥20	99 (32.1)	68 (24.5)	36 (14.0)
IES-avoidance (scale 0–40), *N*	309	277	256
Mean score (SEM)	12.7 (0.5)	10.2 (0.5)	9.7 (0.5)
Median (IQR)	11.0 (6.0–19.0)	8.0 (4.0–15.0)	8.0 (3.0–15.0)
Grouped, *N (%)*			
Minor, score 0–8	117 (37.9)	142 (51.3)	138 (53.9)
Moderate, score 9–19	119 (38.5)	91 (32.9)	77 (30.1)
Severe, score ≥20	73 (23.6)	44 (15.9)	41 (16.0)

Distribution of IES subscales at different time points in 309 women undergoing genetic *BRCA1/2* testing when newly diagnosed with breast or ovarian cancer in western Norway between September 2012 and April 2015.
IES = Impact of Event Scale (Horowitz et al. 1979); SEM: standard error of the mean; IQR: interquartile range.
[a]All paired comparisons between the time points were statistically significant at the 0.001-level using the paired *t*-test or the paired Wilcoxon/Mann–Whitney test except for the comparison of T2 and T3 for IES-avoidance.

Table 3. Simplified linear regression models of IES intrusion and avoidance subscales.

Variables	IES-intrusion			IES-avoidance		
Categories	b	95% CI	*p* value	b	95% CI	*p* value
Intercept	34.35	(25.59, 43.10)	<.001	38.50	(30.48, 46.53)	<.001
Ovarian versus breast cancer	3.53	(1.10, 5.96)	.005	3.36	(1.03, 5.69)	.005
Age per 10 years	−1.80	(−2.58, −1.03)	<.001	−1.02	(−1.75, −0.30)	.006
Months from diagnosis to T1	−0.25	(−0.46, −0.05)	.017	−0.21	(−0.41, −0.01)	.039
DCS per 10 points score	0.67	(0.10, 1.24)	.022			
ISEL	−3.71	(−5.60, −1.83)	<.001	−5.86	(−7.62, −4.09)	<.001
Questionnaire time point			<.001			<.001
T1	0.00	Reference		0.00	Reference	
T2	−2.38	(−3.24, −1.52)		−2.19	(−2.96, −1.41)	
T3	−4.73	(−5.75, −3.70)		−2.67	(−3.57, −1.78)	
Living with a partner	2.56	(0.639, 4.48)	.010			

Final model of mixed linear regression analyses for IES subscales in 309 women undergoing genetic testing when newly diagnosed with breast or ovarian cancer in western Norway between September 2012 and April 2015.
b: estimated regression coefficient; CI: confidence interval; *p* value: from *F*-test; IES: Impact of Event Scale (0–35/40); DCS: Decisional Conflict Scale (0–100); ISEL: Interpersonal Support Evaluation List (1–4); T1: time of inclusion; T2: one week after disclosure of genetic test result; T3: six months after disclosure of genetic test result.

risk, O'Connor et al. [12] reported mean scores of IES-I to be 10.1 and 7.8, 3 months and 15 months after surgery, respectively. The mean scores of IES-A in the same study were 10.0 and 8.4, 3 months and 15 months after surgery, respectively [12]. Like in these previous reported studies, the IES-scores in our study showed a statistical significant decline with time. These findings are also in line with our previous study on persons undergoing genetic testing for hereditary breast or ovarian cancer, with the highest scores of both intrusion and avoidance before genetic testing (mean IES-I: 12.4, mean IES-A: 9.2), and statistical significant lower scores after disclosure of the genetic test result (mean IES-I: 9.6, mean IES-A: 7.7) [7]. Although the mean scores were in the moderate range it should be noted that in our study one-third of the patients had intrusion scores in the severe range and one-fourth had avoidance scores in the severe range, at inclusion. A diagnosis of breast or ovarian cancer is a potential life-threatening event, and receiving the diagnosis is associated with high levels of distress [12,13]. However, adjustment to the new situation takes place quite immediately, and the proportion of patients with higher levels of distress decreases with time [27], as demonstrated in our study.

A high level of distress has a negative impact on the patient's ability to receive and remember information and can lead to lower adherence and compliance to treatment and follow-up [17]. Identification of patients with higher levels of intrusion and avoidance is therefore of interest to ensure better health care for these patients. Our study confirms the significance of young age as a predictor of intrusion and avoidance symptoms after a diagnosis of cancer. Consistent with findings in previous studies in patients with breast or ovarian cancer [12,14,16], we also found that the level of cancer-related distress is inversely correlated to time since diagnosis.

Looking at the two different cancer types in our study group, patients with ovarian cancer had higher levels of both intrusion and avoidance symptoms as compared to patients with breast cancer. This may reflect the severity of the ovarian cancer disease, which was more often diagnosed at an advanced stage. There are few studies in the literature

comparing psychological distress in patients with breast cancer and ovarian cancer directly, but our results are consistent with a recent meta-analysis where PTSD was reported more prevalent among survivors of gynecological cancer compared to survivors of breast cancer [33].

The protective effect of perceived social support on distress following a cancer diagnosis was confirmed in our study, and the effect was evident at all time points. Our findings show that this general resource also plays an important role in how a person copes with specific life events such as receiving a cancer diagnosis and simultaneously undergoing genetic testing. One should be aware that the protective effect is associated with *perceived* social support—as it is experienced by the person herself. In the light of this, our finding of increased intrusion symptoms in women living with a partner is interesting.

Previous research has shown diverging results when it comes to the effect of marriage or marriage-like relationship on psychological distress in patients with cancer [13,25,26,34]. Studies that have looked thoroughly into the complexity of this matter have revealed that the *quality* of the intimate relationship is decisive for whether having a partner has a positive or negative impact on the psychological distress in patients with cancer [35]. Furthermore, there seems to be a gender effect: while men with cancer are less likely to develop symptoms of psychological distress if they are married, female cancer patients have lower levels of psychological distress if they are not married [36]. In addition, both breast and ovarian cancer affect organs inevitable connected to female body image and sexuality, a fact that may be of importance for the observed difference between women with and without a cohabitating partner in our study.

In this study, traditional pretest genetic counseling was not given. Since genetic counseling has been shown to reduce decisional conflict regarding genetic testing [10], the finding that higher levels of decisional conflict at baseline predicted more intrusive thoughts both at baseline and at follow-up measurements is worth noting. Patients with higher levels of decisional conflict could benefit from more counseling and support in the decision making process, with potential both to reduce the level of distress, and to increase the uptake of genetic testing. However, integration of genetic testing into busy cancer clinics requires alternative ways of providing such support. For this purpose, some education and information resources already exist, and new tools for decision-making support are under development [37]. More use of web-based technology and applications based on artificial intelligence, could contribute to more personalized information and counseling of patients undergoing genetic testing.

A limitation to our study is that it was not possible to collect information about the patients who declined genetic testing, due to ethical regulations. The participants in our study may therefore not be representative for all patients with newly diagnosed breast or ovarian cancer. Furthermore, the number of mutation carriers was too low to detect a potential effect of a positive gene test result on the levels of intrusion and avoidance.

In summary, our study documents a moderate level of cancer-related distress in women having genetic *BRCA1/2* testing without pretest genetic counseling shortly after a diagnosis of breast- or ovarian cancer, and that the level of distress decreases with time. Although this indicates that a simplified procedure for genetic testing of large patient groups with newly diagnosed cancer is feasible, we identified possible predictor factors for experiencing increased cancer-related distress: younger age, less perceived social support, higher levels of decisional conflict, and being a woman living with a partner. Clinicians should be aware of this when offering diagnostic genetic testing, to make sure that the more vulnerable patients do not miss the opportunity for personalized treatment.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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