Research Article

Reliability and Validity of the Newly Diagnosed Breast Cancer Stress Scale in the Greek Population

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Abstract

Objective: To examine the validity and the reliability of a novel measurement tool, the Newly Diagnosed Breast Cancer Stress Scale (NDBCSS) in the Greek population. The tool aimed to assess distress in patients recently diagnosed with breast cancer. Methods: We performed a principal component analysis (PCA) of the 17 items of the scale. Results: The PCA resulted in 4 factors: 1. Personal life, 2. Procedural issues, 3. Facing challenges and 4. Psychological load. All subscales showed satisfactory internal consistency and variance, relative to theoretical score ranges. Subscale scores and total score were significantly correlated with perceived stress and hospital anxiety and depression scale, implying good criterion validity. Associations with social, demographic and disease related information were also found. Conclusions: The NDBCSS resulted in acceptable reliability and good validity, and was considered as a valuable tool for health-care workers and oncologists to measure psychological distress in early stage of breast cancer.

Introduction

Despite improvements in medicine, breast cancer remains the most frequent diagnosis in women, with up to 523,000 estimated new cases in Europe for 2018 (Ferlay *et al*. 2013). Breast cancer patients face an accumulation of stressors initiating from the diagnosis itself, the surgical procedure, the following anti-cancer treatments plus the hostile side effects of treatments (Brocken *et al*. 2012). High levels of distress are prominent right after diagnosis. According to a previous study (Henselmans *et al*. 2010) 48% of newly diagnosed breast cancer patients expressed high levels of distress that declined as a few months passed. However, in the same study 15% of those who reported high stress, continued to report high levels of stress during the first year after diagnosis. In such cases, the long-lasting cancer-related discomfort can lead to poor psychosocial and quality of life outcomes (Hulbert Williams *et al*. 2012, Lam *et al*. 2012) as well as a decline in adherence to their treatment programs (Barrera & Spiegel 2014).

Even though acute stress has a protective function that leads to the "fight or flight response", chronic stress has devastating effects in the human organism (Chrousos 2009, Nader *et al*. 2010).

Regarding breast cancer and chronic stress, studies have shown that increased level of stress by means of stress hormones are associated

with decreased survival rates as well as secondary malignancies (Sephton *et al*. 2000, Obradović 2019).

Several studies have pointed out the under-detection of distress in clinical practice (Page & Adler 2008, Passik 1998, Newell *et al*. 1998, Fallowfield 2001). For this reason, the National Comprehensive Cancer Network released guidelines for managing psychological distress. Hence, surveys of American oncologists showed that only one third (32,3%) were aware of these guidelines (Söllner *et al*. 2001, Pirl *et al*. 2007). Health-workers and oncology specialists ought to detect such issues, as part of their medical routine (Howell *et al*. 2011).

For the detection of distress in breast cancer patients, proper tools should be implemented in daily practice, and they should be tested for validity and reliability in the specific population. Such instruments are the Perceived Stress Scale and the Hospital Anxiety and Depression Scale that have shown high psychometric properties in general population. However, they cover general distress perceptions and their items do not specialize in breast cancer patients.

The Newly Diagnosed Breast Cancer Stress Scale (NDBCSS) is a novel tool developed by Lee Tso-Ying *et al*., based on qualitative interviews of women newly diagnosed with breast cancer. The aim of the authors is to aid patients and clinical health-workers to recognize in an early stage, the psychosocial, behavioral and cognitive dimensions of a breast cancer patient, as well as, to assist in the development of a "custom-made" and holistic health plan for the patients (Lee 2013). The purpose of this study is validation of NDBCSS in the Greek population.

Finally, in order to test for validity of NDBCSS, we will also correlate this instrument with questionnaires: the Perceived Stress Scale (PSS-14) and the Hospital Anxiety and Depression Scale (HADS). All of these questionnaires will be used as criterion-related validity testing as in the original paper.

Materials & Methods

The study took place in a Public General Oncology Hospital of Athens, between February 2018 and July 2018. Prior to the initiation of the study, protocol implementation and recruitment of participants, ethical approval was obtained from the Scientific and Ethics Committee of the hospital (protocol n.12590/23-11-2017). Before completion of the questionnaires, patients were fully informed about the purposes of the study and signed informed consent. Volunteers were females over the age of 20, able to read and write in Greek, recently diagnosed (less than 30 days) with primary malignancy of the breast and scheduled for breast cancer surgery. We administered the questionnaires at the time of their entrance at the hospital for their scheduled surgery (±2 days prior to surgery). We calculated the minimum number of participants by multiplying the number of items on the questionnaire by five (Field 2009). A total of 100 participants completed the questionnaires.

The Newly Diagnosed Breast Cancer Stress Scale (NDBCSS)

NDBCSS was created to capture stress perceptions related to a recent diagnosis of breast cancer. The original scale is sub-divided into four components (Heavy Psychological Load, Uncontrollable Perceptions, Unpredictable and Facing Challenges) and consists of 17 phrases that are scored in a Likert scale where 0=disagree, 1=more or less agree, 2=mostly agree, 3 totally agree (Lee 2013). To our knowledge the NDBCSS has not been validated in any other language. Permission was obtained by the authors.

Other measurements

Social, demographic and disease related variables included age, residency (city/province), marital status (married/single/widowed/divorced), presence of children (yes/no), education (primary school/secondary school/high school/higher education), employment (employed/retired/housewife/unemployed), satisfaction from family income (not at all/poor/moderate/well/very well), faith in God (yes/no), self-awareness of health (not at all / poor/moderate/well/very well), smoking (yes/no), days before operation, days after diagnosis, family history of breast cancer (yes/no/unknown). Information regarding the stage of cancer and the type of surgery was retrieved from patients' medical records.

Perceived Stress Scale (PSS 14)

The PSS consists of 14 items that measure to what extent several life conditions are considered stressful by an individual over the previous month. Each item is rated on a 5-degree Likert scale, where 0=never, 1=almost never, 2=sometimes, 3=fairly often, 4=very often. There are seven positive and seven negative items and the total score results from reversing the scores of

Table 1. Social, demographic and disease related characteristics of the study's sample (n=100) .

Age in years Mean (SD)	58.3 (12.3)	Nonsmokers N	51
Residency in Athens N (SD)	67 (0.4)	No family history of Ca breast N	63
Married (SD)	54 (0.8)	Stage I N	37
Having children N(SD)	84 (0.4)	Mastectomy N	71
High school N(SD)	35 (1.2)	PSS score Mean (SD)	29.83 (4.11)
Employed N(SD)	33 (1.6)	HADS-A Mean (SD)	7.6 (4.50)
Dissatisfied with family income N(SD)	36 (1)	HADS-D Mean (SD)	9.3 (2.61)
Believe in God N(SD)	95 (0.2)		
Very Self-aware of health N(SD)	39 (0.9)		
Days before operation Mean(SD)	2.3 (1.3)		
Days after diagnosis Mean (SD)	13.27(4.97)		

Abbreviations: SD, Standard Deviation; Ca, Cancer; PSS, Perceived Stress Scale; HADS-A, Hospital Anxiety Depression Scale-Anxiety score; HADS-D, Hospital Anxiety Depression Scale-Depression score.

positive items and then summing all scores (min.total score=0, max total score=56). The higher the scores, the higher the perceived stress (Cohen *et al* 1983). This scale has been used in Greek population reporting good psychometric properties (Andreou *et al*. 2011). In this study, the Greek translation was used after permission given by the authors.

Hospital Anxiety and Depression Scale (HADS)

The 14 questions of HADS evaluate psychological distress over the past week. The questionnaire is divided into two subscales with seven questions assessing anxiety (HADS-A) and seven questions, assessing depressive symptoms (HADS-D). Scoring of the instrument ranges from 0 to 3. For calculation of the total score, two questions are reversed and then there is summation of the scores (Zigmond *et al* 1983). This questionnaire has been used in the Greek population and has reported good psychometric properties (Michopoulos *et al*. 2008). In this study, we administered the Greek version, after permission by the authors.

Translation

Translation of NDBCSS was carried out using forward/backward translation method by two experienced bilingual translators. The Greek version was pre-tested on a small sample (five individuals who were survivors of breast cancer) in order to detect any obscurity in the content of the scale and to determine the final translation.

Statistical Analyses

Descriptive analyses were used to calculate the means, standard deviations (SD), minimums, maximums and absolute and relative frequencies (%). Principal component analysis (PCA) was used to identify the factors from NDBCSS. Bartlett's test was used to determine whether the correlation between items was adequate; however, a determinant value was calculated to assess unwanted over-correlation of items (determinant should be close to zero). The Kaiser-Meyer-Olkin (KMO) statistic was used to determine sample adequacy. For identifying appropriate number of derived factors we used the Scree-plot (look for inflexion points) and Kaiser's criterion of eigenvalues greater than 1. Loadings of each item on derived factors were maximized by orthogonal varimax rotation. Items with loadings over 0.3 were examined as candidate components of corresponding factor. Cronbach's α values were calculated and assessed for meaningful associations with other measurements of the study. For group comparison, we used Student's t-test, and for scale variables, we used Pearson's rho correlation coefficient. The level of significance was 0.05. Statistical analyses were performed using the SPSS for WINDOWS (version 25.0.0) statistical software (SPSS Inc., Chicago, IL).

Results

Table 1 presents the main characteristics of our sample. The analysis was performed in 100 participants with mean age X=58.3 (SD=12.3), 67% being residents of Athens while 33% lived in the provinces of Greece. As for their family status 54% were married, 24% were divorced, 20% were widowed and 2% were single. Regarding their profession, 33% were employed, 27% retired, 27% housewives and 12% unemployed. In the question regarding satisfaction over family monthly income, 38% answered moderate satisfaction, 36% not at all, 22% little, 3% very satisfied and 1% very much satisfied. As for the presence of children 84% had children while 16% had no children. Regarding belief in God, 97 % believed in God, 3% did not believe in God and 2% did not reply. As for smoking habits, 51% were non-smokers, 21% ex-smokers and 28% were current smokers.

Regarding disease related characteristics, patients had been diagnosed in an average of 13 days before and answered the questionnaires in an average of 2 days prior to operation. Sixty three percent had no family history of breast cancer, 30% had family history of breast cancer and 7% were not aware of their family history. Regarding the degree of self-awareness of health, 39% were very self-aware, 34% had moderate self-awareness, 20% were very much self-aware, 5% had little self-awareness and 2% had no self-awareness. As for cancer stage, 37% were diagnosed with stage I, 24% were stage 0, 13% were stage IIA, 12% were stage IIB, 10% were stage IIIA and 4% were stage IIIB. As for the type of surgery 71% had mastectomy and 29% had lumpectomy. n addition, the Scree-plot of factors' Eigenvalue concerning the NDBCSS gave us the first idea on how many subscales-factors were going to be modulated (Figure 1).

Table 2 demonstrates the results of principal component analysis (PCA) of the 17 items of NDBCSS as well as Cronbach's α if item deleted, according to which there is no need for item deletion, as the index does not increase in any such case.

In order to examine the validity of the scale, a principal component analysis was conducted. In accordance with the statistical analysis of NDBCS scale, based on the correlation matrix, correlations range from 0.75 to 2.01. The KMO index (0.773>0.5) and the Bartlett's test of sphericity (0.00<0.05) revealed that our sample was

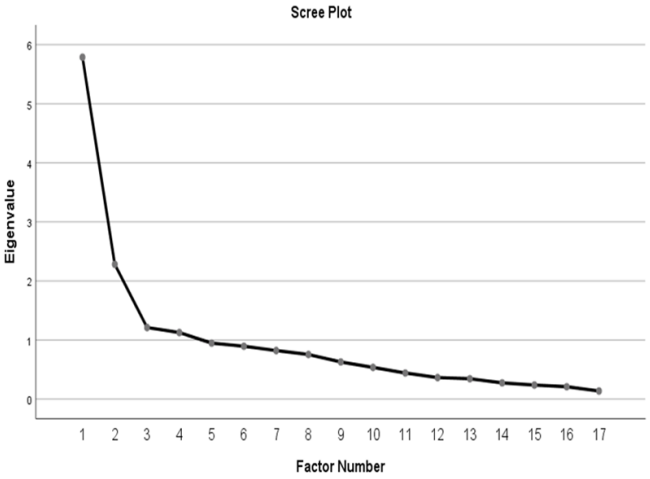

Figure 1. Scree plot of factors' Eigenvalue for the NDBCSS .

sufficient to proceed with factor analysis. The results of factor analysis proposed that the questionnaire's content could be divided into four main factors which explain 61.22% of the variance of phenomenon. Factor 1 consists of the phrases 2, 3, 5, 6, 12 which is labeled as "Personal life". Factor 2 consists of the phrases 7, 8, 11, and 13 and can be labeled as "Procedural issues". Factor 3 consists of the phrases 14, 15, 16, 17 and is named "Facing challenges". Factor 4 consists of the phrases 1, 4, 9, 10 which is labeled "Psychological load".

Furthermore, Table 3 presents the subscales' basic descriptive measures (question 14, 15, 16, 17 have been reversed). To examine the criterion-related validity of the questionnaire, we correlated NDBCSS with two other scales: PSS-14 and HADS. We expect a positive correlation with PSS-14 and sub-scales of HADS 14 (HADS-A, HADS-D). Based on the results of Table 4, it appears that NDBCSS is positively correlated to PSS-14 (r = +0.400, p < 0, 01). There is also positive correlation with HADS-A (r = 0.612, p < 0,01) and HADS-D (r = 0.468, p < 0,01).

In order to examine the convergent validity of NDBCSS, we tested the intercorrelation of the NDBCSS subscales and the NDBCSS total score. In Supplementary Table 1, all subscales have positive correlation among them as well as with the NDBCSS total score (r=0. 274–0.896, p< 0.05).

Reliability of NDBCSS was examined by the Cronbach's α index. This analysis revealed acceptable reliability of the instrument (a=0.777). Cronbach's α for subscales of NDBCSS are explained: "Personal life" was 0.659, "Procedural issues" was 0.654, "Facing challenges" was 0.714

Table 2. Rotated factor loadings of the principal component analysis (PCA) for the 17-items of NDBCSS (N=100)

Item	Factor 1	Factor 2	Factor 3	Factor 4	Cronbach's Alpha if Item Deleted
1. I often cry	0.088	0.400	0.111	**0.514**	0.860
2. Illness makes me worry about my family	**0.475**	0.266	0.119	0.364	0.856
3. Loss of my breast will affect my life	**0.605**	0.269	0.049	0.214	0.857
4. I have fear, anxiety and depression	0.329	0.297	0.379	**0.431**	0.853
5. Illness makes me worry about my work	**0.759**	0.113	-0.109	0.197	0.860
6. I am worried that my arm cannot lift heavy weight and it will affect my life and work	**0.553**	0.155	-0.022	0.499	0.855
7. I am worried that my economic conditions cannot deal with the required expenses	-0,093	**0.709**	-0.081	-0.201	0.872
8. I cannot make decisions for my breast cancer treatment	**0.669**	0.337	0.289	0.035	0.852
9. I think that the road of anti-cancer is lonely, hard and there is lack of support	0.022	0.483	0.306	**0.565**	0.851
10. I am worried about the uncertainty of the progression of the illness	0.541	0.293	0.046	**0.663**	0.849
11. I am worried about the side effects caused by chemotherapy: such as physical discomfort, change of appearance, or future birth plans, etc	0.267	**0.691**	0.151	0.290	0.854
12. Loss of my breast will affect my attractiveness to my partner	**0.817**	-0.011	0.131	0.059	0.860
13. Insufficient breast cancer information scares me	0.241	**0.624**	0.031	0.372	0.855
14. I can accept the diagnosis of breast cancer	-0.061	0.040	**0.843**	-0.078	0.867
15. I am able to make proper arrangements and deal with things affected by illness	0.020	-0.022	**0.827**	0.239	0.863
16. I can accept the staging of breast cancer	0.205	-0.086	**0.714**	0.261	0.862
17. I use some adaptation methods to face cancer	-0.146	0.008	**0.730**	0.210	0.869
Eigenvalues	5.788	2.282	1.212	1.126	
% of Variance	34.045	13.421	7.128	6.626	
Cronbach's α	0.659	0.654	0.714	0.713	

Analysis information: Determinant = 0.00, Bartlett's test = χ^2 ($p < 0.001$), Kaiser-Myer-Olkin = 0.773

and "Psychological load" was 0.713 (shown on Table 2).

Supplementary Tables 2 and 3 present meaningful associations between the NDBCSS subscales and the total scores and the study variables. Significant associations are explained:

1. Younger women (less than 36 years old) seem to worry most about "Personal life" than older ones.
2. Working patients are more concerned about "Personal life" than the rest of the employment groups.
3. Patients that claimed having no health self-awareness, worry most about "Procedural issues" while scored higher in total score of NDBCSS.
4. Smokers are bothered most by the "Psychological load".

Table 3. Subscales' basic descriptive measures (questions 14, 15, 16 and 17 have been reversed).

Factor	Number of items	Mean	SD	Min	Max
Personal life	5	9,23	4,48	1	18
Procedural issues	4	4,57	3,47	0	12
Facing challenges	4	5,14	3,49	0	13
Psychological load	4	3,86	1,86	0	6

Table 4. NDBCSS correlation to PSS-14, HAD-A and HADS-D .

		NDBCSS total	PSS-14score	HADS-A	HADS-D
NDBCSS total	Pearson Correlation	1	.400**	.612**	.468**
	Sig. (2-tailed)		0.000	0.000	0,000
	N	100	100	100	100

**. Correlation is significant at the 0.01 level (2-tailed).

5. Patients who have undergone lumpectomy are most concerned about "Personal life".
6. Patients diagnosed with stage IIIA worry most about "Procedural issues".
7. A higher PSS score was significantly correlated with higher scores in all subscales and the total score of NDBCSS.
8. A higher HADS-A and HADS-D score was significantly correlated with higher scores in all subscales and the total score of NDBCSS.

As for residency, marital status, presence of children, educational level, satisfaction from family income, belief in God, days before the operation, days after diagnosis and family history did not show any level of significance with any of the subscales of NDBCSS (not demonstrated). Moreover , no level of significance was found between total score of NDBCSS and age groups, domestic status, smoking habit, marital status educational level, employment, satisfaction from family income, belief in God, family history of breast cancer, stage of cancer, type of surgery, days before operation and days after diagnosis.

Discussion

The present study presents preliminary support for the reliability and validity of the Greek version of NDBCSS. The scale seems to have adequate psychometric properties for the assessment of psychological distress in patients newly diagnosed with breast cancer in the Greek population.

Our adaptation was based on data collected from 100 patients newly diagnosed with breast cancer with the use of principal component analysis (PCA). The factors' structure was determined by their eigenvalues (higher than 1) and by the scree-plot display. PCA analysis resulted in four factors that were named as follows: 1. Personal life: representing recent worries arising from the diagnosis with breast cancer including work and family, 2. Procedural issues: representing concerns about practical matters including therapy and cancer information, 3. Facing challenges: representing psychological resources to deal with cancer, and 4. Psychological load: representing psycho-behavioral patterns towards breast cancer. The labels of our subscales were based on the meaning of items reflecting psychological distress in response to personal life, procedural issues, facing challenges and the psychological load regarding breast cancer diagnosis. Four factors have been previously supported by the original validation study of Lee T.Y. *et al*. as well, but with different labels (Lee *et al*. 2013). All factors showed satisfactory internal consistency and the scores demonstrated adequate variances in relation to the theoretical ranges. All subscales were significantly positive correlated to each other, which shows that altogether represent the stress perceptions of patients newly diagnosed with breast cancer. Validation was based on PSS-14 and subscales of HADS that were significantly correlated with all the aforementioned subscales and the total score of the instrument.

Regarding socio-demographic and health-related information, our results indicate that patients who claimed having no health self-awareness scored higher in total score of NDBCSS. As for scoring of subscales on NDBCSS study shows that young women (under the age of 38), diagnosed with stage IIIA that had undergone lumpectomy, have higher scores in "Personal life". Also, those with no health self-awareness scored higher in "Procedural issues", while smokers scored higher in the "Psychological load".

Screening of breast cancer patients' distress is hampered by the lack of an instrument at this specific stage of the disease. Studies have shown that anxiety is more severe prior to the operation for breast cancer removal and that patients at this period of time are more anxious about the impact of this diagnosis on their personal life and work (Cheng *et al*. 2012).

Clinical implications

In order to better serve the newly diagnosed breast cancer patients, health care providers should identify the level and nature (problems and concerns) of the distress. Studies showed that health-care professionals were either unaware of 80% of patients' worries or reported other set of concerns than those expressed by the patients (Farrell *et al*. 2005, Sjödén 2000). The patients' responses in this study show that stress at this stage centers on worries about their family and work, as well as on the procedural issues of the disease. The multiple roles of women place stress burdens upon them even before the diagnosis of a disease. Our results regarding health self-awareness and stress, demonstrate that when a patient has less information, his stress increases. This supports the published guidelines for cancer patients of the National Comprehensive Cancer Network (NCCN) that encourages patients to seek information about their disease in order to manage stress by taking control of their health and disease (Holland *et al*. 2007). Meanwhile, our results show the necessity for detailed explanation by the medical staff, starting from the pre-operative stage.

Study limitations

There are several limitations in our study: lack of validation of this scale in other languages resulted in restricted comparison to the original paper. Moreover, future studies might try to use test-retest analysis for further reliability. Maybe, it could be tested as close as possible to the diagnosis. One of the strengths of the present study is that our sample was recruited from one of the biggest central oncology hospital of the country, where patients gather from all around Greece. This is the first validation of NDBCSS in a foreign language that could be considered as the basis for future validations.

Conclusions

This study focused on the Greek NDBCSS and its 4 subscales: "Personal life", "Procedural issues", "Facing challenges" and "Psychological load". Our sample consists of 100 women newly diagnosed with breast cancer that were recruited during admission to the hospital for their scheduled breast operation. Based on our study, the scale seems to have construct and criterion validity. As a result, health-care workers and oncologists have a valuable tool to measure psychological distress in early stage even at the time of diagnosis of the disease.

Data availability statement

We state that data of this study are available on request from the correspondent author.

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Conflicts of Interest

All authors declare that they have no conflicts of interest.

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