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ORIGINAL ARTICLE – BREAST ONCOLOGY

Distress: Characterizing What Causes the Thermometer to Shift in Patients with Newly Diagnosed Breast Cancer Attending a Multidisciplinary Clinic

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ABSTRACT

Background. A diagnosis of breast cancer (BC) can result in multifactorial stress. If not addressed, distress can have a negative impact on outcomes. The experience of patients with newly diagnosed BC has not been sufficiently investigated. This study characterizes distress among new patients in a multidisciplinary care (MDC) clinic. The study aimed to determine the degree of distress at presentation, to characterize the sources, and to evaluate the impact of an MDC visit.

Methods. A retrospective review was performed from January 2015 to November 2017. Charts were accessed for demographics, tumor characteristics, and treatment data. Distress scores (DS) and problems as captured using the National Comprehensive Cancer Network (NCCN) Distress Thermometer were completed before evaluation and in a subgroup after an MDC visit. Predictors of severe distress (DS $\geq$4) were investigated using multivariable logistic regression. The paired *t* test was used to determine the impact of an MDC visit.

Results. The mean initial DS ($n = 474$) was 4.98. The top four sources of distress were worry, anxiety, fears, and sadness. Age younger than 65 years was significantly associated with a higher DS at presentation ($p < 0.003$). Among the patients queried before and after MDC ($n = 137$), a significant reduction in distress was identified (5.58–2.94; $p < 0.0005$).

Conclusions. Severe distress was found in 66 % of the patients with a recent diagnosis of BC, with younger age related to higher distress scores at presentation. Emotional stressors were the predominant factors accounting for distress. A same-day MDC visit was associated with a significant reduction in DS. These data indicate the importance and feasibility of proactively screening patients. Our research lends support to the value of multidisciplinary evaluation in this setting.

Breast cancer (BC) is the most common cancer in women, and in 2019, it will account for more than 268,000 new cases and be the cause of death for more than 41,000 women in the United States.[1] As the 5-year survival rate for early-stage disease approaches 90 %, great focus has been placed on the psychological well-being of patients actively undergoing treatment.[2–4] Despite the importance of patient well-being, data regarding distress at the time of diagnosis is limited.

A BC diagnosis is a source of distress for many patients.[5] This distress has been associated with low physical and psychological quality of life, poor treatment adherence, and significantly decreased disease-free survival.[6–8] Early detection and treatment of distress in patients could potentially decrease long-term psychological effects and improve outcomes. To this end, the Commission on Cancer now requires that accredited centers proactively screen for distress.[9] Despite this mandate, centers have struggled to incorporate protocols into practice. For example, in a 2017 study, Zebrack et al.[10] found

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that the adherence rate for screening protocols was less than half at National Cancer Institute (NCI)-designated cancer centers.

The primary objective of this study was to determine the degree of distress at presentation to the breast MDC among patients with newly diagnosed BC and to better characterize the particular issues identified by patients at the point of new presentation. Secondarily, by examining a subset of patients with repeated measurement after MDC we aimed to evaluate the impact of an MDC visit on distress and elucidate the trajectory of distress.

METHODS

Study Design

This retrospective single-institution medical chart review analyzed the records of both female and male patients referred to the Lifespan Cancer Institute Breast Multidisciplinary Clinic (MDC) consecutively between 1 January 2015 and 30 November 2017 and presented at the tumor board. Eligible patients had histologically confirmed *in situ* and/or invasive BC with a documented MDC evaluation.

In this study, 565 patient charts were reviewed. Patients evaluated at MDC with other primary malignancies were excluded from this study. Institutional review board approval for the study was obtained.

Demographic and baseline information (age at diagnosis, ethnicity, race, medical history, marital status) were collected for the included patients, as were clinicopathologic features of the cancer (tumor pathologic tumor-node-metastasis [TNM] staging and hormone status). The medical history included cardiovascular disease, obstructive pulmonary disease, endometriosis, inflammatory bowel disease, diabetes mellitus, and prior cancer and diabetes mellitus. Data concerning the type of surgical intervention, chemotherapy, hormonal treatment, and radiotherapy also were collected.

Instrument

The Distress Thermometer (DT) is a self-reported screening instrument that uses an 11-point scale to measure the amount of distress patients with cancer have experienced in the past week. Respondents self-report their level of distress from 0 (no distress) to 10 (extreme distress).

The DT has been validated in several studies and a variety of oncology patient settings.[11–13] Distress screening has been in place at the Lifespan Cancer Institute since 2014, and all patients seen in the MDC for BC are asked to complete it before their new patient visit.

The DT was available to the patients in both English and Spanish. In this study, a distress score of 4 or higher was considered to indicate severe distress in accordance with National Comprehensive Cancer Network (NCCN) practice guidelines.[14] In addition to characterizing distress on a scale from 0 to 10, the DT allows characterization of specific concerns including practical, family, emotional, spiritual, religious, and physical issues that are selected by checking corresponding “yes” or “no” boxes. Numeric distress scores as well as specific problems were analyzed from initial distress screens. In the subset of patients that received a second distress screen, numeric value and date of completion were recorded.

Statistical Methods

Descriptive statistics were performed using STATA 15.0 statistical software (StataCorp LLC, College Station, TX, 2017). Categorical variables were analyzed using chi-square or Fisher’s exact test. Predictors of distress scores (in general) and severe distress were investigated using multivariable logistic regression.

RESULTS

Patient and Tumor Characteristics

The mean age of the patients at the time of diagnosis was 63 years (Table 1). The majority of the patients were not Hispanic nor white. The findings showed that 58.5 % were married or had a long-term partner and that 79.2 % had children. Neoadjuvant treatment was given to 21 % of the patients. Most of the patients had pathologic early-stage disease, including 61.4 % with T1 stage, 55.3 % with no nodal disease, and 96.1 % with negative clinical results for metastases. Hormone receptor status demonstrated estrogen and progesterone receptor-positive tumors in 84.8 % and 64.8 % of the patients, respectively. A majority of the tumors (83.1 %) were human epidermal growth factor receptor 2 (HER2)/neu-negative.

Exploration of demographic information associated with severe distress at presentation showed that only age younger than 65 years was significantly associated with severe distress ($p < 0.003$). Severe distress at presentation was not significantly associated with ethnicity ($p = 0.09$) or medical history ($p = 0.31$).

Initial Distress Screen

An initial DT was completed by 474 patients. The mean score was 4.98 (range 0–10), with 66.5 % of the patients reporting severe distress. Table 2 presents the problems indicated at presentation in decreasing prevalence. The

TABLE 1 Patient and tumor characteristics

Variable	*n*	%
Age (years)		
< 45	51	9.0
45–64	238	42.1
≥ 65	276	48.8
Ethnicity		
Hispanic, Latino, or Spanish	40	7.1
Not Hispanic	521	92.9
Race		
White	510	94.2
Black	27	4.9
American Indian/Native Alaskan	2	0.3
Asian/Pacific Islander	2	0.3
Marital status		
Single, never married	86	15.3
Single, divorced	66	11.7
Single with partner	8	1.4
Single, widowed	73	13.0
Married or with long-term partner	329	58.5
Children		
Yes	434	79.2
Tumor size		
Tis	42	7.4
T1	347	61.4
T2	98	17.3
T3	17	3.0
T4	14	2.5
Nodal status		
Nx	145	26.8
N0	298	55.3
Nmic	19	3.5
N1	55	10.2
N2	13	2.4
N3	9	1.7
Metastatic stage		
cM0	523	96.1
pM0	13	2.4
pM1	8	1.5
Hormone status		
Estrogen receptor		
Positive	479	84.8
Negative	86	15.2
Progesterone receptor		
Positive	366	64.8
Negative	115	20.4
HER2/neu		
Positive	81	16.9
Negative	399	83.1
Neoadjuvant treatment		
Yes	133	21.0

HER2 human epidermal growth factor receptor 2

most prevalent problems indicated at presentation were in the emotional category, with worry, anxiety, fears, and sadness present in more than 30 % of the patients. Although only 32 patients indicated that dealing with children was a source of stress, stratification by whether the patient had children showed that this factor was significantly reported ($p = 0.03$). Age younger than 65 years was significantly associated with worry related to work or school ($p < 0.005$). No statistically significant associations with distress scores were identified for sociodemographic factors except for age.

Post-MDC Distress Screen

The 137 patients with an initial DT also completed a second DT the same day after their MDC appointment. The clinical characteristics did not differ significantly between the patients who completed the post-MDC DT and the entire cohort. The mean pre-MDC score in this group was 5.58. The mean post-MDC score was 2.94 (range 0–9; Table 3), which was significantly lower than 4 ($p < 0.0005$). A greater proportion of the 137 patients reported severe distress before MDC than after MDC ($p < 0.005$), with 105 (76.6 %) reporting severe distress before MDC and 60 (43.8 %) reporting severe distress after MDC. When the factors associated with severe distress were examined on the post-MDC DT, the recommended neoadjuvant treatment was significantly associated with severe distress ($p = 0.015$).

DISCUSSION

The study aimed to clarify the proportion of patients that experience psychological distress at initial presentation to MDC and to identify demographics and medical history as well as tumor and treatment data that predict distress severity. Furthermore, we sought to determine the impact of a MDC visit on distress.

Studies examining a population of women facing a new diagnosis of cancer have predominantly reported on the incidence of anxiety and depression. In one such study that included 167 women (101 with a BC and 66 with a gynecologic cancer), the highest rates of anxiety (17.7 %),

TABLE 2 Number and percentage of patients endorsing variable on Distress Thermometer problem list by prevalence

Problem	*n*	%
Worry	302	53.5
Anxiety	277	49
Fears	218	38.6
Sadness	176	31.2
Sleep	163	28.8
Fatigue	146	25.8
Treatment decisions	144	25.5
Depression	95	16.8
Skin dry/itchy	93	16.5
Memory/concentration	90	15.9
Pain	81	14.3
Family health	80	14.1
Loss of interest	67	11.8
Insurance	64	11.3
Constipation	63	11.1
Nose dry/congestion	61	10.8
Neuropathy	60	10.6
Eating	50	8.8
Work/school	45	7.9
Feel swollen	44	7.8
Diarrhea	41	7.2
Indigestion	37	6.5
Breathing	35	6.2
Dealing with children	32	5.7
Appearance	31	5.5
Nausea	29	5.1
Change in urination	27	4.8
Transportation	25	4.4
Dealing with partner	24	4.4
Mobility	22	3.9
Bathing/dressing	17	3
Housing	17	3
Spiritual concerns	12	2.1
Sex	12	2.1
Childcare		< 1
Fertility		< 1
Fevers		< 1
Mouth sores		< 1

depression (32.5 %), or a combination of both (12.7 %) were found at diagnosis.[15] Symptoms, however, significantly improved with time.

In another study of more than 300 women seen at a presurgical consultation visit at a Comprehensive Breast Center, the investigators reported that mean distress scores were tied to reports of depression.[5] Using the DT, Chiang et al.[16] conducted a 6-month study of patient-reported outcomes for patients seen in an ambulatory setting (29 were new patients; 935 were being seen at the follow-up visit). They reported that the average distress was higher for those seen as new patients than for those seen at the follow-up visit (average, 5.4 vs 2.5). None of these reports, however, contextualized the experience of distress in their populations or evaluated the effect of a multidisciplinary clinic.

TABLE 3 Comparison of same-day distress thermometers before and after evaluation at multidisciplinary care clinic

Distress score	Mean	95 % CI
Pre-MDC	5.58	5.12–6.03
Post-MDC	2.94	2.51–3.37

CI confidence interval, *MDC* multidisciplinary care

The prevalence of self-reported distress at presentation in our population was similar to that reported in the literature. Prior studies of patients with a new diagnosis of BC found that 63.5 % to 72 % of the patients had severe distress (DS $\geq$4) compared with 66.5 % of our patients.[17,18]

Our multidisciplinary clinic enables patients to be evaluated by surgery, medical oncology, and radiation oncology in 1 day. Most patients are aware of their diagnosis when the pre-MDC DT is completed. However, patients often experience a time lag between diagnosis, complete staging and a comprehensive treatment plan. This waiting period before definite answers may contribute to the distress noted on the initial screen before the MDC visit. The majority of our patients (81.4 %) received an initial distress screen within 30 days after their diagnosis. Based on our results and those of prior studies, this seems to be an optimal time frame for initiation of screening and intervention, with the aim of preparing patients psychologically for upcoming treatment.[15,19]

We sought to determine what patient factors correlate with distress severity. Other studies have demonstrated an association with a prior diagnosis of psychiatric disorders, specifically anxiety or depression, and higher distress.[5,19] We did not find any medical history that predicted higher DT scores, suggesting that even patients without a psychiatric history are at risk for distress.

At presentation, younger patients (age, <65 years) were at higher risk for reporting severe distress. A relationship between higher distress scores and age has been well established for BC patients with a cancer diagnosis earlier in life, resulting in difficulty adjusting and a negative impact on mental health.[17,20,21] Several possible explanations can be given for the association between younger age and more severe distress. The most prevalent causes of severe distress in younger patients described in other studies have included lost work days, premature menopause, infertility, body image, and child care.[22]

On the post-MDC DT, the patients recommended to undergo neoadjuvant treatment had a significant association with scores of 4 or higher. This is not surprising. As discussed previously, patients receive their comprehensive treatment plan at MDC. Stress associated with confirmed higher-stage disease is expected to be reflected in the post-MDC screen.

Few studies have explored the stressors indicated on the problem list before treatment. Emotional problems accounted for the top four most prevalent problems for our patients. Mertz et al.[21] evaluated distress for patients with newly diagnosed BC using the DT. Similarly, emotional problems were the most frequent problem, with worry and nervousness experienced by more than 70 % of their patients. Their DTs, however, were completed 1–2 days before scheduled surgery which may have driven responses.

The two physical symptoms most reported by our patients were sleep and fatigue, which correlate with those in prior studies. The unique finding was that these problems existed in our population before treatment was started and thus are not attributable to treatment side effects such as "chemobrain."[20,23] Our data suggest that this stems from the new cancer diagnosis itself.

In our study, the patients who were parents reported that dealing with children was a significant source of distress. Likewise, Jorgensen et al.[18] demonstrated that having children living at home was a strong predictor for distress. Therefore, patients with children, especially those living at home, should be closely screened.

To our knowledge, this is the only study to report the impact of a same-day surgery-led MDC visit on distress scores. The subset of patients who completed a DT before and after a MDC visit had significantly lower distress scores. One factor likely contributing to decreased distress is the comprehensive nature of the MDC clinic. Another crucial factor is that at our institution patients who score 4 or higher on the pre-MDC DT are flagged for referral to social work. After that evaluation, patients are referred internally to resources, including psycho-oncology and physical therapy. All patients are provided with a new patient binder that also lists available resources at our institution and within the community.

It must be noted that although distress scores were significantly lowered after MDC, more than 40 % of the patients had persistent severe distress. This emphasizes the need for continued distress monitoring and interventions throughout treatment. This is echoed in numerous studies demonstrating that distress endures into survivorship.[18,24]

One strength of this study was the number of patients included who had not yet started treatment. However, the study had limitations. First, it was conducted at a single institution. Although our MDC screening percentage of 84 % is similar to that of other cancer centers in the literature, it is below the recommendation that all patients be screened.[15] Therefore, external validity and thus generalizability of the study's findings may be compromised by missing data from patients and incomplete follow-up evaluation (24 % of the patients had a post-MDC DT). Also, 14 patients were lost to follow-up evaluation or decided to pursue treatment elsewhere. Finally, the DT is not incorporated into the electronic medical record to date, and inclusion required scanning of the paper copy into the chart. Often, provider notes had to be reviewed to locate distress score.

In summary, the results of this study further the knowledge regarding factors that contribute to the psychological distress of BC patients at diagnosis. We demonstrated the feasibility and critical need of implementing a distress screening protocol to identify patients who may require referral for intervention and treatment.

CONCLUSION

This study showed that more than half of the patients with a new BC diagnosis have severe distress at the time of presentation to MDC. The NCCN DT and problem list can be incorporated as a screening tool in clinical practice to identify patients with distress and provide appropriate intervention. Emotional problems were the most frequently reported. Younger patients reported more severe distress at presentation, and patients recommended to neoadjuvant treatment reported more distress on the post-MDC screen.

This study may help providers to better anticipate the needs of patients and ultimately use the available resources better in an effort to provide more precise psychosocial care of their patients. Future study is needed to develop effective strategies for managing stressors, especially emotional problems, to improve the well-being of patients.

DISCLOSURES There are no conflicts of interest.

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